

The Care Gap Crisis

Agencies Face Challenge in Finding, Keeping Direct Care Staff

As families, people with disabilities and providers can attest, finding and keeping individuals trained as direct support professionals is an ever increasing challenge. The Arc of Indiana, Indiana Conference of Executives of Arcs (ICEArc) and INARF, Indiana's principal membership organization representing providers of services to people with disabilities, are working together to bring public attention to this critical issue.

A report by the Wall Street Journal in April, 2013 notes, "A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age."

While the need is growing, wages for direct care workers, adjusted for inflation, has actually been decreasing.



A study conducted by INARF found that an average starting wage for a DSP ranges from a minimum of \$8.48 to a maximum of \$10.05, the average statewide turnover rate is 39%, and there is an 11% vacancy rate—meaning job openings are left unfilled.

In turn, low wages mean direct support professionals often turn to public assistance themselves. A study published in November, 2013, "Cultivating Competent Frontline Supervisors and Direct Support Professionals," found in direct-care worker households, 49% relied on some form of public assistance,

39% utilized Medicaid, and 34% received food and nutrition benefits in 2011.

At a public forum hosted by Stone Belt Arc, local chapter of The Arc in Monroe County, DSP Tiba Walter said, "Our clients have to be served 24 hours a day, seven times a week, 365 days a year. We don't have slow days. We never shut down. We are it ... that's a big responsibility."

While they work for wages just above minimum wage, DSPs are tasked with critically important work. Components of their training include medication administration, assisting with personal care, learning to address seizures, swallowing/dining difficulties and implementing behavior support plans. But perhaps most importantly, DSP so often provide or support opportunities for people with disabilities to fully experience community living, including working, volunteering, worshipping and recreating with others.

An editorial published in the Bloomington Herald Times states, "...the already low wages aren't even

keeping up with inflation because of state cuts to Medicaid reimbursements. A troubling cycle persists. Less government funding support results in meager and stagnant pay for direct support professionals in these difficult jobs, which leads to high turnover, which leads to a new group of inexperienced caregivers who don't stay around long either. All the while the clients have little continuity and much less support than a caring society should give them."

As noted in his column on page three, John Dickerson, The Arc of Indiana executive director, says new answers are needed to address this important issue:

- Wages for direct support professionals need to increase across the board.
- Regulatory relief is needed to allow DSPs to spend time working with individuals rather than paperwork.
- New models are needed to encourage services to be provided in innovative ways.

The 2015 session of the Indiana General Assembly will be a year in which the two-year state budget is developed. The Arc, ICEArc and INARF teams will be bringing recommendations to the General Assembly to address the DSP issue. The voices of families, self-advocates and DSPs will be critical in this discussion. Legislators will need to hear how difficulties in recruiting and maintaining DSPs impacts families and their loved ones, and they will need to hear of the challenges faced by DSPs who want to work with people with disabilities, but are struggling.

If you have a story to share, contact us at thearc@arcind.org or call us at 317-977-2375 or 800-382-9100.



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Self-Advocates of Indiana President's Corner

**Melody Cooper, President
Self-Advocates of Indiana**



Melody Cooper

SAI is so excited that summer is finally here! After so many months of cold weather, the sunshine is beautiful to see.

In April, we traveled to Washington, D.C. to attend the National Disability Policy Seminar. We attended workshops, listened to speakers and met with several of our members of congress. We also got a chance to have dinner with our former SAI Administrator, Rebecca Scherpelz. We enjoyed catching up with her and hearing about all of her exciting adventures!

On May 14, SAI held the second quarter statewide meeting at St. Luke's United Methodist Church in Indianapolis. Dawn Downer, Chief of Staff for the Division of Disability and Rehabilitative Services (DDRS) presented us with updates at the state level. We were also excited to have

Wayne Schmidt and Desma Belsaas, architects from Schmidt Associates, talk to us about the accessibility features at The Arc Training Institute and Teaching Hotel. Thirteen self-advocate chapters were represented at the meeting.

At the end of May, we traveled to Bloomington, Bedford and Seymour for the annual We Are The Arc visits. We spoke with self-advocates at Stone Belt, The Arc of Lawrence County and The Arc of Jackson County. It was rewarding to hear from self-advocates about what they're doing in their communities.

Don't forget! The SAI Picnic is from 10:00 am – 3:00 pm on Friday, July 18 at Eagle's Crest (Eagle Creek Park) in Indianapolis. You can register online at www.saind.org. We hope to see you there!

Self-Advocates of Indiana Speakers Bureau

Do you need a speaker for a meeting or event? Consider using the SAI Speakers Bureau!

The newly formed Speakers Bureau is made up of six self-advocates from across the state. The speakers can give presentations on dreams/employment and self-advocacy in their local communities and surrounding areas.

The SAI Speakers Bureau includes the following self-advocates:

Nate Breeden, Evansville
Richard Byrd, Ft. Wayne
Courtney Clark, Brownsburg
Shellie Ellison, Shelbyville
Mark Hublar, New Albany
Shawn Rector, West Lafayette

Contact Laura Cummings, SAI Administrator, for more information at 317-224-0249 or lcummings@arcind.org



Nate Breeden of the SAI Speakers Bureau with SAI President Melody Cooper

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 into Sarah's Great Day
- A View into SAI's Speakers Bureau
- A View with Jeff Huffman into Postsecondary Education and The Arc Training Institute and Teaching Hotel
- A View into Membership in The Arc
- A View into The Arc Insurance Project
- A View into Achieving Dreams with Denise Arland
- A View with Kerry Fletcher, Mom and Advocate
- A View into Milestones for The Arc Master Trust

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



Shop for art at

Works of Arc

featuring the work of Indiana artists with developmental disabilities.
www.worksofarc.com

The Arc
Indiana



John Dickerson

Executive Director's Column

Imagine coming home tonight, looking forward to seeing the people you care so much about. You come in, and they are not there. Instead you find someone else. No explanation or getting to know them, and all you are told is, "Hi, I'm Sarah, and I'm here instead of Tammy. Don't worry."

But you do worry. "Why did Tammy leave? Did I do something wrong that made Tammy leave? She was only here a few months, but I really liked her. Who is Sarah? Will I like her? Tonight is the night I take my bath. I'm not sure I want Sarah to help me with that. Tammy knew just how to help me in and out of the bath chair. Will Sarah drop me? I don't like this. I am just going to go to my room and shut the door. I miss Tammy."

The truth is Tammy did not want to leave. She liked her job, but she needs to support her family and took a job with better pay.

Despite their best efforts, providers throughout the state find it increas-

ingly challenging to prevent high staff turnover rates. At the same time, families who finally have a Medicaid Waiver cannot get services because providers do not have the staff to meet their needs. And agencies are finding that some of their long time, loyal workers are stretched way too thin, working many overtime hours away from their own families.

All of the research shows that the greater the continuity of persons in your life, the more progress you make. The more people know you, the more your life has meaning.

The last several years have been difficult ones in Indiana. Much of the state's budget surplus came from cutting program funding, and those cuts continue to add up over time. This has impacted the rates paid to providers, which in turn has impacted the hourly wages provider agencies can offer to DSPs.

New answers are needed to address this important issue:

- Wages for direct support professionals need to increase across the board.

Minnesota recently enacted legislation that raised rates and mandated that 75% of the rate increase go to increase wages and improve benefits for direct support professionals. This will need the attention of the General Assembly.

- Regulatory relief is needed to allow DSPs to spend time working with individuals rather than doing paperwork. The Division on Disabilities and Rehabilitative Services (DDRS) and INARF, Indiana's association representing developmental disability service providers, has been working to develop a new way to bill for services that can address this issue. These efforts need to continue until a resolution is achieved.
- New models are needed which encourage services to be provided in innovative ways. This includes programs that encourage greater independence; provide flexibility for individuals and families to get the services they really want, not just what

has traditionally been offered; and bring more people into employment.

Indiana is fortunate that the Family and Social Services Administration has a team of people looking to the future with fresh approaches, a representative for provider organizations in INARF that is constantly looking to improve Indiana's system of services, and dedicated families and self-advocates working for change – including The Arc of Indiana's 21,000 plus members.

It won't be easy. There are always those who do not see the need for change. There are those that do not see it as a priority. But we have you. This summer and fall we will again be calling on you to talk to your legislators, tell your story and make sure they continue to understand the importance of these issues.

And I am confident we will make it happen, because we have you and YOU MATTER! – your voice, your letter, your showing up to make a difference. You Matter.

Stay tuned and stay involved. Our greatest moments are still ahead.

Blueprint for Change

Celebrating Those Who are Making it Work

The following stories, featured in our 2014 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.

The Arc of Greater Boone County



Trevor Davids and Rickie Petro

Rickie Petro works out at the Witham Family Y in Lebanon with Trevor Davids, Community Connection Specialist. He lives in a group home operated by Indiana Mentor in Indianapolis and attends a workforce development program at The Arc of Greater Boone County where he works

on developing skills toward getting a job in the community. "I am learning reading skills and work skills and I know I need to stay in good shape so I can get a job," says Rickie. His individual support plan allows time in his schedule to do that.

Rickie loves sports and is very involved in Special Olympics. He also was elected Vice President of the Lebanon-Arc Aktion Club, a Kiwanis club for people with intellectual and developmental disabilities. A healthy lifestyle is an important but often neglected preparation for getting a job. "I feel better after I work out," says Rickie.

Stone Belt Arc

Local Chapter of The Arc in Monroe County

Lyle Freeman recently signed a lease to his own apartment. When asked what he was going to like most about living alone, Lyle replied, "Living alone, of course!"

Lyle Freeman's boisterous, fun-loving personality cannot be contained. He's made friends across the community, state and nation through Best Buddies and actively speaks out on



Lyle Freeman

behalf of the organization. Through the IU Chapter of Best Buddies, Lyle has become a leader, most recently serving as president. Each fall Lyle gives presentations to Indiana University's incoming freshman class on the Best Buddies program and the importance of their involvement in the community.

In addition to his Best Buddies activities, he also holds down a job that he secured through Stone Belt Arc's employment services, volunteers with numerous organizations, participates in local 5k marathons and bowls for Special Olympics. Lyle represents all that is possible not only for people with disabilities, but for all people.

Passages, Inc.

Local Chapter of The Arc in Whitley County

Passages Summer Youth Enrichment Program for middle and high

school aged students with intellectual disabilities in Whitley County was developed to help students maintain or improve skills learned in school over the summer months. The students participate in classroom lessons, hands on activities and a variety of field trips to enhance their learning.

Passages has collaborated with The Fort Wayne Dance Collective, The Passages Art Program, volunteers from the community, and others to provide opportunities and experiences the students might otherwise not encounter. This has included creative movement



Students in the Summer Youth Enrichment Program classes, a dance performance at a Tin Caps game in Fort Wayne, field trips to museums and other educational activities.

The students continue to meet during the school year one Saturday a month to maintain their friendships and have opportunities for socialization with their peers.

Sarah's Great Day

If you have not discovered it yet, you definitely want to check out "Sarah's Great Day," the online cooking show featuring Sarah, a 15-year-old with Down syndrome, produced right here in Indiana. In this article, Sarah's mother, Val Strohl, shares how "Sarah's Great Day" came to be.



Sarah's Great Day actually began somewhat by accident. In 7th grade, we had decided to homeschool Sarah, our now 15-year-old daughter with Down syndrome. There was one problem; I'm not a teacher.

So I did what I knew best; I cooked. Suddenly, I realized how much you can teach while cooking with your child. Sarah learned fractions, reading, multiplication (doubling recipes), sequencing, and she developed better hand muscle strength and hand-eye coordination.



Sarah in the kitchen showing off her creations.

So one day I thought, why not have a cooking show to show other families how you can easily teach your child at home and do it in a fun environment.

Today, we have our own website, www.SarahsGreatDay.com and our own YouTube channel, Sarah's Great Day. We just finished taping our twenty-second episode and are excited about so many other opportunities that are coming our way.

What has probably surprised us the most about Sarah's Great Day is the success of the show with people who don't have disabilities, especially among people who do not know how to cook. They love the show because we go very slowly and explain every detail of a recipe.

But perhaps closer to my heart is watching Sarah come out of her shell. She has grown significantly since we began the show back in November 2013. Her confidence and desire to communicate with others has greatly improved. She also gets pretty excited when people find out she has her own cooking show. She's proud of herself, and she should be.

Insurance, First Steps, Criminal Justice Among Issues General Assembly to Study Over Summer

The Indiana General Assembly is a "part-time" legislature that meets for a "long session" January – April and a "short session" January – March 15 on alternate years. However, legislators continue to study issues in interim committees throughout the summer. Issues studied and discussed by interim committees often lead to the introduction of legislation.

Legislation passed in the 2014 legislative session greatly diminished the number of interim study committees and two of the committees closely monitored by The Arc were blended into one. The issues previously covered by the Commission on Autism and the Commission on Developmental Disabilities will now be discussed through the **Interim Study Committee on Public Health, Behavioral Health and Human Services**. This committee will review several issues, including adding blindness and vision impairment services to the First Steps Program.

Following are additional interim study committees that The Arc will monitor:

Interim Study Committee on Education – In-depth study of funding sources for pre-kindergarten and early childhood education.

Interim Study Committee on Business Personal Property and Business Taxation – Comprehensive study regarding the state's tax code, including tax equity, property and income tax, and the business personal property tax.

Interim Study Committee on Corrections and Criminal Code – Issues concerning individuals with autism spectrum disorders as it relates to the criminal justice system.

Interim Study Committee on Fiscal Policy – Issues regarding whether Indiana should implement a state-based health exchange; the current operation of the federal exchange in Indiana; the definition of "essential health benefits" for use in Indiana under the Affordable Care Act, including ensuring the definition results in adequate benefits; and access to consumer choice of health care providers. The committee will also perform a multi-year review, analysis and evaluation of all

tax incentives according to a schedule developed by the committee.

Although many legislators will be spending some days at the State House with the above-mentioned committees, the summer is an excellent time to see your elected officials at local fairs and festivals. The summer is also an excellent time to establish or build on your relationship with your local elected officials and to talk with them about issues important to you.

The Arc will again be hosting legislative forums around the state late this summer and fall to get to know candidates running for the office and talk with them about issues impacting the lives of people with disabilities and their families.

2014 is a big election year with many state-wide offices up for election, as well as all 100 members of the Indiana House of Representatives, 25 State Senators and Indiana's nine members of Congress. Do your part by registering to vote and getting to know the candidates so you can make an informed decision when you cast your vote in November.

Are You Registered to Vote?

Election Day, Tuesday, November 4, 2014 will be here before you know it. Are you registered to vote? You must be registered to vote by October 6 to vote in this year's general election on November 4.

Register to Vote Online

Register to vote online by visiting <http://www.indianavoters.com/>. Indiana residents with a valid Indiana driver's license or Indiana state-issued identification card will be able to use this tool to submit a new voter registration application or to

update an existing voter registration record.

In addition to registering to vote online, <http://www.indianavoters.com/> provides Hoosiers with the ability to validate their voter registration status, find their polling place location, find county contact information, and determine "Who's on My Ballot?" for an upcoming election.

Register to Vote by Mail or In-Person

To register to vote or update your current reg-

istration by mail or in person, you will need to complete and return a Voter Registration Form on or before October 6, 2014 for the November General Election. An easy place to register to vote in person is at a local bureau of motor vehicles office.

Don't forget to vote on Election Day, November 4. When you go to vote, be sure to bring your valid Indiana driver's license or Indiana state-issued identification card.

The Arc Teaching Hotel to Include Unique Accessibility Features

The Arc strives every day to empower people and inspire change in many ways – including expanding employment opportunities for people with disabilities. We not only advocate for change – we are working to be part of that change by developing a hospitality training institute and teaching hotel in Muncie, Indiana.

This first of its kind project in the nation will provide postsecondary education opportunities for people with disabilities in the hospitality and food service industries, train human resource professionals in hiring people with disabilities, employ people with disabilities at the Courtyard by Marriott teaching hotel and Thr3e Wise Men restaurant, and offer the opportunity for people with disabilities to own their own businesses in the hotel.

A key partner for this project is Schmidt Associates, a full-service facility design firm offering architecture, engineering, interior design, landscape architecture, and technology planning. From the start, they have understood and embraced our vision for this unique venture.

As planning began for the design of the teaching hotel and training institute, Wayne Schmidt FAIA and Desma Belsaas AIA sat down with members of Self-Advocates of Indiana to learn what they would like to see in a hotel. Based on their insights, they have developed an architectural plan that will incorporate many unique accessibility features. “Visiting with the Self-Advocates was invaluable. You can read about accessible design, but talking to people who live with it every day allows for insights we never would have thought of. One of the most unique features will be rooms designed specifically to allow for flexibility for people with disabilities that affect

their left or right sides,” Belsaas said. Additional design features include:

- Two accessible suites and extra accessible rooms
- Wider doors to accommodate bigger wheelchairs
- Plugs for electric wheelchairs located beside beds
- Accessible bathrooms that are modern and stylish (you won't feel like you are at the hospital)
- Bathrooms featuring sliding/pocket doors
- A turning radius to accommodate wheelchairs



Hotel designers Wayne Schmidt and Desma Belsaas

Training Institute and Teaching Hotel Goals

1. Provide post secondary education opportunities that will train people with disabilities for jobs in the hospitality industry
2. Employ individuals with disabilities throughout the hotel in various capacities including management
3. Include businesses owned by people with disabilities in the teaching hotel lobby
4. Serve as a resource center for people in the human resources field by offering training on employing people with disabilities



Design team met with SAI members to gain their perspectives.

in two areas of the accessible room instead of the standard one area

- Actuators on the accessible room doors
- A shelter room located in each stairwell to allow people with mobility issues to safely shelter on each floor in case of fire
- Windows identified for firefighters so they know exactly where to find people with mobility issues
- A grassy area outside to accommodate companion dogs

Thanks to the creativity of Schmidt Associates, the Courtyard by Marriott in Muncie will provide a wonderful hotel experience for all guests, including guests with disabilities.

News and information about the project can be found by visiting: www.arcind.org/teaching-hotel. Follow the Training Institute and Teaching Hotel on Twitter @ArcTeachHotel

Training Institute and Teaching Hotel Partners

- | | |
|--|---|
| • The State of Indiana | • Courtyard by Marriott |
| • The City of Muncie | • General Hotels Corporation |
| • Horizon Convention Center | • Schmidt Associates |
| • Muncie-Delaware County Economic Development Alliance | • A Pots and Pans Production / Thr3e Wise Men |

The Arc Training Institute and Teaching Hotel

How You can be Part of Our Capital Campaign

The Arc continues to move forward toward achieving our dream of building a training institute and teaching hotel in Muncie, Indiana to provide postsecondary education opportunities for people with disabilities in the hospitality and food service industry. This unique venture will be unlike anything else in the country. Following the planned opening in 2015, we estimate that 200 people with disabilities each year will earn a Work Force Credential in hospitality or food service – a credential they can then use to gain employment in their own communities. But to help us fully realize this dream, we need the help and support of everyone.

The Arc of Indiana's board of directors made a very deliberate choice to create a for profit subsidiary of The Arc to own and manage the hotel. They felt very strongly that we need to pay back into the system that provides supports and services to the people we advocate for every day. But you may ask, why should I make a donation to help The Arc build a hotel that will be a for profit venture? The answer

is simple – 100% of the hotel profits will be used to support the training institute, create additional employment opportunities for people with disabilities, and further the mission of The Arc.

Please consider contributing to the capital campaign to help build the training institute and teaching hotel. Our goal is to raise 100% of the funds needed for this project. If we achieve that goal, we will earn a profit in year one and can immediately begin creating additional employment opportunities throughout the state through new ventures. There are several ways that you can get involved.

Donations – This is a major undertaking and we are accepting one time gifts, as well as multi-year pledges. Your donations will help make this dream a reality.

Commemorative Bricks – A brick road from the early 1900's was discovered on the property where the training institute and teaching hotel will be built. Those historic bricks are being repurposed and will be used to build a wall around the outside courtyard



Muncie. Visit www.arcind.org/training-institute and scroll to the bottom of the page to find the link to purchase your brick!

Show your support, recognize your business or organization, honor a loved one or make your mark in history by leaving your own personal message on a brick prominently displayed in the courtyard of The Arc's teaching hotel in downtown

area. You can purchase a brick and have it engraved for only \$250.00

Original Artwork – We have incredible talented artists with disabilities here in Indiana. Each hotel room will feature a piece of original artwork from one of these artists. Individuals and companies can sponsor a piece of artwork for \$5,000. A plaque will be placed on each piece with the sponsor's information. In addition, we will produce a coffee table book with all of the pieces and information about the artists and sponsors.

To make a donation, or to learn more, visit www.arcind.org/teaching-hotel or call us at 317-977-2375 or 800-382-9100.

Equal Access: Accessible Travel and Tourism

Karen Pedevilla, Indiana Protection and Advocacy Services

For families that have an individual with a disability, going away for a summer trip is easier said than done. It is that time of year where individuals wanting a break look for vacation ideas. For individuals with disabilities, there often are barriers to full enjoyment when traveling. One of the main limitations people with disabilities have when travelling is a lack of information about the place they want to go to and what are the disability rights associated with accessible travel.

There are many questions. Where can I reserve a suitable adapted hotel for my needs? Are there wheelchair accessible airport transfers available? Can I hire mobility aids such as an electric scooter or hoist? Once I'm there, how do I get around the city?



In the United States, the Americans with Disabilities Act requires that travelers with disabilities receive equal treatment under the law. While this would be the case in a perfect world, it doesn't always work out that way. In real life, especially in foreign countries where accessibility regulations vary widely, travelers with disabilities frequently face inadequate facilities, prejudice, misinformation, general hassles and higher prices than other travelers.

A rights-based approach to tourism claims that there must be equal opportunity of access for people with disabilities allowing them to enjoy the benefits of travel and hospitality whether for business or for leisure. That access must be physical as with the design and construction of buildings or transportation systems. That access must also be to the non-physical benefits available to travelers without disabilities. This could be as simple as receiving the same respect



offered to other customers during a transaction. It could be as complex as comprehensively planning safety and evacuation procedures appropriate to people with various sensory, intellectual, and mobility capacities.

One of the main limitations people with disabilities have when travelling is a lack of information about the place they want to go to and what are the disability rights associated with accessible travel.

There are several pre-trip procedures you can implement to aid in your travels

1. Know your rights!
2. Contact a travel agent familiar with accessible travel.
3. Book hotels and accommodations before arrival.
4. Confirm that accommodations are accessible.
5. Always, always arrive at departure destination early!
6. Pre-arrange for durable medical equipment storage arrangements with travel agent or airline.
7. Familiarize yourself with the location of hospitals and police stations for longer trips.
8. If you are aware that your destination may not comply with all ADA regulations or you are traveling out of the country, be prepared to deal with barriers to your enjoyment.

Helpful Accessible and Disability Travel Resources

Whether you are traveling by bus, plane, train, car or on a cruise, each person's needs are a little different, and traveling in cookie-cutter airline seats, hotel rooms and rental car fleets can be very tricky. The following are resources that can help travelers with disabilities and their companions anticipate some of the snags of accessible travel.

- The ADA Portal: <http://adata.org/ada-document-portal>
- Toll Free Hotline for Air Travelers with Disabilities <http://airconsumer.ost.dot.gov/hotline.htm>
- Travel.state.gov <http://travel.state.gov/content/travel/english.html>
- Federal Aviation Association www.faa.gov
- TSA - Travelers with Disabilities & Medical Conditions <http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>
- DOJ Commonly asked Questions about Service Animals in Places of Business <http://www.ada.gov/qasrvc.htm>
- Disabled Travelers – Wheelchair access guides for cities, states, and countries http://www.disabledtravelers.com/access_guides.htm
- Travelers Aid International - USTravability.org is a new site launched in honor of the ADA anniversary, designed to be a one-stop shop for accessible travel resources. It's got links to the special-needs pages for major airlines and airports, bus, train and cruise lines, along with links to state information and major organizations.
- Information on the latest U.S. guidelines and laws, Disability.gov/transportation
- The Society for Accessible Travel and Hospitality, SATH.org
- Accessible Journeys: <http://www.disabilitytravel.com/>
- Barrier-FreeCruising.com: <http://www.barrier-freecruising.com/>
- CruiseCritic.com: <http://www.cruisecritic.com/cruisestyles/area.cfm?area=30>
- Disabled Traveler's Guide to the World: <http://www.disabledtravelersguide.com/>
- Emerging Horizons: <http://www.emerginghorizons.com/>
- Global Access News: <http://www.globalaccessnews.com/>
- TravelGuides.org: <http://www.travelguides.org/>
- Travel on the Level: <http://www.travelonthelevel.blogspot.com/>
- World on Wheelz: <http://www.worldonwheelz.com/>

The Arc of Indiana Master Trust

Top Ten Myths

The Arc of Indiana Master Trust wants families to have a good overall understanding of special needs trusts, particularly The Arc of Indiana Master Trust. To help build this understanding, following are the top 10 myths routinely heard about special needs trusts and The Arc Master Trust:

The Arc of Indiana Master Trust is a Miller Trust. This myth is the newest myth circulating about special needs trusts, including The Arc's. The Arc of Indiana Master Trust is a special needs trust, NOT a Miller Trust. Effective June 1, Indiana now uses SSI's definition of disability to determine eligibility for Medicaid disability. This change also eliminated the "spend down" provision that allowed Medicaid recipients to maintain Medicaid financial eligibility by "spending down" their monthly income to Medicaid's income eligibility limit. Under the new guidelines, individuals on the Medicaid Waiver and those living in a Medicaid funded group home or nursing home can maintain financial eligibility by placing excess income, anything over \$2,163 a month, in a Miller Trust (also called a Qualified Income Trust). Money placed in the Miller Trust is then used to pay for Medicaid Waiver, group home or nursing home services.

A special needs trust, like The Arc Master Trust, cannot be used to maintain Medicaid eligibility due to excess income. A specific type of special needs trust known as a self-settled trust can be used to maintain Medicaid eligibility due to excess

assets – defined by both Medicaid and SSI as having more than \$2,000 in available assets at the end of the month. The Arc Master Trust II, a self-settled trust, was established for this purpose. Examples of items that could result in having excess assets include funds in a savings account, money received in an inheritance, or a lump sum back payment from SSI. The Arc Master Trust II can be used to protect anything over the monthly \$2,000 asset limit. Once placed in a Trust II account, it can be used to purchase a wide range of items, as long as the purchase is for the "sole benefit" of the trust beneficiary.

The money that is in a special needs trust CANNOT be used to pay any medical bills. This is a myth. Money placed in a special needs trust can be spent for the sole benefit of the beneficiary and for things that government benefits do not pay for. So, the trust CAN be used for medical expenses not covered under Medicaid and/or Medicare.

The Arc Master Trust will not pay for funeral expenses. This is a myth; however, it is important to understand that the trust can only pay for reasonable preplanned funeral and burial expenses prior to the date of death of the beneficiary. The trust CANNOT pay funeral or burial expenses after the date of death of the beneficiary because at that point whatever is left in the trust becomes the property of the Remaindermen of the trust. We encourage all beneficiaries of The Arc Master Trust to pre-pay this important expense.

A trust established through The Arc Master Trust cannot be established for someone that does not have a developmental or intellectual disability. This is a myth. The Arc Master Trust serves people of all disabilities, including physical, mental, emotional, intellectual and developmental disabilities.

The Arc of Indiana Master Trust wants families to have a good overall understanding of special needs trusts.

The Arc Master Trust cannot pay for vacation expenses. This is a myth. We can and do pay for vacations (and camps) out of our beneficiaries' trust accounts.

A family member can be the Trustee of The Arc Master Trust. This is a myth. The National Bank of Indianapolis is the Trustee of our Trust I accounts and The Arc is the Trustee of our Trust II accounts. Most of the time this is a comfort to families that establish trusts on behalf of their loved ones. Administering a special needs trust can be burdensome. Having someone else take on those duties relieves families of this concern.

The Arc Master Trust has offices located in various locations around the state. This is a myth. The Arc Master Trust office is located in downtown Indianapolis; however, we serve beneficiaries around the state and trust staff routinely travel to all areas of the state to meet with families, beneficiaries, support staff and attorneys when there is need.

All state chapters of The Arc around the country administer special needs trusts. This is a myth. Some state chapters (as well as some local chapters) of The Arc administer special needs trusts but not all. All of these trusts are independent of one another and are not affiliated in any way.

Any money left in The Arc Master Trust has to go back to Medicaid. This statement is both true and false. If someone establishes a Trust I type of trust with The Arc, then any money left in the trust upon the beneficiary's death goes to whomever we are instructed to give the money to. This can be other family members, not-for-profit agencies or churches for example. Whoever established the account is in control of where the remainder goes. Our Trust II trust is different. The law instructs us on where any remaining money in this trust goes. With Trust II, we do have to pay back Medicaid up to the amount that has been paid out on behalf of our beneficiary.

The Arc of Indiana Master Trust celebrated its 25th year of serving Hoosiers around the state of Indiana last year. We are happy to share that this is not a myth! The Arc Master Trust was founded in 1988 and has now served Hoosiers for over 25 years. We look forward to the next 25 years of service to individuals with disabilities and their families throughout Indiana.

Do you have a question about special needs trusts or The Arc Master Trust? Visit us at www.thearcctrust.org or contact us at mjustice@arcind.org or 317-977-2375.



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.thearcctrust.org

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?

Make plans now to attend

2nd Annual Indy Cooks for The Arc

Saturday, September 27, 2014
Dallara IndyCar Factory
Speedway, Indiana

Indy Cooks is a cooking competition among area celebrities who will compete for tips as they share their favorite appetizer, beverage, soup, salad, vegetable, side dish, main dish or dessert. The winner of each category will be the chef with the most tips! All proceeds will benefit The Arc.

In addition to sampling all of the great food, you can tour the Dallara IndyCar Factory, take a ride in an Indy racing car, practice your racing skills in a race simulator, and receive a cookbook with recipes from the event.

Online tickets sales will begin August 1 at www.arcind.org. Mark your calendars so you don't miss out!



Chefs John and Jolene Ketzenberger's Maple Bacon Baklava was a huge hit at the 2013 Indy Cooks for The Arc.

We are The Arc, and You Matter!

Thanks to this year's successful "Achieve Your Dreams, Join The Arc" membership campaign there are now more than 21,000 members of The Arc in Indiana, including 2,097 new members, thanks to the efforts of all of the local chapters who participated in this year's campaign.

As part of a network of more than 40 chapters in Indiana and 700 throughout the country, You Matter!



Making the Change

The Arc of Indiana Conference Appreciation Luncheon and Annual Meeting

October 29, 2014
Horizon Convention Center
Muncie, Indiana

Registration Opens September 2
www.arcind.org

October 28
Pre-Conference Trainings

The Changing Face of Transition
for Families, High School Students and Teachers

Leading The Change
for Leaders of Local Chapters of The Arc

All great change in America begins at the dinner table. – Ronald Reagan

The disability movement has always been one about change, beginning with families who demanded a better world for their sons and daughters. And today, self-advocates are speaking out and leading the disability movement in important new directions.

If you do not change direction, you may end up where you are heading.
– Lao Tzu

The Arc of Indiana's 2014 Conference, "Making the Change" will feature speakers, workshops, and discussion on the changing face of education, family and individual supports and services, employment, health care and more.

People are always looking for the single magic bullet that will totally change everything. There is no single magic bullet. – Temple Grandin

There is no one simple path to take toward change. We hope you will join us as we explore "Making the Change" and how you – whether you are a parent, sibling, self-advocate, provider or advocate – are a very important part of continuing to push for change that builds that better world.

Keynote Speakers

The "Shut Up Sisters," Gina Gallagher and Patricia Konjoian, leaders of "The Movement of Imperfection" and Authors of *Shut Up About Your Perfect Kid; A Survival Guide for Ordinary Parents of Special Children*.

