

2014 Public Policy Agenda Guides Advocacy Efforts

The Arc of Indiana's 2014 Public Policy Agenda will guide our public policy efforts throughout the year. Following are highlights from the agenda, focusing on those areas that will have a legislative priority in the 2014 session of the Indiana General Assembly. To read and share the complete agenda, visit www.arcind.org/our-programs/public-policy-advocacy.

Our Guiding Principles

The Arc of Indiana is committed to all people with intellectual and other developmental disabilities, as well as their families, and will work to develop public policy which will assist them in realizing their goals of learning, living, working and playing in the community.

The Arc of Indiana is committed to reducing the incidence of intel-

lectual and other developmental disabilities. We will work to increase public awareness of the importance of strong prenatal care and the dangers created by lead, alcohol and drugs, including tobacco products.

The Arc of Indiana is committed to self-advocates—people who have an intellectual or other developmental disability who advocate for themselves—and will work to ensure they receive the respect, support and access to healthcare and wellness programs to which all people are entitled.

The Arc of Indiana is committed to communities and to our local chapters of The Arc and will work to develop programs and public policy which will help support them in their mission of building communities with people with intellectual and other developmental disabilities.

In February, 2010 The Arc of Indiana embarked on a campaign, *Building Pathways to Empowerment*, to look toward new ways of delivering services to people with



Kerry Fletcher, Governmental Affairs Committee Chairman; and Kim Dodson, Associate Executive Director, lead The Arc of Indiana's public policy activities.

intellectual and other developmental disabilities in Indiana. As we worked with experts from around the country, five initiatives were established in our Blueprint for Change to map a new course in programs and services for people with developmental disabilities:

- Building Career Pathways for All
- Discovering and Realizing Individual Gifts
- Supporting Resourcefulness of Individuals, Families and Government

- Using What You Need
- Shifting the Power to What Works

Key to these initiatives is the understanding that the focus needs to be on doing things that add real value to people's lives.

Career Pathways

Legislative Priority: Support legislation that increases employment opportunities for people with disabilities.

Criminal Justice

Legislative Priority: Support legislation approved by the Autism Commission to convene a joint meeting of the Autism Commission and the Commission on Criminal Issues and Sentencing.

Early Intervention, Prevention and Prenatal Education

Legislative Priority: Support legislation that updates Indiana's Birth Problems Registry to ensure that accurate data is being reported from appropriate health professionals.

Home and Community Based Services and Supports

Legislative Priority: Support legislation directing FSSA to contract with an entity to perform a needs assess-

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Shaylyn Searcy's experience of having her shoes duct taped to her feet at school led to the passage of legislation in the 2013 session of the Indiana General Assembly to establish the Indiana Commission on Seclusion and Restraint in Schools, which recently adopted a Model Seclusion and Restraint Plan for use by schools. WTHR reporter Sandra's Chapman's coverage of Shaylyn's story helped educate policy makers about the need for legislation regarding seclusion and restraint in schools. Pictured: Shaylyn and her family with Sandra Chapman.

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

Celebration of the DD Act

My First Trip to the White House

Betty Williams,
Consumer Education
and Training Coordinator

On Friday, November 15, I attended the 50th Anniversary of the Developmental Disabilities (DD) Act at the Eisenhower Building on the White House grounds. This was one of the most exciting things that I have ever done.



Melody Cooper and Betty Williams express appreciation to veterans this past Veterans Day.

President Kennedy signed the DD Act into law in 1963. This act is important because it chose communities over institutions. The DD Act is the law that governs the National Disability Rights Network (protection and advocacy), university centers on excellence, and the DD councils. The DD Act is one of my favorite laws supporting people with developmental disabilities.

Many people from around the country gathered to listen to speakers talk about the DD Act. Panels at the event were focused on education, employment and long-term services and support for individuals with developmental disabilities. Speakers talked about the poetry of the DD Act. To me, this means that the words are so powerful that they motivate people into action.

Connie Garner, Vice President of Policy at United Cerebral Palsy (UCP), was one of the education panelists. She talked about labels and how they are irrelevant. Instead, she said you should look at the

Self-Advocates of Indiana President's Corner

Melody Cooper
President, Self-Advocates of Indiana

If 2014 is anything like 2013, Self-Advocates of Indiana will be busy. SAI has a lot in store for 2014.

Goals for the New Year include:

- Work more with our state and federal legislators regarding disability rights.
- Meet with legislators at the State House in February.



Melody Cooper

- Continue to work with My Life My Choice – helping people learn their options about community living.
- Start a Speaker's Bureau.
- Hold a picnic during the summer.
- Be present on more committees and advisory councils.
- Become more involved in the DD Commission.

- Open new chapters across the state.
- Create presentations on employment.
- Continue production of our quarterly newsletter, *Nims' News*.
- Travel to Oklahoma City to attend the Self-Advocates Becoming Empowered (SABE) conference.
- Hold quarterly statewide meetings that involve members from all over Indiana.
- Participate in Disability Awareness Month in March.
- Hold effective board meetings.
- Work together as a team of leaders to make our presence known in 2014.

Please check in with SAI throughout the year on Facebook, as well as our website, www.saind.org.

Refrigerator Rights – Pass Them On

Michelle Fischer, host, *A View from My Window* podcast

Dr. Will Miller, the opening speaker at The Arc of Indiana's 2013 conference, both stirred emotions and had the audience laughing until our stomachs hurt. His overall message stressed the importance of developing closely connected relationships, which he affectionately calls "Refrigerator Rights" – those friends who can walk into your house, open your fridge, grab something to eat, sit down, throw their shoes off and feel right at home! They are not mere acquaintances; they are friends who truly become family. I am very fortunate to have these types of relationships in my life, and I'm grateful for them.

I related deeply to this concept of "Refrigerator Rights," mostly because I had to develop these types

of connections to cope with the growing pains of cerebral palsy. As I came into adulthood, the reality of my disability came into focus, and negativity along with it.

I would beat myself up for countless things, mercilessly, until I started to listen to how others felt about me and felt their unwavering support, love and strength. When I took advantage of this support, I was encouraged, rebuilt and refreshed during that rocky, stressful time – things I still draw on to this day.

We all deal with difficult circumstances, but when you have a disability, sometimes, no matter how many steps you take forward, there is always a feeling (at least in

my experience) that you take twice as many steps backward. Those in your circle of support will always be there for you. "Refrigerator Rights" relationships help the human spirit be resilient!

Please make an effort to be the kind of friend that brings resilience to another person's life.

Refrigerator Rights – pass them on! You never know who needs them and how a life can be forever enriched because of them.

Thanks for the reminder, Dr. Will.

Learn more about Dr. Will Miller and "Refrigerator Rights" at www.drwillmiller.com

person's capabilities and their goals in life. This is one of the beliefs of Self-Advocates of Indiana (SAI). SAI supports self-advocates in their quest to live their own lives.

One of my favorite lines of the day came from my friend, Chester Finn, who is employed by the New York State Office for People with Developmental Disabilities. Chester stated, "When told no, I say, 'Just watch me.'" Thanks to this foundation, the DD Act, the future of self-advocacy is bright.

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 to listen to past broadcasts and the latest edition of *A View from My Window*.

Like "A View from my Window with Michelle Fischer" on Facebook

Follow Michelle's Blog – My Life and Stories Behind the Mic

Join Michelle on Twitter @MFView





Executive Director's Column

A wonderful opportunity which comes from working for The Arc is the chance to participate in activities at our nation's capital. It provides a reminder about how broad and extensive this organization we call The Arc is. We stretch from coast to coast, and have state chapters in both Alaska and Hawaii. Through The Arc US, based in Washington D.C., families, self-advocates and professionals can work in concert on critical issues that bind us together.

I recently traveled to Washington D.C. with Mark Hisey, President of The Arc of Indiana. Mark and I were invited to present to The Arc US Board of Directors what we learned from the experience of the closure of several group homes operated by The Arc of Northwest Indiana, and what we were planning as next steps based on those lessons learned. We shared with them in an open and honest way the challenges we as advocates must face in living up to the promises we set out. We learned we are not alone



in facing difficult challenges.

After the meeting I had some time to walk around our nation's capital. As I got close to the White House, I noticed that all around the White House people stood at the fence taking pictures of each other, with the White House in the background. Many languages, heritages, people young and old were present. I snapped a picture of this gray-haired Marine standing next to a young girl whose mother was taking her picture. What I felt at that moment was a shared experience that was bringing

people together – in a nation that the media so often shows as divided.

As I write this column, our own Betty Williams, past president of Self-Advocates of Indiana and the national Self-Advocates Becoming Empowered, is celebrating the passage of the Developmental Disabilities Act at the White House. Special thanks to IPAS, IIDC and the Governor's Council for People with Disabilities for helping with her travel expenses.

Betty, like many people with developmental disabilities, has faced

numerous challenges. Yet, through her own determination and supports from others, today she visits the White House. A lesson we can all learn from Betty is that it is not our problems that define us, but how we respond to them.

Like this old marine and this young girl, The Arc represents a proud tradition and a bright optimism for the future. That our culture is always looking forward is perhaps best reflected in the words of Robert Kennedy, whose sister Rosemary represented the movement to bring forward people with intellectual and developmental disabilities. He said, "There are those who look at things the way they are and ask, 'Why?'... I dream of things that never were and ask, 'Why not?'"

The Arc has always asked "Why not?" Thank you for being part of this marvelous organization which has made great change possible, and whose members, by continuing to ask "Why not?" will change the world for the better, again and again.

Blueprint for Change

Celebrating Those Who are Making it Work

The following stories, featured in our 2013 calendar, exemplify the good work that is happening throughout the state thanks to our local chapters of The Arc. Through their efforts, people with developmental disabilities are building career pathways, utilizing their unique gifts and leading full and meaningful lives in their communities – all key goals of The Arc's *Blueprint for Change*.

Learn more about the Blueprint by visiting www.arcind.org



Grant House and Mike

Wabash Center

Grant House first connected with Wabash Center in early 2011 as a volunteer. While he enjoyed his volunteer work, he really wanted to

earn a paycheck. Soon he became an employee of Greenbush Industries, placing rivets in shims as a subcontractor for a local trailer manufacturer.

Grant is involved in many activities outside of Wabash Center as well. Thanks to CityBus and wonderful drivers like Mike, Grant has learned to navigate the transit system and be more independent.

Grant loves his job, being active in the Lafayette community with his friends, and the independence that comes with utilizing CityBus.

The Arc of LaGrange County

Abby Hart is happy that her daughter, Faith, is able to receive free, periodic developmental screenings through The Arc of LaGrange County's Infant Monitoring Program. Every four months, up to age two, participating families receive a questionnaire to help them evaluate their child's developmental progress. This can help reassure parents that their child is developmentally "on



Faith and Abby Hart

target," and can alert parents to the need for a free evaluation from The Arc if developmental milestones are not being met. If a delay is detected, children are referred to Indiana's First Steps program where they can receive important early intervention services.

Through periodic monitoring, mother's like Abby are armed with important knowledge about their child's development, and if a problem is detected, know that immediate steps can be taken to help their child grow to his or her full potential.

Rest Assured

In 2003, with supports from a Medicaid Waiver, Kim Arbuckle moved from a group home in Indi-

anapolis to her own apartment in Lafayette to live closer to her sister and her family. When they moved away from the area, Kim decided to stay in the town where she had put down roots with friends, a job, and many connections to the Lafayette community.

When funding cuts occurred in the Waiver program, Kim faced the possibility of having to move from the home she had grown to love in order to be able to receive the supports she requires to remain safe. Fortunately, through the use of overnight electronic monitoring provided by Rest Assured, Kim was able to stay safely in her home and maintain her independence.



Kim Arbuckle

Equal Access - For Every Emergency, For Everyone

When disaster strikes, most people with disabilities are unprepared, leaving them vulnerable to injury and even death. Just 20 percent of the world's people with disabilities could evacuate immediately without difficulty in the event of a disaster.

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information and shelters, to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to concerns in all planning, preparedness, response, recovery and mitigation activities.

Individuals with disabilities are best at planning for their safety as they are best able to know their abilities and possible needs during and after an emergency or disaster. They should be included throughout the policymaking and implementation processes regarding emergency preparedness.

Section 504 of the Rehabilitation Act, the Fair Housing Amendments Act (FHAA), the Americans with Disabilities Act (ADA) and the Post-Katrina Emergency Management Reform Act mandates the integration and inclusion of people with disabilities into all emergency management efforts.

What can you do?

Encourage emergency management professionals in your community to consider the varied needs of people with disabilities in all levels of their planning and response activities, and to actively involve members of this community in their efforts; and

Raise awareness among people with disabilities about what they can do to prepare for their own safety and survival during emergencies.

Stock a basic disaster supply kit. <http://www.ready.gov/basic-disaster-supplies-kit>

Inventory what you use every day to live independently. Identify the essential things that you will need to be able to survive for 3-5 days or longer.

Stock these custom essentials in your kit. For example, your kit may contain items such as durable medical equipment, assistive technology, food for special diets, prescription medicines, diabetic supplies, hearing aids and batteries, a TTY, manual wheelchair and supplies for a service animal.

One of the biggest challenges to your safety and access to information is loss of electrical power. You should plan alternate ways to charge your communication and assistive technology devices before disaster strikes.

Helps App

Autism Society of Indiana (ASI) and Indiana Protection & Advocacy Services Commission (IPAS) have partnered to create a mobile application called "Help Everyone Learn Practical Solutions" (HELPS). HELPS is a practical tool for not only law enforcement and emergency responders, but any individual who works or comes into contact with individuals with disabilities. The HELPS purpose is to provide easy guidance on how to act or react in difficult situations to best assist those in need.

This mobile app is an extension of an already created document housed on the IPAS website, titled "TIPS."

For more information on the content that will be accessible through HELPS, please contact ASI at 1-800-609-8449 or visit http://www.in.gov/ipas/files/webpage_format_final_updated_2-3-2010.pdf to read or download the past TIPS document.



Emergency Preparedness Resources

Find links to all of these resources at www.arcind.org. Click on "Supports & Services," "Helpful Resources & Links."

Indiana Protection and Advocacy Services Commission emergency information
<http://www.in.gov/ipas/2382.htm>

Principles for Preparedness; Consortium for Citizens with Disabilities
www.c-c-d.org/fichiers/Final-Principles.pdf

ADA Checklist for Emergency Shelters
www.ada.gov/pcatoolkit/chap7shelterchk.pdf

Emergency Management under Title II of the ADA
www.ada.gov/pcatoolkit/chap7emergencymgmt

Ready.gov
www.ready.gov

An ADA Guide for Local Governments, Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities
<http://www.ada.gov/emerpreguideprt.pdf>

Indiana Department of Homeland Security
<http://www.in.gov/dhs/getprepared.htm>

Partners in Preparedness brochure
<http://nod.org/assets/downloadsPartners-In-Preparedness.pdf>

FEMA: Office of Disability Integration and Coordination
<https://www.fema.gov/office-disability-integration-coordination>

Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters
www.fema.gov/pdf/about/oddc/fnss_guidance.pdf

Prepare For Emergencies Now: Information For People With Disabilities
http://www.ready.gov/sites/default/files/documents/files/PrinterFriendly_Disabilities_1.pdf

News from The Arc US

Autism NOW. The National Autism Resource & Information Center, a project of The Arc, has created a series of seven fact sheets offering information about topics important to individuals with autism and their families such as: Employment, Inclusion, IEPs, Future Planning and Social Security. Each fact sheet offers in-depth information along with links to other resources written specifically to be accessible to individuals with autism. Visit www.autismnow.org.

Book Offers Tools for Combating Abuse. A new book reviewed by Leigh Ann Davis, program manager for The Arc's Justice Initiatives, offers a unique approach to increasing the well-being of individuals with developmental disabilities and reducing the risk of abuse. The book, written by Dr. Nora Bala-darian and released by the Disability

and Abuse Project, offers strategies for both parents/service providers and individuals with disabilities to develop Individual Response Plans on abuse. It includes case examples and provides advice on how to recognize signs of abuse. A companion book written specifically for people with developmental disabilities will soon be released. Orders can be placed at www.disabilityandabuse.org/books.

Comcast NBC Universal Commits \$3.73 Million to The Arc as a National Partner. Comcast NBC Universal (Comcast) has agreed to take on The Arc as one of their National Partners. Comcast will provide The Arc with \$3.18 million in in-kind promotional support over the next three years. This will include airtime for The Arc's public service announcements on cable and broadcast and promotion through Comcast's *xfinity.com* website.

Comcast is also providing \$400,000 in grant support and an additional \$150,000 in technical support for The Arc's new Digital Literacy project. This new project will include creating a dedicated section of The Arc's website with information and resources designed to help people with intellectual and developmental disabilities learn the basics about using computers and getting online.

The Arc Is Number One. Philanthropeida, a division of GuideStar, ranked The Arc at the top of their 2013 poll of 16 outstanding nonprofits. Seventy-four experts were asked to recommend nonprofits that support people with any of the following: developmental disabilities, physical disabilities, mental disabilities, blindness and deafness including groups that engage in research, advocacy, legislative work, education or direct services.

Affordable Care Act Brings Opportunity for Positive Reforms for People with Disabilities, Families

Enactment of health care reform under the Affordable Care Act (ACA) is the most significant law for people with disabilities since the enactment of the Americans with Disabilities Act (ADA) in 1990. It will bring about comprehensive reforms that will benefit Americans with disabilities by prohibiting discrimination based on health status and improving access to care.

Affordable Care Act (ACA) is the most significant law for people with disabilities since the enactment of the Americans with Disabilities Act (ADA) in 1990.

Open Enrollment for health insurance plans available through the ACA began in October and ends in March 2014. However, after March 31 and until the next open enrollment period, you can enroll if you experience a loss of your insurance.

Go to www.healthcare.gov or call 1-800-318-2596 to find out more information about enrollment, benefits, and subsidies and tax credits that may make your plan more affordable.

If you have health insurance through your employer and you are happy with the coverage that is offered for your family, including your loved one with an intellectual or developmental disability, you can keep that coverage.

If you purchase your own health insurance, do not have access to health insurance through your employer, or if your plan does not offer any coverage, or only partial coverage, for developmental disabilities, you will have more options for coverage under the ACA plans.

To check to see if your current health care providers are part of the Anthem ACA Network in Indiana, go to www.anthem.com, and then go to the "provider finder" tool. Search for Indiana Exchange providers. With this tool you can check to see if your physician, ABA provider or other medical provider is in the Anthem ACA Marketplace plan. Be sure to check periodically for updates before choosing a plan, or contact your provider directly to ask if they participate or plan to participate.

If you have had trouble accessing the ACA website or completing an application, contact the national consumer help

line at 1-800-318-2596 or contact a local navigator in your area to complete a paper application over the phone.

Under the ACA, Navigators and Certified Application Counselors are charged with assisting consumers with understanding their options under the ACA, determining if the consumer is able to qualify for subsidies or tax credits, and assisting consumers in completing the application and selecting a plan from the available options.

These Navigators and Certified Application Counselors must be certified by the state, so be wary of fraud or people using the ACA as a means of getting your personal information. No one should be calling you unsolicited to sign you up on the ACA.

A local navigator or certified application counselor can be found on the www.healthcare.gov website under "local help," by calling the national consumer helpline (1-800-318-2596), on the Indiana Department of Insurance website, www.in.gov/idoi, or by contacting your local hospital (many hospitals are navigators, or can direct you to a local navigator).

The over-the-phone application will take approximately 20 minutes for an individual application and about 45 minutes for a family application.

If you have questions about your health insurance, contact Michele Trivedi, Manager of The Arc Insurance Project. The Arc Insurance Project works to assist families who have a loved one with a developmental disability understand and make use of their private insurance policies and increase knowledge of basic health insurance issues, including the Affordable Care Act. Contact Michele at mtrivedi@arcind.org or 317-977-2375 or 800-382-9100.



Michele Trivedi, The Arc Insurance Project Manager and Michelle Fischer, "A View from My Window" Podcast Host

How the Affordable Care Act Helps People with Disabilities

- Reforms Health Insurance Practices
- Eliminates pre-existing condition exclusions
- Bans annual and lifetime limits
- Ends insurance companies retroactively denying coverage
- Improves the appeals process when a person is denied coverage of a treatment or service
- Requires that at least 80% of health insurance premium dollars are paying for health care
- Helps states to limit unfair increases in insurance rates
- Prohibits considering health status in calculating premiums
- Requires guaranteed issue and renewals of insurance plans
- Prohibits discrimination based on health status
- Expands Access to Health Insurance Coverage
- Allows coverage for dependents until age 26
- Creates private health insurance exchanges for individuals and small employers to purchase insurance
- Provides significant subsidies to assist low income individuals to purchase coverage in the exchanges and tax credits to help small employers provide insurance to their employees
- Includes coverage of dental and vision care for children in health insurance plans sold in the exchanges
- Includes mental health services, rehabilitative and habilitative services and devices, and other critical disability services in the health plans sold in the exchanges
- Expands Access to Prevention Services and Other Improvements
- Eliminates co-pays for critical prevention services
- Creates the Prevention and Public Health Fund to expand wellness, disease prevention, and other public health priorities
- Increases opportunities for training of health care providers (including dentists) on the needs of persons with developmental and other disabilities
- Improves data collection on health care access for people with disabilities
- Requires the establishment of criteria for accessible medical diagnostic equipment

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ment survey regarding the services and supports for people diagnosed with both an intellectual or developmental disability and a mental illness or addiction.

Insurance

Legislative Priority: Support legislation that would expand Medicaid in Indiana to help more people without quality healthcare have access to health plans.

Managed Care

Legislative Priority: Monitor any legislation regarding managed care or coordinated care for the aged, blind and disabled populations.

Public Transportation

Legislative Priority: Support legislation that seeks to create a system of public, mass transit.

Special Education

Legislative Priority: Support legislation that increases opportunities for early childhood education. Support legislation regarding training of teachers in teaching students who receive special education services.

Visit www.arcind.org/our-programs/public-policy-advocacy for in depth information on public policy positions on the areas listed above, as well as our position on policies related to Direct Support Professionals, Funding, Guardianship Services and Self-Advocacy.

Family Educators Join The Arc Advocacy Network

The Arc Advocacy Network provides information, referral and advocacy to assist and guide individuals with intellectual and developmental disabilities and their families in the areas of:

- Understanding and applying for government programs, including Medicaid, Medicaid Waivers, and SSI
- Policies and procedures of state and federal programs, including rights and appeals
- Community Connections and Natural Supports
- Community Employment, Career Pathways and Vocational Rehabilitation
- Self Advocacy and Self-Advocates of Indiana

Seven Family Educators have joined The Arc Advocacy Network to assist in reaching out as a resource to families who have loved ones with developmental disabilities throughout the state.

Family Educators will be available to lead informational workshops on Indiana's Medicaid Waiver program, conduct events to assist individuals and families in signing up for the Medicaid Waiver, and staffing exhibit tables at area transition fairs and other disability related events.

If you would like to schedule a Family Educator for your organization, parent group, school, etc., contact Jill Ginn, The Arc Advocacy Network Manager, at 317-977-2375, 800-382-9100 or jginn@arcind.org.

The Arc Advocacy Network

Family Educator Team

Central Indiana
Indianapolis
Traci Kurmay

Southeast Indiana
Columbus
Ella Boyd

Northeast Indiana
Ft. Wayne
Christina Wiler

Mishawaka
Colleen Spano

Northwest Indiana
Lake County
Christine Cangiano

Southern Indiana
Evansville
Earl Townsend

Loogootee
Anna Stanton

When You Need Assistance, We're Here to Help

When families have questions or problems, or they have no idea where to turn next, The Arc Advocacy Network is here to help.

Every day, The Arc Advocacy Network gets calls and emails from families seeking help. "How do I sign up for a waiver?" "My son wants a job. How can he get one?" "Do you know of any support groups in my area?" Sometimes the call for help is more involved.

One such call came from a man seeking help for his brother – a man in his 50s who had never received any services or help from the state, despite his intellectual disability. That's not unusual because for this man's generation, "Help from the state" some 50 years ago largely meant institutionalization. His parents were not going to allow that to happen, and they never realized things had changed. Services were now available to help them support

their son at home or allow him to live more independently nearby, but that help was never received before both mother and father passed away.

The brother shared that in his family they were never allowed to talk about planning for their brother's future. They weren't allowed to talk about what financial plans were in place or what types of government benefits he received. Mom was sure that she would always be there to take care of everything for her son. Two weeks after his mother's death, the brother called because he needed help and didn't know what to do.

Family Advocate Specialist Karly Sciortino-Poulter met with him and walked him through each of the programs that could help. She explained how the various services available through the Medicaid Waiver program could help his brother with a wide array of supports, and that

because he had lost his primary caregivers, he could be eligible for the Community Integration and Habilitation (CIH) Waiver without being on a waiting list. She helped him fill out the applications and get them submitted.

She explained the Social Security benefits his brother received and how he could be designated as the Representative Payee to pay his brother's bills, and she explained how to go to Social Security to get all the paperwork straightened out. She explained what to do if his brother inherited anything from mom's estate, how too many resources could impact his brother's eligibility for government benefits, and how a special needs trust like The Arc Master Trust could help protect benefits.

She also explained that his brother could get supports to begin to work. No one had ever considered that his

brother might actually be able to work. She talked with him about how he could contact Vocational Rehabilitation Services (VR) to discuss employment options.

She answered all of his questions, helped him prioritize what he needed to do, and, for the first time since his mom died, helped him feel a little more in control and a little more empowered.

It wasn't an unusual case, but it was an important one. It made all the difference for that family, and it is something The Arc Advocacy Network does on a regular basis.

Life can be complicated when one has a loved one with a disability. The Arc Advocacy Network is available to make it a little bit easier.

To contact a Family Advocate with The Arc Advocacy Network, call 317-977-2375 or 800-382-9100, or email thearc@arcind.org

Staff Profile

Karly Sciortino-Poulter, Family Advocate Specialist



Karly Sciortino-Poulter, Family Advocate Specialist, with husband Scott and sons Andy and Michael.

Karly Sciortino-Poulter joined The Arc of Indiana in December, 2012 as a Family Advocate Specialist for The Arc Advocacy Network.

Karly works every day to provide guidance and information to families on everything from understanding and applying for government programs, including Medicaid, Medicaid Waivers and SSI; to learning about policies and procedures of state and federal programs; to how to

make use of natural supports to meet needs that government programs do not provide.

Karly and her husband Scott are parents to Michael, 7 and Andy, 13, who was diagnosed with autism one month after his third birthday.

Karly credits Andy's preschool teacher with guiding her to not focus on the "worst case scenario" information she received from the physicians who diagnosed him, and instead focus on becoming Andy's advocate.

On her role as a Family Advocate Specialist, Karly said, "The most important thing I do, when I get those desperation calls from families who are at a point of not being able to move because they simply do not know what to do, is talk them through the process of what to expect and what comes next.

"I let them know that we are here to help and, hopefully, that can allow them to breath and begin to take those next steps. Other people did that for me, and my son would not be where he is today without that help."



The My Life, My Choice Team

My Life, My Choice

The Arc of Indiana and Self-Advocates of Indiana (SAI) believe in and support choice, community living and advocating for the rights of people to move from institutions. In 2012, SAI and The Arc of Indiana worked with the Indiana Family and Social Services Administration (FSSA) to create and implement "My Life, My Choice" (MLMC), a statewide effort to interview people with intellectual and other developmental disabilities living in nursing facilities to talk about their interest in moving into the community. Led by self-advocates, teams of two met with more than 1,000 individuals to talk about choices.

The key part of MLMC was that the interviews were conducted by Self-Advocate Lead Interviewers, who were able to connect with individuals on a more meaningful level. As a result of this program, individuals who wanted to learn more about community living options had the chance to do so.

Thanks to the continued support of FSSA, My Life My Choice will

continue through 2014. Teams of interviewers made up of people with disabilities and a support team member will meet with individuals with I/DD living in Intermediate Care Facilities for People with Intellectual and Developmental Disabilities and people who have lived in Medicaid funded group homes for more than 5 years. In addition, follow-up will be provided to individuals that teams previously met with who expressed interest in receiving additional information about community based services.

The goal of MLMC is to help people realize that they have choices regarding where they live and receive services. This can include moving to a home with Medicaid Waiver supports in the community, developing more community connections should they choose to continue to live in their current placement, or to make no changes at this time if they wish.

For more information, contact Jill Smith, MLMC Project Coordinator, at jsmith@arcind.org or 317-977-2375 or 800-382-9100.

My Life, My Choice Teams

Jill Smith
Project Coordinator

Randy Kriebel
Consultant

Melody Cooper
Self-Advocate Specialist
Lead Interviewer, Marion County Area

Lake County Area
Stacey McGee, Lead Interviewer
Sue Boyer, Support Interviewer

St Joseph County Area
Melvin Bush, Lead Interviewer
Rickey Bonds, Support Interviewer

Allen County Area
Ashley Porter, Lead Interviewer
Pam Porter, Support Interviewer

Richard Byrd, Lead Interviewer
Ron Brockman, Support Interviewer

Cass / Fulton County Area
Keving Callaghan, Lead Interviewer
David Weber, Support Interviewer

Tippecanoe County Area
Ben Wollenburg, Lead Interviewer
Gina Mundell, Support Interviewer

Wayne County Area
Jamie Beck, Lead Interviewer
Dan Stewart, Support Interviewer

Bartholomew County Area
Ella Boyd, Support Interviewer

Knox County Area
Karla Steimal, Lead Interviewer
Molly Horst, Support Interviewer

Martin County Area
Jerry Queen, Lead Interviewer
Anna Stanton, Support Interviewer

Warrick / Vanderburgh County Area
Nathan Breden, Lead Interviewer
Jill Smith, Support Interviewer and Project Coordinator

Harrison / Floyd County Area
Mark Hublar, Lead Interviewer
Nona Besendorf, Support Interviewer

The Arc News in Indiana ...Pass it On

What better way to recycle your copy of *The Arc News in Indiana* than to pass it on!

- Share with a friend
- Share with your child's teacher
- Leave at the doctor's office
- Give to your case manager or support staff

Be creative! What other ways can you share news from The Arc?

The Arc's 2013 Award Recipients

People, Businesses and Organizations Making a Difference

The Arc of Indiana was honored to recognize outstanding individuals and organizations making a difference in the lives of people with intellectual and developmental disabilities at our 2013 Appreciation Luncheon.

Executive Director's Award Indiana House Republican Caucus



Representative Ed Clere, The Arc of Indiana Board President Mark Hisey and Representative Jerry Torr.

President's Award In Honor & Memory of Lloyd Crowe

Education Award Fishers High School Best Buddies

Employment Award Indiana Memorial Union Hotel, Rooms & Housekeeping

Community Involvement Award The Arts Council of Southwestern Indiana

Health Care Award Mary Ciccarelli, MD

Innovation Award Cierra Thomas-Williams, Middle Way House Mary McKinney, Stone Belt Arc

Innovation Award Abhishek "Jay" Chaudhary, Indiana Legal Services

Media Award Sandra Chapman, WTHR

Cathleen Clark Professional Service Award Jennifer Maddux, DSI

Outstanding Professional Achievement Award Brent Cardin, The Arc of Greater Boone County



Cathleen Clark Professional Service Award. Jennifer Maddux



Outstanding Self-Advocate. Brian Kellems

Outstanding Self-Advocate Award Brian Kellems

John Dickerson Leadership Program Award Executive Renewal Grant Jane Ruff, Hopewell Center

Sycamore Award Tom O'Neill, Retired CEO, Passages



Outstanding Professional Achievement. Brent Cardin, The Arc of Greater Boone County



Media Award. Sandra Chapman, WTHR



Sycamore Award. Tom O'Neill, Retired CEO, Passages

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Crisis Line: 800-878-9133

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Case Management Companies Family Supports Waiver & CIH Waiver

The following companies have been approved by the state to provide case management for individuals receiving services through the Family Supports and Community Integration and Habilitation (CIH) Medicaid Waivers.

FUTURES CASE MANAGEMENT, LLC
888-959-2848
www.futurescasemanagement.com

IPMG
317-460-4332
gotoipmg.com

ADVOCACY LINKS, LLC
888-537-5733
www.advocacy-links.com

THE COLUMBUS ORGANIZATION
800-229-5116
www.columbusorg.com

CARESTAR OF INDIANA, LLC
866-423-2220
www.carestarindiana.com

UNITY OF INDIANA
317-697-8326
www.unityofindiana.com

Thanks to IPMG for their sponsorship of The Arc's 2013 Conference.

Online Art Gallery and Store, Works of Arc

Works of Arc, www.worksofarc.com, is an online art gallery and store featuring the work of Indiana artists with intellectual and developmental disabilities.

The pieces are quite varied, featuring the artists' wide variety of mediums and talent. You will find everything from watercolors to jewelry, purses to bird houses, note cards to photo frames. Please be sure to check back often as new pieces and new artists are continually being added.

Whether you are looking for a special piece for your personal collection or the perfect gift, Works of Arc has something for everyone.

Interested in selling your art on Works of Arc?

Contact Jill Vaught at jvaught@arcind.org or 317-977-2375. Artists must be a member of The Arc, receive services from one of The Arc's chapters, or have a Trust Account with The Arc of Indiana Master Trust.

You will be asked to submit the art you would like to sell to be *juried* (an art term meaning evaluated) by a panel. Artists will be notified of the panel's decision.

If your artwork is selected, you will be guided through the process of submitting an artist biography and a photo to be displayed on the website, choosing a distributor, calculating the selling price of the artwork and providing photos of your artwork.

Artists receive 75% of the selling price of their artwork. The distributor receives 10% for shipping and handling, and The Arc of Indiana receives 15% for marketing and maintaining the website.

Works of Arc is a project of The Arc Development Group LLC. The mission of The Arc Development Group is to provide unique avenues and training opportunities that lead to employment and greater self-sufficiency for people with disabilities.



Whether you are looking for a special piece for your personal collection or the perfect gift, Works of Arc has something for everyone. All artwork and photography shown is available at Works of Arc.

Training Institute and Teaching Hotel Dream Moves Closer to Reality

Earlier this year The Arc of Indiana announced plans to build the first hospitality training institute and teaching hotel in the country, in Muncie, Indiana. The project is continuing to move forward, and a major announcement with Governor Pence is being planned for February.

Why is The Arc building a training institute and teaching hotel? The answer is simple – employment opportunities and the Blueprint for Change. The unemployment rate for people with disabilities is 82%. This is unacceptable. Employment opportunities lead to greater independence, higher self esteem and the ability to follow your dreams.

Employment is one of the key focuses in The Arc's Blueprint for Change – a *transformational systems change plan* for people with intellectual and developmental disabilities.

Hospitality is one of the fastest growing segments of the economy, with a new job being added every 2.5 seconds. Providing a postsecondary education opportunity for individuals with disabilities in hospitality makes sense.

The project has four main components. The first is the training institute:

Individuals from around the state will be able to attend and earn a certificate of best practices which will be recognized within the hospitality industry. After completing the training for the hospitality track they have chosen, the person will

be able to return to their home community and secure employment.

A second component will be training for human resource professionals in all industries:

Reasonable accommodations shouldn't be a scary term when hiring individuals with disabilities. A series of training opportunities and workshops will be designed to educate human resource professionals in the advantages of hiring people in this untapped labor pool.

In addition, opportunities for individuals with disabilities to own their own businesses within the hotel will be available:

At The Arc's 2013 Conference and Appreciation Luncheon, we announced a competitive grant program beginning in 2014 which will provide five individuals with disabilities \$10,000 each to help them get their own businesses started.

Finally, the hotel will not only employ individuals with disabilities, all profits will be reinvested. Profits will go toward projects to create additional employment opportunities and further the mission of The Arc.

This project is unlike anything in the country and is already gaining national attention. If you have questions or would like additional information on the project or how you can be involved, please call The Arc at 317-977-2375 or 800-382-9100.



Membership in The Arc Achieves All Time Record

The Arc of Indiana's 2013 membership campaign set an all time record.

A year ago chapters of The Arc engaged in a massive statewide effort to recruit members to local chapters of The Arc, The Arc of Indiana and The Arc US. With more than 19,000 members statewide, The Arc of Indiana challenged local chapters to push our member numbers over 20,000.

At The Arc's Appreciation Luncheon we recognized fifteen chapters who collectively recruited 1,181 new members – resulting in the largest statewide membership in the history of The Arc when combined with current members from all of our 44 chapters.

KCARC, our chapter in Knox County, led the field and received both of our coveted Traveling Membership Trophies. Not only did

they recruit the most new members during the annual membership campaign, their membership totals represented the most per county population – the criteria for the second traveling trophy award.

And as The Arc congratulates all chapters who took part in the campaign, the ones who should be congratulated are you, the members. For it is you who have chosen to be part of this local, state and national movement. As members of a local chapter you also receive membership and benefits as part of The Arcs of Indiana and the United States.

Why do people belong to The Arc?

The primary reason is undoubtedly to support the work and advocacy of their local chapter of The Arc. Members serve in leadership

roles, volunteer with projects and activities and financially support the organization.

Members belong because they believe in the mission of The Arc and the work all three-levels of the organization perform. Chapters at the local, state and national levels provide information, training and services which assist individuals with intellectual and developmental disabilities and families.

Most chapters have websites, and many have Facebook pages and use other social media to share information.

Members receive the printed quarterly newsletters from The Arc of Indiana and The Arc US, as well as having access to electronic newsletters and public policy alerts and information. Members often listen to The Arc of Indiana's podcast "A

View from My Window" and watch The Arc's YouTube channel for videos and information.

In addition to information and staying informed and connected, members may belong because of specific membership benefits. Like most membership organizations The Arc US provides discounts on services and products such as a variety of insurance programs, travel discounts, conference registrations and a rewards credit card.

For many reasons, 20,000 members are associated with The Arc. We hope that all members will renew their support and membership in 2014 to support people with intellectual and developmental disabilities in realizing their goals of learning, living, working and fully participating in communities throughout Indiana and the nation.

Unified Track and Field Tournament announced by IHSAA, Special Olympics Indiana

The Indiana High School Athletic Association (IHSAA) has further enhanced its "Champions Together" partnership with Special Olympics Indiana (SOIN) in sanctioning a Unified Track and Field event set for 2014.

This most recent collaborative effort allows IHSAA-member schools to form teams composed equally of students with and without intellectual disabilities to compete for a state championship in Unified Track and Field. Schools will be able to individually schedule regular season competitions in the spring before state tournament competition.

Special Olympics Indiana will provide technical support to schools participating in Unified Track and Field, as well as financial grants to

a number of schools to assist with startup costs.

According to IHSAA Commissioner Bobby Cox, "The approval by the IHSAA Executive Committee for a Unified Track and Field event is a beginning step in the evolving culture of inclusion between the IHSAA and our partners at Special Olympics Indiana. It seems fitting and proper that the first inclusive sport recognized by the IHSAA is track and field—also the first sport recognized by the IHSAA in 1903."

Michael Furnish, Special Olympics Indiana president and CEO applauds the IHSAA for its leadership. "The vote by the IHSAA to include students with special needs in interscholastic sports competition is historic," he says. "Decades after

people eligible for Special Olympics were brought into public education, they now have new opportunities to bring their competitive spirit and positive attitude to contribute through sports to their schools."

Unified Sports® enables persons with and without intellectual disabilities to participate on the same team for sports training and competition. Special Olympics Indiana is considered a world leader in the development of Unified Sports® programs, having conducted the first-ever pilot test in 1989, and since has developed an all-inclusive approach with unified competition featured in virtually all represented sports.

The "Champions Together" partnership between the IHSAA and Special Olympics Indiana was launched

in December 2012. The partnership evolved from IHSAA Commissioner Bobby Cox challenging the IHSAA Student Advisory Committee (SAC) to engage in "servant leadership" and discover ways to give back to their schools and communities.

The Champions Together partnership seeks to involve a minimum of 50 IHSAA member schools. The partnership will provide a banner to all IHSAA member schools that meet minimum requirements in the areas of student-led servant leadership, awareness, respect and inclusion as it relates to all individuals with intellectual disabilities, volunteerism through service to the school and community, and fundraising to promote the vision and programs of Special Olympics Indiana and the Champions Together partnership.



Be Inspired

Be inspired all year with The Arc of Indiana's 2014 calendar. Each month features great photos and inspirational stories that exemplify some of the very best that is happening throughout the state, thanks to the efforts of local Arc leaders, volunteers, families, self-advocates and advocacy organizations.

Calendars are available for \$12.00 per calendar, including shipping.

To order your calendar, visit: www.arcind.org/news-events/upcoming-events



Important Milestones Achieved by The Arc Master Trust

On October 24, 1988, The Arc Master Trust (Trust I) was founded with an investment of \$180,000, made possible through fundraising and generous donations from Arc chapters across the state. This allowed the first trust director, Alan Kemp, to be hired and begin the work of building what is now known as the nation's premiere special needs trust program.

In 1995, The Arc Master Trust started a second trust program (Trust II) that allows people with disabilities to fund their own trust. Trust II began with an initial balance of \$765.

Over the past 25 years nearly 1000 families have entrusted The Arc Master Trust with funds they have set aside to ensure they can continue to provide for their family member with a disability. Today, Trust I has grown to over \$35 million in assets. In addition, individuals with disabilities continue to open and fund their own Trust II accounts at a high rate. Over 2000 people have enrolled since

Trust II was founded, and that fund now holds over \$15 million.

The Arc Master Trust's total assets are now over \$50 million, thanks to a solid and conservative investment strategy provided by The National Bank of Indianapolis.

The Arc Master Trust staff, Trust Advisory Committee, Family Advisory Committee and The Arc of Indiana Board of Directors are thankful to all who have trusted The Arc Master Trust over the years to provide reliable and proven trust administration for their families and themselves.

Learn more about The Arc Master Trust by visiting www.thearctrust.org.

Listen to Trust Director Melissa Justice talk about milestones achieved by The Arc Master Trust by visiting www.arcind.org/AViewfromMyWindow and clicking on "A View into Milestones for The Arc Master Trust."



Trust Founders Tom Ewbank and Robert Hullett, Trust Director Melissa Justice and Executive Director John Dickerson at the 25th Anniversary Celebration for The Arc Master Trust.

Trust Satisfaction Survey Provides Positive Feedback on Trust Program

The Arc of Indiana intends for The Arc Master Trust to be easy to use. "How are we doing?"

To answer this question, each year we send a User Satisfaction Survey to people using our service. The survey provides valuable feedback for us. It identifies potential problem areas and helps families thinking about enrolling. "Is The Arc Trust easy to access?" some might ask. "Is getting approval difficult?" As the survey shows, we are very accessible and rarely turn down requests. Following are responses to four key questions asked on the survey, as well as comments made on the survey. To review the complete survey, visit www.thearctrust.org.

When I call to use the trust, the person with whom I must speak is immediately available.

Never: 0% Rarely: 1% Sometimes: 11% Usually: 64% Always: 24%

When the person with whom I must speak is not immediately available, he/she does return my call and is able to speak with me within two business days of my request.

Never: 1% Rarely: 0% Sometimes: 2% Usually: 19% Always: 78%

Requesting disbursements is a positive experience for me. The person with whom I speak is receptive

to how I want the trust used. He/she is encouraging and supportive of my efforts.

Never: 1% Rarely: 0% Sometimes: 3% Usually: 12% Always: 84%

On a scale of 1 to 10, what is your overall satisfaction (or dissatisfaction) with The Arc Trust. A score of 10 is the most positive score you can give. A score of 1 is the most negative score you can give.

Ten: 72% Nine: 19% Eight: 6% Seven: 2% Six: 1% Five: 0% Four: 0% Three: 0% Two: 0% One: 0%

"I appreciate the cooperation of the staff when I have a problem to solve."

"Thank God there is someone to maneuver all the government regulations and agencies."

"I have an autistic son who verbalized at the end of his vacation, 'Mom, I enjoyed my vacation.' His statement meant everything to me and made my trip to be with him more than worthwhile. Many thanks to all of you at The Arc Trust for making our union possible."

"I am thankful that we have The Arc Trust in place for my brother, especially since we are getting older and he is in assisted living. I know that his assets are safe."

Stay Connected / Stay Informed

- ◆ Visit: www.arcind.org
- ◆ Join us on Facebook
- ◆ Follow us on Twitter @TheArcIN
- ◆ Sign up to receive E-Newsletters
- ◆ Sign up to receive Legislative Memos & Action Alerts
- ◆ Sign up to join The Legal Network

Learn more about The Arc Master Trust - www.thearctrust.org

The Arc
Master Trust

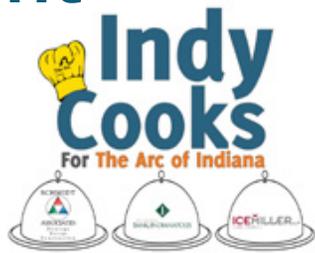
Serving Hoosiers of all disabilities and their families for over 25 years

Regardless of your age, or your child's age or disability, planning for the future is important.

Trust I Helping families plan for the financial future of their loved one
Trust II Helping people with disabilities fund their own trust

www.thearctrust.org

Indy Cooks Event Great Success



The First Annual Indy Cooks for The Arc of Indiana was a tremendous success. Tickets sold out, and The Arc raised valuable funds to support individuals with disabilities and their families. Thank you to everyone who participated and supported this great event.

On October 11, local business leaders and celebrities prepared their signature dishes and competed for tips. The winning chefs were:

Appetizers – Chuck Summers, General Hotels Corporation (Stuffed Mushrooms)

Soups & Salads – Kathleen Lee, Ivy Tech Community College (Butternut Squash Soup)

Vegetables & Side Dishes – Susan Williams, Purdue University (Carrot Puffs)

Main Dishes – The Honorable Jerry Torr, State Representative (Arbita Turbodog Braised Short Ribs)

Special Thank You to Our Indy Cooks for The Arc of Indiana Sponsors

Golden Spoon Sponsors

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Priority Press

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Desserts – Marsha Brooks, The winner of Good Morning America's Best Pie in the Country Contest (Crunchy Carmel Apple Pie)

Everyone who attended will receive a free cookbook with recipes from the event. There are a limited number available for sale at \$15.00 each. If you are interested, please call 317-977-2375.

In addition to the great food, the evening included rides in an Indy racing car, race simulators, admission to the Dallara IndyCar Factory and live music by the Flying Toasters.

The Second Annual Indy Cooks event will take place September 27, 2014. Tickets will go on sale August 1. Mark your calendars so you don't miss out!



Lisa and Andy Dietrick, representing Indiana Farm Bureau, at Indy Cooks for The Arc of Indiana.

2014 Events

Valentine's Day Event

February 13, State House, Indianapolis

Disability Policy Seminar

April 7-9, Washington D.C.

Steve Green's 25th Annual Golf Tournament

June 13, Eagle Creek Golf Club, Indianapolis

National Down Syndrome Congress Convention

July 11-13, Indianapolis

Self-Advocates of Indiana Annual Picnic

July 18, Indianapolis

National Conference of Executive Directors of Arcs

July 24-26, Chicago

Autism Society National Conference

July 23-26, Indianapolis

Indy Cooks for The Arc of Indiana

September 27, Dallara IndyCar Factory, Speedway

The Arc US National Conference

September 30-October 2, New Orleans

Self-Advocates Becoming Empowered Conference

October 8-12, Oklahoma City

The Arc of Indiana 2014 Conference, Appreciation Luncheon & Annual Meeting

October 29, Horizon Conference Center, Muncie

For more information on 2014 events visit

www.arcind.org/news-events/upcoming-events

Support The Arc

Make a difference in the lives of people with intellectual and other developmental disabilities and their families.

Bequests and Other Planned Gift Options

Naming The Arc of Indiana in your estate plans can help ensure the future of The Arc. For information on how to include The Arc in your estate plans or to make a gift to The Arc's George Rowles Endowment Fund, please call 317-977-2375 or 800-382-9100, or email Jill Vaught, jvaught@arcind.org, about bequests or other planned gift options.



Congratulations to Mary Jackson, winner of The Arc of Indiana's Classic '56 Chevy Car Raffle. Mary is a long-time volunteer and supporter of The Arc of Greater Boone County and The Arc of Indiana. The car raffle raised over \$10,000 for The Arc.