

Disability Advocates Prepare for Multiple Attacks on Lifeline Services

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Advocates are bracing themselves for a rollback of community-based supports provided to individuals with disabilities. Regardless of your political affiliation, there are currently a number of challenges facing advocates of persons with disabilities in Washington, with several bills and policy changes that threaten the future of persons with disabilities and their families. The purpose of this article is to call attention to proposed legislation that could have long-term negative impact on the delivery of services. While families are struggling to survive, they may not have heard of some of the less-known attacks on our lifeline to services. Knowledge is power and the more informed we are of legislation and regulations being proposed, the more effective we can be in blocking attempts to tear down years of hard-fought gains in the field of special education, health care, community supports, nutrition and housing programs. It is critical that families advocate for themselves by letting their elected officials know how these cuts to services affect their lives.

The attention given to the repeal of the ACA has overshadowed other legislation the GOP has introduced that will harm families of persons with disabilities. Since the early '70s we have gradually increased the help persons with disabilities and their families have received from the federal government. We made progress chipping away at the institutional bias in federal programs and expanded supports to those families who wanted to keep their special-needs children at home and live more 'normal' lives within the community. The progress from 1970 to 2016 has been slow but steady. For the first time in this author's 50 years as an advocate, I fear the loss of many of the gains we have made and a slipping back in help families can expect to receive from the federal government. Under a GOP-controlled House, Senate and White House, we see the introduction of legislation that appears to target families for discrimination and roll back funding for education, housing assistance programs, nutrition programs and Medicaid.

The press has focused on the GOP proposal to repeal the Affordable Care Act (aka Obamacare) and replace it with the American Health Care Act (aka Trumpcare). The Arc and other advocacy groups claim that Trumpcare will cause thousands of low-income individuals to lose their eligibility for Medicaid and will change Medicaid from an entitlement benefit to a program with long waiting lists, copays and a limited number of services covered. If the American Health

Care Act passes, it will change Medicaid as we know it. This legislation proposes a dramatic change in funding, from assisting states in paying for the actual cost of providing Medicaid services to a "Per Cap" formula. The "Per Cap" 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.

Until now, Medicaid has been an entitlement benefit funded with matching state and federal funds. If a person meets the financial and program criteria, he received the services, and the cost of providing those services was split between the state and 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, and if the actual cost of care is higher than that, the state will have to make up the difference or in the alternative, drop or decrease services. This has a disproportionately negative impact on the elderly and the disabled, who are more expensive to care for than are typically healthier persons. Families who rely on Medicaid should anticipate the likelihood of waiting lists and a decrease in services. Nicole Jorwic, at the Arc, says "Let there be no doubt about it - caps mean cuts. This will lead to cuts in services and longer waiting lists." We are 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 Trumpcare is passed and replaces the ACA.

Other less-known attacks on the gains we have made over the past 46 years include a little-known bill called 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 seriously harmed in a nursing home, or a family breadwinner is permanently disabled due to reckless medical care. In states such as Texas, which has passed similar legislation, the quality of care has dropped substantially. This cap on damages gives medical providers a license to be careless, knowing that their liability is greatly reduced. This bill, coming at a time when states are faced with making

substantial cuts in reimbursements to hospitals and medical providers, creates a danger for persons with disabilities who have greater need for medical care than others.

Another bill introduced by a North Carolina Republican (the “Preserving Employee Wellness Programs Act,” HR 1313) could result in penalties and/or loss of one’s job if a worker refuses to have genetic testing done. Many individuals are concerned about employment discrimination if they test positive for a genetic disorder. Current federal laws protect genetic privacy and nondiscrimination. But this bill will allow employers to get around the current law if the information is required as part of a workplace wellness program. Over 70 groups, including the American Academy of Pediatrics, the March of Dimes and the National Women’s Law Center, have opposed the bill, as it is felt the legislation will undermine basic privacy provisions of the Americans with Disabilities Act. It is not clear how mandating genetic testing will impact hiring or advancement opportunities.

Many advocates have expressed concern about the appointment of Secretary of Education, Betsy DeVos. Ms. DeVos appears at best to be uninformed regarding the Individuals with Disabilities Education Act (IDEA) and at worse to be hostile to spending money on educating persons with disabilities. 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. When reminded that the IDEA is a federal civil rights act to protect the rights of disabled students, she backed off and stated that “perhaps she was confused.” Ms. DeVos has 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 do not learn. Nutrition programs play an integral role in providing children with an education. Subsidized nutrition programs can significantly reduce the number of children who are labeled intellectually disabled in our schools. Such programs have been a cost-efficient way of reducing spending on special education. We can ‘pennies on nutritional subsidies or thousands of dollars on remedial care. We need to get this message across to the GOP that this is a program that should be embraced rather than one to be eliminated or cut back.

Other special education concerns involve the passage of H.J. Res. 57 by the House and Senate. This resolution rescinds

regulations included in the Every Student Succeeds Act (ESSA). It is expected that President Trump will sign the resolution when it reaches his desk. The Arc, National Disability Rights Network, the Council for Exceptional Children, the Autism Society, and other members of the Consortium for Citizens with Disabilities Education Task Force have expressed concern about this resolution. This is the first-time Congress has overturned an education regulation without the opportunity for hearings or a comment period. The resolution weakens the accountability in the schools. Secretary DeVos has indicated she will be sending clarification on the new rules, which are extremely vague and subject to interpretation, soon.

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

It is important that families partner with the Arc and other disability groups to educate our legislators as to the important role Medicaid and other benefits play in our lives and the lives 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. Nicole Jorwick from the Arc says, “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 families to become involved with the Arc’s Disability Advocacy Network to try to hold onto those benefits we have fought so hard for. Go to the Arc’s website thearc.org to see how you can become more involved in the fight to hold onto our lifeline. **FT**

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