

New Hope for Thousands to Receive Medicaid Waiver Changes Coming to Programs, Services for People with I/DD

Section 144 of the 2012/2013 State Budget Bill called on the Family and Social Services Administration (FSSA) to review and make changes to Indiana's Medicaid Waiver program. In response, FSSA has crafted a series of proposals that set a direction for the future to support more people with existing funds, redirect resources to providers who meet quality standards, bring services to those who need them most and provide new supports to people with very challenging needs.

The Arc was invited into the process that led to the development of FSSA's plans for reform. As these reforms move forward and are refined, we continue to lend our voice and advocacy towards the goal

of ensuring these changes benefit the nearly 18,000 Hoosiers currently receiving supports and services, and the over 20,000 people who continue to wait.



FSSA's Section 144 Report, released in April, 2012, recommends developing a new Family Supports Waiver that would improve, expand and replace the current Support Services (SS) Waiver. The goal is to bring services to 6,600 people through the Family Supports Waiver, and an estimated 1,000 people through the Developmental Disabilities (DD) Waiver, over the next three years—April 2012 through March 2015.

FSSA hopes that significantly increasing the number of people receiving supports on the Family Supports Waiver will decrease the need for the Developmental Disabilities Waiver, allowing it to be transitioned to a "needs based" program—those who need the range of supports provided through the DD Waiver would get those supports at the time that they need them.

People currently on the SS Waiver would be transitioned to the Family Supports Waiver, and those currently on the SS Waiver waiting list would receive services through the Family Supports Waiver as they come off that waiting list. Unless they have significant needs, people currently on the DD Waiver waiting list would be transitioned to receive services through the expanded Family Supports Waiver. The DD Waiver would focus on serving those with needs greater than what could be provided through the Family Supports Waiver. FSSA is sensitive to the fact that there are people who have been waiting for years who are near the top of the waiting list. They plan to work with these individuals on a case-by-case basis to determine if they would receive the Family Supports Waiver or the DD Waiver as they come off of the waiting list. It is important to note that people currently receiving services under the DD Waiver would continue to receive DD Waiver services.

If approved by the Centers for Medicaid and Medicare Services (CMS), the new Family Supports Waiver will take effect July 1, 2012 and will include the following reforms:

- Increase the current Support Services Waiver budget cap from \$13,500 to \$16,250 and, based on utilization, increase the cap to \$20,000 over time
- Increase flexibility in how an individual's Medicaid Waiver budget can be used
- Add participant assistance and care as a new waiver service to provide a new level of support to an individual either in the

family home or in an individual's own home

- Add transportation and case management as a waiver service with a wider array and choice of case management entities

Continued on page 7

Update on People New to Waiver Services

Progress is being made in moving people off Medicaid Waiver waiting lists and into services, with 304 new people reported as receiving Medicaid Waiver services January–May 11, 2012.

Waiting List Status Form

The Division of Disability and Rehabilitative Services (DDRS) has mailed letters to all individuals on waiting lists for the Developmental Disabilities, Autism, and Support Services Medicaid Waivers, asking recipients to return an enclosed Waiting List Status Form to DDRS by April 10, 2012 to indicate whether or not they want to remain on a waiting list. If you did not receive a letter, or if you did not realize the importance of returning the form, contact your local Bureau of Developmental Disabilities Services (BDDS) office and let them know you need a Waiting List Status Form to return ASAP. To find your local BDDS office visit: www.in.gov/fssa/files/BDDS.pdf

Waiting List Web Portal

FSSA has created a Waiting List Web Portal to check your status on the waiting list and keep your information updated. For information and to access the portal, visit: www.in.gov/fssa/ddrs/4328.htm

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Printed on recycled paper

The Arc of Indiana
107 N. Pennsylvania St.
Suite 800
Indianapolis, IN 46204
317-977-2375

Self-Advocates of Indiana President's Corner



Melody Cooper

Melody Cooper
President, Self-Advocates of Indiana

My Trip to D.C. on Behalf of SAI

When I think about going to Washington, D.C., I get excited! Being able to see our nation's capitol reminds me that it is a very important place. But what really excites me most of all is to be able to talk to the legislators that we meet with on

Capitol Hill. We let them know that, as *people*, we have a right to express our voices on issues that affect the disability world. This time, I met with staffers for Indiana Congressmen Dan Burton, André Carson, Mike Pence and Joe Donnelly. The Indiana group talked about the ABLE Act and keeping children safe in schools. I talked about employment and how we want to push this issue in Indiana for people with disabilities.

Additionally, I had the chance to meet Senator Tom Harkin (a champion for people with disabilities) and Kareem Dale (Special Assistant to the President on Disability Policy). It was inspiring to talk to Senator Harkin and let him know what's going on here in Indiana for people with disabilities. As for Mr. Dale—who visited Indiana during the 2008 SABE conference—it's amazing to know that President Obama has somebody who represents the disability community, speaking on our behalf.

If you have never been to D.C., I would tell you to go. It is a wonderful place to sight see and tour. We went to memorials, museums, Arlington National Cemetery, and even got to peek at the White House!

There is a lot of history in D.C. I

got to see an amazing memorial for President Franklin D. Roosevelt. Being at that memorial made me realize that people with disabilities can do anything they set their mind to. Can you imagine being the President of this whole United States from a wheelchair? FDR did.

It's important to have memorials and museums so that we can be able to understand our history, and where people started from. It's important to know history—of where *they* have come from, and where *we* are going. It's good to know that people with disabilities have a history too. I would like to be able to see the disability community continue to write our own history, and grow for a better tomorrow.

I look forward to going back again next year.

Blueprint for Change

A blueprint is a plan for action. Change can improve the way things are. The Arc's *Blueprint for Change* is a plan to make life better for individuals with intellectual and developmental disabilities, like me. To make it happen, it will take all of us – including Self-Advocates. **Three ways** I can help are:

- **Be My Best "Me"** – I will advocate for myself and others to have the best opportunities for employment, education, and independence.
- **Support My Supports** – The people in my life who help me (my family, my staff, my community) also have needs. We need to be there for each other.
- **Money Matters** – It is important that money spent for my paid supports is used wisely. Some people don't have enough money. Some people have more than they need.



I am a Self-Advocate for Change.



A View from My Window

Hosted by Michelle Fischer

The Arc of Indiana welcomes you to listen in to *A View from My Window*, our podcast hosted by Michelle Fischer.

Visit www.arcind.org/AViewfromMyWindow to listen to the latest edition and past broadcasts of *A View from My Window*, including these recent shows:

A View with Two Moms

A View into Circle of Friends

A View with John Dickerson into Changes Coming to Programs for People with I/DD

A View on IDOE's Special Education Survey for Parents

A View with Autism Society of Indiana President, Dana Renay

A View from Providers at the 2012 INARF Conference

A View into Storytelling and Filmmaking with Ken Oguss

A View from One Provider, Kelly Hartman, CEO of Insights Consulting and President of Outside the Box

Be sure to join Michelle on Facebook "A View from my Window with Michelle Fischer" and subscribe to her blog, "Behind the Mic," <http://michellefishersmic.blogspot.com>.



SAVE THE DATE

Self-Advocates of Indiana Annual Picnic

Friday July 20, 10:00AM-3:00PM
Eagle Crest Park, Indianapolis

Stay tuned for registration (\$15) info!

All are welcome: Self-advocates, friends, family, staff, and more!



CELEBRATE • FOOD • GAMES • DRINKS • FRIENDS • FUN • SUNSHINE



John Dickerson

Executive Director's Column

Facing Challenges, Shaping Opportunity

It was quite a meeting. When we started planning the meeting that we hosted for families on FSSA's recently released *Section 144 Report*, some thought fifty people might attend; others thought maybe a hundred. When, on April 12th, more than 500 people showed up, all were pleased and surprised. And while we had a few professionals present, the vast majority of people were family members and self-advocates.

I had the chance to talk to a great many people—some who have had family members in the system for over 30 years and some still waiting to get in—and the need for information, for understanding, was so clear.

We have dedicated a great deal of our newsletter and website to sharing whatever we can about changes being implemented and changes still being discussed: a new Family Supports Waiver, proposed changes to

the DD Waiver, establishing a "health home" for people on the waiver, looking for new ways to better serve people with high needs and more.

Since that meeting I have had many conversations with family members, and their concerns are important to hear and understand.

Many waiting are worried that they will never get help. Some don't believe the state will really add 7,000 people to services over the next three years. Others worry that their son's or daughter's services will be cut or eliminated to serve others. Many wonder how the state can add this many people without cutting others. And then there is the clear sentiment out there asking why anything needs to change—why can't the legislature and congress just do the right thing and take care of everyone in need?

All are valid points, ones that The Arc, through our committees, board and *Blueprint for Change* efforts, has struggled with

mightily. All of our efforts have led to the same conclusion—either we advocate for and shape fundamental change, or we turn our back on thousands of people still waiting for help.

FSSA's *Section 144 Report* and other proposed changes to DD services provide a direction—a direction that still offers opportunity for input, refinement and continued development.

So, how can you get involved and have input? Join or start the conversation in Forums on our website by visiting www.arcind.org and clicking on the "Blueprint" icon. Look for information and updates in "News" on our website or join us on Facebook for quick updates. We will keep you updated on meetings FSSA is hosting around the state to share information and listen to concerns and ideas. The next announced meeting following publication of this newsletter is **Thursday, June 14, 6:00-7:30 PM at the Allen County Public Library in Fort Wayne**. Also watch for dates and locations of legislative and candi-

date forums we will host throughout the state. Email us your questions, concerns, and ideas: thearc@arcind.org, or call us at 317-977-2375 or 800-382-9100.

The *Section 144 Report* sets a direction. Like The Arc's *Blueprint for Change*, it is a compass direction, not a final roadmap.

To all who joined us at our Family Meeting on April 12th, thank you for taking the time to be there. To those who could not make it, videos of all the presentations are on our YouTube channel. An article explaining all of the changes and an ongoing list of Questions and Answers are also on our website. Just go to www.arcind.org to find links.

Change is hard, and Hoosier families and people with I/DD are faced with a great deal of change. It is understandable that there are many mixed emotions. While some feel angry and distrustful, others are hopeful that they may finally get help and supports. Together, we need to find the way to focus our collective, positive energy to shape this change. That is our opportunity.

Blueprint for Change

Celebrating Those Who are Making it Work

Throughout 2012 we are sharing stories featured in our 2012 calendar that exemplify the good work that is happening throughout the state to help individuals with I/DD build career pathways and use their unique gifts—and illustrate how we can all work together, to look beyond what others say can and cannot be done, to find a way to make things work through determination and resourcefulness.

The Arc of Greater Boone County

After Nigel Watson's mother became too ill with cancer to provide for his care, he came to live in a group home operated by Indiana Mentor in Indianapolis. At that time, Nigel was diagnosed with Disruptive Behavior Disorder, a moderate to severe intellectual disability, and difficulty communicating.

Finding the right program for Nigel during the day was difficult.

After attempts at several agencies did not work out, Nigel was referred



to The Arc of Greater Boone County. Initially, things did not go well there either. Indiana Mentor staff stepped in and suggested that everyone concerned about Nigel come together to tailor a program that would work for him. After much discussion, a plan was developed.

Nigel is now speaking occasionally, and he rarely gets angry or upset. He enjoys playing basketball, spending time with friends and helping others by running errands.

Rather than giving up because of what was not working in Nigel's life, Indiana Mentor and The Arc of Greater Boone County took the time to find what did work for Nigel, and that has made all the difference in one man's life.

Passages Inc.

Local Chapter of The Arc in Whitley County

Nathaniel Boutelle enjoys his involvement in Passages' Artistry Program and shines as a self-taught photographer, his favorite art form. He is known to take his camera everywhere he goes just in case he comes upon a special moment to capture. He particularly enjoys opportunities to capture unique objects and close-ups.

With the support and encouragement of Passages and their Artistry Program, Nathaniel is developing other new skills. He not only helps with art class preparation but also

leads others to develop their own creative talents by assisting peers in the program. Art work created by the artists has been sold to an enthusiastic public in the Whitley County area.



Nathaniel has had many opportunities to showcase his unique talent, including a one man art show in November, 2011. The recognition he is achieving through his work gives him a great sense of pride and self-confidence as an artist and as an individual.

Continued on page 5

ABLE Act, Seclusion/Restraint, Employment: Key Issues at National Public Policy Conference

In late April a dozen representatives from The Arc of Indiana, local Arc chapters, and Self-Advocates of Indiana traveled to Washington, D.C. for The Arc's National Public Policy Conference. The conference included discussions with key policy staff from Congressional offices and committees, the leading advocacy organizations in Washington, D.C. and a lunch conversation with Kareem Dale, Special Assistant to the President for Disability Policy.

Although there are many issues being discussed in Congress, the Indiana delegation focused on gathering support for Achieving A Better Life Experience (ABLE Act), The Keeping All Students Safe Act (Seclusion and Restraint), and the Workforce Investment Act (WIA). You can find more information on these and other key issues in Congress, by visiting the public policy section of The Arc US website, www.thearc.org. Click on "What We Do" and then click on "Public Policy."

ABLE Act

The ABLE Act is receiving a great deal of attention in Congress. It would provide one way for families to save toward the future needs of a child with disabilities. The ABLE Act creates a new subsection (f) ABLE Account within Section 529 of the



SAI Administrator Rebecca Scherpelz, SAI President Melody Cooper and The Arc's Associate Executive Director Kim Dodson

Internal Revenue Code. Expenses that the ABLE Account could assist with include education, transportation, employment support, and health and wellness. It differs from a special needs trust in that it is more

specific regarding what expenses could be covered from an ABLE Account.

Sponsors of the bill are gathering co-sponsors and hoping to show strong bipartisan support that the measure can be included in larger tax issue bills later this summer. Several Indiana lawmakers have signed on in support:

Congressman Joe Donnelly (D)
Congressman André Carson (D)
Congressman Dan Burton (R)
Congressman Peter Visclosky (D)

Keeping All Students Safe Act

There are no federal laws regulating the use of restraint and seclusion. The Arc supports legislation that only allows restraint and seclusion if there is a threat of harm to someone, requires teachers and other school staff to have training in restraint and seclusion and in positive ways to handle behavior, requires schools to tell parents when restraint or seclusion is used, does not allow the most dangerous types of restraint, and



SAI President Melody Cooper

encourages the use of positive ways to handle behavior.

Workforce Investment Act (WIA)

The Arc supports the reauthorization of the Workforce Investment Act and the Vocational Rehabilitation Act. The Arc also supports policies and practices to assist people with developmental and other significant disabilities in getting real jobs with real pay, improving transition services for youth who are leaving school, and including people with disabilities in jobs bills.

Legislative Wrap-Up / Looking Ahead

The Arc maintained an active presence at the State House throughout the 2012 session of the Indiana General Assembly. Unfortunately, the focus on Right-to-Work legislation made for a difficult and contentious session where few other issues of substance were addressed.

The summer months will be busy with Interim Study Committees and the important 2012 elections. The Arc has several events planned for the summer, including hosting Legislative Forums around the state in collaboration with our local chapters. The goal is to speak with families and self-advocates about the importance of getting involved in the public policy process. We will also be inviting legislative candidates to hear from families and self-advocates about issues important to them. The forums will also focus on making sure self-advocates and families have the opportunity to exercise their right to vote in the 2012 elections.

We will also be inviting the candidates for Governor, John Gregg

(D) and Mike Pence (R), to participate in a conversation about the issues important to people with intellectual and developmental disabilities and their families. Candidates for Superintendent of Public Instruction will be invited to speak to The Arc about their goals for students enrolled in special education services.

Watch for details on our website, www.arcind.org, in our e-newsletter and on Facebook.

Following are highlights of a few key bills The Arc addressed in the 2012 session. A complete summary can be found in the "Public Policy" section of our website, www.arcind.org.

HB 1073 – Despite much discussion, the issue of **public mass transit** never received the debate and conversation we hoped it would. HB 1073 failed to make it out of the House Ways and Means Committee and never received significant discussion. The issue remains an important one, and The Arc will continue to work on this issue along-

side many other organizations this summer.

HB 1318 – A bill regarding **seclusion and restraints in schools**, supported and initiated by The Arc with Representative Greg Porter (D-Indpls), did not receive a committee hearing and died without any discussion. This remains a priority for The Arc, and we will be introducing legislation again next year.

SB 32 – **Allows a minor who has not been adjudicated an incapacitated person and the minor's guardian to jointly petition the court to extend the guardianship beyond the date of the minor's 18th birthday.** Authorizes the court to extend the guardianship, but not beyond age 22, if the court finds that extending the guardianship is in the best interests of the protected person.

HB 1376 – Changes the "super" emergency rule-making authority that FSSA was granted last year in HEA 1001-2011.

SB 15 – Requires the State Department of Health and the Family

and Social Services Administration to **study brain injury services offered in Indiana**, determine whether there are deficiencies in the services, and determine how to implement additional services and neuro-behavioral rehabilitation programs in Indiana.

HB 1169 – Requests the legislative council to establish a study commission on school discipline best practices.

HB 1367 – Establishes the Center for Deaf and Hard of Hearing Education. Requires the Office of Management and Budget to recommend to the General Assembly an appropriate agency to provide support for the center. Specifies that until the center is established, the Indiana School for the Deaf shall continue to provide those services.

SB 268 – Requires the Education Roundtable to establish an Advisory Committee on Early Education, with members from around the state, to provide professional

Continued on page 5

Maximizing Personal Independence

Blog Chronicles Life in Nursing Home, Hopes to Move Back to Community

Greg Anderson is a fifty-seven-year-old man with cerebral palsy who lives in a nursing home, but clearly that life is not what defines him. His blog, "Maximizing Personal Independence," shares experiences of his day-to-day life in the nursing home and his hopes to move back to the community.

Many wonder, "What is it like in a nursing home? How is my loved one being cared for? What does my loved one experience each day?" Following are a few excerpts from Greg's fascinating, funny and heartfelt blog that takes you inside his life in a nursing home and answers these questions. We hope you will follow Greg's journey by visiting: maximizingindependence.blogspot.com. Scroll down to the bottom of the blog page and look for the "subscribe by email" box on the right-hand side.

TUESDAY, FEBRUARY 28, 2012

New Blog, New Post

This blog will focus on the title—maximizing personal independence. Right now, I'm living in a nursing home. It's a nice enough nursing home, but still a nursing home. My goal throughout my adult life—I have cerebral palsy, by the by—was to avoid ending up in such a place. I failed in

that. I don't consider the game to be over, though. I see this as overtime. This blog will largely chronicle my attempt to get my own home, so I can have the maximum amount of independence my physical situation will allow. There seems to be a real chance of this happening. Over the months ahead, we will see.

THURSDAY, MARCH 8, 2012

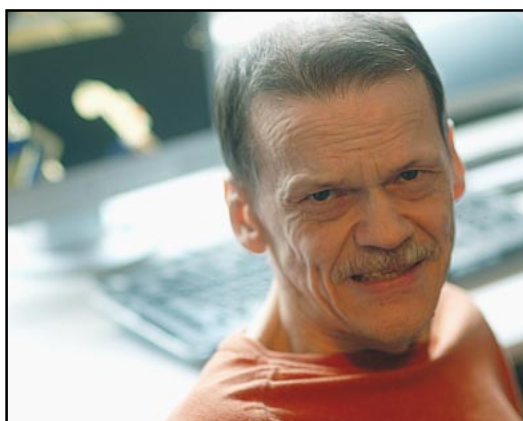
Weighty Matters

They weigh residents here regularly. The first time they weighed me, I weighed all of 95 pounds. The most recent time, I was down to 90. It's puzzling. I have a better, more varied diet here, and I generally eat most or all of what I'm given. One factor might be that I'm not always given much time . . . Most of the aides who feed me now—including several high school kids—are good about it, but some clearly just want to get it over with . . . In my own home, the aide wouldn't be especially concerned with anybody else, and I could have seconds if I wanted—and have home cooking again.

MONDAY, MARCH 19, 2012

Timing the Call

Here, when I need an aide, I press the call button. I only do it when I have to go to the bathroom, which makes timing the call tricky. First, I have to be sure I really have to go; there's no point in getting an aide to come if I can't



make the visit productive. Second, I have to take their arrival time into account. Sometimes it's ten minutes, sometimes twenty, and sometimes longer—sometimes they even come, ask me to wait while they help somebody else, and take off again . . . So, I don't want to push the button too early, but I can't wait too long either . . . In my own small home, with one aide around at any given time, I wouldn't need to worry about timing the call. I wouldn't need a call button. I could simply call.

TUESDAY, MARCH 20, 2012

Pursuing Privacy

I understand staff members in institutions like this, need constant, easy access to residents, in case something goes wrong . . . Having people in and out, however, can be difficult.

I often have someone come into my rooms, look around, and leave . . . It

can be somebody I know, but it can also be a stranger. Most of them are in some sort of uniform, but sometimes they're not . . . In my own home, only people I know would be in my house. No stranger would come in and go through my closet.

TUESDAY, APRIL 3, 2012

A Step Forward

Fairly often, a new aide will come with a regular aide of mine to watch and see what needs doing and how to do it. They also talk between themselves, as if I wasn't there, or couldn't hear, or couldn't understand them, which is odd. Anyway, my regular aides often tell the new ones how self-sufficient I am. I assume that will be a positive for me . . .

TUESDAY, MAY 8, 2012

Another Tough Night

Last night, I again couldn't use the urinal, and again an aide wouldn't take me to the bathroom. She told me the nurse said I'd fallen in the bathroom and injured a toe, so I had to use the urinal. I do have a tough time in the bathroom without my shoes, but I've never fallen in there. Anyway, I tried twice and couldn't go. So, I spent another very uncomfortable sleepless night . . . In my own home, with fewer aides involved, when I needed somebody, the aide could get to me quickly, and I could get comfortable with them.

Legislative Wrap-Up, from Page 4

and technical assistance to the roundtable.

SB 24 – Renames the "Mental Health and Addiction Advisory Council" the "Mental Health and Addiction Planning and Advisory Council." Gives the director of the Division of Mental Health and Addiction the authority to regulate smoking at state hospitals. Requires individuals applying for a social worker, marriage and family therapist, or counselor license to have a criminal history background check.

SB 286 – This bill contains many provisions regarding child services. Requires the department to estab-

lish a residential placement committee and a permanent roundtable to review certain placements of children. Provides that operators of therapeutic foster homes are certified and not licensed. Creates the Interim Study Committee on Underserved Youth With Mental Health Issues.

SB 287 – Requires the department to consult with the Division of Family Resources regarding the adoption of rules concerning child caring institutions and group homes that are licensed for infants and toddlers. Removes certain facilities that may be licensed as a secure private facility.

Celebrating, from Page 3

Janus Developmental Services, Inc.

Local Chapter of The Arc in Howard and Tipton Counties

William Miller is a fun-loving young man who enjoys sports—especially the Colts—bike riding and playing golf. He also enjoys the time he spends in Janus Developmental Services, Inc.'s Community Garden program.

This unique program is sponsored by 22 local businesses, and gardening expertise is provided year round through a partnership with Hamilton County Master Gardeners in the outdoor garden and indoor grow lab.

To help prepare for the growing season, William helped organize



many seed varieties, helped get them started in the indoor grow lab and helped in transplanting them to the outdoor garden.

William, the staff, visitors and others served by Janus all enjoy the lovely results of the work by those involved in the Community Garden program, where flowers and plants attract hummingbirds, goldfinches, hawks and butterflies.

Being involved in the Garden Program allows William and others to give back to their community.

Largest Membership in Our History Result of *Building Pathways to Membership Campaign*



More than 9,000 new members joined The Arc during The Arc's *Building Pathways to Membership Campaign*, setting a record for membership recruitment and boosting The Arc's statewide membership to more than 19,000 members. To those who are receiving *The Arc News in Indiana* as a new member, welcome!

Chapters reporting the most new members include: Easter Seals Arc of Northeast Indiana; ADEC, local chapter in Elkhart County; The

Arc of Northwest Indiana; Hoosier Prairie Arc; and Stone Belt Arc, local chapter in Monroe County.

The Arc's Executive Director, John Dickerson said, "It is exciting that so many Hoosier families, self-advocates, professionals and interested citizens are now part of The Arc family. In these difficult times, it is important not only to have friends to lean on, but also to have friends who can join together in a common mission. We welcome all of our new members who join us in

our ongoing efforts to build a better life for people with developmental disabilities and their families. We hope you will stay involved and informed by signing up to receive our weekly e-newsletter, legislative memos and action alerts. We also invite you to get frequent updates by joining us on Facebook." You can find links to all of these options in the top bar of our website, www.arcind.org.

In related membership news, the Indiana Institute on Disability and

Community (IIDC) is now our first Academic Member, a new membership category recently created by The Arc Board of Directors. Other membership categories available to organizations include Professional, Non-Profit and Business/Corporate.

To learn more about individual and family memberships or the new organizational membership categories, contact Mark Kevitt, Director of Program Services, at 317-977-2375 or mkevitt@arcind.org.

Blueprint for Change Moving Forward

The Arc of Indiana's *Blueprint for Change* sets forth a transformational plan to build a successful system that empowers people with intellectual and developmental disabilities (I/DD) and their families to shape their own future, nurture and create natural systems of support, and strengthen the foundation of publically funded services for those who need supports. It is guided by five key principles to shape the direction of system reform and change:

- Building Career Pathways for All
- Discovering and Realizing Individual Gifts
- Supporting Resourcefulness of Individuals, Families and Communities
- Using What You Need
- Shifting the Power to What Works

It is a daunting task to take the entire *Blueprint for Change* and bring it down to the first steps for implementation. But that is the task that board member Erika Steuterman is undertaking with the Blueprint Steering Committee, building on

the strong foundation provided by Laura Vieck and her team.

The Committee identified the critical first goals that we need to address and who needs to be involved. For this process to work it needs the involvement of many—for this must be something more than a project of The Arc—it has to be developed community wide. There are goals for the disability community, the administration (current and future), legislative, and things we all must share. Here is the beginning working list.

Disability Community Goals

- Develop a "first conversation" script that guides professionals in sharing consistent information with families on natural and community supports.
- Develop and utilize consistent, clear communications to educate the public, providers, families and people with I/DD that there are people who need more,

people who need less and people who have nothing.

- Develop a collaborative model for families of loved ones with substantial needs to mutually support one another, transcending provider and funding source barriers.
- Create a time bank and personal cooperative mechanism supported through local nonprofit agencies and organizations that provides supports to people on the waiting list and encourages families on the waiver to help support those on the waiting list.

Administrative Goals

- Provide greater flexibility to move funds between budgeted areas to meet the needs of the individual and the family.
- Increase the number of people served while maintaining the aggregate spending within the appropriation of the General Assembly.

- Develop and implement a plan with FSSA/DDRS to communicate electronically with all persons served by DDRS through the new Medicaid Waiver as well as the majority of people on the waiting list.
- Shift funding to support families who are caring for loved ones at home with guaranteed access to more intensive supports when life changes affect the ability of the family to provide ongoing support.

Legislative Goal

- Develop a consumer-based evaluation of FSSA to study the effectiveness of the agency, consider ways to build upon strong methods, and identify structural improvements. Consider the Marion County Hospital Corporation model, a quasi-governmental agency, managed as a non-profit organization.

Continued on page 7

The Arc Master Trust Circle of Friends

Parents planning to create a special needs trust for their son or daughter may not have family or friends—*key people* to help their child access their trust after the parents have passed away. Individuals with disabilities who create their own trust, Trust II, may need help in accessing their trust. “Circle of Friends” is an innovative new project of The Arc of Indiana Master Trust. It is designed to connect volunteers with trust beneficiaries who do not have a network of family or friends to help them utilize their trust.

We are seeking volunteers in the Indianapolis and Fort Wayne area with a true and committed desire to help someone live a better quality of life and to ensure that Trust funds are utilized as

efficiently and as effectively as possible. Volunteers must participate in a screening and training process, and commit to volunteer a minimum of two hours per month.

Our goal is to help all trust beneficiaries utilize their trust to the maximum extent possible. If you are interested in volunteering for “Circle of Friends” contact Willaine Sandy at wsandy@arcind.org or call 317-977-2375.

Learn more by listening to “A View into Circle of Friends,” a podcast produced by The Arc for Michelle Fischer’s “A View from My Window” podcast. Find it by visiting: www.arcind.org/AViewfromMyWindow.

Moving Forward, from page 6

Shared Goals

- Increase the number of people engaged in paid employment, self-employment, entrepreneurship, self-directed employment, volunteering and meaningful community activities.
- Provide consistent and ongoing family training whenever families apply for services.
- Change the Objective Based Allocation (OBA) process to allow people who feel their Medicaid Waiver budget exceeds their current needs to *contribute back* a fixed amount to be used by individuals in need of services in the same geographic area of the state—provided that these funds would be available to the individual in the future as his or her needs change.

Each of these areas will have a small working group that will engage others to help develop the right approach to tackle these critical areas. All will need the input and participation of families, advocates and people with I/DD. Please join us on The Arc website, www.arcind.org, to find activities in which you can participate on-line and also activities that will be taking place in your area.

Changes Coming to Programs, Services, from page 1

Several other key reforms addressed in the 144 report include:

Case Management—Only one entity, IPMG, currently provides case management to people receiving services through the DD, Autism or Support Services Waivers. FSSA is moving toward having multiple case management entities in each BDDS district and making case management a waiver service. At this time it has not been determined who would be selected to provide case management or how many entities would provide services in each district.

Supporting People with Challenging Needs—The creation of a new process to pre-qualify providers to serve people with high needs and high costs was recommended, but existing federal policy may not allow that to happen. The goal was to help families find and select providers with the greatest experience in serving people with the most challenging needs. Restricting choice appears to not be allowed by Medicaid rules. FSSA is working on other strategies to get the most challenging individuals the best possible supports that provide the best results. The Arc continues to support finding new answers to this critical problem.

Improved Health Care for People on Medicaid Waivers—FSSA is planning to take advantage of a new federal initiative to provide Health Care Coordination (through the Medicaid State Plan) to people on the waiver. This service would coordinate physician, pharmacy, nursing and dietician services with the goal of making individuals more healthy and lowering overall health care costs.

Increased Payments to Good Providers—FSSA is looking toward implementing a Quality and Outcome Based Provider Reimbursement System to reward good providers who have lower

consumer and staff turnover. Funds saved throughout the year would be reallocated to providers that meet certain benchmarks on quality care.

Health Care Coordination through the Medicaid State Plan to people on the waiver would coordinate physician, pharmacy, nursing and dietician services with the goal of making individuals more healthy and lowering overall health care costs.

Consistent Assessments—In April, 2012, FSSA began assessing people in Medicaid funded group homes with the same assessment used for people receiving waiver services. The goal is to better understand and compare costs and services for those in group homes and those in waiver services.

Voluntary Group Home Conversion - FSSA is working with providers who volunteer to convert to their Medicaid funded group homes to residential services funded through the Medicaid Waiver.

Crisis Beds—FSSA is developing a plan to create 20 “crisis beds” at one facility that would be available to people with I/DD who are experiencing an extreme behavioral or psychiatric problem. While The Arc agrees that crisis placements are sometimes needed, we have concerns about having all crisis beds in one location. Having a geographic distribution would be preferable. This effort is tied to a plan to move people with I/DD who still live in state mental health hospitals to a privately owned ICF/DD—which would also house the crisis beds. The Arc believes that having an independent gate keeper to provide external

oversight and evaluation of this effort is critical. This plan is still being developed and will be finalized in June.

Families as Paid Caregivers—FSSA has already approved a policy change regarding paying families to provide care to their family member under the Medicaid Waiver. Family members are limited to a combined total of 40 hours per week. However, FSSA may approve additional hours on a case by case basis through a waiver process. Families who feel they need approval for additional hours should contact their case manager

Time of Great Change

This is indeed a time of great change. Change is coming. We choose to help shape it and welcome your ideas and participation. On our website we are constantly answering questions, asking questions and seeking input. This work is far from done, and it will take all of us to make it a success. To keep up-to-date and informed, please sign-up to receive our weekly E-Newsletter and join us on Facebook. Find links at the top of our website: www.arcind.org. We will also provide updates in the “News” section of our website.

The Arc News in Indiana

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

Steve Green's 23rd Annual Golf Tournament to Benefit The Arc

June 15, 2012

Eagle Creek Golf Club, Indianapolis

\$150 per individual player

\$575 per foursome

Sponsor a hole for only \$300

Sponsor a hole & field a foursome for \$850

SCHEDULE

10:00 a.m. - Tournament Check-in Opens

11:00 a.m. - Lunch

11:45 a.m. - Golf Ball Bounce

12:00 noon - Modified Scramble, Shotgun Start

5:00 p.m. - Awards

To register online or for more information visit: www.arcind.org, click on "News & Events" or call us at 317-977-2375.

Save the Dates!

The Arc of Indiana 2012 State Conference and Annual Awards Luncheon

October 3, 2012
The Marriot East
Indianapolis, IN

The Arc US 2012 National Convention and International Forum

October 25-28, 2012
Grand Hyatt Washington
Washington, DC

The Arc of Indiana will be chartering a bus to take attendees to the conference. If you are interested in traveling to the national conference in DC on the coach bus, check for information in the upcoming months!

Watch for information about these events at www.arcind.org under "News & Events."



The Arc of Indiana's Fifth Annual Golf Ball Bounce Order Form

\$10 per chance
_____ (# of balls) x \$10 = _____

Please return payment and this form to:
The Arc of Indiana, 107 N. Pennsylvania St., Suite 800,
Indianapolis, IN 46204 or Fax 317-977-2385

- Check enclosed payable to The Arc of Indiana
Or pay with Credit Card
- Master Card Visa Am Exp Discover

Card Number: _____
 Expiration Date: _____ CID# (# on back of card): _____
 Name: _____
 Company Name: _____
 Address: _____
 City: _____ State: _____ Zip: _____
 Telephone: _____ Fax: _____
 Email: _____
 Cardholder Signature: _____

To register online or for more information visit www.arcind.org, click on "News & Events"

The Arc of Indiana's Fifth Annual Golf Ball Bounce

During Steve Green's 23rd Annual Golf Tournament
Friday, June 15, 2012
Eagle Creek Golf Club
Indianapolis, Indiana

A Hole in One Anyone Can Make!

Join us for The Arc of Indiana's Golf Ball Bounce! 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 Eagle Creek's front green. 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. In addition, there is even a prize for the numbered golf ball furthest from the hole—\$250!

Winner will be announced on June 15, 2012* at Steve Green's 23rd Annual Golf Tournament

*Winner will be notified if not present at the tournament.

Cost is \$10 per numbered golf ball

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