

One Family's Story Medicaid Waiver Brings Help, Hope

Keith Powlen recently began receiving services from the Developmental Disabilities Medicaid waiver. The services and supports have made a tremendous difference not only in Keith's life, but the lives of the entire family.

My name is Judy Powlen; and I am a wife, a mother and a teacher. Before receiving help from The Arc of Indiana and the Developmental Disabilities Medicaid Waiver, my husband, Bill, and I were truly at the lowest point of our

lives. I spent so much time crying and really didn't see much hope.

Bill and I have three children—two girls, ages 25 and 20, and a boy, almost 18. As a baby, our son, Keith, never made eye contact, and often put his hands over his ears. At first, he did not make any sounds; but later, began to scream inconsolably. By age three, his condition was even more pronounced, and he was diagnosed with severe autism.

As Keith got older, he began having very aggressive, severe behavior. My husband and I began to be physically attacked daily, furniture was broken, windows smashed.

Our daughters would not come home.

Our doctor convinced us that we couldn't continue to be unsafe in our home and that we needed help desperately. I did not want to give up on Keith, but finally agreed to seek a residential placement. I was so naïve, and I had no idea how the system worked. I thought after I admitted I needed help, people, the state, the school, everyone would immediately help me. What I learned was that little help was out there. We were told that to get a residential place-



Mike Wespiser, caregiver, and Keith Powlen

ment, we would have to give up custody of Keith to the state. To get help at home, we learned we were facing ten plus years to get supports from a Medicaid waiver.

Then, a close family friend suggested we contact The Arc of Indiana. Within a few days The Arc was able to connect us with the right people at the state and local offices, who moved quickly to help us in our crisis.

Keith began receiving services and supports through the Developmental Disabilities Medicaid waiver in August, 2007; and quickly made a positive connection with Mike Wespiser, his direct support staff person.

Mike assists Keith with daily activities, including swimming, art classes, visiting the library, and making trips to area farms and parks. He has gone camping, fishing, hiking, and likes to attend community concerts.

At first, I struggled with my feelings about how well Mike was working with Keith.

I was so jealous that Mike, an outsider, could get my son to do so many things I worked so hard to make happen and couldn't. Mike and I had a heart-to-heart talk. He said he knew we tried our best, but couldn't pull it off alone. We started working as a team.

For several years, Keith would get clear to the church door, but would never make

(Continued on Page 4)



Judy, Bill and Keith Powlen

Young Life Saved Thanks to Training, Action of Direct Support Staff

Tracy Murphy and Amanda Gray, Supported Living staff for Carey Services, local chapter of The Arc in Grant and Blackford Counties, were ultimately responsible for saving the life of a young girl, Lauren Belcher.

Last summer, Tracy and Amanda were at a water park in Marion, Indiana for an afternoon outing with two consumers from Carey Services' Supported Living program. They saw a young girl being pulled from the pool in critical condition. Without hesitation, the CPR training they received as employees at Carey Services kicked in, and they rushed to the child's aid. Not only did their training serve them well, but they showed great judgment and maturity by immediately stepping in when others at the scene were either too hesitant or too overwhelmed to administer interventions properly.



Tracy Murphy, Lauren Belcher, and Amanda Gray

After learning that Tracy and Amanda helped save his daughter's life, Mike Belcher called Carey Services to offer his thanks. He repeatedly expressed his deep appreciation for Amanda and Tracy. "They didn't freeze at a time of crisis;

they reacted and saved my daughter's life!"

The Belcher family had been sitting next to Carey Services staff and consumers at the water park and had been observing their positive interactions when the event occurred.

Mr. Belcher said that while he has always respected what Carey Services does in the community, he now has an even deeper appreciation for the training employees receive, and the professional way they conducted themselves in the face of a crisis.

The Arc of Indiana and Carey Services are extremely proud and thankful that Tracy and Amanda responded as they did. We congratulate them for their life-giving and selfless act.

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Statewide Campaign Brings In New Members Throughout State

With the support of local chapters of The Arc throughout the state, the 2008 *Attitude is Everything, Members are Everyone* Membership Campaign resulted in hundreds of new members statewide.

2008 membership campaign results in hundreds of new members

Formally begun during March, Disability Awareness Month, chapters recruited new members, conducted awareness activities, held information programs for self-advocates, parents and members, and conducted community recreational and social events.

As a result there are 898 new members of The Arc. Fifteen chapters recruited new members. Noble of Indiana/The Arc of Greater Indianapolis recruited 316 members. They will receive the "Membership Traveling Trophy" at The Arc of Indiana's 2008 Annual Awards Program. Chapters who recruited new members were eligible to win blocks of tickets to summer Minor League professional baseball games. Evansville Arc and The Arc of Tippecanoe County will receive tickets to distribute to members, self-advocates, families and staff.

Other chapters recruiting members were:

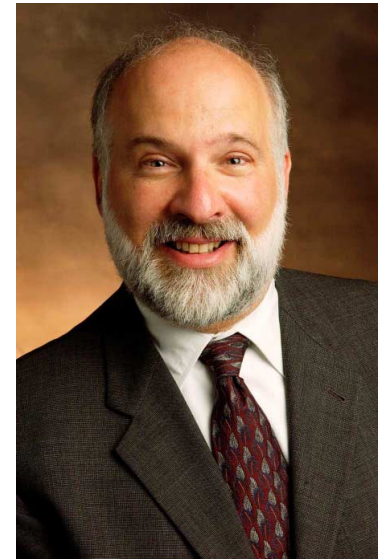
ADEC in Elkhart County
Arc Rehab Services in Boone County
Jayland Arc in Jay County
Pike County ARC
Gibson County ARC
The Arc of Hancock County
Fountain County ARC
Orange County Rehabilitation and Developmental Services
Passages in Whitley County
Evansville Arc
Sycamore Services in Hendricks County
The Arc of Bartholomew County
Arc BRIDGES
The Arc of Jackson County

There were also new individuals and businesses that joined as at-large members of The Arc of Indiana.

New members were eligible for prizes from The Arc. New members receiving 50th Anniversary commemorative T-shirts from The Arc were **Mark Tash** of Zionsville, **Kevin Gernentz** of Hope and **Douglas Werner** of Hebron. Receiving Tony Dungy's book, *Quiet Strength*, were **Anne Pickering**, Portage; **Kay Stevens**, Princeton; **Rick Whiteman**, Zionsville; **Jennifer Luther**, Columbus; **Cassy Davidson**, Woolcottville; and **Conor-Patrick Insurance Services**, Westfield.

The Arc welcomes all our new members. You join with 6,100 other Hoosiers across the state. We're The Arc!

NEW LEADER JOINS THE ARC U.S.



Peter Berns

Peter Berns, a nationally recognized nonprofit sector leader and public interest lawyer, has been named Executive Director of The Arc of the United States. Currently Executive Director of the Maryland Association of Nonprofit Organizations, Berns will assume his duties full-time on July 7, 2008.

In his 16 years at Maryland Nonprofits, he built the Association from a start-up to a position of national prominence in the nonprofit community. In addition, he served as Chief Executive Officer of the Standards for Excellence Institute since its inception in 2004.

"Peter's stewardship of The Arc will lead us to a new era of growth and development. For over 20 years, he has made extraordinary contributions in the areas of nonprofit management, governmental relations and advocacy. As a public policy advocate, he was critical to reforming state and federal Medicaid regulations improving life for persons with disabilities and their families," said Mary V. Jordan, President of The Arc of the United States.

Steve Morgan, Executive Director of The Arc of Baltimore, said, "Among his many accomplishments is the establishment of the Standards for Excellence certification program, whereby nonprofits earn the 'Seal of Excellence' by demonstrating their adherence to fifty-five (55) ethical standards of integrity, accountability and transparency. These standards closely parallel the Core Values of The Arc. Peter understands the importance of delivering 'value-added' service to members who are themselves nonprofit organizations."

Commenting on his appointment, Berns said, "Over the years I have been inspired by the volunteers and professionals in The Arc community that I have had the privilege to work with. The Arc's commitment to civil rights, services and supports for people with intellectual disabilities is more important than ever. I can't wait to get started and use my skills as a public interest lawyer and nonprofit association executive to help knock down the barriers that people with disabilities continue to face on a daily basis."

IN REMEMBRANCE

The Arc of Indiana lost three wonderful women in March and April. They will be greatly missed. The impact they had on the lives of people with developmental disabilities and their families will live on.

Victoria "Vickie" Collins—March 19, 2008, 37, daughter of Donald and Shirley Collins, graduate of Shelbyville High School in 1989, worked for many years at Shares, Inc. in Greenfield and Shelbyville.



Vickie, who was born with Down syndrome and who had rheumatoid arthritis, inspired her parents, Don and Shirley, to advocate not only for Vickie, but for all people with developmental disabilities. Don served as an officer and member of the board of directors of The Arc of Indiana for many years. Shirley served on several committees of The Arc.

Don recently wrote The Arc, "Because of The Arc, Vickie was able to enjoy year-round school from the age of two until she finished high school at age 19. She was able to then work at Shares, Inc. for the next 18 years... As long-time members of The Arc, we feel proud to have been a part of the continuing effort to make life better for the people you, your staff, and other members have worked so hard to help."

Sharon Gary, September 4, 1942—April 11, 2008, was a long-time friend, supporter and volunteer for The Arc of Indiana and The Arc of Hancock County. Sharon served on the board of directors of The Arc of Indiana for many years, including in officer positions. She was past chair of The Arc's Awards Committee,



and was recently honored by The Arc with the Living in the Community Award. Sharon was an active member of The Arc's Development Committee and helped at many of our fundraising events. She was a member of the State Mortality Review Committee and a volunteer for many years for IRL, a provider of residential services for people with developmental disabilities.

Darcus Nims, November 23, 1957—April 12, 2008, was the founder and first President of Self-Advocates of Indiana (SAI). In 1991, Darcus was honored with the *National Victorian Award* from President George H. Bush for overcoming overwhelming challenges in her life. Darcus liked to tell a funny story about the break-in at her room at the Watergate Hotel when she went to Washington D.C. to receive that award. Darcus was a graduate of Indiana's first Partners in Policymaking Class in 1992 and the first person to be awarded the *Community Spirit Award* by the Governor's Council for People with Disabilities.



Betty Williams, her long-time friend and colleague, said, "Darcus was a great friend, role model, teacher and trainer. She lived life 'her own way' everyday, even until her last day. All self-advocates across Indiana, who loved Darcus, will miss her greatly."

Executive Director's Column

Tragedy In Texas; Indiana has a Better Idea

John Dickerson, Executive Director

The *Wall Street Journal* recently featured the tragic story of Kent Dromgoole, a forty-one year old man with Down syndrome, whose elderly mother refused to be admitted to the hospital unless her son was also admitted.

When his mother was placed on a ventilator, Kent remained in the hospital because there were no options for him. One suggestion was that if Kent were taken to a homeless shelter, he could get emergency help. A woman who worked at the hospital finally said she would take Kent home with her.

Relying on the kindness of strangers is no way to plan for the care of people with disabilities.

Thankfully, Indiana has a better plan. With the support of the Secre-



John Dickerson

tary of the Family and Social Services Administration, Mitch Roob, caregivers over the age of 80 can immediately receive help and support from the Developmental Disabilities Medicaid Waiver.

Rather than waiting for a crisis to happen, eligible families can get supports without having to wait for years on a waiting list. Secretary Roob is so committed to this need that he wants to move the eligible age to 79 this year, and continue to move down the caregiver's age for eligibility each year thereafter.

The challenge is to find eligible families and inform them that help is available. Many parents of this "greatest generation" believe others need the services more than they do. Others fear that if they step forward for services, their adult child will be taken from them. It is important for families to know that receiving services now will

assure that supports are in place before a crisis happens.

To reach eligible families, we will need to connect with churches, hospitals, senior citizen centers, and other networks.

It is also important that they understand they have a choice to continue to care for a loved one at home or help their adult child make the transition to a residential program while Mom or Dad is still involved.

Over 150 families over the age of 80 have taken advantage of the opportunity to get supports through the Medicaid waiver. However, The Arc of Indiana estimates there are over 400 more families with caregivers over 80 who could be eligible.

Your help is needed to make aging caregivers aware that supports are available. Arc Opportunities, the local Arc

chapter in LaGrange County, has already helped eight people through this process. Arc Bridges in Lake County is also reaching out to find eligible families. We need you as well.

Many of these families have never received services or supports. To reach them, we will need to connect with churches, hospitals, senior citizen centers, and other networks. We hope you will take some time to make connections in your community to get the word out.

Families can obtain the number of their local Bureau of Developmental Disability Services (BDDS) office by calling (800) 545-7763. When they call their local BDDS office, they should say they want to apply for the priority Medicaid waiver for caregivers over age 80.

This is a wonderful opportunity for aging caregivers and their adult children. However, if we do not find families and inform them, it remains an unfulfilled opportunity, with the risk that, like Kent, an adult child of an aging caregiver will face a crisis.

2008 Legislative Wrap-Up



The 2008 session of the Indiana General Assembly adjourned on Friday, March 14. Following is a brief summary of legislation that The Arc of Indiana followed and worked on during the session, which became law:

Disabilities

- **HEA 1266: Priority for Receiving Services Under Medicaid Waivers**

Requires the Office of Medicaid Policy and Planning to apply to the U.S. Dept. of Health and Human Services to amend Indiana's Medicaid waivers to prioritize providing Medicaid waiver services to specific individuals.

Priority would be given to: (1) people in group homes who no longer qualify for group home services. (2) people in group homes who are at risk and need immediate placement in a new residential program that provides confidence to the family; (3) people who live in a large facility for people with developmental disabilities who want to move to a small residential program; (4) young adults who have "aged out" of a residential program for children and still need a residential program; (5) people who have a caregiver who can no longer provide care; (6)

children who have been diagnosed with a genetic disorder that significantly shortens their life span; (7) other criteria that the Division of Disability and Rehabilitation Services believes warrants a priority placement.

- **SEA 258: Crimes Against People with Disabilities**

Makes committing an offense against a person with a disability an aggravating circumstance when sentencing if the defendant knew or should have known that the victim was a person with a disability.

- **HEA 1171: Autism Training for EMS Personnel**

Requires certified emergency medical services (EMS) personnel to successfully complete a course of education and training on autism, beginning January 1, 2009.

- **HEA 1288: Behavior Analysts**

Makes it a class B misdemeanor to state that you are a certified behavior analyst if you do not hold and maintain certified behavior analyst credentials administered by the Behavior Analyst Certification Board.

- **SEA 143: Childhood Lead Poisoning Prevention**

Establishes the childhood lead poisoning prevention fund for outreach and prevention. Establishes a lead-safe housing advisory council to make recommendations related to lead poisoning prevention. Requires an interim study committee on childhood lead poisoning prevention.

- **HEA 1318: Spinal Cord and Brain Injury Fund / Law Enforcement Continuing Education**

Eliminates the \$10 registration fee on motorcycles designated for the spinal cord and brain injury

fund. Provides for a fee of thirty cents, beginning January 1, 2009, for registration of certain vehicles, for the spinal cord and brain injury fund.

Insurance and Medicaid

- **HEA 1140: Coverage for Orthotic and Prosthetic Devices**

Specifies requirements related to coverage and reimbursement for medically necessary prosthetic devices under a state employee health benefit plan, a policy of accident and sickness insurance, and a health maintenance organization contract.

- **SEA 42: Managed Care Organizations Providing Medicaid Services**

Adds to the duties of the Select Joint Commission on Medicaid Oversight Commission, determining whether a managed care organization contracted with the state to provide Medicaid services has performed the duties outlined in the contract. Requires certain managed care organizations participating in the Medicaid program to be accredited by the National Committee for Quality Assurance and accept electronic claims for payment.

Taxes

- **HEA 1001: State and Local Finance**

The issue of significance to people with disabilities in this major property tax reform bill is that it continues to allow community developmental disability centers to receive funding outside of a property tax levy. However, if money is not received in 2008, it cannot be received in the future. This is problematic as we want to have every opportunity for centers to receive money from their local governments in the future.

The Arc of Indiana will work closely with budget leaders next session to remove this language.



Abbey Walker and Morgan Thune participated in Race for Piece to raise awareness of autism, and raise funds for Autism Speaks. The Race for Piece took place April 26 in Zionsville, Indiana, and generated nearly \$11,000. The Arc of Indiana supplied bags for race participants.

Township Trustees Avenue to Connect with People with Disabilities

Families and advocates know that it can be difficult for people with disabilities to access programs and services. The difficulty is compounded if you have a disability, and you are a minority.

The Arc of Indiana's Minority Outreach Project is working to improve the delivery of services to minorities with disabilities. In Indianapolis, the Minority Outreach staff is working with the Center Township Trustee office in Indianapolis and Trustee Carl Drummer.

Center Township houses a representative payee program. This program serves those who are not able to manage their finances. It serves many people who would like to work, but do not know about services that could help them work and keep their social security benefits.

Center Township Supervisor of case management services, Floyd Worley,

participated in a training hosted by The Arc's Minority Outreach Project in 2007, and saw the benefits of this community connection. "We have a lot of people with disabilities who want to work, and have no idea of how to do it. These people are unaware of Indiana Vocational Rehabilitation Services," Worley said.

After staff from the Minority Outreach Project provided information and training to staff at the Center Township office, over forty people were identified as possible candidates for Vocational Rehabilitation Services. This outreach activity informed low income, minorities with disabilities about resources that previously were unknown to them.

Staff of the Minority Outreach Project has been invited to continue to provide information and training on a regular basis.

ONE FAMILY'S STORY, from page 1

it in. The sound-level of music and the congregation was overwhelming for him. Finally, we gave up and didn't even attempt to attend church. Mike worked with Keith, and was able to help Keith attend Christmas Eve service. It was the best Christmas present our family received. Keith is now able to join us for family dinners for the first time in a long time. He is gaining ground in leaps and bounds.

Our lives have changed so much for

the better. We were out of options due to Keith's extreme behavior problems, and we desperately needed help. Now, we are slowly but surely gaining back trust, respect, and love from our son. Little by little, our family is gaining back confidence and reaping a wealth of blessings.

People First – A Personal Account of Struggles, Hope in Living with a Disability

The following article was written by a young man with disabilities who has received help and assistance through The Arc of Indiana's Minority Outreach Project.

My name is Brent Boskovich. I'm 23 years old, and I've had about eleven jobs in my life. I recently started my twelfth job.

When I was in high school, I had a learning disability. Over the last five to six years I've been diagnosed with all kinds of names—obsessive compulsive disorder with secondary depression, aspergers, social anxiety disorder, slight autism, substance abuse, and now bipolar.

I was 18 when I first used marijuana. I basically used drugs to self medicate to forget about my problems. I have very impulsive behavior, and I can be very silly, which is part of the reason I have been fired at five of the eleven jobs.

I'm getting that I can accept the fact that I am different, but I believe that I am a very good person. I've struggled with anger and self esteem issues throughout my life. I have always had a concerned of wondering of what people think of me. I would also compare myself to others, and that could be the reason why I am insecure.

I am still soul searching about what my life will be like in years to come. My goal is to have a nice home of my own and a nice wife. I have to overcome my issues in order to get there. My dream job is to do something in broadcasting, being on the radio, or controlling the sound behind the scenes of a radio show or a television news broadcast. I would love to have that kind of job, but I see that as being very unlikely at the moment.

I am thankful that I have a job. I am thankful that I have a roof over my head, and that I have a good family. If it wasn't for my family I don't know where I would be in my life. I could be in jail or I could be dead. I have lived a crazy lifestyle in my life, and I am thankful that I am still alive and I'm not in jail.

When people have disabilities it's important to have good support other than their families. Companies like The Arc of Indiana, Janus Development Services, and Goodwill are very good because they are known for their success of helping people find a good job and keeping them.

I was 18 years old I first met Patrick Jamison (who now is the Outreach Coordinator for The Arc of Indiana's Minority Outreach Project). He was my vocational counselor that would help me find a job. Thanks to Patrick I've had some good jobs; and he would help me keep them by talking to my managers. Patrick is a very good man because he decided to stick with me even when he didn't have to. To this day he will still work with me, which makes me very thankful.

WISH COMES TRUE WITH FUNDS FROM ARC TRUST

The Arc of Indiana Master Trust was created to help people with disabilities lead better lives—allowing an individual's Trust to pay for items that government benefits do not cover.

Nick, a Trust beneficiary, recently realized his wish for a puppy through funding from his Trust.

Nick had been in the hospital due to a surgery, and his Mother had been very ill. On the way home from the hospital, he asked his grandmother if his mom was feeling better, and his grandmother said she would need to have more tests to learn what was causing her health problems.

Nick thought for a moment and said, "I think we need to get a wishing well so we can wish Mom to get better."



Nick and Xena

got home, there would be a puppy waiting there for me, but it didn't work. No puppy."

Nick's grandmother, Ginger Fasig, replied, "That's a pretty good idea, but in the meantime, until we can find a wishing well, you can wish on anything, like a star."

Nick thought for a moment again and said, "Nope. Stars don't work for me. I wished on a star one time and it didn't work. I wished that when I

Nick's grandmother thought about Nick's wish and the benefits of having a dog. "Interacting with animals can help children develop nurturing skills and empathy. They encourage laughter, and petting an animal is soothing. They can help people improve fine motor skills, increase verbal interactions, reduce anxiety and loneliness, and improve interactions with others," Ginger said.

Nick got his wish for a puppy, whose name is Xena, with the help of funding through his Arc Trust. Ginger commented, "Xena put a smile on his face and brought laughter to the house, something we had not heard here for a long time."



The Arc of Indiana's

Second Annual

Golf Ball Bounce

Friday, June 20, 2008

The Legends of Indiana

Franklin, Indiana

Steve Green's

19th Annual Golf Tournament

**\$2000 does not just fall
from the sky everyday**

**Join us! Everyone can participate.
You do not have to be present to win.**

Up to 1,000 numbered golf balls will be dropped from approximately 100 feet onto The Legends' Driving Range. The lucky participant whose golf ball lands the closest to the marked hole will win \$1000. The numbered golf ball second closest to the hole will receive \$500, and \$250 will be given to the third closest numbered golf ball. If you feel like you never have any luck and are always last, this is your chance to win \$250 with the numbered golf ball furthest away from the hole.

Winner will be announced on June 20, 2008

**\$10 per numbered golf ball
dropped from helicopter**

The Arc of Indiana is a 501 (c) 3 tax-exempt organization. All contributions to the agency are deductible to the amount allowed by law.

To print and mail an entry form or to enter on-line, go to www.arcind.org; click on "Upcoming Events."

Specialty License Plate Supports Special Olympics

There is a new alternative for Hoosier motorists looking to break away from the traditional state license plate. Special Olympics Indiana was granted a specialty license January 1, 2008, giving Indiana drivers the opportunity to customize their cars in support of Special Olympics.

Amanda Personett, Public Relations-Marketing Director for Special Olympics Indiana, said, "We're very fortunate to have this unique opportunity to raise awareness for Special Olympics."

Like any other specialty plate, the Special Olympics Indiana license plate will cost \$40, with \$25 of that purchase going directly to Special Olympics Indiana and the remaining \$15 for a standard processing fee charged by the Indiana Bureau of Motor



Vehicles. Regular excise and county taxes will still be charged.

The license plate will not only help build awareness for Special Olympics Indiana, but could also generate a new stream of revenue to fund athletic programs across the state. The sale of only 2,000 plates statewide would raise \$50,000 for Hoosiers with intellectual disabilities.

The Special Olympics Indiana license plate is red and white and includes the Special Olympics symbol, "Joy Around the World." The Special Olympics Indiana license plate is available at BMV branches across the state for motorcycles, passenger vehicles and trucks up to 11,000 pounds. For more information visit www.soindiana.org.



**When I am gone, how can I continue
to help my child who is disabled?**

The Arc of Indiana Master Trust
established in 1988, is a reliable choice.

We administer over 332 funded Trust I accounts, and over 850 families are enrolled in Trust I.

In addition, we administer over 750 Trust II accounts. Trust II allows a person with a disability to fund their own Trust.

For information, call:
Melissa Justice
Trust Director

317-977-2375 or 800-382-9100

OASIS MOVING FORWARD

Guide for Consumers #1

On July 1, Indiana's Family and Social Services Administration (FSSA) will begin phasing-in the statewide implementation of OASIS, a new way of allocating funds for people on the Developmental Disabilities, Support Services and Autism Medicaid waivers.

The phase-in will begin in Bureau of Developmental Disabilities (BDDS) District 4, which includes the counties of Benton, Carroll, Clay, Clinton, Fountain, Monroe, Montgomery, Owen, Parke, Putnam, Sullivan, Tippecanoe, Vermillion, Vigo, Warren and White.

FSSA expects to implement OASIS statewide in January 2009.

The following guide is a first step to provide information on OASIS. Because OASIS is not yet ready to be fully implemented, changes will continue to occur. Please check The Arc of Indiana's web site, www.arcind.org, and watch for future newsletters for updates and information on OASIS.

What is OASIS?

OASIS, Objective Assessment System for Individual Supports, is a new system to determine resources available to waiver recipients and reimbursement rates for services providers.

Under OASIS a formula that includes several factors will determine a specific resource allocation that is available to Medicaid waiver recipients to be used for services and supports from Medicaid waiver providers.

*FSSA expects to
implement OASIS
statewide in January
2009.*

How is the resource allocation under OASIS determined?

The resource allocation, which represents a dollar amount that is available for an individual's Medicaid waiver service, is based on a formula. This formula includes:

1. **ICAP score.** Several months ago, FSSA hired Arbitre Consulting to conduct an assessment of people receiving Medicaid waiver services. The assessment is called ICAP—Inventory for Clients and Agency Planning. It is also known as the Objective Assessment (OS). ICAP is an assessment of a person's skills. The assessment produces a service score, which helps determine how much care a person needs.
2. **Age of Medicaid waiver recipient.**

3. **Residence of recipient**—living at home or in residential placement.

4. **If living in a residential placement—housemate arrangement.**

5. **Need for specialized medical or behavior supports.**

These factors are run through a formula, and, based on the end result, a resource allocation amount is determined. For example, an older person might receive more funding than a younger person. A person living with family might receive more funding than a person living in a residential placement.

It is important to note that recipients of the *Support Services Medicaid Waiver* will not go through the resource allocation formula process. They are eligible to receive up to \$13,500 for programs and services.

What happens after you receive your resource allocation?

1. Your IPMG case manager will inform you what your resource allocation is.
2. You will have an opportunity to use a computer-based program, known as a budget allocation tool, that helps you develop a preliminary budget for the services you want to utilize with that allocation.
3. You will meet with a team—which can include your case manager, providers, advocates, etc.—to discuss and determine a plan of care (POC) based on the new resource allocation.
4. Based on the new plan of care, your case manager will develop and submit a Cost Comparison Budget (CCB) to FSSA for approval.
5. If approved, your new plan of care will be implemented. If not approved, your team will need to meet again, make changes, and resubmit the budget.

When and where will OASIS be implemented?

Individuals currently receiving Medicaid waiver services will be phased into the new OASIS system.

Phase One—BDDS District 4

May 2008: People who live in BDDS District 4 who receive services through the Developmental Disabilities or Autism Medicaid waiver will be notified by their case manager of their resource allocation. If this information is not provided, the case manager should be contacted by the Medicaid waiver recipient. Providers will not

receive information about resource allocations unless Medicaid waiver recipients provide authorization for them to receive this information.

July 2008: People who live in BDDS District 4 with a July anniversary date to renew their plan of care will begin receiving services based on their new plan of care, if the Cost Comparison Budget has been approved.

Continued Phase-in of BDDS District 4: Each month, people living in BDDS District 4 will continue to be phased in, based on their anniversary date to renew their plan of care. A new plan of care will be developed based on their resource allocation, and a Cost Comparison Budget will be submitted to FSSA for approval.

Phase Two—Statewide Implementation

October 2008: People throughout the state with a January anniversary date to renew their plan of care will receive their new resource allocation. Their new plan of care, based on this resource allocation, will be implemented in January 2009, when the Cost Comparison Budget has been approved.

November, 2008 and following: Each month, people receiving Medicaid waiver services will receive their new resource allocation approximately three months before their anniversary date to renew their plan of care.

What if you are new to Medicaid waivers?

If you have not received a Medicaid waiver in the past, the following is what must happen before you can receive services under a Medicaid waiver:

1. You will be notified by the Bureau of Developmental Disabilities (BDDS) that you have been targeted to receive a Medicaid waiver.
2. A BDDS Service Coordinator will schedule a time to meet with you to determine if you are in fact eligible to receive services from the Medicaid waiver.
3. Once it is determined that you are eligible for the Medicaid waiver:
 - A case manager from IPMG will contact you to schedule a time to meet to complete a Person Centered Plan (PCP) and Individual Support Plan (ISP).
 - If you do not already have Medicaid, the IPMG case manager will also assist you with applying for Medicaid.

- The Inventory for Clients and Agency Planning (ICAP) will be conducted by an independent company called Arbitre Consulting.

The assessment will produce the service score that will be used in the formula to determine your resource allocation.

4. You will be able to use a computer based program called an "interactive budget tool" to determine how you want to use your resource allocation for services. The Person Centered Plan and Individual Support Plan can be used as a guide for how to use your resource allocation.
5. You will meet with your case manager to develop a plan of care, based on the resources available to you, and ideas generated from the interactive budget tool. Your case manager will submit a Cost Comparison Budget to FSSA.
6. Your case manager will help you select providers to deliver the services.
7. Once your cost Comparison Budget is approved and providers have agreed to deliver services, you will begin receiving services.

Appeals Process

The ICAP score cannot be appealed. However, the state administrative appeals process can be used to appeal services that will be provided under the plan of care.

The state is refining a new policy on how it will address people who have a significant change in the services they will receive.

To appeal, you may request an appeal within 30 days of the date you receive notice. The time limit is extended 3 days if the notice is received by mail. To file an appeal, sign, date and return the Hearings and Appeals copy of the form that you should receive with a notice to:

MS 04, Hearings and Appeals
Indiana Family & Social Services Administration
402 W. Washington St., Room E034
Indianapolis, IN 46204

You will be notified in writing by FSSA of the date, time and location of the hearing. Prior to the hearing, you have the right to examine the entire contents of your case record maintained by your Case Manager. Ask for a copy of all assessments, completed forms and questionnaires that were used in determining your plan of care. You may represent yourself at the hearing, or you may authorize a person to represent you.

Alphabet Soup—Making Sense of All Those Acronyms

As people with disabilities and their families attempt to understand programs and services, they will encounter a large number of acronyms in the materials they read and hear. Below are some of the most common acronyms—and their definitions—affiliated with services to people with developmental disabilities.

BDDS: Bureau of Developmental Disabilities Services, also called “beads” offices. These offices are where you apply for Medicaid waivers, including the Support Services Waiver, Autism Waiver and Developmental Disabilities (DD) Waiver. Obtain the number for your local BDDS office by calling (800) 545-7763.

CCB: Cost Comparison Budget. This budget details the cost of each waiver service and total cost of Medicaid services for each person. It is based on a Plan of Care (POC) that includes a summary of how waiver services will be used for a waiver recipient.

CMS: Centers for Medicare and Medicaid Services, a division of the U.S. Department of Health and Human Services. CMS is the federal agency responsible for administering Medicaid, Medicare, State Children’s Health Insurance (SCHIP), the Health Insurance Portability and Accountability Act (HIPAA) and other health-related programs.

DD: Developmental Disability. The term developmental disability means a severe, chronic disability, caused by a mental and/or physical impairment that occurred before the age of 22, is likely to continue indefinitely and results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency;

DDRS: Division of Disability and Rehabilitative Services, a division of the Family and Social Services Administration (FSSA). DDRS is sometimes referred to as “Dars.” This office administers services for people with disabilities.

DFR: Division of Family Resources. DFR offices handle Medicaid applications and administration. Every Indiana county has its own Medicaid office, so if you need to apply for Medicaid, you can contact your local office. You can find your county office online at: <http://www.in.gov/fssa/dfr/3674.htm>

DSP: Direct Service Provider.

EDS: Electronic Data Systems. The state hired EDS to process healthcare provider claims and payments.

FSSA: Family and Social Services Administration. This is the division of state government that funds social services and healthcare. The FSSA oversees the DDRS.

HCBS: Home and Community-Based Services. These are support services provided in a person’s home or community to either maintain or restore participation in community activities and to prevent admission into a nursing facility or large facility for people with developmental disabilities.

ICAP: Inventory for Clients and Agency Planning. Also known as the Objective Assessment (OS). The state hired Arbitre Consulting to perform ICAP assessments, which are intended to provide an assessment of a person’s skills and produce a “service score,” which helps determine how much care a person needs. This score will not affect how funds are distributed.

ICF/MR: Intermediate Care Facilities for Persons with Mental Retardation. This type of state-licensed facility provides health or rehabilitation services to people with developmental disabilities or similar conditions. ICFs/MR may include group homes or larger institutions that house nine or more people, and are funded through Medicaid.

ISP: Individualized Support Plan. An ISP is intended to provide a plan of care, using all available resources, to accomplish short and long-term goals

of a recipient of the Developmental Disability, Autism, or Support Services Medicaid Waiver. A Person Centered Plan (PCP) should be used to help develop the ISP.

ICLB: Individual Community Living Budget. This is a personalized budget, approved by the BDDS service coordinator, using state funds for individualized support services for people living in the community.

IPMG: Indiana Professional Management Group. This is the group of case managers hired by the state to manage Medicaid Waiver cases.

IPP: Individualized Program Plan. This plan, used in group homes and other non-waiver settings, is developed by the support team and outlines immediate goals that a person will work toward the following year.

MR: Mental Retardation. The preferred term is intellectual or cognitive disability.

OASIS: Objective Assessment System for Individual Supports. OASIS is a new system that government officials say will ensure the fair distribution of resources to people who are on the Autism, Developmental Disabilities and Support Services waivers and will standardize reimbursement rates for service providers.

POC: Plan of Care. This plan includes what waiver services will be used, who

will provide the services and how the services will protect a beneficiary’s health and safety.

PCP: Person-Centered Planning. This approach takes into consideration a person’s preferences and needs and documents what supports are needed to create the lifestyle the person desires. This type of planning is usually facilitated by the case manager and is for people receiving Medicaid waiver services. The PCP should be used to help develop the Individualized Support Plan (ISP).

RCP: Residential Care Providers.

RHSS: Residential Habilitation Support Services. These are services for people on the Autism, Developmental Disabilities or Traumatic Brain Injury Medicaid waivers that are designed to help the person improve the skills needed to live successfully in his or her home.

SSW: Support Services Waiver.

VR: Vocational Rehabilitation. The VR program attempts to help people with disabilities find employment or return to work. There are 25 VR offices throughout the state. If you have access to the Internet, you can find your local VR office at: <http://www.in.gov/fssa/ddrs/4946.htm>

Sources: Indiana Governor’s Council for People with Disabilities; Indiana Family and Social Services Administration; The Arc of Indiana

BDDS District 4 Snapshot

Last May, Indiana’s Division of Disability and Rehabilitative Services sent a letter to people with disabilities and their families asking for volunteers to participate in a pilot of the state’s new OASIS program. The letters were sent to people who live in the Bureau of Developmental Disabilities Services (BDDS) District 4, which includes the counties of Benton, Carroll, Clay, Clinton, Fountain, Monroe, Montgomery, Owen, Parke, Putnam, Sullivan, Tippecanoe, Vermillion, Vigo, Warren and White.

When OASIS is implemented statewide, families will be given a budget to work with and will be asked to select services based on that budget. In order to determine what a person’s budget may be, the OASIS pilot project looked at people in District 4, and what services they receive, with the idea that people with similar disabilities in other parts of the state would need similar services. But at least one mother in District 4 wonders whether that will work.

Sharon Hauss, who works in family support for the Indiana Institute on Disability and Community, volunteered to be a part of the test group. Her son, Michael Ely, receives all the services he needs, she said, but his situation may be unique.

“We can’t say that everyone with cerebral palsy has these needs because the disability is so huge, and the implications are so huge,” she said.

Ely, 25, is a volunteer for TC Steele State Historic Site, where he writes descriptions of paintings for visually impaired visitors. He does not have a guardian and chooses to live in his family home which has been modified to be accessible for him.

A person’s living situation is one of the many factors considered when calculating his or her budget, which families will then input into an interactive budget tool that will allow them to choose services and calculate what they can pay for annually. This tool was not tested in District 4.

“From the little bit that we’ve been told—that we’ll have these menus of services and know how much money we have to spend for the year—it sounds good, but until we try it, I don’t know,” Hauss said.

At a recent meeting of the Indiana Association of Rehabilitation Facilities, a provider from District 4 said that her facility—through the OASIS pilot program—was taking in far less in revenue. Hauss was a panelist at the meeting.

“I know providers are probably just as perplexed as the families are,” Hauss said. “No one seems to know what is happening.”

To help people better understand OASIS, The Arc of Indiana will continue to meet with key people overseeing the project and report via its web site any updates or changes that people may need to know. The Arc will also continue to work with state officials to resolve issues and concerns regarding the impact OASIS will have on people receiving Medicaid waiver services.

*Advocate Profile***Brenda Darrol, The Arc Network**

The Arc Network, a group of ten family advocates and ten self-advocates, works in each Bureau of Developmental Disabilities Services (BDDS) District, as a local resource to:

- Provide information on Supported Living and Medicaid Waivers
- Provide information to residents of nursing homes on programs and supports available to help them move to the community
- Help connect people who have moved from a state institution with local self-advocacy groups
- Assist in the development and promotion of consumer participation in self-directed care and FSSA quality assurance outcome measures

Brenda Darrol, Valparaiso, is one of two Family Advocates for BDDS District 1, covering Jasper, Lake,



Angela and her friend, Hannah



Angela with her parents, Brenda and Bob, and a volunteer from Exceptional Equestrians

Newton, Porter, Pulaski, and Starke counties.

Brenda's daughter, Angela, is 14 and has Down syndrome, a hearing impairment, and a heart defect. Brenda became an advocate through her efforts to assure Angela was given every opportunity to succeed in her school, in her health care, and in her community.

Angela has been active in Girl Scouts, Special Olympics gymnastics, and Challenger Baseball. She is currently riding with Exceptional Equestrians, attending dance class on Saturdays, and has performed in dance recitals.

Like many preteens and teens, Angela loves *High School Musical 1 & 2* and *Hannah Montana*. In March, as a member of her middle school drama club, she had her own opportunity to perform "One Wild Night" in the "Coming of Age" musical drama.

Veteran's Day was particularly special



Angela and her brother, Matt, celebrate his safe return from Iraq.

for the Darrol family, as they watched Angela read a story for her school's Veteran's Day program about her brother Matt who had recently returned from a second tour of duty in Iraq.

A recent significant event for Angela and her family was her confirmation in the Catholic Church on May 8.

Brenda has worked hard and learned much to make a better life for Angela. Now she is using those skills to assist other families who have a loved one with a disability.

For more information on The Arc Network, visit our web site at:

<http://www.arcind.org>



Angela and cousin Melissa at Angela's dance recital

Priority Medicaid Waivers

While waiting lists to receive services from a Medicaid waiver remain a reality, it is important for families to know that "priority" Medicaid waivers are available in specific situations:

1. Primary caregiver is age 80 or older.
2. Young adults, ages 18-24, who have left a high school special education program.
3. Loss of a primary caregiver, where there is no other caregiver available—may include death, long term institutionalization, long term incapacitation, or long term incarceration of the primary caregiver.
4. Indiana State Department of Health requirement that a person move from a Medicaid funded group home.
5. Children aging out of residential or group home settings funded by the Department of Education, Division of Family and Children, or Medicaid. However, before a Medicaid waiver will be approved, there must be a documented effort to obtain a group home placement.

Families can apply for a priority Medicaid waiver by contacting their local office of the Bureau of Developmental Disability Services (BDDS). The number for a local BDDS office can be obtained by calling 800-545-7763.

Crisis Assistance Services Reaches 300 People in First Six Months

Since its inception six months ago, Indiana Crisis Assistance Services has reached 300 people in need of immediate help. Of the 300 served, 90 were people who had never received any type of assistance, and 100 of them were children. Funding for the program came from savings resulting from the closure of Silvercrest, a facility for children in New Albany, Indiana.

Crisis Assistance Services provides supports for people with develop-

mental disabilities experiencing extreme behavioral or psychiatric issues which puts their health and welfare, or the health and welfare of others, in serious jeopardy.

Services include

- 24/7/365 Telephone Crisis Support
- In-Home Technical Assistance
- Out-of-Home Short Term Residential

- Follow-Along Post Crisis Intervention

For help call

North BDDS Districts 1, 2 & 3
1-866-416-4774

Central BDDS Districts 5 & 6
1-866-920-3272

West & South BDDS Dists. 4, 7 & 8
1-866-416-4774

Profile in Commitment—Self-Advocate Betty Williams

When Betty Williams walks into The Arc of Indiana office, she is almost always discussing business on her cell phone and lugging a briefcase full of work along with her. She is a woman on the go, serving as coordinator for consumer education for The Arc of Indiana and vice president for the national organization, Self-Advocates Becoming Empowered (SABE).

As a child Williams envisioned a different career for herself. “I actually wanted to be a special education teacher, because I just felt like I didn’t get everything I needed as a special education student,” Williams said. “I didn’t get to be that teacher, but I do get to talk to people and train others about people with disabilities and what we’re

capable of doing. I’m pretty satisfied with where I’ve gotten to.”

Williams grew up in Richmond, a small eastern Indiana city where “you can get anywhere in town in 15 minutes or so.” She was the only child of a hardworking single mother who did the best she could to take care of her daughter. Twice a year, Williams’ mother, Freda, drove her to Indianapolis for adjustments to the braces she wore to correct the effects of cerebral palsy.

“The first 18 years of my life, nobody helped my mother with anything,” Williams said. “My mom had to do it all. There was nobody out there—from the state or anywhere else—that helped her with anything.”



Melody Cooper and Betty Williams, Self-Advocates of Indiana, went to the polls on primary election day. Self-Advocates of Indiana and The Arc of Indiana does not endorse or support candidates for political office. However, the two organizations strongly encourage people with disabilities and their families to register and exercise their right to vote.

Williams attended public school, where she found her special education classes to be rudimentary and uninspiring. “I felt like we were warehoused, and we were learning the same thing over and over again every year.”

She graduated from high school without being taught some fundamental elements of a formal education.

“As an adult I had to go back and learn how to read, but then I figured out I *could* learn,” she said. “People just didn’t take the time, or they didn’t have the time back then to help us learn how to read and retain that.”

In the early 1990’s, Williams decided to become a self-advocate. She signed up for a class designed to teach self-advocates and parents how they could influence public policy and opinion regarding disabilities. Around that time she met The Arc of Indiana’s executive director, John Dickerson.

“I went through the first Partners in Policymaking class, and I graduated from that in 1992, and somewhere during the course of that year, I met and heard John for the first time,” she said. “I was kind of energized by that because he could answer all those questions. If you asked him a question, he either knew how to answer it or he knew how to find the answer to the question. That intrigued me. And so I was interested in The Arc then.”

A few years later she came to Indianapolis for The Arc’s national convention. She was inspired by the spirit of the conference and knew that she’d found her calling. “I’ve been involved with The Arc ever since.”

In late 2007, The Arc of Indiana established The Arc Network to help people with disabilities and their families learn about the resources available to them. The network, a group of self-advocates and family advocates throughout the state, is directed by Williams and Nanette Whightsel, Director of Family Education and Community Resources.

“There are situations out there where people need our help because they may not be getting everything they need from everywhere—or anywhere—and they may need us to help them figure out where to get help,” Williams said.

People with disabilities may have greater access to services now than when Williams was growing up, but she says that people are still facing the same challenges. “I know that people still have to fight for what they want, and that’s not good,” Williams said. As far as general attitudes toward people with disabilities, “I think it’s better, but we’ve still got a ways to go.”

YOU HAVE THE RIGHT TO VOTE in Indiana if:

- ☆ You are both a U.S. citizen and a resident of Indiana, and
- ☆ You will be at least 18 years of age on or before the next General or Municipal Election, and
- ☆ You are not currently in prison after being convicted of a crime, and
- ☆ You have lived in the precinct where you vote for at least 30 days prior to the election, and
- ☆ You are registered to vote

To learn where to register to vote or to update your registration, and where to go to vote, go to:
www.indianavoters.com or call 1-866-IN-1-VOTE.



Hoosier Honored as Direct Support Professional of the Year

Daisy Diggins, an employee of Mosaic in Northern Indiana, was named the Indiana 2008 Direct Support Professional of the Year by the American Network of Community Options and Resources (ANCOR). She received the award April 15 in New Orleans.

“Being around Daisy is a great experience,” said Bill Cochrane, executive director of Mosaic in Northern Indiana. “She is an amazing caregiver who works hard everyday to make the lives of those around her better. She also is a great motivator for the other staff she comes into contact with. The kindness and passion she demonstrates through her ser-

vice to others is really a part of her commitment to her mission to serve others.”

One example of why Diggins was recognized is the personal commitment she has made to take a former client to church and assist him in his role as an usher.

Mosaic is a provider of services to people with disabilities in fourteen states, including Indiana.

ANCOR is a national association representing more than 850 private providers of community living and employment supports and services to more than 385,000 individuals with disabilities.

THE IMPORTANCE OF WORDS, ACTIONS AND RESPECT

Language

Words are important. Words and phrases shape our perceptions.

While it is common to use labels to describe many things, using labels to describe individuals or groups of people detracts from who a person really is—a unique person with their own wants, needs, hopes, and dreams.

Just as no one person is like another, no person with a disability is the same as another, even if he or she has the same disability. People with disabilities are people first. While disabilities are part of their lives, their disability does not define them.

- Always use people-first language. Refer to the person first and not his or her disability. Do not say “a disabled person.” Instead, refer to “a person with a disability.”
- Never group individuals together as “the developmentally disabled,” which puts the focus on the disability, not on the individual.
- Avoid emotional and sensational words. People with disabilities are often thought of as inspirational and courageous, or pitiful and in need of charity. Both extremes are erroneous stereotypes.
- Be sensitive when choosing words. The reality is that people with disabilities do not succeed “in spite of” their disabilities. They succeed “in spite of” an inaccessible and discriminatory society. They do not “overcome” their disabilities so much as “overcome” prejudice.
- Use nonjudgmental terms and phrases that offer dignity and respect.

Actions and Respect

Just as important as words, are actions—how we interact with and treat people, regardless of their situation in life or what disability they may have. Treat people with disabilities and their families as you would want to be treated—with respect, dignity, and courtesy.

- Don’t be so focused on a person’s disability that you don’t see the person.
- Focus on the person’s capabilities.
- Don’t be afraid to ask questions when you’re unsure of what to do.
- Listen to the person, or when appropriate, the person’s family or guardian.
- Talk directly with the person with a disability; use eye contact and speak directly to that person rather than through a companion or sign language interpreter.
- Offer assistance if asked or if the need is obvious. If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions. Do not insist or be offended if your offer is not accepted.
- Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to others. Likewise, use full name when appropriate.

Cognitive

- When talking with a person with a cognitive disability, if you are in a public area with many distractions, consider moving to a quieter location. Be prepared to repeat what you say, orally or in writing.
- Be patient, flexible and supportive. Take time to understand the person and make sure the person understands you.
- You may need to ask questions which require only short answers or a nod of the head. Provide extra time for decision-making.
- Do not “over-assist” or be patronizing.

Speech

- Listen attentively when you’re talking with a person who has difficulty speaking.
- Be patient and wait for the person to finish, rather than correcting or speaking for the person.
- If necessary, ask short questions that require short answers, a nod or shake of the head. Never pretend to understand if you do not. Instead, repeat what you have understood and allow the person to respond.
- Concentrate on what the person is saying. Do not speak for the individual or attempt to finish her or his sentences.
- If you are having difficulty understanding what the person is saying, consider writing as an alternative, but first ask if this is acceptable.

Mobility

- When speaking with a person who uses a wheelchair or a person who uses crutches, place yourself at eye level in front of the person.
- Never patronize people who use wheelchairs by patting them on the head or shoulder.
- Do not lean on a wheelchair or any other assistive device.
- Do not assume the individual wants to be pushed—ask first.
- When meeting a person who is visually impaired, identify yourself and others who may be with you.

Hearing

- To get the attention of a person who is deaf, tap the person on the shoulder or wave your hand.
- Look directly at the person and speak clearly and slowly to determine if the person can read your lips. Be sensitive to those who lip read by facing the light source and keeping hands and food away from your mouth.
- Do not assume a person with a hearing or speech impairment has a cognitive disability.

Working in a Person’s or Family’s Home

- If you are working in a family home or residential home, remember that it is the individual’s or family’s home, not yours.
- Treat each person in the household as you would like to be treated, with respect.
- Do not walk in without knocking.
- Do not change television or radio channels or play music without asking.
- Do not use the phone without permission, or call long distance. If you answer the phone, just say, “Hello, Cathy speaking.” Do not answer with a label for the house, like “Main Street.”
- Do not answer the phone while talking to a family member.
- Listen to what people with disabilities have to say. They know themselves and know how they want to be treated, and what does and does not work for them. What they can share is important to their well being, safety, and quality of life.
- Listen to what families or guardians say. They have known their loved one much longer than you. Family members know their loved one’s likes and dislikes, what works and what doesn’t. What family members know and can share is important to their loved one’s well being, safety, and quality of life.
- Do not assume people with disabilities and families know everything. Do not use acronyms without an explanation. Use terminology that is understandable, not therapy language, etc.
- Explain what you are planning to do and why you are planning to do it. Ask for input and ideas from the person or family.
- Do not treat a family member or an adult with disabilities as if they were a child. Do not speak down to them. Explain in a respectful, non-condescending manner.
- Do not talk about the person as if they were not there.
- Be respectful of the culture and habits of the home.
- Be considerate of the feelings and privacy of people with disabilities and family members.
- Do not talk in a negative way about the person with a disability or the family to others.
- Do not share private things, negative or positive, that may take place in a family’s home or the home of a person with a disability, with others. Think first—would you want what you may say being said about you?

Sources: People with disabilities and families; Indiana Governor’s Council for People with Disabilities, Indianapolis; *Guidelines to Reporting and Writing About People with Disabilities*, Media Project, *Research and Training Center on Independent Living*, University of Kansas, *Ten Commandments of Etiquette for Communicating with People with Disabilities*, National Center for Access Unlimited, Chicago, IL; *Beyond the AP Stylebook: Language and Usage Guide for Reporters and Editors*, The Advocado Press, Inc.

FSSA COMMITMENT TO COMMUNITY PROGRAMS

2000 New People in Services

In September 2006, the Indiana Family and Social Services Administration (FSSA) made a commitment to fund community programs for people with developmental disabilities with savings from state institutions that had closed.

Now, nearly 20 months later, IPMG, a private company contracted by FSSA to provide case management services statewide, has documented that over 2,000 people with developmental disabilities are receiving community services for the first time. This brings to over 11,000 the number of people

served by the Developmental Disabilities, Autism and Support Services Medicaid waivers. The goal is to bring an additional 1,000 people into services over the next year.

This growth could not have happened without the partnership of community providers, families, advocates, IPMG, FSSA, Governor Mitch Daniels, the Indiana House of Representatives, led by Speaker Pat Bauer; and the Indiana State Senate, led by President ProTempore David Long.

Each month IPMG provides detailed information about the type of waivers people have and where they live. You can find this information on The Arc of Indiana's web site: www.arcind.org.

New Programs Impacting Medicaid

Indiana Eligibility Modernization

Indiana Eligibility Modernization is a program initiated by the Indiana Family and Social Services Administration to allow Hoosiers to apply for and manage benefits for **Cash Assistance (TANF), Food Stamps and Medicaid/ Hoosier Healthwise** on the Internet, www.in.gov/fssa/6175.htm, through a toll-free number, **1-800-403-0864**, or in a local Division of Family Resources (DFR) office. The Arc of Indiana recommends that people with disabilities and their families apply or resolve problems by going directly to their DFR office.

Implementation has been phased in across the state, starting in North Central Indiana in October and November of 2007. The program should be implemented statewide in June.

For help, information, or to apply for benefits, call:

1-800-403-0864 (7:00 am – 7:00 pm, local time) or go to:
<http://www.in.gov/fssa/6175.htm>

Indiana Care Select

Indiana Care Select is a new care management program serving the following Medicaid recipients:

1. People who are aged, blind or disabled
2. Home and Community-Based Waiver participants
3. Adoption Assistance participants
4. M.E.D. Works participants

Care Select is not for people who are on Medicare. This program began in Central Indiana in November, 2007, and should be implemented statewide

in June. Care management will be provided by two Care Management Organizations (CMOs):

1. ADVANTAGE Health Solutions
2. MDwise, Inc.

People already receiving Medicaid will be enrolled in the CMO in which their Primary Medical Provider (PMP) participates. If they do not have a PMP, an Enrollment Broker, MAXIMUS, will contact them.

For help or information, call:

1. Care Select Helpline
1-877-633-7353
2. MAXIMUS (Enrollment Broker)
1-866-963-7383
3. ADVANTAGE Health Solutions, Inc.
1-866-504-6704
advantageplan.com
4. MDwise, Inc.
1-866-440-2449 / mdwise.org

Indiana Public Health Assistance Helpline

Mental Health America of Indiana has been contracted by FSSA to provide the Indiana Public Health and Assistance Helpline to provide information regarding cash assistance (TANF), Food Stamps, and Medicaid. The Helpline may be able to answer questions regarding:

1. How to apply for public assistance
2. Questions and concerns about changes in Medicaid
3. How to find local services

For help or information, call:

1-877-246-3243 Monday – Friday, 9:00 am – 5:00 pm. After hours leave a message and a return phone number.

Moving off Waiting Lists, Help in Time of Need

Since September, 2006, over 2,000 people with developmental disabilities are receiving home and community-based services through Medicaid waivers for the first time.

Following are the number of people new to services in major categories.



1,121 Moved off Medicaid Waiver Waiting Lists



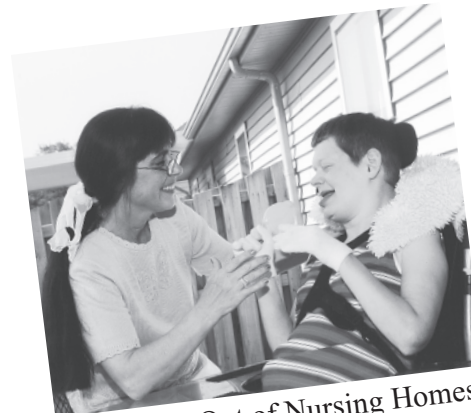
263 Loss of Primary Caregiver



200 Recent Graduates of Special Education Programs



148 Caregiver Age 80 or Older



70 Moved Out of Nursing Homes



40 Moved Out of Large Institution



33 Young Adults Aging Out of Residential Program for Children

Photos from the Self-Advocates of Indiana 2007 picnic and calendars produced by The Arc of Indiana

19th Annual Golf Outing Scheduled for June 20, 2008

Former Indiana Pacer and IU Basketball star Steve Green will once again host the charity golf tournament to benefit The Arc of Indiana. This year's tournament will be held June 20, 2008, at The Legends of Indiana Golf Course in Franklin, Indiana. Lunch will begin at 11 a.m., followed by a shotgun start at 12 p.m. Prizes will be awarded after the round is completed, at approximately 5 p.m. The tournament is open to both advanced and recreational golfers.



This is the 19th annual golf tournament, and it is The Arc's primary fundraising event. All proceeds will go toward enriching the lives of people with developmental disabilities. Your support helps make this important work possible and will positively impact the lives of so many people.

For more information, or to register, please visit our website at www.arcind.org and click on "Upcoming Events." Or, call us at 317-977-2375 or 800-382-9100. We look forward to seeing you this June

for a fun-filled day of golf, fun and fellowship.

\$2000 does not just fall from the sky everyday. Join us for The Arc of Indiana's GOLF BALL BOUNCE!

At the start of this year's golf tournament, 1,000 numbered golf balls will be dropped from approximately 100 feet onto The Legends of Indiana's driving range. The lucky participant whose golf ball lands the **closest** to the marked hole will win \$1,000. The numbered golf ball **2nd-closest** to the hole will receive \$500, and \$250 will be given to the **3rd-closest** numbered ball. In addition, the person whose golf ball lands the **farthest away** will receive \$250.

Tickets for the golf balls, numbered 1 to 1,000 are on sale now for only \$10 each. Whether you are a golfer or just want to support The Arc, everyone can participate. You do not need to be present to win!

To support the very important work of The Arc and purchase your golf ball ticket, please go to our website at www.arcind.org and click on "Upcoming Events." Or call us at 317-977-2375 or 800-382-9100. This is a hole-in-one anyone can make!

First Annual Texas Hold'Em Tournament a Success

Next Tournament Planned for September 28

Players from around the state gathered in February for The Arc of Indiana's First Annual Texas Hold'Em Poker Tournament. From the Texas Hold'Em Beginners Workshop at the start of the day, to the exciting final table competition, the tournament was a huge success. All funds raised during this friendly competition support the work of The Arc.

The success of the tournament was due to the hard work of Kelly Hartman and Jim Altman. We truly appreciate all of the time and effort they put into the event. We would also like to thank our title sponsor, **Circle City Basket Co.**, our event

sponsors, **Insights Consulting, Inc., WPT APL-Indiana, T & T Sales and Promotions, Wiley Publishing, and Brunoscotti**, and our table sponsors, **Ice Miller LLP, St. Malachy Knights of Columbus, Fraternal Order of Eagles Boone Aerie No. 2062, and Jeff Brown at MB2 Advertising.**

Our next tournament will take place Sunday, September 28, 2008 at The Rathskeller in Indianapolis. If you would like to receive information, please call 317-977-2375 or 800-382-9100. Information will also be posted on our web site at: www.arcind.org. Click on "Upcoming Events." Registration will begin in mid-summer and will be limited to the first 140 players.

THE ARC OF INDIANA

107 N. Pennsylvania St., Suite 300
Indianapolis, IN 46204
317-977-2375 or 800-382-9100
www.arcind.org and www.TheArcLink.org

SABE 2008

Indianapolis

REV UP YOUR ENGINES FOR INDIANAPOLIS—
SELF-ADVOCACY'S GOT THE FEVER!

9th Annual Self-Advocates Becoming Empowered National Conference

Brought to you by
Self-Advocates of Indiana

September 4-7

Marriot Downtown

Register early!

Early Bird Registration prior to June 30 - \$350. After June 30 - \$425
Children age 9 and under free

Registration Fee Includes:

- All Conference activities
- Three Nights of Entertainment
- Dinner on Thursday, September 4
- Breakfast, Lunch and Dinner on Friday, September 5
- Breakfast, Lunch and Dinner on Saturday, September 6
- Breakfast on Sunday, September 7
- Ground transportation to and from the airport (during designated shuttle times)

Registration fee does not include:

- Air travel
 - Hotel room
 - Ground transportation for arrivals and/or departures outside of designated shuttle times
 - Optional tours or events
- Conference Hotel**
Indianapolis Marriot Downtown
350 West Maryland Street
Group Rate - \$149 plus tax for single/double room
For Reservations Call: 877-670-7666
For Group Rate, Reference Group Code: SABE
Hotel reservations must be made by Monday, August 4, 2008 to receive group rate.

For Complete Conference Information, go to: www.sabe2008.org

Upcoming Events

June 20

Former Pacer and I.U. Star Steve Green's 19th Annual Golf Tournament

The Legends of Indiana
Franklin, Indiana

www.arcind.org

Click on "Upcoming Events"

June 18 - Evansville

June 24 - Indianapolis

July 10 - Fort Wayne

Minority Outreach Project Trainings

"Diversity, Looking Through
Your Personal Lens"

www.arcind.org

Click on "Upcoming Events"

August 6-7

Statewide Transition Conference

Sheraton Indianapolis Hotel and Suites
8787 Keystone Crossing
Indianapolis, Indiana

<http://www.iidc.indiana.edu/cclc>

August 14

Recognizing and Responding to the Vulnerability Trail for People with Developmental Disabilities

The Fountains Banquet
and Conference Center
Carmel, Indiana

www.arcind.org

Click on "Upcoming Events"

September 4-7

Self-Advocates Becoming Empowered National Convention

The Marriott Downtown
Indianapolis, Indiana

www.SABE2008.org

September 28

The Arc of Indiana Texas Hold 'Em Tournament

The Rathskeller
Indianapolis, Indiana

www.arcind.org

Click on "Upcoming Events"