

Legislative Affairs Report to the Board of Directors

February 12, 2010

President Obama gave his State of the Union address on January 27 during which he highlighted some of his priorities for the coming year including job creation, completion of health care reform and lowering the federal deficit. He mentioned his intention to create a bipartisan commission to explore revenue and entitlement policy aimed at deficit reduction. The President also announced that his proposal to freeze most domestic discretionary spending unrelated to defense, veterans and homeland security.

Budget and Appropriations

The budget freeze is reflected in the Administration's Budget released on February 1. The \$3.8 trillion Fiscal Year (FY) 2011 budget request to Congress level funding or cuts to some programs so that some presidential priorities can be increased. Included in the freeze are all the DD Act programs (UCEDD, DD Councils, and Protection & Advocacy) at \$187 million. University Centers for Excellence in Developmental Disabilities (UCEDD) would receive \$39 million, retaining the \$1 million increase obtained in the previous fiscal year.

For the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, the budget requests \$55 million under HRSA, an increase of \$7 million, as part of the President's Initiative to support children with autism spectrum disorders and their families. This funding will continue to expand Federal and State programs authorized under the Combating Autism Act to research, and support screening and evidence-based interventions when a diagnosis is confirmed. The Maternal and Child Health Block Grant would receive \$673 million, an increase of \$11 million over FY 2010.

The National Institute of Child Health and Human Development (NICHD), which funds the research centers (IDDRCs), would see an increase of \$40 million to \$1.4 billion. Total funding for National Institutes of Health (NIH) would be increased by \$1 billion to \$32.2 billion, showing the continued priority research holds in this administration.

CDC's Birth Defects, Developmental Disabilities, Disability and Health is funded at \$143.5 million, up by only \$171 thousand over FY 2010. The budget justification states that "the Budget's increased investments in [CDC] Health Promotion continue the initiative to expand support for children, families, and communities affected by autism spectrum disorders. In FY 2011, CDC will expand autism monitoring and surveillance and support an autism awareness campaign."

Other AUCD program priorities are included in the table below.

FY 2011 President's Budget for Depts. Of Labor, HHS, and ED (in millions)

	FY 2009	Final FY 2010	President's FY 2011 Budget	Difference over FY 2010
DEP. OF HEALTH AND HUMAN SERVICES				
Administration for Children and Families				
University Centers for Excellence in DD	37.9	38.9	38.9	0.0
DD Councils	74.3	75.1	75.1	0.0
Protection & Advocacy Systems	40.0	41.0	41.0	0.0
Projects of National Significance	14.1	14.1	14.1	0.0
Child Abuse Prevention and Treatment	109.8	97.1	107.0	+10.0
Health Resources and Services Administration				
Maternal & Child Health Block Grant	662.1	662.1	673.0	+11.0
Combating Autism Act – Autism and Other DD	42.0	48.0	55.0	+7.0
Centers for Disease Control and Prevention				
Center on Birth Defects & DD	138.0	143.4	143.5	+171
National Institutes of Health				
Natl. Institute of Child Health and Hum. Dev.	1,295.8	1,329.5	1,369.5	+40.0
Administration on Aging				
Lifespan Respite Care Act	2.5	2.5	5.0	+2.5
Nat'l Family Caregiver Support Program	154.0	154.0	202.0	+48.0
Department of Education				
Individuals with Disabilities Education Act				
Part B State and Local Grants	10,900.0	11,505.0	11,755.0	+250.0
Preschool Grants	374.0	374.0	374.0	0.0
Part C Early Intervention	440.0	440.0	440.0	0.0
Part D National Programs				
State Personnel Development	48.0	48.0	48.0	0.0
Technical Assistance and Dissemination	48.5	49.5	49.5	0.0
Personnel Preparation	91.0	91.0	91.0	0.0
Parent Information Centers	27.0	28.0	28.0	0.0
Technology and Media	38.6	44.0	41.0	-3.0
Research in Special Education (IES)	70.6	71.1	71.1	0.0
Special Education studies and evaluations (IES)	9.5	11.5	11.5	0.0
Dept. of Labor				
Office of Disability Employment Policy	26.6	39.0	39.1	+1.0
Rehabilitation Services and Disability Research				
Voc. Rehabilitation State Grant	2,974.6	3,084.6	3,141.5	+56.9
Supported Employment State Grant	29.2	29.2	0.0	-29.0
*Supported Employment Extended Services Youth			25.0	+25.0
NIDRR	107.7	109.2	111.9	+2.7
State Assistive Technology Programs	31.0	31.0	31.0	0.0
Independent Living Formula Grants	101.0	104.0	110.0	+6.0
Higher Education Act				
Demonstration Projects-Disability (Higher Ed.)	7.0	7.0	7.0	0.0
Postsecondary Program for Students with ID	N/A	11.0	11.0	0.0
AmeriCorp	271.2	372.5	488.0	+115.5
Disability Placement Funds	N/A	5.0	6.0	+1.0

Health Care Reform

The House passed the Affordable Health Care for America Act (HR 3962) on November 7 by a vote of 220 to 215. The Senate passed the Patient Protection and Affordable Care Act (HR 3590) on December 24 (Christmas Eve!) by a vote of 60-39. The final bills retain many of the important private market reforms important to everyone, including people with disabilities, such as the elimination of discrimination based on health status and disability, prohibitions on pre-existing condition exclusions and guaranteed issue and renewal requirements. AUCD had hoped that a conference bill would have been signed into law as soon as Congress reconvened in January. However, the loss of the filibuster-proof 60 vote majority with the election of Mass. Republican Scott Brown put the health care bill in jeopardy. Democratic leaders are now trying to come up with an alternate strategy for passing a final bill. One possibility is to use budget reconciliation in the Senate which would only require a simple 51 vote majority for passage, but would jeopardize any non-budget-related health provisions, such as the autism training provision. In order to maintain the non-budget portions of the bill, the House would need to pass the Senate bill along with a reconciliation bill that would include its “fixes”. Another possibility would be for the House to simply pass the Senate passed bill in its exact form. However, there are some provisions in the Senate bill that are not supported by House members. AUCD has been working in coalition with other disability and health care advocates to urge Congress to work together to pass a final health care reform bill soon. Following are some of the health care items at stake:

Autism

The provision to provide national training initiatives on autism spectrum disorders (Sec. 2527) was included in the final House bill. This provision was championed by Rep. Mike Doyle (D-PA) and is similar to Sec. 11 of the Autism Treatment and Acceleration Act (H.R. 2413). This provision would provide grants to UCEDDs or a comparable interdisciplinary education, research, and service entity to provide interdisciplinary training, continuing education, technical assistance, and information for the purpose of improving services for children and adults with autism and to address their unmet needs. Although we were fortunate to have Senate Majority Whip Durbin (D-IL), Sen. Casey (D-PA), and Sen. Menendez (D-NJ) ready and willing to offer this provision as an amendment during Senate consideration, the Senate was ultimately not able to offer all amendments and this one did not rise to the top of the list of the limited amount of amendments to be offered during the contentious floor debate. AUCD continues to communicate the need for this important provision in a final version of health reform legislation.

Rep. Doyle and Sen. Menendez (D-NJ) also sponsored an amendment (which was retained in the final bill) that adds “behavioral health” to the list of required services that insurance companies must provide. The intention is that behavioral health services will include positive behavioral health interventions for people with autism.

Long Term Services

AUCD is also very pleased to report that the Community Living Assistance Services and Supports Act is included in both the House and Senate bills. The purpose of this title is to establish a national voluntary insurance program for purchasing community living assistance services and supports. This will provide

individuals with functional limitations with tools that will allow them to maintain their personal and financial independence and live in the community. This provision is almost identical to S. 697, introduced and championed by the late Sen. Ted Kennedy. AUCD continues to work with disability and aging groups to ensure the inclusion of the CLASS Act in final health reform legislation.

The “Community First Choice Option,” which is similar to the Community Choice Act (S. 683/H.R. 1670) championed by Sen. Tom Harkin (D-IA), is also included in both bills. This provision would provide an option, not a mandate, to states to provide individuals who are eligible for institutional care equal access to community-based services and supports. It provides states with an enhanced federal matching rate of an additional six percentage points for reimbursable expenses in the program. AUCD continues to work to ensure that both are included in a final bill.

The Senate bill extends the Medicaid “Money Follows the Person Rebalancing Demonstration” program through September 2016 and allocates \$10 million per year for five years to continue the Aging and Disability Resource Center (ADRC) initiatives.

Prevention

Both bills include provisions aimed at preventing illness and promoting wellness. They aim to improve prevention by covering only proven preventive services and eliminating cost-sharing for preventive services in Medicare and Medicaid. Both bills provide grants to small employers that establish wellness programs and require chain restaurants and food sold in vending machines to disclose the nutritional content of each item. The Senate proposal would create a prevention and public health investment fund to expand and sustain funding for prevention and public health programs and provide Medicare beneficiaries access to a comprehensive health risk assessment and creation of a personalized prevention plan. Both bills would award competitive grants to state and local governments and community-based organizations to implement and evaluate proven community preventive health activities to reduce chronic disease rates and address health disparities, including health disparities for people with disabilities.

The House and Senate bills also support the “medical home” model. Medicare and Medicaid pilot programs would be used to test payment incentive models for accountable-care organizations and assess the feasibility of reimbursing qualified patient-centered medical homes. The models would be adopted on a large scale if pilot programs prove successful at reducing costs.

Both bills contain provisions to reduce health disparities throughout, and include disability in the list of identified populations that experience health disparities.

Workforce Provisions

Both bills contain provisions aimed at increasing the health and long term care workforce. They would create a multi-stakeholder advisory committee to assess, evaluate and develop workforce strategies. Both bills also support training of health professionals through scholarships and loans, and establish a primary care training and capacity building program. They also support the development of

interdisciplinary mental and behavioral health training programs and establish a training program for oral health professionals (funds appropriated beginning FY 2011).

The House bill also establishes a Personal Care Attendant Workforce Advisory Panel to formulate recommendations on working conditions and training for workers providing long-term services and supports, including home health aides, certified nurse aides, and personal care attendants; and other workforce issues related to such workers, including with respect to the adequacy of the number of such workers; the salaries, wages, and benefits of such workers; and access to the services provided by such workers.

Both bills increase the number of Graduate Medical Education (GME) training positions by redistributing currently unused slots (with priorities given to primary care and general surgery and to states with the lowest resident physician-to-population ratios), and increasing flexibility in laws and regulations that govern GME funding to promote training in outpatient settings, and ensuring the availability of residency programs in rural and underserved areas. The bills establish "Teaching Health Centers," defined as community-based, ambulatory patient care centers that are eligible for Medicare payments for the expenses associated with operating primary care residency programs.

Employment

The Workforce Investment Act (WIA), which includes the Rehabilitation Act of 1973 (Title IV) has not been reauthorized since 1998. In each of the past three Congresses, bills to reauthorize WIA have been introduced or discussed. A number of good provisions were included in these bills, including strengthening transition services for special education students, expanding supported employment services, and improving physical and programmatic access to one-stops. However, disagreements over provisions unrelated to disability programs have caused the reauthorization to remain stalled.

The Administration and Congress appear to be gearing up again to consider reauthorizing the law. The Department of Labor held a "listening session" from stakeholders on WIA programs. Bill Kiernan, Director of the Institute for Community Inclusion in Boston, and Co-chair of the AUCD Legislative Affairs Committee, testified at the listening session. He also testified before the Senate Health Education Labor and Pensions (HELP) Subcommittee on Employment and Workplace Safety just before the end of the last session of Congress. In both cases Kiernan focused on removing barriers to employment for people with disabilities as well as providing increased accountability and clearer responsibilities for the agencies that serve individuals with disabilities in attaining gainful employment. AUCD has been working with other organizations within the Consortium for Citizens with Disabilities (CCD) to craft a set of principles concerning WIA reauthorization. AUCD's Legislative Affairs Committee also drafted a set of employment principles for AUCD to use during the upcoming reauthorization.

Subminimum wage issues

Senator Harkin (D-IA), chair of the Senate HELP Committee, has expressed an interest in introducing legislation that concentrates on the role of 14(c) certification as well as representative payee procedures in response to the Iowa “Turkey Farm” incident involving a group of older men with developmental disabilities who were being exploited by their employer and who also served as a rent payee for the employees’ housing. AUCD and other advocates have focused on changing the current system into one which focuses on training and transition into higher paying, and higher quality job placements outside of sheltered workshops. Resources guiding the development of these priorities included publications from the Institute for Community Inclusion as well as research from a variety of UCEDDs that focus on this area of policy.

Seclusion and Restraint

As a result of reports by the National Disability Rights Network and the Government Accountability Office on the use of restraint and seclusion in schools, House Education and Labor Committee Chairman George Miller (D-CA) and Rep. Cathy McMorris-Rodgers (R-WA) introduced the Preventing Harmful Restraint and Seclusion in Schools Act (HR 4247) on December 9. Senator Chris Dodd (D-CT) introduced a companion bill (S 2860) in his chamber on the same day. The House Education and Labor Committee approved the bill by a bipartisan vote of 34-10 on January 28. We hope the bill can move through the Senate quickly, especially now that Sen. Dodd has announced his retirement.

The House and Senate bills are almost identical (a summary of the bills are on AUCD’s website), and aim to ensure the safety of students and school personnel by establishing minimum federal standards for the use of restraint and seclusion in schools. They would allow the use of physical restraint and seclusion only in emergency situations when the student’s behavior poses an imminent danger of physical injury and less restrictive interventions would be ineffective in stopping the behavior. The bills prohibit mechanical and chemical restraints, restraints that restrict breathing, and aversive interventions that compromise health and safety. Both bills impose parental notification requirements and require that only trained and certified personnel implement restraint and seclusion. Additionally, the bills authorize grants to state educational agencies to implement the minimum standards and school-wide positive behavioral support approaches. During the House committee markup, Chairman Miller introduced an amendment in the nature of a substitute that largely maintained the language of the bill, but clarified the bill’s application to private schools (only applies to private schools that receive, or serve students who receive, federal funding from the Department of Education) and homeschooling families.

AUCD continues to highlight the work being done at UCEDDs on positive behavioral supports, and with the help of the Legislative Affairs Committee and a workgroup of network members with expertise in this area, developed recommendations, many of which were incorporated into the bills. Republican cosponsors are still needed in the Senate; the bill has not yet been scheduled for markup in that chamber. AUCD continues to educate House members on the benefits of this legislation for children with disabilities. A date has not been set for consideration by the full House.

The National Disability Rights Network (NDRN) released an update to its January 2009 report entitled *School is not Supposed to Hurt*. The new report highlights progress made to prevent and reduce restraint and seclusion in 2009 as a result of grassroots efforts, and the slow response of states despite the strong beginnings of federal efforts. The report also summarizes proposed laws, gives examples of continuing harm, and summarizes efforts in each state to reduce restraint and seclusion.

Education

Secretary of Education Arne Duncan has been very vocal lately about his goal of reauthorizing the Elementary and Secondary Education Act (currently referred to as No Child Left Behind or NCLB). His sentiments have been echoed by President Obama and are reflected in his FY 2011 budget proposal. House and Senate committees have also begun outlining principles and priorities for the overhaul of the Act. These principles include incentivizing best practices in teaching and leadership, helping low-achieving schools gain resources and qualified staff, and improving pre-service education and professional development. AUCD participated in stakeholder forums at the Department of Education.

In addition to participating in meetings with the Department of Education, AUCD has also been working in collaboration with the CCD Education and Employment and Training Task Forces to prepare principles documents related to transition. These principles help to inform the work of both committees and articulate a national initiative on improving services and outcomes for individuals with disabilities.

Policy Seminar

AUCD will once again co-sponsor the annual policy seminar, scheduled for April 12-14, 2010. Co-sponsors include The Arc, UCP, AAIDD, NACDD, and SABE. The first program planning meeting was held in January. Some of the topics discussed to include in the program were employment and the subminimum wage, appropriations and economic recovery, the proposed Entitlement Commission, housing, Rosa's Law, direct support workers, FMAP as an employment issue, and early intervention. Health care reform, if enacted, would be included as an information and implementation workshop.

CCD Annual Meeting

The Consortium for Citizens with Disabilities held its annual meeting on January 14. Jeffrey S. Crowley, White House Senior Advisor on Disability Policy, spoke about what the Administration has done in the last year and its upcoming priorities. He indicated that health care continued to be the main focus, and after that, the Administration would look to jobs and employment. Sam Bagenstos, Civil Rights Division of the U.S. Department of Justice, spoke about DOJ's priorities, including fair lending, disability rights enforcement (namely Title I and II of the ADA), transportation accessibility, education and community integration through the *Olmstead* decision. Sharon Lewis, legislative staff for the House Committee on Education and Labor, received the CCD Chairperson's Award for her work on the Preventing Harmful Restraint and Seclusion in Schools Act. Connie Garner, legislative staff of the late Sen. Kennedy and

currently staff for the Senate HELP Committee, received the newly created Edward M. Kennedy Leadership in Disability Policy Award for her work on the CLASS Act, which Sen. Kennedy saw as his legacy.