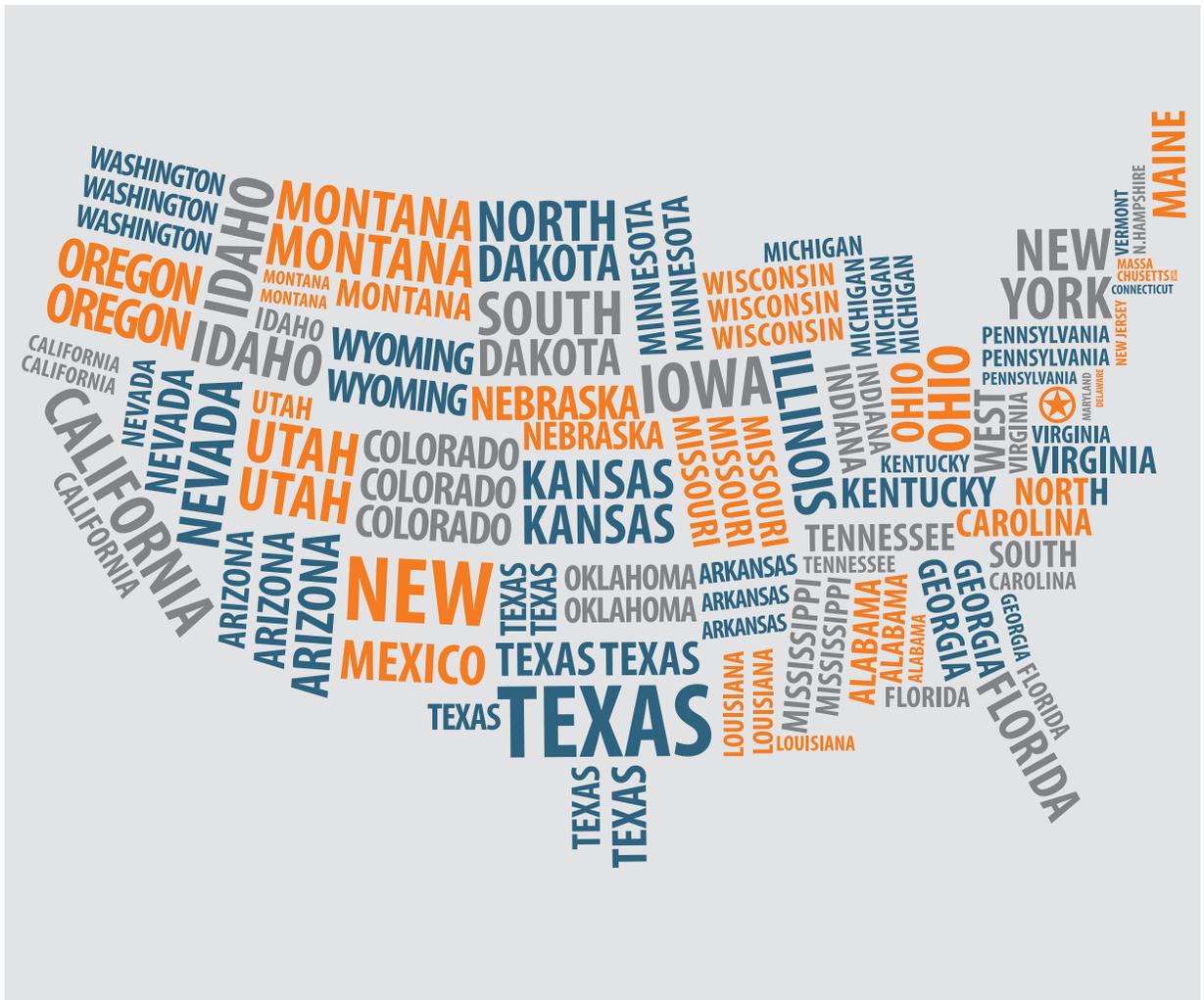




For people with intellectual and developmental disabilities

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State Advocacy Matters



1825 K Street NW
Suite 1200
Washington, DC 20006

800.433.5255
thearc.org

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ABUSE AND NEGLECT



The Arc of Washington State helped secure the passage of [SB 6564](#), “Laura’s Act”, which mandates that the state’s Department of Social and Health Services (DSHS) identify 500 clients who are at risk of abuse and neglect, assign these individuals a case manager, and visit these clients three times per year. DSHS is also required to review cases with poor outcomes to ensure such outcomes will be prevented in the future and holds DSHS case managers and their supervisors accountable when a client experiences abuse due to their negligence. The bill was introduced after DSHS investigators found that Laura Gholston—a 48-year-old woman with I/DD—was severely abused by her sole caregiver over the course of seven years. The annual visits from her DSHS case manager failed to raise any red flags about her deteriorating condition. In

an [article](#) on the passage of the Act, Diana Stadden—The Arc of Washington’s Policy and Advocacy Coordinator—stated that “All of these situations and many others could have been found much earlier and even prevented if some of the provisions of the bill had been in place.”

The Arc of New Jersey helped secure the passage of S157/A1120, a bill that establishes a task force to better protect senior citizens and people with disabilities from abuse. The law was signed by Governor Chris Christie in May 2016. The task force is charged with evaluating current protection policies, identifying inadequacies, and submitting a report of its findings and recommendations to the Governor and the legislature.

CIVIL RIGHTS



The Arc of Maryland:

- ▶ In April 2015, The Arc of Maryland (as well as The Arc of the United States) signed on to an [amicus brief](#) filed in the Fourth Circuit Court of Appeals in support of the plaintiff in the case *National Federation of the Blind v. Lamone*. Here, the Maryland Board of Elections appealed the district court’s ruling requiring it to make its online ballot-marking tool accessible to voters with disabilities by allowing these voters to mark absentee ballots online for printout and mailing to the Board of Elections. The amicus brief requested that the Fourth Circuit affirm the district court’s decision that the Board’s refusal to use the accessible online ballot marking tool violated the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. In February 2016, the Fourth Circuit [affirmed](#) the district court ruling, stating that “We have little trouble concluding from the record before us that Maryland’s

absentee voting program does not provide disabled individuals an ‘opportunity to participate equal to that afforded others, ...Ensuring that disabled individuals are afforded an opportunity to participate in voting that is equal to that afforded others helps ensure that those individuals are never relegated to a position of political powerlessness.”

- ▶ Poetri Deal, Director of Public Policy & Advocacy-Community Services, [testified](#) in opposition to HB404/SB418, bills seeking to legalize physician-assisted suicide. Deal stated that “People with intellectual and developmental disabilities have historically faced discrimination and lack of access to medical care based on their perceived value...Assisted suicide raises significant concerns for people with disabilities as well as those who will acquire a disability as a result of a terminal diagnosis who are perceived as less valuable.” The bill was defeated.

CIVIL RIGHTS



In an important fair housing victory, **The Arc of Delaware** recently settled a disability discrimination complaint against Sugar Maple Farms Property Owners' Association, Inc. (SMFPOA). The complaint, filed in March 2015 with the U.S. Department of Housing and Urban Development (HUD) and the Delaware Division of Human Relations (DHR) sought a declaration that SMFPOA violated the Fair Housing Act when it refused to approve The Arc of Delaware's acquisition of property meant to house four individuals with I/DD in a single family home integrated within the community. The complaint sought damages to compensate for the loss of housing opportunities and for violations of the federal and Delaware Fair Housing Acts due to disability discrimination. After DHR issued a finding of discrimination in March 2016, SMFPOA agreed to settle the case and entered into a Conciliation Agreement with DHR, HUD, and The Arc of Delaware in May 2016. Among

other things, the Conciliation Agreement requires SMFPOA to provide written compliance reports to DHR and HUD upon request, ensure that its members receive training on the Fair Housing Act, and pay The Arc of Delaware \$55,000 in damages. More details about the case can be found in the [press release](#) and Executive Director Terry's Olson's statement in this newsletter. The civil rights law firm Relman, Dane & Colfax served as lead counsel on the case, with **The Arc of the United States** and Community Legal Aid Society, Inc. serving as co-counsel.

The Arc of Minnesota [testified](#) before the Senate Health, Human Services, and Housing Committee in opposition to SB1880, a bill seeking to legalize physician-assisted suicide. [The bill was pulled](#) from further consideration and will not be heard by the Committee again this session.

COMMUNITY LIVING



After more than two years of intensive advocacy efforts, **The Arc of California**, as part of the Lanterman Coalition, helped secure a plan from the state to implement new rates and programs that will result in approximately \$500 million in new money for the community services system for those with I/DD.

In conjunction with the Minnesota Disability Law Center and Association of Residential Resources in Minnesota, **The Arc of Minnesota** helped secure passage of legislation that eliminated the disincentives that caused counties and the state to manage the waiver programs ineffectively, resulting in 5,000 individuals on the waiting list. The *Star Tribune* [reported](#) that as a result of this legislation, the waiting lists have been reduced dramatically. In addition, Senior Public Policy Director Steve Larson, co-chair of the Best Life Alliance—a campaign to increase wages by 5% for the nearly 100,000 direct support professionals (DSPs) statewide—helped organize and spoke at rallies in support

of the Best Life Alliance Bill, SF 2310/HF 2706. Larson also testified before several House and Senate Committees in support of the bill. Coverage of some of these advocacy efforts can be found [here](#).

The Arc of Illinois:

- ▶ Executive Director Tony Paulauski [testified](#) before the Senate Appropriations Committee in opposition to the proposed state budget, requesting more funding for individuals with I/DD, calling on the state to close remaining institutions, and requesting to raise the wage of DSPs, among other issues. Additional coverage of The Arc of Illinois' work to raise the wages of DSPs can be found [here](#).
- ▶ Worked with the Illinois Council for Intellectual and Developmental Disabilities and the Corporation for Supportive Housing to produce a [Supportive Housing Workbook](#) for People with Intellectual and Developmental Disabilities and their Families. This

COMMUNITY LIVING



Workbook assists families in selecting affordable housing that allows individuals with I/DD to utilize person-centered support services required to live independently. If appropriate housing does not exist, the Workbook lays out a strategy that families can follow to ensure developers create appropriate housing in the local community.

The Arc of Michigan, as part of a coalition for the Partnership for Fair Wages, recently published a report entitled “[Recruitment and Retention Challenges for the Workforce Delivering the Most Frequently Used Supports and Services](#),” which describes the issues involved in retaining high quality DSPs for individuals with I/DD. The report concludes that “immediate actions are needed to address the current and worsening staffing challenges and that other state policy changes are needed in the long-term,” such as increasing wages and developing a campaign to build public awareness and appreciation of the work performed by DSPs.

The Arc of New Jersey:

- ▶ Testified in support of S2640 which would establish a New Jersey Caregiver Task Force to evaluate and provide recommendations on caregiver support services. The Arc of New Jersey is included in the legislation and would serve on the Task Force as a representative for people with I/DD. Once established, Task Force members would be required to identify existing caregiver support services available in the state, identify and survey caregivers, and solicit testimony from caregivers about the types of caregiving tasks they perform. After completing these requirements, the Task Force would issue a report with recommendations.
- ▶ As part of The Arc of New Jersey’s Family Institute’s Family Caregivers Awareness Month celebration, a group of families traveled to the capital and spoke to more than 35 legislators about the challenges associated with caring for a family member with I/DD, the importance of respite, the length of the waiting list, and the need for housing. Family representatives were honored and presented with a resolution at the start of the Assembly Human Services Committee meeting.
- ▶ Executive Director Tom Baffuto and Board President,

Robert Hage, testified before the Senate Budget Committee about the impact of the budget on individuals with I/DD. In addition to advocacy surrounding the waiting list and housing vouchers, they urged Budget Committee members to take action in response to the low wages paid to DSPs. The Record [quoted](#) Hage stating “The starting salary for these workers is just barely \$10 an hour, yet they are asked to do a tremendously important job.”

In January, Jamie Liban, Executive Director of **The Arc of Virginia**, provided [comments](#) to the members of the House Appropriations Subcommittee on Health and Human Resources, encouraging support for the redesign of the I/DD waiver program and for proposed amendments that would cut the waiting list in half.

The “Parent to Parent” [bill](#) was signed by Washington Governor Jay Inslee in April 2016. This bill codifies **The Arc of Washington State’s** Parent to Parent program into state statute and secures funding to support the program. The “Parent to Parent” program matches parents of individuals with I/DD who are seeking support with an experienced and trained support parent who educates them about effective advocacy tools and strategies.

NYSARC’s Executive Director Steve Kroll [testified](#) before the Joint Legislative Hearing of the Senate Finance and Assembly Ways and Means Committees on the FY 2017 budget, recommending funding the first year increase in the minimum wage and a 3% cost of living increase for DSPs. Kroll warned that failure to provide for this would lead to “diminishing the quality of care to tens of thousands of New Yorkers with Down syndrome, cerebral palsy, autism, and neurological impairments...The State needs to meet its statutory obligations to support people with developmental disabilities and proportionately fund the not-for-profit developmental disabilities sector with the same wage increases that have been already established for fast food workers and are proposed for all workers in the state budget.” Kroll later appeared on [Capital Tonight](#) to discuss the issue and [published an op-ed](#) in the Albany Times Union. NYSARC’s advocacy ultimately helped

COMMUNITY LIVING



secure the passage of a [budget](#) that, among other things, secured funding to bring the wages of DSPs up to the new minimum wage rate.

The Arc of Maryland helped secure the passage of \$1.1 billion for the state's Developmental Disabilities Administration (DDA), a 6% increase from last year's budget, which was recently signed by Governor Larry Hogan. Executive Director Cristine Marchand noted: "While approximately 8,000 children and adults with developmental disabilities remain on the DDA Waiting List,

the Governor's budget brings hope to those on the waiting list in the most dire situations."

The Arc of Massachusetts' Maura Sullivan, Director of Governmental Affairs, [testified](#) before the Ways and Means Committee to call attention to the shortfalls in the budget line items for individuals who are turning 22 and transitioning out of the system, noting that many require a combination of supports and services with regards to things like employment and transportation.



COMMUNITY ORGANIZING

The Arc of Minnesota developed a "[Take Action](#)" page on its website that provides tips to advocates on communicating effectively with legislators and a "[Tell Your Story](#)" app, among other resources.

In honor of its 60th Anniversary, **The Arc of Indiana** has initiated a #60Stories60Years campaign to share photos and stories of people with I/DD as well as their families and caregivers.

As part of **The Arc of Tennessee's** advocacy efforts, Governor Bill Haslam issued a [proclamation](#) declaring March as Developmental Disabilities Awareness Month.

The Arc of New Jersey brought a delegation of self-advocates from the Statewide Self-Advocacy Network to the State House to help promote and celebrate Developmental Disabilities Awareness Month. The self-

advocates in attendance had the opportunity to speak with more than 50 elected officials, including the Senate President, the Speaker of the Assembly, the Senate and Assembly Majority Leaders, and Budget Committee members, among others. Department of Human Services Commissioner Beth Connolly presented the self-advocates with a proclamation from Governor Chris Christie declaring March Developmental Disabilities Awareness Month.

The Arc of California's Executive Director Tony Anderson received the 2016 Carl Anthony Equity Award from civil rights organization Genesis, an affiliate of [Gamaliel](#). The Arc of California has a statewide partnership with Gamaliel, which seeks to empower individuals to effectively participate in the political, environmental, social, and economic decisions affecting their lives in order to create stronger and more prosperous communities.

CRIMINAL JUSTICE



The Arc of Florida helped secure the passage of Carl's Law, HB387, which provides for stiffer penalties for offenses committed where there is also evidence of disability discrimination. The bill, recently signed into law by Governor Rick Scott, is named after Carl Starke, a man with autism who was killed in August 2015 and was believed to have been targeted due to his disability.

The Arc of Maryland helped secure the passage of HB22/SB147, recently signed by Governor Larry Hogan, which requires the Ethan Saylor Alliance for Self-Advocates as Educators to review or to request the Alliance to review the content and monitor the implementation of the training objectives adopted by the Police Training Commission for a community inclusion program. The review must be conducted at least every four years but may be conducted

more frequently at the request of the Police Training Commission. The Arc of Maryland strongly supported this bill because of its belief that people with I/DD must be included in the implementation and oversight of any training offered to law enforcement.

The Arc of New Jersey helped secure the passage of a new law, recently signed by Governor Chris Christie, that creates a special missing person alert for people with mental illness and/or I/DD. The Most Vulnerable People alert system makes it possible to spread information about missing persons more quickly by skipping the 24-hour waiting period that is required in other cases in which an alert is issued. Sharon Levine, Director of Governmental Affairs, was quoted in an article about the [law](#).

EDUCATION



The Arc of Indiana's Executive Director Kim Dodson was named to a Diploma Taskforce that will address proposals to change diploma options for the state's high school students. The Arc of Indiana has been a leader in advocating for providing a path for students receiving special education services to earn a diploma rather than a certificate of completion.

The Arc of New Jersey:

- ▶ Helped secure the passage of A1029, signed by Governor Chris Christie, which requires a training program for school bus drivers and bus aides on interacting with students with disabilities.
- ▶ Was involved in drafting a [report](#) released by the state Department of Education and authored by the New Jersey Task Force on Improving Special Education for Public School Students. The report, which was sent to Governor Christie and the legislature, includes

recommendations on how to improve the funding, delivery, and effectiveness of special education programs and services in the state.

- ▶ Created a "[Go Bag](#)" for special education advocacy. The "Go Bag" is a collection of resources on special education advocacy intended to help train lay advocates.

The Arc of Florida helped secure the passage of the Postsecondary Comprehensive Transition Program Act, SB672. This Act ensures that students with I/DD have access to meaningful postsecondary education credentials and are afforded the opportunity to have an integrated campus experience. This Act also mandates statewide coordination of the dissemination of information regarding programs and services for students with I/DD. The Arc of Florida is working with the state's Department of Financial Services on the design and implementation of this program.

EDUCATION



The **Arc of Maryland** helped secure the passage of:

- ▶ **HB85:** requires that parents of a child with a disability be provided with written information they may use to contact the school's early intervention and special education family support services staff members as well as a brief description of the services that they provide. This information must be provided at the initial evaluation meeting.
- ▶ **SB77:** lowers the age from 16 to 14 when a juvenile court is required to hold a permanency planning hearing which determines the services needed to assist a child in transitioning from foster care to successful adulthood. The bill also requires a juvenile court at each guardianship review hearing for a child at least age 14 to determine the services needed to assist the child to make the transition from placement to successful adulthood.
- ▶ **HB551:** requires IEP teams to provide parents of children with disabilities with an oral and written explanation of the parents' right to request mediation and contact information regarding pro bono representation. It also requires the state Department of Education to make a staff member available to assist parents in understanding the mediation processes available to them.
- ▶ **SB421/HB86:** authorizes the parents of a child with a completed IEP or individualized family service plan to

request that either of these documents be translated into the parents' native language if that language is spoken by more than 1% of the students in the local school system.

The **Arc of Michigan** initiated a coalition that now includes the state Department of Education to identify, address, and remove or change barriers to schools providing effective transition services relating to employment. The Arc of Michigan also submitted testimony to the House Education Committee supporting HB5409-5418/SB 835-838, bills seeking to end practices of seclusion and restraint in public schools.

The **Arc of Washington State** joined with other disability advocates in filing an [amicus brief](#) with the state Supreme Court in *McCleary v. Washington*, arguing that the legislature has overlooked students with disabilities in planning funding reforms and that the court should consider the unmet needs of students with disabilities when enforcing the state's paramount duty to fully fund education. "Special education funding in Washington is uncoupled from the true costs of educating students with disabilities," said Executive Director Sue Elliott. "The funding formula underestimates the true incidence of disability in the student population as well as the actual amounts that school districts must spend to meet their needs."

EMPLOYMENT



The **Arc of Massachusetts:**

- ▶ As part of the Employment First Initiative, in conjunction with the Department of Developmental Services and the Widening the Circle Project, The Arc of Massachusetts recently released "[Building Friendships at Work: A Toolkit for Employment Specialists, Job Developers, and Job Coaches](#)". This

toolkit was developed to help organizations that provide employment supports take better advantage of opportunities to facilitate relationships between the people they support and their co-workers.

- ▶ As part of The Arc of Massachusetts' employment advocacy efforts, Governor Charlie Baker and Secretary of Labor and Workforce Development Ronald L. Walker, II recently announced new initiatives addressing higher

rates of unemployment for people with disabilities. These initiatives included a \$5 million investment to provide grants to community-based organizations that partner with businesses to develop job training and employment opportunities for populations that face high unemployment rates, such as individuals with I/DD.

The Arc of Maryland:

- ▶ Representatives of The Arc of Maryland recently met with Governor Larry Hogan to discuss strategies to improve employment for individuals with I/DD in the state. In attendance were two local chapters of The Arc of Maryland, individuals with I/DD and their families, a local employer of individuals with disabilities—Acadia Windows and Doors—and one of Acadia’s employees with I/DD.
- ▶ Representatives of The Arc of Maryland testified before the House Economic Matters Committee and the Senate Finance Committee in support of the Ken Capone Equal Employment Act, SB417/HB420. The bill, recently signed into law by Governor Hogan, prohibits 14(c) certificates for subminimum wage from being authorized in Maryland and prohibits work activity centers and sheltered workshops from paying less than minimum wage to employees with disabilities. The 2014 median earnings of a worker with a disability in Maryland were \$27,072 while the median earnings of a worker without a disability in the

same period were \$40,583. The legislation requires the Department of Disabilities and the Developmental Disabilities Administration in partnership with stakeholders to develop and implement a plan to phase out the use of a subminimum wage to an employee with a disability by October 1, 2020. The plan must include benchmarks, tracking outcomes, and recommendations for needed funding and resources with recommendations provided annually to the Governor and legislature.

Governor Andrew Cuomo recently announced that \$2.4 million has been distributed to 100 organizations that provide employment services to individuals with disabilities via the New York State Employment Services System as part of the state’s Employment First Initiative. Nineteen NYSARC chapters received a total of nearly \$450,000 in funding. “This funding continues New York’s legacy of inclusiveness by helping provide the necessary employment services to individuals with disabilities,” Governor Cuomo said. “This action is yet another example of our commitment to expanding opportunity to all New Yorkers.” The Governor also announced that the state received a training grant from the U.S. Department of Labor’s Office of Disability Employment Programs that will provide comprehensive assistance in support of the Employment First initiative and allow for the training of up to 10,000 service providers in the provision of disability employment services.

FINANCIAL SECURITY



The Arc of Maryland testified in support of the Maryland Achieving a Better Life Experience (ABLE) Act, HB431/SB355, which allows individuals with I/DD to save more than \$2,000 for housing, education, community supports, medical, and other disability related expenses without becoming ineligible for federal benefits. The Act was recently signed into law by Governor Larry Hogan.

The Arc of Ohio’s advocacy work led to Ohio becoming the first state in the country to offer STABLE accounts, the state’s version of ABLE accounts. Learn more at www.stableaccount.com.

The Arc of Indiana helped secure the unanimous passage of the state’s ABLE Act, which was recently signed into law

by Governor Mike Pence. The bill signing was attended by representatives of The Arc of Indiana and Executive Director Kim Dodson provided [opening remarks](#) at the event.

The Arc of Florida helped secure the passage of HB7003, which established a financial literacy program for individuals with I/DD in the state’s Department of Financial Services (DFS). The bill requires that DFS, in consultation with public and private stakeholders, develop and implement the program to promote the economic independence and successful employment of individuals with I/DD. Banks, credit unions, savings associations, and savings banks will be key participants in the development and promotion of the program, which must provide

FINANCIAL SECURITY



information, resources, outreach, and education for individuals with I/DD on:

- ▶ Financial education, including instruction on money management skills and the effective use of financial services and products, to promote income preservation and asset development;
- ▶ Identification of available financial and health benefit programs and services;

- ▶ Job training programs and employment opportunities, including work incentives and state and local workforce development programs; and
- ▶ The impact of earnings and assets on eligibility for federal and state financial and health benefit programs, and options to manage such impact.

The Arc of New Jersey helped secure the passage of the state's ABL Act, which was signed into law by Governor Chris Christie in January.

HEALTH



The Arc of Maryland:

- ▶ Providing a major victory to Maryland's foster children with disabilities, the Court of Appeals of Maryland [ruled](#) in *In re Adoption/Guardianship of Dustin R.* that juvenile courts have the authority to order the Department of Health and Mental Hygiene (DHMH) to provide services to children with disabilities whose parental rights have been terminated and who are under court guardianship as they age out of foster care. It also found that juvenile courts have the authority to order DHMH to provide plans for clinically appropriate services to foster children under state guardianship and to specify the level of care needed if DHMH's plans are not clinically adequate. The ruling overturns a line of intermediate appellate decisions that had restricted juvenile court authority to order state agencies to provide needed services to foster children. DHMH had sought to institute substantial cuts in Dustin's care when he turned 21 and left the child welfare system, which would have led to his removal from his long-time home and placement into a residential program. The Arc of Maryland, along with several other disability organizations, signed on to an amicus brief supporting Dustin in the case.
- ▶ The Arc of Maryland helped secure the passage of SB297 which updates the definition of "habilitative

services" to include services and devices—such as occupational, physical, and speech therapies—that help a child keep, learn, or improve skills and functioning for daily living. The bill also clarifies that a carrier must provide coverage of habilitative services for insureds and enrollees who are children until at least the end of the month in which the insured or enrollee turns 19.

Maura Sullivan, Director of Government Affairs for **The Arc of Massachusetts**, [testified](#) before the Health Care Finance Committee in support of SB2143 which establishes an Office of Health Equity in order to reduce disparities linked to disability, race, ethnicity, and gender. Sullivan also submitted written testimony from several constituents as well as research studies demonstrating the dramatic health disparities for people with I/DD in contrast to the rest of the population.

The Arc of Arizona's advocacy helped bring about a bipartisan coalition in both the House and Senate that overruled legislative leaders and forced a vote on SB1457 which restored the state's KidsCare health insurance program. The sudden success in reinstating the children's health insurance program was heralded by legislators, The Arc of Arizona, and other advocacy groups who have long

HEALTH



argued that Arizona should no longer be the only state rejecting federal dollars to provide insurance to children of the working poor.

The Arc of Michigan worked with other statewide advocacy groups in successfully advocating for the removal of language in Governor Rick Snyder's February 2016 proposed budget that would give public Medicaid behavioral health funding to private health plans by September 2017.

STATE EXECUTIVE CORNER



Written by:

Terry Olson, Executive Director of The Arc of Delaware

The Arc of Delaware began its housing partnership with the Delaware Department of Health and Social Services, Division of Developmental Disabilities Services (DDDS) in 1987. Through this partnership, we currently own 82 homes located within communities all across the state of Delaware. These homes are an important part of The Arc of Delaware's mission to actively support the rights of individuals with I/DD to live in integrated, community-based settings with necessary supports.

While The Arc of Delaware has often been pleased to see our community supported housing efforts welcomed throughout the state, we have also, unfortunately, experienced discrimination in these pursuits. When we set out to build a new, universally-designed home to serve 4 individuals with I/DD as well as physical disabilities and significant medical needs in a neighborhood in Milford, we were surprised and disappointed when the Property Owners' Association (POA) rejected our offer after we agreed upon a price with the seller of the lot. Our proactive communications with the POA about our long history of success in providing community supported

housing, our offer to have POA members visit one of our other homes, and our communication with POA members about the rights of our constituents under state and federal disability rights laws did not change their minds.

Because of this, we chose to pursue legal action and are very happy with the state's finding of discrimination and the resulting Conciliation Agreement (both described in more detail in the press release). In pursuing this route, it was our stated objective to publicize the outcome so that other individuals and chapters of The Arc who find themselves in similar situations can benefit from our experience in working to enforce their right to live in the community, free of discrimination. We also hope that, in some small way, this work helps reduce the unfortunate prejudices that we encountered here and educates people about the rights of people with disabilities.

The Arc of Delaware would be happy to share additional details on our experiences with other parties who may be confronting similar discrimination issues. Executive Director, Terry Olson, and Director of Housing, Linda Cox, can be reached at 302.996.9400. We wish to thank our talented group of passionate attorneys for their impeccable representation in this case.