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# ABUSE AND NEGLECT



**The Arc of Arizona** sponsored and helped secure passage of a bill establishing an online, publicly accessible database of individuals convicted of abuse against adults under the state's Adult Protective Services division. Prior to this time, anyone seeking such information had to go through a laborious and time-consuming request process since the information was not readily available to the public.

## **The Arc of California**

- Sponsored AB 1927 meant to protect individuals with I/DD in residential facilities and institutions from predatory staff members who use their power over residents to influence, coerce, or force them into sexual relations and to honor the freedom of individuals with I/DD who are able to consent to sexual relations and are not in inherently exploitative situations to make their own decisions.
- Sponsored AB 1273 which would make it a crime for a residential caregiver to have sexual relations with a person with I/DD who is a resident or in-patient of a treatment or care facility. In this case, prosecutors would not have to prove non-consent which can be a major barrier to convicting assailants of rape in these scenarios. If a person with I/DD and a residential caregiver mutually decide to enter into a consensual sexual relationship, the caregiver would be required to first remove him or herself from the power position over the person with I/DD. This bill mirrors legislation that governs the relationships between doctors, therapists, and substance abuse counselors and their patients/clients. Police would be allowed to make on-the-spot arrests without warrants, like in cases of domestic violence, and officers would be able to get immediate protective orders against the perpetrators.
- Opposed SB 128 which seeks to legalize physician-assisted suicide given that there are no possible regulations or safeguards that could be included that would adequately protect individuals with I/DD from being pressured or forced to end their lives prematurely.

**The Arc of Colorado** helped block the passage of HB 1135, which would have authorized an individual with a terminal illness to request life-ending medication, and SB 077—the Parents' Bill of Rights—which would have given parents unlimited rights over their children's education, curricula, physical and mental health care, and child abuse standards. It helped secure passage of the following bills:

- HB 1183—Child's Statement of Attempted Sexual Crimes—which extends the evidentiary rule for out of court statements by a child who experiences or witnesses an attempted sexual offense.
- HB 1185—Second Offense Sentence-Child Sexual Exploitation—which establishes a minimum sentence for any person who commits a second or subsequent offense for making sexually exploitative material of a child.
- SB 020—Education to Prevent Child Sexual Abuse and Assault—which requires the school safety resource center to collect and make available materials and training regarding the awareness and prevention of child sexual abuse and assault and requires those materials be accessible for people with I/DD.
- SB 109—Mandatory Abuse Reporting for Adult with a Disability—which adds the requirement to include adults with I/DD to mandatory reporting requirements of suspected abuse or exploitation and creates an implementation task force to review issues related to mandatory reporting.
- SB 126—Medical Tests for all Assault Victims—which expands the provisions of assault laws to cover any violation of second or third degree assault.

**The Arc of Maryland** worked with the Autistic Self Advocacy Network, Disability Rights Education & Defense Fund, and Not Dead Yet to oppose the Death with Dignity Act which would "authorize a qualified patient to request aid in dying" with the assistance of a physician prescribing

medication to “bring about the qualified patient’s death.” The Arc of Maryland opposed the bill because of the lack of protections included for individuals with I/DD, historic discrimination based on perceived ‘quality of life’ of persons with disabilities, and lack of treatment and other options for individuals with I/DD (such as palliative care, suicide prevention, mental health services, support services, etc.). The bill was heavily debated during the 2015 session, and

was not voted on in either committee. The bill is expected to be reintroduced next session, and a study group will convene over the summer to look more in depth at the implications of such legislation.



# BUDGET

Tony Anderson, Executive Director of **The Arc of California**, was quoted in an [article](#) stating that Governor Brown's budget is "another broken promise that shows a shocking callousness and disappointing indifference toward Californians with developmental disabilities...Despite mounting data that demonstrates how California's program funding is declining to the bottom of the nation, the governor's budget offers no significant relief."

**The Arc of Colorado** helped secure:

- \$175,000 for cost analysis of fully including people with I/DD in the state Medicaid capitated Mental Health system;
- \$1M for respite for families through the Family Support Services program; and
- \$500,000 for person centered training throughout the state for providers, self-advocates, for person centered training throughout the state for providers, self-advocates, families, advocates and others in the I/DD system.

**The Arc of Illinois** participated in a rally to protest major budget cuts to human services in Illinois.

**The Arc of Indiana** helped to secure funding for key services and supports for people with I/DD in the biennial budget, including:

- Funding to serve 3500 new people on the Family Supports Medicaid Waiver and 600 new people on the Community Integration and Habilitation Waiver over the next two years. This means that individuals will be able to receive waiver services in the same year that they apply rather than waiting years to receive services and supports.
- A significant investment in resources to help the service delivery system recover from years of sustained cuts by providing funding to restore provider reimbursement rates to 2010 levels. Resources were also included in the

budget for the conversion to daily rates for the Community Integration and Habilitation Waiver. This will allow providers to begin to address the critical issue of wages and benefits for direct support professionals.

- \$1M each year of the biennium for Adult Volunteer Guardianship Programs. The language in the budget also allows the match required for the program to recognize in kind donations. This is a major achievement as the demand for quality guardianship services is growing and the availability of programs to meet the demand has been scarce.
- A slight increase each year of the biennium for the public mass transit fund (rather than a 3% funding cut as proposed by the Governor).
- Funds Vocational Rehabilitation Services to respond to anticipated demand. \$6.1M each year for First Steps/ Early Intervention and efforts to study the manner in which Systems Point of Entry and ongoing services are funded to assure transparency and adequacy and study rates.
- Funding for the CHOICE, state funded home care program at \$48.7M each year of the biennium, along with transfers to the Medicaid Waiver of \$18M each year.
- \$1M each year of the biennium for 211 Dialing Code for Human Services Information.

**The Arc of Maryland** helped secure the passage of a budget that included:

- \$10.7M for supported employment or other day supports for 575 youth leaving school in 2015. A portion covers services such as residential supports for transitioning youth.
- \$2.4M for approximately 60 people in emergency situations and in immediate need of assistance.
- \$930,000 to serve people on the waiting list with priority to people living with the oldest caregivers – approxi-

mately 25 people. No additional funds were provided to the 8,000 people on the state's Developmental Disability Administration's (DDA) Waiting List. Historically, \$3 million was provided for the highest category of need – Crisis Resolution. The legislature adopted the budget with \$3 million for 125 people on the Crisis Resolution list; however the Governor failed to issue a Supplemental Budget to specifically authorize funds for this purpose. The Governor can use the funds for this need; or not. Unspent funds will revert to the General Fund. Given the tremendous need, The Arc of Maryland has issued action alerts for members to request the Governor to designate these funds for people on the Crisis Resolution list.

- \$28.1M– 3% Rate Increase to fund community services. The Governor's original budget cut the mandated rate increase in half – from 3.5% to 1.75%. Thanks to tremendous legislative champions and grassroots advocacy, a 3% rate increase was secured for FY 2016; with 3.5% in each of the following years through FY 2019.
- \$429,000 for approximately 10 people involved with the court system who will be assisted to leave facility-based settings for the community and divert others from entering facilities.
- \$9.7M to upgrade the DDA financial system and to develop new assessment tools.
- Directs DDA to use funds that are saved due to weather-related closures and provide payments to providers to offset a portion of their weather-related financial losses.
- Directs DDA to provide a Report on Transitioning Youth Placements. The report will provide the number of youth who exited the educational system since FY 2011 but have not received TY funding and remain without DDA-funded services. The Department is also required to include a plan to ensure TY funds are provided in a timely manner, including a timeline and necessary steps to ensure TY-eligible individuals are able to begin services on July 1, 2015.
- \$16.5M for the Autism Waiver. This means that 1,000 children on the waiver can continue to receive services. While this appropriation is an increase from FY 15, no additional children will be served. The current waiting list is 3,088 children.

- \$4.3M for an expansion of pre-kindergarten which will open the door for \$15M in federal funds to serve an additional 3,000 children, including children with disabilities.

### The Arc of Minnesota

- Created the 5% Campaign to help its constituents connect with legislators and explain why a 5% increase in funding for community services for individuals with I/DD matters. As a reminder of the importance of the many hands that provide support to individuals with I/DD, the campaign created a [5% Hands Template](#) that constituents can mail to legislators.
- Helped secure the passage of the Health and Human Services Omnibus Bill, which was signed by the Governor in late May. Despite disappointment that no funding was allotted to the 5% Campaign, employment funding for those using self-directed services, increases in Advocating Change Together's grant for Self Advocates Minnesota, or expanded Group Residential Housing services for people with disabilities, the bill did allot significant new funding to the following:
  - \$4.8M to lower premiums for Medical Assistance for Employed Persons with Disabilities which will allow more working Minnesotans with disabilities to retain their medical coverage.
  - \$3.4M to reduce Medical Assistance costs for working seniors and people with disabilities who have high medical costs.
  - Spend down eligibility for Medical Assistance was raised to 80% of the Federal Poverty Level.
  - Parental fees on I/DD services were lowered by 10%.
  - \$105,000 in funding to administer ABLE Accounts.
  - \$1.173 million for the State Quality Council and its activities.

**The Arc of New Jersey** has worked to increase funding to address the waiting list, increase the availability of Family Support Services, and ensure all currently proposed funding, including new monies for I/DD specific housing vouchers, remains intact as budget negotiations proceed. A state budget must be signed by June 30.

**The Arc of Ohio** helped to ensure that the spending measure—HB 64—included a compromise plan to recon-

figure intermediate care facilities and the creation of a commission that would examine state-run developmental center closures. It also removed provisions that would have reconfigured the independent provider model in favor of an agency-focused approach.

**The Arc of Wisconsin** successfully advocated for the proposal of an amendment to the state budget that would remove those provisions in the state budget proposal

that would significantly impact disability resource centers and all of the individuals serviced by these programs and resources. The Arc of Wisconsin created a presentation on these issues for the legislature which was well received. The Joint Committee on Finance temporarily postponed votes on budget amendments until revised state revenue figures are released.



# COMMUNITY-BASED SUPPORTS AND SERVICES

As part of the Lanterman Coalition's advocacy efforts, **The Arc of California** got 35 senators and assembly members to agree to sign a letter supporting a 10% emergency funding increase to stop the support service system from collapsing.

**The Arc of Colorado** helped secure passage of the following bills:

- HB 1186—Services for Children With Autism—which expands the Children with Autism Waiver to end the waiting list for that waiver; raises the age limit from 6 to 8 years of age; ensures that all children receive at least 3 years of service regardless of age at entry into the waiver; eliminates the cap of \$25,000 per year and allows the medical services board to establish annual limits; and increases the frequency of program evaluation.
- HB 1233—Respite Care Study Task Force—which establishes a task force to study supply and demand for respite services in CO.
- HB 1318—Consolidate Intellectual and Developmental Disability Waivers—which requires the state to submit a new waiver to the Centers for Medicare and Medicaid Services for implementation by July 2016 or as soon as CMS approves to provide flexible benefits and services; guarantees that persons in service continue to receive same supports; requires the state to submit a plan for implementing conflict free case management with subsequent statutory changes required; requires the state to evaluate the process for eligibility determination and service planning assessment and to evaluate sufficiency of reimbursement rates.
- HB 1368—Cross System Response Pilot—Intellectual and Developmental Disabilities—which establishes a cross system response for behavioral crisis intervention, stabilization, and follow-through for people who also

have an intellectual/developmental disorder. Pilots may be in more than one location. The bill provides funding for the first year of pilots with agreement that pilots can continue for up to three years and requires the dept. to conduct a cost analysis of fully including people with I/DD in the state mental health Medicaid system.

**The Arc of Illinois** released the [Community Integration Makes Sense Toolkit](#) for use when speaking with state legislators about the values of deinstitutionalization and community integration. Among other things, the Toolkit includes relevant laws and litigation, data, expert reports, and editorial support on the issue.

**The Arc of Indiana** assisted with advocacy efforts to transition the last of three large intermediate care facilities for people with I/DD into a traditional nursing home, enabling over 100 individuals with I/DD to find new homes in the community.

**The Arc of Kentucky** supported the Michelle P. Waiver Amendment (five year waiver) to the Final Rule for HCBS requiring statewide transition planning for waiver amendments. The Arc of Kentucky is committed to ensuring that people with I/DD and their families are involved in the amendment process.

**The Arc of North Carolina** issued an action alert urging the Governor to allocate funding for group homes struggling with the loss of Personal Care Services and the depletion of bridge funding. The great response to that alert helped push this issue to the forefront with the administration and legislators, greatly improving the position of disability advocates on this issue. The Arc of North Carolina is continuing to work very closely with House and Sen leadership along with the Governor to find answers to the short term funding crisis as well as the long-term goal of securing a stable funding stream for residents in group homes.



**The Arc of Tennessee** led a successful advocacy campaign to pass SB0017/HB01115—the “Aging Caregiver” bill—that would guarantee HCBS funding through Tennessee’s Self-Determination Waiver for eligible individuals on the waiting list with primary caregivers aged 80 and older. The original legislation targeted individuals with caregivers aged 75 and older. However, the fiscal note was too large and the legislation was amended to work with the \$1.1 million that the legislature found to fund the bill. This is the first increase in funding to address the waiting list for HCBS since 2007 with the exception of funds to address individuals in crisis.

### **The Arc of New Jersey**

- Testified in support of AB 4420 which requires the Division of Developmental Disabilities to alert the community provider when services to an individual with I/DD are being terminated. Currently, the Division alerts the individual and/or the family or guardian but it is not required for them to also alert the provider. The bill also extends the notification of that termination to 90 days, up from current law which is 60 days. The increase in notification time will allow the individual, in conjunction with the family or guardian and the community provider, to either appeal the termination decision or to put substitute arrangements in place to ensure the person’s

continued care. The legislation passed unanimously and has moved to the Assembly Appropriations Committee.

- The Arc of New Jersey’s Executive Director Tom Baffuto advocated for families and community providers while testifying before the Senate Legislative Oversight Committee. The hearing at the State House was an opportunity for legislators to hear more about the significant number of ongoing changes being spearheaded by the Department of Human Services. Tom spoke about the upcoming shift to fee-for-service, the implementation of the HCBS Transition Plan, the recent changes to the DDD eligibility rules, the upcoming start of the Supports Program, and the relocation of children with I/DD to the Department of Children and Families. With all of these transformations happening simultaneously, Tom told legislators that families and providers are feeling a great deal of anxiety and confusion. He advocated for the Department of Human Services to increase communication with stakeholders while all of these changes are taking place. Tom’s testimony was covered in the New Jersey Spotlight: [Advocates for Intellectually Disabled Cry Foul Over Revamped Policies.](#)



# CRIMINAL JUSTICE

## The Arc of California

- Participated in the Association of Regional Center Agencies' Forensics Task Force to examine systemic issues affecting individuals with I/DD from arrest to incarceration. One specific area of concern is access to competency trainings for people with I/DD. Those individuals who, by virtue of their I/DD, are determined incompetent to stand trial may see their legal process delayed, burdening the courts, jails, district attorneys, and public defenders while they attempt to access services meant to restore competency.
- Supported Senate Bills 11 and 29 to better train police in dealing with people with I/DD and mental illnesses. People with I/DD experience much higher rates of serious crime than the general population, and lack of adequate law-enforcement officer training for handling these often-difficult cases may be the single biggest obstacle to arresting and convicting the perpetrators. Lack of enough training can also lead to serious and sometimes tragic mistreatment of persons police think are suspects.

**The Arc of Indiana** helped secure the passage of HB 1304—Various Criminal Law Issues—which allows people with disabilities who are arrested to access diversion programs that they previously could not access as well as providing access to important prescription medications while under arrest. The bill authorizes a prosecuting attorney to require a person participating in a prosecutorial diversion program to receive treatment to reduce recidivism and permits diversion and deferral fees to be used to fund treatment programs to reduce recidivism. The bill also permits a criminal court to appoint a special advocate (in addition to a public defender) to assist a person with I/DD who is charged with a criminal offense.

## The Arc of Maryland

- Helped secure the passage of SB 853/HB 1161 which establishes the Ethan Saylor Alliance for Self-Advocates as Educators in the state's Department of Disabilities. The purpose of the Alliance is to advance the community inclusion of individuals with I/DD by training these individuals to implement evidence-based training with law enforcement and other entities that work with the I/DD population in their communities.
- Ran a Disability Response Team training with [The Arc's National Center on Criminal Justice and Disability](#) to train first responders in order to achieve better outcomes when law enforcement interacts with individuals with I/DD. The event was covered widely in the media, including this Washington Post article: [Group Leads Training for Disability Response](#).

**The Arc of North Carolina** successfully advocated to amend SB 343—Student Assault on Teacher/Felony Offenses—which would increase from a misdemeanor to a felony the penalties for an assault on a teacher or school personnel by a student who is 16 or older. Due to The Arc of North Carolina's advocacy efforts, including a [joint statement](#) issued to state senators, the bill was amended to remove students with IEPs and 504 plans from being charged with a misdemeanor or felony under this law and altered the severity of a first offense charge from an automatic felony charge to a misdemeanor. The bill has passed through the Senate and is now in the House. The Arc of North Carolina continues to raise serious concerns with the legislation, since only some students with I/DD have IEPs and 504 plans while others would remain unprotected by the law. Over the last several years, more than half of reported assaults on school employees were committed by children with special needs.

# EDUCATION



**The Arc of Arizona** helped secure the passage of legislation that for the first time establishes guidelines for the use of restraint and seclusion methods in all of the state's schools—public, private, and charter.

**The Arc of Illinois** helped secure the passage of the following bills:

- HB 1360—Health and Safety Requirements/Charter Schools—which requires state charter schools to comply with all non-curricular health and safety requirements that public schools are required to follow. This includes, home and hospital instruction, self-administration of asthma inhalers, concussion policies and epi-pen administration. The state's Board of Education is required to post a list of requirements on its web site and revise its list annually. The requirements would be incorporated into local charter school agreements.
- HB 3123—School Counselors—which clarifies legislation passed in 2014 regarding the services school counselors may provide to students with IEPs.

**The Arc of Indiana** helped secure the passage of the following bills:

- HB 1108 which provides that if an education center offers teacher training programs, it must offer courses for teachers on dyslexia screening and appropriate interventions. Also provides that guidelines for use by accredited teacher education institutions and departments must include content that prepares teachers to recognize that a student who is not progressing at a normal rate in reading may need to be referred to the school's multidisciplinary team to determine the student's learning needs.
- HB 1194 which ensures that all high school students have access to the general education diploma and will have different career pathways from which to choose to assist them in earning a GED. The bill provides that IEPs developed at the annual case review in grade 8

for students with disabilities must include the type of diploma the student will seek and the courses necessary to obtain the diploma. Beginning in grade 9, the student's teacher of record must communicate with the student's parent at least once each reporting period to review the student's progress toward the diploma.

**The Arc of Kentucky** advocated for the mandated transition IEP to focus on the development of employment skills and help students connect with Vocational Rehabilitation Services and encouraged the state to provide more resources to enable school systems and adult services providers to meet these mandates. The Arc of Kentucky also supported an increase in the amount allowable to students with disabilities that are attending college part-time from \$250 per semester to \$500 per semester (the current amount allowable to students without disabilities).

**The Arc of Maryland** was unable to secure the passage of the following bills despite its advocacy efforts:

- HB 44—Special Education IEP Translation Pilot Program Establishment—which would have allowed a parent to request that their child's IEP or IFSP be translated into their native language. This bill failed by a single vote due to concerns about costs to local school system. The bill will be reintroduced in 2016.
- HB 47—Special Education—Loan Assistance Repayment and Paraprofessional Training—which would have added special education teachers, paraprofessionals, and speech language pathologists to those eligible for the state's loan repayment program. This bill will be reintroduced in 2016.
- HB 342—Special Education Related Services Providers Consortium—which would have required the state Board of Education to create a consortium of substitute related service providers, such as physical, occupational, and speech therapists, so that a student would not regress in the event the student's regular therapist was absent.

- HB 1060—Special Education Individualized Education Program Facilitated Meetings—which would have allowed either the school system or a parent to request the participation of a neutral third party facilitator in a child’s IEP meeting in order to foster greater collaboration between school systems and families and lessen the chances of litigation. This bill will be reintroduced in 2016.
- HB 152/SB 535—Community Colleges-Tuition Waiver for Disabled Individuals-Requirements—which would have made it easier for students on SSI or SSDI to obtain a tuition waiver when they attend a community college in the state.
- HB 344/SB 690—Due Process Hearings for Children with Disabilities-Burden of Proof—which would have shifted the burden of proof in special education due process hearings to the school system except in the area of a unilateral private school placement.

**The Arc of Minnesota** helped secure the passage of an education bill that maintains funding for the school safety technical assistance center, which implements the anti-bullying law and requires disability-specific training for paraprofessionals. The bill did not include additional funding for special education, positive behavior intervention supports (PBIS), seclusion and restraint technical assistance, or the Southwest Minnesota State online program for paraprofessionals who want to become special education teachers, despite the Arc of Minnesota’s advocacy in these areas.

**The Arc of North Carolina** helped secure the passage through the House of:

- HB 921—Educational Opportunities for People with Disabilities—which addresses outcomes and goals for students from K-12 and their transition to post-secondary educational and career opportunities. The bill includes an increase in funding of students with disabilities in public schools. Prior to this bill, IDEA funding for stu-

dents with disabilities had an arbitrary cap of 12% even if enrollment of such students is above this percentage. The overall increase of 1% over two years is a major victory. The bill also:

- Continues the state’s IEP improvement process with a greater focus on outcome-based goals;
- Requires the state to solicit stakeholder input in a variety of areas, including transition planning, for students with disabilities;
- Requires mandatory annual reporting by the state to the Joint Education Oversight Committee on development and implementation of all sections set out in this legislation with the goal of improving graduation rates; and
- Provides \$600,000 for the biennium to the Carolina Institute for Developmental Disabilities in collaboration with the North Carolina Postsecondary Education Alliance to work to build capacity through three regional partnerships for identifying and promoting excellence in postsecondary education for people with I/DD.
- HB 133—Modify Special Education Scholarships—which increases the amount of scholarships for students with disabilities that could be used toward charter or private schools to \$4,000 and tweaks the way the scholarship money is dispersed, with funding being sent direct to private schools each semester. Currently, a child’s private school tuition must be paid for by the guardians and at the end of each semester, after proof of tuition payment is provided, the funds are reimbursed to the families.

# EMPLOYMENT



**The Arc of Colorado** advocated for an amendment to:

- SB 213—Waive Government Immunity for Acts of School Violence—which amends the current law to require schools to exercise a standard of reasonable care to protect staff, students, and others from harm. The bill waives sovereign immunity when violent actions result in serious bodily harm or death and establishes limits on damages that may be recovered. The Arc of Colorado advocated for an amendment, which did not pass, to make the standard for waiver of immunity negligent indifference rather than reasonable care.
- SB 214—Interim Committee Safe Schools Youth in Crisis—which establishes an interim legislative committee to study issues related to school safety, evaluate programs and methods for threat assessment, develop criteria for school personnel to use in assessing potential threats by students, and evaluate the implementation of SB 213. The Arc of Colorado successfully secured an amendment to add an educator with special education experience to the committee and supported the addition of a school resource officer and mental health professional. It also supported an amendment that did not pass that would have added a special education administrator, school safety officer, and others.

**The Arc of Minnesota** supported SF 1517/HF 1790—Consumer Directed Community Supports—which is designed to expand self-directed employment options. Currently, CDCS does not provide additional employment funding when an individual on CDCS graduates from high school or turns 21, which forces individuals with I/DD to choose more expensive, formal supports to get the assistance they need. The Arc of Minnesota also created a fact sheet for advocates, entitled: [“The Olmstead Plan and Employment First: Myths and Realities.”](#)

**The Arc of Nebraska** worked to ensure that a bill which would create contract opportunities for some agencies to create work enclaves or workshop jobs for people with disabilities would include more opportunities for community-based employment for individuals with I/DD. The bill is currently being revised along these lines and will be reintroduced in the next legislative session.

**The Arc of New Jersey** testified before the Assembly Human Services Committee about the important role of vocational services and day programs for individuals with I/DD. Tom Baffuto and Kathy Walsh spoke about The Arc of New Jersey’s support of Employment First while also recognizing that vocational services and day programs afford individuals the opportunity to learn skills, interact with peers and have productive and meaningful activities in their lives. They talked about protecting these programs for the many individuals who need them now and in the future.

**The Arc of Pennsylvania** participated in the Campaign for What Works’ “I Want to Work” advocacy campaign—led by young adults with disabilities—and advocated, through reintroducing HB 2405 and SB 1497, for funding for the Office of Vocational Rehabilitation at a level that draws down the full amount of the available match in federal funds, focused employment support for youth transitioning out of high school, and employment in community settings for young adults with disabilities. The Campaign recently launched its [website](#), which features key legislative updates, personal stories of people with disabilities in the workforce, and notes from sponsors.



## FAMILY SUPPORT

**The Arc of California** supported SB 4506 which would help the families of individuals with I/DD by expanding the number of employees who are eligible to take 2 weeks of family leave each year without losing their jobs. Families supporting children with I/DD typically experience reduced earning potential and single mothers of children with I/DD are more likely to be living in poverty.

**The Arc of Massachusetts** has reached out to the legislature to oppose the elimination of vacation payments to Adult Foster Caregivers (AFC) from MassHealth. Historically, caregivers have received a reimbursement from Medicaid for up to 14 days each year while alternate caregivers provided support to the individual receiving AFC services in their place. Originally The Arc of Massachusetts and others thought that all cuts for AFC were off the table and has reached out to the legislature on this change with the hope of bringing about reinstatement.

**The Arc of Minnesota** supported SF 1493 which would reduce or eliminate the fees that families pay so their children with I/DD can receive services that help them stay in the community and keep their families intact. Parents whose incomes would normally be too high to qualify for Medical Assistance (MA) can receive coverage for in-home supports and medical services through MA. Families accessing these programs pay a fee on a sliding scale. For some middle-class families, this fee can be several hundred dollars a

month. To help balance the state budget over the past decade, lawmakers at times increased parental fees. This increased the burden for Minnesota families and made fees unaffordable for many of them. In some cases, fees equaled a family's mortgage payment or the amount of state taxes it paid. Some families drained their savings accounts or drew down retirement accounts as a result of unaffordable fees. Fees can be so high as to prevent parents from applying for crucial services that would meet their children's needs.

**The Arc of New Jersey** testified before the Senate Health, Human Services, and Senior Citizens Committee in support of S2640. This legislation would create a Caregiver Task Force to evaluate and provide recommendations on caregiver support services. Should the legislation be signed into law and the Task Force be created, The Arc of New Jersey would be among the appointed members. The legislation received unanimous support in Committee and now awaits a full vote in the Senate.

**The Arc of Virginia** helped secure the passage of Conner's Law which provides that a court may order child support for any child over 18 with severe and permanent mental or physical disabilities. This closed a loophole in the law that precluded judges from ordering ongoing financial support when parents of an individual with I/DD divorce after that individual turns 18.





**The Arc of California** supported AB 1147 to open pediatric health facilities to young adults aging out of special education. The bill mirrors standard practice for children with I/DD in group homes and bridges the gap during their remaining years in special education. While it is generally preferable that young adults be served in schools rather than health facilities, health facilities may be the best service available for individuals who are medically fragile.

**The Arc of Colorado** successfully opposed HB 1066, which would have repealed the state's health benefit exchange and helped secure passage of the following bills:

- HB 1029—Health Care Delivery via Telemedicine State-wide—which removes restrictions on in-person health care delivery and precludes a health plan from requiring in-person delivery when telemedicine (benefiting many with I/DD) is appropriate.
- HB 1083—Patient Contribution-Rehabilitation Services—which prohibits insurance carriers from classifying physical therapy, occupational therapy, or chiropractor services as specialty services and limits co-payment for physical rehabilitation to 50% of what the provider is paid for the visit by the carrier;
- HB 1182—Scope of Practice-Certified Nurse Aids—which allows a certified nurse aide deemed competent to perform bowel care, G tube and J tube feedings, and placement in a client's mouth of medication that has been prepared by a nurse or pharmacist.
- HB 1211—License Requirements for Durable Medical Equipment Suppliers—which narrows the definition of durable medical equipment (DME) suppliers and exempts persons or entities that supply or provide insulin infusion products as part of Medicare's national mail-order program. The bill deletes the requirement that the DME supplier have a physical location within the state and allows an applicant for a DME supplier license to instead attest that he or she is capable of selling and

servicing products sold in that state on a 24/7 basis.

- HB 1232—Emergency Use of Epinephrine Auto Injectors—which permits entities and organizations other than schools to acquire and stock epinephrine auto-injectors and exempts them from civil and criminal liability when using these injectors.
- HB 1242—Patient Caregiver Designation—which requires hospitals to give each patient or legal guardian the opportunity to designate a caregiver within 24 hours after the patient's admission to the hospital and prior to release or transfer to another facility. The caregiver will be provided with information about a discharge plan and instructions and training for the aftercare of the patient.
- HB 1309—Protective Restorations by Dental Hygienists—which allows a dental hygienist to place interim therapeutic restorations with approval by the dental board.
- SB 085—Mental Health Parity for Autism Spectrum Disorders—which requires covered state plans to provide autism services and supports as medically necessary, removes the cap on those services, allows coverage for services provided by registered behavior technicians, and repeals a provision in current state law that specifies that autism is not to be treated as a mental health disorder for purposes of health care coverage.

**The Arc of Illinois** helped secure passage of the following bills:

- HB 3158—Down Syndrome Information Act—which requires the state's Department of Public Health to make available up-to-date, evidence-based written information about Down Syndrome that has been reviewed by medical experts and state and national Down Syndrome organizations, including physical, developmental, educational and psychosocial outcomes, life expectancy, clinical course, intellectual and functional development,

and treatment options. The information must include contact information regarding first call programs, information clearinghouses, national, State and local Down Syndrome organizations, and other educational and support programs and shall be made available to persons who render prenatal care, postnatal care, or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down Syndrome. The information shall also be provided to any person who has received a positive test result for Down Syndrome. The information must be culturally and linguistically appropriate for a woman receiving a positive prenatal diagnosis of Down Syndrome and for the family of a child receiving a postnatal diagnosis of Down Syndrome. The bill states that a health care provider may, upon receiving a positive test result for Down Syndrome, provide the expectant or new parent with the information provided by the Department of Public Health.

- **HB 235—Insurance Coverage for Dental Sedation**—which amends the state Insurance Code regarding mandated insurance coverage for anesthesia provided to persons with disabilities in conjunction with dental care. Currently the mandated coverage applies to children age 6 or under when the covered child is in a hospital or ambulatory surgical treatment center. This bill expands mandatory coverage to children under age 19 who have been diagnosed with Autism Spectrum Disorder or a developmental disability. The bill also adds coverage for anesthesia provided in a dental office or oral surgeon's office for the newly covered individuals.

**The Arc of Indiana** helped secure the passage of the following bills:

- **HB 1093—Prenatal Tests Information for Parents**—which requires the state department of health to disseminate information for health facilities and health care providers to share with parents who receive a prenatal test results for Down Syndrome and other conditions diagnosed prenatally.
- **HB 1265—Designation of Caregiver for Patients**—which requires a hospital to provide each admitted patient or the patient's legal guardian with an opportunity to designate a caregiver within a specified time. This will ensure that patients receiving care in hospitals have the availability of a caregiver to also be given instructions for

continued care and follow up post discharge.

- **HB 1269—Health Matters**—which makes the department of corrections an inmate's authorized representative for applying for Medicaid for inmates who are potentially eligible for Medicaid and who incur medical care expenses that are not otherwise reimbursable.
- **SB 166—Spinal Cord and Brain Injury Fund**—which allows the spinal cord and brain injury fund to be used to fund facilities, treatment and services for spinal cord and brain injuries. Requires the spinal cord and brain injury research board to consider applications and make grants to nonprofit health care clinics that employ physical therapists and provide activity-based therapy services in Indiana to individuals with traumatic spinal cord and brain injuries that require extended post-acute care.
- **SB 358—Medication Therapy Management and Medicaid**—which allows for pharmacist reimbursement for medication therapy management services provided to certain Medicaid recipients. Requires the state's Family and Social Services Administration to determine any Medicaid cost savings and improvement in patient quality of care by providing the services and report the findings to the general assembly.
- **SB 460—Comprehensive Care Health Facilities**—which prohibits the state Department of Health from approving new nursing home beds until June 30, 2018.
- **SB 465—Human Services and Health Matters**—which amends the definition of Autism to mirror the definition of Autism Spectrum Disorder as defined in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM). Requires the division for aging to: (1) meet with stakeholders to collaborate on changes in the health facility preadmission screening assessment process; and (2) submit a written report to the general assembly concerning any recommendations for statutory changes to the process. Makes changes to the CHOICE board. Eliminates the age requirement that the representative for people who are elderly be over the age of 60, and defines that the representative for people with disabilities be chosen from an organization that represents people of all age ranges. Urges the legislative council to assign to an interim study committee



the topic of drug testing for individuals receiving public assistance.

**The Arc of Minnesota** helped secure the passage of SF 462/FH 469—the Prenatal Trisomy Diagnosis Awareness Act—which requires medical professionals to provide accurate, current information to expectant parents when they receive an in-utero diagnosis of one of the Trisomy conditions (Down Syndrome, Patau Syndrome, or Edwards Syndrome). It is a pro-information bill that gives families information they need at a crucial time. It does not prevent the medical professionals from giving any medical advice they so choose, ban any current medical procedures, or create additional costs.

**The Arc of Nebraska** successfully opposed LB 50, a bill intended to strip many essential services from Medicaid. The bill was pulled due to The Arc of Nebraska’s strong advocacy.

**The Arc of North Carolina** worked with the Autism Society of North Carolina to support the passage of SB 676/HB 646—Autism Health Insurance Coverage—which provides a clear definition of Adaptive Behavioral treatment that is not limited to one type of therapy but includes Applied Behavioral Analysis as well as other evidence-based interventions, provides access for children living across the state by supporting a range of professional disciplines to implement intensive interventions with necessary oversight, balances concerns about providing quality treatment with a cost-effective model, and provides coverage through age 18.

**The Arc of Pennsylvania** helped secure the passage of Chloe’s Law—the Down Syndrome Prenatal Education Act. This legislation mandates that medical practitioners give expectant or new parents informational publications relating to Down Syndrome. The Arc of Pennsylvania continues to support HB 1474—Paul’s Law—which prohibits organ transplant discrimination against people with disabilities on the sole basis of their disability.

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

- SB 792/HB 1122—Public Health-Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation—which prohibits organ transplant discrimination on the basis of disability by (1) clarifying that health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a

qualified individual’s disability; (2) requiring that health care providers consider, in evaluating the likelihood of a transplant’s success, the full range of supports available to help a person with a disability manage their post-operative care; and (3) including a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.

- HB 5—Department of Health and Mental Hygiene-Newborn Screening Program Fund-Establishment—which establishes a newborn screening fund to help cover costs related to screenings on newborns. It will allow new parents to learn about medical challenges their child with a disability may encounter and alert them to potential early interventions.
- SB 450/HB 660—Expense Reimbursement Claims Forms-Methods for Submission—which will allow families to submit claims from out of network providers electronically to their health insurer. The bill was introduced with the aim of reducing the time families must wait for reimbursements.
- HB 566—Department of Health and Mental Hygiene-Licensees Providing Services to Individuals With Developmental Disabilities-Emergency Action—The Arc of Maryland testified in support of this bill which allows the Department of Health and Mental Hygiene to take immediate action if it finds that a provider has jeopardized the health, safety, or welfare of individuals with I/DD.
- HB 1172—Individuals With Developmental Disabilities-Providers-Licenses—This bill codifies the change in licensing duties from the Developmental Disabilities Administration to the Office of Health Care Quality, and authorizes the Department of Health and Mental Hygiene to issue civil money penalties for failure to substantially comply with State laws, rules or regulations. DHMH will be required to promulgate regulations that define when penalties can be imposed based on the number of problems, their seriousness and if these are repeat incidents.



# HOUSING

**The Arc of California** supported AB 1335 which would charge a modest fee on property-exchange paper work to fund affordable housing opportunities which individuals with I/DD desperately need. The Arc of California also supported AB 35 which prevents the loss of the state's affordable housing supply with a new tax credit program.

**The Arc of Tennessee**, through its contract with the state's Department of Intellectual and Developmental Disabilities, will assign an advocate to each individual transitioning from the Green Valley Developmental Center, the last state-run developmental center in Tennessee, which a court ordered to be closed with an exit plan in January 2015. The advocate from The Arc of Tennessee will be involved throughout the transition process and continue to follow that person in their new community home for a minimum of sixty days. The advocate's role is to ensure that the transition process addresses all the needs of the person includ-

ing medical, behavioral, social, and environmental. The advocate will work with the circle of support to ensure that appropriate providers are chosen and that the individual has the services he/she needs.

**The Arc of North Carolina** attended a federal housing policy roundtable sponsored by Representative David Price, the Ranking Member of the U.S. House Appropriations Subcommittee on Transportation, Housing and Urban Development. The roundtable, comprised of non-profit housing service providers and affordable housing advocates, was an opportunity to share with Representative Price the housing needs of people in his district, including people with intellectual and developmental disabilities. The group discussed key federal housing programs and the challenges these programs are facing with sequestration and the Budget Control Act.



## LITIGATION

In March, the State of California chose not to appeal the decision in favor of the plaintiffs in [\*The Arc of California v. Douglas\*](#). Here, Judge Morrison England, Jr. of the Eastern District of California held that the state violated Section 30(A) of the Medicaid Act—which requires a cost study analyzing potential harm from rate cuts to a constituency—by implementing a half-day billing rule and mandatory holiday schedule that placed consumers at risk and threatened the solvency of provider organizations. Plaintiffs’ motion for partial summary judgment was granted and the court held that the state’s reimbursement reductions were patently invalid and must be enjoined. In April, in light of [\*Armstrong v. Exceptional Child Care Center\*](#), a United States Supreme Court case holding that providers may not sue to enforce this provision of the Medicaid Act—the state moved to vacate the opinion. The court heard the state’s motion on May 14. However, while the *Armstrong* decision precludes private parties from suing a state in court, there are other compliance mechanisms that would come into play if the state is determined to resume cuts that courts have previously held to be unlawful.

In May 2015, [\*The Arc of New Mexico\*](#), along with Disability Rights New Mexico and eight individual plaintiffs, reached a settlement with the state’s Human Services Department and the Department of Health in their *Waldrop*

*v. New Mexico Human Services Department* lawsuit (filed in January 2014) challenging the reductions in services to individuals on the DD waiver program that were imposed as a result of the way the state was using a new assessment tool called the Supports Intensity Scale as well as the lack of due process afforded to the participants who experienced these reductions and whose families and guardians sought to appeal them. In March 2015, federal district court judge Judith Herrera issued a preliminary injunction in favor of the plaintiffs requiring the state to restore all services that had been reduced due to the improper use of SIS for all persons in the DD waiver program. Once that occurs, if the state once again proposes to reduce or terminate benefits or services by setting a cap on a participant’s budget based on their SIS score, the individual and their family or guardian would have to be provided clear notice of the proposed changes and a meaningful opportunity to challenge the reductions in an administrative fair hearing that complies with constitutional requirements. The parties reached a final settlement in May 2015 which restores a person-centered approach to the DD waiver program, provides a meaningful opportunity for individuals to appeal any denials or limitations of services, and allows people to regain access to therapies and other services that were arbitrarily denied using the current system. More details are available in the [full Settlement Agreement and Release](#).

## OTHER



**The Arc of Indiana** helped secure the passage of SB 420—Developmental Disability Terminology—which changes the term “mental retardation” to “intellectual disability” in all parts of the state code.

**The Arc of Maryland** submitted testimony on the state’s Department of Transportation budget focusing on the need to improve paratransit services in various regions and the expense of paratransit for riders.

In collaboration with the Citizens Advisory Board of the Department of Developmental Services, **The Arc of Massachusetts** created a [video](#) that stresses the need for funding services for those with I/DD for the purpose of energizing constituents to contact their legislators.

**The Arc of Nebraska** supported the Governor’s proclamation of March as “Developmental Disabilities Awareness Month” in the state. On hand for the signing of the Governor’s proclamation were board member Lynn Redding and Executive Director Michael Chittenden, among others. Maureen Cronin, the Executive Director of The Arc of Pennsylvania, was appointed to the Governor’s Aging Transition Committee. Board Member and self-advocate Sara Wolff

was invited by Senator Bob Casey to attend the State of the Union address due to her advocacy efforts to pass the ABLE Act. You can read about her experience attending this event in her post on The Arc’s blog: [“Unreal” – My Trip To Washington for the President’s State of the Union Address](#). The federal Achieving a Better Life Experience (ABLE) Act was signed into law in December 2014. This Act allows individuals to open tax free savings (529) accounts that can be used to pay for disability-related expenses without counting toward asset caps that would compromise an individual’s eligibility for federal benefits programs, provided the individual is declared as having a disability before age 26. While the federal law sets the framework, states must create the vehicle for the accounts to be made and administered. State chapters of **The Arc in California** (AB 449), **Colorado** (HB 1359), **Illinois** (SB 1383), **Maryland** (SB 761/ HB 1105), **Montana** (SB 399), **North Carolina** (SB 367/HB 556), and **Virginia** helped support and secure the passage of state bills implementing the ABLE Act in their states. Arizona is in the minority of states in which ABLE Act legislation was not introduced this year, but **The Arc of Arizona** has joined a coalition of organizations to ensure success in implementing this legislation in the state in 2016.