



The Arc of Indiana 2017 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, including Employment First legislation.

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.

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 results in increased community-based, integrated employment opportunities for individuals with I/DD.

The unemployment rate for people with I/DD is estimated at a staggering 80%, according to the September 2016 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 continue to monitor the Vocational Rehabilitation (VR) Hybrid payment model to assess its impact on persons with more significant disabilities or support needs. VR's employment services system must continue to adequately address the ongoing support needs of individuals to help them maintain 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 insure 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 insure 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 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 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 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, 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 The Arc of Indiana understands the problem of illegal drug use in jails and the need for local law enforcement to prevent the use from occurring, 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 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

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 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 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). In Indiana alone, over 26,000 of these professionals

provide critical instruction and assistance to individuals with I/DD in areas ranging from personal hygiene 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. Turnover rates in this workforce segment top 70% annually.

The Indiana General Assembly's restoration of the 2010 reimbursement rates for some Medicaid Waiver services in the 2015-2016 biennium budget is a start toward creating a more sustainable service system. However, this increase is not in line with the market forces that have driven up starting wages in most sectors of the economy. We support taking the next step of allocating additional funding to improve our providers' ability to pay competitive wages in order to attract and retain a quality workforce. 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, service reimbursement rates must be sufficient for providers to be able to offer 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 pilot 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

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 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.

Education

Legislative Priority:

Work to insure that the assessment replacement for ISTEP 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.

Support efforts to increase preschool funding.

The Arc will work to insure all students have access to the appropriate education that allows them to have opportunities for both careers and post-secondary options after high school.

All students deserve the opportunity to learn alongside their peers in the school of their choice and should be provided the appropriate supports, accommodations and modifications to meet their academic goals.

The Arc will closely monitor the availability of all high school diplomas in Indiana's public schools to make sure that access is being provided to all students. A large part of graduation also hinges on the passing of a state assessment test. The Arc will be proactive in making sure the new assessment test allows all students to demonstrate their academic knowledge.

We support a test that shows a student's academic growth rather than a one day pass/fail model. 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.

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 sharing 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 continue to monitor the Certificate of Completion Task Force. We agree that some 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 as would support the certificate of completion being recognized as a graduate credential and should be the path only for students with significant cognitive disabilities.

We support efforts to improve early childhood education. The Arc recognizes the lack of adequate preschool funding for students in special education. We will support efforts to increase preschool 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

Legislative Priority:

The Arc supports improved funding for programs and services that support 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 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 encourages the state to consider raising the annual budget cap on the Family Supports Waiver (FSW). As more individuals on the FSW are leaving school, families are facing the issue of having caregivers quit their jobs because the budget does not support the needed services.

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 as well as supporting 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 update key statutes to make supported decision making 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 to individuals with I/DD to assure they 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 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 I/DD have services made available to them, should they need them. 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 are taken into consideration.

Home and Community Based Services and Supports

Legislative Priority:

Support legislation that provides an appropriation for ABLE Accounts to be made available to Hoosiers with disabilities.

Support legislation that requests a comprehensive study be developed looking at the services and supports for people with I/DD currently and in the next few years.

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 developmental disabilities 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 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 upcoming changes due to the Home and Community Based Services Rule and work 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 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 an 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.

In 2016, the Indiana General Assembly passed legislation putting into place the structure

for Indiana to begin the development of its ABLE Accounts and Board which will allow people with disabilities to establish accounts to save money to use for disability related expenses. ABLÉ accounts can be established without jeopardizing eligibility of critical programs like Medicaid and Supplemental Security Income (SSI). The Arc of Indiana will work with the State Treasurer to advocate for an appropriation in the state budget to adequately staff the ABLÉ authority and ensure Hoosiers with disabilities have the opportunity to set up ABLÉ Accounts that promote independence.

Insurance

Support legislation that puts forth a study of licensure of applied behavior analysts.

The Arc of Indiana strongly believes that people with I/DD 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 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 find ways to make wellness programs and preventative care more available to people with I/DD.

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 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 insure that the professionals providing the service are licensed and held accountable for their practice. Too many people are providing these services without the needed education, professional credentials or supervision by qualified personnel, or are using antiquated practices and causing people with disabilities harm.

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 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. 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 I/DD 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 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 this would provide a greater opportunity for people with I/DD 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 I/DD, 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 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 on employment options and resources. 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 I/DD.

The Arc of Indiana supports day 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 meaningful day services, driven by person-centered approaches, to accomplish these outcomes in all Indiana communities.