



COMMISSION ON DEVELOPMENTAL DISABILITIES

Legislative Services Agency
200 West Washington Street, Suite 301
Indianapolis, Indiana 46204-2789
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MEETING MINUTES¹

Meeting Date: September 7, 2011
Meeting Time: 1:00 P.M.
Meeting Place: State House, 200 W. Washington
St., Senate Chamber
Meeting City: Indianapolis, Indiana
Meeting Number: 2

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

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

I. Call to Order

Senator Connie Lawson, Chairperson, called the meeting to order at 1:10 P.M. Chairperson Lawson told the members that the Family and Social Services Administration (FSSA), Division of Disability and Rehabilitative Services (DDRS) provided answers to questions posed at the August meeting. (Exhibit 1) Senator Lawson asked members to review the answers and to be ready to pose any additional questions at the October 5th meeting.

II. Presentation from Ms. Julia Holloway, Director, DDRS and Ms. Dawn Downer, Director, First Steps

Ms. Dawn Downer, reviewed the goals of the First Steps program and updated the members on the activities of the First Steps program for the previous year. (Exhibit 2) Ms.

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.

Downer reiterated that the state is the payor of last resort for the First Steps program. In answer to questions from Senator Lawson, Ms. Downer explained that the reduction in the number of children served from 2010 to 2011 was caused by children aging out of the program as well as a new screening test being used. Ms. Downer said that there continue to be struggles in providing services in rural Indiana. First Steps is trying to coordinate and combine services to make service delivery easier.

In answer to questions from Representative Klinker, Ms. Downer explained the process used when a family is behind in payments for services. When families are more than 60 days behind in their payments, both oral and written contact is made with a 2 week period to determine why the family is behind. If the family's financial circumstances have changed, a new rate is determined for future payments and a payment plan is developed for the arrearage. Only if the family does not make back payments and or accept a payment plan is the child removed from the program. It appears that families are more likely to reject a payment plan and allow a child to be removed from the program as it becomes closer to the time the child is three years of age and no longer eligible for services. Last year only ten children were removed because of lack of payment.

Ms. Downer, in answer to a question from Senator Breaux, said that families who are delinquent for 60 days actually receive the services 120 days before the billing notice is sent. Ms. Downer said that the average amount of service per month is 4.6 hours per child. Ms. Downer stated that currently First Steps is receiving payment for approximately thirty percent of the claims submitted to insurance companies.

Ms. Holloway told the members that music therapy is one of the services eligible for reimbursement under First Steps. Ms. Downer said that to be eligible to provide services under the music therapy category, the provider must have early childhood training.

III. Direct Support Professionals of Indiana (DSPIN)

Ms Dee Quaglio, Vice Chairperson, DSPIN, testified that DSPIN is a new organization of direct support professionals. (Exhibit 3) The compensation for direct support professionals in Indiana starts at \$8 per hour with the national beginning salary being \$9.46. Ms. Quaglio pointed out that grocery clerks can start in Indiana at a salary of \$13 with no training and with no responsibility for taking care of persons in need of services. The turnover among direct support professionals is approximately thirty percent. The goals of DSPIN include increasing the retention rate through education.

IV. Other Business

Three parents made presentations concerning issues faced by their children. Senator Lawson indicated that FSSA would not be able to respond publicly to the situations of these families because of concerns with the HIPAA laws.

(A) Ms. Sherry Moody discussed concerns she has with the Medicaid waiver. (Exhibit 4) Ms. Moody's son is physically and mentally challenged and needs constant care. According to Ms. Moody, last year her son's budget was decreased by over \$16,000. She is concerned that his residential service budget will decrease in excess of \$25,000 next year. No final decision has been made on the amount Ms. Moody's son will be eligible to receive for 2012, but the family is very concerned.

(B) Ms. Linda Phillips' son is the roommate of Ms. Moody's son. (Exhibit 5) Ms. Phillips is also concerned about the impact cuts will have on the ability of her son to continue his current living situation.

(C) Ms. Laura Fife discussed the situation of her daughter who is on the waiting list for the developmental disabilities (DD) waiver. (Exhibit 6) Ms. Fife has been a case manager for individuals who have been on the DD waiver. Ms. Fife offered the following four solutions for the problems that exist with the waiver:

- (1) Engage civic groups and non-profits in Indianapolis to partner with DD clients to create a meaningful day experience.
- (2) Allow therapies to be part of the behavioral allocation.
- (3) Allow for broader service codes and a simplified billing system.
- (4) Personalize case management.

V. Adjournment

The meeting was adjourned at 2:35 P.M.

The next meeting will be October 5 at 1:00 P.M. in **Room 431 of the State House**. Please note the room change.

Commission on Developmental Disabilities

8/10 DD Commission Deliverables

Meeting 2
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Exhibit 1

Lawson:

- Provide a copy of the "waiver journey" to DD Commission

Copy will be available on September 6, 2011 at <http://www.in.gov/fssa/2328.htm>

- Provide a more detailed explanation of how the inter-agency agreement between Bureau of Developmental Disabilities (BDDS) and Vocational Rehabilitation (VR) is going to work.

DDRS identified money available from BDDS as a result of the Division's efforts to move individuals from 100% state funded services on to federally matched waiver services. The inter-agency "agreement" is simply a statement that BDDS will transfer funds from one account to a VR account.

The Rehabilitation Services Agency (RSA), VR's federal oversight agency, requires we have a Memorandum of Understanding (MOU) for any money transferred to VR for federal match.

- What is the scope of the Demonstration Projects?

The purpose of the Demonstration Projects is to assess & evaluate employment needs and to develop employment opportunities and solutions for individuals with developmental and intellectual disabilities as well as individuals on the autism spectrum.

- How can others participate in the demonstration projects if interested?

These projects are essentially pilots around the state to identify what ideas could work and what ideas may not be effective around employment for individuals with developmental disabilities. They are kept small intentionally in order to allow for good data collection and focused work in specific areas.

The areas identified as demonstration sites were chosen because they represent a wide array of demographic areas and geography ranging from very urban to rural. Any provider, business leader, community leader or citizen was and is welcome to participate in the projects.

The end goal is to identify new ideas on how to employ more individuals with developmental and intellectual disabilities.

- Provide a map (geographical locations) Group Home locations in IN.

<http://www.in.gov/isdh/reports/QAMIS/icfdir/index.htm>

Breaux:

- What is the procedure for the VR match?

For the additional match, an interagency memorandum of understanding will be developed, which is a transfer from one account to another via administrative action.

- Provide OBA data on budgets increasing/decreasing (44%, 55%) in monetary amounts.

Attached is a net allocation table based on OBA. This table compares individuals who had annual dates in 2010 and 2011 in months January through May. This gives a year-to-year comparison of individual's pre-OBA and post-OBA.

- What are the standard questions asked during the PARS process?
 1. What need(s) are not currently met
 2. What documentation supports the request for the Allocation Review? If a specific incident or several incidents support the request, please briefly describe how the request addresses the incidents. Also include other specific conditions or situations.
 3. Does the consumer share the requested services with any other consumers?
 4. Please describe the impact of the unmet needs on the consumer's health and welfare.
 5. What strategies has the team implemented to meet the needs of the consumer within the current allocation (i.e. rearranging house or service mix, exploring natural supports)?
- Why is DDRS placing an emphasis on employment for wait list participants?
 - Does this save the state money? How does it save money?

First and foremost it gives individuals an opportunity for a meaningful productive life. Everyone may not be aware that there is employment assistance for individuals with developmental disabilities and we want to provide the opportunity for everyone to participate. Also, by becoming employed, the amount of waiver services an individual may need is significantly reduced as a result of employment. This is good policy and good use of state dollars.
- Provide a list of accreditation bodies for DD providers.

As stated in IC 12-11-1.1-1:

- (1) The Commission on Accreditation of Rehabilitation Facilities (CARF), or its successor.
- (2) The Council on Quality and Leadership in Supports for People with Disabilities, or its successor.
- (3) The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), or its successor.
- (4) The National Committee for Quality Assurance, or its successor.
- (5) The ISO-9001 human services QA system.
- (6) An independent national accreditation organization approved by the Secretary.

- What is the average length of time on waitlist?

Currently we are serving the following dates on each of the waivers:

DD – 5/2/1999

Autism – 9/8/1999

Support Services – 11/4/2002

- What is the total spend on DD, Support Services and Autism waivers?

DD – \$428,345,000

Autism – \$18,149,000

Support Services – \$36,197,000

Klinker:

- How many clients have appealed their OBA?

Type	Outcome	Number	Total	% of Category
DDW OBA	Voluntary Withdrawal	69	92	75%
	State Favored	12		13%
	Appellant Favored	3		3%
	No decision yet	8		9%
AUW OBA	Voluntary Withdrawal	3	5	60%
	State Favored	1		20%
	Appellant Favored	0		0%
	No decision yet	1		20%

- Of the budgets that are appealed – how many changed?

Of the 97 appeals listed above, 72 were changed before the appeal and withdrawn and 3 changed as a result of the appeal.

Culver:

- Is there a more accurate way to capture waiver wait list numbers?
 - How many people were removed from waitlist due to “clean-up”?

2,533

- How many new added on by application?

915 individuals have been added to the waitlist by application since September 1, 2010 (approximate timeframe of waitlist cleanup).

- How do we figure out if the individuals really need services or are on the list in anticipation of needing services in 10 to 12 years?

This is a policy question that has long been discussed. The waiting list would certainly be a more effective management tool if it was based solely on need, but the system is not currently set up that way. We would need to establish a system that gave families the confidence that their loved one would have access to services at the point they felt they needed them. Due to the fact that the waiver is not an entitlement program and based on the availability of funds, this is a difficult position for the Division to take.

There are a couple of ideas being evaluated to address this problem and we hope that recommendations for a solution are included in the agency's final report as outlined in the HB 1001 Sec. 144.

- Would contracting with a second case worker agency beget more Federal dollars?

- How much exactly would the state receive?

The value of the IPMG Case Management contract in SFY 11 is \$24.3 million. At the current 50/50 admin match rate the state is receiving for case management the state share is \$12.15 million.

All other things being equal, if the state had multiple case management vendors, at current match rates (66.52% federal/33.48% state) the state share would be \$8.14 million.

- When will DDRS make a decision on whether to contract with a second case worker agency?

Several options are being considered at this time, including other options to enhance the federal match, but a decision likely won't be made before the spring of 2012.

January through May 2010/2011 Authorization Comparison

Jan - May 2010 RHS Auth	Jan - May 2010 Day Auth	Jan - May 2010 Bman Auth	Jan - May 2010 Other Auth	Jan - May 2010 Total Auth
\$ 15,022,292.68	\$ 1,098,786.68	\$ 633,347.00	\$ 655,563.75	\$ 17,409,990.11

Jan - May 2011 RHS Auth	Jan - May 2011 Day Auth	Jan - May 2011 Bman Auth	Jan - May 2011 Other Auth	Jan - May 2011 Total Auth
\$ 12,878,515.85	\$ 2,041,287.35	\$ 884,774.40	\$ 736,423.37	\$ 16,541,000.97
-14.3%	85.8%	39.7%	12.3%	-5.0%



00 Commission

Meeting 2

9/7/11

Eph.b.t. Jr

**Serving
Individuals
with
Developmental
Disabilities
in Indiana**

*Presentation to the Indiana Commission on Developmental
Disabilities*

Division of Disability & Rehabilitative Services

September 7, 2011

First Steps Indiana's early intervention system

First Steps is Indiana's implementation of Part C of the Individuals with Disabilities Education Act (IDEA), providing services to infants and toddlers birth up to age 3 and their families.

Eligibility

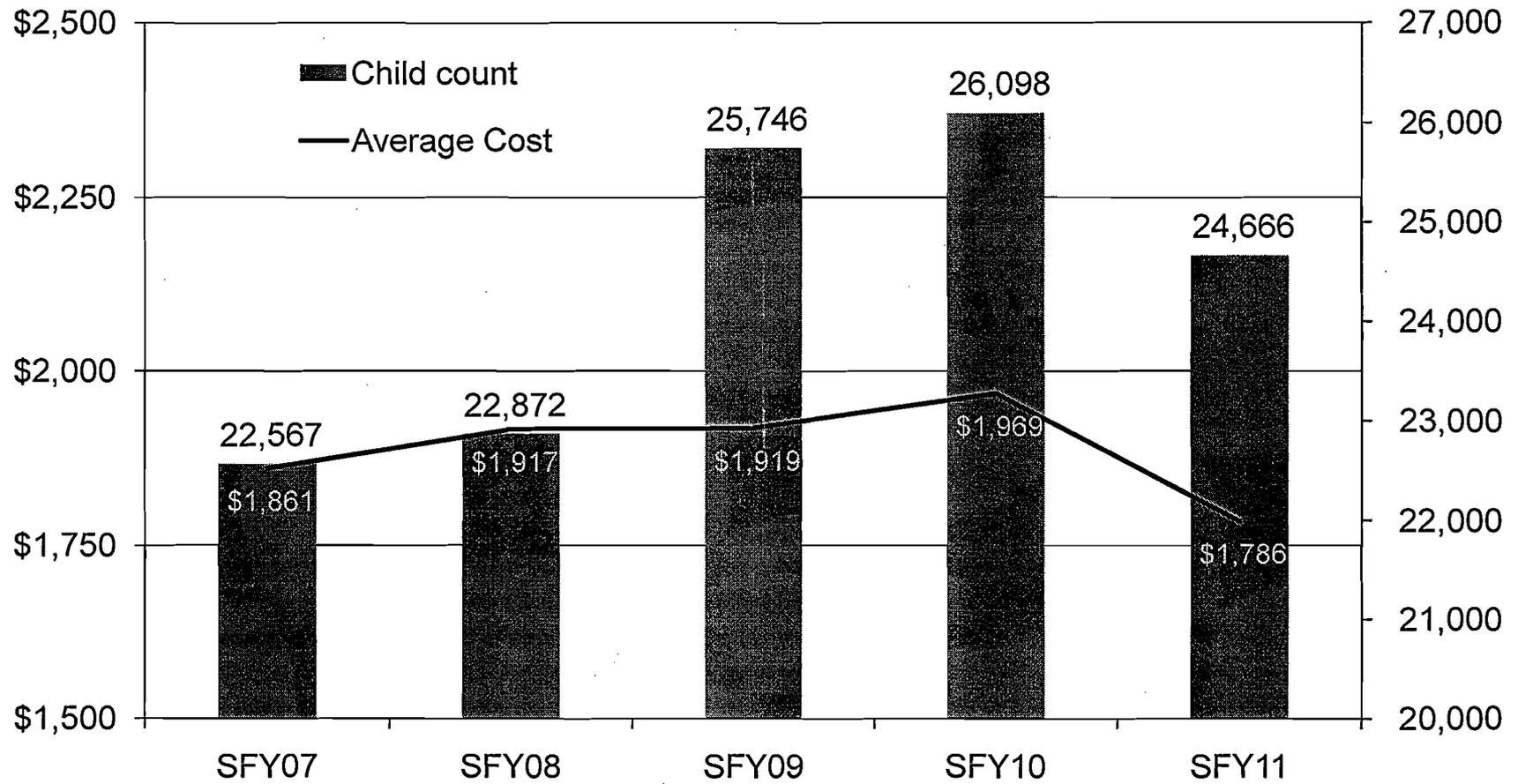
- Children under age 3**
- Experiencing a developmental delay**
- Medical diagnosis with high probability of developmental delays**

During SFY 2011, First Steps served over 24,000 children and their families.

Funding

Federal Part C, Medicaid, TANF, State early intervention funds, private insurance and family cost participation.

Child Counts and Costs



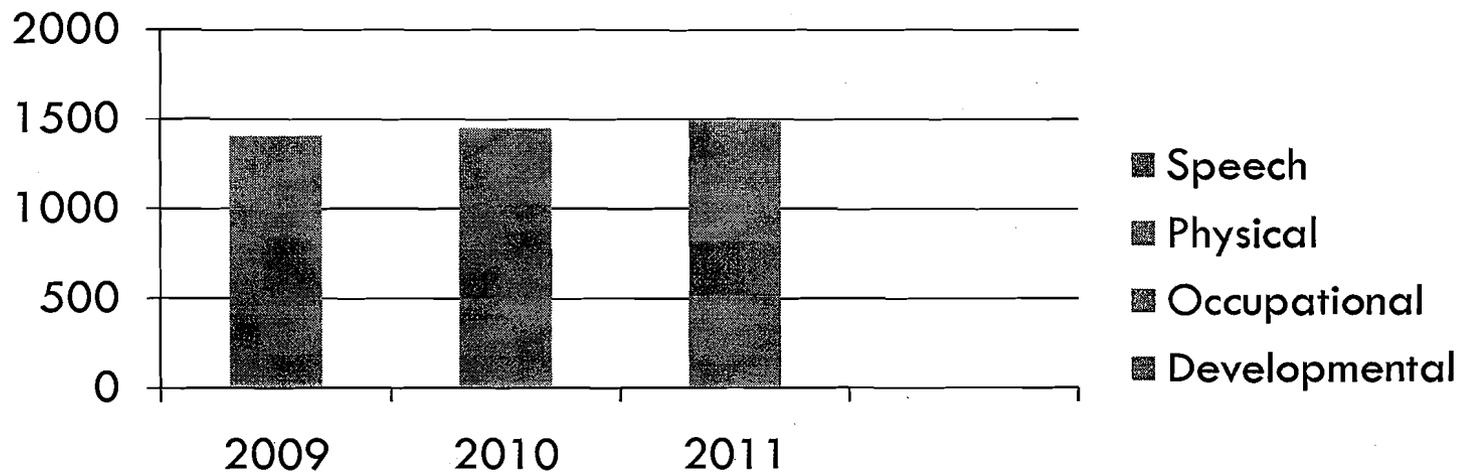
Provider Networks

Agency Requirements

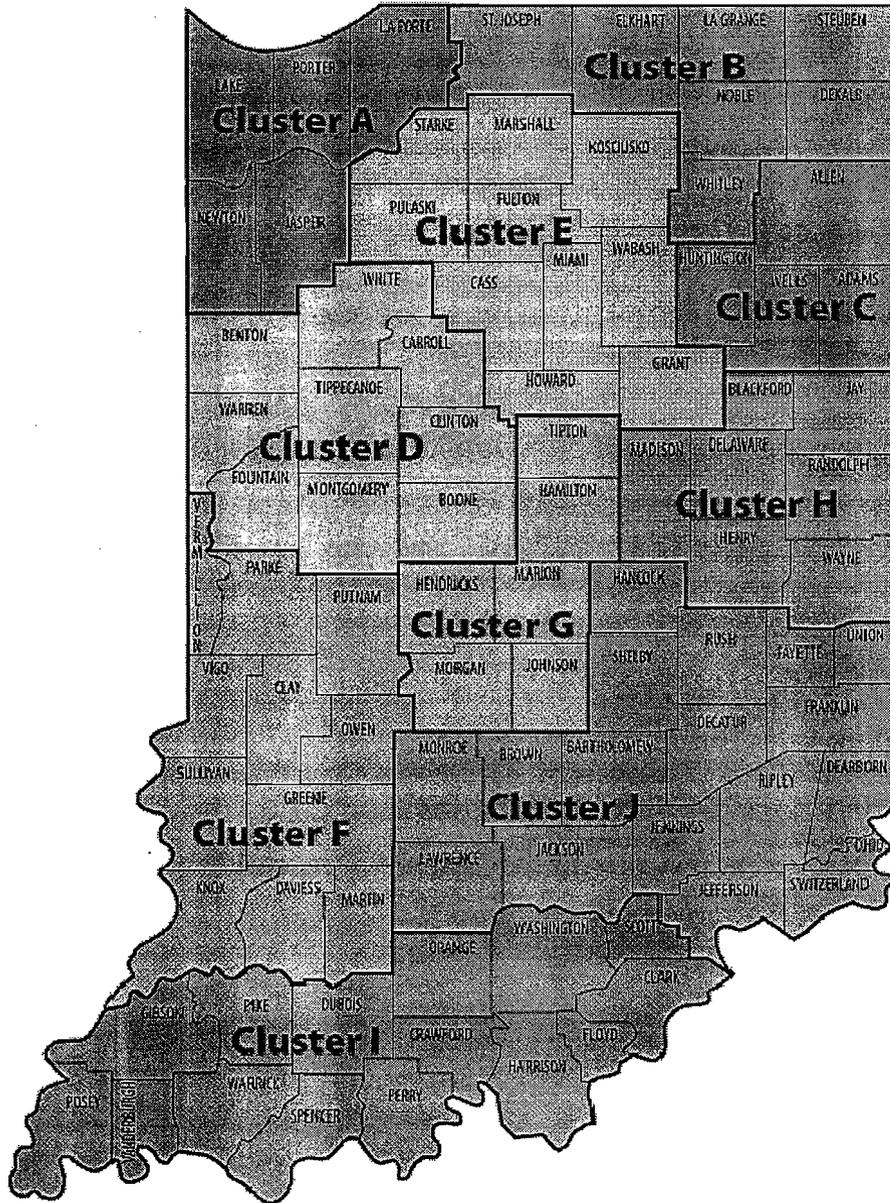
- Ability to meet the comprehensive needs of families
- Demonstrated ability to bill insurance
- Clear line of authority and supervision
- Training or continued education opportunities

42 Agencies

Over 1,400 individual service providers



First Steps Agencies (by Cluster)



Cluster A:

Therapeutic Branches
 Kidworks, LLC
 Opportunity Enterprises, Inc.
 Homefront Family Services
 AWS

Kid Power Therapy
 Wee Care Therapy
 Jacob's Ladder
 St. Margaret Health

Cluster B:

AWS
 LOGAN Community Resources
 Children's Therapy Innovations

Hand in Hand
 Possibilities Northeast

Clusters C, E, H:

Hand in Hand
 Bona Vista Programs, Inc.
 Nutrition Consultants & Assoc.

Possibilities Northeast
 Homefront Family Services
 Hopewell Center

Cluster D:

Therapies at Play, Inc.

Pediatric Physical Therapy

Cluster F:

Kids Only, Inc.
 Developmental Services, Inc.

Sycamore Services
 Collaborating for Kids, Inc.

Cluster G:

Pediatric Specialty Associates, Inc.
 Toddler's Choice
 Talking Time Learning Center
 Feeding Friends
 Children's Therapy Connection
 Sycamore Services
 Peditplay
 Noble of Indiana

Easter Seals Crossroads
 Kids Only, Inc.
 Advanced Children's Therapy
 Janus Development Services
 Cornerstone Rehabilitation
 Collaborating for Kids, Inc.
 Accord Children's Therapy

Cluster I:

The Rehabilitation Center
 SIRS
 Westview West Outpatient Therapy Clinic

Ginger Whitler, Inc.
 Rauch, Inc.

Cluster J:

Peditplay
 Kid's Only, Inc.
 Westview West Outpatient Therapy Clinic
 All Kids Can
 Accord Children's Therapy

Toddler's Choice
 Developmental Services, Inc.
 Collaborating for Kids, Inc.
 A Step Ahead Pediatric Therapy

Cost Savings strategies implemented in SFY 2011

Proposal	Estimated Savings
Prior approval for high intensity services	\$ 500,000
Tighten enrollment requirements for Developmental Therapists	\$ 100,000
Eliminate follow-up for newborn hearing screening	\$ 500,000
Streamline evaluation procedures for ED teams and limit evaluation time	\$ 500,000 -\$1,000,000
Modify reimbursement for IFSP meeting attendance	\$500,000
3 month authorizations with appropriate use of ICD-9 codes	\$1,000,000
Consolidation of providers and use of multidisciplinary agencies 5% rate cut	\$2,000,000
SPOE/LPCC contract reductions – 15% reduction to SPOE/LPCC allocation	\$1,600,000
Cost Participation suspension of services for accounts 60 days or greater past due	\$ 150,000
Eliminate payment for orthosis as a First Steps service	\$ 600,000

Legislative changes

Third Party Liability (TPL) Billing Changes

Non-ERISA plans, as well as Public Employee and State University Employee plans will be billed at a monthly fee (as determined by the Division). Plans will be billed for children who receive services within First Steps and whom are enrolled in a covered insurance plan. If reimbursement is received from the carrier, the State will waive the monthly copay for the family.

Status: Monthly billing will apply to services delivered on or after July 1, 2011. DDRS is currently in the process of finalizing coding changes allow for the new billing process. WellPoint has partnered with First Steps as we implement the new billing process.

Legislative changes – Cost Participation

Cost Participation for the First Steps program specifies that “*Sec. 17. (a) A family shall participate in the cost of programs and services provided under this chapter to the extent allowed by federal law according to the following cost participation schedule...*”. It further requires that the fees be based on income and ability to pay and requires families to consent to the division, billing third party payors for early intervention services provided. The law allows the division to waive the billing to third party payors if the family is able to demonstrate financial or personal hardship on the part of the family member; and must require the division to waive the family's monthly copayments in any month for those services for which it receives payment from the family's health insurance coverage.

Effective July 1, 2011, Indiana legislation put into place the following changes to the CP system:

- **Co-pay schedule for 15 minutes of service rather than “per service”:** Effective July 1, 2011, co-payment fees will be based on each 15 minutes of delivered services. For rates below 650% of poverty, the 15 minute rate is based on a quarter of the prior per service rate. For rates above 651% of poverty the 15 minute rate is higher than a quarter of the current rate.

Legislative changes – Cost Participation

Family Size	251% FPL	351%	451%	551%	651%	751%	851%
2	\$36,922	\$51,632	\$66,342	\$81,052	\$95,762	\$110,472	\$125,182
3	\$46,510	\$65,040	\$83,570	\$102,100	\$120,630	\$139,160	\$157,690
4	\$56,098	\$78,448	\$100,798	\$123,148	\$145,498	\$167,848	\$190,198
Fee per 15 mins of service	\$0.75	\$1.50	\$3.75	\$6.26	\$13	\$19	\$25
Monthly max	\$48	\$96	\$240	\$400	\$800	\$1,200	\$1,600

Music Therapy

Music Therapy

- Music Therapy is currently a day service available on the DD, Support Services and Autism waivers.
- Music Therapy is not a specific service included in the Federal list of early intervention services for First Steps.
 - ▣ If a music therapist has a background and education in early childhood development, they may enroll as a developmental therapist, providing developmental therapy, incorporating music into their service.



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*Presentation to the Indiana Commission on Developmental
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Division of Disability & Rehabilitative Services

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00 Commission
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Exhibit 3

What is DSPIN?

The Direct Support Professionals of Indiana (DSPIN) is a group of Direct Support Professionals (DSPs) from around the state interested in creating a positive change and building a qualified workforce through the formation of a state chapter of the National Alliance of Direct Support Professionals (NADSP). We are committed to being an active partner in shaping public policy on issues critical to professionalizing our workforce, including professional development programs, commensurate wages, and opportunities for advancement.

DSPIN was started with support from INARF, ICEArc, IIDC and the following agencies: ADEC, Cardinal Services, Carey Services, Opportunity Enterprises, Passages, Pathfinder Services, Options, and Stone Belt.

Our Mission:

Support empowered lives for ourselves and those we serve through education, self-awareness and collaborative action.

Our Philosophy:

Educating, equipping and enhancing DSPs will result in a more qualified and competent workforce, which in turn will result in both greater staff retention throughout the industry as well as the highest level of support for the individuals we serve.

Our Purpose:

Professionalize the DSP workforce through our passion and our voices by:

- Educating the community about 'what is a DSP?' and our impact on the individuals we serve and in the communities where we work
- Educate our fellow DSPs on the importance of professionalizing our workforce through education, empowerment, and self-awareness
- Build our membership through the relationships we create with DSPs, those we support, other industry professionals, and the community

Contact Information:

DSPIN, c/o JoAnna Moskal, 615 N. Alabama, Ste 410, Indianapolis, IN 46204

Phone: (317) 634-4957

Email: joanna@inarf.org



OO Commission
Meeting of
9.1.11
E. Moody

2012 Budget Review

Re: Andrew Moody

As the parents and guardians of Andrew Moody, we would like to acknowledge the decrease in the Medicaid Waiver budget for 2012. Last year Andrew's budget was decreased over \$16,000. We now have been informed that Andrew's 2012 residential services will decrease over \$25,000.

With the decrease in Andrew's budget in 2011, we took on an additional provider to help defray the cost. A nursing agency, Advantage Home Care, is helping Andrew with his personal needs on a daily basis. In addition, Andrew also attends a day program to help with the cost...and he is using the maximum amount that is given...\$10,500. This program has worked out very well for Andrew and they are meeting his needs at this time.

With these reductions, residential services will not be able to provide the services Andrew needs:

Safety issue:

- Andrew is a physically and mentally challenged young man that needs constant care. Andrew is very unsteady and requires full assistance while walking. He is a fall risk and has fallen multiple times even with staff support. Andrew has a wheelchair, which is used for long distance walking and for his day program, however, he is incapable of getting in and out of it without staff assistance as well.
- Andrew crawls on his knees at home to get around the home...he will also put anything in his mouth from the floor.
- Andrew is incontinent of bowel and bladder and staff is responsible for toileting every 2 – 3 hours.
- With Andrew's unbalanced walking, parents are not able to care for him at their home. Mom has degenerative disk disease due to caring for him in their home over the years. He is taller than his mother and in the past when Andrew was living at home with his parents, he has fallen at mom's employment causing stitches to his head. Mom cannot take him into the community by herself. The caregivers are younger and strong enough to handle Andrew in the community, and he enjoys being out and about with his caretakers and his roommate. One of Andrew's goals is going out into the community and walking which is very valuable to him physically.
- Should an emergency occur during unstaffed hours, Andrew absolutely would NOT be able to get himself out of his home safely.
- Andrew is at risk of choking. Andrew needs to have his food cut in small pieces, and needs staff by his side at all times when eating. Even when Andrew is eating out, he will usually have a choking episode which is very scary to us and people around us.
- Andrew should NEVER be left alone for all of the above reasons stated.

Behaviors:

- Andrew is non-verbal and has vocal outbursts. His behaviors consist of yelling and chewing on his wrists. Staff is usually able to redirect his behaviors, but there are times when yelling will cause Andy to sweat profusely.
- Andrew has made significant progress over the past year. To make a change in his life at this time will cause increased behaviors. Please see behavior management report included in this review submitted by his Behavior Therapist, Tandy Moffit.

Emotional:

Andrew and his roommate have lived with each other over 2 years and have developed a special bond together. The boys have connected with each other beyond our belief, and if their living situation would change at this time, it would be emotionally devastating for both of them. Andrew has a daily "structured" routine. Taking away the hours that is needed for him would NOT be in his best interest. The boys really love each other...you can tell by the expressions on their faces. Even when both boys come home with the parents for holidays or a family celebration, they can't wait to get back to their own home. **The state is looking at dollars spent, but I would challenge them to come and take a look at their home to see the benefits that the wavier is providing for both boys now.**

Living Residence

Their home is in a very nice location that is very quiet, safe and even has a park across the street, and I really do not want it to change. **We worked so hard getting both of them into their own home that it would be devastating to see all that work go in vain.** We had the opportunity to purchase the residence for Andrew with the help of family, friends and church community with the intention for Andrew to live there for the rest of his life. It has two bedrooms and two bathrooms for each of the boys, but it is not big enough for another roommate. We had no idea in 2009 that down the road the State of Indiana would want to have more than two roommates per residence.

Both parents are willing to help the state reduce costs, but with the reductions of both boys' budget together for this coming year, it is impossible for them to continue living together in this "model home" that is intended for what the wavier program is all about. With the decrease in Andrew's hours, it will only cover 10 hours per day, which does not give Andrew the hours needed for him. We implore and ask that you keep the current residential hours for Andrew and for Christopher so they can continue living together.

Christopher and Andy have developed an incredible bond together and we hope and pray that both of them will be able to live together for the rest of their lives. I would also encourage you to come and take a look at their "model home" and see for yourself the safe environment and see how these boys connect with each other.

Ron and Sherry Moody,

Parents & Guardians

OC Committee
Meeting #
9-3-11
[unclear]

Supplement to Notice of Action Review

Regarding: Funding Program: Developmental Disabilities Waiver August 15 2011

**Christopher Phillips
Down syndrome
Moderate Developmental Disability**

Our son, Christopher Phillips, after 10 years of waiting, received the Medicaid waiver approximately 3 years ago. This has allowed him to move out of our house, into a condo, with a very compatible roommate and to achieve the independence he needed to continue to grow and mature as a productive person. With the proper supports system in place for him, he has exceeded our expectations, and is a very happy and fulfilled young man. He and his roommate, Andrew Moody have become best friends and have developed an incredible bond with each other.

Now the state wants to cut his budget by more than half. With this cut, he will no longer be able to maintain the independence that he has worked so hard to achieve through the support system he currently has in place. Christopher was not able to meet his current goals in the ISP he now has due to his limited hours. He certainly will not be able to attain these goals with even less staffed hours with the new proposed budget. Initially the transition from our home to his current residence was very hard on him and took him a long time before he was able to feel comfortable even being there. He now loves his home which he shares with Andrew. He seems to have found his purpose in life living with Andrew, as his best friend, a relationship that he has never achieved before now. To break this bond would do unimaginable damage to both of them, and neither of them would be able to understand the reasoning behind it. He has matured and blossomed into more than we could ever have imagined was possible for him.

After receiving and reading his ICAP assessment 2 years ago, we were dismayed at the lack of accuracy in the portrayal of Christopher's disability and the ALGO score he received. Because of this assessment his budget was decreased last year and now it appears that another even more drastic cut is proposed. We feel very strongly that this assessment does not accurately reflect our son's needs at all.

Medical

- Two of Christopher's goals are to exercise and to lose weight as instructed by his physician, due to high cholesterol, and a significant weight gain. He has been able to meet these goals due partly to staff encouraging him to make healthy food choices and taking him to the gym, park or various other activities that he enjoys doing. If staff were not present, Christopher will be tempted to make less wise choices and would not be able to go get the physical exercise he needs to maintain his weight. He has been very successful at losing the weight he had gained, but would not have been able to achieve this goal on his own, without staff assistance.
- Maintaining good health is essential for him, and as he is unable to drive, he is unable to take himself to the various the medical appointments needed without help from staff.
- If he were to get sick, because he is non verbal he would not be able to let anyone know that he

needed help. If he needed to take medication for any reason, he would not be able to do that on his own without staff there to assist him.

Safety

- Christopher also needs supervision and assistance with cooking meals in the home. He is unable to set the stove temperature or microwave time independently. There is certainly a possibility that he could get burned while cooking on the stove top. Not having staff there would be a serious safety issue for him.
- If there were an emergency in the home, Christopher would not be able to communicate with emergency personnel, as to what he needed or where he is. If there were a fire, he would not know that he needed to get out immediately.
- Christopher is basically non verbal so he requires staff to interpret his wants and needs. Although he does verbalize some things, his speech is garbled and difficult to understand. He is a very sweet and trusting person who will say "yes" to most questions whether he means it or not. It would be very easy for someone to manipulate and exploit him if he were alone, without supervision, in the home or in the community.
- If Christopher's staffed hours are cut to the severe degree (more than 50%) that is being discussed he will have even less opportunity to get out into the community. He really enjoys being able to go out to eat, bowl, golf, church and participates in various other activities. Who will transport him to these outings? He cannot drive and he has attempted previously to utilize the bus services with no success and in his current community, there is no bus service. Again, he has difficulty meeting his outing goals in his ISP now and certainly would not be able to with even less staffed hours.
- Christopher currently has a part time job, which he thoroughly enjoys and would not be able to continue with the proposed cut of staff hours, as there would be not one to transport him back and forth. It is my understanding that one of this administrations focus on people with disabilities is that they would be able to have and maintain a job, but this would not be possible for him with this new proposed budget.

Behavior

- Currently Christopher does not have a behavior management plan in place, but he may ultimately need one if left alone for long periods of time. He does not like to feel alone or neglected. There was an incident this past year where one his current staff's schedule changed and that particular person no longer had 1:1 time with him. He became so frustrated and upset that he actually tried to punch her. This was the first time he had ever been physically violent towards anyone in the home. We feel very strongly that if he were left alone by himself for long periods of time he would have behaviors. He is a good man with a big heart who typically would not hurt anything or anyone, but if he is unable to express his feelings verbally, he will convey his frustration by any means necessary.

Christopher is not unlike many people in that he does not like change. He is resistant to it and tries to avoid it at all costs. He thrives on structure and routine. We are very concerned about how he will cope if he has to move again. As we stated in the beginning, when he first moved into his current residence he packed his things back up every night waiting to go back home with us. He has finally come out of his shell. He is happy there. He and his roommate love each other and are like brothers. It would break our hearts to see that change, just knowing how hard it would be for him.

This proposed cut in his budget will absolutely be setting him up for failure and negative behaviors and will create a deficit in his life that he may not recover from. We implore you to help him be able to continue living with his best friend, with the supports he has now, in the home that he has grown to love as his own. He happily comes back to our house to visit, but it is very clear that he no longer considers it his home, and is anxious to get back to where he is comfortable, with Andrew, and the support he has there. Isn't that what we all strive for in life?

Please reconsider Christopher's budget for this next year. He deserves to be able to live the best life that he possibly can and to cut his budget is to keep him from doing just that. Thank you for your time and consideration in this matter.

John and Linda Phillips

Parents and Guardians.

My name is Laura and first and foremost, I am a parent of a child on the waiting list for the DD waiver. I am also a taxpayer and want to make sure that my money is spent wisely. Additionally, I have been a case manager for people on the DD waivers in the past and an employee of a provider.

I have been in attendance to the last DD Commission meeting and the Commission for Medicaid Oversight and I have concerns about many of the changes that have been introduced and are slated for introduction.

First, the commission has heard various pieces of information regarding the new Objective Based Analysis (OBA). In theory, it looks at the needs of the client and then allocates their budget according to the needs. While I agree that the needs of the client should be an important factor in determining the budget and services available to the client, the way that the budget is made available to the interdisciplinary team that supports the client provides a huge hurdle. Currently, the OBA provides the client with an overall budget. The overall budget includes a building block or "reserve" that dictates how that portion of the budget is to be spent. When I was a case manager, the way that I explained it to the teams I worked with was that the state issued a "gift card" i.e., the budget but informed us that we needed to spend this portion that gift card in the housewares department of the store. Seems practical enough, until you realize that the client is g-tube fed and has no need for kitchenware. The OBA does not take into consideration natural supports and dynamics for the individual. Clients are allotted a "days reserve" and a "behavior management reserve". Behavior reserves are the part of the budget that can only be spent on behavior management. The problem with this lies in the fact that the client may not be responsive to traditional behavior management services. Many of the lower functioning, non-verbal clients use behavior as a communication tool. Sensory needs that spur behaviors can also be addressed in various ways besides traditional behavior management. Therapies such as music therapy, recreational therapy, occupational therapy, etc., would be more appropriate to address their behaviors and channel them so that others could understand the communication that they are intended to convey.

Clients are also designated a "days reserve". This money is allocated so that the client spends money on services that will provide them with a meaningful day, i.e., work, volunteerism, community involvement, etc. For clients that have ^{school} independent employment or receive Medicaid-PA home health or nursing during the day hours, this can be problematic to utilize in order to support the client fully.

More importantly, it does not take the individual client's circumstances into consideration. The client may have sleep disturbance issues and it is paramount that the family receive this support so that they can sleep. Since sleep is a residential service and the maximum that can be received by a client with maximum need in a

family home is 6 hrs./day with the current formula, it is inadequate to address the basic need.

The client may have a non verbal child that has benefited greatly from music therapy both in communication goals and behavioral goals; however under the new OBA process, the money cannot be used for music therapy only for traditional behavior management.

I believe in the goal of the OBA and service focus which is to build a meaningful day for clients. I believe that the way in which it is being implemented is counter-productive to its mission. Because the state wants to ensure that clients are receiving a meaningful day, different service codes are used to track residential services, community-based services, Medicaid-PA home health services, vocational services, etc. Therein lies part of the problem. Typical people and families try their hardest to find and maintain a healthy work-life balance, not allocate out every activity of the day into a category. Categorizing time for the client does not provide the client with a better service, it simply provides a time study for that client.

I understand that it is essential that the clients are out in their community, having a meaningful day and doing things that are important to them. I want that for my daughter too, but instead of establishing service codes to categorize her time, I believe that the state should be charged with ensuring that the providers that are providing the services to her are doing their job and enabling her to participate in activities.

DDARS also noted that it was their intent to have providers complete certification and that the state's BQIS department would eventually address incident reports and not provide auditing. I believe that this is problematic. While I agree that providers can indeed learn and improve greatly from participating in a certification, the certifying body has no governance over the provider and cannot right any wrongs that are found. It also gives the provider a large bill to pay – certification is costly – and this is likely to prohibit any new providers to join. In fact, it may be the demise of many small to mid-size providers that are in the mix now. Choice is important to ensuring the improvement and success of the services. Choice in case management is needed as well to ensure the usefulness in that service too.

Another concern that came up at the DD meeting last session was the composition of the teams that support the individuals that are in service. Most teams are comprised of the individual, a family member/guardian (if applicable), the case manager, and the conglomerate of paid supports/providers for that individual. The current environment is adversarial because it does not allow the teams to focus on the needs of the client – instead the OBA budget with its reserves must be allocated accordingly to the various service codes. The team and case manager are focused on taking the budget and

cutting it into allotments instead of using it to support that person as they need at that time. Because there is only one case management provider, the checks and balances that used to exist and provide quality control in this system are no longer present. The case manager has become more of a fiscal advocate and has left the disability advocating to the family and the service providers.

I mentioned in my introduction that I am a taxpayer too. I think that is important too. These funds are my taxes that are spent to support these individuals. I feel that the current system is wasteful and administratively difficult. The infrastructures put into place because of the multiple service codes and reserves do not provide any value add for the consumers and their families. Instead, it makes a system that is already difficult to navigate even more confusing.

In conclusion – I offer the following solutions:

- 1) Engage the vast variety of civic groups and non-profits in Indianapolis to partner with our clients to create a meaningful day experience.
 - 2) Allow therapies to be part of the behavioral allocation. That way those reserves can be applied to assuring behavioral change through appropriate therapy modalities.
 - 3) Instead of multiple, complicated services codes – allow broader service definitions to be broader in scope and reduce the amount of time needed to manage the complicated billing system.
 - 4) Personalize case management again. While the role of a fiscal intermediary is important – so too is the role of humanness and compassion in assuring that some of our most vulnerable Hoosiers are cared for responsibly as individuals.
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