

## **Disability Advocates Breathed a Sigh of Relief as the American Health Care Act was Pulled from a Vote on Friday, March 25, 2017**

*By Theresa M. Varnet, MSW, JD*

While this was a victory for disability advocates, we need to understand that we may have won this battle, but the war against critically needed supports and services continues. Speaker Paul Ryan acknowledged that he did not have the votes to pass the AHCA. Families/advocates need to understand it was pulled simply because members of the Freedom Caucus (the most conservative forces in Congress) did not feel the cuts and rollback in services were deep enough to allow them to vote for the bill. On the other end of the spectrum, Peter Berns, CEO of The Arc, said, "This bill showed a callous and dangerous disregard for the well-being of people with disabilities and those with complex medical needs."

Advocates are bracing themselves for continued attacks over the next two years on community-based supports provided to individuals. The GOP proposal to repeal the Affordable Care Act (aka ACA or ObamaCare) and replace it with the American Health Care Act (aka AHCA, RyanCare or TrumpCare) was only the first volley fired against our lifeline of services. We have won this battle, but the war is not over! Since the early 1970s, we have gradually increased the help that persons with disabilities and their families receive from the federal government. There were a few steps backward under the Reagan and George W. Bush administrations, but for the most part, we made progress chipping away at the institutional bias in federal programs. We expanded supports to those families who wanted to keep their special needs child at home and live a more normal life within the community.

The progress from 1970 to 2016 has been significant. For the first time in my 50 years as an advocate, I fear the loss of many of the gains we have made and a slipping back to the family being on their own with little expectation of help from the federal government. Under a GOP-controlled House, Senate and White House, we see the beginning of proposals to roll back funding for education, housing assistance programs, nutrition programs and Medicaid. My goal in writing this article is to educate families on the threat that faces us. Knowledge is power, and the more informed we are of what changes are being proposed, the more effective we can be in blocking attempts to tear down years of hard-fought gains in the fields of special education, health care, community supports, nutrition and housing.

My fears are not just my own but shared by numerous advocacy groups and state agencies. A headline in the March 25, 2017, Boston Globe read, "MassHealth Can Breathe a Sigh of Relief - for Now." Had the American Health Care Act passed, it would have changed Medicaid as we know it. This bill introduced a dramatic change in funding, from matching grants to assist states in paying for the actual cost of providing Medicaid, and Medicaid waiver services to a per capita formula. The per capita reimbursement will completely undermine the Medicaid program and transfer the burden of providing adequate health services and community-based support services to the states and eventually to the individuals who need these services, through possible copays or loss of eligibility entirely.

Up until now, Medicaid has been an entitlement benefit funded with matching state and federal funds. If you met the financial and program criteria, you received the services and the cost of providing those services was split between the state and the federal governments. Under a Medicaid Cap funding formula, the federal government sets a limit on how much it reimburses the state for each person served. Rather than pay a percentage of the actual costs, it would pay a fixed amount. If the actual cost of care is higher than that, the state will have to make up the difference or, in the alternative, decrease services. Nicole Jorwic from The Arc said, "Let there be no doubt about it - caps mean cuts. This will lead to cuts in services and longer waiting lists." We will continue to be at risk of losing home- and community-based services, coverage for mental health services, personal care assistance, rehabilitative services, prescription drug assistance, respite care, and other benefits if the AHCA is reintroduced and replaces the ACA.

Other less known attacks on the gains we have made over the past 46 years include a little-known bill, the Protecting Access to Care Act of 2017. This proposed legislation (2017 H.R.1215) limits damages to \$250,000 for non-economic loss due to medical malpractice. This cap of \$250,000 applies even if a parent loses a child, an elder is harmed in a nursing home or a family breadwinner is permanently disabled due to reckless medical care. Patient safety has decreased in those states, such as Texas, that have passed similar legislation. This cap on damages gives medical providers a license to be careless, knowing that their liability is greatly reduced.

In the area of education, we have a Secretary of Education, Betsy DeVos, who appears to have little awareness of the Individuals with Disabilities Education Act (IDEA). During her confirmation hearings she indicated she would leave it up to the states to determine if they were meeting the needs of disabled students. More recently, Ms. DeVos made statements critical of the free breakfast and lunch programs offered in the public schools to children who meet the low-income guidelines for these programs. These programs were implemented in the early '70s due to overwhelming research that showed that without proper nutrition, students could not learn. These programs play an integral role in providing children with an appropriate education. The nutrition programs offered in the schools were fought for by The Arc as a result of the studies that show 70% of students previously labeled as intellectually disabled (ID) were suffering from malnutrition. When children received adequate nutrition, their so-called ID disappeared, lowering the number of students labeled as ID. Such programs have been an economical way of reducing the costs of special education. We can pay pennies for nutritional subsidies or thousands for remedial care. We need to get the message across to the GOP that this is a program that should be embraced rather than eliminated or cut back.

It is too soon to know what cuts await SSI, SSDI, Medicare, the Supplemental Nutrition Assistance Program (SNAP, aka food stamps), Fuel Assistance, and Section 8 and other HUD housing programs that enable persons with disabilities to live in the community. We know President Trump plans to decrease taxes for the wealthy, and there are few other areas of the budget where the GOP can make cuts to offset the loss of tax income. Advocates anticipate attempts to make dramatic cuts in these programs.

It is important that families partner with The Arc and other disability groups to educate our legislators about the important role Medicaid and other benefits play in our lives and those of our children. If we do not take a strong stand to fend off proposed cuts to services, it may be too late for an entire generation of persons with disabilities. According to Nicole Jorwic from The Arc, "It is very important for advocates to speak up and tell their stories." Now is the time for action. These proposed changes are not a done deal. I hope this article inspires you to become involved with The Arc's Disability Advocacy Network and to fight to hold on to those benefits for which we have fought so hard. Go to The Arc's website, [thearc.org](http://thearc.org), to see how you can become more involved in the fight to hold on to our lifeline. **FT**

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