



## **The Arc of Indiana 2018 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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## **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 Arc of Indiana supports the Family and Social Services Administration’s (FSSA) vision of Employment First as a desired outcome of services provided to individuals with I/DD. Indiana must invest in systems change that increases community-based, integrated employment opportunities for individuals with I/DD.

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.

The Arc of Indiana will monitor the impact of the Bureau of Vocational Rehabilitation Services’ implementation of Order of Selection, which became effective August 1, 2017. VR’s employment services system must continue to adequately address the ongoing support needs of individuals in maintaining their community based employment.

The Arc will work closely with the state as it prepares to implement the changes in the Workforce Investment Opportunity Act (WIOA) to ensure there is a continuum of services available to people, regardless of where they live. We will work to ensure individuals and families are provided choice and sitting at home is not an adequate option.

## **Criminal Justice Issues**

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

***The Arc of Indiana will support bias crimes legislation that increases sentencing to offenders who commit crimes solely based on a person having a disability.***

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.

When criminals target victims on the basis of certain immutable characteristics they not only harm their victims, they threaten and traumatize the larger community of which the victim is a part. Unfortunately the urgent need to confront violent bigotry has only increased in recent years. Indiana needs to join the other 45 states who have enacted stronger sentencing for crimes targeted against a person due to their disability or other characteristics.

The Arc of Indiana recognizes the critical 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 projects and programs that educate and train police officers and other members of the criminal justice system.

We will work with experts in the criminal justice field to explore the development of alternatives 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 rehabilitate people with I/DD, appropriate alternative programs and rehabilitative options must be made available.

When an individual with I/DD experiences a behavioral health crisis and becomes 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 these therapists to have access to the individual to help deescalate situations and provide the ongoing support the person needs.

While we recognize the need for law enforcement to prevent illegal drug use in jails, 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.

After incarceration, individuals need support to ensure a smooth and successful transition back into the community and prevent recidivism. 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**

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 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 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 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 equipped to treat individuals with intellectual and other developmental disabilities.

## **Direct Support Professionals**

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

***The Arc will continue to 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.

The Arc of Indiana was pleased to work alongside other organizations to successfully pass language in HEA 1001 during the 2017 legislative session that provided a 5% Medicaid rate increase, 75% of which, must be used to increase DSP wages. We realize this effort alone will not solve our DSP crisis and other efforts are needed to professionalize this workforce. We support all efforts to ensure a living wage for DSPs that is competitive with other jobs for which these professionals are qualified. Therefore, service reimbursement rates must be sufficient for providers to offer attractive wages and benefits to sustain this important workforce.

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

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 I/DD. 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 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.

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 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.

## **Education**

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

***Work to ensure a clear and accurate interpretation and implementation of Indiana's state plan for the Every Student Succeeds Act (ESSA).***

***Work to ensure that all students have options on graduation pathways leading to a high school diploma.***

***Work to ensure that the implementation of the new certificate of completion does not lead to unintended consequences that harm students receiving special education services.***

***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.***

### ***Support efforts to increase preschool funding.***

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 will closely monitor that all high schools in the state of Indiana offer all state recognized diplomas or have a way to give the student access. We want to see the general diploma, including the waiver process, more widely used and general education classes not currently offered in all schools made available for credit purposes. We believe the waiver process is a viable path to a general diploma and should be utilized consistently throughout all Indiana schools.

A large part of graduation also hinges on the passing of multiple state assessments. The Arc will be proactive in making sure the new assessment test, ILEARN, allows all students to demonstrate their academic knowledge by using all of their testing accommodations allowed throughout the school year. One specific concern on the assessment is the comprehension portion, which currently cannot be read to a student. This test directive needs to be changed to allow students to demonstrate their comprehension skills and without this one accommodation, negatively impacts some students receiving special education services. We support a test that shows a student's academic growth rather than a one day pass/fail model.

We will closely monitor the Indiana Department of Education's state plan on implementing the Every Student Succeeds Act (ESSA). We support the goals of ESSA which (1) Applies to all students and all public schools; (2) Lessens federal requirements and allows

states to determine appropriate accountability methods; (3) promotes high expectations; and encourages collaboration and shared responsibility. Furthermore, we agree that students receiving special education services should be taught a curriculum that is aligned with grade level content standards. We agree that instruction should be designed to meet diverse needs and challenging goals should be set that allow for meaningful progress.

The Arc will also monitor the implementation of the new Certificate of Completion. We agree that a small percentage of students will not be able to attain a high school diploma so the development of a certificate of completion that shows a student's success in taking classes and acquiring knowledge and skills aligned with state standards is important. We do not support making the certificate of completion an alternate diploma only available to students receiving special education services as we feel this would further diminish the value of students with disabilities and could potentially lead to a negative impression by potential employers and preclude post-secondary opportunities. However, we do feel every student should count and would support the certificate of completion being recognized as a graduate credential and an accountability measure. The certificate should be the path only for students with significant cognitive disabilities. In addition, we are committed to working with the business community to make sure they recognize the significance of the new certificate of completion and the career skills that come along with the new certificate. We realize that there still will be some students who are not able to achieve the new requirements for the certificate of completion and will work to ensure that options remain for them in the school setting to learn important skills that provide options for greater independence after high school.

We support efforts to improve early childhood education by including children with disabilities in regular preschool classrooms, where they can model typical behavior. Related services should be included in their daily activities to support the child in this environment and build strong correlation to classroom work and peer relationship building. The Arc recognizes the lack of adequate preschool funding for students in special education. We will support efforts to educate legislators on the differences between the Federal mandate for preschool aged students who require special education and the current state supported preschool programs and the need to increase that funding.

The Arc will continue to closely monitor the implementation of schools' 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 wants to ensure parents are fully informed about their student's education and nothing weakens parental rights or compromises the student'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 (IEP) and that the case conference committee is the deciding stakeholder in the IEP and educational process.

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 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.

## **Funding**

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 all individuals served. We will continue to advocate for better utilization of federal funds for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

The Arc of Indiana realizes the demands on state funds are great; however, it is critical that Indiana makes the necessary financial commitment to its most vulnerable populations. We will work with the State to identify and pursue federal grants and other resources that help people with I/DD 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 individual while promoting a stable workforce to provide these critical services. The rates provided under any system must reflect the actual costs incurred to provide quality supports.

The Arc of Indiana is committed to helping our local chapters finding ways to stabilize funding they receive from local governments. The current financial challenges being placed on local governments have jeopardized the funding received by local disability service providers. The quality and availability of services and programs will be adversely affected if these dollars are lost. We will continue to work toward a viable solution that meets the needs of all entities involved.

The Arc of Indiana will continue to work with the State to identify cost-savings within the system that do not jeopardize the health and safety of individuals with I/DD. This effort must include the development of new and innovative models that are less costly and increase consumer choice by providing opportunities for supported decision making. In doing so, we will continue to ensure dollars “follow the individual” as closely as possible.

## **Guardianship and Supported Decision Making**

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

***Will support efforts to continue to educate lawmakers regarding supported decision making being a viable option for people with intellectual and other developmental disabilities.***

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. 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. The Arc of Indiana encourages the use of supported decision as much as possible, even among those who are under guardianship, so self-advocates can engage in self-determination. 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 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.

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

The Arc of Indiana remains committed to helping families receive the support and services they need to keep their loved ones living at home. We also remain committed to ensuring that people with I/DD can live in the community safely when families decide they can no longer provide for them at home or when individuals decide they want to live on their own.

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. We will continue to work closely with FSSA as they look to replace our “level of care determination tool” to ensure fair and accurate assessments.

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 closely monitor the impact of the Home and Community Based Services Rule and work to ensure that those who are eligible and in dire need of critical services receive them as quickly as possible.

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.

Currently, the state has no dependable programs to help people with a dual diagnosis of I/DD and mental illness or addiction. We support the State’s efforts to implement a needs assessment tool to determine whether such services are necessary for the individual’s health and well-being. We will work closely with the State as this needs assessment is implemented and offer any feedback and assistance as appropriate.

The Arc of Indiana will closely monitor the work of the task force created in HEA 1102, this past legislative session. 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.

## **Insurance**

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

#### ***Support legislation that requires licensure for applied behavior analysts.***

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 self-advocates and the health care community to ensure the availability of wellness programs and preventative 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. We will closely monitor any updates in the fifth edition of the Diagnostics and Statistics Manual to ensure that changes do not adversely affect insurance coverage for people with I/DD.

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 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.

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 to 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 ensure that people with I/DD 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 I/DD.

## **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, 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 understanding 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 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.

The Arc of Indiana supports efforts to expand 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 I/DD, access to transportation is the beginning of a future filled with 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 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.