



**The Arc**

For people with intellectual  
and developmental disabilities

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## State Advocacy Matters



### INTRODUCTION

One of The Arc's 2015 priorities is to strengthen our national network by improving our tracking of all the important work our chapters are doing across the country and beginning to share this information with all of you on a regular basis. In this vein, we are launching the inaugural "State Policy Matters" newsletter. This edition compiles information (arranged by topic) that we received in late 2014 from state chapters regarding their 2014 accomplishments and 2015 priorities in legislation, policy, and advocacy work. This newsletter will be published quarterly.

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## ABUSE AND NEGLECT

### 2014 Updates

- **The Arc of New Jersey** helped secure the passage of “The Protection for Individuals with DD in Institutional and Community Settings Act – Expansion of Tara’s Law.”
- **The Arc of Tennessee** helped to secure the passage of a bill creating an elder abuse task force and requiring the clerk of the court to notify the Department of Health where individuals have been convicted of abuse, neglect, misappropriation, or exploitation of the property of vulnerable individuals.
- **The Arc of Minnesota** helped to secure the passage of “Safe Schools for All,” an anti-bullying bill.

### 2015 Priorities

- **The Arc of Pennsylvania** plans to support the continued funding of the Adult Protective Services Act of 2010 and call on the governor and Department of Public Welfare to prioritize the full implementation of an Adult Protective Services system.

# COMMUNITY SUPPORTS



## 2014 Updates

- **The Arc of Delaware** (along with other disability agencies) worked with the state to plan for the development of additional quality standards for providers of HCBS to persons with I/DD.
- **The Arc of Maryland** helped secure the passage of a budget with \$2.6 million in waiting list funding to help nearly 100 people in the Crisis Resolution category of the waiting list obtain services as well as funding a Waiting List Equity Fund to help 37 individuals with the oldest caregivers receive community supports. The budget also allocated \$4.5 million to low intensity support services (helping 2,200 families) and \$1 million for emergency funds for those previously unknown to the state.
- **The Arc of Massachusetts** helped secure the passage of the “Autism Omnibus Act”—which enables individuals with I/DD, Autism, Prader-Willi Syndrome, and Smith Magenis Syndrome to receive adult services through the state—and the “Real Lives Bill,” which allows for flexibility and choice for individuals with I/DD receiving state funding to allow them to stay in the community.
- **The Arc of New Jersey** helped secure the passage of a bill requiring that the state provide an individual with I/DD transitioning to a community placement as a result of the closure of a developmental center with a comparable level of services and supports within 30 miles of the closed center (which can be waived if the individual chooses to live outside of this radius). **The Arc of New Jersey** also helped secure the Governor’s decision to close two developmental centers and signed onto an amicus brief in support of these closures and helped secure the passage of a budget that included over \$100 million in new state and federal funding for adult supports and services.
- A representative from **The Arc of Tennessee** was appointed to “TennCare” – the state task force on Long Term Supports and Services.
- **The Arc of Washington** helped secure passage of a bill that refinances Medicaid Personal Care through the Community First Choice Option, bringing an extra 6% in matching federal funds.
- In 2014, **The Arc of New Mexico** brought a lawsuit in federal district court (*Waldrop, et al. v. New Mexico Human Services Department, et al.*) seeking a preliminary injunction ordering defendants to return the DD Waiver program to the status quo that existed prior to the implementation of the Supports Intensity Scale, including an order prohibiting defendants from terminating or reducing any DD Waiver services until they provide the recipients with notice and a fair hearing. In March 2015, the court granted plaintiffs’ motion for preliminary injunction.
- **The Arc of North Carolina** helped secure passage of a bill ensuring that all Innovations waiver slots are portable and follow the individual being served regardless of where they move within the state and removing Medicaid county of origin and replacing it with Medicaid county of residence for individuals being served under the 1915 b/c waiver.

## 2015 Priorities

- **The Arc of Delaware** has a representative serving on the DDS Advisory Committee for Development of Family Support Waiver.
- **The Arc of New Jersey** plans to support and monitor the planned closure of Woodbridge Developmental Center.
- **The Arc of Pennsylvania** has called on the Department of Public Welfare to close the five remaining state-run institutions by relocating all residents to community living and to publicly post a quarterly list of the numbers of admissions and transitions and has called on the General Assembly to restore the 10% budget cut to human services funding.
- **The Arc of Tennessee** plans to push for the reintroduction of legislation targeting those on the waitlist with aging caregivers.
- **The Arc of Indiana** will continue to closely monitor the Level of Care Screening Instrument to ensure fair and accurate outcomes and will encourage the state to replace this instrument with a nationally normed and reliable eligibility tool.



# EDUCATION

## 2014 Updates

- **The Arc of Maryland** helped secure passage of bills reaffirming the obligation of local school systems to have a bus attendant ride the bus with a student with a disability if it is required under the student's IEP or 504 plan and requiring that at a child's initial IEP meeting, a parent or guardian be given information "in plain language" about the parent's rights and responsibilities in the IEP process and procedural safeguards. The bill also requires schools to post a list of all special education programs offered by a school system on their website and information on how placement decisions are made and specifies that all placement decisions must be made in consultation with students' parents and in recognition of Least Restrictive Environment requirement of the IDEA.
- **The Arc of New Jersey** secured an appointment on the Governors' Task Force on Improving Special Education for Public School Students, helped secure passage of bills establishing Disability History and Awareness Month and providing equal opportunity in team sports for students with disabilities, and served as a plaintiff in a federal lawsuit against the state to ensure that special education students are served in the least restrictive environment. The settlement requires the state to ensure that the districts with the lowest rates of inclusion follow through on remediation plans.
- **The Arc of North Carolina** helped to secure passage of a bill that made necessary changes to exemptions for students with an IEP that were previously served by alternate testing options.
- **The Arc of Tennessee** helped secure passage of bills adding the administration of insulin to medications school personnel may volunteer to administer and requiring the state to convene a task force to study and make recommendations regarding the accessibility of digital curricula for students with disabilities at state-funded colleges and universities.
- **The Arc of Washington** helped secure the passage of bills requiring accountability for providing opportunities for students receiving special education services to participate in transition services and requiring the creation of a para-educator training work group with the State Board for Community and Technical Colleges and Professional Educator Standards Board.

## 2015 Priorities

- **The Arc of New Jersey** plans to work to amend and expand a bill to offer more protection from restraint and seclusion in special education programs throughout the state and plans to serve on the Special Education Task Force which will deliver a report to the governor.
- **The Arc of Indiana** will work to ensure that educators receive adequate training on behavioral management issues and will support the expansion and funding of educator learning and professional development programs.

# EMPLOYMENT



## 2014 Updates

- **The Arc of Maryland** helped secure the passage of a budget with \$5.1 million in funding to provide employment services to nearly 600 young adults with disabilities who are leaving school and helped block passage of a bill requiring employees to choose to take a lower wage or lose their SSDI benefits.
- **The Arc of North Carolina** helped secure the passage of a budget that included funding for a Joint Education Oversight Committee study on transitions and vocational opportunities for students with I/DD.
- **The Arc of Pennsylvania** has partnered with Mark Gold & Associates to offer an alternative vocational assessment program entitled “Discovery: A Path to Customized Employment” geared towards transition age students (14-21\_ with I/DD planning for life beyond school. Discovery seeks to understand the strengths, needs, and weaknesses of an individual to better help him/her find customized employment that is competitive and fulfilling.
- **The Arc of Indiana** worked to ensure that funding was provided to support individuals in maintaining their community-based employment.

## 2015 Priorities

- **The Arc of Delaware** will continue to participate in the vocational committee for the Pathways to Employment program.
- **The Arc of Maryland** will investigate and develop a best practices guide for the elimination of the use of 14(c) certificates through a subminimum wage working group and push to have a bill introduced to prevent employers who access the tax credit from firing people with I/DD absent documentation justifying the termination.
- **The Arc of Texas** seeks to ensure that funding, policies, and training promote opportunities for individuals with I/DD to be employed in community settings alongside people without disabilities, earn competitive wages, are supported to make informed choices about their work and careers, and have the resources to seek, obtain, and be successful in community employment.
- **The Arc of North Dakota** will advocate for the need for additional job coaches and career planning in the Vocational Rehabilitation budget.
- **The Arc of Indiana** will continue to monitor the Objective Budget Allocation to assess its impact on persons with I/DD and will work to ensure that the needs of individuals with I/DD in community-based employment are met.
- **The Arc of Illinois** will work with the Governor’s Employment Task Force in the implementation of Employment First.



# HEALTH

## 2014 Updates

- **The Arc of Maryland** helped secure the passage of bills requiring that parents receive information outlining the right of an individual born with a disability to receive reimbursement for habilitative services from health insurance companies until age 20; establishing the Behavior Analyst Advisory Committee within the State Board of Professional Counselors and Therapists to ensure that effective community-based therapeutic treatment resources and services are available and properly utilized; and requiring the Medical Assistance Program to provide certain services by telemedicine and repeal limitations on the health care services delivered by telemedicine that are eligible for reimbursement.
- **The Arc of Massachusetts** helped secure the passage of the Autism Omnibus Bill which extended health services at MassHealth for critical therapies and communication devices.
- **The Arc of New Jersey** helped secure the passage of a bill prohibiting discrimination against potential organ transplant recipients on the basis of disability, participated in advocacy supporting the reinvestment of all Medicaid waiver funds, and helped secure the passage of a bill requiring the Commissioner of Health to review the impact of disabilities on minority and underrepresented communities.
- **The Arc of Tennessee** helped secure passage of bills that create an Autism Spectrum Disorder Task Force to study and make recommendations to the General Assembly regarding ways to improve access to programs and services for early screening, diagnosis, and treatment.
- **The Arc of Washington** participated in advocacy to have the state Health Care Authority add reimbursement for developmental and autism screenings to the Medicaid plan.

- **The Arc of Indiana** worked with the Healthcare Exchange Task Force to ensure that issues important to people with I/DD were addressed.

## 2015 Priorities

- **The Arc of North Carolina** plans to work to support a bill that would fund a study on how best to integrate physical health for people with I/DD being served under the four regional local management entities-managed care organizations.
- **The Arc of New Jersey** plans to participate in advocacy related to the state's implementation of Medicaid waivers, develop a position paper on Medicaid Managed Long Term Care for people with I/DD, and will continue to advocate for people with I/DD who have been unable to obtain Medicaid.
- **The Arc of Indiana** will work to ensure that local jails allow individuals with I/DD who have recently been arrested to have access to their medication, will work with the Office of Medicaid Policy and Planning and the local medical community to make sure people with I/DD have access to primary care physicians and medical specialists in their local communities, and will continue its work on the Healthcare Exchange Task Force.
- **The Arc of Illinois** will work on a bill with the Down Syndrome Association that will require the Department of Public Health to provide information for parents and families regarding Down Syndrome to local health care providers and genetic counselors and will work on reforming the state Medicaid Plan to render anyone receiving SSI based on disability to be automatically enrolled in Medicaid without having to fill out a separate application.





## HOUSING

## PROVIDERS



### 2014 Updates

- **The Arc of Connecticut** participated in the I/DD Caucus and the Families for Families Campaign to help secure \$4.4 million for the state's residential waiting list, which was the first time the state put money into the waiting list in over 20 years without a lawsuit, and joined the Waiting List Working Group to identify challenges families face in accessing residential services and propose solutions.
- **The Arc of New Jersey** helped secure passage of a bill requiring the state's Division on Civil Rights to post information regarding disability rights for owners and occupants of condominiums, cooperatives, and other common interest communities.

### 2015 Priorities

- **The Arc of Connecticut** plans to work to annualize the waitlist appropriation provided in 2014, to assist with efforts to close Southbury Training School, and ensure that the state redirects funds to move individuals to community-based living arrangements.
- **The Arc of New Jersey** plans to work more closely with housing advocacy organizations to increase residential opportunities for individuals with I/DD.
- **The Arc of North Dakota** seeks to further reduce the population of the Life Skills and Transition Developmental Center and help individuals transition to community based living arrangements.
- **The Arc of Illinois** will continue to advocate for an end to the state waiting list, closure of state developmental centers, implementation of the Illinois Ligas v. Hamos Class Action Consent Decree, and the transition of people with I/DD into the community.

### 2014 Updates

- **The Arc of Maryland** helped to secure passage of a bill requiring the State Board of Nursing to establish a program through which the Criminal Justice Information System reports all new and additional criminal history information to the board for an applicant who has been fingerprinted for a criminal history records check required by the board; helped secure passage of bill raising the minimum wage and worked with a disability coalition to advocate for a proportionate increase in the hourly wages paid to direct support staff of disability services provides to ensure that such jobs do not become minimum wage jobs.
- **The Arc of Massachusetts** helped to secure the passage of a background check bill that ensures that those accepting jobs with individuals served by the state will be subject to full criminal background checks.
- **The Arc of Delaware** helped to secure over \$1 million in funding (to be doubled by Medicaid matching dollars) to fund the deficit to state service provider agencies despite substantial reductions in state revenue.
- **The Arc of Washington** helped secure a rate increase of 30 cents per hour for supported living providers.
- **The Arc of Minnesota** chaired a successful campaign that secured \$86 million in state money (to be matched by federal dollars) to increase pay rates for direct support staff.

### 2015 Priorities

- **The Arc of Connecticut** will work to secure funding in the state budget to bring low rate providers up to a normalized rate system and will work to change the system to allow providers to support other individuals with money saved by utilizing less costly supports rather than having to return the savings to the state.
- **The Arc of Delaware** will participate in developing a report for the Joint Finance Committee that will outline a plan for the development of quality standards for providers of HCBS to serve as a basis for future provider reimbursement incentives.
- **The Arc of Indiana** will work to support all efforts to ensure a living wage for Direct Support Professionals and seeks to reinstate the Direct Support Professionals Project that was eliminated in 2012 due to budget cuts.
- **The Arc of Illinois** will continue to advocate for increasing the wages and benefits of direct care professionals through the Care Campaign.



# VOTING RIGHTS

## 2014 Updates

- **The Arc of Maryland** helped to block the passage of a bill requiring all voters to provide proof of residency with a state-issued ID card or with a lease, utility bill, or bank statement.
- **The Arc of New Jersey** implemented a comprehensive election year strategy to educate individuals with I/DD and the wider community about candidates, issues, and polling places and created and distributed an election guide for self-advocates.
- **The Arc of California** helped secure the passage of a bill restoring voting rights to individuals with I/DD who are under conservatorship.

## OTHER



- **The Arc of Maryland** helped secure the passage of a bill requiring police officers to receive training on interacting with individuals with I/DD.
- **The Arc of New Jersey** helped secure the passage of a bill calling on the U.S. Senate to ratify the CRPD.
- **The Arc of Connecticut** created a bi-partisan I/DD Caucus that included over 40 legislators and was led by the chair of the Appropriations Committee.
- **The Arc of New Jersey** advocated for the removal of people with I/DD from eligibility in assisted suicide programs and helped secure the passage of a bill establishing the Gold Alert System for missing persons with I/DD.
- **The Arc of Tennessee** helped to create a task force on parking for people with disabilities.
- **The Arc of Washington** helped secure passage of a bill requiring the Children's Administration to make reasonable efforts to work with the state to assist parents with I/DD who are going through dependency hearings and helped secure passage of a bill allowing dependents of military service members to retain eligibility for I/DD services when transferred out of state.
- **The Arc of Texas** is working to support guardianship reform policies.
- **The Arc of Pennsylvania** helped secure the passage of a bill to change the name of the Department of Public Welfare to the Department of Human Services because of the stigma of the word "welfare."
- **The Arc of North Dakota** plans to study the effects of the SSI marriage penalty on married individuals with I/DD who receive less SSI payments than they would if they were not married.
- **The Arc of Indiana** advocated for training law enforcement and first responders on how to interact with people with I/DD and is working with criminal justice experts to explore the development of alternatives to incarceration for people with I/DD.
- **The Arc of Illinois** will work on legislation addressing the treatment of persons with I/DD in the criminal justice system as well as police training, will form a task force with various stakeholders, such as public defenders, prosecutors, and judges, and will work with the Illinois Assistive Technology Project and the Coleman Institute in drafting a legislative resolution on the rights of people with I/DD to technology and information access.