



The Arc of Indiana 2012 Public Policy Agenda

We *can* build a community that invests in families and supports their loved ones, brings help to people when they need it, keeps families together and builds community.

We *can* build a system that does not just look to government for all the answers, but helps families and people with disabilities help one another – a system that asks for responsible use of public resources, but in return empowers individuals to use those resources in ways that best helps them as an individual, as a family and as a community.

We *can* build a system that looks to righting wrongs rather than simply writing more rules.

We *can* build a system that rewards creativity and quality, provides a fair reimbursement to providers and supports direct care staff with a living wage.

We *can* build a system designed for this century that uses technology, embraces and rewards new ideas and replaces models of the past with modern approaches.

In February, 2010 The Arc of Indiana embarked on a campaign, *Building Pathways to Empowerment*, to look toward new ways of delivering services to people with intellectual and other developmental disabilities in Indiana. Key to this effort is implementing The Arc's Public Policy Agenda.

As we worked with experts from around the country, five initiatives have been set out to map a new course in programs and services for people with developmental disabilities:

- Building Career Pathways for All
- Discovering and realizing Individual Gifts
- Supporting Resourcefulness of Individuals, Families and Government
- Using What You Need
- Shifting the Power to What Works

Key to these initiatives is the understanding that the focus for all needs to be on doing things that add real value to people's lives.

In these difficult times, there are many voices telling us what we can and cannot do. Our founders, those parents of children with intellectual and other developmental disabilities who joined together in 1956 determined to build a better and more accepting world for their children, have taught us that we *can* and *will* continue to build that better world.

The Arc of Indiana remains committed to working with the administration, providers and schools to serve the most people in the most meaningful and cost effective way. We will continue to advocate for a system which does 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 a 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.

Table of Contents

Career Pathways.....	pg. 3
Criminal Justice.....	pg. 4
Direct Support Professionals	pg. 4-5
Early Intervention	pg. 5
Funding.....	pg. 5-6
Guardianship Services.....	pg. 6
Home and Community Based Services and Supports	pg. 6-7
Institutional Settings.....	pg. 7-8
Insurance	pg. 8-9
Meaningful Day	pg. 9
Prevention & Prenatal Education	pg. 9
Public Transportation	pg. 9
Self Advocacy	pg. 10
Special Education	pg. 10-12



Career Pathways

The Arc of Indiana supports career pathways for individuals with intellectual and other developmental disabilities that includes a range of options from full time employment with benefits to meaningful work as a volunteer.

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

The employment rate for people with intellectual and other developmental disabilities working in competitive community jobs is estimated at 22%. The Arc of Indiana believes 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. Working with self advocates and the Alliance for Full Participation, The Arc will be a leader in creating and supporting state and national efforts to increase the employment rate of people with intellectual and other developmental disabilities to 44% by the year 2015. This includes active engagement in systems change efforts and the “Think Beyond the Label” campaign.

The Arc will work with the State and the Economic Development Corporation to create incentives for businesses that demonstrate a commitment to integrating people with intellectual and other developmental disabilities into their regular work force.

A major obstacle to the employment of people with intellectual and other developmental disabilities is transportation. 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 the Objective Budget Allocation (OBA) 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. Follow-along supports, provided within the limits of an individual’s overall resource allocation, should continue as long as they are necessary for job maintenance and should not have arbitrary time limits which may put the person at risk of losing his/her job.

The Arc of Indiana supports efforts to ensure that earnings for people with intellectual and other developmental disabilities must be at a level that encourages self sufficiency. Individuals receiving 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 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.



Criminal Justice

The Arc of Indiana values the rights of people with intellectual and other developmental disabilities to receive equal access to justice within the criminal justice system in order to prevent injustice. The Arc recognizes the increased opportunity for people with intellectual and other developmental disabilities to become involved in the criminal justice system, as suspects, offenders and victims. People with intellectual and other developmental disabilities who are suspects or offenders 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 intellectual and other developmental disabilities who become a victim of a crime or witness to a crime should 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 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 intellectual and other developmental disabilities. The Arc of Indiana will continue to monitor and advocate for the projects which currently exist for educating and training police officers and professionals involved in the criminal justice system.

The Arc of Indiana will work with experts in the criminal justice field to explore the development of alternative programs to incarceration for people with intellectual and other developmental disabilities 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 an intellectual or other developmental disability, applicable alternative programs and rehabilitative options need to be available.

The Arc of Indiana will work within the Partners in Equal Justice to explore the development of an alternative program to incarceration for people with intellectual and other developmental disabilities who commit crimes.

Direct Support Professionals

The Arc of Indiana recognizes the importance of a high quality workforce of Direct Support Professionals (DSP). The ability to hire, train and retain quality staff is vital to the growth, sustainability and quality of community services for people with intellectual and other developmental disabilities. Longstanding challenges in having adequate numbers of DSPs are of growing concern because the number of people seeking community services is increasing while wages do not adequately compensate qualified workers. The Arc of Indiana supports all efforts to ensure a living wage for Direct Support Professionals that is competitive with other jobs for which the professionals are qualified. Reimbursement rates for providers should support attractive wages and benefits for this important workforce.

In addition, the Arc of Indiana will support efforts by the State to provide substantial and ongoing training and the development of a career path designed to attract and retain direct support professionals. Indiana's innovative workforce development program, the Direct Support Professionals Project initiated in 2007, was eliminated in 2012 due to budget cuts. Through this model project, DSPs from nine phase-one agencies received best-practices orientation as well as opportunities to advance their skills and 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 statewide.



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, 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 an adequate number of qualified and appropriate 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 remove children from services who are already recognized as meeting eligibility and in need of services.

The Arc is committed to making sure families have access to the First Steps program and are not inhibited by ability to pay the cost participation fee, insurance or any other factor. We strongly believe the commitment to early intervention services is paramount and must continue to be a priority for our children.



Funding

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

The Arc of Indiana realizes the demands for state funds are great, however we also feel strongly 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 which will help people with intellectual and other developmental disabilities achieve their goals. The Arc of Indiana will work with the state to find ways to support individuals with disabilities, families and extended families that fosters resourcefulness.

The Arc will continue to advocate for the state to reinvest any savings from making services and supports more cost effective to provide more opportunities for people to receive supports if they need them.

The Arc of Indiana is committed to making sure crisis response is available to support people in dire need.

Despite the current climate against new taxes or increased taxes, The Arc must remain open to discussing all options for revenue generation, including new or increased taxes which address growing and unmet needs in our state.

The Arc of Indiana will continue to monitor the objective budget allocation (OBA) which was implemented to fairly determine an individual's budget necessary to meet their needs. The system must be determined through accurate assessment and justifiable, predictable formulas which 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.

The Arc of Indiana will continue to work with the State to identify areas of cost-savings in the system which we feel do not jeopardize the health and safety of individuals with intellectual and other developmental disabilities. We will continue to make sure dollars follow the individual in every possible circumstance.

Guardianship Services

Guardianship services can be very important to individuals with intellectual and other developmental disabilities to assure they have the supports necessary to remain healthy and safe in the community. With the closure of Indiana's state institutions, the need for guardianship services has increased.

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

The Arc of Indiana believes Indiana should invest in guardianship. It is estimated that 50% of people with intellectual and other developmental disabilities receiving services have no family or guardian advocating on their behalf. Indiana would benefit from a statewide guardianship program that would provide opportunities for guardianship to people with intellectual and other developmental disabilities who need someone to advocate for their best interest.



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 outlined in *Indiana's Comprehensive Plan for Services for People with Developmental Disabilities*. While nearly 18,000 people receive Medicaid waiver services in Indiana, there are still nearly 20,000 people waiting. Over the last several years, we have seen movement in the Medicaid waiver waiting lists; however, too many families remain in need of vital services and supports. The Arc of Indiana supports efforts to improve the process of applying for a Medicaid Waiver and keeping the waiting list updated. We are committed to helping families realize the natural supports that already exist in their communities while they wait for waiver services.

The Arc of Indiana will support a model of family and community resourcefulness as families cannot depend on government services alone. We must work within local communities to identify ways to support individuals with intellectual and other developmental disabilities. We will work with families and individuals with intellectual and other developmental disabilities on the cultural shift of using only what you need so more is available to others who continue to languish on waiting lists.

The Arc of Indiana remains committed to making sure priorities remain for the Developmental Disabilities Waiver and the Support Services Waiver. Individuals with care givers over the age of 80, 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.

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

It is critical for consumers and families to have choices and knowledge about their rights. The Arc of Indiana will continue to work with the State and self-advocates to develop guidelines for the State's self determination initiatives.



Institutional Settings

The Arc of Indiana is proud that Indiana is the largest state to no longer operate state institutions for people with intellectual and other developmental disabilities. However, too many people with intellectual and other developmental disabilities reside in nursing facilities, state operated facilities for people with mental illness and large, private group homes (ICF/MR). 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. The Arc will oppose any efforts to create more large private institutions.

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 sufficient funds are provided, both for initial appropriate placements and ongoing services. We will work aggressively with other organizations and Task Forces to eliminate institutional biases which exist within the State's budget system.



Insurance

The Arc of Indiana strongly believes that people with intellectual and other developmental disabilities must have quality health insurance available to them. In addition, The Arc will work to ensure 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.

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

Health insurance and health insurance mandates were designed to provide individuals with the medical care they need to live 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 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 laws. We will closely monitor movement on the issue of Assignment of Benefits to make sure people with intellectual and other disabilities are not adversely affected.

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. 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 monitoring the implementation of the federal health care 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 has fought too hard to pass critical health benefit mandates to insure that people with intellectual and other developmental disabilities have access to services

they need. The Arc of Indiana will continue to fight to protect those services people depend upon. We will continue to look at ways to support and move forward other insurance initiatives to expand coverage to all people with intellectual and other developmental disabilities.

Meaningful Day

The Arc of Indiana supports day services that provide substantive and sustained opportunities for people with intellectual and other developmental disabilities to realize self-empowerment; to experience lifelong learning; to achieve optimal health; and to develop relationships through community inclusion; whether in employment, classroom or community-based settings. The Arc will work to promote and ensure the availability of these meaningful day services, driven by Person-Centered approaches, to accomplish these outcomes in all Indiana communities.



Prevention and Prenatal Education

The Arc of Indiana supports more prenatal education to be made available to families to help reduce the incidence of 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, tobacco and controlled substances during pregnancy. Alcohol is known to be the leading *preventable* cause of intellectual disabilities. Recent research has implicated smoking in increasing the risk of intellectual and other developmental disabilities. Other risks include malnutrition, certain environmental toxins and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphilis.

We will support efforts to increase the awareness of fetal alcohol syndrome, shaken baby syndrome, and lead poisoning. We will also support efforts which address the importance of good prenatal care and folic acid supplementation during pregnancy to reduce the risk of intellectual and other developmental disabilities.

The Arc will support efforts that track the prevalence of intellectual and other developmental disabilities and associated environmental causes.

Public Transportation

People with intellectual and other developmental disabilities depend on public transportation in their local communities. They use public transportation to get to work, to attend medical appointments and to patronize local businesses.

The Arc of Indiana supports efforts to secure the availability of quality and dependable public transportation throughout local communities in the state. Every dollar invested in public transportation has a \$6 return to the economy.

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

Self-Advocacy

The Arc of Indiana believes in a strong self advocate organization. We will continue to work along-side Self-Advocates of Indiana and partner with them in seeking additional resources to reach their goals.

The Arc will support the efforts of self-advocates as they seek 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 will support self advocates and they are encouraged 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 available in local communities for people with intellectual and other developmental disabilities

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 toward implementing a more comprehensive mass transportation system that ensures access for people with intellectual and other developmental disabilities.



Special Education

The Arc of Indiana will work to ensure children in special education services in Indiana receive fair and equitable treatment. The Arc will advocate for children with intellectual and other developmental disabilities to have the right to be educated along with their peers in an inclusive educational setting, with appropriate supports, accommodations and modifications so they may earn a high school diploma to allow them the option of choosing post-secondary education to enhance career opportunities.

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

The Arc of Indiana supports the expansion and funding of educator learning and professional development programs in order to meet the wide range of abilities of all students served by our public, charter and private schools. The Arc of Indiana will work to see educators receive adequate training on issues, programs and opportunities relating to people with intellectual and other developmental disabilities.

With significant and systematic changes being implemented for teacher training, teacher evaluations and licensing, and school administrator qualifications, The Arc will work to ensure the education and well-being of students with intellectual and other developmental disabilities will be enhanced, not compromised.

In addition, with an estimated 179,000 students in the special education system, it is imperative educators, administrators, school boards and legislators understand the successful and cost efficient ways to educate students with individualized education plans (IEP) in their classrooms with their peers. Therefore, The Arc recommends all potential educators be required to take classes in special education and all continuing education include special education training.

The Arc recognizes the lack of adequate preschool funding for children in special education. We will work with the Department of Education and other organizations to find a way to increase preschool 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 the focus remains on academic improvement without diminishing the rights and protections afforded to children with intellectual and other developmental disabilities and their families.

The Arc wants to ensure parents are fully informed about their children's education and nothing weakens parental rights nor compromise the child's right to a Free Appropriate Public Education (FAPE). The Arc wants to ensure students and families are equal partners in developing individualized education plans and that the case conference committee is the deciding stakeholder in the IEP and educational process. We will continue to educate parents to be aware of the "Eleven Day Rule" within Article 7 and the need to be a persistent advocate in the shaping of the IEP during the course of the year. The Arc supports efforts to ensure any changes requiring "written notification" are actually submitted to parents in writing and not just discussed during Case Conference Committee meetings. In order to avoid miscommunications between schools and parents, The Arc also wants to ensure any changes made to an 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 of Indiana will closely monitor the use of seclusion and restraints in Indiana's education programs and will advocate for proper training, documentation and notification.

The Arc of Indiana realizes the effects of bullying in schools and the potential of students with intellectual and other developmental disabilities to be victims of bullying. We will work with schools and educators to make sure that appropriate measures are taken to decrease the incidence of bullying.

The Arc believes 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 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 the students graduate.

The Arc of Indiana realizes the difficulty placed on schools through recent cuts in funding. We will continue to work with the Department of Education to ensure special education students are not being disproportionately harmed due to budget constraints. As many schools consider passing referendums to help with funding, The Arc of Indiana will monitor the passage of referendums to ensure that special education programs receive the appropriate portion of any generated funds. We will continue to work with the Department of Education as they develop their school performance measures to ensure that parent surveys remain an important role in the process.