



# **The Arc of Indiana 2016 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 who have 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 which will help support them in their mission of building communities with people with intellectual and other developmental disabilities.

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**Career Pathways**

*Legislative Priority:*

*Support legislation that increases 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 for individuals with I/DD that include a range of options 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.

The Arc of Indiana supports the Family and Social Services Administration’s (FSSA) vision of Employment First as an outcome of services provided to individuals with intellectual and other developmental disabilities. We will work to ensure people with developmental disabilities have substantive work opportunities in the community.

The unemployment rate for people with intellectual and other developmental disabilities working in competitive community jobs is estimated at a staggering 78%. Hiring people with intellectual and other developmental disabilities 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 state and national efforts to increase the employment rate of people with intellectual and other developmental disabilities. In addition, The Arc of Indiana supports efforts to ensure that earnings for people with intellectual and other developmental disabilities are at a level that encourages self-sufficiency.

The Arc of Indiana will continue to monitor the new Vocational Rehabilitation (VR) Hybrid payment model to assess its impact on persons with more significant disabilities or support needs. VR’s new employment services system must continue to adequately address the ongoing support needs of individuals to maintain their community based employment. The Arc commends VR for recognizing that arbitrary time limits on follow-along supports (also known as Extended Services) may put the person at risk of losing his/her job. Therefore, Extended Services should continue to receive adequate funding as it is often key to long term job maintenance.

## **Criminal Justice Issues**

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

***The Arc will monitor and support legislation that will identify people with intellectual and other developmental disabilities within the criminal justice system.***

***The Arc will monitor and support legislation that will create and/or support programs for people with intellectual and other developmental disabilities as they get involved in the criminal justice system.***

The Arc recognizes the increased risk for people with intellectual and other developmental disabilities (I/DD) to become involved in the criminal justice system, as suspects, offenders and victims. The Arc of Indiana values the rights of people with I/DD to receive equal access to justice within the criminal justice system.

The Arc of Indiana recognizes the importance and need for training and educating law enforcement and legal professionals within the criminal justice system at all levels on how to respond appropriately and effectively to situations involving people with I/DD. The Arc of Indiana will continue to monitor and advocate for existing projects that educate and train police officers and professionals involved in the criminal justice system.

We will work with experts in the criminal justice field to explore the development of alternative programs to incarceration for people with I/DD who commit crimes or who are suspected of committing crimes. It is our intention to hold people accountable; however, in order to appropriately rehabilitate people with I/DD, applicable alternative programs and rehabilitative options need to be available.

When an individual with I/DD is in behavioral health crisis and is involved with the criminal justice system, the individual's access to their mental or behavioral health providers is cut off. The Arc encourages Medicaid, the Department of Mental Health, the Department of Corrections and local law enforcement agencies to devise a way for treating therapists to have access to the individual to help deescalate situations and provide the ongoing support the person needs.

While The Arc of Indiana understands the problem of illegal drug use in jails and the need for local law enforcement and county jails to prevent substance abuse and the use of illegal and illicit drugs in the jail, The Arc also realizes that individuals with I/DD and co-occurring mental or behavioral health issues may need medication to ensure their health and to reestablish behavioral control. Interruption of needed medication can lead to further problems.

In order to successfully reenter society after incarceration, individuals with I/DD need a smooth transition back into the community with the supports necessary to be successful and not become reinvolved in the criminal justice system. The Arc of Indiana encourages the Department of Correction and county jails to identify individuals with I/DD and ensure they are connected with the Bureau of Developmental Disabilities Services and VR programs as part of their transition back into the community.

## **Crisis Situations**

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

***The Arc supports the findings from the recent “Gap Analysis” report provided to the Family and Social Services Administration (FSSA) by the University of New Hampshire. The report identified significant gaps in crisis services for people with dual diagnoses, which is a person who has both an intellectual disability and a co-occurring mental health diagnosis. The Arc also supports the report’s recommendation that FSSA initiate a demonstration crisis project, starting with a single region, then followed by implementation throughout the state.***

Despite the efforts of individuals with intellectual and other developmental disabilities 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 intellectual and other developmental disabilities also have a “mental illness or psychiatric diagnosis.” Unfortunately, it is often extremely difficult for individuals with a dual diagnosis 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 dual diagnosis based solely on the person’s diagnosis of an intellectual or other developmental disability. 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 dual diagnosis 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 comfortable and prepared to treat individuals with intellectual and other developmental disabilities.

## **Direct Support Professionals**

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

***The Arc will continue to support efforts to ensure a sustainable system that attracts and maintains the Direct Support Professional workforce.***

The Arc of Indiana recognizes the importance of a high quality workforce of Direct Support Professionals (DSPs). Direct support professionals provide instruction and assistance to individuals with intellectual and other disabilities (I/DD) in areas ranging

from personal hygiene, to household management, to helping them find and keep jobs in the community. The DSP workforce must possess a variety of skills and undergo a good deal of training for effective and safe job performance. Indiana's DSP workforce is over 26,000.

The ability to hire, train and retain quality staff is vital to the growth, sustainability and quality of services for people with I/DD. High turnover and employee vacancy rates that most providers experience leave people with disabilities who are dependent upon DSPs for critical services at risk. In many cases, turnover rates in this workforce segment top 70% annually.

The Indiana General assembly's recent restoration of the 2010 rates for Medicaid services in the current state budget is a good start to creating a more sustainable service system, but we must take the next step. The Arc of Indiana supports all efforts to ensure a living wage for DSPs that is competitive with other jobs for which these professionals are qualified. Therefore, reimbursement rates for providers must support attractive wages and benefits to sustain this important workforce.

Indiana's innovative workforce development program, the Direct Support Professionals Project initiated in 2007, was eliminated in 2010 due to budget cuts. Through this model project, DSPs from nine phase-one agencies received best-practices orientation as well as opportunities to advance their skills and wages through certification at Ivy Tech Community College and other career pathways. The Arc of Indiana supports the development of innovative ways to reinstate funding for this important program and to make it available to all Direct Support Professionals statewide.

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

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

***The Arc will support legislation that extends the age for a child to be diagnosed with a developmental delay.***

The Arc of Indiana 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. Alcohol is known to be the leading *preventable* cause of intellectual disabilities. Recent research has implicated smoking in increasing the risk of intellectual and other developmental disabilities. 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. We will also support efforts which address the importance of good prenatal care and folic acid supplementation during pregnancy.

The Arc of Indiana is committed to helping infants and toddlers with intellectual and other developmental disabilities receive the services and supports they need to reach critical developmental milestones. We will support all efforts for early diagnosis and early intervention services.

We will continue to work closely with the State in its implementation of First Steps, Indiana's Early Intervention Program for Infants and Toddlers. The Arc believes in family-

centered principles and early intervention best practices, including the support of a developmental consultation model of service delivery and a commitment to appropriate levels of service for all eligible children.

In order for children to maximize the benefits from early intervention services, they must have access to qualified therapists. The Arc of Indiana will closely monitor the implementation of new proposals in the First Steps Program. We will protect the choice of families in choosing qualified providers. The Arc of Indiana will strongly oppose any efforts to discontinue services for children who meet eligibility guidelines and are in need of services.

The Arc is committed to making sure 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.

## **Funding**

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

***The Arc will continue to monitor the investments made in reimbursements rates this past year. We will support efforts to improve funding for programs and services which help people with disabilities, their families and service providers.***

The Arc of Indiana is committed to working with the State to ensure developmental disability services are provided efficiently and effectively, while promoting the health, safety and meaningful desired outcomes of the individual served. We will continue to work for better utilization of federal funds for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

The Arc of Indiana realizes the demands for state funds are great, however it is critical that Indiana makes a financial commitment to its most vulnerable populations. We will work with the State to identify and pursue federal grants and other resources which will help people with intellectual and other developmental disabilities achieve their goals. The Arc of Indiana will work with the state to find ways to support individuals with disabilities, families and extended families that foster resourcefulness.

The Arc of Indiana will continue to monitor provider reimbursement methodologies to ensure their adequacy in providing safe, effective and efficient services that meet the needs of the consumer as well as supporting a stable workforce to provide the needed services. The rates provided under any system must reflect the actual costs incurred to provide quality supports.

The Arc of Indiana is committed to our local chapters and finding ways to stabilize funding they receive from local governments. The current financial hardships being placed on local governments has jeopardized the funding received by local developmental disability service centers. Services and programs will be affected if these dollars are lost. We will continue to work with interested parties for a viable solution.

The Arc of Indiana will continue to work with the State to identify cost-savings in the system which we feel do not jeopardize the health and safety of individuals with intellectual

and other developmental disabilities. This effort must include the development of new and innovative models that increase consumer choice and also are less costly. We will continue to make sure dollars follow the individual in every possible circumstance.

## **Guardianship Services**

Guardianship services can be very important to individuals with intellectual and other developmental disabilities to assure they have the supports necessary to remain healthy and safe in the community but it also has very serious consequences for the proposed protected person. The Arc of Indiana believes that guardianship should be as minimal as possible to ensure the safety of individuals with I/DD. Many individuals with I/DD are capable of making decisions and determining their own fate, even if they need help and support in making those decisions. The Arc of Indiana encourages the use of supported decision making in as many situations as possible, even among those who are under guardianship, so self-advocates can engage in self-determination. For those with disabilities throughout the state who have no family or loved ones to assist them in making important life choices, we will continue to work closely with the Indiana Adult Guardianship Task Force and the Office of the Supreme Court to ensure that quality guardianship programs, at reasonable costs, are available throughout Indiana. 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.

The Arc of Indiana believes it is critical people with intellectual and other developmental disabilities have guardianship services made available to them, should they need them. It is our philosophy that guardianship works best when a personal interest in the individual needing services is present and their wishes are taken into consideration.

## **Home and Community Based Services and Supports**

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

***Support legislation that would create an optional state-wide identification card that would identify people with disabilities in emergency situations.***

***Support legislation that provides for stronger sentencing of crimes committed against someone due to their disability.***

***Support legislation that develops ABLÉ accounts to be made available to Hoosiers with intellectual and other developmental disabilities.***

The Arc of Indiana remains committed to helping families receive the support and services they need to keep their loved ones at home. We remain committed to ensuring that people with developmental disabilities can live safely in the community when families can no longer provide for them at home or they make the choice to move.

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 while they wait for waiver services. We will continue to work closely with FSSA as they look to replace our level of care determination tool to ensure fair and accurate outcomes.

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 ways to support individuals with intellectual and other developmental disabilities. We will work with families and individuals with intellectual and other developmental disabilities on the cultural shift of using only what you need so more is available to others who continue to languish on waiting lists.

The Arc of Indiana will closely monitor the upcoming changes to the Community Integration and Habilitation Medicaid Waiver to ensure that those who are in dire need of critical services and are eligible, receive services.

The Arc of Indiana will also work to ensure funding streams follow people and sufficient funds are provided, both for initial appropriate placements and ongoing services. We will work aggressively with other organizations to eliminate institutional biases which exist within the State's budget system.

Currently, the state has no dependable programs to help people who have been diagnosed with both an intellectual or developmental disability and a mental illness or addiction. We support the state's efforts to implement a needs assessment to determine the need for such services. We will work closely with the state as the needs assessment is implemented and offer any information and assistance appropriate.

With more people with intellectual and other developmental disabilities living in local communities, first responders, law enforcement and fire safety personnel need proper training in responding to emergency situations involving someone with a disability. The Arc is committed to working with appropriate stakeholders to ensure that training is developed and/or made available to public safety professionals. In addition, people with intellectual and other developmental disabilities need help in responding to situations where they may encounter criminal justice professionals.

In 2014, President Obama signed into law the ABLE Act which will allow people with disabilities to establish ABLE accounts to save money to use for disability related expenses. ABLE accounts can be established without jeopardizing eligibility of critical programs like Medicaid and Supplemental Security Income (SSI). The Arc of Indiana will continue to work with the State Treasurer to ensure that Indiana's ABLE accounts are developed to ensure people with disabilities and their families are treated fairly and the accounts promote independence.

## **Insurance**

The Arc of Indiana strongly believes that people with intellectual and other developmental disabilities must have quality health insurance and life insurance available to them.

We will work with the Office of Medicaid Policy and Planning as well as the medical community to make sure people with intellectual and developmental disabilities have access to primary care physicians and medical specialists in their local communities. The Arc of Indiana will work closely with self-advocates and the health care community to find ways to make wellness programs and preventative care more available to people with intellectual and other developmental disabilities.

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. We will closely monitor the changes taking place regarding the new definitions in the fifth edition of the Diagnostics and Statistics Manual to ensure that changes do not adversely affect insurance coverage for people with intellectual and other developmental disabilities.

The Arc supports efforts to prevent insurance providers from relying on the educational community to provide medical treatment by excluding coverage for therapies during the school day or in school buildings. The Arc recognizes children with disabilities are in a unique situation of getting support from multiple sources, including both the medical and educational communities. However, The Arc also recognizes schools provide educational support, not medical treatment. The Arc also supports efforts to prevent insurance providers from requiring educational records before determining medical necessity unless the school psychologist is referring the child for treatment.

The Arc of Indiana will continue to monitor the implementation of the federal health care exchange program. As implementation of the health care program moves forward, we remain committed to major insurance market reforms such as elimination of discrimination based on health status, a prohibition on pre-existing condition exclusions, guaranteed issue and renewal requirements and elimination of annual and lifetime caps. The Arc of Indiana will continue its work with the Healthcare Exchange Task Force to ensure that issues important to people with disabilities and their families are moved forward. The Arc of Indiana has fought to pass critical health benefit mandates to insure that people with intellectual and other developmental disabilities have access to services they need. The Arc of Indiana will continue to fight to protect those services people depend upon. We will continue to look at ways to support and move forward other insurance initiatives to expand coverage to all people with intellectual and other developmental disabilities.

### **Managed Care**

Aged, blind and disabled expenditures are a large driver of overall Medicaid costs in Indiana, accounting for 69% of the state's Medicaid healthcare expenditures in SFY 2012. Institutional care accounted for the largest share of those expenditures. With the aging baby boomer population, the cost for Medicaid to this population is expected to rise 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 intellectual and other developmental disabilities are heard.

The Arc of Indiana strongly supports taking the time and care to study the experience of other states regarding managed care for people with intellectual and other developmental disabilities, including the use of a "carve out" for this population. 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 understand the importance of effective use of limited resources, particularly in regard to long term care.

As Medicaid managed care programs for people with disabilities who do not receive waiver services, are not dual eligible for Medicare and Medicaid, and are not in an institutional placement are implemented, The Arc of Indiana will closely monitor this implementation 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.

## **Public Transportation**

The Arc recognizes a major obstacle to the employment of people with intellectual and other developmental disabilities is transportation. The Arc supports efforts to increase the availability of mass, public transportation as this would provide a greater opportunity for people with intellectual and other developmental disabilities to work and gain independence, to attend medical appointments and to patronize local businesses.

The Arc of Indiana supports efforts to secure the availability of dependable public transportation throughout the state. **Studies show that every dollar invested in public transportation has a \$6 return to the economy.**

For people with intellectual and other developmental disabilities, access to transportation is the beginning of a future that becomes easier to realize, bringing with it opportunities and independence.

## **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 78% for nearly a decade. The Arc will continue to partner with self-advocates to increase employment opportunities for people with intellectual and other developmental disabilities. Recognizing that transportation is a significant roadblock to employment, The Arc supports and encourages self-advocates to participate in transportation-related initiatives, councils and coalitions so that their needs and voices are heard.

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 employment opportunities. We will also support their efforts to identify and connect with natural supports (i.e. extended family, neighbors, and church) available in local communities for people with intellectual and other developmental disabilities.

The Arc of Indiana supports day services that provide substantive opportunities for people with intellectual and other developmental disabilities to realize self-empowerment; to experience lifelong learning; to achieve optimal 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 meaningful day services, driven by person-centered approaches, to accomplish these outcomes in all Indiana communities.

## **Special Education**

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

***Support legislation that provides the opportunity for every student to earn a high school diploma with consistent curriculum requirements. In addition, the courses required to earn a diploma need to be accessible throughout all schools.***

The Arc will advocate for students with intellectual and other developmental disabilities to be educated along with their peers in inclusive educational settings, with appropriate supports, accommodations and modifications. We believe every student receiving special education services deserves the right to earn a high school diploma to allow them the option of choosing vocational training, post-secondary education, and/or competitive employment earning a living wage. We support the state administration's commitment in making career and vocational education a priority in every Indiana high school.

We recognize the need to ensure parents realize the options available to students receiving special education services to meet Indiana's state assessment requirements. If passing the End Of Course Assessment (ECA) is not attainable, then parents need to be aware of the possibility of opting out of the Core 40 diploma and entering into the *evidence based waiver* or the *work readiness waiver*. These waivers have specific requirements that must be fulfilled by the student in order to obtain a high school diploma. The Arc of Indiana will work to ensure these options are available state-wide.

The Arc of Indiana will monitor closely the implementation of the new state standards and assessment tools. We will work to ensure families and schools have the information they need to make quality decisions that will further the educational progress of students receiving special education services.

We support the expansion and funding of educator learning and professional development programs in order to meet the wide range of abilities of all students served by our public, charter and private schools. The Arc of Indiana will work to see educators receive adequate training on behavioral management issues, programs and opportunities relating to people with intellectual and other developmental disabilities. With significant and systematic changes being implemented for teacher training, teacher evaluations and licensing, and school administrator qualifications, The Arc will work to ensure the education and well-being of students with intellectual and other developmental disabilities will be enhanced, not compromised.

Sixty-one percent of three to four years olds in Indiana do not have access to quality preschool programs in the state of Indiana. We support efforts to improve early childhood education. The Arc recognizes the lack of adequate preschool funding for students in special education. We will work with the Department of Education and other organizations to increase preschool funding.

The Arc wants to ensure parents are fully informed about their children's education and nothing weakens parental rights nor compromises the child's right to a Free Appropriate Public Education (FAPE). The Arc wants to ensure students and families are equal partners in developing individualized education plans and that the case conference committee is the deciding stakeholder in the IEP and educational process.

The Arc will closely monitor schools implementation of their seclusion and restraint policies and will continue to educate families regarding the law and their rights. We will continue to be an active participant on the Seclusion and Restraint Commission to insure that schools are following the law and students are learning in a safe environment.

The Arc of Indiana realizes the effects of bullying in schools and the potential of students with intellectual and other developmental disabilities to be victims of bullying. We will closely monitor how schools implement their anti-bullying policies to decrease the incidence of bullying.

The Arc believes effective planning is critical for students' successful transition from school to work and 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 work to ensure students with disabilities have service options available to them when they complete their high school education and students' chosen service providers are involved in transition planning before students graduate.