

## 2019 Legislative Session Critical to I/DD Funding, Supports

The 2019 session of the Indiana General Assembly is underway, and The Arc is hard at work focusing on our legislative priorities and tracking legislation.

A key bill to watch is HB 1488, which would implement many of the recommendations made by the Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities, also known as the 1102 Task Force.

### HB 1488 Initiatives

- Increase Direct Support Professionals (DSPs) wages to \$15 per hour to create a sustainable system that attracts and maintains the direct support professionals work-force.

- Create a crisis management system for people with disabilities.
- Revise CIH Medicaid waiver priority categories to allow for some expansion for people with I/DD to transition out of their family home.
- Increase Vocational Rehabilitation funding to ensure appropriate staffing needs to address resource and program shortfalls and assist those who need to utilize the programs. Direct the Division of Disability and Rehabilitative Services to create a plan to move out of Order of Selection by 2021.

### Other key initiatives The Arc is focusing on and will support include:

#### HB 1020

- Support bias crimes legislation that increases sentencing to offenders who commit crimes solely based on a person having a disability.

#### SB 380

- Include Supported Decision Making as an alternative to guardianship.

#### HB 1216

- Increase funding for First Steps, early intervention services

#### HB 1565

- Support a cigarette tax increase, as long as revenue raised from the increased tax goes toward health related programs, including First Steps, and improving Medicaid rates which will help the DSP workforce crisis.

#### HB 1002 & SB 500

- Legislation that could lead to increased employment opportunities for people with disabilities.

#### HB 1296

- Create a priority category for Indiana's Medicaid waivers to serve active military families.

#### SB 190

- Update the accessible symbol on signage and license plates and remove the word "handicapped" from certain code sites.

#### SB 525

- Ensure the alternate diploma is available only to those students where the case conference committee determines that is the most appropriate diploma.

#### SB 559 & HB 1350

- Provide for a tax credit for deposits into an ABL account to mirror 529 tax credits.

#### HB 1117

- Support legislation to carve out from any new managed care initiatives the I/DD population that currently utilize Medicaid waivers and group home living.



Hannah Carlock, The Arc of Indiana Director of Public Policy and State Representative Ed Clere, author of HB 1488, which includes many of the recommendations of the Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities. The bill is co-authored by Rep. Michael Karickhoff, Rep. Gregory Porter and Rep. Peggy Mayfield.

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### Keep Up to Date

Visit [arcind.org/our-programs/public-policy-advocacy](http://arcind.org/our-programs/public-policy-advocacy) to find links to find your legislators and sign up for action alerts and legislative updates.

## Self-Advocates of Indiana President's Corner

**Shawn Fulton, President  
Self-Advocates of Indiana**



Hi, my name is Shawn Fulton, and I am the new President of Self-Advocates of Indiana. I live in Marion, IN, and I am currently the Vice President of the Alliance Seekers of Blackford and Grant County self-advocacy group.

I work part-time at Carey Services and am a contractor for the nursing home transition project. I have been involved with Self-Advocates of Indiana since 2003 and have held different leadership positions during that time, such as vice president and treasurer. I also sit on several committees as

a representative of SAI including last year's 1102 Taskforce, the IDR Commission, DDRS Advisory Committee, and The Arc of Indiana Board of Directors.

As President of SAI, I want to help us grow as an organization and continue to be a strong voice for people with disabilities in Indiana. I want to see more employers hiring people with disabilities and paying them a

fair wage. I also want to work with community members like police and first responders and educate them about disabilities. I am excited to be President of SAI. You can reach me at [saipresident@arcind.org](mailto:saipresident@arcind.org).

We are already busy even though the year has just begun. We are working closely with The Arc of Indiana on advocating for important legislative issues during this new legislative session. We look forward to seeing everyone on February 14 at our annual Valentine's Day at the Statehouse event. This

is always an important day to thank our legislators and remind them to think about us when voting.

We are also busy planning our first SAI Chapter Leadership Training Day which will take place on February 26. This training will be for officers of our chapters and will give them information about how to run their groups, how to advocate for important issues, and give them the chance to meet and share ideas with other leaders. We will also have a separate breakout session that day for chapter helpers to discuss their role in a self-advocacy group.

Please also mark your calendars for the following dates this year:

April 17—Central Regional Meeting

April 24—North Regional Meeting

April 30—South Regional Meeting

July 19—SAI Picnic

October TBD—Annual Meeting  
and Board Elections

## A View from My Window

Hosted by Michelle Fischer

Visit [arcind.org/podcasts](http://arcind.org/podcasts) to listen to our *A View from My Window* podcast, including these recent podcasts.

### A View into the 2019 Legislative Session and Tribute to Betty Williams

Michelle talks with Kim Dodson and Hannah Carlock about the 2019 legislative session and closes the podcast with a special tribute to Betty Williams, The Arc of Indiana's self-advocacy training coordinator and longtime leader in the self-advocate community, who passed away on December 4, 2018.



### A View into the LifeCourse Framework with Heather Dane

Listen in as Michelle talks with Heather Dane, Family Engagement Specialist for the Division of Disability and Rehabilitative Services (DDRS), to learn about the LifeCourse Framework, a program to help individuals and families of all abilities and at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Learn more about the Lifecourse Framework at: [lifecoursetools.com](http://lifecoursetools.com)

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 Instagram, @MFView.

## Executive Director's Column



Kim Dodson

Recently The Arc of Indiana lost two icons, Dorothy Burnside and Betty Williams. Though these women approached advocacy from different perspectives – Dorothy as a mother and Betty as a person with cerebral palsy – both women were tenacious and always felt like there was more to be done.

Dorothy was one of the founders of The Arc of Indiana. Back in 1956 funding was not available to help families in supporting a loved one at home, and schools did not allow children with disabilities to attend school. Faced with no services or supports, Dorothy made the difficult decision to place her daughter at Muscatatuck, one of Indiana's state institutions at that time. But Dorothy



Dorothy Burnside at the Statehouse

journey down a path where the future was unknown but expected to be better. Dorothy spent time at our Indiana Statehouse to educate lawmakers about a better way to provide services and supports to people with disabilities. Back then there were few women at the Statehouse,

and making sure self-advocates had a voice at the table where decisions were being made. When I started



Dorothy Burnside and Ilene Younger Qualkinbush

knew there was a better way. She dedicated herself to changing how Indiana treated people with developmental disabilities. Dorothy was what we now call one of the pioneer families, one of the first families to

but Dorothy and her co-founder friend, Ilene Younger, decided to make sure they stood out and wore hats each and every day. That was who Dorothy was, a woman who said, "Look at me and pay attention to what I have to say." The Arc of Indiana is proud to continue the foundation Dorothy helped put into place.

Betty had been involved with The Arc for over three decades. She was a fierce advocate for many issues important to people with disabilities but was especially passionate about the closing of our state institutions



Betty Williams

with The Arc in 1998, Betty quickly became a mentor, then a friend, and later I was fortunate to work with her as a colleague. I learned so much from her and loved watching her work with other self-advocates as they challenged one another to think differently or dream bigger. I especially enjoyed sitting beside her during many meetings whether at the Statehouse, government center or in DC. She would never

hesitate to correct someone when they diminished what people with disabilities were capable of doing or achieving. She loved the legislative process and thrived on the debate and conversations that took place. Betty's passing has left a void in The Arc office. No one fills a space like she did. I do not think I am speaking only for myself when I say that we will never be the same.



As we bid farewell to these two extraordinary women, I wish I could tell them that "things are good; don't worry." But the truth is things are not good and we should be worried. We are living in a time of many unknowns, and many of our programs could be in jeopardy. We have had great success over the years moving to a more community-based model of services and supports for people with I/DD, but the workforce crisis and plateau of growth in our programs is concerning.

The one thing I can tell them though is, "We have listened and learned from you. You have taught us well, and we will continue to fight for more programs and supports that help people with disabilities live their best and most independent lives."

## The Arc Welcomes New Team Members

Over the past few months, The Arc of Indiana has been pleased to have new staff members join The Arc of Indiana team.

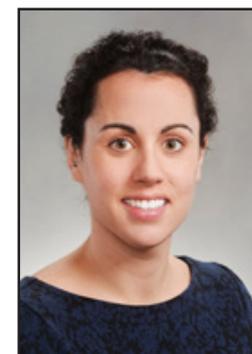
Hannah Carlock joins us as Director of Public Policy; Donna Rezsonya is working with our finance team as Accounts Payable and Receivable Clerk; and Jessica Kaneft is keeping The Arc Advocacy Network programs organized as our Advocacy Administrative Support Specialist. View all of our team members at [arcind.org/about-the-arc/the-arc-team](http://arcind.org/about-the-arc/the-arc-team).



Hannah Carlock



Donna Rezsonya



Jessica Kaneft

# The Arc Advocacy Network

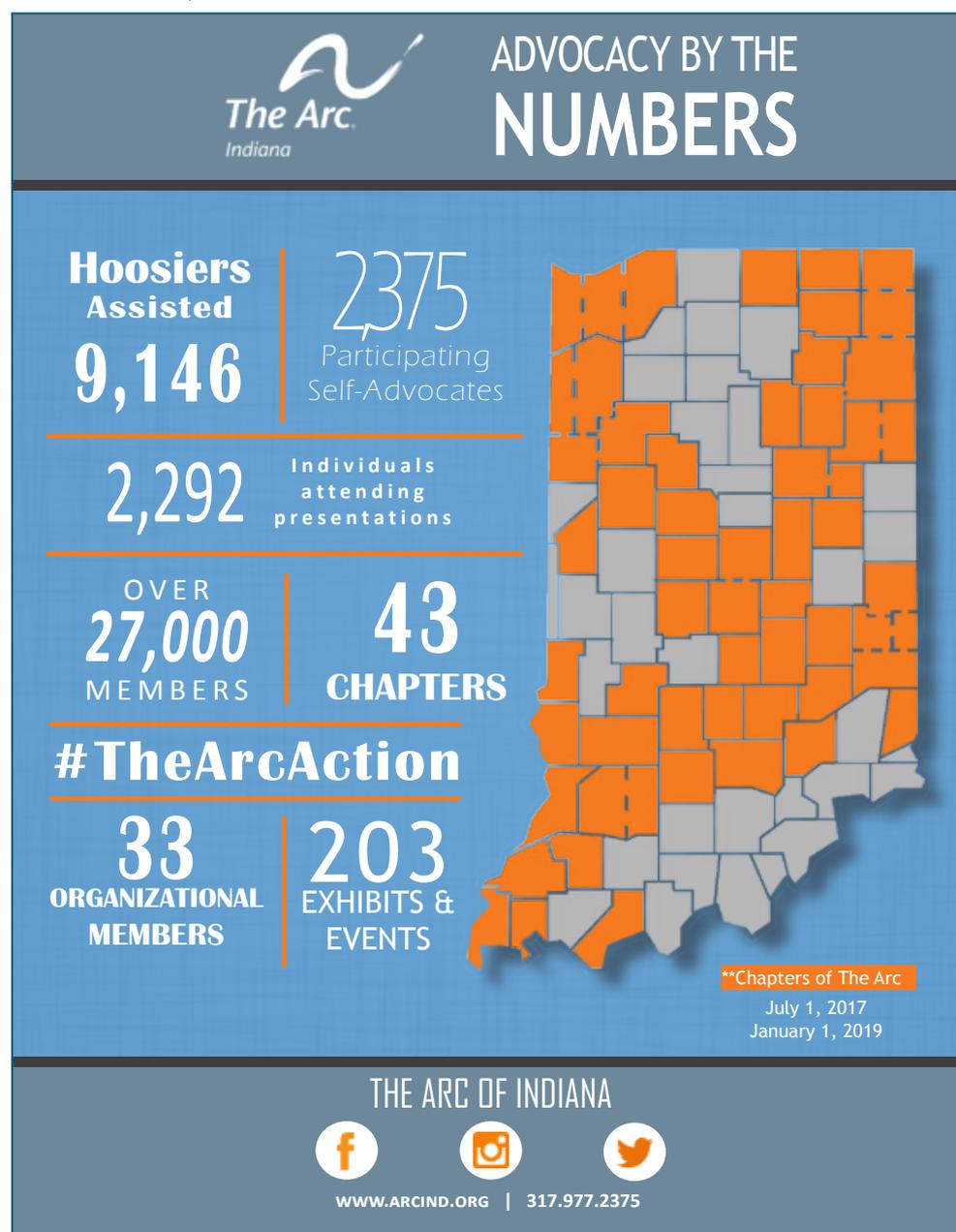
The Arc Advocacy Network provides information, referral and advocacy to assist and guide individuals with intellectual and developmental disabilities and their families with a wide range of issues, including:

- Applying for and navigating government programs including:
  - Medicaid & Medicaid Waivers
  - Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)
  - Vocational Rehabilitation, including learning about and accessing community employment and career pathways
  - Community Living Options
- Developing relationships within the community and using resources and supports that may already exist
- Using the LifeCourse Framework to help families and people with disabilities identify their vision of a good life and identify strengths, resources, and supports to achieve that vision
- Learning about guardianship and alternatives to guardianship, including supported decision-making
- Assisting families in navigating their healthcare coverage, increasing knowledge of basic healthcare coverage issues, and finding resources to cover additional healthcare costs
- Providing information and resources available for individuals interested in transitioning from nursing facilities and group homes to a home in the community
- Becoming a Self-Advocate and connecting to Self-Advocates of Indiana

The Arc Advocacy Network is available for presentations and to exhibit at local events.

Contact us at 317-977-2375, 800-382-9100, [thearc@arcind.org](mailto:thearc@arcind.org)

Learn More at [arcind.org/our-programs/the-arc-advocacy-network](http://arcind.org/our-programs/the-arc-advocacy-network)



The Arc Advocacy Network team recently gathered for a planning meeting on how we can best serve individuals with I/DD and their families. Front Row: Laura Strausburg-Smith, Senior Family Advocate; Michele Trivedi, Insurance Advocacy Resource Center Manager; Cyndi Johnson, Family Advocate; Ofelia Jimenez, Bilingual Family Advocate; Melody Cooper, Self-Advocate Specialist. Back Row: Karly Sciortino-Poulter, Family Advocacy Program Manager; Randy Kriebel, Consultant; Amanda Circle, Advocacy Specialist/Self-Advocates of Indiana Administrator; Jill Smith, The Arc Advocacy Network Director; Ella Boyd, Family Advocate.

## Charting the LifeCourse

Planning for our future is a task that most of us do not readily think of or engage in strategically. How will point A lead me to point B and eventually to point E? Assisting a loved one with a disability in planning for the future can seem even more daunting. Families have shared, how do I plan for what my child will be doing when he is 30, when all I can think of now is getting through this semester of school.

Yet, what happens to us early in our lives can have a significant impact on our quality of life and well-being in the future. It is important to help people have positive, healthy experiences, adequate support, and opportunities to learn and make mistakes so that they can have better outcomes later in life.



The LifeCourse Framework is a program that can help. The program, developed by families for families, can help individuals and families of all abilities, ages and stages of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

While the LifeCourse Framework can be used as part of the planning process for those receiving Home and Community Based Medicaid Waiver services, it can be used as a planning tool to help anyone think about their life, not just those known by the service system.

Information and materials, including these guides, are available at [lifecoursetools.com](http://lifecoursetools.com):

- Charting the LifeCourse: Focusing on Early Childhood
- Charting the LifeCourse: Focusing on School Age
- Charting the LifeCourse: Focus on Transition
- Charting the LifeCourse: Focusing on Adulthood
- Charting the LifeCourse: Focus on Aging

Each guide includes information to help families and those with disabilities think about life domains – daily living, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy – at various stages of life and includes questions to



ask to move toward a vision for a good life that incorporates these domains.

### Save the Date

#### LifeCourse Framework Conference

May 17, 2019  
Marriott East  
Indianapolis

The Division of Disability and Rehabilitative Services, with support from the Governor's Council for People with Disabilities, is hosting a daylong event on May 17 specifically for individuals and families caring for someone with a disability. The sessions will provide information about the LifeCourse Framework as well as how to use the principles and tools in everyday life. Topics will include healthcare financing, transition to adulthood, supported decision making and special education.

## State of the States in Services to People with I/DD

The Coleman Institute for Cognitive Disabilities provides a wealth of information on the status of programs and services to people with intellectual and developmental disabilities in their "State of the States" report.

While a final report will be issued in March 2019, preliminary data provides useful information for advocates and state officials to plan for the future of I/DD services in Indiana. Following are key preliminary findings:

- Indiana is one of 15 states without state operated institutions for people with I/DD. Indiana has been a leader in this area.
- 55% of funding nationally is spent on services to people in residential programs for six people or less and related community services.
- Only 9% of funding nationally is spent on family supports and only 1% on supported employment.
- In 2017 41% of caregivers to people with I/DD in Indiana were under the age of 41. 35% were ages 41-59. 24% were age 60 or over. The growing number of aging caregivers is a significant issue that must be addressed.
- In 2016, 10% of individuals (1,714) in Indiana participated in integrated community employment services as compared to 19% nationally.
- Indiana's use of residential programs for 6 or fewer and 7-15 persons has plateaued. The utilization of 6 or fewer settings is below the national average.
- Indiana has a higher utilization of people with I/DD in nursing facilities than the U.S. and any surrounding states. In 2017 1,598 people with I/DD lived in nursing facilities.
- Indiana has seen positive growth in the use of spending for Home and Community Based Services Medicaid Waivers. The number of individuals served grew by 55% from 2007 to 2017.
- Indiana lead in increased spending for community services from 2015-2017 compared to surrounding states, including Ohio, Minnesota, Wisconsin, Illinois and Michigan.
- The report notes that positive recommendations made by the Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities can continue to move Indiana forward in serving people with I/DD and their families. Key task force recommendations under consideration at the Indiana General Assembly include:
  - Increase Direct Support Professionals (DSPs) wages to create a sustainable system that attracts and maintains the DSP workforce.
- Support efforts to create a crisis management system for people with disabilities.
- Support legislation that revises the priority categories for our Medicaid waivers and allows for some expansion for people with I/DD to transition out of their family home.
- Increases funding for Vocational Rehabilitation Services to ensure appropriate staffing needs to address resource and program shortfalls and assist those who need to utilize the programs. Direct DDRS to create a plan to move out of Order of Selection and serve all categories by 2021.
- Direct the Division on Disability and Rehabilitative Services (DDRS) to develop a plan to serve all eligible for Vocational Rehabilitation Services by 2021 and move Indiana out of Order of Selection.

# EGTI Flipping the Employment Script

In 2016, The Arc of Indiana Foundation founded Erskine Green Training Institute, a one of a kind post-secondary training program for people with disabilities, housed at the Courtyard Muncie at Horizon Convention Center.

EGTI is transformative. We are flipping the script on an employment story that historically did not offer good news. In the first three years of operation, EGTI graduates, who previously would have been part of the 82% unemployment rate for people with disabilities statistic, are now enjoying a nearly 80% employment rate.

EGTI provides training in hospitality, food service, healthcare and inventory distribution to people with developmental and physical disabilities.

During the 10 to 13 week training sessions, students live at the Courtyard Muncie, attend class, master key

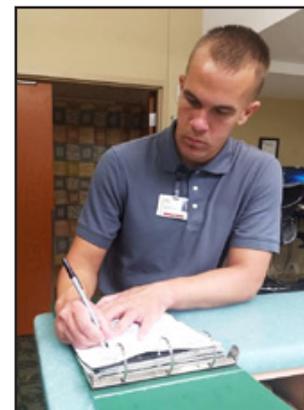
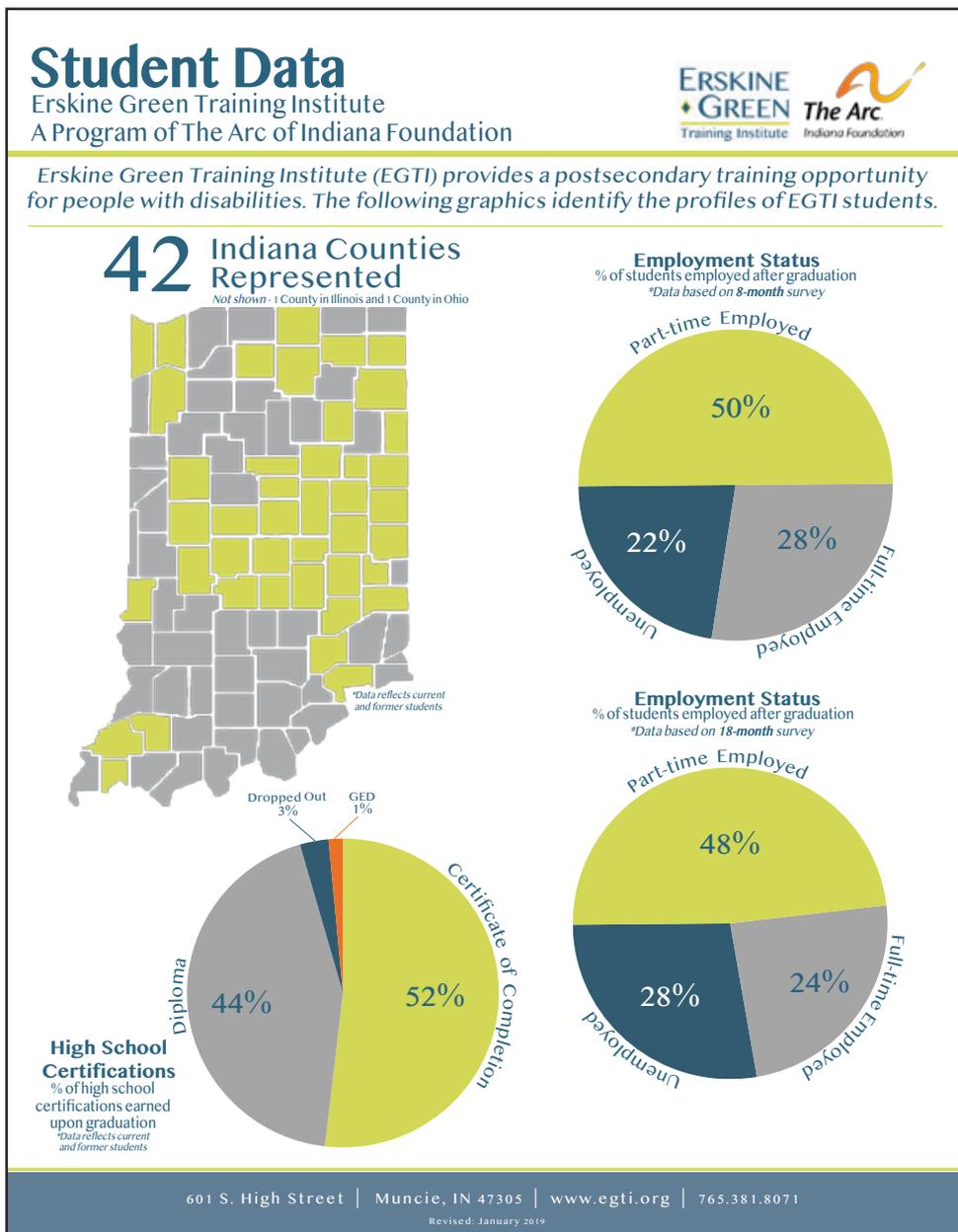
job skills, and gain valuable work experience through internships at Courtyard Muncie, Thr3e Wise Men and IU Ball Memorial Hospital.

In addition to hands-on job training, the curriculum addresses critical soft skills like appropriate work place etiquette, teamwork, taking direction and effective communication skills.

Students gain independence by mastering a Community Access Checklist that teaches them how to navigate public transportation and how to be safe when they are out and about in the community. Ball State University students serve as volunteer mentors and fill part-time

staffing positions. Time spent with peers provides opportunities for EGTI students to enjoy typical college experiences.

But the part of the story we are most proud of is that EGTI is putting people with disabilities to work in communities throughout Indiana.



Alex Becker, a graduate of EGTI's Patient Transport program, now works at IU Health North Hospital in Carmel, Indiana as a patient transporter.



Gill Nicholas, a graduate of the Kitchen Cook program, now works at Oak & Alley in Warsaw as a kitchen cook.



Allison Bainbridge, a graduate of the Environmental Services program, now works at IU Health Ball Memorial in their Environmental Services department.

## Learn About The Arc Master Trust

The Arc Master Trust, a pooled special needs trust, offers families and people of all disabilities an experienced, professional option for special needs trust administration at an affordable price, allowing resources to be saved and easily used for qualified disability and personal expenses.

### What is a Pooled Trust?

Administered by a non-profit, a pooled trust combines the assets of many individuals for investment purposes while maintaining individual accounts for beneficiaries.

### Eligibility

Individuals of all ages and with any type of disability, as defined by the Social Security Administration, can participate in a pooled special needs trust. The Arc Master Trust serves Hoosiers of all disabilities, including those with physical, mental, emotional and intellectual or other developmental disabilities.

### Our Trusts

We offer two trust options. Trust I allows families to create a trust to provide for their loved one. Trust II allows a person with a disability to establish a trust with their own funds. This might include earnings from employment, social security funds, a lawsuit settlement or an unexpected inheritance or gift.

### Creating a Trust

Starting a trust with The Arc Master Trust is a quick process. Simply submit a completed Joinder Agreement, any required documentation, the enrollment fee, and (if funding the trust at this time) a check for the initial deposit.

### Affordable & Easy to Use

As a nonprofit, family-centered organization, The Arc offers trust accounts with low annual fees and no required minimum balance. Using your trust is as easy as 1, 2, 3.

1. Request a disbursement through INtrust, our online trust management system – or call, e-mail or fax your trust account manager.
2. Provide any required documents or receipts by submitting them through INtrust or by mailing or faxing them to your trust account manager.
3. Payments are processed twice a week, on Tuesday and Thursday.

### Why Choose Us?

We offer 30 years of trust administration experience. Our trust director, Melissa Justice, and assistant trust director, Jill Ginn, have a combined work history of almost 40 years with The Arc of Indiana. Our trust account managers have training and experience to work with individuals who have any type of disability.

Safeguarding the assets of trust beneficiaries is a primary concern of The Arc Master Trust. All payments

processed by account managers must be approved by the trust director or assistant trust director.

INtrust, our online trust management system, provides detailed information on account balances and transactions.

Trust funds are safely and securely on deposit with The National Bank of Indianapolis, and a trust advisory committee and The Arc of Indiana board of directors provide advice and oversight.

### Want to Learn More?

Learn more about The Arc Master Trust and find required documents at [thearctrust.org](http://thearctrust.org) or call us at 317-977-2375 or 800-382-9100.

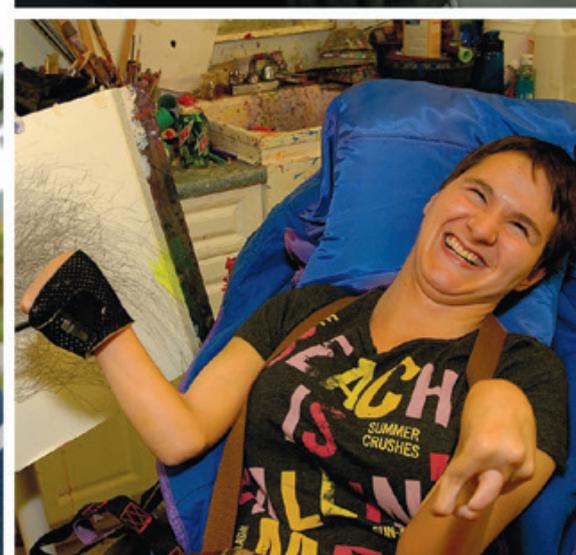
We are happy to provide a complimentary consultation at your home or a location in your community. We also welcome visitors to our location in downtown Indianapolis. Trust staff is also happy to provide presentations to organizations or companies.

### The Arc Master Trust Fast Facts

- Trust I was established in 1988.
- Trust II was established in 1995.
- At the end of 2018, there were a total of 3,483 open trusts. 505 of those were unfunded Trust I accounts.
- 9,469 disbursements were made to trust beneficiaries in 2018, totaling more than \$5.2 million.
- As of December 31, 2018, assets totaled over \$73.8 million.

### Safeguard Protections

- Disbursement requests are entered into the trust's data system by trust staff.
- Separate checkpoints are utilized to process disbursements from trust accounts.
- Requests are verified with the beneficiary's key people.
- Requests are reviewed and approved/declined by the trust director or assistant director.
- Two signatures are required for any check over \$3,000.
- Disbursement checks are reconciled by the The Arc's director of finance.
- The Arc maintains full liability insurance and a crime/dishonesty bond.
- The Arc Master Trust's trust management system, INtrust, allows individual trust accounts to be reviewed online through a password protected portal. Activity related to trust accounts can be viewed by key people and beneficiaries 24 hours a day, 7 days a week.



# 2018 Impact Awards

Congratulations to our 2018 Impact Award recipients. Thank you for the difference you make in the lives of people with I/DD, their families and members of your community.



**Cathleen Clark Professional Service**  
Cynthia Johnson, ADEC, The Arc in Elkhart County



**Employment**  
Troy Frisz, The Arc of Greater Boone County



**Outstanding Professional Achievement**  
Jim Allbaugh, Carey Services, The Arc in Grant and Blackford Counties



**Executive Director's Award**

Supported Decision-Making Team Jamie Beck; Dan Stewart; Erica Costello, Staff Attorney, Indiana Office of Court Services/Adult Guardianship Office; Indiana Disability Rights - Dawn Adams, Executive Director; Melissa Keyes, Legal Director; Justin Schrock, Staff Attorney

## 2018 Conference & Impact Awards Luncheon Thank You to Our Sponsors

- Governor's Council for People with Disabilities
- ICEArc
- Indiana Family and Social Services Administration
- Indiana Disability Rights
- Advocacy Links
- Managed Health Services
- IPMG
- Achieva
- Damar
- Horizon Convention Center
- INARF

**Outstanding Chapter of The Arc**  
Noble, The Arc of Greater Indianapolis



**Innovation**  
KCARC, The Arc in Knox County, 1972 Community Fun Center



**Outstanding Self-Advocate**  
Becky Oaks, The Arc of Greater Boone County



**President's Award**  
Sue Loughlin, Terre Haute Tribune Star