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*Cover and left: The Arc of Virginia staff and volunteers participate in the “Rally to Save Medicaid” on the lawn of the U.S. Capitol.*
The Arizona legislature recently approved a state budget that includes several victories for The Arc Arizona, including an increase in funding for the state’s early intervention program, teacher salary increases, and dropout prevention, as well as additional funding for occupational therapy and emergency dental services under Medicaid. The budget also included increased funding for home and community-based services and funding to partially cover the costs of increasing the wages of direct support professionals (DSPs) to comply with the state’s minimum wage increase.

Connecticut began the new Fiscal Year on July 1 without a state budget. This leaves people with I/DD, their families, and providers uncertain of what services can be provided moving forward. Tom Fiorentino, President of the Board of Directors of The Arc Connecticut, told NBC Connecticut: “These are what I would term massive cuts to the very core of the private provider system in Connecticut, and that’s the system that provides about 90 percent of all assistance to people with intellectual disabilities, not state employees, private providers.” His son Daniel, who has Down Syndrome, works at a dermatologist’s office three days a week with the support of a job coach and attends a day program two days a week. These services are now at risk.

Meg Cooch, Executive Director of The Arc Illinois, and Kimberly Johnson-Evans, mother of a child with I/DD and Ligas Family Advocate, testified at a House Human Services Appropriations hearing on the FY18 Department of Human Services budget. They stressed the need to rebalance funding to focus on home and community-based services, the need for a wage increase for DSPs, and the funding of grant programs that provide services to people with I/DD. After two years without a budget, the Illinois General Assembly recently approved a budget overriding Governor Bruce Rauner’s veto. This budget includes funding for critical information, systems navigation, family support, and other grant funding for people with disabilities. The chapter will work to ensure that the implementation of the budget is done in a manner that limits disruption to services and helps strengthen community living for people with I/DD in the state.

The finalized Maryland budget contains many victories for The Arc Maryland including a 3.5% waiver rate increase to cover the cost of compliance with the state’s Minimum Wage Act, funding for individuals with I/DD who are aging out of the school system to receive employment and day services, waiver slots for individuals with the most urgent needs, reduction of waiting lists, community services for individuals with I/DD involved in the court system, funding for inclusive higher education programs for students with I/DD, new autism waiver slots, and an increase in funding for pre-kindergarten education.

Thanks to the advocacy of The Arc Minnesota, the Minnesota legislature passed and Governor Mark Dayton signed a Department of Health and Human Services funding bill that includes a 13% reduction in parental fees for participation in the state’s program providing medical assistance to children with disabilities, funding for statewide self-advocacy efforts, new services to facilitate competitive employment, and a 1.5% increase in wages for personal care attendants under the SEIU contract.

The California legislature recently passed a budget, signed by Governor Jerry Brown, that lifts the caps on respite services that were imposed during the economic downturn in 2009, a victory for The Arc California.

The Arc Michigan successfully opposed the inclusion of language in HB 4323, which would shift all Medicaid benefits into managed care and require the establishment of a single behavioral health managed care organization. The chapter opposes moving to a managed care system because it would move control of the system from a board appointed by elected officials and subject to open meetings laws to private companies. Additionally, private health plans might not understand person-centered
planning and individualized supports. The final budget does not shift Medicaid benefits into managed care or require the establishment of a single behavioral health unit, but creates pilots for integrating behavioral health into private managed care. It is awaiting Governor Rick Snyder’s signature.

The Arc Ohio has been fighting a proposal to freeze enrollment in Medicaid expansion. This proposal was included in the state budget, but Governor John Kasich exercised his line-item veto authority. Gary Tonks, CEO of The Arc Ohio, penned a letter to Governor Kasich urging him to veto the measure. Additionally, The Arc Ohio and other advocacy groups held a rally outside the statehouse to protest ultimately unsuccessful attempts by the Ohio General Assembly to override the veto.

Governor Chris Christie recently signed a budget that included several victories for The Arc New Jersey, including increased funding for: community-based services for individuals on the Community Care Waiver waiting list, community-based residential placements for individuals currently living in state institutions, and new housing vouchers.

Civil Rights

The Arc Colorado successfully advocated for the passage of:

- **HB 1087**, which creates a pilot office of public guardianship for incapacitated adults without family or friends able to serve as guardian or enough money to pay a private guardian;
- **HB 1046**, which eliminates derogatory terms such as “mental retardation” and “mental deficiency” from state law and replaces them with “persons with an intellectual and developmental disability” and “persons with a mental illness;” and
- **HB 1188**, which makes harassment based on disability or sexual orientation a class 1 misdemeanor, bringing it to the same level as harassment based on race, color, religion, ancestry, or national origin.

The Arc Indiana successfully advocated for the passage of Senate Resolution 44, which urges the legislative council to study the topic of supported decision making as an alternative option to adult guardianship. The Resolution passed in the senate and will go to the legislative council for consideration.

Heather Bump, a self-advocate from the NYSARC network, shared her experience advocating on both the federal and state level in an essay. She visited members of Congress on Capitol Hill as part of the Disability Policy Seminar to advocate against the American Health Care Act. On the state level, she was active with the #bFair2DirectCare Coalition supporting a wage increase for DSPs by writing letters, signing petitions, marching, making phone calls, and meeting directly with elected officials.

The Arc Minnesota has had many successes this year with state and federal advocacy due to the personal stories the chapter received from individuals with disabilities and their families. Many of these stories were delivered through the chapter’s "Telling Your Story" app, developed by the Minnesota Governor's Council on Developmental Disabilities, which can be downloaded to a smart phone or tablet. The app can be used to create a story and send it to elected officials. In addition, Steve Larson, the chapter’s Senior Policy Director for the last fifteen years, recently retired. During his last two months on the job, he received a lifetime achievement award from the Minnesota Consortium for Citizens with Disabilities, an award for his commitment to expand access to and improve consumer-directed services from the National Applied Self-Direction Conference, and a certificate of appreciation from Governor Mark Dayton and the Minnesota Department of Human Services for “for his dedication to improving the quality of life for persons with disabilities and their families throughout a lifetime of service and advocacy.”
Community-Based Long Term Services & Supports

The Arc California, along with community partners, showed up in force at the state capitol for a rally aimed at retaining funding for community services in support of a proposal put forward by Assemblyman Devon Mathis which would require the state to use money saved from the closure of developmental centers for the benefit of community-based services and supports for people with I/DD, instead of simply going to the state’s general fund. Speakers at the rally included many parent advocates and self-advocates. Several legislators were also in attendance and spoke in favor of the proposal. The chapter’s Executive Director, Jordan Lindsey, kicked off the rally summarizing the importance of this issue and the need for the additional funding for community services. A video of his speech is available here.

The Arc Indiana successfully advocated for the passage of HB 1102 which establishes a seventeen-member task force to assess the quality of the services and supports the state provides to people with I/DD.

Criminal Justice

The Arc Arizona successfully advocated for the passage of SB 1031, recently signed by Governor Doug Ducey, which creates a “Committee on Incompetent, Nonrestorable and Dangerous Defendants” to evaluate short and long term treatment and supervision of defendants with disabilities. The Committee will include a member with expertise in developmental disabilities.

The Arc Indiana successfully advocated for the passage of:

- HB 1006, which authorizes the division of mental health and addiction to operate a pilot program under which mental health and addiction forensic treatment services are provided to individuals who are charged with a misdemeanor offense.
- HB 1439, which allows a Medicaid recipient who is incarcerated to have the recipient’s Medicaid suspended for up to two years instead of one year before terminating the recipient’s Medicaid eligibility.

Direct Support Professionals

The Arc California is backing AB 279 and SB 499, which will increase Medicaid reimbursement rates for DSPs to cover local minimum wages that are higher than the state minimum wage. Providers in several counties throughout the state do not receive adequate reimbursement to cover their cost in excess of the state minimum wage. AB 279 passed the Assembly 77-0 and the Senate Human Services Committee 5-0 and has been re-referred to the Appropriations Committee. Governor Jerry Brown has publicly opposed the bill and instead wants to wait until after a rate study is performed in 2019. The Arc California asserts that providers facing these minimum wage increases cannot wait that long for an increase.

The budget recently approved by the Illinois General Assembly includes a $0.75 per hour increase in DSP wages, which currently start at $9.35 per hour. This is a modest victory for The Arc Illinois and the They Deserve More
campaign, which have been advocating for a minimum DSP wage of $15/hour. The was the first DSP wage increase in eight years.

The Arc Arizona successfully advocated for additional funding in the state budget to partially cover the cost of increases to ensure DSP wages are compliant with the state’s minimum wage increase.

The Arc New Jersey, the leader of the Coalition for a DSP Living Wage, successfully advocated for $20 million in funding to increase DSP wages. This measure was included in the state budget recently signed into law by Governor Chris Christie. This accomplishment was the result of vigorous advocacy efforts that included coordinating more than 75 advocates to meet with the Assembly Budget Committee during hearings and in one-on-one sessions, coordinating a Twitter campaign to raise awareness of the issue, and organizing a group of more than 50 family members, self-advocates, providers, and DSPs to visit the state house and meet with over 50 elected officials, including Senate President Steve Sweeney and members of both budget committees. The Coalition will reconvene this summer to begin strategizing advocacy efforts to secure an additional increase in the FY19 budget.

The Arc Wisconsin is advocating for a budget amendment to create a $5 million incentive fund to reward non-profit providers who improve compensation for DSPs. Because Wisconsin uses a managed care model, the state cannot directly increase rates for the purpose of increasing DSP wages. Incentive fund payments could be up to $1000 per full time employee and $500 per part time employee, depending on the number of applicants. Eligible providers must pay at least $10 per hour, contribute at least 70% of health insurance premiums, keep out-of-pocket health insurance costs below $4500, and contribute make an employer contribution of at least 3%; or pay at least $10 per hour and spend at least 65% of their general operating revenue on DSP salaries or benefits.

The Arc Indiana successfully advocated to secure funding to support a 5% increase in DSP wages.

Education

As a result of The Arc Maryland’s advocacy, the Maryland Developmental Disabilities Council is partnering with the University of Maryland to expand capacity and improve quality of post-secondary education for students with intellectual disability. This partnership will be funded by a $250,000 line item in the Developmental Disabilities Administration budget and a $25,000 grant from the Think College National Coordinating Center. When recommending this initiative to the Maryland General Assembly, Governor Larry Hogan said: “Our administration is committed to ensuring all Marylanders have the opportunity to live, work, and thrive in our state. Providing options for students with intellectual disabilities to continue their education with the goal of employment is essential to their future and our vision.”

The Arc Colorado successfully advocated for the passage of HB 1276, which bans prone, mechanical, or chemical restraint in public schools except in cases where (1) a student displays a deadly weapon, (2) the restraint is performed by a trained police officer who has made a law enforcement referral, or (3) the restraint occurs at a school under the jurisdiction of the Division of Youth Corrections.

The Arc Indiana successfully advocated for the passage of SB 61, which requires schools to report all incidents of seclusion and restraint involving school resource officers and requires the Commission on Seclusion and Restraint in Schools to adopt further rules concerning reporting requirements for the use of seclusion and restraint by school resource officers.

The Arc Arizona successfully advocated for the following bills:

- **HB 2208**, which allows schools to offer inhalers to students when permitted by a physician, was recently signed by Governor Doug Ducey.
- **SB 1317**, which allows specially designed instruction aligned with an IEP to be delivered by general education teachers or other certified personnel
and requires the state board of education to amend its rules to eliminate confusion on the instruction options for students with disabilities, was recently signed by Governor Doug Ducey.

**The Arc Michigan** is continuing to oppose the passage of **HB 4205**, which would restrict the ability of state agencies to promulgate rules that go above federal requirements, such as Michigan’s requirement that public schools provide education to students with disabilities up until age 26, rather than the federal requirement of 21. This bill has passed the House of Representatives and has been referred to the Senate Oversight Committee.

**The Arc California** is supporting **SB 354**, which requires school districts to translate IEPs and other communications with students and parents into their primary language. The bill passed the California Senate 30-6 and is pending in the Assembly Committee on Education.

**Employment**

**The Arc Indiana** successfully advocated for the passage of **SB 390**, which provides that the policy of the state is to promote competitive, integrated employment, including self-employment, as the first and preferred option when providing services to individuals with disabilities. The bill adds numerous members and responsibilities to the Commission on Rehabilitation Services in order to achieve these goals.

**Family Support**

**The Arc California** is advocating for passage of **AB 959** in light of a series of articles in the Los Angeles Times in 2011 demonstrating significant disparities in the resources and services accessed by families of color with children with I/DD through the state’s regional centers. The bill requires regional centers to create a standardized list of provider services in order to empower consumers by knowing what services are offered and allowing them to advocate for themselves. In 2012, the newspaper reported that white families received approximately $16,000 in services through regional centers, while African-American and Latino families received approximately $12,000 and $7,000 in services, respectively. A report from the Assembly Human Services Committee showed that the disparities have not decreased in recent years. Placing the information regarding service providers in a prominent location and in plain language that is understandable will enable parents to become more informed and engaged before Individual Program Plan meetings. The bill will also ensure that the consumer is not denied access to certain providers based on their geographic location. For example, if a family moves and seeks to remain with their current service provider who is outside the catchment area of their new regional center, they should be able to retain the same service provider to ensure continued quality care. **AB 959** passed the Assembly and has been referred to the Senate Human Services Committee.

**Health Care**

As a result of **The Arc Minnesota’s** advocacy, the state legislature approved **HF910/SF562** to expand benefits to individuals with autism and related conditions. This bill extends the Early Intensive Developmental and Behavioral Intervention program to 21-year-olds as well as children with other qualifying conditions. Other benefits of the bill include: coverage of individualized treatment plans, training for parents and caregivers, monitoring of
The Arc Colorado is engaging in advocacy to oppose the Better Care Reconciliation Act:

- Kelly Stahlman, a member of the Board of Directors of The Arc Colorado, was featured in a story on NBC.com. The story discusses her twin sons, Eric and Mark, who were born 12 weeks premature with cerebral palsy and other health issues. Their family faced bills running in the hundreds of thousands of dollars per year before qualifying for Medicaid. Because of Medicaid, her sons were able to live fulfilling lives in the community before they passed away at ages 22 and 23. In discussing proposals to change the bill to make less drastic cuts, Stahlman said: “There's no negotiation that can change the core of this bill, which decimates Medicaid.”

- Stephanie Garcia, Executive Director of The Arc Boulder, whose son with autism benefits from Medicaid, took part in a protest at U.S. Senator Cory Gardner’s office.

- Carol Meredith, Executive Director of The Arc Arapahoe and Douglas Counties, and her son Alex were featured in a story in the Denver Post. Alex has autism and is able to live in the community and work at a local thrift store thanks to Medicaid.

The Arc Illinois’ Executive Director Meg Cooch, Ligas Family Advocate Missy Kichline, and her daughter Sam Kichline presented at a press conference with Senator Dick Durbin on the Better Care Reconciliation Act where they highlighted the opportunities Sam has in the community because of Medicaid.

Medicaid

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As part of the Lanterman Coalition, a group of 24 major stakeholders in California’s community based developmental services system, The Arc California sent a letter to California’s Congressional delegation noting its opposition to the American Health Care Act and stating: “Governor Ronald Reagan signed The Lanterman Act into law, calling it a ‘dynamic framework on which we shall build a comprehensive system.’ The American Health Care Act threatens to dismantle that system by proposing sweeping changes to Medicaid, which would result in a loss of $20 billion to California and cause enormous budget pressures on the supports and services people with I/DD and their families rely on. Without these supports and services...people with I/DD will have significantly greater challenges living a fulfilling life in the community, as embodied in the Lanterman Act.”

Medicaid encompasses a wide array of state-administered programs with are unique in their operation and names. Many beneficiaries know the program’s name, but are unaware that it is part of Medicaid, and are therefore unaware it is in jeopardy if Congress passes the Better Care Reconciliation Act. To help educate people with disabilities and their families, The Arc Wisconsin and The Arc Kentucky have released infographics listing the names of all Medicaid-funded programs in their states.

The Arc Minnesota, as part of the “This Is Medicaid” Coalition:

- Met with Congressman Tom Emmer to discuss the impact of the American Health Care Act on Medicaid beneficiaries. Specifically, they discussed the potential of the law to limit access to...
community-based services, increase waiting lists, and limit the ability of schools to bill Medicaid. Mike Gude, the chapter’s Communications Director, shared stories with Congressman Emmer of individuals with I/DD and their families who benefit from Medicaid.

- Hosted three town halls across the state on the proposed Medicaid cuts in the American Health Care Act. At each town hall, coalition members discussed the basics of Medicaid and the many supports and services it provides to Minnesotans. Steve Larson, Senior Policy Director of The Arc Minnesota, and Cindy Owen, Executive Director of The Arc Midstate, were panelists at the St. Cloud town hall. Cindy shared her family’s story and Steve discussed how Minnesotans with a variety of disabilities have benefitted from Medicaid and the Affordable Care Act, noting that Medicaid is a “lifeline for Minnesotans with disabilities and their families.” Attendees filled out cards sharing their families’ stories for the Congressional delegation.

The Arc New Jersey has been actively engaging its congressional delegation in opposition to the American Health Care Act and Better Care Reconciliation Act. Highlights include:

- Following the passage of the American Health Care Act in the U.S. House of Representatives, board President Bob Hage and incoming board member Carolyn Hayer spoke with U.S. Senator Bob Menendez and Congressman Bill Pascrell about the devastating impacts of the legislation and the Medicaid cuts for people with I/DD. Bob and Carolyn talked about their children with I/DD and explained how Medicaid provides for critical long-term supports and services that keep their children in the community. They urged the representatives to do everything they can to prevent this legislation from becoming law, explaining that this would have a far-reaching and shattering impact on individuals with I/DD and their families living in New Jersey.

- The chapter participated in a press conference with U.S. Senator Bob Menendez on the American Health Care Act. Eileen Stuart, mother of Laurie, who lives in a group home run by The Arc of Essex County, discussed the important role Medicaid played in her daughter’s life. She stated: “I can’t even begin to tell you what it would be like if the funding wasn’t there.”

- Joann Bergin, incoming President of The Arc New Jersey, penned letters to the editor published in the Times of Trenton, the Jersey Journal, and the Daily Journal discussing the devastating impacts Medicaid cuts will have on people with I/DD and educating the public about lesser-known but equally important aspects of Medicaid. She wrote: “Although many people know that Medicaid covers the cost of medical expenses for low-income individuals, they are less aware that it pays for the long-term supports and services on which people with I/DD depend. Medicaid provides more services than I can possibly list, but to name a few, it’s what allows people in New Jersey to live in group homes, attend day programs and receive behavioral supports.”

- Congressman Tom MacArthur visited The Arc Ocean County in New Jersey to learn about the services the chapter provides. Executive Director Laura Williams gave Congressman MacArthur an overview of the chapter’s programs and explained the ways in which Medicaid is important to individuals the chapter serves. Additionally, Congressman MacArthur had a conversation with individuals with I/DD and their families who are served by the chapter. Photos from the event can be found on The Arc New Jersey’s Facebook page.

NYSARC has been mobilizing constituent opposition against the American Health Care Act and Better Care Reconciliation Act. Efforts include:

- President Laura Kennedy penned a letter to the editor in the Staten Island Advance. Kennedy wrote: “The defeat of the American Health Care Act (AHCA) is only a short-term victory in a war far from over. We must continue to preserve and support the lifeline that tens of thousands of New Yorkers with intellectual and developmental disabilities and their caregivers rely on...Medicaid. Cutting Medicaid would be catastrophic for people with disabilities and their families.”

- The chapter hosted the fourth annual Community Integration Leadership Institute in collaboration with the New York State Association of Community & Residential Agencies and the New York State Rehabilitation Association. The keynote speaker, Deborah Bachrach, former state Medicaid Director, discussed how the per capita caps in the American Health Care Act could result in the state losing $44
billion in federal funding. Since the per capita cap will be based on the 2016 Medicaid Budget, anything added in 2017, such as the increase in DSP wages the chapter fought for, will not be factored in.

- NYSARC joined 25 other organizations in signing a letter to the New York Congressional delegation opposing the Better Care Reconciliation Act. The letter states: “The Senate bill retains the American Health Care Act’s dramatic cuts to the Medicaid program through the proposed per capita cap, lowering the cap even further in the out years, and targets high-cost states like ours specifically for further reductions.”

The Arc North Carolina has been mobilizing forces to fight the Better Care Reconciliation Act. Service providers in their network have been organizing families to make calls to U.S. Senators Richard Burr and Thom Tillis. Valerie Vizena, Executive Director of The Arc Forsyth County/Enrichment Center, penned a letter to the editor in the Winston-Salem Journal. Regarding Medicaid, she wrote: “This is a program that is pro-family, creates jobs, keeps families in the workforce and treats individuals with disabilities with the respect they deserve.”

The Arc Virginia:

- Kim Goodloe, president of the chapter, published a strong letter in The News Virginian to the state’s Congressional delegation opposing the American Health Care Act and expressing grave concern about the Medicaid per capita cap proposals. Goodloe wrote: “These proposals would cause harm to thousands of Virginians with developmental disabilities who rely on Medicaid for home and community based care and would impede efforts to address the unmet needs of Virginians on the Developmental Disability Waiver waiting list...On behalf of the tens of thousands of Virginians with developmental disabilities and families who are affected by these proposals, we urge you to oppose the AHCA and speak publicly against the Medicaid per capita caps.”

- The chapter has been featured in two recent newspaper stories about its advocacy efforts opposing Medicaid per capita caps. The first, featured in Work It, SoVa, discusses the potential impact on The Arc Southside and their advocacy efforts in fighting it. Tonya Milling, Executive Director of The Arc Southside, described the tough decisions the chapter may have to make: “Do we serve Sally for free or do Sally and her family have to figure something out?”

The second article, featured in The Virginian-Pilot, discusses the impact per capita caps could have on the state, including cuts in eligibility, reduced services, lower reimbursement rates, and shifting of funds from other state programs. Jamie Liban, Executive Director of The Arc Virginia, explained: “It’s going to fall on the state to implement cuts, leaving the feds off the hook.”

- Staff members and volunteers from the chapter network throughout the state also recently participated in the “Rally to Save Medicaid” on the lawn of the U.S. Capitol and attended a round table with U.S. Senator Tim Kaine to discuss Medicaid cuts. During the meeting, Goodloe explained: “You cannot balance the health care act on the back of the most vulnerable citizens.”

The Arc Wisconsin has been advocating in opposition to the American Health Care Act and Better Care Reconciliation Act. Highlights include:

- Lisa Pugh, Executive Director of The Arc Wisconsin, appeared on “Upfront” on Milwaukee’s ABC News affiliate to discuss President Trump’s proposed federal budget. She discussed the proposed $600 billion in cuts to Medicaid beyond the cuts in the American Health Care Act. Additionally, she explained that a block grant or per capita cap would punish Wisconsin because the initial funding would be based on the previous year’s spending. She stated “It locks us in. I think because we have been efficient, the amount of money we would be receiving in that scenario would be lower than a lot of other states and I think it puts people at risk.”

- In conjunction with other disability and aging organizations, the chapter coordinated an informational session for legislators and their staffers on Medicaid and the health care legislation being considered by Congress. Pugh served as an expert speaker and David Boelter, Executive Director of The Arc Fond du Lac, served as a panelist. Read more about the briefing here and watch video of the event here.

Achieve with us.