

# **The Arc of Indiana**

## **2010 Public Policy Agenda**

*The 2010 legislative session is expected to be difficult as the revenues for the state continue to be well behind projections and all eyes are already on the 2010 elections next November.*

*The current economic situation continues to have everyone on standby. As revenues continue to fall short for the state budget, we will likely continue to see further cutbacks. Much of the state's revenue is based on sales tax, approximately 50% and personal income tax, nearly 30%, and both are down dramatically.*

*We must continue to put the needs of people with intellectual and other developmental disabilities in front of the Indiana General Assembly. We need to make sure that in these difficult times Indiana's most vulnerable population is not made more vulnerable.*

*We must continue to work with the state as it works to improve the Medicaid Modernization Project. The Governor's canceling of the IBM contract was the correct action to take and we need to continue to work with the Governor and FSSA in implementing a new system that allows access to critical services for those who qualify for them. We must continue to streamline the process rather than making it more difficult to receive services. We must also remain at the table for the implementation of Care Select and work with the medical community to find more doctors who are willing to see patients who receive Medicaid services.*

*The Arc of Indiana will remain a key partner with the administration in looking for ways to serve the most people in the most cost effective way. We will continue to push for equality in the system but will not lose sight of what is in the best interest of families and individuals with intellectual and other developmental disabilities.*

### **The Arc of Indiana's 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 programs, funding and public policy that 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 create more public awareness of the importance of strong prenatal care and the dangers created by lead, alcohol and drugs.**

**The Arc of Indiana is committed to self advocates - people who have an intellectual or other developmental disability that advocate for themselves - and will work to ensure they receive the respect to which all people are entitled.**

**The Arc of Indiana is committed to our local chapters of The Arc, and will work to develop programs and public policy that will help support them in their mission of providing quality services to people with intellectual and other developmental disabilities.**

## The Arc of Indiana 2010 Public Policy Agenda

Criminal Justice _____	pg. 2-3
Direct Support Professionals _____	pg. 3
Early Intervention _____	pg. 3-4
Funding _____	pg. 4
Guardianship Services _____	pg. 4
Home and Community Based Services and Supports _____	pg. 4-5
Institutional Settings _____	pg. 5
Insurance _____	pg. 5-6
Meaningful Day _____	pg. 6-7
Prevention & Prenatal Education _____	pg. 7
Self Advocacy _____	pg. 7
Special Education _____	pg. 7-9
Supported Employment _____	pg. 9



### Criminal Justice

The Arc of Indiana recognizes the increased opportunity for people with intellectual and other developmental disabilities to become involved in the criminal justice system, both as *offenders* and *victims*. People with intellectual and other developmental disabilities who commit crimes or are suspects of a crime should be held accountable for their behavior, however appropriate and necessary accommodations should be provided to ensure fair and equitable treatment in all areas of the criminal justice system. People with developmental disabilities who become victims of crime or witness to a crime will be treated fairly and provided the appropriate and necessary accommodations to protect their rights in all areas of the criminal justice system.

The Arc of Indiana also recognizes the importance and need for training and educating first responders as well as those involved in the criminal justice process at all levels on how to handle situations involving people with intellectual and other developmental disabilities. The Arc of Indiana will continue to monitor the projects that currently exist for training police officers and those involved in the criminal justice process at all levels.

The Arc of Indiana will work with experts in the criminal justice field to explore the development of an alternative program to incarceration for people with intellectual and other developmental disabilities who commit crimes. It is our intention to hold people accountable but alternative placements need to be available.

### **Direct Support Professionals**

Current difficulties in assuring adequate direct support staff recruitment, retention and competence are widely reported as the single biggest barrier to the growth, sustainability, and quality of community services for people with intellectual and other developmental disabilities. These longstanding challenges are of growing concern because the number of people demanding community services is increasing.

Indiana's innovative workforce development program, The Direct Support Professionals (DSP) Project initiated in 2007, is threatened because of the lack of adequate funding. Through this model project, DSP's from nine phase-one agencies were receiving best-practices orientation as well as an opportunity to advance their skills and earnings through certification at Ivy Tech Community College or other pathways. The Arc of Indiana supports the development of innovative ways to fund this important program and to make it available to all Direct Support Professionals supporting individuals with intellectual and other developmental disabilities.

The Arc of Indiana will support efforts by the State to provide adequate initial and ongoing training, and the development of a career path designed to attract and retain direct support professionals.

We will also support all efforts to ensure a living wage for direct support professionals that are competitive with other jobs for which the professionals are qualified.



### **Early Intervention**

The Arc of Indiana is committed to infants and toddlers with intellectual and other developmental disabilities receiving the services and supports they need to be successful. 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, the state's Early Intervention Program for Infants and Toddlers. The Arc believes in family-centered principles and early intervention best practice, 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 an adequate number of qualified and appropriate therapists. With the First Steps program facing a shortage of qualified therapists, The Arc supports efforts to offer professional support for therapists, to streamline therapist reimbursement procedures at an adequate reimbursement rate, and to increase recruitment of already certified therapists.

The Arc will support efforts for recruitment of potential therapy students in accredited colleges and universities through direct recruitment, tuition tax credits, scholarships-for-service programs.

The Arc is committed to making sure 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.



### **Funding**

The Arc of Indiana is committed to working with the State to ensure that 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, including stimulus dollars, for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

The Arc of Indiana realizes the demand for state funds are great, but, we also feel strongly that Indiana needs to make a financial commitment to its most vulnerable populations. We will work with the State to identify and pursue federal grants and other resources that will help people with intellectual and other developmental disabilities achieve their goals. However, The Arc and our legislators must be open to all options for revenue generation, including new or increased taxes that address growing and unmet needs in our State. Dedicated revenue sources include, but are not limited to, a non-nutritive beverage fee or an Internet sales tax to fund home and community based services.

The Arc of Indiana continues to support a resource allocation methodology such as OASIS or its equivalent that will fairly determine the individual budget necessary to meet each person's needs. The system must be determined through accurate assessment and justifiable, predictable formulas that take into account the most important characteristics of functional abilities. The rates provided under this 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.

### **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. With the closure of Indiana's state institutions, the need for guardianship services have increased.

The Arc of Indiana believes it is critical that 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**

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 assuring 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 remains committed to the goals and the visions out-lined in *Indiana's Comprehensive Plan for Services for People with Developmental Disabilities*. While nearly 14,000 people receive Medicaid waiver services in Indiana, approximately 20,000 people are still waiting. Over the last several years, we have seen considerable movement in the Medicaid waiver waiting lists but too many families remain in need of vital services and supports. Therefore, we will continue to support appropriations targeting reductions in the waiting list.

The Arc of Indiana will monitor the newly re-authorized Developmental Disabilities Waiver and will work to make sure the new priorities under the waiver are fully implemented. Individuals with care givers over the age of 79, 18-24 year olds who have aged out of school and young children who have a diagnosis leading to a shortened life span, remain priorities for The Arc. However, we must also continue to support appropriations targeting reductions in the waiting list.

It is critical that consumers and families have choices and that they are knowledgeable about their rights. The Arc of Indiana is committed to seeing self-determination become a service in Indiana's Medicaid waiver system. We will continue to work with the state and self advocates to develop guidelines for the state's self determination initiatives.

The Arc of Indiana believes that Person Centered Planning is critical in the lives of people with developmental disabilities and their families. We will work to ensure that consumers and families have choices and that they are knowledgeable about their rights.



### **Institutional Settings**

The Arc of Indiana is proud to claim that Indiana is the largest state to no longer operate state institutions for people with intellectual and other developmental disabilities. However, it is estimated that over 2,200 people with intellectual and other developmental disabilities reside in a nursing home setting. Another 180 people with intellectual and other developmental disabilities are estimated to live in state operated facilities for the mentally ill. We will continue to work with the state for the appropriate movement of people out of nursing homes and mental health hospitals and into the community.

We will work to ensure the highest level of quality assurance is put into place for all people with disabilities, no matter where they live. We will work closely with parents and self advocates to help them with the transition of their loved ones into the community.

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

### **Insurance**

The Arc of Indiana believes strongly that people with intellectual and other developmental disabilities must have quality health insurance available to them. In addition, The Arc will work to ensure that people with intellectual and other developmental disabilities are not discriminated against in obtaining life or health insurance.



We will continue to monitor the implementation of Indiana's Comprehensive Health Insurance Association (ICHIA), the state's Healthy Indiana Plan (HIP), and the Medicaid Modernization Plan to make sure access and quality services are available to people with

intellectual and other developmental disabilities. We will continue to work with the various state health insurance programs to make health insurance available to Indiana's most vulnerable populations.

The Arc will continue to be an active participant in the Care Select Program as individuals with intellectual and other developmental disabilities are affected through the state's efforts to make Medicaid more efficient.

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.

Health insurance and health insurance mandates were designed to provide individuals with the medical care they need to live and function in our community. However, insurance companies and health plans have been falling short in meeting those needs. In this economic climate, it is imperative that insurance companies and health plans meet their financial obligations regarding health care instead of passing those costs onto already overwhelmed state 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 laws. We will watch closely the movement on the issue of Assignment of Benefits to make sure that people with intellectual and other disabilities are not adversely affected.

The Arc recognizes that 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 that schools provide educational support, not medical treatment. As a result, 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 year. 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 is committed to closely monitor the health care reform efforts at the national level. As health care reform 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. We have fought too hard to pass critical health benefit mandates and will continue to fight to protect those services that 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.

### **Meaningful Day**

The Arc of Indiana supports services that are driven by Person Centered Planning and that provide meaningful activities in group and individual settings. The Arc of Indiana will work to ensure the availability of day services for adults with intellectual and other developmental disabilities who are not seeking employment as a primary activity or who need supports beyond employment to achieve their goals.

To assure health, safety and meaningful outcomes, day services must be of the highest quality possible. Therefore, The Arc supports the requirement for developmental disabilities day service providers to obtain accreditation by CARF, The Council on Quality or other equivalent processes.



### **Prevention and Prenatal Education**

The Arc of Indiana supports more prenatal education to be made available to families to help reduce the incidence of all intellectual and other developmental disabilities.

The Arc of Indiana will support efforts to educate the public about the dangers and long term effects of the use of alcohol 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 that address the importance of good prenatal care and folic acid during pregnancy to reduce the risk of intellectual and other developmental disabilities.

The Arc will support efforts that will provide tracking for the prevalence of developmental disabilities and associated environmental causes.

### **Self Advocacy**

The Arc of Indiana believes in a strong self advocates 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 Arc will support the efforts of self advocates as they seek for ways to increase the employment for people with intellectual and other developmental disabilities. The current national employment rate is 22% and we are committed to working with self advocates and the business community to double that rate by 2015.

The Arc of Indiana is committed to helping make public transportation available, especially to people with intellectual and other developmental disabilities. We will continue to monitor efforts of a mass transportation system and will work to ensure access for people with intellectual and other developmental disabilities.

### **Special Education**



The Arc of Indiana will work to ensure that children in special education services in Indiana receive fair and equitable treatment. The Arc will advocate for children with special needs to have the right to be educated along with their peers in an inclusive, educational setting, with appropriate supports, so they may earn a high school diploma to enhance job placement and the continuation of higher education.

The Arc of Indiana supports the expansion and funding of teacher learning and professional development programs in order to meet the wide range of abilities of all students served by our public schools. The Arc of Indiana will work to see that teachers receive adequate training on issues relating to people with intellectual and other developmental disabilities. With significant and systematic changes being proposed for

**teacher training and licensing and school administrator qualifications, The Arc wants to ensure that the education and well-being of students with intellectual and other developmental disabilities will not be compromised.**

**In addition with an estimated 179,000 students in the special education system, it is imperative that teachers understand and know how to educate the students in their classrooms. Therefore, The Arc recommends all potential teachers be required to take classes in special education and all continuing education include special education training.**

**The Arc recognizes the lack of adequate pre-school funding for children in special education. We promise to work with the Department of Education and other organizations to find a way to increase pre-school funding.**

**The Arc of Indiana will advocate with other organizations for the development of a plan by the Commission for Higher Education, the Professional Standards Board, and the Division of Exceptional Learners, to address the severe shortage of special education teachers and related service providers, and to review the limited license certification requirements and procedures as they impact special education.**

**We will continue to monitor the Individuals with Disabilities Education Act (IDEA), Article 7, and No Child Left Behind to ensure that focus remains on academic improvement without diminishing the rights and protections afforded to children with disabilities and their families.**

**With significant changes made to Article 7, The Arc wants to ensure parents are fully informed about their children's education and that no revisions weaken parental rights nor compromise the child's right to a Free Appropriate Public Education (FAPE). As the changes to Article 7 are being implemented, The Arc wants to ensure that students and families are equal partners in developing Individualized Education Plans (IEP).**

**Many parents throughout the state are worried by the "Eleven Day Rule," which automatically implements on the eleventh day after the IEP is drafted unless parents file a formal challenge.**

**The Arc of Indiana will continue to monitor the recent changes in Article 7. The Arc supports efforts to ensure that any changes requiring "written notification" are actually submitted to parents in writing and not just discussed during Case Conference Meetings. In order to avoid miscommunications between schools and parents, The Arc also wants to ensure that any changes made to an Individualized Education Plan (IEP) are clearly delineated and enumerated for parents in writing. The Arc supports a requirement for schools to include challenge procedures along with written notice of any changes made to an IEP within a reasonable time period to take action.**

**The Arc of Indiana recognizes the difficulty in the Zero Tolerance Discipline Procedures adopted by many school systems. The Arc will closely monitor the new school discipline law that was passed earlier this year. We will work with families, students, schools, the Department of Education, as well as the Attorney General's office, to work through the difficulties that arise with special education students.**

The Arc believes that effective planning is critical for students' successful transition from school to work or adult life. The mandated transition IEP should focus on the development of employment skills and should help students connect with Vocational Rehabilitation Services. The Arc will work to ensure that students with disabilities have service options available to them when they complete their high school education and that students' chosen service providers are involved in transition planning before the students graduate.



### **Supported Employment**

The Arc of Indiana supports FSSA's vision of Work First as an outcome of services provided to individuals with intellectual and other developmental disabilities. We will work to ensure that people with developmental disabilities have work opportunities in the community. The employment rate for people with intellectual and other developmental disabilities is estimated at 22%. The Arc of Indiana believes that people with intellectual and other developmental disabilities are capable of filling employment positions in the general work force and supported employment, with long-term supports, and is an effective way of integrating people with developmental disabilities into the general work force. The Arc will support national efforts to increase the employment rate of people with intellectual and other developmental disabilities to 44% by the year 2015. The Arc will work with the state and the Economic Development Corporation to help create incentives for businesses who demonstrate a commitment to integrating people with developmental disabilities into their regular work force.

A major obstacle to people with intellectual and other developmental disabilities working is transportation issues. The availability of mass, public transportation would remove this obstacle and provide a greater opportunity for people with intellectual and other developmental disabilities to work and gain independence.

The Arc of Indiana will monitor the implementation of Results Based Funding to assess its impact on persons with more significant disabilities or support needs. The funding system must adequately address the ongoing support needs of individuals to maintain their community-based employment.

The Arc of Indiana advocates that people with disabilities who receive Medicaid/Supplemental Security Income should be able to set aside part of their earned income, unearned income, or resources to save for a PASS (Plan to Achieve Self-Sufficiency). We realize a PASS can be essential in helping a person become successful when making the transition from being unemployed, to working toward gainful employment. The Arc will work with the Office of Medicaid Policy and Planning to permit PASS plans for all Medicaid recipients who are eligible for this provision.