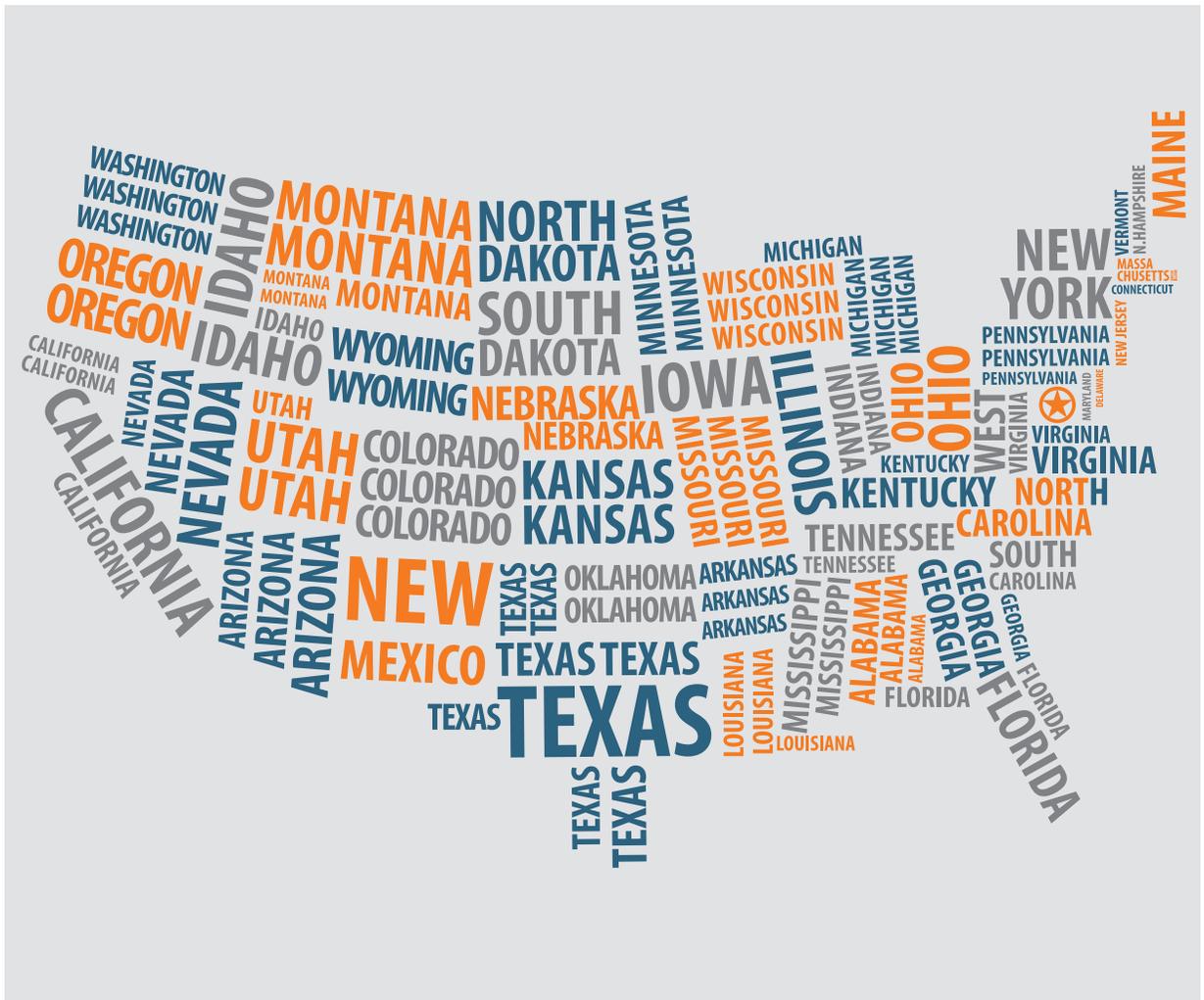




For people with intellectual and developmental disabilities

# State Advocacy Matters



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# CIVIL RIGHTS



**The Arc of New Jersey** has set up a [Get Out the Vote page](#) that includes positions from state legislative candidates on issues related to I/DD, a [Get Out the Vote Guide](#), statements from Self Advocates, and more.

## The Arc of California:

- ▶ Is participating in a coalition of disability rights organizations to discuss increasing engagement of voters with disabilities and addressing the barriers to voters with disabilities posed by SB 450.
- ▶ Supported SB 589 — signed into law by Governor Jerry Brown in October — which codifies the right of proposed conservatees in California to retain their right to vote absent a court finding that they would be unable to do so. Specifically, the bill:
  - Authorizes an individual with a disability to complete an affidavit of registration with reasonable accommodations as needed;
  - Authorizes an individual with a disability under conservatorship to register to vote absent disqualification for other reasons;

- Requires that, regardless of conservatorship status, a person be presumed competent to vote absent a court finding that the person is unable to communicate a desire to participate in the voting process with or without reasonable accommodations
- Provides that in conservatorship proceedings before a jury, the jury must unanimously find by clear and convincing evidence that the person cannot communicate — with or without reasonable accommodations — a desire to participate in the voting process prior to disqualifying the individual from voting; and
- Requires the court investigator during the review of conservatorships to review the individual’s capability of communicating and, if such capability has changed, the court investigator must inform the court and the court must hold a hearing to assess the individual’s communications capabilities.

**The Arc of Texas** published a 2015 [Voting Guide](#) outlining pros and cons of various propositions and providing “Voting Information and Tips.”

# COMMUNITY LIVING



**The Arc of Virginia** continues to be involved in the [United States v. Virginia Consent Decree](#) requiring the Commonwealth to improve its service system for individuals with I/DD to ensure that they have access to services in the most integrated settings. In September, the U.S. filed a brief summarizing how the Commonwealth is failing to comply with the settlement agreement, how this has harmed Virginians with I/DD, and recommends actions that should be taken by the court. The brief highlights that the Commonwealth is lagging in developing integrated housing, a functioning children’s crisis system, and

integrated day and supported employment programs. In late October, federal Judge John Gibney held a public hearing to discuss the Commonwealth’s compliance, where the U.S. primarily emphasized the Commonwealth’s lack of progress in implementing changes to the I/DD Waiver program despite being three years into the agreement. The Commonwealth reported that the General Assembly is expected to review and act on proposed changes to the program in the upcoming legislative session. If approved, the changes would be implemented in July 2016. Judge Gibney assured the parties that the

changes embodied by the Consent Decree would occur whether due to the Commonwealth's legislative actions or by court order. The next hearing will take place in late December. The Arc of Virginia held a statewide advocacy event in late September and issued an [action alert](#) in early November calling on Governor Terry McAuliffe and the General Assembly to uphold the Commonwealth's commitments to properly implement the settlement agreement and eliminate the I/DD Waiver waiting lists.

In late September, U.S. District Court Judge Donovan Frank approved [Minnesota's Olmstead Plan](#), stating that the goals and measurements (in areas such as housing and employment) included in the Plan were now adequate and requiring the state to submit work plans to the court in early October. Judge Frank made it clear in his [opinion](#) that the state is responsible for ensuring proper funding is provided to meet the new goals and objectives. **The Arc of Minnesota** will continue to monitor the implementation of the Plan and partner with the state and other disability rights organizations to ensure adequate funding is available to achieve the new goals.

**The Arc of Illinois** participated in an [amicus brief](#) submitted in support of defendants-appellees to the Seventh Circuit Court of Appeals by Equip for Equality, the state's Protection and Advocacy center in the case *Illinois League of Advocates for the Developmentally Disabled v. Illinois Department of Human Services*. Following the state's 2012 announcement that it planned to close the Murray Developmental Center, guardians of residents in the Center filed a lawsuit seeking to stop the closure. The district court denied the plaintiffs' motion for a preliminary injunction and the plaintiffs appealed to the Seventh Circuit. In October, the Seventh Circuit issued a [decision](#) affirming the district court, holding that the guardians of residents of Murray Developmental Center cannot stop the state from closing the facility. The holding recognized a national trend and the proven benefits of increasing community-based services for people with disabilities. Based on research cited in the amicus brief, the Court described Illinois as a "laggard outlier" in the national movement to transition residents out of institutions into community-based settings, noting that only New Jersey and Texas have a higher number of individuals with I/DD living in state institutions, and cited research demonstrating that people with disabilities have a better quality of life living in the community.

**The Arc Georgia's** Executive Director, Stacey Ramirez, has joined the [Autism Services Initiative for Adults](#) coalition led by the state's Department of Behavioral Health and Developmental Disabilities ("DBHDD") and the Autism Center at Emory University to improve the state's community-based infrastructure for adults with ASD receiving or eligible to receive I/DD services provided by DBHDD to ensure they are person-centered, evidence-based, and informed by self-advocates and families.

**The Arc of Connecticut's** Executive Director, Leslie Simoes, was recently quoted in an article in the Hartford Courant regarding the advocacy her office has engaged in to assist individuals with I/DD who are living at home with aging caregivers to find community placements after decades on the waiting list. The article, [For Parents Of Developmentally Disabled Adults, The Wait For Help Never Ends](#), shares several stories from families participating in The Arc of Connecticut's Families for Families campaign.

**The Arc of Washington's** advocacy was recently featured in a series of articles and videos on Washington's King 5 news entitled "[Last of the Institutions.](#)" The series discusses how the state still has four large facilities open, housing approximately 800 individuals with disabilities, which is well above the national average. Only 13 states operate more institutions than Washington. The Arc of Washington's Executive Director, Sue Elliott, is quoted as saying: "We're very behind the times (on this issue)...We've been advocating to close institutions for 40 years and we still don't have it done. So we're 40 years behind...The legislature appropriates money for the studies and then they sit on a shelf. All the studies say the same thing – that we should move people to the community and not have our institutions. So that's presented to the legislature and (then) ignored."

## CRIMINAL JUSTICE



In late September, **The Arc of Virginia** sent a [letter](#) to Governor Terry McAuliffe urging him to intervene in the case of Alfredo Prieto, a man seeking to correct an unconstitutional assessment of his intellectual disability who was scheduled to be executed by the Commonwealth of Virginia in October. The Supreme Court's decision in *Atkins v. Virginia* prohibits the execution of people with ID. Virginia courts previously applied an unconstitutional definition of ID in Prieto's case, requiring jurors to reject a claim of ID for any person with an IQ score over 70. Despite this error, strict procedural rules prevented courts of the Commonwealth from correcting this mistake. The *Richmond Times-Dispatch* [covered the case](#) and mentioned The Arc of Virginia's advocacy in this area. Despite The Arc's advocacy on his behalf, Prieto was executed in early October.

This summer, **The Arc of Maryland** joined the state's Attorney General Brian E. Frosh and several legislators and law enforcement chiefs for the Attorney General's press conference announcing the issuance of a [Guidance Memorandum to End Discriminatory Profiling by Law Enforcement in Maryland](#) stating that officers in any law enforcement agency may not discriminate on the basis of disability (among other protected classes) to any degree during routine police operations. The Arc of Maryland worked with the Maryland Secretary of Disabilities and the Attorney General's office to ensure that disability profiling was included in the Guidance.

## EDUCATION



**The Arc of Virginia** is [forming education advocacy groups](#) in eight regions across the Commonwealth, to support education system advocacy at local and state levels and educate members about effective ways to promote inclusive education, push back against systems and placement practices that segregate students with disabilities, and more.

**The Arc Georgia** recently sent a [letter](#) with a coalition of other national and state disability rights advocates calling on the state of Georgia to transform its separate

and unequal educational program serving thousands of children with behavioral disabilities into a system that provides needed services and supports to integrate students into their own local schools. The coalition formed after a July 15th [letter](#) from the U.S. Department of Justice finding the state's program illegally segregates children with behavioral disabilities and provides them with unequal educational opportunities in violation of the Americans with Disabilities Act. More information about the letter and the coalition can be found [here](#).

# EMPLOYMENT



**The Arc of New Jersey** created a [web page](#) in honor of National Disability Employment Awareness Month. Every Monday during the month of October, the page highlighted an individual with I/DD who is succeeding in the workforce and also encouraged individuals to seek employment services from its [Project Hire](#) program—a supported employment program designed to connect people with I/DD to integrated employment opportunities in their communities.

With the support of **The Arc of Indiana**, Governor Mike Pence declared the month of October [Disability Employment Awareness Month](#) in Indiana.

**NYSARC** will partner with Our Ability to establish New York State’s only Business Leadership Network (“BLN”) which will be a coalition of at least 100 businesses across the state that value the contributions that people with disabilities make to the workforce and are committed to contracting with businesses owned by individuals with disabilities. BLN

members will have access to Our Ability Connect, an online job matching platform for employers and job seekers and will be able to participate in educational webinars and workshops. Through partnering with Our Ability, NYSARC is creating new opportunities to connect people with I/DD to meaningful employment in the community.

**The Arc of Minnesota’s** Executive Director, Don Lavin, recently published an op-ed in the Minneapolis Star Tribune entitled [Counterpoint: 11 ways we can strive to hire the disabled](#) in response to a prior series of articles in the paper regarding the state of disability services in Minnesota. The article highlights 11 ways in which advocates, family members, and the state can increase the amount of meaningful, community-based, and competitive employment opportunities for individuals with I/DD in Minnesota using approaches that focus on person-centered planning and integration.



# EVENTS, CAMPAIGNS, AND PROGRAMMING

**The Arc of New Jersey’s** Family Institute hosted a [series of webinars](#) on advocacy related topics, such as “Special Education Rights and Advocacy Strategies: What to do When you Hit a Roadblock;” “The Care Act: Empowering Caregivers and their Loved Ones;” “Disability, Sexuality and the Criminal Justice System: Unique Challenges;” and “Preparing Your Student To Be A Self Advocate With Medical Professionals.”

**The Arc of Connecticut** is running a Families for Families campaign which will build a family movement in the state that allows the organization to mobilize hundreds of families and individuals with I/DD to advocate for issues like housing, transportation, education, and employment.

You can find The Arc of Connecticut’s Family Organizing Plan [here](#) and access the Families for Families Toolkit [here](#).

**The Arc of California** is planning and participating in “We’re Still Here to Speak for Justice,” a December protest and march on the capitol and Governor’s mansion led by the California Supported Living Network for the purpose of ensuring that Governor Jerry Brown includes funding for I/DD services in the state budget. Another [rally](#) was held in September to protest long-term funding shortfalls that were exacerbated by more than \$1 billion in cuts, leaving the state’s Lanterman Act severely underfunded. Many services have been decimated and community-based providers across California are being forced to lower

standards, slash programs, or shut down. The coalition is demanding a 10% across the board increase for regional centers and community providers.

To bring attention to issues affecting individuals with I/DD, **NYSARC** has created “[It Matters to Me](#)”, a grassroots advocacy campaign that will conduct statewide awareness events throughout the summer and fall, including town hall meetings, legislative breakfasts, news conferences, and media roundtables. The campaign is designed to share the personal, compelling stories and circumstances of concerned families and providers on the issues that matter most to them.

**The Arc of Washington** is running an advocacy campaign with the state’s Developmental Disabilities Council called “Change is Made by those who Show Up.” This campaign, among other things, runs monthly statewide meetings of parents, self-advocates, and employment and residential providers to discuss issues related to the legislative agenda, hosts a reception to inform legislators about disability

issues, hosts weekly advocacy days during the legislative session, sends out action alerts, organizes experts to testify in support or opposition to disability related bills, and creates a “hot tips” booklet that provides basic information on how to be an effective advocate.

**The Arc of Massachusetts** recently launched a “[Supporting Families](#)” campaign in collaboration with the Association of Developmental Disabilities Providers, Massachusetts Families Organizing for Change, Advocates for Autism of Massachusetts, and the Massachusetts Developmental Disability Council. The campaign seeks to assist more than 18,000 families in the state who are caring for a family member with I/DD in the home and are struggling to meet the individual’s needs by increasing state-funding for these families to ensure their children receive the services they need to remain at home or in other community-based settings. More information about the campaign can be found [here](#). Stories can be shared [here](#).

## FINANCIAL SECURITY



**The Arc of the United States** recently published a [table](#) detailing the progress of ABLE legislation by state that will be continuously updated as legislation develops.

**The Arc of Tennessee** was involved in helping the state’s Treasury Department launch its [website](#) for ABLE accounts which will keep Tennesseans informed about the implementation of the state’s ABLE Programs.

**The Arc of New Jersey** submitted comments to the IRS regarding the implementation of the ABLE Act.

### **The Arc of Michigan:**

- ▶ Supported the passage of the ABLE Act in Michigan which was signed by Lieutenant Governor Brian Calley who stated “The ABLE Act provides Michiganders with

disabilities more financial opportunities that will help them live more self-determined independent lives... Families will now have tax-exempt options to save more money to support their loved ones without worrying about losing access to other benefits.”

- ▶ Supports recently introduced bills SB 395 and HB 4719 providing a tax incentive for individuals who purchase a new residence or retrofit an existing residence that meets accessibility standards. This will help seniors and individuals with a disability stay in their homes while reducing the financial burden of such improvements. The tax credits would be available for up to \$5,000 for the purchase or construction of a new accessible residence and up to 50% of the cost of retrofitting existing units up to \$5,000.

# HEALTH



**The Arc of Maryland** participated in an amicus brief submitted by the Maryland Disability Law Center to the Maryland Court of Appeals advocating for the continuation of medical services for a youth with I/DD who would not survive without such services. The youth had the services he needed through age 21 while under the custody of the state's Department of Social Services and his doctors testified that without the same level of service after turning 21, the youth would die. The trial court ordered the Department of Health and Mental Hygiene to provide the same level of care that had been provided to sustain his life and the state appealed, arguing that only the state agency and not the court has the power to determine the level of services to be provided. The amicus brief supports the right of Maryland courts in guardianship cases to order clinically necessary services. Pending the appeal (to be heard in November), the youth is continuing to receive the level of care that he needs.

**The Arc of Michigan** has prepared a [Guide to the Use of Medical Powers of Attorney](#) to provide guidance on the use of medical powers of attorney, clarification on the

difference between medical powers of attorney and patient advocate designation, and describe other types of forms that can be used. Sample forms are included in the Guide.

## **The Arc of California:**

- ▶ Among many other efforts to oppose California's physician-assisted suicide legislation, **The Arc of California** participated in The Californians Against Assisted Suicide Vigil and Speak-Out at the state Capitol led by disability rights advocates urging Governor Jerry Brown to veto The End of Life Act. Despite all of their efforts, Governor Brown signed the Act into law in October. The Arc of California is participating in the filming of the \_ to discuss the topic of physician-assisted suicide and the disability community's opposition to such legislation;
- ▶ Supported AB 187—signed into law by Governor Brown in October—a critical measure extending the life of the California Children's Services program for an additional year. This program provides important medical, rehabilitation, and other services to 180,000 medically fragile children in California.



# HONORS AND AWARDS

**The Arc of New Mexico's** Director of Public Policy, Doris Husted, was recently awarded the 2015 Cate McClain Mentoring Leaders Award by the University of New Mexico's Center for Development and Disability at the Southwest Conference on Disability in Albuquerque.



# TRANSPORTATION

**NYSARC** recently received nearly \$8 million in funding for 158 accessible vehicles statewide after Governor Andrew M. Cuomo announced that the Federal Transit Administration had approved nearly \$40 million in funding for public and non-profit organizations in New York state to purchase over 400 accessible vehicles and other equipment used to assist in the transportation of seniors and people with disabilities.