Members

Sen. Connie Lawson, Chairperson
Sen. Jean Breaux
Rep. Wes Culver
Rep. Sheila Klinker
Sally Lowery
Suda Hopkins
Betty Williams
Christopher Durcholz
Susan Ferverda Hoback
Bettye Dunham
Scott Sefton
Sharon Kooi

COMMISSION ON DEVELOPMENTAL DISABILITIES

Legislative Services Agency
200 West Washington Street, Suite 301
Indianapolis, Indiana 46204-2789
Tel: (317) 233-0696 Fax: (317) 232-2554

LSA Staff:

Bill Brumbach, Fiscal Analyst for the Commission
Susan Kennell, Attorney for the Commission

Authority: IC 2-5-27.2

MEETING MINUTES[1]

Meeting Date: October 5, 2011
Meeting Time: 1:00 PM P.M.
Meeting Place: State House, 200 W. Washington St., 431
Meeting City: Indianapolis, Indiana
Meeting Number: 3

Members Present: Sen. Connie Lawson, Chairperson; Sen. Jean Breaux; Rep. Wes Culver; Rep. Sheila Klinker; Betty Williams; Christopher Durcholz; Bettye Dunham.

Members Absent: Sally Lowery; Suda Hopkins; Susan Ferverda Hoback; Scott Sefton; Sharon Kooi.

I. Call to Order

Senator Connie Lawson, Chairperson, called the meeting to order at 1:10 PM.

II. Presentation on Music Therapy from Ms. Casey DePriest

Ms. Casey DePriest gave materials to Commission members regarding how music therapy was used in the rehabilitation of U.S. Congresswoman Gabrielle Giffords (Exhibit 1). Ms. DePriest presented the Commission with several documents pertaining to music therapy. Amongst these documents was a letter from Representative Suzanne Crouch detailing her support for music therapy (Exhibit 2), information detailing the benefits of music therapy as a waiver service (Exhibit 3), testimonials from individuals who have benefitted from music therapy (Exhibit 4), as well as a list of states that utilize music therapy in early intervention services for the developmentally disabled (Exhibit 5).

Ms. DePriest also gave the Commission a presentation on the benefits of music therapy (Exhibit 6). She informed the Commission music therapy has been a recognized profession

[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.

since 1950 and music therapists receive board certification (MT-BC). Her presentation outlined that many Indiana constituents cannot access music therapy because the therapy is not specifically listed as a recognized service in many of Indiana's agency regulations and that music therapy credentials are not registered in the state of Indiana. Ms. DePriest recommended increasing awareness and recognition for music therapy by creating a state registry for music therapists and introducing new language in state agency regulations that would list music therapy as an eligible and/or reimbursable service.

During Ms. DePriest's presentation, there were video testimonies from Jennifer Akers and Dr. Klemsz, MD (Medical Director for the Infant Intensive Care Unit at Riley Hospital for Children) and in-person testimonies from Gina Schenk, Mary Driskel, and Cara Kowal regarding how music therapy has helped their children.

Representative Wes Culver asked for clarification regarding the proposal for a board-certified music therapist registry and how this would increase access to music therapy for state residents. Ms. DePriest informed the Commission that music therapy is not an eligible service under the First Steps program, but is under the Medicaid waiver program. Other services covered by the First Steps program are recognized because service providers must obtain professional licensing. By creating a registry for board-certified music therapists and including music therapy as one of the specifically listed reimbursable services in the First Steps program, more state residents can access this therapy.

Representative Sheila Klinker asked Ms. DePriest about the average cost for music therapy services and if parents are currently receiving these services. Ms. DePriest informed the Commission that parents receive the service if they are on the Medicaid waiver and through some insurance providers. She also informed the Commission the average out-of-pocket cost for music therapy is $65 per hour. Ms. DePriest also told the Commission she would like the General Assembly to explore including music therapy as a qualified service in the First Steps program as the therapy has proven effective in infants and toddlers.

Senator Jean Breaux asked if there are currently individuals operating as music therapists in the state who lack board certification. Ms. DePriest responded that there are individuals who operate as music therapists but do not have board certification.

III. Presentation from Ms. Melody Cooper, Indiana Self Advocates

Ms. Melody Cooper provided the Commission with a report from the Town Meeting of the Self Advocates of Indiana Board of Directors (Exhibit 7). She also informed the Commission of some of the meetings the Self Advocates have had recently.

IV. Follow Up on Answers Provided by DDRS from Previous Meetings

Ms. Julia Holloway, Director, Division of Disability and Rehabilitative Services (DDRS), provided answers to the Commission from questions they had from the two previous meetings (Exhibit 8). Ms. Holloway clarified that although music therapy is not expressly mentioned as a reimbursable service in the First Steps program, the service is still available to participants.

Senator Breaux asked Ms. Holloway about a change in the number of emergency waiver slots in the Medicaid waiver program. She specifically wanted to know how the regrouping of emergency waiver slots will affect the total number of slots allocated for emergency waivers. Ms. Jade Luchauer, Director of the Bureau of Developmental Disability Services, informed the Commission that seven of the emergency categories were consolidated in order to allow more flexibility in granting emergency waivers. Previously, each category was allocated a certain number of waiver slots that were non-transferrable to other emergency placement categories.

The change is still pending federal Center for Medicare and Medicaid Services approval, but would allow DDRS to reallocate emergency waivers to certain categories that may have a greater need than others. Ms. Luchauer emphasized that as a result of the change, there will be no decrease in the number of emergency waiver slots available.

Ms. Holloway, Ms. Luchauer, Ms. Nancy Zemaitis (Director of Policy and Planning, Vocational Rehabilitation), Ms. Theresa Koleszar (Director of Program Support, Vocational Rehabilitation), and Ms. Teresa Grossi also made a presentation to the Commission regarding employment opportunities and initiatives for individuals with disabilities (Exhibits 9, 10, 11, 12, 13).

Representative Klinker voiced a concern from her constituents regarding a lack of jobs and services available for the developmentally disabled when they are no longer of school age. Representative Klinker asked DDRS if employers in the vocational rehabilitation program show a willingness to hire the developmentally disabled. Ms. Luchauer replied that successful work has been done to create cultural change of employers in the vocational rehabilitation and that employers have shown a willingness to hire the developmentally disabled. Further, Ms. Luchauer informed the Commission there have been strides made to bring some new large businesses into the vocational rehabilitation program which will provide new employment opportunities for program participants.

V. Presentation from Medicaid Waiver Task Force

Ms. Erika Steuterman, Chairperson for the Medicaid Waiver Task Force, and Mr. John Dickerson, Director of the ARC of Indiana, made a presentation to the Commission regarding the Task Force's findings (Exhibits 14 and 15). The Task Force made four recommendations they would like the General Assembly to act on in the coming legislative session. These recommendations include:

(1) Providing direction to FSSA to develop web capabilities so individuals can access personal information for waiver services.
(2) Directing FSSA to collect collateral information for the waitlist rather than screening individuals to be placed on the waitlist.
(3) Changing HIPAA clearance on waiver application forms to allow individuals to select if they would like to be contacted by advocacy groups regarding nongovernment supported services.
(4) Providing a solution to service rate cuts that threaten service providers.

Representative Culver asked how FSSA has responded to these recommendations. Mr. Dickerson responded that the agency has expressed interest in these recommendations during their discussions.

Chairperson Lawson asked what the Task Force proposes to reduce the number of people on the waiting list. Mr. Dickerson explained to the Commission that other states have annual reviews of their waiting list and remove individuals who have moved on or can no longer be contacted. He further explained that this would take manpower and resources away from services and, ultimately, this would be a policy decision made by FSSA or the General Assembly.

VI. Testimony from Lesa Paddock Regarding Her Experiences with the Waiver System

Ms. Lesa Paddock testified before the Commission about her experiences with the waiver system and how it has helped her child. She urged the Commission to consider allocating additional funding to this program because in her own experience the program is so beneficial.

VII. Other Business

The Commission members agreed to include a statement in the final report expressing support for music therapy, including the continued use and possible expansion of the use of music therapy.

The members further support the concept of a registry for music therapists pending a study by FSSA that the use of such a registry would be fiscally neutral for the state.

VIII. Adjournment

The Commission adjourned at 4:30 PM.

Exhibit 1
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Gabrielle Giffords Undergoes Music Therapy, Continues to Progress

Mark Whittington – Tue Feb 15, 8:15 pm ET

Rep. Gabrielle Giffords continues to progress in her rehab, now having regained the ability to talk, to a certain extent. She is also able to mouth or lip sync the words to rudimentary songs, such as "Twinkle, Twinkle Little Star."

Music therapy has a long tradition, stretching back to the ancient Greeks, as a means to alleviate pain, treat mental illness, and promote well being in patients with a variety of ills. Giffords is apparently undergoing a form of music therapy that causes her to practice singing skills to promote her rehabilitation. In conjunction with her speech, physical, and occupational therapy, it is hoped that Giffords' singing practice will help her to regain cognitive function. The singing helps Giffords to put several words together, something that she at the moment has trouble doing.

Other songs Giffords is said to have lip synced include "Happy Birthday to You", for her husband astronaut Mark Kelly and "I Can't Give You Anything But Love" with friends and family accompanying with keyboard and chorus.

Doctors caution that Giffords still has some "significant deficits" that will take considerable time to overcome. Rehab from such a traumatic injury as a bullet wound to the brain often takes months or even years.

Giffords can walk, pushing a cart, and is also doing exercises to regain muscle tone and function. Her cognitive abilities appear to be substantial. She has demonstrated the ability to answer questions even before the questions are finished. She is able to recognize pictures of historical figures, such as Presidents Obama, Bush, and Washington. Doctors have noted that she has shown such enthusiasm for these exercises that she has been asked to slow down.

Giffords has started to get briefings from members of her staff on subjects ranging from the fall of Hosni Mubarak in Egypt to the retirement of Jon Kyl, Senator from her home state of Arizona. Some fellow members of Congress have paid visits. It is expected that former President George H. W. Bush may stop by eventually. The visits are being rationed to keep from overtiring Giffords.

In the meantime, Gabrielle Giffords is due to undergo another surgical procedure to replace a portion of her skull that was removed to alleviate brain swelling, now that the swelling has subsided.

Gifford's husband, Mark Kelly, is currently training to command the last flight of the space shuttle Endeavour, slated for launch on April 19.

STATE OF INDIANA
HOUSE OF REPRESENTATIVES
THIRD FLOOR STATE HOUSE
INDIANAPOLIS, INDIANA 46204

Suzanne Crouch
12345 Browning Rd.
Evansville, Indiana 47725
website: www.in.gov/h78

COMMITTEES:
Ways and Means, Vice Chair
Public Health
Government Reduction

Exhibit 2
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

May 19, 2011

Brian C. Bosma
Speaker of the House of Representatives
200 W. Washington St.
Indianapolis, IN 46204

Dear Mr. Speaker,

I am writing you today to request that the practice of music therapy in the state of Indiana is assigned to an interim study committee. After the passage of a resolution to encourage the study of increased access to this treatment I am optimistic that we as a General Assembly will continue to make these services more available to those in need. I find it only fitting to point out that many of the physicians surrounding Congresswoman Gabrielle Giffords have attributed a vital part of her amazing recovery to the practice of music therapy.

Music therapy is a service that has been proven to support the needs of many of our Indiana residents such as those in supported living, nursing homes/assisted living, hospitals, schools, rehabilitation centers, hospices, group homes/24-hour sites, and pre-schools. This therapy can encourage rehabilitation or habilitation of skills such as communication, motor, emotional, social, and academics. It can also help those individuals who, because of their maladaptive behaviors, have difficulty accessing the community or employment.

As an allied health profession recognized by the National Institute of Health, music therapists must earn a bachelor's degree or higher in music therapy from one of over 70 American Music Therapy Association (AMTA) accredited colleges and universities, including 1,200 hours of clinical training. At the completion of academic and clinical training, students are eligible to take the national examination administered by the Certification Board for Music Therapists (CBMT), an independent, non-profit certifying agency fully accredited by the National Commission for Certifying Agencies. After successfully passing the exam, graduates are issued the MT-BC (Music Therapist-Board Certified) credential necessary for professional practice.

Indiana is home to three accredited undergraduate programs and two accredited master's level training programs for music therapists. Due to an increased demand for music therapy services across the state, Indiana has experienced a growth rate of 257% in counties served within the state in the past 10 years. In addition, there has been 205% increase in the number of Music Therapists servicing Indiana in the past 10 years. Currently, according to the Certification Board for Music Therapy, there are 117 nationally board-certified music therapists in Indiana employed in residential care facilities, schools, general medical hospitals, adult day centers, geriatric facilities, behavioral and mental health agencies, waiver provider agencies, and private practice.

Indiana's Medicaid waivers have increased the access to music therapy for individuals with developmental disabilities, by making it a choice for families who receive waiver support. The state has received consistent feedback that music therapy is a valuable service to waiver consumers and their families. As reported by one waiver parent recently, "I like the way the music therapist tailors the therapy to the individual. The therapist really makes my son want to work for her. The music really motivates him. He's hard to motivate for everyone else. Our son loves his music and his therapist. I wish everyone who worked with us was as interested in what was best for the consumer. This has been a terrific waiver service!"

Music Therapy can address goals in multiple domains during a single treatment session, therefore making this therapy cost-effective and relevant for individuals with varied needs. Traditionally, music therapists work in the areas of early intervention services, special education, community mental health and addictions, elder care, hospice, pediatrics, medical/surgery, and neonatology to name a few. In Indiana, however, some constituents are not able to access music therapy services when needed. Music Therapy is evidence-based, nationally recognized, and should be considered a viable option for the healthcare choices of all Hoosiers.

Sincerely,

Suzanne Crouch

Rep. Suzanne Crouch

Exhibit 3
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Music Therapy as a Waiver Service:
An effective and fiscally responsible choice

Music therapy is a service offered on the waiver to improve skills in communication, academics, motor, emotional, and social domains. Improvements in these areas often help our client's to reduce behaviors and improve skills that help them to function in community, school, or work settings. We often see these improvements in their lives translate to longer work hours or an increased ability to keep a job, less behaviors and thus better relationships, achievements in school often leading to diplomas, and more meaningful lives. Listed below are testimonials from those who have experienced these improvements in our consumer's lives.

"As a parent of an adult child with disabilities who has anxieties in the work place music therapy has made a huge difference for her! She has been able to take her Ipod to work and listen to her calm song that she created during music therapy, which helps her to get past any panic attacks that would normally impede her ability to stay on the job. We're very grateful for Lindsey, her music therapist, and their ability to work together to improve her coping skills on the job so she can stay employed."

Mindy Ketchum, mother

I have worked with clients that receive music therapy through Integrative Music Therapy, LLC. Significant progress has been noted in these clients' level of functioning, ability to communicate and use coping mechanisms when upset or in an uncomfortable social situation.

All of the aforementioned clients have difficulty with communication. This difficulty encompassed echolalia, expressive language disorders and/or inability to speak. The services provided by the music therapist has provided them a medium in which to communicate, find pleasure and learn self soothing techniques.

I consider this service to be integral in the success of these clients and the improvement that has been displayed. It has proven to be a positive and necessary adjunct to behavioral therapy, psychiatric services and individual therapy services. This service has provided a 1:1 setting in which the client can learn to utilize skills taught in other venues while being involved in a positive, relaxing experience.

In my experience, music therapy services have been an invaluable asset to the progress of the clients served.

David Decker, MSW, LCSW
Evansville, IN

"Our daughter is receiving Music Therapy once a week. At first, we had no idea what Music Therapy was, but we thought since our daughter showed an interest in music that we'd give it a try.

Well, please know that, Music Therapy has changed my daughter's life!!!! It has helped her become more compliant, behaviors have improved so much, her communication skills are growing by leaps and bounds, she is learning how to compose her own music and songs, it's helping her so much, best part? She looks forward to it and enjoys it. She is able to recall songs, i.e. her therapist made up a don't be bossy song, and one day I was giving my daughter a reminder how she was being bossy, 2 seconds later, I hear from the back seat of the car, the Don't be Bossy song :-)

To us, it's the best of both worlds, behavior therapy and music therapy. I recommend this to all families who are looking for help in all the above-mentioned areas. You won't be disappointed."

Michele and Tim Villa
Griffith, Indiana

"My name is Gina Schenk and I am the behavior specialist for a 58 year old gentleman named Oliver who receives music therapy services from OPG. I began working with Oliver in September of 2002 and have been Oliver's behavior specialist for almost 9 years. When I first began to work with Oliver, his speech was mostly unintelligible. There were many times he would call me very upset with an issue and I was unable to understand anything he was saying to me. In person, I had the benefit of his hand gestures and mouth movements to help me understand him, but this was also a challenge.

In that first year of services, I started the process of getting Oliver a speech and language evaluation. At the end of the process, it was found that Medicaid would not cover this evaluation or services due to Oliver's age and Medicaid being used for rehabilitative services only. At this point, I had been informed of the many benefits of music therapy, including speech enhancement. I began to campaign at Oliver's team meetings every 90 days to carve out some of his budget to add this service.

In November of 2003, the team had agreed to add music therapy to Oliver's services. Within 1 year of music therapy services, Oliver's speech on the telephone was approximately 50% intelligible and in person it was approximately 60% intelligible. This progress continued over the last 7 years and I am now able to understand Oliver 100% of the time in person and on the telephone.

In addition to the benefits Oliver has realized to his speech, Oliver has increased his social skills, fine motor skills and receptive communication skills. Oliver's meaningful schedule has in part been improved through adding this service and Oliver does not take nearly as many naps as he used to before adding this as one of the meaningful activities he engages in weekly."

Gina Wilson Schenk, MSW, LCSW
Director of Behavioral Supports
Opportunities for Positive Growth

"Music therapy is a very important therapy that my now four year old son receives on a weekly basis. My son was diagnosed with autism spectrum disorder, developmental delay, sensory processing dysfunction, and language delay. When we could not get his attention music always could. It was this reason why we decided to try music therapy for him at age three along with his other therapies. Since starting music therapy his language skills have increased and this has helped lower his negative behaviors since he can now communicate more what he needs. Music has given us some new strategies to deal with outbursts and regulate his pace. He is also starting to communicate his feelings more often. I feel music therapy has made a big contribution to the progress my son is making and would love for other children like him to get the chance to participate in this type therapy also. I wish this therapy would have been offered to him while he was in First Steps and while he is in developmental preschool. I feel he would have greatly benefited from earlier intervention and continued intervention in early education to his general education. I feel this therapy should be treated equally as other therapies such as occupational, speech and physical therapy and people should have easy access to it with some kind of insurance benefit for everyone."

Alyson Roblero, Waiver Consumer's Mother

"At first I thought the music therapy would be an absolute waste of time for my Abby. I quickly found out that I was wrong. After the first couple of sessions I noticed how Abby would be fully engaged and would ready herself when the music therapist arrived at our house. It was amazing to see the engagement, eye contact and attentiveness. Of course there were good sessions and not so good sessions, however, I did recognize how Abby benefitted from the music therapy. Lastly, I would often hear Abby sing her songs days after her session. This therapy has indeed enhanced my daughter's life in a special way."

Dave Dewitt
Director of Advancement
Damar Services, Inc.

I've always known that my child responds to music, but I wasn't sure how music therapy might benefit her. Since she has started music therapy with the support of the DD waiver, we have seen her more motivated to communicate-her biggest barrier to participating in the community. In making progress towards her goals, she is more motivated by music than any other reward. We have also seen a decrease in her self injurious behaviors when she is able to

access music and its sensory benefits, especially when her therapist uses the auto harp in sessions. We see that carry-over into her daily routines and activities. We are grateful for the support the waiver provides to add this meaningful activity to her day.

Jen, Waiver Consumer's Mother

I would like to submit a summary of the wonderful improvements Alex Garrison, a 16 yr. old male with classic autism, has achieved throughout his participation in Music Therapy.

MT (Music Therapy) was started in 2000. At that time, Alex would barely communicate verbally, would not socialize, except with immediate family...pretty much Alex lived in his own world. Over the years, MT has helped Alex to verbalize his needs, wants, emotions, likes, dislikes. MT has helped Alex's memory. He can recall better and relate the subject to us. MT has helped him to pace his thoughts, and allows for clearer communication. One of the greatest benefits of MT is that Alex has grown in self-confidence. The unique style of MT put Alex at ease from the start. The relaxing and inviting sound of music along with the knowledgeable therapist, would draw Alex into a therapy session without any hesitation. Through what he thought was play, he found his voice, his identity and the desire to connect with others. Alex still needs MT, because as he grows, MT helps him understand himself and access the world around him.

Phyllis Fischer
Boonville, IN

"Thanks for Music Therapy!
We have sensory input, verbal stimulation, physical movement, appropriate social interaction training, eye movement training, and behavior management included with our Kelly! We cannot have those other "therapy" resources due to lack of funding! Our student goes to the piano during the week to "play" one to three fingers, enjoying the music he makes! We do our homework with numerals & singing during the week & enforce the learning Kelly begins on Mondays. Thank you!

Thank you for your input into independence & appropriate social behaviors!"
Sincerely, Jan Robb

April 15: Hello, I knew I would forget to tell you this, so I am emailing you. Mr. Loomis, Wyatt's aid, reported that Wyatt is getting more flexible and has often quoted you, saying you are teaching him to be more flexible. I am always so very happy to let other professionals know the importance of music therapy. This was said during his yearly case conference so many people were told. Have a great session with him!

Blessings,
Christine Van Dyke

May 24: This is a quote from Wyatt during 7th grade, I think it is important to note he is in a regular class with a full time aide and music therapy facilitates these successes. This is not an overstatement! Wyatt is successful because of music therapy. We began with Miss Connie when he was having a really rough time in second grade. He was sent home from school often and I really thought he would not make it in the regular world. Miss Connie helped him be able to start and finish work. He was able to figure out work was a series of steps These steps included a hello song, next several activities, then another activity that was perceived to be the prize for good work, and lastly a good bye song. Wyatt learned from Miss Connie the progression of work.

These days, Wyatt works with Miss Lindsey on social skills to be successful. Flexibility is a wonderful tool he is starting to understand and use. Music therapy for Wyatt is always changing for his needs. It allows a different way to learn. His success in the future is directly tied to the energy and efforts we put into him now. I want Wyatt to be a happy, functioning member of society. A member that will be able to contribute to our world!

Christine VanDyke, SSW consumer's mother

"MUTH has really helped James to be more aware that his actions have a real impact on people's feelings. He enjoys his time with you, so he has to be aware that it doesn't come without conditions. He knows that he can be asked to leave if his behavior becomes intolerable. It has been nice for him to learn that lesson in an environment that does not have any academic pressures."

Laurie Callahan, waiver consumer's mother

Music Therapists have data from sessions and parent testimonials that show how we improve our consumer's lives. However this is not our only evidence of effective therapy, we have a large bank of research that displays the usefulness of this service. Here are just a few of the recent publications.

Annotated Bibliography

Abad, V. & Williams, K. E. (2007). Early intervention music therapy: Reporting on a 3-year project to address needs with at-risk families. *Music Therapy Perspectives,* 25(1), 52-58.

This article describes an early intervention music therapy project called Sing & Grow. The program focused on building on parent's abilities to respond to their child's developmental and emotional needs. After completing the program, eighty-seven percent of parents reported using music for behavior management at home.

De Mers, C. L., Tincani, M., Van Norman, R. K., & Higgins, K. (2009). Effects of music therapy on young children's challenging behaviors: A case study. *Music Therapy Perspectives,* 27(2), 88-96.

This case study incorporated social stories and music therapy with three young children in the special education setting. Analysis revealed that music therapy decreased problem behaviors and increased alternative behaviors. Music therapy proved more successful to the children with the most challenging behaviors.

Lim, H. A. (2010). Use of music in the applied behavior analysis verbal behavior approach for children with autism spectrum disorders. *Music Therapy Perspectives,* 28(2), 95-105.

This article presents various strategies in treating children with autism spectrum disorders. It provides the theoretical and clinical implications for the use of music in Applied Behavior Analysis Verbal Behavior (ABA VB) training. These clinical implications include music therapy interventions to increase verbal and nonverbal communication.

Hooper, J., Wigram, T., Carson, D., & Lindsay, B. (2008). A review of the music and intellectual disability literature (1943-2006) part two: Experimental

writing. *Music Therapy Perspectives,* 26(2), 80-96.

This is a review of music therapy experiments working with those who have intellectual disabilities. The experimental writings display a range of interventions and therapeutic outcomes. They also show the array of functional skills that music therapy can foster. Overall, it establishes the efficacy of introducing those with intellectual disabilities to music therapy.

Mussett, S. A. & Wylie, M. E. (2009). Review. *Music Therapy Perspectives,* 27(1), 62-67.

This review lists publications relating to music therapy that are not found in the music therapy journals. It lists 158 periodicals from nursing, medicine, education, music, and psychology databases all from 2005. Included in the many categories are behavioral-emotional disorders and intellectual disabling conditions.

Exhibit 4
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Music Therapy Testimonials

Dear Music Therapy Staff,

I wished to make you aware of how much the music therapy my son (Dana Rexing) has been receiving means to me. My son looks so forward to the time he has with Eric Lund, his music therapist. I can always see a difference in Dana after one of these sessions. He is more calm and always in a happier mood. I too have learned from this therapy as I now use music as a means too diffuse a situation that has caused Dana to be extremely frustrated and hyperactive with his speech and mannerisms.

The Social Rhythms classes he participated in this summer with his peers has opened new friendships for him as well as myself. I thank you so much for these opportunities.

Dora Rexing-Beaton

3607 Kathleen Ave Evansville, In 47714

Dear Commission on Developmental Disabilities,

Our daughter Megan, who has Down Syndrome, has received Music Therapy for the last several years. It has been one of the highlights of her schedule each week. Not only has it been beneficial to her musical skill development it has particularly been a huge support for her speech skills. The interaction with music seems to make the process of speech development much more interesting and attainable to Megan. So much so that we often forget that she has Music Therapy on a given day and soon reminded when she returns home. She sings and talks so much more on those days we are convinced the therapy is vital to her well being now and in the future. Many people comment on Megan's spontaneous singing and talking when she is receiving this service regularly. We realize her cognition is at a level where retainment of skills are difficult without the on going reminders of regular therapies. We strongly hope that these services will continue to be made available to Megan and other people with developmental disabilities because of the overall impact it has on their attitude and joy of life.

Ric Heeter

Bloomington, IN

Janice M. Sutton

2465 Bannockburn Drive

Henderson, Kentucky 42420

To Whom It May Concern,

On Saturday, January 8, 2011, Arizona Congresswoman Gabrielle Gifford was shot outside of City Hall in Phoenix, Arizona. The bullet hit the Congresswoman in her head, causing severe damage to her left brain hemisphere. Months later, I watched a CNN 360 segment in which host Anderson Cooper described the therapy the Congresswoman had received. The doctors and nurses, whom Mr. Cooper interviewed, credited Music Therapy as being the therapy which had had the most significant impact on the rapid recovery the Congresswoman was making.

As I watched, I wondered if Music Therapy would help Heather, our 40 year old daughter. Heather, who has Down Syndrome, had developed neuro-muscular problems as a result of taking a medication to which she has a unique sensitivity. Her neuro-muscular problems left her unable to reach for items with her hands, or to coordinate hand movements. In other words, she could move her arms, but she could not get her hands to go to where she intended them to go.

After watching Anderson Cooper's interviews with the professionals caring for Congresswoman Gifford, reading every available article on Music Therapy, and consulting with Heather's occupational therapists, my husband and I decided to take Heather to Ms. DePriest's therapy program at Integrative Music Therapy in Evansville, IN.

We are very pleased with Heather's progress. After only two weeks of Music Therapy treatment, Heather was able to reach for an item and to place her hand around it on her first try. To some this accomplishment may sound trite, but to families of persons with neurological issues, it is a huge accomplishment and it is more. It is an indication that even more progress will be made as our loved ones continue to participate in Music Therapy.

I encourage Indiana law makers to consider and to support requests for increased access to and promotion of music Therapy as the very effective rehabilitative therapy that it is.

Thank you in advance for your consideration of this issue.

Sincerely,

Janice M. Sutton

(270)827-3946

Dear Commission on Developmental Disabilities,

My name is Harriet. I want to tell you about the music therapy. I have music therapy. It's interesting and fun! In music therapy, we sing and play musical instruments. And we write some songs and we make our own CDs. It's good to have music therapy. It's better than not having it. If I didn't have it, I won't learn anything.

Everybody should have music therapy who wants to have it. You won't know anything unless you learn. Music therapy can help people to learn. The people making the rules should see how much it's gonna be to give people music therapy. Then see if they learn anything in music therapy. If they're learning, then they should keep getting it.

Sincerely,

Harriet

Bloomington, IN

10/3/2011

Dear Commission on Developmental Disabilities:

I would like to take this opportunity to introduce myself and explain the benefits of Music Therapy for children with disabilities. I am the parent of Aiden, a 6 year old with various developmental delays and Autism. Aiden does not yet speak with words, but began his form of communication through choosing pictures in Music Therapy. Aiden, like many other children, is a puzzle that we are slowly putting the pieces together to figure out. One of our greatest challenges has been to find things that motivate Aiden. We were very fortunate to find a flyer a few years ago for a Music Therapy Open House hosted by Fogerty Music Therapy.

We knew that Aiden responded positively to music, but I could never have predicted the joy we would see in his face as Miss Jonni plays her guitar and sings songs teaching him to use his voice and other appropriate social skills. Without Music Therapy, Aiden's communication would still be that of an infant. Now he has a vocabulary of many pictures that we use at school and home to allow him to communicate his needs. He is also learning to mimic through song, which may lead him to using speech someday. This, also, is a skill that we could have never achieved in any other way than Music Therapy.

I am sure that you hear from many parents telling you about their child's experience. I would also like to broaden my support by telling you of a collaboration between Bloomington Parks and Recreation and Fogerty Music Therapy. We have offered two successful endeavors, one for preschool aged participants and the other for adults. Again, the evidence is clear that music is critical as a therapy component for many people with disabilities. Not only do the participants enjoy the weekly class, they learn valuable skills and have the opportunity to socialize with peers.

Words cannot describe the moment when something clicks for your child and they understand how to do something. Many of these clicks for my son, Aiden, have occurred in Music Therapy and very well may not have in any other way. Thank you for taking the time to hear the stories of those benefited by Music Therapy. I hope you will always consider how important every member of our community is, especially those vulnerable populations who may have difficulty standing up for themselves.

Sincerely,

Amy Shrake, CTRS
Inclusive Recreation Coordinator
City of Bloomington Parks and Recreation
PO Box 848
Bloomington, IN 47402
Phone (812) 349-3747
Fax (812) 349-3785

Exhibit 5
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

State	Advocacy or Recognition for MT in EI? Yes	No	Comments
Alabama	X		Advocacy to include music therapy in early intervention as a related service
Alaska	X		Department of Education and Early Development Recognize the use of music and music-related activities to help the student maintain mental functioning, to facilitate social and emotional growth, to promote communication, to develop constructive use of leisure time and to improve or maintain motor and perceptual skills.
Arizona	X		Regulatory language passed and signed into law for use in the DDD code that specifies the term "Music Therapy" instead of "Habilitation with Music" in order to protect the public and maintain service provision. Effective Fall 2010.
Arkansas		X	
California	X		Advocacy to include music therapy in early intervention as a related service
Colorado		X	
Connecticut		X	
Delaware	X		Several state publications supporting the use of music therapy in early intervention
Florida	X		Advocacy to include music therapy in early intervention as a related service, inclusion of music therapists as qualified providers under the Early Steps program with some additional requirements
Georgia	X		House resolution passed recognizing music therapy as a valuable service, additional advocacy with Babies Can't Wait program for recognition as service providers
Hawaii	X		Inclusion of music therapy in available service supported by state
Idaho		X	
Illinois	X		Can provide services under the "Qualified Support Professional" designation with some additional requirements
Indiana		X	
Iowa		X	
Kansas	X		Inclusion of music therapy in Special Education regulations
Kentucky			
Louisiana	X		Included in list of additional "School Therapies" available, well defined
Maine		X	
Maryland		X	
Massachusetts	X		Music therapy recognized as a "Specialized Service" and services must be provided by an MT-BC to groups or individuals
Michigan	X		MT-BC required to practice within the Special Education Personnel Approval System
Minnesota		X	

Mississippi		X	
Missouri	X		Recognized with additional approval process, seeking adoption of language that would allow MT-BCs to qualify more easily
Montana		X	
Nebraska	X		Services approved on a case by case basis
Nevada	X		Licensure bill passed in 2011
New Hampshire		X	
New Jersey		X	
New Mexico	X		MT-BCs qualify to apply as a Developmental Specialist
New York		X	
North Carolina		X	
North Dakota	X		Licensure bill passed in 2011
Ohio	X		Music Therapists eligible to become an Early Intervention Service Provider, separate billing code in "Help Me Grow" (0-3 program)
Oklahoma		X	
Oregon		X	
Pennsylvania	X		Language does not specifically name MT but if developmental in nature, allowing the possibility of MT being a qualified provider.
Rhode Island		X	
South Carolina		X	
South Dakota	X		Music Therapy recognized as Special Instruction service
Tennessee		X	
Texas		X	
Utah		X	
Vermont		X	
Virginia	X		MT-BCs recognized as providers of early intervention services
Washington		X	
West Virginia		X	
Wisconsin	X		Music Therapy Registry established in 1998
Wyoming		X	

IMPORTANT NOTE-though some states are listed as "No" in terms of advocacy and recognition, they are still bound to comply with the Federal IDEA, Part C regulations, revised and effective 10/28/2011 which recognizes music therapy as an early intervention service. This table simply indicates that these states have not taken a pro-active stance to provide music therapy services for children under the age of 3.

Exhibit 6
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Music Therapy in Indiana

Presented by
Casey DePriest, MT-BC,
and
Members of the
Indiana Association for Music Therapy

Commission on Develop

What is Music Therapy?

Music Therapy

- The **prescribed use of music** and music interventions for the purpose of restoring, maintaining and improving emotional, physical, cognitive, physiological, spiritual health and well-being.
- Administered by a **board-certified music therapist** to persons of all ages who require special services because of behavioral, social, learning, or physical disabilities or medical conditions.
- **Conducted in** hospitals, health clinics, day care facilities, schools, mental health centers, substance abuse facilities, nursing homes, hospices, rehabilitation centers, correctional facilities, music therapy practices and private homes.
- **Addresses non-musical goals.** Therefore, no musical abili needed in order for the client to benefit from Music treatment.

The Music Therapist

- Music therapy is a clinical specialty. Music therapists have **formal training** not only in music but in child development, psychology, sciences, and in the assessment of physical and psychological conditions.
- An accredited training program in Music Therapy includes **extensive course work, field work, and a clinical internship.** After graduation, the candidate must pass an exam to become **nationally certified** by the Certification Board f Music Therapists. The credential "MT-B "Music Therapist, Board Certified"

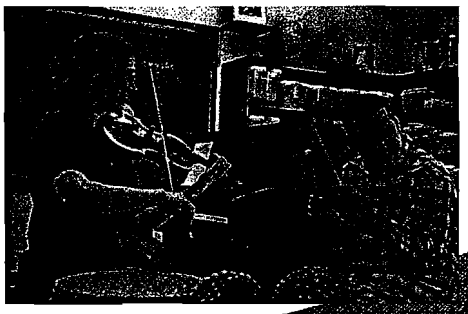
What Do Music Therapists Do?

- Assess the client's therapeutic needs through response to music interventions
- Design interventions for individuals and groups based on client needs
- Treat individuals using music and research supported music strategies
- Document progress
- Participate in interdisciplinary treatment planning
- Evaluate and reassess
- Follow-up

History

- Music Therapy has been a recognized profession since 1950.
- Indiana is home to 3 Undergraduate Music Therapy programs, 2 Graduate programs, and 1 Equivalency program.
- Since 2002, Music Therapy has been a reimbursable service under three (3) Indiana Medicaid Waivers (DD Waiver, Support Servi Waiver, and Autism Waiver)

Waiver Testimonials



Jennifer Akers, Mom to Grace

Gina Schenk,

MSW, LCSW

Director of Behavioral Supports

Opportunities for Positive Growth

History (continued)

- There has been an increased demand for music therapy services in Indiana in the past 10 years.
- From 2000 to 2010, Indiana experienced a 257% growth rate in the number of counties served by music therapists.
- Since 2000, the number of Music Therapists in the state has increased by 224%.

Advocacy at Work

- Indiana created a Task Force to promote advocacy for music therapy in Indiana
- October 2010, Representative Suzanne Crouch presented Concurrent Resolution 1353 urging this Commission to study Music Therapy during the next interim. It passed by a unanimous vote.
- During the 2011 Legislative Session, a similar resolution passed through the house and was later assigned to this study committee.
- March 2011 – AIMT held it's 1st Annual Music Therapy Hill Day at the Indiana State House

Problem:

- Many Indiana constituents cannot access music therapy services when they need them
  - Music Therapy is not specifically listed as a recognized service in many of Indiana's agency regulations
  - Music Therapists, and their music therapy credential (MT-BC), are not listed/registered by the state of Indiana

Proposed Solution:

1. Increase awareness and recognition for Music Therapy and the MT-BC credential by creating a state registry for Music Therapists

Rationale:

- A registry would be the most cost-effective way for the state to recognize the qualified, credentialed music therapy clinicians working within the state of Indiana
- The Certification Board for Music Therapists, (CBMT) has agreed to assist with verification of applicants' training, national certification, and credentials. This would streamline the process and minimize state costs.
- Registration fees received would cover the cost of the minimal administrative tasks needed for processing the applications.

Proposed Solution:

2. Introduce new language that would specifically list music therapy as an eligible and/or reimbursable service in state agency regulations

(i.e.: Article 7: Specifically list MT as a "related service" to more closely match Federal Department of Education guidance)

Rationale:

- Music Therapy provides a cost-effective option as it addresses goals across multiple domains in a single session
- Listing music therapy in agency regulatory documents would increase awareness of music therapy as a viable treatment option
- Listing music therapy will offer constituents more choices for their healthcare

Research Supports Music Therapy

- Research supports the use of music therapy across a broad spectrum of ages and disabilities.
- Research documents categorized by different disabilities and treatment areas provide evidence of music therapy's effectiveness and offer a glimpse at the impact music therapy services could have on our state's residents.

Music therapy is a reimbursable service

- Indiana Medicaid waivers
- Select Medicare programs
- Case-by-case basis with private insurance companies
- Related Services for Special Education IEPs

Music therapy is a reimbursable service

- Music therapy is a covered service in more than 30 states under a variety of state agency programs, such as special education, developmental disabilities, mental health, substance abuse, and social services

You may ask...

What can music therapy do for individuals in my district?

Advocacy in Action

Testimonials

Dr. Klemsz, MD

Medical Director for the Infant ICU
Riley Hospital

Cara Kowal, Mom to

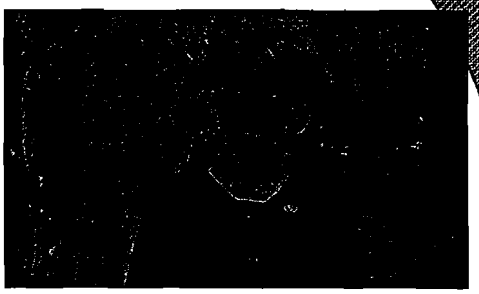
Dagney

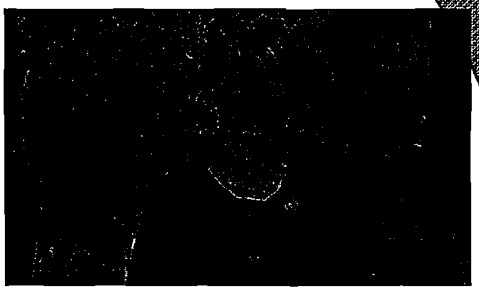
Ann Hannan, MT-BC

Music Therapist-Board Certified
Riley Hospital for Children at IU Health

Mary Driskel, Mom to

Ava



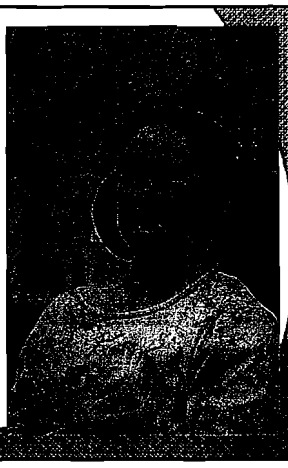


US Congresswoman
Gabrielle Giffords

Janice Sutton, Mom to

Heather

Music Therapy
Makes a
Difference!



Who benefits from Music Therapy?

People with the following health issues have benefited from music therapy services:

AIDS
Autism Spectrum Disorder
Emotional Trauma
Learning Disabilities
Oncology
Pain Control
Physical Disabilities
Traumatic Brain Injuries
Intellectual and Developmental Disabilities
Speech and Language Impairments
Alzheimer's/Dementia
Eating Disorders
Hearing Impairments
Mental Illness
Neonatology
Palliative/Hospice Care
Visual Impairments
Substance Abuse

Association for Indiana Music Therapy

- Professional association for music therapists in Indiana
- Provides professional development/continuing education opportunities for MT-BCs in Indiana
- There are currently 134 Music Therapists living/working in Indiana

What is the State Operational Plan?

- In effect since 2005, the State Operational Plan is a cooperative effort between the American Music Therapy Association (AMTA) and the Certification Board for Music Therapists (CBMT) to help states work towards professional recognition.

AMTA/CBMT State Recognition Operational Plan

Background

Clear strategic relationship between access to services, credential recognition, reimbursement, research, and evidence-based practice

Rationale

Industry preference for state occupational regulation

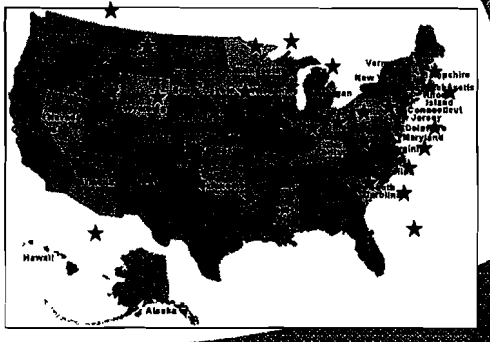
Major Goal - Universal

- Achieve state recognition for the music therapy profession and the MT-BC credential required for competent practice.

Outcome

- Appropriate state agencies will include music therapy and the MT-BC credential within their listing of recognized professions

State Activity



Where does Indiana fit into the Advocacy Picture?

State Regulation Activity

- 1998: Registry established in Wisconsin
- 2010: Music therapy definition language for Developmental Disabilities services signed into law in Arizona
- 2011: Licensure passed in North Dakota and Nevada
- 2012: Licensure or Registry Legislation filed or planned in Colorado, Georgia, Hawaii, North Carolina, Oklahoma, South Carolina and Washington

State Task Force Role

- Working with our national association, the American Music Therapy Association (AMTA) and The Certification Board for Music Therapists (CBMT), Indiana has a state task force that is implementing a state recognition operational plan to increase awareness and insure access to music therapy services.

Summary

Problem:

Many Indiana constituents cannot access music therapy services when they need them

Proposed Solutions:

1. Increase awareness and recognition for Music Therapy by creating a state registry for Music Therapists
2. Introduce new language that would specifically list music therapy as an eligible and/or reimbursable service in state agency regulations.

Q & A

Thank You!

- We would like to thank the Commission on Developmental Disabilities for being committed to meeting the needs of the many individuals and families in Indiana who are affected by developmental disabilities.
- We ask for your support in increasing access to music therapy services across the state of Indiana.

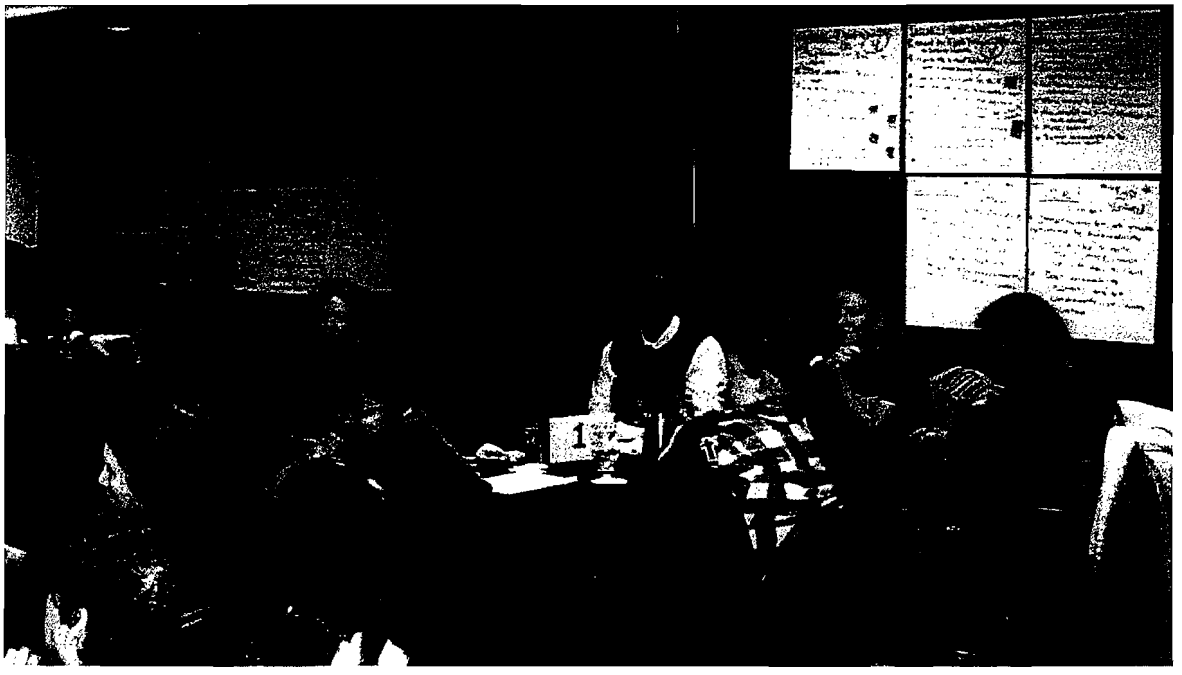
Web Resources

- www.musictherapy.org
  - http://www.musictherapy.org/research/factsheets/
- www.cbmt.org
- www.indianamusictherapists.com
- http://www.facebook.com/home.php#!/pages/Association-for-Indiana-Music-Therapy/108083445879089

Indiana Governor's Council for People with Disabilities

Exhibit 7
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Town Meeting Report



Self Advocates of Indiana Board of Directors

December 13, 2010
1:00 - 3:00 pm
Crowne Plaza Hotel

Commissioned by the Indiana Governor's Council for People with Disabilities
Prepared by the Indiana Institute on Disability and Community — Indiana University
Center for Planning and Policy Studies
2853 East Tenth Street ◆ Bloomington IN ◆ 47408
Indiana's University Center for Excellence on Developmental Disabilities

Table of Contents

Self AdvocatesTown Meeting 1
Overview of the Town Meetings and Focus Groups 1
Participants 1
Town Meeting Design 1
Table Talk Topics 2
What Self Advocates Like to Do in Their Community 2
Visions for Becoming More Active in Their Community 3
Ideas about Reaching the Visions 5
Preferences 6
Acknowledgements 8

Self AdvocatesTown Meeting

Overview of the Town Meetings and Focus Groups

The Indiana Governor's Council for People with Disabilities commissioned the Indiana Institute on Disability and Community to assist them in facilitating eight Town Meetings across the State to gather ideas from individuals with disabilities and family members about priorities that should be addressed in the forthcoming State Disability Plan for 2012 - 2016. In addition, the Council requested time at a meeting of the Board of Directors of the Self-Advocates of Indiana to gather additional input from people with disabilities. This last and ninth Town Meeting was held on Monday afternoon, December 13th at the Crowne Plaza Hotel in Indianapolis.

Participants

There were 16 participants in attendance at the Self Advocates of Indiana Board of Directors meeting.

The Self Advocates participants were from the following cities and towns: Bloomington, Brownsburg, Columbus, Ft. Wayne, Goshen, Indianapolis, Middlebury, New Albany, Richmond, Terre Haute, and Warsaw.

Town Meeting Design

Each Town Meeting was designed to allow ample opportunity for participants to share ideas about issues of concern, especially focusing on potential solutions and strategies for moving the State forward. "Table Talks," a structured process, were conducted to gather ideas about changes that would work best for individuals, family members, and their communities.

Two topic areas were of special interest at the Self Advocates Town Meeting: *Leadership Development* and *Community Participation*. The topics were combined and defined into one general topic for the participants to respond to at their Table Talks – "Becoming Involved in Your Community." There were four tables, each with three to five participants.

During the session, participants worked through a "VIP" process – identifying their VISIONS for becoming more active in Indiana communities, brainstorming IDEAS for possible ways to reach their visions, and expressing their PREFERENCES for the suggested ideas. Institute staff served as small group facilitators and some of the Self-Advocates' staff served as recorders and scribes. The following pages reflect the results of the four Table Talks.

Table Talk Topics

What Self Advocates Like to Do in Their Community

- Attend church
- Going to work
- Bowling
- Ballroom dancing
- Going to Ivy Tech, take classes
- Shopping for clothes and groceries
- Going to the movies
- Communicating with friends through Facebook
- Doing volunteer work --- clerical work and data entry
- Vote
- Doing fun things, like playing board games
- Living on my own
- Getting others involved in advocate groups
- Attending AKtion Club
- Taking classes, learning new things
- Traveling on a Mo-ped to do things
- Speaking to others about disabilities in community/leaders/congressmen
- Participating in my church worship team, two times per week
- Selling crafts that I make at the flea market
- Attending mayors council meetings in Richmond & Indianapolis
- Singing karaoke
- Going to the library
- Crafts, particularly drawing with colored pencils
- Attending local self-advocate groups
- Mall walking
- Playing basketball
- Going out to eat
- Going roller skating
- Visiting family
- Going to conferences
- Going to fitness gym and workout
- Voting, and checking polling places for accessibility (part of the Council's Count Us IN Project)
- Participating in Disability Awareness Activities – went to the Courthouse to raise awareness about disability issues
- Conducting co-training (I used to do it but they don't do it anymore)
- Attending the Building Leadership Series workshops in Bloomington

- Participating on the Membership, Funding, and Marketing committees for Self Advocates of Indiana
- Being a member of the Board of Directors – Vigo County Mental Health Center (Hamilton Center)
- Attending the Indiana Institute's Advisory Council in Bloomington

Visions for Becoming More Active in Their Community

- There are a lot of activities I would like to participate in, but I can't because I am restricted by the city bus system.
- Having more opportunities to work at a job I want.
- I would like to travel on an airplane but I am afraid.
- An opportunity for job growth - not being limited by the accessibility of the building.
- I want to learn how to drive a car.
- I would like to go to church more often but can't due to staff limitations, shortage of hours.
- Door accessibility buttons are not convenient or consistent if any at all, making it hard to get into buildings.
- I would like to go to college but have a learning disability.
- I would like to read more but it is hard, due to small print and understanding the words.
- Go to Colts game but can't, tickets cost too much.
- Go to more concerts but accessibility is poor.
- I would like to have more friends, but I have little opportunity for meeting new people and transportation isn't always available.
- The school of my choice is not accessible.
- I would like to go out of town and/or the state independently to visit friends.
- I would like to go and do more things, like going to the mall and movies but can't due to staffing hours.
- I want to move out of my parent's house, but I can't because of accessibility issues, staffing, and the cost.
- I want the Daytime Savings Time Policy reviewed - don't change the clocks!
- Being more independent.
- I don't want Toll Roads.
- Learning to drive.
- Go out of state for shopping and amusement parks.
- Tight budgets.
- Families don't let you do things in the community, like going to the senior prom, football games, Homecoming dance.
- I would like a job in the community.
- I want to have the choice to work more hours.
- I keep hitting brick walls in getting a job.
- No transportation or the cost of transportation is too much.

- I want to move out by myself - learning how to cook, handle a budget, and live on my own.
- I want to start a business but I don't have SSI & SSDI funding – we need more information before a person gets off of certain programs.
- I want to be an advocate for others. In have staff, but I just need to 'do it.'
- I want to live in my own house. I want to move from my apartment to a house. But I have to wait for my annual meeting to talk about it.
- Drive. I need more practice.
- I want to own a craft shop. Funding and losing benefits are issues, if I have my own business.
- I am needing information on how to start a business.
- I want to get married.
- I want to take a vacation. I can't leave the state --- no staff or funding.
- I want to fly to another destination. Especially the next SABE conference.
- I want to sell or make into cards or postcards pictures that have I have already drawn with colored pencils. Maybe publish my drawings.
- I want to jump from a plane, parachute jumping, but I have a fear of heights.
- I want to be a Kennedy fellow. I need more information on how to apply and if people with disabilities can apply.
- I want to teach people about disability awareness, inform business people and schools about disabilities.
- I want to start more Aktion clubs, especially in Richmond. (Aktion clubs are Kiwanis sponsored group for people with developmental disabilities. There are 23 groups in Indiana so far.)
- I want an Internet connection for my computer. My brother says it's too expensive.
- I would like training on how to use the computer.
- I want to apply for a job independently. Staff stands in my way. I need training on how to complete a resume and job application.
- Volunteering at a pet shelter or nursing home.
- Career and volunteering help – finding out what I am good at.
- Advocacy, speaking out for myself. I need more training or classes on advocacy skills, how to be a better advocate.
- Educate doctors and medical staff about how to talk to people with disabilities about their health.
- More Building Leadership Series, to become better advocates.
- I want to be President.
- City and County Building needs to be accessible, up to code.
- ALL buildings should be accessible.
- I would like to be married in 5 years, my personal goal.
- I want to do more traveling, having more travel opportunities, but I need more time to travel and money.
- I want to be able to take more computer classes.
- Living by myself. I used to do it, but my parent doesn't want that.

- I want to have my own business, like a funeral home.
- People with disabilities should have more independence and be less dependent on staff. Staff don't think we can do it.
- I want to live on my own, but my family thinks I won't have the services that I need, like staff or transportation.
- People need to "listen" to me better.
- We need to protest more.
- People should speak up for their rights, and learn how to do that.
- More transportation options.
- I want to go out and speak on different topics, like how we like to go out without staff.
- I want more opportunities to go to school, more education opportunities.

Ideas about Reaching the Visions

1. Information on services available needs to be advertised better using many different ways, like telephone, hotlines, and websites.
2. Contact the Governor's Council for People with Disabilities to ask for help about changing accessibility in buildings.
3. Call the Bureau of Motor Vehicles and ask about available accommodations for a driver's license.
4. More funding for staff and other workers.
5. New personal van and increase money/mileage for staff to transport.
6. More staff hours are needed to do the things I want to do.
7. Better accessibility at doctor's and dentist's offices.
8. Get the ABLE bill passed/be able to have savings account for more money to use.
9. Teach families that their sons or daughters can be independent, and families won't lose control.
10. Try home schooling for kids who are sick a lot.
11. Self Advocates need to speak out more.
12. Get more jobs for people with disabilities.
13. Get volunteers to provide transportation.
14. More stops for buses, more door-to-door services.
15. Be able to use my transportation budget for more transportation, community activities, for entertainment or after hour activities.
16. More education, more classes to help us learn to be independent, budgets, cooking, financial, and learning to read.
17. Choosing my own staff, including family and friends.
18. Having cell phones for work, for emergencies, to call staff, to call for bus, etc.
19. More funding.
20. Staff need to be more flexible and give us choices.

21. Make it easier for people without disabilities to understand the needs of people with disabilities better.
22. Understand our benefits better and the consequences of dropping benefits in the future.
23. Learn how to speak up – examples are Building Leadership Series and peer mentoring. Take classes on "speaking up."
24. Get encouragement from friends, to build confidence.
25. Join a Self Advocate group.
26. Provide information to families on how people with disabilities can be more independent.
27. More education classes and choices are needed, examples include: Ivy Tech, online classes, and learning at home.
28. More GED classes available online and face to face, in the community.
29. More dating opportunities – it's different for different people, maybe go on double dates, staff can provide transportation and help make the date.
30. Have classes to talk about sexuality and personal relationships.
31. Develop trust with people so you can confide in them.
32. Make the world a safer place.
33. Go to meetings to push ADA in addressing accessibility issues in older buildings.
34. Learn "good skills" – independent living skills.
35. Develop personal accountability and responsibility for more independence.

Preferences

1. I want to learn how to drive a car.
2. Wanting to go to a Colts game but can't due to cost.
3. Would like to go out of town and/or the state independently to visit friends.
4. Opportunity for job growth not being limited by the accessibility of the building.
5. Would like to go to church more often but can't due to staff scheduling and lack of staff hours.
6. Door accessibility buttons are not convenient or consistent if any at all.
7. More education, more classes to help us learn to be independent, budgets, cooking, financial support, and learning to read.
8. Have people with disabilities speak out more.
9. Get the ABLE bill passed (ability to establish tax-exempt accounts for individuals with a disability to pay for certain expenses such as education, housing, transportation, employment support, medical care, and other life necessities).
10. Get more community jobs for people with disabilities.
11. Give people with disabilities cell phones for work, for emergencies, to call staff, to call for bus etc.

12. Teach others, like medical doctors and city workers, how to talk to people with disabilities.
13. Learn how to speak for yourself.
14. Be community trainers.
15. Start your own business.
16. Live how you dream – live in your own house, get married, take vacations, and drive.
17. Classes to talk about personal relationships.
18. We want to be more independent with staff taking a back seat role.
19. Educate doctors to listen and help people with disabilities understand their health.

Acknowledgements

First and foremost, thank you to the Self Advocates Board of Directors who gave up part of their meeting time to participate in this focus group. They were engaged, thoughtful, and serious about their task. Mark Kevitt, advisor to the Self Advocates, was instrumental in arranging the meeting for us.

Thank you also to the Crowne Plaza Hotel for their service. Staff were very helpful in assisting with the room arrangements and helping to make our guests comfortable.

What was the $ amount transferred into the VR account? Do you believe the Federal match will stay consistent? Is the transfer through the 2nd year of the biennium as well as the 1st?

No money has been transferred yet. The VR match is up to $4 million. The Federal match is likely to stay consistent, given the historical formula. (It will likely increase slightly, as it has done historically.)

We are looking for other options, including private donors.

RSA has approved VR's proposal for private donors and third party donors, so we will look at that as a resource for FY13.

Re the pilot projects: Can you let the commission know where the projects are taking place and who is participating? I believe I have also mentioned to you that both the advocates and INARF would like you to be more specific regarding the goal of the pilots.

The goal of the demonstration projects is to look at barriers to employment externally or internally and how can we change systems or attitudes to encourage employment. Members of the industry and community are a part of the projects. This includes both DD and VR providers, education leaders, advocates, civic leaders, case management, and state staff.

Updates for the Demonstration Projects are included in the employment presentation.

Regarding the number of clients who appealed their OBA: Are these numbers the clients who have gone all the way to the formal appeal? Can you tell the commission how many settled in the PARS process?

This number represents individuals who had an appeal hearing scheduled. Of those individuals, 171 (67%) never requested a review prior to submitting an appeal request or submitted new information with the appeal that led to a state initiated review and ultimately a settlement was reached prior to the appealing date

The last question is regarding the authorization comparison: Do the amounts shown reflect plan amounts? If so, what are the spend or utilization amounts?

The amounts shown in our presentation reflect plan amounts.

RHS utilization is about the same.

Day Services is at 71%. We would expect that percentage at this time because when we started OBA only about half of our consumers had day services. As its being added to individual's plans it's taking up to 6 months in a significant number of cases for day services to start.

Exhibit 9
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Employment Opportunities and Initiatives for Individuals with Disabilities

Presentation to the Developmental Disabilities Commission

Division of Disability & Rehabilitative Services Staff

October 5, 2011

Why focus on employment?

- Division of Disability and Rehabilitative Services (DDRS) Philosophy:
  - **Everyone capable of working competitively should be working competitively.**
  - **Everyone should be a part of their communities, which means employment—where they live, where they shop, and where they play.**
  - **We have a refocused direction and want to use State resources for individuals first to be in employment, and to work together to figure out how the available resources can be used to support that individual in their employment.**
- We are focusing on employment because of success stories like Jack Thrasher.
- Emphasis on the importance of employment in the lives of people with disabilities and updating some core service definitions *
- Effort to support States' efforts to increase employment opportunities and meaningful community integration for waiver participants*

* From the Centers for Medicare and Medicaid Services

The Value of Work

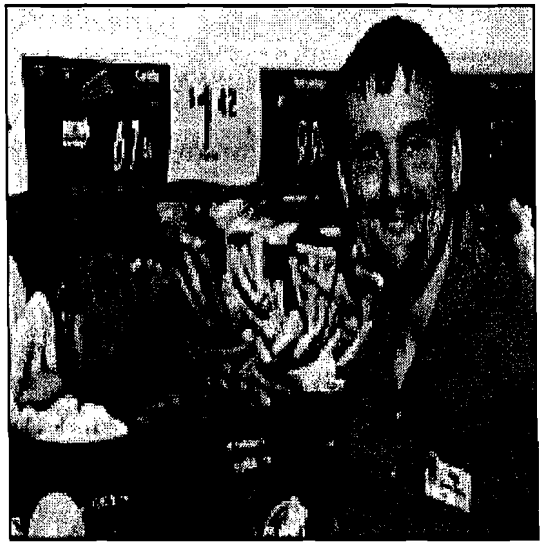
- A fundamental part of adult life for people with and without disabilities
- Provides a sense of purpose, shaping who we are and how we fit into our community
- Meaningful work has been associated with positive physical and mental health benefits and is a part of building a healthy lifestyle as a contributing member of society
- Because it is so essential to people's economic self sufficiency, as well as self esteem and well being, people with disabilities should be provided the opportunity and support to work competitively within the general workforce in their pursuit of health, wealth and happiness.

The Value of Work

- All individuals, regardless of disability and age, can work – and work optimally with opportunity, training, and support that build on each person's strengths and interests.
- Individuals who earn employment wages may become less dependent on public assistance
- Economic benefits – Employed individuals are tax payers and part of the consumer market, adding to state and federal revenue.

Partners in Employment

- Transition Councils
- Centers for Independent Living
- State Employment Leadership Network
- Bureau of Developmental Disabilities Services
- Vocational Rehabilitation
- Service Providers
- Center on Community Living and Careers
  Indiana Institute On Disability and Community
  Indiana University
- Employers
- Schools
- Parents
- Consumers
- Advocates



Joe Kelly, works with Arc Rehabilitation Services in Boone County and is employed at Kroger in Lebanon.

DDRS Employment First Initiatives

- As part of Indiana's Employment 1st Initiative, DDRS became a member of the State Employment Leadership Network (SELN), which brings states together to improve employment outcomes for people with developmental disabilities.
  - Upon joining SELN, Indiana has participated in a site visit and qualitative review, which focused on assessing Indiana's current employment practices and strategies, and will assist with development of employment work plan goals.
  - The work plan will offer guidance and a working set of goals and finite activities that can serve as a blueprint for its efforts to improve the quality and accessibility of employment supports statewide.
- Project SEARCH
- Demonstration Projects

Demonstration Projects Update

- Bloomington:
  - Finalizing a power point training for case managers, and will be developing a general training for consumers, families, providers, educators and other individuals around the employment initiative
  - Once finalized, the group will be working with DDRS on rolling out the training in various formats
  - Participants: BDDS, VR, DOE, IPMG, IIDC, and providers
- South Bend:
  - Met with DDRS to review its proposal that focuses on increasing referrals of students with developmental disabilities from the South Bend School Corporation through the next school year
  - Increasing the amount of referrals of individuals currently in BDDS services by working with case managers as well as local employment providers, including Logan Industries
  - Meeting quarterly to ensure open communication, continued progress toward their goal and to identify and solve any problems that may arise
  - Participants: VR, BDDS, IPMG, DOE, and providers
- Marion:
  - In the process of developing a transition coalition by working to identify potential members and meeting to discuss the details of collaboration between service providers and case management
  - Met in late August to discuss issues, share program information, and discuss ways to improve outcomes.
  - Developed and implemented a procedure with an Employment 1st approach for case managers to utilize with the IDT at team meetings
  - Participants: VR, BDDS, IPMG, providers and self-advocates

Demonstration Projects Update

- Evansville:
  - Developed and currently utilizing an electronic job board for local employment providers
  - 10 providers are participating in the job board currently
  - Developing a letter to inform individuals currently on the wait list for services of VRS and determining how to roll out the letter in phases
  - Participants: BDDS, VR, IPMG, providers, and the DOE
- Kokomo:
  - Developed and started using a survey for Employment to be used at transition meetings and quarterly case manager meetings to begin the discussion of community employment
  - Proposed a web site that would allow individuals, teachers, administrators, DSPs, Employment Specialists, and potential employers' access to interested employees to serve as a bridge of communication opened up through identification of employment as a priority area
  - DDRS is exploring ways to develop the website
  - Participants: VR, BDDS, IPMG, providers, the Autism Society and DOE.

BDDS & Vocational Rehabilitation

- BDDS &VR Referrals:
  - July = 7
  - August = 27
  - September = 50
- Supported Employment Follow-Along:
  - An individual may be able to qualify for SEFA once the individual has completed the VR process for job placement, has been employed, and is determined to be stable on the job, but still needs supports to maintain that job
  - Follow along supports are provided by a job coach and can include regular check-ins on the job, interaction with the Consumer or employer about any issues that have arisen, assistance learning new job tasks, identification and development of accommodations as needed, as well as identification of natural supports in the workplace.

Vocational Rehabilitation 101

- VRS provides quality, individualized services to enhance and support people with disabilities to prepare for, obtain and/or retain employment.
- Competitive, integrated employment at minimum wage or higher.
- Through active participation in their rehabilitation, people with disabilities achieve a greater level of independence in their work place and living environments.

all types of disabilities, not just DD.

VR Eligibility

- The individual must have a physical and/or mental impairment.
- This impairment must constitute or result in a substantial impediment(s) to employment.
- The individual must require VR services to help him or her prepare for, enter, engage in, or retain gainful employment.

fed program w/ fed/st. match $

The VR Process

- The Goal is Competitive, Integrated Employment
- The consumer and VR Counselor work together to develop an Individualized Plan for Employment (IPE)
- Consider the consumer's interests, skills, financial needs, potential, and abilities
- IPE must include a vocational goal, services to be provided, and the specific means by which progress toward objectives are to be measured
- VR Services are Individualized, Employment-driven, Time-limited, and Flexible

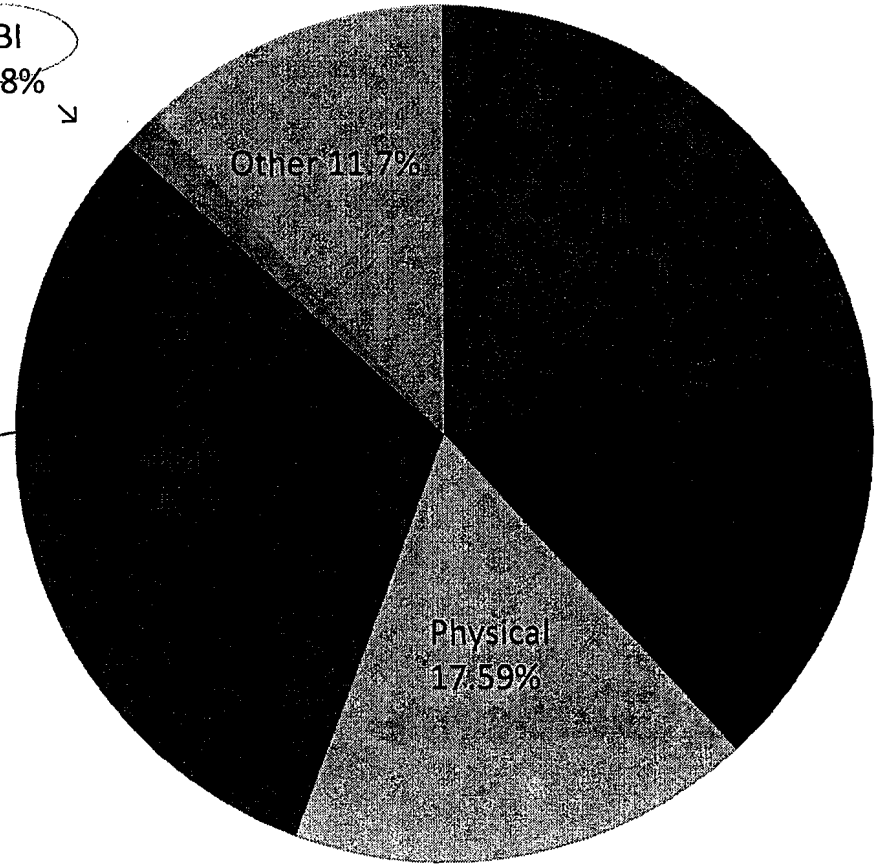
VR Services

- Supported Employment
- Job Placement
- Training
- Physical and Medical Restoration
- Assistive Technology
- Accommodations
- Counseling and Guidance

Ryan Davidson, a client of Noble/ The Arc of Greater Indianapolis, is employed at Carson Manufacturing Company, where he maintains machinery and helps move equipment.

VRS Successful Outcomes by Disability

Traumatic Brain Injury



Blind/deaf

Employment Resources and Initiatives

- Project SEARCH
  - Employability skills training and workplace internships for individuals with significant disabilities, particularly youth transitioning from high school to adult life
  - 11 sites statewide (10 transition + 1 young adult)
  - True partnerships between VRS, Schools, Employment Providers and Businesses.

- last yr of HS elig. spent on-site w/ emp to learn vocational skills.

- sustainable model b/c of funding sources.

- nearing end of HS career, preparing to enter adult world

- last yr of HS elig's 22 y/o

Employment Resources and Initiatives

- Corporate Development
  - Dual-customer approach (consumer and business)
  - Active partnerships with over 50 businesses
  - 71 job placements to date in CY2011
  - Long-term business relationships v. one-time job placements
  - Changing corporate culture

Employment Resources and Initiatives

- Partnerships and Collaboration
  - BDDS/VR
    - Cross-referrals
    - Transfer to SEFA
  - Employment Service Providers (CRP's and MHCs)
    - Supported Employment and Job placement
    - VR Employment Workgroup
  - Transition
    - Collaboration with schools for seamless transition from school to employment, post-secondary, community living
    - Transition policy group – core group includes youth and their family, VR, DOE, BDDS, DMHA, DOC, providers, others

Employment Resources and Initiatives

- Benefits and Work Incentives Counseling
  - Indiana Works Funded by SSA
  - Center on Community Living and Careers at the Indiana Institute On Disability and Community, IU
    - Benefits Information Network
    - Parent Training –
    - Financial Literacy and Asset Development

Mark Price is a client of Arc Northwest Indiana and works at Kelsey's Steak House in Schererville.

Employment Resources and Initiatives

- Blind Vending
  - Randolph Sheppard
  - 44 Licensed Vendors in Indiana
  - Licensed vendors employ others, including individuals with disabilities
  - Average vendor Earnings = over $53,000

Employment Resources and Initiatives

- Centers for Independent Living
  - 51% of Board of Directors are persons with disabilities
  - 51% of staff are persons with disabilities;
  - provides four core services:
    - Information & referral
    - Independent living skills training
    - Individual and systems advocacy
    - Peer counseling

Future Initiatives

- Supported Employment Leadership Network (SELN)– Strategic Plan
- Department of Workforce Development Collaboration – WIB's
- Strategies to improve quantity and quality of employment outcomes

Employment Opportunities and Initiatives for Individuals with Disabilities

Presentation to the Developmental Disabilities Commission

Division of Disability & Rehabilitative Services Staff

October 5, 2011

CENTER ON COMMUNITY
LIVING AND CAREERS

INDIANA UNIVERSITY

Indiana Institute on Disability and Community

CENTER ON COMMUNITY LIVING AND CAREERS INDIANA INSTITUTE ON DISABILITY AND COMMUNITY INDIANA UNIVERSITY

Center on Community Living and Careers - Indiana Institute's Role

- House the Indiana Secondary Transition Resource Center (Department of Education) and a number of projects with VRS and DDRS
- Evaluation Data
- Professional Development and Training
- Technical Assistance and Support

CENTER ON COMMUNITY LIVING AND CAREERS
INDIANA UNIVERSITY
Indiana Institute on Disability and Community

How Do We Know What's Working and Not Working = Data

- Day and Employment Services Outcome System Report (DESOS)
- Evaluation Data on Project SEARCH, Benefits Information Network, Corporate Development

Janivia is a former Project SEARCH Intern now working at Hook Rehabilitation of Community Hospital East in Indianapolis. Janivia makes $10.25 per hour and is working 28 hours a week.

CENTER ON COMMUNITY LIVING AND CAREERS
INDIANA UNIVERSITY
Indiana Institute on Disability and Community

Professional Development And Training

One Example:

- Vocational Rehabilitation Leadership Academy
  - Online training for VRS staff (Core Courses)
  - Specialized and Advance Seminars open to all stakeholders
- Future Development – Developing trainings for DD Service Coordinators and Case manager about Employment Services

See Handout on Outcomes

Technical Assistance And Support

- Project SEARCH – Serve as statewide coordinator and facilitate site development and implementation
- Coordinate the Benefits Information Network and Training
- Future Needs – to develop additional transition & employment models to improve outcomes

See Handout on Outcomes

Cannon IV employee Tony Meyers recycles toner cartridges and works in the company's Indianapolis warehouse. A Noble of Indiana client, Tony works at Cannon in the mornings and at a local landscaping firm in the afternoons.

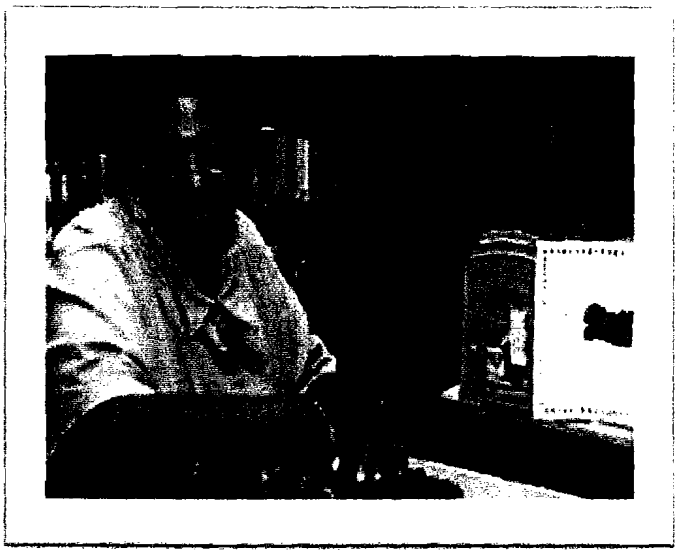
Indiana Day and Employment Services Outcomes System Report

Exhibit 10
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

INDIANA

DESOS

Reporting Period: June 2011



Diane Hodgkin, a client of AWS (formerly Achieva), works at the Morrison Reeves Library in Richmond.

Teresa Grossi, Ph.D., David Mank, Ph.D., and Larry Schaaf, M.A.

CENTER ON COMMUNITY LIVING AND CAREERS

INDIANA UNIVERSITY

Indiana Institute on Disability and Community

Center on Community Living and Careers
Indiana Institute on Disability and Community
Indiana University
2853 East Tenth Street
Bloomington, IN 47408
(812) 855-6508

Contact Information: **tgrossi@indiana.edu**

Day and Employment Services Outcomes System Report

Executive Summary

This report is based upon **9,764** individuals receiving day and employment services from **46 (71%) of the 65 programs** in Indiana. There was a decrease in provider reporting from 85% to 71% for this report.

- ✓ The major question answered in this report is: where do individuals spend their day? There has a slight decrease in Sheltered Employment; a slight increase in Alternatives to Employment and basically no change individual jobs. Of the **9,764 (93%)** responding to this question, **27%** spend the majority of their day in a sheltered workshop, **29%** in individual jobs, **25%** in alternatives to employment (ATE), **19%** in non-employment day program, and **1%** in off-site group placement. This information could be helpful in developing statewide benchmarks. (*Please see page 7 for the primary disability and primary environment table).*

- ✓ Of those **2,321** individuals in Alternative to Employment (ATE), **81%** (**1,880**) of the individuals are looking for employment.

- ✓ There seems to be a slight change in the individuals who are being served by provider which may be a result of the lower percentage of agencies responding. Individuals with the primary disability label of Intellectual Disability /Developmental Disabilities made up 70% of the individuals served in 2005 and 61% in 2011; Autism grew from 3% on 2005 to 5% in 2011; and a slight change for individuals with learning disabilities served that fluctuates between 3 -5%.

- ✓ There are slight changes in the average hourly earnings and average hours worked per week.

  - People in sheltered workshops earned from **$1.69** per hour working in May of 2005 to **$2.53** in May 2011 working an average of **26** hours per week compared to **24** hours per week.
  - People in individual community jobs earned from an average of **$6.15** per hour working in May 2005 to **$7.87** in May 2011 and worked from an average of **21** hours per week to **22** hours per week. (*Please see pages 9 and 10 for more specific information).*

- ✓ This report shows that the largest portion of individuals **(44%)** spend their day with *9 or more individuals with disabilities* and did not have anyone without disabilities (excluding paid staff) in their immediate environment. Nearly **34%** of the individuals indicated being in an environment with only 1 individual with a disability.

- ✓ Of those individuals in community employment, **34%** received 1-4 hours per month of ongoing follow-along support to maintain their jobs, **40%** received 5-10 hours, **2%** received more than 11 hours and **2%** received 16 or more hours. There has been a steady increase in the percentage of individuals not receiving follow-along services per month and a gradual decrease in the percentage of individuals received 5-10 hours per month.

- ✓ Of the **344** individuals who no longer received follow-along support, **46%** was due to successful placement; **42%** was customer choice, **9%** was the agency decision or "graduated"; **3%** of the individuals had moved.

- ✓ Of the **1,536** (**16%**) of individuals who reported that they also spent time in secondary environment, the highest percentage of the individuals (42%), spent time looking for a job. The average hours scheduled for all settings was **7.5 hours per week**. (*See more detail on page 16).*

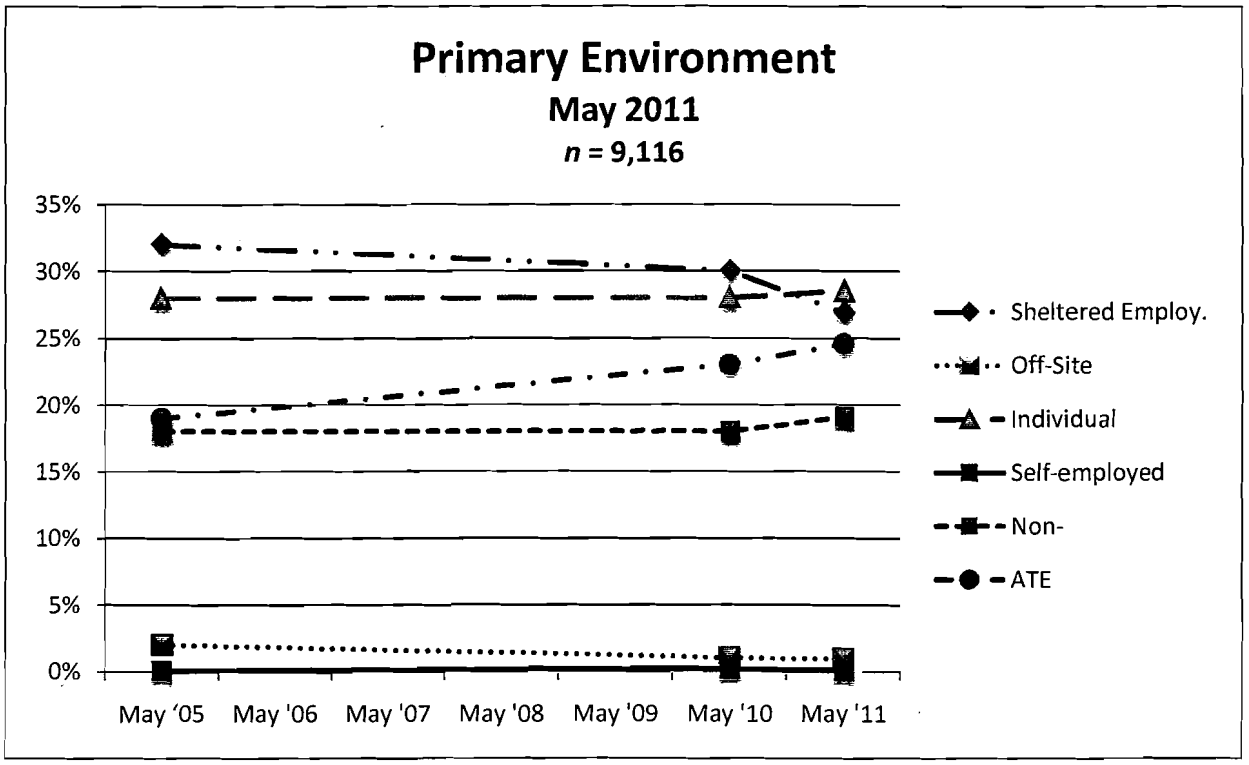
Cat lover and Stone Belt client Cora Slater works at the Bloomington Animal Shelter.

QUESTIONS RELATED TO THE PRIMARY ENVIRONMENT

Primary Environment - Where Do People Spend the Majority of Their Time During the Day?

Of the **9,116** (**93%**) reporting, **2,452** (**27%**) were in Sheltered Employment; **82** (**1%**) Off-site Group Employment; **2,599** (**29%)** Individual Jobs; **7 (.1)%** Self-employment; **1,737 (19%**) were reported in non-employment day program; and **2,239** (**25%**) in Alternatives to Employment (ATE).

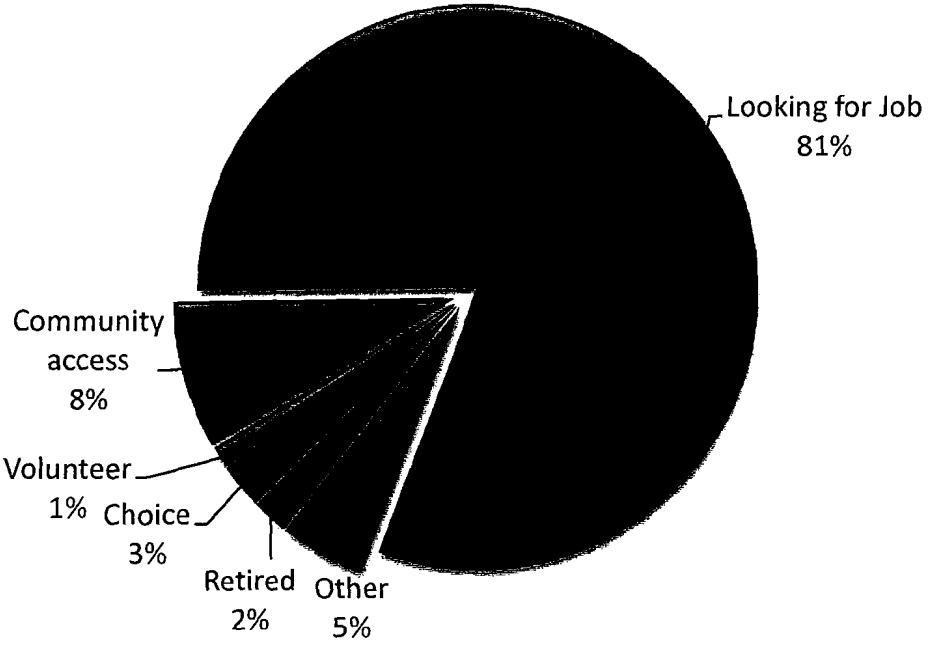
As shown in the chart and table below, there is a slight decrease in Sheltered Employment; a slight increase in Alternatives to Employment and little, if any change in individual jobs.



Time Period	Sheltered Employ.	Off-Site	Individual	Self-employed	Non-employment day programs	ATE
May '05	32%	2%	28%	0.1%	18%	19%
May '10	30%	1%	28%	0.2%	18%	23%
May '11	27%	1%	29%	0.1%	19%	25%

Of the **2,239** individuals in Alternatives to Employment, 81% (1,813) looking for a job.

Alternatives to Employment
Reason or Activity
May 2011
***n* = 2,321**



Time	Retired	Choice	Volunteer	Community	Looking	Other
May '05	7%	2%	3%	14.0%	67%	7%
May '10	2%	2%	2%	7.2%	81%	6%
May '11	2%	3%	1%	8.5%	81%	5%

Primary Disability and Primary Environment

The table below shows that the majority of individuals with intellectual disabilities are in the mild range and have the highest percentage in each of the environments except for non-employment day programs.

Primary Disability and Primary Environment

Primary Disability	Level of ID/DD	Alternative to employment	Individual Job	Non-employment day program	Off-site group employment	Self-Employed	Sheltered employment
ID/DD	ID/DD*	1.71%	4.10%	3.28%	6.10%	0.00%	4.86%
	Mild	21.72%	36.04%	20.51%	59.76%	28.57%	46.94%
	Moderate	6.65%	7.42%	26.56%	17.07%	0.00%	27.70%
	Profound	1.30%	0.00%	17.91%	0.00%	0.00%	1.63%
	Severe	1.30%	0.31%	19.53%	2.44%	0.00%	5.27%
Autism		5.76%	5.34%	5.18%	3.66%	42.86%	3.39%
Brain Injury		2.38%	2.13%	0.81%	1.22%	0.00%	0.86%
Cerebral Palsy		2.43%	1.47%	2.94%	0.00%	0.00%	1.39%
Hearing Imp.		2.74%	4.10%	0.00%	2.44%	0.00%	0.90%
Learning Disability		8.36%	8.97%	0.75%	1.22%	0.00%	0.20%
Mental Illness		17.81%	11.91%	0.81%	3.66%	14.29%	2.37%
Other Health Imp.		9.08%	7.46%	0.75%	0.00%	14.29%	1.14%
Physical		12.68%	7.08%	0.40%	0.00%	0.00%	0.25%
Seizure Disorder		1.12%	1.31%	0.23%	2.44%	0.00%	0.49%
Visual Imp.		4.95%	2.36%	0.35%	0.00%	0.00%	2.61%

* = responded ID/DD only without responding to level of intellectual disability

Referral Source and New Employer

Of **9,313** (**96%**) individuals who responded to this question, **5,145 (55%)** reported Vocational Rehabilitation as the primary referral source, and **2570**(**28%**) reported "N/A" indicating they were already employed or enrolled in a program. Eighty Ninety percent (**89%**) of the individuals did not have a new employer in the last 6 months.

Paycheck

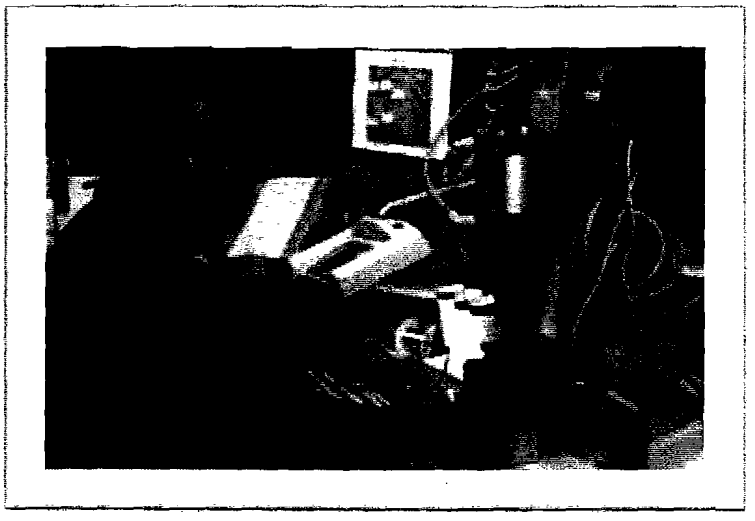
Of the **7,925** (**82%**) individuals who responded to this question, **3,317 (42%)** reported receiving no paycheck, **2,214** (**28%**) received their paychecks from the employer, and **2,394** (**30%**) receive their paychecks from the rehabilitation organization.

Types of Work Performed

There is more diversity than in the past years in the types of jobs individuals obtain in individuals community jobs with the services industry (e.g., food service, custodian/housekeeping/laundry and grocery retail) having the highest number of individuals employed.

Types of Work Performed

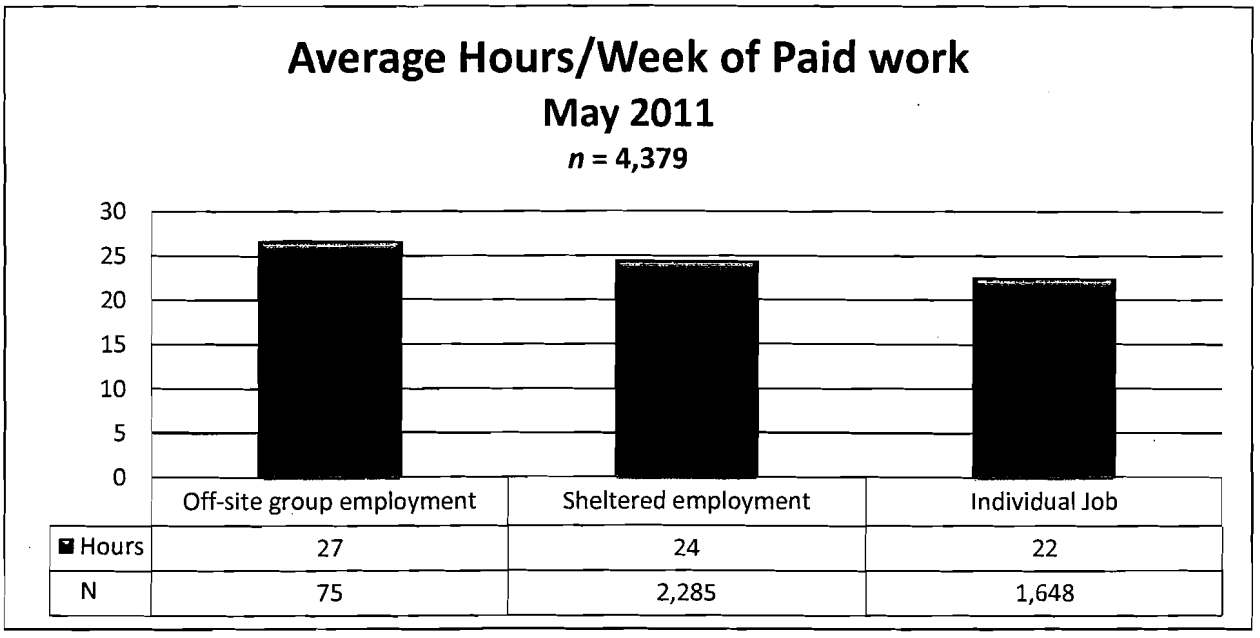
Types of Work	Individual Job	Off-site group employment	Sheltered employment
Assembly/Manufacturing	8.72%	66.67%	91.51%
Food service	28.74%	5.33%	0.53%
Janitorial/Housekeeping/Laundry	18.47%	14.67%	1.71%
Grocery/Retail	17.27%	0.00%	0.26%
Other	10.67%	1.33%	4.55%
Stocking/Warehouse	5.16%	2.67%	0.31%
Clerical/Office	4.88%	1.33%	0.22%
Health/Human Service	3.44%	0.00%	0.09%
Grounds keeping	1.72%	8.00%	0.00%
Sorting/Recycling	0.63%	0.00%	0.83%
Agriculture	0.29%	0.00%	0.00%
	100.00%	**100.00%**	**100.00%**



Ryan Davidson, a client of Noble/The Arc of Greater Indianapolis, is a proud employee of Carson Manufacturing Company, where he maintains machinery and helps move equipment.

Typical Hours Scheduled Weekly for Paid Work

Of the **4,379** individuals reporting about hours scheduled for paid work, Sheltered Employment averaged **24 hrs per week;** Off-Site Group employment averaged **27 hrs per week**, Individual Jobs averaged **22 hrs per week, and Self-Employed averaged 36 hours per week.**



Time Period	Individual Job	Self-employed	Off-site group employment	Sheltered Employment
May '05	21	22	31	26
May '10	20	40	26	23
May '11	22	36	27	24

Typical Hours Scheduled Weekly Non-Paid Work

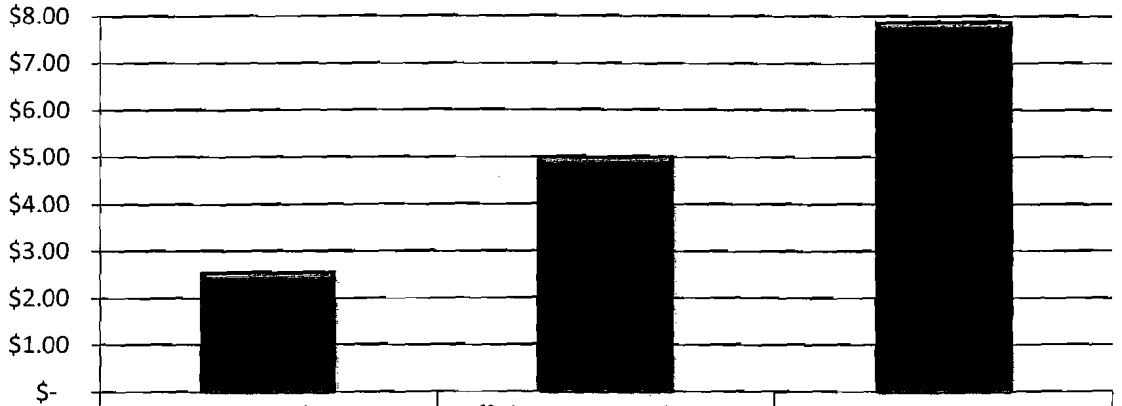
On average, individuals are typically scheduled for **3** hours of non-paid work.

Hourly Earnings

Of the **3,182** individuals who reported hourly earnings, individuals in Sheltered Employment averaged **$2.53** per hour, Off-Site Group employment averaged **$4.99** per hour, Individual Jobs averaged **$7.87** per hour, and Self-Employment averaged **$8.33** per hour.

Since autumn 2010, Dometic LLC, a corporate partner of ADEC in Elkhart, has hired 13 ADEC applicants.

Average Hourly Earnings
May 2011



	Sheltered employment	Off-site group employment	Individual Job
Hourly Earnings	$2.53	$4.99	$7.87
N	1,500	66	1,613

Time Period	Individual Job	Self-employed	Off-site group Employment	Sheltered Employment
May '05	$6.15	$5.00	$4.06	$1.69
May '10	$6.99	$14.00	$5.35	$1.57
May '11	$7.87	$8.33	$4.99	$2.53

Reason for Job Loss

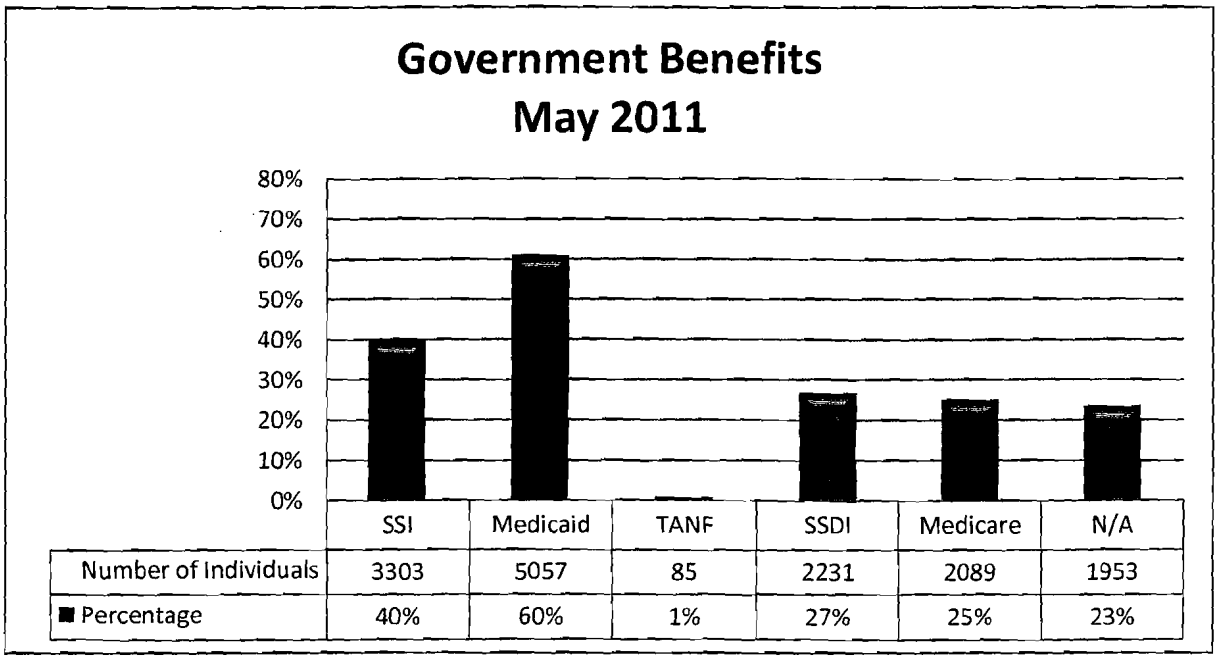
Of the **8,512 (88%)** responding about job loss, **148** (**2%**) reported the reasons as "Voluntary", **209** (**3%**) reported as "Involuntary", **16** (**.2%**) reported a "Job change", and **7501** (**96%**) reported NA.

Employer Benefits Received

Individuals receive a variety of benefits. **7,109 (74%)** individuals responded to this question with **5,535** (**78%**) reporting receiving no fringe benefits from their job or day services, **865** (**12%**) reporting receiving Paid Vacation, **373** (**5%**) reporting receiving Medical, **159** (**2%**) reporting receiving Retirement, **493** (**7%**) reporting receiving Paid Sick Leave, and **828** (**12%**) reporting Other (e.g., free lunch).

Government Benefits

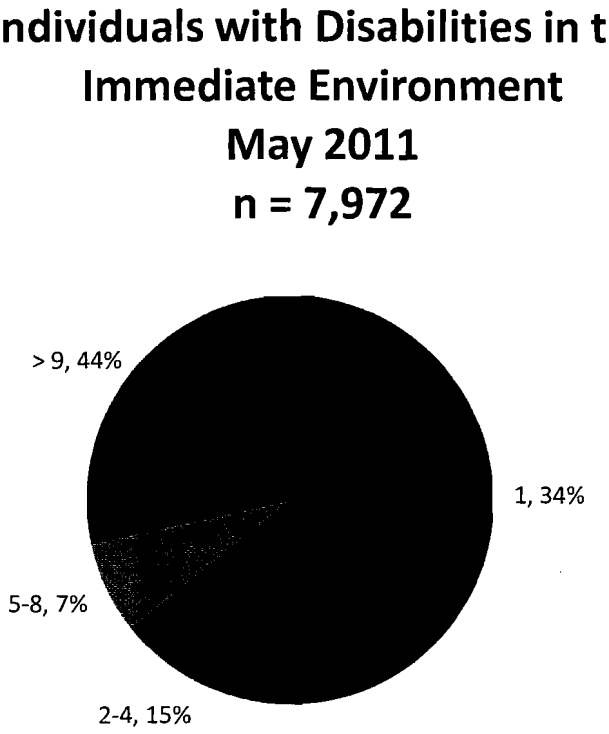
Of the **8,359 (87%)** individuals who reported receiving government benefits, **3,303** (**40%**) reporting receiving SSI; **2,231 (27%)** reporting receiving SSDI; **5,057** (**60%**) reporting receiving Medicaid; **85** (**1%**) reporting receiving TANF, and **2,089** (**25%**) reporting receiving Medicare.



	SSI	Medicaid	TANF	SSDI	Medicare	N/A
Number of Individuals	3303	5057	85	2231	2089	1953
■ Percentage	40%	60%	1%	27%	25%	23%

Number of Individuals with Disabilities in the Immediate Environment

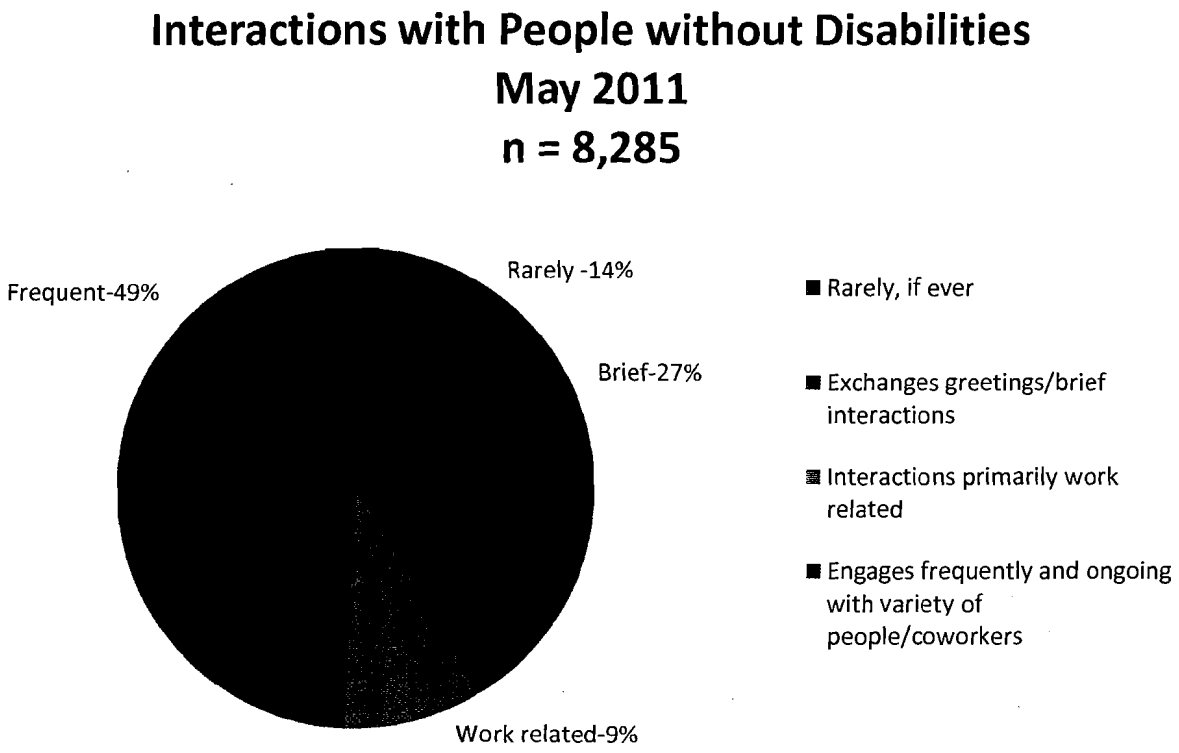
This question focuses on the extent of physical integration in the workplace of individuals with disabilities who are coworkers. Of those **7,972** (**82%**) individuals responding to this question, **2,710** (**34%**) individuals are in environments in which they are the only individual **with** a disability, **1,196** (**15%**) are in environments in which there are 2-4 individuals with disabilities, **558** (**7%**) are in environments in which there are 5-8 individuals with disabilities, and **3,507** (**44%**) are with 9 or more individuals with disabilities in their environment.



Time Period	1 person	2-4 individuals	5-8 individuals	9 or more
May '05	30%	13%	7%	50%
May '10	32%	13%	8%	47%
May '11	34%	15%	7%	44%

Social Interactions with People Without Disabilities Excluding Paid Staff

This question addresses the type of social interaction level in the workplace. Of the **8,285** (**85%**) individuals responding to this question, **1,160** (**14%**) reported interacting rarely, if ever; **2,236** (**27%**) exchange greetings, **745** (**9%**) interact primarily on work related issues and **4,060** (**49%**) interact frequently and/or ongoing.

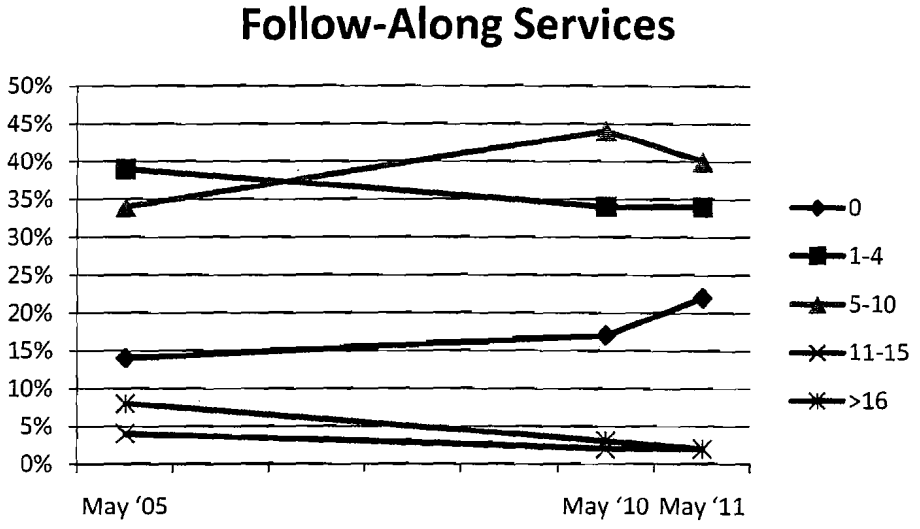


Time Period	Rarely	Greetings	Work Related	Ongoing
May '05	21%	25%	10%	43%
May '10	17%	25%	10%	48%
May '11	14%	27%	9%	49%

Hours of Follow-Along Support in as Typical Month

Lisa Harter works at the Dollar General in LaGrange, where she's a client of Arc Opportunities.

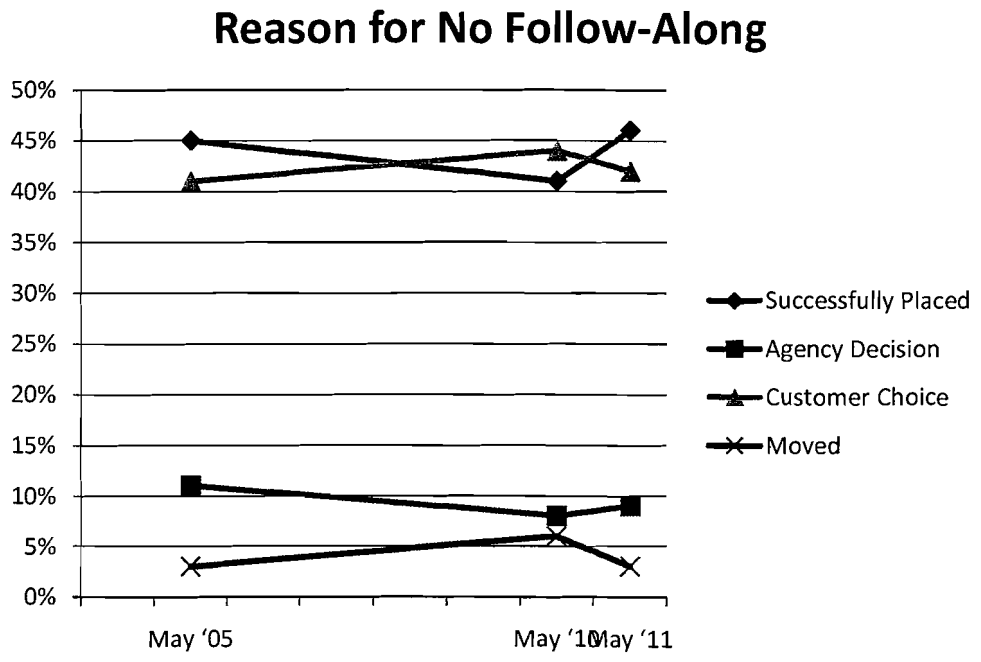
For those individuals in community jobs where follow-along services was applicable (**2,599** responses), **572 (22%)** had 0 hours of follow-along, **884 (34%)** reported 1-4 hours, **1,040** (**40%**) reported 5-10 hours, **52** (**2%**) reported 11-15 hours, and **52** (**2%**) reported 16 or more hours per month.



Time Period	0	1-4 hours	5-10 hours	11-15 hours	16> hours
May '05	14%	39%	34%	4%	8%
May '10	17%	34%	44%	2%	3%
May '11	22%	34%	40%	2%	2%

Reasons No Longer Receiving Follow-along Support

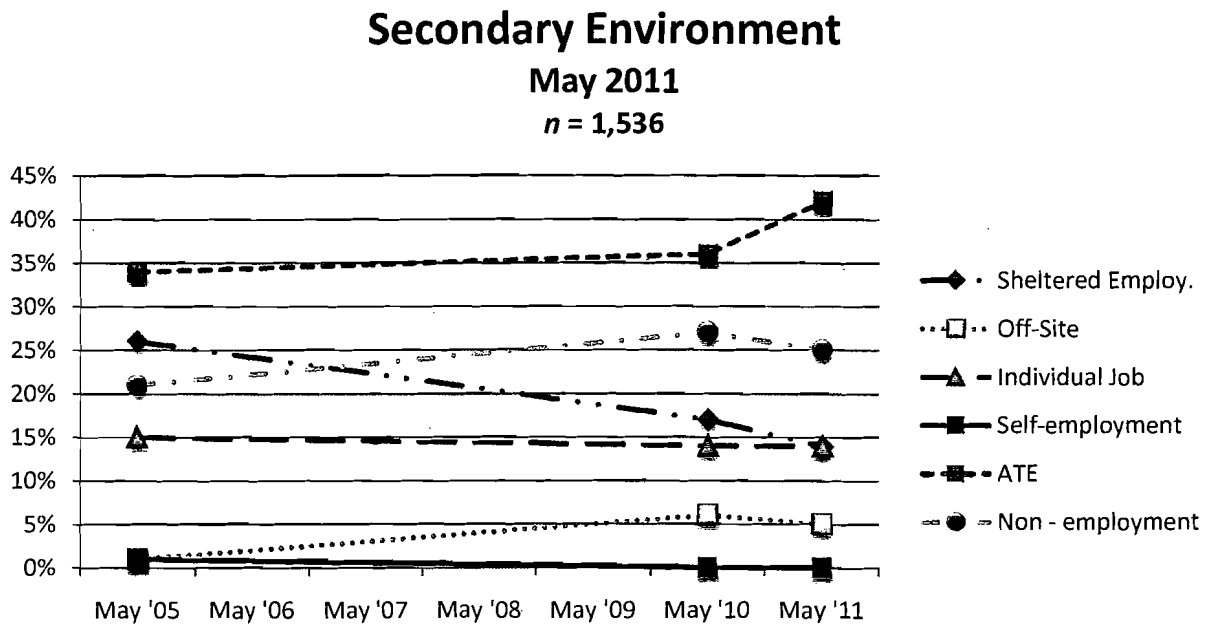
Of the **344** individuals who reported they no longer received follow-along support, **159 (46%)** indicated this was due to successful placement; **144 (42%)** customer choice, **30 (9%)** agency decision or "graduated" and **11 (3%)** the individuals had moved.



Time Period	Successfully Placed	Agency Decision	Customer Choice	Moved
May '05	45%	11%	41%	3%
May '10	41%	8%	44%	6%
May '11	46%	9%	42%	3%

SECONDARY ENVIRONMENT

Some individuals are in one environment part of the day and in a secondary environment some of the day (e.g., community employment and sheltered workshop). **1,536** (**16%**) individuals reported that they also spent time in secondary environment. Fourteen percent **(210)** of the individuals responding (**1,536**) reported receiving employment services in Sheltered Employment; **82** (**5%)** in Group Employment; **212** (**14%)** in Individual Jobs, **639** (**42%)** in Alternatives to Employment (e.g., looking for a job, community access, retired, choice, etc.); and **390** (**25%)** in Non-employment day program. The average hours in all these settings was **7.5 hours per week**.

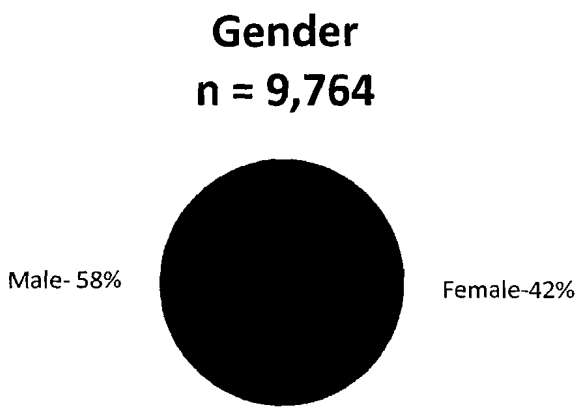


Time Period	Sheltered Employ.	Off-Site	Individual Job	Self-employment	ATE	Non - employment
May '05	26%	1%	15%	1%	34%	21%
May '10	17%	6%	14%	0%	36%	27%
May '11	16%	5%	14%	0%	42%	25%

DEMOGRAPICS

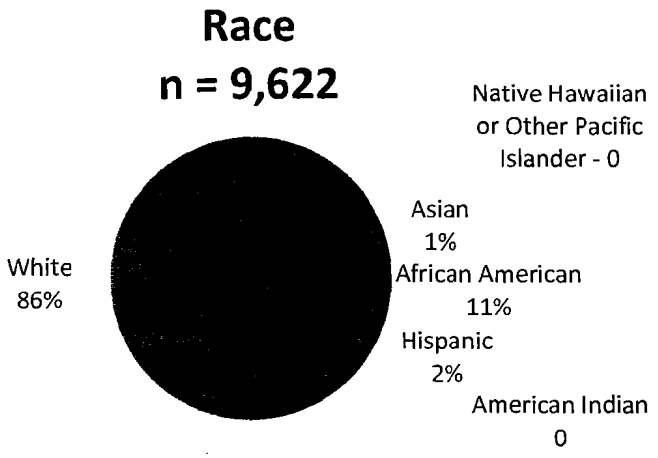
Demographic information is based on the responses from **46 of the 65 programs** of **9,764** individuals with disabilities receiving day and employment services include:

Gender
Data was reported on **58%** of individuals who were male and **42%** who were female.



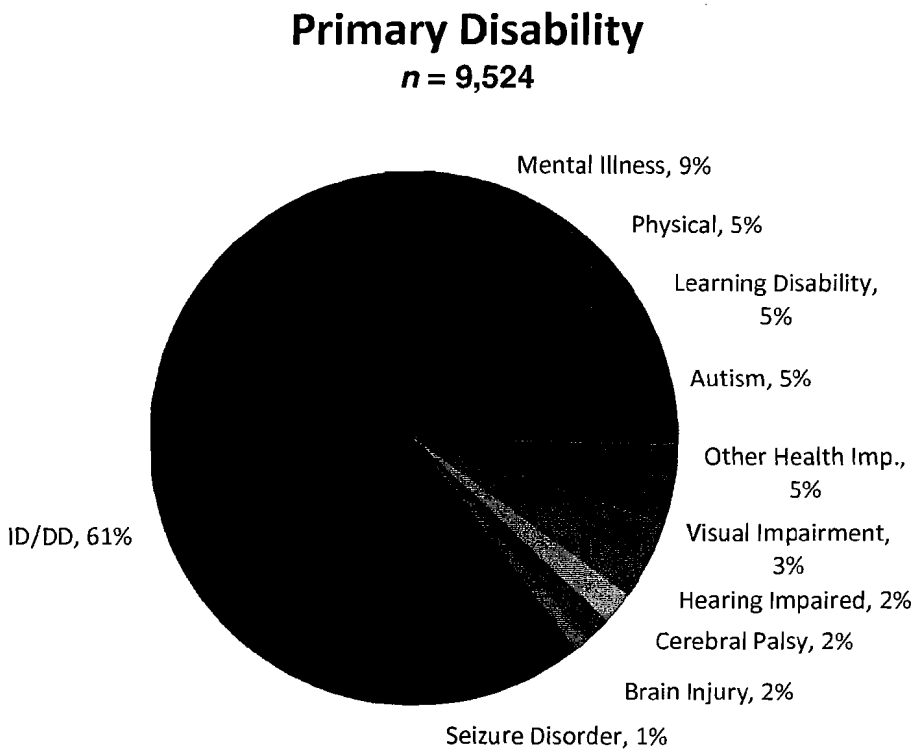
Race

The majority (**86%**) of individuals were White with (**11%**) African-American.



Primary Disability

The majority of individuals (**61%**) served had a primary disability label of intellectual disability/developmental disability.

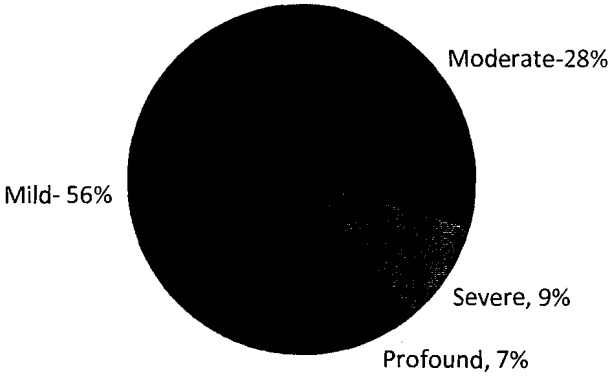


Time Period	ID/ DD	Autism	Mental Illness	Brain Injury	Phys	Visual Imp.	Hear. Imp.	Cereb. Palsy	Learn. Dis.	Seizure	Health
May'05	70%	3%	5%	2%	5%	1%	1%	3%	3%	1%	4%
May '10	64%	4%	8%	2%	6%	2%	2%	2%	4%	1%	4%
May '11	61%	5%	9%	2%	6%	3%	2%	2%	5%	1%	5%

Level of Intellectual Disability

Of the individuals with the label of intellectual disability (**5,469**), the majority of individuals (**56%**) fall in the mild range and (**26%**) in the moderate range.

Level of Intellectual Disability
All Employment
n = 5,469



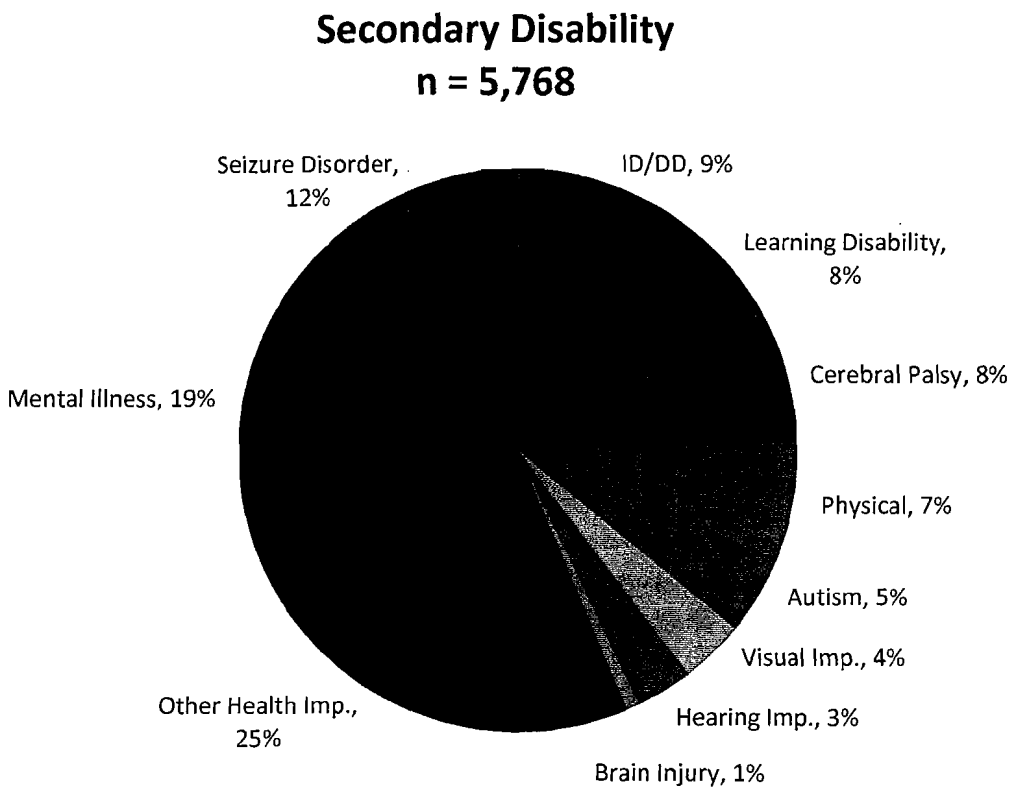
Time Period	ID/DD*	Mild	Moderate	Severe	Profound
May '05	3%	48%	29%	12%	8%
May '10	5%	53%	27%	9%	6%
May '11	6%	56%	28%	9%	7%

* = reported MR/DD only without indicating level of mental retardation

Mark Price is a client of Arc Northwest Indiana (formerly Arc Bridges) and a hard worker at Kelsey's Steak House in Schererville.

Secondary Disability

Sixty percent (**5,768**) of the respondents were identified of having a secondary disability that has an impact on their daily life activities.



Time Period	Total Number	ID/ DD	Autism	Other Health	Mental Illness	Brain Injury	Phys	Visual Imp.	Cereb. Palsy	Learn. Dis.	Hear. Imp.	Seizure
May '05	6313	8%	5%	24%	16%	1%	8%	4%	10%	6%	4%	14%
May '10	6691	6%	3%	16%	13%	1%	5%	3%	6%	5%	2%	9%
May '11	5768	6%	3%	17%	13%	1%	5%	3%	5%	5%	2%	8%

Behavioral Issues

Of the **9,171(95%)** respondents, **4911 (54%)** indicated no behavioral issues that impacted their daily activities. Thirty percent (**2767**) of the respondents indicated behavioral issues that are in the mild range, **1239 (14%)** moderate, and **254 (3%)** severe.

Time Period	None	Mild	Moderate	Severe
May '05	53%	31%	13%	3%
May '10	53%	31%	14%	3%
May '11	54%	30%	14%	3%

Level of Support for Behaviors

Of the individuals needing behavioral support, **29%** needed occasional support, **14%** needed intermittent support, and **12%** needed continuous support. Forty-two percent indicated the level of support question was not applicable to the individual.

Communication

Verbal communication was indicated as the primary mode of communication for over **80%** of the individuals. Very few (**.4%**) individuals used augmentative communication devices.

Time Period	Verbal	Non-Verbal	Limited Verbal	Augmentative Device	Sign language
May '05	76%	8%	13%	0.7%	2%
May '10	80%	7%	11%	0.4%	2%
May '11	80%	6%	11%	0.4%	2%

Mobility

For the majority of individuals (**88%**), the primary mode of mobility is ambulatory and no assistance is needed; **2%** are ambulatory with assistance; **4%** use a walker or other aid; and **6%** use a wheelchair.

Lebanon Kroger employee Joe Kelly works with Arc Rehabilitation Services in Boone County.

Project SEARCH Indiana: Progress Report

Quarter Ending: September 30, 2011

Exhibit 11
Commission on Developmental Disabilities
Meeting #3 October 5, 2011

This Quarter's Notes and Highlights

- Thirty-six implementation meetings were facilitated across the sites for planning, problem-solving and evaluation; six welcome nights for parents; 2 information meetings for parents to recruit interns; 1 VRS/site coordinator meeting
- Nine of ten high school transition sites have had interns start first rotations; the tenth has interns starting first rotations October 3; young adult site has its third class experiencing its second rotations
- October 1 is the census day for nine high school transition sites; November 14 will be the day for the tenth—2012 numbers will be reported next quarter
- Three Indiana sites received national placement awards from Project SEARCH at its annual conference: Cook-Ivy Tech (Stone Belt); Government Center (Sycamore Services) and Union Hospital (Hamilton Center) for 2010 outcomes
- The second annual all-Indiana Project SEARCH meeting day is being scheduled
- Three interns from this year's class (2012) have already been hired; three interns from summer SEARCH pilot have become employed

Project SEARCH Indiana Prior Class Outcomes to Date

Total No. of Interns Beginning Program	Total No. of Interns who Successfully Completed Program	Total No. Hired	Average Starting Wage/Hour	Average Starting Hours Per Week

Project SEARCH Indiana Class of 2011 Outcomes to Date

Total No. of Interns Beginning Program	Total No. of Interns who Successfully Completed Program	Total No. Hired	Average Starting Wage/Hour	Average Starting Hours Per Week

CCLC Project SEARCH Website Data**

Visits	Visitors	Page Views

CENTER ON COMMUNITY LIVING AND CAREERS
INDIANA UNIVERSITY
Indiana Institute on Disability and Community

Project SEARCH Indiana: Site Data

Project SEARCH Indiana Sites	Addl. Partners	Year Estab.	Internships Started	Internships Completed	Hires per Year/ Placement Rate	Change This Quarter	Avg. Starting Wage	Avg. Starting Hrs/Wk
Community Hospital East—Indianapolis	Indianapolis Public Schools, Easter Seals Crossroads	2008-2009	08-09 9 09-10 11 10-11 14	08-09 7 09-10 9 10-11 12	6 hired = 86% 4 hired = 44% 5 hired = 42%	0 1 1	$8.21 $9.13 $8.57	27 28 32
Community Hospital North—Indianapolis	Lawrence Township Schools, Eater Seals Crossroads	2011-2012						
Floyd Memorial Hospital—New Albany	New Albany/Floyd County Community Schools, Humane Resources	2008-2009	08-09	08-09 10	3 hired = 30%	0	$9.68 $8.57	23 28
Indiana Government Center—Indianapolis	Avon Community Schools, Metropolitan School District of Wayne Township, Brownsburg Community Schools, Plainfield Community Schools, Sycamore Services	2008-2009	08-09 9 09-10 11 10-11 12	08-09 9 09-10 9 10-11 11	2 hired = 22% 7 hired = 78% 7 hired = 64%	0 0 5	$11.25 $8.08 $8.64	40 31 27
Gibson General Hospital—Princeton	Gibson-Pike-Warrick Special Education Cooperative, Gibson County Area Rehabilitation Center	2009-2010	09-10 5 10-11 7	09-10 4 10-11 6	1 hired = 25% 3 hired = 50%	0 0	$8.25 $9.45	40 32
IU Health La Porte Hospital—La Porte	La Porte Community School s, Michiana Resources	2009-2010	09-10 5 10-11 7 11-12	09-10 4 10-11 7 11-12	2 hired = 50% 2 hired = 29% 1 hired	0 1 1	$7.39 $7.63 $7.25	20 33 20
Memorial Hospital—South Bend	South Bend Community Schools, ADEC	2011-2012						
Riverview Hospital—Noblesville	Noblesville Community Schools, Noble of Indiana	2011-2012						

SITE NOW CLOSED

Continued, page 3

Project SEARCH Indiana: Site Data, *continued*

St. Vincent Carmel Hospital—Carmel	Hamilton-Boone-Madison Special Services Cooperative, Noble of Indiana	2010-2011	10-11 11	10-11 10	6 hired = 60%	0	$10.61	24
Cook/Ivy Tech—Bloomington Young Adults	Cook Inc., Ivy Tech Bloomington, Stone Belt Arc	2010	1st 4 2nd 8 3rd 7	1st 3 2nd 7	3 hired = 100% 3 hired = 43% 1 hired	0 0 1	$7.88 $7.80 $9.00	31 28 20

Benefits Information Network: Progress Report

Exhibit 12
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Quarter Ending September 30, 2011

This Quarter's Notes and Highlights

- The Indiana Disability Benefits & Work website continues to be updated with SSA news.
- The Google Docs website containing all forms and manuals, so that BIN liaison materials are now available online. https://sites.google.com/site/bindocuments/. All materials and resources are being added to this site .
- A two day Social Security Informational Training is schedule October 19—20, and approximately 50 people have registered.

Benefits Information Network Data

	Basic BIN Training	Advanced BIN Trainings	SSW-Informational Trainings	Consumer/ Parent SSW Trainings	Number Certified BIN Liaisons	CWICS (Tier 3)	Number of Plans Reviewed	Hours of Technical Assistance
Jan-March	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
April-June	1 training 31 registrants	1 training 41 registrants	0 (cancelled due to low numbers)	4 trainings 67 attendees	**205**	**8**	**316**	**395**
July – Sept.	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Oct. – Dec.								
2011 TOTAL	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

Website Data

Disability Benefits Website	CCLC BIN Website
[illegible]	[illegible]

CENTER ON COMMUNITY LIVING AND CAREERS
INDIANA UNIVERSITY
Indiana Institute on Disability and Community

Exhibit 13
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

Vocational Rehabilitation Leadership Academy: Progress Report

Quarter Ending September 30, 2011

This Quarter's Notes and Highlights

- Independent Living Course was taken by 131 participants.
- Webinar series is now complete with a total of 135 participants - over 5 webinars.
- The Summer Mental Health Series has concluded and 112 people participated in 3 courses.

VR Staff Registrations & Orientation Completion

Timeframe	Registered New VRC Orientation	Registered Core Courses	Completed New VRC Orientation
To Date	23 VRCs 8 Area Sup & RMs 6 Central Office Staff 1 Intern	21 VRCs 8 Area Sup & RMs 2 Central Office Staff	56 VRCs 5 Area Sup & RMs 2 Central Office Staff
Totals	38*	31*	61*
May -Dec 2009	7 Staff	6 Staff	27 Staff
2010	18 Staff	15 Staff	26 Staff
Jan—March, 2011	2 Staff	0	1 Staff
Apr-June 2011	10 VRCs 1 Central Office Staff	7 VRCs 1 Central Office 2 Area Sup	7 VRCs
July-Sept 2011	8 VRCs	3 VRCs	3 VRCs

*To date totals only reflect individuals currently registered in Oncourse. Prior to August 2010, when the Oncourse platform was established, 61 people were registered in Articulate, with access to Orientation and the Core Courses. Very few of those individuals are counted in the totals above.

Web Statistics

Documents, Resources and Forms	To Date	Aug-Dec 2010	Jan-Mar 2011	Apr-June 2011	July-Sept 2011
Total number of documents accessed through New VRC Orientation via Oncourse	164	153	11	490	111
Number of VR staff accessing documents	13	10	3	12	3
CCLC Website Leadership Academy Data			Visits-90 Unique Visitors-46 Page Views-602	Visits-86 Unique Visitors-46 Page Views-578	Visits –94 Page Views – 522

CENTER ON COMMUNITY LIVING AND CAREERS
INDIANA UNIVERSITY
Indiana Institute on Disability and Community

Vocational Rehabilitation Leadership Academy: Course Data

Course Category	Number of course completions	2009	2010	Jan-Mar 2011	April-June 2011	July-Sept 2011
Core Courses - for VR Counselors						
Foundations of Rehab.	27	10	12	1	3	1
Case/Caseload Mgt	23	6	14	1	4	1
Consumer Benefits	12		7	1	3	1
Psych/Psychosocial Aspects	12		7	1	2	1
Medical Aspects	14		10	1	2	1
Counselor Roles/Resp.	10		5	3	2	0
Job Related Services	10		6	2	2	0
Mental Health/Add./Couns.	10		5	3	2	0
Assistive Tech	12		6	3	2	1
Career Guidance/Couns.	22	6	12	2	2	0
Specialized Courses						
Employment Specialist Training - for Employment Service Providers	158	113	45	16* (pilot)	21	23
VI Specialist Training - for VI Counselors	(Will go live Oct. 2011)					
Independent Living Centers - for VR Counselors	0	NA	NA	NA	0	131
Advanced Courses - open to all						
Personality Disorders 1 & 2	28					28
Ex-Offenders	54					54

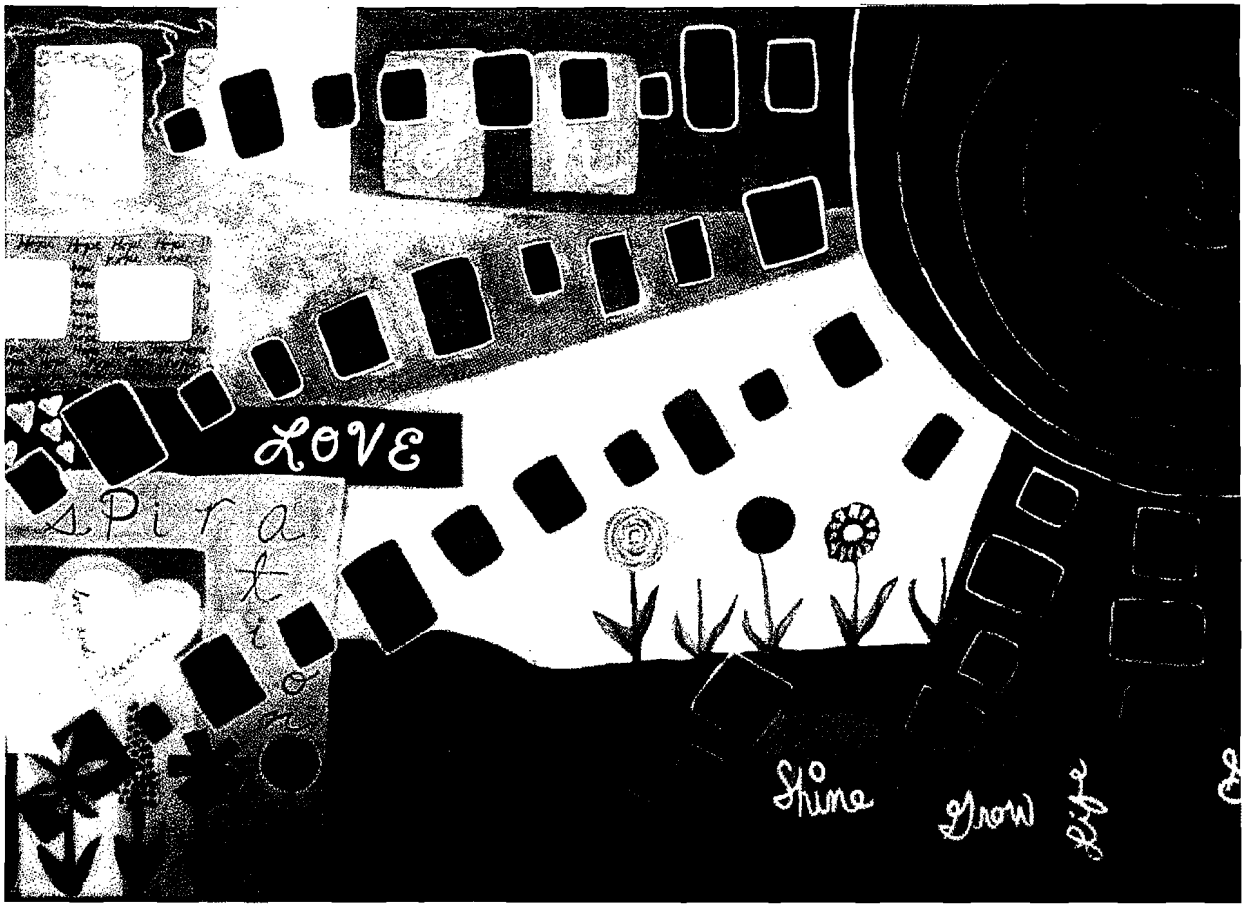
*Reflects number of participants in a pilot program testing an online/face-to-face hybrid training model.

Webinar Data

Topic	Open To	Date	Number of Participants
Time Management & Organizational Skills	All	Broadcast 1/13/11	31 Participants
Communication	All	Broadcast 2/8/11	19 Participants
Customer Service	All	Broadcast 3/3/11	14 Participants
Problem Solving & Strategic Thinking	All	Broadcast 3/30/11	48 Participants
Leadership and Change Management	All	Broadcast 4/20/11	23 Participants

Exhibit 14
Commission on
Developmental Disabilities
Meeting #3 October 5, 2011

The Arc
Indiana



Waiting List Task Force Recommendations

The Arc
Indiana

Achieve with us.

In response to Indiana's growing waiting lists for home and community based services funded by Medicaid waivers, The Arc of Indiana called on self-advocates, family members and partnering advocacy organizations to form a Waiting List Task Force in May 2011.

The Arc.
Indiana

Waiting List Task Force

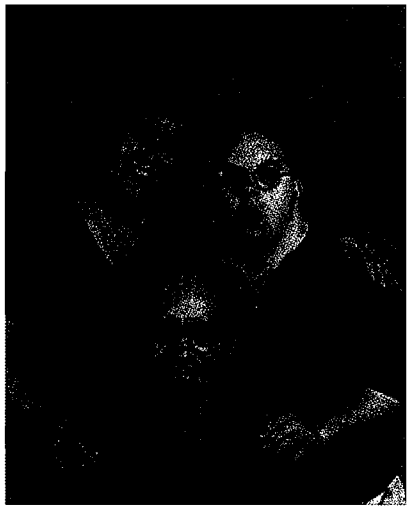
The task force reviewed, discussed and made recommendations on critical issues, including:

- How to manage waiting lists
- Criteria to be on the waiting list
- Criteria to receive waiver services
- Strategies to help those waiting for services
- Strategies on how to best utilize funds and other resources for individuals receiving waiver services

Issue 1 - *How can waiting lists be managed and what should eligibility criteria be?*

Over 19,000 people are on waiting lists for home and community based services.

This includes people who signed up for services over 12 years ago.



This means that someone who signed up for services when he or she was 18 is now 30 years old.

The Arc.
Indiana

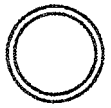
Waiting List Management - Proposals

Management of the waiting list must move to an electronic process to *supplement* the paper process.

- Ability to apply for services and update information online
  supplement paper applications, not replace
- Ask community agencies to host a web access point with information on other community and natural supports
  digital divide narrows every day
- Designate a waiting list day or week to encourage families to update information
  like cable Amnesty week

The Arc.
Indiana

Waiting List Management - Proposals



- Eliminate the Developmental Disabilities Profile (DDP) for individuals applying to be on the waiting list
- Develop criteria that *should* qualify someone to be on the waiting list, making clear that it is *not* a guarantee for future eligibility. For example, a diagnosis of Down syndrome, recipient of special education services with appropriate diagnosis, etc.
- Make clear that families are responsible for keeping contact information current and provide an easy way to do this, including an online service

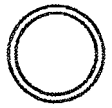
The Arc.
Indiana

Issue 2 - *How can individuals get help and information while waiting?*

How can we best assist families and individuals - who face waiting for the Medicaid waiver for years - with other community supports and services, as well as other government funded programs?

The Arc.
Indiana

Helping People Who are Waiting - Proposals



- Include a "check box" on the waiver application that allows individuals and families to indicate they want to be contacted by an advocacy group to help guide them on what they can do while they are waiting for the waiver

comprehensive (more than a list)

- Require BDDS to provide information to applicants on advocacy group and community organizations, that includes details on how they may be able to help

- Utilize case conferences at all ages to provide information on community resources and supports, as well as government programs such as SSI, children's health insurance, and Voc. Rehab.

The Arc.
Indiana

Issue 3 - *What is the most effective and fair way to distribute resources?*

Decisions on how to distribute scarce resources must be done through a clear and transparent process. A lack of transparency can lead to the belief that preferential treatment is given in some cases and denied in others through a subjective, rather than objective, process.

focus on transparency to achieve objective perception

The Arc.
Indiana

Effective and Fair Distribution of Resources - Proposals

- Continue to bring as many individuals as possible onto the Support Services Waiver
- Allocate a portion of the Support Services Waiver for those leaving high school to dovetail with the state's emphasis on employment
- Do NOT eliminate the Support Services Waiver allocation to students who are still in school

they are receiving services, but prob not receiving all the services they need.

The Arc.
Indiana

Effective and Fair Distribution of Resources - Proposals

- Target individuals for the DD and Autism waivers based primarily on need rather than length of time on waiting list severity/need vs. length of time waiting
- Continue priority waivers for people facing an emergency or crisis – including aging caregivers, loss of caregiver, aging out of facilities for children, transitioning from institutions

The Arc.
Indiana

Effective and Fair Distribution of Resources - Proposals

- Remainder of waivers should be given to individuals who have been on the waiting list the longest
- Make Medicaid available to children under the age of 18 to help families faced with the additional cost of caring for a child with a disability, particularly those with significant medical or behavioral needs that may lead to out-of-home placements
- Provide service coordination to individuals on the waiting list who are over the age of 18 to help them access community supports, Medicaid, Voc. Rehab., and SSI

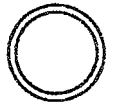
The Arc.
Indiana

Issue 4 - *What eligibility factors should be taken into account to receive waiver services?*

Legislation passed in the 2011 legislative session directs FSSA to study the issue of parental income and co-pays for families of minor children

The Arc.
Indiana

Eligibility for Waiver Services - Proposals



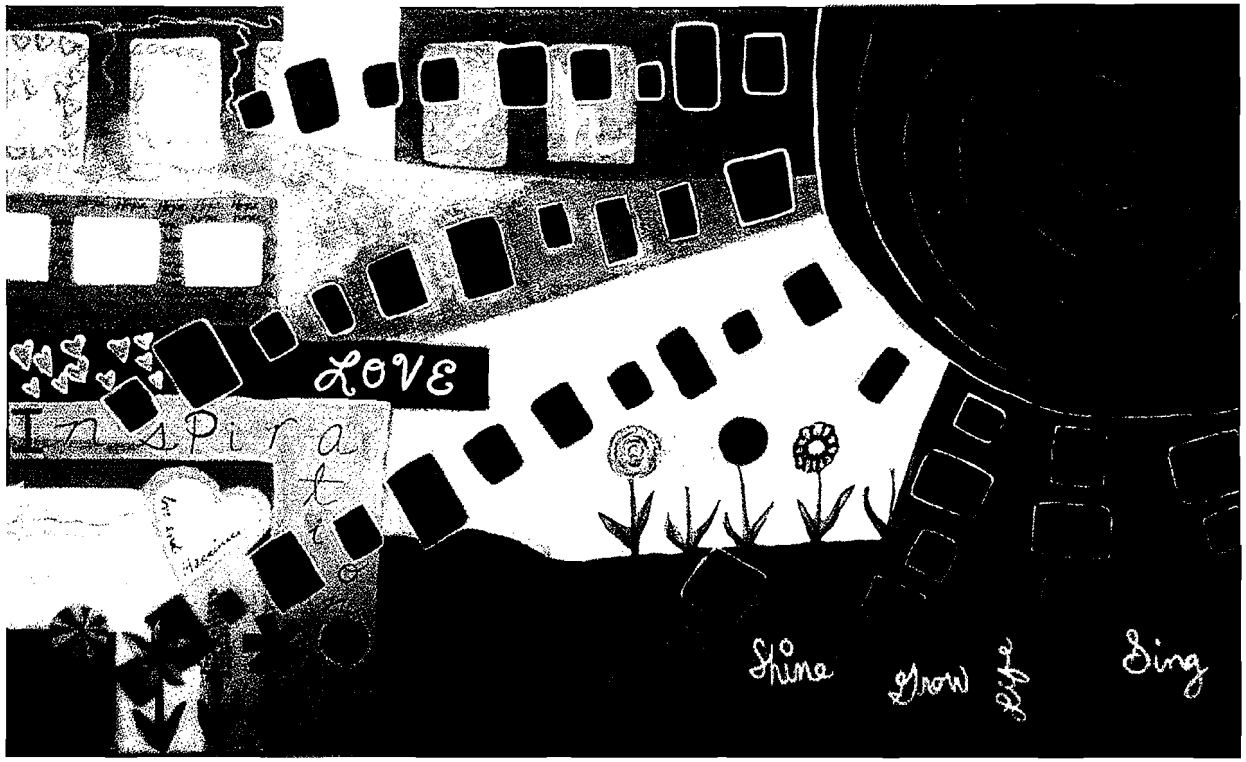
- The Arc strongly believes requiring families to make a copayment for Medicaid waiver services for their child who has a significant disability is neither cost effective for the state or the waiver program – let alone for the family
- The cost to care for a child in a children's facility now approaches $500 per day in state funds. Medicaid waivers help keep families together, save the state money, and are the right thing to do
- We understand and recognize that considerable pressure on the Medicaid system necessitates continuing to find ways to develop a more cost effective system, and we are committed to working with FSSA to do that

not asking for more $, just to better utilize what is available.

The Arc.
Indiana

The Arc of Indiana

800-382-9100



The Arc™

For people with intellectual and developmental disabilities

Achieve with us.

15

Waiting List Task Force

Recommendations

August 2011

ISSUE 1: How can the waiting list be managed and what should the eligibility criteria be?

The current waiting list is over 19,000 people and includes people who signed up over 12 years ago. Recently over 250 people were targeted for the DD Waiver from the waiting list. Often it is difficult to contact people who signed up 12 years ago. How should we manage the waiting list, what steps should be taken to assure people have up-to-date information and know what can be done? What should be the criteria for eligibility to be on the waiting list? For example FSSA is preparing a policy statement that children under six can apply for Medicaid waivers but must come back into the office to have a Developmental Disabilities Profile completed to assure they are eligible.

PROPOSAL 1:

1. The Waiting List Management must move into an electronic environment to **supplement** the paper process:

    a. Develop a website to apply for waiting list, update information and send requests

    b. Add email and cell phone lines to current waiting list document

    c. Ask community agencies to volunteer to host a web access point with info on other community natural supports on site and be available to families

    d. Ask Community Centers to offer web access point with same info – could partner with community agencies to support

    e. Send regular snail mail post card – annually to people on the list sharing info about website and need to update addresses

    f. Every contact with individuals (or their guardians) on the waiting list should ask for their interest in getting more information about community supports and advocacy groups that relate to the individual who has a disability

g. Seek support from BMV to host web access point and include info on DD services in BMVTV on site and to consider simple flyer in license plate renewal information – could focus also on employment and jobs

h. Add to states website at BMV info box on DDRS

i. Get all related Disability groups to add a box on their website

j. Twice a year have waiting list day or week when every agency in the state reaches out to families and consumers to sign up and update records:

    i. March for Disability Awareness Month

    ii. October for Employment Awareness Month

k. Develop commitment from other disability groups to respond to requests for information from people on the waiting list for support

2. Who should go on the waiting list:

    a. There is a legitimate argument that it can give people false hope to be put on a waiting list that they clearly will not meet eligibility

    b. There is also a legitimate argument that screening people just to be on the list is costly and very time consuming. For example if 2,000 people apply to be on the waiting list each year and it takes approximately three hours of staff time to schedule a DDP, conduct the DDP, communicate back to the family and then report on the findings; that would mean the state would spend approximately 6,000 staff hours or three full-time positions just to screen people to put them on a waiting list

    c. In this case we believe the costs far exceed the value received and there is a middle way:

        i. We recommend elimination of the DDP process for people applying to be on the waiting list

        ii. Replace the DDP with a very clear explanation to families applying of the criteria, the information needed to be affirmed on the application to be on the waiting list, a clear statement that just being placed on the waiting list is no guarantee that you will meet future criteria at the time you reach the top of the list, and you will be responsible for keeping the contact information and child's status updated on the list

iii. Any of the following categories should qualify someone to be on the waiting list (again, not a guarantee of eligibility):

a. A child receiving special education services with diagnosis or another appropriate DOE category

b. VR eligibility with appropriate diagnosis

c. Doctor's appropriate diagnosis

d. Served by First Steps with appropriate diagnosis

e. Other collateral information

d. Some may feel this opens up the waiting list for exploitation by families looking to obtain something for which they are not eligible. We disagree. Trying to get on a waiting list that may be 12 years long is not something that will appeal to people that are looking to scam the system

e. In addition to this process, we would suggest only giving a DDP to anyone that does not have documentation to support one of the above categories. BDDS would not have the documentation submitted to avoid the paper collection and storage process

f. Again, there would be clear and strong language that getting on the waiting list does not promise eligibility at some time in the future

g. Placing individuals on the waiting list also allows FSSA to maintain contact with people who then can be directed to natural supports, get electronic information about employment and other ways to develop greater independence and help people not need so many services in the future

ISSUE 2: How can individuals get help and information while waiting?

While waiting, how can we assist these people, (the over 19,000 on the waiting list) with other community supports and services – both state programs like Vocational Rehabilitation as well as non-paid supports and community involvement, and how do we help them connect with Medicaid and SSI when appropriate.

PROPOSAL 2:

1. When a person applies for the waiver they have to sign a release of information. A box should be added to the application that would indicate the individual would like to be contacted by an advocacy group to talk about what to do while you are on the waiting list. Then BDDS would give the contact information directly to the advocacy organization to make the contact after the individual/family had "opted in."

   Additionally, after an individual applies for waiver services, the confirmation letter they receive should include information including name, contact information and details about advocacy organizations --- not just a list, but an explanation of each group and how the group might help if you contact them. BDDS should also have an advocacy organization information page to distribute to families with details and contact information for statewide advocacy organizations.

2. Develop a presentation about community supports and other resources that could be given at a variety of events like kindergarten roundups, transition events, conferences like GPCPD and First Steps transition events (like Cluster G has). It would be important to give the presentation at events targeted for a variety of ages and in a variety of ways like in person and a webinar to reach the largest audience.

3. Utilize case conferences at all ages, much like VR does for transition, to provide information to families about community supports. It would be important to share this information at multiple ages and early while individuals are waiting for waivers like during First Steps transition, entering elementary school, and beginning Jr. High.

ISSUE 3: What is the most effective and fair way to distribute resources?

Evaluate the current recommendations including priorities, waiting list and monies available and then make recommendations back to FSSA.

PROPOSAL 3:

The current recommendations start from the premise that we are making short-term recommendations regarding the waiting list, and we need to develop a more transparent and clear process for making determination based upon need before any major change is made. The identification of need and the extent of that need must be done in an open and clear process to avoid families and consumers misunderstanding the process and becoming both discouraged or disbelieving that there is any process. A lack of transparency and understanding gives way to the idea that somehow personal preferential treatment is given to some cases and denied to others in some subjective manner.

1. SSW:
    a. Continue what is being done to bring as many people on the SSW as possible. Allocate some portion of the waivers for those leaving high school using a sub-list, since the state is emphasizing obtaining employment, and the remainder to those on the waiting list based upon date of application. Allocation to be determined based upon the total number of slots available

    b. Do NOT eliminate SSW allocation to students who are still in school. Continue with the sub-waiting list for those coming out of high school

    c. Make Medicaid available to children under 18 to help families better cope with the additional costs of caring for a child/children with significant disabilities. Particular emphasis should be given to children with significant medical or behavioral needs that if left unsupported will lead to sooner out-of-home placements

    d. Provide service coordination to those on the waiting list who are over 18 in a coordinated effort to access community supports and programs through Medicaid, Vocational Rehabilitation, and SSI to provide greater access to work and community participation

2. DDW/Autism Waiver:
    a. Being targeted for a waiver should be primarily needs based rather than length of time on waiting list

    b. Continue priority waivers for emergency placement situations (previously categorized as Health and Welfare Threatened, Loss/Incapacitation of primary caregiver, Ageing primary caregiver, and crisis management.) Utilize a group (like the Human Rights Committee) to determine whether a case meets the level of crisis. Other priority categories including no longer need/receive active treatment in a group home, transition from 100% state funded, aging out of DOE/DCS/SGL, and institutional transitions need to have some evaluation to determine the level of need and the critical nature of the situation

c. Remainder of waivers should go to those who have been on the waiting list the longest

d. Make Medicaid available to children under 18 to help families better cope with the additional costs of caring for a child/children with significant disabilities. Particular emphasis should be given to children with significant medical or behavioral needs that if left unsupported will lead to sooner out-of-home placements

e. Provide service coordination to those on the waiting list who are over 18 in a coordinated effort to access community supports and programs through Medicaid, Vocational Rehabilitation, and SSI to provide greater access to work and community participation

f. Allocation to be determined based upon the total number of slots available – but the first priority is the crisis cases

g. Develop a means to communicate with those waiting about the process and publish the results of targeting/ priorities and what can be done while waiting

ISSUE 4: What eligibility factors should be taken into account to receive waiver services?

Language in the recently passed Budget Bill H.B. 1001 directs FSSA to study the issues of parental income and suggests a co-pay for families of minor children who earn over 500% of the federal poverty level – approximately $110,000 per year for a family of four. What should our position be on this issue?

PROPOSAL 4:

1. The Arc of Indiana has looked carefully at the issue of establishing, for the first time, a co-pay system for the parents of minor children receiving Medicaid waiver services.

    a. Considerable pressure on the Medicaid system necessitates The Arc of Indiana and FSSA to continue to find ways together to develop a more cost effective system

    b. The Arc strongly believes requiring families who earn over 500% of the federal poverty level to make a co-payment for Medicaid waiver services for their child who has a significant disability is neither cost effective for the state nor the waiver

2. A study of families currently receiving waiver services would show a very small number with incomes over 500% FPL – some estimates are as few as 60 families.

    a. Relatively few children under the age of 18 are currently on the DD or Autism waiver, and even fewer are in families above 500% FPL meaning a system to collect financial data and assess and collect co-pays would not be cost effective when measured against the amount of time and money spent to develop and maintain the system

    b. We believe the cost would far exceed what might be collected from a reasonable co-pay, and might have unintended consequences. For example, many families continue to carry private health insurance for their child even after they become Medicaid eligible. When faced with a co-pay, families might be forced to give up private health insurance for their child in order to afford the co-payment. This would result in a greater cost to Medicaid to cover the child's health care needs – far more than what would be collected from a copayment

3. The Arc and the Task Force strongly believe that requiring a co-pay goes against a primary goal of a community-based system - to allow children to live with their families rather than in children's institutions. The cost to care for a child in a children's facility now approaches $500 per day in state funds as these facilities are not Medicaid funded. Moreover, keeping families together is the right thing to do.

4. The Arc of Indiana and the Task Force strongly oppose co-pays for children under age 18 receiving Medicaid waiver services. We do support and are actively engaged in creating system reforms that will address the overall cost effectiveness of the waiver program.

The Arc of Indiana
Waiting List Task Force

Erika Steuterman (Chairperson), Parent
Judy Abbott, Parent
Jennifer Akers, Parent, Family Voices
Denise Arland, Parent, FUSE
Courtney Clark, Self Advocates of Indiana
Melody Cooper, Self Advocates of Indiana
Heather Dane, Parent, Family Voices
Brenda Darrol, Parent, The Arc Network
Jill Dunn, INARF President, Bona Vista
Debra Easterday, Parent
Laura Fife, Parent
Kerry Fletcher, Parent
Catherine Gray, Parent
Jim Hammond, INARF
Mark Hisey, Parent
David Mank, IIDC
Tom Milvert, Parent
Kim Opsahl, INARF
Dana Renay, Parent, ASI
Cindy Riemersama, Parent
Willaine St. Pierre Sandy, Parent, The Arc Network
Karyn Willmann, Parent

Staff Support: John Dickerson, Jill Ginn

The Arc of Indiana
www.arcind.org
317-977-2375 800-382-9100