



# **Legislative Affairs**

## **Report to the Board of Directors**

**November 2011**

# Autism Policy

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## Combating Autism Act Reauthorization

The path to reauthorize the Combating Autism Act turned out to be very difficult with many hurdles. However, advocates finally prevailed and the Combating Autism Reauthorization Act (Public Law 112-32) was signed into law on September 30, 2011! Without reauthorization, the law was set to expire on September 30 and would have seriously threatened funding for the LEND programs.

For each of the next three years, the bill authorizes \$22 million for surveillance through the Centers for Disease Control (CDC), \$48 million for early detection, professional training and the development of effective interventions through the Health Resources Services Administration (HRSA), and \$161 million for autism research at the National Institutes of Health (NIH). The new law also reauthorizes the Interagency Autism Coordinating Committee.

AUCD Executive Director George Jesien was invited to witness the signing in a small White House oval office ceremony. He was joined by House bill sponsor Representative Chris Smith (R-NJ), Autism Society President Scott Badesch, and Autism Speaks co-founders Suzanne and Bob Wright, along with Board Member Billy Mann and his wife Gena and son Jasper who has Autism.



This is a big victory given that the reauthorization had to overcome several major hurdles. First, although the reauthorization had broad bipartisan support, the House leadership had become determined not to let any laws with sunset provisions be reauthorized as part of an overall strategy to cut federal spending. Republican leaders also developed an unwritten protocol against legislation “mandating disease-specific research”. Finally, AUCD and other advocates had worked for over two

years to develop bipartisan legislation that would expand the law to include services for transition-age youth and adults, including a provision that would provide supplemental funding for UCEDDs to provide technical assistance, train professionals, conduct research and develop model services. When the services provisions were dropped from the bill before introduction, several autism organizations that had supported the original law in 2006 dropped their support for the straight reauthorization.

Bipartisan bills to reauthorize the Combating Autism Act were introduced in both chambers in May. The House bill (H.R. 2005) was introduced by Representatives Chris Smith (R-NJ) and Mike Doyle (R-PA). In the Senate, S. 1094 was sponsored by Senators Robert Menendez (D-NJ) and Michael Enzi (R-WY), ranking minority member of the Senate HELP Committee, along with Sens. Scott Brown (R-MA) and Richard Durbin (D-IL). Both bills were “simple” reauthorization bills. Separate bills to provide additional services to youth and adults (including the national interdisciplinary training provision) (H.R.2007/S. 1132) and a new Autism Office in the department of Health and Human Services to elevate research (H.R. 2006/S. 1128) were introduced separately and referred to the Senate Health, Education, Labor and Pensions (HELP) and House Energy and Commerce Committees. No further action was taken on these bills.

AUCD worked closely with the lead sponsors of the legislation to reauthorize the Combating Autism Act and took a leadership role in developing a strategy to overcome these hurdles. As Chair of the Consortium with Citizens with Disabilities (CCD) Autism Task Force, AUCD led a series of Hill meetings with key staff in the House Energy and Commerce Committee and the Senate Health, Education, Labor and Pensions Committee, as well as with House and Senate leadership offices. AUCD took the lead in developing and advocating for appropriations language to continue funding HRSA programs authorized under the CAA if the law had not been successfully reauthorized. AUCD also coordinated a grassroots strategy, facilitating contact between LEND and UCEDD members and targeted congressional staff. AUCD also worked with members of the Obama Administration to ensure its continued support and advocacy for the law. AUCD members also worked hard to help educate their Members of Congress by meeting with Members personally, writing letter, and making phone calls.

## **Budget & Appropriations**

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### **FY 2012 L-HHS-ED Appropriations**

With just two weeks left in the current continuing resolution (CR) covering federal funding until November 18, none of the 12 annual appropriations bills have been signed into law. Work on FY 2012 appropriations was stalled due to the fight to raise the federal debt ceiling this summer. Although the House passed six of the twelve measures in June and July, it largely halted work on remaining appropriations bills after lawmakers reached a debt ceiling deal. The deal, enacted on August 2 as the Budget Control Act of 2011, established new budget enforcement mechanisms for reducing the federal deficit by at least \$2.1 trillion over the 10-year period FY 2012-FY 2021. The BCA places caps on discretionary spending for each of those 10 fiscal years, which will save an estimated \$1 trillion during that period. These caps set the stage for appropriations bills currently being developed.

Currently, federal programs are operating under a continuing resolution that applied an across-the-board cut of 1.5% to all discretionary programs. Both House and Senate staff have indicated that they hope to complete work on the annual funding bills by the November 18 expiration date. However, given the number of appropriations bills that still need to be completed, the Congress will likely pass another CR in order to finish their business. Both sides have indicated that they do not want a full-year CR and would like to get the bills done before Thanksgiving when the Joint Deficit Reduction (“Super”) Committee is expected to complete its recommendations for reducing the deficit over the next decade.

On September 21, the Senate Appropriations Committee, chaired by Senator Tom Harkin (D-IA), approved its FY 2012 Labor-HHS-Education spending bill strictly along party lines. The bill level-funds many programs important to the AUCD network, but includes some cuts to stay within the overall discretionary figure agreed to by both the House and Senate contained in the Budget Control Act-- \$1.043 trillion – which is \$7 billion less than FY 2011.

Approximately a week later, House Appropriations L-HHS-ED Subcommittee Chairman Denny Rehberg (R-MT) published a draft FY 2012 funding bill on the committee website. The House L-HHS-ED draft provides \$4 billion less than the Senate bill and includes drastic cuts to many education and health care programs. The bill also includes several very controversial policy riders, (e.g. preventing any federal funds to implement the Affordable Care Act, family planning, or National Public Radio, among others). While this draft bill will not likely be considered by any committee, it is nonetheless the only document showing the House Republican priorities and will likely be used to negotiate with the Senate as they finalize funding levels for the 2012 fiscal year.

<b>DEPT. OF HEALTH AND HUMAN SERVICES</b>	<b>FY 2011 Final</b>	<b>President's FY 2012 Request</b>	<b>FY 2012 Senate Committee</b>	<b>Senate compared to 2011</b>	<b>FY 2012 House draft</b>	<b>House compared to 2011</b>
University Centers for Excellence in DD	38.9	38.9	38.9	0.0	35.4	-3.6
DD Councils	75.0	75.0	75.0	0.0	75.0	0.0
Protection & Advocacy Systems	41.0	41.0	41.0	0.0	41.0	0.0
Projects of National Significance	14.1	8.3	8.3	-5.8	8.3	-5.8
Combating Autism Act – Autism and Other DD	47.7	55.0	47.7	0.0	47.7	0.0
Center on Birth Defects & DD	143.0	143.0	138.0	-4.0	121.8	-22.0
Natl. Institute of Child Health and Hum. Dev.	1,326.8	1,352.2	1,303.0	-14.8	1,352.2	+26.0

The current plan to resolve the FY 2012 appropriations dilemma is to package the 12 appropriations bills into groups of three “minibuses,” a process used to take as many bills to the floor as possible. The Labor-HHS-Education appropriations bill that provides funding for most AUCD network programs is the largest and most controversial, and therefore likely the last to be considered. It could be the one bill that is funded as another year-long CR.

AUCD is actively involved in several coalitions that are educating members of Congress and their staff about the impact of cuts and deficit reduction proposals on people with disabilities. To that end, AUCD

has met, along with other advocates, with staff of a majority of the members of the Super Committee and members of the Energy and Commerce and Finance Committees. AUCD has also signed on to numerous letters designed to educate these key members regarding the impact of programs such as Medicaid; Social Security; and health care, job training, education and other discretionary programs that support people with disabilities to live, work, and recreate in the community.

As the budget and appropriations process moves forward, AUCD will continue to advocate for the highest possible funding levels for network programs and other programs that promote the association's mission to advance policy and practice that promotes full participation of people living with developmental and other disabilities in their communities. In this time of fiscal restraint, it is critical that the AUCD network continue to demonstrate its impact and make the best use of our resources.

## Deficit Reduction Committee

The Budget Control Act also created the Joint Select Committee on Deficit Reduction ("Super Committee") tasked with developing legislation to reduce the federal deficit by at least another \$1.5 trillion through FY 2021. In developing its plan, the Committee can consider all means of deficit reduction, including entitlement reform, spending cuts and revenue increases. Its recommendations could have substantial impacts on federal spending in years to come. Congress has until the end of the year to pass the Committee's recommendations through fast-track procedures. If it doesn't, Congress must then use the regular legislative process to pass at least \$1.2 trillion in deficit reduction over the next ten years. If it fails to do so, automatic annual spending reductions would be triggered beginning in January 2013. The reductions would be achieved by lowering the caps on discretionary spending and by automatic across-the-board spending cuts, a process known as sequestration. The cuts would apply equally to non-security and security spending, including defense. The cuts would not apply to Medicaid and Social Security. The Super Committee has until Thanksgiving to agree and submit its recommendations to Congress, a daunting task given the failure of several groups that attempted to develop similar plans. AUCD, through its participation in a number of coalitions, has partnered with other organizations to educate Super Committee members and urge them to protect programs that support people with disabilities.

## Medicaid

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Because of its large proportion of federal spending, Medicaid continues to be a target during ongoing budget negotiations. One proposal, suggested by the Obama Administration, calls for reductions in the federal share of Medicaid and Children's Health Insurance Program (CHIP) spending. Presently, matching rates (Federal Medical Assistance Percentages, or FMAP) vary across state-federal partner programs within each state. The Administration's proposal would establish a "blended rate" for each state which would be lower than the previous federal funding dollar amount and thus save the federal government money. According to a [report](#) from the Center on Budget and Policy Priorities, this proposal has two significant weaknesses. While federal expenditures would decrease, state costs would increase and would likely be shifted to program recipients. Secondly, there is difficulty in

calculating the blended rate of each state in a fair and accurate manner, as the rate would be determined based on assumptions regarding future Medicaid and CHIP enrollment and expenditures.

In an [op-ed](#) published on the website of the Capitol Hill newspaper *The Hill*, Sen. Tom Harkin (D-IA) and Rep. Cathy McMorris Rodgers (R-WA) suggest that federal and state governments should explore the reduction of Medicaid spending through an increase in the number of people with disabilities that live in community-based settings as opposed to more costly institutional facilities. They wrote, “Modernizing Medicaid’s approach to supporting people with disabilities can save money and bring people a better quality of life. It would also promote compliance with the ADA and the *Olmstead* decision. If Medicaid cuts are not done in a thoughtful manner, however, they will have disastrous consequences and will lead to systemic civil rights violations.”

Advocacy groups continue to work on shoring up support of Medicaid-funded programs in order to combat cuts proposed during ongoing budget negotiations. Several leaders of the Consortium for Citizens with Disabilities (CCD) met with Jeff Crowley, a senior health official at the White House, to share concerns about Medicaid cuts. CCD also sponsored two families to travel to Washington, DC and share the importance of Medicaid programs in their lives. Accompanied by AUCD staff, the families met with Melody Barnes, the President’s Domestic Policy Adviser, and Jeffery Crowley, Senior Advisor on Disability Policy, at the White House. The families did a wonderful job articulating the real impact Medicaid cuts would have on the lives of real people. Valerie Jarrett, Senior Advisor to the President, wrote an [article](#) for the White House blog regarding the visits. The article contains a link to the stories of individuals brought in by CCD, The Arc, AAPD, and Easter Seals.

AUCD signed onto a two-page ad in *Roll Call*, a Capitol Hill newspaper, which highlights the need to retain funding in Medicaid for the nation’s most vulnerable older adults and people with disabilities. (View AUCD’s [press release](#) with a link to the full ad). Additionally, AUCD signed onto a [letter](#) to the Joint Select Committee on Deficit Reduction (“Super Committee”) along with nearly 60 other CCD member organizations urging the Committee to protect people with disabilities as they craft deficit-reduction strategies. AUCD has continued to work with its CCD partners to meet with key Congressional members, including those who are members of the Super Committee.

Finally, in September, AUCD proudly stood among nearly 100 disability, aging and civil rights groups that co-sponsored the “[My Medicaid Matters](#)” rally in support of protecting Medicaid-funded programs. In addition to the rally, [local demonstrations](#) were held in California, Kansas, Illinois, Montana, Ohio and Texas. The message was targeted at lawmakers – particularly those on the Super Committee.

## Health Care Reform

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The Department of Health and Human Services continues to implement the Patient Protection and Affordable Care Act (ACA), issuing regulations and disseminating funding to carry out its many provisions. However, the law’s opponents continue to try to dismantle it through every means

possible. Because repeal bills could not pass the full Congress, these opponents are focusing on strategies to halt or redirect funding for the law's implementation. For example, the House Labor-HHS-Education appropriations draft bill states that no funds can be used to carry out ACA. While such proposals could not become law, they are proof that some lawmakers remain deeply critical of health reform. Additionally, the Senate Appropriations Committee passed its L-HHS-ED appropriations bill with zero Republican support, reportedly because the bill contains funding for ACA.

Meanwhile, constitutional challenges to the law's requirement that most Americans purchase health insurance by 2014, the so-called "individual mandate," have worked their way through the courts. Because courts have decided the issue differently, the Supreme Court is expected to take up the issue as early as this session. If it does, its decision is sure to play a role in the 2012 elections.

The Community Living Assistance Services and Supports (CLASS) program encountered a major speed bump last month when the Department of Health and Human Services announced that it was suspending implementation because it could not see a viable path forward for the program at this time. After extensive analysis of the program, HHS determined that it did not have the authority to make the alterations needed to ensure that the program is both fiscally solvent and affordable for enrollees. ACA opponents are trying to paint the decision as evidence that the entire law is flawed and should be repealed. This is a weak argument, however, as the CLASS Act is a distinct title and its provisions do not connect to others in the law. The Obama Administration is opposed to repealing CLASS, and HHS officials recently testified before a House subcommittee that they are determined to continue work to develop solutions to meet the growing national need for long-term services and supports. Disability advocates have urged the Administration to continue implementation efforts and to prevent repeal.

AUCD has continued to work with the CCD Health Task Force, the Coalition for Health Funding and a number of other advocacy groups to support ACA funding and implementation. AUCD signed onto numerous comments prepared by the CCD Health Task Force on proposed rules, most recently related to a Medicaid/Medicare alignment initiative and state-based health insurance exchanges. AUCD has also joined the informal Habilitation Coalition to develop a position statement and comments on the inclusion of habilitative and rehabilitative services in the essential health benefits package. AUCD continues to provide implementation resources and funding announcements to the network through its online [Health Reform Hub](#) and electronic newsletters.

## Education

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### Elementary & Secondary Education Act

After months of tough negotiations, Senators Tom Harkin (D-IA) and Michael Enzi (R-WY) released draft legislation in mid-October to reauthorize and amend the Elementary and Secondary Education Act (ESEA, known as No Child Left Behind). The bipartisan compromise disposes of NCLB's most controversial provisions, including the law's requirement that all students be proficient in math and reading by 2014 - a standard the Department of Education believes at least 80 percent of schools

would fail to meet. Instead, the bill requires states to adopt "college- and career-ready" standards and develop statewide accountability systems to receive federal funding. The bill emphasizes the inclusion of *all* students, calls for expanded and more accessible state and district report cards, strengthens standards and assessment requirements and promotes multi-tiered systems of support, universal design for learning and positive behavioral interventions and supports. Some provisions remain controversial, however. AUCD joined other disability and civil rights organizations in expressing concern over the bill's accountability provisions, which focus federal oversight and resources only on the lowest performing five percent of schools and those identified as having achievement gaps among student subgroups, including students with disabilities. The remaining 90 percent of schools would be governed by the state's accountability system, which some fear will leave out students with disabilities and other subgroups. AUCD also signed onto a letter voicing concern about the bill's teacher quality standards which allow teachers who are enrolled in, but have not yet completed, alternate-route certification programs can be considered "highly qualified". The concern about this policy is that it disproportionately impacts students who are already at a disadvantage because these under-prepared teachers are more often assigned to their schools and classrooms.

On October 19, the Senate Health, Education, Labor and Pensions (HELP) Committee began a two-day markup of the draft. Although 144 amendments were filed prior to markup, most of them were withdrawn and the bill was approved by the committee with a bipartisan 15-7 vote. The HELP Committee will hold a hearing on the bill November 8, then the full Senate must take up the bill. Chairman Harkin said he hopes the bill will reach the Senate floor before Thanksgiving, however, opposition from advocacy groups could hold up the process.

Whether the bill will find support in the House of Representatives is unclear. So far, the Education and Workforce Committee has entertained a series of education reform bills aimed at reducing federal involvement in education and amending the law piece-by-piece. The "Setting New Priorities in Education Spending Act" (H.R. 1891) would eliminate 43 federal education programs; the "Empowering Parents through Quality Charter Schools Act" (H.R. 2218) would expand successful charter schools; and the "State and Local Funding Flexibility Act" (H.R. 2445) would give states more flexibility to use funds they receive under ESEA. The charter schools bill was the only one to gain bipartisan support and pass the House. The Senate has not taken it up.

Because Congress was delayed in taking action on ESEA, the Obama Administration announced that it would create a process to grant waivers to states from some of NCLB's requirements. The Department of Education created a [webpage](#) with detailed information about its flexibility plan and the kinds of policies states must adopt in order to receive a waiver. So far, the Department has received notice that 42 states intend to apply for waivers. Each waiver request will be peer-reviewed by a panel containing at least one expert on disability issues.

AUCD has actively participated on the CCD Education Task Force to provide feedback on the ESEA draft bill and a number of amendments thereto. AUCD has also joined stakeholder meetings with the Department of Education to help develop protections for students with disabilities in its ESEA Flexibility plan.

## Restraint & Seclusion in Schools

The Keeping All Students Safe Act (H.R. 1381), re-introduced by Rep. George Miller (D-CA) earlier this year, has not received attention from the House Education and Workforce Committee. Senator Tom Harkin (D-IA) has worked closely with stakeholders to develop draft language to limit restraint and seclusion in schools. The language is similar to H.R. 1381, but goes a bit further to ban the use of seclusion and provide additional protections to students. Sen. Harkin plans to introduce the language as an amendment to the draft ESEA bill when it reaches the Senate floor. It is not clear how much support there will be for such an amendment. If the amendment does not pass, Harkin's staff have suggested that they will pursue a standalone bill. Any such bill is likely to encounter strong opposition in the House, where the Republican leadership is taking steps to drastically reduce the federal footprint in education.

AUCD continues to work with the CCD Education Task Force and the Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS) to educate members of Congress and highlight the work being done in the network on school-wide Positive Behavioral Interventions and Supports. AUCD also worked with APRAIS to provide feedback to the Department of Education on its plans to develop information for the field on the use of restraint and seclusion in schools. The Department has not said when this information will be disseminated or what, exactly, it will include.

## Employment

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### Workforce Investment Act

Senator Tom Harkin (D-IA), chairman of the Senate Health, Education, Labor and Pensions (HELP) Committee, and Ranking Member Mike Enzi (R-WY) released a bipartisan bill to reauthorize the Workforce Investment Act (WIA) in June. The bill includes increased enforcement measures regarding subminimum wage certificates and provisions aimed at preventing youth from transitioning into segregated or subminimum wage work settings. It does not repeal Section 14(c) of the Fair Labor Standards Act, which allows for the use of subminimum wage certificates. Markup was scheduled several times, then postponed indefinitely due to the inability to gain enough consensus on several provisions in the larger WIA bill.

The HELP Committee held several hearings on employment of people with intellectual disabilities earlier in the year. Bill Kiernan, Director of the Institute for Community Inclusion at the University of Massachusetts, and co-chair of the AUCD Legislative Affairs Committee, provided testimony representing the UCEDD and AUCD. He also provided similar testimony at a meeting of the Equal Employment Opportunity Commission. Additional hearings on employment have been planned to identify what is working and how to break down barriers to employment for individuals with disabilities. Sen. Harkin is also working on other employment initiatives, including working directly with business leaders to encourage their participation in solving the low employment rate of individuals with disabilities.

AUCD collaborated with NCIL and NDRN to sponsor a national disability forum for a dialogue about barriers and legislative solutions around employment. Staff of Sen. Harkin briefed the community groups on the purpose of his draft legislation. The AUCD Legislative Affairs Committee also helped to plan the Employment Symposium during the Annual Meeting that will emphasize “Employment First” strategies to providing more opportunities for competitive, integrated employment.