



**The Arc**

*For people with intellectual  
and developmental disabilities*



The Arc of Indiana  
2024 Public Policy Agenda

## We Are The Arc



The Arc of Indiana was established in 1956 by parents of children with intellectual and developmental disabilities (IDD) who joined together to build a better and more accepting world for their children.

With over 35,000 members and 45 chapters covering 70 counties in Indiana, and 140,000 members in nearly 600 chapters nationwide, The Arc is on the front lines to:

- Empower families with information and resources to assist them in their journey of raising a child with a disability to lead a full and meaningful life.
- Empower people with IDD to be self sufficient and independent to the greatest extent possible.
- Inspire positive change in public policy and public attitudes.
- Prevent disabilities through education about the dangers of drugs and alcohol while pregnant and advocating for all women to have quality prenatal care.
- Serve as a spokesperson and advocate for families and their loved ones.



The combined strength of The Arc at the local, state and national level make The Arc the largest national community-based organization advocating for and serving people with IDD and their families.

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## *Insurance/Medicaid*

### **Legislative Priority:**

**Support legislation regarding Applied Behavior Analysis (ABA) therapy.**

The Arc of Indiana strongly believes that people with IDD must have access to quality services and supports and much of those are provided through insurance and Medicaid.

We will work with the Office of Medicaid Policy and Planning as well as the medical community to make sure people with IDD have broad access to primary care physicians, mental health providers, dentists and other medical specialists in their local communities. The Arc of Indiana will work closely with the Office of First Steps, self-advocates and the health care community to ensure the availability of wellness programs, preventative and habilitative care.

Health insurance and health benefit mandates were designed to provide individuals with the medical care they need to live in our community. However, insurance companies and health plans have been falling short in meeting those needs.



In this economic climate, it is imperative insurance companies and health plans meet their financial obligations regarding health care instead of passing those costs onto already overwhelmed state (Medicaid and First Steps) and school programs. We will continue helping families as they maneuver through the red tape of private health insurance and will hold insurance companies accountable for not following state and federal laws that require non-discrimination in benefit design and delivery of health care to people with disabilities.

## *Insurance/Medicaid (continued)*



Currently, a lot of conversation is taking place around ABA therapy. We will closely monitor the implementation of a new rate and methodology within Medicaid to ensure this important support remains available to people with IDD. ABA therapy is a medical treatment to improve social, cognitive and behavioral outcomes in people with IDD, including Autism, and is the preferred treatment for children with Autism, according to the US Surgeon General and the American Academy of Pediatrics.



We appreciate the work the Office of Medicaid Policy and Planning has done to bring stability to the ABA market to ensure that families can continue to receive coverage through Medicaid. The Arc of Indiana supports efforts to set a meaningful rate for reimbursement.



We also believe oversight is needed of the independent centers that provide ABA services. These centers provide important care to people with IDD and we need to ensure they are utilizing best practices in a safe and healthy environment.

### Education

#### **Legislative Priority:**

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

**Update Indiana's Seclusion and Restraint law.**

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



The Arc will work to ensure all students have access to the appropriate education that allows them to have opportunities for both careers and post-secondary options after high school. We strongly believe in the concept of inclusion, meaning all students deserve the opportunity to learn alongside their peers in the school or environment of their choice and should be provided the appropriate instruction, supports and accommodations to meet their academic goals.

The Arc believes effective planning is critical for students' successful transition from school to work in adult life. The mandated transition IEP should focus on the development of employment skills and the connection to Vocational Rehabilitation Services while the student is still in high school. The Arc will remain committed to making sure everyone who can earn a high school diploma has an opportunity to do so. We know that a diploma provides a pathway to a job and a career, and we need to continue to develop pathways to make that a reality for students who receive special education services.

### *Education (Continued)*

In 2021, the General Assembly established Education Scholarship Accounts for students receiving special education services. We want to make sure the program is utilized appropriately and students and families have good guidance and that schools still provide special education services.

The United State's Department of Education continues to monitor and work toward the elimination of seclusion and restraint in our schools. Seclusion and restraint is being used as disciplinary tools and there is large concern about incidents going unreported or inaccurately reported. This past summer, The Arc of Indiana received an outpouring of communication from families concerned with the utilization of “timeouts” by schools to get around the reporting requirements of seclusion. We need to make sure Indiana is up-to-date on reporting methods and ensuring that student and staff safety isn't at risk.



### *Career Pathways*

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

A key mission of The Arc of Indiana is supporting and promoting real choice in the employment and career paths that people with IDD choose. We support career pathways that range from volunteer opportunities, part-time work or full-time employment. People with IDD should be able to focus on doing a good job without the fear of losing important government benefits.

With Indiana's overall unemployment rate estimated at 3%, now is the time for us to educate Indiana employers about how it is simply good business to hire people with disabilities. By providing them with information on the benefits of diversifying their workforce, we can strengthen our entire community.

The unemployment rate for people with IDD remains at nearly 80%, according to the U.S. Department of Labor. Hiring people with IDD in competitive community jobs is good for business as they are a proven asset to our workforce. Through our Erskine Green Training Institute, and employment services provided by chapters of The Arc across the state, The Arc will continue to be a leader in creating and supporting local, state and national efforts to increase the employment rate of people with disabilities. In addition, The Arc of Indiana supports efforts to eliminate sub-minimum wage environments and grow job opportunities in communities around our state.



### *Transportation*

The Arc recognizes a major obstacle to the employment of people with IDD is transportation. The Arc supports efforts to increase the availability of mass public transit, which is essential for people with IDD to work, gain independence, attend medical appointments and patronize local businesses. For people with IDD, access to transportation is the beginning of a future filled with opportunities and independence.

Concerns have risen regarding the safety and access of the Non-Emergency Medical Transportation (NEMT) program through the State. The Arc will continue to work with FSSA, stakeholders and transportation providers on the NEMT Work Group to ensure each Hoosier needing this critical transportation service to get to medical appointments is safe, punctual and easy to use.



### *Home and Community Based Services*

#### ***Legislative Priority:***

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

***Establish new priorities for the Community Integration and Habilitation (CIH) waiver as well as a pilot program for a Special Service Review Team to review requests for the CIH Waiver.***

***Monitor any changes made to ABLÉ Accounts and the ABLÉ tax credit.***

The Arc of Indiana remains committed to ensuring people with IDD and their families have access to home and community-based services and are free of threats of institutionalization, including group homes.

We realize changes need to be made to both the CIH and FSW waivers to more align with the needs of people with IDD today. As the state puts forth initiatives to use monies from the American Rescue Plan, we are hopeful that services can be added and/or changed to make our waivers more usable and accessible. The approval rate for the CIH waiver is low and some individuals are going without much needed services and supports. By creating a Special Service Review Team of professionals from the disability field to help the Director of the Division of Disability and Rehabilitative Services approve, deny or find other services for the individual, more individuals will receive the services and supports needed to thrive in their community. The Arc of Indiana will work closely with FSSA to ensure resources are used in the best way to create more opportunities for people with IDD.

The Arc of Indiana is committed to the Life Course Framework, and will work with families and DDRS to ensure Life Course principles are shared and utilized with people with IDD and their families. We also remain committed to helping realize their natural supports that already exist for them in their community.

The Arc of Indiana will support a model of family and community resourcefulness as families cannot depend on government services alone. We must work within local communities to identify natural supports for individuals with IDD. We will work with families and individuals with IDD in making a cultural shift toward using only what you need in order to re-allocate those dollars to others in need.

The Arc of Indiana will also work to ensure funding streams such as, “money follows the person (MFP)” and sufficient funds are provided for initial appropriate placements as well as ongoing services. We will work aggressively with other organizations to eliminate institutional biases that exist within the state’s budget system.

## *HCBS (Continued)*

The Arc of Indiana supports efforts to make sure that only highly qualified people are providing therapy services to people with IDD. Many Hoosiers, beyond Hoosiers with IDD, utilize music, art, dance and developmental therapies to facilitate movement and rehabilitation. As these therapies become more readily available to families and individuals, we need to ensure that the professionals providing these services are licensed and held accountable for their practice. Too many people are providing these services without the necessary education, professional credentials or supervision by qualified personnel, or are using antiquated practices that can harm people with disabilities.

These services are already being provided through First Steps and can be billed through Medicaid and commercial insurance. Not only should lawmakers be ensuring that Hoosiers are being provided the highest quality of service, lawmakers should be ensuring that only qualified people are delivering these important services.

## *Crisis Situations*

### ***Legislative Priority:***

#### ***Monitor efforts for crisis intervention and prevention for the IDD community.***

Despite the efforts of individuals with IDD and their caregivers, sometimes crises occur in which the individuals themselves or others in the community are in danger. According to data collected across the United States by the National Core Indicators project ([nationalcoreindicators.org](http://nationalcoreindicators.org)), about 50% of people with IDD also have a mental illness or psychiatric diagnosis. Unfortunately, it is often extremely difficult for individuals with a co-existing condition and their families to find services and supports that address their specific needs. A large part of the problem is that some mental health providers, including inpatient facilities, refuse services to people with co-existing conditions based solely on the person's diagnosis of an IDD. The lack of access to trained mental and behavioral health providers often results in increasing problems that eventually can escalate into dangerous crises. The outcomes can be very problematic, expensive and difficult to reverse. Those include strained interpersonal relationships, placement to a more restrictive setting, incarceration, as well as difficulty integrating into community settings and events.

The Arc of Indiana supports the mission of the 9-8-8 initiative and the utilization of the Crisis Now Model: someone to talk to; someone to respond; and a place to go.

Work will need to continue to ensure that the ongoing crisis needs of individuals with IDD and their families are met. The new 9-8-8 crisis line is not the solution for the crisis happening in the lives of Hoosiers with IDD. A bridge between expectations created by the 1102 Task Force and goals associated with 9-8-8 is critical to the long-term success of any comprehensive crisis response plan.

In addition, The Arc encourages efforts to develop training for mental health providers, so they feel equipped to treat individuals with intellectual and other developmental disabilities.

### *Criminal Justice Issues*

The Arc recognizes the increased risk for people with IDD to become involved in the criminal justice system as suspects, offenders and victims. The Arc of Indiana values all initiatives that ensure people with IDD receive equal access to justice within the criminal justice system.

To prevent recidivism, individuals need support to ensure a smooth and successful transition back into the community. The Arc of Indiana encourages the Department of Corrections and county jails to connect individuals with IDD with the Bureau of Developmental Disabilities Services and VR programs as part of their transition.



### Managed Care

#### **Legislative Priority:**

**Monitor FSSA's prioritization of self-directed care in the implementation of risk-based managed care.**

As the state transitions individuals over the age of 60 who reside in nursing homes and on the Aged and Disabled Waiver into managed care, we will continue to share that managed care has a different impact on the IDD population than it does on the elderly and physical disability populations. Managed Care Organizations need to meet the needs of ALL individuals they are going to serve.

As we look at other states who have moved to managed care, there is no information on managed care bringing a higher quality of life to the individual and their family. The major outcomes identified have been the fiscal impact it has on the state and the loss of community based, not-for-profit service providers. We believe a successful managed care program engages individuals in a shared savings concept that incentivizes the wise use of resources. Beneficiaries must be engaged in developing healthy lifestyles and understanding the importance of effective use of limited resources, particularly in regard to long-term care.

The Arc of Indiana will closely monitor the implementation of Medicaid managed care programs for people with disabilities who fall within the LTSS initiative. While The Arc understands the state's desire to reduce health care costs, The Arc wants to ensure that cost savings do not come at the expense of needed medical care for individuals with disabilities, including home health care services.



### *Early Intervention, Prevention and Prenatal Education*

The Arc of Indiana will support efforts to address the importance of good prenatal care during pregnancy. Alcohol is known to be the leading preventable cause of intellectual disabilities, and research has implicated smoking in increasing the risk of IDD. We will support efforts to educate the public about the dangers and long-term effects of the use of alcohol, tobacco and controlled substances during pregnancy. Other risks include malnutrition, certain environmental toxins and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphilis. We will support efforts to increase the awareness of fetal alcohol syndrome, shaken baby syndrome, and lead poisoning.

The Arc of Indiana is committed to helping infants and toddlers with IDD and developmental delays receive the early intervention therapies and supports they need to reach critical developmental milestones. With the state's recognition of the opioid crisis in our state, the demand for early intervention services is higher than ever. We will support all efforts for early diagnosis and early intervention services.

The Arc remains committed to ensuring that families have access to the First Steps program and are not inhibited by ability to pay the cost participation fee, insurance or any other factor. We strongly believe the commitment to early intervention services is paramount and must continue to be a priority for our children.



### *Guardianship and Supported Decision Making*

**Legislative Priority:**  
**Support legislation updating statutes to reflect Supported Decision Making.**

Many individuals with IDD are capable of making decisions that determine the course of their lives, even if they need help and support in making those decisions. Guardianship and other services that allow for supported decision making can be very important in ensuring that people with IDD have the supports necessary to remain healthy and safe in the community.

The Arc of Indiana believes that guardianship should be as limited as possible to ensure the safety of individuals with IDD, and we encourage the use of supported decision making as much as possible, even among those who are under guardianship. We will continue to work closely with stakeholders to ensure that quality guardianship programs, at reasonable costs, are available for those individuals who have no family or loved ones to assist them in making important life choices. In addition, The Arc of Indiana wants to ensure that individuals who are paying for the services of a professional guardian are receiving appropriate attention and having their needs met.

It is our philosophy that guardianship and supported decision-making works best when a personal interest in the individual needing services is present and their wishes drive any decisions being made.





### *Self-Advocacy*

The Arc of Indiana believes in a strong self-advocate organization. We will continue to support Self-Advocates of Indiana in their pursuit of achieving equality for people with IDD in employment, transportation, safe, affordable and accessible housing, and in addressing the DSP crisis.

The unemployment rate for people with disabilities in the state of Indiana has been an estimated 80% for nearly a decade. The Arc will continue to partner with self-advocates to increase employment opportunities for people with IDD and educate the community and self-advocates on employment options and resources. Recognizing that individuals with IDD often face roadblocks to successful, long-term employment, The Arc supports and encourages self-advocates to address these roadblocks, learn about their options and available resources, and raise awareness that will lead to more inclusive communities and workplaces.

The Arc of Indiana encourages self-advocates to explore and make the use of their individual gifts and talents a reality, as this builds confidence and can lead to greater independence and self-determination. We will also support an individual's right to direct and implement a vision for their future that leads to a fulfilling life and achieving dreams.

The Arc of Indiana supports services that provide meaningful opportunities for people with IDD to realize self-empowerment, experience lifelong learning, achieve better health, and develop relationships through community inclusion through education, employment, and/or community-based settings.

The Arc will work to promote and ensure the availability of these crucial services that are driven by person-centered approaches, to accomplish these outcomes throughout our state.



# THANK YOU

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