



2020 Public Policy Agenda

Our Guiding Principles

The Arc of Indiana is committed to all people with intellectual and other developmental disabilities, as well as their families, and will work to develop public policy which will assist them in realizing their goals of learning, living, working and playing in the community.

The Arc of Indiana is committed to reducing the incidence of intellectual and other developmental disabilities. We will work to increase public awareness of the importance of strong prenatal care and the dangers created by lead, alcohol and drugs, including tobacco products.

The Arc of Indiana is committed to self-advocates - people with an intellectual or other developmental disability who advocate for themselves - and will work to ensure they receive the respect, support and access to healthcare and wellness programs to which all people are entitled.

The Arc of Indiana is committed to communities and to our local chapters of The Arc and will work to develop programs and public policy that support them in their mission of building communities that welcome the contributions of all people.

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Direct Support Professionals

Legislative Priority:

Seek legislation to create a registry of Indiana’s Direct Support Professionals.

Support efforts to educate legislators about the need for a sustainable system that attracts and maintains the Direct Support Professional workforce.

We recognize the importance of a high-quality workforce of Direct Support Professionals (DSPs). In Indiana alone, over 26,000 DSPs provide supports to individuals with I/DD in areas ranging from personal care to household management to finding and keeping jobs in the community. To do so safely and effectively, the DSP workforce must possess a variety of skills and undergo a significant amount of initial and ongoing training.



The ability to hire, train and retain quality staff is vital to the sustainability of quality services for people with I/DD. High turnover and employee vacancy rates that most providers experience place people with disabilities at risk because they depend on DSPs for a range of critical services. A DSP registry will allow providers an opportunity to ensure they are hiring people who deliver these important services who have not had a history of abuse or neglect.

Insurance

Legislative Priority:

Seek legislation to require health insurance providers to cover habilitative services documented within an Indiana First Steps Plan for infants in need of services.

Seek legislation for a quicker turnaround time for denial of claims from health insurance providers and require FSSA to follow-up on denied claims.

Support legislation requiring licensure for applied behavior analysts.

Support transparency of health care costs.

The Arc of Indiana strongly believes that people with I/DD must have access to quality health insurance and life insurance.

We will work with the Office of Medicaid Policy and Planning as well as the medical community to make sure people with I/DD have access to primary care physicians, mental health providers, 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 insurance 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 to help 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.

The Arc of Indiana supports efforts to make sure that only highly qualified people are providing applied behavior analysis therapy services to people with I/DD, in addition to traumatic brain injury, and other medical conditions that fall within the scope of practice for board certified behavior analysts and board certified associate behavior analysts. As this systemic application of behavior principles becomes more available to families, we need to ensure that the professionals providing the service 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.

Education

Legislative Priority:

Seek legislation requesting the Department of Education to gather information on graduates who have left high school with a certificate of completion since 2000 and provide a report to the State Advisory Council on the Education of Children with Disabilities and to the Interim Study Committee on Education.

Work to ensure that the assessment replacement for ISTEP(ILEARN) includes opportunities for students receiving special education services to have access to a test that allows them to demonstrate academic progress with the appropriate accommodations and resources, including comprehension, as determined by the case conference committee.

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 of their choice and should be provided the appropriate instruction, supports and accommodations to meet their academic goals.



The Arc of Indiana will work to ensure the recently implemented assessment test, ILEARN, offers the same accommodations students are allowed to use in the classroom throughout the year to demonstrate their academic knowledge. Our concerns regard the current accommodation of closed captioning and beginning to include a reader and calculator accommodations on the assessment. The current closed captioning needs some technical attention to ensure it is placed directly with the content it is relating to on the assessment. The comprehension portion does not allow for content to be read to a student and the mathematical portion does not allow for a calculator to be used. These test directives need to be updated to allow students to demonstrate their comprehension and mathematical skills as long as it is directed within the student's IEP. We support a test that shows a student's academic growth rather than a one-day pass/fail model.

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.

Career Pathways

Legislative Priority:

Support workforce legislation that could lead to increased employment opportunities for people with disabilities.



A key mission of The Arc of Indiana is supporting and promoting real choice in the employment and career paths that people with intellectual and other developmental disabilities (I/DD) choose. We support career pathways that range from full-time employment with benefits to meaningful volunteer work. A greater effort must be made to help individuals engage in activities they choose that comprise a meaningful day for them. If individuals are actively engaged in making the choices that frame their lives,

especially through work and volunteer opportunities, they will become more active participants in their communities.

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 I/DD remains at an estimated 80%, according to the Disability Employment Statistics of the US Department of Labor. Hiring people with I/DD in competitive community jobs is good for business as they are a proven asset to our workforce. Through its Training Institute and Teaching Hotel, and employment services provided by Arc chapters 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 ensure that wages for people with I/DD are at a level that encourages self-sufficiency.

Transportation

The Arc recognizes a major obstacle to the employment of people with I/DD is transportation. The Arc supports efforts to increase the availability of mass, public transportation as it is essential for people with I/DD to work, gain independence, attend

medical appointments and patronize local businesses. For people with I/DD, 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 and Supports

The Arc of Indiana remains committed to helping individuals and families receive the support and services they need to keep their loved ones living either at home or in the community. Currently, we are working with The Self-Advocates of Indiana and FSSA on redesigning the CIH and FSW waivers to ensure that people with I/DD can live, work and thrive in the community safely.

The Arc of Indiana supports efforts to improve the process of applying for a Medicaid Waiver and keeping the waiting list updated. We are also committed to helping families utilize the natural supports that already exist in their communities.



The Arc of Indiana will continue to engage in the discussion taking place about the federal Medicaid program and the potential of a block grant or per capita payment model. We feel that either of these options could have a potentially negative impact on the overall health and healthcare access for people with I/DD. We will continue to have conversations with all stakeholders regarding Medicaid and remain focused on solutions

that take into account the unique circumstances and needs of people with I/DD.

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 I/DD. We will work with families and individuals with I/DD 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 “follow the person” 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.

The Arc of Indiana will closely monitor the work of the 1102 Task Force. We will work to ensure the comprehensive study provides thorough discussion and consideration of innovative ideas that continue to provide people with I/DD and their families quality choices to gain independence and take full advantage of communities throughout our state.

Crisis Situations

Despite the efforts of individuals with I/DD 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 (<http://www.nationalcoreindicators.org/>), about 50% of people with I/DD 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 I/DD. 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 encourages the Division of Mental Health and Addiction (DMHA) and the Division of Disability and Rehabilitation Services (DDRS) to develop treatment options for people of all ages who have a co-existing condition and are in crisis. We also recommend that any crisis treatment options be in coordination with an individual's current behavior management provider, which is available to people receiving waiver services. Coordinated services can help reduce refusal of services from acute psychiatric providers because they will have a community-based clinical partner to ensure smooth transition back to the individual's home.

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 I/DD to become involved in the criminal justice system as suspects, offenders and victims. The Arc of Indiana values all initiatives that ensure people with I/DD 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 Correction and county jails to connect individuals with I/DD with the Bureau of Developmental Disabilities Services and VR programs as part of their transition.

Managed Care

Aged, blind and disabled expenditures are a large driver of overall Medicaid costs in Indiana, with institutional care accounting for the largest share of those expenditures. With the aging baby boomer population, the cost of providing Medicaid is expected to increase considerably in the near future.



As the state discusses options regarding managed care, we will work closely with the administration to ensure that concerns for people with I/DD are addressed.

The Arc of Indiana strongly supports efforts to analyze the experience of other states regarding managed care for people with I/DD. 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 do not receive waiver services to ensure individuals have access to the medical care they need. 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 I/DD. 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 I/DD 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

Many individuals with I/DD 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 I/DD 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 I/DD, 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 work along-side Self-Advocates of Indiana and partner with them in seeking additional resources to reach their goals.

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 I/DD and educate the community and self-advocates on employment options and resources. Recognizing that individuals with I/DD 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 realize their individual gifts and talents, as this confidence 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 in their community.

The Arc of Indiana supports services that provide meaningful opportunities for people with I/DD to realize self-empowerment; to experience lifelong learning; to achieve better health; and to develop relationships through community inclusion; whether in employment, classroom 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 in all Indiana communities.

