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arcind.org

# Advocacy – The Core of Our Mission

The Arc of Indiana has served as the state's leading advocacy organization for people with intellectual and developmental disabilities (I/DD) for over 60 years. Our advocacy efforts continue to be the core of our mission. Over these past many months, the entire team at The Arc of Indiana, our chapters, and The Arc of the United States have pulled together to guide and assist families and people with I/DD, and advocate for their rights through unprecedented times.

In the initial phases of the COVID-19 pandemic leadership at The Arc of Indiana worked to help our provider chapters access



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The Arc of Indiana 143 W. Market St. Suite 200 Indianapolis, IN 46204 317-977-2375 desperately needed personal protective equipment (PPE), and chapters banded together to purchase bulk PPE. Weekly virtual meetings were held with chapter leaders to share information on best practices to keep those they serve and Direct Support Professionals safe, while at the same time continue to provide supports and services in a new way. At our request, Kylee Hope, director of the Division of Developmental Disability Services, and Lt. Governor Suzanne Crouch joined in the weekly meetings to share information on action the state was taking to address the needs of people with I/DD and their families and learn about ongoing needs and concerns from providers throughout the state.

The Arc of Indiana, our chapters, and The Arc of the United States have pulled together to guide and assist families and people with I/DD, and advocate for their rights through unprecedented times.



As congregate services began to shut down and the switch was made to virtual programming for those programs and home and community based services, The Arc Advocacy Network's family advocacy team helped families deal with reduced or eliminated staffing, how to address increasing behaviors, and how to adjust to the new "normal" of staying home. Videos were produced and shared on masks, staying healthy and safely reopening services. Webinars were conducted with the Bureau of Developmental Disability Services to help families learn about available resources and how they could access help. And Self-Advocates of Indiana worked to find new ways to keep SAI members and others with I/DD connected (see page 2 for more on SAI).

Spring 2021

As schools shut down, our family advocates helped families navigate e-learning and discussed how to get additional supports from schools, including making e-learning accessible and appropriate for students with disabilities. They talked about alternative options including online public charter school e-learning and non-virtual options for families who did not have virtual capabilities due to lack of devices or internet access.

Families were guided through difficult conversations. "I'm a single mom, and we have no family. What happens to my child if I get COVID?" "If my child gets COVID, will the hospital let me in?" "Do I need to get guardianship because of COVID?" Our family advocates talked through options, including designating health care representatives, Powers of Continued on page 3

## Self-Advocates of Indiana President's Corner

Shawn Fulton, President Self-Advocates of Indiana

We're only a few months into 2021, but it's already been a big year for Self-Advocates of Indiana!

In February, we hosted our first Virtual Valentine's Day at the Statehouse event. We had a great opportunity to speak virtually with several of our elected leaders and state



officials about issues important to self-advocates and our top legislative priorities for the 2021 session. We've also been hard at work producing informational videos about self-advocacy and the COVID-19 vaccine. If you haven't already, be sure to check out the Self-Advocates of Indiana Facebook page and YouTube channel to see some of our videos, and stay tuned

for more to come. You can find links on our website, *saind.org* 

In April, SAI will launch our new Monthly Issues Forums. Once a month, SAI will host speakers and panels to lead discussions on issues facing self-advocates. Our first forum will be April 14<sup>th</sup> at 4:00 pm EDT. We are very excited to announce that our first guests will be Lieutenant Governor Suzanne Crouch and incoming DDRS Director Kim Opsahl to talk about recommendations of the 1102/Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities and the 2021 legislative session. Going forward, we plan to hold these forums on the third Wednesday of the month at 4:00 p.m. Eastern. To register for April's Monthly Issues Forum, please visit the Self-Advocates of Indiana website.

Now, for the news you've all been waiting for— we are planning to hold our 2021 SAI picnic IN PERSON!! We've scheduled this year's picnic a bit later in the year, September 24<sup>th</sup>, with the hope that it will be safe enough in Indiana for a large gathering. We're taking another run at Self-Advocates of Indiana's 30<sup>th</sup> Anniversary, and we plan to celebrate big! We can't wait to celebrate together.



For over 30 years, Self-Advocates of Indiana has been a driving force for disability rights in Indiana, bringing the voices and needs of people with disabilities to the discussion table. SAI has been part of efforts to close institutions in Indiana, remove the r-word from state statutes, and advocated for the passage of Supported Decision Making legislation as a less restrictive alternative to guardianship. In addition to the Self-Advocate representatives currently serving on numerous boards, committees, and task forces across the state, in 2020 SAI successfully chaired the Employment Array Work Group as part of the 1102/Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities

SAI has even had federal representation when former SAI President Betty Williams served on then-President Obama's Committee for People with Intellectual Disabilities. From the local level

## **Nothing About Us Without US**

to the national stage, SAI has been hard at work ensuring people with disabilities are being heard.

The COVID-19 pandemic presented new challenges and obstacles for people with disabilities,. SAI set to work to recognize and address the needs of people with disabilities under this "new normal." Early in the shutdown, SAI set up weekly, state-wide video calls for self-advocates to share information and stay socially connected during a time of physical isolation. These calls created an excellent platform to share information quickly and widely across the state while also serving as a way to gather information about how self-advocates were being impacted by the pandemic.

# SAI is a driving force for disability rights.

SAI put out accurate, up-to-date information about the pandemic, available resources, impact on services, safety measures, and vaccine information. In the midst of this public health crisis, SAI also worked to circulate information on the 2020 census, produced a number of election and voting related videos and was part of a collaborative panel discussion with Indiana Disability Rights on "Voting as Self-Advocacy." SAI completed all of these initiatives while still carrying out their core mission—to amplify the voices of people with disabilities. They continued work on Medicaid Waiver redesign, gathered feedback for the Governor's Council for People with Disabilities' new 5-year plan, and supported initiatives to expand employment opportunities for people with disabilities. SAI has also led and collaborated on efforts related to cultural and linguistic competency, institutional modernization, community integration, and youth engagement.

### From the local level to the national stage, SAI has been hard at work ensuring people with disabilities are being heard.

For more information on Self-Advocates of Indiana or to find a self-advocacy chapter near you, visit *saind.org*.

Self-advocacy is important because it is a way for people to know that all people, including people with disabilities, have rights. We help people understand that we want to be treated with respect. It is a way for our voices to be heard.

### Message from The Arc of Indiana CEO Welcome to a special I quickly went to the people who I know to people wanting m



Kim Dodson

I remain in awe of the work The Arc of Indiana's team put forth this past year. While dealing with anxiety, depression and the stress of juggling work-from-home, as well as perhaps e-learning and taking care of family members of their own – The Arc team continued to be that trusted shoulder of support for the thousands of people who made their way to The Arc looking for answers and resources.

advocacy focused issue of

I am glad to share

information on key issues

which we know have been

at the forefront of minds for

people with disabilities and

their families this past year.

The Arc News in Indiana.

The core of The Arc's mission is to support people with disabilities and their families – to be that warm voice on the end of the phone to help them through difficult situations. Our core mission was jeopardized last year when we unexpectedly received a 67% cut in our state contract to support our advocacy efforts. We quickly needed to devise a plan to ensure that our small but mighty team could continue, families would not be abandoned and calls left unanswered. I quickly went to the people who I know support The Arc and value not only our mission but our strong commitment to people with disabilities and their families.

I am proud to share in this newsletter the unveiling of our *Circles of Support*, highlighted on page four, and those who stepped up to save our advocacy efforts. I am extremely grateful to all who support us but specifically our Mission Circle members who have made a considerable investment in us during difficult and troubling times.

2021 has started off exceptionally busy, as so many more issues are now on the table with vaccines and priority lists, as well as the return to school, case conference committees and reopening of programs. Our calls have increased and the length of time we are spending on those calls have nearly doubled.

As I have spoken with a great many families, I find they are hungry for information and just want a trusted resource to turn to. We are committed to continual improvement of our efforts here at The Arc and want families to know we continue to be here for them.

Self-Advocates also are engaged more than ever, and we are asking them to provide feedback on so many efforts and provide direct outreach to their peers. They too are responding to people wanting more information, and Self-Advocates of Indiana is starting a monthly issue forum with guest speakers to talk with selfadvocates on a wide range of topics.

I hope you find the information in this newsletter helpful, and I hope you take a moment to learn more about our local chapters of The Arc and all the great organizations we so closely partner and work with to improve the lives of people with developmental disabilities.



#### ADVOCACY from Page 1

Attorney, or a standby guardian. They worked with local hospitals to change their polices to allow a support person to be with a person with a disability when they were admitted with COVID, and leadership at The Arc of Indiana worked with the Indiana Hospital Association to ensure people with disabilities had equal access to critical COVID treatment.

Calls increased from families seeking help with basic living needs and information on stimulus checks and how that might impact Social Security benefits. The Arc team constantly



sought and shared new information on what was happening at the national and state level to keep information up-to-date and accurate.

Throughout the pandemic, The Arc of Indiana and local chapters joined in The Arc of the United States' tireless efforts to include relief for providers of I/DD services by making

### A year of advocacy efforts finally resulted in additional dedicated funding for home and community based services.

sure Indiana's congressional delegation was fully informed of the need to support these efforts. A year of advocacy efforts finally resulted in \$12.7 billion in additional dedicated funding for Medicaid home and communitybased services, stimulus payments extended to adult dependents with I/DD, and \$3 billion in additional funding for the Individuals with Disabilities Education Act.

As the good news of the development of COVID-19 vaccines began, The Arc of Indiana's

public policy director, Hannah Carlock, was appointed to the state's vaccine distribution advisory committee and was able to be a voice for people with I/DD to receive the vaccine as rapidly as possible. The Arc team worked to quickly provide updates on how people in residential programs, then people with Down syndrome and other comorbidities, and then people receiving Home and Community Based Medicaid Waiver services could access the vaccine.

It has been a hard year. One article cannot begin to sum up the tireless efforts of The Arc at the national, state and local level. We hope you know we have been here and will continue to be here to help. Now, there is light ahead. Our commitment to our advocacy mission continues as we work through the ongoing pandemic and begin the shift to a "new normal." Please be sure to stay informed by following us on social media, signing up for our weekly e-newsletter and legislative updates, and getting connected to your local chapter of The Arc. You can find links to all at *arcind.org/get-involved*.



## Individually, we are one drop. Together, we are an ocean.

The Arc of Indiana has served as the state's leading advocacy organzation for people with intellectual and developmental disabilities for over 60 years. Our advocacy efforts continue to be the core of our mission.

Key to that mission is The Arc Advocacy Network's team of family advocates who work tirelessly to provide a critical circle of support to families and people with disabilities.

Thank you, to the key organizations and trusted partners who join in support of our advocacy efforts through our Circles of Support initiative.

### **Mission Circle**

**KCARC Mike Carney, President** Since 1972, KCARC, The Arc in Knox County, has led the effort to effectively play a positive role in lives of those who have disabilities within their community. KCARC has been at the forefront of Knox County by being an economic asset, a major employer, and a haven for individuals and families served.

Mission: To advocate and provide opportunities in a dignified and respectful manner for the total well-being of individuals and families with special needs.

#### knoxcountyarc.com



#### Donna Elbrecht, President/Chief Executive Officer

Easterseals Arc of Northeast Indiana works to help people with

intellectual and developmental disabilities succeed at home, at work, and at play. Easterseals Arc offers a broad range of services including employment services, day programs, residential services, recreation, respite, and support in the community and at home.

Mission: Our purpose is to change the way the world defines and views disability by making profound, positive differences in people's lives every day.

#### easterseals.com/neindiana



#### Christine Dahlberg, Executive Director

The Indiana Governor's Council for People with Disabilities is an independent state agency that facilitates change. The Council is consumer-driven and is charged with determining how the service delivery system in both the public and private sectors can be most responsive to people with disabilities. The Council receives and disseminates federal

funds to support innovative programs that are visionary, influence public policy, empower individuals and families and advocate systems change.

Mission: To advance the independence, productivity and inclusion of people with disabilities in all aspects of society. This mission is accomplished through planning, evaluation, collaboration, education, research and advocacy.

in.gov/gpcpd

### My company, Vour company, Our company!

#### Karen Brummet, Chief Executive Officer

Indiana Professional Management Group (IPMG) provides person-centered case management services to individuals with intellectual and developmental disabilities, and wraparound facilitation services to

children with emotional and/or behavioral challenges.

Mission: To create an exceptional organization that supports its Employee Owners to become expert navigators, guiding individuals and families to access quality, integrated services and supports that result in the betterment of their lives.



#### Dan Strick, President/Chief Executive Officer

New Star serves people with intellectual and developmental disabilities throughout the

Chicagoland area and Northwest Indiana.

Mission: To provide choices and opportunities for persons with disabilities and their families through a culture of innovation and caring to enrich their lives and maximize their independence. newstarservices.org

#### **DREAM CIRCLE**

Indiana Institute on Disability and Community Hylant

#### ALLY CIRCLE

Duke Energy Hillcroft Services/The Arc in Delaware County Katz Sapper & Miller

#### **FRIEND CIRCLE**

Hopewell Center/The Arc in Madison County Noble/The Arc of Greater Indianapolis Putnam County Comprehensive Services Stone Belt Arc/The Arc in Monroe County The Arc of Vigo County Wabash Center

To learn more, including joining our Circles of Support initiative, contact Jill Vaught, Chief Development Officer, jvaught@arcind.org or 317-977-2375

## Together, We are The Arc

The Arc of Indiana was established in 1956 by parents of children with intellectual and developmental disabilities (I/DD) who joined together to build a better and more accepting world for their children. There are over 30,000 members and 42 chapters in Indiana covering 60 counties, and over 140,000 members in over 600 chapters nationwide.

Twenty chapters provide direct services to people with I/DD and their families across the age spectrum. Twenty-two chapters provide information, resources, activities and more to their I/DD community. Chapters across the state support the efforts of Self-Advocates of Indiana through local SAI chapters.Chapter leaders and volunteers strive every day to advocate for the rights of people with I/DD in their community and through The Arc's

public policy efforts they advocate for positive change in public policy and public attitudes at the local, state and national level.

Just some of the advocacy efforts of local chapters of The Arc include:

For many years, volunteers at **The Arc of LaGrange County** have joined families in special education case conference committees to ensure the rights for their children to receive a "free and appropriate" education.

**The Arc of Bartholomew County** has built a strong partnership with the Columbus Autism Network and Down Syndrome Support Group. Their combined efforts help individuals with I/DD and their families throughout the county.

The Arc of Jackson County and Bi-County Services, The Arc in Adams and Wells Counties, advocated to bring accessible playground equipment and a fully accessible playground for all in the community to enjoy.

The guardianship program of **Achieva, The Arc in Wayne County**, helps ensure people with I/DD have strong guardians. Through their program, Jamie Beck became the first person with I/DD in Indiana to have guardianship removed and replaced with a Supported Decision Making agreement. This led to the enactment of Indiana's landmark law in 2019 that recognizes Supported Decision Making Agreements as an alternative to guardianship and requires Less Restrictive Alternatives (LRAs), including Supported Decision Making, to be considered before the court will appoint a guardian.



Photos Clockwise: ADEC prior to mask requirements, Easterseals Arc of Northeast Indiana's Mini Dreamers program, The Arc team traveled statewide to thank chapters for their hard work, DPS were in the first wave to receive the vaccine, Stone Belt Arc's campaign to increase DSP wages.

In 2016, **The Arc of Shelby County**, led by Don Collins, President of The Arc of Indiana from 1976 to 1978, and his daughter, Holly Forville, developed the unique Senses Gym, designed especially for sensory recreation, but enjoyed by children of all abilities. In 2017, Senses Gym began a partnership with Shelbyville Central Schools to move to a larger space and utilize the gym for children receiving special education preschool services.

**Stone Belt Arc**, The Arc in Monroe County, hosts Advocacy Luncheons throughout the year to share information on important legislative and public policy issues affecting people with disabilities and how families, people with I/DD and community partners can advocate for them.

Sometimes quietly, always determinedly, the advocacy efforts of chapters of The Arc throughout Indiana have made and continue to make a difference

in their communities. They always welcome new members and volunteers to join in making "a better world" for people with I/DD and their families. Find chapters in your area at: *arcind. org/about-the-arc/local-chapters* 



## EGTI Program Leads to Independence, Self-Advocacy

The unemployment rate for people with disabilities is 83%. Of the 17% who are employed, only 4% live above the poverty level. To address this issue, The Arc of Indiana Foundation was created to provide postsecondary vocational training for people with disabilities that empower and lead to meaningful employment. To achieve this mission, in 2016 the foundation opened Erskine Green Training Institute (EGTI), the first of its kind postsecondary vocational training program in the country, housed within the Courtyard Muncie at Horizon Convention Center.

EGTI's program focuses not only on job skills, but also "soft skills," including appropriate workplace etiquette, teamwork, taking direction, effective communication, increasing personal independence and learning how to be a selfadvocate.

A recent success story demonstrates how EGTI's mission has lead to personal growth for a recent graduate.

In January 2020, Damarius began his 13 week Kitchen Cook training program at EGTI. With two weeks until graduation, his program abruptly ended due to the COVID-19 pandemic. Damarius returned to his hometown of Kokomo where he completed his training virtually and began job searching. Although searching for a job in the middle of the pandemic presented challenges, Damarius secured a cooking position at a local restaurant.

As he applied the skills he learned at EGTI to his new position, Damarius began considering



Damarius graduated from EGTI's kitchen cook program and is now enrolled in Ivy Tech's culinary program.



how to further enhance his skills to become a chef. He was aware of Ivy Tech's culinary program, and he and his parents explored this option. After gathering information, and with the support of his parents, Damarius made the decision to move to Muncie to enroll in Ivy Tech's culinary program. He felt confident in moving from home for the first time to Muncie due to the training he received at EGTI in navigating the city using the Muncie Indiana Transit System (MITS).

In January 2021, Damarius moved into his first apartment and began his courses at Ivy Tech. EGTI not only increased his skill set but also his confidence and ability to advocate to achieve his dreams.

Learn more about EGTI at *egti.org* or call us at 317-977-2375 or 800-382-9100.



The Arc News in Indiana

# Spotlight on The Arc Master Trust's Beneficiary Advocacy

An important goal of The Arc Master Trust is to ensure trust beneficiaries are able to easily access their trust for purchases and certain expenses. Often "key people" for the beneficiary make those requests. When beneficiaries do not have a key person and have trouble making requests, the trust has a trust beneficiary advocate who can assist.

In May of 2012, The Arc of Indiana Master Trust opened a Trust II account, with an initial deposit of \$500, for a beneficiary we will refer to as Linda. Neither Linda nor her key people made any disbursement requests for a few months; however, Linda made periodic deposits so the balance of her trust grew.

Linda lives on her own, but has staff come who provide assistance for part of the day and overnight. In 2019 Linda and a staff member who served as a key person for Linda contacted us about using her trust for some events Linda wanted to attend. A trust account manager worked with the staff person to purchase the tickets for the events exactly how Linda wanted. Unfortunately, there were problems with those purchases getting to Linda, and it eventually came to light that the staff person



Trent Barnes, Trust Beneficary Advocate

did not have Linda's best interests in mind.

The decision was made by The Arc Trust to remove agency staff people as key people on Linda's trust, and communicate directly with Linda on any disbursement requests she wanted to make from her account.

It is difficult for Linda to speak with her account manager by phone, so since 2019 The Arc Trust's beneficiary advocate, Trent Barnes, has been visiting with Linda a few times a month to make sure she has what she wants and needs from her trust.

Over the last couple of years her trust has been used to purchase a new bed including mattress and frame, prescriptions that were not covered by her medical insurance, cable and internet service, a new computer, and, finally, yes, she has enjoyed attending several events.

#### The Arc Master 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.

Trust I, established in 1988, helps families provide for the financial future of their loved one without affecting eligibility for government benefits.

Trust II, established in 1995, allows people with disabilities to save their own money in a trust while maintaining eligibility for government benefits.

To learn more about The Arc Master Trust, visit *thearctrust.org* or call us at 317-977-2375 or 800-382-9100.

## Insurance Advocacy Resource Center

A unique program of The Arc of Indiana is The Arc Insurance Advocacy Resource Center (INARC).

INARC works to assist families who have a loved one with a disability navigate their public and/or private insurance policies and increase knowledge of health insurance options, including the Health Insurance Marketplace.

Michele Trivedi, INARC Manager, Master of Health Services Administration, is a longtime autism insurance advocate and mother of a daughter with autism. She works to help families and individuals throughout the state with complicated health insurance issues and concerns.

### INARC has its roots in The Arc of Indiana's 2001 campaign to pass the nation's first comprehensive autism treatment coverage law.

INARC has its roots in The Arc of Indiana's 2001 campaign to pass the nation's first comprehensive autism treatment coverage

law, which led to the requirement that health insurance cover ABA therapy. Even with the protection of the new law, it required three years of appeals and administrative court hearings for Michele to receive payment for ABA therapy claims. Through INARC, Michele continues to guide families through the process of gaining coverage for autism treatment.

#### Managed Care

Aged, blind and disabled expenditures are a large driver of overall Medicaid costs in Indiana. To help control costs, Indiana has already begun, and is now taking additional steps, to move the state's Medicaid program to a Managed Care system.



The Aged and Disabled Waiver has already been moved to managed care. The focus now is to implement Managed Care for those 65 and older residing in nursing facilities. Indiana has just over 1400 people with intellectual and developmental disabilities (I/DD) living in nursing facilities, half of whom are over the age of 65. It seems clear that the next step will be to implement Managed Care for people with I/DD receiving Medicaid Waiver services.

People with I/DD have faced significant barriers accessing health care, and historically, Managed Care Entities have typically not covered many needed services for people with I/DD. The Arc of Indiana will strive to work

> collaboratively with the Family and Social Services Administration and Managed Care Entities on this issue and will strongly advocate that people with I/DD have access to the services and care coordination that they need.

INARC assists families in obtaining insurance coverage for ABA therapy, including this program at Little Star.

## We Need You! **Campaign to Increase DSP Wages**

Nearly 18,000 Direct Support Professionals in Indiana provide critical supports to people with intellectual and developmental disabilities (I/DD). Reimbursement rates have not allowed providers to pay DSPs a competitive, livable wage for many years, leading to widespread, ongoing problems in recruiting and retaining quality staff.

Our major campaign for the 2021 session of the Indiana General Assembly is to increase DSP wages. Thanks to the advocacy efforts of The Arc of Indiana, local chapters of The Arc, families, DSPs, and people with disabilities, a wage increase to \$13/hour was included in HB 1001, the state budget bill, passed by the House of Representatives. This was a great victory, but the job is not done. We must all continue to advocate for a wage increase to \$15/hour before the



General Assembly adjourns at the end of April.

Our biggest barrier in the campaign to increase DSP wages to \$15/hour is that legislators do not know what a DSP is or what they actually do.

We need your help in sharing what DSPs do and why they need a wage increase! We need to make sure that by the end of this session DSPs are a household name with legislators.

Our biggest barrier in the campaign to increase DSP wages is that legislators do not know what a DSP is or what they actually do.

Contact your legislators and share what you do as a DSP, how a DPS helps you or your family, and why they need a wage increase to \$15/hour. Share how having or not having a DSP impacts your life and why they deserve a pay increase. If you're a DSP, share what you

do for your clients, what your job means to you, and what hardships the job brings to you due to wage rates.

The combined advocacy efforts of leaders at The Arc, families,



DANIE'L MIZE Help me access the supports I need for everyday living The Are

> people with disabilities, providers and other advocates has shaped public policy and funding for programs and services since our founding in 1956. We need you to join in or continue in this

> > important campaign to increase DSP wages. Find links for more

complete information, sign up for Action Alerts and Legislative Updates, and find your legislators at arcind.org/ our-programs/publicpolicy-advocacy.



Sign up for our E-Newsletter, Action Alerts, and Legislative Updates at arcind.org/get-involved arcind.org • egti.org • thearctrust.org • saind.org



The focus of camp EGTI is to improve social and work skills to assist with the transition from school to adulthood. Learn more by visiting *egti.org* and

clicking on the "Program" tab. Contact EGTI at 765-381-8071 or info@eqti.org