

Community Living

FACT SHEET



DISABILITY POLICY SEMINAR
— WASHINGTON, DC —

AAIDD | The Arc | AUCD | NACDD | SABA | UCP

Background

Long Term Supports and Services: The federal/state Medicaid program is the major - sometimes the *only* - source of funding for long term supports and services (LTSS) that many people with intellectual and developmental disabilities (I/DD) rely on to live in the community. This effective and cost efficient program is a lifeline for people with I/DD, making it possible for them to live and work among their neighbors.

Many states, however, have long waiting lists for participation in such Medicaid-funded community-based supports and services. Due to medical and technological advances, people have longer life expectancies and often live with aging parents. As the population ages, the need for LTSS will increase for both people with I/DD and their caregivers.

Housing: Medicaid provides essential supports and services, but by law typically cannot pay for a person's rent or mortgage payment. Programs operated by the Department of Housing and Urban Development (HUD) help make housing affordable (through rent subsidies) and help create new affordable, accessible housing. These include HUD's Section 811 Supportive Housing for Persons with Disabilities program and Housing Choice Voucher program. Despite these programs, the need for affordable, accessible housing for people with disabilities is far greater than the availability. Housing is one of the top barriers as states seek to implement *Olmstead* plans, Money Follows the Person grants, and other initiatives to help people with disabilities live in the community.

Key Message to Congress

Congress must preserve Medicaid, Medicare, Social Security, SSI, and other vital programs for people with disabilities.

Key Issues

Medicaid Per Capita Caps: There are proposals to place per capita caps on Medicaid federal spending. Such caps would put pressure on programs to reduce costs by cutting services and threaten states' ability to support or expand community-based options. These proposals could cause substantial conflict between groups with diverse needs which compete for scarce dollars.

Medicaid Block Grant or Flexible State Allotments: A Medicaid block grant will not control health care costs which will continue to rise as people get older, use more health care services, and as the general cost of all health care increases. Block grants or flexible state allotments would only shift costs to the states and increase out of pocket health expenses for individuals.

Medicaid Managed LTSS: The rush to Medicaid managed LTSS continues even though there is little to no evidence that it provides better services to people with I/DD. These efforts are a

fundamental shift in our health and LTSS system from services mostly based on need to services based on a reduced budget.

Affordable Housing: The ongoing effects of deficit reduction and sequestration continue to pressure HUD's affordable housing programs, limiting production of much-needed new affordable housing, and putting existing affordable housing at risk.

LTSS Crisis: Much more needs to be done to address the looming need for an affordable and accessible system of LTSS that complements the Medicaid program. People should not have to become impoverished in order to become eligible to receive needed LTSS.

Recommendations

- Congress must understand that Medicaid is a lifeline to people who have I/DD and their families!
- Congress should protect the individual entitlement to Medicaid and Medicare.
- Congress should reject Medicaid reductions, caps, block grants, or flexible state allotments.
- Congress should address the nation's need for an affordable, accessible system of long term supports and services.
- Congress should provide at least \$252 million for HUD's Section 811 Supportive Housing for Persons with Disabilities program in FY 2016.
- Congress should provide full funding for HUD's Housing Choice Voucher program in FY 2016 to ensure that all Housing Choice Vouchers can be renewed and that no tenants are displaced.
- Members of Congress should join the Bicameral, Bipartisan Assisting Caregivers Today (ACT) Caucus that was created to help bring greater attention to the needs of family caregivers and engage legislators in developing solutions to the LTSS crisis.

Relevant Committees

House and Senate Appropriations Committees
House and Senate Budget Committees
House Ways and Means Committee
House Energy and Commerce Committee
House Financial Services Committee
Senate Finance Committee
Senate Banking Committee

For more information, please contact The Arc at (202) 783-2229, United Cerebral Palsy at (202) 776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABEnation@gmail.com.

3/25/2015



Education

FACT SHEET

AAIDD | The Arc | AUCD | NACDD | SABLE | UCP

Background

The U.S. Congress is considering several bills in the 114th Congress related to education:

Elementary and Secondary Education Act (ESEA) reauthorization: ESEA governs general education, where most students with disabilities spend most of their time. This law requires that all students in public schools participate in the statewide assessment program. Tests are provided for specific grades in reading, mathematics, and science. Taking these assessments means that schools are supposed to teach the children to grade level and provide the services and supports they need to achieve at grade level. The vast majority of students with disabilities, with the appropriate supports, can make grade level progress.

The Higher Education Act (HEA) reauthorization: The HEA provides loans, services, and supports to students in postsecondary education. The most recent HEA in 2008 authorized the Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) programs, the first program of its kind. Great strides are being made with TPSID programs with the majority of participants from these programs earning jobs in competitive, integrated workplaces.

The Keeping All Students Safe Act: The legislation would allow the use of restraint and seclusion only in emergency circumstances, require parental notification and training of school personnel, and promote school-wide strategies to improve school climate. Rep. Don Beyer (D-VA), with Rep. Bobby Scott (D-VA), recently re-introduced the "Keeping All Students Safe Act" (H.R. 927). To date, there is no companion bill in the Senate.

Key Issues

Assessments: A very small percentage of students with the most significant cognitive disabilities are unable to participate in the general assessment, even with accommodations. Research shows that this small group of students is less than 1% of all students (up to 10% of all students with disabilities). Under current law, there is only a cap for state accountability purposes. No more than 1% of scores for students who take an alternate assessment based on alternate achievement standards (AA- AAS) can be counted as proficient or advanced (known as the "1% cap"). ESEA reauthorization should limit the number of students with the most significant cognitive disabilities who take the AA-AAS to 1% of all students. Participation in AA-AAS often limits access to the general curriculum that is needed to obtain a regular high school diploma.

Parental Notification: In many states, students with disabilities who take an AA-AAS are taken off-track from receiving a regular high-school diploma because they are unable to meet graduation requirements. States often do not provide the necessary guidelines for parents and educators to help in their decision making for determining when it is appropriate for a child to take an AA-AAS.

Postsecondary Educational Opportunities for Students with Intellectual Disabilities: There are still far too few postsecondary options available for youth with disabilities and further efforts are needed to encourage inclusive academic postsecondary programs for students with disabilities. In addition, students with disabilities experience multiple barriers in accessing college and other post-secondary education experiences. Colleges and universities need technical assistance to assist with

recruitment of students with disabilities as well as with providing accommodations to students with all types of disabilities.

Restraint and Seclusion: Restraint and seclusion in schools is often unregulated and used disproportionately on children with disabilities, frequently resulting in injury, trauma, and even death. Federal minimum safety standards are needed to limit the use of restraint and seclusion in schools that receive support from federal education funds.

Recommendations

Congress should:

- Maintain high expectations for students with disabilities in ESEA by ensuring that most students will participate in the general assessments with any needed accommodations.
- Cap the number of students in ESEA who take an alternate assessment based on alternate achievement standards at 1 percent of all students (10% of students with disabilities).
- For the small group of students with the most significant cognitive disabilities who need alternate assessments, ensure they are provided access to the general curriculum; receive the instruction to make steady academic progress; and are not prevented from earning a regular high school diploma.
- Ensure that parents are fully informed about the consequences of their child taking an AA-AAS.
- Ensure that HEA reauthorization includes technical assistance centers focused on post-secondary education programs to recruit and support students with disabilities and ensures that students with disabilities and their families have up-to-date information that supports their search for and participation in postsecondary education. Congress must also strengthen and fully fund the postsecondary programs for students with intellectual and developmental disabilities.
- Congress should pass restraint and seclusion protections.

Relevant Committees:

House Education and the Workforce Committee

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

For more information, please contact The Arc at (202) 783-2229, United Cerebral Palsy at (202) 776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABEnation@gmail.com.

3/25/15

Federal Funding

FACT SHEET



AAIDD | The Arc | AUCD | NACDD | SAGE | UCP

Background

Congress is divided on the fundamental issue of the role and size of the federal government. This is reflected in differing positions on the key issues of the entitlement programs (Medicaid, Medicare, Social Security, and Supplemental Security Income) and the revenue that pays for these programs (individual, corporate, and social insurance taxes).

People with disabilities, their families, and advocates remain extremely concerned about the outlook for federally funded programs. While Medicaid, Medicare, Social Security, and SSI have so far largely been protected from deficit reduction efforts, there are growing calls to cut eligibility and benefits for these essential programs. As the population ages, more demands are placed on these critical programs. Meanwhile, the discretionary programs that people with disabilities also rely on to live in the community (such as employment, education, housing, and more) have been cut in the last several years and continue to face real threats to be cut further.

Key Message to Congress

Congress must preserve Medicaid, Medicare, Social Security, SSI, and other vital programs for people with disabilities.

The President's Budget Request

On February 2, the President sent his Fiscal Year (FY) 2016 Budget Request to Congress, the first step in the annual federal budget and appropriations process. The President's budget request proposes a 7% increase in discretionary spending and provides sizable increases to a few important programs that assist people with disabilities to live, work, and fully participate in our society. However, most disability-related programs were generally level funded, failing to keep pace with inflation. The President's budget request would also do away with the automatic spending cuts (sequester) established under the 2011 deficit law (PL 112-25). To provide these increases and eliminate the sequester, the President's budget request would close tax loopholes and raise revenues on high income earners to help pay for proposals that the Administration believes will help the middle class. The budget would also trim certain discretionary and mandatory programs.

Congressional Budget Resolutions

The House and Senate Budget Committees released their proposals in mid-March. The budget resolutions provide a blueprint for federal spending, taxes, and program priorities for the next decade. The House and Senate FY 2016 Budget Resolutions assume significant cuts to Medicaid, Medicare, and to the discretionary programs that people with disabilities rely on to live in the community.

Key Issues

Entitlement Programs: The Congressional budget proposals threaten critical lifeline programs such as Medicaid, Medicare, Social Security, and Supplemental Security Income. These programs provide vital health, long term supports and services, and income support for people with intellectual and developmental disabilities (I/DD). The FY 2016 House and Senate Budget Resolutions would dramatically cut and restructure the Medicaid program through block grants or “flexible state allotments.”

Discretionary Programs: There are many critical education, employment, housing, developmental disability, and other programs that provide support to people with I/DD that have not seen increases in funding sufficient to meet program needs. Unless Congress ends the automatic spending cuts known as sequestration, funding for these programs will again fail to keep pace with inflation. The Congressional budget proposals would make the cuts even greater. The Senate proposal would flatten non-defense discretionary spending through FY 2025 at essentially the FY 2015 level regardless of inflation or the growth in population, need, or demand.

Revenue: Disability-related programs are funded through taxes. Congress is currently developing proposals to reform the tax code. Many of these proposals seek to reduce taxes which would result in greater deficits and more pressure to cut disability-related programs. The House FY 2016 Budget Resolution would reduce revenue by \$1.5 trillion over 10 years.

Recommendations

- Congress should oppose cuts and structural changes to Medicaid and Medicare and oppose eligibility and benefit cuts to Social Security and SSI.
- Congress should increase funding for critical education, employment, housing, developmental disability programs, and other programs that support people with developmental disabilities.
- Congress should cancel sequestration.
- Congress should raise sufficient revenues to help reduce the deficit and finance the federal government’s role in providing essential supports, services, and benefits for people with disabilities and their families.

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 at (202) 783-2229, United Cerebral Palsy at (202) 776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABEnation@gmail.com.

March 25, 2015

Health Care

FACT SHEET



DISABILITY POLICY SEMINAR
— WASHINGTON, DC —

AAIDD | The Arc | AUCD | NACDD | SAGE | UCP

Background

Our nation's core health insurance programs - Medicare, Medicaid, the Health Insurance Marketplaces, and Children's Health Insurance Program (CHIP) - all provide crucial health care access for people with disabilities.

Medicaid is the largest and most robust funder of services for people with disabilities, including acute and primary health care and long-term supports and services. Medicaid covers 68 million Americans, including 39 million children and 10 million adults with disabilities. Most Medicaid beneficiaries have very low incomes. It covers a wide range of benefits with strong protections against out-of-pocket costs. Medicaid also provides comprehensive benefits for children with disabilities through the Early and Periodic Screening, Diagnosis, and Treatment coverage which ensures access to early intervention services.

The Children's Health Insurance Program (CHIP) provides health care coverage for 8 million children from families with low to moderate incomes who earn above Medicaid eligibility limits. Generally, it provides more robust benefits for children with disabilities than private insurance. It is estimated that over a third of children with special health care needs depend on Medicaid or CHIP for some or all of their health care coverage.

Medicare provides coverage for 54 million Americans, including 8 million younger adults with disabilities. About 9 million people in the United States are covered by both Medicare and Medicaid, including low-income seniors and younger people with disabilities. These dually eligible beneficiaries have complex and often costly health care needs. These beneficiaries have been the focus of many recent initiatives to improve care coordination aimed at both raising the quality of their care while reducing costs.

The Affordable Care Act (ACA) expanded coverage and reformed insurance to end discrimination against people with disabilities and enhance access to health care. The private health insurance marketplaces allow individuals or small businesses to shop for coverage and potentially receive subsidies to help offset the cost of insurance. It expanded Medicaid and increased incentives to provide home and community-based services. It reformed insurance by ensuring that people with disabilities can access coverage without discrimination, are protected from high premium increases or out-of-pocket costs, and receive coverage of "essential health benefits" including mental health care and rehabilitative/habilitative services and devices.

Key Message to Congress

Congress must preserve Medicaid, Medicare, Social Security, SSI, and other vital programs for people with disabilities.

Key Issues

While partisan disagreements over the Affordable Care Act continue to dominate discussions of health policy, we also expect Congress to take action on Medicaid and CHIP. Funding for the CHIP program expires on September 30, 2015 and Congress must act before that date to ensure its continued operation. As a federal-state program, Congress must act soon to give states time to plan and prepare their budgets for the continued operation of the CHIP program.

Medicaid may also be under threat. Cost-cutting proposals that change the fundamental financing structure of the program have resurfaced this year, including block grants, flexible state allotments, and per capita caps. Block grants or flexible state allotments, would provide a lump sum of money to states rather than a federal match. Per capita caps are a similar proposal that would provide a fixed amount of money per beneficiary. Both would come with reduced protections for beneficiaries and create a large cost shift to states and beneficiaries. With reduced federal financial participation, states may cut optional services like home and community based services or expensive services like specialty providers, wheelchairs, and other disability-specific needs.

Congress may also consider major changes to the Medicare program. Recent proposals to reform Medicare have decreased short term health care expenditures by cost shifting to beneficiaries or decreasing benefits. Of particular concern to people with disabilities are proposals to limit access to rehabilitation services.

Recommendations

- Congress should reauthorize the Children's Health Insurance Program (CHIP) and maintain or enhance current benefits.
- Congress should oppose full or partial repeal of the ACA.
- Congress should provide adequate funding for ACA programs
- Congress should support the Medicaid program and oppose proposals to change the financial structure of the Medicaid program, like block grants, flexible state allotments, or per-capita caps on funding.
- Congress should support the Medicare program and oppose structural changes that would impede access to critical Medicare services, devices and medications.

Relevant Committees

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

For more information, please contact The Arc at (202) 783-2229, United Cerebral Palsy at (202) 776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABEnation@gmail.com.

3/25/2015

Social Security

FACT SHEET



DISABILITY POLICY SEMINAR
— WASHINGTON, DC —

AAIDD | The Arc | AUCD | NACDD | SABA | UCP

Background

Social Security insures nearly all Americans and provides benefits to nearly 56 million individuals, including over 12 million people with disabilities, their spouses, and children. Social Security is an interrelated system built up over many decades, so even small changes may affect everyone.

Social Security Old Age and Survivors Insurance (OASI) and Disability Insurance (DI) insure workers against poverty in retirement or when disability may limit the ability to work, and provide life insurance for workers' survivors. Additionally, spouses and children may receive benefits based on the earnings record of a parent or spouse. People with disabilities and their families access benefits under all parts of the Social Security system, and all parts of the system are important to people with disabilities.

Social Security benefits are paid from two Trust Funds (one for OASI and one for DI), which are funded with payroll contributions (FICA taxes) paid by employees and employers.

Supplemental Security Income (SSI) is a cash assistance program operated by the Social Security Administration that provides benefits to people who are aged, blind, or have disabilities and have very low income and assets. Over 8 million people receive SSI. Funding for SSI comes from general revenues.

Key Issues

People with disabilities and their families have an enormous interest in any proposed Social Security or SSI changes. These issues are bipartisan. All policymakers must address the concerns of people with disabilities and their families.

Future Challenges for the Trust Funds: By law, Social Security's Trust Funds must be able to pay benefits for at least the next 75 years. Social Security is currently running a planned surplus to address the retirement and disability needs of the baby boom generation. At the end of 2013 the Trust Funds had reserves of about \$2.7 trillion, which are expected to grow to \$2.9 trillion by the end of 2020. Social Security's Trustees project that, without any changes, the combined Trust Funds can pay full scheduled benefits until 2033, and would then cover about 77 percent of scheduled benefits.

Key Message to Congress

Congress must preserve Medicaid, Medicare, Social Security, SSI, and other vital programs for people with disabilities.

Congressional Action Needed by 2016 to Prevent a 20% Cut in Social Security Disability Insurance (SSDI): On its own, the DI Trust Fund is projected to be able to pay full scheduled benefits through the end of 2016. After 2016, the DI fund's reserves are projected to be depleted, and SSDI would only be able to pay about 80 percent of scheduled benefits, based on money coming into the system. Social Security's actuaries estimate that temporarily raising the share of FICA taxes going to the DI Trust Fund would enable both funds to pay full scheduled benefits through 2033. This process, called "reallocation," can only happen if Congress acts. Congress has authorized this kind of shift 11 times in the past, about equally from one Trust Fund to the other, and has always done so in a bipartisan manner.

Cuts to Social Security and SSI on the Table: Unfortunately, many cuts to Social Security and SSI benefits and/or eligibility proposed in recent years by Members of Congress continue to be on the table. Most recently, this includes several bills that would cut SSDI for people who also receive Unemployment Insurance (UI). Currently, individuals may receive benefits from both UI and SSDI because they receive SSDI, have attempted to work, but lost their job through no fault of their own and as a result also qualify for UI. These proposals single out SSDI beneficiaries and treat them differently from all other workers under the UI program, create disincentives to work, and erode the economic security of SSDI beneficiaries and their families.

Improvements Needed: Many parts of the SSI and Social Security disability systems need to be strengthened to better meet the needs of people with disabilities. These include: increasing the substantial gainful activity (SGA) level for people with disabilities (currently \$1,090 per month) to the level for people who are blind (currently \$1,820 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; improving work incentives; and addressing policy issues which have a harsh impact on people eligible for Title II benefits as disabled adult children.

Recommendations

- Congress should promptly reallocate Social Security payroll taxes to prevent a 20 percent across-the-board cut in SSDI benefits at the end of 2016 and to ensure that SSDI can pay full scheduled benefits through 2033. Congress should reject proposals to do a short-term patch or to include cuts to benefits or eligibility along with reallocation.
- Congress should consider Social Security and SSI outside of deficit reduction and should reject benefit cuts, including cuts to concurrent SSDI and UI benefits.
- Congress should request a beneficiary impact statement on any proposal to change Social Security, to look beyond budgetary issues to the impact on people's daily lives.
- 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 at (202) 783-2229, United Cerebral Palsy at (202) 776-0406, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, or Self-Advocates Becoming Empowered at SABENation@gmail.com

March 25, 2015