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HEALTH FINANCE COMMISSION

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Authority: IC 2-5-23

MEETING MINUTES[1]

Meeting Date:	**September 14, 2011**
Meeting Time:	**10:00 A.M.**
Meeting Place:	**State House, 200 W. Washington St., the Senate Chambers**
Meeting City:	**Indianapolis, Indiana**
Meeting Number:	**2**

Members Present: **Sen. Patricia Miller, Chairperson; Sen. Ryan Mishler; Sen. Vaneta Becker; Sen. Ed Charbonneau; Sen. Beverly Gard; Sen. Ron Grooms; Sen. Jean Leising; Sen. Jean Breaux; Rep. Timothy Brown, Vice-Chairperson; Rep. Ronald Bacon; Rep. Suzanne Crouch; Rep. Richard Dodge; Rep. Donald Lehe; Rep. Eric Turner; Rep. Charlie Brown; Rep. John Day; Rep. Scott Reske; Rep. Peggy Welch.**

Members Absent: **Sen. Earline Rogers; Sen. Vi Simpson; Rep. Steven Davisson; Rep. David Frizzell; Rep. Craig Fry.**

Senator Patricia Miller called the meeting to order at 10:10 a.m.

Traumatic brain injury issues

Ms. June Holt, a caregiver of an adult son who suffered a traumatic brain injury,

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[1] These minutes, exhibits, and other materials referenced in the minutes can be viewed electronically at http://www.in.gov/legislative Hard copies can be obtained in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for hard copies may be mailed to the Legislative Information Center, Legislative Services Agency, West Washington Street, Indianapolis, IN 46204-2789. A fee of $0.15 per page and mailing costs will be charged for hard copies.

testified concerning her struggles in retaining the appropriate services for her son. See Exhibit 1 for a written copy of her testimony. Ms. Holt commented that there is an ad hoc committee studying the problems and solutions to brain injury care in Indiana but that the committee does not include consumers or family members who have firsthand knowledge and expertise about existing problems. Ms. Holt testified that she did not have a resource facilitator to assist her in navigating the vast array of issues that confront an individual with a brain injury. Ms. Holt stated that the services that her son received in Illinois could be provided in Indiana, allowing for Indiana to receive federal matching funds. See Exhibit 1.

Dr. Lance Trexler, Chairperson of the Brain Injury Association of Indiana, told the Commission about a committee led by the Brain Injury Association of Indiana that was developed to review resources, investigate strategies used by other states, and develop a consensus on possible solutions for providing adequate brain injury services in Indiana. See Exhibit 2 for information provided to Commission members. Dr. Trexler stated that care for individuals with brain injuries in Indiana is fragmented and there is a need for neuro-behavioral treatment in Indiana for patients who are currently and needlessly being sent for treatment to other states. Dr. Trexler stated that the committee has determined three solutions: (1) establishing a licensing category for neuro-behavioral rehabilitation facilities to be administered by the Indiana State Department of Health that would require accreditation by the Commission on Accreditation of Rehabilitation Facilities (CARF); (2) modifying existing Medicaid waivers and investing in resource facilitative services that improve return to work rates for people with brain injuries; and (3) ensuring quality coordination and cost effectiveness of brain injury services through an oversight committee. Dr. Trexler informed the Commission of two grants the committee received from the Health Resources and Services Administration concerning a trial that compiled information on employment rates of individuals with brain injuries after the individuals received certain services and the economic impact. See Exhibit 2 for more information.

Mr. Doug Beebe, Director of Hook Rehabilitation Center, and co-chair of the committee with Dr. Trexler, commented that breakthroughs in medical science have resulted in individuals with brain injuries surviving with their injuries, and that the services being provided in Indiana have just not caught up with this change. Mr. Beebe stated that the rules existing for intermediate care facilities for the mentally retarded (ICF/MR) could be amended to address individuals with brain injuries since these rules are more functionally based.

Ms. Doris Parlette, a caregiver of a daughter with a brain injury, told the Commission about her experience through the process and stated that finally,18 years after her daughter's accident, her daughter is working and living on her own. Ms. Parlette stated that she wonders if this level of independence would have happened sooner for her daughter if she had received the appropriate services earlier.

Ms. Pat Casanova, Director of the Office of Medicaid Policy and Planning (OMPP), stated that services to individuals with brain injuries are a statewide problem, not just a Medicaid problem. Ms. Casanova briefly discussed the Medicaid waivers that Indiana individuals with brain injuries can access and the issues and the level of care needed to qualify for the waivers. When asked whether the Medicaid waivers could be amended and increased, Ms. Casanova stated that waiver slots could be increased if Indiana could demonstrate to the federal government that Indiana has available funding. Ms. Casanova remarked that the Traumatic Brain Injury Medicaid waiver is up for renewal next year.

Mr. Vince McGowen, representing Magnolia Health, responded to a question from the Commission concerning the feasibility of transitioning existing long term care facilities

that are under-utilized into neuro-behavioral rehabilitation facilities, stating that the answer comes down to the money and reimbursement. Mr. McGowen indicated that it may be feasible if an "add on" payment of as much as $300 per day to the current nursing home reimbursement system was included to provide additional money for this type of specialized care. Mr. McGowen also commented that it may also be necessary to allow for some exemptions from current Department of Health long term care rules for this type of facility.

Mr. Zach Cattell, representing the Indiana Health Care Association, agreed with Mr. McGowen that additional reimbursement would be needed for the operation of a neuro-behavioral rehabilitation facility. Mr. Cattell stated that one of his Association members had looked at this business model but found the current facility structure and reimbursement to be unaffordable.

Mr. John Cardwell, representing the Generations Project, commented on home and community based care, the need for possible Medicaid waiver amendments, and the fact that brain injuries are often misdiagnosed as dementia or Alzheimer's disease.

Diabetes educator licensing and diabetes prevention

Mr. James Specker, representing the American Association of Diabetes Educators, testified that state licensure of diabetes educators is the first step for legal recognition of the profession and will encourage growth of the profession. Mr. Specker stated that licensure would protect consumers and establish quality guidelines and standards of care within the profession. Mr. Specker commented that educating individuals who have diabetes about the disease improves health outcomes and results in cost savings by fewer incidences of hospitalization, but stated that providing education to individuals diagnosed with diabetes is under-utilized. Mr. Specker stated that guidelines for the profession already exist and that Kentucky is the only state that currently licenses diabetes educators.

Ms. Mary Teipen, a registered nurse and certified diabetes educator, told the Commission that she works for a home health care network. Ms. Teipen explained that her job entails traveling to train staff and individuals about diabetes care. Ms. Teipen gave several examples of problems that she has experienced with respect to clients not understanding the disease or caregivers who were not properly trained or given misinformation.

Mr. David Miller, a registered nurse and certified diabetes educator, told the Commission that he works statewide in educating groups and individuals concerning Type 1 diabetes. Mr. Miller stated that he feels licensure will help ensure patient safety and supports legislation that would license diabetes educators.

Ms. Joyce Irwin, representing Roche Diagnostics, stated that she supports licensure of diabetes educators. Ms. Irwin stated that the prevalence of diabetes is increasing and costs as much as $13,000 per year per patient. Ms. Irwin stated that she believes that licensure would improve clinical outcomes while lowering health care costs and providing consumers with access to qualified educators.

Ms. Anne Doran, representing Eli Lilly and Company, testified that licensing diabetes educators is a matter of patient protection and that Eli Lilly supports this effort.

Ms. Libby Cierzniak, representing the YMCA of Greater Indianapolis, provided the Commission with information on a YMCA initiative and pilot study program. See Exhibit 3.

Ms. Anne Graves, Director of Health Initiatives, YMCA of Greater Indianapolis, described the five-year program for individuals who are pre-diabetic that YMCA established in partnership with the Indiana University School of Medicine. Ms. Graves stated that the first 16 weeks of the program include the participant attending weekly meetings in which information is provided concerning lifestyle changes; and the second 16 weeks include a meeting once a month at which lifestyle strategies and support are given and the individual is weighed. Ms. Graves stated that the YMCA has partnered with several insurance companies for reimbursement for this program for qualified insured. Ms. Graves concluded by stating that 43 YMCA's in 22 states are being trained to provide this program and that the challenges include screening possible qualified participants and the cost of the program.

HIV testing and consent

Dr. Elaine Cox, Riley Hospital for Children, IU Health, testified that modern medicine has changed the HIV disease from a terminal to a chronic disease. Dr. Cox provided the Commission with statistics about HIV and stated that 23 additional medicines in five different drug classifications have been developed to fight the disease. Dr. Cox informed the Commission that the Centers for Disease Control (CDC) has recommended an opt out approach for HIV testing, indicating that general consent for medical care should be sufficient to allow for HIV testing. Currently, Indiana law requires an opt in approach for HIV testing. Dr. Cox stated that from a medical standpoint, HIV is a medical disease and should be treated this way and testing should be ordered when medically indicated. Dr. Cox stated that requiring an opt out of the testing would assist with early diagnosis and help prevent the disease. Dr. Cox informed the Commission that 14 states have HIV testing included as part of the general medical consent and 12 states don't require consent to test for HIV.

Dr. Lindsay Harmon, an emergency room physician, testified that she agreed with the CDC's position that HIV testing should be an opt out provision, stating that a physician needs all possible information to accurately provide the best care to patients.

Dr. Madonna Biritwum, Parkview Hospital, provided the Commission with statistics concerning AIDS and HIV. See Exhibit 4. Dr. Biritwum advocated for a process of informed consent that includes education and assistance to patients who test positive for HIV or AIDS and provides confidentiality for the patient. Dr. Biritwum stated that the current opt-in process that Indiana uses is complicated and time consuming, does not routinely test many patients, and does not help with the stigma related to HIV and AIDS. Dr. Biritwum testified that she previously worked in New York which changed its HIV and AIDS testing laws in 2010, resulting in more individuals getting screened and earlier detection. See Exhibit 4. Dr. Biritwum testified that New York provides patients with a fact sheet about the HIV disease and the risks entailed with HIV.

Mr. Paul Chase testified that he has concerns with changing Indiana's laws concerning testing for HIV and AIDS. Mr. Chase stated that a stigma and distrust still exists about the disease, and he feels that testing should occur in an ethical manner, be based on science, and respect the civil rights of the patient. Mr. Chase said that an increase in screening and early detection must include high standards of care, education about HIV and AIDS, and follow up care for those patients whose tests are positive.

Mr. Brian Carnes, Indiana State Department of Health, testified that services for patients who have tested positive for HIV or AIDS are available through a federal grant administered by the Department and that a case coordinator is provided for the patient to help educate the patient and ensure that the appropriate services are received. Mr.

Carnes stated that the federal funding for this program is allotted to a state based on the state's needs.

Outpatient benefits and relationships between providers and the insured

Ms. Heather Macek, representing Medco, informed the Commission that Medco is a pharmacy benefit manager, is currently in the process of being acquired by Express Scripts, and does not know if the acquisition would affect any future policies. Ms. Macek stated that there has been a move away from brand name drugs to the use of generic drugs as a cost savings mechanism to curb health care spending. Ms. Macek said that the average cost to a patient for a brand name drug is $194.27 whereas the average cost of a generic drug is $26.97. Ms. Macek stated that if a provider specifies on the prescription to "dispense as written", Medco will still contact the provider to inform them that a generic is available but will follow the provider's orders. Ms. Macek testified that focusing on generic drugs is part of benefit design for a contract and that contracts sometimes include goals to decrease the number of brand name drugs filled for covered individuals. Ms. Macek set forth the policy that Medco follows if a brand name drug is prescribed: the provider is contacted by fax regarding the availability of a generic and if the provider declines, Medco blocks the system from further requests to the provider. Ms. Macek added that Medco will follow-up with a provider if no response to the fax is received or if another brand name prescription is ordered.

Mr. David Dederichs, Express Scripts, confirmed that Express Scripts is in the process of acquiring Medco. Mr. Dederichs testified that Express Scripts strives to eliminate waste in the prescribing of drugs. Mr. Dederichs informed the Commission that 20% of prescriptions are brand names but account for 80% of drug costs. Mr. Dederichs stated that its clients work with Express Scripts in designing the benefit model to be used for the contract and that Express Scripts administers that design.

Mr. Don Stumpp, Indiana Medical Group Managers Association, testified that physicians often comment on the amount of uncompensated time that is spent dealing with a pharmacy benefit manager concerning benefit issues. Mr. Stumpp informed the Commission of a 2010 study concerning the amount of time spent in an office talking to pharmacy benefit managers. See Exhibit 5.

Ms. Rylin Rogers, Indiana Chapter of the American Academy of Pediatrics, testified that she has spent a lot of time dealing with pharmacy benefit managers and benefit issues. She introduced Ms. Heather Dane, the mother of a seven year-old son who has numerous medical conditions. Ms. Dane told the Commission about her experiences dealing with pharmacy benefit managers in an attempt to get her child the medication that their doctor had prescribed and that he needed. Ms. Dane stated that on several occasions, it took several days to go through the process once the pharmacy benefit manager had declined payment for a brand name drug and that her child did not receive the brand name medication he needed during that time.

Employment and training opportunities for individuals with disabilities

Senator Brandt Hershman discussed his resolution from the last legislative session and his work on employment issues concerning individuals with disabilities and the attempt to find incentives and opportunities to encourage employment of these individuals as well as to maximize the leverage of funds.

Mr. Mike Cruz, Executive Director of CDC Resources, stated that CDC operates its program in a five county rural area for individuals with cognitive and physical impairments.

Mr. Cruz has been working with other individuals to identify revenue neutral means to improve opportunities for individuals they serve. Mr. Cruz testified that one solution identified would be to establish a preference for the approximate 50 statewide companies that provide services to this population in order to allow the companies to effectively compete for state contracts. Mr. Cruz testified that this preference would allow for expansion without costing the state money. Mr. Cruz informed the Commission that the unemployment rate for this population is currently approximately 70%.

Ms. Jill Dunn, President of Bona Vista Programs, stated that Bona Vista provides services to 200 adults in North Central Indiana with intellectual and physical limitations, and that some of their clients that they have placed in the community in jobs are losing their jobs due to the economy. Ms. Dunn stated that the organizations have experienced rate reductions and need to diversify their work by increasing their participation in state contracts. Ms. Dunn asked for a level playing field in bidding for these contracts. Ms. Dunn introduced the Commission to one of her clients, George Schaffer, who testified concerning his experiences at Bona Vista Programs. Ms. Dunn testified that she did not feel that the incentive she is requesting would provide her organization with an advantage over a for-profit organization.

Mr. Jim Hammond, Indiana Association of Rehabilitation Facilities, provided the Commission with information on the state use program. See Exhibit 6. Mr. Hammond testified that this program provides a preference but is governed by a commission that has statutory duties. Mr. Hammond informed the Commission that between 60-75% of individuals with disabilities are unemployed. Mr. Hammond stated that this preference would be merely a tool to allow for more jobs and diversification. Mr. Hammond testified that the state needs to invest more in vocational rehabilitation and reinvest in community rehabilitation programs. Mr. Hammond said that requesting this preference is not trying to supplant the existing preference for minorities and women. Mr. Hammond provided some statistics concerning the effect of individuals being employed, including tax receipts collected when the individual is employed and an employed individual's quality of life.

The meeting was adjourned at 2:05 p.m.

HFC 9/14/11 Exh. 1

Testimony to the Health Finance Commission

June Holt, mother of adult child with acquired brain injury

September 14, 2011

First, I want to thank Senator Miller for her perseverance in addressing brain injury issues. It was two years ago that a group of families and individuals with brain injury asked her to look into services in Indiana. She has been focused on this issue ever since and is determined to see that something is done. **Thank you.**

I would also like to thank the members of the ad hoc subcommittee that was given the task of determining what needs to be done to allow us to stop sending our family members out of state to get the treatment they need. The ad hoc committee consisted of brain injury professionals, state employees, nursing home representatives, insurance professionals, and Brain Injury Association of Indiana Board members. I know that they have worked very hard to bring their proposal and solutions to you today and I thank them. I only regret that the committee didn't officially include anyone that lives with brain injury 24 hours/day 7 days/week - individuals with brain injury and their families. These folks can provide firsthand knowledge and expertise that no paid professional or state employee can. Please don't leave us out of the conversation and the planning for the futures of our loved ones.

The map that you see on the projection screen is a picture of my son's journey after suffering an acquired brain injury. Joe was lucky to be residing in Indianapolis, which is the hub of brain injury research and services in Indiana. And he was lucky that he had a parent that was already working in the field of long term care advocacy before he became ill. Joe had no resource facilitator to connect him with

the services and therapies he needed. No one was there to help his family find out what nursing facilities would admit a 25 year old in a partial coma with a tracheotomy tube and a G-tube. No one was there to guide him and his family through the maze of Medicaid, Social Security Disability, Medicaid Waivers, acute rehabilitation, post-acute rehabilitation and community reintegration. But Joe was lucky again because he had a parent who knew people that could answer our questions. I was never more than two phone calls away from any answer . Without these connections, Joe may have fallen through the cracks as so many people here in Indiana do. He could have lingered in nursing facilities for more than the two years he spent in five facilities.

Without the encouragement of my network of colleagues and friends, I would not have had the courage to challenge the state in its denial of sending him out of state for services. Joe spent two years living in Carbondale, learning how to become a part of society again, learning how to take control of some parts of his life, making friends, trying to understand what happened to the life he once knew and could never regain, learning to be independent in a different body and with a different brain. Joe went through this part of his recovery in a kind of vacuum - without the daily support of family and friends. If we had been closer, could we have helped him more and possibly accelerated his recovery? And if he'd received this kind of help in Indiana with the proper follow-up, would he now be more engaged in his community and new life instead of spending days alone in his own apartment with only the company of his waiver attendants? He is embarrassed about the way he looks and how he functions, he isn't making new friends and his old friends are gone. I fear for his mental health because he continues to be so isolated. I worry about what will happen to Joe when his dad and I die. Will he have made any new friends? Will he still need a legal guardian? Will his brain cancer return?

But, still, Joe is one of the lucky ones.

Today I am asking you, the Health Finance Commission, to listen to the report from Dr. Trexler and his committee. Take what he says into your heart, imagine how you would feel if it was your child, spouse, parent or best friend that had a brain injury. How would you like to send them into another state, hours away for months or years to get the treatment they needed?

Take the first step today that will bring our loved ones with brain injuries back into the state to receive post-acute neurorehabilitation. Let Indiana provide the full array of services that individuals with brain injury need. Please begin the process to enable capable therapists, counselors, and other brain injury professionals **that are already here in Indiana** to set up programs that will do far more for people with brain injury than what can be done out of state. Bringing back our folks from out of state also means that there will be a federal match added to the more than $10million that Indiana spends on their treatment.

As a family member I ask that you insist that only the highest quality programs will be provided by people trained in brain injury and rehabilitation of the body and the brain. The programs should be based on scientific evidence of what works to help individuals regain function that will lead to reentry into the community.

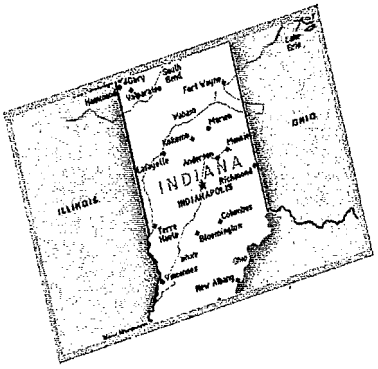
In closing I want to thank Senator Miller, the ad hoc subcommittee lead by Dr. Trexler, And the Health Finance commission for listening to me today.

But I also want to say, please don't cut families and persons with brain injuries, your constituents, out of the process of building a strong and lasting continuum of services for persons with brain injury. We are committed to the process for the rest of our lives

HFC Sept. 14, 2011 Exh. 2

Completing the Continuum of Care in Indiana:

Brain Injury Services & Support



Lance Trexler, PhD
Chair

September 2011

1 Presentation: Overview and Summary

2 List of Participants

3 Resource Facilitation: Community Participation and Vocational Outcomes

4 Resource Facilitation: Potential Economic Impact

5 Traumatic Brain Injury: Data Report (Indiana) 2007

6 Traumatic Brain Injury: Synthesis of Indiana Medicaid Data 2010

7 Neurobehavioral Rehabilitation Services: Iowa Administrative Rules-*DRAFT*

8 Traumatic Brain Injury Program Placement Criteria

9 Issue Brief: A Survey of Medicaid Brain Injury Programs

10 Appendix J - Guidance to Surveyors: Care Facility for People with Brain Injuries

Annotated Table of Contents

I. Presentation:
   a. Overview
   b. PPT presentation

II. List of Participants

III. Prospective Randomized Controlled Trial of Resource Facilitation on Community Participation and Vocational Outcome Following Brain Injury
   Lance E Trexler et al. Journal of Head Trauma Rehabilitation (2010).

IV. Potential Economic Impact of Resource Facilitation for Post-Traumatic Brain Injury Workforce Re-Assimilation
   Ian Reid et al. Research Note: Ball State University Center for Business and Economic Research (Nov/Dec 2010).

V. Data Report on Traumatic Brain Injury
   Jodi Hackworth and Joan Marciniak, Injury Prevention Program ISDH (December 12, 2007).

VI. Traumatic Brain Injury: Synthesis of Indiana Medicaid Data
   Medical Medicaid Advisory Cabinet (November 31, 2010).

VII. Neurobehavioral Rehabilitation Services: Draft Administration Rules (Iowa)
   Geoff Lauer, Executive Director BIA-IA (2011).

VIII. Traumatic Brain Injury Program Placement Criteria
   John Hinton, D.O., Senior Medical Director, Vulnerable Populations ADVANTAGE Health Solutions (2011).

IX. Issue Brief: A Survey of Medicaid Brain Injury Programs
   Leslie Hendrickson and Randall Blume. Rutgers Center for State Health Policy (March 2008).

X. Appendix J - Guidance to Surveyors: Care Facility for People with Brain Injuries
   Doug Beebe, Director, Hook Rehabilitation Center (Draft-2011). Expanded binder only.

XI. Indiana Medicaid Home and Community Based Services Waiver Programs: A Guide for Consumers
   Indiana Governor's Council for People with Disabilities (March, 2007).

BRAIN INJURY ASSOCIATION OF INDIANA

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THE VOICE OF BRAIN INJURY

Completing the Continuum of Care in Indiana: Brain Injury Services and Support

Testimony Overview

September 14, 2011

Lance E. Trexler, Ph.D.
Chair, Brain Injury Association of Indiana

Indiana currently lacks specialized brain injury rehabilitation services for those with neurobehavioral impairments. As a consequence, we are sending many of our patients with brain injury to out-of-state facilities. This practice results in separating the patient from their families and friends and fragmenting the continuity of care. Moreover, it also means that Indiana is sending approximately $12 million per year to out-of-state facilities.

A committee comprised of members of public and private-sector organizations as well as consumers led by the Brain Injury Association of Indiana (BIAI) was developed to a) cull key source documents, b) investigate the strategies other states have used to solve this problem, and c) develop consensus on possible solutions for Indiana. The committee has developed positive momentum and has shown a strong commitment to improve our care for people with brain injury.

The proposals that this committee suggests are appropriate are to:

- Create a new licensure category that will provide for a residential neurobehavioral "level of care"
- Modify an existing/create a new Medicaid waiver that includes neurobehavioral services
- Invest in services that significantly improve return to work rates for people with brain injury and would result in preventing over $22 million in lost wages each year as well as $10 million in lost business taxes and $4.8 million in personal tax revenues
- Ensure quality, coordination and cost effectiveness of brain injury services through an oversight committee

This cost-neutral legislation will result in bringing revenue and jobs to Indiana, improving outcomes for people with brain injury, and bringing a positive economic impact to Indiana.

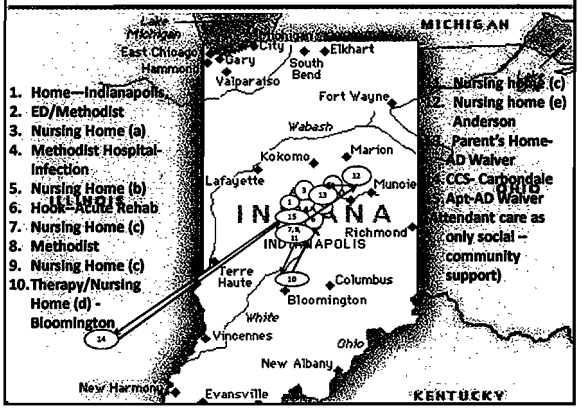
Completing the Continuum of Care in Indiana

Brain Injury Services and Support

Lance Trexler, PhD
Chair

BRAIN INJURY ASSOCIATION OF INDIANA

BRAIN INJURY JOURNEY: *Joe*

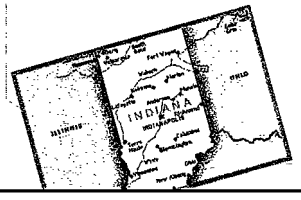


Completing the Continuum of Care in Indiana

Brain Injury Services and Support

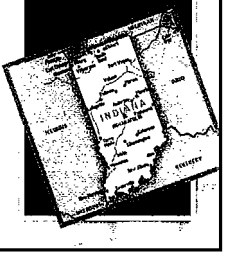
Lance Trexler, PhD
Chair

BRAIN INJURY ASSOCIATION OF INDIANA



Task Force Members

Lance E Trexler, Task Force Chair, BIAI Chair (Rehabilitation Hospital of Indiana)
Doug Beebe, Task Force Co-Chair, BIAI Board Member (Community Health Network)
Rebecca Bartle - Hoosier Owners & Providers for the Elderly
Brian Carnes - ISDH
Pat Casanova - OMPP/IFSSA
Tory Castor - IU Health
Zach Cattell - Indiana Health Care Association
Anna Garrett - Brain Injury Association of Indiana
Flora Hammond – IU School of Medicine
Julia Holloway – DDRS/FSSA
John Hinton - ADVANTAGE Health Solutions, Inc
Jeff Huffman – CarDon and Associates Inc.
Thomas John - Ice Miller LLP
Sean Keefer – ISDH
Rebecca Koors - FSSA
Faith Laird - FSSA
Sid Norton - Rehabilitation Hospital of Indiana
Megan Ornellas – Chief of Staff, FSSA
Kim Rhoades - ISDH
Karen Smith Filler - FSSA
Carole Surratt-Bradley – VR/FSSA
Terry Whitson – ISDH



Executive Summary

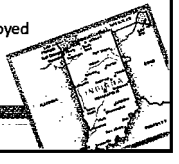
What is the problem?

Patients and their families are not being well served:

- Enter into a fragmented system of services
- Available facilities do not provide neurobehavioral treatments
- Lack of coordinated resource facilitation services to improve vocational outcomes

As a result, many patients are:

- Sent out of state to receive services
- Unnecessarily lose their jobs/remain unemployed
- End up in other state facilities
- Not served at all

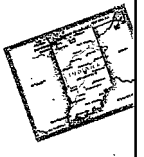


BRAIN INJURY ASSOCIATION

Executive Summary-*cont.*

What are the solutions?

1. Create a new licensure category that provides for residential neurobehavioral services
2. Invest in resource facilitation services
3. Ensure quality, coordination and cost effectiveness through an oversight committee



BRAIN INJURY ASSOCIATION

Why This is Important: Brain Injury in Indiana (ISDH 2007)

- 1,167 deaths/yr due to BI
- Annual ED visits=21,312; $39.7m (mild TBI)
- Annual inpatient admissions=4,587; $140.7m (moderate to severe BI)
- *Underestimated due to the lack of an Indiana trauma registry system*

Averaged over 2003-05

BRAIN INJURY ASSOCIATION

Brain Injury in Indiana: ISDH 2007

Incidence

Total Charges*

*Total charges due to TBI patients admitted to the hospital; 36% had Medicare/Medicaid

Averaged over 2003-05

BRAIN INJURY ASSOCIATION

Nursing Home Services

- Must have deficits in at least three activities of daily living (ADL):
  - Personal hygiene
  - Dressing/undressing
  - Self-feeding
  - Functional transfers
  - Toileting
  - Mobility

Yet many patients have significant cognitive deficits such as neurobehavioral and memory impairments that include:

- agitation
- aggression
- impulsivity
- impaired judgment
- severe mood swings

Not captured in the NF eligibility ADLs

BRAIN INJURY ASSOCIATION

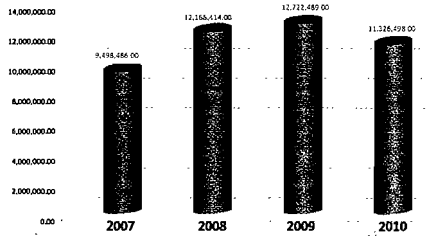
Neurobehavioral Facility

- To provide adequate treatment and services for brain injury patients which may include additional therapies or interventions beyond those available in a Nursing Facility.

Specifically neurobehavioral treatment protocols which would lead to successful rehabilitation/reintegration rates

BRAIN INJURY ASSOCIATION

Total Payment to BI Facilities Outside Indiana



BRAIN INJURY ASSOCIATION

Additional Challenges: Without Appropriate Care Model

Lack of continuity of medical management pre, during, and post rehabilitation	Neurobehavioral impairments typically re-emerge
Disrupts continuity and consistency of care	Out-of-state placement limits transition planning and family interaction
Thwarts access to state agency services (e.g. vocational rehabilitation, "money follows the person")	Removes patients from family and natural supports
Reintegration back into system of care, providers and family difficult	Lack of waiver funds delay discharge

BRAIN INJURY ASSOCIATION

Indiana's Current Residential Care Options for Persons with Neurobehavioral Disorders

1. ~~Nursing Facilities~~
2. Medicaid Waivers
   - ~~Developmental Disability Waivers~~ (under age 22)
   - ~~Traumatic Brain Injury Waiver~~
   - ~~Aged and Disabled Waiver~~
3. ~~Out-of-state neurobehavioral Medicaid placements~~
4. ~~Default settings: State hospital; Incarceration; homelessness~~ (i.e. It costs an avg of $54.28/day for adult inmate in Indiana or approx. $20,000/yr.)

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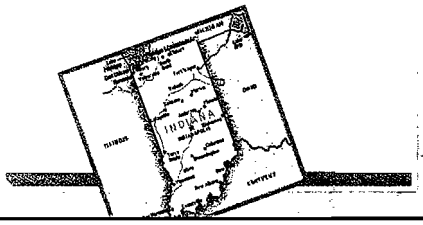
SO WHAT CAN WE DO?

Identifying Three Critical Priorities



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1. Provide Neurobehavioral Svc	Request DOH to establish licensure category for neurobehavioral facility to meet needs of persons with TBI
2. Coordinating Systems of Care/Returning Hoosiers to Work	Invest in Resource Facilitation Services
3. Ensuring Quality & Coordination	Establish an Oversight Committee

BRAIN INJURY ASSOCIATION

Priority 1: *Establish Neurobehavioral Residential Services in Indiana*

2 Strategies

1. ISDH create facility licensure to include:
   - Menu of clinical treatment and therapies
   - Develop/endorse assessment and treatment levels
   - CARF accreditation requirements
   - A review of current TBI waiver services
2. Open dialogue with states who are innovators in providing services to persons with TBI and learn from them

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States Using Neurobehavioral Level of Care:

Hendrickson & Blume, 2008

State	Level of Care
CT	Chronic Disease Hospital Acquired Brain Injury Facility
KS	TBI Rehabilitation Hospital
MN	Neurobehavioral Hospital
PA	Specialized Rehabilitation Nursing Facility
WI	Inpatient Traumatic Brain Injury Rehabilitation

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Priority 2: *Invest in Resource Facilitation Services*

Partnership that helps the client navigate the complex system of services and resources

Resource Facilitation (RF):

- "Systems-free" case management (e.g., medical, state, community agencies) for public/private resources
- Specialized in brain injury
- Proactive
- Promotes access to natural & purchased resources
- Supports person with brain injury & their family

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Demonstrated Success:

(Trexler et al, 2010. 2006-09 DDRS/BRS HRSA Grant)

- With Resource Facilitation 64% were able to return to work versus 36% in the control group
- Resource Facilitation subjects were found to be significantly more independent at home and in the community

HRSA
2010 "IMPACTING SYSTEMS CHANGE AWARD"

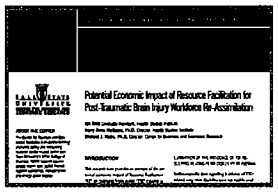
BRAIN INJURY ASSOCIATION

Economic Impact:

2009-13 DDRS/BRS HRSA Grant

If 64% of Individuals with BI in Indiana returned to work:

- Approx. 1,003 BI survivors would return to work each year
- Avoid approx. $31m annually in lost wages
- Prevent annual losses $10m from business tax; $4.8m from personal tax revenues



Cost : $1,000/patient

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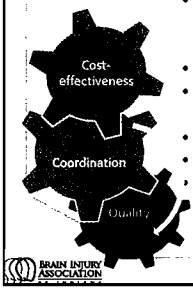
Priority 3: *Establish Oversight Committee to Ensure Cost Effectiveness, Coordination & Quality*



- Establish Indiana State Plan for Brain Injury to coordinate services across agencies and provider sectors
- Set facility and provider standards
- Monitor outcomes, quality and cost effectiveness
- Review and disseminate best practices
- Recommend minimum training requirements
- Advise and inform the administration and General Assembly on brain Injury issues

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Technical Strategies

- There are two pressing needs that need to be addressed: 1) Services that are appropriate for those who are injured after the age of 22; and 2) Services that meet the needs of the person

Visual

Waiver Strategy

- In order to have a waiver, there must be an institutional level of care. The requirement that the person be in an institution is waived so the person can receive services in the community.
- To accomplish this, the group is looking at taking the regulations that govern facility-based care for people with developmental disabilities as model for brain injury care and asking that the under age 22 requirement be dropped.

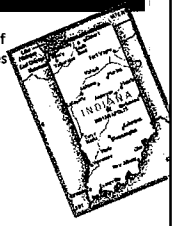
Visual

Facility Strategy

- CMS is very comfortable with the rules governing nursing home care
- The rule for Alzheimer's special care units has assisted nursing facilities to provide appropriate care for those needs
- We are looking at creating a special care unit rule for people with Brain Injuries that would allow enhanced services to meet their needs

Visual

This project is funded — in part — by a US Department of Health and Human Services, Health Resources and Services Administration, Traumatic Brain Injury Implementation Grant — grant number H21MC06756.

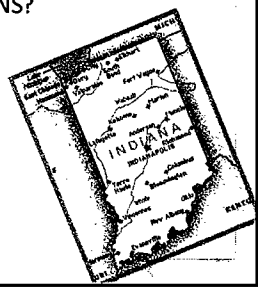


BRAIN INJURY ASSOCIATION OF INDIANA

...dedicated to reducing the incidence and impact of brain injury through education, advocacy, support, prevention ond by facilitating inter-agency commitment and collaboration.

Thank you!

.....QUESTIONS?



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Director, Department of Rehabilitation Neuropsychology, Program Director for Neurobehavioral Services
Rehabilitation Hospital of Indiana

Co-Chair: Douglas Beebe
Director, Hook Rehabilitation Center
Community Health Network

Rebecca Bartle
Regulatory Affairs Director
Hoosier Owners & Providers for the Elderly

Brian Carnes
Director of Legislative Affairs
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Brain Injury Association of America

Focus on Clinical Research and Practice, Part 3

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Prospective Randomized Controlled Trial of Resource Facilitation on Community Participation and Vocational Outcome Following Brain Injury

Lance E. Trexler, PhD; Laura C. Trexler, OTR; James F. Malec, PhD, ABPP-Cn, Rp; Daniel Klyce, MA; Devan Parrott, BS

Objective: To examine the impact of resource facilitation (RF) on return to work, participation in home and community activities, and depression. **Participants:** Twenty-two people with acquired brain injury (mean age = 43 years; mean education = 13.3 years). **Design:** A prospective randomized controlled trial of RF compared with standard care. All participants received standard follow-up services, but participants in the RF group were also assigned a resource facilitator to assist them in returning to work. **Results:** Participation increased significantly for both groups ($F = 60.65$, $P < .0001$), but the interaction between groups and time demonstrated greater improvement for the RF group relative to controls ($F = 9.11$, $P < .007$). Also, 64% of the RF group was employed at follow-up compared with 36% of the control group (Wald-Wolfkowitz $z = -3.277$, $P < .0001$). No significant differences were found between groups on measures of depression. **Conclusion:** Resource facilitation services that have a clear focus on return to work may have a substantial impact on participation and unemployment after brain injury. **Keywords:** *acquired brain injury, rehabilitation, resource facilitation, vocational rehabilitation*

THE number of individuals in the United States living with a long-term disability from traumatic brain injury (TBI) was estimated in 1999 to be more than 5 million.[1] An estimated 10 million Americans are affected by acquired brain injury (ABI), making ABI the second most prevalent injury and disability in the United States.[2] Acquired brain injury includes a variety of injuries to the brain after birth that affect its structure and functioning,[2] but are not hereditary, congenital, or degenerative. These injuries include trauma, intracranial hemorrhage and stroke, brain infections, and damage caused by systemic or metabolic disorders. The long-term challenges faced by these individuals include impairments of attention, learning and memory, and executive functions,[3–8] as well as reduced awareness and self-monitoring—factors all capable of compromising home, community, and work reentry, functional independence, and family/social long-term stability.[9,10]

The impact of brain injury on return to work is devastating. Several reviews have found rates of employment after TBI to be less than 40%. Wehman[11] and Ben-Yishay and colleagues[12] found that 10% or less of people with moderate to severe brain injury were employed. A recent systematic review of the literature on return to work after ABI was conducted by Velzen et al[13] for articles published between 1992 and 2008. These investigators found return to work rates of (*a*) 39.3% for subjects with stroke or subarachnoid hemorrhage at 2 years postinjury, (*b*) 40.7% for subjects with TBI at 1 year postinjury, and (*c*) 40.6% for subjects with TBI at 2 years postinjury. These estimates may be optimistic for natural recovery after brain injury since some studies that were reviewed appeared to include participants who may have received vocational interventions to assist their return to work.

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This research was in part funded by a US Department of Health and Human Services, Health Resources and Services Administration, Traumatic Brain Injury Planning and Implementation Partnership Grant and by the Dr Lisa Thompson Center for Family Education at the Rehabilitation Hospital of Indiana.

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A variety of clinical interventions have been tested with respect to their impact on return to work. Three overall approaches to vocational rehabilitation after TBI were found in a systematic review of articles published from 1990 to 2007[14]: (*a*) program-based vocational rehabilitation, (*b*) a supported employment model, and (*c*) a case coordination model. Exemplifying a program-based model of treatment, comprehensive day-treatment models were developed by Prigatano[15] and Ben-Yishay and colleagues,[12] which included individual and group therapies as well as vocational trials and supported employment. Programs that have implemented these models have demonstrated employment rates as high as 50%[16] and 75% to 85%.[17] These findings suggest that post-ABI day-treatment programs may substantially improve employment outcomes. Supported employment models, originally developed by Wehman et al,[18] emphasize on-the-job intervention provided by job coaches. The review by Fadyl and McPherson,[14] however, found relatively weak evidence to support this model. The case coordination model was developed by Malec and colleagues,[19,20] who evaluated the impact of an integrated medical/vocational case coordination (VCC) system on employment outcomes. The VCC services were offered in addition to post-ABI rehabilitation and provided for (*a*) early case identification and hospital-based VCC, (*b*) early medical and vocational rehabilitation interventions, (*c*) work trials, (*d*) employer education, and (*e*) temporary or long-term supported employment. These researchers demonstrated that 80% or more of subjects with brain injury who received VCC were employed in the community. Those who got earlier intervention had a better outcome, and rehabilitation gains were maintained at 1-year follow-up for all. It was also noted that reductions in psychiatric comorbidity might be achieved through early vocational interventions. The review by Fadyl and McPherson[14] demonstrated the strongest support for the case coordination model after considering the evidence and the quality of the research.

In most settings, however, medical/rehabilitative care continues to be poorly coordinated, with limited or scattered specialized treatment resources and providers lacking specialized brain injury treatment skills. Complex, dynamic, individualized needs must be matched with appropriate, accessible, timely, acceptable, and affordable services. Without assistance, individuals are often unable to locate, enter, or navigate complex systems of care, with additional challenges of dwindling personal resources, inadequate long-term private insurance funding, high rates of denial for state disability support, and extensive waiting lists on state Medicaid and Medicaid waivers.

Resource facilitation (*RF*), defined as "a partnership that helps people and communities choose, get and keep information, services and supports to make informed choices and meet their goals,"[21(p2)] could become a vehicle to break down barriers, increase access, and facilitate timely, coordinated management of resources, all designed to improve outcomes. Resource facilitation is referred to by many names: brain injury information and referral (I&R), neuroresource facilitation, early referral, brain injury resource facilitation, service coordination, and case management, to name several.[22] Despite this nominal variability, the conceptual underpinnings appear to be appreciably similar. Ragnarsson and colleagues[23] identified the components of comprehensive systems of care: access to an interdisciplinary team and services; spanning all phases of recovery from emergency care to home and community reentry; including vocation and education; behavior support; case management; and more. In 1989, the Minnesota Head Injury Foundation, now known as the Brain Injury Association of Minnesota, initiated the nation's first statewide RF program. Missouri, in 2003, established the TBI Early Referral Program and examined the benefits, utilizing a treatment/control design, of early RF.[24] Results indicated significantly better social integration, emotional well-being, and vocational functioning than the control group at follow-up, despite the fact that the group that received RF presented with greater functional limitations at enrollment. By any name, early, consistent, timely, and well-coordinated RF appears to be gaining notoriety and momentum across the United States.

Health Resources and Services Administration's (HRSA's) Federal TBI Program, TBI Technical Assistance Center at the National Association of State Head Injury Administrators, coordinates activities and projects completed by the Person and Family Directed Services Focus Area Work Group. This work group was formed in 2006, based on 1 of the 3 guiding principles of the Federal TBI Program: Person and Family Directed Services, and has expanded to include a subgroup on RF. In July 2008, the work group invited states, territories, and the District of Columbia to participate in a survey, providing information and details on RF services for individuals with TBI and family members. Eighty-three percent of the respondents (48/57 possible) indicated that they provide RF; however, breadth and depth were variable and primarily contingent on funding.

A variety of factors provided the framework for the present study, including the growth in the provision of RF services for people with brain injury, the interest of the HRSA work group, and, in particular, the previous research on RF. The primary hypotheses of the study were that the individuals with brain injury receiving RF services would have increased success in return to work as well as better participation at home and in the community.

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METHODS

Participants

A total of 23 people with ABI (and their caregivers) were recruited while either an inpatient or an outpatient at a large acute rehabilitation hospital in the Midwest of the United States. Inclusion criteria were as follows: (*a*) ABI, (*b*) injury in the last year or less, (*c*) aged between 18 and 60 years, (*d*) English as native language or nonnative speaker with conversational proficiency in the English language, (*e*) a caregiver willing to participate in the study, (*f*) the survivor had been employed and/or had attended school for 2 years prior to the injury, and (*g*) the survivor had a return-to-work or return-to-school goal. Exclusion criteria were as follows: (*a*) the presence of acute psychosis or the emergence of psychosis during the course of the study, (*b*) a history of treatment of substance abuse, (*c*) significant impairment of verbal expression, (*d*) noncompliance by the survivor or caregiver regarding treatment recommendations, and (*e*) the survivor was deemed not to have the potential to return to work or return to school within the time frame of the study (6 months) as determined by their attending neuropsychologist. For example, subjects who had protracted posttraumatic confusion throughout acute rehabilitation or who had never been gainfully employed were excluded. Following recruitment and obtaining informed consent, participants were randomly assigned to either RF ($n = 12$) or regular follow-up control conditions ($n = 11$). Analyses were performed on only 11 RF subjects because of missing data on primary measures for 1 subject. Data were not systematically collected on the number of subjects assessed for eligibility or for the number excluded because of not meeting eligibility criteria. Retrospective review of the recruitment process revealed that fewer than 5 eligible subjects refused to participate.

Measures

Nine RF participants and 11 controls were given the O-Log[25] and the C-Log,[26] respectively, as part of their routine clinical examination in the acute rehabilitation center prior to enrollment. These data were then used to determine the initial severity of cognitive impairment. Both the O-Log and C-Log were developed for bedside use in the acute rehabilitation setting as screening measures for orientation to time, place, and circumstances, and for attention, memory, and executive functions, respectively.

Ratings on the Participation Index of the Mayo-Portland Adaptability Inventory (M2PI)[27] were obtained for 11 RF participants and 11 controls both prior to intervention and at 6-month follow-up. The M2PI is composed of 8 items that measure the extent to which the subject experiences difficulties with social contact, recreational activities, self-care, transportation, management of finances, and productivity, including 1 item for paid employment and another item for other productive activity, including childrearing, volunteering, or participating as a student. The employment item of the M2PI, which provides information about extent of employment (ie, full-time, part-time, full or part-time employment) with support, sheltered, or unemployed, was rated for all participants. Scores on the PHQ-9[28] depression measures were available for 10 RF participants and 11 controls both at enrollment and at 6-month follow-up.

Procedures

Consenting participants were randomly assigned to either RF services or control conditions. Those in the RF group were assigned to 1 of 2 resource facilitators. The resource facilitators contacted the participants in the RF group every 2 weeks; facilitators had access to both the primary and secondary authors for supervision and clinical problem solving on a weekly or biweekly basis. In addition, case conferences were conducted 3 times during the 6 months of RF; these included the resource facilitator, the primary and secondary authors, and the subject's vocational rehabilitation counselor from the vocational rehabilitation state agency. The main priority of the RF services was to assist the participants in returning to work. Resource facilitation services were provided according to the model developed by the Brain Injury Association, and the primary domains of activity are summarized in Table 1.

All subjects receiving RF services were seen in an initial face-to-face evaluation, and services were provided in a variety of settings and through telephonic communication, including in an outpatient neurorehabilitation clinic, at their home, and in the community, including their place of work. A clear focus of the intervention was, when appropriate, to proactively engage the subject's former employer in a return-to-work plan. Employer education, titrating return-to-work schedules and functions, and facilitating utilization of job supports through both clinical (eg, occupational therapy) and employment specialists in collaboration with the state vocational rehabilitation agency were strategies frequently utilized to promote return to work. The subjects presented, however, very heterogeneous needs that were either directly or indirectly related to return to work and included arranging transportation, promoting access to mental health services, promoting family education, and assisting with access to a variety of state agency resources. The mean number of hours of intervention that the RF participants received was 10.6 and the median was 8.0.

Participants randomized into the control condition were contacted again at 6 months post enrollment to obtain follow-up measures, but there was no other contact

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TABLE 1 *Resource facilitation methods and activities*

Assess to identify current status, needs, and resources in life domains.
Plan and document mutually agreed upon, person-centered goals and service/resource needs.
Identify community-based resources, whenever possible, for services and supports, including emotional supports. Evaluate, through subjective report from participants, effectiveness of what has been utilized in the past.
Facilitate access to resources through education and advocacy.
Proactively monitor the status of the plan as well as the quality and appropriateness of the services and supports, and resources through telephone, Internet contact or personal contact when possible. Contact with either the caregiver or the individual with a brain injury occurred, at a minimum of, every 2 wk.
Provide education to the individual with a brain injury and principal support/caregiver. Education will include information on brain injury, personal advocacy and partnership development, and the development and maintenance of a personalized *Resource Facilitation Handbook* including a projected discharge plan.

[a]From Connors.[21]

during the interval. All participants received follow-up services recommended by their healthcare providers to which they had access, but no attempt was made to facilitate access or receipt of services for control condition participants. Depending on the recommendations of the team at the acute rehabilitation hospital at the time of discharge, members of the control group may have been receiving outpatient rehabilitation therapies, neuropsychological services, or medical follow-up. No additional attempt from a resource facilitator was made to facilitate access, coordinate systems, ensure acceptability, or assist with follow-through of tasks or service acquisition for those assigned to the control group.

Data were collected, describing the services participants were receiving, other than RF, including day-treatment outpatient programs, specialized brain injury outpatient programs that also included neuropsychological services, traditional outpatient programs, psychological services, whether or not they had become a client of the state vocational rehabilitation department, and if so, whether they received vocational rehabilitation services such as supported employment or assistance with job placement.

Analyses

The demographic variables gender and type of brain injury were analyzed using either the 2-tailed χ^2 test or the Fisher exact test to discover any differences between the 2 groups. Student's t test (2-tailed) was employed to identify group differences based on the time since injury (days from the time of injury until their enrollment in the study), age of the participants, education, and severity of cognitive impairment at the time of recruitment, and responses to the PHQ-9 and ratings of the M2PI at baseline.

A repeated-measures between-group analysis of variance (ANOVA) was used to examine changes in scores on the PHQ-9 and M2PI from baseline to 6-month post-treatment follow-up. A Wald-Wolfowitz nonparametric (2-tailed) test of the M2PI employment item was performed to compare the distributions of the 2 groups. Finally, a 2-tailed Fisher exact test compared the 2 groups' participation with rehabilitation and vocational services other than RF.

RESULTS

Analyses of demographic and injury-related characteristics revealed no significant differences between the groups at enrollment for age, sex, or education (Table 2). Seven of the 22 participants had TBI, 7 had intracranial hemorrhage, 6 had cerebral infarcts, and 2 had other diagnoses (leukoencephalopathy and tentorial meningioma with compression). Table 3 provides diagnostic information by group. Comparisons between the 2 groups revealed no between-group differences with respect to diagnoses ($\chi^2 = 0.286$, 2-sided, $P = .96$).

As Table 4 shows, the 2 groups were not significantly different with respect to time since injury, although

TABLE 2 *Demographic characteristics by groups*

Variable	Resource facilitation ($n = 11$)	Control ($n = 11$)	Statistic
Age, mean (SD)	43.18 (11.97)	42.64 (12.79)	$t = 0.103$, $P = .92$
Male/female	6/5	8/3	Fisher exact test, $P = .67$
Education, mean (SD)	13.27 (2.10)	13.36 (3.14)	$t = -0.08$, $P = .94$

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TABLE 3 *Diagnoses by groups*

	Diagnosis				
	Traumatic brain injury	Intracranial hemorrhage	Stroke	Other	Total
Control	4	3	3	1	11
Treatment	3	4	3	1	11
Total	7	7	6	2	22

noteworthy differences in the mean values were evident, where the control group was having considerably more chronic illness. It should be noted, however, that the median time since injury for the RF group was 52 days as compared with 85 days for the control group. The 2 groups did not differ on initial level on the O-Log and C-Log prior to intervention. Both groups showed mild levels of depression on the PHQ-9, with no significant differences between groups. The RF group was also significantly more impaired on M2PI ($t = 2.126$, $P = .046$) at the initial evaluation.

The effect of treatment was analyzed using repeated-measures ANOVA. Participation, as measured by the M2PI, increased for both groups over the course of the treatment period ($F = 60.65$, $P < .0001$). There was no main effect for groups. However, the interaction between groups and time was statistically significant ($F = 9.11$, $P = .007$), demonstrating a greater improvement for the RF group relative to controls, as illustrated in Figure 1. Examining the employment item of the M2PI specifically, 64% of the RF group was employed at follow-up (4 full-time; 3 part-time) compared with 36% of the control group (3 full-time; 1 part-time). The distributions of these ordinal data (ie, full-time, part-time, unemployed) were significantly different between the 2 groups (Wald-Wolfkowitz $z = -3.277$, $P < .0001$). PHQ-9 scores declined to 6.7 for the RF group and to 5.09 for the control group at follow-up. However, repeated-measures ANOVA of PHQ-9 scores revealed no significant differences between groups over time or for the interaction of these factors ($F = 0.539$, $P = .47$).

Examination of treatments other than RF demonstrated that no significant group differences were present for types of post-ABI rehabilitation or receipt of psychological services when these services were examined individually (Fig 2). Participants in the RF group were significantly more likely to have become a client of the State Bureau of Vocational Rehabilitation (Fisher exact test, $P < .0001$). These findings are consistent with the overriding goal of the RF services to promote return to work, and as such, soon after RF services were initiated, subjects were referred to the State Bureau of Vocational Rehabilitation. However, not all RF subjects who became clients of the State Bureau of Vocational Rehabilitation were found to need employment services such as job coaching or supported employment. Nonetheless, more RF participants received services from vocational rehabilitation but the difference between groups was not statistically significant (Fisher exact test, $P = .15$).

TABLE 4 *Time since injury and initial cognitive and outcome measures by groups*

	Mean (SD)		
Variable	Resource facilitation	Control	Statistic
Time since injury, d	64.50 (46.93) $n = 12$	124.18 (107.38) $n = 11$	$t = -1.754$, $P = .11$
O-Log	25.56 (4.82) $n = 9$	26.36 (3.93) $n = 11$	$t = -0.413$, $P = .68$
C-Log	22.67 (6.26) $n = 9$	20.91 (5.61) $n = 11$	$t = 0.662$, $P = .52$
M2PI	21.90 (5.20) $n = 11$	16.82 (6.00) $n = 11$	$t = 2.126$, $P = .046$
PHQ-9	9.91 (7.31) $n = 11$	6.18 (5.36) $n = 11$	$t = 1.36$, $P = .19$

Abbreviations: C-Log, the Cognitive Log; O-Log, the Orientation Log; M2PI, Mayo-Portland Adaptability Inventory.

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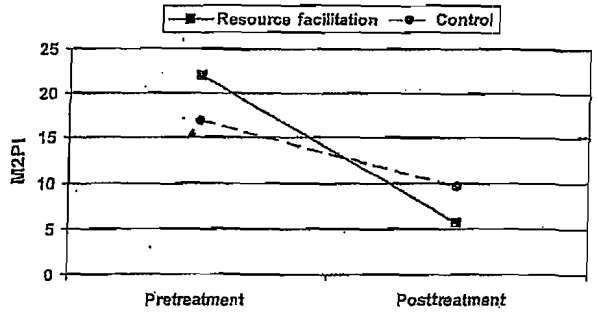

Figure 1. The Mayo-Portland Adaptability Inventory (M2PI) by group and time.

DISCUSSION

The rates of unemployment following brain injury without specialized rehabilitation or interventions are disturbing, ranging from 60% to 90%. Interventions that not only improve employment outcomes are salient from a socioeconomic perspective but also, as shown by a variety of investigators, return to work is associated with improved quality of life[29] and perceived mental health.[30] Various rehabilitation strategies have been developed to improve employment outcomes, including comprehensive day treatment,[12,15,17] supported employment,[11] and VCC.[19,20] Some studies have found significant improvements in the rate of employment following brain injury, with as many as 70% to 90% employed in either supported or competitive jobs. In contrast, a recent review of literature has demonstrated that the prevailing rate of employment after ABI was approximately 40% after 2 years,[13] although these investigators did not control for postacute rehabilitation received.

The present study suggests that RF may have a significant impact not only on return to work but also on participation in the community and at home. While all participants improved on the M2PI, those receiving RF demonstrated a significant improvement over the controls. Resource facilitation did not appear to affect mental health, at least with respect to our measure of depression. The results clearly indicated that persons in the RF group were more engaged in vocational services, and promoting accessibility to vocational rehabilitation was a clear priority of the RF process. There were no significant differences between the groups in terms of their participation in other outpatient services.

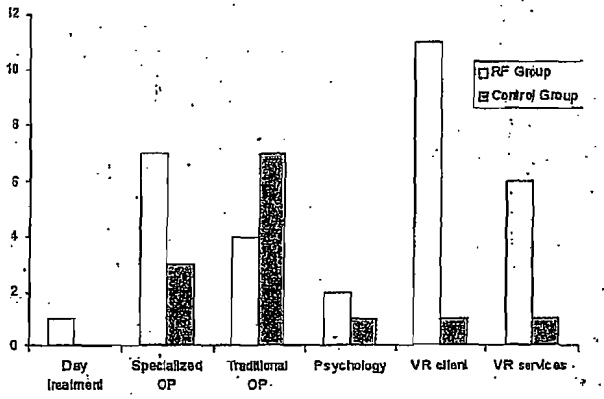

Figure 2. Frequency of rehabilitation services by group. OP indicates outpatient program; VR, vocational rehabilitation.

While the ratings on the M2PI item for employment are quite objective and discreet, for example, "full-time (>30 h/wk) without support" versus "part-time (3–30 h/wk) without support," the outcome data were collected by the people who provided RF services. This "unmasked" feature represents a significant limitation of the present study. The other obvious limitation of the present study is the sample size; future studies need to include more participants. In addition, while there were no differences between the groups in terms of diagnosis or initial severity of cognitive impairment, the present study employed diagnostically heterogeneous individuals. Generalizing the present findings to each of these diagnostic groups is not possible because of the significant variability in severity of injury, trajectory of recovery, and types of impairments that follow.

Other limitations of the present study include possible differences in terms of other postacute services received. As demonstrated in Figure 2, a nonsignificant difference can be seen in the number of RF participants who received specialized brain injury outpatient rehabilitation as compared with the number of controls who received traditional outpatient discipline-specific services. It may be that RF services directed more persons in the RF group to specialized brain injury rehabilitation services (eg, programs of rehabilitation designed explicitly for people with brain injury), and the findings herein demonstrated may, in part, be attributable to the effects of specialized outpatient brain injury rehabilitation beyond the effects of RF services. Moreover, those in the RF group more frequently received vocational services, again most likely because they were receiving RF, which may account for their better outcomes. While group differences were not statistically significant in terms of vocational services received, this may be attributable to the small sample size. Future studies should seek to better measure the quantity and types of other outpatient services to determine the extent to which RF promotes outcome in contrast to the services to which the individual has access by virtue of RF.

Finally, future studies should gather systematic data for the level and type of preinjury and postinjury employment. The present study did not examine how many of those persons who did return to work rejoined their former position or organization or to a new employer. The present study did not examine the influence of type and level of preinjury employment on RF outcomes.

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Additional data on these variables would better guide clinical practice and future research. Nonetheless, the present study has demonstrated that 6 months of RF, particularly if provided soon after discharge from acute rehabilitation, may be an effective model to proactively promote access to and coordination of services that result in better community participation and return to work. Furthermore, the present study has identified a variety of opportunities to refine methodology in future studies of RF.

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March 2011

Dear Friends,

I am pleased to share with you a recent research note from the Center for Business and Economic Research regarding the potential economic impact of resource facilitation for post-traumatic brain injury workforce re-assimilation.

It is estimated that over 6,180 Hoosiers experience TBI-related long term disability each year, and it can be assumed that the economic impact of brain injury on the state of Indiana is significant, including lost wages, cost of Medicare and Medicaid and other tax revenues. The goal is to get these individuals back to their communities, homes and workplaces as soon as possible. However, many Hoosiers do not have access to resources to facilitate such a return. A recent study showed that 64% of brain injury patients who had access to resource facilitation were able to return to work, versus 36% who could not.

With this latest research note, we are now able to quantify the cost of lost wages and other revenue to Indiana and even more importantly, the potential recaptured earnings as a result of resource facilitation. For example, based on the average earnings of $30,925 for those employed in Indiana (age 25 years +), the conservative ANNUAL economic impact of resource facilitation treatment is:

- $22 million dollars in avoidance of lost wages;
- $10 million in business tax revenues; and
- $4.8 million in personal tax revenues.

The average cost of resource facilitation services per patient is $1,000. Even with over 6,000 Hoosiers impacted by brain injury each year, the potential return on investment for the state and our citizens is exponential.

Those of you who know me recognize that I am committed to increasing awareness and understanding of brain injury across our state, but the impact of this study goes beyond just awareness and understanding. The way we serve those impacted by brain injury is also directly affecting our economic and social stability. I urge you to take a closer look at this study and the potential for positive change for all us.

Sincerely,

Patricia L. Miller
State Senator

Enclosure

BALL STATE UNIVERSITY.
CENTER FOR BUSINESS AND ECONOMIC RESEARCH

Potential Economic Impact of Resource Facilitation for Post-Traumatic Brain Injury Workforce Re-Assimilation

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Michael J. Hicks, Ph.D. Director, Center for Business and Economic Research

INTRODUCTION

This research note provides an estimate of the potential economic impact of Resource Facilitation (RF) on traumatic brain injury (TBI) patients in Indiana. We simulate the economic impact of this intervention on the estimated population of traumatic brain injury patients in Indiana per year and provide estimates of the earnings losses associated with TBI associated long-term disability. These losses will, potentially, be avoided as a result of RF interventions.

METHOD & ESTIMATION ISSUES

A major benefit of RF is return to work. A recent randomized clinical trial describes those who were treated with RF versus a control group were significantly more likely to return to work.[3] Therefore, in order to quantify the economic impact of RF in Indiana, we begin by modeling the potential annual workforce loss due to TBI-related long-term disability. Then, we can estimate a portion of the economic impact of RF by comparing the lost earnings of TBI patients who were and were not treated with RF. This estimate is a lower bound estimate of the total economic impact. Further discussions will provide estimates of the economic value of additional considerations such as fringe benefits, Medicare/Medicaid costs, and state-level taxes.

ESTIMATION OF THE INCIDENCE OF TBI RESULTING IN LONG-TERM DISABILITY IN INDIANA

Indiana-specific data regarding incidence of TBI-related long-term disability were not readily available. Therefore, national statistics (as described below) were adjusted by a weight of Indiana's population relative to the United States' population to determine the incidence of TBI-related long-term disability in Indiana. The national incidence data was drawn from various sources: specific national statistics for the annual number of TBI-related long-term disabilities; national estimates of the annual number of TBI-related long term disability by age, gender and level of disability; the national statistics of the number of hospitalizations associated with TBI-related long-term disability annually.

ESTIMATION OF WAGES LOST IN INDIANA DUE TO TBI-RELATED LONG-TERM DISABILITY

Methodology 1: The first estimate we provide is a baseline estimate of the potential annual earnings applicable to those in Indiana who suffer a long-term disability due to TBI. This estimation has two parts. First, we use the estimation of TBI incidence in Indiana, as previously described, to estimate the annual workforce loss. Data indicating the number of persons who return to work

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ABOUT THE STUDY

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with and without RF treatment in conjunction with employment statistics for persons before suffering a TBI are used to adjust the Indiana TBI incidence. Next, we adjust the workforce loss estimation by average annual earnings of an Indiana resident to estimate the annual amount of wages lost due to TBI-related long-term disability.

Methodology 2, Age—Education Adjusted Estimates: To provide estimates of the wages lost in Indiana due to TBI-related long-term disability, we modify the baseline model to incorporate age and educational attainment statistics. First, national statistics for TBI incidence, by age group and education level, were adjusted for Indiana. For this method, we assume workforce eligible persons are individuals no younger than 15 and no older than 79. Another important factor included in this methodology is gender. Males are twice as likely as females to be subject to a TBI and the average male's earnings in Indiana is greater than the average female's earnings for all education attainment groups. Finally, the estimation of workforce loss is adjusted to account for those who return to work with and without RF treatment.

RESULTS

THE INCIDENCE OF TBI RESULTING IN LONG-TERM DISABILITY IN INDIANA

80,000 and 99,000 people in the United States suffer a TBI resulting in a long-term disability due to TBI annually.[5,6,7] The aggregate TBI incidence in the United States annually is between 1,500,000 and 1,700,000.[1,2] This range can be further categorized by injury severity as: mild, moderate, and severe. Approximately, 15%-25% of TBI are moderate to severe requiring hospitalization.[1,3,6,10,11] Using these incidence rates Indiana's share of TBI-related long-term disability is 6,181 persons per year.

ESTIMATION OF WAGES LOST IN INDIANA DUE TO TBI-RELATED LONG-TERM DISABILITY

Methodology 1: With RF treatment, a clinical trial shows 64% are employed post-treatment; while without RF treatment, 36% are employed post-treatment.[3] Therefore, on average 1,003 Indiana residents would return to work with RF treatment. The average earnings for those employed in Indiana and who are 25 years old or older is $30,925.[14] Therefore, the average economic impact of RF treatment is $31,017,775 annually in avoided lost wages.

TABLE 1: TBI-RELATED DISABILITIES PER AGE GROUP IN INDIANA

Age Group	Percentage	Persons	Percent Employed
0-4	15.8 %	979	
5-9	6.8 %	418	
10-14	7.6%	472	
15-19	11.0%	680	36.7%
20-24	9.6%	591	65.5%
25-34	12.5%	770	77.1%
35-44	9.6%	595	77.1%
45-54	8.0%	497	77.8%
55-64	5.0%	311	61.1%
65-74	4.2%	262	23.2%
75 +	9.8%	607	5.8%
Total	**100 %**	**6,181**	

Methodology 2, Age—Education Adjusted Estimates: Next, the lost wages are further adjusted by age, percent employed, and educational attainment. Please see Table 1.[1,2,14]

Adjusting by age, we assume only age groups 15-79 are workforce eligible. This results in approximately 4,313 persons per year who suffer a long-term disability due to TBI. Using the age distribution for Indiana residents affected by TBI-related long-term disability, the percentage of persons employed per age group, and the educational attainment and respective average salaries (Please see Table 2[14]) we estimate the potential annual earnings lost. We adjust this by the return to work rate with and without RF treatment, as previously mentioned.

To map the 15-19 and 20-24 age groups, we assumed persons in those age groups to have less than high school, high school graduate, or some college or associate's degree level of educational attainment. The average earnings for the appropriate educational attainment groups are multiplied by the number of estimated Indiana residents in the respective age groups. The individuals between 25-79 years old were appropriately distributed across each educational attainment level and the respec-

TABLE 2: EDUCATIONAL ATTAINMENT & EARNINGS OF INDIANA RESIDENTS

Education Level	Percentage of Residents	Average Male Wages	Average Female Wages
Less than high school	14.2%	$24,767	$14,259
High school graduate*	36.5%	$34,855	$21,089
Some college or associate's degree	27.3%	$41,415	$25,726
Bachelor's Degree or higher	14.0%	$55,177	$35,480
Graduate degree or higher	7.9%	$68,895	$49,401

**includes equivalency*

tive earnings per educational attainment group were applied. Using this methodology, we estimate the average economic impact of RF treatment to be $22,561,796 annually.

DISCUSSION

It is important to bear in mind the estimates of approximately $31 million and $22.5 million in additional earnings recaptured as a result of RF treatment is a very conservative, annual estimate. Further analysis could be done to illustrate additional loss by incorporating long-term projections of wages lost as opposed to only annualized estimates. This could be done utilizing age groups, similar salary estimates as in method 2, and tracking when each particular age group enters and leaves the workforce; and the present value of the flows. For example, when a 45 year old suffers a disability due to TBI, the economy forgoes roughly 20 years of their earnings. Assuming those wages are $30,000 annually, the present value of the lost earnings is over $1 million over the remainder of the individuals working life. Aggregating this example across our sample provides avoidable lost earnings with a present value in billions of dollars due to annual undertreated TBI in Indiana.

As previously mentioned, there are other potential losses to the state of Indiana due to the annual workforce loss that are not reflected in our estimates. For instance, the estimates do not reflect the annual losses to business tax revenues ($10 million) or personal tax revenues ($4.8 million) that result from workforce loss. Fringe benefits and Medicare/Medicaid costs are other examples of such losses not reflected in this research note.

This study assumes only those who suffer a long-term disability from TBI are lost from the workforce. TBI-related injuries that do not result in a long-term disability could still cause temporary loss to the workforce. However, the current methodology implicitly makes the derived estimates more conservative.

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CENTER FOR BUSINESS AND ECONOMIC RESEARCH RESEARCH NOTE

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Indiana State Department of Health
Injury Prevention Program
Data prepared by Jodi Hackworth and Joan Marciniak
December 12, 2007

Data Report on Traumatic Brain Injury

DATA HIGHLIGHTS

- The leading causes of TBI in the United States and in Indiana are falls, motor vehicle crashes, struck by/against events, and assaults. The estimated direct and indirect costs of TBI in the United States in 2000 were $60 billion.[1]

- In the United States, 1.4 million people sustain a TBI each year. Of the 1.4 million people, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department (ED) each year.[2]

- The CDC has estimated that at least 5.3 million Americans, approximately 2% of the U.S. population, currently have long-term or lifelong need for help to perform activities of daily living as a result of a TBI.[3]

Indiana Data for 2003-2005:

Mortality Data

- There were 3,500 TBI deaths in Indiana. More males (2,557) died than females (943), with males dying at a rate almost three times greater than females. Although the number of deaths among whites (3,107) was higher than in blacks (368), the age-adjusted death rate shows that blacks died more often than whites in relation to their population.

- Males and females over 65 years of age had the highest TBI death rates. While whites over 65 years of age had the highest death rate, in blacks the highest death rate was in those ages 25-34 years.

- White males over 65 years of age (64.8 per 100,000) and black males 25-34 years of age (64.5 per 100,000) had almost identical TBI death rates.

Indiana Emergency Department Data

- Of the 1,662,783 outpatient/emergency department (ED) visits with a primary diagnosis for injury or poisoning, 63,936 were visits related to TBI, which represented 4% of all outpatient/ED visits. Of those receiving treatment at the outpatient/ED, 57% (36,663)

were male, and 43% (27,270) were female. The age-adjusted rates for visits to the outpatient/ED were similar for whites and blacks.

- The age group with the highest age-adjusted rate of outpatient/ED visits due to TBIs was 0 to 4 year olds with a rate of 1,671.12 per 100,000, followed by individuals 15 to 19 years of age with 680.74 per 100,000.

- The total charges for TBI that were treated in an outpatient/ED were $119 million. The majority of the patients had commercial insurance (34%) or Medicare/Medicaid (28%).

Indiana Hospital Inpatient Data

- There were 161,198 inpatient hospitalizations with a primary diagnosis of injury or poisoning. Of these, 13,762 were for TBI, which represents 9% of all hospital admissions patients who had a primary diagnosis of injury or poisoning.

- Of those admitted to the hospital for TBI, 62.5% were male and 37.5% were female. When comparing rates, males were 1.8 times more likely to be admitted to the hospital following a TBI than females. The age-adjusted rate for hospital admissions was higher in blacks compared to whites.

- The age group with the highest age-specific rate of hospital admissions due to TBIs was the 85+ year olds. The lowest age-specific rate of hospital admissions due to TBIs was the 1-4 year old population. The age-specific rates began increasing with the 65+ year olds.

- For 2003-2005, the total charges due to TBI patients who were admitted to the hospital were $422 million. The majority of the patients had Medicare/Medicaid (36%) or commercial insurance (30%). The average length of stay for a TBI patient was 6.79 days (Range 1- 152 days) and the median length of stay was four days.

Traumatic Brain Injury

2003-2005

Introduction

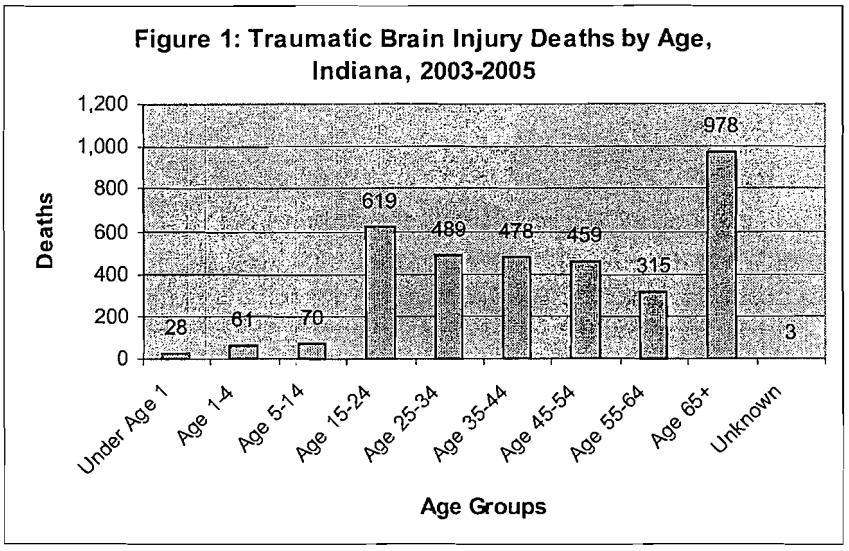
A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in TBI. The severity of TBI may range from "mild" to "severe" and can result in short or long-term problems with independent functioning. The leading causes of TBI are falls, motor vehicle crashes, struck by/against events, and assaults. The estimated direct and indirect costs of TBI in the United States in 2000 were $60 billion.[1]

According to data from the Centers of Disease Control (CDC), 1.4 million people sustain a TBI each year in the United States. Of the 1.4 million people, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department (ED) each year. In the United States, males are about 1.5 times as likely as females to sustain a TBI. Blacks have the highest rate of death from TBI compared to all other races. The age groups at highest risk for TBI are 0-4 year olds and 15 to 19 year olds.[2] The CDC has estimated that at least 5.3 million Americans, approximately 2% of the U.S. population, currently have long-term or lifelong need for help to perform activities of daily living as a result of a TBI.[3]

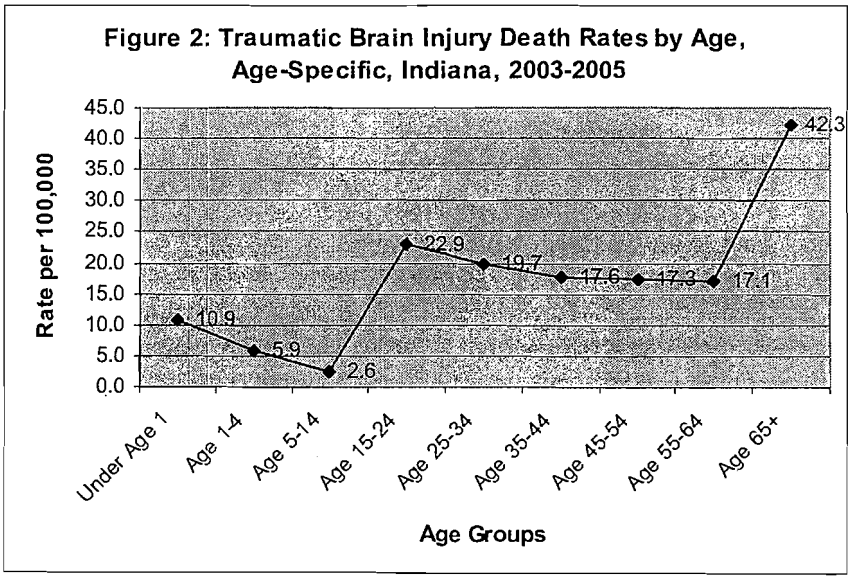
Mortality

Between 2003 and 2005, there were 3,500 TBI deaths in Indiana. More males (2,557) died than females (943), with males dying at a rate almost three times greater than females (27.8 per 100,000 for males, 9.9 per 100,000 for females). Although the number of deaths among whites (3,107) was higher than in blacks (368), the age-adjusted death rate shows that blacks (22.5 per 100,000) died more often than whites (18.7 per 100,000) in relation to their proportion in the population. Figure 1 shows the number of deaths per age category. When comparing death rates, Indiana residents over 65 years of age died most often from TBI injuries (42.3 per 100,000) followed by those ages 15-24 years (22.9 per 100,000) (Figure 2). When combining age and sex, males and females over 65 years of age had the highest rates (62.9 per 100,000 for males, 28.0 per 100,000 for females) (Table 1).[4]

When looking at race and age, whites over 65 years of age (43.6 per 100,000) had the highest rate; however for blacks the highest rate was in those ages 25-34 years (36.5 per 100,000) (Table 2). Blacks ages 15-24 years followed closely with a death rate of 34.8 per 100,000. When considering all race, sex, and age categories, white males over 65 years of age (64.8 per 100,000) and black males 25-34 years of age (64.5 per 100,000) had the highest rates with the death rates being almost identical (Table 3a). For females, whites over 65 years of age had the highest rate (28.8 per 100,000) followed by whites ages 15-24 years (11.7 per 100,000) (Table 3b). Rates for black females by age were unstable due to the low numbers of deaths in each category.[4]



Source: Indiana State Department of Health, Mortality Data, 2003-2005



Source: Indiana State Department of Health, Mortality Data, 2003-2005

Table 1: Traumatic Brain Injury Deaths and Rates by Sex and Age, Indiana, 2003-2005

	Male Number	Male Age-adjusted Rate	Female Number	Female Age-adjusted Rate
Under Age 1	15	U	13	U
Age 1-4	36	6.8	26	5.1
Age 5-14	48	3.5	22	1.7
Age 15-24	474	34.3	145	11.0
Age 25-34	393	31.2	96	7.9
Age 35-44	376	27.6	102	7.5
Age 45-54	373	28.3	86	6.4
Age 55-64	244	27.4	71	7.5
Age 65+	596	62.9	382	28.0
Unknown	3	--	0	--
Total	2,558	27.8	943	9.9

U=numerator is less than 20 and the rate is unstable.
Source: Indiana State Department of Health, Mortality Data, 2003-2005

Table 2: Traumatic Brain Injury Deaths and Rates by Race and Age, Indiana, 2003-2005

	White Number	White Age-adjusted Rate	Black Number	Black Age-adjusted Rate	Other Number	Other Age-adjusted Rate
Under Age 1	26	11.9	2	U	0	U
Age 1-4	54	6.1	6	U	1	U
Age 5-14	60	2.6	9	U	1	U
Age 15-24	522	22.2	94	34.8	3	U
Age 25-34	397	18.4	87	36.5	5	U
Age 35-44	417	17.2	54	23.5	7	U
Age 45-54	406	16.9	51	25.0	2	U
Age 55-64	285	16.8	28	23.8	2	U
Age 65+	939	43.6	37	27.4	2	U
Unknown	1	--	0	--	2	--
Total	3,107	18.7	368	22.5	25	5.2

U=numerator is less than 20 and the rate is unstable.
Source: Indiana State Department of Health, Mortality Data, 2003-2005

Table 3a: Traumatic Brain Injury Deaths and Rates by Race and Age, Males, Indiana, 2003-2005

	Males			
	White Number	**White** Age-adjusted Rate	**Black** Number	**Black** Age-adjusted Rate
Under Age 1	13	U	2	U
Age 1-4	32	7.1	2	U
Age 5-14	39	3.3	8	U
Age 15-24	387	32.2	85	62.5
Age 25-34	317	28.7	74	64.5
Age 35-44	328	26.9	42	38.5
Age 45-54	331	27.6	40	42.5
Age 55-64	219	26.6	23	43.0
Age 65+	573	64.8	21	39.5
Unknown	1	--	0	--
Total	2,240	27.4	297	37.9

U=numerator is less than 20 and the rate is unstable.
Source: Indiana State Department of Health, Mortality Data, 2003-2005

Table 3b: Traumatic Brain Injury Deaths and Rates by Race and Age, Females, Indiana, 2003-2005

	Females			
	White Number	**White** Age-adjusted Rate	**Black** Number	**Black** Age-adjusted Rate
Under Age 1	13	U	0	U
Age 1-4	22	5.1	4	U
Age 5-14	21	1.9	1	U
Age 15-24	135	11.7	9	U
Age 25-34	80	7.6	13	U
Age 35-44	89	7.4	12	U
Age 45-54	75	6.2	11	U
Age 55-64	66	7.6	5	U
Age 65+	366	28.8	19	U
Unknown	0	--	0	--
Total	867	10.3	74	8.7

U=numerator is less than 20 and the rate is unstable.
Source: Indiana State Department of Health, Mortality Data, 2003-2005

Morbidity

Hospital discharge data was queried using SAS, version 9.0 for TBI-related codes in any diagnosis field. Due to some patients having multiple TBI diagnosis, the data summarizes the first TBI code presented for each patient. TBI codes include: 800(.0-.9), 801 (.0-.9), 803(.0-.9), 804(.0-.9), 850(.0-.9), 851(.0-.9), 852(.0-.5), 853(.0-.1), 854(.0-.1), 950(.0-.3), 959.01, and 995.55.

Hospital discharge data give an indication of the number of TBI injuries in Indiana although the data have limitations. The hospital data base does not contain a patient-specific unique identifier, meaning that it does not distinguish whether one person had five visits or whether five people visited once. Therefore, statistics only reflect visits and not specific numbers of people. Also race/ethnicity data is not very accurate because race/ethnicity is at the discretion of the person reporting the data and may not reflect how the individuals would define themselves.

A major limitation of the hospital discharge data is that Indiana law does not mandate e-coding of hospital records. Only 55% of hospital records are e-coded. Also, Indiana law only requires hospital discharge data submission by acute care hospitals. Therefore, a few psychiatric and behavioral health hospitals do not submit data. All acute care hospitals are submitting inpatient data. However, one of the three Level 1 Trauma center hospitals has not submitted outpatient/emergency department data yet. As a result, **the total number of TBI incidents for the outpatient/emergency department data is an underestimation of the actual number of traumatic brain injuries and should be used with caution.**

Emergency Department Data

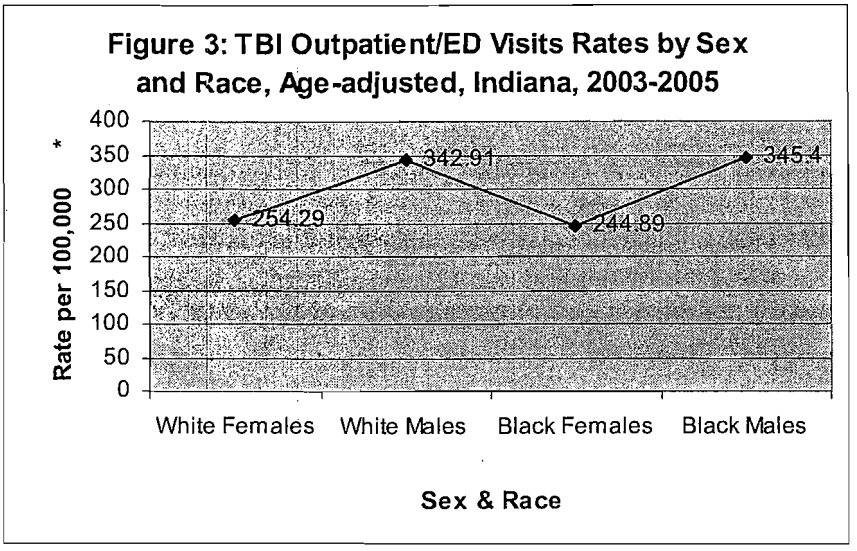
During 2003-2005, there were 1,662,783 outpatient/emergency department (ED) visits with a primary diagnosis for injury or poisoning (ICD-9-CM) codes 800-999. Of the 1,662,783 outpatient/ED visits, 63,936 were visits related to TBI and represented 4% of all outpatient/ED visits.[5]

Of those receiving treatment at the outpatient/ED, 57% (36,663) were male, and 43% (27,270) were female (three people's gender was unknown). When comparing rates, males had a higher rate of outpatient/ED visits than females (393.51 per 100,000 compared to 287.50 per 100,000). The majority (49,351/63,936) of the admissions to the outpatient/ED were white Indiana residents. Blacks made up 7.9% (5,074/63,936) and those in the minority/other category were 14.9% (9,511/63,936) of visits. The age-adjusted rates for visits to the outpatient/ED were similar for whites and blacks (300.50 per 100,000 versus 295.41 per 100,000). White males accounted for 43.9% (28,036/63,936) of all visits to the outpatient/ED, white females for 33.3% (21,313/63,936), black males for 4.6% (2,947/63,936), and 3.3% for black females. However, when comparing rates black males had the second highest age-adjusted rate (345.40 per 100,000) despite the lower number of injuries (Figure 3).[5]

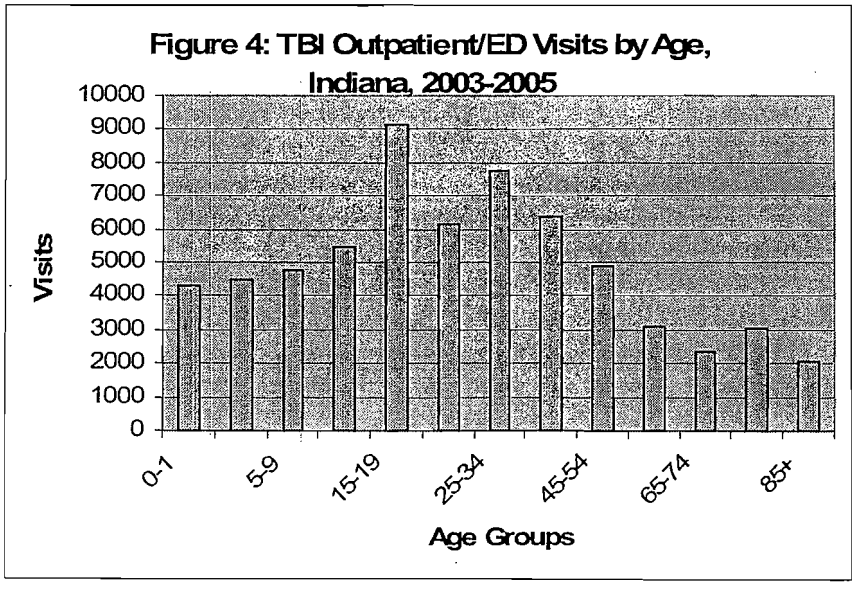
During 2003-2005, the age group with the highest age-adjusted rate of visits to the outpatient/ED due to TBIs was the 0 to 4 year olds with a rate of 1,671.12 per 100,000 followed by individuals 15 to 19 years of age with 680.74 per 100,000. The lowest age-adjusted rate of visits to the outpatient/ED due to TBIs was for those 55 to 64 years of age. Figure 4 shows the actual number of hospital outpatient/ED for each age group while Figure 5 shows the age-adjusted rate for each age group.[5]

The median total charge for patients seen in the outpatient/ED for TBI injury was $1,410.00 (Range $0-$70,658) as compared to the mean total charge for all ages of $1,875.00 (Range $0 - $70,658) (4). For 2003-2005, the total charges for TBI that were treated in an outpatient/ED

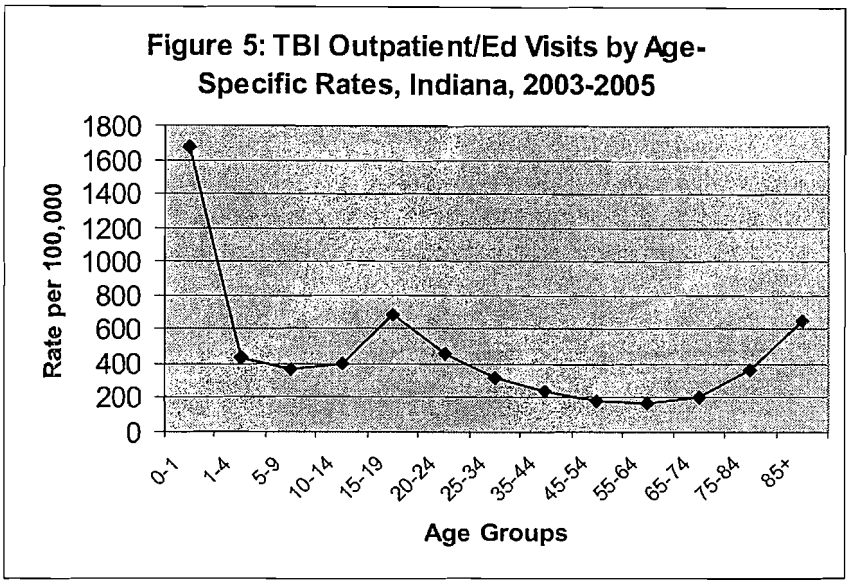
were $119 million. The majority of the patients had commercial insurance (34%, 21,819/63,936) or Medicare/Medicaid (28%, 17,992/63,936) (Figure 6).[5]



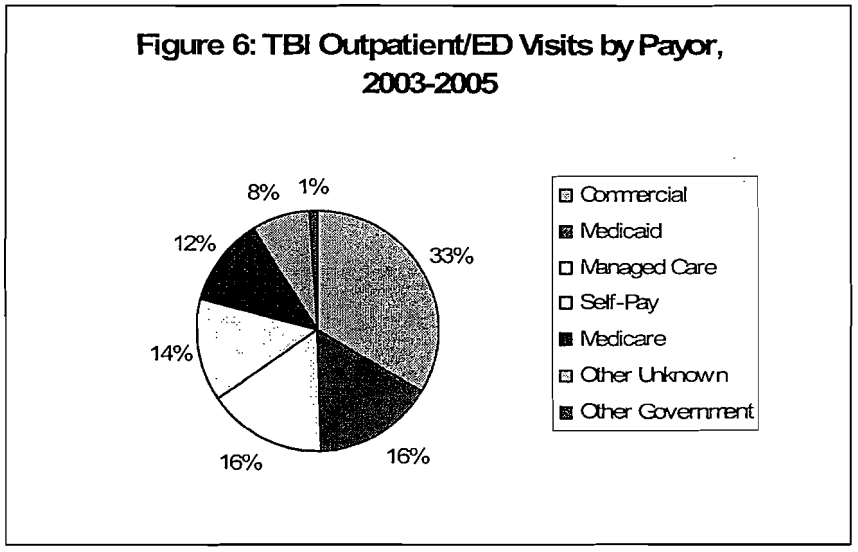
Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005

Inpatient Hospital Data

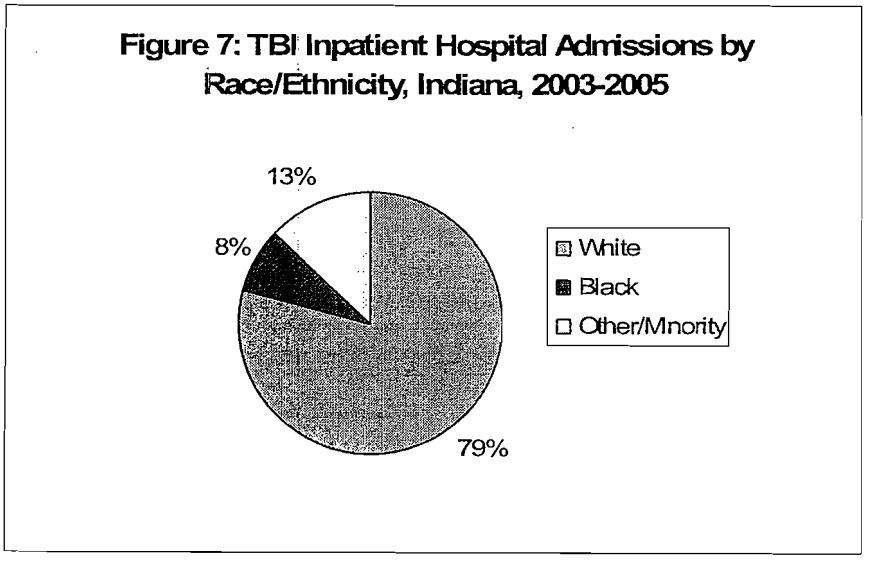
From 2003-2005, there were 161,198 inpatient hospitalizations with a primary diagnosis of injury or poisoning. Of these, 13,762 were TBI which represent 9% of all hospital admissions for patients who had a primary diagnosis of injury or poisoning.[5]

Of those admitted to the hospital 62.5% (8,599/13,762) were male and 37.5% (5,162/13,762) were female (one person's gender was unknown). When comparing rates, males were 1.8 times

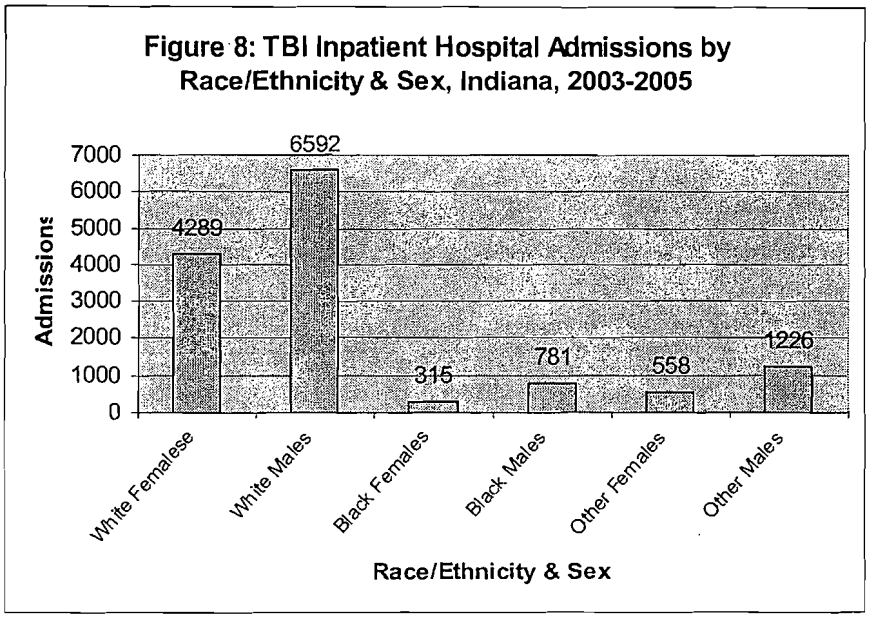
more likely to be admitted to the hospital following a TBI than females. The majority (79%, (10,882/13,762) of the hospital admissions were white Indiana residents (Figure 7). However, the age-adjusted rate for hospital admissions was higher in blacks compared to whites (70.56 per 100,000 versus 65.00 per 100,000). White males accounted for 61% (6,592/10,881) of all hospital admissions by white residents (Figure 8). However, black males had a higher age-adjusted rate (105.75 per 100,000) compared to white males (82.16 per 100,000). White females though had a higher adjusted rate of hospital admission compared to black females (47.73 per 100,000 and 39.17 per 100,000).[5]

During 2003-2005, the age group with the highest age-specific rate of hospital admissions due to TBIs was the 85+ year olds (396 per 100,000). The lowest age-specific rate of hospital admissions due to TBIs was the 1-4 year old population. The age-specific rates began increasing with the 65+ year olds. However, the 0-1 year olds and 15-19 year olds had rates over 100 (131 per 100,000 and 100 per 100,000). Figure 9 shows the actual number of hospital admissions for each age group while Figure 10 shows the age-adjusted rate for each age group.[5]

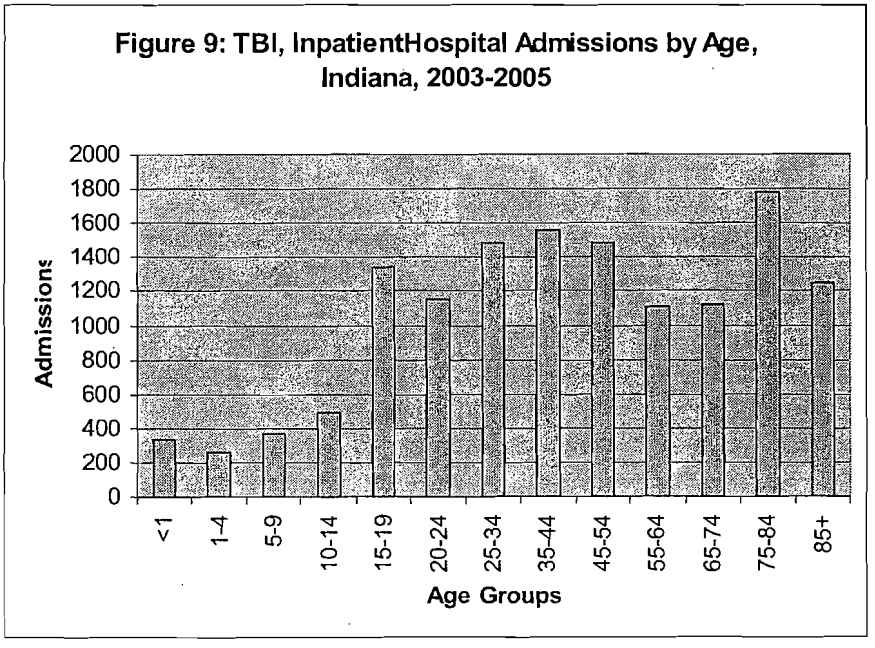
The median total charge for patients admitted to the hospital for TBI was $30,803 (Range $63.00-$780,345) as compared to the mean total charge for all ages of $15,037 (Range $63.00-$780,345) (4). For 2003-2005, the total charges due to TBI patients who were admitted to the hospital were $422 million. The majority of the patients had Medicare/Medicaid (36%, 4,979/13,762) or commercial insurance (30%, 4,014/13,762) (Figure 11). The average length of stay for a TBI patient was 6.79 days (Range 1- 152 days) and the median length of stay was four days.[5]



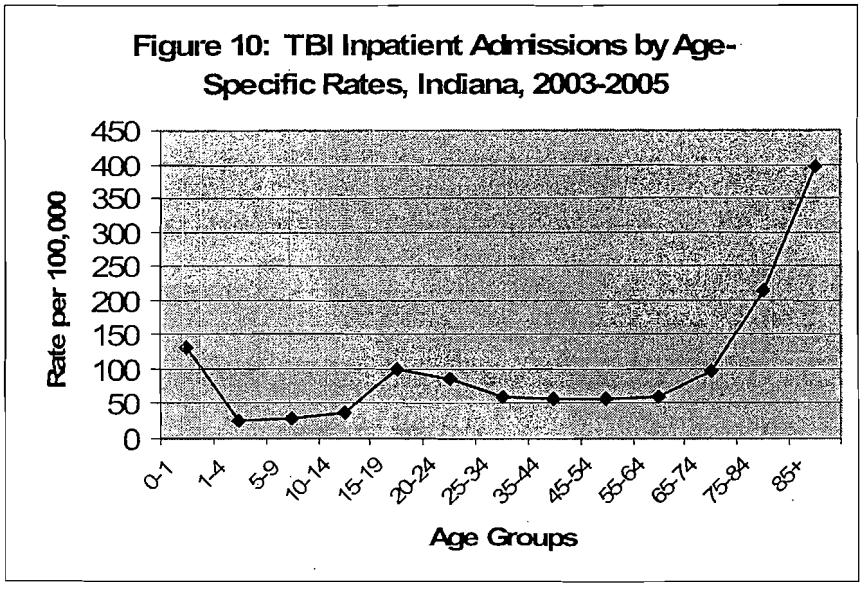
Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



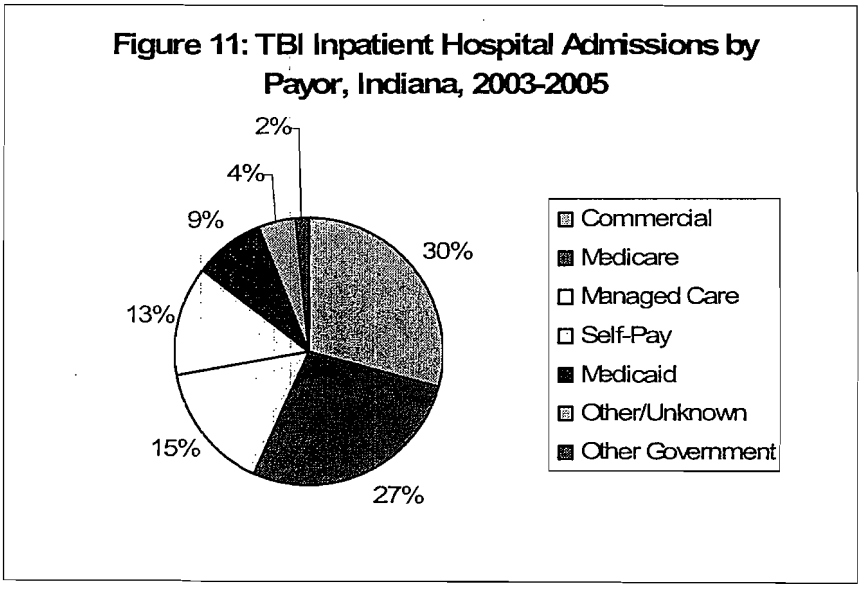
Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005



Source: Indiana State Department of Health, Hospital Discharge Data, 2003-2005

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Traumatic Brain Injury:
Synthesis of Indiana Medicaid Data

Background and Context

The Medicaid Medical Advisory Cabinet (MMAC) was asked to analyze data to better understand Traumatic Brain Injury care in Indiana Medicaid recipients as part of the Traumatic Brain Injury (TBI) project (original report submitted 6/25/09 and a second report regarding Systems of Care, Staffing Models, and Funding Models submitted 10/30/09). The goal of the data analyses was to develop data-driven recommendations regarding the feasibility of Indiana establishing a long-term brain injury rehabilitation facility within state, to replace the current practice of referral of Indiana Medicaid patients to out-of-state rehabilitation facilities (e.g., Mentor ABI Center for Comprehensive Services in Carbondale, IL).

This report describes TBI in the state of Indiana, specifically for Medicaid recipients. The results are preceded by a description of the methodology and definitions of the sample and variables included in the analyses. The data analyses are broken down into several sections, each providing details about different aspects of TBI care including: TBI severity, where TBI patients receive care, the duration for which care is provided at various locations, and costs for each stage of treatment from the acute injury until 24 months post-injury. The last section of this report closes with conclusions based upon the data analyses and our recommendations.

Method Overview

The purpose of the TBI data analyses was to describe the types of services used and distribution of costs (Medicaid payments) for a cohort of Medicaid-enrolled individuals with moderate to severe TBI as defined by having a hospitalization with a TBI diagnosis (see specific definition below). The time period for tracking service utilization and associated costs was through 24 months following the index hospitalization date for the TBI injury. Persons on both Medicaid and Medicare (dual eligibles) were also excluded from the cohort, because of the difficulty of fully accounting for costs/source of payments in this subgroup.

We contrast service utilization and costs in the cohort of moderate-severe TBI cases to individuals without TBIs, recognizing this is not a true comparison because the groups differ markedly from each other in age and sex. In order to draw inferences about the additional service use and costs attributable to those individuals with moderate to severe TBI, we separately examined costs associated with the initial (i.e., index) hospitalization and costs associated with the 24 months following this index hospitalization.

Traumatic Brain Injury: Synthesis of Indiana Medicaid Data

We evaluated service utilization and costs by major demographic categories, including race and ethnicity, age, and sex, as well as Medicaid aid category and severity of the TBI diagnosis (i.e., moderate vs. severe). Examining service utilization and costs by these other variables enabled us to describe 1) which of these factors contributed to a greater risk for severe TBI, and 2) which factors were associated with different patterns of service use and/or impact the distribution of TBI-related costs.

Categorizations of moderate and severe TBI were based, in part, upon research conducted by the state of Michigan [1], which is a 9-year, ongoing project to better understand the incidence and causes of TBI in the state of Michigan. In their work, The Michigan Public Health Institute used the CDC's definitions of moderate to severe TBI, based on ICD-9 codes [2-9] The study examines the incidence, severity, costs, utilization patterns, potential demographic correlates, etc., of TBI in the state of Michigan. One of the goals of the research is to develop a TBI Medicaid waiver for Michigan residents living with TBI, which was pending approval in the summer of 2009 [10].

In total, there are six separate analyses reported below, each one with specific goals.

Sample

We identified an incident cohort of patients who had a primary or secondary diagnosis of TBI during the four calendar years from 1/1/03 to 12/31/06. Members of the cohort were considered to have moderate or severe TBI if there was a hospitalization associated with a primary or secondary TBI diagnosis (or if there was an ER/outpatient visit for TBI within 24 hours of the hospitalization, the event was also counted as a hospitalization). Mild TBI was defined as an ER or outpatient visit associated with a primary or secondary TBI diagnosis and no hospitalization. In addition, those with mild TBI could not have had a TBI diagnosis in the preceding 182 days. The sample, however, did not have to be continuously enrolled for that time period. Death related to TBI was also pulled from the Medicaid data. However, these data may have poor sensitivity and may be underestimating the number of deaths from TBI.

Members of the cohort were enrolled in Medicaid at the time of the Index TBI hospitalization (enrollment may also have been retroactive to the date of that hospitalization). Importantly, we did not include persons who had a TBI and became enrolled in Medicaid at a later date (e.g., after a period of Medicaid spend-down or disability determination). Hence, there are other people who have a diagnosis of TBI in the Medicaid claims data but are not included in the study because Medicaid did not pay for the initial hospitalization.

TBI was defined using the CDCs definitional set of codes:

- codes 800.0--801.9 (fracture of the vault or base of the skull);
- codes 803.0--804.9 (other and unqualified multiple fractures of the skull);
- codes 850.0--854.1 (intracranial injury, including concussion, contusion, laceration, and hemorrhage); and

- code 959.01 [Note: The ICD-9-CM codes for TBI included in the analyses differ from the "Barrel Matrix," which is a recommended categorization of ICD-9-CM codes for nonfatal injuries. The inclusion of 959.01 (head injury, unspecified) is consistent with the current CDC TBI case definition.]
- Also added are 950.2 and 950.3 (re: optic nerve/pathways) and 995.55 (shaken baby) because there were discrepancies between the CDC TBI cohort definition ICD9s and the Michigan severity definition (e.g., these were in the severity definition but not in the cohort denominator).

The definition of severe TBI injury was based upon research conducted by the state of Michigan, which identified the following severe injury code set:

- Skull Fracture (codes in range of 800-804, but excluding those with 4th digits = 0 or 5)
- Intracranial Laceration or Contusion (diagnosis codes: 851, 800.1, 800.6, 801.1, 801.6, 803.1, 803.6, 804.1, 804.6)
- Intracranial Hemorrhage (852, 853, 800.2, 800.3, 800.7, 800.8, 801.2, 801.3, 801.7, 801.8, 803.2, 803.3, 803.7, 803.8, 804.2, 804.3, 804.7, 804.8)
- Injury to optic nerve and pathways (950.1, 950.2, 950.3)
- Shaken baby syndrome (995.55)

[Note: The above categories of "more serious injuries" are not mutually exclusive – patient may have more than one TBI ICD-9 code]

All other TBI hospital admissions not being captured by this "severe" code set were considered "moderate."

Descriptive Variables

For the TBI cohort described above, we examined aid category status two months prior to the index TBI rather than at the time of hospitalization. This allows us to identify members who were not enrolled prior to, but became members after, the TBI. For the non-TBI comparison cohort, aid category was based on December of the calendar year. Race and ethnicity were classified as non-Hispanic white, non-Hispanic black, Hispanic or other. Sex is reported as the proportion of members that are male. Age is described as a continuous variable (mean, median) or divided into categories. Age grouping cutoffs include those under 22 years old (twenty two was chosen because those with developmental problems beginning before that age may be eligible for the Developmental Disabilities waiver and have an impact on long term benefits and costs), and those 22 years to 64 years of age. The last age grouping is those who are ≥65 years old. Data from this age group should be viewed with caution as they may be enrolled in Medicare, making it difficult to accurately trace costs, and the numbers for members in this age group in our cohort tend to be very small. Table 1 below summarizes the Medicaid aid category and age groupings that were used in our analyses.

Table 1. Aid Categories and Relevant Age Groupings Used in the Analyses

Aid Grouping for Analyses	Aid Category
Packages A & C ≥ 22 years and < 65 years <22 years old >65 years old	C, E, F, M, N, S, T, U, X, Y, Z, 1, 2, 9, 10
Care Select –non-waiver Disabled, Blind, Adoption Assistance, M.E.D.Works, Ineligible for TANF due to SSI payments, Breast/cervical cancer, Wards < 18 not IVE, Title IVE fosters <18, Transitional for Fosters 18-20. ≥ 22 years and < 65 years <22 years old >65 years old	A, D, B, 8, DW, DI, U, R, 12, 3, 4, 14
Duals	G, I, J, K, L
Waivers*	LOC

** Waiver category classification was based on LOC [note: Waiver individuals may not have claims, so LOC was used to define this group)*
*** Waiver and non-waiver patients were mutually exclusive; i.e. Care Select population did not include those on waivers.*
**** We excluded category Refugee Medical Assistance – MA-Q.*
*****HC and HN are new programs and likely to not have many claims so they were excluded from analyses.*
****** The Pregnancy aid categories (E,M,N) had so few TBI cases so they were also excluded.*

Definition of Transition Settings

A patient's "state" (i.e., disposition) following discharge after incident hospitalization and thereafter was categorized into eight settings or states: the community (which was the default category), nursing home (by LOC), facilities billing under COS 2500/2510 as rehabilitation facilities (i.e., primarily chronic rehab facility (CRF), or facilities such as Mentor ABI Center for Comprehensive Services at Carbondale, IL, that provide longer-term services), inpatient hospitalization (COS 0100, 0110), waiver services (waiver LOC), hospice (by LOC), facilities billing under COS 0120 or inpatient hospital with rehabilitation services (i.e.. primarily acute rehab facility (ARF), or centers such as Rehabilitation Hospital of Indiana, RHI, that provide shorter-term services usually not long after the TBI injury was sustained), or deceased.

One important note is that, due to the fact that many patients from the community and in nursing homes will experience brief hospitalizations as a result of other illnesses or injuries not necessarily related to TBI, we developed a set of rules to identify setting. For example, if a patient in a nursing home was admitted to a hospital for a few days as a result of bronchitis but retained their nursing home LOC during that entire time, this individual would be considered to be in the nursing facility the entire time. The exceptions are if an individual received services falling under COSs 2500/2510 or COS 0120 which denote some sort of inpatient rehabilitation. If this was the case, the person was considered to have re-entered the "rehabilitation" setting (even if the person still retained a nursing facility LOC). COSs 0320-2440 in Table 2 denote services that indicate "outpatient rehabilitation," which members in the community or in nursing homes might have received, though they were not admitted to a particular rehabilitation facility or hospital; these COSs are coded as "rehab" in the data tables that follow below.

Definition of COSs Used in These Analyses

There are 227 COSs, with 40 Rollup categories that group similar COSs. With respect to the current analyses, we defined the following specific COSs as representing rehabilitation services (see Table 2).

Table 2. COS Categories Used in These Analyses

0120	Inpatient - Rehabilitation
0320	Outpatient - Rehabilitation
0652	Physician - Physical Medicine
2000	Therapy Services - Physical
2010	Physical Therapy - Therapist
2020	Physical Therapy - Physician
2030	Physical Therapy - Chiropractor
2040	Physical Therapy - Other
2100	Therapy Services - Speech
2110	Speech Therapy - Therapist
2120	Speech Therapy - Physician
2130	Speech Therapy - Other

2200	Therapy Services - Occupational
2210	Occupational Therapy - Therapist
2220	Occupational Therapy - Physician
2230	Occupational Therapy - Other
2400	Therapy Services - Audiology
2410	Audiology Therapy - Therapist
2420	Audiology Therapy - Audiologist
2430	Audiology Therapy - Physician
2440	Audiology Therapy - Other
2500	Rehabilitation Facilities Services
2510	Rehabilitation Facility Care

*******Note: In every best effort to comply with HIPAA guidelines, the data reported herein containing numbers of less than 10 individuals have been "masked" with either "<10," with approximated percentage estimates, or dashes where necessary.***

Traumatic Brain Injury: Synthesis of Indiana Medicaid Data

Analysis #1: Describe the cohort of Interest.

Goals Analysis #1 was conducted to explore descriptive information about those in Medicaid with TBI. Analysis #1 was designed to answer the following questions:

- What are the number, proportion and overall cost of people in Medicaid with TBI?
- What are the characteristics of those with TBI?
- What is the overall cost of people with TBI?
- Of those with TBI, what are the number, proportion, characteristics, and cost for those with mild TBI?
    - Who die within *one month* of the TBI?
    - Admitted to the hospital with TBI (i.e., with moderate to severe TBI)? See Table 3.

Results

Over 40,000 or 4.0% of people enrolled in Medicaid had an incident TBI event over the 4-year evaluation period. Of those, there were 317 deaths (0.03% of all Medicaid enrollees), 38,482 (3.8%) outpatient visits with mild TBI, 468 (0.05%) outpatient visits for severe TBI (using the CDC's definition of TBI codes, see above), 134 patients (0.01%) with TBI who were residing in a nursing home, ICF/MR or receiving hospice services, and 1,296 (0.1%) who were hospitalized, and thus, by definition, had moderate to severe TBI. Those with TBI were predominantly male (53%), have a mean age of 20.4 years and were predominantly white (18% non-Hispanic-black, 6% Hispanic and 2% other). This contrasts with the overall Medicaid population without TBI, which is primarily composed of children and pregnant women and is, therefore, younger (mean age 16), only 40% male and has a higher proportion of minorities (only 65% non-Hispanic white), as reported in Table 3.

On average, over $200M per annum is spent on Medicaid patients with TBI. This accounts for about 4% of the total Medicaid dollars spent each year. We evaluated the PMPM for patients with TBI not including the index hospitalization so that we could compare their costs to other Medicaid enrollees. Because the vast majority of TBI patients (>90%) have mild TBI, the PMPM for the overall TBI group was only $427 (compared to the younger, mostly female Hoosier Healthwise population PMPM of $200, and Care Select and Care Select "Potentials" PMPM of $1,174, reported as of November 2008 [11]). The non-TBI cohort PMPM in our study was approximately $160, calculated by dividing the total 2-year costs of $2,496,634,260 by the 978,589 members with an average number of "member months" of 15.96. In contrast, the 317 members with TBI who die within the first month after injury are the most expensive group costing $2,299 PMPM and an average of $364,000 per year. The 1,296 people with moderate to severe TBI requiring a hospitalization contributed the most to overall costs (an average of $25M per annum or $1,700 PMPM), while those in nursing homes had the highest per capita monthly costs ($3,665 PMPM).

Of those with TBI, 7,807 of the 40,697 (19% or nearly 1 of every 5) had no Medicaid two months prior to the injury. Most striking is that about one third of people who die or have moderate to severe TBI had no Medicaid in the two months prior to their TBI. It is possible that when those with TBI

seek medical care, they are merely found to be eligible but not enrolled in Medicaid. Another explanation is that those with TBI become eligible because they are not able to work or afford health insurance. The majority of those with mild TBI are likely to be less than 22 years old; however, the majority of those who have moderate to severe TBI are over age 22. The exception is in those who have the severe TBI codes but are only found to have services in the outpatient setting. It is unclear why a person would have TBI codes indicating a severe injury but only have services in the outpatient setting. It is possible that the codes lack specificity (i.e., they are finding people who actually have mild injuries) or it is possible that people with severe injury had a hospitalization paid by another source (self-pay or private insurance) but then the person with TBI lost employment or insurance and became eligible for Medicaid.

Table 3. Demographic Characteristics of Medicaid Enrollees with TBI vs Those without TBI

Characteristics	Die (within 30 days of index hospitalization)	Outpatient Mild	In NH, ICF/MR, or hospice at the time of TBI *	Outpatient severe*	Inpatient Moderate-Severe	Total TBI	Total Without TBI
N (4 year case finding period)	317	38,482	134	468	1,296	40,697	978,589
% (N/total Medicaid population)	0.03	3.78	0.01	0.05	0.13	3.99	96.01
Age (mean, median, range)	33.1, 32, 0 to 89	19.4, 10, 0 to >90	68.5, 72, 25 to >90	24.7, 17, 0 to >90	27.4, 22, 0 to >90	20.4, 10, 0 to >90	16, 12, 0 to >90
% male	66	53	42	52	61	53	40
% Race/Ethnicity							
Non-Hispanic white	75	74	80	80	75	74	65
Non-Hispanic black	19	18	14	14	18	18	23
Hispanic	4	6	<7	5	6	6	10
Other	<4	1	<7	<3	1	2	2
Cost all claims for the two years after index hospitalization	$728,735	$390,936,588	$11,787,402	$14,209,252	$51,215,422	$417,661,977 in two years	$2,496,634,260 in two years
Cost PMPM	$2,299*	$423	$3,665	$1,293	$1,696	$427	$160

Table 3 Continued on Next Page

Traumatic Brain Injury: Synthesis of Indiana Medicaid Data

Characteristics	Die (within 30 days of index hospitalization)	Outpatient Mild	In NH, ICF/MR, or hospice at the time of TBI *	Outpatient severe*	Inpatient Moderate-Severe	Total TBI	Total Without TBI
Aid categories							
None	114	7,171		130	392	7807	N/A
65+ years old	0	20		<10	27	56	N/A
> 22 years and < 65 years	86	2,022		~45	199	2,349	N/A
<22 years old	28	5,129		~85	166	5,402	N/A
Packages A and C	160	29,229		297	899	30,585	818,388
65+ years old	<10	29		15	66	113	19
> 22 years and < 65 years	77	5,050		101	364	5,592	159,424
<22 years old	80	24,150		181	469	24,880	658,945
Medicaid/Care Select****	25	1,546		40	293	1,904	93,320
65+ years old	<10	41		<10	<10	~41	188
> 22 years and < 65 years	~25	1,267		~40	~253	1,576	63,453
<22 years old	0	238		0	~40	276	29,679
Waivers	<10	344	0	19	<10	~344	4,925
Nursing Home	14	191	118	20		343	2,762
ICF/MR			<10	<10		~20	1,142
Hospice			<10	0		<10	1,317
Duals	0	<10	58	31	116	~205	5,735
Proportion (%) with severe injury	20%	0%	10%	100%***	30%	2.3%	N/A

* excluded from later analyses

** (gives everyone in the die column a full "month")

***had to be severe to qualify for "outpatient severe"

****based on the aid category "operationalization" method

Analysis #2: What is the Primary Transition Setting (State 2) for Those with Moderate to Severe TBI?

Goals Analysis #2 was conducted to establish where 1,296 individuals with moderate to severe TBI transition to following discharge from their incident hospitalization. This analysis was designed to answer the following questions:

- Where do moderate to severe TBI patients receive services after hospital (timeframe for establishing the primary transition is 48 hours following discharge following the incident hospitalization)?
- How long do they stay in this setting (mean, median, and range of time)?
- What are the costs associated with each setting (mean, median, and range)?
- Of those in each setting, what proportion has "severe brain injury" (as defined by the Michigan code set taken from the CDC, see above)
- What aid categories do patients fall under at the time of discharge/exit from this setting (or at the 24 month cutoff)?

Results

The vast majority of people were discharged to the community (75%); the next most common setting after discharge from the initial hospitalization for TBI was inpatient hospital (11%) followed by acute rehab hospital (8%). Four percent were discharged to a nursing home and 1% were in the community receiving waiver services (see Table 4a).

Of the 1,296 people admitted to the hospital with TBI, over three quarters (78%) left the initial hospital stay and had no rehabilitation claims. Nearly 1 out of 5 (18%) had a rehabilitation claim in some setting. About 9% were transitioned into the community and received at least one rehabilitation service after their initial hospital stay; 67% were discharged to the community without any rehabilitation claims. One percent of the 1,296 went to a nursing home and received at least one rehabilitation service, whereas 3% went to a nursing home and did not receive a rehabilitation service. No patient was discharged from the initial hospitalization to a primarily longer-term, chronic rehabilitative (CRF) setting. Four percent of patients left the hospital and were transferred to another inpatient hospital, where they received at least one rehabilitation service, and almost 7% went to another in-patient hospital stay but did not have any claims for rehabilitation services. Another possibility is that there is a problem in the encounter data (e.g., lack of specificity or missing). In one example, a patient was in risk based managed care during their inpatient rehabilitative state and had $0 charge. If so, it is possible that we are underestimating rehabilitation services received in hospitals and other settings as well.

Of those in the acute inpatient rehabilitation services, 56% went to RHI of Indiana, 15% went to Southern Indiana Rehabilitation Hospital, 14% went to HealthSouth Deaconess Rehabilitation Hospital, 6% to Frazier Rehabilitation Center, 6% to CHOW and 2% to others. About 98% of the other situations defined as an inpatient hospital stay with rehab in Table 4a had a COS 0652 (PM&R clinician) claim. Among the 55 patients, the hospitals, ranked by descending frequency, are: 1) Community East, 2) Wishard, 3) Memorial South Bend, 4) Clarian and then 5) others with very few in each.

On average, those in nursing homes and waivers were the oldest with mean ages of 48 and 53, respectively. Those in nursing homes, inpatient hospital, and waivers were very disproportionately male. Those discharged to the community were more evenly divided between males and females. It is possible that males have more severe injury [12] and/or that females are less likely to be referred or to accept rehabilitation services. Whereas, the overall population hospitalized with TBI is 18% non-Hispanic black, 25% of people who got rehab in a nursing home and 24% who got rehabilitative services in an inpatient hospital were non-Hispanic black. In contrast, only 8% of people getting services in an in-patient rehabilitation center were non-Hispanic black. One explanation may be rooted in observed healthcare disparities for racial and ethnic minorities [13-15], particularly that black TBI survivors may be less likely to be referred to acute inpatient rehabilitation centers [16]. Whereas 30% of the incident hospitalized TBI cohort had severe TBI (using the CDC's and Michigan's codes), a disproportionate number of people who transitioned to an inpatient hospitalization or an inpatient rehabilitation setting had severe TBI (35% and 49%, respectively). Nearly one-quarter (26%) of people who transitioned to the community after their incident hospitalization had severe TBI codes.

Table 4a. Patient Characteristics of Those with Moderate/Severe TBI by Transition Setting After Discharge from Incident Hospitalization

STATE 2	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased
*Categories Are Exclusive	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab			
N	112	817	46	12	43	0	55	88	<10	14	0	98	<10
% (N / those d/c from hospital)	8.7%	63.2%	3.6%	0.9%	3.3%	0.0%	4.3%	6.8%	0.2%	1.1%	0.0%	7.6%	0.7%
Age mean	29	24		44	48		31	31	58	52		30	46
Age median	24	17		41	49		27	27	58	52		28	43
Age range	0 to 80	0 to >90		18 to >90	0 to >90		3 to 64	0 to 64	45 to 72	25 to 86		0 to 62	1 to 82
% male	56	58		~75	67		82	69	–	71		71	67
% race Non-Hispanic white	77	74		<83	77		73	78	–	93		84	78
Non-Hispanic black	20	19		–	<23		24	14	–	–		<11	22
Hispanic	<9	6		–	–		–	<11	–	–		<11	0
Other	<9	<2		–	–		–	0	–	–		–	0
% severe injury	36	26		~33	~30		40	32	0	29		49	33

The average length of time in the inpatient hospitalization or inpatient rehabilitation after the incident TBI admission was ~23 and 20 days, respectively. There were large variations in the length of time in the environment as shown by the ranges. The vast majority of people with TBI went

back to the community, received no rehab, and, on average, remained the longest in that setting. However, there is a huge amount of variation in each of these variables.

Costs are reported for the time spent in each setting. Therefore, the PMPM gives the best measurement for comparison. Those in inpatient hospitals had the highest costs (~$20,000 PMPM) followed by inpatient rehabilitation (~$17,000 PMPM; see Table 4b). The PMPM costs for nursing home stays were substantially lower and the stays were much longer, on average, than for the inpatient hospital and inpatient rehabilitation facilities. Persons on waivers or in hospice had lower costs PMPM than nursing home residents with TBI. As expected, the lowest PMPM costs and longest length of stay were for the majority of persons who went to the community and used few Medicaid services.

Although there was a higher proportion of people (49%) in an inpatient rehabilitation setting with severe TBI than in the inpatient hospital setting (35%; see Table 4a), hospitalized members were more expensive. It is possible that those in the inpatient hospital setting have more co-morbidities or more complicated injuries than those in the inpatient rehabilitation setting. It is also possible that it is more expensive to care for people at the same level of care in an inpatient hospital setting. No patient was discharged from the incident hospital to a long-term, chronic rehabilitation center (CRF).

Table 4b. Length of Time and Cost in First Transition Setting (State 2) for Those with Moderate/Severe TBI

STATE 2	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased
*Categories Are Exclusive	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab			
N	112	817	46	12	43	0	55	88	<10	14	0	98	<10
% (N / those d/c from hospital)	8.7%	63.2%	3.6%	0.9%	3.3%	0.0%	4.3%	6.8%	0.2%	1.1%	0.0%	7.6%	0.7%
Length of time in setting (days)	66,185	463,972		4,823	12,496		1,433	1,918	1,081	6,491		1,924	6,007
Mean	591	568		402	291		26	22	541	463		20	667
Median (2 years = 730 days)	718	724		357	148		20	16	541	706		14.5	667
Range	2 to 728	1 to 729		83 to 726	5 to 724		4 to 103	2 to 90	355 to 726	10 to 728		2 to 81	628 to 697
Cost all claims in setting	$735,728	$3,142,195		$1,386,566	$2,944,195		$1,062,974	$1,251,619	$51,409	$1,543,149		$1,074,993	
Mean	$6,569	$3,846		$115,547	$68,470		$19,327	$14,223	$25,704	$110,225		$10,969	
Median	$3,640	$1,429		$70,318	$30,943		$12,442	$9,869	$25,704	$94,684		$9,394	
Min	$0	$0		$15,597	$0		$94	$0	$20,790	$86		$0	
Max	$95,931	$160,861		$354,501	$235,833		$128,091	$93,815	$30,618	$389,627		$81,408	
PMPM	$339	$207		$8,768	$7,186		$22,624	$19,903	$1,450	$7,251		$17,042	
Aid Categories Pkg A/C	45	513		<10	<10		14	19	—			25	
Care Select	47	260		~10	~40		34	54	<10	14		57	

We also examined the incident hospital costs of people with moderate to severe TBI in relation to their discharge setting (Table 4c). On average, people receiving waiver services after discharge had the least expensive incident hospitalization (but the sample size is small <15). It is unclear why those getting waiver services would have smaller incident hospitalization costs – perhaps as a vulnerable population, they are more likely to be hospitalized for observation of their injury. However, the proportion with severe injury is similar to the proportion of severe injury overall. Those who died had the highest incident hospital costs followed by those who were discharged to the nursing home. The incident hospital costs for those discharged to inpatient rehabilitation were slightly higher than those discharged to an inpatient hospital. This is interesting in light of the fact that costs for an inpatient hospital stay after the incident hospitalization are higher than an inpatient rehabilitation stay (see Table 4b). If the difference was attributable to the more impaired patients being discharged to the hospital rather than rehab, one might expect that the initial hospital stays would also be more expensive.

Table 4c. State 1 Costs as a Function of State 2: Index Hospitalization Costs of Those with Moderate to Severe TBI Who Were Discharged to the Various Settings

STATE 2	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased
*Categories Are Exclusive	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab			
N	112	817	46	12	43	0	55	88	<10	14	0	98	<10
% (N / those d/c from hospital)	8.7%	63.2%	3.6%	0.9%	3.3%	0.0%	4.3%	6.8%	0.2%	1.1%	0.0%	7.6%	0.7%
State 1 Costs as a Function of State 2	$1,325,981	$8,884,932		$620,481	$1,871,908		$1,823,874	$2,138,195	$3,011	$49,989		$3,309,993	$816,376
Mean	$11,839	$10,875		$51,707	$43,533		$33,161	$24,298	$1,506	$3,571		$33,775	$90,708
Median	$4,010	$3,794		$55,277	$54,784		$20,777	$13,580	$1,506	$675		$25,176	$79,484
Min	$0	$0		<$100	$0		$2,087	<$100	<$100	<$100		$786	$67,793
Max	$189,218	$228,100		$150,770	$110,727		$149,255	$207,556	$2,990	$29,861		$184,431	$157,609
State 1 Cost PMPM	$27,776	$33,169		$50,873	$39,051		$43,975	$49,405	$11,479	$9,900		$46,825	$43,228

Analysis #3: What is the Secondary Transition Setting (State 3) for Those with Moderate to Severe TBI?

Goals Analysis #3 was conducted to establish where moderate to severe TBI patients transition to following the initial transition from the incident hospitalization (i.e., Transition #2). This analysis was designed to answer the following questions:

- Where do moderate to severe TBI patients receive services when/if they make a second transition?
- How long do they stay in this setting (mean, median, and range of time)?
- Of the "hospital" settings, how many TBI patients go to rehabilitation facilities vs. hospitals? What are the costs associated with each setting (mean, median, and range)?
- Of those in each setting, what proportion has "severe brain injury" (as defined by the CDC's code set)?
- What aid categories do patients fall under at the time of discharge/exit from this setting (or at the 24 month cutoff)?

Results

Forty-four percent (570/1,296) of patients with TBI transitioned to another setting after their "state 2" (first transition after incident hospitalization) setting. The majority of patients left their second state and transitioned into either the community (44%) or to an in-patient hospital setting (42%; see Table 5a). Of those hospitalized with TBI who went to another transition state (state #3) from state #2, just under a quarter (22%) received rehabilitative services in state 3. It is important to note that the inpatient stay may be due to any diagnosis (i.e., not necessarily related to the TBI) and can occur at any time in the 2-year, post-incident, follow-up time span. The median age for those who got rehabilitation in a nursing home (35 years) was similar to those getting rehabilitation in an inpatient hospital (34 years), and to those getting inpatient rehabilitation in a long term (CRF) rehab center (38 years). Those receiving services in an inpatient rehabilitation center were somewhat younger (27 years) but the numbers are small. Those who have service codes for rehabilitation in any of the settings are predominately male (63-80%). Considering the demographics of the moderate-severe TBI incident cohort (which is 75% white, 18% black, 6% Hispanic and 1% other), we see that those getting rehab services in the community, in nursing homes, and inpatient hospitals are 83-100% white. Those getting inpatient rehabilitation have a higher proportion of blacks with Hispanics being underrepresented. Whereas 30% of the incident cohort had severe TBI, 40-57% of those getting rehab in "state 3" (in any setting) had a severe injury.

Table 5a. Characteristics by Setting of Those with Moderate/Severe TBI by Secondary Transition Setting (State 3)

STATE 3	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased
*Categories Are Exclusive	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab			
N	96	140	14	<10	~30	<10	<10	~230	<10	<10	<10	<10	16
% in setting	44%			~7%		<2%	42%		<2%		<2%	<2%	3%
% (N / # d/c from State 2)	17.0%	24.7%	2.5%	<2%	~5%	<2%	<2%	~40%	<2%	<2%	<2%	<2%	3%
Age mean	30	32		37	66	~47	34	35	30	57	44	27	
Age median	28	31		35	69	38	34	35	30	65	41	25	
Age range	1 to 61	0 to 69		~15 to ~75	21 to 87	~20 to ~80	~10 to ~60	0 to ~90	~25 to ~35	~15 to ~80	~20 to ~70	~1 to ~45	
% male	80	69		~67	~57	~60	~63	~50	—	~75	~40	~67	
% race Non-Hispanic white	83	78		100	83	—	88	~80	—	75	100	~78	~78
Non-Hispanic black	12	15		0	--	—	--	~18	—	—	0	~22	~22
Hispanic	<10	<7		0	--	—	0	<5	—	—	0	0	0
Other	<10	<7		0	0	—	0	--	—	—	0	0	0
% severe injury	45	40		~11	~7	0	~50	~25	~50	0	~40	~44	~33
Number of Duals	—	—		—	60%	—	—	20%	—	—	—	—	—

On average, those who transition from state 2 into the community in state 3 stay there for more than a year (Table 5b). The median length of stay for those in a longer-term (CRF) facility was 3-4 months, whereas those admitted to an inpatient hospital or inpatient rehabilitation hospital stayed about 1 month. The most expensive settings (PMPM) were inpatient hospital or inpatient rehabilitation. The costs in these settings in "state 3" were higher than similar costs in state 2. Those who went to a longer term rehab (CRF) facility in state 3 had a lower PMPM ($17,000) than those in an inpatient hospital or rehabilitation center ($20-23,000), but they also stayed an average of 3-4 months as compared to about a month for inpatient hospitalization or inpatient rehabilitation. The state 3 PMPM costs for nursing home stays were substantially lower and the stays much longer, on

average, than for a longer-term rehabilitation facility. Persons on waivers or in hospice still had lower costs. By far, the lowest PMPM costs were for the majority of persons who went to the community.

Table 5b. Tenure and Costs of Those with Moderate/Severe TBI by Secondary Transition Setting (State 3)

STATE 3	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased
*Categories Are Exclusive	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab			
N	96	140	14	<10	~30	<10	<10	~230	<10	<10	<10	<10	16
% In Setting	44%			~7%		<2%	42%		<2%		<2%	<2%	3%
% (N/# d/c from State 2)	17.0%	24.7%	2.5%	<2%	~5%	<2%	<2%	~40%	<2%	<2%	<2%	<2%	3%
Length of time in setting (days)	49,850	65,163		3,641	7,008	519	278	1,765	790	963	350	242	8,024
Mean	519	465		405	234	104	35	8	395	241	70	27	501
Median	672	649		659	168	97	38	4	395	222	80	27	538
Range	5 to 723	1 to 725		88 to 706	16 to 706	5 to 235	20 to 43	1 to 190	330 to 460	90 to 430	36 to 108	3 to 47	184 to 695
Cost all claims in setting	$516,748	$873,192		$741,349	$1,129,253	$293,316	$212,381	$1,169,991	$57,907	$77,042	$52,251	$166,828	
Mean	$5,383	$6,237		$82,372	$37,642	$58,663	$26,548	$5,132	$28,953	$19,261	$10,450	$18,537	
Median	$3,372	$1,728		$89,433	$13,145	$52,497	$23,419	$2,656	$28,953	$13,584	$7,483	$20,097	
Min	$151	$6		$441	$0	$0	$2,851	$0	$8,089	$1,176	$1,699	$1,965	
Max	$29,179	$303,791		$235,242	$231,883	$132,588	$64,707	$92,287	$49,818	$48,699	$22,880	$32,997	
Cost PMPM	$316	$409		$6,210	$4,915	$17,237	$23,301	$20,218	$2,236	$2,440	$4,553	$20,966	

A summary of transition from state 2 to state 3 is shown in Table 5c (below). The majority of patients who transition to the community for state 2 remain in the community (72%) while 28% of those discharged from their incident hospitalization have some other transition during their two year follow-up. Forty-two percent of those in a nursing home in state 2 next transition to the community in state 3. Ninety-four percent of those transitioning from an inpatient hospital stay and 90% of those transitioning from an inpatient rehabilitation stay go into the community in state 3.

Table 5c. Characteristics of Those with Moderate/Severe TBI Transitioning from a Nursing Home (State 2) into the Community (State 3)

State 2 (top row) by State 3 (left column)	Community	Nursing Home	Primarily CRF	Inpatient Hospital	Waiver	Hospice	Primarily ARF	Deceased	Total
Community		24	0	135	<10	0	90		~250
Nursing Home, inpatient rehab, longer term rehab, waiver or hospice	266	15	0	<10	<10	0	<10		~290
Deceased	<10	<10	0	0	<10	0	0		~20
State 2 lasted until day 730	701	11	0	0	<10	0	0	<10	~730
Total	~980	~60	0	~145	~20	0	~100	<10	1,296

Analysis #4: What are the most common patterns of care and predominant costs for patients with moderate to severe TBI?

Goals Analysis #4 was designed to summarize costs and capture the most prevalent patterns of care (i.e., transition settings) experienced by most moderate to severe TBI patients. This analysis was designed to answer the following questions:

- What are the cumulative costs associated with states?
- What are the most common patterns of care for moderate to severe TBI patients for the 24 months following incident hospitalization?

Results

As seen in Figure 1 and Table 6, about $21M was spent on initial care of Medicaid patients with moderate to severe TBI. Nearly another $20M was spent on the transitions to states 2 and 3, $5M on people moving from states 3 to 5, and an additional $5M on people moving from states 5 to 8. The total cost of the cohort over the 2-year period was $51.4M.

Figure 1. Costs for Moderate to Severe TBI Patients as a Function of State Number

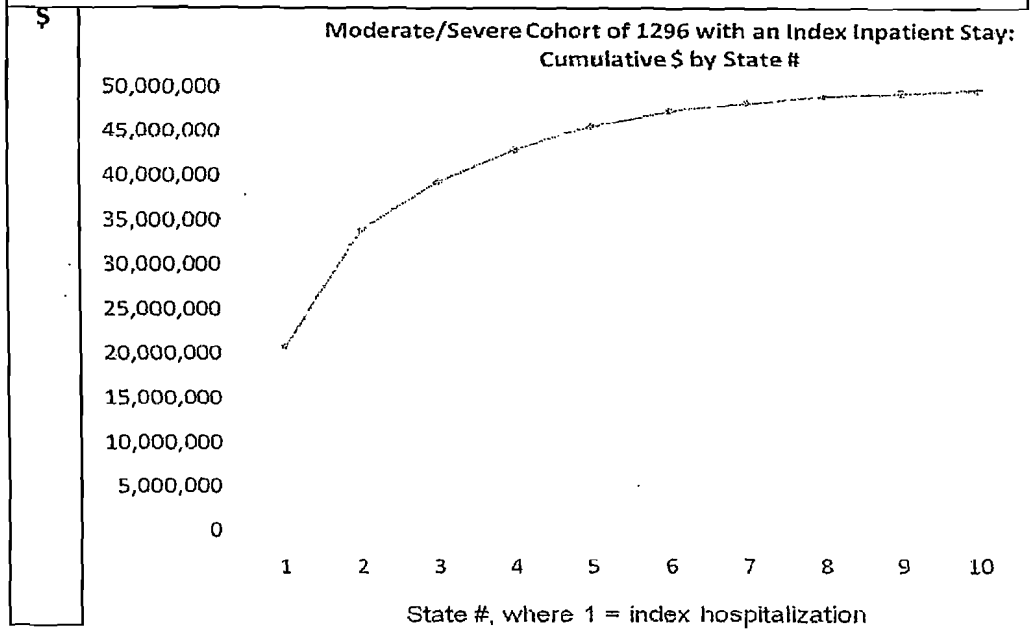


Table 6. Costs for Moderate to Severe TBI Patients as a Function of State Number and Setting

Costs by State & Setting	Community			Nursing Home		Primarily CRF	Inpatient Hospital		Waiver		Hospice	Primarily ARF	Deceased	Total
	Rehab	No Rehab	No Claims	Rehab	No Rehab		Rehab	No Rehab	Rehab	No Rehab				
State 1 (Index Hospitalization)	$1,325,981	$8,884,932		$620,481	$1,871,908		$1,823,874	$2,138,195	$3,011	$49,989		$3,309,993	$816,376	$20,844,740
State 1 PMPM	$27,776	$33,169		$50,873	$39,051		$43,975	$49,405	$11,479	$9,900		$46,825	$43,228	$355,681
State 2 Total Costs	$735,728	$3,142,195		$1,386,566	$2,944,195		$1,062,974	$1,251,619	$51,409	$1,543,149		$1,074,993		$13,192,828
State 2 PMPM	$339	$207		$8,768	$7,186		$22,624	$19,903	$1,450	$7,251		$17,042		$84,770
State 3 Total Costs	$516,748	$873,192		$741,349	$1,129,253	$293,316	$212,381	$1,169,991	$57,907	$77,042	$52,251	$166,828		$5,290,258

State 3 PMPM	$316	$409	$6,210	$4,915	$17,237	$23,301	$20,218	$2,236	$2,440	$4,553	$20,966	$102,801

Figure 2 and its sub-figures (included in the appendices, pp. 31-33) pictorially capture moderate and severe TBI Medicaid members' transition patterns. Each line of the transition figures represents one individual's index hospitalization and following transitions for 24 months after index hospitalization. Figure 2 depicts the transitions of all 1,296 moderate-severe TBI members (who had an index hospitalization between 2003 and 2006) in Medicaid during the study period. There are several dominant transition patterns. The most easily discernible pattern is the transition from index hospitalization (brick red) to community (light aqua). Indeed, echoing results discussed above, this was the most common transition pattern. Other dominant transition patterns were from index hospitalization (brick red) to another inpatient hospitalization (burnt orange) or into primarily acute rehab (ARF; green).

The mean number of transitions was 2.4; the median was 1; and the range was 1-41 transitions over the 2 years post-index hospitalization. Therefore, the maximum number of "states" experienced by any moderate or severe TBI member in the cohort was 42 in the 2 years post-index hospitalization. Note that members who died within 30 days of index hospitalization are counted as having one transition (from the index hospitalization to the "state" of death).

Appendix A (p. 31) includes any moderate or severe TBI member who had a "Primarily Chronic Rehabilitation Facility" (CRF) stay in the 24 months following their index hospitalization. These individuals did not enter the CRF immediately following their index hospitalization stays; rather, they entered the CRF after having transitioned to another inpatient hospitalization, a "Primarily Acute Rehabilitation Facility" (ARF), a nursing home, or after having gone back into the community. These members predominantly had other transitions to nursing homes, waiver services, or back into the community following their stays in a CRF.

Appendix B (p. 32) includes any moderate or severe TBI member who had an ARF stay in the 24 months following their index hospitalization. These individuals generally experienced a transition to an ARF immediately following their index hospitalization, and then re-entered the community following their ARF stays.

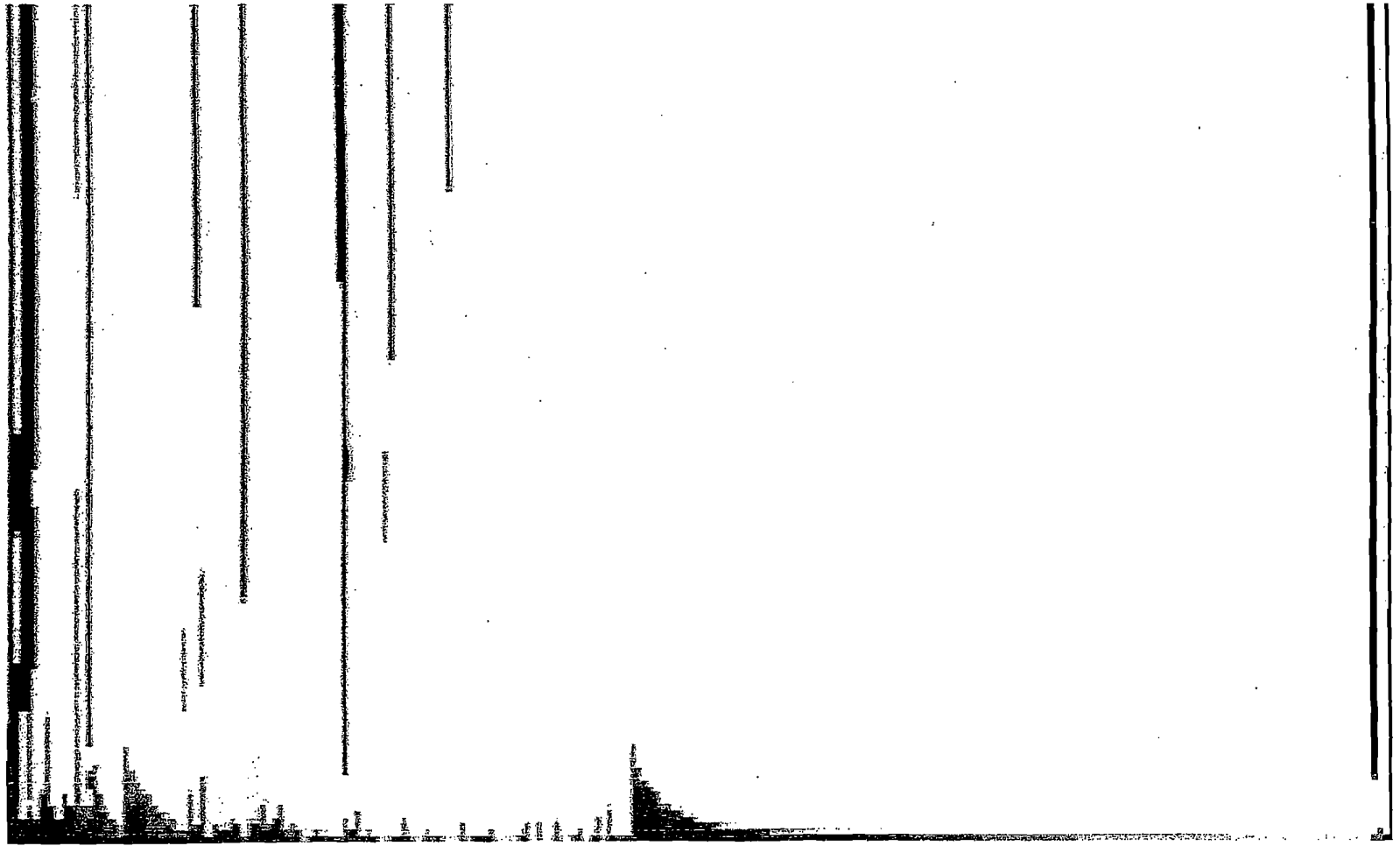
Finally, Appendix C (p. 33) includes any moderate or severe TBI member who had a nursing home stay or was on a waiver in the 24 months following their index hospitalization. These individuals either tended to remain in nursing homes or on waivers, or they died or re-entered the community. It is noteworthy that these individuals tended to have the least amount of transitions back into the community in comparison to other individuals in the cohort.

Please note that all members included in the transition figures had to have experienced an index hospitalization between 2003 and 2006 with a moderate or severe TBI in order to be included in the 1,296 cohort depicted in the following transition graphs. All transition graphs have been

"blurred" to mask the actual length of stay for each transition setting so as to mask individually identifying information for the sake of HIPAA compliance. Some members may appear in multiple sub-figures in the appendices (i.e., they figures are not mutually exclusive).

Legend	
Yellow	Nursing Home
Dark Blue	Hospice
Pink	Waiver
Green	Primarily ARF
Red	Primarily CRF
Black	Death
Light Aqua	Comm-unity
Burnt Orange	Inpatient Hosp
Brick Red	Index Hosp

Figure 2: Transition Patterns for all Moderate to Severe TBI Patients with an Index Hospitalization Between 2003 and 2006; N=1,296



Analysis #5: What differences exist between TBI and non-TBI patients with regard to types of COSs received and costs of services?

Goals Analysis #5 describes the categories of services received by those with moderate to severe TBI and the differences between those with moderate to severe TBI compared to those without TBI in terms of COS Rollups utilized, as well as costs associated with those COS Rollups. This analysis was designed to answer the following questions:

- What services do Medicaid patients with moderate to severe TBI patients receive and how much do they cost?
- How does the moderate and severe TBI patient group look with regard to common COS Rollups and costs?
- How do the TBI groups differ from the non-TBI group in costs and COS Rollups in the 24 month post incident TBI period?

Results

The costs and proportion of members with each COS are shown in Table 7a below. The 12 services that account for 94% of the costs of TBI patients are highlighted in dark yellow. The 12 services that account for 88% of non-TBI members are highlighted in the darker blue. The services are listed in order of costs for the non-TBI cohort with the services contributing to the highest proportion of the costs listed at the top. The comparison cohort (N=978,591) is comprised of those without TBI in Medicaid during the two-year time period from 1/1/2004-12/31/2005. Many of the most costly services overlap with the exception of ICF/MR service, child dental and other mental health services that contribute to a higher proportion of costs for non-TBI members. Medical supplies, transportation and rehabilitation facilities services contribute to a higher proportion of TBI patient costs.

The light yellow (TBI) and light blue (non-TBI) shaded service areas denote services which were received by 10% or more of members. Approximately 70-100% of TBI patients received the top 6 services (inpatient, physician, x-ray, outpatient, drugs, and clinical). About 40-50% received lab services, eye exams, and mental health services. About a quarter of TBI members receive durable medical equipment, dental services (child or adult), and eyewear. Prescribed drugs were the COS with the highest proportion of non-TBI members (44%). Between 30-43% of non-TBI members received physician services, outpatient services, dental services and clinic services, and between 20 and 24% received x-ray services, lab services and eye exams. Ten to thirteen percent received other mental health, inpatient hospital, eyewear and adult dental services. In comparison to the non-TBI members, the TBI members used as much or more of every COS except ICF/MR, home health and child dental services. In fact, even among the most frequently used services for non-TBI members (with the exception of child dental services), the proportion of TBI patients using those services was generally 2-3 times higher.

Table 7a. Categories of Service for TBI members and Non-TBI member with Most Frequent and Highest Cost Services Highlighted

		Moderate-Severe TBI Members N=1,296				Non-TBI Members N=978,591			
COS Rollup	COS Rollup description	Total $ for COS	% of costs	N of members	% of members	Total $ for COS	% of costs	N of members	% of members
1	Inpatient Hospital	26,166,744	50.8%	1296	100.0%	617,872,423	17.7%	112,076	11.5%
7	Prescribed Drugs	2,849,205	5.5%	995	76.8%	593,223,905	17.0%	434,398	44.4%
26	Mental Health Services	874,626	1.7%	211	16.3%	317,815,907	9.1%	72,256	7.4%
36	Waiver Services	2,084,661	4.0%	44	3.4%	270,653,952	7.7%	5,448	0.6%
6	Physician Services	2,549,779	4.9%	1267	97.8%	224,803,651	6.4%	424,906	43.4%
15	ICF/MR Services	0	0.0%	0	0.0%	215,687,458	6.2%	1,241	0.1%
14	Nursing Home Services	6,182,354	12.0%	136	10.5%	206,872,417	5.9%	4,504	0.5%
3	Outpatient Services	1,734,597	3.4%	1134	87.5%	194,396,498	5.6%	334,251	34.2%
27	Dental Services-Child	222,427	0.4%	324	25.0%	163,248,949	4.7%	314,092	32.1%
17	Clinic Services	908,887	1.8%	903	69.7%	106,219,251	3.0%	232,085	23.7%
26	Mental Health Other	284,906	0.6%	494	38.1%	79,115,035	2.3%	117,882	12.0%
16	Home Health Services	610,628	1.2%	108	8.3%	74,234,560	2.1%	7,975	0.8%
2	Inpatient Psych Svcs	343,600	0.7%	30	2.3%	63,310,600	1.8%	10,575	1.1%
28	Dental Services-Adult	217,781	0.4%	284	21.9%	62,094,683	1.8%	95,594	9.8%
9	Durable Medical Equipment (DME)	431,278	0.8%	341	26.3%	44,449,645	1.3%	39,558	4.0%
8	Medical Supplies	511,360	1.0%	199	15.4%	38,725,772	1.1%	39,432	4.0%
13	Transportation Services	1,516,042	2.9%	752	58.0%	30,227,782	0.9%	55,356	5.7%
12	X-Ray Services	418,407	0.8%	1153	89.0%	28,919,675	0.8%	204,314	20.9%
5	Targeted Case Management (TCM) Services	325,467	0.6%	125	9.6%	21,090,602	0.6%	16,868	1.7%
11	Lab Services	85,841	0.2%	604	46.6%	19,546,349	0.6%	191,779	19.6%
18	Hospice Services	88,517	0.20%	0	0.0%	17,511,740	0.5%	1,377	0.1%
31	Eye Care and Exams	85,182	0.2%	513	39.6%	14,183,090	0.4%	131,250	13.4%
34	School Corporation Services	11,799	0.0%	24	1.9%	11,417,614	0.3%	15,610	1.6%
33	Freestanding Dialysis Services	106,978	0.2%	10	0.7%	10,928,720	0.3%	644	0.1%
19	Ambulatory Surgical Services	30,968	0.1%	58	4.5%	8,802,699	0.3%	11,742	1.2%

32	Eyewear	28,139	0.1%	300	23.1%	7,958,934	0.2%	97,255	9.9%

Table 7a Continued Below

		Moderate-Severe TBI Members N=1,296				Non-TBI Members N=978,591			
COS Rollup	COS Rollup description	Total $ for COS	% of costs	N of members	% of members	Total $ for COS	% of costs	N of members	% of members
38	EPSDT Services	19,469	0.0%	191	14.7%	7,286,907	0.2%	79,172	8.1%
29	Chiropractic Services	19,803	0.0%	43	3.3%	4,709,598	0.1%	13,092	1.3%
25	Rehabilitation Facilities Services	2,459,819	4.8%	28	2.2%	3,589,197	0.1%	2,338	0.2%
30	Podiatrist Services	7,995	0.0%	80	6.2%	2,167,554	0.1%	10,034	1.0%
99	Unknown Services by Claim Type	178,869	0.3%	60	4.6%	1,324,109	0.0%	2,116	0.2%
20	Therapy Services - Physical	10,219	0.0%	46	3.5%	1,139,531	0.0%	4,818	0.5%
23	Therapy Services - Respiratory	29,999	0.1%	180	13.9%	843,580	0.0%	21,652	2.2%
24	Therapy Services - Audiology	3,748	0.0%	77	5.9%	780,836	0.0%	15,068	1.5%
37	Nursing Services	2,404	0.0%	20	1.5%	585,085	0.0%	3,554	0.4%
10	Prosthetic/Orthotic Services	3,325	0.0%	20	1.5%	274,366	0.0%	2,820	0.3%
22	Therapy Services - Occupational	1,239	0.0%	0	0.0%	189,128	0.0%	760	0.1%
21	Therapy Services - Speech	96	0.0%	0	0.0%	163,346	0.0%	194	0.0%

Table 7b, below, shows the services accounting for the highest proportion of costs in the 2 years after the incident hospitalization shown as the total, for those with moderate TBI and those with severe TBI. The green shaded areas are the top 10 most costly total services, the yellow are the top 10 most costly services for those with moderate injury, and the red shaded area is the services for those with severe injury. Those with severe injury had a somewhat higher proportion of their costs spent on medical supplies and inpatient psychiatric services, while those with moderate injury had a higher proportion of their costs spent on transportation and mental health services.

Table 7b. COS Rollups Accounting for the Highest Proportions of Costs in 2 Years Post-Index Hospitalization

COS Rollup	COS Rollup Description	% of cohort's total costs	% of moderate total costs	% of severe total costs
1	Inpatient Hospital	27.50%	25.40%	31.50%
14	Nursing Home Services	20.10%	21.80%	16.70%
7	Prescribed Drugs	9.00%	10.00%	7.00%
25	Rehabilitation Facilities Services	8.00%	7.00%	10.10%
36	Waiver Services	6.80%	6.80%	6.80%
3	Outpatient Services	5.40%	5.30%	5.60%
6	Physician Services	4.40%	4.40%	4.30%
26	Mental Health Services	2.80%	3.60%	1.30%
13	Transportation Services	2.20%	2.70%	1.30%
16	Home Health Services	2.00%	2.00%	2.00%
8	Medical Supplies	1.60%	1.50%	2.00%
2	Inpatient Psych Svcs	1.10%	0.30%	2.60%

Analysis #6: What are characteristics of patients going specifically to the Carbondale (Mentor ABI Center for Comprehensive Services) facility in the study period?

Goals Analysis #6 describes the characteristics of patients who entered the Mentor ABI Center for Comprehensive Services in Carbondale, IL. This analysis was designed to answer the following questions:

- How many members in the study cohort entered the Carbondale facility during the study period?
- What were these members' primary COSs and associated costs?

Results

Sixteen of the 1,296, or 1.2% of the incident cohort of moderate to severe TBI patients received services from the Carbondale Facility over the 24 months of follow-up after index hospitalization (some of these falling into "states" beyond the scope of these analyses). The majority had moderate TBI diagnoses. They were predominantly white (13/16) and male with a median age of 28 (mean 31; range 17- 58). Over $2,000,000 was spent on TBI patients in Carbondale over the two-year follow-up period. The median cost of a Carbondale stay was $106,000 (mean $126,500; range $20,300 - $354,200; the PMPM cost was just over $17,000). The median length of stay was about 7 months (213 days; mean 229 days; range 6 days—661 days). The vast majority of claims were paid for the category of services 2500 (Rehabilitation Facilities Services). See Table 8a below.

Table 8a. COS Rollups and Costs of the 16 Patients Who Received Services at Carbondale

COS Rollup	COS Rollup Description	$ in Carbondale	% of costs (% of Carbondale total)
25	Rehabilitation Facilities Services	1,901,490	93.90%
7	Prescribed Drugs	55,625	2.70%
1	Inpatient Hospital	33,649	1.70%
14	Nursing Home Services	20,213	1.00%
3	Outpatient Services	6,032	0.30%
28	Dental Services-Adult	3,144	0.20%
6	Physician Services	1,120	0.10%
13	Transportation Services	1,086	0.10%
31	Eye Care and Exams	668	0.00%
9	Durable Medical Equipment (DME)	553	0.00%
12	X-Ray Services	163	0.00%
17	Clinic Services	86	0.00%
32	Eyewear	72	0.00%
5	Targeted Case Management (TCM) Services	47	0.00%
11	Lab Services	18	0.00%

	Total	2,023,966	100%

In a separate analysis to better understand the number of Medicaid recipients receiving services in Carbondale, IL, during the study period, there were 151 unique Indiana Medicaid patients with "Memorial Hospital of Carbondale" claims over the course of the six years 2003-2008. The numbers of unique patients per year in the study period are in Table 8b below.

Table 8b. Indiana Medicaid Patients with "Memorial Hospital of Carbondale" Claims (2003-2008)

Year	Unique Patients
2003	34
2004	46
2005	47
2006	36
2007	37
2008	45

Of the members with Carbondale location codes on their claims, 45% were in the mild TBI group; 10% were in the moderate to severe TBI group; and 40% were in neither group (attending Carbondale with a primary or secondary diagnosis other than TBI). This separate analysis looking at all unique Indiana Medicaid patients receiving services in Carbondale, IL, serves to illustrate an important point: there is a substantial number of individuals that ultimately go to the facilities in Carbondale, IL, to receive services that were not "picked up" in our cohort sample. Recall that 16 members were "picked up" in the cohort of moderate-severe TBI patients who received services at the Mentor ABI Center for Comprehensive Services in Carbondale, IL. We estimate that the number of individuals receiving services at Carbondale's facilities is actually 4-5 times the number included in our cohort sample. Reasons that individuals may not have been "picked up" in the sample for this study are that they had private insurance (or another payer source besides Medicaid) at the time of their TBI injury and reached their limit or cap and then became Medicaid eligible. Another explanation is that they could be individuals whose TBI ICD-9 diagnosis would not have fallen under our definition of TBI or moderate-severe TBI. Extrapolating the $2M in costs over a two year period for the 16 people receiving services at Carbondale that were included in our sample, we estimate that Medicaid is paying approximately $4M to over $5.5M for 34-47 individuals receiving services at Carbondale in a given two year period.

Summary & Discussion of Findings

Demographics of the Indiana Medicaid TBI Cohort.

The study cohort of moderate to severe TBI members in Indiana Medicaid with index hospitalizations occurring in calendar years 2003-2006 (plus 2 years post-index hospitalization) account for only 0.13% of members, but a disproportionate amount (1.5%) of total Medicaid costs. These prevalence figures are not dissimilar to national data, which estimate that 5.3 million (2%) of Americans in the general population currently live with TBI, with 20% of these (or 0.4%) having had the moderate-severe injuries associated with longer-term impairment [17]. In addition, our finding in the moderate-severe TBI Medicaid cohort that there is a preponderance of males (61%), Caucasians (75%), and young adults (median age=22) is consistent with the overall results of the Traumatic Brain Injury Model Systems (TBIMS) research program [18].

We observed that African-American Medicaid members with moderate-severe TBI were less likely than Caucasian Medicaid members to get inpatient rehabilitation after incident hospitalization. This finding has been demonstrated in the literature [16]. However, other research did not find evidence of racial disparities in access to rehabilitation, but rather that there was variation in long-term functional outcomes by racial and ethnic group [16, 19-20], arguing that this is more reflective of disparities in acute trauma care [21-23]. In addition, we noted, in our cohort, that females were less likely to get any type of rehabilitation. This could reflect a genuine healthcare disparity, or, alternatively, could be a function of systematic differences between males and females with regard to TBI severity [24-25]. For example, females have been repeatedly shown to have better outcomes after neurotrauma, even after controlling for severity of injury. This "advantage" has been attributed to neuroprotective and restorative effects of estrogen and progestin both at time of injury and post-injury [12, 26-30]. In contrast, one meta-analysis concluded the opposite, namely that females fared worse than males in terms of recovery from TBI [31].

Costs and Disposition of Moderate-Severe TBI Patients in Medicaid

The incident hospital costs for those discharged to inpatient rehabilitation were a little higher than for those discharged to an inpatient hospital. This is interesting in light of the fact that costs for an inpatient hospital stay after the incident hospitalization are higher than an inpatient rehabilitation stay (see Table 4b). If the difference was attributable to the "sicker" patients being discharged to a hospital rather than to rehabilitation, one might expect that the initial hospital stays would also be more expensive. The majority (78%) of moderate-severe TBI patients are discharged to the community and remain there without admittance to rehabilitation facilities or hospitals. Both costs and Medicaid service use are highly concentrated in a relatively small proportion of moderate to severe TBI cases. The highest-cost utilizers tend to (a) use inpatient services short of longer-term rehabilitation, followed by (b) nursing home and hospice, and then followed by (c) waiver. They also tended to use the following categories of service: inpatient hospital care, prescription drugs, nursing home care, rehabilitation care, and outpatient, waiver, and mental health services. Just over 1% (16) of the moderate-severe TBI cohort sampled by this study went on to receive longer-term rehabilitation services at Carbondale, IL. These patients were predominantly younger white males (median age of 31). The median cost of a stay at Carbondale was $106,000.

Relatively few patients are receiving acute inpatient rehabilitation (7.5%), after initial hospitalization, while 18% received a rehabilitation service in some setting (not necessarily inpatient). These rates for rehabilitation services seem rather low, and beg the question of the need to encourage short-term, intensive rehabilitation to improve outcomes, and eventual community reintegration.

Recommendations

Improving Indiana's infrastructure for TBI management is our primary recommendation. This involves several steps, and we recommend that these improvements be a function of collaborative efforts between the Indiana State Department of Health, the Office of Medicaid Policy and Planning, as well as other key stakeholders.

1) First, building on the MMAC's previous two reports on Traumatic Brain Injury (TBI reports I and II, dated June 2009, and October 2009, respectively) we recommend that, because TBI impacts such a small proportion of Indiana's population that the Home and Community Based TBI waiver be revised and expanded to provide services to more individuals. Because >75% of those with moderate and severe TBI are discharged into the community without receiving rehabilitative services, and given that a sizable number (over 25%) have "severe" TBI diagnoses, waiver expansion could provide significant opportunities for improvement to these individuals. It is tempting to assume that these individuals must have good prognoses because they do not receive rehabilitation; however, such an assumption is not testable by these claims-based data due to the impossibility of analyzing such individuals' outcomes. Further, expanding waiver services could provide an opportunity for individuals, who might otherwise be placed in rehabilitation facilities or nursing facilities to receive assistance in their communities, a strategy cited as leading to even more improvement in outcomes post-TBI by site leaders of the Model TBI Systems Program [32-33]. With this in mind, we also recommend that Indiana increase its provision of vocational rehabilitative services with the intent of returning as many TBI survivors to the workforce.

2) Next, we strongly recommend that, in lieu of pursuing a single, large-scale, Carbondale-like facility in the state of Indiana, that consideration be given to the establishment of regional TBI facilities (possibly one for each of the 8 Medicaid care regions across Indiana). Improving regional infrastructure to enhance TBI outcomes will help serve rurally located individuals, and increase the chances that more individuals could remain closer to home to receive treatment.

3) Similarly, we recommend that existing facilities in the state, both rehabilitative and nursing facilities, work to train staff in TBI treatment, or hire staff specifically for treating individuals with TBI. Enhanced Medicaid reimbursement could be offered to nursing homes that meet criteria for offering specialized TBI care (e.g., have staff with accredited specialized training in behavior management, and space renovated to suit the needs of TBI patients, such as monitored seclusion room areas).

4) If longer-term rehabilitation (chronic rehabilitative facility, "CRF," care) is clinically necessary, we recommend that OMPP incentivize the utilization of these rehabilitative services within the first two years of injury (as recommended in the previous MMAC TBI reports I and II) in order to maximize clinical outcomes, and limit longer-term costs. Case review of a number of Carbondale TBI patients together with our current analyses suggest that there are significant delays in the delivery of these services, which likely limits their effectiveness. Further, incentivizing immediate, post-injury rehabilitative services will help to keep better track of when an individual's injury occurred in relation to rehabilitative services they either have or are seeking to receive. This is expected to be especially pertinent in the cases of individuals who became Medicaid-eligible months (or years) post-injury, and had another source paying for any prior TBI-related care. Tracking date of injury and use of services will help to determine whether an individual will (most likely) benefit more from rehabilitative care (i.e., it has been approximately two years or less since the date of the person's TBI), or care that assists the individual in compensating for their TBI-related deficits (i.e., it has been more than two years since the date of the person's TBI).

5) We also recommend that efforts be made to increase primary prevention approaches. The data reported herein demonstrate the significant costs associated with index hospitalizations, which could be avoided with primary prevention efforts, such as seatbelt, distracted driving, and helmet laws and enforcement. For moderate and severe TBI patients in our cohort, of the $51.4M spent from the time of index hospitalization through two years thereafter, nearly $21M of this was attributable just to the index hospitalization. Strong primary prevention efforts, again recommended to be collaborative between key stakeholders in the state of Indiana, could substantially decrease these costs. Funding models of the type recommended in TBI report II, such as the establishment of "Auto no-fault" fund, through a levy on auto insurance or a portion of traffic violations being allocated to increased TBI funding, could also help defray the cost of acute care, allowing more Medicaid dollars to be utilized for rehabilitative efforts.

6) Since, in the current analysis, we did not have access to some key mediating/moderating clinical variables such as type or severity of disability, we recommend that for future quality monitoring purposes, OMPP consider including a reporting requirement of standardized functional assessment data in Medicaid patients with moderate-severe TBI (we recommend utilizing either the FIM, DRS or GOS-E as described in MMAC TBI report I). This information could be captured upon admission and discharge from acute hospitalization, pre- and post-acute rehabilitation care, and each six months thereafter for patients receiving some type of sub-acute rehabilitation. This would facilitate outcomes comparisons with those achieved in other TBI programs across the country.

7) Finally, we strongly recommend that OMPP further investigate whether differences in receiving inpatient rehabilitation for minorities and for women, compared to Caucasian men, reflect disparities in care for individuals sustaining TBIs. Based on the differences emerging in the current analyses, Caucasian men with moderate or severe TBI were disproportionately more likely to receive inpatient rehabilitation after their index hospitalization. OMPP could also consider monitoring outcomes for moderate to severe TBI patients to examine whether disparities in long-term outcomes emerge for minorities and/or women and compare this to national and other states' statistics.

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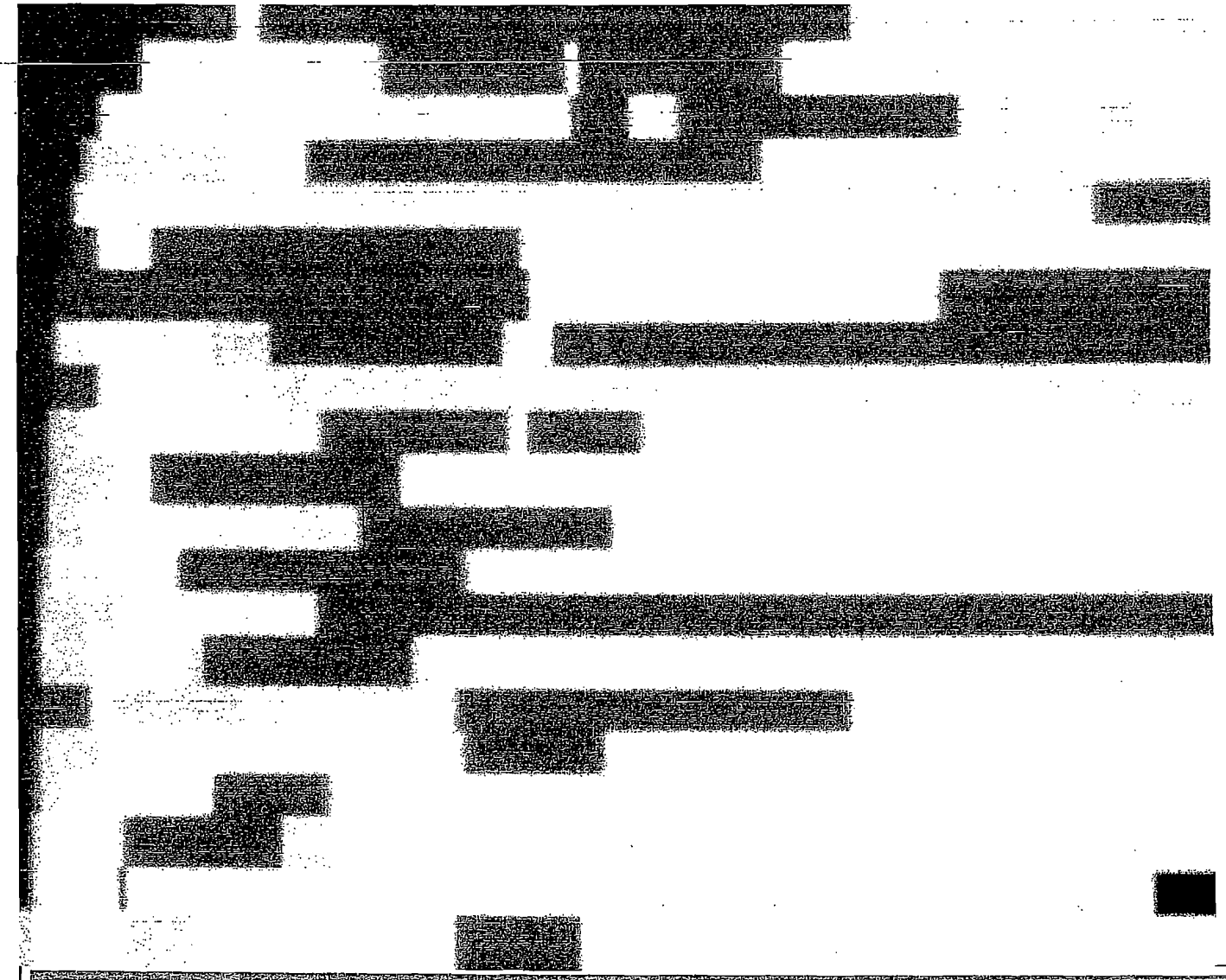
Appendix A

Any Moderate or Severe TBI Member with a Primarily Chronic Rehab Stay (COSs 2500/2510); N = 21



Legend	
Yellow	Nursing Home
Dark Blue	Hospice
Pink	Waiver
Green	Primarily ARF
Red	Primarily CRF
Black	Death
Light Aqua	Community
Burnt Orange	Inpatient Hosp
Brick Red	Index Hosp

Appendix B

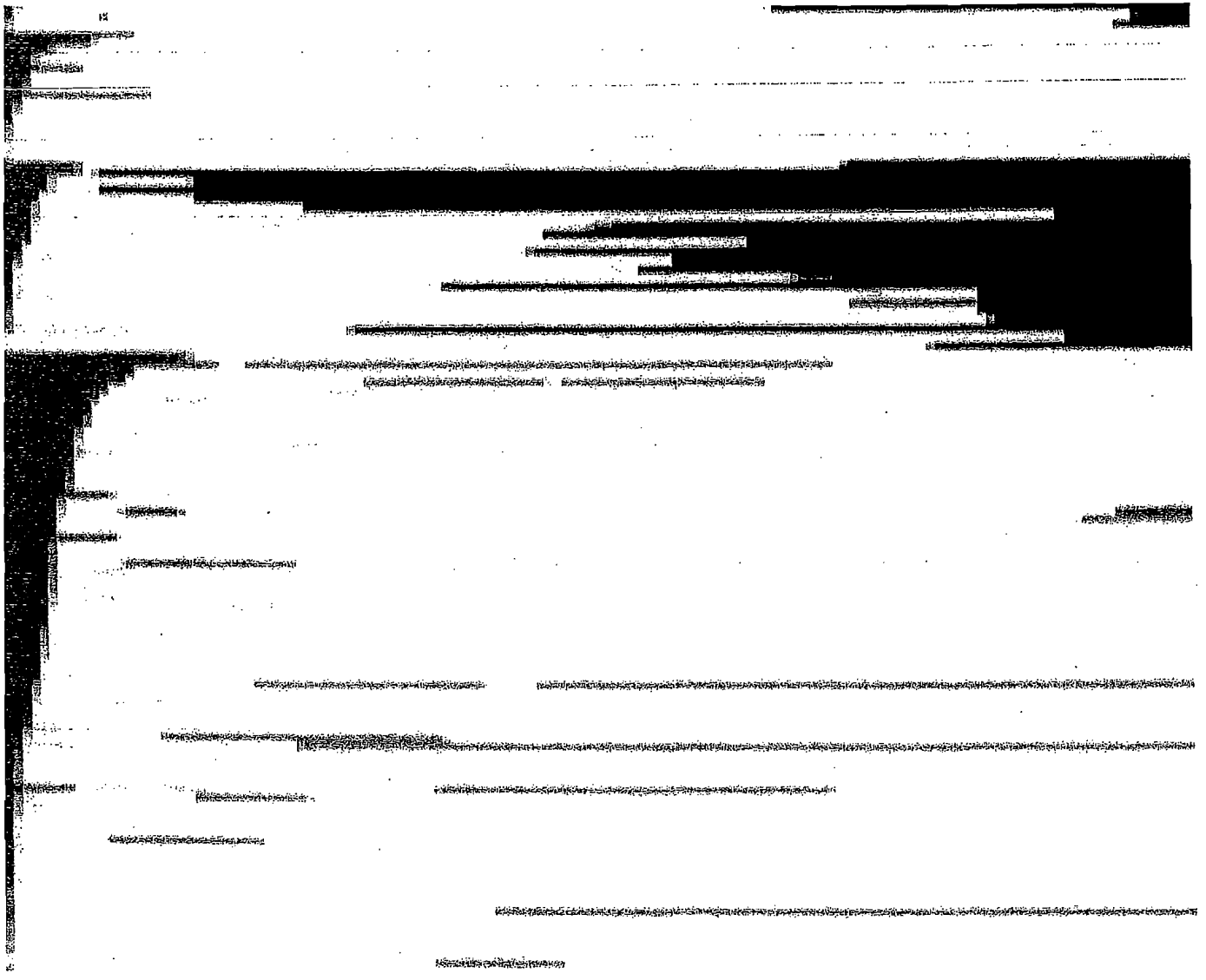
Any Moderate or Severe TBI Member with a Primarily Acute Rehab Stay (COS 0120); N = 96

Legend	
Yellow	Nursing Home
Dark Blue	Hospice
Pink	Waiver
Green	Primarily ARF
Red	Primarily CRF
Black	Death
Light Aqua	Community
Burnt Orange	Inpatient Hosp
Brick Red	Index Hosp

Traumatic Brain Injury: Synthesis of Indiana Medicaid Data

Appendix C

Any Moderate or Severe TBI Member with a Nursing Home Stay or on a Waiver; N = 167



Legend	
Yellow	Nursing Home
Dark Blue	Hospice
Pink	Waiver
Green	Primarily ARF
Red	Primarily CRF
Black	Death
Light Aqua	Community
Burnt Orange	Inpatient Hosp
Brick Red	Index Hosp

Neurobehavioral Rehabilitation Services

Draft Administrative Rules

ITEM 1. Adopt the following **new** rule 441—77.47:

441- 77.47 Community Based Neurobehavioral Rehabilitation Services.

a. The following agencies may provide community based neurobehavioral services

(1) An agency that is accredited by a nationally recognized accreditation agency as a specialty brain injury rehabilitation service provider~~Residential Rehabilitation Program for persons with a brain injury.~~

(2) Agencies not accredited by a nationally recognized accreditation agency as a specialty brain injury rehabilitation service ~~Residential Rehabilitation Program for~~provider ~~persons with a brain injury~~ that have applied for accreditation within the last 16 months to provide services may be enrolled. ~~that qualify as residential rehabilitation for persons with a brain injury~~. However; a~~A~~n agency that has not received accreditation within 16 months after application ~~is~~ shall no longer be a qualified provider

b. All Neurobehavioral Rehabilitation Service providers shall meet the following criteria:

(1) *Organizational standards (Outcome 1).* Organizational outcome-based standards for Community-based Neurobehavioral Rehabilitation Service providers are as follows:

(a) The organization demonstrates the provision and oversight of high-quality supports and services to ~~consumer~~members,

(b) The organization demonstrates a defined mission commensurate with ~~consumer~~member's needs, desires, and abilities,

(c) The organization establishes and maintains fiscal accountability.

(d) The organization has qualified staff trained in the provision of direct care services to people with a brain injury. The training is commensurate with the needs of the ~~consumer~~members they serve. These staff demonstrate competency in performing duties and in all interactions with clients including but not limited to:

(1) Structure and support for persons served so they can learn or regain their skills in a new reality

(2) Assistance with ADL's (activities of daily living)

(3) Quality of life issues

(4) Behavioral Supports, identification of antecedent triggers and self recognition

(5) Medication Management

(6) Dietary and nutrition programming

(7) Sobriety Support

(8) Structured leisure

(9) Promotion of maximum community inclusion and access

(10) Self management and self interaction skills

(11) Flexibility in programming to meet individual needs

(12) Importance of teaching compensatory strategies

(13) Community accessibility and safety

(14) Household maintenance

(15) Service support to family

~~(d)~~

~~(1)~~

~~(2)~~

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(e) The organization provides needed training and supports to its staff. This training is provided before direct service provision and includes at a minimum:

(1) Completion of the DHS, IME Brain Injury Training Modules~~(1)~~

(2) The services listed in 77.47 (b) (1) (d).

(3) ~~Consumer~~Member- rights.

(4) ~~(2)~~ Confidentiality and privacy.

~~(3) Provision of consumer medication.~~

(5) ~~(4) Identification~~Member identification and reporting of child abuse ~~and~~ dependent adult abuse.

(6) ~~(5)~~ Individual ~~consumer~~member- rehabilitation treatment plans.

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(f) The organization demonstrates that it has an outcome management system which measures the efficiency and effectiveness of service provision, member and stakeholder satisfaction, and access to services.

(g) The organization has a systematic, organization wide, planned approach to designing, measuring, evaluating, and improving the level of its performance. The organization:

(1) Measures and assesses organizational activities and services annually.

(2) Gathers information from ~~consumer~~members, family members, and staff and shares the information with stakeholders. ~~.~~

(3) Conducts an internal review of ~~consumer~~member service records, including all major and minor incident reports according to subrule 77.37(8).

(4) Tracks incident data and analyzes trends annually to assess the health and safety of ~~consumer~~members served by the organization.

(5) Identifies areas in need of improvement.

(6) Develops a plan to address the areas in need of improvement.

(7) Implements the plan and documents the results.

(hg) ~~Consumer~~Members and their legal representatives have the right to appeal the provider's implementation of the organizational outcomes, or staff or contractual person's action which affects the ~~consumer~~member. The provider shall distribute the policies for ~~consumer~~member appeals and procedures to ~~consumer~~members.

(ih). The provider shall have written policies and procedures and a staff training program for the identification and reporting of child and dependent adult abuse to the department pursuant to 441—Chapters 175 and 176.

(ji) The governing body has an active role in the administration of the agency.

(kl). The governing body receives and uses input from a wide range of local community interests and ~~consumer~~member representation and provides oversight that ensures the provision of high-quality supports and services to ~~consumer~~members.

(2) *Rights and dignity.* Outcome-based standards for rights and dignity are as follows: (Outcome 2) ~~Consumer~~Members are valued

(a) (Outcome 3) Individuals using the service and staff mutually develop an individualized service plan that focuses on the neurobehavioral issues and problems identified at admission. Goals are based on the individual's need for services.

~~(a)~~(b) (Outcome 4~~3~~) ~~Consumer~~Individuals ~~s~~ ~~live in positive environments.~~receive appropriate residential services and employment supports

~~(b) (Outcome 4) Consumers work in positive environments.~~

~~(c) (Outcome 5) Consumers exercise their rights and responsibilities.~~

~~(d) (Outcome 6) Consumers have privacy.~~

~~(e) (Outcome 7) When there is a need, consumers have support to exercise and safeguard their rights.~~

~~(f)~~(c) (Outcome ~~5~~8) ~~Consumer~~Members decide which personal information is shared and with whom.

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~~(g) (Outcome 9) Consumers make informed choices about where they work.~~

~~(h) (Outcome 10) Consumers make informed choices on how they spend their free time.~~

~~(i) (Outcome 11) Consumers make informed choices about where and with whom they live.~~

~~(j) (Outcome 12) Consumers choose their daily routine.~~

~~(k) (Outcome 13) Consumers are a part of community life and perform varied social roles.~~

~~(l) (Outcome 14) Consumers have a social network and varied relationships.~~

~~(m) (Outcome 15) Consumers develop and accomplish personal goals.~~

~~(n)~~(d) (Outcome ~~6~~16) ~~Management of consumers' money is addressed on an individualized basis~~ Members receive assistance with financial managements needed.

~~(o)~~(e) (Outcome ~~7~~17) ~~Consumer~~Members ~~maintain good health.~~receive appropriate and timely health care

~~(p)~~(f) (Outcome ~~8~~18) The ~~consumer~~member's living environment is reasonably safe in the ~~consumer~~member's home and community.

~~(q)~~(g) (Outcome ~~9~~19) The ~~consumer~~member's desire for intimacy is respected and supported.

~~(r)~~(h) (Outcome ~~2~~010) ~~Consumer~~Members have an impact on the services they receive.

(3) When a member has a guardian or legal representative that person will provide informed consent to treat and provide informed consent for any restrictive measures that may be required to protect the health or safety of the member.

Item 2. Adopt the following **new** rule 441—78.53

441- 78.53 Community Based Neurobehavioral Rehabilitation Services.
Payment will be made for Neurobehavioral Rehabilitation Services that do not duplicate other services covered in this chapter.~~not otherwise covered in this chapter that are designed to enhance and promote a member's neurobehavioral rehabilitation~~.

78.53(1) Definition
Brain injury" means a diagnosis ~~a diagnosis~~ in accordance with 441 IAC 83.81:
Member" means a person who has been determined to be eligible for Medicaid under 441IAC Chapter 75.
"Neurobehavioral intervention" means skill-building services that focus on:

(1) Addressing the physical, emotional, cognitive, medical and psychosocial residuals of the brain injury that negatively affect a member's integration and stability in the community and quality of life; and

(2) Improving a member's health and well-being, ~~related to the member's neurobehavioral residuals~~ by reducing or managing the symptoms and ~~or~~ behaviors that ~~prevent~~ inhibit the member from functioning at the member's best possible functional level; and

(3) Promoting a member's recovery and resilience through increasing the member's ability to manage ~~symptoms; and~~symptoms and behaviors

(4) Modifying or adapting the member's environment to improve overall functioning.

"Standardized Assessment" means a ~~nationally recognized~~ valid, reliable assessment tool approved by the department for use in the assessment of an individual's needs.

78.53 (2) Member Eligibility

Member eligibility. To be eligible to receive community-based neurobehavioral rehabilitation services, a member shall meet the following criteria:

a. Brain injury diagnosis

To be eligible for community based neurobehavioral rehabilitation services the member must have brain injury diagnosis as listed in **83.81**

b. Risk factors. The member has at least one of the following risk factors:

(1) The member has undergone or is currently undergoing treatment more intensive than outpatient care more than once in the member's life; or

(2) The member has a history of presenting with neurobehavioral or psychiatric symptoms resulting in at least one episode of continuous, professional supportive care other than hospitalization, institutionalization, incarceration or homelessness; ~~or~~and

(3) The member is exhibiting neurobehavioral symptoms in such frequency and severity that the member is at risk of hospitalization, institutionalization, incarceration or homelessness

c. Need for assistance. The member has a need for assistance demonstrated by meeting the following criteria on a continuing or intermittent basis:

(1~~3~~) The member shows severe inability to establish or maintain a personal social support system, and

(4~~2~~) The member exhibits neurobehavioral symptoms in such frequency, severity and/or intensity that ~~results in a demand for~~ intervention is required.

d. Income. Be eligible for Medicaid under SSI, SSI-related, FMAP, or FMAP-related coverage groups or be eligible under the special income level (300 percent) coverage group consistent with a level of care in a medical institution.

e. *Needs assessment.* A standardized neurobehavioral assessment has been completed by a ~~certified brain injury specialist trainer or other a~~ qualified professional licensed as a Psychologist, M.D. or D.O trained in the completion of ~~an~~ the approved standardized assessment tool(s) for persons with brain injury. The neurobehavioral assessment documents the member's need for service, and, based on that assessment, the Iowa Medicaid enterprise medical services unit has determined that the member is in need of specialty neurobehavioral rehabilitation services.

(1) Standards for assessment. Each assessment of a member's individual physical, emotional, ~~cognitive~~cognitive, medical and psychosocial residuals related to their brain injury must include:

(a) identification of the neurobehavioral needs that put them at risk including: verbal aggression, physical aggression, self-harm, unwanted sexual behavior, perseveration, repetitive behavior, wandering or elopement, lack of motivation, lack of initiation or other unwanted social behaviors not otherwise specified.

(b) Identification of triggers of unwanted behaviors and the member's ability to self regulate

~~(b)~~(c) the member's medication history and status

~~(c)~~(d) the member's ability to work and the member's barriers to work

~~(d)~~(e) the member's ability to develop and maintain social and personal relationships

~~(e)~~(f) the member's dietary and nutritional needs

~~(f)~~(g) the member's community accessibility and safety

~~(g)~~(h) the member's history of substance abuse

~~(h)~~(i) the member's history of psychiatric treatment

~~(i)~~(j) the member's ability to self-protect and history of susceptibility to victimization

~~(j)~~(k) the member's history of relationships and socialization including social isolation

78.53(3) Covered Services

a. Service Setting.

(1) Community based neurobehavioral services are available to a member living in a community based living environment licensed by the Department of Inspections and Appeals or

(2) in their primary residence

(3) Neurobehavioral Rehabilitation services are not available in a medical institution such as a intermediate care facility for persons with mental retardation,

~~(3)~~ nursing facility~~,~~ or skilled nursing facility ~~or intermediate care facility for persons with mental retardation,~~

b. Neurobehavioral rehabilitation services may include:

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(1) Structure and support for persons served so they can learn or regain their skills in a new reality~~- No Change~~

(2) Assistance with ADL's (activities of daily living) ~~- No Change~~

(3) Need to address quality of life issues~~- No Change~~

(4) ~~Case management oversight – change title to~~ Auxiliary Service Coordination

(5) ~~Behavioral Management programming – change title to~~ Behavioral Supports

(6) Medication management and consultation with pharmacy~~- No Change~~

(7) Dietary and nutritional programming~~- No Change~~

(8) ~~Substance Abuse Treatment and new skills – determined that this falls under Behavioral Health Services, but that "~~Ssobriety support development~~" could be offered~~

(9) Structured leisure activities~~- No Change~~

~~*(9)*~~*(10)*

~~*(10)*~~ ~~Individual counseling to build social skills – change to "~~Assist with the self-identification of antecedent triggers ~~triggers" or "Behavioral Supports". and/or "self recognition of antecedents"~~

(11) ~~Assistan~~Assistance~~t~~ with preparation for transition including community accessibility

(12) Flexibility in programming to meet individual needs

(13) ~~Importance of~~ Assistance with learning ~~teaching~~ coping and compensatory strategies

(14) ~~counseling to~~ Ssupport and assistance in seeking substance abuse and co-occurring disorders counseling

(15) Assistance with c~~C~~ommunity accessibility and safety

(16) Assistance with learning h~~H~~ousehold maintenance

(17) Assistance with r~~R~~ecreational and l~~L~~eisure s~~S~~kill d~~D~~evelopment

(18) Assistance with the development and application of s~~S~~elf-advocacy skills to navigate the service system

(19) Opportunities to learn about brain injury and individual needs following brain injury

(20) Support for carrying out the individuals' goals in the rehabilitation treatment plan

(21) Assistance with pursuit of ~~Support for~~ education and employment ~~activities~~goals

(22) Assistance with p~~P~~articipation in the community with protective oversight

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~~(22)~~*(23)* Assistance and education to family and friends supporting the person receiving neuro-behavioral rehabilitation services.

c. Neurobehavioral rehabilitation services shall include a minimum of 12 hours post service support to family/staff.

C. *Approval of treatment plan.*

The Community based neurobehavioral services provider shall submit the treatment plan, the results of the formal assessment, and medical documentation supporting a brain injury diagnosis to the Iowa Medicaid enterprise (IME) medical services unit for approval before providing the services.

a. Initial treatment plan. The IME medical services unit shall approve the provider's initial treatment plan if:

(1) The treatment plan conforms to the medical necessity requirements in subrule **78.53(3)**

(2) The treatment plan is consistent with the written diagnosis and treatment recommendations made by a licensed medical professional trained in the diagnosis and treatment of brain injury and are a Neuro-Psychologist, Neurologist, M.D., or D.O.

(3) The plan is sufficient in amount, duration, and scope to reasonably achieve its purpose;

(4) The provider can demonstrate that the provider possesses the skills and resources necessary to implement the plan

(5) The plan does not exceed six months' duration; and

(6) A treatment summary detailing the member's response to treatment during the previous approval period must be submitted when requesting approval for subsequent plans.

b. Subsequent plans. The IME medical services unit may approve a subsequent neurobehavioral rehabilitation treatment plan according to the conditions in paragraph *"a"* if the services are recommended by Neuro-Psychologist, Neurologist, MD, or D.O. ~~or CNP~~ who has:

(1) ~~Reexamined~~Examined the member;

(2) Reviewed the ~~original~~ most recent diagnosis and treatment plan;

(3) Evaluated the member's progress, including a review of the member's most recent neuro-behavioral assessment

(4) Submitted the results of the assessment review with the recommendation ~~for continued services.~~that this level of specialty care is medically necessary.

d. ***Quality review.*** The IME medical services unit will establish a quality review process. Reviews will evaluate:

(1) The time elapsed from referral to rehabilitation treatment plan development;

(2) The continuity of treatment;

(3) The length of stay per member

(4) The affiliation of the medical professional recommending services with the neurobehavioral rehabilitation services provider;

(4) Gaps in service;

(5) The results achieved; and

(6) Member satisfaction.

78.53(3) ***Medical necessity.*** Nothing in this rule shall be deemed to exempt coverage of neurobehavioral rehabilitation services from the requirement that services be medically necessary. "Medically necessary" means that the service is:

a. Consistent with the diagnosis and treatment of the member's condition;
b. Required to meet the medical needs of the member and is needed for reasons other than the convenience of the member or the member's caregiver;
c. The least costly type of service that can reasonably meet the medical needs of the member; and
d. In accordance with the standards of good medical practice. The standards of good practice for each field of medical and remedial care covered by the Iowa Medicaid program are those standards of good practice identified by:
    (1) Knowledgeable Iowa clinicians practicing or teaching in the field; and
    1. The professional literature regarding best practices in the field.

This rule is intended to implement Iowa Code section 249A.4

79.1(25) Reimbursement for Neurobehavioral Rehabilitation Services

Reimbursement for community based neurobehavioral rehabilitation services shall be made on the basis of a unit rate that is calculated retrospectively for each provider, considering reasonable and proper costs of operation. The unit rate shall not exceed the established unit-of-service limit on reasonable costs pursuant to subparagraph 79.1(23) *"c"* (1). The unit of service may be a quarter-hour, a half-hour, an hour, a half-day, or a day, depending on the service provided.

a. Interim rate. Providers shall be reimbursed through a prospective interim rate equal to the previous year's retrospectively calculated unit-of-service rate. On an interim basis, pending determination of the neurobehavioral rehabilitation provider costs, the provider may bill for and shall be reimbursed at a unit-of-service rate that the provider and the Iowa Medicaid enterprise may reasonably expect to produce total payments to the provider for the provider's fiscal year that are consistent with Medicaid's obligation to reimburse that provider's reasonable costs. The interim unit-of-service rate is subject to the established unit-of-service limit on reasonable costs pursuant to subparagraph 79.1(25) *"c"* (1).

b. Cost reports. Reasonable and proper costs of operation shall be determined based on cost reports submitted by the provider.

(1) Financial information shall be based on the provider's financial records. When the records are not kept on an accrual basis of accounting, the provider shall make the adjustments necessary to convert the information to an accrual basis for reporting. Failure to maintain records to support the cost report may result in termination of the provider's Medicaid enrollment.

(2) The provider shall complete Form XXX-XXXX Financial and Statistical Report for Neurobehavioral Rehabilitation Services, and submit it to the IME Provider Cost Audit and Rate Setting Unit, P.O. Box 36450, Des Moines, Iowa 50315, within three months of the end of the provider's fiscal year.

(3) A provider may obtain a 30-day extension for submitting the cost report by sending a letter to the IME provider cost audit and rate setting unit before the cost report due date. No extensions will be granted beyond 30 days.

(4) Providers of services under multiple programs shall submit a cost allocation schedule, prepared in accordance with the generally accepted accounting principles and requirements specified in OMB Circular A-87. Costs reported under neurobehavioral rehabilitation services shall not be reported as reimbursable costs under any other funding source. Costs incurred for other services shall not be reported as reimbursable costs under services.

c. Rate determination. Cost reports as filed shall be subject to review and audit by the Iowa Medicaid enterprise to determine the actual cost of services rendered to Medicaid members, using an accepted method of cost apportionment (as specified in OMB Circular A-87).

(1) A reasonable cost for a member is one that does not exceed 110 percent of the average allowable costs reported by Iowa Medicaid providers for providing similar neurobehavioral rehabilitation to members who have similar diagnoses and live in similar settings, less 5 percent.

(2) When the reasonable and proper costs of operation are determined, a retroactive adjustment shall be made. The retroactive adjustment represents the difference between the amount received by the provider through an interim rate during the year for

covered services and the reasonable and proper costs of operation determined in accordance with this subrule.

d. Documentation Standards. Neurobehavioral Rehabilitation Service Providers shall maintain service provision records, financial records, and clinical records in accordance with the provisions of 441 IAC 79.3.

79.3 d. Basis for service requirements for specific services

(40) Neurobehavioral Rehabilitation Services

1. *Physician orders.*
2. *Progress or status notes.*
3. *Service notes or narratives.*
4. *Procedure, laboratory, or test orders and results.*
5. *Physical therapy, occupational therapy, and speech therapy notes.*
6. *Medication administration records.*
7. *Form 470-0042, Case Activity Report. (RCF placement)*

Traumatic Brain Injury Program Placement Criteria

The Continuum of Services

Higher (Central) ⟷ **Lower** (Local)

Level I Intense NeuroRehabilitation/ NeuroBehavioral Programming	**Level II** Active NeuroRehabilitation/ NeuroBehavioral Step-Down Program	**Level III** NeuroRehabilitation/ NeuroBehavioral Step-Down Program	**Level IV** NeuroRehabilitation/ NeuroBehavioral Step-Down Support Services
Admission Conference • Identify roles and goals for key participants (facility, State, member, caregiver/family • Initiate discharge/transition planning • Determine guardianship need • Waiver applications made • Validate member's ability and motivation to actively participate • Review how therapy endpoint determinations will be made	**Interval Reviews** • Assess progress/ identify barriers • Match needs and services to level of care • Identify new needs (medical, behavioral & social) • Provide transparency of program and needs	**Interval Reviews** • Assess progress/identify barriers • Match needs and services to level of care • Identify new needs (medical, behavioral & social) • Provide transparency of program and needs	**Discharge/Transition Planning Conference** • Residential needs • Continued therapy needs • Continued Medical and Behavioral Health needs • Family support • Waiver availability
Member Profile: • Mayo-Portland score >50 • Injury within 1 year or unable to begin aggressive rehabilitation due to medical complexity • Potential for improvement professionally identified • Received Acute Rehabilitation • Needs focused neuro-cognitive and/or behavioral intervention • Defined goals for improvement • Brain injury specialist	**Member Profile:** • Progress noted on Mayo-Portland • Progress toward goals • Continued benefit for neuro-cognitive rehabilitation • Continued behavioral needs	**Member Profile:** • Progressive improvement of Mayo-Portland • Some goals accomplished or achieved maximum benefit • Behavioral improvements noted • Working toward discharge in near future and transition to community resources	**Member Profile:** • Optimal residential/inpatient service achievement • Transition for custodial services • Requires continued support due to complexity of care and/or continued behavioral management

evaluation/rererral			
Needs Experienced in at least 7 of 10 following Areas: **Medical:** Requires daily nursing availability to ensure safety/wellbeing **Medication management:** Unable to self-manage **Physical:** Coordination of physician specialists and/or any orthotic/prosthetic devices **Cognition:** Memory, impulsivity, poor judgment, lack of initiation, poor problem solving, poor social skills—that significantly impact safety and well being **Supervision:** which may require one-on-one supervision for behaviors **Environment:** which may require durable, secure, highly supervised living environment to decrease risk to self or others **Behavioral:** Non-compliance with traditional therapies due to cognitive/behavioral barriers **Pharmacological intervention:** required through psychiatrist	**Needs Experienced in the following Areas:** **Medical:** requires training in self-management of Challenges **Physical:** requires training in self-management of challenges **Cognition:** requires training in self-management of challenges **Behavioral:** requires training in self-management of challenges	**Needs Experienced in the following Areas:** **Medical:** Supported practice with individualized strategies to minimize health and safety risk **Physical:** Supported practice with individualized strategies to minimize health and safety risk **Cognition:** Supported practice with individualized strategies to minimize health and safety risk **Behavioral:** Supported practice with individualized strategies to minimize health and safety risk	**Needs Experienced in the following Areas:** **Medical:** Supported practice with individualized strategies to minimize health and safety risk **Physical:** Supported practice with individualized strategies to minimize health and safety risk **Cognition:** Supported practice with individualized strategies to minimize health and safety risk **Behavioral:** Supported practice with individualized strategies to minimize health and safety risk **Therapy:** At least 3 of the following are

consult
 	
Therapy: <u>**10**</u> of the following are identified as medically necessary at a high level:
 	
• Residential
  ○ Significant assistance with residential needs
 	
• Case Management
  ○ Significant management of complex medical and social issues
 	
• Medical Management
  ○ Significant and complex medical issues
 	
• Speech Language Therapy
  ○ Intensive speech therapy for language, speech, and receptive skills
 	
• Productive Activity/ Physical Activity
  ○ Intensive and frequent services requiring skilled
	Therapy: at least <u>7</u> of the following are identified as medically necessary at a moderate or high level:
	
	• Residential
	  ○ Moderate assistance with residential living, **OR**
	  ○ Significant assistance with residential needs
	
	• Case Management
	  ○ Moderate coordination of care and family engagement, **OR**
	  ○ Significant management of complex medical and social issues
	
	• Medical Management
	  ○ Moderate basic medical services and care delivery, **OR**
	  ○ Significant and complex medical issues
	
	• Speech Language Therapy
	  ○ Moderate frequency of speech therapy with progress to goals, **OR**
	  ○ Intensive speech therapy for language, speech, and receptive skills
	
	• Productive Activity/ Physical Activity
		Therapy: At least <u>5</u> of the following are identified as medically necessary at a moderate or high level:
		
		• Residential
		  ○ Moderate assistance with residential living, **OR**
		  ○ Significant assistance with residential needs
		
		• Case Management
		  ○ Moderate coordination of care and family engagement, **OR**
		  ○ Significant management of complex medical and social issues
		
		• Medical Management
		  ○ Moderate basic medical services and care delivery, **OR**
		  ○ Significant and complex medical issues
		
		• Speech Language Therapy
		  ○ Moderate frequency of speech therapy with progress to goals, **OR**
		  ○ Intensive speech therapy for language, speech, and receptive skills
		
		• Productive Activity/ Physical Activity
		  ○ Moderate individualized
			identified as medically necessary at a low or moderate level:
			
			• Residential
			  ○ Basic residential services, **OR**
			  ○ Moderate assistance with residential living
			
			• Case Management
			  ○ Minimal logistical assistance, **OR**
			  ○ Moderate coordination of care and family engagement
			
			• Medical Management
			  ○ Routine medical care, **OR**
			  ○ Moderate basic medical services and care delivery
			
			• Speech Language Therapy
			  ○ Maintenance services for speech and language skills, **OR**
			  ○ Moderate frequency of speech therapy with progress to goals
			
			• Productive Activity/ Physical Activity
			  ○ Basic activity that does not require skilled staff, **OR**
			  ○ Moderate individualized therapy with progress to goals
			
			• Occupational Therapy
			  ○ Basic activity that does not require skilled staff, **OR**

professional staff

- Occupational Therapy
  - Intensive and frequent services requiring skilled professional staff
- Rehabilitation Therapy
  - Intensive and frequent services requiring skilled professional staff
- Vocational Therapy
  - Intensive and frequent services requiring skilled professional staff
- Neuro-Cognitive Therapy
  - Intensive and frequent services requiring skilled professional staff
- Mental/Behavioral Therapy
  - Intensive and frequent services requiring skilled

  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff

- Occupational Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Rehabilitation Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Vocational Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Neuro-Cognitive Therapy
  - Moderate individualized therapy with progress to goals, **OR**

therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff

- Occupational Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Rehabilitation Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Vocational Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring skilled professional staff
- Neuro-Cognitive Therapy
  - Moderate individualized therapy with progress to goals, **OR**
  - Intensive and frequent services requiring killed

  - Moderate individualized therapy with progress to goals

- Rehabilitation Therapy
  - Basic activity that does not require skilled staff, **OR**
  - Moderate individualized therapy with progress to goals
- Vocational Therapy
  - Basic activity that does not require skilled staff, **OR**
  - Moderate individualized therapy with progress to goals
- Neuro-Cognitive Therapy
  - Basic activity that does not require skilled staff, **OR**
  - Moderate individualized therapy with progress to goals
- Mental/Behavioral Therapy
  - Basic activity that does not require skilled staff, **OR**
  - Moderate individualized therapy with progress to goals

Other Services:

Discharge Planning Goals: prepare participant for future placement in the home community

Supported Living Skill Training: with supervision and feedback. Experience and feedback with a variety of daily living situations to ensure self-management skills

professional staff **Other Services:** **Discharge Planning Goals:** to match home/ Indiana State resources **Transportation/Escort** **Family/Caregiver Training** **Crisis Intervention and Ultra High Risk Support** **Billing Information** Per diem reimbursement rates are based on average score for intensity of services on the 10 domains of therapy. Service intensity for each domain is rated on a scale from 0-10 (with 0 being none/low and 10 being high). The scores for each domain are	o Intensive and frequent services requiring killed professional staff • Mental/Behavioral Therapy o Moderate individualized therapy with progress to goals, **OR** o Intensive and frequent services requiring skilled professional staff **Other Services:** **Discharge Planning Goals:** geared toward exploring and securing living environments, therapeutic services, and productive activities that match the needs and desires of the participant with a focus on returning to the home community **Goal Maintenance:** therapeutic interventions geared toward maintaining the durability of goals achieved as well as continued work on upgraded objectives **Billing Information** Per diem reimbursement rates are	professional staff • Mental/Behavioral Therapy o Moderate individualized therapy with progress to goals, **OR** o Intensive and frequent services requiring skilled professional staff **Other Services:** **Discharge Planning Goals:** prepare participant for transfer to an alternative environment or to reside in the most independent environment possible **Supported Living Skill Training:** with supervision and feedback. Experience and feedback with a variety of daily living situations to ensure self-management skills are effective and risk is minimized **Billing Information** Per diem reimbursement rates are based on average score for intensity of	are effective and risk is minimized **Billing Information** Per diem reimbursement rates are based on average score for intensity of services on the 10 domains of therapy. Service intensity for each domain is rated on a scale from 0-10 (with 0 being none/low and 10 being high). The scores for each domain are averaged and per diem rates are broken into 10 levels and reimbursed accordingly. **Billing Level IV** **Average Score of Domains** / **Corresponding per diem rate** 2 / $ 317 1 / $ 285

averaged and per diem rates are broken into 10 levels and reimbursed accordingly.

Billing Level I

Average Score of Domains	Corresponding per diem rate
10	$ 567
9	$ 541
8	$ 509

Other Information:

This level of service is intended for immediate admission and may be appropriate for up to the first 4 months of intervention.

Available continuum of treatment/environmental options to practice skill acquisition and simulate discharge environment.

Interagency communication/coordination

based on average score for intensity of services on the 10 domains of therapy.

Service intensity for each domain is rated on a scale from 0-10 (with 0 being none/low and 10 being high).

The scores for each domain are averaged and per diem rates are broken into 10 levels and reimbursed accordingly.

Billing Level II

Average Score of Domains	Corresponding per diem rate
7	$ 477
6	$ 445
5	$ 413

Other Information:

Still unable to access their home environment, independent living options, or transitional supported living due to the continual unwanted behaviors or the significant cognitive/physical challenges.

This level of program offers individualized support that is needed services on the 10 domains of therapy.

Service intensity for each domain is rated on a scale from 0-10 (with 0 being none/low and 10 being high).

The scores for each domain are averaged and per diem rates are broken into 10 levels and reimbursed accordingly.

Billing Level III

Average Score of Domains	Corresponding per diem rate
4	$ 381
3	$ 349

Other Information:

Participant has made progress in more intensive, active rehabilitation and is appropriate for step down services to maintain goals achieved through supportive services. Participants who are appropriate for this level of step down support services will attempt to replicate the type of interventions the person will experience once they return to their home community. Participants will continue to practice learned strategies to increase independence, safety, and behavioral self management while pursuing discharge placement in the appropriate community. During times of crisis, participant may respite or be provided additional residential and programmatic support. If the crisis maintains, the participant will be recommended that a move to Level I, II, or III with corresponding rate until he or she is stabilized.

	at any given time, specifically during times of crisis, and a participant may respite or be provided additional residential and programmatic support. The team may change the intensity of assistance from time to time, while taking advantage of certain "therapeutic windows" that may arise. Regardless of the setting or type of program, rehabilitation interventions are intended to help participants practice strategies to remain free from harm and attain personal goals that are durable over time.		

Rutgers Center for
State Health Policy

The Institute for Health, Health Care Policy and Aging Research

Issue Brief:

A Survey of Medicaid Brain Injury Programs

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March 2008

RUTGERS

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Summary

In late 2007, the Center for State Health Policy surveyed 23 states that operate Medicaid waivers targeted to individuals with brain injuries. Data was obtained about the cost and number of individuals served by these waivers for the waiver years 2002 through 2006. Three states began waivers for individuals with brain injuries in 2002 or later, and three other states discontinued waivers in 2006. Every state except Arizona has multiple Medicaid 1915(c) home and community-based services (HCBS) waivers. Arizona operates its long-term care system as an 1115 Waiver.

Conversations with state staff about why brain injury waivers were established indicate two frequently mentioned reasons: lobbying by advocates and the desire to end expensive out-of-state placements. Federal funding was invariably mentioned in discussions with states about why a waiver was established; however, only one state responded that the motivation to begin the waiver was primarily fiscal.

Data developed for the Kaiser Commission on Medicaid and the Uninsured show that in 2004 there were 263 waivers nationally, providing services to over one million individuals at a cost of $20.5 billion.[1] These data also show that for a 5-year period, from 2000 through 2004, the total number of participants in all Medicaid 1915(c) HCBS waivers increased 31% and expenditures increased 62%. The Rutgers data indicate that waivers for individuals with brain injury grew more rapidly over the 5-year period than waivers in general.

The waivers for individuals with brain injury are small in comparison to other waivers, providing services to approximately 11,214 unduplicated persons in 2006. According to the national data for 2004, 9,393 persons were served on brain injury and spinal cored waivers, only the waivers targeted to individuals with mental health needs were smaller, having 2,089 participants. Only slightly larger were the waivers for children with special needs, 11,982 participants, and for individuals with HIV/AIDS, 14,254 participants. All of these waivers combined account for only 10% of the individuals served in 2004 and comprise 7% of the total expenditures.

Although small, waivers for individuals with brain injuries have grown significantly in recent years, doubling from 5,400 individuals served in 2002 to 11,214 in 2006, at a cost of $155 million in 2002 to $327 million in 2006. Three states with the largest waivers account for most of this growth. If these three states are excluded, the percentage increase reported by the remaining states is similar to the national data. The per capita cost remained relatively constant in this period although there was a dramatic variation in per capita costs in 2006, ranging from almost $12,000 to over $82,000. Providing HCBS to individuals with brain injury is less expensive than providing services

[1]Kaiser Commission on Medicaid and the Uninsured (2007, December); *Medicaid Home and Community-Based Service Programs: Data Update,* The Henry J. Kaiser Family Foundation, Washington D.C. Table 4 Retrieved on 2-28-08 from http://www.kff.org/medicaid/upload/7720.pdf

in nursing homes, hospitals, and similar institutions. Data from 17 of the surveyed states indicate that when compared to institutional costs, a total of almost $273 million was saved by Medicaid through the use of these brain injury waivers. On average $30,000 per person was saved

As reported by Kaiser, in 2006 waiting lists for traumatic brain injury (TBI) waiver services were reported in eight states and totaled 1,658 persons. In late 2007, the Rutgers survey found that nine states had waiting lists for services, with a total of 1,228 individuals.

Services provided under the brain injury waivers vary considerably from a single waiver service to extensive arrays of services. The size of the waivers also varies from 19 individuals to over 3,600 individuals served in a year.

Introduction

This paper addresses waivers targeted to individuals with a brain injury, a specific type of disability. States that had such waivers were identified and contacted to obtain information about how the state decided to create a waiver program, what the eligibility requirements were to obtain services, how many persons were served, what the services were, and what the cost of the services were.

Background on Waiver Development

Waiver services granted under the authority of section 1915(c) of the Social Security Act are designed to help Medicaid-eligible individuals who might otherwise be admitted to a hospital or nursing facility to live independently in the community and to permit a state to provide services that are not typically covered under the state's regular Medicaid program. This paper addresses waivers targeted to individuals with a brain injury.

In order for a state to receive approval for a waiver, in its waiver request the state's Medicaid agency must:

- Provide assurances that the waiver will protect the health and welfare of participants.

- Specify how many people will be served during each year of the waiver's operation. Unlike its regular Medicaid program, a state can limit the number of individuals it will serve. This allows a state to control the costs of a waiver and have a waiting list when that number is reached.

- Identify what services are in the wavier. A waiver allows a state to cover services that are not permitted in the regular Medicaid program and provides a

waiver participant with "optional" Medicaid services that a state has chosen not to include in its regular Medicaid program. A state may also provide a waiver participant with more of a service than it will provide to an individual through its regular Medicaid program.

- Finally, the state must show that the cost of waiver services will not exceed what the state would have spent in the absence of the waiver; this is also referred to as cost neutrality.

The Social Security Act lists seven specific services that may be provided under a HCBS waiver. In addition, states may apply for permission to provide other optional services as the state defines them, which are above and beyond the services provided in the Medicaid State plan. The services that each of the states covers in its brain injury waiver are categorized, for the most part, according to categories and definitions used in a report examining waiver services targeted to support individuals with intellectual and developmental disabilities.[2]

A waiver is also required to be cost neutral: "under such waiver the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for such individuals if the waiver had not been granted."[3]

Following federal policy, state Medicaid programs have medical requirements an individual must meet in order to be eligible for a waiver. The federal requirement for "level of care" assessment calls for the state to determine "that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or intermediate care facility for the mentally retarded, the cost of which could be reimbursed under the State plan."[4] The "such services" referred to in this section are the services provided to individuals under a state's Medicaid waiver.

When the brain injury is a result of either birth trauma or a degenerative disease, an individual is, in almost all states, not eligible for waiver services. Medicaid waivers providing home and community-based services are generally considered part of the long-term care service system. The services provided under these brain injury waivers vary considerably from a single waiver service to extensive arrays of services. In most states, the waiver for individuals with brain injury can also be characterized in this fashion. Individuals are provided with services that support them in a community-based living arrangement, and they continue to receive services for as long as they are needed.

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[2] Smith, G.; Agosta, J.; Fortune, J. and O'Keeffe, J., Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Final Project Report, April 2007 available at: http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm. Using the same service categories make it easier to compare the descriptions of services in the different reports.

[3] Social Security Act, Section 1915(c) (2) (D)

[4] Social Security Act, Section 1915(c) (1), found at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm

Five states have structured waiver services in another way; they focus primarily on rehabilitation. Rather than provide supports designed to meet the long-term care needs of those individuals in the waiver, services are designed to provide rehabilitation and community reintegration, as well as to provide the other supports needed to reside in a community-based living arrangement. These "rehabilitation" waivers may have level of care requirements that are more stringent than nursing facility requirements.

Table 1: States Surveyed

State	Individuals Served in 2006	Year Waiver Established
Colorado	293	1995
Connecticut	344	1997
Florida*	283	1999
Idaho**	19	2001
Illinois	3,601	1999
Indiana	131	2000
Iowa	825	1996
Kansas	269	1991
Kentucky	98	1999
Maryland	23	2003
Massachusetts	90	2001
Minnesota	1,372	1992
Nebraska	26	2000
New Hampshire	140	1992
New Jersey	276	1993
New York	1,953	1995
North Dakota**	29	1994
Pennsylvania	324	2002
South Carolina*	497	1995
Utah	91	1995
Vermont**	59	1994
Wisconsin	334	1995
Wyoming	137	2002
Total	11,214	

Source: Center for State Health Policy, Rutgers University

Note: Mississippi also operates a waiver; requested information was not received.

Kentucky and Vermont based on 2005 data

* Serves individuals with spinal cord injuries as well

** Waiver no longer in operation

National Waiver Data

Every state except Arizona has multiple Medicaid 1915(c) HCBS waivers. Arizona operates its long-term care system as an 1115 Waiver. In 2004, there were 263 waivers nationally, providing services to over one million individuals at a cost of $20.5 billion. Data presented in a report produced by the Kaiser Commission on Medicaid and the Uninsured show that for a five-year period, from 2000 through 2004, the total number of participants in all Medicaid 1915(c) HCBS waivers increased 31% from 770,000 to 1,015,000, and expenditures increased 62% from $12.6 billion to $20.5 billion.[5]

Table 2: National Data – All Waivers

Year	Total # Participants (000)	Total Expenditures (billion)
2000	770,000	$12.60
2001	841,000	$14.30
2002	924,000	$16.90
2003	982,000	$18.90
2004	1,015,000	$20.50

Source: Medicaid Home and Community-Based Service Programs: Data Update

The information from the Rutgers Center for State Health Policy survey is based on interviews with state staff in 23 states that operate Medicaid waivers for individuals with brain injury, as well as on participant and expenditure data from these states. Whenever it was available from the state, data from the federal reporting form called the CMS 372 was used. When CMS 372 data was not available, expenditure or participant data reported by a state from other sources was used.

The Rutgers survey indicates that waivers for individuals with brain injury grew at a higher rate over five years than all waivers. Both the number of participants and the total expenditures doubled, while the per capita cost remained relatively constant in this period.

The three states with the largest waivers account for most of this growth. If these three states are excluded, the percentage increase reported by the remaining states is quite similar to the Kaiser data, which shows a 31% increase in individuals served and a 62% increase in expenditures.

[5] Kaiser Commission on Medicaid and the Uninsured (2007, December); *Medicaid Home and Community-Based Service Programs: Data Update,* The Henry J. Kaiser Family Foundation, Washington D.C. Retrieved on 2-28-08 from http://www.kff.org/medicaid/upload/7720.pdf

Table 3: Increases Over Time in Brain Injury Waivers

	Individuals Served		
	Three Largest Waivers	Remaining Waivers	Total
2002	2,501	2,908	5,409
2006	6926	3807	10,733*
Growth	185%	24%	98%
	Expenditures (Million		
	Three Largest Waivers	Remaining Waivers	Total
2002	$71.5	$85.0	$157
2006	$190.4	$138.6	$329
Growth	166%	63%	110%

*Represents only those states that provided 2006 expenditure data
Source: Center for State Health Policy, Rutgers University

Table 4: Annual Changes in Brain Injury Waivers

	Number of states	Number of Participants	Expenditures	Per Capita Expenditures
2002	21	5,409	$156,719,621	$28,974
2003	22*	6,901	$204,951,815	$29,699
% Change from prior year		28%	31%	3%
2004	23*	8,446	$255,978,429	$30,308
% Change from prior year		22%	25%	2%
2005	23*	9,920	$317,809,438	$32,037
% Change from prior year		17%	24%	6%
2006	20**	10,733	$328,983,064	$30,652
% Change from prior year		8%	4%	-4%

* States began new waivers
** Data not available from all states
Source: Center for State Health Policy, Rutgers University

The waivers for individuals with brain injury are small in comparison to other waivers. According to the Kaiser data for 2004, only the waivers targeted to individuals with mental health needs are smaller with 2,089 participants. Only slightly larger are the waivers for children with special needs with 11,982 participants, and individuals with

HIV/AIDS with 14,254 participants. When combined, all of these waivers account for only 10% of the individuals served and 7% of the total expenditures.[6]

In conversations with state staffs, the Center for Health Policy was told that three states began waivers for individuals with brain injuries in 2002 or later.[7] In addition, three states discontinued their small waivers in 2006 and individuals enrolled in these waivers continued to receive services through another of the state's waivers.[8]

Rationale for Establishing a Brain Injury Waiver

Conversations with state staff about why brain injury waivers were established indicate two frequently mentioned reasons: lobbying by advocates and the desire to end out of state placements. Seven states reported that lobbying efforts of advocates and advocacy groups, such as the brain injury association in the state, were major factors in the decision to establish the waiver.[9] In one state, the waiver resulted from a citizen-based initiative.[10] In another, the legislature created an advisory board charged with conducting a needs assessment; the needs assessment ultimately led to the waiver.[11] A third state's legislature required a plan to address the needs of individuals with brain injuries; this plan led to the waiver.[12] The remaining four states reported their waivers were established because advocates very actively lobbied the legislature and executive. In one other state, the waiver began as a response to litigation.[13] The organizations involved in the litigation, the state's Office of Protection and Advocacy and the legal services organization, participated in the planning and development of the waiver, as did the state brain injury association. Two states reported beginning their waiver, as a proactive response to the unmet service needs of individuals with brain injuries.[14]

Six states reported that prior to their waiver, Medicaid eligible individuals with brain injuries were frequently placed in specialized, high cost facilities outside the state.[15] The decision to establish waivers in these states was an effort on the state's part to return its citizens to the community. In one state, families and advocates petitioned to "repatriate" its citizens.[16] These states indicated that the high cost of the out of state facilities was a principal driver of the decision to establish the waiver. Three of these states also indicated that a waiver was established because the state lacked the capacity to provide specialized services to individuals with brain injuries and that the waiver was a

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[6] The data reported by Kaiser show that waivers targeted to individuals who are aged and disabled account for 50% of the participants and 19% of the expenditures, and waivers targeted to individuals with developmental disabilities account for 40% of the participants and 74% of the expenditures.
[7] Maryland, Massachusetts and Pennsylvania
[8] Idaho, North Dakota and Vermont
[9] Colorado, Illinois, Iowa, Kansas, Kentucky, Minnesota and Wyoming
[10] Colorado
[11] Illinois
[12] Minnesota
[13] Connecticut
[14] New York and Pennsylvania
[15] Indiana, Maryland, New Hampshire, New Jersey, Vermont and Wisconsin
[16] New Hampshire

key element in building this capacity.[17] Two additional states cited building their service capacity as a primary reason for their waiver, without linking it to returning citizens to the state.[18]

Medicaid waivers provide a mechanism for states to obtain federal reimbursement for covered services provided to Medicaid eligible individuals. During discussions with states about why a waiver was established, federal funding was invariably mentioned as part of the rationale. However, only one state responded that the motivation to begin the waiver was primarily fiscal.[19] This state was already operating a large state-funded program for individuals with brain injuries and state administrators viewed a waiver as a mechanism to maximize revenues. This state's waiver is one of the smaller waivers among those states surveyed, serving 90 individuals in 2006 with expenditures of just under $5 million. By comparison, its state-funded program serves approximately 1,200 individuals with expenditures of approximately $15 million. Both programs provide identical services and operate in the same manner; waiver enrollment does not require any specific action on the part of the participant; and, enrollment decisions for Medicaid eligible individuals are made based upon revenue maximization and cost neutrality considerations. The state noted that waiver approval entailed a five-year process before approval was received in 2001.

Eligibility

Waiver services granted under the authority of section 1915(c) of the Social Security Act are designed to help Medicaid-eligible individuals who might otherwise be admitted to a hospital or nursing facility live independently in the community.[20] Federal regulations permit a state to provide services that are not typically covered under the state's regular Medicaid program. This permission is called a wavier and the use of waivers is regulated by the Social Security Act and the Code of Federal Regulations. Under these wavier rules, states are permitted to limit services to specific geographical regions of a State and to target services to certain groups, such as persons over the age of 65 and individuals with a general or a specific disability. Normally, such limitations are not allowed under the regular Medicaid program.[21]

For an individual to be eligible for Medicaid, and specifically for one of the waivers for people with brain injury, the individual must meet financial criteria (i.e.,

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[17] Indiana, New Jersey and Vermont

[18] Colorado and South Carolina

[19] Massachusetts

[20] There are two types of waivers based on two provisions of the Social Security Act, sections 1115 and 1915. This paper discusses 1915(c) waivers regarding the provision of home and community-based services for persons who have brain injuries. See HCBS.org for reports on waivers. For a list of waivers by state see http://www.hcbs.org/files/122/6066/HCBSWaivers2006--Table1.xls and http://www.hcbs.org/files/122/6065/HCBSWaivers2006--Table2.xls retrieved 2-27-08

[21] The Northeast Center for Special Care has an excellent collection of articles about Medicaid waivers and readers are referred to their collection at http://www.northeastcenter.com/links_hcbs_medicaid_waivers.htm

income and resources) and non-financial criteria. States have flexibility, within limits defined by the federal requirements to determine the specific eligibility criteria for a waiver.

Financial Eligibility

To be eligible for home and community-based waiver services a person must meet the financial requirements of a state's Medicaid program for services in a hospital, nursing home, or intermediate care facility for the mentally retarded.[22] In an institution, an individual can have an income up to 300% of the federal Supplemental Security Income, (SSI) benefit. The federal SSI benefit is $637 a month in 2008, and 300% equals $1,911 a month.[23]

Waivers allow states to cover individuals who "over income" for Medicaid while living in the community if their income would allow them to be eligible in an institution such as a hospital or nursing facility. Federal rules allow states to set higher income limits for people in institutions or in a waiver, up to 300% of the federal Supplemental Security Income (SSI) benefits or higher if a state has a medically needy program. A state is not required to cover individuals with incomes up to this limit; each state can determine the income level it will cover.

Typically, the maximum amount of resources (savings and other assets) that an individual may have and still be eligible for Medicaid is $2,000; this amount is the SSI resource limit. Fifteen of the states use this amount for waiver eligibility: three have a lower resource limit, either $1,500 or $1,600; and, five states a higher resource limit, ranging from $3,000 to $8,000.

Nationally, financial eligibility is 300% of SSI in 77% of all HCBS waivers according to the Kaiser data. It is set at SSI in 20% of the waivers and is between these amounts in only 3% of the waivers.[24] Of the 23 states Rutgers Center for State Health Policy surveyed, 15 set the income level at 300% of the federal SSI payment[25]. In the remaining eight states, the income eligibility criteria are set at a lesser amount: three at the SSI income level and five at between 300% of SSI and the SSI income level. Three states set eligibility at the SSI income level[26]. States are permitted, and some choose, to supplement the Federal SSI benefit with additional payments based on income, living

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[22] There is a substantial literature on Medicaid financial eligibility. For short fact sheet on financial eligibility see Mollica, R. (2005, October), *Medicaid Financial Eligibility*, Center for State Health Policy, Rutgers University, New Brunswick, NJ Retrieved on 2-28-08 from http://www.cshp.rutgers.edu/cle/Products/MedicaidFinancialEligibilityWEB.pdf
See also, Mollica, R. (2005, October), *Medically Needy Individuals*, Center for State Health Policy, Rutgers University, New Brunswick, NJ Retrieved on 2-28-08 from http://www.cshp.rutgers.edu/cle/Products/MedicaidEligibilityMedicallyNeedyWeb.pdf

[23] The Supplemental Security Income program is described at http://www.ssa.gov/ssi/

[24] Kaiser, ibid. Table 8

[25] Colorado, Connecticut, Florida, Iowa, Idaho, Kansas, Kentucky, Maryland, New Jersey, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin, and Wyoming

[26] Illinois, Indiana and North Dakota

arrangements, and other factors.[27] As a result, the actual income for Medicaid waiver eligibility in a state may be higher than the federal SSI payment ($637 per month).

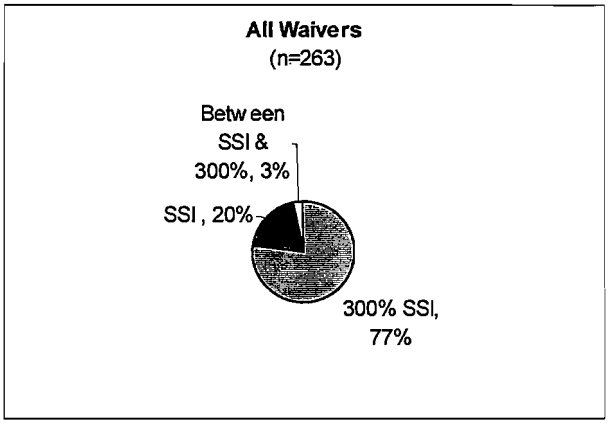
Table 5: Eligibility – Income Limits

Income Eligibillity Standard	SSI Income Limit	Federal Poverty Guideline	$1,250	300% SSI ($1,911 in 2008)
All states	3 states	4 states	1 state	15 states

Source: Rutgers University, Center for State Health Policy, 2008

The following figures show the comparison of income eligibility standards between all waivers nationally and the states with waivers for individuals with brain injuries. The data for all waivers represent all states except Arizona. Data for Brain Injury Waivers represent 23 states. Typically, states use the same eligibility criteria for all waivers that they operate. Therefore, the differences in eligibility criteria observed may be attributable to differences in state's eligibility policies.

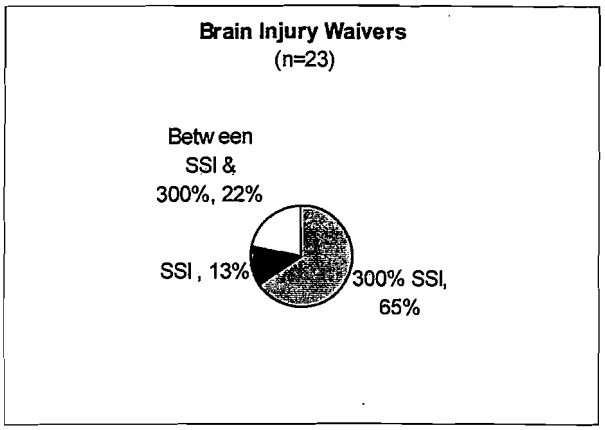
Figure 1: Income Eligibility: All Waivers



Source: Medicaid Home and Community-Based Service Programs: Data Update

[27] Understanding Supplemental Security Income SSI Benefits, found at http://www.ssa.gov/ssi/text-benefits-ussi.htm

Figure 2: Income Eligibility – Brian Injury Waivers



Source: Rutgers University, Center for State Health Policy, 2008

This resource amount is used by 15 of the states for Medicaid eligibility.[28] Three have a lower resource limit for Medicaid than the SSI limit, either $1,500 or $1,600.[29] Five states utilize a higher limit for Medicaid, ranging from $3,000 to $8,000.[30]

Table 6: Eligibility – Resource Limits

Resource Limit for Eigibility	Less than SSI resource limit	Uses SSI resource limit	More than SSI resource limit
All states	3 states	15 states	5 states

Source: Rutgers University, Center for State Health Policy, 2008

[28] Colorado, Florida, Iowa, Idaho, Illinois, Kansas, Kentucky, Maryland, Massachusetts, New Jersey, South Carolina, Utah, Vermont, Wisconsin and Wyoming
[29] Connecticut, Indiana and New Hampshire
[30] Minnesota, Nebraska, New York, North Dakota and Pennsylvania

Non-Financial Eligibility

The non- financial eligibility requirements for Medicaid waivers can be characterized as "Level of Care" and "other criteria." Individuals seeking services on a brain injury waiver must also meet the state's non-financial criteria for admission to a nursing home or other institution. These criteria are often referred to as "medical," functional," or "Level of Care," and these have been developed to assure that only individuals needing institutional service are admitted to one of those settings. Waivers are intended to substitute for institutional care and, therefore, are limited to serving only individuals who could be admitted to a nursing home or institution if they applied, or individuals who live in one of these institutions and want to move to the community. States also set additional requirements that individuals must meet in order to be enrolled in one of these waivers. These criteria vary from state to state and are discussed later; the specific requirements are also listed in each state's summary (see Appendices).

Waivers for aged and disabled persons invariably use a nursing home level of care, and waivers for persons with intellectual and developmental disabilities invariable use a ICFs/MR institutional level.

The level of care that a state specifies has a significant effect on the cost neutrality calculation for a waiver. A non-specialized nursing facility is, in all likelihood, the least expensive of the institutional options potentially available to an individual. To the extent that a state has other higher cost facilities and there are individuals enrolled in the waiver that meet the level of care for those facilities, there is the potential to provide a more expensive service package and still meet the federal cost neutrality test. States can and do include more than one level of care in brain injury waivers.

In evaluating eligibility, states also consider the causation of the individual's brain injury, the age of onset of the disability, and the current age of the individual as criteria for waiver eligibility. Within these broad categories, states use these specific criteria to structure eligibility for these waivers. Rather than try to compare states' specific criteria, we used broader, more easily comparable criteria.

Individuals with a traumatic brain injury may be eligible for the waiver in all of the surveyed states. Six[31] of the surveyed states limit their waiver to individuals who have a traumatic brain injury, an additional three states specify that the individual must have a traumatic brain injury, but have a broad definition of "traumatic" that may include stroke.[32] The remaining 14 states have broader eligibility criteria to include individuals with an acquired brain injury.[33] Three states list specific ICD-9 codes that are required in

[31] Florida, Indiana, Kansas, Maryland, Nebraska a and Pennsylvania
[32] New Jersey, New York and Vermont
[33] Colorado, Connecticut, Idaho, Iowa, Illinois, Kentucky, Massachusetts, Minnesota, New Hampshire, North Dakota, South Carolina, Utah, Wisconsin and Wyoming

order for an individual to be eligible.[34] In addition, the waiver in Florida and South Carolina is designed to serve individuals with a spinal cord injury in addition to individuals with a brain injury.

When the brain injury is a result of either birth trauma or a degenerative disease, an individual is, in almost all states, not eligible for waiver services. New Hampshire does include individuals with a degenerative disease if it occurred between the ages of 22 and 60. Three[35] states specifically require that the brain injury occur after adulthood (age 21) and one state requires in its waiver that participants be age 16 or older with a "recent" brain injury.[36] Most of the other states indicated that a child with a brain injury would, in all likelihood, be considered developmentally disabled and, therefore, would be enrolled in the DD/MR waiver; however, they did not specify an age of onset/acquisition of the brain injury.

Regardless of the cause, brain injuries result in a range of effects. Some may be subtle and difficult to initially diagnose; others may be obvious and serious. Some individuals who have experienced a minor brain injury may recover completely in a relatively short time, while others may experience life-long disability.[37] The effects of a brain injury may be physical (e.g., ambulation problems, speech difficulties, seizure or fatigue), cognitive (e.g., memory loss, difficulty concentrating, or poor judgment), and/or behavioral (e.g., impulsiveness or the need to be reminded to begin or finish tasks). Services needed by individuals with brain injury are specialized, such as substance abuse or cognitive therapy, and are not normally included in the waivers for individuals with physical disabilities such as those that suffer a loss of limbs in a car accident.

The level of care that a state specifies has a significant effect on the cost neutrality calculation for a waiver. A non-specialized nursing facility is, in all likelihood, the least expensive of the facility/institutional options potentially available to a state.[38] To the extent that a state has other higher cost facilities and individuals enrolled on the waiver meet the level of care, there is the potential to provide for the persons who require more resources than others require and still meet the federal cost neutrality test. Persons in states that seek to establish a brain injury waiver, such advocates in West Virginia and Alaska, should take this consideration into account.

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[34] International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), is the official system of assigning codes to diagnoses in the United States and is used by Colorado, Idaho and Iowa.

[35] Idaho, Maryland and New Jersey

[36] Vermont

[37] Of the 1.4 million who sustain a TBI each year in the United States: 50,000 die; 235,000 are hospitalized; and 1.1 million are treated and released from an emergency department. The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.

[38] One of the states surveyed reported a per capita cost of a specialized facility almost 700% of the per capita nursing facility cost.

The cost neutrality calculations for brain injury waivers are markedly different than the cost neutrality of other waivers that use a uniform level of care comparison.

Of the states surveyed, six reported using more than one level of care in their waiver; accordingly, the figures below add up to more than 23. Nineteen of the states use a nursing facility as the level of care. Five of the states require the nursing facility to be a specialized facility.[39] Six states utilize a hospital, generally a specialized hospital, as the 'Level of Care."[40] Four states use an intermediate care facility for the mentally retarded as the "Level of Care."[41]

Table 7: Level of Care: Institution

Level of Care Used	Nursing Facility (NF)	Specialized NF	Hospital	Intermediate Care Facility for the Mentally Retarded
All states	19 states	5 states	6 states	4 states

Source: Rutgers University, Center for State Health Policy, 2008.

"Other criteria" for Medicaid waiver eligibility include the causation of the individual's disability, the age of onset of the disability, and the current age of the individual. Within these broad categories, states use these specific criteria to structure eligibility for these waivers.[42] Rather than try to compare states' specific criteria, broader, more easily compared criteria were used.

States vary considerably in the designation of the age of individuals who may be eligible for the waiver. Fourteen of the states provide services only to adults. However, the definition of "adult" varies slightly, with a range of 18, 21 or 22.[43] Three states provide services to individuals as young as 16.[44] The remaining six states include individuals "any age".[45] Twelve of the states have an upper age limit, most typically 64,

[39] Colorado*, Connecticut, Florida, Idaho, Illinois, Indiana, Kentucky, Maryland, Massachusetts*, Minnesota, Nebraska, New Hampshire*, New Jersey, New York, North Dakota, Pennsylvania*, South Carolina, Utah and Vermont*
* must be specialized
[40] Colorado, Connecticut, Kansas, Maryland, Minnesota and Wisconsin
[41] Connecticut, Iowa, South Carolina and Wyoming
[42] These criteria are more specific than the criteria for mandatory eligibility groups such as aged, blind and disabled individuals who receive benefits under the federal SSI program.
[43] Connecticut, Florida, Idaho, Kentucky, Maryland, Massachusetts, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Pennsylvania, Utah and Wyoming
[44] Colorado, Kansas and Vermont
[45] Illinois, Indiana, Iowa, Minnesota, South Carolina and Wisconsin

with one state using 62 and two states using 65 years old.[46] Those states that have a lower age limit generally report that younger persons are potentially covered by the waiver for individuals with developmental disabilities/mental retardation. States with an upper age limit similarly report that those individuals who "age out" are provided services through the waiver for the aged and/or the disabled.

Two states responded that an individual must be assessed and attain "scores" in a defined range, using a specific, standardized measure of neuropsychological or cognitive functioning.[47] Other states may include one or more of these measures in the assessment process, but do not require that the results of the measure be within a specified range.

Waiting Lists

In 2006, waiting lists for TBI waiver services were reported in eight states and totaled 1,658 individuals, as reported by Kaiser. In late 2007, the Rutgers Center for State Health Policy survey found that nine states had waiting lists for services, with a total of 1,228 individuals. The different states included in the Center's survey and Kaiser's *Medicaid Home and Community-Based Service Programs: Data Update* do not appear to have any bearing on the decrease in the number of persons on the waiting list from one year to another. The preponderance of the change is a result of one state that reported that it uses waiting lists kept by local agencies and that it has been working over time to establish greater consistency in waiting list practices.

[46] Colorado, Connecticut, Iowa, Kansas, Kentucky, Massachusetts, Minnesota, Nebraska, New Jersey, New York, South Carolina and Wyoming.
[47] New Jersey and Wyoming

Table 8: Eligibility for Waiver Services

State	Level of Care	Income	Resources	Other
CO	Specialized Nursing Facility Hospital	300% of federal SSI	$2,000	Age 16 to 64 with a condition in a specified group of ICD-9 codes.
CT	Nursing Facility Intermediate Care Facility-Mental Retardation (ICF-MR) Chronic Disease Hospital Acquired Brain Injury Facility	300% of federal SSI	$1,600	Age 18 and to 64 with an acquired brain injury not from a degenerative or a developmental disorder.
FL	Skilled Nursing Facility	300% of federal SSI	$2,000	Age 18 or older with a brain injury caused by external trauma and/or a spinal cord injury; must be medically stable.
IA	ICF-MR Intermediate Care Facility	300% of federal SSI	$2,000	Age one month to 64 with a traumatic or non-traumatic injury to the brain that occurred since birth in a specified set of ICD-9 codes.
ID	Skilled Nursing Facility	300% of federal SSI	$2,000	Have a brain injury attained after the age of 21 in one of a specified set of ICD-9 codes
IL	Skilled Nursing Facility	SSI MN, spend down to FPL	$2,000	Any age with an acquired brain injury not including degenerative, congenital, or neurological disorders related to aging.
IN	Skilled Nursing Facility	SSI	$1,500	Any age and have experienced an external insult resulting in a traumatic brain injury.
KS	Traumatic Brain Injury Rehabilitation Hospital	300% of federal SSI MN spend down to $716	$2,000	Age 16 to 64 and have a traumatic injury to the brain.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
KY	Skilled Nursing Facility	300% of federal SSI	$2,000	Age 21 to 65 with a post-birth acquired brain injury excluding a stroke treatable in a nursing facility providing routine rehabilitation services, spinal cord injury with no brain injury, progressive dementia of a chronic degenerative nature (including alcoholism or another addiction),
MD	Skilled Nursing Facility Chronic Hospital	300% of federal SSI	$2,000	Have a traumatic brain injury that occurred after age 21 and inpatient in a state Mental Hygiene Administration facility, a state owned and operated nursing facility, or placed by Medicaid in an out-of state facility.
MA	Specialized NF	100% FPL	$2,000	Age 21 to 62 with a traumatic or non-traumatic brain injury that has occurred since birth.
MN	Skilled Nursing Facility Neurobehavioral Hospital	FPL MN spend down to 75% of FPL	$3,000	Under age 65 at the time of application with a traumatic or acquired brain injury, or a degenerative disease (not congenital) with a cognitive impairment.
NE	Skilled Nursing Facility	FPL	$4,000	Ages 21 to 64 and have a traumatic brain injury.
NH	Specialized NF	$1,250	$1,500	Age 22 or older with an acquired brain disorder (including degenerative conditions such as Multiple Sclerosis and Huntington's Disease) acquired between age 22 and 60.
NJ	Skilled Nursing Facility	300% of federal SSI	$2,000	Ages 21 to 65 with a traumatic or acquired brain injury with an age of onset of 21 and a minimum score of 4 on the Rancho Los Amigos Levels of Cognitive Functioning Scale.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
NY	Skilled Nursing Facility	FPL	$4,200	Age 21 to 64 with traumatic brain injury: individuals with deficits similar to traumatic brain injury because of anoxia, toxic poisoning, stroke or other neurological conditions may also be eligible. Gestational or birth difficulties or degenerative diseases are not eligible.
ND	Skilled Nursing Facility	SSI	$3,000	Age 18 and older, determined disabled according to Social Security criteria. (See profile as this Waiver is now merged into the state's Aged and Disabled waiver
PA	Specialized Rehabilitation Nursing Facility	300% of federal SSI	$2,000 after a $6,000 disregard	Age 21 and older with a diagnosis of traumatic brain injury not of a degenerative, congenital or post-operative nature and requiring a service plan designed specifically to meet the needs of individuals with traumatic brain injury.
SC	Skilled Nursing Facility ICF-MR	300% of federal SSI	$2,000	Under 65 with a brain injury that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder and is not congenital or induced by birth trauma. "Similar disabilities" are included if not progressive; degenerative; a result of chronic disease or alcohol/drug use; or not a neurological disorder related to aging.
UT	Skilled Nursing Facility	300% of federal SSI	$2,000	Age 18 or older with an acquired brain injury that occurred after birth.
VT	Specialized Nursing Facility	300% of federal SSI	$2,000	Age 16 or older with a recent traumatic brain injury that is not degenerative but that may include stroke.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
WI	Inpatient Traumatic Brain Injury Rehabilitation	300% of federal SSI	$2,000	Any age and have a mechanical or infectious brain injury including one vascular in origin that is sustained by the person prior to attaining age 22. Not including alcoholism, Alzheimer's disease or a like irreversible dementia.
WY	ICF-MR	300% of federal SSI	$2,000	Age 21 to 64 with a traumatic or non-traumatic brain injury that has occurred since birth caused by an external physical force or by a metabolic disorder; not including congenital or birth trauma related injury and a specified score range on one or more standard assessments.

Source: Rutgers University, Center for State Health Policy, 2008.

Abbreviations used

300% of federal SSI – Is three times the amount of Supplemental Security Income paid by the federal government to eligible individuals. In 2008, this is $1,911 (federal SSI is $637).

SSI – the actual amount of SSI varies from state to state because the state may make supplemental payment in addition to the federal portion. There may also be variations within a state as the supplemental payment may differ with the type of setting of the individual.

FPL – In 2008, it is $866.66/month for a single person in all states except Hawaii and Alaska. 75% of the Federal Poverty Level (FPL) is $650.

MN – Medically Needy is an optional eligibility group that a state may elect to cover in its Medicaid State plan. However, even if a state covers this group for some services, they are eligible for waiver services in a state if specified in the state's waiver. Medically Needy individual's a have incomes too high to qualify for Medicaid. This option allows them to "spend

down" to Medicaid eligibility limits by paying for medical care. The exact amount to which they need to spend down varies by state.

Waiver Services

The Social Security Act lists seven specific services that may be provided under a home and community-based services waiver: case management, homemaker services, home health aid services, personal care services, adult day health, habilitation, and respite care. In addition, states may apply for permission to provide other optional services above and beyond the services provided in the Medicaid state plan.[48] The state requests and defines the services it plans to provide on its waiver application.

The services that each of the states covers in its brain injury waiver were categorized, for the most part, according to a set of categories and definitions used in a report examining waiver services targeted to support individuals with intellectual and developmental disabilities.[49] These service categories are:

- Case Management/Service Coordination
- Supports of Participant Direction (Support Broker)
- In-Home Services
- Person-Directed Goods and Services
- Equipment/Supplies
- Vehicle Repair/Modification
- Respite
- Clinical Services
- Day Supports
- Environmental Accessibility Adaptations
- Health Related
- Financial Management Services
- Supported Employment
- Family and Caregiver Training
- Transportation
- Other

In order to not to over use the "other" category for the services developed and targeted to the needs of individuals with brain injuries, four additional categories were created for this report, in order to better quantify and describe offered services and they included:

- Residential

[48] Section 1915 of the Social Security Act available at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm

[49] Smith, G.; Agosta, J.; Fortune, J. and O'Keeffe, J., Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Final Project Report, April 2007 available at: http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm
Using the same service categories make it easier to compare the descriptions of services in the different reports.

- Night Supervision
- Substance Abuse
- Behavioral Services

Table 10 (see page 31) indicates the specific categories of services included in each state's waiver. The Appendix "States Profiles," contains more detailed information about the specific services that are included in the each state's waiver.

Case Management is intake, assessment, service planning, and on going monitoring of individuals applying for, or enrolled in, the waiver.[50] All of the states surveyed provide case management. In all but four of the states, it is a waiver service. In these four states, it is a service available either through the State plan[51] or included as a specified component part of the waiver service[52].

Supports of Participant Direction is assistance to individuals/families that use consumer-directed services. Such assistance may include the development of the person-centered plan, managing individual budgets, recruiting workers, and accessing generic services and supports.[53] This service was reported available in only three states. It is a waiver service in only one of the three states, where it replaces case management if the individual chooses to utilize consumer-directed services.[54] The other two states reported that this service is required if the waiver participant chooses to use consumer-directed services.[55]

In-Home Services include personal care/assistance, chore services, companion services, and homemaker services.[56] These services are available in all states except for two.[57] We have chosen to expand the definition of this category to include other waiver services that may be provided in an individual's home and other settings, for example a workplace or a provider's office. Examples of these services are:

- Behavioral programming
- Community Integration Counseling Service and Personal Adjustment Counseling and Training, a counseling service provided to a waiver participant who is coping with altered abilities and skills, the need to revise long term expectations, and changed roles in relation to significant others.
- Crisis Response Services which may also include training to staff related to the needs of the individual and/or emergency back-up staff to assist during the crisis.

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[50] Smith et al.
[51] Illinois, Kansas, and Massachusetts.
[52] Nebraska offers one Waiver service, Assisted Living.
[53] Smith et al.
[54] Kentucky
[55] Iowa and Utah.
[56] Smith et al.
[57] Nebraska offers one Waiver service (Assisted Living) which specifically includes personal care and other services related to homemaker or chore services. North Dakota, which no longer operates a separate brain injury Waiver, included a service (Residential Care) that provided the essential elements of In-Home Services as major components.

- Family Counseling and Training as well as Family Assistance and Supports
- Home delivered meals
- Independent Living Skills Training and Transitional Living Skills
- Interim Medical Monitoring and Treatment
- Residential habilitation
- Respite care
- Supported living, individual support services, community support services, and home and community support services. These services are provided to waiver participants able to live independently or semi-independently in the community if provided services and supports to meet their needs. These include assistance in daily living skills, instrumental activities of daily living, use of community resources, community safety, and social skills. These may also include coaching/cueing services for consumers needing minimal or no "hands on" assistance.
- Therapy such as: occupational therapy, physical therapy, speech-language therapy, behavioral therapy, cognitive therapy, and drug and alcohol therapy

Person-Directed Goods and Services permit waiver participants to purchase goods and services that are not specifically covered in a waiver but contribute to meeting the person's needs for assistance.[58] Services provided in this manner may also be referred to as "Cash and Counseling."[59] Fourteen states provide at least one element of this service for participants in their brain injury waiver. Eleven provide this as a waiver service[60] and three permit participants to use consumer-directed options as included in the state plan.[61] These last three states were among the initial participants in the Cash and Counseling Demonstration and Evaluation.[62] As such, they may be expected to have more robust options available in their service system for all Medicaid beneficiaries, not just waiver participants. Six more of the states that cover these services in their brain injury waiver are expansion states in Cash and Counseling.[63]

Equipment/Supplies including but not limited to adaptive equipment, augmentative communication devices, control switches, chairs and other mobility aids, and personal emergency response systems (PERS).[64] Nineteen states have specific waiver services that meet this definition. Two states cover items that meet this definition as part of Environmental Accessibility Adaptations but do not specifically include one or more waiver services, such as adaptive equipment or PERS that are clearly in this category.[65] The two remaining states[66] that do not provide this service cover a very

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[58] Smith et al.
[59] http://www.cashandcounseling.org/about
[60] Connecticut, Iowa, Illinois, Kansas, Kentucky, Minnesota, New Hampshire, Pennsylvania, South Carolina, Utah and Wisconsin
[61] Florida, New Jersey and New York (which did not complete the demonstration)
[62] Florida, New Jersey and New York (which did not complete the demonstration) http://www.cashandcounseling.org/resources/20051205-134040/CDocumentsandSettingsVITALEBDesktopcclibDeterminingPreferenceSurveyResults.pdf
[63] http://www.cashandcounseling.org/about/participating_states
[64] Smith et al.
[65] Kentucky and New Jersey

limited number of services, primarily in a residential setting, to a small number of individuals.

Executive function deficits are common and associated with damage to the frontal lobes of the brain. These impairments can have marked impact on a person's ability to initiate, plan, organize, and complete everyday and higher-level tasks related to activities of daily living and to work tasks. They may hinder the person's ability to follow-through with suggestions and to use compensatory strategies.[67] Providing flexibility in the types of equipment that can be purchased can be beneficial in assisting an individual to compensate for these functional deficits and at the same time help the persons to be self-reliant. A wide variety of "off the shelf" electronic equipment, specialized equipment, adaptive aids, as well as web-based applications and computer software, is available to assist individuals.

Vehicle Repair/Modification provides for alterations to a vehicle to accommodate a person with a physical disability.[68] Either eleven states cover this as a waiver service either explicitly or as an option that can be covered through Environmental Modifications.[69]

Respite is relief to a person's primary caregiver and is provided in 18 states as a distinct service.[70] As noted above, three states, the two previously noted,[71] and a third[72] provide a very limited number of services, primarily in residential settings staffed by paid shift workers, where respite would not be an expected or appropriate service. Another state's waiver has a strong rehabilitation focus and provides the supportive services an individual needs to become independent;[73] the focus of respite is on the caregiver, so it is not surprising that it is not a covered service in this waiver. One state that offers a wide array of waiver services and does not offer respite as a distinct service does provide "companion care" for up to 6 hours/day of supervision and assistance as relief for caregivers.[74]

Clinical Services include physical therapy, occupational therapy, behavioral interventions, speech and language services, and similar services performed by credentialed professionals.[75] These services are included in 18 states as a waiver service. Of the five states not offering clinical services, one state provides these services through the state plan with few limitations, as long as the individual is making progress towards

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[66] Maryland and Nebraska
[67] http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact
[68] Smith et al.
[69] Connecticut, Iowa, Indiana, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, South Carolina, Wisconsin and Wyoming
[70] Smith et al.
[71] Maryland and Nebraska
[72] North Dakota
[73] Kansas
[74] Florida
[75] Smith et al.

goals.[76] Another also uses its state plan for these services despite there being issues with the state plan limits on scope and duration of services.[77] Finally, three states provide residential service as a component the primary waiver service but do not consider residential services as a distinct waiver service.[78]

For the purposes of this report, we also included additional therapies provided by professional specialists. Cognitive, physical, emotional, and behavioral impairments may follow brain injury. Physical, motor, and basic sensory functions can be affected. Individuals with brain injury may also have subtle to significant impairments in their perception, language, attention, concentration, information processing, learning, and/or memory.[79] In addition to the basic clinical services noted above, we expanded the definition to include additional specialized services (cognitive therapy, psychological and other counseling, other specialty services and crisis response) that are needed to rehabilitate and provide on-going support to many individuals with a brain injury.

Thirteen states provide one or more of these services as a defined waiver service: cognitive therapy is provided by eight states[80], psychological and other counseling is provided by six states,[81] other specialty therapy is provided by two states,[82] and crisis response is offered by one state.[83] The individual state profiles provide information about the specific services covered and whether they are unique waiver services or extended state plan services.

Day Supports are services furnished outside the person's residence in facility-based settings such as day habilitation centers or in the community to promote community inclusion (e.g., community participation).[84] Eighteen states provide this service,[85] and one state includes day service in its definition of specialized assisted living.[86] Supported employment is a separate category and was, therefore excluded from this category. Pre-vocational service is, however, included in this category and is provided by seven states.[87] One state provides day supports as a component of crisis service.[88]

Environmental Accessibility Adaptations are home modifications to accommodate physical disabilities (e.g., ramps, bathroom modifications, and others). Nineteen states provide this service. The three states that provide residential service as

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[76] Iowa
[77] Utah
[78] Maryland, Nebraska and North Dakota provide primarily residential service.
[79] http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact
[80] Colorado, Connecticut, Illinois, Kansas, Minnesota, New Jersey, Pennsylvania and Wyoming
[81] Florida, New Jersey, New York, Pennsylvania, South Carolina and Wisconsin
[82] New Hampshire and Vermont
[83] New Hampshire
[84] Smith et al.
[85] the exceptions being Connecticut, Florida and North Dakota
[86] Nebraska
[87] Iowa, Illinois, Minnesota, Pennsylvania, South Carolina, Wisconsin and Wyoming
[88] Vermont

the sole or primary waiver service[89] do not provide these modifications because the residential setting is expected to be accessible. Only one state provides a broad array of waiver services does not cover this service.[90]

Health-Related Services are "typically skilled nursing services."[91] These services are provided as waiver services in seven states.[92] These services are also included by one additional state in its definition of specialized assisted living.[93]

For the purposes of this report, the definition of health-related services was expanded to reflect additional ways states are meeting the specialized needs of individuals with brain injury. One state that provides nursing services also provides health education for individuals using consumer-directed care as a waiver service.[94] Another state provides Interim Medical Monitoring and Treatment, which it defines as monitoring and treatment of a medical nature, requiring specially trained caregivers beyond those normally available in a day care setting for persons age 20 and under.[95] One state provides limited oral health services not available through its state plan.[96] One state provides both crisis response services and specialty services for participants whose medical, behavioral, therapeutic, health and personal well being require these specialized services for the unique conditions and aspects of acquired brain disorders.[97]

Financial Management Services are those that support individuals who directly hire their own workers and/or manage an individual budget.[98] These services include payroll, accounting, hiring, training in employer skills, and similar activities that individuals exercising the consumer-directed services option need to perform. Only three states provide these services as part of waiver services.[99] Four additional states make these services available to individuals who choose consumer direction, but it is not considered a waiver service.[100] One of these latter four states requires that financial management service be used if an individual elects to use consumer-directed services.[101]

Supported Employment is a service to assist individuals to secure regular community jobs and support their on-going employment. It is offered by waivers in 16 states.[102]

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[89] Maryland, Nebraska and North Dakota
[90] Utah
[91] Smith et al.
[92] Idaho, Illinois, Indiana, Pennsylvania, South Carolina, Wisconsin and Wyoming
[93] Nebraska
[94] South Carolina
[95] Iowa
[96] Kansas
[97] New Hampshire
[98] Smith et al.
[99] Connecticut, New Hampshire and Wisconsin
[100] Iowa, Kansas, New Jersey and Utah
[101] Iowa
[102] Connecticut, Idaho, Illinois, Indiana, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, New Hampshire, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin and Wyoming

Family and Caregiver Training includes services that teach family members and/or caregivers to perform activities that address one or more dimensions of a person's disability.[103] Rather than limit the definition to training, we have expanded it to include counseling, therapy, and treatment involving the family and/or caregiver as well as the individual. Twelve states provide one or more services that have at least one of these elements.[104] One of these states specifically includes substance abuse treatment services,[105] two of these states specifically include services of a dietician,[106] and three of these states specifically include family training as part of the behavioral programming service.[107]

Transportation to community activities and/or other waiver services is a service offered by 12 states,[108] and another state specifically includes transportation in the single broadly defined waiver service that it provides.[109]

The following service categories were created for this report:

Residential Services are services that provide the individual with a place to live as well as some, or all, of the supports needed by the individual. This is one additional category developed for this paper. Fifteen states make some type of residential service available to waiver participants.[110] Federal matching funds may only be used to make deposits on residences and for services within the living setting, but not for room and board. These services include 24-hour support and assistance from a licensed or otherwise approved, provider. Examples of residential services are:

- Assisted Living, Assisted Living Plus and Specialized Assisted Living
- Habilitation and Support as well as Residential Habilitation
- Residential Care Facility, Residential Care Services, Residential Care
- Supportive Living, Supported Community Living, Community Residential Services, Personal Care Services and Community Living Supports
- Transitional Living – designed to be a short-term service to prepare an individual for more independent living.

  Note: In some cases, these services may also be provided to individuals living with family or in a home of their own.

These services are provided in several different settings as detailed below.

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[103] Smith et al.
[104] Colorado, Connecticut, Florida, Idaho, Iowa, Kentucky, Massachusetts, Minnesota, New York, Pennsylvania, Utah and Wyoming
[105] Colorado
[106] Pennsylvania and Wyoming
[107] Connecticut, Florida and New York
[108] Colorado, Connecticut, Idaho, Iowa, Massachusetts, Minnesota, New Jersey, New York, Pennsylvania, South Carolina, Utah and Wisconsin
[109] Nebraska
[110] Colorado, Connecticut, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, Nebraska, New Hampshire, New Jersey, North Dakota, Pennsylvania, Utah, Wisconsin, Wyoming

Table 9: Residential Service Settings

Type of Setting	Number of States
Residential Care Facility	3
Assisted Living Facility (may be specialized for individuals with a brain injury)	2
Group Home, or other small home with paid staff	5
Foster Care	4
Unspecified Congregate Facility	6

Note: Totals to more than 15 because some states offer services in more than one type of setting
Source: Rutgers University, Center for State Health Policy, 2008.

Night Supervision services provide physical assistance and/or supervision during normal sleeping hours in the individual's place of residence. Typically, this service includes: physical assistance or supervision with toileting, transferring, turning, feeding of liquids, mobility; and prompting and reminding of medication when the individual's mobility, memory and cognition is affected by the brain injury. These services are provided in eight states. In four of these states, the service is referred to as either night supervision or sleep cycle support.[111] In the other four states, the service is part of a broader community living support service.[112]

Other states that did not specifically report providing this service provide similar in-home supports for waiver participants. Additionally, one state reported that night supervision was not billable by providers of residential service because it was expected that providers would deliver essentially the same service whenever it was required by the resident(s).[113] We believe it is reasonable to consider it likely that this service is more widely available than reported.

Substance Abuse Services assist the individual in building skills to resist alcohol and drug use, to replace alcohol and/or drug-using activities with constructive and rewarding non-alcohol and non-drug-using activities, and to address associated problems. The incidence of substance abuse among individuals who survived a traumatic brain injury is high. It is estimated that over half of the individuals who sustained a traumatic brain injury were substance abusers prior to the injury, and that from 25% to 50% continue to abuse alcohol after their injury.[114]

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[111] Kansas, Minnesota, New Jersey and Pennsylvania
[112] Connecticut, Iowa, Utah and Vermont
[113] New Jersey
[114] Katz, R., "Substance Abuse In TBI Survivors" available at http://www.tbihelp.org/substance_abuse_in_tbi.htm

These services are available as waiver services in seven states[115] and are either a stand-alone service specifically for substance abuse or part of a broader counseling service. One state reported that substance abuse services are available to waiver participants through its mental health system. [116]

Behavioral Services assist the individual to change behavior, replacing maladaptive, badly adjusted, or self-destructing behaviors by learning new, more appropriate behaviors. A brain injury can modify an individual's emotional behavior and behavior patterns. Emotional changes may include depression, anxiety, and problems with substance abuse. Behavioral problems include difficulties with emotional control and problems with controlling anger and aggression.[117] Behavioral issues often are the greatest challenge faced by family and other persons involved with an individual sustaining a brain injury. Individuals with brain injury are effectively served by providers that are aware of or sensitive to the unique issues faced by the individual with a brain injury. If the provider is not aware of the unique issues, there is an increased chance that the relation between the brain injury and the behavior will become blurred, disregarded, or sometimes completely lost.[118]

Sixteen states provide behavioral services as a distinct waiver service, and two states[119] provide behavior services as a defined part of their residential service. Although five states do not provide a discrete service labeled "behavioral," they each offer broad services such as residential care, habilitation, or support services that may be expected to provide behavioral interventions.[120]

Other - Eleven states offer one or more of the services described briefly below.

- Adaptive Health and Wellness - membership in a "health studio" to follow an exercise regimen ordered by a physician and designed by a physical therapist.[121]
- Community Integration Services and related training enable the consumer to plan for and engage in meaningful adult activities.[122]
- Community Transition – one-time costs to relocate from an institution to the community or to obtain the individual's first community home is offered in four states.[123]
- Home delivered meals are available to waiver participants in four states.[124]
- Independent Living Skills Therapies – art, music and recreation therapies[125]
- Interpreter service[126]

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[115] Colorado, Florida, Kansas, Kentucky, Massachusetts, New Jersey, and New York
[116] Connecticut
[117] http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact
[118] http://www.nashia.org/issues/neurobehavioral.html
[119] Maryland and Nebraska
[120] Massachusetts, North Dakota, Utah, Wisconsin and Wyoming
[121] Florida
[122] Pennsylvania
[123] Minnesota, New York Pennsylvania and Wisconsin
[124] Illinois, Indiana, Minnesota and Wisconsin
[125] Minnesota

- Mental Health, including Psychological Testing[127]
- Prescribed drugs beyond state plan limits.[128]
- Specialized Assisted Living – with service components of: adult day care, escort services, essential shopping, health maintenance activities, housekeeping activities, laundry services, meal service, medication assistance, personal care services, transportation services, behavioral services.[129]
- Training or education services that help the waiver participant re-learn or regain skills and knowledge that were lost due to the brain injury, or assist in acquiring new skills to compensate for lost skill(s), are available in three states.[130]
- Transitional living designed to assist an individual move from a congregate or institutional setting to his/her own home.[131]

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[126] Massachusetts
[127] Minnesota
[128] South Carolina
[129] Nebraska
[130] Florida, Pennsylvania and Wisconsin
[131] North Dakota

Table 10: Services Covered as Waiver Services

Services Offered by States	CO	CT	FL	IA	ID	IL	IN	KS	KY	MD	MA	MN	NE	NH	NJ	NY	ND	PA	SC	UT	VT	WI	WY
Case Management	X	X	X	X	X	X	X	1	X	X	1	X	4	X	X	X	X	X	X	X	X	X	X
Supports of Participant Direction (Support Broker)				1,2					X3											2			
In-Home Services	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X
Person-Directed Goods and Services		X	1	X		X		X	X			X		X	1	1		X	X	X		X	
Equipment/Supplies	X	X	X	X	X	X	X	X			X			X		X	X	X	X	X	X	X	X
Vehicle Repair/Modification		X		X			X					X		X	X	X		X	X			X	X
Respite	X	X		X	X	X	X		X		X	X		X	X	X		X	X	X	X	X	X
Clinical Services	X	X	X	1	X	X	X	X	X		X	X		X	X	X		X	X		X	X	X
Day Supports	X			X	X	X		X	X	X	X	X	4	X	X	X		X	X	X	X	X	X
Environmental Accessibility Adaptations	X	X	X	X	X	X	X	X	X		X	X		X	X	X		X	X		X	X	X
Health Related				X	X	X	X	X					4	X				X	X			X	X
Financial Management Services		X		1,2				1						1	1					2		X	
Supported Employment		X		X	X	X	X		X	X	X	X		X				X	X	X	X	X	X
Family and Caregiver Training	X	X	X	X	X				X		X	X				X		X		X			X
Transportation	X	X		X	X						X	X	4		X	X		X	X	X		X	
Residential	X	X		X					X	X	X	X	4	1	X		X	X		X		X	X
Night Supervision		X		X				X				X			X			X		X	X		
Substance Abuse	X	1	X					X	X		X				X	X							
Behavioral Services	X	X	X	X	X	X	X	X	X			X	4	X	X	X		X	X		X		
Other			X			X	X				X	X	X			X	X	X	X			X	

Note: See State profile for specific services. State plan services may provide a service not specifically indicated.

1 – Service is available to Waiver participants, but not as a specific Waiver service.

2 – Service is required if the individual is using consumer-directed services.

3 – Replaces case management if the individual is using consumer-directed services.

4 – The service is specifically delineated in the definition of Assisted Living.

Source: Rutgers University, Center for State Health Policy, 2008.

Other Considerations

Focus of the Waiver

Medicaid waivers providing Home and Community-Based Services are generally considered part of the long-term care service system. In most states, the waiver for individuals with brain injury can also be characterized in this fashion. Individuals are provided with services that support them in a community-based living arrangement, and they continue to receive services for as long as they are needed.

Five states have structured their waiver services in another way: they focus primarily on rehabilitation.[132] Rather than provide supports designed to meet the long-term care needs of those individuals in the waiver, the services provided are designed to provide rehabilitation and community reintegration, as well as to provide the other supports needed to reside in a community-based living arrangement.

These "rehabilitation" waivers may have level of care requirements that are more stringent than nursing facility, including specialized nursing facility, hospital, rehabilitation hospital, or intermediate care facility. There may also be additional requirements that:

- the brain injury be relatively recent;
- the individual requires goal-oriented therapy with medical management;
- the individual requires and benefits from specialized rehabilitation services;
- significant supervision and structure is necessary to manage the individual;
- there is a prognosis for continued functional improvement;
- there is potential for rehabilitation and reintegration into the community;
- progress must be demonstrated in the annual review;
- an administrative review be conducted when an individual is in the waiver for a specified number of years; and,
- the individual demonstrates benefit from the program from which he/she is referred.

Kentucky submitted a long-term care waiver to CMS for individuals with brain injury. CMS approval had not been received at the time of contact with the state. Vermont's waiver had a very strong rehabilitation focus, but not all of the individuals initially enrolled had made the progress that they needed to be successfully discharged from the waiver. Accordingly, there was a long-term services option for these individuals.

Cost Effectiveness

[132] Colorado, Iowa, Kansas, Kentucky and Vermont

Providing home and community-based services (HCBS) to individuals with brain injury is less expensive than providing services in nursing homes, hospitals, and similar institutions. Data including institutional costs were available from 17 of the surveyed states: only waiver data were available from the remaining states. In these 17 states alone, a total of almost $273 million was saved annually by providing home and community-based services when compared to the institutional cost of services for the same number of individuals. On average, $30,000 per person was saved.

Table 11 shows the state data for home and community-based services and institutional services costs, as well as the number of individuals who received services in that year. Data from the most recent waiver year available was used. Typically, this was 2006, but in a few cases it was an earlier year (indicated with a note). Institutional cost data was not available for every state.

In waiver applications, a state must demonstrate that the estimated cost of HCBS under the waiver will not exceed the estimated cost of providing institutional services. Two terms are used in the waiver application that states must submit, as well as in annual reports that are required for waivers. "Factor D" is the total cost of waiver services provided during the year, divided by the number of individuals who received waiver services in that year. "Factor G" is the average per person cost of services in the institution(s) used for the waiver's level of care.

As indicated in Table 11, states experience cost savings with HCBS, as these costs are lower than the cost of institutional services.

Table 11: Cost-Effectiveness of Brain Injury Waivers

State	Factor D Per Capita Cost HCBS	Factor G Per Capita Cost Institution	Difference Factor G & Factor D	Unduplicated Participants	Total Savings
Colorado	$30,811	$58,556	$27,745	293	$8,129,172
Connecticut (1)	$74,683	$117,588	$42,905	344	$14,759,261
Florida	$20,860	$32,521	$11,661	283	$3,300,033
Idaho	$59,660	nr		19	
Illinois	$11,814	$20,008	$8,194	3,601	$29,507,582
Indiana	$25,884	$39,322	$13,438	131	$1,760,424
Iowa	$13,192	nr		825	
Kansas	$23,379	$61,603	$38,224	269	$10,282,136
Kentucky (2)	$66,659	nr		98	
Maryland (1)	$64,753	$171,710	$106,957	23	$2,460,009
Massachusetts	$54,265	nr		90	
Minnesota (1)	$50,266	$105,052	$54,786	1372	$75,166,045
Nebraska	$28,202	$67,058	$38,856	26	$1,010,261
New Hampshire (3)	$82,223	$118,346	$36,123	119	$4,298,637
New Jersey	$66,575	$83,727	$17,152	276	$4,733,855
New York	$40,465	$71,297	$30,832	1953	$60,213,921
North Dakota	$27,496	nr		29	
Pennsylvania (2)	$45,380	$125,587	$80,207	285	$22,858,995
South Carolina (1)	$24,642	$40,586	$15,944	497	$7,924,114
Utah	$22,848	$29,916	$7,068	91	$643,215
Vermont (3)	$53,719	$160,600	$106,881	51	$5,450,931
Wisconsin	$60,165	nr		334	
Wyoming	$28,766	$175,715	$146,949	137	$20,132,077
Total Savings					$272,630,668

Notes:

(1) state uses 2 or more institutions

(2) 2005 data

(3) 2004 data

.nr "nr" indicates no response. Factor G data not reported, state data provided was in a form other than a complete CMS 372 report

Source: Rutgers University, Center for State Health Policy, 2008

Conclusions

Medicaid waivers targeted to individuals with brain injuries operate in half of the states and are small when compared to waivers targeting other groups. These waivers provide significant cost savings, on average $30,000 annually per person, when compared to institutional facility-based services.

A state's experience and policies for its other waivers, especially financial eligibility, will set the parameters within which a waiver for individuals with brain injuries will operate. State officials, advocates, and others considering whether to pursue a new waiver or modifying an existing waiver may benefit from the experiences of other states by examining and considering the waivers described in this paper in order to make decisions about four key areas:

- What age range and how many persons will be included in the waiver?
- What services will be included and what costs may be expected? Will the waiver have a long-term care focus, a rehabilitation focus, or both? Will the cause of the brain injury (e.g. traumatic or acquired) be a determining factor in an individual's eligibility for the waiver?
- What institution will be used to determine the level of care? Will more than one be used?
- What providers will be enrolled and how will case management be done?

These waivers have been successful both programmatically and financially. In addition to cost savings, these waivers have provided other significant benefits. The existence of these waivers supports the growth of community non-profit brain injury agencies. There is clear evidence of the desirability of home and community-based services among those directly affected by brain injury: there has been growth of these waivers that has resulted in a doubling of the number of persons served over five years; and, there is a visible role played by advocates in encouraging states to develop these waivers. These waivers, over time, have contributed to states' efforts to create and grow an in-state service capacity to provide services to individuals with brain injuries.

Terminology/Glossary

The following frequently used terms in this report may not be familiar to every reader.

Acquired Brain Injury - According to The Brain Injury Association of America (BIAA), acquired brain injury is an injury to the brain which is not hereditary, congenital, degenerative, or induced prior to birth or by birth trauma.[133] An acquired brain injury may result in mild, moderate, or severe impairments in one or more areas, including cognition; speech-language communication; memory; attention and concentration; reasoning; abstract thinking; physical functions; psychosocial behavior; and information processing.[134]
This definition does not exclude traumatic brain injuries.

Birth trauma - refers to a physical injury to the infant that occurred during the birth process.

Centers for Medicare and Medicaid Services (CMS) - The federal agency, within the Department of Health and Human services, that administers the Medicare and Medicaid programs; it also administers the State Children's Health Insurance Program. It was initially established as the Health Care Financing Administration.[135]

Cost neutral (or cost neutrality) - When the average per capita expenditure by the State in any fiscal year for medical assistance provided under a Waiver to Waiver participants does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for these individuals if the Waiver had not been granted.[136] A state uses estimates of these service costs when applying for a Waiver. Once a state is operating a federally approved Waiver, actual costs are used.

Developmental Disability - according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, the term "developmental disability" means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or

[133] http://www.biausa.org/education.htm#causes
[134] http://www.biausa.org/Pages/types_of_brain_injury.html#aquired
[135] http://www.hhs.gov/about/whatwedo.html/
[136] Social Security Act, Section 1915(c) (2) (D)

other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.[137]

Federal Poverty Level - The commonly used term for the federal Health and Human Services Poverty Guideline. The poverty guidelines are a federal poverty measure issued each year by the Department of Health and Human Services (HHS). The guidelines derived from more detailed "poverty thresholds." The guidelines are used for administrative purposes, for instance, determining financial eligibility for certain federal programs.

The poverty guidelines are designated by the year in which they are issued; the guidelines issued in January 2008 are designated the 2008 poverty guidelines. However, the 2008 HHS poverty guidelines only reflect price changes through calendar year 2007 as measured by the Consumer Price Index.[138] The 2008 poverty guideline for a one-member household is $10,400 in all states except Alaska and Hawaii where it is higher.[139]

Medicaid 1915(c) Home and Community-Based Services (HCBS) Waiver - these are frequently referred to as an HCBS Waiver, a Medicaid Waiver, or just Waiver. According to the federal Department of Health and Human Services,[140] states may offer a variety of services to consumers under an HCBS Waiver program with no limit on the number of services that can be provided. A combination of traditional medical services as well as non-medical services (i.e. respite, case management, environmental modifications) is permitted. Similarly, states may determine the maximum number of individuals that will be served in a HCBS Waiver program.

Spinal Cord Injury - According to the National Spinal Cord Injury Association, spinal cord injury (SCI) is damage to the spinal cord that results in a loss of function such as mobility or feeling. In addition, individuals with SCI also experience other changes such as: bowel and bladder dysfunction; in the case of very high neck injuries, loss of many involuntary functions including the ability to breathe, necessitating breathing aids such as mechanical ventilators or diaphragmatic pacemakers; low blood pressure; inability to regulate blood pressure effectively; reduced control of body temperature; inability to sweat below the level of injury; and chronic pain.

The spinal cord is the major bundle of nerves that carries nerve impulses to and from the brain to the rest of the body. It is surrounded by rings of bone called vertebra. These bones constitute the spinal column (back bones) and neck. In general, the higher in the spinal column the injury occurs, the more dysfunction a person will experience.

Frequent causes of damage are trauma (car accident, gunshot, falls, etc.) or disease (polio, spina bifida, Friedreich's Ataxia, etc.). The spinal cord does not have to be severed in order for an individual to experience loss of functioning; most of the time

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[137] 114 STAT. 1684 Public Law 106-402
[138] http://aspe.hhs.gov/poverty/08poverty.shtml
[139] *Federal Register*, Vol. 73, No. 15, January 23, 2008, pp. 3971–3972
[140] http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp

the spinal cord is intact, but damaged. SCI is very different from back injuries such as ruptured disks, spinal stenosis or pinched nerves.

It is possible for an individual to "break their back or neck" yet not sustain a spinal cord injury. This would occur when only the bones around the spinal cord (the vertebrae) are damaged, but the spinal cord is not affected. In these situations, the individual may not experience paralysis after the bones are stabilized.[141]

Stroke (also referred to as cerebrovascular accident or CVA) – According to the National Stroke Organization, [142] there are two types of stroke:

- Ischemic stroke – blocked arteries resulting from blood clots or by the gradual build-up of plaque and other fatty deposits and
- Hemorrhagic stroke - a blood vessel in the brain breaks, leaking blood into the brain.

When an individual has a stroke, brain cells begin to die and brain damage occurs. Where the stroke occurs in the brain and how serious the brain damage is determine what abilities (such as speech, movement and memory) are lost and how serious the loss is.

Supplemental Security Income (SSI) - a federal program that gives monthly cash payments to people who are age 65 or older or are blind or have a disability and who also have low income and few resources. The Social Security Administration runs the SSI program deciding who is eligible, making payments and keeping a master record of recipients. Even though Social Security runs the program, SSI is not Social Security; it is not financed by Social Security trust funds.

In 2008, the highest federal SSI payment is $637 a month for a person and $956 a month for a couple. States may add money to the federal SSI payments and may change the payment amounts based on where and with whom people live. States can let the federal government manage the state supplement and pay the costs. In these states, individuals apply at a Social Security office. Or, a state may manage its own supplement. In states that manage the supplement, individuals must apply to the state for the supplement. States managing their own supplement are: Alabama, Alaska, Arizona, Colorado, Connecticut, Florida, Idaho, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Minnesota, Missouri, Nebraska, New Hampshire, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Virginia, Washington, Wisconsin and Wyoming.[143]

Traumatic Brain Injury - According to the Centers for Disease Control, a traumatic brain injury is an injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury:

- observed or self-reported decreased level of consciousness,
- amnesia,

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[141] http://www.spinalcord.org/news.php?dep=17&page=94&list=1190

[142] http://www.stroke.org/site/DocServer/STROKE_101_Fact_Sheet.pdf?docID=4541

[143] http://www.socialsecurity.gov/pubs/11015.html and *Federal Register*, Vol. 73, No. 15, January 23, 2008, pp. 3971–3972

- skull fracture,
- objective neurological or neuropsychological abnormality,
- diagnosed intracranial lesion[144]

The BIAA defines a traumatic brain injury (TBI) as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment.[145]

Typically, the cause is a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," i.e., a brief change in mental status or consciousness, to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short or long-term problems with independent function.[146]

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[144] Thurman DJ, Sniezek JE, Johnson D, et al. Guidelines for Surveillance of Central Nervous System Injury. Atlanta: Centers for Disease Control and Prevention, 1995
[145] http://www.biausa.org/Pages/types_of_brain_injury.html#tbi
[146] http://www.biausa.org/aboutbi.htm

APPENDIX: STATE PROFILES

Colorado

Waiver Name: Home and Community-Based Services Brain Injury Waiver

Operated by the single State agency (Department of Health Care Policy and Financing).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Hospital
Nursing Facility

Must be between the ages 16 and 64, have injury to the brain of traumatic or acquired origin which results in residual physical, cognitive, emotional, and behavioral difficulties of a non-progressive nature and that fall within a specified group of ICD-9 codes.
The level of care is determined by a case manager of a single entry point agency or utilization review contractor.
Hospital level of care: client is currently receiving inpatient hospital care in an acute medical facility or rehabilitation facility no more than six-months post Brain Injury; continues to require goal-oriented therapy with medical management by a physician; continues to require and benefit from medically necessary specialized rehabilitation services; cannot be therapeutically managed in the home without significant supervision and structure, specialized therapy and support services; and has a prognosis for continued functional improvement.
Specialized nursing facility level of care: continues to require and benefit from medically necessary specialized supportive services; requires long-term specialized daily assistance that cannot be provided in a nursing facility; independence can be maximized in the community by provision of 24-hour supervision, structure and supportive services provided by staff with specialized behavioral and cognitive management training; and has maximized his or her acute care recovery and rehabilitation potential.

Focus: Individuals must demonstrate benefit from the waiver or transfer to the state's elderly, blind and disabled waiver. Such transfers are infrequent and usually voluntary.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Independent Living Skills Training Personal Care Supported Living
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Assistive Equipment
Vehicle Repair/Modification	N	
Respite	Y	Respite Care
Clinical Services	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Day Support	Y	Adult Day Services Day Treatment
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Transportation	Y	Non-medical Transportation
Residential	Y	Supported Living Transitional Living
Night Supervision	N	
Substance Abuse	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Behavioral Services	Y	Behavioral Programming

Monthly cost limit: $22,500.

Background:

Colorado began this Medicaid Waiver in 1995 as a result of legislation stemming from a citizen based initiative calling for the development of a comprehensive community-based rehabilitation program for Medicaid funded people who had sustained acquired or traumatic brain injuries.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	384	$6,462,081	$16,828	235	$72
2003	404	$8,337,702	$20,638	267	$77
2004	368	$8,945,382	$24,308	278	$87
2005	328	$9,002,955	$27,448	255	$108
2006	293	$9,027,736	$30,811	247	$125

Waiver year is July 1, to June 30

Waiting List: None.

Connecticut

Waiver Name: Acquired Brain Injury Waiver

Operated by the Department of Social Services, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $1,600 or less.

Levels of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)
Chronic Disease Hospital
Acquired Brain Injury Facility
Nursing Facility

Must be between the ages 18 and 64 with an acquired brain injury; it does not include degenerative disorders or developmental disorders. An individual with cognitive impairment who does not qualify for the state's mental retardation services may qualify for the waiver; the state defines the developmental period as ending at 18.

After an initial screening of records, the individual is assessed by a social worker in person to determine the level of care.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal Care Assistance Homemaker Services Chore Services Respite Care Companion Services Home Delivered Meals Independent Living Skill Training – development and implementation of a plan to assist the individual to meet ADL and IADL needs. Individuals are expected to require this service for a limited duration and then transition to companion services.
Person Directed Goods and Services	Y	Personal Care Assistance Homemaker Services Chore Services Companion Services
Equipment/Supplies	Y	Specialized Medical Equipment and Supplies Personal Emergency Response Systems
Vehicle Repair/Modification	Y	Vehicle Modification Services
Respite	Y	Respite Care
Clinical Services	Y	Cognitive/Behavioral Programs
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Accessibility Adaptations
Health Related	N	
Financial Management Services	Y	One has been selected by the state to be available to participants.
Supported Employment	Y	Supported Employment
Family and Caregiver Training	Y	Cognitive/Behavioral Programs
Transportation	Y	Transportation
Residential	Y	Transitional Living Services – time limited and also limited to individuals requiring increased supports when relocating from an institution.
Night Supervision	Y	Community Living Support Systems – scheduled one to one supervision, typically overnight. May be shared among roommates in an apartment or among several apartments if there is a cluster.

Service Category	Y/N	Specific Service
Substance Abuse	N	This service is available, through the state's mental health system
Behavioral Services	Y	Cognitive/Behavioral Programs

Monthly cost limits are defined by policy as 200% of the level of care cost. The waiver is managed in aggregate.

Nursing facility - $10,260
Acquired Brain Injury Facility - $19,600
ICFs/MR – $25,867
Chronic Disease Hospital - $57,200

Background:

Connecticut began this waiver in 1997, in part because of litigation. Advocates, including the state's brain injury association, protection and advocacy, and legal services participated in developing the waiver. Among the reasons for developing the waiver were: service maximization, provision of long-term care supports in the community and an effort to move away from a model of "intrusive" staff support.

The waiver has remained generally stable since its inception. In the most recent renewal, the waiver was changed to allow individuals already enrolled to remain in this waiver after they are 65. Application still must be made before age 65.

One unique aspect of the waiver administration is that the state uses a separate entity to process all bills for waiver services. Case mangers submit service authorizations to this entity, which then enters them into a claims management system. Waiver providers submit their bill(s) to this entity and the bill is reviewed to assure that it is based on an authorized service. The entity then submits the appropriate claim to the state's Medicaid fiscal intermediary for payment.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	157	$9,072,381	$57,786	293	$197
2003	193	$12,278,239	$63,618	292	$218
2004	232	$15,750,722	$67,891	242	$281
2005	304	$21,949,671	$72,203	301	$240
2006	344	$25,691,011	$74,683	305	$245

Waiver year is January 1 to December 31

Waiting List: None at this time, but close to maximum number of individuals of 369.

Florida

Waiver Name: Traumatic Brain Injury and Spinal Cord Injury HCBS Waiver

Operated by the Department of Health, a separate department from the single State agency (Agency for Health Care Administration).

Target Population: Traumatic Brain Injury (and/or Spinal Cord Injury)

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Skilled Nursing Facility

Be age 18 or older, have a brain injury caused by an external trauma and/or a spinal cord injury and be medically stable. The Department of Elder Affairs determines the level of care based upon an assessment instrument and administrative process designated by the single State agency.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Community Support Coordination – every individual enrolled in the waiver must receive this service
Support Broker	N	
In-Home Services	Y	Attendant Care (may also be provided in the workplace) Behavioral Programming Companion Services Personal Adjustment Counseling and Training - ongoing therapeutic services to resolve interpsychic or interpersonal conflict resulting from the traumatic injury. Counseling may be provided as an adjunct to behavioral programming, and may include services for substance abuse. Personal Care Services

Service Category	Y/N	Specific Service
Person Directed Goods and Services	N	Available through a separate waiver. Some waiver services may be provided by independent vendors, not affiliated with an agency, who are enrolled Medicaid providers
Equipment/Supplies	Y	Assistive technologies Consumable Medical Supplies as an expanded State plan service Rehabilitative Engineering Evaluation
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	Y	Personal Adjustment Counseling and Training
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Accessibility Adaptations
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	Behavioral Programming Personal Adjustment Counseling and Training
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	Y	If needed provided as either Personal Adjustment Counseling or Behavioral Programming
Behavioral Services	Y	Behavioral Programming

Service Category	Y/N	Specific Service
Other	Y	Adaptive Health and Wellness – membership in a "health studio" to follow an exercise regimen ordered by a physician and designed by a physical therapist. Life Skills Training - includes assistance and training: with financial resource management; utilization of community resources; management of personal assistance services; activities of daily living such as grooming and personal hygiene; household management, cooking and nutrition; family and child support activities; health and disability self-management; and social integration skills and interpersonal relationships.

Background:

Florida began this waiver in 1999; almost half of the individuals enrolled have sustained a brain injury. Most live in their own homes or with family; about 20-25 are estimated to be assisted living residents. The focus is on community reintegration.

In addition to the waiver, Florida has a very similar state funded program, a trust fund (based on motor vehicle surcharges). The state has a TBI/SCI registry with mandatory reporting and once reported, staffs of the registry are required to have a face-to-face meeting with the injured individual. Most referrals for the waiver come through this the registry.

The waiver was initially approved for 100 individuals; this has increased to 375.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	152	$1,835,909	$12,078	249	$49
2003	200	$2,918,408	$14,592	274	$53
2004	230	$3,938,491	$17,124	311	$55
2005	265	$5,282,840	$19,935	321	$62
2006	283	$5,903,410	$20,860	316	$66

Waiting List: 450 as of October 2007, prioritized based on a needs assessment.

Idaho

Idaho no longer has a brain injury waiver. Because of the small number of individuals served, when it expired in 2006, it was combined with the state's aged and disabled waiver. The information that follows reflects the operation of the waiver up until its expiration.

Operated by the single State agency (Department of Health).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing Facility

Have a diagnosis of brain injury attained after the age of 21 in one of a specified set of ICD-9-CM codes. Staff of the Regional Medicaid Unit develop the initial comprehensive assessment including: A Uniform Assessment Instrument, a written narrative, medical, physical, and social history and, as necessary, specialized assessments, e.g. medical, behavioral, mobility, etc.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	
Support Broker	N	
In-Home Services	Y	Personal care services as an extension of State plan services. Residential habilitation Chore services
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized medical equipment and supplies Personal emergency response system
Vehicle Repair/Modification	N	
Respite	Y	Respite care
Clinical Services	Y	As extended State plan services: Physical therapy Occupational therapy Speech, hearing and language services

Service Category	Y/N	Specific Service
Day Support	Y	Day Rehabilitation: assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that takes place in a non-residential setting, separate from the home or facility in which the individual resides.
Environmental Accessibility Adaptations	Y	Environmental accessibility adaptations
Health Related	Y	Skilled nursing
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Residential habilitation includes family and caregiver training.
Transportation	Y	Transportation services
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Residential Habilitation includes behavior shaping. Behavior consultation/crisis management.

Background:

Idaho's brain injury waiver was incorporated into the state's aged and disabled Waiver as noted previously. Most of the services were already contained in the aged and disabled waiver. However, the following services were added and restricted to individuals with traumatic brain injury:

- Residential habilitation
- Day rehabilitation
- Supported employment
- Behavioral consultation/crisis management

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	20	$741,856	$37,093	318	$117
2003	19	$1,175,119	$61,848	301	$205
2004	19	$965,435	$50,812	297	$171
2005	20	$1,037,525	$51,876	318	$163
2006	19	$1,133,542	$59,660	354	$169

Illinois

Waiver Name: HCBS Waiver for Persons with Brain Injury

Operated by the Department of Human Service, Division of Rehabilitation Services under an agreement with the single State agency (Department of Healthcare and Family Services).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: SSI recipients, Medically Needy at 100% of FPL, TWWIIA Basic Coverage Group: countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing facility

May be of any age, with an acquired brain injury; does not include degenerative, congenital or neurological disorders related to aging. The state utilizes a "Determination of Need" instrument, administered by case managers to determine eligibility for nursing facility and this, and other, waivers. A minimum score is required for waiver eligibility, and the score is used to establish a maximum service cost.

Focus: Long-Term Care.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	Y	Personal Assistant Homemaker Respite Home health Care (as an extended State plan service)
Person Directed Goods and Services	Y	Personal Assistant Individual may also hire Certified Nursing Assistant or Nurse (LPN or RN)

Service Category	Y/N	Specific Service
Equipment/Supplies	Y	Assistive Equipment Specialized Medical Equipment and Supplies Personal Emergency Response System
Vehicle Repair/Modification	N	
Respite	Y	Respite
Clinical Services	Y	Cognitive/Behavioral Services As extended State plan services: Speech, hearing, and language Physical Therapy Occupational Therapy
Day Support	Y	Adult Day Care Day Habilitation Pre-vocational Services
Environmental Accessibility Adaptations	Y	Environmental Modifications
Health Related	Y	Skilled Nursing through Home health Care (as extended State plan service)
Financial Management Services	N	See Background
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Cognitive/Behavioral Services
Other	Y	Home Delivered Meals

Monthly service cost limits vary from $1,659 to $3,349 depending upon the individuals score from the "Determination of Need" instrument. The limit may be exceeded on a monthly basis to meet a temporary increase in need for services if the average monthly cost for services during the twelve-month period does not exceed the limit.

Background:

Illinois began the waiver in 1999 after a needs assessment conducted by the Head and Spinal Cord Injury Advisory Board in partnership with the state. A waiver advisory committee (whose membership includes persons with brain injury, family members, advocates, services providers and state government representatives) developed the waiver program. The waiver is growing more rapidly than other waivers in the state. This growth is attributed to older individuals who have had strokes accessing the waiver in order to get services.

The consumer directed services were developed even before this waiver was implemented. Personal assistants, while hired and fired by the waiver participant, are covered under a collective bargaining agreement, and their wages are set. The rates for certified nursing assistants and nurses can be negotiated up to an established cap. A state operated payroll system is used for these employees.

A comprehensive assessment tool was developed to address all services needs and assist in planning. The waiver was amended to include the TWWIIA eligibility group.

The brain injury waiver is part of a larger program called the Home Service Program (HSP) that also includes the HIV or AIDS program and the persons with disabilities program; both these programs have corresponding waivers. HSP is operated identically to the HCBS Waiver programs, with the exception of the financial eligibility requirements; these are more generous than Medicaid. Approximately 75% of the HSP participants are Medicaid eligible. All applicants for HSP services must also apply for Medicaid. If found eligible for Medicaid, they become part of the waiver. If they do not meet the Medicaid eligibility requirements, they are not included in the waiver, but receive all of the same services.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	955	$7,959,572	$8,335	213	$39
2003	1,641	$15,884,602	$9,680	230	$42
2004	2,404	$25,933,490	$10,788	246	$44
2005	3,085	$36,885,093	$11,956	260	$46
2006	3,601	$42,541,226	$11,814	264	$45
2007	3,619	$41,641,308	$11,506	255	$45

Waiver year is July 1 to June 30

Waiting List: None

Indiana

Waiver Name: Traumatic Brain Injury Waiver

Operated by the Division of Aging, a separate division within the single State agency (Family and Social Services Administration).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: SSI income eligibility countable resources of $1,500 or less.

Level of Care in approved waiver: Nursing facility

No age criteria and have experienced an external insult resulting in a traumatic brain injury. The Area Agency on Aging determines level of care based upon review of an assessment by an independent case manager.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	Y	Attendant Care Homemaker Home Health Aide Residential Based Habilitation
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Special Medical Equipment and Supplies Personal Emergency Response System
Vehicle Repair/Modification	Y	Vehicle Modification
Respite	Y	Respite
Clinical Services	Y	Extended State Plan Services: Physical Therapy Occupational Therapy Speech Therapy
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Modifications
Health Related	Y	Nursing Health Care Coordination

Service Category	Y/N	Specific Service
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Behavior Management
Other	Y	Home Delivered Meals

Background:

Indiana began this Medicaid Waiver in 2000 and has an approved renewal that is effective January 1, 2008. The waiver was developed to increase the state's capacity to provide services to individuals with brain injury and to decrease the number of out of state placements.

The state has authority to serve 200 individuals but is serving far fewer, in large part because there is a lack of providers. In addition, a slot stays with an individual for a full year, so there is no mechanism to add someone to the waiver when a slot is vacated.

There is consideration to changing the income level for eligibility to 300% of SSI, the eligibility level for the state's aged and disabled waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	139	$3,193,875	$22,978	342	$67
2003	170	$3,210,380	$18,885	285	$66
2004	164	$3,751,083	$22,872	326	$70
2005	139	$3,424,024	$24,633	351	$70
2006	131	$3,390,758	$25,884	355	$73

Waiver year is January 1 to December 31

Waiting List: Yes, 173 reported as of November 2007. However, each Area Agency on Aging maintains its own waiting list with inconsistent criteria. Individuals listed on the waiting list may be receiving services through the state's aged and disabled waiver (which has a higher income eligibility threshold), not have been assessed for level of care, or not have had financial eligibility determined.

Iowa

Waiver Name: HCBS Brain Injury Waiver

Operated by the Department of Human Services, which is also the single State agency.

Target Population: Traumatic and Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)
Intermediate Care facility
Skilled Nursing Facility

Must be between the ages one month and 64, have a traumatic or non-traumatic injury to the brain that has occurred since birth and that falls into a specified set of ICD-9 codes. The individual is assessed by a case manager or facility discharge planner who collects information using a state developed tool and forwards it to a nurse reviewer employed by Iowa Foundation for Medical Care (IFMC). The IFMC nurse will confirm the brain injury diagnosis and determine the level of care.

Focus: The goal of the waiver is rehabilitation to the maximum extent possible. An individual must, at a minimum, receive case management services each quarter and use at least one BI waiver service each quarter.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	Although not a waiver service, must be used if participating in the Consumer Choice Option
In-Home Services	Y	Consumer Directed Attendant Care Supported Community Living Family Counseling and Training Interim Medical Monitoring and Treatment Respite Behavioral Programming

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Consumer Directed Attendant Care (in home or community) Note: the Consumer Choice Option is available to participants. It also includes self-directed supported community living and individually directed goods and services.
Equipment/Supplies	Y	Personal Emergency Response System Specialized Medical Equipment
Vehicle Repair/Modification	Y	Home and vehicle Modification
Respite	Y	Respite
Clinical Services	N	Physical therapy, occupational therapy and speech services available as regular State plan services.
Day Support	Y	Adult Day Care Pre-vocational Services
Environmental Accessibility Adaptations	Y	Home and vehicle Modification
Health Related	Y	Interim Medical Monitoring and Treatment - Monitoring and treatment of a medical nature requiring specially trained caregivers beyond what is normally available in a day care setting for persons age 20 and under
Financial Management Services	N	Although not a waiver service, must be used if participating in the Consumer Choice Option.
Supported Employment	Y	Supported Employment
Family and Caregiver Training	Y	Family Counseling and Training
Transportation	Y	Transportation

Service Category	Y/N	Specific Service
Residential	Y	Supported Community Living - one to twenty-four hours of support per day based on the individual's needs. This service is designed to assist the consumer with daily living needs. Assistance may include, but is not limited to: Personal and home skills, community skills, personal needs, and transportation and treatment services. SCL may be provided in the family home, the guardian home or other typical community settings (i.e., houses, apartments, condominiums, townhouses, trailers, etc.) All living arrangements must be integrated into the community. If not the individual's own home, the living unit may include a "waiver home," one to four persons sharing a home and living with staff or a Residential Care Facility, up to 20 persons with 24-hour supports.
Night Supervision	Y	Supported Community Living
Substance Abuse	N	
Behavioral Services	Y	Behavioral Programming (in home or community)

Monthly cost limits: $2,730 (an exception is possible).

Background:

Iowa's waiver was approved and implemented in October 1996 based upon legislation influenced by a strong advocacy group. These advocates were active participants in developing the waiver. Initially, the waiver could serve 150 individuals and this grew gradually over time.

Waiver services are provided to children, and their care plans are required to be coordinated with the child's individual education plan (IEP) and EPSDT (Care For Kids) plan(s).

In 2006, the state started a new, state funded program, offering the same services and using the same providers as the waiver. It is operated by a different department (the Department of Health) than the waiver. Individuals on the waiting list for the waiver, as well as those determined ineligible for Medicaid, are referred to this program.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	473	$3,637,669	$7,691	233	$33
2003	526	$6,354,695	$12,081	299	$40
2004	569	$7,511,880	$13,202	313	$42
2005	662	$8,638,048	$13,048	286	$46
2006	825	$10,883,459	$13,192	296	$45

Waiting List: 35 as of September 2007. It is 'first come, first served" based on date of application. Eligibility is evaluated when admission can be offered.

Kansas

Waiver Name: Traumatic Brain Injury Waiver (formerly known as the Head Injury Waiver).

Operated by the Department of Social and Rehabilitative Services separate agency from the single State agency (Kansas Health Policy Authority).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI or Medically Needy spending down to $716, countable resources of $2,000 or less.

Level of Care in approved waiver: Traumatic Brain Injury Rehabilitation Hospital

Must be between the ages 16 and 64 and have a traumatic injury to the brain. Assessments are conducted by a private "enrolled case management agency" (Center for Independent Living, Home Health Agency) using the state's TBI Uniform Assessment Instrument and the TBI Assessment Addendum.

Focus: Rehabilitation – no limit on the length of time an individual may be enrolled in the waiver if progress is demonstrated.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	Targeted Case Management (a State plan service) is required.
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal Services – may include health maintenance activities when delegated by a physician or nurse. Transitional Living Skills – comprehensive home and community training and support services designed to prevent and/or minimize chronic disabilities while restoring the individual to optimal levels of functioning. This service is required of all waiver participants. Occupational Therapy, Physical Therapy and Speech Language Therapy as extended State plan services Behavioral Therapy Cognitive Therapy Drug and Alcohol Therapy
Person Directed Goods and Services	Y	Personal Services Sleep Cycle Support
Equipment/Supplies	Y	Assistive Services – provides adaptive equipment and assistive technology as well as durable medical equipment. Personal Emergency Response Systems.
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	Y	Occupational Therapy, Physical Therapy and Speech Language Therapy as extended State plan services. (State plan covers six months post injury, and then it becomes a waiver service.) Cognitive Rehabilitation
Day Support	Y	Transitional Living Skills – comprehensive home and community training and support services designed to prevent and/or minimize chronic disabilities while restoring the individual to optimal levels of functioning. This service is required of all waiver participants.
Environmental Accessibility Adaptations	Y	Assistive Services

Service Category	Y/N	Specific Service
Health Related	Y	Oral Health Services not covered through the State plan dental services and limited to $600 per year.
Financial Management Services	N	Consumers partner with Centers for Independent Living and Home Health Agencies as co-employers of the individuals who provide the self-directed service(s). Consumer selects and may fire employee.
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	Y	Sleep Cycle Support
Substance Abuse	Y	Drug and Alcohol Therapy
Behavioral Services	Y	Behavior Therapy

Monthly cost limits: NA aggregate used; there are limits on utilization of each service.

Background:

Kansas began the waiver in 1991 as a Model Waiver; in 2004 it was changed to a regular 1915(c) Waiver and; in 2006, it was amended to: modify service limits, add oral health service, modify provider qualifications, expand the age group served to allow individuals who demonstrate progress in rehabilitation to remain on the waiver and reduce the maximum number served.

There is no limit on the length of time an individual may be enrolled in the waiver. However, progress must be demonstrated in the annual review, and an administrative review is conducted when an individual is in the waiver for four years. All plans of care are reviewed and approved at the program management office for the operating agency.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	156	$3,596,736	$23,056	226	$102
2003	178	$4,835,317	$27,165	279	$97
2004	190	$5,255,859	$27,662	264	$105
2005	240	$5,427,857	$22,616	245	$92
2006	269	$6,289,071	$23,379	242	$97

Waiver year is July 1 to June 30

Waiting List: None at this time. The state has a waiting list policy that is "first come first served" based on the date of assessment. This can be superseded for 1) individuals transferring from the HCBS/PD waiver; 2) those exiting a Kansas Medicaid approved TBI Rehabilitation Facility or state hospital; or 3) those approved by the TBI Program Manager.

Kentucky

Waiver Name: Acquired Brain Injury Waiver Program

Operated by the Department of Medicaid, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 65 and have a post birth acquired brain injury. The following conditions excluded: stroke treatable in a nursing facility providing routine rehabilitation services, spinal cord injury in which there is no known or obvious injury to the intracranial central nervous system, progressive dementia of a chronic degenerative nature (including alcoholism or another addiction), depression or a psychiatric disorder in which there is no known or obvious central nervous system damage, birth defect, mental retardation without an etiology to an acquired brain injury or a condition which causes an individual to pose a level of danger or an aggression which is unable to be managed and treated in a community. Additionally, must have the potential for rehabilitation and reintegration into the community. The determination is made by Kentucky Health Services, the state's QRO.

Focus: Rehabilitative

Waiver Services

Service Category	Y N	Specific Service
Case Management	Y	Case Management
Support Broker	Y	Only for those utilizing the "consumer directed option." It is then required and replaces case management.
In-Home Services	Y	Personal Care Companion Respite
Person Directed Goods and Services	Y	The option includes personal care, residential services and companion.
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	Y	Respite

Service Category	Y/N	Specific Service
Clinical Services	Y	Occupational Therapy Speech and language services Counseling and Training (Physical therapy is a State plan service)
Day Support	Y	Structured Day Program - previously supported employment was a stand alone service; now it is incorporated into Structured Day Program
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	Y	Counseling and Training
Transportation	N	
Residential	Y	Community Residential Services
Night Supervision	N	
Substance Abuse	Y	Counseling and Training
Behavioral Services	Y	Behavioral Programming

Background:

Kentucky began this waiver in 1999 with strong support and significant input from advocates, particularly the state's Brain Injury Association. Originally, the service package did not include residential services. After about two years of waiver operation, the need for these services became apparent, and they were added. As of October 2007, 73% of the waiver participants utilize these services.
The present waiver is considered rehabilitative; the state has recently submitted a similar, but long-term care, waiver for CMS approval. Additional services (physical therapy, nursing and transitional housing), not in the present waiver, would be provided to the individuals served under this new.
In a recent reorganization, the office operating the waiver was moved to the state Medicaid agency.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	104	$2,617,877	$25,172	270	$93
2003	96	$3,841,498	$40,016	259	$154
2004	92	$5,244,346	$57,004	287	$199
2005	98	$6,532,587	$66,659	285	$234
2006			Data not available		

Waiver year is January 1 to December 31

Waiting List: Over 100 individuals are on a first come first served waiting list. The state has a review panel and a process to allow individuals with urgent needs to be prioritized on the waiting list

Maryland

Waiver Name: Waiver for Adults with Traumatic Brain Injury

Operated by the Mental Hygiene Administration, a separate agency within the single State agency (Department of Health/Mental Hygiene).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Chronic Hospital
Nursing Facility

Individuals with a traumatic brain injury that occurred after the age of 21 and who are inpatients in State Mental Hygiene Administration facility, inpatients in a state owned and operated nursing facility, or individuals who have been placed by Medicaid in an out-of state facility.
Information is provided by medical staff at the facility and reviewed by a nurse at the state's utilization control unit.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	..Specific Service
Case Management	Y	Case management
Support Broker	N	
In-Home Services	Y	Individual Support Services
Person Directed Goods and Services	N	
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	Y	Day habilitation
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	N	
Transportation	N	

Service Category	Y/N	Specific Service
Residential	Y	Residential habilitation – all Waiver participants receive this service as of October 2007.
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Background:

Maryland began this waiver in 2003; it was designed to provide community-based residential services to individuals who require extensive supports and were living in institutional settings.

It initially was restricted to residents of state operated facilities with the expanding to other settings, including out of state neuro-behavioral facilities, at renewal.
Individual support services were added as a "step down" from residential habilitation; it is designed for individuals who reside in their own home or with family. As of October 2007, this service has not been used.

The waiver was initially approved for 10 individuals, growing at 10 additional per year for the initial waiver; it was renewed for 30.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2004	5	$196,272	$39,254	106	$370
2005	12	$1,033,886	$86,159	296	$219
2006	23	$1,489,321	$64,753	255	$254

The difference in the annual per capita cost between 2005 and 2006 can be explained by the significantly different costs between the two levels of care and the small number of individuals in the much more expensive chronic hospital level of care.

Waiver Year	# served	Expenditures	Annual per capita cost
2005	CH – 2	$280,691	$140,346
	NF – 12	$793,195	$79,320
2006	CH – 3	$281,487	$93,829
	NF – 20	$1,207,835	$60,392

Waiver year is July 1 to June 30

Waiting List: As of October 2007, this waiver is closed to enrollments and there is a waiting list of eight.

Massachusetts

Waiver Name: Traumatic Brain Injury Home and Community-Based Services Waiver

Operated by the Brain Injury and Special Community Services Department, Mass Rehabilitation Commission, a separate organization within the same Secretariat as the single State agency.

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income at or below 100% of federal poverty level, countable resources of $2,000 or less.

Level of Care in approved waiver: Specialized Nursing facility

Be between the ages 21 and 62 and have a traumatic or non-traumatic injury to the brain that has occurred since birth. MDS Homecare and supplemental information are completed by Case Manager, and a neuron-psychologist on staff makes the determination of eligibility.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	Y	Personal Care Assistance Chore Service Homemaker Service Companion Services
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized Medical Equipment
Vehicle Repair/Modification	N	
Respite	Y	Respite Care
Clinical Services	Y	Occupational Therapy Physical Therapy Speech and Language Services
Day Support	Y	Day Services
Environmental Accessibility Adaptations	Y	Environmental Adaptation
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment

Family and Caregiver Training	Y	Family Training

Service Category	Y/N	Specific Service
Transportation	Y	Non-medical Transportation
Residential	Y	Residential Habilitation – approximately half of the individuals in the waiver receive this service.
Night Supervision	N	
Substance Abuse	Y	Substance Abuse Services
Behavioral Services	N	
Other	Y	Interpreter Services

Monthly Cost Limits: NA aggregate used.

Background:

Massachusetts began this waiver in 2001 after many years of negotiation with CMS. The state views this waiver as a revenue maximization effort coordinated with its large, state funded program. The waiver is authorized to provide services for approximately 100 individuals and is a mirror of the state funded program that provides services to approximately 1200 individuals.

Initially, the waiver was authorized to serve 200 individuals and provided therapeutic recreation. When the waiver was renewed, the number of persons served was decreased and therapeutic recreation service was discontinued.

As of November 2007, the state is negotiating with CMS for an 1115 Waiver that will subsume this waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	28	$1,043,710	$37,275	240	$240
2003	32	$1,304,919	$40,779	189	$216
2004	33	$1,107,087	$33,548	118	$284
2005	88	$5,042,421	$57,300	304	$188
2006	90	$4,883,813	$54,265	315	$172

Waiver year is July 1 to June 30

Waiting List: None at this time.

Minnesota

Waiver Name: Traumatic Brain Injury Waiver

Operated by the Disability Service Division, a separate division within the single State agency (Department of Human Services).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: Income up to 100% of federal poverty or medically needy with spend down to 75% of federal poverty, resources up to $3,000.

Level of Care in approved waiver: Nursing Facility
Neurobehavioral Hospital

Be under 65 years of age at the time of application to the waiver and have a documented diagnosis of traumatic or acquired brain injury or degenerative disease diagnosis where cognitive impairment is present, provided the diagnosis is not congenital. An individual who turns 65 while on this waiver may choose to remain in this waiver or transfer to the state's aged waiver.

A county based Long-Term Care Consultant meets with the applicant and conducts an assessment using the state's standardized assessment tool. The individual must also experience significant/severe behavioral and cognitive problems related to the injury or disease and be assessed at Level IV or above on the Rancho Los Amigos Levels of Cognitive Functioning Scale.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Adult Companion Service Chore services Extended Home Care Services – home health aide, personal care aide, private duty nursing and therapies (physical, occupational, speech language/pathology and respiratory) beyond what is provided by the State plan. Homemaker Independent Living Skills Respite
Person Directed Goods and Services	Y	Consumer Directed Community Supports - includes both goods and services
Equipment/Supplies	Y	Specialized Supplies and Equipment – including durable medical equipment not provided or denied by the State plan
Vehicle Repair/Modification	Y	Modifications and Adaptations
Respite	Y	Respite
Clinical Services	Y	Cognitive Remediation Training - Services and interventions specifically designed to improve cognitive functions, including: Attention and concentration, information processing skills, learning and memory, planning, problem solving, executive functions (processes by which a person plans, prioritizes, organizes, sets goals, executes strategies and monitors personal behavior), self-control and Visual-spatial deficits
Day Support	Y	Adult Day Care Adult Day Care Bath Pre-vocational Services Structured Day Program – that includes physical, occupation, speech language and cognitive therapies if required in the care plan

Service Category	Y/N	Specific Service
Environmental Accessibility Adaptations	Y	Modifications and Adaptations
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	Y	Family Training, Education and Counseling
Transportation	Y	Transportation
Residential	Y	Assisted Living Assisted Living Plus - includes 24-hour on-site supervision in addition to services provided by home care aides, home health aides or residential staff. Foster Care Residential Care Services - supportive and health supervision services provided in a licensed residential setting
Night Supervision	Y	Night Supervision Services
Substance Abuse	N	
Behavioral Services	Y	Behavioral Programming
Other	Y	Independent Living Skills Therapies – specifically art, music and recreation therapies Home Delivered Meals Mental Health Mental Health Psychological Testing Transitional Services – needed to relocate from an institution or licensed setting to the individuals own home

Monthly cost limits do not apply as the waiver is managed in aggregate.

Background:

Minnesota began this waiver in 1992; in 1995, the waiver was amended to remove the "Model" status. Advocacy groups, particularly the state's brain injury association, were instrumental in obtaining legislative approval for the waiver. Initially, the waiver provided for only nursing facility level of care with an amendment to permit neurobehavioral hospital level of care approved in 1993. In addition, eligibility criteria were changed substantially in 1993, expanding waiver coverage to include individuals with acquired as well as traumatic brain injuries that are not caused by a congenital

condition. In 2003, the waiver was amended to manage funding in aggregate rather than by individual.

The state lead agency for brain injury services, the Department of Human Services, formed an ad hoc Advisory Committee to facilitate communications and coordination of policy and service development. There is also a TBI Interagency Leadership Council that works through a formal Interagency Cooperative Agreement between the departments of: Human Services, Economic Development, Health, and Corrections as well as, the Brain Injury Association, the Minneapolis Veterans Affairs Medical Center and the state Disability Law Center. The state anticipates that the Mayo Clinic will join in 2008. The formal purpose of this interagency group is "To coordinate, support, evaluate and improve the effective and efficient provision of services for Minnesotan's with brain injury. Neither of these groups has direct, formal decision-making powers concerning the waiver; they do have great influence.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	574	$22,376,846	$38,984	307	$127
2003	895	$33,964,408	$37,949	274	$139
2004	1196	$49,599,230	$41,471	308	$135
2005	1311	$60,575,581	$46,206	315	$147
2006	1372	$68,965,299	$50,266	320	$157

Note: there are two levels of care in the waiver. For the most recent year, approximately 25% of the individuals were neurobehavioral hospital level of care and accounted for approximately half of the expenditures.

Waiver year is April 1 to March 31

Waiting List: No.

Nebraska

Waiver Name: Traumatic Brain Injury Waiver

Operated by the Department of Health and Human Services, Medicaid & Long-Term Care Division, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 100% of federal poverty level, resources of $4,000 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 64 and have a traumatic brain injury. A functional assessment tool is utilized by a service coordinator to gather information about activities of daily living, risk (physical such as falls and behavioral) and cognition that are needed to determine the level of care.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	N	
Person Directed Goods and Services	N	
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	N	
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	N	

Transportation	N
Residential	N

Service Category	Y/N	Specific Service
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	
Other	Y	Specialized Assisted Living – With service components of: adult day care, escort services, essential shopping, health maintenance activities, housekeeping activities, laundry services, meal service, medication assistance, personal care services, transportation services, behavioral services.

Monthly Service cost cap: NA as aggregate used.

Background:

Nebraska developed this waiver in 2000 to transition individuals from acute rehabilitation setting. In addition to the service components noted above, there is a community focus for supported employment and volunteer activities. There is one provider of waiver service.

A Quality Council, begun through a Quality Assurance/Quality Improvement grant from CMS, is in place and acts in an advisory capacity for all the state's HCBS Waivers.

The state was approved to serve 40 individuals and has consistently served about 20 to 25. There are a limited number of discharges and enrollments; a few individuals have transitioned into more independent settings.

Individuals with brain injury are one of the groups targeted in the state's Money Follows the Person grant. It is anticipated that this will lead to an increase in the number of persons served and an expansion of services. The state's aged and disabled waiver provides services to many individuals with acquired brain injury.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	22	$682,455	$31,021	358	$87
2003	24	$705,374	$29,391	332	$89
2004	25	$772,133	$30,885	335	$92
2005	25	$840,975	$33,639	356	$94
2006	26	$733,247	$28,202	335	$84

Waiver year is May 1 to April 30

Waiting List: No

New Hampshire

Waiver Name: Acquired Brain Disorder Waiver

Operated by The Bureau of Developmental Services, an agency within the single State Medicaid agency (Department of Health and Human Services).

Target Population: Acquired Brain Disorder

Eligibility:

Financial eligibility:

Level of Care in approved waiver: Skilled Nursing Facility (a specialized facility).

Must be over 22 years of age and have an Acquired Brain Disorder, this includes individuals with degenerative conditions such as Multiple Sclerosis and Huntington's disease. In order to be eligible, the brain disorder must be acquired between the ages of 22 and 60; the age of the person at the time of application is not considered. If an individual is over 60 and has had more than one incident, the incident that led to the level of care being met must have occurred prior to 60. An individual who acquired a brain disorder prior to age 22 may be eligible for this waiver if he/she is ineligible for the state's developmental disability waiver.
The level of care determination is a two-step process. Staff of an Area Agency, the state contracts with 10 agencies in distinct areas, conducts an assessment to determine whether the individual has an acquired brain disorder and obtain other pertinent information. If the individual has an acquired brain disorder, then the information is sent to the Bureau of Development Services where an eligibility committee meets to determine whether the individual meets the level of care criteria.

Focus: Long-Term Care –

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Service Coordination
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal Care Services Community Support Services – services provided to individuals who have skills to live independently in the community if provided continuous availability of, and access to, services and supports, to assure that needs are met. Community support services include assistance in areas such as: daily living skills, money management, shopping skills, food preparation, laundry, household maintenance, use of community resources, community safety, and social skills. This service may begin while the individual is still residing with his/her family. Crisis Response Services - may also include training to staff related to the needs of the individual, and or emergency back-up staff for the direct support of the individual in crisis.
Person Directed Goods and Services	Y	Consolidated Acquired Brain Disorder Services – provides participants with full freedom and control in choosing provider(s) for each aspect of their services.
Equipment/Supplies	Y	Assistive Technology Support Services
Vehicle Repair/Modification	Y	Environmental Modification Services
Respite	Y	Respite Services
Clinical Services	Y	Specialty Services - services intended for participants whose medical, behavioral, therapeutic, health and personal well being require services which are specialized pertaining to unique conditions and aspects of acquired brain disorders Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.
Day Support	Y	Day Services
Environmental Accessibility Adaptations	Y	Environmental Modification Services

Service Category	Y/N	Specific Service
Health Related	Y	Specialty Services - services intended for participants whose medical, behavioral, therapeutic, health and personal well being require services which are specialized pertaining to unique conditions and aspects of acquired brain disorders Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.
Financial Management Services	Y	Included as a part of Consolidated Acquired Brain Disorder Services.
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	N	
Transportation	N	
Residential	N	Personal Care Services - may be provided to an individual residing in a setting that is not independent in the community, such as a group home or in Enhanced Family Care (adult foster care).
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.

Monthly cost limits: None, as the waiver is managed in the aggregate.

Background:

New Hampshire began this waiver in 1992 because of efforts by families and advocacy groups to return individuals placed in out-of-state facilities to the state. The waiver has grown substantially over time. The waiver is unique because individuals with neuro-degenerative disorders may be enrolled in the waiver if they meet the other eligibility criteria.

The state has a Brain and Spinal Cord Injury Council that provides advice on service needs and related matters. While not dedicated to this waiver, they may advise on issues related to the waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	103	$7,386,833	$71,717	304	$236
2003	109	$8,965,150	$82,249	342	$240
2004	119	$9,784,562	$82,223	332	$248
2005	129	$10,283,470	$79,717	nr	na
2006	140	$11,487,626	$82,054	332	$247

Waiver year is November 1 through October 31.

Waiting List: Yes, 16 as of December 2007. In order to be placed on the waiting list the individual must meet the level of care criteria. Medicaid eligibility determination need not be finalized if it is clear that financial eligibility criteria are met.

New Jersey

Waiver Name: HCBS Waiver for Persons with Acquired Traumatic Brain Injuries

Operated by the Division of Disability Services (DDS), an agency within the single State Medicaid agency, the Department of Human Services.

Target Population: Brain Injury – "acquired traumatic"

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing facility

Be between the ages 21 and 65 for enrollment; individuals already enrolled may remain in the waiver after reaching 65. Additionally, professional staff of the DDS verifies that a traumatic or acquired brain injury occurred with an age of onset of 21 or older and meet in person with the applicant.
In addition to the routine NF level of care determination, the Rancho Los Amigos Levels of Cognitive Functioning Scale is administered with a minimum score of 4 being required.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management – acceptance of case management is required of all enrollees.
Support Broker	N	
In-Home Services	Y	Personal Care Assistant Chore Services Companion Services
Person Directed Goods and Services	N	Personal assistant services (PAS) may be consumer directed
Equipment/Supplies	N	
Vehicle Repair/Modification	Y	Environmental Modification
Respite	Y	Respite Care – in home and out of home (not available to individuals residing in a community residential service setting).

Service Category	Y/N	Specific Service
Clinical Services	Y	Therapy services which include: physical and occupational therapy, speech-language pathology Cognitive Therapy services. Counseling services
Day Support	Y	Structured day program - Supported day program - independent activities (in-home or out of home) requiring initial and periodic support from a professional to sustain the program; it is a step-down alternative to structured day program.
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	Available if using PAS
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	Y	Transportation – to access services in the individual plan; in addition to, but not replacing, State plan service; family members are not reimbursed
Residential	Y	Community residential services (CRS) is a package of services provided to a beneficiary living in a community residence owned, rented or supervised by a licensed community residential services provider and includes personal care, companion services, chore services, transportation, night supervision and therapeutic activities. Approximately 2/3's of the waiver participants reside in these settings.
Night Supervision	Y	Night Supervision services (not available to individuals receiving CRS)
Substance Abuse	Y	Counseling services (indicated in "clinical services") specifically include substance abuse counseling.

Service Category	Y/N	Specific Service
Behavioral Services	Y	Behavioral program services - a daily program provided by and under the supervision of a licensed psychologist and by aides (specialists) trained by a licensed psychologist; designed to serve individuals who display severe maladaptive or aggressive behavior; provided in or out of the home; time limited and designed to treat the individual and caregivers, if appropriate.

Monthly cost limits are $8,178 for individuals receiving day services and living in the community and $10,032 for persons placed in CRS settings.

Background:

New Jersey began this waiver in 1993 as a way to return individuals with brain injury to New Jersey from expensive out of state placements. It initially was approved to serve 150 individuals and is now approved to serve 350. Age of onset of the brain injury was changed from 16 to 21.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	236	$13,563,248	$57,471	330	$174
2003	231	$14,577,348	$63,105	343	$184
2004	232	$14,626,416	$63,045	343	$184
2005	264	$17,378,970	$65,829	334	$197
2006	276	$18,374,797	$66,575	329	$202

Waiver year is July 1 to June 30

Waiting List: In October 2007, 44 individuals were on the "referral list" of individuals waiting for enrollment. A referral form, which can be submitted by anyone, is used to apply for the waiver. Upon receipt of this form, professional staff of DDS reviews medical and other pertinent records, meet with the individual to explain the waiver and assess the likelihood of eligibility and appropriateness for the waiver. Arrangements are also made for one or more providers to meet with the individual to determine whether there is a willing, appropriate provider. Then, when a vacancy occurs, the next appropriate person on the "referral list" is offered waiver enrollment.

New York

Waiver Name: Adult HCBS Medicaid Waiver for Individuals with Traumatic Brain Injury

Operated by the single State agency (Department of Health).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 100% of federal poverty level or medically needy and spend down to this level with countable resources of $4,200 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 64 and have a brain injury. Have a diagnosis of traumatic brain injury; individuals who experience deficits similar to a traumatic brain injury because of anoxia, toxic poisoning, stroke or other neurological conditions may also be eligible. Individuals with gestational or birth difficulties such as cerebral palsy or autism or who have a degenerative disease are not eligible for the waiver. Be assessed by a nurse or licensed social worker using the state's Hospital and Community Patient Review Instrument and SCREEN tool as needing nursing facility level of care.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Service Coordination is a required service
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Independent Living Skills Training and Development Services – not intended as a long-term support. Services may include assessment, training, and supervision of, or assistance to, an individual with issues related to self-care, medication management, task completion, communication skills, interpersonal skills, socialization, sensory/motor skills, mobility, community transportation skills, reduction/elimination of maladaptive behaviors, problem solving skills, money management, pre-vocational skills and skills to maintain a household. Respite Community Integration Counseling Service – as described below. Home and Community Support Services - individually designed support services essential for the participant's health and welfare. These services include cueing, prompting and supervision with activities of daily living (ADLs) and Independent Activities of Daily Living (IADLs) as well as supporting integration into the community. It is not intended as a "hands-on" service and cannot assist with the administration of medication, dress open wounds, assist with tube feedings, or perform any other activities that are within the scope of practice of a nurse, PCS or HHA under any circumstance.
Person Directed Goods and Services	N	Available for State plan services of personal care assistance, home health and nursing.
Equipment/Supplies	Y	Assistive Technology Services
Vehicle Repair/Modification	Y	Environmental Modifications Service
Respite	Y	Respite

Service Category	Y/N	Specific Service
Clinical Services	Y	Community Integration Counseling Service - a counseling service provided to a participant coping with altered abilities and skills, the need to revise long term expectations, and changed roles in relation to significant others. It is available to participants and/or anyone involved in an ongoing significant relationship with the participant when the issues to be discussed relate directly to the participant.
Day Support	Y	Structured Day Program Services
Environmental Accessibility Adaptations	Y	Environmental Modifications Service
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	An element of an Intensive Behavioral Program as described below Community Integration Counseling Service as described above
Transportation	Y	Waiver Transportation
Residential	N	
Night Supervision	N	
Substance Abuse	Y	Substance Abuse Program Services
Behavioral Services	Y	Intensive Behavioral Program - include but are not limited to: comprehensive assessment of the individual's behavior, a detailed behavioral treatment plan, arrangements for training informal supports and waiver and non-waiver service providers to effectively use the basic principles of the behavioral plan, regular reassessments of the plan and modifying the plan as needed, and an emergency intervention plan when there is the possibility of the participant becoming a threat to himself, herself or others.

Service Category	Y/N	Specific Service
Other	Y	Community Transitional Services - funding for the reasonable costs of one-time set-up expenses for individuals transitioning from a nursing home to their own home or apartment in the community.

Monthly cost limits are not applicable as the waiver is managed in aggregate.

Background:

New York began this waiver in 1995. The State Department of Health administers the waiver through the Regional Resource Development Centers and Specialists who serve specific counties throughout the State.

Initially, the age of onset of the brain injury was 18; this requirement has been eliminated. Individuals have to be no more than 64 years old to apply for the waiver; they may remain enrolled in the waiver after turning 65.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	972	$41,350,022	$42,541	335	$127
2003	1157	$49,434,784	$42,727	314	$136
2004	1446	$61,124,741	$42,272	320	$132
2005	1684	$76,654,494	$45,519	326	$140
2006	1953	$79,029,120	$40,465	310	$131

Waiver year is April 1 to March 31

Waiting List: None statewide at this time, but in the Metropolitan New York City area there is one due to a shortage of providers.

North Dakota

Waiver Name: Traumatic Brain Injury

North Dakota no longer has a brain injury waiver; in 2006, it was merged with the state's aged and disabled waiver at the urging of CMS. The information that follows reflects the operation of the waiver up until its expiration.

Operated by the Developmental Disabilities Division, a separate division within the single State agency (Department of Health).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income, SSI eligible and countable resources of $3,000 or less.

Level of Care in approved waiver: Nursing Facility

Individuals over 18 and determined disabled according to Social Security criteria.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	N	
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Emergency Response
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	N	
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	N	
Residential	Y	Residential Care
Night Supervision	N	
Substance Abuse	N	

Behavioral Services	N	
Other	Y	Transitional living

Background:

North Dakota began this waiver in 1994; in 2006 it was merged with the state's aged and disabled waiver at the urging of CMS. Residential Care was the primary service used in this waiver; only one or two individuals used emergency response or transitional living.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	31	$781,645	$25,214	296	31
2003	30	$817,096	$27,237	330	30
2004	31	$841,110	$27,133	326	31
2005	29	$826,438	$28,498	337	29
2006	29	$797,371	$27,496	315	29

Waiver year is July 1 to June 30

Waiting List: NA

Pennsylvania

Waiver Name: COMMCARE – Community Care

Operated by the Office of Long-Term Care, a separate office within the single State agency (Department of Public Welfare).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less after a $6,000 disregard.

Level of Care in approved waiver: Specialized Rehabilitation Nursing Facility. This is a facility where more than 70 percent of the residents have a neurological-muscular diagnosis and severe functional limitations.

Determining level of care is a two-step process for this waiver. First, as is routine for all long-term care applicants, the Area Agency on Aging determines eligibility for nursing facility level of care for individuals 21 years of age and older using the state's Options Assessment Tool. Then, if the applicant demonstrates a medically determinable diagnosis of traumatic brain injury not of a degenerative, congenital or post-operative nature, the specialized facility assessment is conducted. This second step assessment determines whether the applicant will require overall management of a service plan designed specifically to meet the needs of individuals with traumatic brain injury involving technical and professional personnel to meet the needs of the individual to promote recovery.

Focus: Long-Term Care, although residential services in group homes are considered short term to lead to an individual moving to another setting.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Service coordination
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal care services Chore services Habilitation and support services - up to a full day of services and/or supports designed to ensure the health and welfare of the individual, and to assist in the acquisition, retention and/or improvement in skills necessary to support individuals to live successfully in their homes. Expressly included is the provision of personal care services as well as chore type services and household maintenance Coaching/Cueing Services (Behavioral Therapy Coach) are provided to consumers needing minimal or no "hands on" assistance. Provides prompting and cueing to carry out the routines and tasks of daily living. Coaching/cueing can be provided in or out of the home
Person Directed Goods and Services	Y	Personal Care Services Coaching/Cueing Services (Behavioral Therapy Coach) Night Supervision Respite Care
Equipment/Supplies	Y	Assistive technology/specialized medical equipment and supplies. Personal Emergency Response Systems.
Vehicle Repair/Modification	Y	Environmental modifications
Respite	Y	Respite Care –
Clinical Services	Y	Cognitive Therapy Counseling services Extended State plan services to include: Physical Therapy Occupational Therapy Speech Therapy

Service Category	Y/N	Specific Service
Day Support	Y	Pre-vocational services Structured Day Program: services may include social skills training, sensory/motor development, and reduction/elimination of maladaptive behavior, and preparation for community reintegration (teaching concepts such as compliance, attending to a task, task completion, problem solving, safety, money management, etc.). Cognitive rehabilitation therapy will also be provided as part of the structured day program if needed.
Environmental Accessibility Adaptations	Y	Environmental modifications
Health Related	Y	Extended State plan services: Part time nursing
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Cognitive Retraining Services Dietician Services Counseling services
Transportation	Y	Non-medical transportation
Residential	Y	Habilitation and support services as described above may be offered in a licensed or certified setting, group homes with less than six residents.
Night Supervision	Y	Night supervision services Habilitation and support services may be provided around the clock.
Substance Abuse	N	
Behavioral Services	Y	Coaching/Cueing Services (Behavioral Therapy Coach) are provided to consumers needing minimal or no "hands on" assistance. Provides prompting and cueing to carry out the routines and tasks of daily living. Coaching/cueing can be provided in or out of the home Behavioral Specialist Consultant

Service Category	Y/N	Specific Service
Other	Y	Educational services Community transition services limited to $4,000 per person. Community Integration Services and related training enable the consumer to plan for and engage in meaningful adult activities including domestic and leisure activities. Community integration can include cues, on-site modeling of behavior, and/or supervision to assist the consumer in maintaining maximum independent functioning. Community integration is limited to: money management, interpersonal communication, development of relationships, development of decision-making skills, civil rights and protections, and volunteer work.

Background:

Pennsylvania began this waiver in 2002, and the service package has remained stable. The unduplicated number of persons served in the waiver year ending 2007 was 324.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2003	14	$545,038	$38,931	124	$314
2004	68	$2,542,810	$37,394	219	$171
2005	152	$6,897,762	$45,380	285	$159
2006	324		Data not available		

Waiver year is July 1 to June 30.

Waiting List: None at this time. Some advocates may refer to the "pending application list," a list maintained to track individuals going through the application process, as a waiting list. As of October 2007, all eligible individuals have been enrolled.

South Carolina

Waiver Name: Head and Spinal Cord Injury (HASCI) Waiver Services

Operated by the Department of Disabilities and Special Needs (DDSN), Head and Spinal Cord Injury (HASCI) Division. The single State agency is the Department of Health and Human Services.

Target Population: Traumatic Brain Injury and/or Spinal Cord Injuries (Acquired brain injuries are effectively included as "similar disabilities" which are included by law.)

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing Facility
Intermediate care facility for mentally retarded persons (ICFs/MR)

Be between the ages 0 and 65, have a medically documented injury to the brain that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder; it does not include brain injuries that are congenital or brain injuries induced by birth trauma. "Similar disabilities" are included; however they are not defined except that: there is no limit by early age of onset, it is not progressive or degenerative, it is not dementia resulting from chronic disease or alcohol/drug use and it is not a neurological disorder related to aging.
A service coordinator conducts a functional assessment to determine level of care. The assessment focuses on functional/ADL deficits and the need for skilled nursing service(s); this results in it being weighted towards individuals with spinal cord injuries and therefore approving fewer individuals with brain injuries.

Focus: Long-Term Care.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	
Support Broker	N	
In-Home Services	Y	Attendant care
		Private Duty Nursing
		Behavior Support
		Non-institutional Respite Care
		Residential Habilitation

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Personal care Assistant Attendant care Health Education for Consumer Directed Care Peer Guidance for Consumer Directed Care
Equipment/Supplies	Y	Specialized Equipment Specialized Supplies Personal Emergency Response System
Vehicle Repair/Modification	Y	Private Vehicle Modification
Respite	Y	Institutional Respite Care Non-institutional Respite Care
Clinical Services	Y	Psychological Services Speech Therapy Physical Therapy Occupational Therapy Audiological services (Extended beyond age 21, the limits of State plan services)
Day Support	Y	Day Habilitation Pre-vocational Habilitation
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	Y	Private Duty Nursing Health Education for Consumer Directed Care
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Behavior Support
Other	Y	Prescribed drugs – State plan limits beneficiaries to 4 prescriptions, waiver participants are allowed up to seven prescriptions.

Background:

South Carolina began this waiver in 1995; with the exception of adding consumer directed services, it has remained relatively consistent.

Estimates are that 5-10% of participants have had a brain injury, 60-70% have had a spinal cord injury and 20-25% have had injury to both brain and spinal cord.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	478	$9,847,528	$20,602	326	$63
2003	478	$11,181,049	$23,391	343	$68
2004	489	$10,741,579	$21,966	341	$64
2005	489	$12,146,034	$24,839	346	$72
2006	497	$12,247,128	$24,642	338	$73

Waiver year is July 1 to June 30

Waiting List: 218 individuals are on the waiting list as of October 2007. The waiting list has two categories, urgent and routine. 25 individuals are classified as urgent, and waits are typically three to four months. Individuals may be reassessed and reclassified.

Utah

Waiver Name: HCBS Section 1915(c) Acquired Brain Injury Waiver

Operated by the Department of Human Services, Division of Services for People with Disabilities (DSPD), a separate agency of the State,

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI and medically needy spending down to 100% of federal Poverty Level. Countable resources of $2,000 or less.

Level of Care in approved waiver: Nursing Facility

Be 18 or older and have an acquired brain injury that occurred after birth and be assessed as meeting the level of care by a Division of Services for People with Disabilities' ABI support coordinator. Oversight of the level of care determination process is the responsibility of the single State agency. The State Medicaid Agency retains authority to review level of care determinations made by the Division of Services for People with Disabilities and to make necessary modifications to the determinations.
A specialized form and assessment are used by the ABI Support Coordinators for the waiver's level of care determination; the assessment is scored and eligibility is determined by the score falling within a specific range.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	ABI Support Coordination
Support Broker	N	
In-Home Services	Y	Chore Services
		Community Living Supports
		Companion Services (if not receiving Community Living Supports)
		Family Assistance and Supports
		Homemaker Services
		Respite Care Services (Unskilled)

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Chore Services Community Living Supports Family Assistance and Supports Homemaker Services Respite Care Services (Unskilled)
Equipment/Supplies	Y	Personal Emergency Response System Specialized Medical Equipment and Supplies (includes both purchase and ongoing service fee)
Vehicle Repair/Modification	N	
Respite	Y	Respite Care Services (Unskilled)
Clinical Services	N	
Day Support	Y	Day Habilitation (Structured Day Program)
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services		See note
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	Y	Family Assistance and Supports
Transportation	Y	Transportation Services (Non-medical)
Residential	Y	Community Living Supports (provided in a congregate setting or "host home")
Night Supervision	Y	Community Living Supports
Substance Abuse	N	
Behavioral Services	N	

Note: The self-directed employee model requires the enrollee to use a Waiver Personal Services Agent as an integral component of the waiver service to assist with managing the employer-related financial responsibilities associated with the self-directed employee model. The Waiver Personal Services Agent is a person or organization that assists waiver enrollees and their representatives, when appropriate, in performing a number of employer-related tasks, without being considered the common law employer of the enrollees' service workers. Tasks performed by the Waiver Personal Services Agent include documenting service workers' qualifications, collecting service worker time records, preparing payroll for enrollees' service workers, and withholding, filing and depositing federal, state, and local employment taxes.

Enrollee-employed service workers complete a time sheet for work performed. The enrollee confirms the accuracy of the time sheet, signs it, and forwards it to the Waiver Personal Services Agent for processing. The Waiver Personal Services Agent files a claim for reimbursement through the Medicaid MMIS system and

upon receipt of payment completes the employer-related responsibilities, deducts the established administrative fee, and forwards payment directly to the service worker for the services documented on the time sheet.

Background:

Utah began this waiver in 1995 as a traumatic brain injury waiver. In 2004 it was changed to provide services to individuals with acquired brain injury. The number of individuals served grew gradually over time.

An amendment to unbundled services is pending. In addition to unbundling services, a new service, "behavioral consultation" is being proposed.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	85	$1,813,437	$21,335	292	$73
2003	83	$2,192,061	$26,410	336	$79
2004	78	$2,393,342	$30,684	346	$89
2005	101	$1,980,338	$19,607	291	$67
2006	91	$2,079,141	$22,848	333	$69

Waiver year is July 1 to June 30

Waiting List: Yes, 93 individuals. A standardized statewide assessment is used to prioritize individuals' placement on the waiting list. An individual may request a reassessment if needs change.

Vermont

Vermont no longer has a separate brain injury waiver. It was discontinued in 2006 when services to individuals with traumatic brain injury were included in the state's consolidated waiver. The information that follows reflects the operation of the waiver up until the consolidation.

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Specialized Nursing Facility (out of state)

Be age 16 or older and have a recent traumatic injury to the brain that is not degenerative and that may include stroke. The individual must have the potential to benefit from rehabilitation and demonstrate benefit from the program in which he participates at the time of referral. Additionally, the individual must agree to participate in a substance abuse treatment program if there is a history of such abuse.

Focus: Primarily rehabilitation with a long-term care option.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	Y	Respite Community Supports
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Environmental and Assistive Technology
Vehicle Repair/Modification	N	
Respite	Y	Respite
Clinical Services	Y	Habilitation Services
Day Support	Y	Crisis Supports
Environmental Accessibility Adaptations	Y	Environmental and Assistive Technology
Health Related	N	
Financial Management Services	N	

Supported Employment	Y	Employment Supports
Family and Caregiver Training	N	

Service Category	Y/N	Specific Service
Transportation	N	
Residential	N	
Night Supervision	Y	Community Supports
Substance Abuse	N	
Behavioral Services	Y	Crisis Supports

Monthly cost limits

Background:

Vermont's separate brain injury waiver, which began in 1994, was discontinued in 2006 when services to individuals with traumatic brain injury were included in the state's Global Commitment to Health 1115 Waiver.

Vermont began the waiver in 1994 in order to be able to provide in-state services to its residents who experienced a traumatic brain injury. There were no specialized nursing facilities in Vermont: all individuals were sent out of state. Recently, the number of Vermonters sent out of state has been one per year. As noted above the separate 1915(c) waiver was ended and combined into the state's 1115 Waiver.

The waiver had a very strong rehabilitation focus but not all individuals initially enrolled made the progress needed to be successfully discharged from the waiver. Accordingly, there was a long-term services option for these individuals.

Advocates were very involved in the waiver development and ongoing operation.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	47	$2,168,528	$46,139	271	$170
2003	48	$2,401,808	$50,038	294	$170
2004	51	$2,739,681	$53,719	309	$174
2005	59	$2,566,906	$43,507	No data	
2006	68		$5,500/month	No data	

Waiver year is October 1 to September 30

Wisconsin

Waiver Name: Adult Brain Injury Waiver

Operated by the Division of Long-Term Care, Developmental Disabilities Services Section, a separate division within the single State agency (Department of Health and Family Services)

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI and countable resources of $2,000 or less.

Level of Care in approved waiver: inpatient traumatic brain injury rehabilitation

Be any age and have brain injury, occurring at any age, whether mechanical or infectious, the result of which constitutes a substantial impairment to the individual and is expected to continue indefinitely. Brain injury includes any injury to the brain that is vascular in origin that is sustained by the person prior to attaining age twenty-two. Brain injury does not include alcoholism, Alzheimer's disease or a like irreversible dementia.

A nurse determines level of care based upon review of a functional assessment conducted by a case manager as well as a review of the individual's care plan.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Support and Service Coordination
Support Broker	N	
In-Home Services	Y	Supportive Home Care - support and supervision and household services in the home Daily Living Skills Training Skilled Nursing Services; when not covered by the State plan Respite Care
Person Directed Goods and Services	Y	Consumer-Directed Supports

Service Category	Y/N	Specific Service
Equipment/Supplies	Y	Specialized Medical and Therapeutic Supplies when not covered by the State plan Communication Aids Adaptive Aids Personal Emergency Response Systems
Vehicle Repair/Modification	Y	Adaptive Aids
Respite	Y	Respite Care
Clinical Services	Y	Counseling and Therapeutic Services
Day Support	Y	Adult Day Services Children's Day Services Adult Day Care – for older adults Pre-Vocational Services
Environmental Accessibility Adaptations	Y	Home Modifications
Health Related	Y	Skilled Nursing Services when not covered by the State plan
Financial Management Services	Y	Financial Management/Fiscal Intermediary Services
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	Y	Specialized Transportation
Residential	Y	Residential Support Services - support and supervision in the following settings: Adult Family Home (County certified or state licensed), Children's Foster Homes, (including treatment Foster Homes), and Community-Based Residential Facilities of 5-8 residents
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Service Category	Y/N	Specific Service
Other	Y	Daily Living Skills Training - teaching skills to function in the home and community; Housing counseling - assists individuals find or buy homes in the community Housing Start-up - assistance with furniture & start-up costs of first home in the community Home-Delivered Meals

Monthly cost limits: $5,400 for state matched funds; additional available if the county provides funding to be used in the match.

Background:

Wisconsin began this waiver in 1995 in order to provide home and community-based alternatives for people with traumatic brain injuries who were then currently being served in high cost rehabilitation and treatment facilities both in state and out of state. One of the waiver's purposes was to address the high cost of out of state facilities. The provision of Wisconsin-based, community alternatives was perceived as beneficial for the people served and the state's financial position.

The state's brain injury association was involved in developing training and advising on waiver issues.

The counties are very involved in the waiver and county funds may be used for waiver services, and federal match, over and above the state funding.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	268	$15,966,889	$59,578	337	$177
2003	303	$17,756,141	$58,601	340	$172
2004	322	$19,194,295	$59,610	350	$170
2005	334	$20,032,784	$59,978	348	$172
2006	334	$20,095,110	$60,165	351	$171

Waiver year is January 1 to December 31.

Waiting List: Yes, as of November 2007, 121 are on wait list, managed on a first come first served basis.

Wyoming

Waiver Name: Adult Acquired Brain Injury HCBS Waiver

Operated by the Developmental Disabilities Division, a separate division within the single State agency (Department of Health).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of $2,000 or less.

Level of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)

Be between the ages 21 and 64, have an traumatic or non traumatic injury to the brain that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder; it does not include brain injuries that are congenital or brain injuries induced by birth trauma. Additionally, a medical team will review the medical documentation from the time of the injury/incident.
A team with a physician and a registered nurse will engage in a collaborative evaluation process with a neuropsychological examination by a licensed psychologist with one year of post-doctoral work in ABI. Initial assessments include: a neuropsychological evaluation that includes a standard battery of tests used to determine the Individual Budget Amount using DOORS.[147] In addition, any of the following tests from the neuropsychological and other evaluations:
• Mayo Portland Adaptability Inventory (MPAI) score of 42 or more
• California Verbal Learning Test II, Trials 1-5, T Score or 40 or less
• Supervision Rating Scale of 4 or more Inventory for Client and Agency Planning (ICAP) Service Score of 70 or less

Focus: Long-Term Care – since its inception, only 36 individuals have disenrolled from the waiver.

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[147] DOORS is the financial model used for using an individual budgeted amount based on the characteristics for each person served. This model considers the characteristics of the adults with ABI, and the services and settings they may choose. The primary purpose of this is to match ABI Waiver service dollars to individual consumer's needs and to allow for fiscal accountability. (Wyoming Waiver application at http://wdh.state.wy.us/Media.aspx?mediaId=942) More information about DOORS may be found at http://ddd.state.wy.us/Documents/architec.htm.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management – acceptance of case management is required of all enrollees.
Support Broker	N	
In-Home Services	Y	Personal Care Services In-Home Support Services: provision of habilitation services to individuals who reside with their family or independently. In-home support services included conducting a designed program to allow the individual with acquired brain injury to acquire, retain, and improve the self-help, socialization, and adaptive skills necessary to reside successfully in the community.
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized medical equipment and supplies to include devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live and are in addition to any medical equipment and supplies furnished under the State plan.
Vehicle Repair/Modification	Y	
Respite	Y	Respite Care –

Service Category	Y/N	Specific Service
Clinical Services	Y	Extended State Plan Services: Physical Therapy and Occupational Therapy. Waiver Services: Speech, Hearing, and Language Services Cognitive Retraining Services: Training provided to the person served or family members that will assist the compensation or restoring cognitive function (e.g. ability/skills for learning, analysis, memory, attention, concentration, orientation, and information processing) Dietician Services include menu planning, consultation with and training for care givers, and education for the individual served.
Day Support	Y	Day Habilitation Pre-vocational services.
Environmental Accessibility Adaptations	Y	Environmental accessibility adaptations
Health Related	Y	Skilled nursing services - provided to clients who have been ordered by an attending physician to receive specific skilled nursing treatments and care.
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Cognitive Retraining Services Dietician Services
Transportation	N	
Residential	Y	Residential Habilitation – approximately 45% of waiver participants live in a congregate setting.
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Background:

Wyoming began this waiver in 2002 because of legislation influenced by a strong advocacy group. Several services initially covered (vision, psychological) were deleted from the waiver as they were not significantly different from State plan Services.

The waiver was initially approved for 100 individuals with no more than 85 to be served at any one time. This has been increased by amendments.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	25	$620,525	$24,821	164	$151
2003	70	$2,270,680	$32,438	256	$127
2004	83	$3,018,483	$36,367	311	$117
2005	102	$3,368,779	$33,027	301	$110
2006	137	$3,940,878	$28,766	297	$97

Waiver year is July 1 to June 30

Waiting List: None at this time, but close to maximum enrollment. However, waiting lists have existed at times in the past; placement on waiting list was based on a priority, need assessment.

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State Operations Manual

Appendix J - Guidance to Surveyors: Care Facility for people with Brain Injuries

Part 1 - Investigative Procedures for Care Facility for people with Brain Injuries

I - Introduction II - Principal Focus of Surveys III - Survey Process

A - Fundamental Survey B - Extended Survey C - Full Survey

IV - Components of Active Treatment A - Comprehensive Functional Assessment (42 CFR 483.440(c)(3)) B - Individual Program Plan (IPP) (42 CFR 483.440(c)) C - Program Implementation (42 CFR 483.440(d)) D - Program Documentation (42 CFR 483.440(e)) E - Program Monitoring and Change (42 CFR 483.440(f))

V - Task 1 - Sample Selection A - Purpose of the Sample B - Sample Size C - Sample Selection

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D - Program Audit Approach E - Sampling on Follow-Up Survey VI - Task 2 - Review of Facility Systems to Prevent Abuse, Neglect and Mistreatment and To Resolve Complaints

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X - Task 6 - Visit to Each Area of Facility Serving Certified Individuals A - Purpose B - Protocol

XI - Task 7 - Record Review of Individuals In the Sample A - Introduction B - The Individual Program Plan (IPP) C - Program Monitoring and Change D - Health and Safety Supports

XII - Task 8 - Team Assessment of Compliance and Formation of the Report of CF/BI Deficiencies A - General B - Team Assessment of Compliance C - Analysis 1 - Facility Practice Statements 2 - Condition Level Compliance Principles D - Composing the Report of CF/BI Deficiencies (CMS-3070H/(10/95)) XIII - Additional Survey Report Documentation (For the File)

\ - Summary Listing of all CF/BI Individuals Comprising the Survey Sample (include any additional individuals added to the sample) B - Description of the Representative Sample Selection C - Summary of Individual Observations D - Summary of Interviews E - Drug Pass Worksheets (Form CMS-677) or Surveyor Notes of the Drug Pass Observation F - Other Relevant Facility Data XIV - Completing the Revised Form CMS-3070-G-I (10/95) CF/BI Survey Report Form (SRF)

Part II- Interpretive Guidelines-Responsibilities of Care Facility for people with Brain Injuries

440.150 Intermediate Care Facility Services, Other Than in Institutions for Mental Diseases §483.410 Condition of Participation: Governing Body and Management §483.410(a) Standard: Governing Body §483.410(b) Standard: Compliance With Federal, State and Local Laws. §483.410(c) Standard: Client Records §483.410(d) Standard: Services Provided Under Agreements With Outside Sources §483.410(e) Standard: Licensure §483.420 Condition of Participation: Client Protections §483.420(a) Standard: Protection of Clients' Rights §483.420(b) Standard: Client Finances §483.420(c) Standard: Communication With Clients, Parents, and Guardians §483.420(d) Standard: Staff Treatment of Clients §483.430 Condition of Participation: Facility Staffing §483.430(a) Standard: Qualified Brain Injury Professional §483.430(b) Standard: Professional Program Services §483.430(c) Standard: Facility Staffing §483.430(d) Standard: Direct Care Residential Living Unit Staff §483.430(e) Standard: Staff Training Program §483.440 Condition of Participation: Active Treatment Services §483.440(a) Standard: Active Treatment §483.440(b) Standard: Admissions, Transfers, and Discharge

§483.440(c) Standard: Individual Program Plan §483.440(d) Standard: Program Implementation §483.440(e) Standard: Program Documentation §483.440(f) Standard: Program Monitoring and Change §483.450 Condition of Participation: Client Behavior and Facility Practices §483.450(a) Standard: Facility Practices - Conduct Toward Clients §483.450(b)Standard: Management of Inappropriate Client Behavior §483.450(c) Standard: Time-Out Rooms §483.450(d)Standard: Physical Restraints §483.450(e) Standard: Drug Usage §483.460 Condition of Participation: Health Care Services §483.460(a) Standard: Physician Services §483.460(b) Standard: Physician Participation in the Individual Program Plan §483.460 (c) Standard: Nursing Services §483.460(d) Standard: Nursing Staff §483.460(e) Standard: Dental Services §483.460(f) Standard: Comprehensive Dental Diagnostic Services §483.460(g) Standard: Comprehensive Dental Treatment §483.460(h) Standard: Documentation of Dental Services §483.460(i) Standard: Pharmacy Services §483.460(j) Standard: Drug Regimen Review §483.460(k) Standard: Drug Administration §483.460(l) Standard: Drug Storage and Recordkeeping §483.460(m) Standard: Drug Labeling §483.460(n) Standard: Laboratory Services §483.470 Condition of Participation: Physical Environment §483.470(a) Standard: Client Living Environment §483.470(b)Standard: Client Bedrooms §483.470(c) Standard: Storage Space in Bedrooms §483.470(d) Standard: Client Bathrooms §483.470(e) Standard: Heating and Ventilation §483.470(f) Standard: Floors §483.470(g) Standard: Space and Equipment §483.470(h) Standard: Emergency Plan and Procedures §483.470(i) Standard: Evacuation Drills §483.470 (j) Standard: Fire Protection §483.470(k) Standard: Paint §483.470(l) Standard: Infection Control §483.480 Condition of Participation: Dietetic Services §483.480(a) Standard: Food and Nutrition Services §483.480(b) Standard: Meal Services §483.480(c) Standard: Menus §483.480(d) Standard: Dining Areas and Service

Part 1 - Investigative Procedures for Care Facility for people with Brain Injuries

I - Introduction

This revised CF/BI survey protocol is to assist surveyors to focus attention on the outcomes of individualized active treatment services. The Centers for Medicare & Medicaid Services (CMS) intends the revised survey process to be less resource intensive for providers who consistently demonstrate compliance with the regulations. The survey process is based on the October 3, 1988, regulation and is applicable to all CFs/BI, regardless of size.

The field of BI is increasingly emphasizing supporting individuals in their own homes and communities, rather than placing people in facilities. In addition services in virtually all States are placing increased emphasis on person-centered planning and person-centered services that focus on the preferences, goals and aspirations of each individual and on supporting them in reaching their personal goals. The field of QA is placing increased emphasis on outcomes related to choice, control, relationships, community inclusion, and satisfaction with life, as well as satisfaction with services and supports.. Many QA systems also include organizational self-assessment and continuous quality improvement components. These trends have contributed to the perception by providers and advocates that the CF/BI regulation and oversight process is too prescriptive and cumbersome, and should be altered to reflect newer values of quality enhancement and continuous quality improvement.

This revised survey protocol gives facilities broader latitude to develop the processes by which it implements active treatment services. While the facility practice must comply with the requirements of 42 CFR 483, Subpart I, the survey is to center on the fundamental requirements that produce outcomes for individuals. When those outcomes occur, review of additional supporting requirements of process and structure is not indicated.

A survey that focuses on observations of staff/consumer interaction and on interviews with consumers regarding their participation and choice of services is sufficiently informative to determine the outcomes of active treatment. In the presence of problems, a more in-depth review of how the process unfolded for a particular individual(s) occurs.

A facility may receive reimbursement only for the cost of care of individuals classified as eligible for the CF/BI level of care who are receiving active treatment. Determine facility compliance with Conditions of Participation and with standards in the context of individual experiences within the facility. When performing certification surveys to assess facility compliance, assess whether individuals are receiving needed active treatment services.

II - Principal Focus of Surveys

The principal focus of the survey is on the "outcome" of the facility's implementation of CF/BI active treatment services. Direct your principal attention to what actually happens to individuals: whether the facility provides needed services and interventions; whether the facility insures individuals are free from abuse, mistreatment, or neglect; whether individuals, families and guardians participate in identifying and selecting services; whether the facility promotes greater independence, choice, integration and productivity; how competently and effectively the staff interact with individuals; and whether all health needs are being met.

Use observation and interview as the primary methods of information gathering. Conduct record reviews after completion of observations and interviews to confirm specific issues. Verify that the facility develops interventions and supports that address the individuals' needs, and provides required individual protections and health services. Do not conduct in-depth reviews of assessments, progress notes or historical data unless outcomes fail to occur for individuals.

III - Survey Process

The survey process is divided into three stages. They are the fundamental, extended and full survey. (Note: These stages do not apply to the Life Safety Code survey. Every certification and annual re-certification requires a complete Life Safety Code survey (see instructions in Appendix I)).

A - Fundamental Survey

A fundamental survey is conducted to determine the quality of services and supports received by individuals, as measured by outcomes for individuals and essential components of a system which must be present for the outcomes of active treatment to occur. Certain requirements are designated as fundamental and are reviewed first. The remaining requirements (that are not designated as fundamental) are supporting structures or processes that the facility must implement. A decision that a provider is in compliance with the fundamental requirements indicates an outcome-reviewed compliance with the non-fundamental requirements and associated conditions of participation. Focus initial attention on the fundamental requirements of the conditions of participation for:

42 CFR 483.420 - Client Protections
Fundamental requirements:

483.420(a)(2) - (7)	W124 - W130
483.420(a)(9)	W133
483.420(a)(11) - (12)	W136 - W137
483.420(c)(1) - (6)	W143 - W148
483.420(d)(2) - (4)	W153 - W157

42 CFR 483.440 - Active Treatment Services and Facility Practices
Fundamental requirements:

483.440(a)(1) - (2)	W196 - W197
483.440(c)(2)	W209
483.440(c)(4)	W227

42 CFR 483.450 - Client Behavior

42 CFR 483.420 - Client Protections
Fundamental requirements:

483.420(a)(2) - (7)	W124 - W130
483.420(a)(9)	W133
483.420(a)(11) - (12)	W136 - W137
483.420(c)(1) - (6)	W143 - W148
483.420(d)(2) - (4)	W153 - W157

Fundamental requirements:

483.440(a)(1) - (2)	W196 - W197
483.440(c)(2)	W209
483.440(c)(4)	W227
483.440(c)(6)(i)	W240
483.440(c)(6)(111)	W242
[illegible]	[illegible]

All fundamental requirements must be reviewed in every annual recertification survey. When observations and interviews are complete, review the individuals' records, as needed, to verify observation and interview findings. If indicated, verify that individual health needs are met and protections are in place. When the fundamental requirements are "met," the facility meets the Conditions of Participation.

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42 CFR 483.420 - Client Protections

Fundamental requirements:	
483.420(a)(2) - (7)	W124 - W130
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483.440(c)(6)(111)	W242
483.440(c)(6)(vi)	W247
483.440(d)(1)	W249
483.440(f)(1)	W255 - W257
483.440(f)(3)(i) - (ii)	W262 - W263
In aBlition include:	
483.410(d)(3)	W120
483.430(d)(2)	W186
483.470(g)(2)	W436
483.470(i)(4)	W448 - W449
Fundamental requirements:	
483.450(b)(2)	W285
483.450(b)(3)	W286 - W288

fundamental requirements are "not review the condition-level compliance principles found in the interpretive guidelines for W122, W266, and W318. Determine deficiencies at the fundamental requirements, when viewed as a lead you to believe that one or more "not met" compliance principles is If this is the case, conduct an survey, as instructed below. When "met" compliance principles are the facility is assumed to be in compliance with all conditions of participation. This is the end of the fundamental survey. The survey would prepare a Form CMS-2567, Statement of Deficiencies, and any standard-level deficiencies the findings from the fundamental

B - Extended Survey

An extended survey is conducted when standard-level deficiencies are found during the fundamental survey and the survey team has determined or suspects that one or more Conditions of Participation examined during the fundamental survey (42 CFR 483.420, 42 CFR 483.440, 42 CFR 483.450, and 42 CFR 483.460) are "not met." The team would need to gather additional information in order to identify the structural and process requirements that are "not met" and to support their condition-level compliance decision.

The team reviews all of the requirements within the Condition(s) for which compliance is in doubt. Using the condition-level compliance principles in the interpretive guidelines as a guide, determine if the facility complies with the relevant Condition(s) of Participation.

When the survey team determines that the facility is in compliance with the relevant Conditions of Participation, conclude the survey and prepare a Form CMS-2567 for facility practices not in compliance with standards. When the facility is not in compliance with one or more Conditions of Participation, prepare a Form CMS-2567 describing the deficient facility practices which are not in compliance with the Conditions of Participation of either 42 CFR 483.420, 42 CFR 483.440, 42 CFR 483.450, or 42 CFR 483.460. Base any required adverse action on these findings. Review of additional requirements under other Conditions of Participation is at the option of the survey agency based on the criteria under paragraph "C" of this section.

NOTE: Neither the fundamental nor the extended survey process precludes the survey agency from review of any standard, if evidence of non-compliant facility practice is suspected during any survey.

C - Full Survey

A full survey is conducted at an initial survey and at the discretion of the survey agency, based on the survey agency's identification of concerns related to the provider's capacity to furnish adequate services. This decision may be based on criteria, including but not limited to, the following:

- A condition-level deficiency on the previous year's recertification survey,
- The existence of a time-limited agreement of less than twelve months due to programmatic deficiencies, or
- Evidence related to diminished capacity to provide services based on other sources, such as complaints, inspection of care findings or State licensure deficiencies that are relevant to Federal requirements.

The team reviews all the requirements in all Conditions of Participation to determine if the facility maintains the process and structure necessary to achieve the required outcomes. Based on the information collected, determine whether facility practice is in compliance with all Conditions of Participation.

IV - Components of Active Treatment

The definition of "active treatment in Care Facility for people with Brain Injuries" in 42 CFR 435.1009 refers to treatment that meets the requirements specified in the standard for active treatment 42 CFR 483.440(a). The components of the active treatment process are:

A - Comprehensive Functional Assessment (42 CFR 483.440(c)(3))

The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data, within 30 days after admission, that identify all of the individual's:

- Specific developmental strengths, including individual preferences;
- Specific functional and adaptive social skills the individual needs to acquire;
- Presenting disaddlities, and when possible their causes; and
- Need for services without regard to their availaddlity.

B - Individual Program Plan (IPP) (42 CFR 483.440(c))

The interdisciplinary team must prepare an IPP which includes opportunities for individual choice and self-management and identifies: the discrete, measurable, criteria-based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports, and techniques to be employed. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible, and the prevention or deceleration of regression or loss of current optimal functional status.

C - Program Implementation (42 CFR 483.440(d))

Each individual must receive a continuous active treatment program consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives.

D - Program Documentation (42 CFR 483.440(e))

Accurate, systematic, behaviorally stated data about the individual's performance toward meeting the criteria stated in IPP objectives serves as the basis for necessary change and revision to the program.

E - Program Monitoring and Change (42 CFR 483.440(f))

At least annually, the comprehensive functional assessment of each individual is reviewed by the interdisciplinary team for its relevancy and updated, as needed. The IPP is revised, as appropriate.

V - Task 1 - Sample Selection

A - Purpose of the Sample

The purpose of drawing a sample of individuals from the facility is to reflect a proportionate representation of individuals by the four functional levels (mild, moderate, severe, and profound Brain Injury) as defined by the American Association on Mental Deficiency, "Classification in Brain Injury," (eighth edition, 1983).

The sampling process is not designed to produce a "statistically valid" sample. Apply the method with flexibility based upon the prevailing developmental strengths and needs presented by the individuals served by the facility. A "statistically valid" sample would not accommodate this need.

While the individuals in the sample are targeted for observation and interview, conduct each program audit of the individual within the context of each of the environments in which the individual lives, works, and spends major leisure time. Although you focus on the individual, the behavior and interactions of all other individuals and staff within those environments also contribute to the total context and conditions for active treatment. Therefore, other individuals will be included in the overall sample.

As the sample is built, additional information about the facility's services and special individual needs may emerge. If you find that a disproportionate number of disaddlities or needs are present within the facility's population add to or replace originally selected individuals of the same functional level in the program audit sample to ensure that the appropriate care and services are reviewed. Staff interview for individual characteristics (see the back of Form CMS-3070G) may help identify areas of individual need that should be reflected in the sample.

For example, if you discover a significant percentage of individuals are nonambulatory, and this characteristic has not been represented in the sample, add additional individuals.
Likewise, if while observing Individual A (a member of the sample), you note that Individual B (who was not targeted for the sample) engages in a particular problematic behavior for which staff do not appear to provide appropriate intervention, add Individual B to the sample in order to probe further if needs are addressed. You are free by this methodology to add to the sample on an as needed basis.

B - Sample Size

Calculate the size of the sample by the following guidance:

Number of Individuals residing in the Facility	Number of Individuals in the Sample	Number of Interviews with Individual/Family
4 - 8	50 percent	50 percent of sample
9 -16	4	4
17 -50	8	5
51 - 100	10	5
101 - 500	10 percent	50 percent of sample (max.: 15)
Over 500	50	15

C - Sample Selection

Do not allow the facility staff to select the sample.

1 - Facilities Serving 100 or Fewer Individuals

Draw a sample that evenly distributes the individuals among buildings and functioning levels. Usually, by asking the staff to provide a full list of the individuals with their building locations and functional levels you can do this choosing the names..

2 - Facilities With Over 100 individuals

Request a listing of all individuals by overall functional (cognitive and adaptive) level (i.e., mild, moderate, severe, profound) and building location.

Determine the number of individuals to draw based upon the total individuals from Section III B.

Determine the percentage occurrence of each functional level in the overall population (e.g., 12 percent mild; 24 percent moderate; 63 percent severe).

Determine the number of individuals to draw in each functional category (for example, if the sample size is 50, and 12 percent of the individuals have mild Brain Injury, then multiply 50 by .12 = 6, and draw 6 individuals who have mild Brain Injury into the sample).

Draw the sample for each functional category. (Assume there are 60 with mild Brain Injury, and 6 are to be sampled. Divide 60 by 6 = 10, and draw every tenth individual.) The interval of selection varies with each functional category because there will be a different percentage occurrence at each. Thus, assuming there are 16 individuals with severe Brain Injury and 4 are to be sampled, draw every fourth name from the list of individuals with severe Brain Injury.

Locate each selected individual's living unit on a map of the facility building(s) to see if too many are concentrated in too few buildings. To provide a comprehensive look at the facility, drop some individuals and add others in other buildings for a better distribution. Each individual replacing an originally selected individual must be of the same functional level.

3 - Alternate Sampling Procedure

In the rare situation in which the facility is unable to produce the necessary data on which to draw the sample, draw a random sample, to the maximum extent possible. Supplement it as described in Section VA.

Brain Injury, as defined by the American Association on Brain Injury (AAMR) in "Brain Injury: Definition, Classification and Systems of Supports" (ninth edition, 1992), is no longer classified in four functional levels (mild, moderate, severe, and profound.) Most facilities have not yet adopted the 1992 classification system; however, when the facility does use the 1992 classification system and information regarding the four functional levels is not available, revise the sampling procedure. Follow the instructions in A and B above but, instead of using the four functional levels referenced in AAMR's Classification System of 1983, use the four levels of intensity of supports (intermittent, limited, extensive, and pervasive) on Dimension I for Self-Care from the new classification system. Although not equivalent to the 1993 classifications, this method should provide a sample of individuals within the facility who represent a variety of functional addlities.

D - Program Audit Approach

To maximize the advantage of an interdisciplinary survey team, the team leader assigns each member an equitable number of individuals on whom to focus. For each individual, assess all applicable fundamental requirements of the CF/BI Conditions of Participation based on the individual's need for that particular service. Each member of the team shares salient data about findings relative to his or her assigned individuals. Consult with one another, on a regular basis during the survey, to maximize sharing of knowledge and competencies.

E - Sampling on Follow-Up Survey

The purpose of the follow-up survey is to verify correction of deficiencies previously cited on the Form CMS-2567. It is NOT necessary to do a full review of all services being received, only those areas in which deficiencies were previously cited. Sample selection on the follow-up survey is, therefore, dependent on the nature of the deficiencies for which follow-up must be done.

If the last survey found multiple standard-level deficiencies that are not limited to a specific area or issue, follow t' procedure described in paragraphs A through D above to select a new sample and use the same sample size specified in paragraph B. This procedure may result in inclusion of some individuals from the previous sample, however, approximately 50 percent of the sample on the follow-up survey should be individuals who were not previously reviewed in order to assure systemic correction of the identified deficiencies. This can be accomplished by beginning the interval of selection at a different point on the list of individuals residing at the facility. The maximum sample size on a follow-up survey is 30.

When Conditions of Participation have been found not met in the annual survey and the types of deficiencies are limited to a specific need or service area, then the follow-up sample may be drawn from the specific universe of individuals who have that specific need. To select the sample, start with the total number of individuals affected by the specific need, then choose the sample size. The sample universe will be the total number of individuals who have that specific need. For example, if the facility has 20 individuals receiving medications to manage behavior, the sample size would be 8, in accordance with paragraph B.

VI - Task 2 - Review of Facility Systems to Prevent Abuse, Neglect and Mistreatment and To Resolve Complaints

During the entrance conference, determine how the facility resolves individual complaints and allegations of abuse, mistreatment and neglect. While no specific system is required, 42 CFR 483.420(d)(4) does require that the results of all investigations are reported to the administrator and are reported in accordance with State law. The facility, therefore, should have a reproducible mechanism to assure its responsiveness to concerns of individuals and their families. That system must assure prompt detection, reporting, investigation and resolution of complaints and of allegations and occurrences of abuse, mistreatment and neglect and injuries from unknown sources.

Review the facility's system (e.g., accident and injury logs and reports) for any evidence that suggests that individuals are being abused or are vulnerable to abuse and injury. Data that is derived from these reports are important in the event that you find an immediate and serious threat to an individual's health and safety. If you discern any patterns that suggest abuse, follow up on the status and condition of those individuals. Also review investigations completed and those in process to determine that the facility protects individuals from abuse, mistreatment and neglect while the allegation is under investigation. If the State law or regulation requires the facility to report such allegation to other agencies, determine that this occurs.

Conducting this review early in the survey process facilitates any necessary follow-up during later observations, interviews or record reviews of individuals. Use the Interpretive Guidelines and Additional Data Probes at 42 CFR 483.420(a)(5) or W127 for further guidance. If you believe serious and immediate threat to individual's health and safety exists, consult Appendix Q.

III - Survey Process

The survey process is divided into three stages. They are the fundamental, extended and full survey. (Note: These stages do not apply to the Life Safety Code survey. Every certification and annual re-certification requires a complete Life Safety Code survey (see instructions in Appendix I)).

A - Fundamental Survey

A fundamental survey is conducted to determine the quality of services and supports received by individuals, as measured by outcomes for individuals and essential components of a system which must be present for the outcomes of active treatment to occur. Certain requirements are designated as fundamental and are reviewed first. The remaining requirements (that are not designated as fundamental) are supporting structures or processes that the facility must implement. A decision that a provider is in compliance with the fundamental requirements indicates an outcome-reviewed compliance with the non-fundamental requirements and associated conditions of participation. Focus initial attention on the fundamental requirements of the conditions of participation for:

42 CFR 483.420 - Client Protections
Fundamental requirements:

483.420(a)(2) - (7)	W124 - W130
483.420(a)(9)	W133
483.420(a)(11) - (12)	W136 - W137
483.420(c)(1) - (6)	W143 - W148
483.420(d)(2) - (4)	W153 - W157

42 CFR 483.440 - Active Treatment Services and 42 CFR 483.450 - Client Behavior Facility Practices
Fundamental requirements:

483.440(a)(1) - (2)	W196 - W197
483.440(c)(2)	W209
483.440(c)(4)	W227

42 CFR 483.420 - Client Protections
Fundamental requirements:

483.420(a)(2) - (7)	W124 - W130
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483.420(a)(11) - (12)	W136 - W137
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483.420(d)(2) - (4)	W153 - W157

Fundamental requirements:

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483.440(c)(6)(i)	W240
483.440(c)(6)(111)	W242
483.440(c)(6)(ii)	W247

All fundamental requirements must be reviewed in every annual recertification survey. When observations and interviews are complete, review the individuals' records, as needed, to verify observation and interview findings. If indicated, verify that individual health needs are met and protections are in place. When the fundamental requirements are "met," the facility meets the Conditions of Participation.

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42 CFR 483.420 - Client Protections	
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483.440(c)(6)(vi)	W247
483.440(d)(1)	W249
483.440(f)(1)	W255 - W257
483.440(f)(3)(i) - (ii)	W262 - W263
In aBlition include:	
483.410(d)(3)	W120
483.430(d)(2)	W186
483.470(g)(2)	W436
483.470(i)(4)	W448 - W449
Fundamental requirements:	
483.450(b)(2)	W285
483.450(b)(3)	W286 - W288

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B - Extended Survey

An extended survey is conducted when standard-level deficiencies are found during the fundamental survey and the survey team has determined or suspects that one or more Conditions of Participation examined during the fundamental survey (42 CFR 483.420, 42 CFR 483.440, 42 CFR 483.450, and 42 CFR 483.460) are "not met." The team would need to gather additional information in order to identify the structural and process requirements that are "not met" and to support their condition-level compliance decision.

The team reviews all of the requirements within the Condition(s) for which compliance is in doubt. Using the condition-level compliance principles in the interpretive guidelines as a guide, determine if the facility complies with the relevant Condition(s) of Participation.

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NOTE: Neither the fundamental nor the extended survey process precludes the survey agency from review of any standard, if evidence of non-compliant facility practice is suspected during any survey.

C - Full Survey

A full survey is conducted at an initial survey and at the discretion of the survey agency, based on the survey agency's identification of concerns related to the provider's capacity to furnish adequate services. This decision may be based on criteria, including but not limited to, the following:

- A condition-level deficiency on the previous year's recertification survey,
- The existence of a time-limited agreement of less than twelve months due to programmatic deficiencies, or
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The team reviews all the requirements in all Conditions of Participation to determine if the facility maintains the process and structure necessary to achieve the required outcomes. Based on the information collected, determine whether facility practice is in compliance with all Conditions of Participation.

IV - Components of Active Treatment

The definition of "active treatment in Care Facility for people with Brain Injuries" in 42 CFR 435.1009 refers to treatment that meets the requirements specified in the standard for active treatment 42 CFR 483.440(a). The components of the active treatment process are:

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The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data, within 30 days after admission, that identify all of the individual's:

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C - Program Implementation (42 CFR 483.440(d))

Each individual must receive a continuous active treatment program consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives.

D - Program Documentation (42 CFR 483.440(e))

Accurate, systematic, behaviorally stated data about the individual's performance toward meeting the criteria stated in IPP objectives serves as the basis for necessary change and revision to the program.

E - Program Monitoring and Change (42 CFR 483.440(f))

At least annually, the comprehensive functional assessment of each individual is reviewed by the interdisciplinary team for its relevancy and updated, as needed. The IPP is revised, as appropriate.

V - Task 1 - Sample Selection

A - Purpose of the Sample

The purpose of drawing a sample of individuals from the facility is to reflect a proportionate representation of individuals by the four functional levels (mild, moderate, severe, and profound Brain Injury) as defined by the American Association on Mental Deficiency, "Classification in Brain Injury," (eighth edition, 1983).

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As the sample is built, additional information about the facility's services and special individual needs may emerge. If you find that a disproportionate number of disaddlities or needs are present within the facility's population add to or replace originally selected individuals of the same functional level in the program audit sample to ensure that the appropriate care and services are reviewed. Staff interview for individual characteristics (see the back of Form CMS-3070G) may help identify areas of individual need that should be reflected in the sample.

For example, if you discover a significant percentage of individuals are nonambulatory, and this characteristic has not been represented in the sample, add additional individuals.

Likewise, if while observing Individual A (a member of the sample), you note that Individual B (who was not targeted for the sample) engages in a particular problematic behavior for which staff do not appear to provide appropriate intervention, add Individual B to the sample in order to probe further if needs are addressed. You are free by this methodology to add to the sample on an as needed basis.

B - Sample Size

Calculate the size of the sample by the following guidance:

Number of Individuals residing in the Facility	Number of Individuals in the Sample	Number of Interviews with Individual/Family
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101 - 500	10 percent	50 percent of sample
Over 500	50	15 (max.: 15)

C - Sample Selection

Do not allow the facility staff to select the sample.

1 - Facilities Serving 100 or Fewer Individuals

Draw a sample that evenly distributes the individuals among buildings and functioning levels. Usually, by asking the staff to provide a full list of the individuals with their building locations and functional levels you can do this choosing the names.

2 - Facilities With Over 100 individuals

Request a listing of all individuals by overall functional (cognitive and adaptive) level (i.e., mild, moderate, severe, profound) and building location.

Determine the number of individuals to draw based upon the total individuals from Section III B.

Determine the percentage occurrence of each functional level in the overall population (e.g., 12 percent mild; 24 percent moderate; 63 percent severe).

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Locate each selected individual's living unit on a map of the facility building(s) to see if too many are concentrated in too few buildings. To provide a comprehensive look at the facility, drop some individuals and add others in other buildings for a better distribution. Each individual replacing an originally selected individual must be of the same functional level.

3 - Alternate Sampling Procedure

In the rare situation in which the facility is unable to produce the necessary data on which to draw the sample, draw a random sample, to the maximum extent possible. Supplement it as described in Section VA.

Brain Injury, as defined by the American Association on Brain Injury (AAMR) in "Brain Injury: Definition, Classification and Systems of Supports" (ninth edition, 1992), is no longer classified in four functional levels (mild, moderate, severe, and profound.) Most facilities have not yet adopted the 1992 classification system; however, when the facility does use the 1992 classification system and information regarding the four functional levels is not available, revise the sampling procedure. Follow the instructions in A and B above but, instead of using the four functional levels referenced in AAMR's Classification System of 1983, use the four levels of intensity of supports (intermittent, limited, extensive, and pervasive) on Dimension I for Self-Care from the new classification system. Although not equivalent to the 1993 classifications, this method should provide a sample of individuals within the facility who represent a variety of functional addlities.

D - Program Audit Approach

To maximize the advantage of an interdisciplinary survey team, the team leader assigns each member an equitable number of individuals on whom to focus. For each individual, assess all applicable fundamental requirements of the CF/BI Conditions of Participation based on the individual's need for that particular service. Each member of the team shares salient data about findings relative to his or her assigned individuals. Consult with one another, on a regular basis during the survey, to maximize sharing of knowledge and competencies.

E - Sampling on Follow-Up Survey

The purpose of the follow-up survey is to verify correction of deficiencies previously cited on the Form CMS-2567. It is NOT necessary to do a full review of all services being received, only those areas in which deficiencies were previously cited. Sample selection on the follow-up survey is, therefore, dependent on the nature of the deficiencies for which follow-up must be done.

If the last survey found multiple standard-level deficiencies that are not limited to a specific area or issue, follow the procedure described in paragraphs A through D above to select a new sample and use the same sample size specified in paragraph B. This procedure may result in inclusion of some individuals from the previous sample, however, approximately 50 percent of the sample on the follow-up survey should be individuals who were not previously reviewed in order to assure systemic correction of the identified deficiencies. This can be accomplished by beginning the interval of selection at a different point on the list of individuals residing at the facility. The maximum sample size on a follow-up survey is 30.

When Conditions of Participation have been found not met in the annual survey and the types of deficiencies are limited to a specific need or service area, then the follow-up sample may be drawn from the specific universe of individuals who have that specific need. To select the sample, start with the total number of individuals affected by the specific need, then choose the sample size. The sample universe will be the total number of individuals who have that specific need. For example, if the facility has 20 individuals receiving medications to manage behavior, the sample size would be 8, in accordance with paragraph B.

VI - Task 2 - Review of Facility Systems to Prevent Abuse, Neglect and Mistreatment and To Resolve Complaints

During the entrance conference, determine how the facility resolves individual complaints and allegations of abuse, mistreatment and neglect. While no specific system is required, 42 CFR 483.420(d)(4) does require that the results of all investigations are reported to the administrator and are reported in accordance with State law. The facility, therefore, should have a reproducible mechanism to assure its responsiveness to concerns of individuals and their families. That system must assure prompt detection, reporting, investigation and resolution of complaints and of allegations and occurrences of abuse, mistreatment and neglect and injuries from unknown sources.

Review the facility's system (e.g., accident and injury logs and reports) for any evidence that suggests that individuals are being abused or are vulnerable to abuse and injury. Data that is derived from these reports are important in the event that you find an immediate and serious threat to an individual's health and safety. If you discern any patterns that suggest abuse, follow up on the status and condition of those individuals. Also review investigations completed and those in process to determine that the facility protects individuals from abuse, mistreatment and neglect while the allegation is under investigation. If the State law or regulation requires the facility to report such allegation to other agencies, determine that this occurs.

Conducting this review early in the survey process facilitates any necessary follow-up during later observations, interviews or record reviews of individuals. Use the Interpretive Guidelines and Additional Data Probes at 42 CFR 483.420(a)(5) or W127 for further guidance. If you believe serious and immediate threat to individual's health and safety exists, consult Appendix Q.

VII -Task 3 - Individual Observations

Upon completion of Task 2, surveyors are to conduct observations of the individuals selected for the sample. DO NOT:

- Conduct a detailed review of individual's records;
- Conduct an inspection tour of the facility's environment; or
- Request facility staff to keep people home from scheduled activities, such as work or day programs.

A - Purpose

Determine if the necessary relationship between the individual's needs and preferences, and what staff know and do with individuals, in both formal and informal settings throughout the day and evening, is made.

As a result of any observation, the surveyor should be able to determine whether:

- Competent interaction occurs between staff and the individual(s);
- Individuals are given the opportunity to exercise choice and function with as much self-determination and independence as possible; and
- Staff provides the needed supports and interventions to increase skills or prevent loss of functioning.

The primary purpose of the visit to the out-of-home program is to determine whether the individual is receiving services that promote growth and independence and how the residence assures consistent delivery of services. Generally the out-of-home program and residence should be using the same interventions, communication methods, and behavior shaping strategies. If not, determine the justification for the difference in services. For example, if the day program is using physical restraints as an intervention and the home is not, determine the justification for the restraints.

B - Survey Conduct

Be present when individuals are present. If individuals are in a program other than in the residence, go to that location. Observe each person in the sample in the home environment and in the day program. Observations across the entire survey (e.g., early morning, afternoon and evening observations) are absolutely essential. One method to conduct observations over this time span is to alter the workday of the survey team members. For example, some members might work from 6:30 a.m. to 3:00 p.m., while others work from 1:00 p.m. to 9:30 p.m.

Schedule your time to observe special training programs that are critical to the individuals' development. Use your observations to determine if individual training is carried out consistently at all appropriate times throughout the day. Observations of meal times, individuals' communication with staff and others, behavior shaping interventions, and routine activities should reflect a consistent pattern of interaction with the individual and demonstrate the staff's knowledge of the individual. Take steps to validate any discrepancies noted. Additional observations within similar situations, locations or activities may be necessary to identify a systemic deficient practice as opposed to a onetime occurrence.

Show respect for the individuals' home and their privacy. As a courtesy, always request permission before entering a bedroom. Do not observe activities in which individuals are undressed unless that observation is essential to your assessment of facility compliance and the information cannot be obtained from other reliable sources. Most information about routine hygiene activities during which individuals are undressed can be obtained through interview of individuals or staff. As a general policy, it is preferable to ask permission to make these types of observations from the individual, or from the staff person who is present if the individual cannot communicate. An individual's request not to be observed while undressed should be honored, when possible. The surveyor does have authority, however, to access information that is essential to determining compliance without asking permission. This authority may need to be exercised in regard to an individual who is undressed, for example, in order to observe for bruises or other signs of injury when it is suspected that the individual is being abused. These observations should be conducted in private, with as little of the body exposed as possible, and with a staff person present. Consent from staff or guardians are not required in order to access information or make observations.

For individuals who are working in competitive employment sites, ask the individual's permission to visit that site If the individual is unable to communicate, discuss with the staff the advisaddlity of visiting the competitive site. The intent is that the individual is not identified as different from other workers at the site. If the individual works in a restaurant, for example, you may be able to visit as a "customer" to observe the work environment. If an interview with a job supervisor or support person is indicated, attempt to conduct this interview in a private or inconspicuous area. Upon arrival, introduce yourself to the individual and to the staff and explain the purpose of your visit.

C - Observation Procedure

Initially the surveyor should note the general impressions of the area. Note things such as:

1 - General Impressions

- How are individuals dressed?
- What activities are taking place?
- What materials and supplies are present?
- Is the environment pleasant and conducive to learning? (e.g., odors, noise, furniture, and adequate bathroom facilities)
- How many staff is present? How many individuals?
- What types of adaptive equipment or assistive devices are used?

2 - Specific Activities and Interactions

After noting the general setting, the surveyor should begin to focus on the specific activities and interactions. For example:

Are individuals involved and participating in the activity? Are the activities active or passive? Does the activity appear to have a purpose? Is staff able to explain how the activity is promoting greater independence for each of the individuals present?

Are there supplies and materials used to assist the individuals? Do individuals use the materials? Do they seem appropriate for the task or activity? Are they appropriate for the individuals?

What interaction is occurring between staff and individuals? Do the interactions give evidence of respect, dignity? Does staff recognize efforts made by the individuals and provide positive reinforcement?

Is the number of staff present sufficient for the number of individuals based on the individual needs or the type of activity?

Are individuals encouraged to make their own choices and decisions? Are they encouraged to complete tasks with as much independence as possible? Is staff doing the activity for the person, or is the person encouraged to do things for him or herself?

Are any maladaptive behaviors exhibited? How does staff respond?

Are any individuals ignored or isolated from the activity? If so, what is the reason or justification for this?

3 - Individuals in Sample

The third step of the observation process focuses on the individual(s) in the sample. The surveyor should specifically note:

- What is the appearance of the individual? Is the individual dressed neatly? Does the person appear clean and is his/her hair combed?

- Does the individual exhibit any apparent physical or medical needs? Is the individual over or under weight, edentulous, continent? Does the individual have contractures, vision, or hearing impairments?

- What adaptive devices/assistive devices are used? Does the individual use a hearing aid, glasses, plate guard, etc.? Does the device(s) appear to be used correctly?

- How does the individual move about in the environment? Does the individual use a walker, ambulate, move his own wheelchair, etc.?

- How does the person communicate? Does the person talk, use sign or a communication board, make facial expressions or behavioral responses? Do others appear to understand the person's communications?

- What is the person's level of social skill or behavior toward others? What types of interactions occur and with whom? Does the individual exhibit any maladaptive behaviors?

- What is the individual's observed skills relative to the activity or task observed? For example, if observed during dining, does the individual eat without assistance? What utensils are used?

- Are applicable skills developed or encouraged during the activity, such as passing food, pace of eating, social conversations? Is the individual receiving any special diet?

- What level of assistance does staff provide? What types of assistance are used - verbal prompts, gestures, hand over hand?

- Are there any individual needs that are not being addressed? Is staff aware of the observed needs? Is there a reason it is not being addressed?

4 - Areas for Further Observation

The surveyor will then identify areas to which to pay attention during other observations.
Those areas may include any supports, interventions or skills that would be expected to occur consistently across settings or any apparent needs, concerns or discrepancies noted during the observation. For example, if the surveyor notes that the individual uses sign language for communication, does all staff working with the individual understand and use sign with him/her? Or if an individual is observed to have good gross motor skills, do staff feed the person or perform other tasks for him/her that your observation indicates the person could possibly do independently? Focus interviews and record review based on concerns, issues, inconsistencies and needs noted from these observation(s).

D - Documentation

Record your observations. The optional individual observation worksheet (CMS-3070I (10/95)) may be used. If your behavior or presence disrupts the activity being observed, wait five minutes before recording the observation.

VIII - Task 4 - Required Interviews With Individuals and/or Family/Advocate Direct Care Staff

A - Purpose

Individuals living in the facility, their families/guardians and advocates, and direct care staff are important sources of information about the receipt of active treatment on a daily basis. Interviews are conducted for two purposes: to determine how the individual perceives the services delivered by the facility, and to clarify information gathered during observations. Only interviews with the individuals, their family members/guardians, advocates, and direct care staff count toward the total number of required interviews (as reflected in the sample chart shown in Section 5B - Sample Size).

B - Interview Procedure

Start with the individual in the sample and the people most closely associated with the individual's daily program implementation. Use the following hierarchy of sources, to the maximum extent possible, in the order shown:

- Individual;
- Families, legal guardian, or advocate;
- Direct care staff;
- Qualified Brain Injury professional (QMRP) and/or professional staff; and
- Managers, administrators, or department heads.

Determine from your observations and from the staff how the individual communicates with others. Also determine from the staff the extent of involvement of family members, guardians or advocates with the individuals in the sample. Based on this information, select the individuals from the sample with whom you will conduct more in-depth interviews. Select those individuals who will be able to communicate at least some basic information or those who have actively involved family members, guardians or advocates. Do not exclude from interviews individuals who use alternate means of communication, such as communication boards, sign language, and gestures. Most individuals are able to communicate in some manner. At a minimum conduct the number of in-depth interviews specified in Section V, Task 1B.

Attempt to obtain the required number of interviews first from individuals and then from family members, guardians or advocates. In the absence of individuals who are able to communicate and active significant others, interview the direct care staff person who works most closely with the individual in order to obtain the required number of in-depth interviews.

The questions and communication method will vary from person to person. For individuals who use a specialized communication method, attempt to begin the interview on a one to one basis. If you find you are unable to communicate with the individual, ask someone familiar with the person to assist you (e.g., a family member or a staff person.) For this individual, pay close attention to how the staff communicates with him or her. If the person uses sign language or a communication board, does staff understand and interact with the individual using the same method? If the person uses gestures, does staff take time to determine his or her needs?

Family members, guardians or advocates may be interviewed at the facility, at a location convenient to both the surveyor and the interviewee, or by telephone. All interviews should be conducted in private locations and scheduled at mutually agreed upon times in order to minimize disruptions to individual, family, or staff activities.

C - Content of Indepth Interviews

Determine what the facility does to provide individualized services and supports; and how individuals and families participate in service planning and in making choices about matters important to them.

- Are individuals treated with respect and dignity?
- Does the facility attempt to help the person set and attain individual goals?
- Are there consistent opportunities for making choices?
- When a choice is not an option, how is the individual assisted to understand?
- For example, if a planned activity is to go to a restaurant for dinner, who chooses the restaurant?
- Is it staff or the individuals living in the facility?
- If one group of people does not want to go, how is this choice accommodated?
- Is the accommodation based on individual choice, staff convenience, or a reasonable justification if a choi is not an option?

See section D for suggested interview questions. Unless designated that certain questions be directed to a certain person, questions are relevant to whoever is being interviewed (individual, family member, advocate or staff person.) Modify the wording of the questions based on the person being interviewed (individual, family member, or staff) and on the communication skills of that individual. For example, you may discover that the person responds better to questions that can be answered "yes" or "no" than to open-ended questions. Be sensitive to signs that the individual is tiring or becoming uncomfortable and either end the interview or continue it at a later time if this occurs. It is not necessary to ask every question in the guide, but do try to ask at least one question from each topic area.

D - Suggested Interview Questions

If you have not met the person before, begin the interview by explaining who you are and what your role is. To put the person at ease you may want to begin with some general conversation, e.g., about the weather or a special event coming up. At the end of the interview, if you think you may need to discuss or confirm personal information with staff or family, ask the person if it is OK to share that information.

Questions Related to Choice and Community Participation (W136, W147, W247):

- What sorts of things do you like to do for fun?
- Do you go out to activities or events in the community (like shopping, movies or church)?
- How often do you do this?
- How do you get there?
- Who chooses where you go?
- Do you go to visit family members or take vacations?

• Is there something you would like to do more often? Questions Related to Personal Finances and Possessions (W126, W137):

- Do you earn money on your job (at your day program)?
- What do you like to buy with your money?
- Do you have enough money to buy the things you want or need?
- Does someone help you with spending or saving your money?
- When you go to the store, do you pay for items or does a staff person pay for them?
- Do you have enough clothes and shoes?
- Do you always have enough deodorant and toothpaste, etc.?
- What do you do if you need to buy something?

Questions Related to Personal Relationships and Privacy (W129-W130, W133, W143 - W148):

- Do you have family or friends who visit you?
- Does your family write to you or telephone you?
- Does someone help you read their letters/ call them on the phone?
- If you feel like being alone or spending private time with a friend or family where do you go?

• Does staff knock on your door before they come into the room? For family member/advocate:

- How do you learn about things like the services your family member receives, an illness or a change in medication?
- Are there any restrictions on when you visit your family member or where you can go within the home?

Questions Related to Individual's and Family's Participation in the IPP Process (W209, W247):

- Do you go to (team) meetings with the staff where they talk about the services you get?
- Does your family/advocate come to these meetings?
- Were you asked if the date and time of the meeting were OK with you?
- What would you like to learn to do for yourself?
- Does the staff ask you what you want?
- Who chooses what you do?

• Does the staff listen to you and make changes based on what you want? For staff:

• How do you communicate with this individual?

• What does (s)he like and dislike? How do you know that? Questions Related to Service Delivery (W242, W249, W436):

- What help do you need from staff to dress, eat, bathe, etc?
- Do you get any special therapy (e.g., speech or physical therapy)?
- What new things are you learning to do?
- What chores do you help with around the house?
- Who helps you when you do not know how to do something?
- What special equipment do you use?

Questions Related to Individual's Rights and Protections: W124-W125, W127, W153 - W157, W127-W128, W263:

- Who do you tell if you do not like something, or something is wrong?
- Are there rules that everyone who lives here must follow?
- What sorts of things are you allowed to do or not do?
- How does the staff treat you?
- Are staff loud?
- Does staff yell, swear or hit?
- Do you ever do things you are not supposed to do? What happens then?
- Were you ever asked to give consent for any treatments or services?

• Were you told the benefits, risks and alternatives? Questions Related to Health Status (W322, W356):

- How often do you see a doctor? A dentist?
- Do you have any health problems?
- • Do you take any medicines? Do you know what they are for? Wrap-up Questions:
- Is there anything you especially like about living here? Anything you especially dislike?
- Is there anything else you think I should know about what it is like to live here?

E - Interviews to Clarify Observations

In the absence of finding appropriate interaction between staff and individuals during observations, it may be necessary to judge whether or not staff is knowledgeable about individual objectives and techniques for implementation of programs. If possible, interview staff following the interval in which the individual was observed with the particular staff member. (For example, if you have just observed Individual A engaging in stereotypical behaviors, ask: "Can you tell me what, if anything, you do when he rocks back and forth?") Ask questions that elicit information about how staff learns what to do with individuals across the spectrum of support and programming activities they are expected to perform. Ask professional staff questions to see if they know how to implement programs for an individual other than their professional discipline (e.g., how to carry through with a behavior program in the midst of communications training).

Ascertain whether the staff is competent to carry out the individual's choices and skill development activity. Is there evidence that programs are in fact being carried out throughout the individual's waking hours? Are interventions revised based on changes in the individual's progress toward goals? If staff cannot demonstrate the skills necessary to implement the individual's programs and choices, if interventions are not being carried out consistently, or if revisions to interventions do not occur, you have findings that active treatment is not being delivered.

F - Documentation

Record each interview you conduct with individuals, staff, consultants, off-site day program staff, legal guardians, etc., in your personal notes or on the optional observation worksheet (Form CMS-3070I). Include the following information in your notes for each interview:

- Date and time of interview;
- Job title and assignment at the CF/BI;
- Relationship to the individual or reason for the interview; and
- Summary of the information obtained.

IX - Task 5 - Drug Pass Observation

Observe the preparation and administration of medications to individuals. With this approach, there is no doubt that the errors detected, if any, are errors in drug administration, not documentation. Follow the procedure in the interpretive guidelines at W369 for conducting the drug pass observation. Notes on observations of the drug pass may be recorded on Form CMS-677 (LTC Medication Pass Worksheet) or in the surveyor's personal notes. The purpose of the review is to direct the facility's attention to assuring an error free drug distribution system and away from the paper processes that often do not represent actual errors in medication administration. For the purposes of this task, a "small" facility is one that houses 16 or fewer residents.

X - Task 6 - Visit to Each Area of Facility Serving Certified Individuals A - Purpose

By the end of the survey, visit each area of the facility serving certified individuals in order to:

- Ensure that all areas of the facility (including those that are not represented by individuals in the sample) are providing services in the manner required by the regulations.
- Assess generally the physical safety of the environment.
- Assess that individual rights are proactively asserted and protected.

B - Protocol

After individuals in the sample have been assigned to team members, review the facility's map or building layout. Assign members to visit each remaining residential and on-campus day program site prior to completing the survey. Insure that each area of the facility that is utilized by individuals has been visited. This visit may be done with or without facility staff accompanying you, as you prefer, and subject to their availaddlity. Record your observations in your notes.

Converse with individuals, family members/significant others (if present), and staff. Ask open-ended questions in order to confirm observations, obtain additional information, or corroborate information, e.g., accidents, odors, apparent inappropriate dress, adequacy and appropriateness of training activities. Observe staff interactions with other staff members as well as with individuals for insight into matters such as individual rights and staff responsibilities.

XI - Task 7 - Record Review of Individuals In the Sample A - Introduction

Do not spend an excessive amount of time looking at fine details in the record review of the selected sample. The purposes are to:

- Verify the applicable information obtained from your observations and interviews;
- Review revisions that have been made to the objectives; and
- Verify that needed health and safety supports are in place.

Do not review in detail the written training programs that are developed for each individual unless you discover serious differences between the record and your observations and interviews. Review those parts of the record most relevant to your purposes as described below.

B - The Individual Program Plan (IPP)

Identify the developmental, behavioral, and health objectives the facility has committed itself to accomplish during the current IPP period. Identify what, if any, behavioral strategies (e.g., behavior modification programs, use of psychotropics) are being used with individuals in your sample. Determine what, if any, health or other problems might interfere with participation in program services.

C - Program Monitoring and Change

Skim the most recent interdisciplinary team review notes to identify what revisions were made to the IPP. Determine whether revisions were based on objective measures of the individual's progress, regression, or lack of progress toward his/her objectives.

D - Health and Safety Supports

Verify, either through the interdisciplinary team review notes or through the most recent nursing notes, that the individual has received follow-up services for any health or dental needs identified in the IPP and check the person's current drug regimen. For individuals with whom restrictive or intrusive techniques are used, verify that the necessary consents and approvals have been obtained.

If this information is consistent with your observations and interviews, conclude the record review. If discrepancies are found, conduct further observations or interviews as needed to verify your findings.

XII - Task 8 - Team Assessment of Compliance and Formation of the Report of CF/BI Deficiencies

A - General

The Survey Report Form (Form CMS-3070H) is composed during the pre-exit conference and contains the negative findings that contribute to a determination that an CF/BI requirement is "not met." Meet as a team, in a pre-exit conference, to discuss the findings and make conclusions about the deficiencies, subject to additional information provided by facility officials. Review the summaries/conclusions from each task and decide whether further information and/or documentation is necessary. Ask the facility for additional information or clarification about particular findings, if necessary. Consider information provided by the facility. If the facility maintains that a practice in question is acceptable, request reference material or sources that support the facility's position.

B - Team Assessment of Compliance

During the pre-exit conference, the survey team reviews each survey tag number reviewed during either the fundamental, extended or full survey, and comes to a consensus as to whether or not the facility complies with each requirement. The team reviews all data collected. For each standard determined to be not met, record salient findings on the Form CMS-3070H. With the exception of the Life Safety Code Survey, individual surveyors do not make compliance when more than one surveyor has conducted the survey.

C - Analysis

Analyze your findings relative to each requirement reviewed during either the fundamental, extended or full survey for the degree of severity, frequency of occurrence and impact on delivery of active treatment or quality of life. The threshold at which the frequency of occurrences amounts to a deficiency varies. One occurrence directly related to a life-threatening or fatal outcome can be cited as a deficiency. On the other hand, a few sporadic occurrences may have so slight an impact on delivery of active treatment or quality of life that they do not warrant a deficiency citation.

The interpretive guidelines contain two types of guidance designed to assist the survey team in analyzing their findings and making consistent compliance decisions:

1 - Facility Practice Statements

The purpose of facility practice statements is to clarify the information that is relevant to specific requirements, and to increase the survey focus on outcomes for individuals. Facility practice statements are provided for those requirements which experience has shown, are difficult to interpret. The practice statements are not necessarily all inclusive, but rather represent the practices most commonly associated with compliance for specific requirements. Each facility practice statement relates directly to the language of the requirement to which it applies. Positive outcomes identified by the practice statements should be observed in operation in the facility during the survey. When the team's negative findings indicate that a practice is not present, a citation of the requirement may be appropriate, depending upon the frequency and the severity of those findings. Use the practice statements during the pre-exit conference to assist the team in analyzing negative findings and determining the appropriate requirement at which to cite negative findings. When stated in the negative, facility practice statements may form the basis for a citation on the Form CMS-2567.

2 - Condition Level Compliance Principles

The purpose of the compliance principles is to assist in consistent decision-making about facility compliance at the Condition of Participation level. The primary focus of those decisions is placed on the outcomes to the individuals and their actual experiences of daily life. At each Condition of Participation, the guidelines contain compliance principles that identify those outcomes that must be present in order for the Condition to be found "met," and those outcomes that indicate the Condition is "not met." The compliance principles are based on the requirements that fall under the Condition. This guidance is NOT to replace professional surveyor judgment. It is possible that the surveyor may encounter a situation that is not covered by the compliance principles, however, such instances are expected to be rare. In the event the survey team makes a determination that the Condition is "not met," and the situation causing that determination is not identified in one of the "not met" compliance principles, notify CMS' Central Office in writing within 10 days after the completion of the survey for purposes of review, possible dissemination to other surveyors, and to ensure consistency within the survey process.

Some of the compliance principles for the Conditions of governing body, facility staffing and physical environment reference other Conditions. Governing body, facility staffing and physical environment tend to address organizational processes that support the provision of active treatment, protection of rights and adequate health and dietary services. Therefore, the governing body, facility staffing and physical environment Conditions are usually "met" unless it is first determined that there are serious deficiencies in services or protections which fall under one or more of the other areas.

After the survey team reviews its positive and negative findings for the requirements within a particular Condition of Participation and determines which of those requirements are deficient, examine the findings for that Condition as a whole. When analysis of these findings leads the team to conclude that each of the "met" compliance principles for that Condition is present, then the facility is in compliance with that Condition. When analysis of the standard level deficiencies viewed as a whole, leads the team to conclude that one or more of the "not met" compliance principles for that Condition is present for one or more individuals or situations, consider the frequency and the severity of the negative finding(s) in relation to the applicable "not met" compliance principle(s) in order to determine whether Condition level noncompliance is warranted.

D - Composing the Report of CF/BI Deficiencies (CMS3070H/(10/95))

During the pre-exit conference, the survey team records on the Form CMS-3070H those requirements that are determined to be deficient and the findings that support that determination. Write the deficiency statement in terms specific enough to allow a reasonably knowledgeable person to understand the aspect(s) of the requirement(s) that is (are) not met. Do not delve into the facility's policies and procedures to determine or speculate on its root cause, or sift through various alternatives to prescribe an acceptable remedy. Indicate on the Form CMS-3070H the data prefix tag, followed by a summary of the deficient facility practice(s). Briefly identify the supporting findings for each deficiency (i.e., transfer to the Form CMS-3070H the identifier numbers of all individuals to whom the deficient practice applies.) It is not necessary to write a full description of the findings on the Form CMS-3070H since they will be described in more detail on the completed Statement of Deficiencies (Form CMS-2567). It is necessary to complete the Form CMS-3070H for each survey because the Form CMS-3070H is the only document in which the survey team's recommendations for deficiencies are recorded (which may be changed later on the final Form CMS-2567 as a result of supervisory review) and because not all individual examples may be used on the Form CMS-2567. Instructions for the Form CMS-3070H are found in "Section XIV - Completing the Revised Form CMS-3070-G-I."

Alternatively, when the survey team enters its findings directly into a computerized system such as Automated Survey Processing Environment during the pre-exit conference, the statement of deficiencies (Form CMS-2567) that is generated onsite at the facility may be substituted for the Form CMS-3070H. The Form CMS-2567 generated onsite then must contain the information required for the Form CMS-3070H and must be clearly marked "DRAFT - SUBJECT TO STATE AGENCY REVIEW" on each page.

XIII - Additional Survey Report Documentation (For the File)

Upon the completion of each survey, the team leader completes the following additional documentation. This information remains at the survey agency with the Form CMS3070-G-H (10/95) in the official file:

A - Summary Listing of all CF/BI Individuals Comprising the Survey Sample (include any additional individuals added to the sample)

At a minimum, identify:

- The name or Medicaid number of each individual chosen to be part of the sample;
- Any individual identifier codes used as a reference to protect the individual's confidentiality; and

The reason for including the individual in the sample (e.g., "Random Program Audit," "Discharge," "New Admission," "Death," "Abuse Investigation," "Drugs to Control Behavior"). This listing serves as a future reference to any individual identifiers recorded in surveyors' notes, the Form CMS-3070-G-I, and the Form CMS-2567.

B - Description of the Representative Sample Selection

At a minimum, identify at the time of the survey:

- How the sample was selected;
- What was the percentage occurrence of each functional level of Brain Injury in the facility's overall population;
- The distribution of the individuals in the sample across the facility's living units;
- The number of people in the sample;
- The number, if any, of individuals substituted in the sample, and the reason; and
- Any other characteristic of individuals served that was specifically introduced into the sampling process and the reason.

C - Summary of Individual Observations

Include all individual observation worksheets (Form CMS-3070I) and any surveyor notes containing information regarding observations. These notes should include the dates, locations, and starting and ending times for each observation.

D - Summary of Interviews

Include all surveyor notes containing information obtained during interviews with individuals, families, guardians, direct care staff, QMRPs, professional staff or consultants, administrators and managers, and others. These notes should identify the person interviewed by name or position, and date and time of interview.

E - Drug Pass Worksheets (Form CMS-677) or Surveyor Notes of the Drug Pass Observation

F - Other Relevant Facility Data

Include other salient data used in support of the survey findings with the Form CMS-3070G-H (10/95) (e.g., photographs, affidavits). The survey agency's documentation of the justification for the decision to conduct a full survey must be maintained in the survey agency's file.

XIV - Completing the Revised Form CMS-3070-G-I (10/95) CF/BI Survey Report Form (SRF)

Part 1 This is the cover sheet for the CF/BI SRF which summarizes (3070G):

data relative to: facility characteristics; description of the individual population served; special needs represented by that population; and essential characteristics of the survey conducted. Portions of this information are entered into the Onsite Survey and Certification Automated Reporting (OSCAR) System and used to review trends about the CF/BI program nationwide.

1. Complete all portions of Part 1 onsite, preferably during the first day of the survey. Work with the facility to complete the form General according to these instructions and to ensure accurate information is

Instructions: obtained prior to leaving the facility.

2. If a number is requested (e.g., No. of beds, No. of individuals), and the answer is NONE or ZERO, enter a "O" in the space provided.
3. If a box is provided to "check one" of the answers provided, enter a check mark.
4. Abbreviations used: "CEO" means Chief Executive Officer; "QMRP"
5. Regulatory references on the form refer to regulations found in the Code of Federal Regulations, and refer to regulations applicable to CFs/BI.
6. Review all portions for accuracy prior to leaving the facility.

Specific instructions: Blocks

1-10, 13-14: Enter identifying data, as requested.

Block 11: Enter the dates of the first and last days of the survey (even if there is a break in survey days).

Block 12: Enter the number describing the ownership/control type in the box marked "W6." If "other" best describes the facility, specify the other type on the space provided.

Blocks 15 (Col. 1): Enter the No. of disciplines that best describe your team's composition. If a surveyor has multiple areas of expertise (e.g., a

e surveyor who is also a dietitian), include each discipline of expertise. (Col. 2) Enter the No. of disciplines represented on the team that also qualified as a QMRP (as per 42 CFR 483.430(a)(1)(2)(i)-(iii) and 42 CFR 483.430(b)(5) of the CF/BI Conditions of Participation. Blocks 15

(N-O): Enter the number, as requested. Blocks 16 A "Yes" indicates that the CEO directs not only the activities of the CF/BI, but also those of another residential services program (e.g.,

(A-B): another CF/BI; another Medicare/Medicaid Provider that serves persons with MR regardless of funding source). A "No" indicates that the CEO of the CF/BI does not direct the activity of another residential services program for persons with MR. If "Yes" was indicated for 16A, identify the name, address and CEO of the larger organization or agency in 16B (could be the same information for this CF/BI in Block 7. Enter the total bed capac of all residential services for which the CEO is directly responsible (including the CF/BI bed capacity) in "W14." Do not include beds for which the CEO is indirectly responsible. (For example, in some States the CEO of a State-operated institution is also indirectly

Block 16C:

Block 16 D:

le for all beds in a region, including those operated by private providers within that region. Do not include beds directly operated by another agency or organization for the purposes of W14.) Enter the total No. of individuals residing in the beds (including CF/BI individuals) in "W15."

Block 16 E:

Block 16 F:

Enter the No. as requested. A "Yes" indicates that this CF/BI (i.e., the beds under this provider number) is the only house or apartment at the address stated in Block 2 and is located in close proximity to other houses or apartments occupied by people who are not disabled. A "No" indicates that there is other bed capacity to provide residential services to persons with disaddlities at the address stated in Block 2 or that this CF/BI is surrounded by other buildings or residential units serving people with disaddlities. Enter the No., as requested.

Block 16 G:

Block 16 H:

Enter the total No. of discrete units. If the CF/BI encompasses several bldgs, count the total No. of discrete living units within all buildings.

List the ages of the youngest individual in W20 and oldest in W21.

Blocks 17 (A-D):

Each day's program site included in this number should be located off the grounds or campus of the CF/BI. Any individual going to this program should be scheduled to attend regularly (at least 3 hrs.a day, 2-5 days a wk.). If the day program provides 2 or more programs at the same address, for purposes of this item, consider it one site.

Enter the full time equivalents (FTEs) for each category listed. For 17A, include only staff who provides direct care services to individuals at their living units. Include direct care supervisors only if they are also responsible to provide direct care as part of their duties. (See 42 CFR 483.430(d).) For 17D, include all personnel, including the No. of direct care and licensed nursing personnel, as well as professional and support staff employed by the facility. To determine FTEs: add the total No. of hrs. worked the week prior to the survey, by all employees identified in each category of 17 (A-D);

Divide this No. by the No. of hrs. in the standard workweek. Express FTE's to the nearest quarter decimal (i.e. ".00," ".25," ".50," and ".75").

Block 18 A:

Enter the No. of individuals in the total sample (i.e., the representative sample and any other individuals added to the sample for other reasons.)

Block 18 B:

Enter the No. of sites visited in which observations of individuals in the sample were completed. INDIVIDUAL CHARACTERISTICS: The last date of the survey is

Blocks 20

responsib

(A-L):

20 A (1):

Blocks 20 A

(2): Blocks 20 (B-C):

the date by which age is determined. The term "Total" No. refers to the No. of CF/BI individuals fitting the characteristic listed who are currently in the facility.

Enter the total No. of individuals within each age group regardless of sex. Enter the No. of individuals by sex and the total. The total should equal the No. entered in 20 (A)(1), Total (W33).

Enter the total No. of individuals by each characteristic requested; and the total. Count individuals with more than one disaddlity in every applicable column. Use the following definitions:

Autism is a diagnosis whereby the individual exhibits extreme forms of self-injurious, repetitive, aggressive, or withdrawal behaviors; extremely inadequate social relationships; or extreme language disturbances.

Cerebral Palsy is a diagnosed condition whereby gross and fine movements and speech clarity of the individual may be impaired but performance of activities of daily living is functional; or, the individual is unable to perform adequately activities of daily living such as walking, using hands, or using speech for communication.

Brain Injury levels (mild, moderate, severe, and profound) are described in the American Association on Mental Deficiency's Manual on "Classification in Brain Injury" (1983 edition).

Nonambulatory means unable to walk independently.

Mobile nonambulatory means unable to walk independently, but able to move from place to place with the use of such devices as walkers, crutches, wheelchairs, and wheeled platforms.

Nonmobile means unable to move from place to place.

Epilepsy means a neurological disorder characterized by seizures of motor and sensory movements.

Hard of Hearing means able to hear speech, including with amplification.

Deaf means unable to hear speech, even with amplification.

Impaired vision means able to see objects, with correction.

Blind means unable to see objects.

Blocks 20 (D-K): care needs or characteristics: Medical Care Plan (i.e., requires 24 hour licensed nursing care as defined at

(42 CFR 483.450(a)(2)); Drugs to Control Behavior (42 CFR 483.450(b)(1)(iv)(C)); Restraints (42 CFR 483.450(b)(1)(iv)(B)); Time-out rooms (42 CFR 483.450(b)(1)(iv)(A)); Application of Painful or Noxious Stimuli (42 CFR 483.450(b)(1)(iv)(D)); Attend Off-Campus Day Programs; Court Ordered Admissions; and the No. Over Age 18 with a Legally Appointed Guardian.

Block 20 L: If the facility or you believe that a particular individual or program characteristic that describes the population has not been requested on this form, identify it, programs provided, etc., in the space provided. Enter the total Nos. of individuals having this characteristic.

REPORT OF DEFICIENCIES

Part 2 (3070-H): Use this part in conjunction with the regulation text and interpretive guidelines. Include basic information on non-compliance. Complete the report during the pre-exit conference for all surveys. Record all deficiencies found during the survey. Sign it, certifying that all other facility requirements not documented as deficiencies, are in compliance.

Evaluate each discrete requirement identified by a tag number in the CF/BI Interpretive Guidelines. For each identified deficiency:

In the first column, identify the data tag number;
In the second column, write the standard number. If it is a Condition of Participation, enter "CoP" below the standard number. Identify the deficient facility practice, findings and evidence in the "Comments" column. Draw horizontal lines to separate identified tag numbers.

Use as many sheets as needed.
Each surveyor must sign the appropriate certifying statement on the last page of Part 2. INDIVIDUAL OBSERVATION WORKSHEET

Part 3 (3070-I): Enter the total No. of CF/BI individuals who have the following Part 3 of the SRF is an optional worksheet that may be used to record and structure observations so that individual data relative to compliance with the statutory active treatment requirement are available for analysis and retrieval. This is completed for each observation as follows:

Heading: Enter requested names, locations, codes, times and dates. Enter "individual codes" only if individuals in the sample are

present.

Column 1 - Time: Enter the time of discrete observations or consecutive time intervals. Column 2 - Observation: Include the information specified in

Section V-B of this Appendix for each observation (e.g., number of individuals; number of staff; activity in progress).

Part II- Interpretive Guidelines-Responsibilities of Care Facility for people with Brain Injuries

§440.150 Intermediate Care Facility Services, Other Than in Institutions for Mental Diseases

W100

§440.150(c) "Intermediate care facility services" may include services in an institution for the mentally retarded (hereafter referred to as Care Facility for people with Brain Injuries) or persons with related conditions if--

(1) The primary purpose of the institution is to provide health or rehaddlitative services for mentally retarded individuals or persons with related conditions;

(2) The institution meets the standards in Subpart E of Part 442 of this Chapter; and

(3) The mentally retarded recipient for whom payment is requested is receiving active treatment as specified in §483.440.

Facility Practices §440.150(c)

The facility is in compliance with the Condition of Participation at W195, i.e., individuals are in need of and receiving active treatment.

Guidelines §440.150(c)

The statutory and regulatory use of the word "institution" includes settings that serve four or more people with Brain Injury and/or related conditions.

See §435.1009 for definition of "persons with related conditions."

The presence or absence of an individual requiring a medical care plan, as defined at W320, is not salient in the determination of whether a facility is eligible to participate in the CF/BI program.

W101

W101 is reassigned to §483.410(e). Section 442.251, the standard which requires that facilities meet the requirement for a State license, is redesignated to §483.410(e) and W101 is reassigned as well to afford a sense of continuity.

W102 §483.410 Condition of Participation: Governing Body and Management Compliance

Principles §483.410

The Condition of Participation of Governing Body is met when each of the other Conditions of Participation are also met.

The Condition of Participation of Governing Body is not met when:

- One or more of the other Conditions of Participation have first been determined to be not met, and the governing body has failed to take action that identifies and resolves systemic problems of a serious and recurrent nature; or

- The facility has been denied any license or approval required by Federal, State or local law by the authority having jurisdiction for that law.

§483.410(a) Standard: Governing Body W103 §483.410(a)The facility must identify an individual

or individuals to constitute the

governing body of the facility. The governing body

must--W104

(a)(1) Exercise general policy, budget, and operating direction over the facility; Facility Practices

§483.410(a)(1)

The governing body provides, monitors, and revises, as necessary, policies and operating directions which ensure the necessary staffing, training resources, equipment and environment to provide individuals with active treatment and to provide for their health and safety.

Guidelines §483.410(a)(1)

The responsibility for direction includes areas such as health, safety, sanitation, maintenance and repair, and utilization and management of staff, especially when problems in these areas are of a serious or recurrent nature. Condition level deficiencies (other than the Governing Body Condition) or repeat, pervasive patterns of deficiencies at the Standard level may be an indication that the governing body is not providing sufficient operating direction over the facility. When a pattern of serious or repeated deficiencies is identified during the survey, interview the administrator or review the minutes of governing body meetings, if available, to determine whether or not the governing body has identified and addressed the problem.

Staff who have been trained, but are not implementing programs or are inappropriately deployed (e.g., there are enough staff but they are assigned to duties like record keeping which prevents them from delivering needed services), may indicate a failure of the governing body to adequately direct the staff's activities.

W105

§483.410(a)(2) Set the qualifications (in addition to those already set by State law, if any) for the

administrator of the facility; and W106 (a)(3) Appoint the administrator of the facility. §483.410(b)

Standard: Compliance With Federal, State and Local Laws.

The facility must be in compliance with all applicable provisions of Federal, State and local laws, regulations

and codes pertaining to W107 health, W108

safety, and

W109 sanitation. Facility Practices §483.410(b)

The facility has received no adverse action(s) by the Federal, State or local authority having jurisdiction in these areas.

The facility is in compliance with W101, W105, W153, W156, W170, W265, W328, W345, W370, and W374.

Guidelines §483.410(b)

Licenses, permits, and approvals of the facility must be available to you upon request. Current reports of inspections by State and/or local health authorities are on file, and notations are made of action taken by the facility to correct deficiencies.

Some State or local laws are more stringent or prescriptive than the Federal Medicaid requirement on the same issue. Failure of the facility to meet a Federal (i.e., non-Medicare or Medicaid), State or local law may be cited only when the authority having jurisdiction (AHJ) has both made a determination of non-compliance and has taken a final adverse action.

An adverse action is defined as any procedure that goes beyond the approval of a plan of correction, such as a civil money penalty, ban on admissions, denial of payment, or loss of license, and is not under appeal by the provider. The AHJ is the public official(s) having authority to make a determination of noncompliance, and is responsible f signing correspondence notifying the facility of the adverse action.

If you believe you have identified a situation indicating the provider may not be in compliance with a Federal, State or local law, refer that information to the AHJ for follow-up action. If a final adverse action results, then the facility could be found to not meet §483.410(b).

§483.410(c) Standard: Client Records W110 (c)(1) The facility must develop and maintain a

recordkeeping system that includes
a separate record for each client and

W111 **that documents the client's health care, active** treatment, social information, and protection of the

client's rights. Guidelines §483.410(c)(1)

The structure and content of the individual's record must be an accurate, functional representation of the actual experience of the individual in the facility. This should be identified through interviews with staff and, when possible, with individuals being served, as well as through observations.

The regulations do not specify that all information about an individual be located in the individual program plan (IPP) document, only that information explicitly identified in the regulations. The regulations do not prescribe the manner, form or where in the individual's record this information is to be recorded.

W112 §483.410(c)(2) The facility must keep confidential **all information contained in the clients' records,**

regardless of the form or storage method of the records. Facility Practices §483.410(c)(2)

The facility has in place sufficient safeguards to ensure that access to all information regarding individuals is limited to those individuals designated by law, regulation, policy, or duly authorized consent as having a need to know.

No unauthorized access or dissemination has occurred.

Guidelines §483.410(c)(2)

"Keep confidential" means safeguarding the content of information including video, audio, and/or computer stored information from unauthorized disclosure without the specific informed consent of the individual, parent of a minor child, or legal guardian, and consistent with the advocate's right of access, as required in the Developmental Disaddlities Act. Facility staff and consultants, hired to provide services to the individual, should have access to only that portion of information that is necessary to provide effective responsive services to the individual.

Confidentiality applies to both central records and information kept at dispersed locations. If there is information considered too confidential to place in the record used by all staff (e.g., identification of the family's financial assets, sensitive medical data), it may be retained in a secure place in the facility (e.g., social worker's locked desk). A notation must be made in the record of the location of confidential information (e.g., "Family information is available from the social worker").

The sharing of individual specific information with members of the "specially constituted committee" required by §483.450(f)(3), who are not affiliated with the agency, does not violate an individual's right to have information about him or her kept confidential. The committee needs to know relevant information to function properly.

The facility is allowed the flexibility to work out arrangements with its members to maintain confidentiality.

W113

§483.410(c)(3) The facility must develop and implement policies and procedures governing the release of any client information, including consents necessary from the client, or parents (if the client is a minor) or legal guardian.

Facility Practices §483.410(c)(3)

The facility has developed the required policies and procedures and follows them.

Release of any personally identifiable information does not occur unless appropriate consent(s) is obtained prior to the release.

Guidelines §483.410(c)(3)

Although one facet of the requirement is that the facility must decide how this is to be accomplished (i.e., policies and procedures), the surveyor's primary focus should be on the second part of the requirement, i.e., the facility's implementation or "outcome" that consent is obtained prior to the release of any individual information (e.g., records, photographs, interviews, or other means of exposure to public view or identification). The following guidance is provided to assist in determining whether informed consent for release of information is adequate:

1 Was the confidential information to be released specifically identified?

2 Was the person or agency to whom the information was to be released identified to the consenting party?

3 Was the consent time-limited (i.e., include the date the consent was given, and the date which the specific consent would be invalid)?

4 Was the person giving consent legally able to give consent?

Information regarding an individual's HIV status may not be released without specific consent and may not be in the record if that consent has not been given. Staff are expected to use universal precautions when dealing with all individuals, therefore, it is unnecessary to routinely share information about HIV status with all staff. Under some conditions, knowledge may be shared with those directly involved in the care of infected persons. Surveyors should be familiar with State law requirements.

W114 **§483.410(c)(4) Any individual who makes an entry in a client's record must mak**e it legibly, date it,

and sign it. Guidelines §483.410(c)(4)

In cases in which facilities have created the option for an individual's record to be maintained by computer, rather than hard copy, electronic signatures are acceptable.

Given the large number of entries that are made in individual's records, this requirement is cited only when a systemic problem is identified.

W115

§483.410(c)(5) The facility must provide a legend to explain any symbol or abbreviation used in a client's

record. W116 §483.410(c)(6) The facility must provide each identified residential living unit with

appropriate aspects of each client's record. Facility Practices

§483.410(c)(6)

The staff of the residential living unit has, and can access, all information which is relevant to implementing individual program plans, appropriate care of, interaction with, and provision of services for the individual.

Guidelines §483.410(c)(6)

"Appropriate" means those parts of each individual's record most likely (or known) to be needed by the residential staff to carry out the individual's active treatment program in the unit, to alert staff to health risks and other aspects of medical treatment, to support the psychosocial needs of the individual, and anything else necessary to the staff's addlity to work on behalf of the individual.

§483.410(d) Standard: Services Provided Under Agreements With Outside Sources

W117

§483.410(d)(1) If a service required under this subpart is not provided directly, the facility must have a written agreement with an outside program, resource, or service to furnish the necessary service, including emergency and other health care.

Guidelines §483.110(d)(1)

Federal statute (P.L. 94-142) requires all school-aged children to receive a free and appropriate school education. Therefore, a written agreement between CFs/BI and public schools is not necessary.

§483.410(d)(2) The agreement must W118 (d)(2)(i) Contain the responsibilities, functions, objectives, and

other terms agreed

to by both parties; and W119 (d)(2)(ii) Provide that the facility is responsible for assuring that the outside

services

meet the standards for quality of services contained in this subpart. Guidelines

§483.410(d)(2)(ii)

Outside providers of day services would not have to meet certain requirements relating to physical environment under §§483.470 (a)-(g), (j), and (k) unless that source also provides living quarters for CF/BI individuals. Outside sources must, of course, meet any applicable State and local requirements.

The facility's responsibility includes assuring that any restrictive techniques proposed for use by outside service providers are used only when warranted and with the required safeguards and approvals.

W120

§483.410(d)(3) The facility must assure that outside services meet the needs of each client.

Facility Practices §483.410(d)(3)

Outside service providers meet the needs of each individual as identified by the interdisciplinary team.

Programs and services are coordinated/integrated and consistent with those provided by the facility.

Guidelines §483.410(d)(3)

"Assure" means that the facility's staff actively participate with staff in outside programs in the assessment process and in development of objectives and intervention strategies. For example, if a public school is implementing a manual communication system with an individual, the direct care staff in the individual's living unit should have instructions to implement the program in the residential environment. Likewise, if the facility is implementing a behavior management program for the individual, it should be shared with and implemented as needed by the outside program. This communication is often difficult, but nevertheless essential to the provision of active treatment.

Probes §483.410(d)(3)

Is there evidence of shared communication, program planning and implementation, and problem solving?

Is there a relationship among the objectives, data, techniques, etc., within the programs or services delivered? Does the facility periodically observe services that are provided by the outside resource?

W121

§483.410(d)(4) If living quarters are not provided in a facility owned by the CF/BI, the CF/BI remains directly responsible for the standards relating to physical environment that are specified in §483.470(a) through (g), (j) and (k).

Guidelines §483.410(d)(4)

Even though the facility's premises may be rented from a landlord, the facility must ensure that the requirements for physical environment are met, either through arrangement with the landlord or through the facility's own services.

§483.410(e) Standard: Licensure W101 The facility must be licensed under applicable State and local law.

Facility Practices §483.410(e)

The facility has a current, valid State license when required under State law.

W122 §483.420 Condition of Participation: Client Protections Compliance Principles §483.420

The Condition of Participation of Client Protections is met when:

- Individuals are free from abuse and neglect;
- Individuals are free from unnecessary drugs and restraints; and
- Individual freedoms are promoted (e.g., individuals have choice and opportunities in their money management, community involvement, interpersonal relationships, daily routines, etc.).

The Condition of Participation of Client Protections is not met when:

- Individuals have been abused, neglected or otherwise mistreated and the facility has not taken steps to protect individuals and prevent reoccurrence;
- Individuals are subjected to the use of drugs or restraints without justification; or
- Individual freedoms are denied or restricted without justification (e.g., systemic lack of privacy, of freedor of access to the community or to other individuals, in use of personal possessions and money, etc.).

Guidelines §483.420

A citation of W127 or W150, which require that individuals are not subjected to verbal, sexual, or psychological abuse or punishment, is sufficient justification that the facility has failed to comply with the most fundamental of protections and, therefore, does not comply with this Condition of Participation.

§483.420(a) Standard: Protection of Clients' Rights The facility must ensure the rights of all

clients. Therefore, the facility must Guidelines §483.420(a)

"Ensure" means that the facility actively asserts the individual's rights and does not wait for him or her to claim a right. This obligation exists even when the individual is less than fully competent and requires that the facility is actively engaged in activities which result in the pro-active assertion of the individual's rights, e.g., guardianship, advocacy, training programs, use of specially constituted committee, etc.

W123 **§483.420(a)(1) Inform each client, parent (if the client is a minor), or legal guardian, of the client's**

rights and the rules of the facility; Facility Practices §483.420(a)(1)

Individuals and their representatives, if applicable, are aware of the individual's rights and the rules of the facility.

Information has been provided to the individual and their representatives, if applicable, in terms and language they understand.

Individuals who are unable to understand their rights have family members, legal guardians or advocates who are involved in protection of their rights.

Guidelines §483.420(a)(1)

The obligation to inform requires that the facility present information in a manner and form which can be understood, e.g., use of print materials, specialized programs to inform individuals who are deaf or blind, use of interpreters, etc

Probes §483.420(a)(1)

How does the facility determine if an individual can or cannot understand his/her rights? How does the facility inform staff, individuals, parents and/or guardians , or non-English speaking individuals of rights (e.g., use of printed materials, specialized programs to inform deaf and/or blind individuals, informal conferences)?

To what extent has the question of advocacy been raised if individuals do not have family members? If individuals have family members who do not wish to have contact made with them? If the individual does not want the family to participate in decision making?

What manner of assistance is provided once a decision is made that an individual has a need for advocacy, guardianship, or protective services?

W124

§483.420(a)(2) Inform each client, parent (if the client is a minor), or legal guardian, of the client's medical condition, developmental and behavioral status, attendant risks of treatment, and of the right to refuse treatment;

Facility Practices §483.420(a)(2)

Individuals and their representatives, if applicable, are aware of the individual's medical condition and treatment, therapies, services and other treatment or prescribed approaches being received, the reason for their use, as well as any risks involved in those treatments or approaches.

Individuals and their representatives, if applicable, understand the alternatives to proposed treatments, that they can refuse treatment, and the possible consequences/ alternatives to such refusal of treatment.

Guidelines §483.420(a)(2)

The term "attendant risks of treatment" refers to all treatment, including medical treatment. An individual who refuses a particular treatment (e.g., a behavior control, seizure control medication or a particular intervention strategy) must be offered information about acceptable alternatives to the treatment being refused, if acceptable alternatives are available. The individual's preference about alternatives should be elicited and considered in deciding on the course of treatment. If the individual also refuses the alternative treatment, or if no alternative exists to the treatment refused, the facility must consider the effect this refusal may have on other individuals, the individual himself or herself and the facility, and if it can continue to treat the individual consistent with these regulations. Thus, every effort must be made to assist the individual to understand and cooperate in the legitimate exercise of the IPP.

An individual being considered for participation in experimental research must be fully informed of the nature of the experiment (e.g., medication, treatment) and understand the possible consequences of participating or not participating. The individual's written consent must be received prior to participation. For an individual who is a minor or who has been adjudicated as incompetent, the written informed consent of parents of the minor or the legal guardian is required.

The determination as to whether the individual was sufficiently "informed" is based on the following:

1. Was the individual aware of the proposed program or treatment, the procedures to be followed, and the identification of the person who will perform the treatment activity?
2 Was the individual aware of the intended outcome or benefits of the proposed program or treatment?
3 Was the individual aware of the possible risks, including side effects and attendant discomfort of the proposed program or treatment, and the steps to be taken to minimize risk?
4 Was the individual aware of the ramifications if he or she decided not to participate, and of the alternatives to the proposed activity, particularly alternatives offering less risk or adverse effects?
5 Did the individual participate voluntarily? Did the individual have the opportunity to have questions about the activity answered?
6 Was the information about the activity presented in language that could be readily understood by the individual?

Additionally, for experimental, invasive or potentially harmful treatment, activities or procedures for which written informed consent is recommended, if not otherwise required by State or Federal law:

1 Was the consent time-limited (i.e., include the date the consent was signed and the date it becomes invalid)?

2 Did the individual realize that consent to participate could be withdrawn at any time without risk of punitive action?

3 Was the person who gave consent the legally appropriate party to do so for the individual?

Probes §483.420(a)(2)

How does the facility inform the individual/parent/guardian of the individual's condition, and of other significant events (e.g., through written correspondence, phone calls, informal conferences, in native language, in a timely manner)?

Is there correspondence in the record informing the appropriate guardian of the individual's condition?
Is there evidence of informed consent when needed?

Are alternative treatment procedures made available for those who refuse specific treatment?

What kinds of treatments do individuals refuse (if any)? Why? How does the facility respond to refusals?

How does the facility ensure that the concept of informed consent has been taught to individuals, including the ramifications of refusal of treatment?

Is there evidence that appropriate people are informed of benefits and risks of treatments, including psychoactive drugs?

What does the facility do when individuals show consistent patterns of refusal of treatments or programs?

W125

§483.420(a)(3) Allow and encourage individual clients to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process.

Facility Practices §483.420(a)(3)

Individuals are taught and encouraged to claim and exercise their rights.

A personal advocate or legally sanctioned surrogate decision-maker has been identified, when appropriate, and is encouraged to assist/support the individual in exercising these rights.

Individuals and their representatives, if applicable, are aware of how to file a complaint and are free from reprisal when they do so.

Individuals have the opportunity to register to vote and are taught skills to assist them in exercising this right.

Guidelines §483.420(a)(3)

The facility must ensure protection of the individual from any form of reprisal or intimidation as a result of a complaint or grievance reported by an individual.

As long as there are no decisions or circumstances which require action by a legally- appointed surrogate, a spokesperson or advocate could assist the individual in exercising his or her rights as a citizen of the United States and as a person residing in the facility. Some examples might include assisting the individual to express his/her needs, wants and interests, to utilize community resources or to file a complaint. A spokesperson might also express opinions regarding situations in which consent by the beneficiary, parent of a minor, or legal guardian is required in order to bring to the attention of the facility potential concerns or problems.

The extent to which any person can act on behalf of another individual who has been assessed as needing a guardian, however, is entirely dependent upon the needs of the individual client and upon the laws and regulations of the State in which that individual resides. The facility and surveyor must be familiar with the laws and regulations of the State in which the facility is located. It is inappropriate for the facility to unofficially delegate the individual's rights to others (e.g., parents, family, advocacy groups, etc.) To the extent that the individual is able to make decisions for himself or herself, it is inappropriate to delegate the person's rights to others.

Individuals who need guardianship or advocacy, and do not have this need addressed, are not prepared to exercise their rights as citizens of the United States. The facility's failure to ensure guardianship or advocacy for those who need it should be cited. Further deficiencies may also be cited under W123, W124, W143, and W263, depending upon the survey findings

Probes §483.420(a)(3)

How are individuals prepared to exercise their rights?

Are provisions made for all individuals to assert their rights including those with mobility, sensory and communication impairments? Can staff explain individual rights and how they facilitate individual exercise of rights? Do individuals use advocacy systems? Are there established individual grievance procedures? Are advocates given access to the individual and his/her records, as appropriate,

consistent with the Developmental Disaddlities Assistance and Bill of Rights Act, as

amended? Are rights that are modified or limited specific, general, or blanket? Are they reviewed to ensure continued appropriateness to the individual?

What ways show that individuals assert their rights (e.g., do they vote, self-advocate, participate in self-governance council, participate in citizenship training, participate in community political activities)?

What type of complaints do individuals report (if any) and how well does the facility

respond? When interviewing individuals, do they describe situations which demonstrate the exercising of their rights?

On what basis does the facility accept, or not accept, an individual's informed choice? In what manner is due

process ensured? How does the team fit into this process?

W126 §483.420(a)(4) Allow individual clients to manage their financial affairs and teach them to do so to the extent of their capaddlities; Facility Practices §483.420(a)(4)

Individuals receive instruction (either as part of a formal program or a more general, informal series of activities) on handling their money which is geared to the individual's functional level.

Individuals have opportunities to hold and manage their own money to the maximum extent of their capaddlities.

Guidelines §483.420(a)(4)

Since the use of money is a right, determine if the facility demonstrated, based on objective data, that the individual was unable to be taught how to use money before the decision was made to restrict that right.

Probes §483.420(a)(4)

How many individuals does the facility report manage their own funds?

Through interview and observation of staff and individuals served, are there individuals who are able to manage their own money with assistance, if needed? Are individuals allowed to spend funds as they choose? Are there spending

opportunities? Do they have cash?

Does staff, in fact, make financial decisions for use of individual funds which the facility reports are managed by the individual? Do staff work closely with particular individuals to participate in decisions about

spending their money?

For those individuals who manage their financial affairs, are they knowledgeable of their income source and amount? What evidence is manifest by individuals that they know what to do with personal

finances? To what extent do individuals know how to conduct bank transactions? How are individuals paid?

Cash? Check? Vouchers? Tokens?

W127 §483.420(a)(5) Ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment; Facility Practices §483.420(a)(5)

No patterns, isolated incidents, unexplained functional regression, or other evidence of physical, verbal, sexual or psychological abuse or punishment posing a serious and immediate threat to individuals are present, are likely to occur, or have occurred without corrective action.

The following situations constitute evidence of abuse:

1. Individuals are involved in serious incidents (e.g., injuries, elopements) caused by one or more of the following:

- Insufficient or incompetent supervision, regardless of the location of the incident;
- Program structure not meeting individual needs;
- Failure to intervene when indicated (i.e., neglect);
- Active treatment strategies that have proven to be ineffective and have not been revised to meet individual needs;
- Placement in an unsafe environment;
- Monitoring systems that are absent or are inadequate to prevent such incidents; or
- Placement with aggressive/assaultive individuals in the absence of adequate supervision.

1 Individuals are found with serious injuries of unknown origin that are suspicious based on the nature or circumstances of the injury, and on the functional or medical status of the individual.

2 Individuals are found with suspicious injuries of unknown origin and have been provided care and supervision by a person who has a confirmed history of abuse.

3 Individuals are subject to punitive techniques in the absence of positive teaching strategies or in the absence of their effectiveness.

4 Individuals suffer death/deterioration due to lack of medical attention and oversight.

5 There is observed abuse and the facility takes no action to correct the situation and protect the individual.

Guidelines §483.420(a)(5)

The facility is responsible to organize itself in such a manner that it proactively assures individuals are free from serious and immediate threat to their physical and psychological health and safety. Citing of this requirement indicates that there is a high probaddlity that abuse to individuals could occur at any time, or already has occurred and may well occur again, if the individuals are not effectively protected from the serious physical or psychological harm or injury, or if the threat is not removed. A citation of this requirement, therefore, must result in a determination of Condition level non-compliance due to immediate and serious threat. Cross reference W122 for additional guidance.

"Threat," as used in this guideline, is any condition/situation which could cause or result in severe, temporary or permanent injury or harm to the mental or physical condition of individuals, or in their death.

"Abuse" refers to the ill-treatment, violation, revilement, malignment, exploitation and/or otherwise disregard of an individual, whether purposeful, or due to carelessness, inattentiveness, or omission of the perpetrator.

"Physical abuse" refers to any physical motion or action, (e.g., hitting, slapping, punching, kicking, pinching, etc.) by which bodily harm or trauma occurs. It includes use of corporal punishment as well as the use of any restrictive, intrusive procedure to control inappropriate behavior for purposes of punishment. Observe individuals to see if they are bruised, cut, burned (cigarettes, etc.).

"Verbal abuse" refers to any use of oral, written or gestured language by which abuse occurs. This includes pejorative and derogatory terms to describe persons with disaddlities.

"Psychological abuse" includes, but is not limited to, humiliation, harassment, and threats of punishment or deprivation, sexual coercion, intimidation, whereby individuals suffer psychological harm or trauma.

Individuals must not be subjected to abuse by anyone (including, but not limited to, facility staff, consultants or volunteers, staff of other agencies serving the individual, family members or legal guardians, friends, other individuals, or themselves).

Since many individuals residing in CFs/BI are unable to communicate feelings of fear, humiliation, etc., the assumption must be made that any actions that would usually be viewed as psychologically or verbally abusive by a member of the general public, is also viewed as abusive by the individual residing in the CF/BI, regardless of that individual's perceived addlity to comprehend the nature of the incident.

The facility must take whatever action is necessary to protect the individuals residing there. For example, if a facility is forced by court order or arbitration rulings to retain or reinstate an employee believed to be abusive, the facility may need to take other measures (such as assigning the employee to an area where there is no contact with beneficiaries, providing increased supervision and additional training for the employee, appealing the arbitration or court decision or pursuing formal criminal charges) in order to ensure beneficiary safety.

Survey Procedures §483.420(a)(5)

Use the following procedures in the order shown:

- Review incident/accident reports or logs for at least a 3-6 month period and for all three shifts.

- Review recent hospitalizations or transfers to the facility infirmary as a result of an individual incident or accident.

- Note any failure of the facility to provide protective supervision, especially after knowing an individual has in the past been injured as a result of omissions in supervision. (For example, usually after 3 incidents of injury, within a short timeframe, one begins to think about the repetitive nature of the incidents. However, if even one very serious incident resulting in medical intervention has occurred, review it to assure that the facility has taken effective, corrective action.)

- After identifying those individuals repeatedly being injured, go to the living unit or wherever the injuries are reoccurring and observe the level of supervision provided.

- There are going to be unexplained injuries, given the nature of the population served. However, as a surveyor, you are examining what the facility has done to reduce the probaddlity of further injury.

- Observe individuals to determine if there is a pattern of individuals appearing fearful, suspicious, timid, shaking when approached, avoiding eye contact, overly obedient, etc.

- Other factors to evaluate include: the needs of the individuals served, the degree of program structure available in the environment, the effectiveness of active treatment strategies, and whether or not the frequency or intensity of injuries is

abnormally high or low, etc. These conditions may indicate the potential for a threat which requires in-depth investigation and evaluation.

Probes §483.420(a)(5)

Are there patterns of staff conduct which may be punitive, abusive, retributive, counterproductive or a substitute for programming towards self-control?

Is there a systematic pattern of incident reports which suggest or allege abuse?

How is the facility organized to prevent abuse (i.e., investigative systems, abuse management, analysis of incident and injury patterns, individual/parent/guardian ombudsman systems)?

Cross-reference W150 for more probes.

W128 §483.420(a)(6) Ensure that clients are free from unnecessary drugs and physical restraints and are provided active treatment to reduce dependency on drugs and physical restraints; Facility Practices §483.420(a)(6) The use of all drugs and physical restraints is based on individual need and the presenting problem cannot be addressed by other means. An active treatment program which includes mechanisms to reduce dependency on drugs and restraints is in effect, and is based on the needs of the individual. The use of a drug or restraint is discontinued if it is not effective. Drugs are not used at levels which are toxic or otherwise result in deterioration of the individual.

Guidelines §483.420(a)(6)

The chronic use of restraints may indicate one or more of the following: the individual's developmental and/or behavioral needs are not being met and the appropriateness of placement should be questioned; staff behavior may be prompting behaviors in individuals which result in the chronic use of physical restraints and drugs to control behavior; staff may have inadequate training and/or experience to provide active treatment and employ preventive measures that reduce the levels of behaviors judged to require physical restraints and drugs to control behavior; and restraints may be applied to behaviors which are, in fact, not threatening to the health and welfare of the individual or other individuals and staff.

Probes §483.420(a)(6)

Is there evidence of substitutions of one form of restrictive procedures for another, e.g., as drug usage is reduced, is there widespread increase in the use of time-out and restraint procedures and vice versa?

Does the active treatment plan address drug use, physical restraint and/or time-out modification?

Are individuals receiving any drugs for which there are no substantiated uses or active monitoring to support their use? How long is use of a psychoactive drug allowed to continue without improvement to the individual? What criteria must be satisfied before a psychiatric consultation is requested?

Cross reference W295 and W311 for more probes.

W129 §483.420(a)(7) Provide each client with the opportunity for personal privacy and Facility Practices

§483.420(a)(7)

Individuals have time to be alone, when appropriate, and to have privacy for personal interactions/activities.

Guidelines §483.420(a)(7)

The facility must have a method of arranging for privacy of visits between individuals with significant relationships, if they do not both reside at the facility.

Probes §483.420(a)(7)

Do individuals actually seek out and utilize opportunities for privacy?

Do individuals actually have places to go to be alone and are they allowed to do so? For example, are individuals allowed to go to their room alone? Allowed to go to a quiet private area, or do staff routinely "herd" individuals preventing opportunities for privacy?

Are these rights afforded to less-disabled individuals only?

Are individuals taught "private area" behavior and responsibilities?

What do you see staff do when individuals are not mindful of their or other's privacy? To what extent are

individuals talked about in the presence of other individuals?

W130 ensure privacy during treatment and care of personal needs; Facility Practices §483.420(a)(7)

Individuals have privacy during personal hygiene activities (e.g., toileting, bathing, dressing) and during medical/nursing treatments that require exposure of one's body.

Guidelines §483.420(a)(7)

The facility must examine and treat individuals in a manner that maintains the privacy of their bodies. Only employees directly involved in the treatment are present when treatments are given. Some method or mechanism which ensures privacy (such as a closed door, a drawn curtain or systematically implemented training for an individual to use their own methods) must be employed to shield the individual from passers-by. People not involved in the care of the individual should not be present without their consent while they are being examined or treated.

If an individual requires assistance during toileting, bathing, and other personal hygiene activities, staff should assist, giving utmost attention to the individual's need for privacy. There is no prohibition, however, on staff to work with individuals of the opposite sex.

Exercise special attention to ensure that your behavior, during onsite observations in the individual's home, does not violate an individual's right to privacy during treatment and care of personal needs.

Probes §483.420(a)(7)

To what extent have accommodations been made so that individuals with physical disaddlities, who otherwise would be independent, can perform basic personal hygiene activities without staff present?

How does staff preserve personal privacy of individuals when visitors are present?

W131

§483.420(a)(8) Ensure that clients are not compelled to perform services for the facility and

W132

ensure that clients who do work for the facility are compensated for their efforts at prevailing wages and commensurate with their addlities;

Facility Practices §483.420(a)(8)

The individual is not required or expected to do chores or work for the facility, other than appropriate care of one's own personal space or shared responsibility for common areas.

Guidelines §483.420(a)(8)

"Work," as used in the regulation, means any directed activity, or series of related activities which results in benefit to the economy of the facility or in a contribution to its maintenance, or in the production of a salable product. In deciding whether a particular activity constitutes "work" as defined above, the key determinant is if an individual was unavailable to perform the particular activity or function, would the facility be required to hire additional full or part-time staff (or pay overtime to existing staff) in order to properly maintain the facility or to provide necessary care services to individuals, in order to carry out its assigned mission?

Individuals are not to be used to provide a source of labor for a facility against their will or in opposition to the objectives of the IPP.

Seriously question any situation in which an individual is observed or reported to be "volunteering" to do real work that benefits the facility, or its maintenance without compensation. Interview such individuals to determine if they have given informed consent to such practices and understand that by providing employable services they are able to be compensated. This does not preclude an individual from helping out a friend or being kind to others. Self-care activities related to the care of one's own person are not considered "work" for purposes of compensation.

Regular participation in the domiciliary activities of maintaining one's own immediate household or residential living unit which can lead to the individual's greater functional addlity to perform independent household tasks is also not considered "work" for the facility. Shared duties are common and appropriate. Included in, but not limited to, these domiciliary tasks are:

- Meal planning, food purchasing, food preparation, table setting, serving, dishwashing, etc.;
- Household cleaning, laundry;
- Clothes repair;
- Light yard and house maintenance (painting, simple carpentry, etc.); and
- General household shopping, including clothing.

In general, participation in any household task which promotes greater independent functioning (and which the individual has not yet learned) is permitted as long as tasks are included in the IPP in written behavioral and measurable terms. This participation must be supervised, and indices of performance should be available. No task may be performed for the convenience of staff (e.g., supervising individuals, running personal errands) or which has no relationship to the individual's IPP.

As individuals become widely competent and independent in household tasks, they must not be used in those capacities and represented as "in training" and serious consideration should be given to the individual's potential for even less restrictive residential environments. (See also §§483.440(a)(2) and (b)(1).) However, it is acceptable for individuals to engage in household tasks which are in common with other individuals, all sharing the total household tasks commonly shared in nuclear family units. The test in this regard is:

- The expectation is that tasks are the general responsibility of the individual, and that the duties rotate to the maximum extent possible; and/or

- The individual can assume control in performing the responsibility given (e.g., John has until Thursday at 8 p.m. to clean the living and dining rooms), thereby adding to the development of internal controls and assumption of responsibility by individuals.

Work performed by the individual which no other individual is required or expected to do, or is not a regular part of running the household, must be compensated.

"Compensated" means the receipt of money or other forms of negotiable compensation for work (including work performed in an occupational training program) which is available to the individual, to be used at his or her discretion in determining the benefits to be derived therefrom.

"Prevailing wage" refers to the wage paid to non-disabled workers in nearby industry or the surrounding community for essentially the same type, quality and quantity of work or work requiring comparable skills.

A working individual must be paid at least the prevailing minimum wage except when an appropriate certificate has been obtained by the facility in accordance with current regulations and guidelines issued under the Fair Labor Standards Act, as amended.

Any individual performing work, as defined above, must be compensated in direct proportion to his or her productivity as measured in work equivalents of a regular employee's output. For example, if an individual's productivity for a particular work activity or function is determined to be 30 percent of normal output for an average non-disabled worker, and the prevailing wage is $4.00 an hour, then the individual should be compensated in money at a rate of one dollar and twenty cents per hour (.30 x $4.00 = $1.20). If a piece rate can be determined for a particular job, an individual is paid based on the number of pieces he or she produces. An individual's pay is not dependent on the production of other individuals when he or she works in a group.

When the individual's active treatment program includes assignment to occupational or vocational training or work, specific work objectives of anticipated progress should be included in the IPP along with reasons for the assignments. If the training of individuals on particular occupational activities or functions involves "real work" to be accomplished for the facility, the individuals must be compensated based on addlity. For example, if in the process of work training activities involved with learning to clean a floor, the floor for a particular building is cleaned and does not require further janitorial cleanup, then the individual must be compensated for this activity.

Probes §483.420(a)(8)

Are individuals assigned to bathe, toilet or feed other individuals?

Is each individual who provides work for the facility allowed to refuse to work for the facility? Are there individual payment records? If an individual makes less than the prevailing

wage, can that person's individual production or performance record be retrieved?

If time studies were conducted, did the facility measure the same skills as performed by persons who are not disabled? Are household tasks assigned and changed equitably? Do individuals have reasonable responsibilities, to the extent possible, for keeping their

own private areas of living unit clean and neat? Are individuals coerced to work for staff in order to gain privileges?

Are individuals trained to perform services for the facility for reinforcers or tokens rather

than pay? Do individuals work the same job everyday without pay?

W133 §483.420(a)(9) Ensure clients the opportunity to communicate, associate and meet privately with individuals of their choice, Guidelines §483.420(a)(9)

Space must be provided for individuals to receive visitors in reasonable comfort and privacy.

Probes §483.420(a)(9)

Does the facility provide individuals with the opportunity to form individual relationships with others including opportunities to experience personal relationships both within and outside the facility?

What pattern of freedom of movement do you see at the facility? Do most individuals move freely? Few?

On what basis is freedom of movement restricted? Is this dealt with programmatically in the individual program plan for each individual?

How often is this restriction re-evaluated?

W134 and to send and receive unopened mail; Guidelines §483.420(a)(9)

Assistance must be provided to individuals who require help in reading or sending mail. Refer to W145.

Probes §483.420(a)(9)

How do individuals send and receive mail?

Do staff assist individuals who are unable to open and read mail themselves? Is writing assistance provided?

W135 §483.420(a)(10) Ensure that clients have access to telephones with privacy for

incoming and outgoing local and long distance calls except as contraindicated by factors identified within their individual program plans; W136 §483.420(a)(11) Ensure clients the opportunity to participate in social, religious, and

community group activities; Facility Practices

§483.420(a)(11)

Individuals are involved in various types of activities in the community (e.g., going to parks, movies, restaurants, church, community meetings and events) based on their interests and choices.

Individuals are taught the skills and are provided with appropriate levels of support, commensurate with functional levels, for community participation.

Guidelines §483.420(a)(11)

Outdoor and out of home activities are planned for all individuals on a regular basis.

Probes §483.420(a)(11)

Are all activities agency-centered or sponsored? Are religious preferences known and honored? What is the level of individual participation (relevant to level of individual functioning):

- Fully independent?
- Staff assisted/individual participation?
- Total staff assistance?

Are the individuals allowed to participate independently in activities commensurate with their level of functioning and interest? What is the facility's system to facilitate an individual's participation?

What does the facility do to draw out non-participating individuals to the point that the individual makes his/her own active choice to participate or not?

Does the facility arrange for individuals to participate in community integrated activities individually or in small groups (3 or less) at least part of the time?

Does the facility arrange age and interest appropriate outside activities for individuals with the community (e.g., recreation centers, churches, social clubs)?

W137 §483.420(a)(12) Ensure that clients have the right to retain and use appropriate personal possessions

and clothing, and Facility Practices §483.420(a)(12)

Individuals have personal possessions and clothing which meet their needs, interests and choices.

Individuals have free access to their own possessions and clothing.

Individuals, who are unable to access and use personal possessions and clothing appropriately, are involved in programs to learn the necessary skills to do so.

Guidelines §483.420(a)(12)

All individual possessions regardless of their apparent value to others must be treated with respect, for what they are and for what they may represent to the individual. The facility should encourage individuals to use or display possessions of his or her choice in a culturally normative manner. Appropriate personal possessions includes personal care and hygiene items. Individuals should not be without personal possessions because of the behavior of others with whom they live. If a method for identifying personal effects is used, it should be inconspicuous and in a manner that will assist the individual to identify them.

"Appropriate" clothing means a supply of clothing that is sufficient, in good repair, accounts for a variety of occasions and seasons, and appropriate to age, size, gender, and level of activity. Modification or adaptation of clothing fasteners should be considered based on the needs of an individual with a physical disaddlity to be independent.

As appropriate, each individual's active treatment program maximizes opportunities for choice and self-direction with regard to choosing and shopping for clothing which enhances his or her appearance, and selecting daily clothing in accordance with age, sex and cultural norms.

Individuals are permitted to keep personal clothing and possessions for their use while in the facility. Determine how the facility both ensures the safety of personal possessions while at the same time providing individual access to them when the individual chooses.

Individuals are provided the opportunity, encouraged, and trained to use age-appropriate materials. The term "age-appropriate" refers to anything that reinforces recognition of the individual as a person of a certain chronological age. The facility's environment must be furnished with materials and activities that will enhance opportunities for growth. Determine whether the failure of an individual to achieve functional, adaptive skills, or to have opportunities to make informed choices, or to achieve any positive outcomes is a result of the constant use of materials or participation in activities that are age-inappropriate.

Probes §483.420(a)(12)

Are individuals dressed in their own clean, neat and attractive clothing? Is it of the correct size and in good condition? Is clothing appropriate for the weather and type of activity? To what extent is there a pattern of slacks that are too long or too short? Are cords and

pins used to keep pants up instead of belts?

To what extent does the facility provide items of lesser quality or provide only one type of a particular item? Is there clothing for a variety of activities (e.g., clothing for church, casual social

functions, sport events)? Do colors, styles, and designs match and conform with community standards? Are individuals assisted in clothes selection, room decoration and other forms of

self-expression?

Are individuals satisfied with the access to and choice of the kinds and numbers of personal possessions they have? How frequently during the course of the day do you observe individuals using their

personal possessions? Are individuals' personal decorative possessions displayed? Are individual possessions protected?

To what extent is there a pattern of individual loss, due to theft or destruction by others? What does the facility do to prevent loss? Is it successful? W138 ensure that each client is dressed in his or her own clothing each day; and Probes §483.420(a)(12)

To what extent are items of clothing such as pajamas, underwear, and socks, considered "stock" items as opposed to belonging to individuals?

W139

§483.420(a)(13) Permit a husband and wife who both reside in the facility to share a room. §483.420(b) Standard: Client Finances

(b)(1) The facility must establish and maintain a system that W140 §483.420(b)(1)(i) Assures a full and complete accounting of **clients' personal funds**

entrusted to the facility on behalf of clients; and Guidelines

§483.420(b)(1)(i)

A "full and complete accounting for personal funds" does not need to document accounting for incidental expenses or "pocket money," funds a capable individual handles without assistance, funds dispensed to an individual under a program to train the individual in money management, and funds that are not entrusted to the facility (e.g., funds paid directly to the individual's representative payee).

W141 §483.420(b)(1)(ii) Precludes any commingling of client funds with facility funds or with the funds of any person other than another client. Guidelines §483.420(b)(1)(ii)

Although prudent to do so, there is no Federal requirement to maintain individuals' personal funds in financial institutions in interest bearing accounts, or in accounts separate from other individual accounts. However, if the facility elects to pool individuals' funds in an interest bearing account, including common trust accounts, it is expected to know the interest separately accrued by each individual, as part of its required accounting of funds. Interest accumulated to an individual's account belongs to the individual, not the facility.

W142 **§483.420(b)(2) The client's financial rec**ord must be available on request to the client, parents (if the client is a minor) or legal guardian. Guidelines §483.420(b)(2)

Parents or other family members should not have automatic access to the financial records of adult individuals. It is not necessary that a facility be required to furnish an annual financial statement to the individual or the individual's family, since the facility is already required to make the financial record available at any time upon request. The individual, in turn, is free to choose to make his or her financial record available to anyone else.

§483.420(c) Standard: Communication With Clients, Parents, and Guardians The facility must--W143 §483.420(c)(1) Promote participation of parents (if the client is a minor) and legal guardians in the process of providing active treatment to a client unless their participation is unobtainable or inappropriate; Guidelines §483.420(c)(1)

"Unobtainable," as used in this standard, means that the facility has made a bonafide effort to seek parental or guardian participation in the process, even though the effort may ultimately be unsuccessful (for example, the parent may be impossible to locate or may prove unwilling or unable to participate).

"Inappropriate" as used in this standard means that the parent or legal guardian's behavior is so disruptive or uncooperative that others cannot effectively participate; the individual does not wish his or her parent to participate, and the individual is competent to make this decision; or there is strong evidence that the parent or guardian is not acting on the individual's behalf or in the individual's best interest. In the case of the latter, determine what the facility has done to bring effective resolution to the problem.

Probes §483.420(c)(1)

Are families contacted for involvement in planning services/treatments for individuals?

On a routine basis, what kinds of activities, information, and problems get communicated? How does the facility develop and maintain active family/guardian participation? Does the facility respond to the wishes of non-adjudicated adult individuals who do not

wish their family's involvement? Does information in the individual record correlate with information provided families? Are parents and guardians allowed to talk to direct care and service providers? What is the facility's basis for denying participation by the parents or guardians? Is there a pattern to the denials or to the reasons stated? How does the facility explain the meaning of "active treatment" to parents and

guardians?

To what extent are families informed of how to reinforce training and/or the maintenance of skills while individuals are with them? What efforts has the facility made to accommodate scheduling problems for

interdisciplinary team or other meetings of families?

W144 **§483.420(c)(2) Answer communications from clients' families and friends promptly and**

appropriately; Guidelines §483.420(c)(2)

Where possible, randomly select a family or guardian to validate the quality, nature and frequency of the communications between the facility and families or guardians (but only with their consent). There is no requirement that each contact with family and friends be documented.

Probes §483.420(c)(2)

How does the facility communicate with families and friends of those served?

Is there a pattern of lag time between contact and response which suggest responses are not timely?

W145

§483.420(c)(3) Promote visits by individuals with a relationship to the client (such as family, close friends, legal guardians and advocates) at any reasonable hour, without prior notice, consistent with the right of **that client's and other clients' privacy, unless the interdisciplinary team determines that the visit would not** be appropriate;

Guidelines §483.420(c)(3)

Any limitations of visitors are recorded by the interdisciplinary team with reason and time limits given. Decisions to restrict a visitor must be reviewed and re-evaluated each time the IPP is reviewed or at the individual's request. If you find broad restrictions, review general facility access policies.

The facility should have arrangements available to provide privacy for families and others when visiting with individuals.

Probes §483.420(c)(3)

Is there a systematic pattern of unreasonable restrictions on visitors in terms of when they can come, where they can go on the facility's property and to whom they can speak?

W146

§483.420(c)(4) Promote visits by parents or guardians to any area of the facility that provides direct client **care services to the client, consistent with the right of that client's and other clients' privacy;**

Probes §483.420(c)(4)

Is there a pattern to the types of restricted locations?

Is there evidence such as "no admittance" signs or policies against visitors in any of these areas?

W147

§483.420(c)(5) Promote frequent and informal leaves from the facility for visits, trips, or vacations; and Guidelines §483.420(c)(5)

It is not acceptable for a facility to sponsor or allow individuals to take a particular type of trip that is contraindicated. For example, in the situation of an individual subject to abuse by a parent, the facility obviously is not required to permit such a trip. However, as with any right that may need to be modified or limited, the individual should be provided with the least restrictive and most appropriate alternative available.

Probes §483.420(c)(5)

What is the frequency of these outings? What types of outings? Are outings age-appropriate? How does the facility provide choice in outings? Can individuals choose not to participate?

W148

§483.420(c)(6) Notify promptly the client's parents or guardian of any significant incidents, or changes in the client's condition including, but not limited to, serious illness, accident, death, abuse, or unauthorized absence.

Guidelines §483.420(c)(6)

"Significant" incidents or changes in the individual's condition refers to any type of occurrence or event, that is perceived to have some level of importance to the individual, family or guardian. Examples include, but are not limited to, allegations of mistreatment, psychological trauma experienced by the individual, loss or change of a program service or staff person, entry or placement in new programs or agencies, day-to-day events on which family members express interest to be informed, etc.

Probes §483.420(c)(6)

Are family members/guardians informed of incidents/alleged abuse?

Are telephone numbers and addresses for parents and guardians kept and periodically updated? What is the time frame for notification?

§483.420(d) Standard: Staff Treatment of Clients W149 §483.420(d)(1) The facility must develop

and implement written policies and

procedures that prohibit mistreatment, neglect or abuse of the client. Facility Practices

483.420(d)(1)

The facility, through implementation of its policies, has set up a structure which protects individuals from mistreatment, neglect and abuse.

Guidelines §483.420(d)(1)

"Mistreatment" as used in this standard, includes behavior or facility practices that result in any type of individual exploitation such as financial, sexual, or criminal.

"Neglect" means failure to provide goods or services necessary to avoid physical or psychological harm.

See W127 for definitions related to "abuse."

Probes §483.420(d)(1)

Refer to W186 because there is often a relationship between the adequacy of facility staffing and staff treatment of individuals.

Is there a pattern among incidents of alleged abuse, accidents, behavior programs, psychoactive drug use, staff training, and adequacy of staffing levels that may suggest possible mistreatment, neglect or abuse of individuals?

How does the facility monitor staff treatment of individuals to ensure that the requirements are not being violated?

W150 §483.420(d)(1)(i) Staff of the facility must not use physical, verbal, sexual or psychological abuse or

punishment. Guidelines §483.420(d)(1)(i)

See W127, Facility Practices, as related specifically to staff of the facility.

A citation of this requirement indicates that abuse to an individual by staff of the facility is highly likely to occur or has already occurred and may well occur again if the individual is not effectively protected. A citation of this requirement, therefore, must result in Condition-level non-compliance due to immediate and serious threat. Cross reference W122 and W127.

Probes §483.420(d)(1)(i)

Can staff define what constitutes abuse and punishment? Are programs or policies "masks" for punitive, abusive controls? How does the facility actively promote respect for individuals? How do staff members set acceptable behavioral limits for individuals? Does group punishment occur? Does demeaning, belittling or degrading punishment occur? Do staff speak loudly, harshly? In negative, punishing terms? With threats, coercion?

Cross-reference W127 for definitions and additional probes.

W151 §483.420(d)(1)(ii) Staff must not punish a client by withholding food or hydration that contributes to a nutritionally adequate diet. Guidelines §483.420(d)(1)(ii)

Cross-reference W465.

W152

§483.420(d)(1)(iii) The facility must prohibit the employment of individuals with a conviction or prior employment history of child or client abuse, neglect or mistreatment.

Facility Practices §483.420(d)(1)(iii)

No one hired after October 3, 1988, has had a conviction or a prior employment history of child or client abuse, neglect or mistreatment of which the facility was aware based on pre-employment screening.

No one with a conviction or substantiated allegation of child or client abuse, neglect or mistreatment occurring outside the jurisdiction of the CF/BI after October 3, 1988, regardless of employment date, is employed by the facility.

Guidelines §483.420(d)(1)(iii)

This regulation applies to the hiring of new employees on or after October 3, 1988. The facility is required to screen potential employees for a prior employment history of child or client abuse, neglect or mistreatment, as well as for any conviction based on those offenses. The abuse, neglect or mistreatment must be directed toward a child or an individual who is a client (resident, patient) in order for the prohibition of employment to apply.

This requirement also applies to acts of abuse, neglect or mistreatment committed by a current CF/BI employee outside the jurisdiction of the CF/BI (e.g., in the community or in another health care facility). A substantiated allegation of abuse, neglect or mistreatment which occurred after October 3, 1988, (regardless of the date of the person's employment in the CF/BI), and which resulted in the termination of that person's employment from another health care facility, becomes a part of the person's employment history and the CF/BI is prohibited from continuing to employ the individual. For example, an individual who abused a resident in a nursing facility and as a result, is barred from employment in the nursing home setting would also be prohibited from employment in the CF/BI. While facilities are not required to periodically screen existing employees, if the facility becomes aware that such action has been taken against an employee, the facility is required to prohibit continued employment. This is also true of any conviction in a court of law for child or client (resident, patient) abuse, neglect or mistreatment. Therefore, conviction for abusing one's own child is also a reason employment would be prohibited.

The definition of "mistreatment" under the guideline at W153 includes financial exploitation. Therefore, if an employee was convicted or had a prior employment history of theft of an individual's funds, that would also be a reason employment would be prohibited.

Access other information, as appropriate, including information contained in "closed" records, in order to adequately evaluate compliance.

Probes §483.420(d)(1)(iii)

How does the facility screen employees for previous convictions?

Who are the facility's new hires? Has the facility implemented its system in such a fashion to ensure that W152 has been achieved?

W153

§483.420(d)(2) The facility must ensure that all allegations of mistreatment, neglect or abuse, as well as injuries of unknown source, are reported immediately to the administrator or to other officials in accordance with State law through established procedures.

Guidelines §483.420(d)(2)

The facility is responsible for reporting any injuries of unknown origin and any allegations of mistreatment to an individual residing in the facility regardless of who is the perpetrator (e.g., facility staff, parents, legal guardians, volunteer staff from outside agencies serving the individual, neighbors, or other individuals, etc.).

Probes §483.420(d)(2)

How many alleged violations have been reported this year? Last year?

What mechanisms are in place to ensure prompt detection, reporting, and appropriate follow-up?

W154

§483.420(d)(3) The facility must have evidence that all alleged violations are thoroughly investigated and

W155 must prevent further potential abuse while the investigation is in progress.

Guidelines §483.420(d)(3)

The facility is responsible for investigating all injuries of unknown origin and

Probes §483.420(d)(3)

After you review reports of investigation, do you identify a pattern to the depth, thoroughness, conclusions and actions taken that suggest:

- Comprehensive and responsive investigations?
- Well conducted but negated or altered reports?
- Shallow or routinized investigations?

W156

§483.420(d)(4) The results of all investigations must be reported to the administrator or designated representative or to other officials in accordance with State law within five working days of the incident and,

Guidelines §483.420((d)(4)

Some States require that allegations of abuse must be reported to the police. CMS cannot regulate the activities of the police. However, if the police take longer than five working days for their investigation, the facility is still required to complete an internal investigation report of findings within the five day timeframe. "Working days" means Monday through Friday, excluding State and Federal holidays.

Probes §483.420(d)(4)

If a report of known or suspected abuse or neglect involves the acts or omissions of the administrator, how has the provider arranged for an unbiased review of the allegation (such as, an authority outside of the facility investigating the report and, if necessary, taking appropriate corrective action)?

W157 if the alleged violation is verified, appropriate corrective action must be taken. Facility Practices

§483.420(d)(4)

The seriousness of the violation is considered by the facility to determine appropriate corrective action.

When the intentional action or inaction of a staff person has resulted in abuse, neglect or mistreatment which was a serious and immediate threat to the individual's health and safety, the staff person's employment is terminated.

The corrective action taken by the facility is reasonably likely to assure that the abuse, neglect, mistreatment or injury will not occur again.

Guidelines §483.420(d)(4)

This requirement refers to corrective action taken based upon findings of investigations of incidents which have occurred within the jurisdiction of the facility. It requires that the seriousness of infractions be weighed in the determination of what action is necessary by the facility to correct the situation appropriately. In cases of abuse, neglect or mistreatment by staff, where extenuating circumstances exist and dependent on the nature of the infraction, a remedy that is consistent with appropriate progressive disciplinary measures may be acceptable. When the intentional action or inaction of a staff person has resulted in abuse, neglect or mistreatment which poses a serious and immediate threat to individuals' health and safety, termination of employment is the only acceptable corrective action.

Appropriate corrective action is also required for findings of abuse, neglect or mistreatment by other individuals residing in the facility, staff of outside agencies, parents or any other person, and for injuries to individuals resulting from controllable environmental factors.

Appropriate corrective action is defined as that action which is reasonably likely to prevent the abuse, neglect, mistreatment or injury from recurring.

When an employee appeals a finding of abuse by the facility, whether through arbitration or in a court of law, the decision of the arbitrator or the court of law is then considered the final finding. If the arbitrator found that the charges lacked substance, the allegation would be considered unsubstantiated. The facility, however, is still required to ensure that individuals residing in the facility are not subjected to physical, verbal, sexual or psychological abuse or punishment by W127.

An arbitrator may find that the allegation of abuse is substantiated, but impose a lesser penalty than that which was sought by the facility. For example, the facility may seek termination of employment as the appropriate corrective action but the arbitrator determines that a 10 day suspension is more appropriate. The facts of the situation will have to be evaluated by the surveyor and a judgment made regarding appropriateness. Therefore, while the facility is permitted by the regulation to exercise judgment regarding appropriate corrective action, the surveyor must also exercise judgment and may determine that the corrective action is NOT reasonably likely to prevent the abuse from recurring.

Probes §483.420(d)(4)

After investigations have been completed, how many alleged violations culminated in progressive discipline actions? Staff discharges?

As a result of the facility's investigations, is there a pattern of reduction of allegations?

W158 §483.430 Condition of Participation: Facility Staffing §483.430 Compliance Principles

The Condition of Participation of Facility Staffing is met when:

- The Condition of Participation of Active Treatment is met (i.e., there are sufficient numbers of competent, trained staff to provide active treatment.); and

- The Condition of Participation of Client Protections is met (i.e., there are sufficient numbers of competent, trained staff to protect individuals' health and safety.).

The Condition of Participation of Facility Staffing is not met when:

- The Condition of Participation of Active Treatment has first been determined to be not met and the lack of active treatment has resulted from insufficient numbers of staff or lack of trained, knowledgeable staff to design and carry out individual's programs; or

- The Condition of Participation of Client Protections has first been determined to be not met and the lack of client protection has resulted from insufficient numbers of competent, trained staff to protect the health and safety of individuals.

§483.430(a) Standard: Qualified Brain Injury Professional W159 **Each client's active**

treatment program must be integrated, coordinated and

monitored by a qualified Brain Injury professional Facility Practices §483.430(a)

There is an assigned qualified Brain Injury professional (QMRP). There are sufficient numbers of QMRPs to accomplish the job. The QMRP observes individuals, reviews data and progress, and revises programs based on individual need and performance. The QMRP ensures consistency among external and internal programs and disciplines.

The QMRP ensures service design and delivery which provides each individual with an appropriate active treatment program.

The QMRP ensures that any discrepancies or conflicts between programmatic, medical, dietary, and vocational aspects of the individual's assessment and program are resolved.

The QMRP ensures a follow-up to recommendations for services, equipment or programs.

The QMRP ensures that adequate environmental supports and assistive devices are present to promote independence.

Guidelines §483.430(a)

View the person serving in the QMRP role as pivotal to the adequacy of the program the individual receives, since it is this role that is intended to ensure that the individual receives those services and interventions necessary by competent persons capable of delivering them. The paramount importance of having persons competent to judge and supervise active treatment issues cannot be overstated.

An individual's IPP may be coordinated and monitored by more than one QMRP or by other staff persons who perform the QMRP duties. There must, however, be one QMRP who is assigned primary responsibility and accountaddlity for the individual's IPP and the QMRP function.

The regulations do not specify if the person designated as QMRP must do the duties of a QMRP exclusively, or is allowed to perform other professional staff duties in addition. The facility has the flexibility to allocate staff resources in whatever manner it believes is necessary as long as it ensures that the QMRP function is performed effectively for each individual.

The test of whether the number of QMRPs is adequate rests with the addlity of the facility to provide the services described in §483.430(a) in an effective manner. The number will vary depending on such factors as the number of individuals the facility serves, the complexity of needs manifested by these individuals, the number, qualifications and competencies of additional professional staff members, and whether or not other duties are assigned to the QMRP function.

Probes §483.430(a)

Are the QMRP functions actually being carried out, or is paperwork simply reviewed?

Are timely modifications of unsuccessful programs or development of programs for unaddressed, but significant needs made or ensured by the QMRP function?

Are program areas visited and are performance and problems of individuals discussed?

Does the plan flow from only the original diagnosis/assessment? Does it take into consideration interim progress on plans and activities?

Does the QMRP make recommendations and requests on behalf of individuals? How does the facility respond?

W160 Who--§483.430(a)(1) Has at least one year of experience working directly with persons

with Brain Injury or other developmental disaddlities; and (a)(2) Is one of the following: W161 (a)(2)(i) A

doctor of medicine osteopathy. W162

(a)(2)(ii) A registered nurse. W163 **(a)(2)(iii) An individual who holds at least a bachelor's degree in a**

professional

category specified in paragraph (b)(5) of this section. §483.430(b) Standard: Professional Program

Services W164 §483.430(b)(1) Each client must receive the professional program services needed to

implement the active treatment program defined by each client's individual program plan. Facility Practices

§483.430(b)(1)

Individuals receive professional services when the comprehensive functional assessment or the active treatment program defined by the IPP requires the knowledge, skills and expertise of someone specially trained in a given discipline in order to be effectively implemented.

In the presence of a functional deficit, there is input by the relevant professional discipline(s) in order to assess the individual and develop a relevant active treatment program.

Guidelines §483.430(b)(1)

For an active treatment program to be responsive to the individual's unique needs, there must be a foundation of competent professional knowledge that can be drawn upon in the implementation of the interdisciplinary team process. Individuals with developmental deficits will require initial, temporary, or ongoing services from professional staff, knowledgeable about contemporary care practices associated with these areas. A special mention needs to be made that individuals should not be provided with services that are not needed (e.g., if an individual is basically healthy and not on medication, then the individual should not be provided extensive health and health-related services).

The needs identified in the initial comprehensive functional assessment, as required in §483.440(c)(3)(v), should guide the team in deciding if a particular professional's further involvement is necessary and, if so, to what extent professional involvement must continue on a direct or indirect basis.

Since such needed professional expertise may fall within the purview of multiple professional disciplines, based on overlapping training and experience, determine if the facility's delivery of professional services is adequate by the extent to which individuals' needs are aggressively and competently addressed. Some examples in which professional expertise may overlap include:

- Physical development and health: nurse (routine medical or nursing care needs that do not interfere with participation in other programs); physician, physician assistant, nurse practitioner (acute major medical intervention, or the treatment of chronic medical needs which will be dependent upon an individual's success or failure in other treatment programs).

- Nutritional status: nurse (routine nutritional needs that do not affect participation in other programs); nutritionist or dietitian (chronic health problems related to nutritional deficiencies, modified or special diets).

- Sensorimotor development: physical educators, adaptive physical educators, recreation therapists, (routine motor needs involving varying degrees of physical fitness or dexterity); special educators or other visual impairment specialists (specialized mobility training and orientation needs); occupational therapist, physical therapist, physiatrist (specialized fine and gross motor needs caused by muscular, neuromuscular, or physical limitations, and which may require the therapeutic use of adaptive equipment or adapted augmentative communication devices to increase functional independence); dietitians to increase specialized fine and gross motor skills in eating.

- Affective (emotional) development: special educators, social workers, psychologists, psychiatrists, mental health counselors, rehaddlitation counselors, behavior therapists, behavior management specialists.

- Speech and language (communication) development: speech-language pathologists, special educators for people who are deaf or hearing impaired.

- Auditory functioning: audiologists (basic or comprehensive audiologic assessment and use of amplification equipment); speech-language pathologists (like audiologists, may perform aural rehaddlitation); special educators for individuals who are hearing impaired.

- Cognitive development: teacher (if required by law, i.e., school aged children, or if pursuit of GED is indicated), psychologist, speech-language pathologist.

- Vocational development: vocational educators, occupational educators, occupational therapists, vocational rehaddlitation counselors, or other work specialists (if development of specific vocational skills or work placement is indicated).

- Social Development: teachers, professional recreation staff, social workers, psychologists (specialized training needs for social skill development).

- Adaptive behaviors or independent living skills: Special educators, occupational therapists

W165 Professional program staff must work directly with clients Facility Practices §483.430(b)(1)

Individuals receive interventions or services directly from professional staff when required by individual needs, program design, implementation, or monitoring.

W166 and with paraprofessional, nonprofessional and other professional program staff who work with clients. Facility Practices §483.430(b)(1)

When required by individual need, program design, implementation, or monitoring, professional staff work directly with paraprofessional, nonprofessional and other professional program staff to assure that these individuals have the skills necessary to carry out the needed interventions.

Guidelines §483.430(b)(1)

There are some individuals in CFs/BI who can often have their needs effectively met without having direct contact with professional staff on a daily basis. The intent of the requirement is not to require that professionals work directly with individuals on a daily basis, but only as often as an individual's needs indicate that professional contact is necessary. The amount and degree of direct care that professionals must provide will depend on the needs of the individual and the addlity of other staff to train and direct individuals on a day-to-day basis.

W167

§483.430(b)(2) The facility must have available enough qualified professional staff to carry out and monitor the various professional interventions in accordance with the stated goals and objectives of every individual program plan.

Facility Practices §483.430(b)(2)

Each individual receives professional interventions as needed and specified in the IPP, in sufficient quantity to assure correct implementation.

Guidelines §483.430(b)(2)

If there is sufficient evidence that para- and non-professional staff demonstrate the needed competencies to carry through with intervention strategies, you may be satisfied there is sufficient professional staff to carry out the active treatment program. However, if the professional's expertise is not demonstrable at the para- and non-professional staff level, question both the numbers of professional staff and the effectiveness of the transdisciplinary training of para- and non-professional staff.

Probes §483.430(b)(2)

Are these services available when they are most beneficial for the individual? Are these people available to staff on

other shifts? Weekend staff? Are professional staff available to monitor the implementation of individual programs

if

necessary?

W168 §483.430(b)(3) Professional program staff must participate as members of the interdisciplinary team in relevant aspects of the active treatment process. Facility Practices §483.430(b)(3)

When necessary to develop, implement or monitor an individual's active treatment program, appropriate professional staff participate as interdisciplinary team (IDT) members.

Guidelines §483.430(b)(3)

"Participate" means providing input through whatever means is necessary to ensure that the individual's IPP is responsive to the individual's needs. The purpose of the interdisciplinary team process is to provide team members with the opportunity to review and discuss information and recommendations relevant to the individual's needs, and to reach decisions as a team, rather than individually, on how best to address those needs. Therefore, determine whether or not there is a pattern of active treatment based on professional participation in the process.?

Without a negative outcome to demonstrate that professional involvement in any aspect of the active treatment process (e.g., comprehensive functional assessment, IPP development, program implementation, etc.) was insufficient or inaccurate, the facility is allowed the flexibility to use its resources in a manner that works in behalf of the client, in accordance with the regulations.

W169

§483.430(b)(4) Professional program staff must participate in on-going staff development and training in both formal and informal settings with other professional, paraprofessional, and nonprofessional staff members.

Facility Practices §483.430(b)(4)

Professional staff receive training in their own discipline to assure adequate delivery of services and to be aware of developments in their field.

Professional staff receive training in other disciplines to the extent necessary to meet the needs of each individual.

Professional staff provide training to others.

Guidelines §483.430(b)(4)

"Participate" means both seeking out self-training and provision of training to others.

W170

§483.430(b)(5) Professional program staff must be licensed, certified, or registered, as applicable, to provide professional services by the State in which he or she practices.

Probes 483.430(b)(5)

How does the facility verify that its professionals meet State licensing requirements?

Those professional program staff who do not fall under the jurisdiction of State licensure, certification, or registration requirements, specified in §483.410(b), must meet the following qualifications:

W171

§483.430(b)(5)(i) To be designated as an occupational therapist, an individual must be eligible for certification as an occupational therapist by the American Occupational Therapy Association or another comparable body.

Guidelines §483.430(b)(5)(i)-(ix)

The introductory phrase "to be designated as..." means that a provider is allowed to represent him or herself as a professional provider in that discipline, only if the provider meets State licensing requirements, or if the particular discipline does not fall under State licensure requirements, the provider meets the qualifications specified in §§483.430(b)(5)(i)-(ix). A person who is not qualified, for example, as a social worker, may not be referred to as a social worker per se. Nevertheless, such a person may be able to provide social services in an CF/BI if there is no conflict with State law, and as long as the individuals' needs are met.

W172

§483.430(b)(5)(ii) To be designated as an occupational therapy assistant, an individual must be eligible for certification as a certified occupational therapy assistant by the American Occupational Therapy Association or another comparable body.

W173

§483.430(b)(5)(iii) To be designated as a physical therapist, an individual must be eligible for certification as a physical therapist by the American Physical Therapy Association or another comparable body.

W174

§483.430(b)(5)(iv) To be designated as a physical therapy assistant, an individual must be eligible for registration by the American Physical Therapy Association or be a graduate of a two year college-level program approved by the American Physical Therapy Association or another comparable body.

W175

§483.430(b)(5)(v) To be designated as a psychologist, an individual must have at least a master's degree in psychology from an accredited school.

§483.430(b)(5)(vi) To be designated as a social worker, an individual must-

W176

§483.430(b)(5)(vi)(A) Hold a graduate degree from a school of social work accredited or approved by the Council on Social Work Education or another comparable body; or

§483.430(b)(5)(vi)(B) Hold a Bachelor of Social Work degree from a college or university accredited or approved by the Council on Social Work Education or another comparable body.

§483.430(b)(5)(vii) To be designated as a speech-language pathologist or audiologist, an individual must-

W177

§483.430(b)(5)(vii)(A) Be eligible for a Certificate of Clinical Competence in Speech-Language Pathology or Audiology granted by the American Speech-Language-Hearing Association or another comparable body; or

§483.430(b)(5)(vii)(B) Meet the educational requirements for certification and be in the process of accumulating the supervised experience required for certification.

W178

§483.430(b)(5)(viii) To be designated as a professional recreation staff member an individual must have a **bachelor's degree in recreation or in a specialty** area such as art, dance, music or physical education.

W179

§483.430(b)(5)(ix) To be designated as a professional dietitian, an individual must be eligible for registration by the American Dietetics Association

Guidelines §483.430(b)(5)(ix)

The Commission on Dietetic Accreditation of the American Dietetic Association is the organization to whom the American Dietetic Association delegates this responsibility.

W180

§483.430(b)(5)(x) To be designated as a human services professional an individual must have at least a **bachelor's degree in a human services field (including, but not limited to: sociology, special education,** rehaddlitation counseling, and psychology).

Guidelines §483.430(b)(5)(x)

The intent for including a "human services professional" category is to expand the number and types of persons who could qualify as QMRPs, while still maintaining acceptable professional standards.

"Human services field" includes all the professional disciplines stipulated in §§483.430(a)(3)(i)(ii) and §§483.430(b)(5)(i)-(ix), as well as any related academic disciplines associated with the study of: human behavior (e.g., psychology, sociology, speech communication, gerontology etc.), human skill development (e.g., education, counseling, human development), humans and their cultural behavior (e.g., anthropology), or any other study of services related to basic human care needs (e.g., rehaddlitation counseling), or the human condition (e.g., literature, the arts).

An individual with a "bachelors degree in a human services field" means an individual who has received: at least a bachelor's degree from a college or university (master and doctorate degrees are also acceptable) and has received academic credit for a major or minor coursework concentration in a human services field, as defined above. Although a variety of degrees may satisfy the requirements, majors such as geology and chemical engineering are not acceptable.

Taking into consideration a facility's needs, the types of training and coursework that a person has completed, and the intent of the regulation, the facility and you can exercise wide latitude of judgment to determine what constitutes an acceptable "human services" professional. Again, the key concern is the demonstrated competency to do the job.

W181 **§483.430(b)(5)(xi) If the client's individual program plan is being successfully implemented by facility** staff, professional program staff meeting the qualifications of paragraph (b)(5)(i) through (x) of this section are not required--(b)(5)(xi)(A) Except for qualified Brain Injury professionals; (b)(5)(xi)(B) Except for the **requirements of paragraph (b)(2) of this section concerning the facility's provision of enough qualified** professional program staff; and

(b)(5)(xi)(C) Unless otherwise specified by State licensure and certification requirements. §483.430(c) Standard: Facility Staffing W182 §483.430(c)(1) The facility must not depend upon clients or volunteers to perform

direct care services for the facility. Facility Practices

§483.430(c)(1)

The facility has sufficient staff to provide needed care and services without the use of volunteers or enlisting the help of individuals residing in the facility.

Guidelines §483.430(c)(1)

Volunteers may provide supplementary services. The facility may not rely on volunteers to fill required staff positions and perform direct care services.

Examine closely the adequacy of staffing when individuals served are engaged in the care, training, treatment or supervision of other individuals, either as part of training, "volunteer work," or normal daily routines. (See W131-W132 for additional interpretation of productive work done as a "volunteer" or as part of the individual's active treatment program.) The test of adequacy is whether or not there is sufficient staff to accomplish the job in the absence of the individual's work. Work done as part of an active treatment training program requires that the staff are monitoring and teaching new skills as part of the IPP.

Probes §483.430(c)(1)

After observing client or volunteer activities done with individuals served, can you determine whether or not those same services should and could have been provided reasonably by the facility, in the absence of those clients or volunteers?

Are individuals served assigned to bathe, toilet, feed or supervise other individuals served in the absence of hired staff?

W183 §483.430(c)(2) There must be responsible direct care staff on duty and awake on a 24-hour basis, when clients are present, to take prompt, appropriate action in case of injury, illness, fire or other emergency, in each defined residential living unit housing--(c)(2)(i) Clients for whom a physician has ordered a medical care plan; (c)(2)(ii) Clients who are aggressive, assaultive or security risks; (c)(2)(iii) More than 16 clients; or (c)(2)(iv) Fewer than 16 clients within a multi-unit building. Facility Practices §483.430(c)(2)

Staff are awake and providing needed care and services for the types of individual living arrangements specified.

Staff know how to handle emergency situations for the types of individual living arrangements specified.

Guidelines §483.430(c)(2)

The test of adequacy about "awake" staffing is how well the facility has organized itself to detect and react to potential emergencies, such as fire, injuries, health emergencies described in the medical care plan (e.g., aspiration, cardiac or respiratory failure, uncontrolled seizures) and behavioral crises described in the IPP.

Probes §483.420(c)(2)

Are there incidences of aggression, assault, or individuals leaving the building at night, without immediate detection?

W184 §483.420(c)(3) There must be a responsible direct care staff person on duty on a 24 hour basis (when clients are present) to respond to injuries and symptoms of illness, and to handle emergencies, in each defined residential living unit housing (c)(3)(i) Clients for whom a physician has not ordered a medical care plan; (c)(3)(ii) Clients who are not aggressive, assaultive or security risks; and (c)(3)(iii) Sixteen or fewer clients.

Facility Practices §483.430(c)(3)

Staff are available and know how to respond to individual needs and emergencies at all times.

Guidelines §483.430(c)(3)

The intent of the regulation is that at all times a staff person is in a position to help if individual needs arise. For purposes of this provision, "on duty" staff need not be awake during normal bedtime hours.

Facilities sending some or all of the individuals to out of home or off grounds active treatment programs for a majority of the day need not provide a full complement of direct care staff in the residence during their absence. However, a minimum of one staff person must be on duty, if even one individual is present.

W185

§483.420(c)(4) The facility must provide sufficient support staff so thatdirect care staff are not required to perform support services to the extent that these duties interfere with the exercise of their primary direct client care duties.

Facility Practices §483.430(c)(4)

Direct care staff are not diverted from their primary direct care duties to perform support functions (e.g., making beds, cooking, cleaning, etc.) when individual needs and programming require their presence and involvement.

Guidelines §483.430(c)(4)

"Support staff" include all personnel hired by the facility that are not either direct care staff or professional staff. For example, support staff include, but are not limited to, secretaries, clerks, housekeepers, maintenance and laundry personnel.

Direct care staff should be utilized at their highest level of competence, but they may assume other roles as long as their addlity to exercise their primary direct care duties is not diluted. For example, direct care staff may serve as aides in a training program during the hours individuals are away from the living unit.

Probes §483.430(c)(4)

Is there observational or other evidence to suggest that individuals are being neglected (e.g., demonstrate need for toileting, changing, active treatment interventions) while staff do laundry, housekeeping, cooking or serving household tasks?

§483.430(d) Standard: Direct Care Residential Living Unit Staff W186

(1) The facility must provide sufficient direct care staff to manage and supervise clients in accordance with their individual program plans.

Facility Practices §483.430(d)(1)

There are sufficient numbers of direct care staff over and above minimum ratios to meet individual's needs and to implement the active treatment program as defined in the IPP. There are sufficient numbers of direct care staff to provide needed care and services so that individuals do not injure themselves, others, or destroy property.

Special staffing needs identified by the IPP (e.g., 1:1s) are provided.

There are adequate numbers of direct care staff to supervise individuals during periods of time when other direct care staff are unavailable, e.g., breaks, meals, meetings, training, etc.

Guidelines §483.430(d)(1)

"Sufficient" direct care staff means the number of staff, over and above the ratios specified in §483.430(d)(3), necessary to implement active treatment, as dictated by the individual's active treatment needs.

Do not look at numbers alone. The facility is responsible for organizing and evaluating its individual appointments, programming schedules, activities, materials, equipment, grouping assignments and available staff in such a way that maximizes benefit to the individual. During the course of the onsite survey, you should be able to observe behavioral evidence of such organization. Evaluate this data in light of the success or failure observed relevant to providing active treatment, and come to a judgment about the adequacy of the facility's staffing.

§483.420(c)(2) Direct care staff are defined as the present on-duty staff calculated over all shifts in a 24-hour period for each defined residential living unit.

Guidelines §483.430(d)(2)

"Direct care staff" are those personnel whose daily responsibility it is to manage, supervise and provide direct care to individuals in their residential living units. This staff could include professional staff (e.g., registered nurses, social workers) or other support staff, if their primary assigned daily shift function is to provide management, supervision and direct care of individuals' daily needs (e.g., bathing, dressing, feeding, toileting, recreation and reinforcement of active treatment objectives) in their living units. However, professional staff who simply work with individuals in a living unit on a periodic basis cannot be included. Also, supervisors of direct care staff can be counted only if they share in the actual work of the direct care of individuals. Supervisors whose principal assigned function is to supervise other staff cannot be included.

W187

§483.420(d)(3) Direct care staff must be provided by the facility in the following minimum ratios of direct care staff to clients:

(d)(3)(i) For each defined residential living unit serving children under the age of 12, severely and profoundly retarded clients, clients with severe physical disaddlities, or clients who are aggressive, assaultive, or securi' risks, or who manifest severely hyperactive or psychotic-like behavior, the staff to client ratio is 1 to 3.2;

(d)(3)(ii) For each defined residential living unit serving moderately retarded clients, the staff to client ratio is 1 to 4;

(d)(3)(iii) For each defined residential living unit serving clients who function within the range of mild retardation, the staff to client ratio is 1 to 6.4.

Guidelines §483.430(d)(3)

The minimum ratios in this standard indicate the minimum number of direct-care staff that must be present and on duty, 24 hours a day, 365 days a year, for each discrete living unit. It does not include anyone functioning as direct care staff. For example, to calculate the minimum number of living unit staff that must be present and on duty in a discrete living unit serving 16 individuals with multiple disaddlities: divide the number of individuals "16," by the number corresponding to the regulation "3.2," the result equals "5." Therefore, the facility must determine how many staff it must hire to ensure that at least 5 staff will be able to be present and on duty during the 24 hour period in which those individuals are present.

Using the living unit described above, "calculated over all shifts in a 24-hour period" means that there are present and on duty every day of the year: one direct care staff for each eight individuals on the first shift (1:8), one direct care staff for each eight individuals on the second shift (1:8), and one direct care staff for each 16 individuals on the third shift (1:16). Therefore, there are five (5) direct care staff present and on duty for each twenty-four hour day, for 16 individuals. The same calculations are made for the other ratios, whichever applies. Determine if absences of staff for breaks and meals results in a pattern of prolonged periods in which present and on-duty staff do not meet the ratios.

W188

§483.420(d)(4) When there are no clients present in the living unit, a responsible staff member must be available by telephone. §483.430(e) Standard: Staff Training Program W189 §483.420(e)(1) The facility must provide each employee with initial and continuing

training that enables the employee to perform his or her duties effectively, efficiently, and competently

Facility Practices §483.430(e)(1)

Staff have received training, both upon hiring and on an ongoing basis, which results in the competencies needed to do their job.

Probes §483.430(e)(1)

Is there an observed systemic lack of appropriate interactions and interventions with individuals?

Does interview of staff and review of in-service records confirm little or no training activities?

Does new staff receive orientation to the facility and the individuals with whom they are to work?

§483.420(e)(2) For employees who work with clients, training must focus on skills and competencies **directed toward clients'**

Guidelines §483.430(e)(2)

View in-service training as a dynamic growth process. It is predicated on the view that all levels of staff can share competencies which enable the individual to benefit from the consistent, wide-spread application of the interventions required by the individual's particular needs.

In the final analysis, the adequacy of the in-service training program is measured in the demonstrated competencies of all levels of staff relevant to the individual's unique needs as well as in terms of the "affective" characteristics of the caregivers and the personal quality of their relationships with the individuals. Observe the staff's knowledge by observing the outcomes of good transdisciplinary staff development (i.e., in the principles of active treatment) in such recommended competencies as:

- Respect, dignity, and positive regard for individuals (e.g., how staff refers to individuals, refer to W150);
- Use of behavioral principles in training interactions between staff and individuals;
- Use of developmental programming principles and techniques, e.g., functional training techniques, task analysis, and effective data keeping procedures;
- Use of accurate procedures regarding abuse detection and prevention, restraints, medications, individual safety, emergencies, etc.;
- Use of adaptive mobility and augmentative communication devices and systems to help individuals achieve independence in basic self-help skills; and
- Use of positive behavior intervention programming.

Probes §483.430(e)(2)

Does the staff training program reflect the basic needs of the individuals served within the program?

Does observation of staff interactions with individuals reveal that staff know how to alter their own behaviors to match needs and learning style of individuals served?

W190 developmental, Facility

Practices §483.430(e)(2)

Staff are observed to demonstrate cross-cutting skills which are appropriate when training and interacting with any individual with developmental disaddlities (e.g., shaping, breaking tasks into small steps, providing positive reinforcement, providing informal opportunities to practice skills, using appropriate materials, etc.).

W191 behavioral, Facility Practices §483.430(e)(2)

Staff are observed to demonstrate cross-cutting skills and interactions which are effective in addressing inappropriate behavior and in supporting appropriate behavior for any individual (e.g., teaching and reinforcing positive, adaptive or incompatible behaviors, diffusion strategies, environmental manipulation, differential reinforcement of other behaviors (DRO), differential reinforcement of incompatible behaviors (DRI), physical management techniques, etc.).

W192 and health needs. Facility Practices §483.430(e)(2)

Staff display the knowledge and competence to address the health and emergency medical needs of the individuals residing in the facility.

W193

§483.430(e)(3) Staff must be able to demonstrate the skills and techniques necessary to administer interventions to manage the inappropriate behavior of clients. Facility Practices §483.430(e)(3)

Staff have the knowledge to correctly and consistently implement the intervention techniques specified in the behavior plans of individuals with whom they are working.

Guidelines §483.430(e)(3)

Observe staff interactions with individuals to see if the specific interventions, techniques and strategies to change inappropriate behavior outlined in the sampled individual's program plans are correctly implemented. In the absence of implementation, investigate further to determine if there was a justifiable reason for not implementing an intervention (e.g., the plan was revised, the specific situation demanded a different approach, the conditions for use of a particular technique were not present, etc.) When staff are unable to demonstrate how to correctly implement an intervention, or are unable to explain when and how the intervention is to be implemented, inadequate training is evident

W194

§483.430(e)(4) Staff must be able to demonstrate the skills and techniques necessary to implement the individual program plans for each client for whom they are responsible.

Facility Practices §483.430(e)(4)

Staff have the knowledge to correctly and consistently implement the specific IPPs of the individuals with whom they are working.

Guidelines §483.430(e)(4)

Observe whether or not staff are competent and knowledgeable about the needs, programs and progress of each sampled individual with whom they are assigned to work.

Staff should be able to demonstrate in practice the results of training for the individuals for whom they are responsible. See guidelines at §483.430(e)(3). W195 §483.440 Condition of Participation: Active Treatment Services Compliance Principles §483.440

The Condition of Participation of Active Treatment Services is met when:

- Individuals have developed increased skills and independence in functional life areas (e.g., communication, socialization, toileting, bathing, household tasks, use of community, etc.);
- In the presence of degenerative or other limiting conditions, individuals' functioning is maintained to the maximum extent possible;
- Individuals receive continuous, competent training, supervision and support which promotes skills and independence; and
- Individuals need continuous, competent training, supervision and support in order to function on a daily basis.

The Condition of Participation of Active Treatment Services is not met when:

- Individuals functional addlities have decreased or have not improved and the facility has failed to identify barriers and implement a plan to minimize or overcome barriers;

- Individuals are not involved in activities which address their individualized priority needs;

- Individuals do not have opportunities to practice new or existing skills and to make choices in their daily routines; or

- Individuals are able to function independently without continuous training, supervision and support by the staff.

§483.440(a) Standard: Active Treatment

W196

§483.440(a)(1) Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services described in this subpart, that is directed toward--

(a)(1)(i) The acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and

(a)(1)(ii) The prevention or deceleration of regression or loss of current optimal functional status

Facility Practices §483.440(a)(1)

When viewed as a whole, the active treatment program is pervasive, systematic and sufficient in scope to assure that individuals are appropriately served.

The major elements of the active treatment process are present and functioning in a consistent, cohesive manner including:

- Each individual's needs and strengths have been accurately assessed and relevant input has been obtained from team members;

- Each individual's IPP is based on assessed needs and strengths and addresses major life areas essential to increasing independence and ensuring rights;

- Identified priority needs are addressed formally and through activities which are relevant and responsive to individual need, interest and choice;

- Active treatment is consistently implemented in all relevant settings both formally and informally as the need arises or opportunities present themselves;

- Each individual receives aggressive and consistent training, treatment, and services by trained staff in accordance with their needs and the IPP;

- New skills and appropriate behaviors are encouraged and reinforced;

- Each individual has the adaptive equipment and assistive technology necessary for him/her to function with increased independence;

- Individual's routines and environments are organized to facilitate acquisition of skills, appropriate behavior, greater independence and choice;

- Each individual's performance is accurately measured and programs are modified based on data and major life changes; and

- Individuals with degenerative conditions receive training, treatment and services designed to maintain skills and functioning and to prevent further regression to the extent possible.

Guidelines §483.440(a)(1)

"Continuous" is defined to mean the competent interaction of staff with individuals served at all times, whenever the need arises or opportunities present, in both formal and informal settings.

Verify that active treatment is identifiable during formal and informal interactions between staff and individuals served. The performance of the individual should reflect the success, if any, of interventions being applied or the need to alter the intervention procedures.

The CF/BI ensures that each individual receives active treatment daily regardless of whether or not an outside resource(s) is used for programming (e.g., public school, day haddlitation center, senior day services program, sheltered workshop, supported employment).

Those "active" interventions necessary to prevent or decelerate regression are considered to be part of the overall active treatment program. For example, if the application of a specific stimulation technique to the area of the mouth of an individual with severe physical and medical disaddlities, decelerates the individual's rate of reliance on tube feedings, and helps the individual retain addlity to take food by mouth, then this intervention is considered to be a component of active treatment for the individual.

Active treatment for elderly individuals may increasingly need to focus on interventions and activities which promote physical wellness and fitness, socialization and tasks that stress maintaining coordination skills and reducing the rate of loss of skills that accompanies the physical aspects of the aging process. Attending a senior center may be a justifiable part of an active treatment program for an elderly person.

Active treatment is the sum total of the major components of the active treatment process or loop which make up the requirements under this Condition of Participation (i.e., assessment, individual program planning, implementation, program documentation, program monitoring and change). It defines the primary nature of the services which must be provided by a facility (and received by its clients) in order to make it eligible under the law to be "certified" as an CF/BI. Active treatment results in the positive outcomes identified by the Condition-level compliance principles. Surveyors must examine and evaluate all negative findings related to active treatment, and if determined to be significant, those findings should be cited at the salient tag numbers related to each of the components of the active treatment process. When review of those deficiencies leads to the conclusion that active treatment is not being received, then this standard and the explicit statutory requirement for active treatment at §1905(d)(2) of the Social Security Act are not met. A determination of noncompliance with this requirement, therefore, must also result in a determination of noncompliance at the Condition of Participation level for Active Treatment Services and at §440.150(c), tag number W100.

Although the active treatment process must be identifiable in documentation, it must be observable in daily practice. Determine how the CF/BI accomplishes (or fails to accomplish) an environment of competence that enables active treatment to occur.

Survey Procedure §483.440(a)(1)

Record each observation done of individuals served by the facility. The optional Client Observation Worksheet (CMS-3070-I) is the mechanism by which answers to identified data probes may be recorded. The worksheet is applicable to any observation, regardless of whether or not the individual is part of the representative random sample. See Section VII - Task 3 - Individual Observations, for instructions for completing observations.

Probes §483.440(a)(1)

How does the facility address the active treatment needs of individuals along their full life span?

As you conduct each observation, determine:

- Is the activity scheduled or planned?
- Are materials present to implement the activity?
- Are they used?
- Are all individuals present involved or engaged in the activity?
- Are the activity and materials age-appropriate, adaptive and functional?
- Are new skills and behaviors being taught or reinforced?
- Are all individuals reinforced and prompted frequently?
- Are all staff verbally and physically involved?
- Are there sufficient staff for the activity?
- Are interactions characterized by a "mentor/friend" tone? Does the activity relate directly to specific objectives and needs? Do staff demonstrate the skills necessary to train or reinforce training on the IPP objectives?
- Are individuals observed to engage in aggression, self-injurious behavior or self-stimulatory behavior (e.g., finger flicking)? If so, do staff intervene as per the IPP?

W197

§483.440(a)(2) Active treatment does not include services to maintain generally independent clients who are able to function with little supervision or in the absence of a continuous active treatment program.

Facility Practices §483.440(a)(2)

As a practice, the facility does not serve individuals who, to a large extent, are able to care for their own basic needs, require minimal supervision and do not require the structure, support and resources of a comprehensive service program on an ongoing basis.

Guidelines §483.440(a)(2)

The regulations define the target population eligible for the CF/BI benefit, by defining the services that are required for a facility to provide in order for it to qualify as an CF/BI and receive Federal Financial Participation (FFP). At the front end, one of the "required services" is training in basic fundamental skills. The type of skills described in W242, by their very nature, target a population who have significant deficits in growth and development.

The presence of any group of individuals (court-ordered or not), could call into question the overall nature of the services provided by the CF/BI. Individuals displaying some or all of the characteristics described in the Interpretive Guideline at §483.440(b)(1), do not "need active treatment services" or CF/BI level of care, and are not appropriately placed. Agencies which provide residential services to persons with Brain Injury do not qualify automatically for participation in Medicaid as CFs/BI. Although the facility may be providing services to meet the needs of these types of individuals, the services provided by the facility do not meet the regulatory definition of "active treatment."

Furthermore, if the primary purpose of the facility is no longer to provide services to persons with Brain Injury or related conditions who are in need of active treatment, then the facility does not meet the statutory requirement at §1905(d) of the Social Security Act and the regulatory definition of an CF/BI, and therefore cannot be certified. A determination of noncompliance with this requirement, therefore, must result in a determination of noncompliance at the Condition of Participation level and at §440.150(c).

Conversely, if the overall facility meets the definition of an CF/BI, the law does tolerate the presence of a few individuals for whom payment cannot be claimed. If an entity must serve both people who are generally independent and people who are in need of active treatment, then the entity may need to consider establishing a distinct part CF/BI to serve those individuals who are in need of active treatment.

Negative findings about active treatment with regard to generally independent clients may be in conflict with level of care determinations made by State inspection of care (IOC) teams. Bring these negative active treatment findings to the attention of the IOC agency within the State for appropriate disposition of Medicaid CF/BI certification. (See also W198, if the negative findings involve newly admitted individuals.)

There are some individuals who need the help of an CF/BI to continue to function independently because they have learned to depend upon the programmatic structure it provides. The fact that they are not yet independent, even though they can be, makes it appropriate for them to receive active treatment services directed at achieving needed and possible independence.

§483.440(b) Standard: Admissions, Transfers, and Discharge

W198

(b)(1) Clients who are admitted by the facility must be in need of and receiving active treatment services.

Facility Practices §483.440(b)(1)

The facility has determined that each individual admitted into the CF/BI benefit program since October 3, 1988, is in need of a program of active treatment.

Each individual needing active treatment receives it from the time of their admission to the facility.

Guidelines §483.440(b)(1)

Individuals with the following characteristics do not necessarily require a continuous active treatment program in order to function or to achieve optimal independence. Review closely to what extent the CF/BI serves individuals, who in the aggregate:

- Are independent without aggressive and consistent training;
- Are usually able to apply skills learned in training situations to other settings and environments;
- Are generally able to take care of most of their personal care needs, make known to others their basic needs and wants, and understand simple commands;
- Are capable of working at a competitive wage level without support, and to some extent, are able to engage appropriately in social interactions;
- Are engaged in productive work within the facility which is done at an acceptable level of independence (i.e., not done as part of a training program to teach the individual new skills);
- Are able usually, to conduct themselves appropriately when allowed to have time away from the facility's premises; and
- Do not require the range of professional services or interventions in order to make progress.

Based on the order of a court, the CF/BI may be required to admit individuals who do not need active treatment. Although CMS has no jurisdiction to prevent the courts from ordering the placements of such individuals into institutions certified as CFs/BI, the individuals, by definition, would be ineligible to be classified by Medicaid for the CF/BI benefit. To the extent that the placement of these court-ordered individuals does not interfere with the addlity of the CF/BI to provide active treatment for its individuals, the facility's overall certification is not affected.

W199

§483.440(b)(2) Admission decisions must be based on a preliminary evaluation of the client that is conducted or updated by the facility or by outside sources. Facility Practices §483.440(b)(2)

A preliminary evaluation to determine the need for active treatment is conducted, obtained or updated.

The information from the preliminary evaluation is used by the facility to make an admission decision.

Guidelines §483.440(b)(2)

No admission should be regarded as permanent. Readmission of an individual to the CF/BI falls under the same requirements as initial admission.

In the absence of State regulations designating the person(s) authorized to approve admission (e.g., State or Regional Admissions Committees), the decision to admit an individual to the CF/BI is based on the findings of an interdisciplinary team, including a QMRP.

Occasionally, emergency admissions of individuals may occur without benefit of a preliminary evaluation having been conducted prior to admission. For purposes of §483.440(b)(2) and consistent with §456.370(a), this requirement will be considered as "met" at such time that an evaluation is conducted which supports the need for an individual's placement in the CF/BI. Refer to W210.

W200

§483.440(b)(3) A preliminary evaluation must contain background information as well as currently valid assessments of functional developmental, behavioral, social, health and nutritional status to determine if **the facility can provide for the client's needs and if the client is likely to benefit from placeme**nt in the facility.

Facility Practices §483.440(b)(3)

Information in the preliminary evaluation accurately describes the individual.

The preliminary evaluation contains specific information that identifies the individual's needs and whether or not the facility has the addlity to respond to those needs in a manner which is likely to benefit the individual.

Guidelines §483.440(b)(3)

The facility must decide, based on objective data, whether or not needs can be met. In some cases, the facility may be required to meet the "reasonable accommodation" requirement of the Americans with Disaddlities Act. Failure to admit individuals merely because they have a particular medical condition may constitute a civil rights violation. All such instances should be reported to the Office of Civil Rights for investigation.

W201 §483.440(b)(4) If a client is to be either transferred or discharged, the facility must

(b)(4)(i) Have documentation in the client's record that the client was transferred or discharged for good cause; and

Facility Practices §483.440(b)(4)(i)

Transfer or discharge occurs only when the facility cannot meet the individual's needs, the individual no longer requires an active treatment program in an CF/BI setting, the individual/guardian chooses to reside elsewhere, or when a determination is made that another level of service or living situation, either internal or external, would be more beneficial, or for any other "good cause," as defined below.

Guidelines §483.440(b)(4)(i)

"Transfer" means the temporary movement of an individual between facilities, the temporary movement from the CF/BI to a psychiatric or medical hospital for medical reasons, the permanent movement of an individual between living units of the same facility, or the permanent movement of an entire facility (including individuals served, staff and records) to a new location. "Discharge" means the permanent movement of an individual to another facility or setting which operates independently from the CF/BI. Moving an individual for "good cause" means for any reason that is in the best interest of the individual.

Probes §483.440(b)(4)(i)

Can you identify a pattern of transfer or discharge that occurs suBlenly and that cannot be accounted for on an emergency basis?

What are the facility's criteria for emergency transfer or discharge and what are the procedures?

Do parents/family members/friends/advocates/guardians participate with the individual in the transfer/discharge decision-making process?

Does the reason for transfer/discharge given by the individual and/or family correspond with what is reported in the record?

W202 §483.440(b)(4)(ii) Provide a reasonable time to prepare the client and his or her parents or guardian

for the transfer or discharge (except in emergencies). Facility Practices §483.440(b)(4)(ii)

The individual and the family or guardian are involved in planning for movement.

The individual and the family or guardian receive the services necessary to assist in preparing for movement, unless an emergency situation prevents that involvement.

Guidelines §483.440(b)(4)(ii)

The family and the individual should be involved in any decision to move an individual, since this decision generally, should be part of a team process that includes the individual or guardian. If an individual has an advocate, the advocate should participate in the decision-making process.

Probes §483.440(b)(4)(ii)

What do individuals who are being considered for transfer/discharge (and/or parents, etc.) report about their participation in the process (if any)?

Does the IPP reflect objectives preparing the individual for transfer or community placement?

How are individual and family views recognized by facility staff? How do they deal with them?

W203 §483.440(b)(5) At the time of the discharge, the facility must

(b)(5)(i) Develop a final summary of the client's developmental, behavioral, social, health and nutritional status

Facility Practices §483.440(b)(5)(i)

A final summary is developed.

The final summary accurately describes the individual, including his/her strengths, needs, required services, social relationships and preferences.

W204 and, with the consent of the client, parents (if the client is a minor) or legal guardian, provide a copy

to authorized persons and agencies; and Facility Practices §483.440(b)(5)(i)

The final summary is released only with the consent of the legally appropriate party.

W205 §483.440(b)(5)(ii) Provide a post-discharge plan of care that will assist the client to adjust to the new

living environment. Facility Practices §483.440(b)(5)(ii)

Information in the post-discharge plan is sufficient to allow the receiving facility to provide the services and supports needed by the individual in order to adjust to the new placement.

The facility supports and assists the individual in this transfer.

Guidelines §483.440(b)(5)(ii)

The discharge plan required by 42 CFR 456.380 and the "post-discharge plan of care are the same. The regulations require only one discharge plan which meets the requirements.

§483.440(c) Standard: Individual Program Plan W206 (c)(1) Each client must have an individual

program plan developed by an
interdisciplinary team that represents the professions, disciplines or service areas

that are relevant to (c)(1)(i) Identifying the client's needs, as described by the comprehensive functional

assessments required in paragraph (c)(3) of this section; and

(c)**(1)(ii) Designing programs that meet the client's needs.**

Facility Practices §483.440(c)(1)

The individual's interdisciplinary team is composed of those individuals (professionals, paraprofessionals and non-professionals) who possess the knowledge, skills and expertise necessary to accurately identify the comprehensive array of the individual's needs and design a program which is responsive to those needs.

Guidelines §483.440(c)(1)

There is no "correct" number of individuals who comprise the interdisciplinary team. The regulation also does not specify the professional disciplines which make up the interdisciplinary team. Based upon outcomes, assess whether the expertise available to the team was appropriate to meet the needs of the individual.

The facility must make every effort to coordinate the IEP or program plan from an outside day program with the IPP process. This may result in a single IEP/IPP document, but there is no requirement for the IPP to be one document. The "collective" IPP must contain the information required under the regulations, and observation should confirm integration of the IPP across the various settings.

Negative answers to the following probes may indicate a lack of input from appropriate team members. Evaluate findings for systemic lack of input by a particular team member, lack of communication among team members, or lack of team effort and cooperation.

Probes §483.440(c)(1)

Do the plans from individual to individual have a predictable sameness about them?

Does the plan flow from only original diagnosis/assessment? Does it take into consideration interim progress or emergent needs?

Does the team create an integrated plan or is the plan a "stapling together" of individual pieces with little or no discussion as to how pieces relate/impact on each other? Are conflicts seen among various pieces of the plan? Refer to W120.

When prepackaged programs are used, are needed individual adaptations tailored to the needs, and functional skills of an individual?

W207

§483.440(c)(2) Appropriate facility staff must participate in interdisciplinary team meetings.

W208 Participation by other agencies serving the client is encouraged. W209 Participation by the client, his or her parent (if the client is a minor), or **the client's**

legal guardian is required unless the participation is unobtainable or inappropriate. Guidelines

§483.440(c)(2)

Meetings should be scheduled and conducted to facilitate the participation of all members of the team, but especially the individual, unless he or she is clearly unable or unwilling, the individual's parents (except in the case of a competent adult who does not desire them to do so) or the individual's guardian or legal representative. The CF/BI is expected to pursue aggressively the attendance of all relevant participants at the team meeting, (e.g., a conference call with a consultant during deliberations meets this requirement). Question routine "unscheduled" absences by individuals, guardians and particular disciplines or consultants, and determine the impact on effectiveness and responsiveness of the IPP to meet the individual's needs.

Probes §483.440(c)(2)

Does the facility have a working means of gathering all needed data for IPP sessions? Are the views of staff not present at the team meeting incorporated in the plan? Are individuals/parents/guardians provided with information prior to a meeting which

will be used at the meeting to make decisions?

Does the scheduling of the program planning meeting take into account the schedules of day programs and the availaddlity of family? If unable to attend, does someone review the results of meetings, and act on areas of question, dispute?

If individuals served do not attend IPP meetings, what reasons do staff give to explain their absence? How does staff prepare individuals to participate in interdisciplinary team meetings? Does the facility respect individual wishes for additional representatives on the

interdisciplinary team, such as friends or advocates?

W210

§483.440(c)(3) Within 30 days after admission, the interdisciplinary team must perform accurate assessments or reassessments as needed to supplement the preliminary evaluation conducted prior to admission.

Facility Practices §483.440(c)(3)

For new admissions, the assessment is completed within 30 days of admission.

New, revised or updated assessments accurately identify the functional addlities of the individual (whether or not that individual is a new admission). Observations and interviews confirm the accuracy of these assessments.

Guidelines §483.440(c)(3)

"Accurate" assessments refer to assessment data that are current, relevant and valid, and that the skills, addlities, and training needs identified by the assessment correspond to the individual's actual status. Additionally, for assessment data to be accurate, the cultural background and experience of the individual must be reflected in the choice, administration and interpretation of the evaluation(s) used. A few examples of appropriate adaptations might be: specialized equipment, use of an interpreter, use of manual communication, tests designed to measure performance in the presence of visual disaddlity, etc.

The contents of assessments or the particular assessment which must be used are not specified. A nursing assessment, for example, would not need to reference all domains, or a psychiatric or psychological evaluation would not necessarily have to be based on a particular "tool." Similarly, the results of the comprehensive assessment are not required to be written into a narrative report(s). Verify that the tests, evaluations, etc. that comprise the comprehensive functional assessment, yield data that are accurate, reflect the current status and needs of the individual, and can serve as a functional basis for an IPP to be developed.

W211

The comprehensive functional assessment must take into consideration the client's age (for example, child, young adult, elderly person) and the implications for active treatment at each stage, as applicable, and must

Facility Practices §483.440(c)(3)

Assessments address areas and active treatment needs which are relevant to the person's chronological age.

The individual is given opportunities to participate in age-appropriate activities to assess the person's functioning in those activities or settings.

Guidelines §483.440(c)(3)

The active treatment assessment process should be sensitive to the behaviors of individuals throughout their life span. For example, infants and toBllers are expected to engage in more play-related, exploratory activities, adolescents are expected to engage in activities of increasingly greater responsibility in preparation for adulthood, adults are expected to support themselves or at least be engaged in training or education activities toward that end, and elderly citizens, are expected to choose whichever form of productive activity meets their needs and interests (employment, handiwork, pursuit of leisure, etc.) for as long as they are able.

W212 §483.440(c)(3)(i) Identify the presenting problems and disaddlities and where possible, their causes

Facility Practices §483.440(c)(3)(i) - (iv)

Diagnoses are present, when applicable. Diagnoses are based on relevant, objective and accurate data. Diagnoses

are modified as accurate, relevant, and updated as medical or other

professional information becomes available.

Guidelines §483.440(c)(3)(i)

In the presence of a diagnoses (medical or otherwise), evaluation data must be available to support the determination.

W213 **§483.440(c)(3)(ii) Identify the client's specific developmental strengths; Facility Practices**

§483.440(c)(3)(ii)

The individual's preferences, methods of coping/compensation, friendships and positive attributes are clearly described in functional terms in assessments.

Identified strengths are current, complete and consistent with the individual's observed functional status.

W214 **§483.440(c)(3)(iii) Identify the client's specific developmental and behavioral management needs;**

Facility Practices §483.440(c)(3)(iii)

The individual's needs, skill deficits, and functional limitations are clearly described in functional terms in the assessments.

Identified needs are current, accurate, complete and reflect the individual's observed functional status.

Guidelines §483.440(c)(3)(ii-iii)

The comprehensive functional assessment (CFA) may be a report synthesizing the results of salient assessments or a series of reports. If individual reports are utilized, the complete diagnostic work-up or problem list identified by others is not required to be repeated unless it is relevant to the particular assessment. Findings are recorded in terms that facilitate clear communication across disciplines. Diagnoses or imprecise terms and phrases (including, but not limited to, "grade level," "age level," "developmental level," "good attending skills," and "poor motor addlity") in the absence of specific terms, are not acceptable.

Assessment of the behavior assumed to be maladaptive should include analyses of the potential causes, such as lack of exposure to positive models and teaching strategies, lack of addlity to communicate needs and desires, lack of success experiences, a history of punishing experiences, presence of a physiological condition, or other environmental or social conditions which may elicit or sustain the behavior.

Specific "developmental" strengths and needs describe what the individual "can" and "cannot" do.

Probes §483.440(c)(3)(i) - (iii)

Do assessments interpret the significance of the results in terms of the individuals' functional daily life needs or do they simply describe diagnoses, test performances or clinical impressions?

Do assessments merely report scores or functioning age levels or in the absence of strengths/needs lists, are the skills necessary to support those determinations identified within the assessment?

Do the strengths and needs identified by the facility correspond to what you see individuals do or not do during observations?

Does the assessment reflect how the environment could be changed to support the person?

W215 **§483.440(c)(3)(iv) Identify the client's needs for services without regard to the actual ava**iladdlity of the services needed; and Facility Practices §483.440(c)(3)(iv)

Identification of needed services is based on the comprehensive functional assessment. Recommendations are present to address areas of deficits.

Guidelines §483.440(c)(3)(iv)

In the presence of significant developmental deficits, it is not acceptable for the comprehensive evaluation to identify that a particular professional therapy or treatment is not needed. To meet the requirement for "need for service," the assessment must identify the course of specific interventions recommended to meet the individual's needs in lieu of direct professional therapy or treatment.

Probes §483.440(c)(3)(iv)

Do assessments conclude whether or not "hands-on" therapy conducted by professionals is indicated, and if an individual problem still exists, does the assessment recommend how the team should deal with the problem?

Is there a pattern of individual need areas not addressed in individuals' IPP objectives that correspond to the absence of those professional service areas at the facility?

§483.440(c)(3)(v) Include Facility Practices §483.440(c)(3)(v)

Assessment of each area is present.

Assessment of each area provides specific information about the person's addlity to function in different environments, specific skills or lack of skills, and how function can be improved, either through training, environmental adaptations, or provision of adaptive, assistive, supportive, orthotic, or prosthetic equipment.

Guidelines §483.440(c)(3)(v)

The facility must assess in developmental areas, but not by professional disciplines unless the functional assessment shows a need for a full professional evaluation. Findings relative to the domains required under §483.440(c)(3)(v) include, but are not limited to:

W216 physical development and health, Guidelines §483.440(c)(3)(v)

1. Physical development and health. Physical development includes the individual's developmental history, results of the physical examination conducted by a licensed physician, physician assistant, or nurse practitioner, health assessment data (including a medication and immunization history), which may be compiled by a nurse, and skills normally associated with the monitoring and supervision of one's own health status, and administration and or scheduling of one's own medical treatments. When indicated by physical examination results, consultations by specialists are provided or obtained. The need for advance directives or do not resuscitate (DNR) orders may be assessed on a case-by-case basis, as part of this area by individuals qualified to do so.

W217 nutritional status, Guidelines §483.440(c)(3)(v)

2. Nutritional status. Nutritional status includes determination of appropriateness of diet, adequacy of total food intake, and the skills associated with eating, (including chewing, sucking and swallowing disorders), food service practices, and monitoring and supervision of one's own nutritional status.

W218 sensorimotor development, Guidelines §483.440(c)(3)(v)

3. Sensorimotor development: Sensory development includes the development of perceptual skills that are involved in observing the environment and making sense of it. Motor development includes those behaviors that primarily involve: muscular, neuromuscular, or physical skills and varying degrees of physical dexterity. Because sensory and motor development are intimately related, and because activities in these areas are functionally inseparable, attention to these two aspects of bodily activity is often combined in the concept of sensorimotor development. Assessment data identify the extent to which corrective, orthotic, prosthetic, or support devices would impact on functional status.

W219 affective development, Guidelines §483.440(c)(3)(v)

4. Affective (Emotional) development. Affective or emotional development includes the development of behaviors that relate to one's interests, attitudes, values, and emotional expressions.

W220 speech and language development Guidelines §483.440(c)(3)(v)

5. Speech and language (communication) development. Communication development refers to the development of both verbal and nonverbal and receptive and expressive communication skills. Assessment data identify the appropriate intervention strategy to be applied, and which, if any, augmentative or assistive devices will improve communication and functional status.

W221 and auditory functioning, Guidelines §483.440(c)(3)(v)

6. Auditory functioning. Auditory functioning refers to the extent to which a person can hear and to the maximum use of residual hearing if a hearing loss exists and whether or not the individual will benefit from the use of amplification, including a hearing aid or a program of amplification. An individual's treatment might need to include being desensitized to tolerate the use of a hearing aid or assistive listening device to prevent the device from being rejected or destroyed. Assessment may include teaching techniques for conducting the assessment or the use of electrophysiologic techniques.

W222 cognitive development, Guidelines §483.440(c)(3)(v)

7. Cognitive development. Cognitive development refers to the development of those processes by which information received by the senses is stored, recovered, and used. It includes the development of the processes and addlities involved in memory, reasoning and problem solving.

W223 social development, Guidelines §483.440(c)(3)(v)

8. Social Development. Social development refers to the formation of those self-help, recreation and leisure, and interpersonal skills that enable an individual to establish and maintain appropriate roles and fulfilling relationships with others.

W224 adaptive behaviors or independent living skills necessary for the client to be able to function in the community, Guidelines §483.440(c)(3)(v)

9. Adaptive behaviors or independent living skills. Adaptive behavior refers to the effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected of their age and cultural group. Independent living skills include, but are not limited to, such things as meal preparation, doing laundry, bed-making, and budgeting. Assessment may be performed by anyone trained to do so. Standardized tests are not required. Standardized adaptive behavior scales which identify all or predominantly all "developmental needs" are not sufficient enough to meet this requirement, but can serve as a basis for screening.

W225 and as applicable, vocational skills. Guidelines §483.440(c)(3)(v)

10. Vocational (prevocational) **development, "as applicable."** Vocational development refers to work interests, work skills, work attitudes, work-related behaviors, and present and future employment options. The determination of whether or not a vocational assessment is "applicable" is typically based on age (adolescents or adults more than likely require this type of assessment).

Probes §483.440(c)(3)(v)

For all domains, do assessments describe what individuals can and cannot do in terms of skills needed within the context of their daily lives?

Is the assessment based on:

- Actual performance of the individual against objectified criteria?
- Reports by staff/parents/guardians?
- Observed performance in a variety of settings?
-

• **Simple checklists? Are assessments individualized?** Are assessments conducted in appropriate environments?

W226

§483.440(c)(4) Within 30 days after admission, the interdisciplinary team must prepare for each client an individual program plan W227 that states the specific objectives necessary to meet the **client's needs, as** identified

by the comprehensive assessment required by paragraph (c)(3) of this section Facility Practices

§483.440(c)(4)

The IPP contains a list of specific objectives based on needs identified in the CFA.

There is a clear link between the specific objectives and the functional assessment data and recommendations.

Objectives are developed for those needs that are observed to most likely impact on the individual's addlity to function in daily life.

Guidelines §483.440(c)(4)

The presence of a comprehensive list of behaviorally stated needs is acceptable for this portion of the requirement. "Comprehensive" means that objectives are stated for the needs identified in each domain included in the comprehensive functional assessment.

Objectives may address services to be provided, learning/treatment needs, adaptive equipment, etc., §§483.440(c)(4)(i)-(v) regulate requirements for current IPP training objectives (as opposed to staff, service, or long term objectives).

Validate that the needs identified by the team are appropriate for the individual based upon review of the comprehensive functional assessment data, observations, and interviews with the individual and staff.

Probes §483.440(c)(4)

Is there a predominant pattern of staff-oriented objectives rather than learner-oriented objectives?

Is there repetition and predictaddlity of programming across individuals?

W228 and the planned sequence for dealing with those objectives. Facility Practices §483.440(c)(4)

The objectives identified in W227 are arranged in a sequence identifying the logical order in which they will be addressed.

Objectives are organized in a sequence relevant to the individual's long term development.

Guidelines §483.440(c)(4)

To organize objectives into a planned sequence the CF/BI must consider the outcomes it projects for the individual in the long term. For example, if the long term objective is for the individual to travel independently in the community, the planned sequence may involve training the individual to recognize traffic signs, cross a street safely, and to obtain help when needed if lost or an emergency arises. Interview staff to discover the purpose to be achieved upon completion of the objective. For example, does staff know why an individual is taught to stack rings?

§483.440(c)(4) These objectives must--W229 §483.440(c)(4)(i) Be stated separately, in terms of a single

behavioral outcome; Facility Practices §483.440(c)(4)(i)

Each objective clearly states one expected learning result.

Guidelines §483.440(c)(4)(i)

"Single" behavioral outcome means that for each discrete behavior that the team intends the individual to learn a separate objective is assigned. (For example, "Mary will bake a cake and clean the oven" are two separate behaviors and, therefore, should be stated in two separate objectives.) Performance of a series of separate behaviors could constitute a single behavioral outcome when appropriate for the individual. For example, completing a hygiene routine of face washing, tooth-brushing and hair-combing is one behavioral outcome when the individual is able to perform each of those skills, but needs to learn to complete the entire routine each morning.

W230 §483.440(c)(4)(ii) Be assigned projected completion dates; Facility Practices §483.440(c)(4)(ii)

Completion dates are based on the individual's rate of learning.

Completion dates are assigned to each objective on which the individual is currently working.

Completion dates are individualized (i.e., not all the same for all clients and all objectives).

Guidelines §483.440(c)(4)(ii)

The "projected date of completion" for an IPP objective is not the same as a "review" date. For each objective assigned priority, the team should assign a projected date (month and year) by which it believes the individual will have learned the new skill, based on all of the assessment data. This date triggers the team to evaluate continuously whether or not the individual's progress or learning curve is sufficient to warrant a revision to the training program. There is no requirement to identify an implementation date for each objective in the plan.

W231 §483.440(c)(4)(iii) Be expressed in behavioral terms that provide measurable indices of performance;

Facility Practices §483.440(c)(4)(iii)

The learning outcome is stated in a manner which enables all staff working with the individual to consistently identify the target behavior and to clearly identify when it is being displayed.

The objective is stated in a manner which permits it to be quantifiably measured.

Guidelines §483.440(c)(4)(iii)

"Behavioral" terms include only those behaviors which are "individual" rather than "staff" oriented and those that any person would agree can be seen or heard. Determine if all staff who work with the individual can define the exact same outcome on which to measure the individual's performance. "Measurable indices of performance" are the quantifiable criteria to use in determining successful achievement of the objective. Criteria include various measurements of intensity and duration. For example, "M. will walk ten feet, with her tripod walker, for 5 consecutive days."

W232

§483.440(c)(4)(iv) Be organized to reflect a developmental progression appropriate to the individual; and

Facility Practices §483.440(c)(4)(iv)

Objectives and criteria for success are based on the individual's current or baseline functional addlities.

Objectives are designed to allow the individual to experience success in achieving those objectives.

Objectives are individualized to take into consideration the individual's addlities and disaddlities.

Objectives are organized to begin with the next logical step, given the individual's current functioning, and move toward more complex behavior.

Guidelines §483.440(c)(4)(iv)

To organize an objective in an appropriate progression, the CF/BI must consider the person's current functional addlities and project what steps, methods and strategies are likely to be effective in achieving the objective. Baseline data are one means of establishing an appropriate starting point for an objective. Objectives must be adapted based upon the person's functional addlities. For example, if the objective is to learn to put on shoes independently and the person does not have the manual dexterity to tie shoe laces, then the objective could include the use of slip-on shoes or shoes with velcro closures in order to facilitate the person learning this skill.

Probes §483.440(c)(4)(iv)

Are chosen objectives the most direct means for resolving identified needs? Do programs and strategies have a

relationship to needs identified and objectives chosen?

W233 §483.440(c)(4)(v) Be assigned priorities. Facility Practices §483.440(c)(4)(v)

The IDT identifies which objectives are the most important to work on now.

Skills and behaviors which significantly impact upon the individual's day-to-day functioning are worked on first.

Guidelines §483.440(c)(4)(v)

After all the training objectives have been established as required by W227, the IPP identifies those objectives which the team considers to be most important, or which need to be implemented before others can be accomplished, and then assigns them priority. Some examples of assigning priority include, but are not limited to, rank ordering (most important to least important), assignment of "priority" or "non-priority," etc.

Probes §483.440(c)(4)(v)

Is there a pattern of most individuals' objectives having the same "prioritization" assignment (e.g., do most individuals have a number one objective as handwashing or does the facility select a specific number of objectives of equal importance)?

Are objectives and priorities based on each individual's needs?

§483.440(c)(5) Each written training program designed to implement the objectives in the individual program plan must specify:

Guidelines §483.440(c)(5)

The written training program refers only to those objectives to which the team has assigned priority status for formal implementation.

W234 §483.440(c)(5)(i) The methods to be used; Facility Practices §483.440(c)(5)(i)

The training program provides clear directions to any staff person working with the individual on how to implement the teaching strategies

W235 §483.440(c)(5)(ii) The schedule for use of the method; Facility Practices §483.440(c)(5)(ii)

The training program provides clear directions to any staff person working with the individual about when the strategies are to be implemented.

W236 §483.440(c)(5)(iii) The person responsible for the program; Facility Practices §483.440(c)(5)(iii)

The person who will monitor the program and ensure it is being implemented appropriately, is clearly identified on the written training program.

Guidelines §483.440(c)(5)(iii)

This may or may not be the same person who implements the program. There is no requirement to identify who implements the program.

W237 §483.440(c)(5)(iv) The type of data and frequency of data collection necessary to be able to assess progress toward the desired objectives; Facility Practices §483.440(c)(5)(iv)

The training program provides clear directions to any staff person working with the individual about the type of data to record, and the frequency which data is to be recorded.

The data collection system is directly related to the outcome stated in the objective.

Guidelines §483.440(c)(5)(iv)

The facility must determine the type of data necessary to judge an individual's progress on an objective, and describe that data collection method in the written training program.
The facility determines what data to collect, but the system chosen must yield accurate measurement of the criteria stated in the individual's IPP objectives. For example, if the criteria in the individual's IPP objective specified some behavior to be measured by "accuracy," or "successes out of opportunities," then it would not be acceptable for the prescribed data collection method to record "level of prompt."

Methods of data collection on IPP training programs should be based on the total (including direct care) facility's staff analysis and observations of an individual's behavior. Examples of a few data collection systems include, but are not limited to, level of prompt, successful trials completed out of opportunities given, frequency counts, frequency sampling, etc. The facility should collect data with enough frequency and enough content that it can measure appropriately the individual's performance toward the targeted IPP objective.

W238 §483.440(c)(5)(v) The inappropriate client behavior(s), if applicable; and Facility Practices §483.440(c)(5)(v)

Any behaviors which would interfere with the individual's addlity to function in, or benefit from the training program are identified.

W239

§483.440(c)(5)(vi) Provision for the appropriate expression of behavior and the replacement of inappropriate behavior, if applicable, with behavior that is adaptive or appropriate.

Facility Practices §483.440(c)(5)(vi)

The training program provides specific information as to how to elicit or strengthen appropriate behavior and what behaviors to teach, reinforce or encourage which would reduce or replace the inappropriate behavior.

Replacement behaviors are functionally related to the targeted behavior.

§483.440(c)(5)(6) The individual program plan must also: W240 §483.440(c)(6)(i) Describe relevant

interventions to support the individual toward

independence. Facility Practices §483.440(c)(6)(i)

The IPP provides specific information to any staff person working with the individual about what services and supports they are to provide to assist the individual in functioning at a more independent level.

W241 §483.440(c)(6)(ii) Identify the location where program strategy information (which must be accessible

to any person responsible for implementation) can be found Facility Practices §483.440(c)(6)(ii)

Staff know where to find information about the programs to be implemented.

W242

§483.440(c)(6)(iii) Include, for those clients who lack them, training in personal skills essential for privacy and independence (including, but not limited to, toilet training, personal hygiene, dental hygiene, self-feeding, bathing, dressing, grooming, and communication of basic needs), until it has been demonstrated that the client is developmentally incapable of acquiring them.

Facility Practices §483.440(c)(6)(iii)

All individuals who lack the skills listed have training programs designed to meet their needs.

These programs are consistently implemented in both formal and informal settings.

There is documentation of consistent, appropriate attempts to teach individuals these skills, or specific evidence as to a medical condition which would preclude acquisition, prior to determination of developmental incapaddlity.

Appropriate materials, adaptations and modifications to equipment and the environment are available in order to promote and support individual training programs.

Guidelines §483.440(c)(6)(iii)

The receipt of training targeted toward amelioration of these most basic skill deficit areas is a critical component of the active treatment program needed by individuals who are eligible for the CF/BI benefit, and therefore, is a required CF/BI service. Some ADL skills overlap with each other (e.g., personal hygiene, oral hygiene, grooming and bathing). It is acceptable for the interdisciplinary team to set priorities within these overlapping skills. It must be clear, however, that the facility has organized its services to emphasize training in these areas. This will be seen not only in the IPP, but also in the competent interaction of staff with individuals, in both formal and informal settings. This basic skill training defines the nature of CF/BI services. To the extent that individuals demonstrate that they increasingly do not need the types of services described in this requirement, and increasingly correspond to the characteristics of clients described at W197 such that the "overall" nature of the facility services would not be required to provide the type of emphasis described at W242, question the appropriateness of the individual's placement in an CF/BI and/or the certification of the facility as an CF/BI (see W197 and W198).

"Training" as used in this regulation means:

- Aggressive implementation of a systematic program of formal and informal techniques (competent interactions);
- Continuously targeted toward the individual achieving the measurable behavioral level of skill competency specified in IPP objectives;
- Conducted in all applicable settings; and
- Conducted by all personnel involved with the client.

"Developmental incapaddlity" is a decision to be made by the interdisciplinary team based on its assessment of the individual's developmental strengths and needs. For example, there is ample evidence that even individuals with the most severe physical and mental disaddlities can be toilet trained. Recognition is given to the fact that some individuals, however, have insufficient sensory and neuromuscular control ever to be totally independent in toileting skills. For most of this group, there are intermediate steps which can be achieved, including toilet scheduling, in which the individual is able to be trained to a schedule of elimination with needed assistance from staff. The intent of the toileting part of this regulation is met if there is evidence that the individual has been provided an aggressive, well organized, and well executed toilet training program in the past and that the team determines the individual's "developmental incapaddlity."

Probes §483.440(c)(6)(iii)

Is evidence of "developmental incapaddlity" based on individual performance, medical evidence, historical efforts at training; or is it based on "opinions" of staff (in the absence of performance data)? Does the activity prepare individuals to function more independently or does it merely train the individual to adapt to his/her particular facility (e.g., large institutional living)?

Do staff direct their activities toward the acquisition of individuals to learn increasingly complex skills or do staff accept that individuals will not or cannot grow and change?

§483.440(c)(6)(iv) Identify mechanical supports, if needed, to achieve proper body position, balance, or alignment. The plan must specify--W243 the reason for each support, W244 the situations in which each is to be applied, W245 and a schedule for the use of each support. Guidelines §483.440(c)(6)(iv)

Mechanical devices used to support an individual's proper body position or alignment may be essential to prevent contractures and deformities, but the staff should be sensitive to the fact that mechanical supports may restrict movement and the individual should not be in the supports all the time or as a substitute for programs or therapy which may reduce the dependency on the support. Some supports allow movement and provide opportunity for more increased functioning. Some examples of devices used as mechanical supports include splints, wedges, bolsters, lap trays, etc.

Wheelchairs are not generally used to position or align the body and would not alone constitute a mechanical support. However, adaptations to wheelchairs which do position or align the body would have to be specified according to this requirement. Adaptations to a wheelchair which facilitate correct body alignment by inhibiting reflexive, involuntary motor activity are also mechanical supports.

W246

§483.440(c)(6)(v) Provide that clients who have multiple disabling conditions spend a major portion of each waking day out of bed and outside the bedroom area, moving about by various methods and devices whenever possible.

Facility Practices §483.440(c)(6)(v)

Individuals with sensory or physical difficulties have the same opportunities to move around in their environments as individuals who do not have those difficulties.

Guidelines 483.440(c)(6)(v)

With the exception of those individuals who are acutely ill (such as those who are hospitalized or incapacitated by a short term illness), all individuals should be out of bed and outside their bedroom area as long as possible each day, and in proper body alignment at all times. This is a necessity in order to prevent regression, contractures, and deformities and to provide sensory stimulation.

Question patterns of bed rest "orders" or "scheduled" bed rest as a routine part of an individual's program. A nap period of an hour, for example, is not "bed rest." However, if the CF/BI, as a general pattern of scheduling, expects an individual to be one - two hours in bed in the morning, one - two hours in bed in the afternoon, and an 8:00 p.m. bedtime in the evening, for example, then the practice becomes "bed rest," and the intent of the regulation will more than likely not be met. Question seriously large amounts of time during which a resident is confined to bed.

§483.440(c)(6)(v) Probes

For those for whom out-of-bed activity is a threat to their health and safety, look for:

- Individuals and staff engaged in activities to increase sensory stimulation; and
- Equipment designed to promote increasing the individual's sensory stimulation. Is equipment available to provide access to community activities?

Are mobility devices available and used as needed by individuals

W247 §483.440(c)(6)(vi) Include opportunities for client choice and self-management. Facility Practices

§483.440(c)(6)(vi)

Individuals are provided opportunities for choice, encouraged and taught to make choices, and to exercise control over themselves and their environment.

Guidelines §483.440(c)(6)(vi)

Due to the basic underlying importance "choice" plays in the quality of one's life, the CF/BI should maximize daily activities for its individuals in such a way that varying degrees of decision-making can be practiced as skills are acquired. Examples of some activities leading toward responsibility for one's own self-management include, but are not limited to, choosing housing or roommates, choosing clothing to purchase or wear, choosing what to eat, making and keeping appointments, and choosing from an array of appropriate activities. Interview staff to determine how attitudes and activities of the team and consultants facilitate or impede individual choice.

Choices can be made by all individuals. The type of choices the person makes may vary from very simple to more complex, depending upon individual addlities. Look at choices in the context of the individuals served by the facility.

W248

§483.440(c)(7) A copy of each client's individual plan must be made available to all relevant staff, including staff of other agencies who work with the client, and to the client, parents (if the client is a minor) or legal guardian.

Facility Practices §483.440(c)(7)

The individual or legal representative, as well as the facility staff, and staff from outside agencies have, or can access, a copy of the plan.

§483.440(d) Standard: Program Implementation

W249

§483.440(c)(1) As soon as the interdisciplinary team has formulated a client's individual program plan, each client must receive a continuous active treatment program consisting of needed interventions and services in sufficient number and frequency to support the achievement of the objectives identified in the individual program plan.

Facility Practices §483.440(d)(1)

Each individual is receiving training and services consistent with the current IPP.

Staff use the adaptive equipment, assistive devices, environmental supports, materials, supplies, etc., specified in each individual's IPP to accomplish stated objectives. A consistent approach is being implemented in all environments.

The pattern of interactions observed supports the active treatment program (e.g., informal opportunities to reinforce learning or appropriate skill development are taken, needs are addressed as they present themselves).

The active treatment program is not delayed or suspended while waiting for the written IPP document.

Activities support the accomplishment of the IPP objectives.

An individual's persistent refusal to participate in active treatment is being addressed by the IDT.

Guidelines §483.440(d)(1)

For an individual newly admitted to the CF/BI, the time period between admission and the 30 day interdisciplinary team meeting should be primarily for purposes of assisting the individual to become adjusted and acclimated to his or her new living environment and completing the functional assessment. During this time period the facility should also be providing those services and activities determined during the pre-admission assessment as essential to the individual's daily functioning. In order to be able to produce the comprehensive assessment, the facility must evaluate the individual's status in as many naturally occurring, functional environments as possible.

It must be clear that the active treatment program received by the individual is internally consistent and not simply a series of disconnected formal intervention applications within certain scheduled intervals.

The criteria of what constitutes a "sufficient number and frequency of interventions" are based on the individual's assessment and the progress the individual makes toward achieving IPP objectives.

Whether "structure" must be imposed by staff or whether the individual can direct his or her own activities for a period of time (without direct staff observation) is based on the individual's addlity to engage in constructive, age-appropriate, adaptive behavior (without engaging in maladaptive behavior to self or others). Be certain that an individual's time in the home or living unit is maximized toward the further development and refinement (including self-initiation) of appropriate skills, including, but not limited to, leisure and recreation.

For the active treatment process to be effective, the overall pattern of interaction between staff and individuals must be accountable to the comprehensive functional assessment and the IPP process. During the overall observation of individuals, you should be able to track that: the individual's comprehensive assessment identified the specific developmental need or strength justifying the activity, technique or interaction; in the case of a "need," the team projected a measurable objective or target to address it; and the technique, interaction, or activity which is observed, produced the desired target, produced a close approximation of the target, or was modified based on the individual's response.

Probes §483.440(d)(1)

Does the activity schedule and the content of the activities relate directly to the strengths, needs and objectives in the IPP for each individual or are the activities/content "make work," generalized, non-developmental time fillers?

Can staff describe how activities relate to strengths, needs and IPP objectives?

Are active treatment activities integrated into a "normal daily rhythm"?

Are individuals observed performing scheduled active treatment activities?

Are there sufficient and appropriate staff to implement IPPs?

Is training on priority objectives implemented at discrete time intervals exclusively, or is training implemented as the individual's needs emerge during the course of the day, as well?

Is there a consistent discernible pattern of evidence that staff implement, practice, reinforce, and otherwise carry out strategies to achieve individual objectives?

At any point in time are IPP interventions observable during staff and individual interactions, in formal and informal settings alike, throughout the individual's living experience?

Does the classroom, therapy or activity environment lend itself to the learning experience or are distractions, noise levels, or other individual behaviors obstacles to individual learning?

W250

§483.440(d)(2) The facility must develop an active treatment schedule that outlines the current active treatment program and that is readily available for review by relevant staff.

Facility Practices §483.440(d)(2)

The schedule is individualized and consistent with the individual's objectives. The schedule is known to staff working with the individual. Staff know where to locate a schedule when they need it. The active treatment schedule allows flexibility and is adjusted to the needs and

preferences of the individual, as necessary. The active treatment schedule reflects

normal daily rhythms.

Guidelines §483.440(d)(2)

The active treatment schedule directs the intensity of the daily work of the staff and the individuals in implementation of the IPP in both informal and formal training activities. To the extent possible, the schedule provides a range of options, rather than a fixed regimen. Individuals should have opportunities to choose activities and to engage in them as independently and freely as possible. Staff routines and schedules should be supportive of this goal and result in the presence of reasonable choices by individuals. Investigate any pattern of staff action or scheduling which results routinely in all or the majority of individuals engaging in the same activity or routine at the same time. For example, everyone is out of bed, awake and dressed before staff on the third shift go home, or everyone goes to bed before the third shift arrives.

The active treatment schedule is not required to be posted.

While the facility should have the individual's schedule from the day program, there is no requirement that this schedule and the residential schedule be merged into one document.

W251

§483.440(d)(3) Except for those facets of the individual program plan that must be implemented only by **licensed personnel, each client's individual program plan must be implemented by all staff who work with** the client, including professional, paraprofessional and nonprofessional staff.

Facility Practices §483.440(d)(3)

All staff working with the individual implement all aspects of the active treatment program unless such implementation is restricted to licensed personnel.

Each discipline works together to provide a uniform, consistent approach to implementation of the IPP across disciplines.

Guidelines §483.440(d)(3)

The facility is responsible for ensuring that during staff time spent with individuals, the staff member is able to provide needed interventions or reinforce acquired skills in accordance with the IPP. This is one of the ways the CF/BI implements continuous active treatment. "All" staff includes direct care staff.

The activities of the CF/BI are coordinated with other haddlitative and training activities in which the individual may participate outside of the CF/BI, and vice versa.

Probes §483.440(d)(3)

Do staff assigned to work with the individual encourage him or her to perform activities of daily living with maximum independence? Is development and reinforcement of these skills implemented regularly?

Is there evidence that each discipline working with the individual integrates, as appropriate, other disciplines' objectives and techniques? (For example, does direct care staff implement manual communications systems? Does the O.T. implement behavior management programs, if needed by the individual, during O.T. training sessions?)

Are informal daily activities designed to promote choice, self-management, skill enhancement or reinforcement?

§483.440(e) Standard: Program Documentation W252 §483.440(e)(1) Data relative to

accomplishment of the criteria specified in client

individual program plan objectives must be documented in measurable terms. Facility Practices

§483.440(e)(1)

Data are collected in the form and frequency required by the plan. Data are accurate, i.e.,

reflective of actual individual performance.

Guidelines §483.440(e)(1)

Data collection is evidence of individual performance and should not be taken constantly as evidence for surveyors that "treatments" occurred. "Data" are defined to be performance information collected and reported in numerical or quantifiable form on training objectives assigned priority in the IPP.

Data are those performance measurements recorded at the time the treatment, procedure, intervention or interaction occurs with the individual. They should be located in a place accessible to staff who conduct training.

Probes §483.440(e)(1)

Do the data collected on an individual basis vary according to the nature of the task, or are data collected the same way for all individuals on all tasks?

Do the data collected yield information relevant to making program decisions? Are the data collected on objectives implemented outside the agency also reviewed and analyzed to justify change in the objectives?

Is there a correlation between recorded data and observed individual performance?

§483.440(e)(2) The facility must document significant events that Guidelines

§483.440(e)(2)

See also §483.410(c) Client Records.

W253 **are related to the client's individual program plan and assessments and Facility Practices**

§483.440(e)(2)

Changes in the individual's functional status, health condition, accomplishments, activities or needs which affect the CFA and IPP are documented.

Probes §483.440(e)(2)

Is there a discernable pattern indicating that the facility routinely fails to detect the need to change individual programs?

Does the facility record unusual episodes and other incidents that suggest the staff needs to respond with a changing program or other special attention?

W254

that contribute to an overall understanding of the client's ongoing level and quality of functioning.

§483.440(f) Standard: Program Monitoring and Change

(f)(1) The individual program plan must be reviewed at least by the qualified Brain Injury professional and revised as necessary, including, but not limited to situations in which the client

W255

§483.440(f)(1)(i) Has successfully completed an objective or objectives identified in the individual program plan; W256

§483.440(f)(1)(ii) Is regressing or losing skills already gained; W257 §483.440(f)(1)(iii) Is failing to progress

toward identified objectives after reasonable
efforts have

W258 §483.440(f)(1)(iv) Is being considered for training towards new objectives. Facility Practices

§483.440(f)(1)(i)-(iv)

The QMRP ensures the program has been modified or changed in response to the individual's specific accomplishments, need for new programs, or difficulties in acquiring or maintaining skills.

Guidelines §483.440(f)(1)(i) - (iv)

The interval within which IPP reviews are conducted is determined by the facility. However, the facility's review system must be sufficiently responsive to ensure that the IPP is reviewed whenever the conditions specified in §§483.440(f)(1)(i-iv) occur. Information relevant to IPP changes should be recorded as changes occur.

Probes §483.440(f)(1)(i)--(iv)

Is the QMRP actually monitoring individual programs, or does the QMRP simply review paperwork? See also W159.

Are timely modifications of unsuccessful programs or development of programs for unaddressed, but significant needs made or ensured by the QMRP?

Does the QMRP routinely visit program areas and discuss performance and problems of individuals?

Is there evidence that collected data are systematically recorded, analyzed, and used to make changes in programs?

Can the QMRP describe the programs implemented with individuals for whom they are responsible or do they need to go to the record for this information?

§483.440(f)(2) At least annually, Guidelines

§483.440(f)(2)

For the "annual" review to meet the requirement, it must be completed by at least the 365th day after the last review. The CF/BI may be required to conduct reviews at more frequent intervals by other, more stringent regulations (e.g., 90 day reviews required by §456.380(6)(c), State regulation, etc.). The facility's failure to comply with these other, more stringent regulations would NOT be cited under this requirement. Refer cases of suspected non-compliance to the authority having jurisdiction for the regulations in question.

W259 the comprehensive functional assessment of each client must be reviewed by the interdisciplinary team for relevancy and updated as needed; Facility Practices §483.440(f)(2)

The comprehensive functional assessment (CFA) is reviewed at least within the required timeframe. The review of the CFA occurs sooner than annually when indicated by the needs of the individual. The CFA reflects changes in the individual since the last assessment. The CFA incorporates information about individual's progress, regression, etc.

Guidelines §483.440(f)(2)

The review of the CFA applies to all evaluations conducted for an individual, unless otherwise specified in the regulation (e.g., annual physical examination). It is not required that each assessment be completely redone each year. It is required that at least annually the assessment(s) be updated when changes occur so as to accurately reflect the individual's current status. Systematic behaviorally stated data become part of the comprehensive functional evaluation of the individual.

W260

and the individual program plan must be revised, as appropriate, repeating the process set forth in paragraph (c) of this section.

Facility Practices §483.440(f)(2)

The IPP reflects and responds to functional changes which have occurred since the last IPP.

Guidelines §483.440(f)(2)

Look for IPPs that are unchanged from one year to the next, for priority skills and behaviors that are deferred or ignored for one reason or the other, and for informal, vague, and programmatically worthless statements in the review (such as "John did better this year - he wasn't as upset most of the time like he used to be"). If the CF/BI has not been providing the individual with a systematic, behaviorally-oriented active treatment program during the year, the review will be incapable of making systematic, behaviorally-oriented statements about progress and change. If you find problem behaviors which do not decrease significantly, relatively frequent usage of restraint or other intrusive restrictive procedures, a "plateauing" (e.g., reaches partial desired performance, but does not improve over time and staff does not reassess) of skills development, or any other signs of "sameness" year after year, questions should be raised about the extent to which the CF/BI is providing active treatment, the adequacy of IPPs, staff training, etc., particularly, if many individuals' annual reviews reveal these characteristics.

Probes §483.440(f)(2)

Does the annual review result in actual changes in the individual's programs, or is it a "rubber stamp" duplication of the prior year's plan?

Does the facility respond routinely to the need for change in an individual's program or does an individual's program tend to be changed only once a year or on a time periodic basis (e.g., every quarter or six months)?

Is there a logical relationship among goals and objectives from year to year or are objectives established in a fragmented, unrelated pattern from year to year?

Can the reason for changes, deletions, or additions to IPP objectives be identified?

W261

§483.440(f)(3) The facility must designate and use a specially constituted committee or committees consisting of members of facility staff, parents, legal guardians, clients (as appropriate), qualified persons who have either experience or training in contemporary practices to change inappropriate client behavior, and persons with no ownership or controlling interest in the facility to

Facility Practices §483.440(f)(3)

The facility has a specially constituted committee.

The committee is used to accomplish the requirements of W262, W263 and W264.

The committee has the required membership and those members participate regularly in the functioning of the committee.

Guidelines §483.440(f)(3)

Depending on its size, complexity and available resources, the CF/BI may establish one multi-purpose committee to serve it for all advisory functions, or it may establish separate single-purpose committees. The facility's human rights committee may be shared among other agencies or the CF/BI may utilize a human rights committee established by another governing body, e.g., a county or a statewide group, as long as all pertinent regulatory requirements are met.

The regulation does not specify the professional credentials of the "qualified persons who have either experience or training in contemporary practices to change inappropriate client behavior." There is no requirement that any specific disciplines, such as nurse, physician or pharmacist be members of the committee.

The intent of including "persons with no ownership or controlling interest" on the committee is to assure that, in addition to having no financial interest in the facility, at least one member is an impartial outsider in that he/she would not have an "interest" represented by any other of the required members or the facility itself. Staff and consultants employed by the facility or at another facility under the same governing body cannot fulfill this role.

Although occasional absences from committee meetings are understandable, patterns of absence by the required membership of the committee is not acceptable. At least a quorum of committee members must review, approve and monitor the programs which involve risk to client rights and protections. Depending upon the size of the facility and the number of individuals who need intrusive or restrictive techniques as a part of active treatment programs, more than one specially constituted committee may be needed to effectively meet the intent of the regulation. The facility is responsible to organize itself in a manner which permits the timely review of proposed programs.

W262

§483.440(f)(3)(i) Review, approve, and monitor individual programs designed to manage inappropriate behavior and other programs that, in the opinion of the committee, involve risks to client protection and rights;

Facility Practices §483.440(f)(3)(i)

Any programs which incorporate restrictive techniques (e.g., restraints, medication to manage behavior, restrictions on community access, etc.) have been reviewed and approved by the committee prior to implementation.

The committee periodically monitors restrictive programs to determine if the restriction of rights or risk to protections remains justified.

Guidelines §483.440(f)(3)(i)

Each individual program developed to decrease inappropriate behavior and which involves potential risk to rights and protections must be reviewed and approved by the committee prior to the program's implementation. Some examples of programs requiring review include, but are not limited to, programs incorporating usage of restraints, aversive conditioning, any medication used to modify behavior, contingent denial of any right or "earning" of a right as part of a behavior shaping strategy, and behavioral consequences involving issues of client dignity. There is no requirement for the committee to function as a peer review for technical or clinical adequacy of plans submitted for approval. The purpose is to assure that each individual's rights are protected through use of a group of outside individuals who are not invested in the maintenance of facility practices. The committee reviews the context by which each program is recommended, and then evaluates whether the program's level of intrusiveness is warranted. The committee should consider factors such as whether less intrusive methods have been attempted and whether the severity of behavior outweighs the risks of the proposed program.

The committee need not reapprove a program when revisions are made, as long as those revisions are in accordance with the approved plan. For example, if the physician changes the dosage of a medication in accordance with the drug treatment component of the active treatment plan to which the legally authorized person has given consent and which has already been approved by the committee, then there is no need for the committee or the legally authorized person to reapprove the plan. (See also W263.) Generally, this would also apply if the medication was changed to another within the same therapeutic class or family. Reapproval would be needed, however, if the reason for the change was the individual's strong untoward response to the original medication. Due to the differences in side effects and potential adverse response between drugs of a different class, reapproval would also be required if the new medication was from a different therapeutic class or family of drugs.

Probes §483.440(f)(3)(i)

Does the committee generally approve whatever staff recommends without substantive review?

Does the committee require that less restrictive means be demonstrated to be ineffective?

What is the length of time from program submission to committee review?

Do you discern a pattern of committee involvement in the ongoing monitoring of approved programs? Does the committee seek changes, if indicated?

If staff assigned to the committee(s) are also members of the particular individual's interdisciplinary team, does that staff member abstain from approving formally the individual's program?

W263

§483.440(f)(3)(ii) Insure that these programs are conducted only with the written informed consent of the client, parents (if the client is a minor) or legal guardian; and

Facility Practices §483.440(f)(3)(ii)

Written consent is present prior to implementation of any restrictive program. Consent is given by the legally appropriate party. The consent is for the program which incorporates the use of a restrictive technique, rather than the restrictive technique alone. The consent is informed, i.e., the person giving consent is aware of the risks, benefits, alternatives, right to refuse and consequences.

Guidelines §483.440(f)(3)(ii)

Informed consent consists of permission by the legally responsible party after having been informed of the specific issue, treatment or procedure; the individual's specific status with regard to the issue, treatment or procedure; the attendant risks and benefits; alternative forms of treatment; the right to refuse treatment and the consequences of that refusal. Informed consent implies that the person who is to give consent is competent to evaluate the decision requiring consent.

For children up to the age of 18 the parent (natural guardian) or legally appointed guardian must give consent for him or her. At the age of 18, however, children become adults and are assumed to be competent unless otherwise determined by a court.

For individuals who are minors or who are clearly incompetent, but have no appointed legal guardian, informed consent for use of restrictive programs, practices or procedures must be obtained from the legal guardian, parent or someone or some agency designated by the State, in accordance with State law, to act as the representative of the individual's interests. Become familiar with the statutes of the State in which the CF/BI is located to determine who or what mechanism is designated to give informed consent in such circumstances. Verify whether or not consent was obtained in accordance with law. Additionally, under these circumstances, the facility is required to identify those individuals, and expected to advocate for them by demonstrating continuing efforts to obtain timely adjudication of the individual's legal status.

The committee must ensure that the informed and voluntary consent of the individual, parent of a minor, legal guardian, or the person or organization designated by the State is obtained prior to each of the following circumstances: the involvement of the individual in research activities, or implementation of programs or practices that could abridge or involve risks to individual protections or rights.

Informed consent should be specific, separate ("blanket" consents are not allowed), and in writing. In case of unplanned events requiring immediate action, verbal consent may be obtained, however, it should be authenticated in writing as soon as reasonably possible.

W264

§483.440(f)(3)(iii) Review, monitor and make suggestions to the facility about its practices and programs as they relate to drug usage, physical restraints, time-out rooms, application of painful or noxious stimuli, control of inappropriate behavior, protection of client rights and funds, and any other areas that the committee believes need to be addressed.

Facility Practices §483.440(f)(3)(iii)

The committee has been made aware of and reviewed facility programs and practices which may affect the rights of individuals.

Committee recommendations have been addressed by the facility.

The committee has established and uses a mechanism for monitoring individuals' rights issues.

Guidelines §483.440(f)(3)(iii)

The function of the committee is not limited to the review, approval and monitoring of restrictive behavior management practices. Examples of individual rights issues that might be reviewed by the committee, in addition to behavior management, include, but are not limited to, research proposals involving individuals, abuse, neglect and mistreatment of individuals, allegations dealing with theft of an individual's personal property or funds, damage to an individual's goods or denial of other individual rights, individual grievances, visitation procedures, guardianship/advocacy issues, rights training programs, confidentiality issues, advance directives/DNR orders, etc.

W265 §483.440(f)(4) The provisions of paragraph (f)(3) of this section may be modified

only if, in the judgment of the State survey agency, Court decrees, State law or regulations provide for equivalent client protection and consultation. W266 §483.450 Condition of Participation: Client Behavior and Facility

Practices Compliance Principles §483.450

The Condition of Participation of Client Behavior and Facility Practices is met when:

- Individual programs and activities regularly include use of positive techniques, teaching strategies, and supports. Efforts are made to reduce and eliminate use of restrictive techniques with positive results;

- Staff teach and reinforce appropriate behaviors, such as communication skills, social skills, independence and choice-making skills, coping skills, and leisure skills which serve as functional substitutes for inappropriate behaviors; and

- Restrictive techniques are used only when warranted by the severity of the behavior, and result in desired behavioral outcomes.

The Condition of Participation of Client Behavior and Facility Practices is not met when:

- Restrictive, intrusive techniques are used to manage or control behavior in lieu of positive teaching strategies;

- Individuals are physically or psychologically injured or harmed as a result of the use of the restrictive interventions and the facility has failed to adequately monitor the use of the intervention; or

- Restrictive interventions are used when they are not warranted or without first attempting less restrictive/more positive measures.

§483.450(a) Standard: Facility Practices - Conduct Toward Clients W267

(1) The facility must develop and implement written policies and procedures for the management of conduct between staff and clients.

§483.450(a)(1) Facility Practices

Observed practices regarding the behavior and interactions of staff and individuals served demonstrate proactive assertion of the individual's right to learn to exercise his or her rights.

Guidelines §483.450(a)(1)

"Conduct between staff and clients" refers to the language, actions, discipline, rules, order, and other types of interactions exchanged between staff and individuals or imposed upon individuals by staff during an individual's daily experiences and which affect the quality of an individual's life.

While the regulation requires the development of written policies and procedures, the primary survey emphasis should be placed on the latter aspect of the regulation, i.e., implementation of those policies and procedures. Observations of interactions between staff and individuals should confirm that, to the maximum extent possible, individuals are provided with opportunities for growth and self-determination. Individual's dignity is respected by staff and their behavior is within the context of any rules of conduct which have been established.

These policies and procedures must W268 §483.450(a)(1)(i) Promote the growth, development and

independence of the client;

Facility Practices §483.450(a)(1)(I)

Staff are observed engaged in activities which promote the individual's growth,

development and independence. Individual program plans and data support the fact that from the time of admission, individuals are learning new adaptive and functional skills while becoming more independent.

There are consistent positive interactions between individuals and staff.

Staff teach and encourage individuals to interact with each other in a socially acceptable manner. Opportunities to teach and reinforce skill acquisition are utilized. Staff identify and remove impediments in the learning environment. Staff encourage individuals to complete tasks with as much independence as possible. Staff encourage individuals to take risks while providing reasonable safeguards to

prevent injury.

W269

§483.450(a)(1)(ii) Address the extent to which client choice will be accommodated in daily decision-making, emphasizing self-determination and self-management, to the extent possible;

Facility Practices §483.450(a)(1)(I)

Staff actively engage in practices which provide individuals with opportunities for choice, decision-making and self-management, promote participation in these opportunities and provide necessary supports as the individual becomes more independent.

Appropriate and purposeful activities and materials known to be preferred by the individual are available.

Alternatives are available for individuals who do not choose to participate in a planned activity.

Individual's preferences and choices play a key role in daily decision-making.

W270 §483.450(a)(1)(iii) Specify client conduct to be allowed or not allowed; and Facility Practices

§483.450(a)(1)(iii)

Individuals know the benefits and consequences of their conduct or behavior.

Staff are aware of what is or is not permissible and the positive or negative consequences which may be utilized. Staff behavior is consistent with this policy.

Guidelines §483.450(a)(1)(iii)

"Client conduct" refers to any behavior, choice, action, or activity in which an individual may choose to engage alone or with others. The policy or "house rules" include(s), for example: allowable individual conduct (e.g., swearing or cursing, freedom of choice in religion, consumption of alcohol, smoking, sexual relations), reasonable locations where this conduct may or may not occur, and parameters for decision-making when an individual's choice conflicts with the group's choice (e.g., consensus, voting, taking turns, negotiation of differences).

"House rules" on the other hand, may not authorize staff or other individuals served to use a "laundry list" of discipline techniques to control an individual's inappropriate behavior, without regard to individualized need. If it is determined that staff must use a technique or intervention, then its use must be incorporated into an individual program plan that meets all applicable requirements specified in §483.450(b)-(e). Refer to W123.

W271

§483.450(a)(1)(iv) Be available to all staff, clients, parents of minor children, and legal guardians. W272

§483.450(a)(2) To the extent possible, clients must participate in the formulation of these policies and procedures.

Facility Practices §483.450(a)(2)

Input and participation of the individuals residing in the facility has been obtained in developing/revising the policies and procedures

W273

§483.450(a)(3) Clients must not discipline other clients, except as part of an organized system of self-government, as set forth in facility policy.

§483.450(b)Standard: Management of Inappropriate Client Behavior W274 (b)(1) The

facility must develop and implement written policies and procedures that

govern the management of inappropriate client behavior. Facility Practices

§483.450(b)(1)

Programs and practices used to manage behaviors are consistent with written policies and procedures.

Guidelines §483.450(b)(1)

Use of items, procedures, or systems which are potentially stigmatizing to the individual or otherwise would represent a substantial departure from the behavior of comparable peers without disaddlities, to control or prevent inappropriate behavior, falls under this requirement as well. (For example, requiring an individual to live in a locked residence and not providing the individual with a key, using a high crib with bedrails for an adult who gets out of bed at night and wanders or upsets other individuals, requiring an individual who strips off his clothes at inappropriate times to wear a jumpsuit turned backwards, or other oBI usages of fashion.)

These policies and procedures must be W275 consistent with the provisions of paragraph (a) of this section.

These procedures must--

W276 §483.450(b)(1)(i) Specify all facility approved interventions to manage inappropriate client behavior;

Facility Practices §483.450(b)(1)(i)

All positive as well as intrusive behavioral interventions approved for use in the facility are clearly stated in its policy.

W277 §483.450(b)(1)(ii) Designate these interventions on a hierarchy to be implemented, ranging from most positive or least intrusive, to least positive or most intrusive; Facility Practices §483.450((b)(1)(ii)

There is a clear progression in how techniques are implemented from the most positive, functionally appropriate approaches to most intrusive approaches authorized.

W278

§483.450(b)(1)(iii) Insure prior to the use of more restrictive techniques, that the client's record documents that programs incorporating the use of less intrusive or more positive techniques have been tried systematically and demonstrated to be ineffective; and

Facility Practices §483.450(b)(1)(iii)

In emergency situations where an unanticipated behavior requires immediate protection of the individual or others, the technique chosen is the least restrictive clinically appropriate technique possible.

Based on a functional analysis of the behavior and the data resulting from use of positive/less restrictive techniques, there is clinically sound, professionally accepted justification before the implementation of any more restrictive techniques.

Guidelines §483.450(b)(1)(iii)

You should see clear evidence to justify the use of a more restrictive technique. This requirement does not take away the team's discretion to use technology which represents reasonable standards of good practice, but it does require that there be evidence that justifies any decision not to use a positive or less restrictive technique first.

Based on extraordinary circumstances resulting in an emergency, a facility may need to use a more restrictive method of intervention to protect the individual and others from harm than is consistent with the hierarchy it has established. This regulation does not prohibit a facility from using good judgment in this situation.

The surveyor should assess the use of emergency restrictive interventions to assure that the facility could not have reasonably anticipated the behavior, and verify that the team has reviewed the individual program plan for its adequate attention to the problem precipitating the emergency measure.

The facility is not required to justify discontinuing the use of a more restrictive technique before initiating a less restrictive technique, since the intent of the regulation is to use the most positive, least intrusive technique possible.

Probes §483.450(b)(1)(iii)

Do individuals observed with behavior problems (e.g., aggression, withdrawal, stereotypical, self-abusive) have individually designed behavior programs?

Does the "maladaptive" behavior ever occur as an "appropriate" response given the individual's circumstances?

How has the staff tried to determine what the individual is trying to accomplish or communicate by displaying the maladaptive behavior? How do they respond to the behavior and the need being communicated?

Was the possibility addressed that the inappropriate behaviors might be an expression of a mental disorder? Was a medical and/or psychiatric consultation obtained, especially if a treatment program was unsuccessful for a reasonable length of time?

Are there consistent positive reinforcement procedures used with individuals? What specific individual behaviors do staff report they are to reinforce or are observed to be reinforcing?

Would environmental alterations alone reduce or eliminate the maladaptive behavior? Does the team consider attempting environmental changes before instituting a more restrictive program to control inappropriate behavior?

Is there evidence of interventions to change the conditions which lead to inappropriate behavior?

§483.450(b)(1)(iv) Address the following: W279 §483.450(b)(1)(iv)(A) The use of time-out rooms; W280

§483.450(b)(1)(iv)(B) The use of physical restraints;

"Physical restraint" is defined as any manual method or physical or mechanical device that the individual cannot remove easily, and which restricts the free movement of, normal functioning of, or normal access to a portion or portions of an individual's body. Examples of manual methods include therapeutic or basket holds and prone or supine containment.

Examples of mechanical devices include arm splints, posey mittens, helmets, and straight jackets. Excluded are physical guidance and prompting techniques of brief duration and mechanical supports as defined in §483.440(c)(6)(iv) guidelines to position or support an individual. See also §483.450(d).

W281 §483.450(b)(1)(iv)(C) The use of drugs to manage inappropriate behavior;

"Drugs to manage inappropriate behavior" is defined as medications prescribed and administered for purposes of modifying the maladaptive behavior of an individual. See also §483.450(e).

W282 §483.450(b)(1)(iv)(D) The application of painful or noxious stimuli;

"Application of painful or noxious stimuli" is defined as a clinical procedure by which staff apply, contingent upon the exhibition of maladaptive behavior, startling, unpleasant, or painful stimuli, or stimuli that have a potentially noxious effect.

The application of painful or noxious stimuli is used as a last resort and only when documentation shows that implementation of consistent positive reinforcement methods have failed and that to withhold the procedure would cause irreparable harm to the health of the individual or others. Discomfort to the individual should not extend beyond the point of application of the stimuli. There must be continuous monitoring while the procedure is in effect. The procedure must not result in physical or mental harm to the health and safety of the individual.

W283

§483.450(b)(1)(iv)(E) The staff members who may authorize the use of specified interventions; W284

§483.450(b)(1)(iv)(F) A mechanism for monitoring and controlling the use of interventions.

As interventions become more restrictive, the specificity with which they must be explained increases, as does the intensity of the control established by the facility. This includes other techniques having similar degrees of intrusiveness to those defined above, such as positive practice and overcorrection training of extended duration and satiation.

W285

§483.450(b)(2) Interventions to manage inappropriate client behavior must be employed with sufficient safeguards and supervision to ensure that the safety, welfare and civil and human rights of clients are adequately protected.

Facility Practices §483.450((b)(2)

Monitoring has insured that individual rights are protected.

Monitoring which is appropriate to the type of intervention being used, is in place to assure that the individual does not suffer unfavorable effects from the intervention.

Probes §483.450(b)(2)

What mechanism does the facility use to ensure that approval does not extend longer than warranted?

To what extent is the special review committee involved in monitoring? Do the procedures deny requisite human needs, such as sleep, shelter, beBling, or use of bathroom facilities?

Are rights denied in the absence of the required consent and approvals? Are drugs used to manage inappropriate behavior monitored for unfavorable side effects?

§483.450(b)(3) Techniques to manage inappropriate client behavior must never be used W286 for disciplinary purposes. Facility Practices §483.450(b)(3)

No technique, whether a part of a formal program or in informal situations, is used as retaliation or retribution.

Probes §483.450(b)(3)

How commonly are these techniques used? What types of problems are they used for?

Do these techniques continue to be implemented and/or authorized regardless of individual success on individual program plan objectives?

Are restraints, time-out rooms or drugs used for environmental deficiencies (e.g., lack of staff, program structure)?

W287 for the convenience of staff Facility Practices §483.450(b)(3)

No technique, whether a part of a formal program or in informal situations, is used to compensate for lack of staff presence or competency.

Probes §483.450(b)(3)

Are the behaviors listed as problematic occurring only in certain situations, such as in living areas and on weekends, possibly indicative of understaffing? Are the problematic behaviors occurring during day programs, possibly indicative of inappropriate placement?

Is there a systematic pattern showing restrictive technique usage occurring more frequently in units where staffing is not optimal? Where there is frequent staff turnover?

Is usage tied directly to a carefully approved behavior reduction program? Or, is it in practice, a means of locking individuals at the convenience of staff or in the absence of effective programming?

W288 or as a substitute for an active treatment program. §483.450(b)(3) Facility Practices

Any intervention used is tied to a specific active treatment program which addresses both the inappropriate behavior and mechanisms to teach, improve, support, or substitute appropriate behaviors.

§483.450(b)(3) Probes

Does the program to control inappropriate behavior actually address the problems identified, or is it, in fact, a behavior control/punishment program that does not result in desired behavior outcomes?

W289

§483.450(b)(4) The use of systematic interventions to manage inappropriate client behavior must be **incorporated into the client's individual program plan, in accordance with §483.440(c)(4) and (5) of t**his subpart.

Facility Practices §483.450(b)(4)

All behavior interventions/supports are part of the individual program plan.

All interventions are written as rigorously as other individual program plan training objectives and, in addition, include the extra provisions required by tags W238 and W239.

Probes §483.450(b)(4)

Are behavior programs demonstrably implemented in formal and informal settings alike as per the individual program plan?

Is there a complete description of the behavior occurring and evidence to show that as inappropriate behaviors diminish, desired, appropriate behaviors increase??

Does the facility change the program as individual behavior indicates?

What specific appropriate behaviors are being taught, improved, supported or substituted for the maladaptive behavior?

W290 §483.450(b)(5) Standing or as needed programs to control inappropriate behavior are not permitted.

Facility Practices §483.450(b)(5)

All interventions addressing the control of inappropriate behaviors are justified by the functional assessment and the current level of behavior.

Guidelines §483.450(b)(5)

Ongoing authorization for "programs" or "programmatic usages" of restrictive techniques, in the absence of evidence to justify such usage, constitutes a "standing" or "as needed program" to control inappropriate behavior, and are therefore not permitted.

Probes §483.450(b)(5)

Is there a pattern of restrictive techniques used in tandem (e.g., an individual is released from time-out but is then put in another type of restraining device)?

Is there a long term pattern of usage without discernible gains in individual progress?

Do individual records contain "approved" programs incorporating restrictive techniques, yet there is:

- Only episodic frequency of the maladaptive behavior?
- Relatively rare usage of the restrictive technique?
- No previously tried and implemented positive strategies showing lack of success?

§483.450(c) Standard: Time-Out Rooms W291 §483.450(c)(1) A client may be placed in a room

from which egress is prevented only

if the following conditions are met: (c)(i) The placement is a part of an approved systematic time-out

program as

required by paragraph (b) of this section. (Thus, emergency placement of a client into a time-out room is not allowed.) (c)(ii) The client is under the direct constant visual supervision of designated staff.

(c)(iii) The door to the room is held shut by staff or by a mechanism requiring constant physical pressure from a staff member to keep the mechanism engaged.

Guidelines §483.450(c)(1)

The use of time-out rooms is effective only if the individual does not like to be removed from an activity or from people. Look for patterns of frequent, lengthy time-out usage which often indicates that the environment is not reinforcing to the individual (i.e., the activities in and of themselves are not engaging, and/or the scheduled activities are potentially engaging yet the schedule is not implemented). If the individual who is in a time-out room engages in self-abuse, becomes incontinent or shows other signs of illness, staff should immediately discontinue the procedure and intervene.

Verify whether or not anyone standing or lying in any position, in any part of the time-out room can be seen.

Key locks, latch locks, and doors that open inward without an inside doorknob are not devices or mechanisms which require constant physical pressure from a staff member to keep a door shut, and, therefore, are not permitted by the regulations.

Pressure sensitive mechanisms must allow staff to enter the room at the moment the need arises.

Probes §483.450(c)(1)

What reasons cause individuals to be placed in time-out rooms most frequently? Is there a pattern of time-out usage? What is it?

On the average, how long are individuals placed in "time-out rooms"? Is time-out room usage extended on a routine basis?

Does the frequency of time-out room usage indicate that isolation is more reinforcing to the individual than the environment?

Are there plans to move to less restrictive means of modifying the behavior?

Is criterion clearly specified for use/discontinuance of time-out rooms? What do staff do with individuals after they leave time-out rooms?

Is usage directly tied to a carefully approved behavior reduction program or is it in practice a means of locking individuals at the convenience of staff or in the absence of effective programming?

How do staff monitor individuals in time-out rooms? What do staff do if an individual in a time-out room screams? Engages in self-abuse? Becomes incontinent? Shows signs of medical illness?

W292 §483.450(c)(2) Placement of a client in a time-out room must not exceed one hour. W293

§483.450(c)(3) Clients placed in time-out rooms must be protected from hazardous

conditions including, but not limited to, presence of sharp corners and objects, uncovered light fixtures, unprotected electrical outlets. Guidelines §483.450(c)(3)

A door that opens inward can potentially be held closed, either intentionally or inadvertently, by the individual in the room, thereby denying staff immediate access to the room.

W294 §483.450(c)(4) A record of time-out activities must be kept. Facility Practices §483.450(c)(4)

The record accurately reflects planned (i.e., part of the individual program plan) and emergency usage and presents a picture of events prior to, during, and following the use of time-out.

Probes §483.450(c)(4)

Can staff show how long and frequently time-out has been used? Can staff describe what environmental variables

contributed to each time-out usage?

§483.450(d)Standard: Physical Restraints (d)(1) The facility may

employ physical restraint only W295

§483.450(d)(1)(i) As an integral part of an individual program plan that is intended to lead to less restrictive means of managing and eliminating the behavior for which the restraint is applied;

Facility Practices §483.450(d)(1)(i)

The use of physical restraint is specified within the individual program plan.

Physical restraint is used only in response to a specific type and/or severity of behavior and only for the amount of time specified in the individual program plan. The plan is directed toward reduction of the use of restraints.

Probes §483.450(d)(1)(i)

What is the reason for the restraint? Does the individual program plan identify the type of restraint to be used? Does the severity of the behavior justify its usage?

Does the facility consider factors other than the individual in determining causes for need for restraints (e.g., other individuals, staff, building noise, sufficiency of program structure)?

Are there clear, performance-based linkages between use of restraints in practice and behavior programs that use restraints? Or are restraints used in ways and at times other than prescribed in the individual's program?

W296 §483.450(d)(1)(ii) As an emergency measure, but only if absolutely necessary to protect client or others from injury; or Facility Practices §483.450(d)(1)(ii)

Emergency physical restraint for an unanticipated type or severity of behavior is used only to prevent injury to the individual or others.

Guidelines §483.450(d)(1)(ii)

"Emergency measure" is defined as use of the least restrictive procedures and for the briefest time necessary to control severely aggressive or destructive behaviors that place the individual or others in imminent danger when those behaviors reasonably could not have been anticipated, and only as they are necessary within the context of positive behavioral programming. Examine closely how frequently "emergency measures" are employed. Repeated applications of such measures within short intervals of time, without subsequent incorporation into a written active treatment program, as required by §483.440(c), raises serious questions about the individual's receipt of active treatment and the individual's right to be free from unnecessary restraint.

Probes §483.450(d)(1)(ii)

Is there a systematic pattern of incidents being called "emergencies" in order to apply restraints without use of an approved program?

Are repeated emergency applications of restraints followed up with development of systematic behavior management programs? Is use of an emergency application documented and reviewed by the QMRP or designee with appropriate follow-up?

W297

§483.450(d)(1)(iii) As a health-related protection prescribed by a physician, but only if absolutely necessary during the conduct of a specific medical or surgical procedure, or only if absolutely necessary for client protection during the time that a medical condition exists

Facility Practices §483.450(d)(1)(iii)

Physical restraint is employed for medical reasons only when no other option is available or when no other option has proven effective in achieving the needed result for a particular individual, based on input from the IDT.

In the presence of a restraint intended to be a health-related protection, there is an active medical condition at the time the physical restraint is used.

Probes §483.450(d)(1)(iii)

What do staff do to prepare individuals for medical or dental examinations in order to reduce the need for physical or mechanical restraints?

Have other options such as desensitization training, behavior shaping, intensive positive reinforcement, environmental changes, etc. been tried?

Are individuals routinely restrained before medical or dental examinations?

§483.450(d)(2) Authorizations to use or extend restraints as an emergency measure must be

Guidelines §483.450(d)(2)

The facility determines who may authorize use of emergency restraints.

W298 §483.450(d)(2)(i) In effect no longer than 12 consecutive hours; and Guidelines §483.450(d)(2)(i)

The specific 12-hour authorization and re-authorization to use or extend usage of physical restraints does not apply to restraints used as an integral part of the individual program plan or to those that qualify as a health-related protection, as defined in the regulation.

W299 §483.450(d)(2)(ii) Obtained as soon as the client is restrained or stable. W300 §483.450(d)(3) The

facility must not issue orders for restraint on a standing or as

needed basis. Guidelines §483.450(d)(2)(ii)

This refers to the reporting and retrospective authorization of the emergency measure when no prior use authorization could be obtained due to the seriousness and immediacy of the event

W301

§483.450(d)(4) A client placed in restraint must be checked at least every 30 minutes by staff trained in the

use of restraints, W302 released from the restraint as quickly as possible, and

W303 a record of these checks and usage must be kept Guidelines §483.450(d)(4)

The frequency of monitoring will vary according to the type and design of the device and the psychological and physical well-being of the individual. For example, an individual in four-point restraints might require constant monitoring while someone in soft mittens may require less frequent monitoring. It is also true that for some individuals, constant visual supervision would serve to reinforce the inappropriate behavior and thereby reduce the clinical effectiveness of using the restraint. However, in no case may the 30 minute time limit be extended.

"As quickly as possible" means as soon as the individual is calm or no longer a danger to self or others.

Probes §483.450(d)(4)

Is there a pattern that individuals are placed in restraints repeatedly for 2-hour consecutive applications during the entire restraint authorization period?

Does the team decide whether constant or frequent monitoring is helpful or contraindicated for an individual? On what basis is this decision made?

When staff apply restraints do they demonstrate proper usage per each individual's program? Is the use of restraints well documented to present a clear picture of the events prior to, during, and following its use? Is this information reviewed by the IDT and addressed?

§483.450(d)(5) Restraints must be designed and used Probes §483.450(d)(5)

Is there documentation in an individual's record regarding contraindications, if any, to certain types of restraints?

How will the individual's safety be ensured? How do staff decide which type of restraint to use for a particular individual?

W304 so as not to cause physical injury to the client

W305 and so as to cause the least possible discomfort. §483.450(d)(6) Opportunity for motion and exercise

must be provided Guidelines 483.450(D)(6)

"Motion and exercise" includes an opportunity for liquid intake and toileting, if needed by the individual.

W306

for a period of not less than 10 minutes during each two hour period in which restraint is employed,

Guidelines §483.450(d)(6)

In the presence of a restraint being worn during sleeping hours, surveyors must determine whether it is truly the nature of the individual's behavior which warrants this significant level of intrusion, or whether it in fact is a substitute for lower staffing during night time hours. The "motion and exercise" requirement applies to all restraints which restrict the range of motion of a limb or joint. Therefore, for example, if a helmet is applied to protect a head wound during sleeping hours, and the individual's range of motion in the neck has not been affected, then this requirement does not apply.

This requirement also does not apply to cases of medical restraints that are specifically ordered for the immobilization of bones and joints during the physical healing process involved with fractures, sprains, etc. (e.g., a broken bone immobilized by a cast or splint).
However, if a physical restraint was applied to an extremity to prevent an individual from removing post-operative sutures, the restraint would be required to be released every two hours for a period of not less than 10 minutes.

Even though usage of mechanical supports, defined at §483.440(c)(6)(vi), may confine the movement of an individual, W306 does not apply to such usage.

W307 and a record of such activity must be kept. §483.450(d)(7) Barred enclosures

W308 must not be more than three feet in height and W309 must not have tops.

Probes §483.450(d)(7)

For what reason does staff use barred enclosures? How long do individuals remain in these devices? What other interventions have been tried? Are use of these enclosures incorporated into individually designed plans, aimed at elimination of the behavior causing the need?

§483.450(e) Standard: Drug Usage W310 (e)(1) The facility must not use drugs in doses that interfere with the individual

client's daily living activities. Facility Practices

§483.450(e)(1)

Individuals who are receiving medications are alert and available for participation in daily living activities, unless a well-documented condition (e.g., significant seizure activity) warrants the use of medication in sedating quantities to adequately control that condition.

Guidelines §483.450(e)(1)

Section 483.450(e)(1) applies to all medications, including medications prescribed to control inappropriate behavior.

Overmedication occurs for many reasons. For medications prescribed to control maladaptive behavior, the most common reasons are: the individual's maladaptive behavior may not be responsive to drugs (e.g., if an individual has a non-drug-responsive form of self injury, then use of psychotropics may simply lead up to maximum drug doses without suppressing the behavior), drug therapy may be exacerbating the behavior (e.g., if a drug-induced side effect is mistaken for agitation, then the physician may mistakenly believe that the individual is undermedicated and increase the dose), presence of polypharmacy within the same drug class may result in a drug dose that would exceed the maximum daily limit for any one drug, the individual may be receiving too frequent injections which may result in significant drug accumulation over time, and the use of daily medication plus PRN or stat (one time) doses may result in greater than the recommended daily doses being prescribed (especially since intramuscular administration may be up to four times as potent). Overmedication may also occur as a result of the interaction between drugs, whether these drugs were prescribed for control of inappropriate behavior, or for a physical or medical condition.

Administration of PRN or stat doses for periods greater than a few weeks may indicate that the individual's daily dose is sub-therapeutic, the problem will not respond to the prescribed drug or the drug is exacerbating the problem. In such instances, the surveyor should verify whether or not the drug regimen has been reassessed.

Probes §483.450(e)(1)

Are individuals who receive medications lethargic and inactive during the day? If so:

- How long has the individual been on medication?
- How long have the overt behaviors of lethargy and inactivity been noticed?
- Have there been any attempts to taper the medication down?

Is there evidence that the medication helps to facilitate the individual's participation in his/her individual program plan objectives?

§483.450(e)(2) Drugs used for control of inappropriate behavior must W311 be approved by the

interdisciplinary team and Facility Practices §483.450(e)(2)

The physician and other team members have discussed the risks and benefits of the medication to address the target behavior/symptoms, and has approved the use of the drug as being consistent with the active treatment program.

W312

be used only as an integral part of the client's individual program plan that is directed specifically towards the reduction of and eventual elimination of the behaviors for which the drugs are employed.

Facility Practices §483.450(e)(2)

The individual program plan identifies the drug usage and how it may change in relation to progress or regression in the objective.

The individual program plan contains specific criteria for any PRN usage.

Guidelines §483.450(e)(2)

For drugs to be an effective therapeutic tool, they must be prescribed only to the extent that they are necessary for normal medical management of the individual.

In an emergency, a physician may authorize the use of a drug to control an inappropriate behavior. However, orders for continued emergency drug usage cannot continue until the team gives approval and the drug's usage has been included in the plan. Psychotropic drug therapy may not be used outside of an active treatment program targeted to eliminate the specific behaviors which are thought to be drug responsive.

Although only a physician can prescribe medication, the decision to use medication for control of behavior must be based on input from other team members. W329 and W330 address the physician's participation in the person's individual program plan as part of the interdisciplinary team. The interdisciplinary team involvement in this decision-making process is inextricably linked to an obligation to develop and implement effective non-drug interventions that address the targeted behavior. This obligation requires constant monitoring of the non-drug interventions to determine its efficacy, and to determine whether the judicious use of drug therapy may at times be appropriate.

Individuals who receive psychoactive drugs for behaviors associated with a diagnosed mental disorder, require an active treatment program designed to reduce, ameliorate, compensate or eliminate the psychiatric symptoms. The psychiatric diagnosis must be based on a comprehensive psychiatric evaluation in which the evidence supports the conclusion of a psychiatric diagnosis as required by W212. The focus of active treatment, in this instance, would be on the mental health of the individual.

Drugs from categories other than the principle drug classes that have behavior controlling properties (e.g., antipsychotic, antianxiety, and antidepressants) are sometimes used to control inappropriate behavior. Examples include the use of propranolol (Inderal), which is classified as an antihypertensive and antianginal drug, for self-injurious behavior, and carbamazepine (Tegretol), which is an anticonvulsant, for aggression. The regulation was written to encompass any drug when its use is for purposes of controlling inappropriate behavior. This requirement does not apply to drugs, such as propranolol, when they are used to treat medical conditions. However, if their use (e.g. dose, duration, etc.) indicates that they are being used to control inappropriate behavior, the interdisciplinary team must be involved in the decision to use them, and they must be incorporated into the active treatment program plan.

In order for an individual to receive dental or medical treatment, the physician may need to prescribe a sedative as part of the normal medical management for that individual. This situation, occurring rarely, would not require an active treatment program targeted toward elimination of the behavior. The decision to use sedation for medical appointments must be made on an individual basis, and with input from the interdisciplinary team. When the individual is regularly exhibiting behaviors that are interfering with the addlity to receive routine medical and dental treatment, then use of the sedative is required to be incorporated into a specific active treatment program.

Probes §483.450(e)(2)

Is there documentation that alternative interventions have been considered and tried where appropriate?

Is there a pattern of prescription of the same drug used for many individuals, regardless of the problem?

Is the overall rate of psychotropic medication usage appropriate to the nature of the population served (e.g., in relation to case mix)?

Is there evidence that the individual can be and is placed on psychotropic medications without a full review and the protection processes of these requirements?

Is there an identifiable working mechanism to reduce or eliminate the need for psychotropic drug use on each affected individual? Are data collected so that the effect of drug usage can be assessed?

Does the physician, psychologist, pharmacist, nurse, and other program and health staff work together to reduce psychotropic drug utilization?

Are drug reduction plans actually implemented as indicated by reaching criteria in the behavior management programs?

W313

§483.450(e)(3) Drugs used for control of inappropriate behavior must not be used until it can be justified that the harmful effects of the behavior clearly outweigh the potentially harmful effects of the drugs.

Facility Practices §483.450(e)(3)

The risk(s) associated with the drug being used is consistent with the type and severity of the behavior/symptoms it is intended to affect.

§483.450(e)(4) Drugs used for control of inappropriate behavior must be (e)(4)(i) Monitored closely, W314

in conjunction with the physician and the drug regimen review requirement at §483.460(j), Facility Practices

§483.450(e)(4)(i)

The physician and the pharmacist regularly review use of medication for its effectiveness in changing the targeted behavior/symptoms, untoward side effects, contraindications for continued use, and communicate this information to relevant staff.

W315 for desired responses and adverse consequences by facility staff; and Facility Practices

§483.450(e)(4)(i)

Staff are aware of what response the drug is expected to achieve, what side effects to watch for, and communicate this information to the appropriate persons.

Guidelines §483.450(e)(4)(i)

Unless the physician regularly evaluates the individual and meets with those who work most closely with the individual to review treatment progress, it will be difficult to assess whether the individual responded positively to the treatment.

Since each drug has a specific profile of side effects, potential reactions should be looked for by direct examination and questioning. It is important that everyone who works with the individual be aware of the conclusion drawn from these drug reviews.

In addition to monitoring at regular intervals, the individual should be assessed at the time the medication is changed, as well. Individuals receiving long term antipsychotic drug therapy should be examined regularly for motor restlessness, such as Parkinsonian symptoms or tardive dyskinesia.

Probes §483.450(e)(4)(i)

How does the physician monitor usage of drugs prescribed and is this monitoring and decision-making for drug usage a part of the team process or is it done in isolation by the medical staff? Is there sufficient time for the physician to review the individuals with the team?

What do staff report about the medications the individual receives? Their purpose? Side effects? What would they do if side effects suBlenly appeared (e.g., extrapyramidal side effects in a person on antipsychotic drugs)?

Is there evidence that the effects of the therapeutic intervention are being assessed and modified in light of the presence or absence of the desired response? In light of the emergence of side effects?

§483.450(e)(4)(ii) Gradually withdrawn W316 at least annually Facility Practices §483.450(e)(4)(ii)

A gradual withdrawal occurs annually or sooner if warranted by progress to the criteria for reduction established in the individual program plan, by the particular drug which is being used, or the specific condition for which the drug is being prescribed.

W317 in a carefully monitored program conducted in conjunction with the interdisciplinary team, unless

clinical evidence justifies that this is contraindicated. Facility Practices §483.450(e)(4)(ii)

The IDT is aware of and involved in planning the drug reduction program and participates in its implementation and monitoring.

Progress or regression of the individual is monitored and taken into consideration in determining the rate of withdrawal and whether to continue withdrawal.

In the absence of an annual drug withdrawal program, there must be strong, objective clinical evidence (e.g., results of previous reduction, research-based justification, etc.) which supports that decision. Changes in the individual, his environment or program is taken into consideration in determining the validity of this evidence.

Guidelines §483.450(e)(4)(ii)

Planned drug withdrawals must be carefully instituted. For example, usage of antipsychotic drug therapy may not only cause tardive dyskinesia but may mask the clinical manifestations of tardive dyskinesia during treatment.

This requirement applies only to drugs prescribed to modify behavior; therefore, if Thorazine is prescribed to decrease aggressive behavior, the annual drug withdrawal requirement applies. However, if Phenobarbital is prescribed to prevent seizures, or Insulin is prescribed to control diabetes, then this requirement does not apply.

In determining whether there is clinical contraindication to the annual drug withdrawal, the physician and interdisciplinary team should consider the individual's clinical history, diagnostic/behavioral status, previous reduction/discontinuation attempts, and current regimen effectiveness. The individual's current clinical status or the nature of a psychiatric illness may indicate that gradual withdrawal of the drug is unwise at this time. It is not acceptable, however, to preclude a gradual drug withdrawal for a person, including a person with a psychiatric impairment, merely because of the possibility that his or her behavior may be exacerbated. Data which shows a direct relationship between past attempts at withdrawal, and an increase in the targeted behavior or symptoms should be available to support the decision not to attempt a gradual withdrawal. This data should reflect the programmatic interventions utilized to respond to the behavior prior to determining that gradual withdrawal is contraindicated. The team should periodically reevaluate the decision not to attempt a gradual withdrawal based on the individual's progress or other changes in clinical status.

Probes 483.450(e)(4)(ii)

Are staff aware of possible withdrawal symptoms, and are plans developed to assist the individual through these periods of stress?

Is drug therapy prescribed for an indefinite period of time?

W318 §483.460 Condition of Participation: Health Care Services Compliance Principles

§483.460

The Condition of Participation of Health Care Services is met when:

- Individuals receive preventative services and prompt treatment for acute and chronic health conditions; and
- Individuals' health is improved or maintained unless the deterioration is due to a documented clinical condition for which deterioration or lack of improvement is an accepted prognosis.

The Condition of Participation of Health Care Services is not met when individuals do not receive adequate health care monitoring and services, including appropriate and timely follow-up, based upon their individualized need for service.

§483.460(a) Standard: Physician Services W319 (a)(1) The facility must ensure the availaddlity of physician services 24 hours a day.

Guidelines §483.460(a)(1)

Procedures must be established that provide steps to be followed when the designated physician is not available.

Staff should be aware of procedures for contacting physicians in the event of an emergency.

W320

§483.460(a)(2) The physician must develop, in coordination with licensed nursing personnel, a medical care plan of treatment for a client if the physician determines that an individual client requires 24-hour licensed nursing care.

Guidelines §483.460(a)(2)

The use of a medical care plan is intended only for those who are so ill or so at medical risk that 24-hour licensed nursing care is essential. A medical care plan need not be developed unless the individual requires licensed nursing care around the clock. Thus, individuals with chronic, but stable health problems such as controlled epilepsy, diabetes, etc. do not require a medical care plan.

It is not required that an individual have a health deficit and/or a medical care plan in order to receive CF/BI services. The regulation is sufficiently flexible that the entire range of individuals, from those in good physical health to those who are very medically fragile, may be served.

A medical care plan may be temporary, in that it may be established to address acute health problems and then discontinued when those problems are resolved.

W321 This plan must be integrated in the individual program plan. Facility Practices §483.460(a)(2)

The medical care plan is a part of the IPP and, therefore, known and available to the inter-disciplinary team (IDT) and all staff working with the individual.

Training programs take into consideration medical needs/status.

§483.460(a)(3) The facility must provide or obtain W322 preventive and general care as well as annual physical examinations of each client

that at a minimum include the following Facility Practices

§483.460(a)(3)

The individual receives the services indicated by his/her health status.

There is follow-up to recommendations for referrals to specialists, specific examinations or evaluations, and treatments.

Guidelines §483.460(a)(3)

Medical services are provided as necessary to maintain an optimum level of health for each individual and to prevent disaddlity. Medical services include evaluation, diagnosis and treatment, as needed, by individuals.

Medical services, including sources for laboratory, radiology, and other medical and remedial services available to the individual must be provided if not provided in-house. There must be a written agreement that specifies the responsibilities of the facility and outside provider. (See §483.410(a).)

Probes §483.460(a)(3)

Are referrals made to other specialists when appropriate? Are referrals followed up? Are women provided with gynecological services? Are individuals referred to neurologists, if they have poor seizure control over a long period of time? A noted toxicity of seizure medications? Are individuals with apparent mental illness (e.g., depression, psychosis, obsessive/compulsive disorder) referred to specialists for proper diagnosis and treatment?

W323 §483.460(a)(3)(i) Evaluation of vision and hearing;

Facility Practices §483.460(a)(3)(i)

The individual receives a screening of vision and hearing at least annually.

Observation, documentation, or interview indicates that any vision or hearing problems which are suspected by staff are reported and follow-up assessments done.

Special studies are conducted in accordance with the timeframe recommended by the relevant specialist when more traditional approaches to evaluation cannot be conducted.

Guidelines §483.460(a)(3)(i)

This standard is intended to be an annual screening so that individuals who need further indepth examination can be identified. If hearing screens are conducted annually by speech-language pathologists or audiologists the physical exam does not need to repeat this information.

Information relevant to knowing if the individual can see or hear, and how well, is tantamount for designing an appropriate active treatment strategy responsive to need.

If an individual's vision or hearing can only be assessed through examinations conducted by specialists (e.g., comprehensive ophthalmological examinations and evoked response audiometry (ERA)), these tests need not be conducted yearly, but rather upon specialist's recommendations. In such situations determine if yearly, the team evaluates the individual's vision and hearing response behaviors for change, and makes referrals, if necessary.

Probes §483.460(a)(3)(i)

Do assessments of vision and hearing include acuity measures, as well as physiological measures, as appropriate?

W324

§483.460(a)(3)(ii) Immunizations, using as a guide the recommendations of the Public Health Service Advisory Committee on Immunization Practices or of the Committee on the Control of Infectious Diseases of the American Academy of Pediatrics;

Guidelines §483.460(a)(3)(ii)

These immunization guides can be obtained from the American Academy of Pediatrics, Elk Grove, IL, telephone: (708) 228-5005, or from the Centers for Disease Control, Division of Immunization Center for Preventive Services, telephone: (404) 639-8215.

W325 §483.460(a)(3)(iii) Routine screening laboratory examinations as determined necessary by the physician, Guidelines §483.460(a)(3)(iii)

This does not preclude screening tests available to the general public such as tests for urine sugar.

Probes §483.460(a)(3)(iii)

Has physician justification been provided when the physician determines that a standard laboratory test is not necessary for the individual?

W326 and special studies when needed; W327 §483.460(a)(3)(iv) Tuberculosis control, appropriate to the

facility's population, and
in accordance with the recommendations of the American College of Chest Physicians or the section on diseases of the chest of the American Academy of Pediatrics, or both

Facility Practices §483.460(a)(3)(iv)

When one or more individuals display tuberculosis (TB) symptoms, as substantiated by positive lab/x-ray results, appropriate treatment and precautions are in place.

Guidelines §483.460(a)(3)(iv)

These recommendations can be obtained from the American Academy of Pediatrics, Elk Grove Village, IL, telephone: (708) 228-5005, or the American College of Chest Physicians, Northbrook, IL, telephone: (708) 498-1400.

The American College of Chest Physicians and the American Academy of Pediatrics endorse the recommendations of the Center for Disease Control and Prevention, Guidelines for Preventing the Transmission of Tuberculosis in Health Care Facilities, (most recent edition). The facility should have in place a system appropriate to its population for the identification, reporting, investigation, and control of TB in order to prevent its transmission within the facility. This system should include policies and procedures for screening new employees, new clients, and other people who interact on a consistent basis with individuals residing in the facility; for reporting positive TB test results to the appropriate State authorities; for the investigative procedures that would be put in place should an individual or staff person test positive for TB; and for the evaluation of the effectiveness of the entire system. There should be arrangements with outside service providers, when needed, to ensure that any individual who tests positive for TB will receive appropriate medical treatment. Also, the system should address the issue of any staff member who tests positive for TB. The Occupational Health and Safety Administration (OSHA) requirements regarding exposure control plans and activities may also apply.

W328

§483.460(a)(4) To the extent permitted by State law, the facility may utilize physician assistants and nurse practitioners to provide physician services as described in this section.

§483.460(b) Standard: Physician Participation in the Individual Program Plan

A physician must participate in

W329

(b)(1) The establishment of each newly admitted client's initial individual program plan as required by §456.380 of this chapter that specifies plan of care requirements for ICFs; and

§483.460(b)(1) Guidelines

During the admission process, which extends from the time the individual is admitted to the time the initial IPP is completed, a physician is required to ensure that an assessment of the individual's medical status is thoroughly considered and addressed by the team as it develops the IPP. The physician's input may be by means of written reports, evaluations, and recommendations.

42 CFR 456.380 requires that a physician must establish a written plan of care for each applicant or recipient before admission to an ICF. This is done in conjunction with the interdisciplinary team. (See §483.440(c).) The written plan of care required by §456.380 and the IPP required by §483.440(c) may be the same document, which can fulfill both requirements.

W330

§483.460(b)(2) If appropriate, physicians must participate in the review and update of an individual program plan as part of the interdisciplinary team process either in person or through written report to the interdisciplinary team.

Facility Practices §483.460(b)(2)

Based on the needs and health status of the individual, the physician participates in the IPP review and update in such a way as to ensure accurate and appropriate consideration of the individual's health status and functioning in the plan's creation and implementation.

Guidelines §483.460(b)(2)

The need for physician participation is determined by the medical needs of the individual.
How the participation (whether through written report, telephone consultation, attendance at the meeting, etc.) is to be accomplished is left to the discretion of the facility.

§483.460 (c) Standard: Nursing Services W331 The facility must provide clients with nursing services in accordance with their needs. Facility Practices §483.460(c)

Individuals on a medical care plan receive 24-hour nursing service as indicated by that plan.

Individuals not on a medical care plan receive services as indicated by the assessment, the IPP, and in accordance with any changes in health status.

These services must include W332 §483.460(c)(1) Participation as appropriate in the development, review, and update
of an individual program plan as part of the interdisciplinary team process; Facility Practices §483.460(c)(1)

A licensed nurse participates as a member of the IDT in the IPP process for all individuals on a medical care plan and, if individual needs dictate, for other individuals as well.

Guidelines §483.460(c)(1)

Unless the individual is on a medical care plan, this participation may be through a written report.

W333

§483.460(c)(2) The development, with a physician, of a medical care plan of treatment for a client when the physician has determined that an individual client requires such a plan;

§483.460(c)(2) Guidelines

See also W416.

§483.460(c)(3) For those clients certified as not needing a medical care plan, a review of their health status

which must W334 §483.460(c)(3)(i) Be by a direct physical examination; Guidelines §483.460(c)(3)(i)

A direct physical examination means a visual review of the body as well as examination of body systems that mig be necessary. This includes observing for any clues (including visual, tactile, nonverbal gestures, grimaces, etc.) to detect if there is a potential for needed follow-up and monitoring. A paper review of the individual's medical record and health statistics is not a direct physical examination.

If an individual is on a medical care plan, it is not necessary to perform the quarterly direct nursing physical examination.

Probes §483.460(c)(3)(i)

An example of a body system review is foot care, and appropriate questions to ask in assessing the status of foot care would be:

- Is there evidence of abnormal swelling?
- Is skin supple?
- Are there signs of skin cracking or breaking?
- Are ulcers present?
- Is fungus present?
- Are there signs of ingrown nails?
- Are nails painful when pressed?

- Is there dampness between toes? W335 §483.460(c)(3)(ii) Be by a licensed nurse; Guidelines

§483.460(c)(3)(ii)

The term "licensed nurse" for purposes of this requirement means a registered nurse, a licensed practical nurse or a licensed vocational nurse. A facility is allowed to use a physician, in place of a licensed nurse, although this is certainly not required.

W336 §483.460(c)(3)(iii) Be on a quarterly or more frequent basis depending on client need; Guidelines

§483.460(c)(3)(iii)

"On a quarterly basis" means that the examination must be performed within the month in which the end of the quarter falls. If during the course of a year, there were three examinations conducted by a licensed nurse and one annual examination performed by a physician, each of which is performed within the month in which the end of the quarter or year falls, the intent of this requirement is met.

W337 **§483.460(c)(3)(iv) Be recorded in the client's record; an**d Guidelines §483.460(c)(3)(iv)

The record includes the date of the exam.

W338 §483.460(c)(3)(v) Result in any necessary action (including referral to a physician to address client health problems). Facility Practices §483.460(c)(3)(v)

The nurse makes appropriate referrals and communicates or addresses problems if the quarterly exam yields physical findings considered abnormal or atypical for the individual.

This communication results in timely changes in the individual's health care when needed.

Guidelines §483.460(c)(3)(v)

Some physical findings discovered by the nurse while conducting the physical exam will not necessarily result in referral to the physician. This practice is acceptable if the nurse is acting within the scope of the Nurse Practice Act of the State in which he or she is licensed.

Probes §483.460(c)(3)(v)

What is the feedback mechanism to the physician? Is there a traceable relationship between facility staff and physicians that results in timely changes in individuals' health care?

W339 §483.460(c)(4) Other nursing care as prescribed by the physician or as identified by client needs; and

Facility Practices §483.460(c)(4)

Health and wellness are actively promoted, problems are attended to before they become serious, and steps are taken to prevent the recurrence of such problems while responding promptly to individual's needs.

Nursing interventions are implemented as required by the IPP.

Guidelines §483.460(c)(4)

This includes nursing care for individuals without a medical care plan.

Probes §483.460(c)(4)

Is skin integrity maintained and breakdown prevented?

Are measures used to prevent skin breakdown (e.g., padding pressure points, use of emollients)?

§483.460(c)(5) Implementing with other members of the interdisciplinary team, appropriate protective and preventive health measures that include, but are not limited to

W340

§483.460(c)(5)(i) Training clients and staff as needed in appropriate health and hygiene methods;

Facility Practices §483.460(c)(5)(i)

Individuals and staff receive direct training in how to care for health needs/conditions, personal hygiene, health maintenance, and disease prevention.

Individuals are trained in areas such as taking medicine, sexuality, family planning, prevention of sexually transmitted diseases, control of other infectious diseases, self-monitoring of health status and self-prevention of health problems, etc., when such training is relevant to the needs of the individuals.

Guidelines §483.460(c)(5)(i)

Facility staff need to know what the limits of their responsibilities are with medically involved individuals, and how to teach individuals on a continuing basis how to take care of minor accidents until further care can be provided.

W341

§483.460(c)(5)(ii) Control of communicable diseases and infections, including the instruction of other personnel in methods of infection control; and W342 §483.460(c)(5)(iii) Training direct care staff in detecting signs and symptoms of

illness or dysfunction, first aid for accidents or illness, and basic skills required to meet the health needs of the clients. Facility Practices §483.460 (c)(5)(iii)

Direct care staff receive training in skills relevant to the population of individuals served by the facility.

§483.460(d) Standard: Nursing Staff W343 (d)(1) Nurses providing services in the facility must have a current license to

practice in the State. W344 §483.460(d)(2) The facility must employ or arrange for licensed nursing services sufficient to care for cl**ients' health needs including those clients with medical care plans. Facility Practices** §483.460(d)(2)

The facility provides for nursing services based on the health needs and conditions of individuals residing there.

Individual health care needs are being met in a timely manner by the available nursing staff.

Guidelines §483.460(d)(2)

In evaluating whether or not there is sufficient licensed nursing staff, evaluate the need for licensed nursing care represented by the health characteristics of the individuals served (as described in physical exam results, IPPs, and medical care plans) in relation to the competency and qualifications represented by the staff who provide care (through the onsite survey). Make a judgment about the sufficiency of nursing staff to care for this particular population.

Survey Procedure §483.460(D)(2)

In most circumstances, when one or more individuals in the facility require a medical care plan (i.e., the medical risk of an individual is so potentially life threatening that the individual requires continuous licensed nursing care in order to ensure his or her health and safety,) then that individual's needs are such that licensed personnel must be present.
In the presence of such a situation, validate that 24-hour on duty staffing patterns of licensed personnel are provided.

W345

§483.460(d)(3) The facility must utilize registered nurses as appropriate and required by State law to perform the health services specified in this section.

W346

§483.460(d)(4) If the facility utilizes only licensed practical or vocational nurses to provide health services, it must have a formal arrangement with a registered nurse to be available for verbal or onsite consultation to the licensed practical or vocational nurse.

W347

§483.460(d)(5) Non-licensed nursing personnel who work with clients under a medical care plan must do so under the supervision of licensed persons.

§483.460(e) Standard: Dental Services

W348

§483.460(e)(1) The facility must provide or make arrangements for comprehensive diagnostic and treatment services for each client from qualified personnel, including licensed dentists and dental hygienists either through organized dental services in-house or through arrangement.

W349

§483.460(e)(2) If appropriate, dental professionals must participate, in the development, review and update of an individual program plan as part of the interdisciplinary process either in person or through written report to the interdisciplinary team.

Facility Practices §483.460(e)(2)

Based on the needs of the individual, dental personnel participate in development and monitoring the IPP to ensure accurate and appropriate consideration of the individual's dental needs in the plan's design and implementation.

W350 §483.460(e)(3) The facility must provide education and training in the maintenance of oral health.

Facility Practices §483.460(e)(3)

Training in the maintenance of oral hygiene is provided to individuals who require it, and to those who are responsible for carrying out such activities.

§483.460(f) Standard: Comprehensive Dental Diagnostic Services Comprehensive dental

diagnostic services include W351 §483.460(f)(1) A complete extraoral and intraoral examination, using all

diagnostic
aids necessary to properly evaluate the client's condition not later than one month after admission to the facility (unless the examination was completed within twelve months before admission);

Guidelines §483.460(f)(1)

A "month" is defined as the interval between the date of admission and close of business of the corresponding day in the following month.

§483.460(f)(2) Periodic examination and diagnosis performed Guidelines §483.460(f)(2)

The requirement applies to all individuals (including those without teeth), and more frequently as dictated by the individual's needs.

W352 at least annually, W353 including radiographs when indicated and detection of manifestations of

systemic

disease; and W354 §483.460(f)(3) A review of the results of examination and entry of the results in the **client's dental record.**

§483.460(g) Standard: Comprehensive Dental Treatment

The facility must ensure comprehensive dental treatment services that include

Guidelines §483.460(g)

Comprehensive dental treatment might include, but is not limited to:

1. Periodic examination and diagnosis, including radiographs, when indicated and detection of all manifestations of systemic disease;

2. Elimination of infection or life hazardous oral conditions, oral cancer, or cellulitis;

1. Treatment of injuries;
2. Restoration of decayed or fractured teeth;
3. Retention or recovery of space between teeth in children, when indicated;
4. Replacement of missing permanent teeth, when indicated; and
5. Appropriate pain control procedures for optimal care of the patient.

W355

§483.460(g)(1) The availaddlity for emergency dental treatment on a 24-hour-a-day basis by a licensed dentist; and W356 §483.460(g)(2) Dental care needed for relief of pain and infections, restoration of

teeth, and maintenance of dental health. Probes §483.460(g)(2)

Are individuals' dental needs neglected until there is pain or other emergency?

Do examinations indicate that services were furnished, rather than notes indicating that the individual was "unable to be examined" or "as best as can be determined?"

§483.460(h) Standard: Documentation of Dental Services §483.460(h)(1) If the facility maintains an in-house dental service, the facility must W357 keep a permanent dental record for each client, W358

with a dental summary maintained in the client's living-unit

Guidelines §483.460(h)(1)

A "dental summary" means a brief written report of each visit to the dentist and includes any care instructions to be followed-up by facility staff as a result of treatment.

§483.460(h)(2) If the facility does not maintain an in-house dental service, the facility must W359 obtain a dental summary of the results of dental visits

W360 **and maintain the summary in the client's living unit. Guidelines §483.460(h)(2)**

The dentist used by the facility must agree to release the records and final recommendations for future care when the individual is discharged or discontinues service with the dentist.

§483.460(i) Standard: Pharmacy Services

W361

§483.460(i) The facility must provide or make arrangements for the provision of routine and emergency drugs and biologicals to its clients. Drugs and biologicals may be obtained from community or contract pharmacists or the facility may maintain a licensed pharmacy.

Guidelines 483.460(i)

Emphasis is placed on the provision of the service, and not on its method of delivery.

Whether the facility utilizes the unit dose, individual prescription or a combination of these systems, or whether the facility has its own pharmacy or provides the service through arrangement with a community pharmacy, the emphasis is on the accuracy of the drug distribution system and the effectiveness of the drug therapy.

§483.460(j) Standard: Drug Regimen Review W362 §483.460(j)(1) A pharmacist with input from

the interdisciplinary team must review

the drug regimen of each client at least quarterly. Facility Practices

483.460(j)(1)

The IDT provides the pharmacist with relevant input for the drug regimen review (e.g., changes in behavior, new medication the person has begun taking, etc.).

Reviews are performed as often as individual need dictates, but not less than quarterly.

Indiana Medicaid Home and Community-Based Services

Waiver Programs

A GUIDE FOR CONSUMERS

Fourth Edition

March 2007

Information courtesy of:

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for People with Disabilities

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Introduction

This booklet describes Indiana Medicaid Home and Community-Based Services Waiver Programs as well as other home and community services that help adults and children with disabilities **(of any age)** receive the supports they need to live, work and recreate in the community.

The Waiver services described may be revised and changed at any time, depending upon future legislative action or administrative decisions. If the information you receive from another source differs from this booklet, it may be because of actual changes, or because the person you asked is not aware of the changes. It is always best to check further before relying on information from a single source.

Thank you for your interest in learning more about Indiana's Medicaid Waivers for Home and Community-Based Services.

Your Feedback Requested!

Please complete and return the evaluation form at the back of the booklet. Your feedback will help us to determine whether this booklet meets your needs for information and ways it can be improved.

Accessible Formats and Additional Copies

Additional print copies of this document are available on request. The document is also available in Spanish, accessible formats, on line and electronically in MS Word and Adobe Acrobat PDF.

- To download a copy, go to: www.in.gov/GPCPD/publications
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Thank You

This booklet has been reviewed and revised by a group of people from the following agencies and organizations:

- About Special Kids (formerly IPIN)
- Department of Education, Division of Exceptional Learners
- Division of Aging (Family and Social Services Administration [FSSA])
- Division of Disability and Rehabilitative Services (FSSA)
- Family to Family
- Family Voices
- Governor's Council for People with Disabilities
- Office of Medicaid Policy and Planning (FSSA)
- The Arc of Indiana

Printed with assistance from the Division of Disability and Rehabilitative Services

Additional Waiver Resources

In addition to this booklet there are several sources of information about Indiana's Medicaid Waiver program that may be useful for people with disabilities and families:

The Waiver Provider Manual for Home and Community-Based Services is a primary reference document for Home and Community-Based Services (HCBS) Medicaid Waiver providers. The manual provides instruction to case managers, other service providers, state staff, family members, advocates, and Waiver participants and is available to assist all those who administer, manage, and participate in Indiana's HCBS Waiver programs. This manual was issued by the Office of Medicaid Policy and Planning on February 13, 2007 and will be updated on a quarterly basis. It is the authorized reference document for Indiana Medicaid HCBS Waiver service providers and the administration of those programs. The manual is posted to the Indiana Medicaid web page at www.indianamedicaid.com Click on manuals
A printed copy can be ordered from BDDSHelp@fssa.in.gov.

Additional information about the Department of Aging and the Aged & Disabled and Traumatic Brain Injury Waivers is available on the Internet:

- New Initiatives Options and Services: www.in.gov/fssa/elderly/options/
- Waiver Information: http://www.in.gov/fssa/elderly/aging/programs-services.html

Additional information about the Division of Disability and Rehabilitation Services and the Autism, DD and Support Services Waivers is available on the Internet:

- Available Services: www.in.gov/fssa/disability/avail_services.html
- Forms and Information Needed to Apply: www.in.gov/fssa/disability/services/medicaidneed.html
- Providers Page: www.in.gov/fssa/disability/providers.html

What is Medicaid?

Medicaid is a federal and state medical assistance program that makes reimbursements for reasonable and necessary medical care to people meeting eligibility requirements. The program is state administered by the Office of Medicaid Policy and Procedure (OMPP), a part of the Family and Social Services Administration.

The Waiver services described in this booklet are only one part of the Medicaid program. Unlike regular Medicaid, Waiver services are not entitlement programs.

What is the Medicaid Waiver Services Program?

The Medicaid Waiver program began in 1981, in response to the national trend toward providing Home and Community-Based Services (HCBS). In the past, Medicaid paid only for institutionally based long term care services, such as nursing facilities and group homes. This new program "waived" the requirement of an admission into an institution in order for Medicaid to pay for the Home and Community-Based Services (HCBS).

Indiana applied for permission to offer Medicaid Waivers from the Centers' for Medicare and Medicaid Services (CMS). The Medicaid Waivers make use of federal Medicaid funds (plus state matching funds) for Home and Community-Based Services (HCBS), as an alternative to institutional care, under the condition that the overall cost of supporting people in the home or community is no more than the institutional cost for those people.

The Office of Medicaid Policy and Planning (OMPP) is responsible for the development and operation of the Waivers, in agreement with the Division of Aging and the Division of Disability and Rehabilitative Services. Each Division works to create the service definitions and standards for services and providers and then certifies provider applicants in order to provide the Waiver services.

The goals of Waiver services are to provide to the person meaningful and necessary services and supports, to respect the person's personal beliefs and customs, and to ensure that services are cost-effective. Specifically,

Waivers for children and adults whose needs are primarily medical in nature assist a person to:

- Be as independent as possible
- Live in the least restrictive environment possible while maintaining the safety in the home

Waivers for children and adults with a developmental disability assist a person to:

- Become involved in the community where he/she lives and works
- Develop social relationships in the person's home and work communities
- Develop skills to make decisions about how and where the person wants to live
- Be as independent as possible

Who is Eligible for Medicaid Waiver Services?

A resident of Indiana must meet a combination of state and federal requirements in order to be eligible for a Medicaid Waiver. Specifically, a person must meet categorical eligibility (aged, blind, or disabled), financial, and non-financial eligibility requirements. When a person becomes 'targeted' for the Waiver, some of the Medicaid eligibility requirements are removed, such as the family income is not considered as part of the financial consideration for children under age 18.

Just because the person has been denied Medicaid eligibility in the past does not mean that the person should not re-apply when there are Waiver services available. Refer to tables for specific requirements for each Waiver on pages 24 and 25.

Where Can You Live and Receive Waiver Services?

Waiver services are individually tailored supports that enable children and adults to live successfully in home and community settings. These settings include:

- **Family Home:** A person can live in his/her family home, or in the home of his/her extended family or guardian.
- **House/Apartment:** A person can live in his/her own home with or without a housemate(s). "Own home" means a home that is not licensed as a foster care home or as an ICF/MR (group home) or nursing facility.
- **Foster Care:** A person can live in a specialized Waiver approved foster care home.
- **Assisted Living Facility:** A person can live in a Waiver approved Assisted Living Facility (only available under the Aged and Disabled Waiver).

What Are the Different Types of Waivers?

There are two different types of Indiana Medicaid Home and Community-Based (HCBS) Waiver Services Programs. One type, **for children and adults whose needs are primarily medical in nature,** is called the Nursing Facility Level of Care Waiver also know as the Medical Model Waivers and includes two Waivers – the **Aged and Disabled Waiver (A&D)** and the **Traumatic Brain Injury Waiver (TBI).**

The other type, **for children and adults with developmental disabilities,** is the Intermediate Care Facility for the Mentally Retarded (ICF/MR) Level of Care Waiver also known as the Developmental Disability or DD Waivers. There are three Indiana Medicaid Waivers requiring ICF/MR Level of Care - the **Autism Waiver,** the **Developmental Disabilities Waiver,** and the **Support Services Waiver.**

Frequently Used Terms

The following terms are related to Medicaid Waivers and other Home and Community-Based Services. Often providers or Area Agency of Aging and Bureau of Developmental Disabilities staff speak using acronyms and terms. This is sometimes confusing and frustrating. If you don't understand someone who uses letters or abbreviated terms, ask the person to explain right away.

Aged and Disabled Waiver (A&D Waiver)
The Aged and Disabled Waiver provides an alternative to nursing facility admission for adults and children with a disability. The Waiver is designed to provide services to supplement informal supports for people who would require care in a nursing facility if Waiver services or other supports were not available. Indiana's 16 Area Agencies on Aging act as the entry points for this Waiver. Waiver services can be used to help people remain in their own homes, as well as assist people living in nursing facilities return to community settings such as their own homes, apartments, or congregate community settings like assisted living.

Autism Waiver
The Autism Waiver provides community supports and services to persons with Autism, including the Autism Spectrum Disorder, who meet eligibility requirements. The Waiver is designed to provide services for the person living with family, or in other community settings to assist him/her gain and maintain optimum levels of self-determination and community integration.

Case Management
Waiver case management is a comprehensive service that includes specific tasks and activities designed to coordinate all services required in the person's place of care. Case management is required in conjunction with the provision of any Home and Community-Based Services. *Case management services for people who are on **Nursing Facility Level of Care** Waivers* are provided by the Division of Aging (DA) certified case managers through one of the local Agencies on Aging. A case manager from the AAA will be assigned to an applicant. After an applicant has been determined to meet the eligibility criteria and approved to receive a Nursing Facility Level of Care Medicaid Waiver, he/she may choose to retain their current AAA case manager or choose a non-AAA or independent case manager, for ongoing case management services. *Case management services for people who are on the **ICF/MR Level of Care** Waivers* are provided as a Medicaid Administrative service by one case management company and are *not* Medicaid Waiver services.

Cost Comparison Budget / Plan of Care (CCB/POC)
The Cost Comparison Budget (CCB) details the cost of each Waiver service and total cost of the Medicaid services for each person. The Cost Comparison Budget is based upon the Plan of Care (POC). The POC includes written explanation of the person's need for the Waiver services; what provider will be used; how the services protect the person's health and safety; the person's needs that will not be met; and a description of emergency back-up plans. The person receiving services or a guardian must approve and sign the CCB.

Developmental Disability (DD) State Definition
A severe, chronic disability which: 1) is attributable to a mental or physical impairment or combination of mental and physical impairments; 2) is manifested before the person attains age 22; 3) is likely to continue indefinitely; 4) results in substantial limitations in three or more of the seven areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and 5) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care treatments or services which are of lifelong or extended duration, and are individually planned and coordinated. All criteria must be met for a person to be eligible for Developmental Disability (DD) services.

Developmental Disabilities (DD) Waiver
This Waiver provides services that enable persons to remain in their homes or in community settings and assists those people who transition from state operated facilities or other institutions into community settings. This Waiver is designed to provide supports for persons to gain and maintain optimum levels of self-determination and community integration while allowing flexibility in the provision of those supports.

Developmental Disabilities Waiver Ombudsman
By law, the Ombudsman receives, investigates, and attempts to resolve complaints and concerns that are made by or on behalf of people with developmental disabilities in the ICF/MR Level of Care Waiver programs.

Disability
Any physical, mental or social limitation of a person. Definitions vary depending on the requirements of the specific state or federal program.

Early Periodic Screening, Diagnosis, and Treatment (EPSDT)
Provides a comprehensive set of preventive and health care services to Medicaid-eligible children from birth to 21 years of age and is administered through Division of Family Resources.

Entitlement
An "entitlement" within the Medicaid program means that certain benefits are guaranteed to all people who meet the eligibility requirements for those benefits. Under the Medicaid State Plan, eligible persons are entitled to all services available under that plan as soon as they are found eligible. Medicaid Home and Community-Based Waivers Services are not an entitlement. The number of people who can receive services from Waivers is limited to the number of Medicaid Waiver "slots" that are approved. Therefore, a person may be eligible for Waiver services, but may be on a waiting list until a Waiver slot becomes available.

Federal Poverty Level (FPL)
The federal poverty guidelines are issued each year in the *Federal Register* by the **Department of Health and Human Services** (HHS). The guidelines are a simplification of the poverty thresholds for use for **administrative** purposes — for instance, determining financial eligibility for certain federal programs. Programs using the guidelines (or percentage multiples of the guidelines — for instance, 125 percent or 185 percent of the guidelines) in determining eligibility include Head Start, Food Stamps, School Lunch, Low-Income Home Energy Assistance, and the Children's Health Insurance Program.

Habilitation
The coordinated use of medical, social, educational, and vocational measures for training persons with disabilities to the highest possible level of functional ability, usually applies to children or adults with lifelong disabilities. There are several different types of habilitation, including vocational, social, psychological, medical and educational.

Home and Community-Based Services (Medicaid Waivers)
Support services provided in a person's residence or community in order to maintain or restore participation in community activities in order to prevent admission into a nursing facility or group home.

Individualized Support Plan (ISP)
The ISP translates the person's long and short-range goals into reality by creatively using all available resources to accomplish those goals. It is based at least partly upon the Person Centered Planning process. *(Used with ICF/MR Level of Care Waivers only)*

Individual Program Plan (IPP)
The IPP is developed by the interdisciplinary or support team, which outlines immediate goals, and objectives that a person will be working toward next year. (Used in group home settings and other non-waiver settings)

Informed Choice
Informed choice means the person, family, or legal guardian makes a voluntary decision after learning of all options and alternatives. During the creation of the Waiver Cost Comparison Budget/Plan of Care, the individual and/or legal guardian will be asked to choose types of services desired, the provider of each service and his/her ongoing case manager.

Intermediate Care Facility for People with Mental Retardation (ICF/MR)
An Indiana State Department of Health licensed facility in which persons with developmental disabilities may live. There is 24-hour supervision by paid staff that assists and trains each resident in order to develop daily living skills. These residences may be facilities for nine or more residents (large private ICF/MR) run by private companies or group homes for four to eight residents (small ICF/MR). Each resident has a program plan based upon his/her needs.

Level of Care (LOC)
Nursing Facility Level of Care – For the purposes of Level of Care eligibility for the **Aged and Disabled or the Traumatic Brain Injury** Waivers, a person must have either unstable complex medical condition which require direct assistance from others for the following conditions: decubitus ulcers, comatose condition, or management of severe pain; OR direct assistance from others for medical equipment, such as ventilator, suctioning, tube feeding, central intravenous access (I.V.); OR direct assistance for special routines or prescribed treatments from others such as tracheotomy, acute rehabilitation conditions, administration of continuous oxygen; OR medical observation and physician assessment due to a changing, unstable physical condition; OR other substantial medical conditions. The initial Level of Care determination is made by the Area Agency on Aging. LOC is required in order for the person to be admitted into a nursing facility or initially start Waiver services. The Waiver case manager completes the annual Level of Care for Waiver services.

ICF/MR Level of Care – For the purposes of ICF/MR Level of Care eligibility for the **Autism, DD or Support Services** Waivers, a person must have a disability that is attributable to: 1) Mental retardation, autism, epilepsy, cerebral palsy or a condition (other than mental illness) similar to mental retardation that results in impairment of functioning similar to that of a person who is mentally retarded; 2) Originates before the person is twenty-two (22) years of age; 3) Has continued or is expected to continue indefinitely, and 4) Constitutes a substantial disability to the person's ability to function normally in society due to substantial functional limitations in three of the <u>six</u> major life areas: self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living. The disability must result in the person requiring 24-hour supervision (*For purposes of the Waiver, the person must require access to 24-hour assistance, as needed. This can be provided through emergency beepers, telephone systems or in other ways.)* and needing lifelong or for an extended duration an aggressive program of both specialized and generic services, individually planned and coordinated by an interdisciplinary team, and intended to promote greater self-determination and functional independence. The Level of Care is required in order for a person to be admitted into a group home setting (ICF/MR) <u>or</u> to receive Waiver services.

The Level of Care for **Group Home** admission is determined by the Bureau of Developmental Disabilities Services <u>Level of Care Unit</u>.

The Level of Care for **Waiver** services: The <u>Initial</u> LOC is determined by the Bureau of Developmental Disabilities Service Coordinator. The <u>Annual</u> Level of Case for Waiver services is determined by the Waiver case manager.

Frequently Used Terms (cont'd)

Individual Program Plan (IPP)
The IPP is developed by the interdisciplinary or support team, which outlines immediate goals, and objectives that a person will be working toward next year. (Used in group home settings and other non-waiver settings)

Informed Choice
Informed choice means the person, family, or legal guardian makes a voluntary decision after learning of all options and alternatives. During the creation of the Waiver Cost Comparison Budget/Plan of Care, the individual and/or legal guardian will be asked to choose types of services desired, the provider of each service and his/her ongoing case manager.

Medicaid (Title XIX)
A Federally aided, state-operated and administered program, which provides medical benefits for people with low incomes and are elderly and/or have a disability. Subject to broad federal guidelines, states determine the benefits covered, eligibility, and rates of payment for providers and methods of administering the program.

Mental Retardation (MR)
The preferred term is intellectual or cognitive disability.

Notice of Action (NOA)
The NOA is the state form used to notify a waiver applicant/recipient of any action affecting the person's Medicaid Waiver benefits, including approving or denying eligibility and/or services, as well as terminating, reducing, increasing, or suspending eligibility or any amount of covered services. The NOA contains appeal rights and instructions for appealing any of the above decisions.

Nursing Facility (NF)
Comprehensive care facility or a health facility licensed by the Indiana State Department of Health that provides nursing care, room, food, laundry, administration of medications, special diets, treatments, and may provide rehabilitative and restorative therapies under the order of an attending physician.

Person Center Planning (PCP)
Person Centered Planning is a process for a person with developmental disabilities and family/guardian to direct the planning and allocation of resources to meet the person's life goals. This personal life plan is based on the person's preferences, dreams and needs; shows how the person makes decisions; how the person is and can be productive; what the person likes and dislikes; supports long-term hopes and dreams; documents and explains what supports are needed for this lifestyle; documents a short-term support plan based on reasonable costs and needs; includes a range of responsibilities for all participants; and includes a range of supports including funded and community natural supports. Person Centered Planning should be conducted as often as the needs of the person change, or at least annually. Usually, the facilitator for the Person Centered Planning is a case manager. (*For ICF/MR Level of Care Waivers*)

Prior Authorization (PA)
A process within Medicaid, initiated usually by the primary care physician so that a medical procedure, medical supply or therapy, etc. may be paid by Medicaid as long as the procedure, supply or therapy is authorized prior to the procedure, supply or therapy being performed, purchased or provided. HCBS waiver members are required to exhaust all services on the (Indiana Medicaid) State Plan before utilizing HCBS waiver services. HCBS waiver programs are considered funding of last resort.

Provider
A generic term describing any person, organization or company enrolled to deliver specific services. Qualifications vary depending on the type of service.

Rehabilitation
The coordinated use of medical, social, educational, and vocational measures for retraining people with disabilities to the highest possible level of functional ability. There are several different types of rehabilitation, such as vocational, social, psychological, medical, and educational rehabilitation.

Spend Down
People, who are not financially eligible for Medicaid, may become eligible by paying for a certain amount of his/her medical and remedial service costs each month until the specific spend down amount is met. (This spend down amount is determined by the Division of Family Resources at the time of Medicaid eligibility determination.) When the spend down is met, then Medicaid becomes effective and it pays for the remainder of the monthly medical expenses, which can include the Waiver services.

Spousal Impoverishment Provision
Protects some assets and income for the spouse who is not receiving Aged and Disabled Waiver services. This is similar to a provision that protects the spouse of Medicaid nursing home residents.

Support Services Waiver
The Support Services Waiver is designed to provide limited, non-residential supports to persons with developmental disabilities residing with their families, or in other settings with informal supports.

Targeted
A term used to indicate that funding is now available for the person identified (frequently from a waiting list) as a potential recipient of Waiver services. For the **Aged and Disabled and Traumatic Brain Injury** Waivers, the person will be notified by the local Area Agency on Aging. After being targeted, the person will work with the Area Agency on Aging to determine eligibility for Waiver services. For the **Autism, Developmental Disabilities and Support Services** Waivers, the person will receive a letter from the Division of Disability and Rehabilitative Services, indicating that he/she is identified to potentially receive Waiver services. After being targeted, the person will be contacted by the Bureau of Developmental Disabilities Services District Office to determine eligibility for Waiver services.

TheArcLink
www.TheArcLink.org provides information and resources to families and people with developmental disabilities. It provides a comprehensive database of approved providers, service coordinators, and how to apply for services.

Traumatic Brain Injury (TBI)
For the purpose of the Medicaid Waiver, TBI is an injury to the brain due to an outside cause, including closed or open head injuries, toxic chemical reactions, anoxia, near drowning, and focal brain injuries. TBI does not include injuries that are vascular in origin (CVA or aneurysm), alcoholism, Alzheimer's disease or the infirmities of aging. As a result of the TBI, the person shows serious physical, cognitive, emotional and/or behavioral impairments.

Traumatic Brain Injury Waiver
Medicaid eligible people of any age who have experienced an external insult resulting in a traumatic brain injury, and who require services ordinarily only available in a nursing facility, may receive services under this Waiver. This Waiver is designed to provide supports such as personal assistance, limited habilitation services, and respite care, as well as limited environmental modifications.

Waiver Program
This program allows Indiana's Medicaid programs to pay for services that are provided in a person's home or other community setting rather than a Medicaid funded facility/institution. Persons must qualify for institutional care in order to be eligible for home and community-based services. Waiver refers to the waiving of certain federal requirements that otherwise apply to Medicaid program services.

State of Indiana and Federal Agencies

This section provides a brief description of the various state and federal agencies mentioned in this booklet that are part of the service system.

Area Agencies on Aging (AAA)
Also known as Area Agencies, AAA, Triple A, Area Agencies are contracted by the Division of Aging to coordinate intake, determine eligibility and to develop plans of care for eligible people who are elderly or have disabilities. These agencies are the single point of entry within a specific geographic area for adults and children who are interested in applying for the Aged and Disabled and the Traumatic Brain Injury Waivers. Area Agencies also provide other non-Waiver home and community-based services such as CHOICE to people with disabilities and people who are aging. See page 40 for a list of offices.
www.in.gov/fssa/elderly/aaa/index.html

Bureau of Developmental Disabilities Services (BDDS)
A part of Family and Social Services Administration/Division of Disability and Rehabilitative Services (DDRS), BDDS administers a variety of services for persons with developmental disabilities, which include the Autism, the Developmental Disabilities, and the Support Services Waiver. There are eight District Offices serving specific counties. The Service Coordinators determine eligibility for developmental disabilities' services and facilitate the determination of Level of Care for ICF/MR services. See page 41 for a listing of local offices.
www.in.gov/fssa/disability/bqis/bddsguide.html

Bureau of Quality Improvement Services (BQIS)
A part of the Family and Social Services Administration/Division of Disability and Rehabilitative Services, BQIS researches trends in service delivery, quality improvement and best practices, analyzes quality data, and assures compliance with quality standards for the Autism, Developmental Disabilities and Support Services Waivers. www.in.gov/fssa/disability/services/bqis.html

Centers for Medicare and Medicaid Services (CMS)
The federal agency within the Department of Health and Human Services, which directs the Medicare and Medicaid programs (Titles XVIII and XIX of the Social Security Act) and conducts research to support those programs. CMS must review and approve all Waiver proposals and amendments submitted by each state.
www.cms.hhs.gov/

Department of Education (DOE) / Division of Exceptional Learners (DEL)
The Indiana Department of Education is the state agency responsible for overseeing the public school services in the state of Indiana. A part of the Department of Education, the Division of Exceptional Learners oversees special education services for eligible children from ages three (3) through twenty-two (22) in both public and private schools. http://ideanet.doe.state.in.us/exceptional/

Developmental Disabilities Waiver Ombudsman
By law, the Ombudsman receives, investigates, and attempts to resolve complaints and concerns that are made by or on behalf of people with developmental disabilities in the ICF/MR Level of Care Waiver programs. Contact the DD Waiver Ombudsman at 800-622-4484.

State of Indiana and Federal Agencies (cont'd)

Division of Aging (DA)
A part of the Family and Social Services Administration, the DA implements the Nursing Facility Level of Care Medicaid Waivers, CHOICE, and other home and community-based services for people who are elderly and/or have disabilities. www.in.gov/fssa/elderly/services.html

Division of Disability and Rehabilitative Services (DDRS)
A part of the Family and Social Services Administration, DDRS assists people with disabilities and their families who need support to attain employment, self-sufficiency or independence. The Bureaus of Developmental Disabilities Services and Quality Improvement Services are under DDRS' responsibilities. The DDRS implements the ICF/MR Level of Care Medicaid Waivers and other services for people with developmental disabilities. www.in.gov/fssa/disability/

Division of Family Resources (DFR) and Indiana Department of Child Services (DCS)
The part of FSSA that provides Medicaid and Children's Services, including the First Steps program for infants and toddlers with developmental delays. Offices in each county serve as a single point of entry for many of the social services available to Hoosiers. Some of these services include Temporary Assistance to Needy Families (TANF), Medicaid, Medicaid-Disability, Food Stamps and Hoosier Healthwise. www.in.gov/fssa/family/ See page 42 for a list of local offices.

Family and Social Services Administration (FSSA)
Indiana's social services agency that provides services related to low income, mental illness, addiction, mental retardation, disabilities, aging, and children at risk for healthy development. Contains the Division of Family Resources, the Division of Aging, the Division of Disability and Rehabilitative Services, the Division of Mental Health and Addictions, and the Office of Medicaid Policy and Program. www.in.gov/fssa/ and www.in.gov/fssa/admin/

Hearings and Appeals Section
An administrative section within FSSA that receives and processes appeals from people receiving services within any FSSA program and many others. Administrative hearings are held throughout the State of Indiana, usually at county Division of Family Resources locations, at which time all parties have the opportunity to present their case to an Administrative Law Judge.

Indiana Protection and Advocacy Services (IPAS or P & A)
A state agency that assists people with physical, emotional and/or mental disabilities to resolve disability related problems with the service delivery system and access discrimination issues. www.in.gov/ipas/.

Office of Medicaid Policy and Planning (OMPP)
A part of FSSA, OMPP is the State Medicaid Agency. It is responsible to the Centers for Medicare and Medicaid Services for administration and oversight of the Medicaid Waiver program, as well as the funding for nursing facilities and group homes. It is also responsible for the State's Medicaid Health Care Program overall. www.in.gov/fssa/programs/healthcare/index.html and for Medicaid eligibility requirements: www.in.gov/fssa/disability/medicaid/elig.html

Medicaid Waiver Myths

Despite everyone's best effort to provide training and updated information, there are still some common Indiana Medicaid Waivers for Home and Community-Based Services' myths that persist. The following is a list of common myths along with the facts about the issue and suggested solutions. If the issue is with your case manager/case management agency, or if you have attempted the suggested solution and still have questions/concerns, please refer to page 32, 'How Are Problems Resolved?'

1. **Myth:** When applying for Medicaid for a child under the age of 18 who is targeted to receive the Medicaid Waiver services, families must provide information on parental income and resources.
   Fact: ***Only the income and resources of a child are counted if the child is enrolling in or receiving Waiver services. When a person turns 18, he/she is considered an adult, and again only his/her income and resources are counted for Medicaid eligibility. When the family applies for Medicaid on behalf of the child, the family needs to present to the DFR caseworker, the letter received from the AAA or the Division of Disability and Rehabilitative Services that shows that the child is targeted for a Waiver.***
   Solution: Mention that your application falls under Senate Bill 30 provisions. Senate Bill 30, passed in 1991, allows parental income and resources to be disregarded when determining Medicaid eligibility for children under the age of 18 who are in a Medicaid certified facility or who are enrolled or in the enrollment process for a Medicaid Waiver. If this does not work, ask to speak to the office supervisor. If that does not work, call the State Office of Medicaid Policy and Planning. See page 46.

2. **Myth:** Your Plan of Care cannot be increased, because it will put you over the cost cap.
   Fact: ***With the exception of the Support Services Waiver, there are no overall individual Waiver cost caps; however, there are some limits on specific services.***
   Solution: Ask to speak with your case manager's supervisor.

3. **Myth:** You cannot change to a different provider at this time because...
   Fact: ***You can change to a different approved provider at any time.***
   Solution: Inform your case manager that you want to change providers. In some cases the change can be made immediately. In other cases, it may take time to find a new provider, based upon availability of a new provider that can meet your specific needs. You should interview a prospective provider before making the final decision regarding a change of providers.

4. **Myth:** If you are on the Developmental Disabilities Waiver, you must utilize one of the habilitation services.
   Fact: ***You must use at least one Waiver service but are not required to utilize any specific Waiver service or combination of services. Each Plan of Care is individually tailored to meet each individual's needs. Those needs may be met with Waiver services and non-Waiver services.***
   Solution: Contact your case manager or the case manager's supervisor.

Medicaid Waiver Myths (cont'd)

5. **Myth:** Now that I am on the Waiver, it can follow me wherever I move.
   Fact: ***If you move out of the State of Indiana, the Waiver does not transfer with you. It will follow you as long as you live in the state, although the number and availability of providers may vary.***
   Solution: If you plan to move to another state or across the State of Indiana, make sure your new community has the appropriate support services you will need and that they are readily available. Ask if there is a waiting list.

6. **Myth:** Once I get on a Waiver, I will always be eligible.
   Fact: ***No, you must meet the requirements for both Medicaid eligibility and Waiver eligibility every year.***
   Solution: Make sure to keep your appointments regarding Medicaid eligibility re-determination. The Waiver case manager will re-determine your Waiver eligibility every year also. Make sure you notify your case manager immediately if you are going to have difficulty keeping the Medicaid eligibility re-determination appointment.

7. **Myth:** Your Plan of Care needs to include extra services now to ensure you can get what you need later.
   Fact: ***No, the Cost Comparison Budget / Plan of Care are always based upon the individual's current support needs. When those needs change, then the Plan can be revised accordingly. "Padding" the CCB with services not needed is not allowed***
   Solution: Contact your case manager or the case manager's supervisor.

8. **Myth:** You can only be on one Waiver waiting list at a time.
   Fact: ***No, you can be on more than one Waiver waiting list. There are reasons why it would be appropriate to be on more than one Waiver waiting list at a time. For example, waiting lists move at different rates, so it may make sense to be on the list for as many Waivers as you are eligible for. However, with the preliminary Level of Care determination, the type of Waiver Level of Care will prescribe the appropriate waiting lists for which to apply. For example, if you meet the Level of Care for the Nursing Facility, you can only apply for the Aged and Disabled or the Traumatic Brain Injury Waivers.***
   Solution: Contact the Area Agency on Aging office or the Bureau of Developmental Disabilities Services District Office. See page 40 & 41.

9. **Myth:** If you are already getting Waiver services, you cannot be on a waiting list for a different Waiver.
   Fact: ***There are reasons why it would be appropriate to be on one Waiver and be on the waiting list for a different Waiver. For example, if you are receiving the Support Services Waiver services, but plan on needing residential type services in the future, you might also be on the waiting list for the Autism and/or DD Waivers. Another example, if you are receiving Traumatic Brain Injury Waiver services and plan to request Assisted Living services, you might also be on the waiting list for the Aged & Disabled Waiver.***
   Solution: Contact the Area Agency on Aging office or the Bureau of Developmental Disabilities Services District Office. See page 40 & 41.

Medicaid Waiver Myths (cont'd)

10. **Myth:** A person with Nursing Facility LOC can transfer to an ICF/MR LOC Waiver.
    Fact: ***A person can transfer to another Waiver only when there is another Waiver slot available within the new Waiver type. It is not an automatic transfer. The person must meet the Level of Care for the new Waiver also. The person will remain on the current Waiver until such time as there is a new Waiver slot available.***
    Solution: Contact your case manager for assistance with this decision and resulting action.

11. **Myth:** If my child goes onto the Medicaid Waiver, the state will put a lien on my estate at some point in time.
    Fact: ***No, Medicaid cannot and will not place a lien on the parent's home when your child is receiving Waiver services. The only circumstance under which Medicaid can file a lien on property is where an individual is permanently institutionalized, does not have a spouse, minor child, or disabled child living in the home. Even then, the lien can only be placed on the Medicaid recipient's real property and only to the extent of his/her ownership interest.***
    Solution: Contact your case manager for assistance with this issue.

12. **Myth:** I have been told to discontinue or drop the private insurance before the Waiver services start.
    Fact: ***The private insurance should be continued. The private insurance can add supports and benefits to the plan of services.***
    Solution: Contact your case manager and your insurance agent for assistance.

13. **Myth:** If no provider is available, you cannot include the service in the PCP and ISP. If there is no provider in your area, then you cannot have the service on the CCB.
    Fact: ***Your case manager should include the services that are included in the ISP and needed at this time. The case manager will indicate that the provider is to be announced (TBA). However, in order for the Waiver services to be approved and started, at least one provider must be identified within the CCB/POC.***
    Solution: Contact your case manager or the case manager's supervisor.

How Do You Apply?

1. People with a developmental disability (DD) and/or a diagnosis of Autism may apply for Waiver services at the local Bureau of Developmental Disabilities Services (BDDS) District Office by completing an Application for Long-Term Care Services. There are other forms to complete as well. Documentation from schools, hospitals, doctors' offices and therapies are helpful in determining eligibility. See the listing of the BDDS District Office locations page 41.

2. The BDDS District Office staff determines whether or not the applicant has a developmental disability as defined by the State. If DD eligible, the District Office staff also determines eligibility for ICF/MR Level of Care Waivers, meaning that the individual with the developmental disability would be at risk of placement in an institution without the home and community-based services provided by these Waivers and other informal supports.

3. The ICF/MR Level of Care is based upon the medical form completed by the physician, the completion of the Developmental Disabilities Profile (DDP) and the documentation used to determine eligibility for state DD services. In addition, the District Office staff must indicate within the Level of Care documentation that the person can be safely served within the community. (For children under the age of six (6), the BDDS Level of Care unit will determine Level of Care eligibility.)

4. In addition to the above, the applicant for the Autism Waiver **must** have a diagnosis of Autism or within the Autism Spectrum, as documented by a physician. All applicants applying for the Autism Waiver should also apply for the DD Waiver.

5. If there are no slots available for Waiver services, the applicant's name is placed on the waiting list for the appropriate Waiver(s). The waiting lists for the Autism, DD and Support Services Waivers are statewide.

6. Once targeted, the person must also apply for Medicaid at the local Division of Family Resources (DFR), if not already eligible under one of the categories of "Aged," "Blind," or "Disabled." When applying for Medicaid solely for the purpose of Waiver eligibility, <u>only</u> the income of the applicant seeking a Waiver is considered. For a child under the age of eighteen (18), parental income does not affect the child's eligibility for Medicaid.

Eligibility Criteria

Autism, Developmental Disabilities and Support Services Waivers

For each Waiver, the Eligibility Criteria is the following: The individual must be

- Eligible for Developmental Disability Services,
- Eligible for ICF/MR Level of Care;
- Diagnosis of Autism for Autism Waiver;
- Medicaid eligible based on 300% of maximum SSI amount (as of January 2007, SSI was $624 per month); Parental income for children under 18 years of age is disregarded.

See page 10 for more information on Level of Care.

OASIS Project for ICF/MR Level of Care Waivers

(suspended on March 23, 2009)

Objective Assessment System for Individual Supports (OASIS)

The Division of Disability and Rehabilitative Services is engaged in an effort to redesign the system that provides home and community-based services through the Autism, Developmental Disabilities and the Support Services Waivers.

This initiative will result in:

1) an objective assessment process,
2) a new resource allocation model, and
3) an individual budget allocation tool unique to Indiana.

The individual budget allocation tool will empower people and their support teams by increasing personal control over services and supports.

Project Goal

The goal of this project is to create a uniform funding model and to determine levels of needed services and supports for persons with developmental disabilities under the Autism, DD and Support Services Waivers. The model will be based on an objective assessment of the individual, the identified differences unique to the individual, and driven by the principles of person centered planning, measurable Individualized Support Plan (ISP) outcomes and budget neutrality for the State.

Services Descriptions

All services must be identified in the Person Centered Plan and be outlined in the Individualized Support Plan.

Adult Day Services (ADS): (*Autism, DD, Support Services Waivers*) Structured, non-residential, community-based group programs designed to meet the needs of adults with disabilities through individual plans of care. ADS provides a variety of health, social, recreational and therapeutic activities, supervision, support, meals, and in some cases personal care.

Adult Foster Care: (*Autism, DD Waivers*) Twenty-four hour care consisting of personal care, homemaker, chore, attendant care, companion services, provided in a private home by a caregiver who is not related to the individual(s). Foster care homes are limited to a maximum of four people with DD.

Applied Behavior Analysis: (*Autism Waiver*) A therapy service that is a highly intensive individualized instruction and behavior intervention to assist an individual in developing skills with social value. It is provided to people between the ages of two and seven.

Behavior Support Services / Crisis Assistance: (*Autism, DD and Support Services Waivers*) Training, supervision, or assistance in appropriate expression of emotions and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors.

Community Transition Services: (*Autism, DD Waivers*) Reasonable, one-time set-up expenses for an individual who makes the initial transition from an institution to his/her own home in the community. Items purchased are the property of the individual receiving the service and the individual takes the property with him/her in the event of a move to another residence. Expenses may include: security deposits, essential furnishings and moving expenses, deposits for utilities, pest eradication, allergen control or one-time cleaning prior to occupancy. There is an allowance of up to $1,000 for this one-time only service.

Crisis Assistance: (*Autism, DD, Support Services Waivers*) See Behavior Support Services.

Day Services: (*Autism, DD, Support Services Waivers*) Services outside of an individual's home that support, in general, learning and assistance in any of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living, including development of employment skills. These activities are directly related to the Individualized Support Plan (ISP). Each individual receiving Day Services works toward acquiring the skills to become an active member of the community. The continuum of services within Day Services provides opportunities in the community based services to become more independent and more integrated within the community. Day Services can be delivered to an individual one-on-one or in a group setting and in the community, work setting. (This service includes the previously offered Waiver services: Community Habilitation and Participation, Pre-Vocational Services, Supported Employment Follow Along Services, Transportation)

Services Descriptions (cont'd)

Environmental Modifications: (*Autism, DD Waivers*) Necessary adaptations to the home ensuring the health, safety, and welfare of the individual, and enable the individual to function with greater independence in the home. There is a lifetime cap of $15,000 for these modifications.

Environmental Modifications Maintenance: (*Autism, DD Waivers*) A $500 per year maximum amount is available permitted for maintenance and repair of prior modifications.

Family and Caregiver Training: (*Autism, DD, Support Services Waivers*) Service provides training and education related to treatment regimes, use of equipment, community integration, parenting, family dynamics, stress management, behavior interventions and mental health, conferences to a parent, other family members or unpaid primary caregiver. Airfare, meals, hotel are not allowed. This service must be related to the enhancement of the unpaid caregivers' or family members' ability to give care to the person receiving Waiver services.

Music Therapy: (*Autism, DD, Support Services Waivers*) Systematic application of music in the treatment of the physiological and psychological aspects of a disability and focusing on the acquisition of nonmusical skills and behaviors.

Occupational Therapy: (*Autism, DD, Support Services Waivers*) Evaluation and training programs in areas of gross and fine motor function, self-care and sensory and perceptual motor function. It includes assessments; planning and reporting, direct therapeutic intervention, design, fabrication, and adaptation of materials, and equipment to meet personal needs in assisting independence. (A Medicaid Prior Authorization denial must be obtained before this service can be provided through the Waiver.)

Personal Emergency Response System Supports: (*Autism, DD, Support Services Waivers*) An electronic device that enables the person to secure help in case of an emergency.

Physical Therapy: (*Autism, DD, Support Services Waivers*) Treatment and training designed to preserve and improve abilities for independent functioning, such as gross motor skills, fine motor skills, range of motion, strength, muscle tone, and mobility. (A Medicaid Prior Authorization denial must be obtained before this service can be provided through the Waiver.)

Recreational Therapy: (*Autism, DD, Support Services Waivers*) Medically approved recreation program with the purpose to restore, remediate, or rehabilitate in order to improve functioning and independence, as well as reduce or eliminate the effects of a disability.

Rent and Food for Unrelated Live-In Caregiver Services: (*Autism, DD Waivers*) Reimbursement directly to the person receiving Waiver services in order to offset rent and food expenses for an unrelated caregiver living in the person's home.

Services Descriptions (cont'd)

Residential Habilitation and Support: (*Autism, DD Waivers*) Services and supports which are designed to ensure the health, safety and welfare of a person, and to assist in the acquisition, retention and/or improvement in skills necessary to support the person to live successfully in his/her home. Includes personal care, meals, shopping, bill paying, etc. Up to 24 hour assistance can be provided, as needed. (This service includes previously offered Waiver services: Community Habilitation and Participation, Independence Assistance Services, Health Care Coordination, Transportation)

Respite Care: (*Autism, DD, Support Services Waivers*) Periodic, short-term care to a person when the family member or the primary caregiver cannot be there or needs a rest from his/her care responsibilities. Includes camp programs. Does not include "child care" to enable caregiver to work or attend school.

Specialized Medical Equipment and Supplies / Adaptive Aids and Devices: (*Autism, DD, Support Services Waivers*) Devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their ability to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live. Items that are not of direct medical or remedial benefit are excluded. Examples include communications equipment, computer adaptations, wheelchairs, environmental controls, safety restraints, or other equipment that increase the person's independence. (Equipment and services that are available under the Medicaid State Plan are not allowed under this Waiver service.) **Includes Vehicle Modifications:** Vehicle Modification may be authorized when necessary to increase a person's ability to function in a home and community-based setting to ensure accessibility. The necessity for such service must be documented in the Plan of Care by a physician's order. There is a lifetime maximum of $15,000 for vehicle modifications. There is an allowable annual maintenance fee. (A separate prior approval must be obtained before any modifications can be completed.)

Speech / Language Therapy: (*Autism, DD, Support Services Waivers*) Service seeks to improve, maintain, or slow regression of the person's ability to communicate. (A Medicaid Prior Authorization denial must be obtained before this service can be provided through the Waiver.)

Supported Employment Follow Along: (*Autism, DD, Support Services Waivers*) Supports for persons to establish and maintain employment in work settings in which people without disabilities are employed. No longer a separate service, see definition for **Day Services**

Therapy Services (Psychological Therapy): (*Autism, DD, Support Services Waivers*) Services provided by a psychologist that lead to changes from a less adaptive state to a more adaptive state in the person's thoughts, feelings, and behavior. Includes group, family and individual counseling and substance abuse counseling. (This service is not available if services are available through the Medicaid State Plan.)

Flow Chart of the Enrollment Process

(If at any point, eligibility or services are denied, the person will be notified in writing and have appeal rights. See page 33 for information on appeal rights.)

WAIVER APPLICATION

- Contact local Bureau of Developmental Disabilities Services (BDDS) staff
- Complete applications for DD Services and for Long Term Care (Waiver services)
- Provide documents to BDDS re: eligibility criteria

ASSESSMENT / ELIGIBILITY

- Intake service coordinator contacts applicant in 10 days to complete DDP or refers D&E team for assessments
- Determination of DD eligibility
- Preliminary Level of Care determined
- Applicant on Waiver waiting list. (When on the waiting list, the applicant must inform the BDDS Field Offices' staff of any changes in address or telephone immediately.)

TARGETED FOR WAIVER

- DDRS notifies applicant when slot is available
- Service Coordinator contacts applicant and verifies Level of Care (or for children younger than 6 years old, Level of Care determined by BDDS Level of Care Unit)
- Contact local Division of Family Resources (DFR) for Medicaid eligibility
- Referral to the case management company

PLAN DEVELOPMENT

- Person Centered Planning/Individualized Support Plan and Plan of Care completed with case manager
- Selection of services and providers
- Cost Comparison Budget (CCB) submitted to Waiver Unit by case manager

SERVICE BEGINS

- CCB reviewed and, if approved
- Case manager communicates approval with DFR caseworker and BDDS staff and confirms Waiver start date
- Notice of Action form sent to individual and providers
- Providers contact individual and services begin

ICF/MR Level of Care Waivers
For Children and Adults with Developmental Disabilities

	Developmental Disabilities (DD) Waiver **Established 2001** (Formerly ICF/MR Waiver- established 1992)	**Autism Waiver** **Established 1990**	**Support Services Waiver** **Established 2002**
TO APPLY: CONTACT YOUR LOCAL BUREAU OF DEVELOPMENTAL DISABILITIES DISTRICT OFFICE- SEE PAGE 41			
Eligibility Criteria	Developmentally Disabled ICF/MR Level of Care (LOC) (Parental income and resources disregarded for children under 18) Medicaid eligibility is based on 300% of maximum SSI amount. As of January 2007, SSI benefits = $624 per month	Diagnosis of Autism ICF/MR Level of Care (LOC) (Parental income and resources disregarded for children under 18) Medicaid eligibility is based on 300% of maximum SSI amount. As of January 2007, SSI benefits = $624 per month	Developmentally Disabled ICF/MR Level of Care (LOC) (Parental income and resources disregarded for children under 18) Medicaid eligibility is based on 300% of maximum SSI amount. As of January 2007, SSI benefits = $624 per month Limited to $13,500 per year of services
Note: Income Eligibility levels for individuals on the ICF/MR Level of Care Waivers can be up to three times of maximum SSI benefits. This eliminates the spend down for most people. The SSI benefits change on an annual basis. Check with your caseworker each January for changes. For other Medicaid services, the Federal Poverty Level (FPL) is used for determination of eligibility.			
Services Available	Adult Day Services Adult Foster Care Behavioral Support Services//Crisis Assistance Community Transition Services Day Services includes: Community Habilitation and Participation Srvc Pre-Vocational Services Supported Employment Follow Along Services Transportation Services Environmental Modification Family and Caregiver Training Music Therapy Occupational Therapy Personal Emergency Response System Physical Therapy Recreational Therapy Rent and Food for Unrelated Live-in Caregiver Residential Habilitation and Support, includes: Community Habilitation and Participation Srvc Health Care Coordination Services Independence Assistance Services Transportation Services Respite Care Specialized Medical Equipment and Supplies Including Vehicle Modifications Speech-Language Therapy Therapy Services (psychological therapy)	Adult Day Services Adult Foster Care Applied Behavioral Analysis Behavioral Support Services//Crisis Assistance Community Transition Services Day Services includes: Community Habilitation and Participation Srvc Pre-Vocational Services Supported Employment Follow Along Services Transportation Services Environmental Modification Family and Caregiver Training Music Therapy Occupational Therapy Personal Emergency Response System Physical Therapy Recreational Therapy Rent and Food for Unrelated Live-in Caregiver Residential Habilitation and Support, includes: Community Habilitation and Participation Srvc Health Care Coordination Services Independence Assistance Services Transportation Services Respite Care Specialized Medical Equipment and Supplies Including Vehicle Modifications Speech-Language Therapy Therapy Services (psychological therapy)	Adult Day Services Behavioral Support Services//Crisis Assistance Day Services includes: Community Habilitation Participation Srvc Pre-Vocational Services Supported Employment Follow Along Service Transportation Services Family and Caregiver Training Music Therapy Occupational Therapy Personal Emergency Response System Physical Therapy Psychological Therapy Recreational Therapy Respite Care (up to $2,000/year) Specialized Medical Equipment and Supplies Including Vehicle Modifications Speech-Language Therapy Therapy Services (psychological therapy)
Case Management	Case Management Service for ICF/MR Level of Care Waivers are provided through the State Medicaid Plan. When you are targeted for a Waiver, you will be referred to a case management company to help you plan for Waiver services.		
Waiting List Information	Local BDDS office - see page 41	Local BDDS office – see page 41	Local BDDS office – see page 41

Nursing Facility Level of Care Waivers For Children and Adults with Disabilities

	Aged and Disabled Waiver Established 1990	Traumatic Brain Injury Established 2000
TO APPLY: CONTACT YOUR LOCAL AREA AGENCY ON AGING AT 800-986-3505 OR SEE PAGE 40 FOR A LIST OF THE OFFICES AND LOCAL NUMBERS		
Eligibility Criteria	Nursing Facility Level of Care (Parental income and resources disregarded for children under 18) Spousal impoverishment protections similar to those for nursing homes are available under this Waiver. Medicaid eligibility is based upon 300% of the SSI maximum benefit.	Diagnosis of Traumatic Brain Injury Nursing Facility Level of Care (Parental income and resources disregarded for children under 18) The Medicaid eligibility is based upon 150% of the SSI maximum benefit.
Note: Income Eligibility levels for individuals on the Aged and Disabled can be up to three times the maximum SSI benefits and for individuals on the Traumatic Brain Injury can be up to one and one-half times the maximum SSI benefits. This eliminates spend down for most people. For other Medicaid services, the Federal Poverty Level (FPL) is used for determination of eligibility. SSI benefits change yearly so check with your caseworker each January.		
Services Available	Adult Day Services Adult Foster Care Assisted Living Attendant Care Case Management Community Transition Services Congregate Care Environmental Modifications Home Delivered Meals Homemaker Nutritional Supplements Personal Emergency Response System Pest Control Respite Care Specialized Medical Equipment and Supplies Including Vehicle Modifications Transportation	Adult Day Services Attendant Care Behavior Management/Behavior Program and Counseling Case Management Day Habilitation/Structured Day Program Environmental Modifications Health Care Coordination Homemaker Occupational Therapy Personal Emergency Response System Physical Therapy Residential Habilitation Respite Care Specialized Medical Equipment and Supplies Including Vehicle Modifications Speech-Language Therapy Supported Employment Transportation
Waiting List Information	Area Agency on Aging (AAA) 800-986-3505 See page 40	

Flow Chart of the Enrollment Process

WAIVER APPLICATION

- Contact local Area Agency on Aging (AAA) for Waiver application
- Case manager assists in the completion of application within three weeks and refers applicant to other services, as eligible
- Applicant on Waiver waiting list, if applicable*

When on the waiting list, the applicant must inform the case manager of any changes in address or telephone immediately!

TARGETED FOR WAIVER

- Division of Aging (DA) notifies AAA when a slot is available
- AAA contacts applicant within a week
- Applicant contacts local Division of Family Resources (DFR) for Medicaid eligibility, if not already receiving Medicaid benefits

ASSESSMENT/ELIGIBILITY

- AAA case manager arranges for evaluation within a week
- Case manager gathers Level of Care information
- AAA or DA determines Nursing Facility Level of Care

PLAN DEVELOPMENT

- Plan of Care (POC) is completed based on your needs and choices
- AAA submits Plan of Care to DA
- DA reviews issues determination to AAA

SERVICES BEGIN

- Once authorized, case manager sends a Notice of Action
- Once the initial Waiver CCB/POC is approved, individual selects an on-going case manager
- Provider contacts individual and services begin

If at any point, eligibility or services are denied, the person will be notified in writing and have appeal rights. See page 33 for information on appeal rights.

How Do You Apply?

1. The local Area Agency on Aging (AAA) is the single point of entry for NF Level of Care Waivers. An applicant will be assigned a case manager. See page 40 for a list of regional offices. The case manager will assist the applicant in completing an Application for Long-Term Care Services. You may apply for one or both of the Waivers, as appropriate.
2. The applicant seeking a Waiver must also apply for Medicaid Eligibility at the local Division of Family Resources (DFR), if not already eligible under one of the categories of "Aged," "Blind," or "Disabled." When applying for Medicaid solely for the purpose of Waiver eligibility, only the income of an applicant seeking a Waiver is considered. For a child under the age of eighteen (18), the parental income does not affect the child's financial eligibility for Medicaid.
3. The Level of Care is determined by the Area Agency on Aging (AAA) and/or the Division of Aging based upon a physical examination and physician's recommendation of home and community-based services on a 450B form. The case manager will have the form for the physician. The Level of Care required for the Aged & Disabled (A&D) and Traumatic Brain Injury (TBI) Waivers is Nursing Facility Level of Care, meaning that the person would be at risk of being placed in a nursing facility without the services provided by these Waivers.
4. If there are no slots available on the Waiver, the applicant will be placed on the waiting list for that Waiver. The waiting lists for the A&D and TBI Waivers are held within each of the Area Agencies on Aging (AAA).

Eligibility Criteria

Aged & Disabled Waiver: The child or adult must be aged or disabled; Nursing Facility Level of Care; Medicaid eligibility (based on 300% of maximum SSI amount, as of January 2007, $624 per month); Parental income for children under 18 years of age is not considered (disregarded); Spousal impoverishment protection is the same as if a spouse was in a nursing facility.

Traumatic Brain Injury Waiver: The child or adults must be aged or disabled; Nursing Facility Level of Care; Traumatic Brain Injury; Medicaid eligibility (based on 150% of maximum SSI amount, as of January 2007, $624 per month); Parental income for children under 18 years of age is not considered (disregarded).
For more information on Level of Care see page 10.

Services Descriptions

Adult Day Services (ADS): (*Aged and Disabled, Traumatic Brain Injury Waivers*) Structured, non-residential, community-based group programs designed to meet the needs of adults who are elderly and/or with disabilities through individual plans of care. ADS provides a variety of health, social, recreational and therapeutic activities, supervision, support, meals, and in some cases personal care.

Adult Foster Care: (*Aged and Disabled Waiver*) Twenty-four hour care consisting of personal care, homemaker, chore, attendant care, companion services, provided in a private home by a principal caregiver who is not related to the individual(s). Foster care homes are limited to a maximum of three people in one foster home.

Assisted Living: (*Aged and Disabled Waiver*) 24 hour site providing personal care and services, homemaker, chore, attendant care, companion services, medication oversight, therapeutic, social and recreational programming. Licensed (by Indiana State Department of Health) residential care facility. Includes on-site response staff to meet scheduled or unpredictable needs.

Attendant Care: (*Aged and Disabled, Traumatic Brain Injury Waivers*) Assistance to meet daily living needs and ensure adequate functioning in a community-based setting. Some allowable activities include assistance with dressing, eating, bathing, hygiene, activities of daily living, meal preparation and household chores.

Behavior Management / Behavior Program and Counseling: (*Traumatic Brain Injury Waiver*) Training, supervision, and assistance in appropriate expression of emotions and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors.

Behavior Support Services / Crisis Assistance: (*Autism, DD and Support Services Waivers*) Training, supervision, or assistance in appropriate expression of emotions and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors.

Case Management: (*Aged and Disabled, Traumatic Brain Injury Waivers*) In general, a case manager helps people obtain the supports needed to live as independently as possible in their community, by finding and coordinating available resources and services to meet the person's needs. Case managers also help to plan, monitor and evaluate the person's services, and assist with the process and necessary paperwork. This service coordination or case management is sometimes provided by the direct services agency, but may also be provided by the person's family or an advocate, or, for the Medicaid Waiver services, by a private case manager.

Community Transition Supports: (*Aged and Disabled Waiver*) Reasonable, **one-time** set-up expenses for a person who makes the initial transition from an institution to his/her own home in the community. Items purchased are the property of the person receiving the service and the person takes the property with him/her in the event of a move to another residence. Expenses may include: security deposits, furnishings and moving expenses, deposits for utilities, pest eradication, allergen control or one-time cleaning prior to occupancy. There is up to $1,000 allowance for this one-time only service.

Services Descriptions (cont'd)

Congregate Care: (*Aged and Disabled Waiver*) Twenty-four (24) hour supervision and the coordination of other services by a subsidized housing provider for residents who live in an apartment/living unit owned by the provider. Services are based on the Plan of Care.

Day Habilitation / Structured Day Program: (*Traumatic Brain Injury Waiver*) Regularly scheduled activities that focus on training to enhance social and daily living skills apart from the person's living arrangement. The person must have an Individual Program Plan (IPP) listing goals and objectives.

Environmental Modifications: (*Aged and Disabled, Traumatic Brain Injury Waivers*) Necessary adaptations to the home that ensure the health, safety, and welfare of the person, and enable the person to function with greater independence in the home. There is a lifetime cap of $15,000 for these modifications. Documentation of 'Prior Authorization' denial from Medicaid may be required.

Environmental Modifications Maintenance: (*Aged and Disabled, Traumatic Brain Injury Waivers*) A $500 per year maximum amount is available to repair or replace modifications.

Health Care Coordination: (*Traumatic Brain Injury Waiver*) Medical coordination provided by an RN or LPN to manage the health care of the person including physician consultations, medication ordering, and development and oversight of a health care support plan.

Home-Delivered Meals: (*Aged and Disabled Waiver*) Provides meals (including the preparation, handling and serving of the meals) to person unable to prepare his/her own daily meals, and for whom there are no other people available to do so. Limited to two meals per day.

Homemaker: (*Aged and Disabled, Traumatic Brain Injury Waivers*) General household activities that assist the person to remain in a clean, safe, healthy home environment, that are provided when the person or an informal caregiver is unable to manage the home.

Nutritional Supplements: (*Aged and Disabled Waiver*) Nutritional (Dietary) supplements include liquid supplements, such as "Boost" or "Ensure" to maintain a person's health in order to remain in the community.

Occupational Therapy: (*Traumatic Brain Injury Waiver*) Evaluation and training programs in areas of gross and fine motor function, self-care and sensory and perceptual motor function. It includes assessments; planning and reporting, direct therapeutic intervention, design, fabrication, and adaptation of materials, and equipment to meet personal needs in assisting independence. (A Medicaid Prior Authorization denial must be obtained before this service can be provided through the Waiver.)

Personal Emergency Response System Supports: (*Aged and Disabled, Traumatic Brain Injury Waivers*) An electronic device that enables the person to secure help in case of an emergency.

Pest Control: (*Aged and Disabled Waiver*) Services that prevent, suppress, or eradicate pest infestation such as roaches, mosquitoes, fleas, mites, ticks, rats and mice. There is a cap of $600 per year.

Services Descriptions (cont'd)

Physical Therapy: (*Traumatic Brain Injury Waiver*) Treatment and training designed to preserve and improve abilities for independent functioning, such as gross motor skills, fine motor skills, range of motion, strength, muscle tone, and mobility. (A Medicaid Prior Authorization denial must be obtained before this service can be provided.)

Residential Habilitation: (*Traumatic Brain Injury Waiver*) Services and supports which are designed to ensure the health, safety and welfare of an person, and to assist in the acquisition, retention and/or improvement in skills necessary to support the person to live successfully in his/her home.

Respite Care: (*Aged and Disabled, Traumatic Brain Injury Waivers*) Periodic, short-term care to a person when the family member or the primary caregiver cannot be there or needs a rest from his/her care responsibilities. Does not include "child care" to enable caregiver to work or attend school.

Specialized Medical Equipment and Supplies (formerly Adaptive Aids and Devices): (*Aged and Disabled, Traumatic Brain Injury Waivers*) Devices (communications equipment, computer adaptations, etc.), wheelchairs, environmental controls, safety restraints, or other equipment that increase the person's independence. Includes assessment, inspection and training, as needed. (Equipment and services that are available under the Medicaid State Plan are not allowed to be included in this Waiver service.)
Includes Vehicle Modifications: Vehicle Modifications may be authorized when necessary to increase a person's ability to function in a home and community-based setting to ensure accessibility. The necessity for such service must be documented in the Plan of Care by a physician's order. There is a lifetime maximum of $15,000. There is an allowable annual maintenance fee. (A separate Prior Authorization must be obtained before any modifications can be completed.)

Speech / Language Therapy: (*Traumatic Brain Injury Waiver*) Service seeks to improve, maintain, or slow regression of the person's ability to communicate. (A Medicaid Prior Authorization denial must be obtained before this service can be provided.)

Supported Employment: (*Traumatic Brain Injury Waiver*) Supports for persons to establish and maintain employment in work settings in which people without disabilities are employed.

Transportation: (*Aged and Disabled, Traumatic Brain Injury Waivers*) Transportation needed for the person to access Waiver and other community resources. (This service is not to be used for accessing medical or therapy appointments.)

What is Quality Monitoring?

People receiving Medicaid Waiver services, their families, case managers, providers and the State all have an important role in helping maintain high quality services under any of the Waiver programs. All providers, including case managers, have internal quality assurance and monitoring systems. You should expect the providers and case managers to identify and solve problems quickly.

The Family and Social Services Administration require quality assurance and quality improvement processes that assist in monitoring the Waiver services. These processes include, but not limited to:

1. On site surveys of providers and case managers based on the Provider Standards and Case Management Standards contained within the IAC 460 – 6.

2. Quality of Life and Improvement Process and Consumer Satisfaction Surveys: People and their families are encouraged but not required to participate in these surveys and assessments.

3. Complaint Process: People receiving Waiver services, their families/guardians, providers, case managers and others can file formal complaints with FSSA when issues related to a Waiver are not resolved appropriately or in a timely manner. To file a complaint with the Division of Aging, call 317-232-7132 or 800-545-7763, ext. 2-7132. To file a complaint with the Developmental Disabilities Bureau of Quality Improvement call 317-234-2736 or 800-545-7763, ext. 4-2736.

4. Incident Reporting Process: Providers are required to report any incidents of suspected abuse, neglect or exploitation with Adult Protective Services or Child Protective Services. In addition, all Waiver providers must file an incident report with FSSA when a critical incident occurs.

5. Committees: There are various committees that help advise FSSA about waivers. If a person or family member would like to be a member of a committee related to the Quality Improvement process, contact the Division of Disability and Rehabilitative Services at 317-232-1147 or 800-545-7763, ext. 2-1147 or the Bureau of Developmental Disabilities at ext. 2-7842.

How Are Problems Resolved?

If you are having a problem with your service provider staff or case manager, talk first with the service provider staff or the case manager. You should expect a quick and appropriate response to your concern or problem. If the issue is not resolved, speak to the supervisor of staff or case manager. After a reasonable number of days, and if you are still concerned about the problems, you can contact the following:

For Nursing Home Level of Care Waivers:

If the problem remains unresolved, or if the problem is with your Area Agency on Aging (AAA), contact the Division of Aging at 317- 232-7132 or 800-545-7763, ext. 2-7132 to report the problem.

For ICF/MR Level of Care Waivers:

- If the problem with a provider or case manager remains unresolved, contact the Bureau of Quality Improvement Services (BQIS) at 317-234-2736; or 800-545-7763, ext. 4-2736.
- If the problem is with the local BDDS District Office, contact the Director of Client Services at 317-234-3719; or 800-545-7763, ext. 4-3719.
- Another resource: contact the DD Waiver Ombudsman at 800-622-4484. By law, the Ombudsman receives, investigates, and attempts to resolve complaints and concerns that are made by or on behalf of people with developmental disabilities in Waiver programs.

Other resources for assistance in complaint resolution include:

1. Adult Protective Services (APS) 800-992-6978 conducts investigations and provides least restrictive intervention for adults who are endangered by abuse, neglect, or exploitation.
2. Child Protective Services (CPS) 800-800-5556 conducts investigations and protects children from abuse or neglect and prevents, remedies, or assists in solving problems that may result in abuse, neglect, exploitation or delinquency of a child.
3. Indiana Protection and Advocacy Services (P&A) 800-622-4845 will investigate consumer complaints, assist in the appeals' process, if needed, or take other action needed to resolve problems.
4. Medicaid Fraud Hot Line 800-382-1039 will investigate reports and allegations of providers or people inappropriately using Medicaid benefits or funding.

Choosing a new provider

Freedom of choice is guaranteed under the Waiver program. Exercising your freedom of choice is the best way to make sure you receive the services that you need. You have the right to CHOOSE to change to a different provider or case manager (as long as the different provider is certified by the Medicaid program for your area.) The process is designed to be flexible to meet changing needs and/or provide better delivery of services.

Provider discontinuing services

A Waiver provider can discontinue Waiver services for a variety of reasons.

A provider of **Nursing Facility Level of Care** Waiver services that decides to stop delivering a service must give a thirty (30) day written notice to you, the case manager, and the Division of Aging Provider Relations Specialist. If proper notice is not given, contact your case manager. The case manager will also assist you in selecting another provider.

A provider of **ICF/MR Level of Care** Waiver services that decides to stop delivering a service must give a sixty (60) day written notice to you, the case manager, the District Office Service Coordinator, and the State Provider Relations Specialist. If proper notice is not given, contact your case manager. The case manager will also assist you in selecting another provider. The provider is expected to continue to deliver the Waiver services until another provider is selected and begins the services.

What Are Your Appeal Rights?

An appeals' process is available to every person who thinks that an action taken is adverse to him/her. For example, a person is denied initial eligibility for a Waiver, or your Level of Care eligibility is denied during the annual review process or a specific Waiver service, such as an assistive technology device, has been denied. Denial of non-Waiver Medicaid services–referred to as "state plan" or "regular Medicaid" services--may also be appealed.

When the State denies your eligibility for a program or service, you will receive a written Notice of Action. The effective date of the action will be in the Notice of Action you receive. The Notice of Action will include the appeals' procedure, describing what should be sent with the written appeal request, to whom the appeal request should be sent, and the timelines. Most appeal requests must be filed within 30 days. During the appeal process, benefits and services will continue, until there is a hearing decision. If you are in doubt, always request an appeal. The appeals' process is the only way to preserve your rights under federal and Indiana administrative law.

The State will schedule a hearing before an Administrative Law Judge and must send a written notice of the hearing at least ten days before the scheduled date. You, as the person who has filed an appeal, have a right to:

1. Be represented at the hearing by legal counsel, advocate, friend, and/or relative,
2. Review the entire case file prior to the hearing; to bring witnesses and cross-examine adverse witnesses, and
3. Present evidence.

Hearings are usually conducted in a Division of Family Resource office in your county of residence.

The decision of the Administrative Law Judge may be further appealed by requesting an "Agency Review." This consists of a review of the record from the hearing and the Administration Law Judge's decision by a Family and Social Services Administration designee, in order to determine if the decision is appropriate. No new evidence is accepted for the review; however, you or your representative may submit a "Memorandum of Law" summarizing the case. To appeal the Agency Review decision, you must file for judicial review in a civil court.

For further information regarding your appeal rights, contact your case manager. You may also contact one of the advocacy agencies for more information or support on appeals or services. See page 46 for contact information.

How Do You Select Good Providers?

Selecting good providers is critical. It's helpful to think about the issues that are important to you/your family member before you begin the process. A list of certified Waiver providers for each county, including case managers, for the **Nursing Facility LOC Waivers** is available from the AAA offices; and for the **ICF/MR LOC Waivers** from the local BDDS District Offices.

You will be able to make an informed choice by reading information, such as this booklet, or by discussing alternatives with the case manager, or an advocate. You may want to visit an individual who is currently receiving Waiver services or meet with various service providers. Case managers can assist in setting up visits or meeting with service providers.

Sometimes a provider can arrange for you to visit people who are receiving services from the provider. Remember, when you visit a house or apartment where Waiver services are being provided, you are visiting someone's home.

On the following pages are some questions to consider when selecting Waiver providers. Which questions you ask will depend on what kind of service it is, and whether you will be served in your family home, your own home/apartment with or without housemates. Many of the questions are applicable to any setting, and others can be skipped or modified as needed.

When meeting with providers or case managers, it is important to take notes, because it is easy to forget details later. Ask for copies of any written materials, write down names, titles, phone numbers, email addresses, etc., and the date of the meeting. It's important to maintain accurate information.

General Topics to Discuss with Service Providers and Case Managers

1. Discuss all areas of service that are absolute requirements for you/your family member such as: medications always administered on time, 24 hour direct supervision, sign language training, etc.
2. What makes you/your family member happy? What causes pain? How will the provider maximize opportunities for the first, and minimize or eliminate instances of the second?
3. What things do you/your family member want to have happen? A job? Member of a church? How many housemates? Living within a half hour drive of family? Anything else? Are these wishes or requirements?
4. What are the risks for you/your family member? For example, daily seizures; no street safety skills; does not talk or use sign language; forgetful; hits others when angry, etc. How will the provider deal with those risks?

Specific Questions to Ask a Case Manager

1. What is your experience working with children and/or adults with disabilities or adults who are elderly?
2. How would you ensure the implementation of my Person Centered Plan (for DD Waivers)?
3. What connections have you established in my community? How would you assist me in building a support system in my community?

How Do You Select Good Providers?(Con't)

Specific Questions to Ask a Case Manager (Con't)

4. In what capacity do you see yourself fitting into my team of family and friends, and with each of the service providers that I choose?
5. What, and how often, would you routinely communicate with me and other team members? How do you approach negotiation and conflict resolution among team members?
6. Can I page or call you in the event of an emergency?
7. How often would you expect to see me/my family member each month?

Questions to Ask Prospective Service Providers

1. What is the provider's mission? (Does it match the intent you are seeking?)
2. Is the provider certified, accredited, or licensed? What are the standards of service?
3. What kind of safety measures does the provider have to protect and assure treatment?
4. How does the provider assure compliance with person's rights? Do you (and/or family members/advocates) receive copies of your rights as a consumer of services, as well as have these rights explained?
5. Is the provider interested in what you/your family member wants or dreams about?
6. Is the provider connected to other programs that you may need, such as day support, local school/education services, or work programs? How is the provider connected? Ask for specific contacts.
7. If you are to live in a home shared with other people, can families drop in whenever they wish?
8. How are birthdays, vacations, and special events handled?
9. How would family money issues be handled? What is the policy on personal/client finances?
10. How would minor illnesses and injuries be handled? Major illnesses/injuries?
11. What kinds of things are routinely reported to families?
12. Can we get a copy of your complaint policies and procedures? Is there someone else who family members can talk to if there is a disagreement?
13. How are behavior problems handled? Are staff allowed to contact a behavioral support provider? How are new staff trained on the behavior support plan? Are they trained before working with our family member? What is the relationship between residential provider and behavioral provider?
14. How is medication handled? What happens if medication is refused?
15. What is the smoking policy?
16. How are planning meetings scheduled and conducted, and who attends? Can a family member call a meeting? How do you assure that what is agreed upon in the meeting actually is provided?
17. Who would be the provider contact person, and how will that contact occur, and how often? Is someone available 24 hours a day in case of emergencies?
18. How many people with disabilities has the agency terminated or discontinued from services? Why? What happened to them?
19. Has the agency received any abuse/neglect allegations? Who made these allegations? What were the outcomes? What is the process for addressing abuse/neglect allegations?

How Do You Select Good Providers?(Con't)

Questions to Ask Prospective Service Providers (Con't)

20. What challenges do you think my family member will create for you?
21. As a provider of Waiver services, what are your strengths and weaknesses?
22. What is the process for hiring staff? Are background checks conducted and training given? What happens to our family member while a new staff person is hired and trained?
23. How is direct staff supervised? What training does the staff receive? What is the average experience or education of staff?
24. How is staffing covered if regular staff is ill? What happens if staff does not show up for the scheduled time? How often does it happen?
25. What is the staff turnover rate? How are staff's respite needs handled?
26. What kind of supports do staff have? Who can staff call if a problem develops?

What to Look For and Ask About During Visits to Supported Living Settings (DD Waivers only)

1. How do the staff and housemates interact? Do they seem to respect and like each other?
2. Does the environment look comfortable? Is there enough to do? Are there things happening in the home?
3. What kind of food is available and who picks it? Are choices encouraged/available? Are diets supervised?
4. Do people have access to banks, shops, restaurants, etc? How is transportation handled? Are trips to access these resources planned or on an as needed basis?
5. Is there a telephone available to housemates (with privacy)? Is the telephone accessible (equipped with large buttons, volume control, other access features) if needed?
6. Does each person have his/her own bedroom? Can each person individually decorate the bedroom?
7. Do housemates seem to get along well? What happens when they don't?
8. Are there restrictions on personal belongings? What are the procedures for lost personal items? Are personal items labeled? Are lost items replaced?
9. Are pets allowed? What are the rules regarding pets?
10. How much time is spent in active learning (neighborhood, home or community) and leisure activities? Is there a good balance with unstructured time?
11. Is there evidence that personal hygiene and good grooming (hair, teeth, nails, etc.) are encouraged?
12. How are personal need items, clothing, etc. paid for?
13. Does each person have privacy when he/she wants to be alone or with a special friend?
14. Does each person have the opportunity to belong to churches, clubs, community groups, etc?
15. Do staff knock on doors (and wait for a response) before entering a private room?
16. What kind of rules is there within the living situation? What are the consequences for breaking rules?
17. Does each housemate have opportunities to pursue his/her own individual interests, or do they travel in a group with everyone doing the same thing, attending the same movie, etc.?

What Other Community Based Services Are Available?

Beside Waiver Services, you may also be eligible for other programs and services beyond the scope of the Waiver. You can apply for these programs and services while you are waiting for Waiver services to start; and you can use them to supplement the Waiver services. Some of the services available are listed below.

1. **Brain Injury Association of Indiana:** Helps persons with brain injuries and the families of those persons. Provides support groups and resources. 317-356-7722

2. **Children's Special Health Care Services:** Helps families of children with **serious chronic medical conditions** receive treatment related to the child's condition. Income eligibility standards are 250% of poverty. To apply, contact the **Indiana State Department Health** 800-475-1355.

3. **CHOICE (Community and In-Home Options to Institutional Care for the Elderly and Disabled):** A state-funded program under the Division of Aging that provides support to both the **elderly and people with disabilities including children**. In-home services such as respite care, home modification, personal assistance, and other services can be accessed. There is a waiting list for services. For more information, contact your local **Area Agency on Aging.** See page 40 or call 800-986-3505.

4. **Department of Education / Division of Exception Learners / Community-Supported Services:** Intensive special education and related services, necessary to enable a student to remain in the community, without resorting to residential placement, or to return a student to the local community from a residential placement. The Case Conference Committee determines if community-supported services are needed after the local educational corporation's continuum of services has been exhausted.

5. **Employment Supports:** A wide range of supports is available for **adults with disabilities** who are seeking employment or training, including work incentives through the Social Security Administration www.socialsecurity.gov/work/ to support working adults with disabilities. For more information, contact your local **Vocational Rehabilitation Services** office.

6. **Family Subsidy Program:** Provides limited financial support for respite care called 'Caregiver Support,' to assist families to keep the child or adult with **developmental disabilities** in the family home. Caregiver Support Services provide a 'break' for the primary caregiver. By definition, the primary caregiver is not allowed to use Caregiver Support Services to work or attend school classes. For more information, contact the **Bureau of Developmental Disabilities Services** District Office in your area. See page 41.

7. **First Steps Infant and Toddler Program:** Provides early interventions services to Indiana families with infants and toddlers from birth through age three who have developmental delays or disabilities. Services may include: Special instruction, Health services, Vision services, Diagnostic services, Assistive Technology, Nursing services, Psychological services, Audiology, Transportation, Nutrition services, Physical therapy, Occupational therapy, Social work services, Speech pathology, and Family support. Co-pays are b-ased on family income. Call 800-441-7837. www.in.gov/fssa/first_step/index.html

What Other Community Based Services Are Available? (cont'd)

8. Hoosier Healthwise / Children's Health Insurance Program (CHIP): Indiana's health care program for children, pregnant women, and low-income working families. Based on family income, children up to age 19 may be eligible for premium-free, or low-cost coverage under the Children's Health Plan. Benefits are similar to the regular Medicaid State Plan. (Children must apply for and be transferred to regular **Medicaid** health coverage once they are on a Waiver.) For more information call 800-889-9949.

9. Medicaid / Medicaid Select: People not yet on the Waiver may be eligible for Medicaid State Plan benefits. You apply at the local **Division of Family Resources (DFR)**. See page 42. The caseworker can also provide more comprehensive information about services available and limitations of the program. When you receive Waiver services, you must be enrolled in the Medicaid State Plan, since both programs are used to meet your needs. A brief list of regular Medicaid services includes (but is not limited to) the following:

- Hospital (inpatient, outpatient and emergency)
- Family planning services and supplies
- Durable medical equipment and supplies
- Nursing facility
- Long term care home health services
- Rural health clinics and health centers
- Other care services (PT, OT, speech, etc.)
- Lab and X-ray, prescribed drugs
- Mental health services
- Dental services
- Nurse practitioners
- Psychiatric hospital (under 21 and over 65)
- EPSDT (under age 21)
- Prosthetic devices
- Eyeglasses
- Diagnostic/screening/preventative
- Rehabilitation
- Case management for select people, including people receiving ICF/MR type Waiver services
- Hospice care
- Transportation

10. Medicaid for Employees with Disabilities (M.E.D. Works): Working adults with disabilities, including those receiving a Medicaid Waiver, can participate in this Medicaid program and may pay a premium based on their earned income to continue Medicaid coverage. The premiums are calculated at a lower rate than spend down and replaces traditional spend down. M.E.D. Works provides the full-range of traditional Medicaid-covered services and requires the same co-payments for services. Contact your local **Division of Family Resources** (DFR) for enrollment information. See page 42. For information about work incentive programs for people with disabilities including M.E.D.Works: www.in.gov/fssa/healthcare/med/medicaid/receivessdi.html

11. Medicare: A hospital, medical insurance, and prescription drug program for retired people and people receiving Social Security Disability Insurance (SSDI) benefits for at least 24 months. Under certain conditions a child may be eligible for Medicare based on the parents work history. Contact the Medicare Customer Service Information at 800-622-4792 (800-MEDICARE) or www.medicare.gov

What Other Community Based Services Are Available? (cont'd)

12. Section 8 Rent Subsidy: For individuals on a limited income, rent subsidies, such as Section 8 vouchers, may be available through local public housing authorities. These subsidies allow people with limited income to live in an integrated environment in a regular apartment building. Most communities have a Housing Authority and there is usually a waiting list. For contact information look in your telephone book or go to: www.hud.gov People from communities that do not have local housing agencies/authorities should contact the Indiana Rental Housing Help Line at 800-872-0371

13. Section 8 Home Ownership Program: For eligible individuals and families with low income, Section 8 vouchers can be used as mortgage subsidies rather than strictly for rent. This program is not currently available in all communities. Call your local Housing Authority or Rental Housing Help Line at 800-872-0371

14. Self-Directed Care or Private Hire: Children and adults who receive attendant/personal care services under the **Aged and Disabled Waiver** or **CHOICE** (or an individual who is responsible for making health-related decisions for the person) have the option to assume the responsibility to initiate self-directed care and exercise judgment regarding the manner in which those Waiver or CHOICE services are delivered, including the decision to employ, train, and dismiss a personal service attendant. Speak to your **AAA** case manager about this option.

15. Social Security Administration: For application and status of benefits call 800-772-1213 (automated answering resource). Contact website www.ssa.gov/disability/ Only people who have a disability and meet medical criteria are eligible for the two income disability programs (see **Social Security Disability Insurance and Supplemental Security Income** below).

16. Social Security Disability Insurance (SSDI): An income disability program that pays benefits to an eligible person with a disability and certain members of the family if the person is "insured," meaning they have worked long enough and paid Social Security taxes.

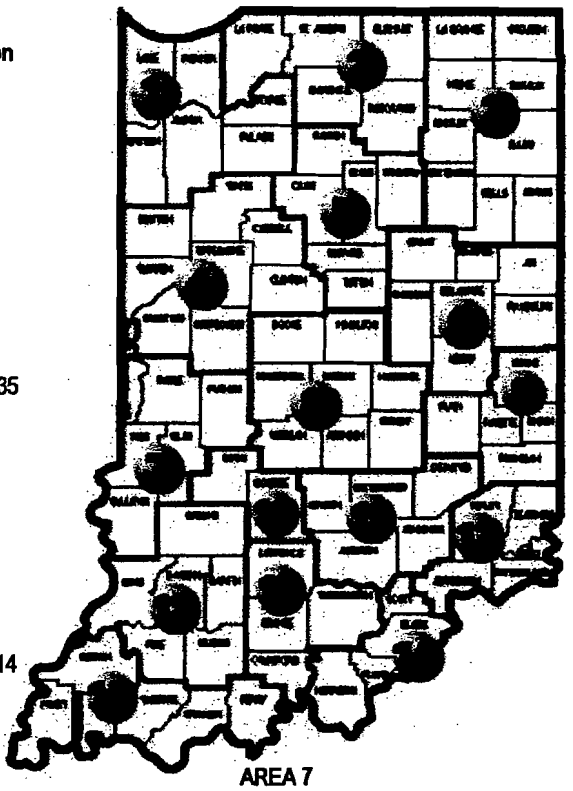
17. Supplemental Security Income (SSI): An income disability program that pays benefits to eligible adults and children with disability based on financial need.

18. Special Education: IDEA (Individuals with Disabilities Education Act) a federal entitlement program that provides free appropriation public education in the least restrictive environment to **special education** students up to age 22 (including infants and toddlers-First Steps Program). Services include therapies and assistive technology. For more information, contact the Special Education Director at your local school corporation or call the state office toll free at 877-851-4106. For information about **First Steps** see page 37

19. State Funded Supported Living Services: An array of residential services and residential living allowance that allows a person eligible for **developmental disabilities** services to be supported in his/her own home. Currently, limited state funds are available for those people who are moving from institutional settings to supported living settings. For more information, contact the **Bureau of Developmental Disabilities Services** District Office in your area. See page 41.

Area Agency on Aging Offices

Contact your local Area Agency on Aging toll free at 800-986-3505



AREA 1
NW IN Community Action Corp, Inc.
5240 Fountain Dr
Crown Point, IN 46307
219-794-1829
800-826-7871
FAX 219-794-1860

AREA 2
REAL Services, Inc.
1151 S. Michigan St.,
P.O. Box 1835
South Bend, IN 46634-1835
574-233-8205
800-552-2916
FAX 574-284-2642

AREA 3
Aging and In-Home Services of Northeast Indiana
2927 Lake Avenue
Fort Wayne, IN 46805-5414
260-745-1200
800-552-3662
FAX 260-456-1066

AREA 4
Agency on Aging & Community Action Programs
660 North 36th St.
P.O. Box 4727
Lafayette, IN 47903-4727
765-447-7683
800-382-7556
TDD 765-447-3307
FAX 765-447-6862

AREA 5
Agency on Aging & Community Services, Inc.
1801 Smith Street
Suite 300
Logansport, IN 46947-1577
574-722-4451
800-654-9421
FAX 574-722-3447

AREA 6
LifeStream Services, Inc.
1701 Pilgrim Drive
P.O. Box 308
Yorktown, IN 47396-0308
765-759-1121
800-589-1121
TDD 800-589-1121
FAX 765-759-0060

AREA 7
West Central Indiana Economic Development District, Inc.
1718 Wabash Ave., P.O. Box 359
Terre Haute, IN 47808-0359
812-238-1561 or 800-489-1561
TDD 800-489-1561
FAX 812-238-1564

AREA 8
CICOA Aging & In-Home Solutions
4755 Kingsway Dr., Suite 200
Indianapolis, IN 46205-1560
317-254-5465 or 800-489-9550
TDD 317-254-5497
FAX 317-254-5494

AREA 9
In-Home& Community Services Agency
520 South 9th St.
Richmond, IN 47374-6230
765-966-1795 or 800-458-9345
FAX 765-962-1190

AREA 10
Agency on Aging
630 West Edgewood Drive
Ellettsville, IN 47429
812-876-3383 or 800-844-1010
FAX 812-876-9922

AREA 11
Aging & Community Services of South Central Indiana, Inc.
1531 13th Street Suite G-900
Columbus, IN 47201-1302
812-372-6918
866-644-6407
FAX 812-372-7846

AREA 12
***Life*Time Resources, Inc.**
13091 Benedict Drive
Dillsboro, IN 47018
812-432-5215
800-742-5001
FAX 812-432-3822

AREA 13
Generations
P.O. Box 314
Vincennes, IN 47591
812-888-5880
800-742-9002
TDD 812-888-5762
FAX 812-888-4566

AREA 14
Lifespan Resources, Inc.
426 Bank Street, # 100,
P.O. Box 995
New Albany, IN 47151-0995
812-948-8330
888-948-8330
FAX 812-948-0147

AREA 15
Hoosier Uplands Agency on Aging and Disability Services
521 West Main Street
Mitchell, IN 47446
812-849-4457
800-333-2451
TDD 800-473-3333
FAX 812-849-4467

AREA 16
Southwestern Indiana Regional Council on Aging, Inc.
16 West Virginia St
P.O. Box 3938
Evansville, IN 47737-3938
812-464-7800
800-253-2188
FAX 812-464-7811

Bureau of Developmental Disabilities Services Offices

Central Office
Indianapolis
P O Box 7083
Indianapolis, IN 46207-7083
317-232-7842
800-545-7763
Fax: 317-234-2099

District 1
Merrillville
5800 Broadway, Suite P
Merrillville, IN 46410
219-887-0503
877-218-3053
Fax: 219-985-8652

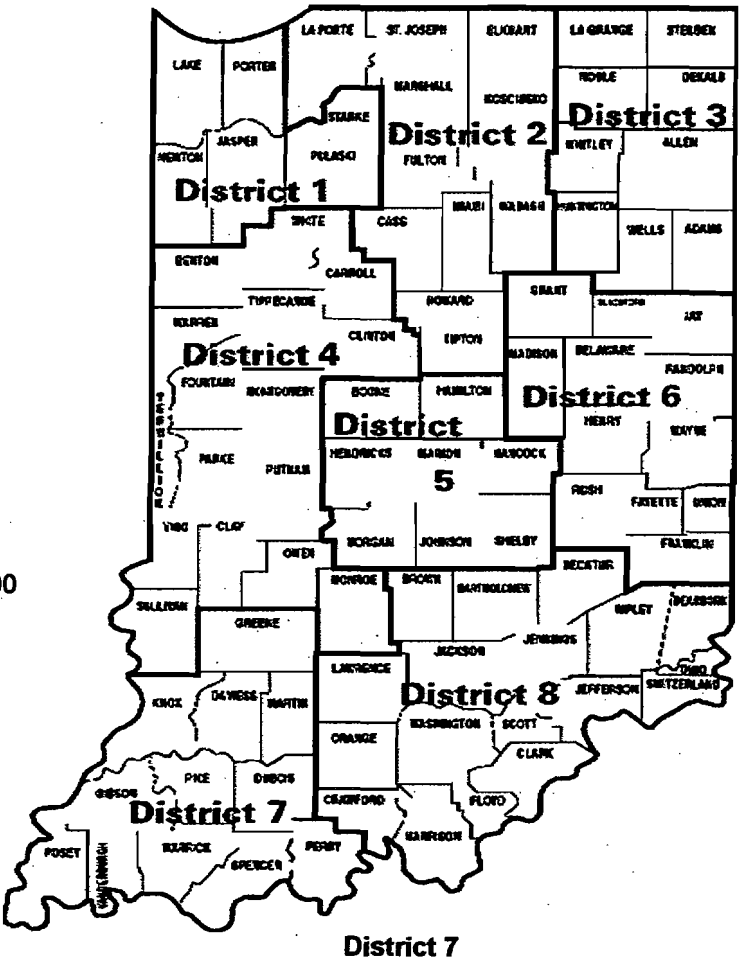
District 2
South Bend
224 W Jefferson Blvd, Suite 200
South Bend, IN 46601
574-232-1412
877-218-3059
Fax: 574-287-5482

District 3
Fort Wayne
219 W. Wayne Street.
Fort Wayne, IN 46802
260-423-2571
877-218-3061
Fax: 260-424-2830

District 4
Greencastle
1007 Mill Pond Lane, Suite A
Greencastle, IN 46135
765-653-2468
877-218-3096
Fax: 765-653-7152

District 5
Indianapolis
4701 N. Keystone, Suite 427
Indianapolis, IN 46205-1541
317-254-2065
877-218-3530
Fax: 317-254-2075

District 6
Muncie
1200 S.Tillotson Overpass, Suite 4
Muncie, IN 47304
765-288-6516
877-218-3531
Fax: 765-288-8529



District 7
Evansville
700 E. Walnut Street
Evansville, IN 47713
812-423-8449
877-218-3528
Fax: 812-428-4146

District 8
Clarksville
P. O. Box 2517
1452 Vaxter Avenue
Clarksville, IN 47131-2517
812-283-1040
877-218-3529
Fax: 812-285-9533

District 8
Seymour
200 E. Third Street
P. O. Box 930
Seymour, IN 47274-0930
812-522-5859
877-218-3532
Fax: 812-523-1160

Division of Family Resources Offices

Check your local telephone book for counties with multiple office locations or go to:
www.in.gov/fssa/family/children/dfc/directory

Adams Co. Office
1145 Bollman St., P.O. Box 227
Decatur, IN 46733
260-724-9169
Director: Steven E. Scott

Allen Co. Office
201 E. Rudisill Blvd., Suite 100
Fort Wayne, IN 46806
260-458-6200
Director: Michelle Savieo

Bartholomew Co.
1531 13th St., Suite 2700
Columbus, IN 47201-1311
812-376-9361
Director: Keith Weedman

Benton Co. Office
403 W. 5th St.
P.O. Box 226
Fowler, IN 47944-0026
765-884-0120
Director: Elva A James

Blackford Co. Office
124 N. Jefferson St., P.O. Box 717
Hartford City, IN 47348
765-348-2902
Director: Betty Lyons

Boone Co. Office
953 Monument Dr., P.O. Box 548
Lebanon, IN 46052
765-482-3023
Director: Kamilla Aeschliman

Brown Co. Office
121 Locust Lane, P.O. Box 325
Nashville, IN 47448
812-988-2239
Director: Debora L. Dailey

Carroll Co. Office
6931 West 300 North
Delphi, IN 46923-0276
765-564-2409
Director: Janis C. Mullen

Cass Co. Office
1714 Dividend Drive
Logansport, IN 46947
574-722-3677
Director: Anita S. Closson

Clark Co. Office
1200 Madison St.
Clarksville, IN 47129-7725
812-288-5400
Director: Patrick Brown

Clay Co. Office
1015 E. National Ave.
Brazil, IN 47834
812-448-8731
Director: Pam Connelly

Clinton Co. Office
57 W. Washington St.,
P.O. Box 725
Frankfort, IN 46041-0725
765-654-8571
Director: Janis Mullen

Crawford Co. Office
304 Indiana Avenue, P.O. Box 129
English, IN 47118
812-338-2701
Director: Herbert Gordon

Daviess Co. Office
4 N.E. 21st St., P.O. Box 618
Washington, IN 47501
812-254-0690
Director: Melinda Berry

Dearborn Co. Office
230 Mary Ave., Suite 150
P.O. Box 401
Lawrenceburg, IN 47025
812-537-5131
Director: Randy Hildebrand

Decatur Co. Office
1025 E. Freeland Rd., Suite B
P.O. Box 484
Greensburg, IN 47240-9427
812-663-6768
Director: Traci Lynn Eggleston

DeKalb Co. Office
934 W. 15th St., P.O. Box 870
Auburn, IN 46706
260-925-2810
Director: Mary E. Southern

Delaware Co. Office
333 S. Madison
P.O. Box 1528
Muncie, IN 47308
765-751-9565, Ext. 250
Director: Jacqueline S. Fisher

Dubois Co. Office
611 Bartley St.
Jasper, IN 47546
812-482-2585
(or P.O. Box 230
Jasper, IN 47547-0230)
Director: Leslie Rowland

Elkhart Co. Office
347 West Lusher Avenue
Elkhart, IN 46517-1825
574-293-6551
Director: Tony Sommer

Fayette Co. Office
3662 Western Avenue
Connersville, IN 47331-3428
765-825-5261
Director: Mark Munchel

Floyd Co. Office
1421 E. Elm St.
New Albany, IN 47150
812-948-5480
Director: John Barksdale

Fountain Co. Office
981 E. State St., Suite A
P. O. Box 67
Veedersburg, IN 47987
765-294-4126
Director: Cindy Mason

Franklin Co. Office
9127 Oxford Pike, Suite A
Brookville, IN 47012-9284
765-647-4081
Director: Terry Suttle

Fulton Co. Office
1920 Rhodes St.
Rochester, IN 46975-0820
574-223-3413
Director: Chris (Christina) Ackerman

Gibson Co. Office
321 S. 5th Avenue
Princeton, IN 47670-3519
812-385-4727
Director: Susan Blackburn

Grant Co. Office
840 N. Miller Avenue
Marion, IN 46952
765-668-4500
Director: Charles Osterholt

Greene Co. Office
104 County Road 70 E, Suite A
P.O. Box 443
Bloomfield, IN 47424
812-384-4404
Director: Vacant

Hamilton Co. Office
938 N. Tenth St.
Noblesville, IN 46060
317-773-2183
Interim Director: Peggy Surbey

Hancock Co. Office
120 W. Mckenzie, Suite F
Greenfield, IN 46140
317-467-6360
Director: Laura Gentry

Harrison Co. Office
2026 Highway 337 NW, P.O. Box 366
Corydon, IN 47112-0366
812-738-8166
Director: James Miller

Hendricks Co. Office
6781 E. US 36, Suite 200
Avon, IN 46123
317-272-4917
Director: Andrea Goodwin

Henry Co. Office
1416 Broad St., 2nd Floor
New Castle, IN 47362
765-529-3450
Director: Michael Fleming

Howard Co. Office
101 W. Superior
Kokomo, IN 46901-4670
765-457-9510
Director: Marilyn Robinson

Huntington Co. Office
88 Home St.
Huntington, IN 46750-1346
260-356-4420
Director: Elizabeth (Liz) J. Learned

Jackson Co. Office
220 S. Main St., P.O. Box C
Brownstown, IN 47220
812-358-2421
Director: Dennis Carmichael

Jasper Co. Office
215 W. Kellner Blvd., Suite 16
P. O. Box 279
Rensselaer, IN 47978
219-866-4186
Director: Sharon R. Mathew

Jay Co. Office
1237 W. Votaw St.
SR 67, P.O. Box 1034
Portland, IN 47371-9590
260-726-7933
Director: Chris Wagner

Jefferson Co. Office
493 W Hutchinson Lane
P.O. Box 1189
Madison, IN 47250-1189
812-265-2027
Director: Robert G. King

Jennings Co. Office
2017 Crestwood Drive, P.O. Box 1047
North Vernon, IN 47265
812-346-2254
Director: Michael L. Williams

Johnson Co. Office
1784 E Jefferson St
Franklin, IN 46131-7277
317-738-0301
Director: Vacant

Knox Co. Office
1050 Washington Ave., P.O. Box 235
Vincennes, IN 47591
812-882-3920
Director: Larry Marchino

Kosciusko Co. Office
205 N. Lake St.
Warsaw, IN 46580
574-267-8108
Director: Peggy Shively

LaGrange Co. Office
836 N. Detroit St.
LaGrange, IN 46761-1112
260-463-3451
Director: Jan Lung

Lake Co. Office
661 Broadway
Gary, IN 46402-2407
Mailing Address: P.O. Box 2270
Gary, IN 46409-2270
219-886-6000
Director: Jane Bisbee (all locations)

LaPorte Co. Office
1230 State Road 2 W, P.O. Box 1402
LaPorte, IN 46352
219-326-5870
Director: Terrance K. Ciboch

Lawrence Co. Office
918 16th Street, Suite 100
Bedford, IN 47421-3824
812-279-9706
Director: Steve Adam

Madison Co. Office
222 E. 10th Street, Suite D
Anderson, IN 46016
765-649-0142
Director: Christopher Wagner

Marion Co. Office
129 E. Market St., Suite 1200
Indianapolis, IN 46204
Please refer to offices listed throughout Marion Co.
Director: Dan Carmin

Marshall Co. Office
1850 Walter Glaub Drive
P.O. Box 539
Plymouth, IN 46563
574-935-4046
Director: Michael J. Carroll

Martin Co. Office
51 Ravine Street, P.O. Box 88
Shoals, IN 47581
812-247-2871
Director: Melinda Berry

Miami Co. Office
12 S. Wabash, P.O. Box 143
Peru, IN 46970-0143
765-473-6611
Director: Fay Russell

Monroe Co. Office
401 E. Miller Drive
Bloomington, IN 47401
812-336-6351
Director: Lindsey A. Smith

Montgomery Co.
307 Binford St.
Crawfordsville, IN 47933
765-362-5600
Director: Steve Vaughn

Morgan Co. Office
1326 S. Morton Avenue
Martinsville, IN 46151
765-342-7101
Director: Tim Miller

Newton Co. Office
4117 S 240 W, P.O. Box 520
Morocco, IN 47963-0520
219-285-2206
Director: Ronald S. Fisher

Noble Co. Office
107 Weber Road
Albion, IN 46701
260-636-2021
Director: Sue Romans

Ohio Co. Office
125 N. Walnut, PO Box 196
Rising Sun, IN 47040
812-438-2530
Director: Randy Hildebrand

Orange Co. Office
535 N. Greenbriar Dr, PO Box 389
Paoli, IN 47454
812-723-3616
Director: Leslie Rowland

Owen Co. Office
450 E. Franklin St.
Spencer, IN 47460-1824
812-829-2281
Director: Debora L. Dailey

Parke Co. Office
116 W. Ohio
Rockville, IN 47872
765-569-3156
Director: Katie Edington

Perry Co. Office
316 E. Hwy 66
Tell City, IN 47586
812-547-7055
Director: Georgann Gogel

Pike Co. Office
2105 E. Main
Petersburg, IN 47567
812-354-9716
Director: Steve Cunningham

Porter Co. Office
152 Indiana Avenue
Valparaiso, IN 46383-5514
219-462-2112
Director: Jon Rutkowski

Posey Co. Office
1809 Main St., PO Box 568
Mount Vernon, IN 47620
812-838-4429
Director: Susan Blackburn

Pulaski Co. Office
429 N Logan St., P.O. Box 130
Winamac, IN 46996-0130
574-946-3312
Director: Laurel J. Myers

Putnam Co. Office
121 Ridgeland Rd.
Greencastle, IN 46135
765-653-9780
Director: Barbara South

Randolph Co. Office
325 S Oak St., Ste 201
Winchester, IN 47394-2242
765-584-2811
Director: Steven Cox

Ripley Co. Office
630 S. Adams, P.O. Box 215
Versailles, IN 47042
812-689-6295
Director: India Turner

Rush Co. Office
1340 N. Cherry
Rushville, IN 46173
765-932-2392
Director: Terry Suttle

St. Joseph Co. Office
4634 W. Western Ave.
South Bend, IN 46619-2304
574-251-8668
Director: Charles Smith

Scott Co. Office
1050 W. Community Way
Scottsburg, IN 47170-7768
812-752-2503
Director: Joan Kelley

Shelby Co. Office
2565 Parkway Dr., Suite 2
Shelbyville, IN 46176-8677
317-392-5040
Director: Mary Ann Medler

Spencer Co. Office
900 Old Plank Road, P.O. Box 25
Rockport, IN 47635
812-649-9111
Director: Connie Branch

Starke Co. Office
318 E. Culver Road
Knox, IN 46534
574-772-3411
Director: Larry Harris

Steuben Co. Office
317 S. Wayne St., Suite 2a
Angola, IN 46703
260-665-3713
Director: Jan Lung

Sullivan Co. Office
128 S. State St.; PO Box 348
Sullivan, IN 47882
812-268-6326
Director: Pam Connelly

Switzerland Co. Office
506 Ferry St.-SR 56, PO Box 98
Vevay, IN 47043
812-427-3232
Director: Robert G. King

Tippecanoe Co. Office
111 North 4th St.
Lafayette, IN 47901-1305
765-742-0400
Director: Angela Smith Grossman

Tipton Co. Office
202 S. West St.
Tipton, IN 46072-1848
765-675-7441
Acting Director: Jennifer (Jenny) R. Hoffman

Union Co. Office
303A N. Main St., P.O. Box 344
Liberty, IN 47353
765-458-5121
Director: Gene Sanford

Vanderburgh Co.
100 E. Sycamore St., P.O. Box 154
Evansville, IN 47701-0154
812-421-5500
Director: Lark Buckman

Vermillion Co. Office
215 W. Extension St., P.O. Box 218
Newport, IN 47966
765-492-3305
Director: Katie Edington

Vigo Co. Office
30 N. 8th St.
Terre Haute, IN 47807
812-234-0100
Director: Glenn Cardwell

Wabash Co. Office
89 W. Canal St.
Wabash, IN 46992
260-563-8471
Director: Margery Justice

Warren Co. Office
20 W. Second St.
Williamsport, IN 47993-1118
765-762-6125
Director: Linda Akers

Warrick Co. Office
1302 Millis Avenue, P.O. Box 265
Boonville, IN 47601
812-897-2270
Director: Judith Harper

Washington Co. Office
711 Anson St.
Salem, IN 47167-9777
812-883-4305
Director: Nancy Lambring

Wayne Co. Office
50 S. Second St.
Richmond, IN 47374-4276
765-935-0078
Director: Jean Cates

Wells Co. Office
221 W. Market Street, P.O. Box 495
Bluffton, IN 46714
260-824-3530
Director: Jenny Tsakkos

White Co. Office
715 N. Main St.
Monticello, IN 47960
574-583-5742
Director: Barbara Bedrick

Whitley Co. Office
115 S. Line St.
Columbia City, IN 46725
260-244-6331
Director: Steve Weaver

Additional Resources and Contacts

Family & Social Services Administration (FSSA)

- Website: www.state.in.us/fssa/. The FSSA website links to the state agencies below.
- To call Toll Free, use **800-545-7763** and extension -the last five digits of the FSSA office telephone number you are calling.
- For other FSSA numbers and contacts go to: www.in.gov/fssa/admin/about/directory

1. Bureau of Developmental Disabilities Services, DDRS
P.O. Box 7083 MS-18
Indianapolis, IN 46207-7083
317-232-7842
402 West Washington Street, Room W453
800-545-7763 ext. 2-7842

2. Bureau of Quality Improvement Services, DDRS
P.O. Box 7083 MS-46
Indianapolis, IN 46207
317-234-2736
402 W. Washington Street, Room W 451
800-545-7763 ext. 4-2736
800-622-4484 DD Waiver Ombudsman

3. Division of Aging , FSSA
P.O. Box 7083 MS-21
Indianapolis, IN 46207-7083
317-232-7122
402 W. Washington Street, Room W454
800-545-7763 ext. 2-7122

4. Hearing and Appeals, FSSA
MS-04
402 W. Washington Street, Room E024
Indianapolis, IN 46204-2739
317-234-3488
866-259-3573 (toll free)
317-232-4412 (fax)

5. Office of Medicaid Policy and Planning, FSSA
402 W. Washington Street, Room W382
Indianapolis, IN 46204-2739
317-232-7930 (Autism, DD & Support Services Waiver)
317-232-0049 (A&D & TBI Waivers)
800-545-7763 ext 2-7930 or ext 2-0049

6. Division of Family Resources, FSSA
402 W. Washington Street, Room W 392
Indianapolis, IN 46204-2739
800-545-7763 ext 2-4704, 317-232-4704

Social Security Administration Office
Contact website www.ssa.gov/disability/
800-772 1213 (automated answering resource)

Centers for Independent Living (CIL)
Provides peer support, self-help, self-determination, and individual and system advocacy for all people with disabilities. To locate a CIL near you call (800) 545-7763 ext 2-1367 or go to: www.in.gov/fssa/disability/services/vr/ilcenters.html

IN*SOURCE
Indiana Resource Center for Families with Special Needs
809 North Michigan Street
South Bend, Indiana 46601
574-234-7101 or (800) 332-4433
574-234-7279 (Fax)
insource@insource.org
www.insource.org/

About Special Kids (formerly IPIN)
7275 Shadeland Avenue, Suite 1
Indianapolis, IN 46250
317-257-8683
800-964-4746
FamilyNetw@aboutspecialkids.org
www.aboutspecialkids.org
[formerly IPIN - Indiana Parent Information Network)]

Indiana Protection & Advocacy Services
4701 N. Keystone, Suite 222
Indianapolis, IN 46205
317-722-5555
800-622-4845
800-838-1131 (TTY only)
317-722-5564 (Fax)
info@ipas.state.in.us/
www.in.gov/ipas

The Arc of Indiana
107 N. Pennsylvania Street, Suite 300
Indianapolis, IN 46204
317-977-2375
317-977-2385 (Fax)
800-382-9100
www.arcind.org
TheArc@arcind.org

TheArcLink
www.TheArcLink.org/

Governor's Council for People with Disabilities
150 West Market Street, Suite 628, Indianapolis, IN 46204
Voice: 317-232-7770 • Fax: 317-233-3712
GPCPD@gpcpd.org • www.in.gov/gpcpd

Notes

It is important to keep a record of who you talked to, when you sent in forms, etc. Use this page to list contact names, numbers, what was discussed and other important information.

Notes (continued)

Waiver Guide Feed Back and Evaluation Survey

Please let us know whether this booklet is helpful and any suggestions you have for improving it by returning the completed survey via mail or fax. The survey is available as a separate document on request.

To fax: Send to Brenda Wade 317-233-3712

To mail: Fold, tape the ends together, affix postage and drop in your nearest mailbox.

1. How helpful is the Consumer Guide to Waiver Programs as a source for information about waivers?

   ____ Very helpful ____ Helpful ____ Somewhat helpful ____ Not helpful

2. Overall, how satisfied are you with Consumer Guide to Waiver Programs?

   ____ Very satisfied ____ Satisfied ____ Somewhat satisfied ____ Not satisfied

3. What do you think about the length of the booklet and how well the topics are covered?

   ____Too short/not enough information ____ Just right ____Too long/too much information

4. Which describes your interest in Waivers and this booklet? (Please check all that apply)

   ____ I am currently receiving a waiver

   ____ I have recently been "targeted" for a Waiver opening

   ____ I am on the waiting list for a Waiver

   ____ I plan to apply for a Waiver

   ____ I will use the book to educate others about the Waiver program

5. Which describes you? (Please check all that apply.)

   ____ Person with a disability ____Parent of a person/child with a disability

   ____ State agency personnel ____Service provider

   ____ Advocacy organization ____ Parent group

   ____ Educator ____Other:_____

6. Comments and Suggestions:

7. Would you like to receive the Council's free monthly newsletter ***On Target***? __Yes __No __Already receive

8. Would you like to receive **Council E-mail News** (about twice each month)? __Yes __No __Already receive

If you said yes to either of the last two questions, please include your contact information when returning this form. Or if you prefer, e-mail the information separately to Brenda Wade at: BWade@gpcpd.org

Name: _____

Address:_____, IN ZIP:_____

E-mail: _____ Telephone:_____

Revised 200901

Place
Stamp
here

Governors Council for People with Disabilities
Consumer Guide to Waivers Survey c/o Brenda Wade
150 West Market Street, Suite 628
Indianapolis, IN 46204-2801

Revised 200901

Sept. 14, 2011 Health Finance Ex

IBJ.com
Powered By Indianapolis Business Journal

Indy anti-diabetes experiment takes off

April 21, 2010

UnitedHealthcare believes a program tested in the Indianapolis area will help it save money on claims.

The Minnesota-based health insurance giant is rolling out the program to cities across the country this month after trying it out at YMCA of Central Indiana locations and relying on Indiana University to crunch numbers to ensure the program got results.

UnitedHealthcare, which claims the second-largest share of the market in central Indiana, pays the YMCA directly if it successfully helps patients lose weight; Walgreens also is paid for its pharmacists' spending time reviewing patient prescriptions and compliance.

In the pilot, UnitedHealthcare paid for patients determined to be pre-diabetic to join a 16-week program at the YMCA. The YMCA taught the participants how to count calories and fat grams, to set daily ceilings on each, and to record everything they eat to make sure they don't exceed their daily limits.

Beyond that, the YMCA let participants eat whatever they want. But they also got them to use the exercise equipment at YMCA facilities and coached them on how to handle stress without resorting to eating and how to maintain their diet discipline even when schedules and social situations work against it.

"We've learned skills that I'm going to use for the rest of my life," said Peggy Brown, 58, who with her husband Robert is in the 15th week of her program at the YMCA in Greenwood. He has lost 23 pounds and she has lost 29 pounds, which has helped drop their blood sugar levels so they are no longer "pre-diabetic."

The Browns and others like them helped the YMCA participants lose, on average, 6 percent of their body weight after six months, compared with only 2 percent lost by similar patients trying other diet and exercise programs, according to IU's research.

Those proven results make Dan Krajnovich, CEO of UnitedHealthcare's Indiana subsidiary, confident that employers will want to join the program. He said it would certainly improve UnitedHealthcare's competitiveness among employers in Indiana.

"No question about it," he said. "We're actually offering this program to non-UnitedHealthcare customers as well," which means employers can pay to have their employees participate, even if they do not choose UnitedHealthcare to provide their health benefits.

Krajnovich said the key difference about this program, compared with previous wellness efforts, is the way UnitedHealthcare has structured its payments to the YMCA. The organization receives no money unless a patient completes the program. It can then receive extra money if a patient loses at least 6 percent of his or her weight and another bonus on top of that if a patient loses 9 percent of his or her weight.

Peggy Brown and her husband had lost 7 percent of their body weight by week 11 of their program and have lost even more since.

"I don't want to go back," she said. "I've got energy. I'm able to keep up with my grandkids. We can do things, and can go places. And we're having fun."

In addition to Indianapolis, UnitedHealthcare, YMCA and Walgreens are launching their anti-diabetes program in Minneapolis-St. Paul, Phoenix, Cincinnati, Columbus, Ohio, and Dayton, Ohio.

www.IndyStar.com

November 18, 2010

Diabetes prevention outside doctor's office

Ronald T. Ackermann

At least 57 million Americans -- more than a quarter of the adult population -- have pre-diabetes, a condition that places them at high risk for developing type 2 diabetes. Even worse, approximately one-quarter of individuals suffering from diabetes, and nearly 90 percent of those at high risk of developing the disease, remain undiagnosed.

In Indiana, the State Department of Health estimates that 9.6 percent of adults have diabetes and that a quarter of a million people are unaware that they are diabetic. Diabetes is now the seventh-leading cause of death in our state.

One out of every five health-care dollars is spent caring for someone with diagnosed diabetes, a figure that has increased 32 percent since 2002, according to the Centers for Disease Control and Prevention. Closer to home, the Department of Health reports that the cost of diabetes care in the Hoosier state was $47.1 billion in 2007. If current obesity trends continue, by 2018 some 103 million Americans will be considered obese to the tune of an estimated $344 billion in health system dollars, according to a report by the American Public Health Association, and Partnership for Prevention and United Health Foundation.

The early identification and involvement of populations most at risk of developing diabetes and other obesity-related health complications might be our nation's top health-care priority. Fortunately, new "partnered" approaches offer proven solutions. UnitedHealth Group has partnered with the YMCA to offer the Diabetes Prevention Program.

The program is based on the original U.S. Diabetes Prevention Program funded by the National Institutes of Health and the CDC, which demonstrated that, with lifestyle changes and modest weight reduction, pre-diabetic individuals can prevent or delay the onset of the disease by 58 percent. Researchers at the Indiana University School of Medicine were able to replicate the successful results with the YMCA of Greater Indianapolis in a group setting.

The program uses a group-based lifestyle intervention designed especially for people with pre-diabetes. In a communal setting, a trained coach teaches participants to eat healthier, increase their physical activity and learn about other behavior modifications. After 16 core sessions, participants meet monthly for added support.

The results: At the Indianapolis-area YMCAs, program participants shed 6 percent of their body weight within six months, compared with 2 percent in a control group, and sustained the weight loss one year later. The YMCA and the CDC successfully adapted this program to serve other communities, and UnitedHealth Group is now helping the program expand and grow in many more communities across the nation. UnitedHealth covers the DPP services at no charge to participants enrolled in employer-provided health insurance plans.

Curbing our nation's diabetes epidemic extends beyond the doctor's office and hospital room. It should involve the active engagement of educated pharmacists, community centers, lifestyle coaches and individuals most at risk, their families and communities.

HFC, Sept. 14, 2011, Exhibit 4

CONSENT BEFORE HIV TESTING

Madonna Biritwum, M.D.
Parkview Hospital
Fort Wayne

Outline

- HIV/AIDS background
- HIV in Indiana
- CDC recommendations about HIV testing
- Informed consent
- Components of the amended HIV testing law
- Should the current policy in Indiana be amended

HIV/AIDS Background

- In USA, as of Dec 2008, 1.18 million people were living with HIV/AIDS
- 21% of this population were unaware of this
- 33% of these patients presented with late diagnosis-AIDS
- 50,000 new cases annually

Facts about HIV/AIDS in the U.S.

- Since 1994 there has been an increase in the number of cases among blacks, and other minorities
- 1990-1992 the proportion of persons who first tested positive for HIV, less than a year before AIDS, was 51%
- 1993-2004 the proportion declined to 39%
- By 2002, 38%-44% of all adults had been tested for HIV
- 87% received their first positive HIV test in an acute or referral medical care setting
- 65% were tested because of illness

HIV/AIDS in Indiana

- As of Dec 2009, 9,646 people were living with HIV/AIDS
- Out of the 9,646 cases, 4267 (44%) had HIV and 5379 (56%) had AIDS
- Indiana ranked 24 highest among 50 states with AIDS
- Ratio of male to female predominance is 4:1
- Age group 20-25, and up to 40 yrs were mostly infected
- In 2009, newly reported cases of HIV were 313 and 176 patients reported initially with AIDS
- Could we have identified the 176 people when they had HIV, not AIDS?

CDC and HIV Testing Law

- 1985- Testing started mainly to improve safety of blood supplied for transfusion
- 1987-USPHS issued guidelines for counseling and testing
- 1993- CDC provided guidelines for voluntary counseling especially in high seroprevalence sites
- 2001- Extension to pregnant women to be tested, and also included more clinical venues

CDC and HIV Testing Law

- 2003- New strategies made to make HIV testing a routine part of medical care, though voluntary
- Universal testing of all pregnant women, to reduce perinatal transmission rates
- From 2003 to 2005, various groups have met to decide on how best to expand HIV testing

The Issue of Informed Consent

- A process put in place to educate and help patients cope with HIV/AIDS
- To ensure some degree of confidentiality
- It is a specific document, different from general medical care consent form

What does Informed Consent Involve?

- Communication between patient and provider
- Elements include
  - Explanation of what HIV/AIDS is
  - Mode of acquisition
  - Preventive strategies
  - Risk and benefits of testing
  - Implications of the test results
  - Treatment options
  - Opportunity to ask questions
- Patients could accept or decline the HIV Testing

Indiana –HIV Testing Laws

Components of CDC Recommendations	Indiana Laws
Informed Consent	Informed consent required
Counseling	No specific provisions
Testing Provision Anonymous Rapid Routine	Testing must be made available anonymously No specific provisions No specific provisions
Disclosure	No specific provisions
Minor/Adolescent Testing	Persons 14 or older may consent
Testing of Pregnant Women	Opt-out testing of pregnant women

The issue with this process

- The process could be complicated and time consuming
- Not many people could be tested “routinely”
- Did not completely help with the “stigma” related to HIV/ADS

Objectives of CDC Revised Recommendations of HIV Testing

- To increase HIV screening of patients, including pregnant women in health care settings
- Foster earlier detection of HIV infection
- Identify and counsel persons with unrecognized HIV infection and establish them into care
    - For clinical benefits
    - For preventive services
- Further reduce perinatal transmission of HIV in the US

- HIV screening is recommended for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines (opt-out of screening)

Health-care Settings

- Patients on admission in hospitals
- Emergency Department
- Physician's office
- Other Health care providers
  - Nurse Practitioners
  - STD clinics

CDC Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health Care- Settings

- Persons at high risk for HIV infection should be screened for HIV at least annually
- Separate written consent for HIV testing should not be required, general consent for medical care should be considered sufficient to encompass consent for testing
- Preventive counseling should not be required with HIV diagnostic testing or as part of HIV screening programs in health-care settings

For Pregnant Women

- HIV screening should be included in the routine panel of prenatal screening tests for all pregnant women
- HIV screening is recommended after the patient is notified that testing will be performed unless the patient declines (opt-out screening)
- Separate written consent for HIV testing should not be required, general consent form is sufficient
- Repeat screening in the third trimester is recommended in certain jurisdictions with elevated rates of HIV infection among pregnant women

Trends in Perinatal HIV/AIDS

- 1982- First reported perinatal transmission
- 1992- number of patients was 945
- 2004- decline to 48 (95%)
- 2004- 38% of AIDS cases from perinatal transmission were in children less than 1 year
- Currently rates of transmission is less than 2%, with intervention compared to 23%-30% without
- This is due to increased identification of infected mothers, and timely intervention

Summary

- Everyone between the age of 13-64 years should be offered HIV Testing in a routine clinical setting
- Everyone, including pregnant women, can opt out of screening
- HIV is a chronic disease, and needs to be screened for, like other diseases
- Effective treatment for HIV is available
- Treatment is valuable in the prevention of the spread of the disease

Advantages of Amending the Law on Informed Consent

- Many more people will be tested, especially the youth, who may not identify risk factors
- The earlier we identify infected people, the better the chances of non progression to AIDS
- The long face to face process of informed consent can be eliminated
- Patients will identify this as a routine blood tests like wbc, and rapid test which provide quick test results
- This will reduce perinatal transmission rates
- Sometimes Primary care givers may not be able to identify the risk population, or acute phase of HIV
- The testing process can "de-stigmatize" the perceptions of HIV/AIDS
- Test for HIV can create awareness for those with risk factors, and provide continual education

Points to note

- Despite the revision, clinicians will still need to ask for consent before testing
- Consent will be incorporated in the consent form for general care
- It is helpful to have a fact sheet about the HIV disease, and patients can ask questions
- Patients can opt out of screening, and this needs to be documented

Concerns about the Law

- Concern has been that there will be removal of an important mechanism for educating individuals about HIV
  - Research has shown that pre-test counseling does not eliminate risk behavior
  - Documented facts needs to be provided, and patients can ask questions

- Will patient's protection be weakened?
  - It should not, as patients will always have confidentiality and clinicians should abide by that

- Will this necessarily increase testing
  - Access to health insurance and regular provider form the basis- and people will end up at these health care settings

New York State

- Other states amended this law prior to NY
- July 30 2010, the HIV testing public law was amended in NY
- Came into effect September 2010
- Other new legislation added, such as release of confidential HIV information in health care setting, and HIV in health care exposure

Conclusion

- Success story in marked reduction in perinatal transmission of HIV with routine maternal HIV testing

- The hope is that routine testing would increase the number of HIV-positive people aware of their status, increasing the likelihood of receiving adequate care, as well as reducing transmission rates, by affecting risk behavior

References

- Center of Disease Control (CDC)
- Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings, MMWR September 22 2006 (55/9RR14;1-17)
- Indiana: http://www.in.gov/isdh
- Indiana state complimentary plan
- Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection --- United States, 1985—2005, MMWR June 2006 55(21)

Thank you

HFC09/14/11 Exhibit 5

Dr Potter

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: Carmel
Prepared by: S Riggins LPN

Patient Initials: JM Pt DOB: 12-25-90 Date: 4/13
Call Start Time: pm
Call End Time:
Duration: 20 min
Number Called: NA

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	Medco	MR/CT	Approved/Solved
✓ UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	✓ Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	✓ Payer	EKG	Need to call someone else
Sagamore	✓ Other	Other (explain)	Transferred
Other	RxOptions		Other (explain below) — unresolved

Comments on call: Chart reviewed / form completed & faxed

(1)

Patient Initials: TB Pt DOB: 5-8-60 Date: 4/14
Call Start Time: pm
Call End Time:
Duration: 10 min.
Number Called: 823-6829 / 1-800-421-2342

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	Medco	MR/CT	✓ Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	✓ CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: This was done last week but we keep receiving forms to submit.

Patient Initials: JB Pt DOB: 3-23-47 Date: 4/15
Call Start Time: pm
Call End Time:
Duration: 10 min
Number Called: 844-2775

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	✓ Medco	MR/CT	✓ Approved/Solved
UHC	✓ ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: Received approval — local pharm & pt notified

(#2)

Dr. Potter

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: Carmel
Prepared by: S Riggins LPN

Patient Initials: JM | Pt DOB: 12-25-90 | Date: 4/12 | Call Start Time: pm | Call End Time: | Duration: 15 min. | Number Called: 867-3022

#3

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	Medco	MR/CT	Approved/Solved
✓ UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	✓ Form ~~Sent~~ to AHN to be sent
Humana	Payer	EKG	Need to call someone else
Sagamore	✓ Other Rx Options	Other (explain)	Transferred
Other			✓ Other (explain below) unresolved

Comments on call: PA phone # on form from local pharm is incorrect. 3 calls made to obtain the PA form/correct #. End of day still no form.

Patient Initials: JB | Pt DOB: 3-23-47 | Date: 4/12 | Call Start Time: pm | Call End Time: | Duration: 10 min. | Number Called: 800-662-0210

#4

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	Medco	MR/CT	Approved/Solved
UHC	✓ ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	✓ Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			✓ Other (explain below) unresolved

Comments on call: Need to review chart for prior tx c NSAIDS (paper & computer charts) & complete form.

Patient Initials: CH | Pt DOB: 9-7-51 | Date: 4/12 | Call Start Time: pm | Call End Time: | Duration: 21 min. total | Number Called: 1-800-753-2851

#6

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	✓ Medco	MR/CT	✓ Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: Spent 10 min. on-line but could not get case started! Spent 11 min. on phone c medco only to be told NO PA was needed!! Waste of time!!

Dr. DeSilvester

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: Carmel
Prepared by: N McDaniel

Patient Initials: CS Pt DOB: 4/28/60 Date: 4/15/10
Call Start Time: 8:55
Call End Time: 9:20
Duration: 25 min
Number Called: 2

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	X CareMark	Pharmacy (PA)	X Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

#5

Comments on call: on hold 25 min. still no results on answer

Patient Initials: CB Pt DOB: 2/25/66 Date: 4/15/10
Call Start Time: 4:50
Call End Time: 5:14
Duration: 24 min
Number Called: 1

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	X Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	X Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

#7

Comments on call: (no real person) puts you on hold and only gets a automatic teller form to fax

Patient Initials: RS Pt DOB: 12/27/48 Date: 4/15/10
Call Start Time: 5:10
Call End Time: 5:30
Duration: 20 min
Number Called: 1

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	X Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	X Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: Couldn't send the form on the fax had to talk to representative was put in hold for awhile

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: Avon
Prepared by: Debi

Patient Initials: FG Pt DOB: 1-17-49 Date: 4-14
Call Start Time: 847
Call End Time: 852
Duration: 5
Number Called: 800-533-5044

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
[ ] Anthem	[ ] Medco	[X] MR/CT	[X] Approved/Solved
[ ] UHC	[ ] ExpressScripts	[ ] Other Radiology	[ ] Leave VM/Callback
[ ] CIGNA	[ ] CareMark	[ ] Pharmacy (PA)	[ ] Pending Clinical Review
[ ] AETNA	[ ] AnthemRx	[ ] Pharmacy (other)	[ ] Form Sent to AHN
[ ] Humana	[ ] Payer	[ ] EKG	[ ] Need to call someone else
[X] Sagamore	[ ] Other	[ ] Other (explain)	[ ] Transferred
[ ] Other			[ ] Other (explain below)

Comments on call:

Patient Initials: KC Pt DOB: 12-6-46 Date: 4-14
Call Start Time: 910
Call End Time: 927
Duration: 17
Number Called:

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
[X] Anthem	[ ] Medco	[ ] MR/CT	[ ] Approved/Solved
[ ] UHC	[X] ExpressScripts	[ ] Other Radiology	[ ] Leave VM/Callback
[ ] CIGNA	[ ] CareMark	[X] Pharmacy (PA)	[X] Pending Clinical Review
[ ] AETNA	[ ] AnthemRx	[ ] Pharmacy (other)	[ ] Form Sent to AHN
[ ] Humana	[ ] Payer	[ ] EKG	[ ] Need to call someone else
[ ] Sagamore	[ ] Other	[ ] Other (explain)	[X] Transferred
[ ] Other			[ ] Other (explain below)

#2

24-72H

Comments on call: Went to Dr Review 24-72H Response

Patient Initials: ZB Pt DOB: 9-01-35 Date: 4-14
Call Start Time: 946 952
Call End Time: 949 955
Duration: 3 3
Number Called: 866-492-5878

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
[ ] Anthem	[ ] Medco	[X] MR/CT	[X] Approved/Solved
[ ] UHC	[ ] ExpressScripts	[ ] Other Radiology	[X] Leave VM/Callback
[ ] CIGNA	[ ] CareMark	[ ] Pharmacy (PA)	[ ] Pending Clinical Review
[ ] AETNA	[ ] AnthemRx	[ ] Pharmacy (other)	[ ] Form Sent to AHN
[ ] Humana	[ ] Payer	[ ] EKG	[ ] Need to call someone else
[ ] Sagamore	[ ] Other	[ ] Other (explain)	[ ] Transferred
[X] Other Marion			[ ] Other (explain below)

Comments on call: on Hold then automatically went to a V mail. Called back for auth.

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: Avon
Prepared by: Lori Evans

Patient Initials: B R | Pt DOB: 2-5-72 | Date: 4-16-10
Call Start Time: 9:18
Call End Time: 9:38
Duration: 20 min
Number Called:

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	X Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	X Other: HIP	Other (explain)	Transferred
X Other: Medicaid			X Other (explain below)

Comments on call: Need to fax new PA req. form. recieved Denial fax @ 3:51 pm.

Patient Initials: T D | Pt DOB: 9-4-70 | Date: 4-16-10
Call Start Time: 10:20
Call End Time: 10:25
Duration: 5 min
Number Called: 18007532851

#9

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	X Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	X Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
X Other: Golden Rule			X Other (explain below)

Comments on call: Med "Ambien" Denied.

Patient Initials: C D | Pt DOB: 6-8-29 | Date: 4-16-10
Call Start Time: 10:30
Call End Time: 10:48
Duration: 18 min
Number Called: 18669077088

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	X Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	X Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	X Other: CHP	Other (explain)	Transferred
X Other: CHP			Other (explain below)

Comments on call: Valid Thru 12-31-2010

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office
Prepared by:

GF

Patient Initials: JH | Pt DOB: 4/27/90 | Date: 4-14-10
Call Start Time: 4:50
Call End Time: 5:02
Duration: 12
Number Called: 800-753-2851

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	X Medco	MR/CT	Approved/Solved
X UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	X Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			X Other (explain below)

#10

Comments on call: fax form to be faxed to be filled out. form faxed 4/15/10

Patient Initials: HD | Pt DOB: 1-16-39 | Date: 4-15-10
Call Start Time: NOON
Call End Time: 12:09
Duration: 9
Number Called: 800 922 1557

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
X Anthem	X Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	X Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	X Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

#11

Comments on call:

Patient Initials: | Pt DOB: | Date:
Call Start Time:
Call End Time:
Duration:
Number Called:

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call:

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office: AHN - Ofld
Prepared by: Alisha (Ewalt)

Patient Initials: MK Pt DOB: 6/16/72 Date: 4/16/10
Call Start Time: 11:20AM
Call End Time: 11:34AM
Duration: 14 MIN.
Number Called: 1-800-882-4462

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
✓ CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

✓ Approved/Solved

#12

Comments on call: Celebrex approved by phone

Patient Initials: _____ Pt DOB: _____ Date: _____
Call Start Time: _____
Call End Time: _____
Duration: _____
Number Called: _____

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: _____

Patient Initials: _____ Pt DOB: _____ Date: _____
Call Start Time: _____
Call End Time: _____
Duration: _____
Number Called: _____

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call: _____

6F

American Health Network of Indiana, LLC
Authorization and Referral Time Study Project (4/12-16/2010)

Office
Prepared by:

#13

Patient Initials: M. E. D Pt DOB: 5-10-26 Date:
Call Start Time: 4:00
Call End Time: 4:30
Duration: 30
Number Called: 1-866-630-3820

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
✓ Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other: Next Rx	Other (explain)	Transferred
Other			✓ Other (explain below)

Comments on call: Denied, ~~st~~ Sent PA on 4-9-10 had to call 2x for form. Then Denied on 4-13-10.

Patient Initials: F. D. G Pt DOB: 8-7-32 Date:
Call Start Time: 1:05
Call End Time: 1:20p
Duration: 15
Number Called: 753-2851 800 ~~327~~-9791

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	✓ Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	✓ Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
✓ Other: Budgetine Am.			Other (explain below)

Comments on call: Do fax PA form then will fax back want about 24 hrs.

Patient Initials: _____ Pt DOB: _____ Date:
Call Start Time:
Call End Time:
Duration:
Number Called:

Patient's Payer (check)	Organization Called	Reason for Call	RESOLUTION
Anthem	Medco	MR/CT	Approved/Solved
UHC	ExpressScripts	Other Radiology	Leave VM/Callback
CIGNA	CareMark	Pharmacy (PA)	Pending Clinical Review
AETNA	AnthemRx	Pharmacy (other)	Form Sent to AHN
Humana	Payer	EKG	Need to call someone else
Sagamore	Other	Other (explain)	Transferred
Other			Other (explain below)

Comments on call:

Cholesterol letter being sent to pt's

PHARMACARE

March 21, 2007

0904

PharmaCare manages the prescription drug benefit program for DaimlerChrysler Corporation (DCC) employees, retirees, and their covered dependents. Beginning April 1, 2007, **simvastatin, pravastatin, and lovastatin will become the preferred statins on the DCC drug formulary.**

According to our records you may have recently had a prescription filled for one of the non-preferred statin drugs: **Lipitor®, Crestor®, Vytorin®, Zetia®, Advicor®, Altoprev®, Zocor®, Mevacor®, or Pravachol®**. If you are taking any of these statins, **note: your prescription may not be covered the next time you place an order for it.** Your plan now requires you first try one of the plan's preferred statins. A prior authorization will be necessary before a non-preferred statin drug is covered.

Prior authorization is a pre-approval process that requires a physician to obtain approval for a specific drug before it is covered by your prescription drug plan. *You may be required to pay 100% of DCC's discounted price for your prescription if you do not have a prior authorization request approved from PharmaCare.*

To avoid any interruption in your therapy, we suggest you contact your physician and ask if one of the generic statins can help you achieve your cholesterol goal. If your physician determines a generic statin will help lower your cholesterol:

- **Ask your physician to call or fax a new prescription for one of the generic statins to your pharmacy before April 1, 2007.**

If your physician wishes you to continue your current medication:

- **Ask your physician to complete a prior authorization form and fax it to us immediately. Please allow at least 3 – 5 days for us to process your request.**

You can check to see if a prior authorization request submitted to PharmaCare is approved by either calling your physician's office to ask if they received approval from PharmaCare for the medication, or PharmaCare's Customer Service department at 1-866-329-4448 to find out if your physician's prior authorization request for this medication is approved. In addition, you will receive a letter from PharmaCare once your physician's prior authorization request is received and approved.

For your information, prior authorization forms are available to print at our member website: http://www.pharmacare.com/members. We encourage you and/or your covered family members to register on the website. Once you register, you'll have access to forms, find valuable information about your prescription drug plan, and access other important drug information.

If your physician has questions about this prior authorization process, he/she can call PharmaCare's Clinical Authorization department at 800-754-3187.

PharmaCare Management Services, Inc.

DOB 10-29-57 Don P Zent

Failed Acplex

4-9-07 task to Dr. Zent. MFLPL

letter for PPI's being sent to the pt's —

PHARMACARE

PharmaCare manages the prescription drug benefit program for DaimlerChrysler Corporation (DCC) employees, retirees, and their covered dependents. Beginning April 1, 2007, ***omeprazole* will be the covered proton pump inhibitor (PPI)** for DaimlerChrysler (DCC).

According to our records you may have recently had a prescription filled for a different PPI: **Prilosec®, Zegerid®, Protonix®, Aciphex®, Prevacid® or Nexium®.** If you are taking any of these PPIs, **note: your prescription may not be covered the next time you place an order for it. *Omeprazole* will be the only covered PPI for the plan**, unless you have been diagnosed with a hypersecretory condition such as Barrett's esophagitis or Zoellinger-Ellison syndrome. Patients with either of these two medical conditions may request additional coverage through our prior authorization process.

Prior authorization is a pre-approval process that requires a physician to obtain approval for a specific drug before it is covered by your prescription drug plan. *You may be required to pay 100% of DCC's discounted price for your prescription if you do not have a prior authorization request approved from PharmaCare.*

To avoid any interruption in your therapy, **we suggest you contact your physician and ask your physician to call or fax a new prescription for *omeprazole* to your pharmacy before April 1, 2007.**

If your physician wishes you to continue your current medication because you have one of the approved medical conditions, Barrett's esophagitis or Zoellinger-Ellison syndrome, please ask your physician to complete a prior authorization form and fax it to us immediately. Please allow at least 3 – 5 days for us to process your request.

You can check to see if a prior authorization request submitted to PharmaCare is approved by either calling your physician's office to ask if they received approval from PharmaCare for the medication, or PharmaCare's Customer Service department at 1-866-329-4448 to find out if your physician's prior authorization request for this medication is approved. In addition, you will receive a letter from PharmaCare once your physician's prior authorization request is received and approved.

For your information, prior authorization forms are available to print at our member website: http://www.pharmacare.com/members. We encourage you and/or your covered family members to register on the website. Once you register, you'll have access to forms, find valuable information about your prescription drug plan, and access other important drug information.

If your physician has questions about this prior authorization process, he/she can call PharmaCare's Clinical Authorization department at 800-754-3187.

PharmaCare Management Services, Inc.

1951 Bishop Lane
Suite 500
Louisville, KY 40218

HUMANA.
Guidance when you need it most

Prescription Benefit Information

Important information about your prescription(s)

February 18, 2007

Plan Information
Your Humana, Inc. Plan

Member Name/ID
[redacted]
[redacted] IN 46917
000000031532522000

[redacted]
[redacted] IN 46917

000614

This letter is to inform you that the following prescription(s) was filled as temporary fill:

Name of drug	CELEBREX 200 MG CAPSULE
Date filled	02/16/2007
Pharmacy	CVS PHARMACY #06536
Reason for notification	This drug is not on our formulary. This drug will be covered only if you try other drugs on our formulary first, as part of a step therapy program.

Unless you obtain an exception from Humana, Inc., we will no longer pay for the drugs listed above. If you wish to continue to receive these drugs we strongly encourage you to call your doctor. He or she may switch you to another drug that is covered on our formulary, or you or your physician may request a formulary exception.

How do I change my prescription?
You can ask us if we cover another drug used to treat your medical condition. If we cover another drug for your condition, you can ask your doctor if any of these drugs is an option for you. If your doctor tells you that none of the drugs we cover for treating your condition is medically appropriate for treating your condition, you have the right to request a formulary exception from us. You also have the right to request a formulary exception if your doctor tells you that a prior authorization, quantity limit, or other limit we have placed on a drug you are taking is not medically appropriate for treating your condition.

How do I request an exception?
The first step in requesting an exception is for you or your prescribing doctor to contact us. Humana, Inc., attn: Humana Clinical Pharmacy Review, 1951 Bishop Lane, Suite 500, Louisville, KY, 40512, 1-800-555-2546 (Phone).

Your doctor must submit a statement supporting your request. The doctor's statement must indicate that the requested drug is medically necessary for treating your condition because none of the drugs we cover for treating your condition would be as effective as the requested drug or would have adverse effects for you. If the exception involves a prior authorization, quantity limit, or other limit we have placed on a drug you are taking, the doctor's statement must indicate that the prior authorization or limit would not be as effective for treating your condition or would have adverse effects for you.

Once the physician's statement is submitted, we must notify you of our decision no later than 24 or 72 hours depending on whether the request is an expedited request or a standard request. Your request will be

ARG..*14110*.0327260004.01227.01227.E01TLRS1.0000018191427|0000614

COMPANY :

HUMANA

Guidance when you need it most

Humana Clinical Pharmacy Review
1-877-486-2621 (Fax)
www.humana.com

Please try Humana's New Web Prior Authorization Tool at the Provider Portal on Humana.com.

Fax form: Celebrex® (celecoxib) or Mobic® (meloxicam)

Prescriber Information

Name: Dr Zent	TAX ID#: 350108729		
Address: 2500 N St Rd 29	City: Camden	State: IN	Zip code: 46917
Telephone: 7658455401	Fax: 7658653782		
Physician Specialty (if applicable): MD			
Physician signature (required): Dr P Zent/MFCD		Date: 3-6-07	

Diagnosis and Medical Information

Is this a reauthorization? Yes ☐ No ☑

ICD-9 code: 715.09 J-code:

Has the patient failed on TWO separate trials of prescription-strength NSAID therapy?

Drug	Dose	Duration
1. Ibuprofen	800mg TID	? Freq Sch
2. Tylenol Arthritis	2 tabs BID	? Freq Sch

Please check any of the following applicable to the patient:

- ☐ Currently on prescription-strength GI medication, e.g., Zantac (ranitidine), Tagamet (cimetidine), Pepcid (famotidine), Axid, Prevacid, Prilosec (omeprazole), Aciphex, Protonix, Nexium, or Cytotec?
- ☐ History of/current PUD (peptic ulcer disease)
- ☐ History of/current GI bleed or perforation
- ☐ Currently on anticoagulation therapy, e.g., Coumadin/Heparin
- ☐ Currently on chronic oral corticosteroid therapy, e.g., prednisone, dexamethasone, hydrocortisone, methyprednisolone, prednisolone, triamcinolone
- ☐ Currently on bisphosphonate drug, e.g., Fosamax, Didronel, Actonel, Skelid, Boniva, or Aredia
- ☐ Currently being treated with antineoplastic (anti-cancer) drugs
- ☐ Currently on antiplatelet therapy, e.g., Ticlid or Plavix
- ☐ History of hemophilia, von Willebrand's disease, or thrombocytopenia
- ☐ A diagnosis of Familial Adenomatous Polyposis (FAP) with colorectal polyps (if the request is for Celebrex)

Please provide any medical information which may support approval:
Pt has been taking since 8-18-05 & doing well

Note: Medications may be subject to a quantity limitation sufficient for a 30 day supply per fill based on FDA approved dosages.

Medication Information

☑ Celebrex	☐ Mobic
Dosage: 200 mg	Dosage:
Sig: 1 tab daily	Sig:

The information contained in the document is confidential. This information is intended only for the use of the individual or entity named above. If you are not the intended recipient of this information, you are hereby notified that any disclosure, copying or distribution of this information or the taking of any action in reliance on this information is strictly prohibited. If you have received this message in error please immediately notify the sender by telephone to arrange for its return.

Prior Authorization of Benefits is not the practice of medicine or the substitute for the independent medical judgment of a treating physician. Only a treating physician can determine what medications are appropriate for a patient. Please refer to the applicable plan for the detailed information regarding benefits, conditions, limitations, and exclusions.

Please note any information left blank or illegible may delay the review process

HUMANA
Toll Free: 1-800-555-2546
1951 Bishop Lane
Louisville, KY 40218

2-3 denials even tp Dr zent stated could be harmful or even cause death - MFUPR

0000088702346

March 15, 2007

Notice of Denial of Formulary Exception

We have denied coverage of the following prescription drug(s)on which you or your physician requested we make an exception to our formulary or formulary rules:
Celebrex

We denied this request because:
The patient's benefit provides coverage for medications that have been considered medically necessary based upon evidence based medicine. Humana medical necessity guidelines have not been met; the medical information submitted did not support approval for the drug requested.Our authorization criteria include the trial and failure of anti-inflammatory medications on the drug list or the presence of high-risk conditions such as stomach ulcers, bleeding problems, or the taking of other drugs that might increase the risk of bleeding. Generic Mobic (meloxicam) which has a similar safety profile to Celebrex is available to the member 30 tablets per 30 days.

What If I Don't Agree With This Decision?

You have the right to appeal. If you want to appeal, you must request your appeal within 60 calendar days after the date of this notice. We can give you more time if you have a good reason for missing the deadline. Your right to appeal includes **the right to ask us for an exception** if you believe you need a drug that is not on our list of covered drugs (formulary) or believe you should get a drug at a lower cost-sharing amount. Your physician must provide a statement to support your request.

Who May Request an Appeal?

You or someone you name to act for you (your **appointed representative**) may request an appeal. You can name a relative, friend, advocate, attorney, doctor, or someone else to act for you. Others may already be authorized under State law to act for you. You can

American Health Network

family medicine
located in Kokomo

2330 South Dixon Road
Kokomo, Indiana 46902
P. 765.455.5400 | F. 765.865.3912
ahni.com

April 11, 2007

Humana Appeals
Fax# 1-800-949-2961

This letter is being sent in behalf of the above patient asking that you please reconsider our request to approve Celebrex for her treatment. She is allergic to other NSAIDs, and she cannot tolerate them. I cannot and will not give her Mobic as it could be harmful to her and possibly cause her death. She has also tried Naprosen, aspirin, ibuprofen, Tylenol Arthritis, and Lodine with severe reactions to all of these. Please see the attached documentation. Due to this, please approve her for Celebrex, 200 mg, 1 capsule per day.

If you have any questions, please contact my nurse, Monica, at 765-865-3822 or fax her at 765-865-3782. Thank you for your consideration in this matter.

Sincerely,

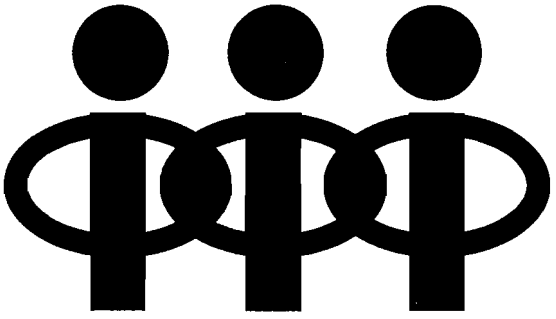
Don Zent MD

Don P. Zent, M.D.

DPZ:jsh

Sondi Bowley, MD
Tonya Brown, MD
Stuart Devaul, MD
Keith Ennis, MD, PhD
Martha Hoshaw, MD
Nicole Lockwood, MD
Ronald Maus, MD
William Mohr, MD
Jeffry Rendel, MD
Odell G. Smith, MD
Eric Tuchscherer, MD
Jeffrey Wilson, MD
Don Zent, MD
Jack Scherger, Executive Director

HFCA 9/14/11 Exhibit 6



State Use Committee

It's MORE than just a purchase...

It's MORE than just a purchase.

It's changing lives
for a better Indiana.

State Use Program
Empowerment Through Employment

Competitive pricing

High quality

Fast delivery

Changing someone's life for the better

When you buy from Indiana's

State Use Program

You get it all

Buying from Indiana's State Use Program gets you quality products and services, plus it gives employment to people with disabilities. As a result, Hoosiers with disabilities are making their own money and living more independently – many for the first time in their lives. Their income also means more tax dollars are added to Indiana's treasury and fewer dollars are used for public assistance.

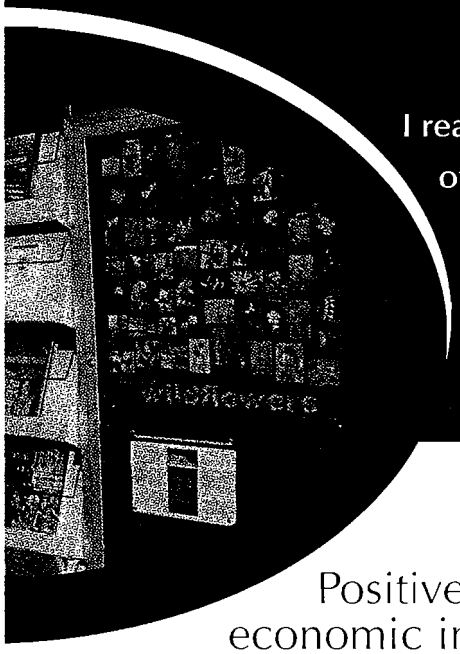
Here's how it works:

- The State Use Program's qualified work centers provide employment and training opportunities for Hoosiers with disabilities.
- Hoosiers with disabilities produce high quality, fairly priced products and services.
- State agencies and other units of local government purchase approved products and services.

To see how much the State Use Program benefits purchasers who buy its goods and services, the Indiana Association of Rehabilitation Facilities, which oversees the State Use Program, commissioned a study. Crowe Chizek and Company LLC, a leading national consulting firm, was hired to analyze three principal areas of the State Use Program:

- The program's fiscal benefits and costs based on products and services purchased.
- The program's fiscal benefits associated with the reduction of public assistance services and the paychecks received by people with disabilities.
- The program's quality of life benefits for Hoosiers with disabilities.

This report summarizes the results of the Crowe Chizek study.



I realize a 30 percent savings in the cost of staff and a 50 percent increase in the quality of work when I use workers from the State Use Program.

Environmental Manager,
Indiana Department of Transportation

Positive economic impact

Every dollar earned by a State Use Program employee who earns at least $10,000 annually saves about $1.07 in state resources. This results in an almost $11,000 savings per year per employee when you combine the average reduction in government assistance with the local, state and FICA tax dollars ($1,205 per year) collected for an employee.

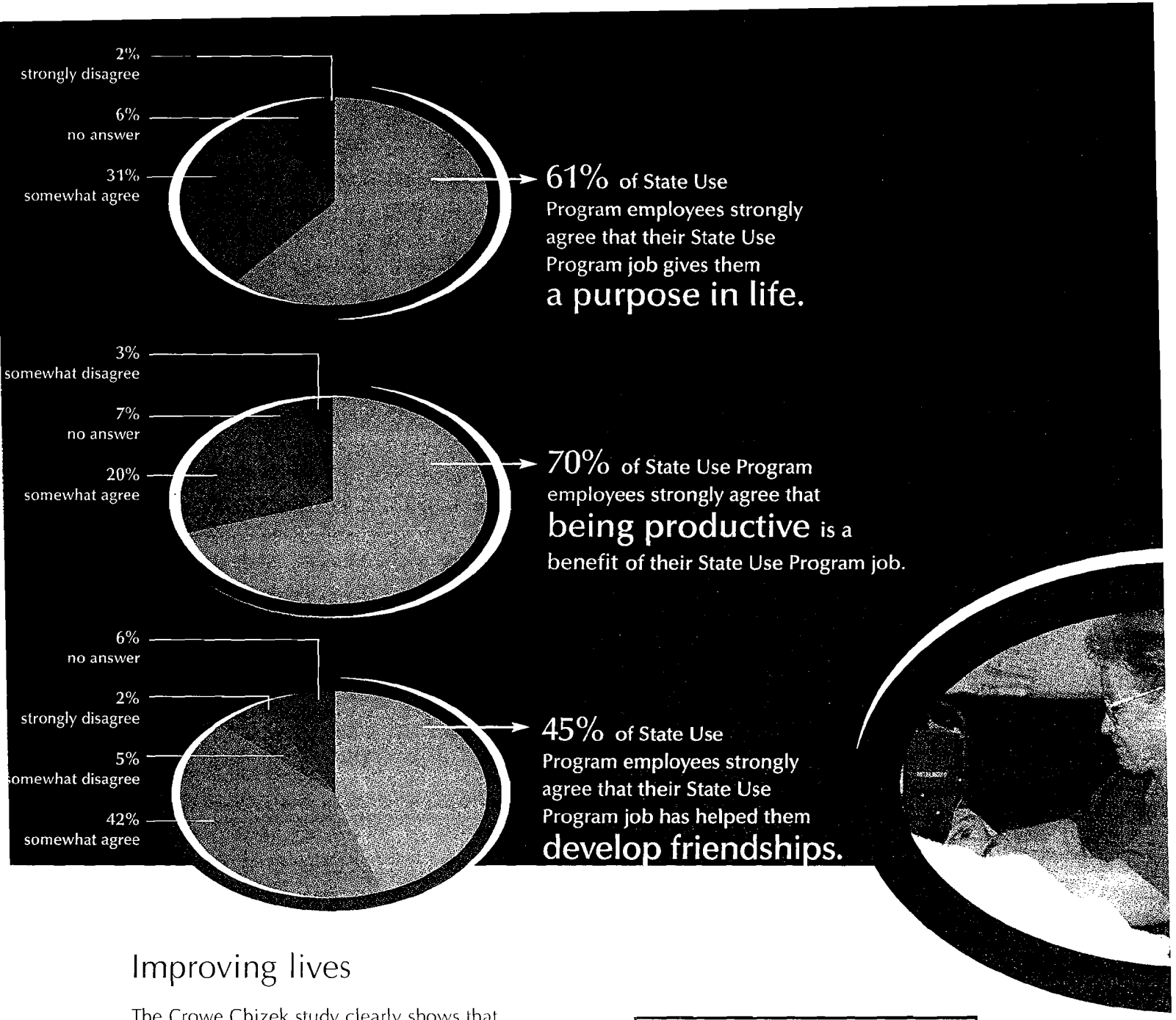
Twenty-six percent of the State Use Program participants responding to the survey indicated that their previous primary income was from public assistance, either SSI or SSDI payments.

When a State Use employee's earned income rises, it displaces public assistance and reduces the burden on state and federal programs.

Type of public assistance*	An individual earning $0 annually receives:	An individual earning $10k annually receives:
	Public assistance received per month	
Temporary assistance for needy families	$155.56	$0.00
Food stamps (person with a disability, living alone)	$47.00	$0.00
Supplemental security income for disabled	$425.03	$183.00
Housing assistance	$352.90	$0.00
compare totals	$980.49	$183.00

* [illegible] amounts for 2001 through 2004

[illegible] and Social Security Administration, Social Security [illegible] Benefits Specialist, Easter Seals Crossroads



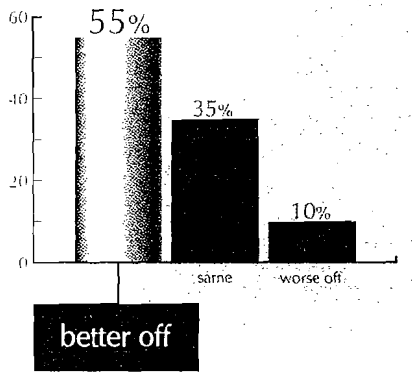
Improving lives

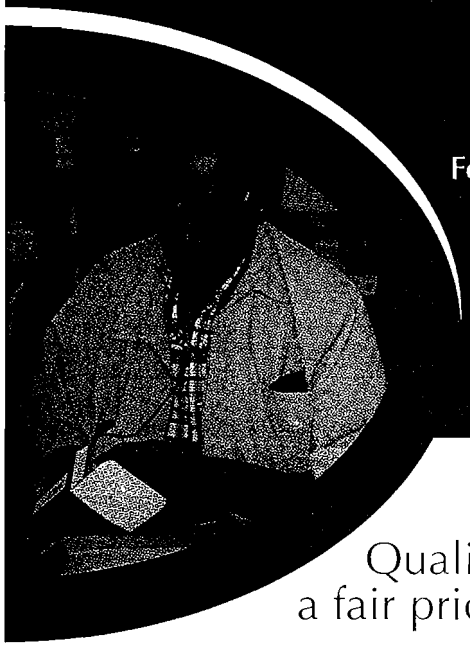
The Crowe Chizek study clearly shows that Hoosiers with disabilities employed by the State Use Program get far more from their jobs than just wages and benefits. Employees say their jobs make them feel productive and independent and, as an added benefit, the workplace offers new friendships.

Thanks to employment with the State Use Program, 65 percent of employees said they own or rent vehicles and 73 percent said they have apartments or homes, all of which enables them to lead more independent lives.

Finally, 84 percent of the State Use Program employees said they enjoy their jobs, and 80 percent said they would rather work than not work. Considering that only about half of all Americans surveyed generally say they are happy in their jobs, these figures are quite positive.

Percent of State Use Program employees who say they are better off since starting their State Use Program job.





For every person that was once on public assistance but now is employed in the Program, there is one more person requiring less public assistance and paying greater taxes.

From the Crowe Chizek study

Quality at a fair price

The State Use Program has a long history of providing quality products and services at fair market prices. The Crowe Chizek study found the products provided by Bosma Industries and rest area services typically cost the same or less than goods and services purchased through conventional sources. Purchasers also cite timeliness of delivery, quality and productivity as positive factors affecting their decisions to buy from the State Use Program.

One environmental manager of rest area facilities for the Indiana Department of Transportation said he realizes a 30 percent savings in the cost of staff and a 50 percent increase in the quality of work when he uses workers from the State Use Program.

State Use Program (SUP) vs. Commercial Sourcing: Product Price Comparison

Product	SUP price	Commercial average
Regular coffee, yield 1 gallon	$0.44/gal	$0.77/gal
Yellow cake mix, six 5 lb. bags per case	$26.81/case	$33.73/case
Vinyl gloves, 1,000 count	$0.05225/ glove	$0.052/glove
Fruit drink mix	$0.05/serving	$0.048/ serving

Source: Central Coordinating Agency and the Indiana Department of Administration

For more information on the State Use Program visit www.inarf.org

Mission statement

The State Use Committee, through the Central Coordinating Agency, creates a partnership among the public and private sectors to enhance employment and training opportunities for Indiana's citizens with disabilities. This coordinated effort provides an opportunity for individuals to achieve greater self-worth and esteem, improved economic independence and social inclusion, while the state realizes a savings through its investment in its citizenry.

State Use Program
Empowerment Through Employment

615 North Alabama Street, Suite 410 • Indianapolis, IN 46204 • 317.634.4957

inarf
ADVANCING LEADERSHIP. BUILDING RESOURCES.

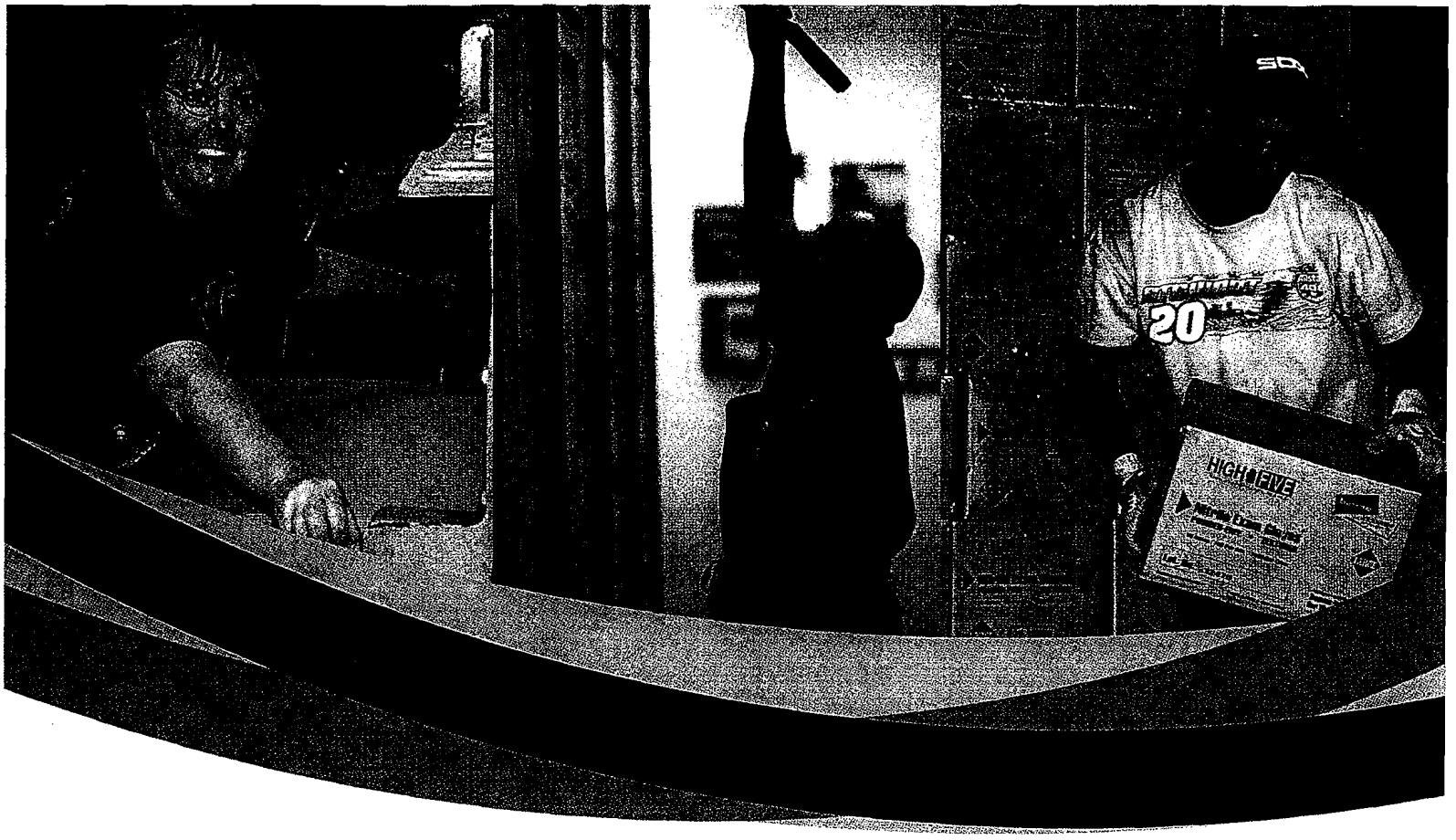
BARBARA YOUNG
Vice President/CFO

615 N. Alabama St., Ste. 410, Indianapolis, IN 46204
tel 317 – 634 – 4957 fax 317 – 634 – 3221
email barb@inarf.org web www.inarf.org

inarf
ADVANCING LEADERSHIP. BUILDING RESOURCES.

JAMES M. HAMMOND, III
President/CEO

615 N. Alabama St., Ste. 410, Indianapolis, IN 46204
tel 317 – 634 – 4957 fax 317 – 634 – 3221
email jmh@inarf.org web www.inarf.org



Indiana's State Use Program: Creating Jobs in Communities Across Indiana

2011 Highlights, Accomplishments, and Opportunities

317.634.4957
www.smartpartnersalliance.org
www.inarf.org

State Use Program
Empowerment Through Employment

Creating Jobs in Communities Across Indiana

The State Use Program does just that. Through the program, products and services are created by participants affiliated with qualified nonprofit organizations, and then purchased by state and local government agencies. In 2010, the program created jobs and training opportunities for hundreds of Hoosiers with disabilities in communities across the state.

An independent study performed clearly shows that Hoosiers with disabilities working through the State Use Program get far more from their jobs than just wages and benefits. Participants say their jobs make them feel productive and independent and, as an added benefit, the workplace offers new friendships.

The State Use Program is a viable option for people with disabilities to learn different skills and experience meaningful work and training opportunities. We invite you to learn more about our partnering nonprofit organizations located in your community, listed on the reverse side of this flyer.

The Program's Mission:

The State Use Committee, through the Central Coordinating Agency, creates a partnership among the public and private sectors to enhance employment and training opportunities for Indiana's citizens with disabilities. This coordinated effort provides an opportunity for individuals to achieve greater self-worth and esteem, improved economic independence and social inclusion, while the state realizes a savings through its investment in its citizenry.

The Program's Benefits:

The program benefits Indiana's communities by employing individuals that may otherwise not have the opportunities and assists with alleviating additional public assistance. For every individual employed through the Indiana State Use Program . . . There is one more person requiring less public assistance and paying greater taxes.

How the Program Works:

Indiana State agencies are required by law to purchase products and services offered through the Program. State Use is codified as IC 16-32-2 and IC 5-22-13, which means state, city, and county government entities can establish a contract without using the normal competitive bidding process.

Indiana's State Use Program
Highlights, Accomplishments, and Opportunities

Program Highlights

- ⇒ Creates Employment Opportunities
- ⇒ Our Customers Receive Quality Products at Fair Market Price
- ⇒ Operates Without a Direct Fiscal Appropriation
- ⇒ People Who Work Pay Taxes and Rely Less on Public Assistance
- ⇒ Saves Time with Purchasing
- ⇒ Contracts are Negotiated—Customers Get What They Want

Program Accomplishments

- ⇒ Thirty-Five Work Centers Produce About Forty Products and Services
- ⇒ Over 475 People with Disabilities Working In The Program
- ⇒ Workers Earned Over $1.8 Million in Wages in SFY 2011
- ⇒ Total State Use Program Sales Were Approximately $9 Million
- ⇒ Eighty People with Disabilities Transitioned Into Competitive Employment
- ⇒ Annually, Indiana's Rest Areas Ranked In Top Five in the U.S.

Program Opportunities and Challenges

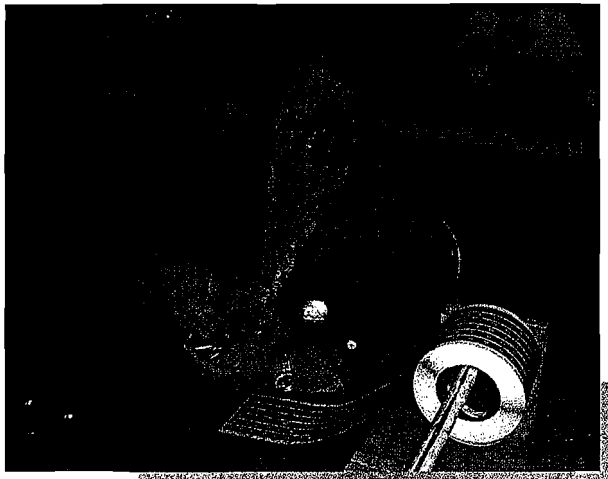
- ⇒ Use Directed Source Provisions for Prime Contracting and Outsourcing
- ⇒ State Use Program as the First Stop for Procurement Decisions
- ⇒ Supporting Work First Initiatives Within State Government
- ⇒ Enlisting the Support of All State Agencies
- ⇒ Retaining the Program's Current Customer Base
- ⇒ Creating Business Partnerships to Develop New Products and Services
- ⇒ Support the "Greening of the Government"

Nonprofit Organizations Participating in the State Use Program

Organization	City	State Use Product/Service
Abilities Services, Inc.	Crawfordsville	Janitorial services
ADEC, Inc.	Bristol	Trash liners
Arc Opportunities, Inc.	Howe	Janitorial services
AWS (d/b/a Post Masters)	Ft. Wayne/Indianapolis	Mail services
AWS (d/b/a Highway Safety Specialists)	Ft. Wayne	Highway safety supplies
Blue River Services, Inc.	Corydon	Janitorial services
Blue River Services (d/b/a BR Grafix)	Corydon	Screen printing services
Bona Vista Programs, Inc. (d/b/a BVI Services)	Kokomo	Spill kits, first aid kits, document shredding service
Bosma Enterprises	Indianapolis	Disposable gloves, signage, vaccination kits, call center services
Carey Services, Inc.	Marion	Corrugated boxes, document shredding services
CDC Resources, Inc.	Monticello	Janitorial services
Child-Adult Resource Services, Inc.	Rockville	Janitorial services, embroidery services
Developmental Services, Inc.	Columbus	Janitorial services
Easter Seals Arc of Northeast Indiana	Ft. Wayne	Towels, washcloths, laundry bags
Evansville Association for the Blind, Inc.	Evansville	Industrial brooms, mops, brushes, squeegees, cutlery
Evansville Goodwill Industries, Inc.	Evansville	Industrial wipers (cleaning rags)
Four Rivers Resource Services, Inc.	Linton	Red danger flags, reflective bands
Goodwill Industries of Central Indiana, Inc.	Indianapolis	Janitorial services
Hillcroft Services, Inc.	Muncie	Janitorial services
Hopewell Center (d/b/a Cartridge King)	Anderson	Remanufactured toner cartridges, binder clips
Jay-Randolph Developmental Services, Inc.	Portland	Janitorial services
Knox County ARC, Inc.	Vincennes	Document shredding services
Michiana Resources, Inc.	Michigan City	Janitorial services, stocking caps, safety vests
New Horizons Rehabilitation, Inc.	Batesville	Janitorial services
Noble of Indiana (d/b/a Noble Industries)	Indianapolis	Janitorial services
Opportunity Enterprises, Inc.	Valparaiso	Document shredding services, janitorial services
Passages, Inc.	Columbia City	Janitorial services
Pathfinder Services, Inc.	Huntington	Three ring vinyl binders
Peak Community Services	Logansport	Document shredding services, work gloves
Putnam County Comprehensive Services, Inc.	Greencastle	Janitorial services
Shares, Inc.	Shelbyville	Document shredding services
Southern IN Resource Solutions, Inc.	Boonville	Janitorial services
Stone Belt Arc Inc.	Bloomington	Leather products, belts
Tradewinds Services	Gary	Custom signage
Wabash Center, (d/b/a Greenbush Industries)	Lafayette	Janitorial services

2010 State Use Committee Annual Report

State Use Program
Empowerment Through Employment

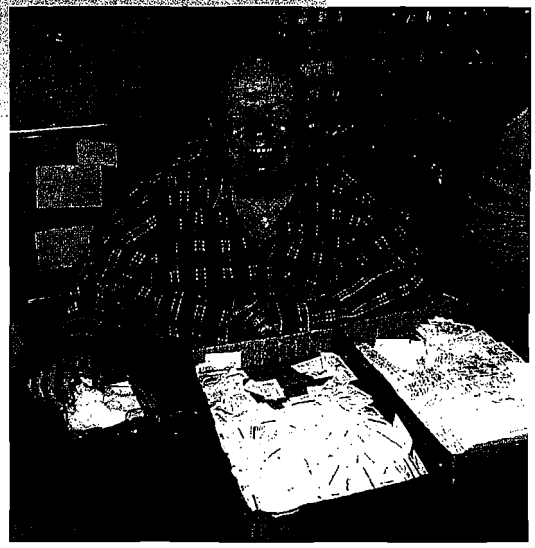


Mission

The State Use Committee, through the Central Coordinating Agency, creates a partnership among the public and private sectors to enhance employment and training opportunities for Indiana's citizens with disabilities. The coordinated effort provides an opportunity for individuals to achieve a greater sense of self worth and esteem, improved economic independence and social inclusion, while the state realizes a savings through its investment in its citizenry.

Purpose

The purpose of the State Use Law is to enhance employment and training for people with disabilities by encouraging state agencies and units of local government to purchase products and services made by people with disabilities employed at qualified nonprofit work centers throughout Indiana.



Pictured front cover, left to right: Elizabeth Abbott, Pathfinder Services; Daryl Walker, Goodwill Industries of Central Indiana; and Jim Huizenga, Bosma Enterprises.
Pictured this page: above is Norma Jean Schwering, and right is David Magers, BVI Services.

Dear Friends and Supporters,

As we reflect on the accomplishments and challenges of 2010 we recognize that this was among the most difficult and challenging years in our history. Despite difficulties resulting from the changing economic cycles and uncertain and unresolved public policy issues, the year became one of the most rewarding years in our history.

We helped celebrate the twenty year anniversary of the signing of the Americans With Disabilities Act (ADA) and as a result created and/or sustained numerous new employment and training opportunities for Indiana's citizens with disabilities. We also coordinated with State Use work centers throughout Indiana to build awareness and offer increased opportunities through this and other related programs.

A key contributor to our success this year was that all staff within the Central Coordinating Agency (CCA) came together with a singular focus on turning challenges into opportunities. Everyone from the State Use Committee to operations staff and sales staff focused on addressing difficult tasks and situations confronting the program and its intended beneficiaries. As a result of these combined efforts we had a better year than expected.

We are proud of everyone's contributions and of our team's swift, comprehensive and effective response to the unprecedented challenges of the year. With our results, we showed once more that Indiana's State Use Program is committed to delivering on its expectations and promises.

Sincerely,

Bix Branson
Chair, Indiana State Use Committee

James M. Hammond, III
President/CEO, INARF

Pictured: James M. Hammond, III and Bix Branson

Report of Progress

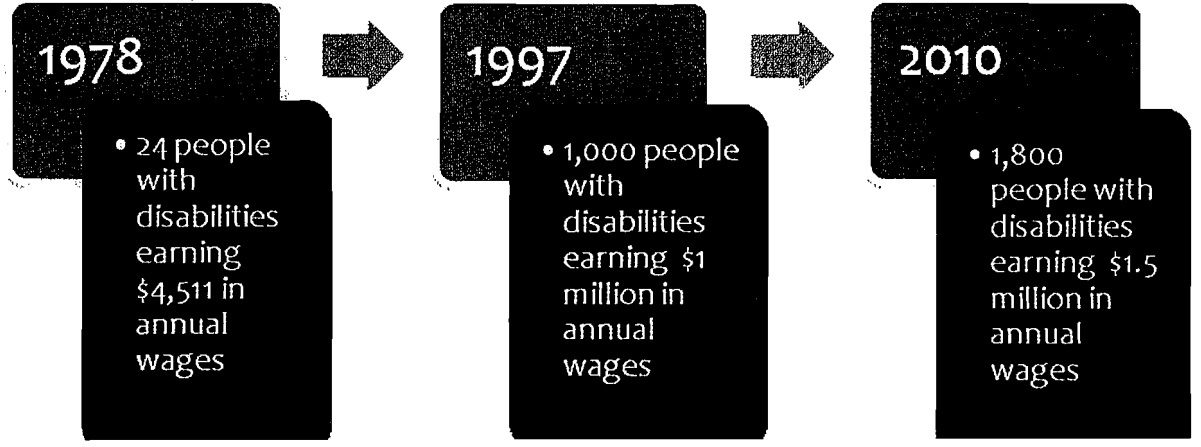
With 2010 marking the 20th anniversary of the signing of the Americans with Disabilities Act (ADA), this year's Report of Progress takes on additional significance. The ADA is one of our nation's important victories in fulfilling a promise of equality for all. Title 1, the employment provision, extends to every aspect of society and impacts the lives of thousands of Hoosiers annually. From a statewide perspective, it is important to recognize that Indiana's State Use Program has not only created a multitude of employment opportunities, but it has created a variety of jobs, upward mobility opportunities and further options to obtain jobs in the competitive labor market. To mark this milestone, this Annual Report is revisiting some of the accomplishments that have occurred throughout the program's rich history.

In 1978, during the State Use Program's first year, 24 people with disabilities earned a total of $4,511 in annual wages, contributing to total sales of $21,782. By 1997 there were over 1,000 people with disabilities working through the program, earning a cumulative gross of over $1 million in annual wages. By 2010, the program was successful in providing jobs for more than 1,800 individuals with disabilities, earning approximately $1.5 million in annual wages, and adding to total sales of more than $9.3 million.

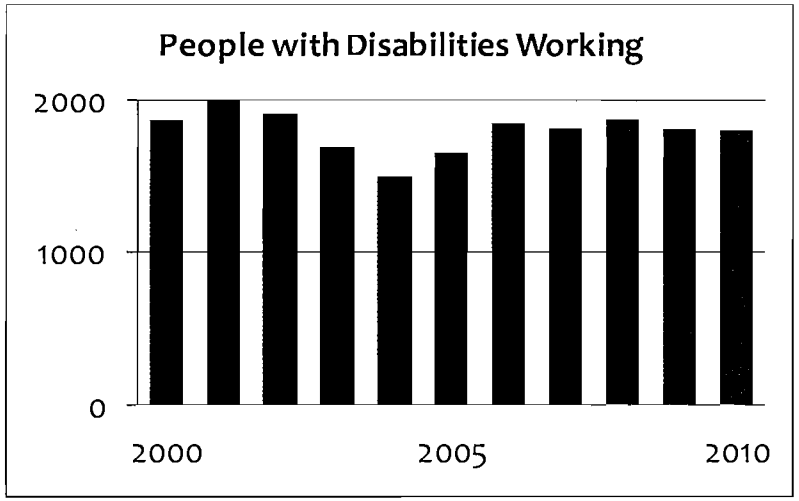
2010 also brought the program another channel for greater visibility. State Use Products and services available on state quantity purchase agreements can be now be found in the OneIndiana web based searchable catalog. The OneIndiana website is part of a state funded initiative encouraging local governments to take advantage of savings available when purchasing from state negotiated contracts.

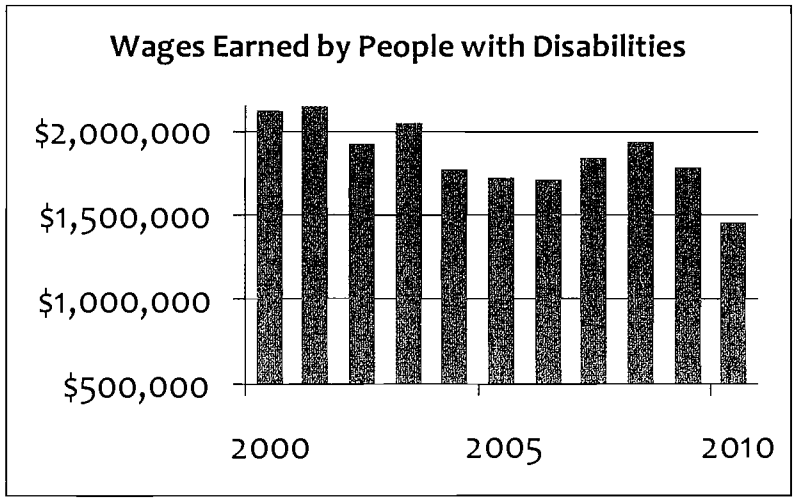
Additionally, 2010 witnessed growth in the number of contracts that provided work through the program. Janitorial services with Indiana State Police (Noble of Indiana), and the Integrated Public Safety Commission (Noble of Indiana) were added to the roster. New product lines included Bosma Enterprises' vaccination kits and Tradewinds Services' custom signs. With steadfast marketing efforts, awareness of the State Use Program merits and the quality of its products and services continues to grow. We are optimistic that several new contracts will be added to the program in 2011.

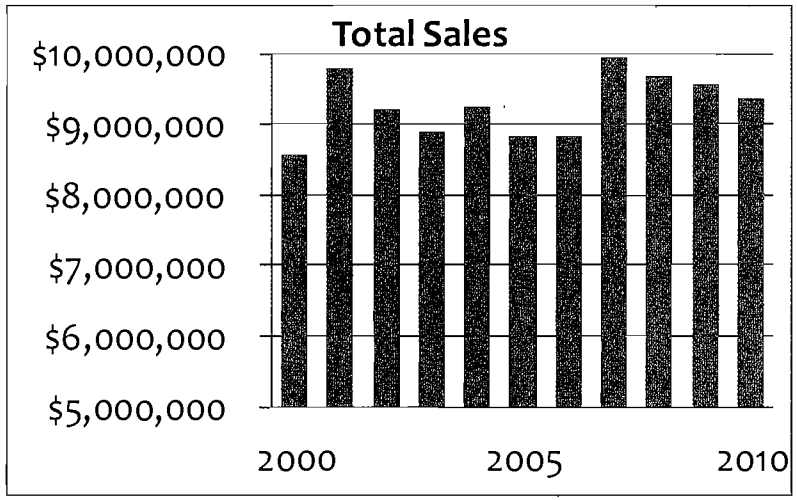
The next few years promise to be just as challenging as the last, as the state continues to contend with a tough economy and conservative spending trends are gaining momentum. Despite these economically difficult times, the State Use Program has made tremendous progress over the years, and its resilience provides optimism that jobs will continue to be sustained and created for people with disabilities. The dedication and stewardship of the work centers that participate in the program and the state agency partners that support the program are key components to the longevity and success this program has and will continue to experience.

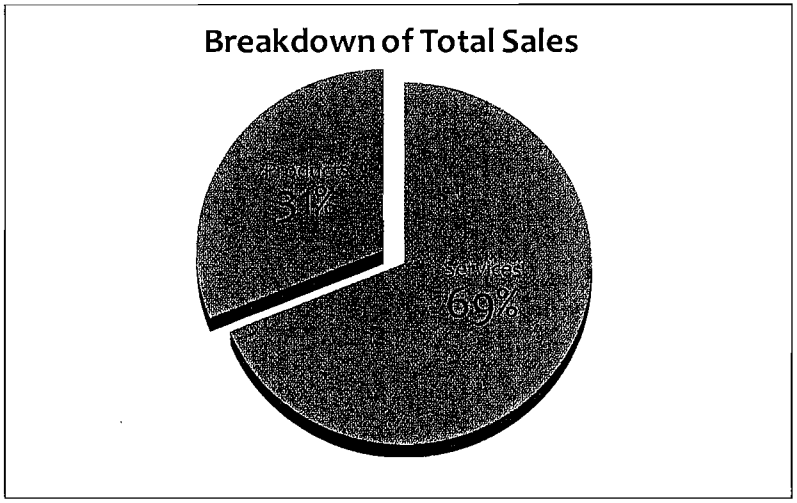


Key Performance Indicators







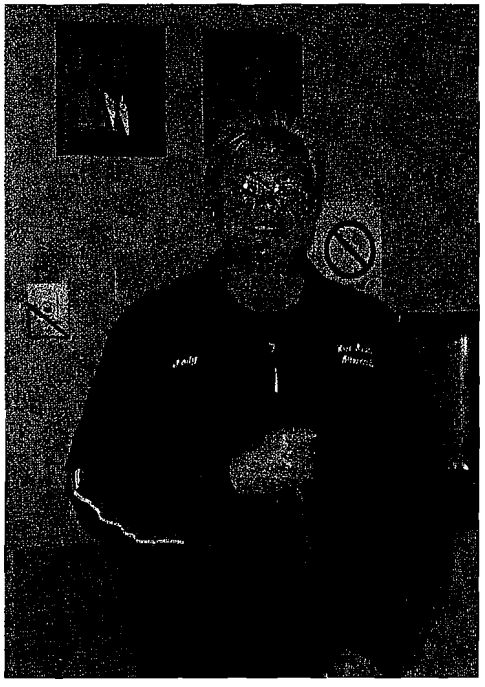


Using 2009 as a benchmark for key performance indicators, 2010 saw a 2.2% drop in overall sales. Total wages earned by people with disabilities experienced a decrease, largely attributed to changes in some service contracts (service contracts typically offer a higher wage than product contracts). 1,810 people with disabilities were able to work through the State Use Program, holding steady with the previous fiscal year. Equally important, 80 people were able to transition into competitive employment positions with skills learned from working on State Use contracts. Product sales experienced an increase of 25% over 2009, due to increased purchasing from a variety of existing contracts as well as the establishment of new contracts.

Janitorial Services: A Successful State Use Service Line

Service contracts, especially janitorial service contracts, are a great example of the Indiana State Use Program's rich history, having experienced increased numbers of people with disabilities contributing to our state's workforce over the past 25 years. Janitorial service jobs provide employment and ongoing training which develop skills that can transfer to employment positions in the community at large. This has collectively become the most consistent business line offered through the State Use Program.

State Use janitorial services began in 1985, when a pilot program began with the Indiana Department of Transportation (INDOT). Two State Use work centers, Pathfinder Services and Hopewell Center were selected to provide janitorial services at two sites along Interstate 69. Having witnessed the successful partnership of the Ohio Department of Highways' with State Use work centers cleaning their rest areas and welcome centers, INDOT wanted to test the model in Indiana.



Pictured above, left to right: Jody Kreider, Passages, Inc. and Phillip Spaulding, Blue River Services.

The blueprint succeeded, and blossomed into the State Use janitorial program it is today. This past year, 12 State Use work centers performed janitorial services at all 18 Indiana rest areas and welcome centers open to traveling motorists. More so, Indiana is known to have among the cleanest rest area and welcome center facilities in the United States (Truckers News Magazine, www.truckersnews.com).

While State Use janitorial services began with INDOT at the state's rest areas and welcome centers, many other state agencies also utilize this service, including Department of Revenue, Department of Administration, Bureau of Motor Vehicles, Department of Environmental Management, Department of Family Resources, and the State Police. Janitorial services have grown tremendously, from initial sales of $75,000 to 2010 sales topping $5.5 million; what's more, this service line has been a boon for thousands of people with disabilities to seek gainful employment and new, marketable skills.

Great appreciation goes to all of the State Use work centers for their participation in the development and evolution of such a lasting, remarkable program. Their success is a significant contributing factor to the growth of this service line throughout the years. We also thank INDOT and the other participating state agencies for their partnership, which has and continues to further the mission of the State Use Program.

Pictured above, left to right: Bennie Quisenberry, CDC Resources, Inc.; Ron Stemshorn & Michael Heymig, Noble of Indiana; and Peggy Odle, CDC Resources, Inc.

Delivering Quality Products while Creating Jobs

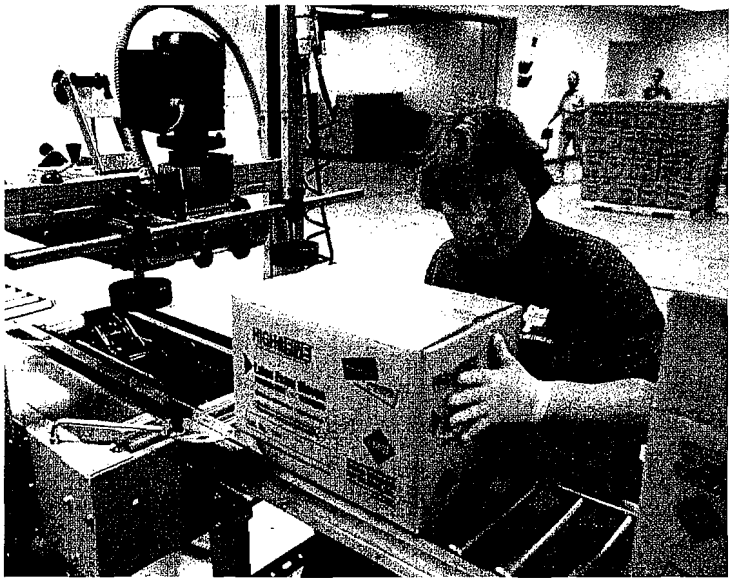
One of the widely sold products available through the State Use Program is industrial wipers, more commonly known as "cleaning rags." More than 61,000 pounds of cleaning rags were sold in 2010 to 48 customers, employing 20 people with disabilities. Industrial wipers were one of the first products to be sold through the program and this product line is still successful today.

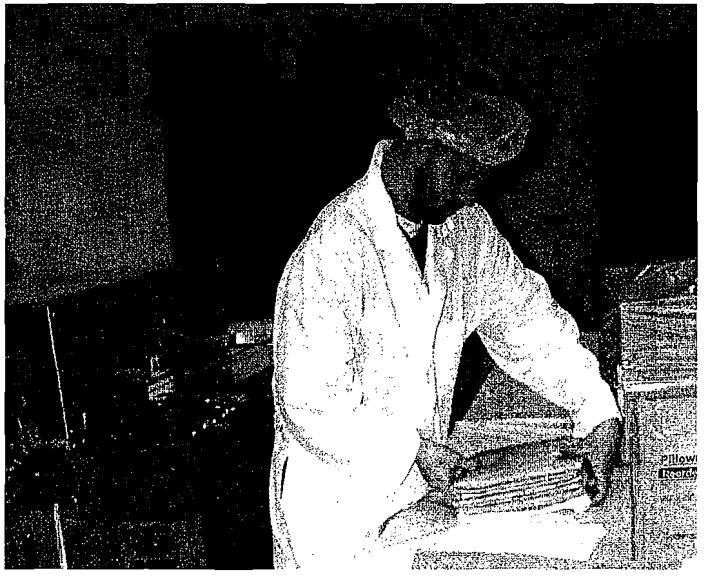
Twila Archer, Plant Supervisor at Vincennes Goodwill Industries (a branch of Evansville Goodwill Industries) where the industrial wipers are made says, "For many years Evansville Goodwill Industries, Inc. has enjoyed a successful partnership with the State Use Program producing industrial wipers. Our State Use contract provides employees with disabilities with meaningful work that increases their self confidence and self-worth. Through hands-on experience they are able to build different skill sets that range from cutting, sorting, and boxing the wipers to taking orders from our valuable customers and shipping them to various locations across the state. The contract not only puts people with disabilities to work, it provides them with transferable skills that will help them advance in the work place."

In addition to providing meaningful work for Hoosiers with disabilities, this vital product meets the needs of our customers. "We purchase the industrial wipers quite often and use them throughout the entire shop. Evansville Goodwill has always provided us with timely deliveries," said Evansville INDOT store clerk, Donna Waninger. Karen Bates of Pen Products (Westville) added, "Evansville Goodwill Industries has prompt delivery of ordered products. Purchase order and delivery issues are addressed and solved promptly and their staff is always courteous and professional in handling and answering questions." Today, with more than 30 different products and services sold through the State Use Program, industrial wipers remain a cornerstone of the State Use catalog.

Pictured above, left to right: Richard Wood and Dean Hargis, Evansville Goodwill Industries.

Creating Value while Saving Resources





Pictured, above, left to right: Joni Stanley and David Gallagher, Bosma Enterprises.

In 2010, Bosma Enterprises began providing vaccination kits for the Indiana Department of Health (ISDH) through the State Use Program. ISDH determined they were in need of a better method when purchasing bulk supplies and dispersing them to vaccination clinics throughout the state proved to be cumbersome. ISDH had purchased personal protection kits from Bosma through the program in the past, and were optimistic that Bosma could create a kit that would meet their needs. Working with IDOA representatives, State Use staff established a quantity purchase agreement (QPA) for vaccination kits.

Exceeding ISDH's expectations, Bosma produced the vaccination kits within an expedited time frame so that they could be used at all the clinics. What's more, Bosma was able to offer the vaccination kits for a better price than the cost of supplies ISDH was purchasing in bulk. Tom Boyd of Bosma Enterprises reported "Bosma is extremely pleased with the opportunity to work with ISDH in providing vaccination kits. The project not only provides a cost savings to the State, but enables people who are blind and/or visually impaired to assemble a beneficial product. Bosma workers want a meaningful job."

State Use Staff

Pictured above, left to right: Kim Jones, Marketing Manager; Dionne Castelli, Account Executive; Jim Hammond, President/CEO; Pat Huxley, Admin. Assistant/ Program Support; Barb Young, Vice President/CFO; Ryan Speers, Account Executive; and Wes Bickers, Account Executive.

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2010 State Use Committee Members

Bix Branson
Chairperson
Evansville, Indiana
At Large

Charles Boyle
Vice Chairperson
Indianapolis, Indiana
Representing Division of Mental Health and Addictions

Greg McAloon
Indianapolis, Indiana
Representing Division of Disability & Rehabilitative Services

Suellen Jackson-Boner
Indianapolis, Indiana
Indiana Governor's Council for People with Disabilities

Mike DuValle
Indianapolis, Indiana
Representing Department of Administration

Anna Welch
Indianapolis, Indiana
Representing Department of Health

Thomas K. "Buddy" Downs
Zionsville, Indiana
At Large

Kenneth R. Cross
Lebanon, Indiana
At Large

Cynthia Brandon-Harris
Executive Secretary
Indianapolis, Indiana
Bureau of Rehabilitation Services

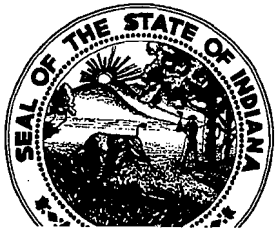
Participating State Use Work Centers

Abilities Services, Inc.	Crawfordsville	Janitorial services
Achieva Resources Corporation, Inc.	Richmond	Janitorial services
ADEC, Inc.	Bristol	Trash liners
Arc Opportunities, Inc.	Howe	Janitorial services
AWS (d/b/a Post Masters)	Fort Wayne/Indianapolis	Mail services
AWS (d/b/a Highway Safety Specialists)	Fort Wayne	Highway safety supplies
Blue River Services, Inc.	Corydon	Janitorial services
Blue River Services (d/b/a BR Grafix)	Corydon	Screen printing services
Bona Vista Programs, Inc. (d/b/a BVI Services)	Kokomo	Spill kits, first aid kits, document shredding services
Bosma Enterprises	Indianapolis	Disposable gloves, food products, ADA signage, call center services
Carey Services, Inc.	Marion	Corrugated boxes, document shredding services
CDC Resources, Inc.	Monticello	Janitorial services
Child-Adult Resource Services, Inc.	Rockville	Janitorial services, embroidery services
Developmental Services, Inc.	Columbus	Janitorial services
Easter Seals Arc of Northeast Indiana	Fort Wayne	Towels, washcloths, laundry bags
Evansville Association for the Blind, Inc.	Evansville	Industrial brooms, mops, brushes, squeegees, cutlery, window solvent
Evansville Goodwill Industries, Inc.	Evansville	Industrial wipers (cleaning rags)
Four Rivers Resource Services, Inc.	Linton	Red danger flags, reflective bands
Goodwill Industries of Central Indiana, Inc.	Indianapolis	Janitorial services
Hillcroft Services, Inc.	Muncie	Janitorial services
Hopewell Center (d/b/a Cartridge King)	Anderson	Remanufactured toner cartridges, binder clips
Knox County ARC, Inc.	Vincennes	Document shredding services
Michiana Resources, Inc.	Michigan City	Janitorial services, stocking caps, safety vests
New Horizons Rehabilitation, Inc.	Batesville	Janitorial services
Noble of Indiana (d/b/a Noble Industries)	Indianapolis	Janitorial services
Opportunity Enterprises, Inc.	Valparaiso	Document shredding services, janitorial services
Passages, Inc.	Columbia City	Janitorial services
Pathfinder Services, Inc.	Huntington	Three ring vinyl binders
Peak Community Services	Logansport	Document shredding services, work gloves
Putnam County Comprehensive Services, Inc.	Greencastle	Janitorial services
Shares, Inc.	Shelbyville	Document shredding services
Southern IN Resource Solutions, Inc.	Boonville	Janitorial services
Stone Belt Arc Inc.	Bloomington	Leather products, belts
Tradewinds Services	Gary	Custom signage
Wabash Center, Inc. (d/b/a Greenbush Industries)	Lafayette	Janitorial services

It's MORE than just a purchase,
it's changing lives for a better Indiana.

For more information about the State Use Program
and to view our catalog of products and services, visit our website:
www.smartpartnersalliance.org

State Use Program



Mitchell E. Daniels, Jr.
Governor

Indiana Association
of Adult Day Services

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President
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Cell: 317-340-3667
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Or Freespeakr@aol.com
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FAX (317) 536-7241
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term expires 2012

4/22/11 mag

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Vacant

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aperez@franciscancommunities.com
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Region 4 Representative
Open Poistion

Region 5 Representative
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christinaraj@justfriendscolumbus.com
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term expires 2012

	Organization Name	Organization Representative	Title	Year Opened
1	Lean On Me, Inc.**	Veda Forte		TBD
2	ADS at Pine Knoll	Dan McMullen	President	2010
3	ResCare ADC	Barbara Porter	Director	2007
4	A Caring Place ADS	Sr. Susan Dinnin	Program Director	1990
5	Pathways ADC	Terri Hebble	Director	1990
6	Still Waters ADC	Kathy Pellman	Executive Director	2011
7	Franciscan ADS	Andrea Perez	Program Nurse Coordinator	1995
8	Joy's House	Tina McIntosh	President & CEO	1990
9	Alpha Center, Inc.	Connie Hacker	Executive Director	1978
10	St. Agnes ADS Center	Barbara Kubiszak	Director	1997
11	Just Friends, inc.	Christina Rajanayakam	Program Director	1988
12	Milton ADS	Loretta Madden	Director	2004
13	A Day Away ADC, Inc.	Stephanie Stilabower	Executive Director	2002
14	Hand-in-Hand ADC of Richmond	Johanna Hensley	Executive Director	1988
15	Four Rivers Resource Services, Inc.**	Rachel Headley	Deputy Director	TBD
16	Loving Hands ADC, Inc.	Charleszetta Lewis	Executive Director	2010
17	Senior Care, Inc.**	Chester Newton	President/CEO	TBD
18	Bridge of Hope ADC	Charlye Vance	President/Executive Director	2009
19		Margaret Scott	Retired ADS Director	n/a
20	Reliable Care Adult Day Care, Inc.	Chloe Ricketts	Co-Owner	2001
21	Riverwalk Communities	Cheryl Rheinlander	Director	2003
22	Recourse Resource	Emily Tisdale	Principal	2010
23	Southport ADC	Helen Caldwell	Director	1998
24	Daybreak & Visiting Nurse Care	Diane Sexton	Program Director	1997
25	Elder Alternative ADS	Lovie King	Director of Senior Services	1985
26	Young in Heart**	Audrey Young Lane	Manager	TBD
27	Turnstone Center	Tina Acosta	Director	
28	HomePoint Care Services, Inc.	Lauri Cadle	President	2010
29		Pam Toft		TBD
30	McMillan ADS	Patty Butterfield	Director	1975
31	Seasons Home Care	Curt Hermann	Owner	2011
32	Golden Gardens	Kim Smith	Director of Operations	2009
33	Heavenly Helping Hands	Mary Amezquita/Tia Slone		2010

34	Riverview ADC, Inc.	Wendy White	Executive Director		
35	Lamplight Inn of Fort Wayne	Bobby Petras	COO		2010
36	Courtyard Club @ Saint Anne's	Lisa Budde	ADS Coordinator		2010
37	Senior and Family Services, Inc.	Laura Greenfield	Interim Director		1987
38	YMCA Bettye J. McCormick Sr Ctr ADS	Nola Davis	Executive Director		1974
39		Joyce A. Read	Executive Director	TBD	
40	Active Day - Indianapolis South	Ryan Skinner	Center Director		2008
41	Active Day - Merrillville	Maria Cubero	Center Director		2010
42	Active Day - Indianapolis North	Susan Susskind	Center Director		
43	Bestcare Seniors Services	Willy Okwara	Director of Program	TBD	
44		James Bobian		TBD	
45	Active Day - Indianapolis West	Cheryl Wilson	Center Director		2008
46	Second Family ADC	Raisa Grishin	Administrator		2004
47	Christian Care Retirement Community	Leon R. Gerber	Executive Director		1989
48	Jennings House ADS	Dennis Beasley	Administrator		
49		Charlene Guthrie			
50	SarahCare of Indianapolis	Vicki Maynard	Executive Director		2009

Address	City	State	Zip	Phone	FAX
5125 Staughton Dr.	Indianapolis	IN	46226	317-847-2987	
607 Wilson Creek Rd.	Lawrenceburg	IN	47205	812-537-4422	
3711 Rupp Dr., Ste. 106	Fort Wayne	IN	46815	260-483-2888	260-483-2899
4609 N. Capital Ave.	Indianapolis	IN	46208	317-466-0015	317-475-3093
Grant St. at Mercer Ave.	Decatur	IN	46733	260-724-2145 x 4227	260-728-3844
7160 Shadeland Station	Indianapolis	IN	46256	317-284-0837	
205 Franciscan Dr.	Crown Point	IN	46307	219-661-5200	219-661-5205
2028 Broad Ripple Ave.	Indianapolis	IN	46220	317-254-0828	317-254-9377
315 S. Monroe St.	Muncie	IN	47305	765-286-2800	765-286-3907
1859 Harrison blvd.	Valparaiso	IN	46385	219-477-5433	219-462-9553
3600 25th St.	Columbus	IN	46203	812-372-6415	812-372-6415
922 E. Colfax Ave.	South Bend	IN	46617	574-232-2666	574-232-4235
1701 Freeman St., Ste. 3	Fort Wayne	In	46802	260-432-0011	866-466-9603
2727 East Main St.	Richmond	IN	47374	765-966-0852	765-962-4003
Hwy 59 South, P.O. Box 249	Linton	IN	47441	812-847-2231	812-847-8836
614 E. Boulevard	Kokomo	IN	46902	765-455-2300	765-455-4035
2511 E. 46th St., Ste 0	Indianapolis	IN	46205	317-442-6738	317-802-7378
5325 E. 30th St.	Indianapolis	IN	46216	317-430-3144	
1833 No. 8th St.	Terre Haute	IN	47804	812-236-3958	
1530 Vogel Rd.	Evansville	IN	47715	812-477-1707	812-477-1006
401 S.E. 6th St.	Evansville	IN	47713	812-425-1041	812-421-6773
P.O. Box 50794	Indianapolis	IN	46250	317-496-5259	
1427 Southview Dr.	Indianapolis	IN	46227	317-536-7245	317-536-7241
1304 Main St.	Anderson	IN	46016	765-640-1065	765-640-1665
2236 E. 10th St.	Indianapolis	IN	46201	317-633-3104	317-633-3006
2101 Jeorse Circle	East Chicago	IN	46312	219-398-5316	
3320 N. Clinton St.	Fort Wayne	IN	46805	260-483-2100	260-484-5059
14074 Trade Center Dr. #234	Fishers	IN	46038	317-774-7764	317-282-0582
1447 W. Blubaugh Ave.	Thorntown	IN	46071	765-325-9102	
486 1st. Ave.	Terre Haute	IN	47807	812-232-4627	812-238-1564
1101 Husky Trail	Warsaw	IN	46582	574-268-9000	574-268-2268
2636 Mitthoeffer Place	Indianapolis	IN	46229	317-897-8555	317-8978561
128W 1000S	Twelve Mile	IN	46988	574-398-9407	

2715 E. Jackson Blvd.	Elkhart	IN	46516	574-293-6886	
300 East Washington Blvd.	Fort Wayne	IN	46802	260-422-5511	
1900 Randalia Dr.	Fort Wayne	IN	46805	260-484-5555	260-482-8929
211 E. Main St.	Washington	IN	47501	812-254-1881	812-254-1887
2009 Prospect Ave.	Vincennes	IN	47591	812-882-2285	812-882-2186
P.O. Box 722	East Chicago	IN	46312	219-644-9355	
5425 Victory Dr.	Indianapolis	IN	46203	317-783-2155	317-783-2257
8672 Broadway	Merrillville	IN	46410	219-769-6235	219-769-6342
9615 N. College	Indianapolis	IN	46280	317-569-0014	317-569-1364
5717 Prairie Rose Dr.	Schererville	IN	46375	219-769-1697	
10737 Gateway Dr.	Fishers	IN	46037	317-331-9975	
7545 Rockville Rd.	Indianapolis	IN	46214	317-271-2939	
1717 West 86th St., Ste. 180	Indianapolis	IN	46250	317-251-1225	317-251-1204
720 E. Dustman Rd.	Bluffton	IN	46714	260-565-3000	260-565-3009
1050 W. O & M Ave.	North Vernon	IN	47265	812-346-4663	
7636 Timber Hill North Dr.	Indianapolis	IN	46217	317-431-1484	
2805 E. 96th St., Ste. E	Indianapolis	IN	46240	317-815-8300	317-815-8338

Indiana Association
of Adult Day Services

P.O. Box 20348 | Indianapolis, IN 46220 | (317) 254-4538 | www.iaads.net

What is the Current Situation?

Indiana does not have a general operating license requirement to open and operate an Adult Day Service (ADS). In the last 8 years, MetLife Mature Market Institute reports a 35% increase in the opening of Adult Day Services across the United States. There are a reported 4,600 centers in the United States, with 29% of those centers having a waiting list. In Indiana, the facts are unknown. The lack of oversight of ADS in Indiana suggests that there is an unknown in human services within the state. Individuals are being cared for, yet our state cannot adequately account for their care. Medicaid Waiver provides us an accurate reflection of those receiving care under that certification, however, how does the state account for those ADS who do not opt into the Medicaid Waiver program? Care is being provided, yet, we cannot say by whom, by how many, and at what true cost to the consumers of Indiana. In response to this unknown, coupled with the rise in demand, we are leading the way to ensure that these centers, and their consumers, will be provided basic licensure from the State of Indiana. By regulating the ADS environments, the public can rest assure that safety, care, and best practices, are being upheld by all providers statewide.

What is the Goal?

IAADS envisions legislation that encompasses MA W standards, including provisions for centers that serve food, signed into law by 2012.

How Prevalent is Licensure and Certification Legislation in the US?

- 25 states currently require a license to open
- 10 states currently require certification only to operate
- 4 states currently require both to open and operate
- 13 states currently require a different requirement to open and operate (contracts with HHS, Community Care Programs, etc.)

How Substantial is the Impact of Caring for an Elderly Parent or Loved One on Business?

- American businesses lose an average of 2.8 million work days each year due to unplanned absences;
- Those absences cost employers nearly $74 billion;
- Work day interruptions due to care giving of adults cost employers around $3 billion;
- Absenteeism due to care giving costs employers nearly $5 million.

U.S. Bureau of Labor Statistics

National News

Potential funding source for agencies that are licensed for limited payment. Legislation seeks to require that centers must hold either a license or formal certification from a yet-to-be-named national agency.

HR 3043 - Medicare Adult Day Services Act of 2011 (formally 2009)

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Industry Support

"There is an ever growing need for Adult Day Services in the healthcare continuum. As the baby-boomers age, it is imperative that there are options to keep them at home as long as possible. There needs to be a variety of options to help keep our elderly in the community where they are familiar and comfortable. Of course, I also believe in the need for nursing home care, however, CMS is even supportive of this initiative as they have changed nursing home reimbursement to disincentivise having individuals under our care that could potentially remain at home with alternative community-based care. Even as a nursing home administrator who is passionate about our business, I believe this is the right thing to do. Adult Day Services are actively sought out by caregivers and provides that alternative to nursing home placement to keep individuals at home until they truly require that placement. And when they do need nursing home placement, we are here to continue to provide a safe and comfortable environment with quality healthcare."

Carrie A. C. Dixon, HFA, MHA
Executive Director
Golden Living Center Brookview

"Many IAHSA members operate adult day service programs and adult day services is expected to play an increasingly important role in meeting the long term care needs of Hoosier seniors in the future. This service is particularly important for families caring for loved ones in their homes. Currently, there is no state oversight or standards for these important services. We support having the Health Finance Commission to study the appropriate role of state government in overseeing this growing long term care option."

Jim Leich
President & CEO
Indiana Association of Homes and Services for the Aging

"There is nothing more important in life than caring for our loved ones, particularly those who are most vulnerable – children, those with mental health issues, and the elderly. The role of licensure legislation is to ensure proper care and to assure the caregivers that their loved one is safe while away from their personal attention. Our government requires licensure for children's day care facilities and for facilities that care for those with mental illness. Why would we not think it appropriate to do the same for those who provide care through adult day care?"

Jessica White
President
Jessica White Associates

IAADS

is the leading voice of the adult day services industry in Indiana, and is the state focal point for adult day services providers.

Organized in 1981, IAADS is committed to providing its members with effective advocacy, educational and networking opportunities, technical assistance, research and communication services.

IAADS Core Purpose.

- Disseminate information concerning the provision of adult day services
- Foster cooperation with colleagues in same and allied fields
- Engage in activities which may be considered advantageous to those serviced by the Association
- Develop & facilitate maintenance of minimum standards for adult day services
- Conduct an ongoing educational campaign to inform consumers, service providers and policymakers of the existence of adult day services as a viable option to institutional care

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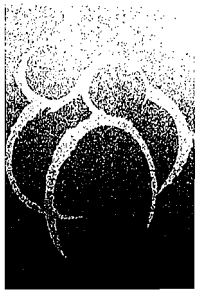
Standing together to make the right choice.



Indiana Association of Adult Day Services

What are Adult Day Services?

Adult Day Services programs offer a safe, positive, caring alternative to nursing home care for those who do not need 24-hour skilled nursing. These programs are designed to help people stay mentally and physically active, reduce isolation, improve their health and slow the decline of their abilities. People usually attend a program two to five times a week. Program hours of operation vary from four to eight or more hours a day.

Services provided.

Services vary from program to program but may include therapeutic activities such as art, singing, age-appropriate games, health monitoring, social work, meals, dietary counseling, physical, occupational and speech therapy. Programs help families with information and referral to other services as needed. All programs either provide or can assist with transportation arrangements.

Some programs focus on a specific population - for example, those who share a similar cultural or ethnic background or young adults living with head injuries.

Many programs specializing in Alzheimer's care offer extended hours to accommodate working caregivers, and provide caregiver support groups and training.

- Safe, comfortable and homelike environment
- Group activities and peer interaction
- Community trips and outings
- Therapeutic programs and fun recreational activities
- Well-trained and caring staff
- Nutritious snacks and lunch
- Support for caregivers
- Health monitoring with communication between caregiver and physician
- Costs less than Assisted Living, Homecare and Skilled Nursing care
- Multiple services under one roof for one fee

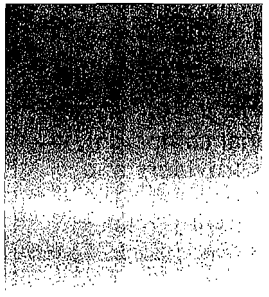
Who pays?

Third party payors may include Medicaid Waiver, CHOICE, long-term care insurance policies and Veteran's Administration. Fees vary according to the type of program and services offered. Some programs offer financial support or reduced rates, based on ability to pay.

Those who benefit

from Adult Day Services are:

- People whose activities are limited by injury, disease or frailities of age
- Those with memory problems, confusion or other dementias
- Patients with Alzheimer's disease or Parkinson's disease
- Individuals with development disabilities
- People recovering from strokes, heart attacks or accidents
- Adults who are homebound and need social stimulation of a group setting
- Those suffering from depression or other psychiatric problems
- Those in need of medical monitoring
- Adults who are simply not safe if left at home alone

To find a program near you, contact info@IAADS.net or visit:

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