

Washington Update

For people with intellectual and developmental disabilities



Presentation Outline

- Background & Context
- What is Happening Now
 - Medicaid
 - Affordable Care Act
 - Social Security & Supplemental Security Income (SSI)
 - Budget & Appropriations
 - CRPD & ABLE Act
- Looking Ahead & New Champions

Public Policy

- Policy and Positions Committee of the Board of Directors
 - Public Policy Agenda
 - Legislative agenda, regulatory/administrative goals
 - Legal Advocacy
 - Participation in amicus ("friend of the court") briefs
 - Guided by mission and core values of The Arc
 - Develops/ revises the position statements

The Arc's Public Policy Team

- Annie Acosta, Policy Advocate
- Maureen Fitzgerald, Director, Disability Rights
- Marty Ford, Senior Executive Officer, Public Policy
- T.J. Sutcliffe, Policy Advocate
- Julie Ward, Director, Health Policy

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History & Context: Observations

Public Policy Development – How things Get Done:

- Gone are the days: Bipartisan, bi-cameral,
 Administration, and advocates together but we can always try
- Major change vs. incremental change
- Clear-cut, first-time efforts vs. nuanced improvements
- Coalitions, coalitions, coalitions
- Where are the Congressional champions?

Where are We Now? Reauthorizations stalled

- Workforce Investment Act (WIA) / Rehabilitation Act (1998)
- Developmental Disabilities Act (2000)
- Elementary and Secondary Education Act (2002)
- Individuals with Disabilities Education Act (2004)
- Temporary Assistance for Needy Families (2005)
- Supplemental Nutrition Assistance Program (2008)

Where are We Now? Looming Threats

- Medicaid
 - Severe cuts
 - Per Person Caps
- Social Security & SSI
 - Risk of cuts as part of deficit reduction, tax reform, entitlement reform
- ADA
 - Notification bills
 - Restrict DOJ's enforcement authority
 - Allow opt out of class

Medicaid – LTSS

- States moving to managed Long Term
 Services and Supports for I/DD
 - Kansas Jan 1, 2014
 - NY 1915(b)(c) People First Waiver pending
 - CA 1915(i) for those not meeting ICF/ID level of care - pending
 - NH 1932(a) I/DD phase II in Jan, 2014

Affordable Care Act (ACA)

- Reforms Insurance Markets
- Expands Coverage
 - Optional Medicaid expansion to 133% of poverty



- Health insurance marketplaces (formerly called exchanges)
 - Enrollment period October 2013-March 2014
 - Federal government, state or partnership models
 - Subsidized private insurance for low and moderate income

Insurance Reforms in 2014

- Can't consider health status when calculating premiums
- Prohibit discrimination based on health status
- Eliminate use of annual limits for all
- Guaranteed issue and renewability
- Pre-existing condition clauses eliminated for adults



ACA Implementation

- Politically divisive law--each state different
- Builds on our complicated health insurance system
- Few resources for implementation
- The Arc emphasis on shaping the regulations
 - Through meetings with officials
 - Comments on regulations and guidance
 - Developing materials
 - Updating Website

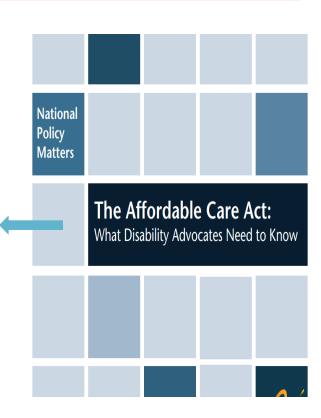
ACA Resources: In-depth analysis

Public Policy

Home ... What We Do ... Public Policy ... Policy Issues ... Health Care Issues

Health Care Issues for People with Disabilities

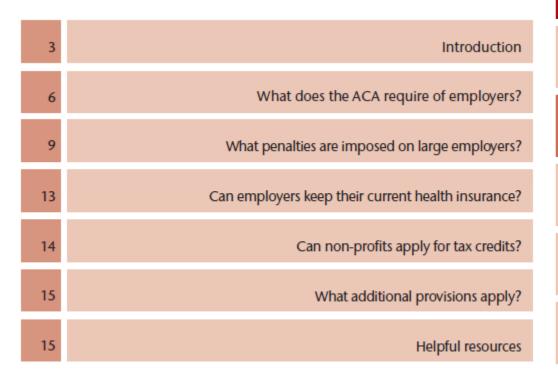
Enactment of health care reform, known as the Affordable Care Act (ACA), is the most significant law for people with disabilities since the enactment of the Americans with Disabilities Act (ADA) in 1990. It will bring about comprehensive reforms that will benefit Americans with disabilities by prohibiting discrimination based on health status and improving access to care. Read The Arc's in-depth guide for advocates on the ACA, and read a one page summary of the guide for a shorter version. Watch the video below to learn about how the ACA works and how it will benefit all groups.

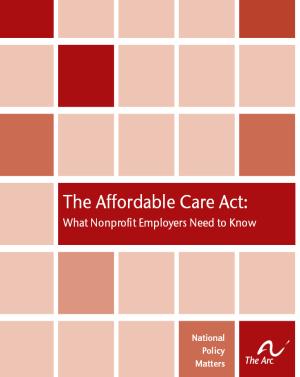


ACA Resources: Impact on nonprofit employers









HHS Resources

- For individuals needing health insurance
 - https://www.healthcare.gov/
- For chapters wanting educational and training resources
 - http://marketplace.cms.gov/

HHS Resources, continued

 http://marketplace.cms.gov/getofficialresour ces/widgets-and-badges/mp-badgesenglish.html



Learn about the Health Insurance Marketplace & your new coverage options. ▶

Social Security & SSI – Under Attack

- Social Security is no longer the Third Rail
- Attempts to include in deficit reduction, tax reform, entitlement reform
- Many attacks on Social Security disability programs
- Skewed media coverage
- Timing is bad



Specific Proposals

- Specific Congressional proposals to cut Social Security and SSI include:
 - Chained CPI: Reducing annual cost-of-living increases
 - Raising the Social Security retirement age
 - Changing the definition of "disability" / eligibility
 - Time limiting benefits
 - Block granting SSI
 - SSI "family maximum" and/or sliding scale



SSDI & SSI: Trends & Challenges

- Social Security Trust Fund solvency
- Social Security disability program growth
- Adequate funding for program administration
- Stronger work incentives and opportunities
- Program enhancements
 - SSI Restoration Act (H.R. 1601)
 - COLA enhancement legislation

Social Security Trust Fund Solvency

- Social Security OASI and DI Trust Funds:
 - By law must be considered over a 75 year period
 - Large surpluses, currently
 - Can pay full scheduled benefits through 2033
- However, DI Trust Fund, by itself: 2016
- Solutions that in the past were often routine today bring risk of attacks:
 - Trust Fund reallocation, and/or
 - Revenue enhancements

Social Security Disability Program Growth

- Largely due to:
 - SSDI Demographics
 - SSI Population growth, rising poverty
- Projected for many years
- Expected to slow
- Costs are manageable and can be addressed through simple solutions

SSDI Growth

Mostly, demographics:

- Growing labor force
- Boomers entering high disability years
- Dramatic rise in work among women
- Additionally:
 - Increase in the Social Security full retirement age
 - Economic factors (<5%)
 - Other: women's incidence, less forgiving workplace, declines in health insurance coverage,

The Arc's Response

Advocacy to:

- Preserve benefits for current and future beneficiaries
- Keep Social Security and SSI out of deficit reduction efforts
- Maintain the basic structure of Social Security and SSI
- Support adequate administrative funding and program enhancements for people with disabilities



The Arc's Peter Berns speaks out in Washington to protect Social Security from cuts in budget negotiations. At left, Sen. Sheldon Whitehouse (D-RI).

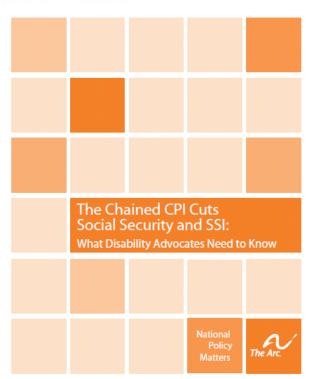
Social Security & SSI Resources



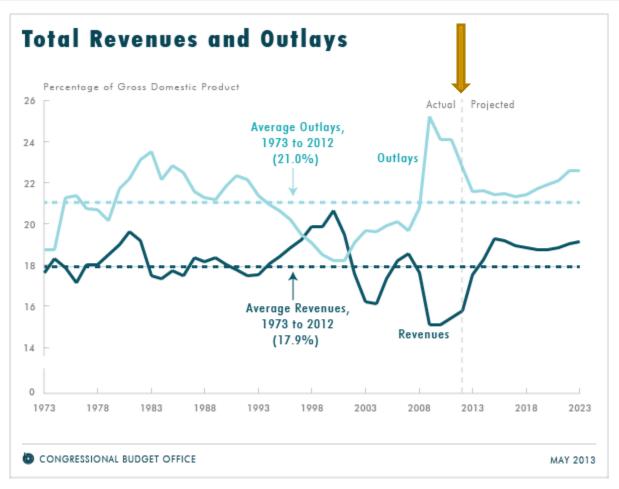


The Chained CPI Cuts Social Security and SSI: What Advocates Need to Know

With Congress gearing up for more "fiscal cliff" battles this year, The Arc is concerned about threats to Social Security and Supplemental Security Income (SSI). These lifelines provide essential financial security for millions of Americans, including people with intellectual and developmental disabilities (I/DD).



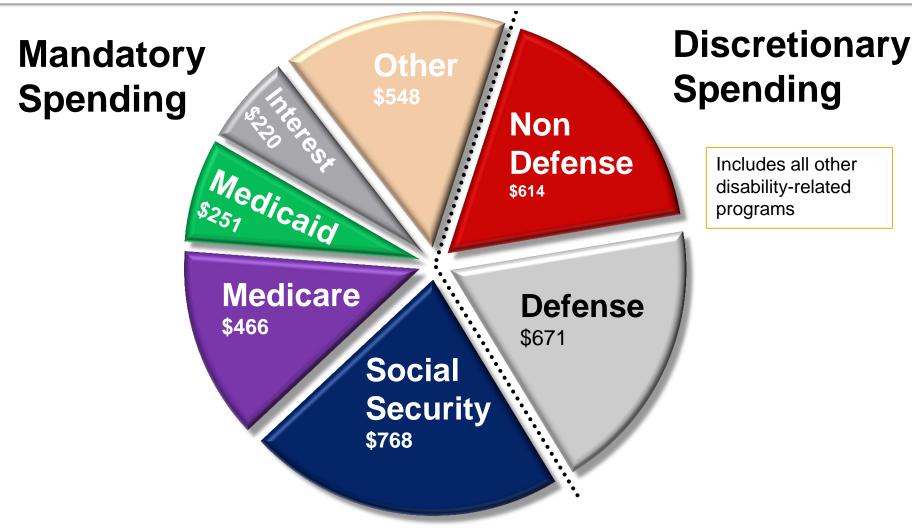
Federal Budget – The Big Picture



- Deficits the difference between revenues and outlays - shrink in the short term but increase again in long term.
- Long term deficits to increase due to:
 - aging population
 - rising health care costs
 - growing interest payments on federal debt

Outlays (What We Spend)

In FY 2012 = \$3.537 Trillion (shown in billions)



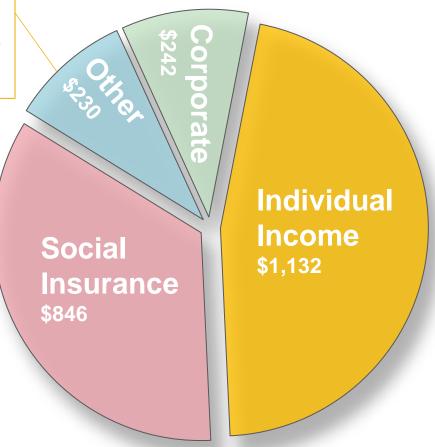
Source: Fiscal Year 2014 Budget of the U.S. Government

Revenue (What We Bring In) In FY 2012 = \$2.45 Trillion (shown in billions)

Other:

- Deposits of earnings, Federal Reserve - \$82

- Excise -\$79
- Customs Duties -\$30
- Estate & Gift -\$14
- Miscellaneous -\$25



The Federal Budget - Political Dynamics

- Fundamental disagreements about the size and role of government.
- Stark partisan differences:

On Spending (outlays)

House

- Medicaid Block grants and cut by \$810 billion
- Discretionary \$3.8 trillion cut beyond the across-the-board cuts

Senate

- Medicaid No structural changes and cut by \$10 billion
- Discretionary Replaces acrossthe-board spending cuts with \$493 billion with targeted spending cuts

On Revenue

No increases

 \$975 billion in increases for highest income earners and corporations

Timeline of Events



- Mar 1 Across-the-board spending cuts ("sequestration") took
 effect for FY 2013
- Sept? Continuing resolution for 2014?
 (House & Senate spending plans are currently \$91 billion apart)
- Oct 1 Start of FY 2014
 - Government shutdown?

Fall • Tax Reform?

- "Grand Bargain" deal to cut spending and raise revenue?
- Need to raise debt ceiling

Our Position on Spending and Revenue



- Federal and state government provides critical services and supports to live in the community.
- Longstanding position of The Arc's to:
 - Protect the safety net
 - Raise revenues when needed
- \$ 2.5 trillion in deficit reduction has already been enacted:
 - For every \$1 dollar in new revenue, \$2.50 has been cut from spending:
 - \$1.5 trillion in spending cuts
 - \$0.6 trillion in revenue
 - \$0.4 trillion in interest payments on the debt
- We need a balanced approach to deficit reduction
- If revenue is not part of discussion, cuts will devastate programs

Bipartisan bills in play

- Convention on the Rights of Persons with Disabilities
 - Opposition overwhelming supporters
- Achieving a Better Life Experience (ABLE)
 Act, H.R. 647, S.313
 - Would help people with disabilities and their families save to meet their long term ongoing support needs
 - Special accounts would not affect SSI or Medicaid eligibility
 - Treated as 1st-party funds subject to Medicaid payback at death

Looking Ahead: What's Next? What Should Be Done?

- Don't get discouraged by current issues focus on the big picture – work together at the local, state, and national levels
- People with disabilities stand to lose a lot if we are not vigilant – but, remember how far we have come
- Respond to alerts and appeals
- Disability Policy Seminar April 6-9, 2014

The Arc, AAIDD, AUCD, NACDD, SABE, UCP

Looking Ahead: Goals and Champions

- Shared Public Policy Agenda The Arc,
 AAIDD, AUCD, NACDD, ANCOR, UCP
- Shared Position Statements –The Arc & AAIDD

- Need to work together to cultivate new champions
- Members of Congress and staff
 - Family members
 - Good experiences

Looking Ahead: Find and Cultivate Congressional Champions

- Email and social media are not enough!
- Meet with Congressional delegations and staff at home – August recess ends Sept. 9
- Attend events get to know Members and staff – let them get to know you
- Keep them up to date on your issues
- As they rise in Leadership or move on to other policy positions, stay in touch
- Mentor young colleagues, staff, families

SAVE THE DATE

2014 Disability Policy Seminar

April 6-9, 2014 Grand Hyatt Washington

2015 Disability Policy Seminar - New Location

April 13-15, 2015 Renaissance Washington DC