

# 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

Affordable  
Care Act

Housing

Employment

Education

Budget,  
Appropriations  
& Tax Reform

Social Security

Medicaid/Medicare

D.D. Act



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Dear Arc Members and Friends,

I had the privilege to attend the 2011 Disability Policy Seminar held in Washington, D.C. on February 14-16, 2011. This year's theme was **"Cultivating New Champions on Capitol Hill"**.

Disability advocates from The Arc of The United States (The Arc), United Cerebral Palsy (UCP), American Association on Intellectual and Developmental Disabilities (AAIDD), 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 national public policy issues that are critical for people with disabilities. Issues such as: Employment, Affordable Care Act, Medicaid and Medicare, Social Security & Supplemental Security Income, Budget & Appropriations, Developmental Disabilities Assistance & Bill of Rights Act, Education, Autism Spectrum Disorder and Housing.

Being there this year reminded me of an article I read several years ago about **"Keeping the Promises"** - promises the United States has made to its citizens with intellectual and developmental disabilities. Promises such as those found in the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act, Supreme Court decisions, the Individuals with Disabilities Education Act, and the Rehabilitation Act to name a few. All of which express national values and commitments to people disabilities.

These promises are coming under close scrutiny as our nation experience economic crises. "The words come easily, but living up to them requires commitment, knowledge and capacity to change the words into concrete results". We must therefore continue to be vigilant with our grass roots advocacy in order to help "Keep the Promises".

We must educate ourselves, friends, neighbors, colleagues and constituents and their families about what is happening at all levels of government. Please take time to read through the Fact Sheets developed by our Disability Policy Collaboration. Take action and call or write your legislator with your concerns and issues.

If you should have questions or need additional information, please call me at (734) 729-9100 or email me at [cherylp@thearcww.org](mailto:cherylp@thearcww.org). You can also contact The Arc Michigan Governmental Affairs Committee at (800) 282-6851 or the The Arc Disability Policy Office at (202) 534-3700.

*Cheryl*

Cheryl Polite  
Executive Director



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# 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 in January 2010, the percentage of people with disabilities in the labor force was 21.8% compared with 70.1% for persons with no disability. Far too many people with intellectual and developmental disabilities are underemployed, are in segregated settings, and earn very little money. For example, according to the Government Accountability Office, 424,000 people are earning less than the federal minimum wage and of that number about 74% are people with intellectual disabilities.

According to the Census Bureau, weekly wages for people with any disability decreased from \$353 in 2000 to \$288 in 2006. Weekly wages for people with an intellectual or developmental disability decreased from \$234 in 2000 to \$188 in 2006. In 2007, the state Developmental Disability Agencies provide day or employment supports to an estimated 566,895 individuals yet only 115,239 individuals were supported in integrated employment. The reasons for these problems are complex, often tied to limited exposure to the workforce, reduced expectations, lack of access to jobs and competing federal policies regarding the employment potential for persons with disabilities.

The state vocational rehabilitation (VR) program is significantly under-funded to meet the employment needs of hundreds of thousands of individuals with significant disabilities who need these services to obtain and retain 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. However, physical and programmatic access to WIA services is inconsistent for individuals with disabilities, despite Federal requirements that such services be accessible.

Even given the current economic downturn, with the declining birth rate as well as the aging of the current workforce, it has become more apparent that there will be a shortage of workers to meet employer demands in the coming decade. We must ensure that all people who want to work have the training and support they need to be employed.

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, namely 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 112th Congress. It was last reauthorized in 1998.

## Recommendations

The 112th Congress should:

- Place a high priority on reauthorizing the Workforce Investment Act (WIA) and the Rehabilitation Act;
- Expand supported employment services and create a new competitive grant program for youth with the most significant disabilities;



- Support innovative strategies to assist persons with developmental and other significant disabilities in entering competitive, integrated employment with appropriate supports and services;
- 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 (Individualized Education Program) process;
- Assure that people with disabilities have physical and programmatic access to the WIA system;
- Support employment first strategies, policies and practices that target integrated employment at minimum wages or above for all individuals with developmental and other significant disabilities;
- Support the utilization of national and community service opportunities in transition and vocational planning for individuals with disabilities as a gateway to integrated employment; and
- Ensure that people with disabilities are fully included in any efforts to create jobs and stimulate the economy.

### 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.

# AFFORDABLE CARE ACT

## Background

The Affordable Care Act (ACA) of 2010 will provide access to affordable health insurance for 32 million Americans who are currently uninsured. According to the non-partisan Congressional Budget Office, it will reduce the federal deficit by \$130 billion over the first ten years and \$1.2 trillion over the second ten years. The law represents a sea change in expanding access to affordable, quality health care for persons with disabilities.

The Arc, AAIDD, AUCD, UCP, NACDD and SABE are long standing advocates for universal access to quality, affordable care and fully support funding and implementing the ACA. Our support is not a partisan choice rather it is based on the many provisions that eliminate discrimination against people with health conditions, expand coverage, improve prevention, and expand long term services and supports.

The ACA's most critical provisions for people with disabilities are:

## Insurance Market Reforms

- Prohibit pre-existing condition exclusions, lifetime and annual caps, discrimination based on disability and health status, and rescission of coverage;
- Prohibit consideration of health status when setting premiums; and
- Require guaranteed issue and renewal of insurance policies;

## Expanding Access to Coverage

- Establish temporary high risk pools to provide coverage to those who are currently uninsured;
- Provide significant subsidies to assist low income individuals to purchase coverage in the Ex changes;
- Include coverage of dental and vision care for children in the Exchanges; and
- Include coverage of critical disability-related services, such as mental health services, rehabilitative and habilitative services and devices, in the Exchanges.

## Establishing a New Long Term Services and Supports Program

- The Community Living Assistance Services and Supports (CLASS) Act creates 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.

## Medicaid and Medicare

- Expands Medicaid eligibility to 133 percent of the federal poverty level with significant federal funding;
- Establishes the Community First Choice Option for states to cover comprehensive community attendant services under the state's optional service plan and includes several other provisions to encourage home and community based services; and
- Improves care coordination for dual eligibles (those who receive both Medicare and Medicaid benefits), eliminates drug coverage (Part D) co-pays for dual eligibles receiving waiver services, and improves access to key medications.

## Prevention, Provider Training, Data Collection

- Eliminates co-pays for critical prevention services;
- Creates the Prevention and Public Health Fund to pay for essential prevention programs;



- Increases opportunities for training of health care providers, including dentists, on the needs of persons with disabilities, including those with developmental disabilities; and
- Improves data collection on where people with disabilities access health services and where accessible facilities can be found.

### **Action Taken by Congress and the Administration**

The partisan disagreements over the law continue in the 112th Congress with multiple strategies to repeal all or portions of the law and other efforts to block implementation and funding for key provisions. Currently, the biggest target is the law's individual responsibility provision (commonly referred to as the "individual mandate") which requires that individuals who can afford to do so maintain a minimum level of health insurance coverage or else pay a tax penalty. This provision, the cornerstone of the ACA, brings down costs by broadening the insurance risk pool to make coverage expansions and consumer protections possible.

On January 19th the House of Representatives voted 245-189 in support of a bill (H.R. 2) to repeal the law. The Senate is not expected to consider the legislation. The House has charged four committee Chairmen - Dave Camp (R- MI) of Ways and Means, Fred Upton (R-MI) of Energy and Commerce, John Kline (R-MN) of Education and the Workforce, and Lamar Smith (R-TX) of Judiciary, to hold oversight hearings and draft bills to replace elements of the ACA. Members of Congress have also begun introducing legislation to repeal or revise specific provisions. The House leadership is also looking at ways to defund the ACA, including eliminating the Prevention and Public Health Fund.

### **Recommendations**

Members of Congress should work with the Administration to ensure that the new health reform law operates as intended for people with disabilities and other Americans.

They should:

- Oppose full or partial repeal of provisions that are important to people with disabilities;
- Provide adequate funding to implement the ACA;
- Support the individual responsibility provision as it is key to making sure that insurance risk is shared and premiums do not become cost prohibitive;
- Oppose repeal of the CLASS program; and
- Preserve the Medicaid expansion which can help people with disabilities in the waiting period for Medicare, people who have disabilities that do not meet the standard for Social Security, and people who have too much income or assets to be eligible.

### **Relevant Committees**

House and Senate Appropriations Committees  
 House Education and the Workforce, Senate Health Education Labor and Pensions  
 House Ways and Means, House Energy and Commerce, Senate Finance  
 House and Senate Budget 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.

# MEDICAID AND MEDICARE

## Background

The federal/state Medicaid program provides critical health and long term services and supports for people with severe disabilities. The federal Medicare program provides health insurance to approximately 8 million Americans with disabilities under the age of 65. Combined, these two programs provide health coverage and long-term services and supports to roughly one-third of the estimated 53 million people with intellectual, developmental, physical, and/or mental disabilities in the United States. In addition, Medicaid and Medicare providers employ many professionals, paraprofessionals, and direct support workers throughout our nation.

## Federal Medical Assistance Percentage (FMAP)

States across the country are facing huge budget deficits due to the economic downturn of the last few years. Many states are required by their own laws to balance their budgets and, as a result, have cut many human services programs. Almost all states have chosen to cut Medicaid services for people with disabilities. For example, many states have reduced the number of hours for home health aides for people with developmental disabilities. In February 2009, the American Recovery and Reinvestment Act (ARRA - known as the economic stimulus bill) was enacted. It included a two-year \$87 billion increase in the federal share of Medicaid spending (known as the FMAP). This temporary FMAP increase has provided needed relief to state Medicaid programs, averting more severe cuts in health care and other critical services that allow people with disabilities to live in their communities. In August 2010, the FMAP increase was extended at gradually reducing levels for an additional six months until June 30, 2011.

## Maintenance of Effort on Eligibility

One legislative battle this year will involve the maintenance of effort on eligibility requirements for the Medicaid program established by the Affordable Care Act (ACA), otherwise known as "health reform". The ACA requires states to maintain at least their current Medicaid eligibility criteria through 2014 (when the health reform law's Medicaid expansion and higher federal Medicaid matching payments will take effect). Recently, every Republican governor signed a letter to President Obama and to the Congressional leadership calling for an end to this provision.

## Deficit Reduction

Several proposals to reduce the federal deficit have included a number of entitlement cuts which would have had a very negative impact on people with disabilities. The National Commission on Fiscal Responsibility and Reform (often referred to as the "Deficit Commission") proposed several cuts to Medicaid. These included: eliminating the provider tax payment method used by states to increase the federal Medicaid match; cuts to administrative services reimbursement; placing dual Medicaid and Medicare eligibles in managed care; and the possibility of a Medicaid block grant. The Deficit Commission also proposed significant cuts to the Medicare program and increased cost-sharing for beneficiaries. These recommendations are premised on the belief that Medicare beneficiaries use too much health care and need to pay more for it.

Finally, there have been proposals to put global caps on federal expenditures for health care spending. If such caps were imposed, they would likely put pressure on these programs to move away from an individual entitlement. They could also result in a block grant for Medicaid and health care vouchers to replace Medicare. This is a fundamental shift in our health and long term services and supports system from services mostly based on eligibility to services based on a set budget.

## Action Taken by Congress and the Administration

The House of Representatives passed H.R. 2 to repeal the ACA in January. It is unlikely that the Senate will pass similar legislation. It is expected that the House will pass bills to repeal various sections of the ACA this session of the 112th Congress.

### **Recommendations**

The 112th Congress should:

- Protect the individual entitlement to Medicare and Medicaid;
- Extend the temporary FMAP increase until 2014 when the new Medicaid expansion takes effect;
- Ensure that cost savings proposals such as reducing Medicaid spending and raising Medicare cost-sharing do not have a disproportionate impact on people with disabilities; and
- Oppose removing the maintenance of effort on eligibility provision in the ACA for Medicaid.

### **Relevant Committees**

House and Senate Budget

House Ways and Means and Energy and Commerce

Senate Finance

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

## Background

Social Security provides benefits to over 53 million individuals, including at least 11 million people with disabilities, their spouses, and children. Any changes in Social Security will affect everyone who receives benefits. While most people think of Social Security only as a retirement program, over one-third of people who receive monthly checks are not retirees.

People with disabilities receive benefits from all three programs commonly called "Social Security" - the Old Age, Survivors, and Disability Insurance (OASDI) programs established in Title II of the Social Security Act. These are insurance programs covering people who retire, die, or become disabled. The benefits are designed to insure against poverty in retirement years and when disability may limit the ability to work and to protect dependent survivors. When workers become disabled, retire or die, their spouses and children receive benefits based on the earnings record of their parent or spouse. People with disabilities and their families who receive Social Security include a wide range of individuals:

- Disabled workers and their dependents,
- Retirees with disabilities (not counted in the 11 million),
- Disabled dependents of retirees,
- Disabled survivors, and
- Disabled adult children and disabled widow(er)s.

Funding for the OASDI Social Security programs comes from two Trust Funds which are funded with payroll taxes (FICA taxes) paid by employees and employers. The goal is for the Social Security Trust Funds to be able to pay benefits over the long term – to be solvent for at least the next 75 years.

Future Challenges for the Trust Funds: Social Security is currently running a planned surplus to address the retirement and disability needs of the baby boom generation. According to the Social Security Trustees 2010 Report, the surplus is at \$2.6 trillion and is expected to grow to \$4.2 trillion by the end of 2024. To meet all financial obligations over the next 75 years, the Trust Funds show a projected shortfall of less than one percent of the Gross Domestic Product (GDP). Previous Trustee forecasts made similar projections. In later years, when the surplus has been spent, Social Security will be able to pay reduced benefits from the taxes it collects. According to a July 2010 Congressional Budget Office Report, Social Security can pay full scheduled benefits until 2039; 80 percent of scheduled benefits in 2040; and 76 percent in 2084. Social Security will not be bankrupt: the program is not in crisis and no drastic changes are needed now.

As a result of the current deep recession, Social Security's income is down. However, this is not expected to have a long term effect on the program's solvency.

People with disabilities and their families have an enormous interest in any proposed Social Security changes. These issues are bipartisan; all policy makers must address the concerns of people with disabilities and their families.

Improvements Needed to Supplemental Security Income (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 \$1,000 per month) to the level for people who are blind (currently \$1,640 per month); 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 work incentives; and addressing policy issues which have a harsh impact on people eligible for Title II benefits as disabled adult children.

In its quest to find solutions to the federal fiscal crisis, the National Commission on Fiscal Responsibility and Reform has made a number of recommendations for changes to the Social Security system, despite the fact that the Social Security system has accumulated a significant surplus. In addition, a number of private commissions and Members of Congress have also put forward several proposals to make changes to the Social Security programs. The various proposals include combinations of eligibility and benefits changes and revenues increases. Many of the proposals would be harmful to people with disabilities and their families.

### *Action Taken by Congress and the Administration*

In his State of the Union speech, President Obama called for finding a bipartisan solution to strengthen Social Security for future generations without putting at risk current retirees, the most vulnerable, or people with disabilities; without slashing benefits for future generations; and without subjecting Americans' guaranteed retirement income to the whims of the stock market. Members of Congress have begun debate on Social Security issues in floor statements.

### *Recommendations*

- Congress should ensure the long term solvency of the Social Security Trust Funds by making modest adjustments that spread the costs widely while preventing privatization or depletion of the Social Security Trust Funds;
- Congress should request a beneficiary impact statement on every major component of proposals to change Social Security. For a program that affects millions of individuals of all ages, it is essential to look beyond the budgetary impact to understand the actual impact on people's daily lives now and in the future; and
- 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

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.

# FEDERAL BUDGET AND APPROPRIATIONS FOR FY 2011 and 2012

## Background

### FY 2011 Funding

The outlook for various federal programs and systems of supports for citizens with disabilities looks grim at the outset of the 112th Congress as leaders lay out proposed strategies for reducing the federal deficit, shrinking the size of government, and slashing federal spending.

With none of the 12 annual appropriations bills for the current year (Fiscal Year 2011) signed into law, Congress extended the current funding levels for federal programs in a Continuing Resolution (CR) through March 4th. House Republican leaders plan to use the next CR as a vehicle to impose deep cuts in domestic discretionary programs and to defund implementation of key elements of the health reform law. Appropriators may begin writing a new omnibus appropriations bill for FY 2011 which began October 1, 2010. Whether the House and Senate can negotiate a compromise agreement – and whether the President will veto the appropriations bill if it is too extreme and thereby set up a confrontation over a potential government shutdown – remains to be seen. Other possibilities include a series of short-term continuing resolutions while debate continues or a CR for the remainder of FY 2011, but at levels significantly below the current FY 2010 funding. There is no doubt that these types of cuts will have a serious impact on programs that support people with developmental and other disabilities who are already suffering under deep cutbacks caused by state budget deficits, unemployment, and the recession.



### Fiscal Commission

On December 1, 2010 President Obama's Commission on Fiscal Responsibility and Reform released its final report, *The Moment of Truth*, outlining their plans to reduce the deficit and debt. A recent analysis by the Center for Budget and Policy Priorities points out that the plan does not represent a truly balanced approach to bringing deficits under control. Specifically, the plan starts to take effect in fiscal year 2012, which could threaten the fragile economic recovery; it proposes policy steps that would prove a serious hardship for some of the nation's most disadvantaged individuals, such as those with disabilities; it relies far too much on spending cuts as opposed to revenue increases; and it calls for adopting policies that will hold annual revenues and spending to 21 percent of Gross Domestic Product (GDP) in future decades, which is both unrealistic and unwise, according to economic experts at the Center.

While the Commission recommendations did not receive enough votes (14 of 18) to be considered final recommendations, some extremely troubling proposals have emerged based on the recommendations and will be part of the deficit reduction debate. These include imposing multi-year caps on discretionary spending at levels that would require severe cuts in this part of the budget; placing caps on total Medicare and Medicaid expenditures that could lead to converting Medicare to a voucher system and block-granting Medicaid; closing Social Security's shortfall primarily through benefit cuts; and imposing limits on total federal spending and taxes at levels far below what will be needed in coming decades. These limits will continue to require deep cuts in basic programs for years to come.

### President's Budget Request

President Obama is expected to send the Administration's Budget Request to Congress on February 14. It is expected to be the most austere budget in decades. In his State of the Union address, the President proposed a five-year freeze on annual domestic spending and acknowledged that such a freeze would require painful cuts. He also mentioned the recommendations of the fiscal commission, including its recommended changes to the Social Security program, stating that "we must strengthen it without putting at risk current retirees, the most vulnerable, or people with disabilities..."

Like all Americans, we want a strong economy. However, a truly strong and secure nation can only be achieved if federal funding decisions and tax policy do not result in a federal budget that is crafted at the expense of people with disabilities. Federal fiscal policy can and should be used to decisively address the crises facing people with disabilities and their families. However, adequate funding for the program services and supports are vital to enable people with disabilities and their families to be productive and fully included in society.

### **Recommendations**

The 112th Congress should:

- Reject cuts to disability programs;
- Strengthen, not weaken, vital entitlement programs such as Social Security, Medicaid, Medicare, TANF, and food stamps;
- Oppose any process which prevents Members of Congress from exercising their legislative responsibilities to carefully consider and vote on legislative changes;
- Address the significant unmet needs of people with disabilities and their families by expanding the federal government's investment in people with disabilities to enable them to live and work as independently as possible in the community with appropriate and flexible long term individual and family supports;
- Ensure that any deficit reduction proposals are balanced and do not result in increases in poverty or inequality; and
- Address the unmet needs of people with disabilities and their families before making further tax cuts or reforming tax policy in a way that negatively impacts low wage earners and other vulnerable people.

### **Relevant Committees**

House and Senate Budget Committees

House and Senate Appropriations Committees

House and Senate Appropriations Subcommittees on Labor, Health and Human Services, Education and Related Agencies

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 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. It was last authorized in 2000.

The DD Act focuses on the estimated 5 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 education, access to healthcare and employment.

## 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.

## 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

Over 75% of people with ID/DD live with families, often with aging parents. However, families and caregivers often struggle to access any level of formal support. 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 expense of out-of-home placement. The Family Support program should be expanded with a state funding formula based on need.

## Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date. The Administration on Developmental Disabilities (ADD) has held nationwide listening sessions to gather input in preparation for the reauthorization. ADD will hold a number of regional summits on self-advocacy this year. The National Council on Disability will soon publish its report on progress made by DD Act programs: *Rising Expectations: The Developmental Disabilities Act Revisited*.

## Recommendations

The 112th Congress should work toward timely reauthorization of the DD Act that:

- Increases the authorization for appropriations for all programs authorized under the DD Act;
- Reauthorizes the Title III Program for Direct Support Workers to address the direct support work force shortage and improve the recruitment, training, support, and retention of a qualified direct service professional workforce in each state;
- Reauthorizes and funds the Title II Family Support program and provides a formula grant to every state and territory with a separate authorization and appropriation line item;
- Protects and expands the authority of Protection and Advocacy Systems to investigate abuse, neglect, and deaths and to pursue class action litigation on behalf of our constituents wherever they live; and
- Support federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports.

## 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 Self Advocates Becoming Empowered (802) 760-8856.

# EDUCATION

## Background

The U.S. Congress may complete work on two key education laws in 2011: the Elementary and Secondary Education Act (known as No Child Left Behind) and legislation to limit the use of restraint and seclusion in schools. Both pieces of legislation impact the education of students with disabilities.

## Elementary and Secondary Education Act

The Elementary and Secondary Education Act (ESEA), called “No Child Left Behind” in its last reauthorization, requires that all students in elementary and secondary schools be assessed to determine educational progress by individual schools and school systems. The disability community continues to support ESEA because the law requires the inclusion of all students with disabilities in the student achievement system. ESEA’s authority expired in September 2007, and Congress is expected to begin work on reauthorization this year.

There has been much controversy about how to measure educational progress for students with disabilities, a population that is frequently blamed by educators for their schools’ poor test scores. The Bush Administration responded to these criticisms by adopting two regulations aimed exclusively at certain students with disabilities. The first rule allows up to 1% of all students (10% of special education students) with significant cognitive impairments to be assessed using alternate assessments based on alternate standards. The other rule, not yet fully implemented, allows for assessments based on modified achievement standards aligned to the general curriculum for those students with disabilities (up to 20%) who can make progress toward, but may not reach, grade-level achievement standards in the same time frame as other students. The U.S. Department of Education has also allowed the states to employ so-called “growth models” to assess student performance by measuring a student’s progress within a certain time frame.

The Obama Administration released its blueprint for ESEA reauthorization in March 2010; it proposes providing incentives for states to adopt academic standards that prepare students to succeed in college and the workplace and create accountability systems that measure student growth toward meeting the goal that all children graduate and succeed in college or the workplace. Although the Administration acknowledges that the primary funding for programs that support students with disabilities is through the Individuals with Disabilities Education Act (IDEA), it promises that its ESEA proposal will “increase support for the inclusion and improved outcomes of students with disabilities”.

## Restraint & Seclusion

Both chambers introduced legislation to limit the use of restraint and seclusion in schools during the last Congress. Research and recent reports show that restraint and seclusion in education are often unregulated and used disproportionately on children with disabilities, frequently resulting in injury, trauma, and even death. In January 2009, the National Disability Rights Network issued a report detailing the harmful use of these interventions in over two-thirds of states, involving children as young as three years old in both public and private school settings. Following that report, the Government Accountability Office (GAO) conducted an investigation finding no federal laws restricting the use of these interventions in schools, and that state laws vary widely if they exist at all.



Restraint and seclusion are often used for behaviors that do not pose danger or threat of harm and implemented by untrained school personnel. Students are not the only ones injured by restraint and seclusion; school personnel have suffered significant injuries while implementing these techniques. The use of restraint and seclusion can be traumatizing for everyone involved, including the students who witness it. Numerous alternatives to restraint and seclusion exist, including positive behavioral interventions and supports and other de-escalation techniques that could prevent the need for these dangerous interventions in many circumstances.

The Keeping All Students Safe Act (H.R. 4247, S. 3895) was passed by the House of Representatives in March 2010 but was never considered in the Senate. New legislation must be introduced in the 112th Congress, and the issue could be addressed within the reauthorization of ESEA.

The previously-introduced versions of the bill were very similar. They aimed to establish federal minimum safety standards to limit the use of restraint and seclusion in public and private early childhood, elementary and secondary schools that receive support from federal education funds, as well as Head Start programs. The bills would have banned the use of the worst types of restraints and limited the use restraint and seclusion to emergency situations where physical injury is imminent and less restrictive interventions would be ineffective in controlling the student's behavior. Additionally, the bills would have required continuous monitoring of students while being restrained or secluded, parental notification any time restraint and seclusion are used, and training and certification of school personnel who implement these techniques to do so safely and use alternative interventions when possible.

### **Action Taken by Congress and the Administration**

House and Senate leaders have not introduced any bills to reauthorize ESEA and no hearings have been scheduled.

### **Recommendations**

The 112th Congress should:

Elementary and Secondary Education Act (ESEA):

- Ensure that any changes to ESEA do not negatively impact students with disabilities, such as using the student's IEP for purposes of assessing adequate yearly progress;
- Require closer coordination of ESEA and IDEA policies;
- Substantially increase authorized funding for teacher preparation in the ESEA.

Restraint and Seclusion legislation:

- Pass legislation limiting the use of restraint and seclusion in schools, including personnel training and certification requirements, parental notification requirements, and bans on the most dangerous types of restraint.

### **Relevant Committees**

House Education and Workforce Committee

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

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.

# AUTISM SPECTRUM DISORDER

## Background

In 2006, President Bush signed into law the Combating Autism Act (CAA, PL 109-416). This law is unique in that it is wide-reaching by targeting and coordinating every available system in order to efficiently and effectively address this developmental disability that now affects one percent of the American population. The law focused on expanding research and coordination at the National Institutes of Health (NIH), increasing awareness and surveillance at the Center for Disease Control (CDC), and expanding the interdisciplinary training of health professionals to identify and support children with ASD and their families. This law is scheduled for reauthorization this year. Due to sunset language this law will expire if it is not reauthorized by September 2011.

According to a recent congressionally mandated report to Congress, in the past four years under the provisions of the CAA, significant advances have been made in our understanding of ASDs. Notably, reliable estimates of the prevalence and a clearer picture of both the opportunities and gaps that exist in ASD research and services are now available. With federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASDs. Large-scale efforts in data collection, consolidation, and sharing are empowering researchers and health practitioners with knowledge not available only a few years ago. Within the biomedical research community, there is optimism that a continued rigorous focus on identifying genetic and environmental triggers to ASDs will yield innovative treatment and prevention strategies.

While the median age for ASD diagnosis (approximately 4.5 years of age) appears to be favorably on the decline, new CDC data indicates a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years but with a continued focus on ASD awareness and training this critical time gap can be lessened. Strategic efforts aimed at underserved populations are under way to encourage awareness, early diagnosis, and intervention, but additional efforts will be needed to provide the necessary evidence base to support a wide variety of new interventions and services and supports for individuals on the autism spectrum. In addition, Federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD. This critical progress must not end.

In addition, services for those already diagnosed with ASD are desperately needed. These services include housing, education, supported employment, family supports, and transition services across the lifespan. Individuals with ASD and their families also continue to need access to accurate information about scientifically-supported interventions. The training of a wide range of interdisciplinary professionals to provide these services must be a top priority. A well-trained workforce will ensure that the findings coming out of our research institutions can be translated and made available to parents and providers across the country, and will ensure that services can be implemented as quickly as possible.

In the 111th Congress, Sens. Durbin (D-IL), Casey (D-PA), and Menendez (D-NJ) introduced the Autism Treatment Acceleration Act. A companion bill was introduced in the House by Reps. Doyle (D-PA) and Smith (R-NJ). This bill would accelerate the development of a service system to meet the needs of individuals with ASD and related developmental disabilities. The House of Representatives also passed the Training and Research for Autism Improvement Nationwide Act in the last Congress. And former Sen. Dodd (D-CT) introduced a bill to reauthorize the Combating Autism Act in the waning days of the 111th Congress. President Obama has repeatedly pledged support to increase research, training and services for individuals on the spectrum.



### *Action Taken by Congress and the Administration*

No bills have been introduced yet and no hearings have been scheduled.

### *Recommendations*

The 112th Congress should:

- Reauthorize and fully fund the Combating Autism Act; and
- Support 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 Disabilities (301) 588-8252, AAIDD (202) 387-1968, or National Association of Councils on Developmental Disabilities (703) 739-4400, or Self Advocates Becoming Empowered (802) 760-8856.

# HOUSING FOR PEOPLE WITH DISABILITIES

## 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. 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.

In a huge victory for the disability community, the Frank Melville Supportive Housing Investment Act (The Melville Act) was enacted on January 4, 2011. The Melville Act makes a number of important changes designed to streamline the Housing and Urban Development (HUD) Section 811 program in order to increase the supply of integrated supportive housing opportunities for people with disabilities. Lead co-sponsors of this overwhelmingly bi-partisan legislation included Representative Christopher Murphy (D-CT) and Representative Judy Biggert (R-IL) as well as Senator Bob Menendez (D-NJ) and Senator Mike Johanns (R-NE).

## The Melville Act Improves the Section 811 program

The reformed Section 811 program will be able to create thousands more units of integrated permanent supportive housing every year by:

- Streamlining the administrative processes for non-profit housing developers;
- Creating a new "Project Rental Assistance Contract (PRAC) only" option within 811 that will allow states to use project-based assistance to integrate supportive housing into larger rental housing developments. (The PRAC ensures affordability by paying the housing operating costs (maintenance, insurance, certain utilities, etc) that are not covered by tenant rents.);
- Allowing 811 capital financing and project-based operating subsidies to be used in multifamily developments; and
- Authorizing a shift of funding for renewal of 811 "mainstream" tenant-based rental assistance out of 811 into the Section 8 account.

## Section 8 Rental Assistance – The Housing Choice Voucher Program

The Section 8 Housing Choice Voucher program bridges 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. An estimated 2.1 million Housing Choice Vouchers have been created by Congress since the program began in the mid-1970s. However, as many as 2.4 million non-elderly adult renter households with disabilities are currently paying more than 50 percent of their income for housing and/or are living in substandard housing. Hundreds of thousands of other individuals with disabilities are living unnecessarily in institutional settings or are at-risk of institutionalization because they live at home with aging parents. These individuals need a Housing Choice Voucher to afford safe, decent housing of their own in the community.

## The National Affordable Housing Trust Fund Act

This 2008 law was enacted to develop 1.5 million new units of rental housing affordable to very low-income and extremely low-income households. It creates the first new federal housing production program specifically targeted to extremely low income households since the Section 8 Housing Choice Voucher program was created in 1974. It has not yet received any appropriations.

### *Action Taken by Congress and the Administration*

No bills have been introduced and no hearings have been held.

### *Recommendations*

- Support the full implementation of the Frank Melville Supportive Housing Investment Act which reforms the HUD Section 811 Supportive Housing for Persons with Disabilities program. Provide at least level funding of \$300 million for the FY 2012 Section 811 program, which will create as many as 3,000 new supportive housing units – triple the number created during the last competitive funding round;
- Provide full funding for the Housing Choice Voucher program in FY 2011 to ensure that all Housing Choice Vouchers can be renewed and that no tenants are displaced;
- Provide \$30 million in funding for new Housing Choice Vouchers targeted to non-elderly people with disabilities who are institutionalized or at-risk of institutionalization; and
- Provide \$1 billion for the National Affordable Housing Trust Fund.

### *Relevant Committees*

House & Senate Appropriations Committees  
House Financial Services Committee  
Senate Banking 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.

# Communicating with Congress

Heightened security measures have dramatically increased the time it takes for a letter sent by post to reach a congressional office. More and more, citizens are using e-mails and faxes to communicate their concerns and increasingly elected officials' offices prefer electronic communications for constituent contact. As a general rule, Members of Congress are far more likely to heed your message if you are one of their constituents.

## Purpose of Your Letter:

- State your purpose for writing in the first sentence of the letter.
- If your letter pertains to a specific piece of legislation, identify it. Make sure that you are referencing the correct legislation to the correct body of Congress. House bills are H.R. \_\_\_\_; Senate bills are designated as S. \_\_\_\_.
- Be courteous.
- If appropriate, include personal information about why the issue matters to you.
- Address only one issue in each letter or e-mail.

## Addressing Your Correspondence:

- To a Senator

The Honorable (Full Name)  
United States Senate  
Washington, D.C. 20510  
Dear Senator (Last Name)

- To a Representative

The Honorable (Full Name)  
United States House of Representatives  
Washington, D.C. 20515  
Dear Mr./Mrs./Ms. (Last Name)

Note: When writing to the Chair of a Committee or the Speaker of the House, it is proper to address him/her as:

Dear Mr. Chairman or Madam Chairwoman:  
or Dear Madam Speaker:

## Tips for Phoning Congress

Telephone calls are usually taken by a staff member. Ask to speak with the aide who handles the issue about which you wish to comment.

After identifying yourself as a constituent, tell the aide you would like to leave a brief message, such as: "Please tell Senator/Representative (Name) that I support/oppose (S. \_\_\_\_ or H.R. \_\_\_\_)."

State your reasons for your support or opposition to the bill. Ask for your senators' or representative's position on the bill. You may also request a written response to your telephone call.

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