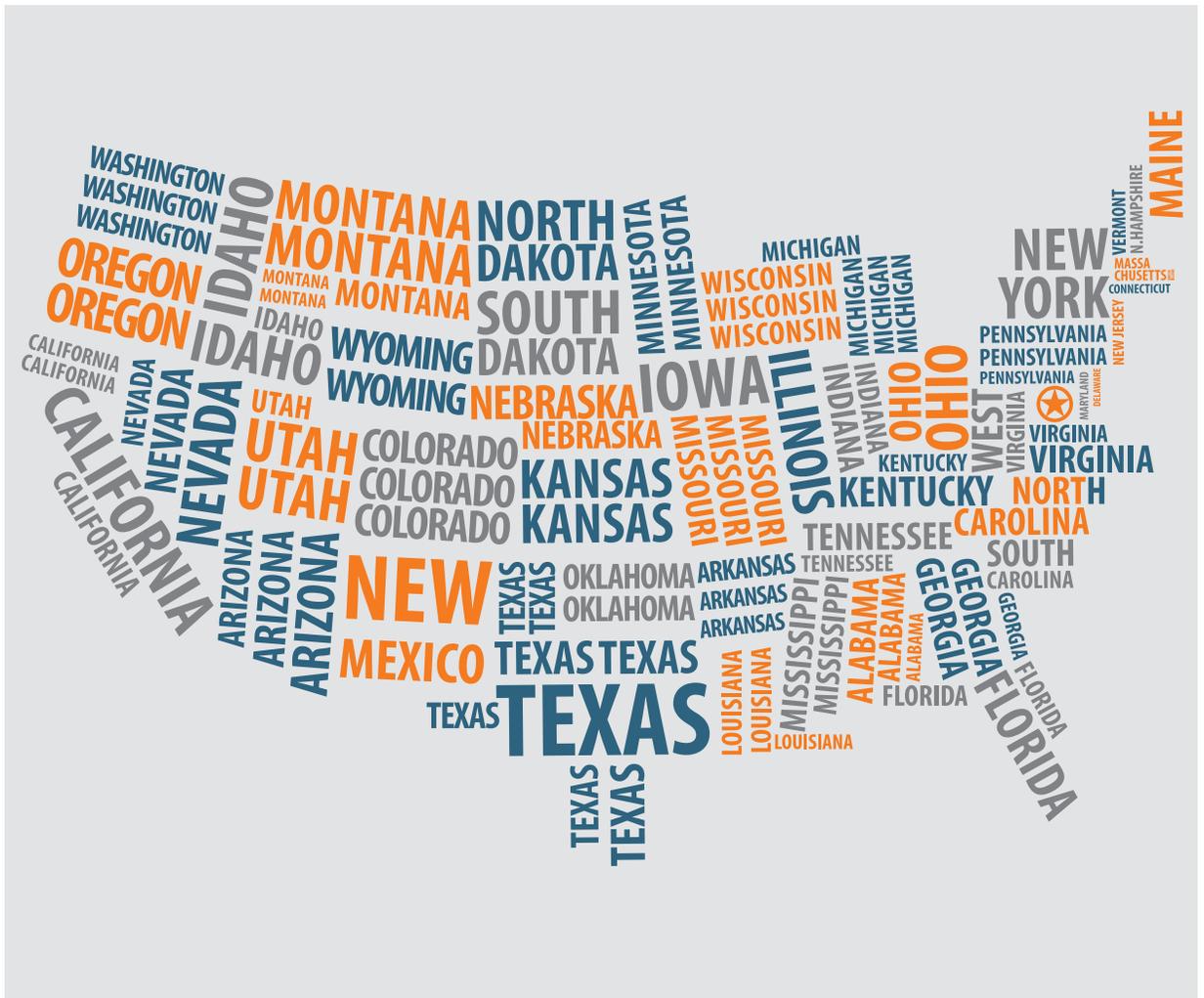




The Arc®

For people with intellectual
and developmental disabilities

State Advocacy Matters



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CIVIL RIGHTS



The Arc of Colorado helped defeat HB 1054 seeking to legalize physician-assisted suicide. Proponents of the bill have secured enough signatures to put this issue on the ballot in November.

The Arc of New Jersey's Board President, Robert Hage, sent a [letter to the editor](#) that was published in the Daily Journal. In honor of the 26th anniversary of the Americans with Disabilities Act (ADA), Hage wrote about the need to improve services for people with disabilities in New Jersey, particularly with regards to employment, transportation, and community living. Hage noted: "...while celebration is certainly warranted, the anniversary of the ADA should also galvanize conversation about ways we can continue to improve equality and increase opportunities for people with disabilities...The Arc of New Jersey encourages you to use this occasion to celebrate the past, but also to think and plan for a future that addresses the needs of people with disabilities in 2016 and beyond."

Over the summer, **The Arc of New Mexico** brought together self-advocate leaders and other advocates

and funders to brainstorm about how to create a comprehensive and sustainable statewide self-advocacy movement in New Mexico. In addition to the chapter, attendees came from organizations such as People First, Allies in Advocacy, Parents Reaching Out, the Department of Health – Developmental Disabilities Supports Division, and the Developmental Disabilities Planning Council/Center for Self-Advocacy. The group developed a two-year vision that outlined a path to ensuring the voices of self-advocates become a force in public policy in New Mexico via, among other things, training self-advocates in legislative advocacy, seeking to create a disability history curriculum in public schools, and improving accessible transportation in rural areas.

The Arc of Indiana, through a grant from the National Resource Center for Supported Decision Making and the Administration for Community Living, recently published the report "[Supported Decision Making in Indiana: Guardianship, Civil Rights and the Case for a Less Restrictive Environment.](#)"

COMMUNITY LIVING



The Arc of Illinois:

- ▶ The Arc of Illinois received an award from the state's Division of Developmental Disabilities for its [Ligas Family Advocate Program](#). The *Ligas v. Hamos* case was a class action lawsuit filed in 2005 on behalf of individuals with I/DD seeking community-based services in Illinois. The *Ligas* consent decree directed the state's Department of Developmental Disabilities to "maintain a fair and accessible process by which individuals with developmental disabilities or their legal guardians can affirmatively request in writing to receive community-based services and/or placement in a community-based setting...the State will ensure that class individuals with developmental disabilities

and their families/guardians are provided information about all options for services." The chapter's Family Advocate Program connects recipients of *Ligas* award letters seeking community independent living arrangements (CILAs) — an Illinois term for group homes — and their families with family advocates who are knowledgeable about creative ways to utilize their *Ligas* funding to build successful lives in the community. During outreach activities, the chapter provides information about the consent decree, the rights of class members, and information about available services.

- ▶ The Arc of Illinois was featured in a Chicago Tribune editorial: "[Tamekia Lewis and other pawns: The](#)



[victims of Madigan vs. Rauner.](#)” The editorial criticized Governor Bruce Rauner’s failure to approve a wage increase for direct support professionals (DSPs) and highlighted the impact these low wages have on individuals with disabilities. One example of this is Tamekia Lewis, an individual with I/DD who relies on the assistance of DSPs in her daily life and is the daughter of Shirley Perez, Director of the chapter’s *Ligas* Family Advocate program. The editorial resulted from a meeting the chapter had with the Tribune’s editorial board to urge Governor Rauner to approve the wage increase legislation.

The Arc of New Jersey’s Executive Director, Tom Baffuto, spoke out in favor of increasing wages for DSPs at a press conference hosted by State Senate President Stephen Sweeney. The press conference was held in response to Governor Chris Christie’s line-item veto of funding in the 2017 budget designated for DSPs. A number of representatives from various human services organizations attended, but The Arc of New Jersey was the only group asked to provide remarks about DSPs and the impact of their work on people with I/DD. Tom implored the Governor to value the work of DSPs by paying them wages that are in line with the crucial work that they do and he emphasized that the current low wages cannot be tolerated any longer. He also spoke about the challenges associated with hiring and retaining employees for these positions and the fact that community provider agencies have not seen increases in their contracts in almost 10 years.

The Arc of Minnesota successfully advocated for two provisions that will provide protections to married Minnesotans who use home and community-based services waivers and are affected by recent federal rule changes. These changes include: (1) raising the community spouse asset allowance to \$119,220, which is the maximum allowed under federal law and (2) creating an undue hardship exclusion for retirement and college savings accounts. The new spousal impoverishment protection rules apply to individuals who request services from waiver programs. The changes also apply to spouses who reside in long-term care facilities. Hardship waivers

are available to a long-term care spouse when the other spouse refuses to make assets available to the long-term care spouse, or if funds cannot be withdrawn from an account such as a retirement account without a penalty.

NYSARC:

- ▶ NYSARC has led in the development of the #bFair2DirectCare coalition of providers to advocate for increased Medicaid funding to provide a living wage for DSPs and other support staff in light of Governor Andrew Cuomo’s announcement regarding raising the minimum wage to \$15 per hour throughout the state over the course of five years. 2015 data from the seven major providers throughout the state indicates a 9.3% vacancy rate for DSPs, a 23% one-year turnover rate, and reliance on more than 6.4 million hours of overtime. The coalition’s position is that failing to provide funding to increase pay to DSPs places providers at a great disadvantage in a competitive labor market. “It is not uncommon to see talented and dedicated DSPs driven to leave our field to take jobs at big box stores so they can better provide for their families,” said NYSARC Executive Director Steven Kroll. The campaign has been garnering media coverage and gaining awareness as it takes its message statewide. In June, the coalition held a press conference outside of the Nassau County Supreme Court to highlight the “300 Days to Better Pay” campaign. The press conference highlighted how providers of supports and services for New Yorkers with I/DD face inadequate funding and policies that threaten community integration. Organizations that support individuals with I/DD have seen only one rate increase since the recession of 2008, an average increase of less than one-half of 1% per year. Now they face as much as a 67% increase in the mandated minimum wage, new overtime rules, and growing competition from other employers. Read more in the coalition’s [press release](#) and an [article](#) covering the coalition’s work in Newsday. Follow the coalition on [Facebook](#) and [Twitter](#).
- ▶ Executive Director Steven Kroll was recently quoted in an article in Politico entitled: “[Developmentally Disabled New Yorkers Face Residential Crunch.](#)” The

COMMUNITY LIVING



article highlights the severe shortage of community-based residential placements in New York State and the crisis facing aging caregivers of individuals with I/DD who are unable to help transition their children with I/DD to appropriate placements before they die.

The Arc of Colorado conceived of and found sponsors for HB 1321, which was recently signed into law by Governor John Hickenlooper. The bill directs the Department of Health Care Policy and Financing to seek federal authorization for and to implement a Medicaid buy-in program for individuals who are eligible for home and community based services under the supported living services, spinal cord injury, and brain injury waivers.

The Arc of Tennessee:

- ▶ The Arc of Tennessee helped to secure the passage of SB2003/HB2014, the “Aging Caregiver Bill.” This bill allows individuals with I/DD on the waiting list for Home and Community Based Services to be enrolled into waiver services when their primary caregiver reaches the age of 75. Prior to this bill, the individual was not eligible for waiver services until the caregiver reached the age of 80.

- ▶ The Arc of Tennessee worked actively with TennCare (Tennessee’s Division of Health Care Finance and Administration) on the implementation of the new Employment and Community First CHOICES waiver by providing information sessions across the state and written comments on the waiver itself. This waiver includes three benefits packages based on eligibility and level of care. As a result of the chapter’s advocacy, respite services and alternatives to conservatorship counseling are now available for all three packages rather than just one. In addition, transportation coverage now extends to buses, taxis, ride-sharing services, and carpooling options, rather than being limited to transportation from provider agencies.

The Arc of Massachusetts helped secure a significant increase in funding for the Department of Developmental Services’ Family Support line item via its Supporting Families Campaign. The Arc of Massachusetts initiated this campaign with six other disability advocacy organizations in the state in order to advocate for more meaningful supports for families and call attention to the issues facing aging caregivers.

CRIMINAL JUSTICE



The Arc of Colorado advocated for the passage of HB1254, which requires the Peace Officer Standards and Training Board to provide a training curriculum on abuse and exploitation of individuals with I/DD who are 18 or over. Governor Hickenlooper recently signed this bill into law.

Governor Jerry Brown recently signed a groundbreaking criminal justice bill that **The Arc of California** fought to help pass over the last two years. AB 1272 helps crime victims with I/DD by notifying licensing agencies of misconduct by their licensees and requiring investigations. It will also aid in the prosecution of alleged abusers by

requiring courts to make reasonable efforts to assist prosecuting attorneys in avoiding more than one case involving certain crimes against people with disabilities and other cases on the same day. This will help district attorneys assign trained, experienced prosecutors to these often complex and difficult cases.

The Arc of Tennessee helped secure the passage of SB1485/HB1512, which expands the categories of missing citizens for whom a media alert is sent to include people with disabilities.

EDUCATION



The Arc of Colorado supported HB 1328, recently signed into law by Governor Hickenlooper. This bill strengthens the safety provisions for the use of restraint and seclusion on individuals being detained by a state or local agency. The bill makes it clear that absent a demonstrated emergency, restraint and/or seclusion must never be used as a punishment, sanction, as part of a treatment plan, for retaliation, or for protection. The bill also established a committee to produce a research report for the legislature on the effects of restraint and/or seclusion on youth.

The Arc of New Jersey has supported a number of special education bills:

- ▶ S2266/A3481 seeks to establish mandatory, statewide regulations restricting the use of restraint and seclusion. In the fall, The Arc of New Jersey will work to support the passage of the bill through the state Assembly.
- ▶ S446 requires the New Jersey Department of Education (NJ-DOE) to train public school teachers and administrators on how to prevent the over-identification or disproportionate representation by race and ethnicity of students classified eligible for special education programs and services. The bill also requires school districts to provide annual data to NJ-DOE on the race and ethnicity of students classified as eligible for special education programs and services. This bill is awaiting a vote.

- ▶ S447, recently passed out of the Senate Education Committee, requires NJ-DOE to maintain an electronic database of all decisions rendered by the New Jersey Office of Administrative Law in a special education due process hearing. NJ-DOE must make the database available on its website so that it can be easily accessed by the public.
- ▶ S451, recently signed into law by Governor Christie, establishes the Office of the Special Education Ombudsman in DOE. The duties of the Ombudsman include, among other things, serving as a resource for the public to better understand state and federal laws governing special education, providing support to parents of students with disabilities in navigating the process of obtaining special education services, educating parents about the available options for resolving special education disputes, identifying patterns of special education complaints and recommending strategies for improvement to NJ-DOE, and serving as a general resource for disability-related information and referrals.

The Arc of Tennessee helped secure the passage of SB1584/HB1983 which amends the state's STEP UP Scholarship program to fund students for up to four years instead of just two. The STEP UP scholarship provides approximately \$3,500 per year to students with I/DD attending one of five approved post-secondary programs for people with I/DD throughout the state.

EMPLOYMENT



The Arc of Colorado conceived of and found sponsors for SB 77, recently signed into law by Governor Hickenlooper. This law requires multiple state agencies to work through the State Rehabilitation Council to develop an Employment First policy that increases competitive integrated employment for people with disabilities. These agencies

will develop a strategic plan to incentivize employers to hire individuals with I/DD and provide training and support for people with disabilities to identify, secure, and maintain community based jobs in integrated settings.

EMPLOYMENT



The Arc of Tennessee:

- ▶ As a result of The Arc of Tennessee’s advocacy around the Employment and Community First Choices waiver, students with I/DD who graduate high school at 18 are now immediately eligible for employment services rather than having to wait until age 21.

- ▶ The Arc of Tennessee is actively involved in Governor Bill Haslam’s Employment First Task Force and facilitates monthly family support meetings around the topic of employment in each grand region of the state. The chapter also conducts workshops for local chambers of commerce and the Society for Human Resource Management on the “Business Case for Employment” to educate businesses about the benefits of hiring people with I/DD.

FINANCIAL SECURITY



The Arc of Minnesota recently organized its staff, self-advocates, and other volunteers and chapters to meet with Third District Congressman Erik Paulsen. Most of the participants shared their stories about the importance of Medicaid and Social Security — two of the federal lifelines

for people with disabilities and their families. Senior Policy Advocate Gene Martinez encouraged Representative Paulsen to support the three bills introduced in the House this year to build on the provisions of the ABLE Act.

HEALTH



The Arc of Florida is developing a statewide initiative to address an increase in choking deaths of individuals with I/DD who are served through the Florida Agency for Persons with Disabilities. The first phase of the initiative, aimed at providing primary outreach to front line staff, is developing durable plastic cutting boards to be distributed to all residential and other programs throughout Florida. The cutting boards display the appropriate cutting size of food and other tips to reduce choking hazards. The Arc of Florida is also working with nursing staff to develop

additional training materials on choking prevention, including posters and short videos, as an advocacy effort to provide outreach to a broader audience.

The Arc of Colorado supported HB 1277, recently signed into law by Governor Hickenlooper. This law requires the Department of Health Care Policy and Financing to provide 20 days of notice to a Medicaid recipient if medical assistance benefits will be suspended, terminated, or modified. The bill also extends the time for appeal of the intended action from 30 days to 60 days.



HONORS AND AWARDS

Betty Williams, Consumer Education and Training Coordinator for **The Arc of Indiana**, has been reappointed by President Barack Obama to serve on the President's Committee for People with Intellectual Disabilities. The Committee provides advice to the President and to the Secretary of Health and Human Services concerning a broad range of topics relating to people with I/DD. Williams was also recently honored by the National Association of Councils on Developmental Disabilities (NACDD) with the NACDD Champions of Equal

Opportunity Award. The award is given to an individual who shares and promotes NACDD's values of self-determination, independence, productivity, and inclusion. Williams was a member of the Indiana Developmental Disabilities Commission from 1998-2013 and has been an active member in Indiana's self-advocacy movement since its founding in 1990. She served as President of Self Advocates Becoming Empowered from 2010 to 2012 and as President of Self Advocates of Indiana from 2005 to 2010.



TECHNOLOGY

The Arc of Massachusetts helped secure the passage of legislation approving MassHealth to fund non-federally funded augmentative or assistive devices as long as the cost is below the state's typical shares for such equipment. This will allow for state funding of items like iPads

which can be very helpful for people with I/DD and are significantly cheaper than many of the machines that are federally reimbursable.