

Governmental Affairs

Issues Critical to People with Developmental Disabilities
Prepared for you by The Arc of Western Wayne County Public Policy Committee

**Autism Spectrum
Disorder**

Housing

Medicaid

Employment

Education

**Budget,
Appropriations &
Tax Reform**

Social Security

Health & Wellness



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Dear Arc Members & Friends:

Grassroots activism continues to be the foundation of The Arc movement. This was evident when I attended the 2009 Disability Policy Seminar in Washington, D.C. on April 27-29, 2009. The theme was "A New Era: Embracing Opportunities in the Face of Grave Challenges". Over 550 people attended representing 48 states and Puerto Rico. Michigan was well represented and our delegation visited members of Congress and their legislative aides.

Disability advocates from The Arc of the United States, (The Arc), United Cerebral Palsy (UCP), American Association on Intellectual and Developmental Disabilities (AIDD), Association of University Centers on Disabilities (AUCD), National Association of Councils on Developmental Disabilities (NACDD), and Self Advocates Becoming Empowered (SABE), came together to discuss a wide range of public policy issues affecting people with disabilities and their families. Issues such as: Budget and Appropriations, Entitlements (Medicaid, Medicare, Social Security) and Health Care and Long Term Services Reform.

To help you understand some of these issues, we have again prepared our special Governmental Affairs Newsletter Edition. Please take time to read through the Fact Sheets and call or write your legislator with your concerns and issues. Your grassroots advocacy is needed now more than ever.

If you have questions or need additional information, please call me at (734) 729-9100 or email me at cherylp@thearcww.org. You can also contact The Arc Michigan Governmental Affairs Committee at (800) 282-6851 or the Disability Policy Collaboration at (202) 783-2229.

Cheryl Polite
Executive Director

The
Arc

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ACHIEVING A BETTER LIFE EXPERIENCE ACT OF 2009 (ABLE Act) S. 493/H.R. 1205

Background

Many families have been searching for a way to plan for the future of a child with severe disabilities. While they are able to save for the educational needs of their other children through "529" college tuition plans, they find that those plans do not fit the needs of their child with severe disabilities. Since their children may now, or in adulthood, need the long term services and supports of the Medicaid program and the income assistance of the Supplemental Security Income (SSI) program, many have considered using the existing options for supplemental needs planning in the Medicaid program. However, often families have found it to be too expensive to hire an attorney to establish a trust which meets the requirements of the Medicaid and SSI programs. These families recognize that their loved ones may live for many decades beyond the ability of the parents or other family members to assist them through supplementing services they receive through Medicaid. Others want to ensure the financial security of family members who have the level of disability required for Medicaid eligibility, but for now, are managing to function without the use of those benefits. Still others want to ensure that their family member can exercise control over the funds in the account without endangering the Medicaid and SSI benefits on which they may rely.

Achieving a Better Life Experience Act of 2009 (ABLE Act)

The ABLE Act would give individuals with disabilities and/or their families access to savings accounts that would allow individual choice and control while protecting eligibility for Medicaid, SSI, and other important federal benefits for people with disabilities. They could create a disability savings account that would accrue interest tax-free. Withdrawals would not be taxed as long as they are used to pay for qualified expenses. The account could fund a variety of essential expenses for the person with a disability, including educational expenses; medical and dental care; health, prevention, and wellness expenditures; employment training and support; assistive technology; personal supports services; transportation; housing; and other expenses for life necessities.

Savings accounts opened under the ABLE Act would differ from other savings instruments with tax advantages because they provide substantial flexibility:

- * The individual with disabilities could hold/control the account, or parents or a guardian could hold it in trust.
- * The allowed expenses are designed to be broad enough to accommodate the individual needs of account-holders.
- * Most of the allowed expenditures are not limited to adulthood or retirement age, so they can be used whenever they are needed.
- * The flexibility in expenses also allows families to save with confidence even though they cannot always predict how independent their child will become.
- * A family that has saved money in a traditional account for a child who becomes disabled later in life can roll-over the funds into a disability savings account without penalty.
- * The account should be easy and inexpensive to open, like a simple savings account.
- * Unlike some savings instruments, such as "529" college accounts, the ABLE Act accounts would be created and regulated on the federal level, so they would operate under the same rules in every state, ensuring that they are portable for individuals and families who move across state lines.
- * Individuals and families who find that the current individual or pooled trusts available under the Medicaid program will better address their needs may roll-over the account into the trusts.
- * The ABLE accounts can be managed by pooled trusts, if the individual or family so choose.

In a manner similar to the treatment of Medicaid trusts, funds remaining in the accounts at the individual's death would be used to "pay-back" the state Medicaid program up to the value of services provided to the individual during life.

The ABLE Act would give individuals with disabilities and their families an option for saving for their future financial needs in a way that supports their unique situation and makes it more feasible to live full, productive lives in their communities.

Action Taken by Congress and the Administration

The ABLE Act was introduced in the House (H.R. 1205) by Representatives Crenshaw (R-FL), Meek (D-FL), and Kennedy (D-RI), and McMorris Rodgers (R-WA), and in the Senate (S. 493) by Senators Casey (D-PA), Hatch (R-UT), Dodd (D-CT), Brownback (R-KS), Burr (R-NC), and Kennedy (D-MA). Both bills have a growing bipartisan list of co-sponsors. No hearings have yet been held.

Recommendations

Members of Congress are urged to co-sponsor the ABLE Act and to urge Committee action on the bills.

Relevant Committees

Senate Finance Committee
House Ways and Means Committee
House Energy and Commerce Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

EMPLOYMENT

Background

Working age people with disabilities are among the most unemployed and underemployed segments of our society. The United States Bureau of Labor Statistics (BLS) reported that the official unemployment rate for people with disabilities in February 2009 was 14% (8.7% for those with no disability). While this statistic is alarming, even more troubling is the lack of labor force participation by people with disabilities. BLS reported that for the same month only 23% of adults with disabilities were in the labor force as compared with 71% of the non-disabled. The vast majority of these individuals can work and want to work.

The state vocational rehabilitation (VR) program is significantly under funded to meet the employment needs of hundreds of thousands of individuals with severe disabilities who need VR services to obtain employment. Many individuals with disabilities could also greatly benefit from the employment and training services delivered through the Workforce Investment Act (WIA) One-Stop system, though the WIA track record for serving people with disabilities is very poor. Physical and programmatic access to WIA services is woefully lacking for individuals with disabilities, despite Federal requirements that such services be accessible.

In each of the past three Congresses, bills to reauthorize WIA and VR 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.

Action Taken by Congress and the Administration

Legislation to reauthorize WIA and Vocational Rehabilitation has yet to be introduced in the 111th Congress. The House Education and Labor Committee is holding hearings on WIA. On the appropriations front, the President has not yet submitted a detailed budget plan and the Appropriations Committee is preparing their bills.

Recommendations

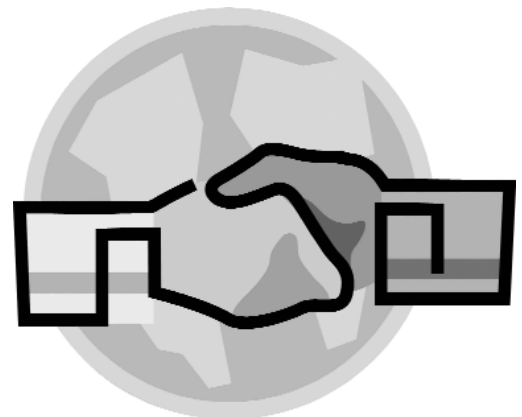
The Congress should:

- * Place a high priority on reauthorizing WIA and VR;
- * Assure that people with disabilities have physical and programmatic access to the WIA system;
- * Assure that WIA prioritizes services to people with disabilities and dedicates funding to those services.
- * Support expanded supported employment services by removing the 18 month limit that VR has to pay for SE.
- * Improve transition services by strengthening the VR role in the transition from school to adult life for students with disabilities, particularly requiring VR counselors to actively participate in the IEP process.
- * Increase funding for the VR and WIA system, including increasing funding for Supported Employment State Grant program and dedicated funding for transition services.;

Relevant Committees

House Appropriations Committee
House Education and Labor (WIA and VR)
Senate Appropriations Committee
Senate Health, Education, Labor and Pensions (WIA and VR)

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.



COMMUNITY LIVING ASSISTANCE SERVICES AND SUPPORTS ACT (CLASS ACT), S. 697/H.R. 1721

Background

Many Americans who are born with or develop severe functional impairments can access coverage for the long term services critical to their independence (such as personal assistance, assistive technologies, long term therapies, and training in basic skills) only through the federal/state Medicaid program. Since there is currently no national public program to address long term needs, the Medicaid program has become the default long term services program and the last resort for millions of individuals and families who have nowhere else to turn to have their long term needs met. To become eligible for Medicaid, the individual must "spend-down" income and assets, essentially becoming impoverished and remaining in poverty for as long as she or he needs supports, often for a lifetime.

While recognizing the important role that Medicaid plays in the provision of long term services and supports, many policy makers believe that it is time to develop an approach that takes the pressure off of the Medicaid program and helps individuals and families avoid poverty. It is also critical that such an approach must be included in health care reform efforts to ensure that individuals are able to function as independently as possible within their homes, families, and their communities.

The Community Living Assistance Services and Supports Act (CLASS Act) would offer a meaningful non-means-tested complement to the Medicaid program with a focus on helping individuals overcome barriers to independence that they may confront due to severe functional impairments. The CLASS Act is hailed as a way to provide critical coverage without forcing people into impoverishment to qualify for Medicaid services; therefore, it would relieve pressure on the Medicaid program which now serves as the fall-back program for people without private insurance coverage for long term care. The Leadership Council of Aging Organizations and the Consortium for Citizens with Disabilities together have supported long term services financing principles which are reflected in the CLASS Act. A coalition of 96 national organizations representing the aging and disability communities wrote to President Obama on March 25, 2009, urging inclusion of such a program in health care reform efforts.

CLASS Act Legislation

The CLASS Act would create a new national insurance program to help adults who have or develop severe functional impairments to remain independent, employed, and stay a part of their community. Financed through modest voluntary payroll deductions (with opt-out enrollment like Medicare Part B), this legislation would help remove barriers to choice and independence (e.g., housing modification, assistive technologies, personal assistance services, transportation) that can be overwhelmingly costly, by providing a cash benefit to those individuals who need support for basic functions. The large risk pool to be created by this approach would make added coverage affordable. It would give individuals added choice and access to supports without requiring them to become impoverished to qualify for Medicaid.



Premium payments collected through payroll withholding would be placed in a "National Independence Fund" managed by the Department of Health and Human Services as a new insurance program. Any individual who is at least 18 years old and actively working would be automatically enrolled (unless they opt out), and pay their premiums through payroll deduction or another alternative method. Any non-working spouse could enroll in the program and pay their premiums through an alternative method.

To qualify for CLASS Act benefits, individuals must be at least 18 years old and have contributed to the program for a "vesting" period of 5 years. Eligibility for benefits would be determined by state disability determination centers and will be limited to: (1) individuals who are unable to perform two or more activities

of daily living (ADL) (e.g. eating, bathing, dressing), or (2) individuals who, due to a cognitive or psychiatric impairment, require supervision, cueing, or hands-on assistance to engage in activities that will enable the individual to perform at least 2 of the following critical life functions: communicating; taking medications; household management; and basic money management.

To account for differences in independence support needs, there would be two cash benefit tiers. Tier 1 benefits (\$50/day) will be payable to eligible individuals who are unable to perform 2 or 3 ADLs or have a cognitive or psychiatric impairment requiring assistance with 2 or 3 critical life functions. Tier 2 benefits (\$100/day) will be payable to individuals who are unable to perform 4 or more ADLs or have a cognitive or psychiatric impairment requiring assistance with 4 or more critical life functions. The cash benefit would be posted monthly to a debit account or a "Choice Account". If an eligible individual does choose to move into an institutional facility, CLASS Act benefits would be used to defray those associated expenses.

Eligibility for CLASS Act benefits would have no effect on eligibility for Social Security retirement, survivors, or disability benefits, Supplemental Security Income (SSI) benefits, Medicare, or Medicaid. If an individual is eligible for both CLASS Act benefits and long term services under Medicaid, CLASS Act benefits could be used to offset the costs to Medicaid, thus producing Medicaid savings for the state. The CLASS program benefit would not replace the need for basic health insurance --- rather it is complementary to acute health care services and provides a mechanism to pay for those non-medical expenses that allow a person with a disability to remain independent. In addition, an individual could supplement CLASS program benefits through private insurance products.

Action Taken by Congress and the Administration

The CLASS Act was introduced by Senator Edward Kennedy (D-MA) as S. 697 and Representative Frank Pallone (D-NJ) as H.R. 1721. The Senate Special Committee on Aging held a hearing in March 2009 at which the CLASS Act was discussed extensively. Also in March, the Senate Finance Committee's Subcommittee on Health Care considered long term care, including the CLASS Act, as part of health reform. President Obama was a co-sponsor of the CLASS Act in the 110th Congress.

Recommendations

The 111th Congress should act swiftly to pass the CLASS Act to relieve the pressure on the Medicaid system and to ensure that workers and their families are covered by an affordable, premium-based long term support insurance program. The CLASS Act should be included as an essential element of national health care reform.

Relevant Committees

Senate Finance Committee
Senate Health, Education, Labor and Pensions Committee
House Energy and Commerce Committee (Subcommittee on Health)
House Ways and Means Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

HEALTH CARE REFORM: KEY DISABILITY ISSUE

Background

There is broad consensus that America's health care system needs reform. Over 46 million Americans are uninsured and more join their ranks every day as unemployment rises. A March 2009 U.S. Department of Health and Human Services report which summarized several studies found that U.S. health care spending doubled from 1996 to 2006, reaching \$2.2 trillion in 2007, nearly double the average of other developed countries. All stakeholders agree that reform must provide affordable coverage, improve quality and lower costs. To achieve these goals, emphasis has been given to prevention to transform our health care system's focus from sickness to wellness, care coordination, chronic disease management, and shifting payment rates to focus on performance rather than services provided. Many Members of Congress have focused on the need to address the national shortage of physicians, nurses, and dentists which is especially severe in rural areas.

Reform must address the health care disparities faced by individuals with developmental disabilities. According to the 2002 U.S. Surgeon General's report, *Closing the Gap: A National Blue Print to Improve the Health Care Needs of Persons with Mental Retardation*. These individuals experience poorer health and have less access to medical care than the general population. People with developmental disabilities often have difficulty recognizing and communicating their own health care needs. Moreover there is a significant shortage of qualified, trained health care professionals who are willing to treat them.

In addition to improving access to quality medical care for persons with developmental disabilities, health reform legislation must improve the way our nation provides long term services and supports (such as assistance and supervision with activities of daily living, taking medication, managing a home, and preparing meals, managing money). Removing Medicaid's institutional bias so that persons with disabilities can receive services in community-based settings that are preferred and more cost-effective rather than in large congregate settings is critical. Huge waiting lists for long term services and supports across the country constitute a major crisis.

Advocates in the disability and aging communities have urged the inclusion of long term services and supports in health care reform. The effort should be two-pronged: 1) there should be a national long term services insurance program which assists eligible individuals and their families to meet long term needs with a cash benefit and without forcing them into poverty to receive Medicaid benefits; and 2) the current Medicaid program should be improved to eliminate the institutional bias and allow a real choice for the individual to receive needed services at home or in the community. Two recently introduced policy proposals would address these issues and should be incorporated in healthcare reform: the Community Living Assistance Services and Supports (CLASS) Act and the Community Choice Act (see separate Fact Sheets on these bills).

Action Taken by Congress

During a March White House Health Reform Summit, President Obama stated that health care reform is essential to achieving economic recovery. Summit attendees, including both Republican and Democratic Members of Congress, the insurance industry, health care providers, and consumer groups, agreed that achieving health care reform this year is a necessary and bipartisan priority.

President Obama has set forth general principles for reform but Congress, not the Administration, will be developing legislation. Several Congressional Committees with jurisdiction over health reform issues have held numerous hearings and have set an ambitious goal of House and Senate passage before the August recess. However, there is no consensus on many significant issues such as whether a public plan should be included and how to pay for overall reform.



The President's FY 2010 budget outline includes a reserve fund of more than \$630 billion over 10 years to finance a down payment on comprehensive health reform. The House and Senate Budget Resolutions include funding for this reserve fund; however, offsets will be required to comply with Congressional PAYGO (pay-as-you-go) rules. The House and Senate must also resolve the issue of whether the final resolution will contain reconciliation instructions on how the Senate deals with its health reform bill. Reconciliation would allow the Senate to avoid any filibuster by the minority and require only 51 votes, rather than the usual 60 votes, to pass health care reform. If reconciliation is in the Budget Resolution, a bipartisan approach to health care reform will prove more difficult. Nevertheless, health reform might be expedited if the Senate only needs 51 votes to move it forward.

Recommendations

Support health reform legislation that:

- * Ensures that the private insurance system covers ALL Americans so that Medicaid and Medicare are not the only option for coverage of people with disabilities;
- * Incorporates long term services and supports by including the CLASS Act and the Community Choice Act;
- * Strengthens the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities enrolled in the program; and
- * Increases the education of physicians and dentists by amending the Public Health Services Act to require that medical schools, dental schools, and their residency programs provide training to improve competency and clinical skills in providing care to patients with disabilities (including those with intellectual disabilities) as a condition of receiving federal funds.

Relevant Committees

Senate Finance Committee
Senate Health, Education, Labor, and Pensions (HELP) Committee
Senate and House Budget Committees
House Energy and Commerce Committee
House Ways and Means Committee
House Education and Labor Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT (D.D. ACT)

Background

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. For over 30 years, the DD Act has enjoyed strong bipartisan support.

The DD Act focuses on the estimated 5.4 million children and adults in the United States and territories who have developmental disabilities. The Act provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self-determination.

The DD Act consists of four programs that create an intersecting network. Grant funds support initiatives in civil rights protections, education and early intervention, child care, health, employment, housing, transportation, recreation, family support, and other services. The DD Act components are:

State Councils on Developmental Disabilities (DD Councils)

Councils on Developmental Disabilities are located in every State and Territory and include volunteers who are appointed by Governors. More than 60% of these volunteers must be people with developmental disabilities or family members. Councils are charged by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost effective ways to address those needs in a manner that upholds the dignity and value of people with developmental disabilities. Councils work to promote the independence and productivity of people with developmental disabilities and promote systems change that will eliminate obvious inequities in areas such as employment, education, and access to healthcare.

Protection and Advocacy (P&A) systems

Under the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, P&As are required to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities.

Collectively, the P&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. The federally mandated P&As serve individuals with a wide range of disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems

On March 3, Rep. Barney Frank (D-MA) reintroduced a bill (H.R. 1255) that would limit the ability of Protection and Advocacy Systems to protect individuals with developmental disabilities in institutions. The bill was introduced with 11 other bipartisan co-sponsors and referred to the House Judiciary Committee. The Voice of the Retarded (VOR), a parent group, is making a strong push to get cosponsors for this legislation. Members of Congress need to be educated about the true nature of this bill and urged to NOT co-sponsor or in any way support H.R. 1255.

University Centers for Excellence in Developmental Disabilities (UCEDDs)

The DD Act authorizes core funds to 67 UCEDDs, at least one in every state and territory, that are components of a university system or are public or not-for-profit entities associated with universities. UCEDDs provide interdisciplinary training to students and professionals, engage in cutting-edge research, provide technical assistance, and direct services and supports to people with disabilities of all ages and their families. UCEDDs share information and research findings.

Projects of National Significance (PNS)

PNS is a discretionary program that focuses on emerging areas of concern. This program supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change.

Family Support Programs

Title II of the DD Act authorizes the Family Support Program to promote and strengthen the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities. Family support services are effective in reducing the costs associated with life-long disability, and in preventing the expensive of out-of-home placement. However, this Title needs its own line item funding (\$15M.)

Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date. The Omnibus Appropriations Act (passed in February 2009) included modest increases in funding for DD Act programs for FY 2009.

Recommendations

1. Congress should provide a significant increase in appropriations over FY 2009 Levels for DD Act programs so that these programs can continue to respond to the needs of people with disabilities. With state budget cuts and inflation, these programs struggle to meet the demands of the growing population of people with developmental disabilities who experience multiple barriers to get and keep jobs, an education, and appropriate community based supports and services. Specifically, disability advocates seek a \$6 million increase for each of the three main components of the Act: UCEDDs, DD Councils, and P&As, a \$3 million increase for Programs of National Significance (PNS) and a \$2 million increase for Protection and Advocacy System for Voting Access (PAVA) program. In addition, we urge Congress to provide \$15 million towards family support activities as authorized in Title II of the DD Act.
2. Congress should work toward timely reauthorization of the DD Act that:
 - * Increases the funding authorization levels for the programs under the Act to expand the capacity of the DD Network and Family Support
 - * Supports a separate title and funding authorization level (above and beyond funding for existing DD Act Programs) for self-advocate-directed Training and Information Centers.
 - * Reauthorizing Title III - Preparation of Direct Support Professional Workforce to provide grants to states for personal preparation, model demonstrations and systems change projects to improve the recruitment, training, support and retention of a qualified direct service professional workforce in each state.

Relevant Committees

House and Senate Appropriations Committees
House Energy and Commerce Committee
House Education and Labor Committee
Senate Health, Education, Labor and Pensions Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

EDUCATION

Background

The U.S. Congress may work this year to reauthorize the No Child Left Behind Act (NCLB). NCLB significantly impacts the education of students with disabilities. The No Child Left Behind Act requires all students up to high school to be assessed to determine educational progress by individual schools and school systems. The disability community has been and continues to be among NCLB's strong supporters since this law finally requires students with disabilities to be part of the student achievement system.

The NCLB Act authority expired in September 2007. There has been much controversy about how to measure educational progress for students with disabilities, who are frequently blamed by educators for poor results by schools. Despite two sets of regulations aimed at assuring that certain students with disabilities are assessed appropriately, the controversy continues inside and outside of the disability community.

The recently reauthorized Higher Education Act funds student loans for post secondary education and funds programs to prepare school administrators and teachers, including special education teachers. The Congress authorized new post secondary educational opportunities for students with disabilities who want to continue their education beyond high school, particularly for those students with significant cognitive impairments who are not likely candidates for admission to typical colleges and universities but could profit from community college and other post secondary education opportunities. Changes in the law include:

- * Model programs to create and expand programs to serve students with intellectual disabilities;
- * Technical Assistance, training and support to facilitate higher education access;
- * Expanded student loan benefits for veterans with disabilities; and
- * Programs to train teachers and other personnel to teach students with disabilities.

There is also a well-documented severe shortage of qualified special education teachers and related services personnel. Personnel preparation funding is available through Part D of the Individual with Disabilities Education Act and the Higher Education Act.

Action Taken by Congress and the Administration

It is unclear whether the Congress will pass a NCLB reauthorization bill this year. There are many policy and political hurdles to overcome. Many Members of Congress and President Obama have expressed support for NCLB but seek to adjust some of NCLB's key provisions. No Administration or Congressional leadership bills have been introduced in this Congress.

Recommendations

- * Assure that any changes to NCLB do not negatively impact students with disabilities;
- * Require closer coordination of NCLB and IDEA policies;
- * Fully fund the new provisions in the Higher Education Act that increase postsecondary opportunities, provide access to work study and financial aid for students with significant cognitive disabilities;



- * Increase funding for all components of the Individuals with Disabilities Education Act (IDEA), particularly the Part B State Grant, the Part C Early Intervention State Grant and the Preschool Program; and
- * Increase funding for programs to increase the cadre of administrators, highly qualified teachers and related services personnel needed to address the critical shortage of special education staff in our nation's public schools.

Relevant Committees

House Education and Labor Committee

Senate Health, Education, Labor and Pensions (HELP) Committee

House Appropriations Committee

Senate Appropriations Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

FY 2009 BUDGET AND APPROPRIATIONS

Overview

In February 2009, the U.S. Congress enacted the American Recovery and Reinvestment Act (ARRA) (P.L. 111-5) to provide \$787 billion in emergency economic stimulus spending. A substantial portion of this new stimulus money, which must be spent during the next two years, will increase funding for key disability programs such as Medicaid, the Individuals with Disabilities Education Act (IDEA) State Grant and Early Intervention programs, and the Vocational Rehabilitation State Grant and Independent Living programs. SSI and Social Security recipients will receive a one time payment of \$250 this spring.

In March 2009, the Congress passed the Fiscal Year 2009 Omnibus Appropriations Act (P.L. 111-8). This Act appropriates funds for nine of the twelve appropriations bills for the fiscal year that began on October 1, 2008 and ends on September 30, 2009. The table on the next page lists key disability programs and their funding for FY 2009.

In February, 2009, newly inaugurated President Obama submitted a bare bones FY 2010 Budget Request, since he had been in office for only a few weeks. This Budget Request would total \$3.6 trillion and create vast new investments in areas such as health care, education, energy independence and tax policy. A more complete Obama Administration FY 2010 Budget Request is anticipated in late April.

The enactment of a FY 2009 Omnibus Appropriations bill six months after the start of a fiscal year is unusual. The enactment of the ARRA may be a once in a lifetime occurrence where huge sums have been appropriated to spur the economy, save and develop new jobs and expand our nation's infrastructure and human services system. These actions may affect the FY 2010 appropriations in negative or positive ways, depending on how the public and the Congress react to the status of the economy and the impact of the stimulus funding.

Action Taken by Congress and the Administration

Following the submittal by the Obama Administration of its FY 2010 Budget Request, the Congress began work on its FY 2010 Budget Resolution. A Budget Resolution establishes the overall budget blueprint for discretionary spending and any adjustments to tax policy and entitlement programs like Medicaid. In early April, both Houses of Congress adopted their respective FY 2010 Budget Resolutions. Each House made certain reductions to the Obama Administration request to lower the projected deficit. In mid to late April, House and Senate conferees will meet to resolve the differences between their respective resolutions.

A key sticking point is expected to be whether the final resolution will contain reconciliation instructions in regards to how the Senate deals with health care reform later in this Congress. Reconciliation would allow the Senate to avoid any filibuster by the minority and require only 51 votes, rather than the usual 60 votes, to pass health care reform. If reconciliation is in the Budget Resolution, a bipartisan approach to health care reform will probably prove more difficult. Nevertheless, health care reform might be expedited if the Senate only needs 51 votes to move it forward.

Recommendations

- * Adopt an FY 2010 Budget Resolution that allows for the expansion of disability discretionary programs, strengthens entitlement programs and reforms health care and long term services and supports;
- * Increase FY 2010 appropriations for key disability programs in accordance with the recommendations in the table below; and
- * Increase funding for the Social Security Administration and those federal government agencies that enforce disability rights.

The following table compares FY 2008 and FY 2009 appropriations for key disability programs with our recommendations for FY 2010 funding.

| Labor, Health and Human Services and Education (in millions) | FY 2008 | FY 2009 Final | FY 2010 Recommendation |
|---|----------------|--------------------------|-----------------------------------|
| IDEA State Grant (Part B) | 10,947.5 | 11,500.0 | 19,229.0 |
| IDEA Preschool | 374.1 | 374.1 | 814.0 |
| IDEA Early Intervention (Part C) | 435.7 | 439.0 | 725.0 |
| IDEA Parent Training Centers | 26.5 | 27.0 | 28.6 |
| HEA Postsecondary Education for Students with Disabilities | 6.7 | 6.7 | 10.0 |
| Demonstration Projects to Support Postsecondary Faculty | | <i>new</i> | 10.0 |
| Model Comprehensive Transition Programs | | <i>new</i> | 10.0 |
| Coordinating Center for Comprehensive Transition | | <i>new</i> | 1.5 |
| National Center for Information and Technical Support | | <i>new</i> | 3.0 |
| Access to Postsecondary Instructional Materials | | <i>new</i> | 5.0 |
| Vocational Rehabilitation State Grant | 2,874.0 | 2,974.0 | 3,274.0 |
| VR Supported Employment State Grant | 29.2 | 29.2 | 50.0 |
| Office of Disability Employment Policy | 26.7 | 26.7 | 47.5 |
| Work Incentive Grants | 14.4 | 17.5 | 28.0 |
| Assistive Technology | 29.9 | 30.9 | 38.3 |
| University Centers for Excellence in DD | 36.9 | 38.0 | 44.0 |
| Developmental Disabilities Councils State Grants | 72.5 | 74.3 | 80.3 |
| DD Protection and Advocacy Systems | 39.0 | 40.0 | 46.0 |
| Projects of National Significance | 14.2 | 14.2 | 17.2 |
| Title II Family Support | 0 | 0 | 15.0 |
| Title XX Social Services Block Grants | 1,700.0 | 1,700.0 | 1,700.0 |
| Maternal and Child Health Block Grant | 659.3 | 662.1 | 850.0 |
| HRSA Autism and other Developmental Disabilities | 36.4 | 42.0 | 47.0 |
| CDC Center on Birth Defects | 127.3 | 138.0 | 148.0 |
| Lifespan Respite Care Act | 0 | 2.5 | 71.1 |
| National Institute on Child Health & Human Development | 1,254.7 | 1,294.9 | 1,341.0 |
| Social Security Administrative Expenses | 9,745.0 | 10,453.5 | 11,600.0 |
| Housing and Urban Development | | | |
| Section 811 Supportive Housing for Persons with Disabilities | 237.0 | 250.0 | 265.0 |
| Vouchers Targeted to Nonelderly People with Disabilities | 30.0 | 30.0 | 30.0 |

Relevant Committees

House and Senate Budget and Appropriations Committees

HOUSING FOR PEOPLE WITH DISABILITIES: THE CRISIS AND THE OPPORTUNITY

Background

Being part of the community and living as independently as possible are among the most important values and goals shared by people with disabilities, their families, and advocates. A home of one's own - either rented or owned - is the cornerstone of independence for people with disabilities. However, across the nation, people with developmental and related disabilities face a severe crisis in the availability of decent, safe, affordable, and accessible housing. Today many still live in large congregate facilities or other inappropriate places like institutions. Over 700,000 people with developmental disabilities live with aging parents (one of whom is over age 65). For people who use wheelchairs or other mobility devices, finding housing with even basic accessibility features (e.g. an entrance with no steps) ranges from daunting to impossible.



The affordability gap for people with disabilities has exponentially worsened in recent years. According to *Priced Out* in 2008, on a national average, over 4 million Americans with disabilities who rely on federal monthly Supplemental Security Income (SSI) of \$674 for all their basic needs would have to pay 112.1 percent of their entire monthly income to rent a modest one-bedroom unit. The cost of renting a smaller studio/efficiency unit is 99.3% of monthly SSI.

Action Taken by Congress and the Administration

Section 811 Supportive Housing for Persons with Disabilities Program

HUD's Section 811 provides housing for people with physical or developmental disabilities, or people with chronic mental illness who are 18 years of age or older and have very low incomes (at or below 50 percent of the area median income). Section 811 participants may live in supportive housing units developed and owned by non-profit organizations, or they may receive tenant-based rental assistance that helps them rent decent, accessible and safe housing in the private rental market. Tenants pay 30 percent of their adjusted income for rent which ensures affordability for those receiving SSI benefits.

Section 811 is the only HUD program that produces affordable and accessible housing for non-elderly people with disabilities. Historically HUD has used Section 811 funds to provide interest-free capital funding to non-profit sponsors to help finance the development of fully accessible rental housing - primarily independent living projects and small group homes - many of which offer voluntary supportive services for people with significant disabilities. A project-based contract (also known as a PRAC) is linked to the capital funding to cover housing operating costs such as insurance and maintenance. The Section 811 law also allows HUD to use up to 25 percent of the program's funds for tenant-based rental assistance (known as the "Mainstream Housing Opportunity for People with Disabilities" voucher program). Renewal funding for these 14,000 vouchers is "taken off the top" of each year's Section 811 appropriation. In 2008, renewing these vouchers cost \$80+ million of Section 811's small \$237 million budget. As a result, only 930 new 811 units could be funded. All Section 811 stakeholders agree that the program needs to be reformed to survive and meet the needs of people with disabilities for supportive housing.

In March of 2009, the Frank Melville Supportive Housing Investment Act of 2009 (H.R. 1675) was introduced by Reps. Christopher Murphy (D-CT) and Judy Biggert (R-IL). This groundbreaking legislation streamlines Section 811 processing requirements, removes outdated regulatory barriers, transfers funding for the "Mainstream" voucher program to the Section 8 voucher program and - most importantly - authorizes a new PRAC-Only Demonstration program. This Demonstration program will provide the essential rental subsidy to reduce rents to affordable levels for people receiving SSI in a small but significant percentage of the hundreds of thousands of units that are routinely created every year through the Low Income Housing Tax Credit Program (LIHTC) and HOME programs administered by states and local jurisdictions. By using

LIHTC, HOME, or other federal or state funds to pay construction costs and the PRAC to pay for operating costs, this Demonstration program will keep 811 units affordable to SSI beneficiaries, significantly increase integrated housing opportunities, and triple the number of 811 units funded without increasing the program's appropriation.

Section 8 Rental Assistance - Section 8 Housing Choice Voucher Program

Section 8 vouchers, which are administered by Public Housing Agencies (PHAs), are designed to bridge the gap between income and rent by paying the difference between what a very low-income household can afford (e.g., 30 percent of income) and modest rental housing costs. Unfortunately, non-elderly adults with disabilities comprise only 19% of all Section 8 voucher holders - far less than their relative need for assistance. In an effort to direct more vouchers to people with disabilities, Congress appropriated funding in FY 2008 and FY 2009 for an estimated 7,000 new vouchers targeted exclusively to non-elderly people with disabilities. It is extremely important that Congress continue this policy by providing at least \$30 million for new vouchers in FY 2010.

Increasing Production of Affordable and Accessible Housing

The National Affordable Housing Trust Fund Act was enacted last year to establish dedicated funding for the production, preservation and rehabilitation of 1.5 million affordable homes over 10 years. At least 67.5% of the funds must be spent on rental housing for extremely low income households with incomes at or below 30% of median income. SSI payments are equal to only 18 percent of median income. This new rental housing production program could significantly expand the supply of deeply affordable and accessible rental housing units for people with disabilities with the lowest incomes. President Obama's budget FY 2010 budget outline requests \$1 billion for the National Affordable Housing Trust Fund.

Recommendations

- * Provide an increase of at least \$25 million for the Section 811 Supportive Housing for Persons with Disabilities program (to bring the program to \$275 million), at least \$30 million for new Section 8 vouchers targeted to non-elderly persons with disabilities, and support President Obama's request for \$1 billion for the National Affordable Housing Trust Fund; and
- * Support the Frank Melville Supportive Housing Investment Act of 2009 (H.R. 1675).

Relevant Committees

House & Senate Appropriations Committees
House Committee on Financial Services
Senate Banking, Housing and Urban Affairs Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

LONG TERM SERVICES AND SUPPORTS

Background

In addition to expansion of community-based long-term services and supports through the Community Choice Act and the Community Living Services and Supports Act (CLASS) Act (see separate fact sheets), there are other important improvements needed. Three of these include: 1) increased wages for direct support professionals; 2) improvements to the Medicaid Home and Community-Based State Plan Option; and 3) removal of the two-year waiting period for Medicare for individuals with disabilities eligible for Social Security Disability Insurance (SSDI).

Direct Support Professionals Fairness and Security Act

For millions of individuals with disabilities of all ages, direct support professionals are the key to living successfully in their home communities. Direct support professionals are personal care assistants, home care aides, or staff in community residential supports programs that assist individuals with disabilities. Unfortunately, there is a crisis in the availability of professionals to provide these direct supports. This crisis is in partially a result of low wages and poor benefits these workers receive. As a result, individuals with disabilities often experience continuous turnover of direct support workers or they find themselves unable to get workers at all. Unable to obtain adequate assistance, people find their health, safety, and sometimes, their lives in jeopardy.



Representatives Lois Capps (D-CA) and Lee Terry (R-NE) introduced the Direct Support Professionals Fairness and Security Act (H.R. 868). The bill would take important steps to ensure that direct support professionals are paid wages and benefits that enable them to stay in their jobs and provide the critical services that people with disabilities rely upon. The bill would amend the Medicaid program to provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. In order to receive the enhanced FMAP, states would be required to submit a five-year plan and would have to assure continuation of the increased wage rate after the five-year period. The state plan must be developed in conjunction with individuals with disabilities and family members, private providers, and direct support professionals.

Improvement to Home and Community-Based Services State Plan Option

The Deficit Reduction Act of 2005 (DRA) established a new Medicaid Home and Community Based Services state plan option. The 1915(i) option allows states to provide home and community-based services (HCBS) without requiring that states use a waiver process. To add this new option to its state Medicaid plan, a state would have to file a Medicaid state plan amendment. The new option also requires states to establish stricter eligibility criteria (level of care) for institutional services than for community-based services. For the first time, a state will be able to offer HCBS services to people who would not otherwise qualify for the institutional services in that state.

While the new option has many good features, there are some limitations in the way it was drafted which have resulted in few states adopting the option. The following improvements are needed to the HCBS option:

- * Remove the authority for states to cap services and maintain waiting lists;
- * Allow states to provide the full range of services that can currently be provided under the HCBS waiver (including other services approved by the Secretary);
- * Remove the limit on coverage of people with incomes up to 150 percent of poverty and allow the full range of income eligibility allowed for people in facility-based settings; and

* Eliminate the states' ability to limit services to certain sections of the state.

Senators Kerry (D-MA) and Grassley (R-IA) introduced the Empowered at Home Act (S. 434) on February 13, 2009. Sections of this legislation would make the improvements outlined above and establish incentives for states to take up the option.

End the Medicare Two-Year Waiting Period

In the United States, nearly 7 million people under age 65 qualify for Medicare due to severe and permanent disabilities. However, these individuals with disabilities must wait two years after they are deemed eligible for Social Security Disability Insurance (SSDI) to receive Medicare coverage. As a result, there are as many as 1.5 million men and women who are too disabled to return to work but who must wait to receive Medicare coverage at a time when they likely most need health care. Nearly 39 percent are uninsured for at least some of the time during the waiting period, and 26 percent have no insurance throughout the waiting period. This policy devastates families financially, contributes to the development of preventable secondary conditions, worsening of health status, and death for some individuals.

Senators Jeff Bingaman (D-NM), Sherrod Brown (D-OH), and Susan Collins (R-ME) introduced the Ending the Medicare Disability Waiting Period Act of 2009 (S. 700). Representatives Gene Green (D-TX) and Lee Terry (R-NE) introduced a companion bill in the House (H.R. 1708). This legislation would gradually phase out the two-year waiting period for Medicare.

Action Taken by Congress and the Administration

The Direct Support Professionals Fairness and Security Act (H.R. 868), Empowered at Home Act (S. 434), and the Ending the Medicare Disability Waiting Period Act (S. 700/H.R. 1708) have been reintroduced.

Recommendations

Members of Congress should co-sponsor these bills and work towards passage as stand-alone legislation or as part of comprehensive health care reform.

Relevant Committees

Senate Finance Committee

House Energy and Commerce Committee (Subcommittee on Health)

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME

Background

The Supplemental Security Income (SSI) and the Old Age, Survivors, and Disability Insurance (OASDI) programs, along with the related Medicaid and Medicare health care benefits, are the means of survival for millions of individuals with severe disabilities. With years of inadequate funding for the Social Security Administration (SSA) administrative costs, many people with severe disabilities have experienced long delays and decreased services in accessing these critical benefits. Without adequate appropriations to fund administration for SSA, the situation will deteriorate even more. The OASDI programs, established in Title II of the Social Security Act, are part of the debate over the long-term solvency (75 years) of the Social Security Trust Funds. Congressional action to resolve the funding shortfalls will have a major impact on people with disabilities. While the disability programs provide critical benefits for daily living, there continue to be numerous areas in which the programs need adjustment to ensure that they meet the needs of the people who are intended to be served.

SSA's Administrative Expenses

Social Security benefits are not subject to the annual appropriations process because benefits must be paid to those people who are entitled to them. However, the administrative functions of SSA are funded as SSA's Limitation on Administrative Expenses (LAE) through the annual appropriations process. SSA has a national workforce of over 60,000 people and 1,400 facilities nationwide. The current hearing processing time averages 500 days nationally. These delays hurt people with disabilities who file applications for benefits and/or request hearings on denials and who must then wait months or years to receive benefits to which they are entitled, as well as those who become so discouraged with the process that they quit trying.



SSA's funding for its LAE for FY 2009 is \$10.454 billion, which is \$709 million above the FY 2008 spending levels. At least \$400 million of it is necessary to cover the annual cost of living adjustments for SSA staff and increases in the cost of rent and security services for local offices. SSA received an additional \$500 million through the American Recovery and Reinvestment Act (ARRA) to assist in addressing the growing backlog in disability decisions and another \$500 million to begin replacement of its National Computer Center. With the ARRA funding and the final appropriation for FY 2009, SSA projects hiring 5,000 to 6,000 new staff over the next few months. For FY 2010, the President's request is for \$11.6 billion.

Efforts to Address Solvency

More than one-third (37 percent) of all Social Security benefit payments are made to over 18.6 million people who are non-retirees, including 7.4 million disabled workers, 1.6 million children of disabled workers, and over 870,000 disabled adult children covered by the survivors, retirement, and disability programs (OASDI). Other non-retirees include non-disabled survivors and dependents. The Title II programs are insurance against poverty and are essential to the protection of people with disabilities, who draw their benefits from all parts of the Trust Funds. Workers earn coverage for themselves and their family members through payment of Social Security taxes during their working years. The insurance protection they receive is targeted to prevent poverty in old age, in case of disability, or where there are dependent survivors after the death of the worker or retiree. Proposals that would partially or fully eliminate the current broad-based sharing of risk (social insurance) and replace it with the risks of private investment (privatization) would be harmful to people with disabilities, because substantial Social Security benefit cuts would be necessary. Beneficiaries would no longer be able to count on a guaranteed amount of benefits adjusted for inflation annually. Privatization would shift the risks of investment from the federal government back to the individual, resulting in a devastating impact on people with disabilities and their families. Many sponsors of past proposals to privatize portions of Social Security were not aware of the potential impact of their proposals on people with disabilities. While President Obama has not put Social Security solvency on the list of issues to be addressed this year, recent budget estimates suggest that the Trust Funds' surplus may be lower than expected with the recent loss of millions of jobs from the economy.

Improvements Needed to SSI and Social Security Disability Programs

There remain many issues in the SSI and Social Security disability programs which need to be addressed in order to make the programs work better to meet the needs of people with disabilities. These include: increasing the substantial gainful activity (SGA) level for people who are disabled (currently \$980 per month) to the level for people who are blind (currently \$1,640 per month); permanently extending SSI eligibility for refugees and asylees who are disabled or elderly; increasing, and indexing for inflation, the asset limits and income exclusions for SSI; eliminating marriage penalties for people with disabilities; eliminating the two-year waiting period for Medicare; making needed improvements to the Ticket to Work program and other work incentives; establishing a \$1.00 for \$2.00 offset in the Title II OASDI disability programs so that beneficiaries will be better able to work despite severe disability; and addressing policy issues which have a harsh impact on people eligible for Title II benefits as disabled adult children.

Action Taken by Congress and the Administration

SSA received an additional \$500 million through the American Recovery and Reinvestment Act to assist in addressing the growing backlog in disability decisions and another \$500 million to begin replacement of its National Computer Center. With the ARRA funding and the final appropriation for FY 2009, SSA projects hiring 5,000 to 6,000 new staff over the next few months. For FY 2010, the President's request is for \$11.6 billion.

Recommendations

- * Congress should appropriate \$11.6 billion for SSA's Limitation on Administrative Expenses. Congress should remove SSA's budget authority from discretionary spending caps. SSA's LAE would still be subject to the annual appropriations process and Congressional oversight.
- * Congress should ensure the solvency of the Social Security Trust Funds by making limited adjustments that spread the costs widely while preventing privatization of, or depletion of, the Social Security Trust Funds. Congress should request a beneficiary impact statement on every major proposal under serious consideration and should carefully assess the possible impact of any Social Security reform proposals on people with disabilities who rely on Title II programs.
- * Congress should address the many areas in which improvements are needed in the SSI and Social Security disability programs.

Relevant Committees

House Ways and Means Committee
Senate Finance Committee
House Budget Committee
Senate Budget Committee
House Appropriations Committee
Senate Appropriations Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

COMMUNITY CHOICE ACT

Background

Nearly half of all long-term services and supports are financed through Medicaid. However, there is a long-standing "institutional bias" within the Medicaid program. While states are required to provide services within nursing homes, community-based services and supports are optional. As a result, over 60% of Medicaid funding for long-term services and supports is spent on institutional services. The developmental disabilities service system has effectively utilized the Medicaid Home and Community Based Services waiver to shift the majority of funding from institutional settings towards the community. Yet the extent to which this has occurred varies considerably among states. In addition, there are extensive waiting lists within states for community-based services and supports. Not all states maintain detailed waiting list information, but, conservatively, hundreds of thousands of individuals with developmental disabilities are awaiting services. Many of these individuals are residing with aging family caregivers. Recent estimates indicate that over 711,478 adults with intellectual and developmental disabilities are living with family caregivers who are 60 years of age or older.

Community Choice Act

The Community Choice Act would provide Americans with equal access to community-based services and supports. It would provide individuals with disabilities in nursing homes and other institutional settings with options to receive community-based services. It would also help address waiting lists by providing guaranteed access to a community-based benefit within Medicaid. Specifically, the legislation would amend Medicaid to require state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals. States would receive an enhanced federal matching rate for meeting certain benchmarks and for serving people whose costs exceed 150 percent of average nursing home costs.

Services under this legislation would include services to assist individuals with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision, or cueing. ADLs include assistance with eating, toileting, grooming, dressing, bathing, and transferring. IADLs include assistance with meal planning and preparation; managing finances; shopping for food, clothing, and other essential items; performing essential household chores; communicating by phone and other media; and traveling around and participating in the community. Health-related tasks are defined as those tasks that can be delegated or assigned by licensed health-care professionals under state law to be performed by an attendant. Services also include assistance in learning the skills necessary for the individual to accomplish these tasks him/herself. Services must be provided in a home or community setting based on a written plan.

States would be required to establish a Development and Implementation Council to work with the state in developing and implementing the state plan amendment necessary in order to provide the services. The majority of Council members must be individuals with disabilities, elderly individuals, or representatives of such individuals, and must collaborate with providers and advocates. Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.

Action Taken by Congress and the Administration

Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) along with Representative Danny Davis (D-IL) introduced the Community Choice Act (S. 683; H.R. 1670) on March 23, 2009. The legislation has bi-partisan support. The Community Choice Act has been referenced in testimony at hearings concerning long-term services and supports within the context of health care reform.

Recommendations

Members of Congress should co-sponsor and pass the Community Choice Act either as a stand-alone piece of legislation or as part of comprehensive health care reform that addresses the needs of Americans for long-term services and supports.

Relevant Committees

Senate Finance Committee

House Energy and Commerce Committee (Subcommittee on Health)

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202-783-2229), Association of University Centers on Disabilities (301-588-8252), American Association on Intellectual and Developmental Disabilities (202-387-1968), or National Association of Councils on Developmental Disabilities (703-739-4400).

HATE CRIMES

Background

Hate crimes against people with disabilities are disturbingly prevalent and pose a significant threat to full participation in American society. Despite the deep impact of hate violence on individuals, families and communities, current law limits federal jurisdiction over hate crimes to incidents directed against individuals on the basis of race, religion, color or national origin - but only when the victim is targeted because he/she is engaged in a federally protected activities. The law does not provide for federal involvement in cases where crimes are motivated by bias against a victim's real or perceived disability.

Action Taken by Congress and the Administration

- * In 2005, the Senate approved a measure to add hate crimes legislation as an amendment to the National Defense Authorization Act for Fiscal Year 2005 (S. 2400). The House approved a "Motion to Instruct" its conferees to retain this provision in conference by a vote of 213-186, but the language was removed.
- * In the 109th Congress, the House of Representatives approved the text of hate crimes legislation, HR 2662, as an amendment to the Children's Safety Act, but it was not passed in the Senate.
- * In the 110th Congress, both Houses of Congress passed hate crimes legislation only to hit a dead end in conference. The bill was stripped off a Defense Reauthorization bill under threat of a Presidential veto.
- * This year, Representative John Conyers (D-MI) introduced a bill (HR. 1913) with 42 co-sponsors. This bill is identical to what passed in the 110th Congress and is expected to have wide support. The Senate has yet to introduce a companion bill.
- * President Obama has stated that he supports the addition of disability as a protected class in hate crime legislation.

Recommendations

Members should co-sponsor the Local Law Enforcement Hate Crimes Prevention Act of 2009; Senators should introduce and sponsor an identical bill; and Congress should pass the Local Law Enforcement Hate Crimes Prevention Act of 2009.

Relevant Committees

House and Senate Judiciary Committees

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.



AUTISM SPECTRUM DISORDER (ASD)

Background

According to the Centers for Disease Control and Prevention (CDC) on the prevalence of Autism Spectrum Disorders (ASD), approximately 1 in every 150 American children has a potential diagnosis of ASD. Continued research is needed to document trends in the growth of ASD, as well as research into and development of effective interventions. In 2006, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416) to authorize more research on ASD through the National Institutes of Health (NIH) and CDC. The Act also provides the first step to expand the interdisciplinary training of health professionals to identify and support children with ASD and their families. However, greater commitments are also needed to expand access to services such as early identification, diagnosis, early intervention, education, family support, and long-term services and supports to better meet the needs of individuals with ASD and related developmental disabilities. Individuals with ASD and their families need access to accurate information about scientifically-based interventions. The training of a wide range of interdisciplinary professionals also needs to be a top priority so that the findings coming out of our research institutions can be translated and made available to parents and providers across the country as quickly as possible.

Action Taken by Congress and the Administration

On April 2, Sens. Durbin (D-IL), Casey (D-PA), and Menendez (D-NJ) introduced the Autism Treatment Acceleration Act (S. 819). This bill, originally drafted with President Obama when he was in the Senate, incorporates some of the provisions of the Expanding the Promise to Individuals with Autism Act introduced by Sen. Clinton in the last Congress, but also adds several new provisions to accelerate the development of a services system to meet the needs of individuals with autism spectrum disorders and related developmental disabilities.

The bill creates demonstration projects to increase access to quality health care services and coordination of care as well as to develop and provide an array of services to adults with autism spectrum disorders; develops a national multimedia campaign to increase public education and awareness about healthy milestones and autism throughout the lifespan; establishes a national network to link research and service initiatives at the federal, regional, state and local levels; and, establishes an Interdepartmental Coordinating Committee to coordinate Federal activities relating to research, services, and programs for individuals with autism spectrum disorders.

The bill also establishes multiyear national training initiative on autism and a technical assistance center to significantly develop and expand interdisciplinary training and continuing education on autism spectrum disorders. These training initiatives will promote and engage in training for health, allied health, and educational professionals to identify, diagnose, and provide interventions for individuals with ASD; collect data; provide technical assistance; and work to expand training on and disseminate of information regarding effective, lifelong interventions, educational services, and community supports, including training for criminal justice system personnel and emergency first responders.

A requirement that health insurers cover the diagnosis and treatment of autism spectrum disorders, including Applied Behavior Analysis, assistive communication devices and other effective treatments is also added.

The bill was referred to the Health, Education, Labor and Pensions Committee. No corresponding bill has been introduced in the House.

Recommendations

The 111th Congress should:

- * Provide the necessary funds to focus our country's researchers on explaining the apparent increase in prevalence, on finding the causes, and on determining the most effective ways of supporting children and adults with Autism Spectrum Disorders by fully funding the Combating Autism Act:

- > \$143.5 million to expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder.
- > \$19.5 million for the CDC's Disabilities Surveillance and Research Program.
- > \$47 million to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions, and train professionals.
- * Support the Autism Treatment Acceleration Act and other legislation that addresses the direct service and interdisciplinary training needs associated with the increasing number of individuals with Autism Spectrum Disorders.

Relevant Committees

House and Senate Appropriations Committees

Senate Health, Education, Labor and Pensions Committee

House Energy and Commerce Committee (Subcommittee on Health)

House and Senate Labor, Health and Human Services and Education Appropriations Subcommittees

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

Communicating with Congress

Since the Anthrax postal scare of 2001, e-mail is the preferred option for sending written communication to Members of Congress. E-mail is just as effective as a First Class letter and it is received immediately by the Member, not in the six to eight weeks it takes a mailed letter to arrive. Communicating by fax is also effective.

Some specific tips:

1. Try to stick to one typewritten page; two pages at most. If writing a regular letter, don't write on the back of a page. If writing longhand, take care to write legibly. In e-mail, always use proper net etiquette (avoid using all upper case letters as this connotes shouting, etc.).
2. In a short paragraph, state your purpose. Stick with one subject or issue. Support your position with the rest of the letter.
3. If the subject of your letter is a bill, cite it by name and number.
4. Be factual and support your position with information about how legislation is likely to affect you and others. Avoid emotional, philosophical arguments. Don't flame (insulting or derogatory e-mail) or spam (to inundate someone with e-mail, usually in an attempt to overload and crash the person's Internet system) legislators.
5. If you believe legislation is wrong and should be opposed, say so. Indicate the likely adverse effects, and suggest a different approach.
6. Ask for the legislator's views and his or her support, but do not demand that support. Remember, Senators and Representatives respond to a variety of views, and even if they do not support your position on one issue or bill, they may support it the next time. So, ask for the legislator's views and express that you look forward to hearing from them on this issue soon.
7. If writing a letter, make sure your name and address are legible. In e-mail, make sure your name, full address and e-mail address are included.
8. If writing a letter, the suggested style is:

The Honorable _____
United States Senate
Washington, D.C. 20510
Dear Senator _____

The Honorable _____
United States House of Representatives
Washington, D.C. 20515
Dear Representative _____

(Begin e-mail by Dear Representative _____ or Dear Senator _____)

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