

The Arc News in Indiana



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2023 Public Policy Agenda

The 2023 session of the Indiana General Assembly begins January 9th and must end by April 29th. The state's biennial budget will be developed in this session. As always, we will be advocating for funding and legislation that will have a positive impact on the lives of people with intellectual and developmental disabilities and their families across all ages and stages of life.

First Steps/Early Intervention

Monitor and support legislation increasing the state's investment in the First Steps program and the elimination of the costparticipation sliding scale.

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Education

Establish legislation redefining Indiana's special education categories regarding funding.

Support legislation providing families of children receiving special education services with more protections and rights.

Require schools to inform families of alternatives to guardianship when they discuss seeking guardianships for their students.

Monitor legislation updating access to services through the Education Scholarship Accounts program.

Employment

Support workforce legislation that could lead to increased employment opportunities for people with disabilities, including reducing barriers such as a "benefit cliff."

Home and Community-Based Services

Monitor and support legislation that protects and increases Medicaid home and community-based services and direct support professional rates due to inflation.

Monitor and support funding to increase rates for home and community-based case management services.

Establish new criteria for the Community Integration and Habilitation (CIH) Waiver as well as a Special Service Review Team to review application denials for the CIH Waiver.

Establish a direct support professional training curriculum, certification and a registry.

Establish an incident report appeals process for direct support professionals reported on the registry.

Monitor the construction of an outreach plan for Structured Family Caregiving.

Therapies

Monitor and support legislation to provide funding to increase rates of important therapy services, including physical, occupational, ABA, music, art, developmental and dance therapies.

Support licensure of music, developmental, art and dance therapies.

Public Health

Monitor legislation increasing the state's investment in the public health of Hoosiers.

Medicaid & Managed Care

Monitor legislation regarding the make-up of the Medicaid Advisory Committee.

Monitor actions taken to move Long Term Services and Supports into risk-based managed care.

Monitor the creation of a Medicaid Ombudsman for long-term care services for risk-based managed care.

Monitor FSSA's prioritization of self-direct care in the development and implementation of risk-based managed care.

Other Funding Issues

Monitor the state's utilization of American Rescue Plan dollars for services for people with intellectual and developmental disabilities.

Monitor funding efforts for Indiana's 9-8-8 Crisis Line.

Your Voice Matters

The Arc of Indiana works to inspire positive change in public policy and public attitudes. We have a full time presence at the Indiana Statehouse, and, as an affiliate of The Arc of the United States, in the halls of Congress. But, we also need you!

Whether you are a parent, sister, brother, grandparent, friend or a person with a disability – YOU can make a difference by

joining The Arc's public policy advocacy efforts.



Scan the QR code or visit arcind.org/get-involved/sign-up to sign up for our e-newsletter, public policy updates and action alerts

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Message from Self-Advocates of Indiana

Nicki Hinkle, President





Self-Advocates of Indiana's first annual picnic since 2019 was a huge success!

We had beautiful weather and over 430 attendees. Indiana Disability Rights staffed a table where they provided pro-bono lawyers who were able to speak with and assist over 30 self-advocates in gaining a health care representative or advanced directive. We also registered over 15 people to vote or helped them check their voter registration status

The first week of November, board member Megan Burger attended the NACDD Annual Conference in Washington, D.C. to learn about State Developmental Disability Councils' initiatives. Megan also was able to hear presentations about home and community based services, efforts to increase the number of people with disabilities in competitive integrated employment, and a session on diversity, equity, and inclusion.

Past president Shawn Fulton and I attended The Arc National Convention in November. We were able to participate in the National Council of Self-Advocates Symposium. Other sessions we attended included sessions on employment, peer mentoring programs, honoring disability by reframing language, and supporting self-advocates in leadership roles. It was great to see the example of other self-advocates and learn from the experience of everyone in attendance.

The first week of December, past president Shawn Fulton traveled to Phoenix, Arizona to attend the TASH Annual Conference. While there, Shawn gave a presentation on increasing community employment for individuals transitioning out of sheltered workshops.

This past quarter, SAI, in partnership with Indiana Disability Rights, provided four in person Voter Empowerment Trainings. Goals of the trainings included teaching self-advocates how to prepare to vote, learning about voting rights and how to advocate for them, and learning how to find information about who is on their ballot. These trainings also assisted self-advocates in registering to vote

SAI held our board of director's elections on November 30th. We are thrilled to welcome the following new board members: Claire VanWassenhove (At-Large), Lexi Westerfield (At-Large), Lizzy Drew (West-Central), LeAnn Dusenbery (West-Central), Danie'l Mize (South), and Noah Upchurch (Vice President).

We are so excited to see what 2023 will hold for Self-Advocates of Indiana!

Spotlight on Lizzy Drew

Elizabeth (Lizzy) Drew was recently elected to represent Self-Advocates of Indiana's West Central Region on the SAI board of directors. She is also the recipient of the 2022 Darcus Nims Self-Advocate of the Year award. Named in memory of the founder of SAI, the award recognizes an individual with an intellectual or developmental disability for their outstanding contribution to their community.

Lizzy began participating in The Arc of Greater Boone County's Main Street Enterprises and art programs in 2016. Over the years, she has grown from a shy, reserved young lady to one who is willing to share her story and is a strong self-



Claire VanWassenhove and Lizzy Drew at the 2022 SAI Annual Picnic. Claire and Lizzy serve on the SAI board.

advocate for both herself and others with disabilities.

Lizzy currently serves as president of The Arc of Greater Boone County's Self Advocates of Indiana Chapter and has taken on roles of guiding meetings, establishing and writing agendas and representing the chapter with the board of directors. Lizzy participates in the board meetings and provides meaningful feedback to the board on issues

important to the people they serve and support.

She has also steered her local Aktion Club in their service projects, this year leading a fundraiser for people impacted by the war in Ukraine

Lizzy has written a book detailing her early years, sharing her rough start in life and eventual relationship with her loving, adoptive family after several years in the foster care system. She hopes that sharing her story will provide hope for others in similar situations.

Recently, Lizzy began discussing ending her guardianship with her parents, explaining how supported decision making could work as an alternative. She has also discussed her interest in pursuing community work. A step towards this goal began when she started working at The Arc of Greater Boone County's front desk.



Message from The Arc of Indiana CEO

Oh, it is that time when the new year has just begun and we are supposed to look back at the past year and reflect on all the positives that happened and then look toward the year ahead with optimism ... I am having trouble with that this year.

Certainly, when I reflect on 2022, I think about many positive things that happened for The Arc of Indiana and find things to be thankful for regarding services and supports for people with intellectual and developmental disabilities (IDD) and their families ... but I am also frustrated.

COVID stopped several good plans to improve services in their tracks and it is taking too long to get things back on track. People were frustrated and tired before 2020 and I feel like all we have said the last few years is, "WAIT...It will be better soon." Meanwhile, the workforce crisis continues and people still struggle to find qualified and reliable direct support professionals.

Leaders at the Indiana Family and Social Services Administration (FSSA) are also frustrated. The FSSA team, especially within the Division of Disability and Rehabilitation Services, is made up of good, smart people who continue to work there because they genuinely want to make Indiana's Home and Community Based Services (HCBS) system one that truly supports people with IDD in living their best life. The issue is that state government never works fast unless in crisis mode and many act as if the COVID crisis is over. Unfortunately, COVID lives on and continues to take a toll on the system that people with IDD and their families rely on each and every day for services and supports.

Most of all, I hear families frustration in trying to make sense of the HCBS "system" that has developed over many years that, for many, does not serve them well. They have every right to be frustrated. The truth is, there is not always a logical path to follow in how the system got to where it is today. We want to put our energy into finding the best path forward. We pledge to continue to seek ways to target our collective frustration toward developing and achieving shared solutions.

One action we are taking is to advocate, once again, for funding in the state's biennial budget to increase Medicaid rates. Thanks to collective advocacy and action, the legislature acted just as we requested in 2021 and invested heavily to raise Medicaid rates to provide an increase in DSP's average wages. That happened just months before the statewide workforce crisis came to a head and we saw increases in wages across all industries, putting DSP wages behind once again. To better level the playing field, we need a collective renewed effort to increase Medicaid rates to help Medicaid services survive over the next two fiscal years.

Throughout the 2023 legislative session, we need families and people with IDD to share their concerns with their elected officials. Tell your story, your lived experience about what is working and not working in Indiana's service system. The state has many opportunities in 2023 regarding the use of millions of dollars from the American Rescue Plan. At a time when the state is enjoying a huge surplus and has a one-time opportunity to invest American Rescue Plan funds, let's work together to stabilize services that are already in place and use our combined efforts to turn the state from crisis towards a strong and stable HCBS system that works for all.

Leadership Honors

The Arc of Indiana's leaders were honored at The Arc of the United States National Convention in November. CEO Kim Dodson received the Chair's Leadership Award and COO Andy



Kirby was recognized as a Rising Star. Leslie Green. former CEO of Stone Belt Arc was recognized for her 43 years of service in the disability industry. We have great leaders throughout Indiana and it's wonderful to see them recognized for their work at the national level.



New officers and directors were elected at our annual meeting in November. Pictured are Dick Rhoad, treasurer; Cody Mullen, past president, Arvie Anderson, president and William Hawkins, vice president. Find all of our board members at: arcind.org/about-the-arc/board-of-directors. We greatly appreciate their time, dedication, and commitment to The Arc.

Supreme Court Ruling Could Strip Disability Rights

Federal courts have for decades said recipients of Medicaid and other safety-net programs have the right to sue if they believe states are unlawfully withholding benefits. But now, a U.S. Supreme Court case rooted right here in Indiana could unravel that right. In November, the court heard oral arguments on Health and Hospital Corporation (HHC) v. Talevski, concerning alleged mistreatment and abuse of Gorgi Talevski at one of HHC's 78 nursing homes in Indiana. The Arc of the United States filed an amicus brief urging the court to rule against HHC.

The case started when the family of Gorgi Talevski sued a nursing home in Valparaiso owned by HHC over allegations of improper care. The family claimed that their father was overmedicated to keep him asleep, his dementia wasn't properly managed, and he was involuntarily transferred to different facilities hours away from the family's home, which accelerated his decline and death.

A federal judge in the U.S. District Court for the Northern District of Indiana ruled against Talevski's family, saying their lawsuit wasn't allowed by federal law. The Seventh Circuit Court of Appeals reversed that decision and allowed Talevski's suit to go forward. That ruling prompted HHC to take the case to the Supreme Court.

HHC not only asked the U.S. Supreme Court to reconsider the ruling in their case against a former resident, they went further to attempt to make sure that no one can challenge a civil rights violation by providers of safety net programs.

The implications of this case are far reaching. Safety net programs, including Medicaid, the Supplemental Nutrition Assistance Program (SNAP), the Children's Health Insurance Program (CHIP) and Temporary Assistance to Needy Families (TANF), have been a lifeline for millions of people, especially people with disabilities. A negative ruling will leave them without any legal recourse if they face mistreatment or abuse or their benefits are taken away or denied.

At their monthly board meeting in October, advocates, including The Arc of Indiana pleaded with the HHC board to withdraw the case. We also joined in multiple "Calls to Action" asking for public outreach to board members imploring them to withdraw in the interest of vulnerable citizens. No action was taken by the board and the case proceeded to be heard.

As the operator of the Marion County Health Department, Eskenazi Hospital and 78 skilled nursing facilities across the state the HHC board is a health powerhouse. The board's refusal to take action or make any statement regarding their reason to move forward with a case that will harm citizens across the country leaves us with no confidence in the board being willing to represent Hoosiers they were appointed to serve.

HHC is facing a new lawsuit over how it handled the Supreme Court petition. Morgan Daly, public policy director at the Indiana Statewide Independent Living Council, has sued the agency and its board members in Marion County court. The suit claims HHC violated Indiana's Open Door Law by going to the Supreme Court without having the board first participate in a public-facing vote on the petition.

As we await the ruling, The Arc of Indiana has now called on Indianapolis Mayor Joe Hogsett, the Indianapolis City-County Council and the Marion County Commissioners to remove their HHC board appointments and appoint people that care about vulnerable Hoosiers with disabilities and the services they receive.

Real Life Impact

A negative ruling by the Supreme Court in the HHC case will leave vulnerable citizens without legal recourse if they face mistreatment or abuse or their benefits are taken away or denied. The following stories exemplify people who would have suffered if they had not been able to sue to receive critical services and care.



Families and individuals across the country who rely on Medicaid Waivers to provide home and community-based care will be harmed if the Marion County Health and Hospital Corporation succeeds in its Supreme Court case. Edna Chadwell, a 61-year-old, who has cerebral palsy and depends on a wheelchair, is able to live independently with Medicaid supports. According to an IndyStar report, that almost ended in 2008 when she learned the Indiana Family and Social Services Administration was planning on cutting her Medicaidfunded care nearly

in half. Chadwell sued the state, claiming the administration violated federal Medicaid law by declining to cover the medically-necessary services that allowed her to live in the community. In 2010, a Clay County judge agreed with Chadwell. The decision kept her from being confined to a nursing home and allowed her to continue to live independently with vital supports.

In another case reported on by the IndyStar, state Medicaid officials refused to pay for maintenance therapy services for severely disabled children. One of those children, a 9-year-old boy, could not walk, but he could roll and stretch his legs. Without therapy services the state was denying, he would lose even those abilities. The boy's mother and the parents of two other children filed a class action lawsuit. A judge ruled in their favor, forcing the state to cover the necessary therapy costs.

In a Florida case, a father sued the state's Medicaid program after it refused to pay for diapers for his 16-year-old daughter who had cerebral palsy. A federal judge ruled in favor of the child, forcing Florida to begin covering the cost of medicallynecessary diapers.



Medicaid, SSI and other government benefits allow people with disabilities to live independent lives. The Arc opposes Marion County Health and Hospital Corporation's effort to end the right for people to sue if benefits are denied or improper care results in harm.

The Arc's Disability Policy Priorities Included in Federal Appropriations Bill

On December 23, the U.S. House and Senate passed a \$1.7 trillion federal spending bill. The Arc of the United States has compiled a summary of important provisions included in the funding package.

HCBS and Community Living:

- Extends the Medicaid Money Follows the Person program (MFP)
 through 2027. MFP enables state Medicaid programs to transition
 people out of institutions and into the community. The Arc of
 Indiana has worked on this issue for several years.
- Extends the requirement that states apply Medicaid's spousal impoverishment protections to Home and Community Based Services (HCBS) through 2027.

Medicaid and other Health Care Priorities:

- Requires states to provide children with 12 months of continuous eligibility when they enroll in Medicaid or the Children's Health Insurance Program (CHIP). This will help children continue health coverage even when there are changes in the family's income.
- Extends the authorization of the CHIP program and funding until 2029.
- Permanently extends the option states have to provide 12 months of Medicaid postpartum coverage but does not require states to provide this critical coverage. Indiana Medicaid provides this coverage.

Financial Security and Social Security:

- Expands ABLE account eligibility by increasing the age of disability onset to access an ABLE account from prior to age 26 to age 46, effective in 2026.
- Makes a technical change to the tax code that makes it easier to allow a charity to be a remainder beneficiary of a special needs trust that inherits a retirement account.
- Expands funding for the Social Security Administration by 6%, the largest increase in more than a decade.

Judge Rotenberg Center and Electrical Stimulation Device:

 While the bill does not specifically ban the torturous device used by the Judge Rotenberg Center, it does create a pathway for the FDA to issue a new ban on the device and have the ban upheld in court.

Education and Child Care:

- Increases IDEA funding, including a 21% increase for Personnel Prep, which can help address the special educator shortage.
- Increases the funding for numerous child care and early learning programs, including a 30% increase for the Child Care Development Block Grant.

Housing:

- Provides 8.1 billion in additional funding for Housing and Urban
 Development's public housing programs for a total of \$61.8 billion.
- Funds the Section 811 program, which is specifically for people with disabilities, with an additional \$360 million through September 30, 2026. This includes up to \$148 million for new project rental assistance [PRA] and capital advance awards. This report language specially mentions housing needs for people with IDD.

Food Insecurity:

- Includes \$154 billion for the Supplemental Nutrition Assistance Program, an increase of \$13.4 billion.
- Includes \$28.544 billion for Child Nutrition Programs, including \$40 million for the Summer Electronic Benefit Program to provide grocery benefits to the nation's low-income families with schoolage children when schools are closed for the summer. However, this is paid for by creating an earlier end date for temporary emergency SNAP benefits that still exists in some states.

Things To Be Aware Of:

- SSI Asset Limits: The bill does not include the bipartisan SSI asset limit increase that The Arc advocated for. The Arc will continue to advocate for this legislation in the 118th Congress.
- Public Health Emergency and Medicaid Coverage: During the
 Public Health Emergency, states have been prohibited from
 removing anyone from Medicaid programs due to an increase in
 income or change in "categorical eligibility" (e.g., pregnancy, age,
 disability) that would ordinarily make them ineligible for Medicaid.
 Beginning April 1, states, including Indiana, will have 12 months to
 evaluate who still qualifies for Medicaid.

What to know about the triple threat of COVID, influenza, and RSV

We are approaching the third year of the COVID-19 pandemic. While vaccines and new treatments have allowed a return to a more normal life, it is important to continue to take precautions and stay up to date with vaccines. In addition, multiple respiratory viruses are co-circulating in the United States, including COVID, influenza and respiratory syncytial virus (RSV). Taking precautions and having vaccines up to date can help ward of sickness and the spread of the viruses.

COVID

The CDC recommends everyone stay up to date with COVID-19 vaccines. Updated boosters are now available for adults and children aged 6 months and older. To find COVID-19 vaccine locations, visit vaccines.gov, text your ZIP code to 438829, or call 800-232-0233.

Influenza

The CDC recommends that everyone 6 months and older get a flu vaccine to help protect against flu and its potentially severe complications. If you test positive for the flu, receiving an antiviral may help reduce the severity and length of symptoms. It is most effective if given up to 48 hours after the illness begins.

RSV

Pediatric hospitals are experiencing a rise in the number of patients admitted with RSV. Health care providers should consider RSV in patients with respiratory illness, particularly children under 5 years and adults 65 years and older. Wheezing is more common in children with RSV. A fever over 103 may be more common for influenza infections.

ERSKINE◆ **GREEN**

Training Institute

Contact Us

765.381.8071 | 877.216.2479 egti.org Erskine Green Training Institute (EGTI), founded by The Arc of Indiana Foundation, is the first of its kind postsecondary vocational training program in the country. Opened in 2016, EGTI provides training in hospitality, food service, healthcare, and inventory distribution.

Housed within the Courtyard by Marriott in Muncie, Indiana, the program provides a personalized training experience in 12 career areas. During 10 – 13 week training sessions, students attend class, master key job skills, and gain valuable work experience through an internship.

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







Hotel Programs

- ➤ Front Desk Agent
- ➤ Heart of the House
- ➤ Laundry Attendant
- ➤ Houseman/Hotel Cleaning & Meeting Room Set Up
- ➤ Room Attendant/Guest Room Cleaning

Food Service Programs

- ➤ Host
- ➤ Server Assistant
- ➤ Kitchen Cook
- ➤ Dishwasher

Lacy Family Healthcare Programs

- Nutrition Services/ Dish Room & Tray Transport
- ➤ Environmental Services/ Housekeeping
- ➤ Patient Transport
- ➤ Inventory Distribution

Erskine Green Training Institute 2022 Success

- ★ 444 people attended onsite presentations & tours
- ★ 223 people attended offsite presentations
- ★ 57 prospective students attend Career Sampling Sessions
- ★ 34 graduates, bringing 7 year graduation total to 277
- ★ 78% of graduates employed 8 months after graduation
- ★ 78% employed 18 months after graduation







2023 Training Sessions

Training Session One January 9 - April 7

Applications Closed

- Front Desk Agent
- Heart of the House
- Kitchen Cook
- **Patient Transport**

Training Session Two April 17 - June 23 Applications Close

Nutrition Services

- **Inventory Distribution**
- **Environmental Services**

January 20

- Server Assistant
- Dishwasher

Training Session Three July 17 - October 23

Applications Close April 21

- Front Desk Agent
- Heart of the House
- Kitchen Cook
- Patient Transporter

Training Session Four October 16 - December 22

Applications Close July 21

- · Nutrition Services
- **Inventory Distribution**
- **Environmental Services**
- Server Assistant
- Dishwasher



EGTI's training program provides learning beyond employment training, including learning how to safely navigate in the community and learning how how to independently access public transportation.



Connecting EGTI students to mentors, typically Ball State students, is an important component of EGTI's program. Fitness mentors participate with students in activities that they choose, including biking, running, lifting, walking, swimming or attending aerobics

Community mentors are responsible for providing social guidance by supporting students in community activities, including attending sporting events, concerts, movies and shopping.



Join us in this annual event benefiting **Erskine Green Training Institute** as we celebrate the employment dreams of EGTI students realized in the past year & honor those who help make those dreams come true.

We will also have some Mardi Gras fun, a silent auction, 50/50 raffle & more all in support of EGTI students.

To learn more and register, scan the QR Code or visit erskinegreeninstitute.org/about-us/news/events/





> The Arc of Indiana and Self-Advocates of Indiana congratulates our 2022 Impact Award recipients, who were honored on November 30 during our virtual conference. It was wonderful to celebrate good people doing good things to make a difference in the lives of people

2022 Impact Awards Celebration

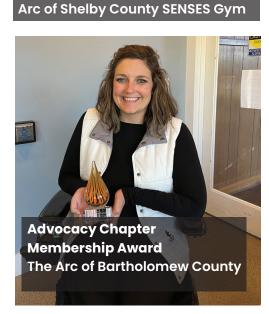
Self-Advocates of Indiana

Lt. Governor Suzanne Crouch

President's Award

Family Advocate Award Carol-Anne & Don Hossler | Stone Belt Arc







with intellectual and developmental disabilities and their families.



The Arc of Indiana, The Arc Master Trust, and Erskine Green Training Institute staff were honored to receive The Arc of Indiana President's award from outgoing president Cody Mullen.







Make a difference in the lives of people with intellectual and developmental disabilities and their families across Indiana through your gift.



Simply scan the QR code or visit arcind.org/get-involved/donate to give a gift online.

Your support, no matter the amount, makes an impact on so many people.



The Arc Indiana

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