

Social Security and SSI for People with I/DD and Their Families

National
Policy
Matters



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Introduction

Social Security, Supplemental Security Income (SSI), and related health insurance under Medicare and Medicaid provide lifelines for people with intellectual and developmental disabilities (I/DD) and their families.

This edition of National Policy Matters explores how these systems operate, the vital support they provide, and current policy proposals that may impact people with I/DD and their families.

Social Security and SSI: Overview

What is Social Security?

In the [words](#) of President Franklin Delano Roosevelt, our nation's Social Security system was created to provide for **“security of the men, women, and children of the Nation against certain hazards and vicissitudes of life.”** To accomplish this, Social Security provides income insurance that protects workers, their dependents, and survivors from extreme poverty when a worker retires, dies, or loses the ability to engage in substantial work due to a significant disability. Over [58 million](#) people, or 1 in 5 Americans, receive Social Security Old-Age, Survivors, or Disability Insurance (OASDI) benefits.

Social Security is an earned benefit, paid for by workers and their employers. Payroll contributions go into two dedicated trust funds: an Old-Age and Survivors Insurance Trust Fund, and a Disability Insurance Trust Fund. Benefits can be paid out of incoming payroll taxes, fund reserves, and interest earned on fund reserves.

People pay into Social Security during their working years, and generally become fully insured under the system after about 10 years (less for younger workers). Benefits are based on workers' average

earnings during their years of work. For workers with mid-range earnings, Social Security benefits replace about [40 percent](#) of career earnings in retirement, and about [40 to 45 percent](#) of career earnings in the event of a qualifying disability.

Why is Social Security necessary?

Social Security provides insurance that most American workers cannot get from another source. Social Security insures [over 211 million Americans](#), or nearly all U.S. workers, in the event of retirement,



President Franklin Delano Roosevelt signs the Social Security Act of 1935.

Over 9 in 10 U.S. workers are insured for retirement, death, and disability.

Social Security



4 in 10 civilian workers have no employer-based life insurance.

Private Life Insurance



1 in 2 workers have no employer-based pension.

Private Pensions



7 in 10 civilian workers have no employer-based long-term disability insurance.

Private Disability Insurance



Sources: *Social Security Administration and Bureau of Labor Statistics.*

death, or a qualifying disability. Access to these types of insurance in the private sector is far less widespread, and for many workers has declined over the last several decades.

Additionally, most American families have limited savings to sustain them in retirement or to fall back on if a worker dies or experiences a significant disability. Only about [half of families have a retirement account](#), and only about [half of families were able to save](#) in the last year. The majority of people in the U.S. have [no rainy day funds](#) set aside, and people with disabilities often have even less to fall back on, with 8 in 10 reporting that they have no rainy day funds.

What is Supplemental Security Income (SSI)?

Congress created SSI in 1972 to provide basic income support for low-income seniors and people with significant disabilities, to protect against extreme poverty and help recipients meet basic needs.

SSI is reserved for people with very low income and very limited assets (e.g., can have savings of no more than \$2,000 for an individual or \$3,000 for a couple). Unlike Social Security, SSI has no

requirement for a prior work history or prior contributions. As described below, payments are extremely modest, averaging less than \$600 per month for non-elderly adults.

SSI is funded by general federal revenues and administered by the federal government. Forty-four states and the District of Columbia also offer a monthly [state-funded payment](#) that supplements the federal SSI benefit.

Over [8 million](#) people receive SSI.

What health insurance is associated with Social Security and SSI?

Eligibility for Social Security is associated with health insurance under [Medicare](#); eligibility for SSI is associated with health insurance under [Medicaid](#).

Like Social Security, Medicare is an earned benefit with no income or asset limits, administered by the federal government. Social Security beneficiaries who are over age 65 or who qualify for Social Security on the basis of a disability are eligible. People who qualify for Social Security on the basis of a disability typically must wait 24 months to become eligible for Medicare. Medicare provides inpatient care (“Part

A”) as well as voluntary options for outpatient care coverage (“Part B”), prescription drug coverage (“Part D”), and for delivery of Medicare by managed care contractors (“Part C” or Medicare Advantage).

Medicaid is generally reserved for people with very low income. States administer Medicaid using funding from both the federal government and the state. In most states, people who qualify for SSI automatically qualify for Medicaid; [10 states](#) use at least one eligibility criterion that is more restrictive than SSI. Medicaid mandates coverage of a core set of services for all beneficiaries and gives states

the option to cover a range of additional services. Many optional services—such as physical therapy, speech and language therapy, occupational therapy, prescription drugs, prosthetic devices, habilitation and rehabilitation services, personal care services, and home and community-based services—are critical for people with I/DD and their families. Under the [Affordable Care Act](#), states have the option to [expand Medicaid](#); currently, 30 states including the District of Columbia have done so.

How do people with I/DD and their families access Social Security and SSI?

All parts of Social Security—retirement, survivors, and disability benefits—as well as SSI are important to people with I/DD and their families.

Key Benefits for People with I/DD and Their Families

Age	Social Security and/or SSI Benefit
Children with I/DD	<ul style="list-style-type: none"> • Social Security family or “ancillary” benefit for children and spouses • Social Security Survivor’s benefit • Social Security benefit for spouses and widow(er)s caring for a child beneficiary • Social Security received by a relative living in the same household • SSI childhood disability benefit
Adults with I/DD	<ul style="list-style-type: none"> • Social Security Disability Insurance • Social Security Disabled Adult Child benefit • Social Security family or “ancillary” benefit • Social Security benefit for disabled widow(er)s • Social Security received by a family caregiver • SSI disabled adult benefit
Seniors with I/DD	<ul style="list-style-type: none"> • Social Security retirement benefit • SSI seniors’ benefit

Like all Americans, people with I/DD and their families may need to access different benefits at different times in their lives. For example:

- After the death of a parent, Social Security Survivors' Insurance may provide essential income for a parent caring for a child with I/DD by providing benefits to both the widow(er) and child.
- An adult with I/DD may work for many years, paying into and becoming insured for Social Security. If that worker acquires an additional, significant disability that prevents substantial work, he or she may become eligible for Social Security disability benefits.
- As a senior, an insured worker with I/DD will receive Social Security retirement benefits.

Additionally, Social Security and SSI can play a critical role in assisting families to support a child or adult with I/DD. While many people with I/DD live independently, according to "[The State of the States in Intellectual and Developmental Disabilities, 2015](#)" over 3.5 million families across the United States provide care for a child or adult with I/DD, including over 860,000 people with I/DD who live with a caregiver age 60 or older. Income from Social Security or SSI can be essential to helping families meet some of the costs of caring for a child with I/DD, and can also be a vital tool for future planning for families with aging caregivers.

Key parts of Social Security and SSI for people with I/DD include the following.

■ **Social Security and SSI benefits for seniors**

Like other retirees, many seniors with I/DD worked during their adult years and now receive Social Security retirement benefits, paid out of the Social Security Old-Age Insurance (OASI) Trust Fund. They qualify because they have worked in Social Security covered jobs for long enough (generally, 10 years) and have reached their Social Security "early retirement age" of 62 or their "full retirement age,"

which is [66 for today's retirees](#). Nearly [40 million retirees](#) receive Social Security retirement benefits. Additionally, many seniors with I/DD receive Social Security retirement benefits because they previously received Social Security Disability Insurance (SSDI). SSDI beneficiaries who reach their full retirement age begin receiving Social Security retirement benefits paid out of the OASI fund. In 2013, nearly [500,000 SSDI beneficiaries](#) reached their full retirement age and converted to Social Security retirement benefits.

Seniors with I/DD who have very low incomes and assets may also receive SSI. Nearly [1.2 million SSI beneficiaries](#) age 65 or older also receive a low Social Security benefit. Additionally, [over 900,000 seniors](#) receive SSI only and do not qualify for Social Security.

■ **Social Security and SSI disability benefits for adults**

Many non-elderly adults with I/DD qualify for Social Security, SSI, or both due to a disability. Eligible adults must meet the Social Security Act's disability standard—one of the most stringent standards in the developed world. They must have a medically determinable physical or mental impairment that is expected to last at least one year or result in death, and that prevents them from engaging in "substantial gainful activity" (SGA), defined as earnings at or above the [SGA level](#) (\$1,090 per month for non-blind individuals, in 2015). An individual must be unable to perform SGA at any job in the national economy, given a person's age and education. The application process requires extensive medical evidence and can take months and often years to complete. Fewer than 4 in 10 applicants for [SSDI](#) or [SSI](#) are awarded benefits, after all appeals.

To qualify for SSDI, workers who meet the Social Security Act's strict disability standard also must have worked in Social Security covered jobs for long enough and recently enough. Generally, a person must have worked for a quarter of their adult life and for 5 out of the last 10 years; younger workers can qualify with a less extensive work history. Qualified workers must also be below their full Social Security retirement age.

Beneficiaries with Disabilities: Snapshot

Social Security:

Over 59 million beneficiaries, including:

- ◆ Over [10 million](#) beneficiaries who qualify due to a disability:
 - Nearly 9 million workers with disabilities
 - 258,000 widow(er)s with disabilities
 - 1 million people who receive [Disabled Adult Child](#) benefits
- ◆ About [2 million](#) children and spouses of workers with disabilities

SSI:

Over 8 million beneficiaries, including:

- ◆ 1.3 million children with disabilities under age 18
- ◆ 4.9 million adults with disabilities age 18 to 64
- ◆ 2.1 million seniors age 65 and older

Medicaid:

Over 68 million enrollees, including:

- ◆ 9.8 million adults with disabilities

Medicare:

Nearly 51 million enrollees, including:

- ◆ [8.6 million](#) adults with disabilities

To qualify for SSI, adults who meet the Social Security Act's strict disability standard must also have very low income and assets, as discussed above. Many individuals with I/DD start out receiving SSI benefits but over the years build up enough work history to qualify for Social Security disability and/or retirement benefits based on their earnings and payroll contributions.

In some cases, adults with disabilities may receive both SSI and Social Security benefits because they qualify for a very low Social Security benefit that falls under the [SSI federal payment amount](#), and also have very limited resources that fall under the SSI asset limits.

Currently, over [10 million people](#) qualify for Social Security on the basis of a disability, including over 850,000 adults who qualify on the basis of intellectual disability. Many Social Security beneficiaries have developmental disabilities, but the exact number is unknown. The Social Security Administration reports on broad categories of qualifying disabilities, but not on the presence of a developmental disability. Additionally, because the agency only reports one impairment per beneficiary, individuals who have I/DD and multiple impairments may be reported as having other disabilities (see box at end for more information).

Additionally, [4.9 million](#) adults age 18 to 64 receive SSI on the basis of a disability. This includes over [930,000 individuals](#) who qualify due to intellectual disability, or nearly 1 in 5 non-elderly adult beneficiaries.

About [1.6 million](#) adults age 18 to 64 receive both Social Security and SSI on the basis of a disability.

■ **Social Security benefits for spouses and children**

Many people with I/DD and their families receive Social Security benefits based on the earnings record of a parent or spouse who is deceased ("survivors' benefits") or who is receiving Social Security retirement or disability benefits. Benefits are up to 50 to 75 percent of the worker's full benefit; if several individuals receive these family or "ancillary" benefits, total benefits are subject to a [family maximum](#) that is generally 150 to 180 percent of the worker's full benefit.

Children of retired, disabled, or deceased workers may also receive benefits if they are a minor child under the age of 18, a high school student under the age of 19, or an adult who qualifies as a Disabled Adult Child (described below). Currently, about [4.3 million individuals](#) receive these benefits.

Additionally, about [3.4 million minor children](#) live with a relative who receives Social Security benefits, a group that is likely to include many children with I/DD.

Spouses of retired or disabled workers may receive benefits if they are over age 62 or caring for a child entitled to a Social Security child's benefit, as described above. Surviving spouses of a deceased worker may also qualify for benefits if they are over age 60, are over age 50 and have a disability that meets the Social Security disability standard, or are caring for a child entitled to a Social Security child's benefit. Benefits for parents caring for children and adults with disabilities can be a critical source of support for many family caregivers of people with I/DD.

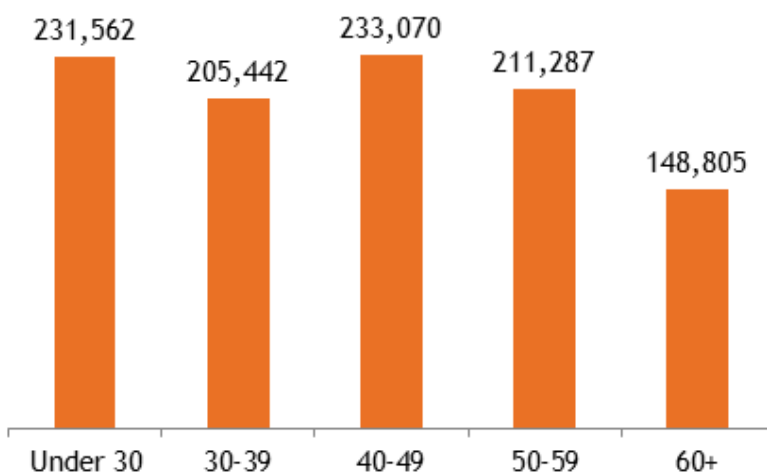
Currently, about [6.7 million people](#) receive some type of spousal or widow(er)s' benefits. This includes [nearly 110,000 spouses](#) caring for children.

■ Social Security Disabled Adult Child benefits

Social Security's Disabled Adult Child (DAC) benefit is particularly important to many people with I/DD. The DAC benefit assists many people with I/DD to live independently, and can be a critical source of support for families caring for an adult child with I/DD.

Although only adults can qualify for DAC benefits, the benefit is considered to be a type of Social Security child's benefit because it is paid based on the earnings record of a parent. To qualify a person must be age 18 or older, be unmarried (or married to another Social Security beneficiary), and have a disability that started before age 22 and meets the definition of disability under the Social Security Act (described above).

Age, Social Security DAC Beneficiaries, Dec. 2013



■ SSI childhood disability benefits

SSI's childhood disability program provides a critical source of support for many families raising children with I/DD. To qualify, a child must have a medically determinable physical or mental impairment that

results in marked and severe functional limitations and must live in a household with very low income and less than \$3,000 in assets. The overwhelming majority of children with disabilities do not qualify for SSI, either because they do not meet this stringent disability standard, or because their families do not

meet the financial eligibility criteria. Only about [4 in 10 applicants](#) are approved, after all appeals.

Currently, about [1.3 million children](#) under age 18 receive SSI. [Over 120,000 or about 1 in 10](#) qualified due to intellectual disability. Many are also likely to have a developmental disability, having qualified on the basis of disabilities such as intellectual disability (9 percent), developmental disorders (21 percent), autistic disorders (10 percent), and congenital anomalies (5.5 percent).*

*Note: Terms reflect diagnostic categories reported by the Social Security Administration.

How are Social Security and SSI lifelines for people with I/DD?

Social Security and SSI benefits are extremely modest, but can play an essential role in alleviating poverty and hardship—helping children and adults with I/DD preserve a basic living standard and providing access to essential health care and long-term services and supports.

■ Vital Income Support

People with I/DD often use their benefits to pay for everyday necessities such as food, housing, clothing, transportation, out-of-pocket medical costs, and out-of-pocket disability related costs. For many, Social Security or SSI provides the income that allows them to secure housing in the community and live independently. Without Social Security or SSI, many beneficiaries would be at risk of severe hardship such as homelessness, institutionalization, hospitalization, or death.

SSI's childhood disability benefits, Social Security's DAC benefit, and Social Security benefits for survivors and family caregivers can be [essential to helping families](#) raise and support children with I/DD. Benefits can help families pay for basic expenses needed to help a family care for a child with a disability at home, instead of in an institution or other restrictive setting. Benefits can also assist families with meeting the additional costs often associated with raising a child with a disability, such as out-of-pocket costs for

therapies and medical treatments. Benefits can also help replace some of the family income lost when one or both parents must stay home or reduce their hours worked to care for a child with a significant disability.

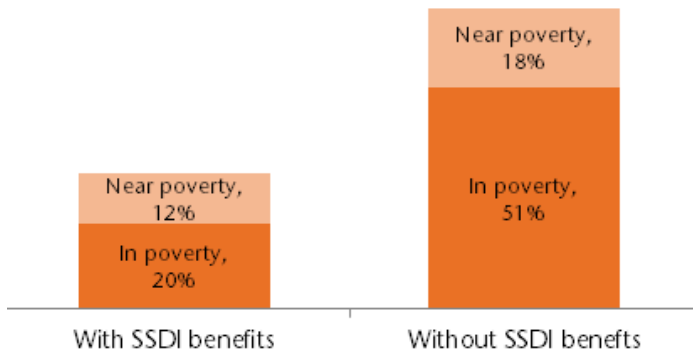
The Social Security and SSI disability programs also include many features designed to encourage beneficiaries to work. Important [work incentives](#) include the SSI benefit offset, the SSDI trial work period and extended period of eligibility, continued Medicare and Medicaid, and expedited reinstatement. The benefits individuals with I/DD receive from Social Security or SSA often provide most or all of their income. SSDI makes up [75% or more of income](#) for 6 in 10 non-institutionalized beneficiaries. One in three non-institutionalized SSI beneficiaries has [no other source of income](#) and must get by on an average benefit of just \$18 per day.

Additionally, Social Security and SSI play an important role in protecting many beneficiaries against extreme poverty. **Research has found that even with SSDI, 1 in 3 beneficiaries lives below or near the Federal Poverty Level (\$11,770 for a single person in 2015), if SSDI were excluded from total household income, fully 7 in 10 beneficiaries would find themselves living in or near poverty.**

Average Benefits for People with Disabilities: Snapshot, December 2014

	Daily	Monthly	Yearly
Social Security			
Disabled worker	\$39	\$1,165	\$13,980
Disabled widow(er)	\$24	\$724	\$8,688
Disabled adult child	\$25	\$751	\$9,012
SSI			
Child	\$21	\$633	\$7,596
Adult age 18-64	\$18	\$551	\$6,612

SSDI Beneficiaries Living in or Near Poverty: With and Without SSDI

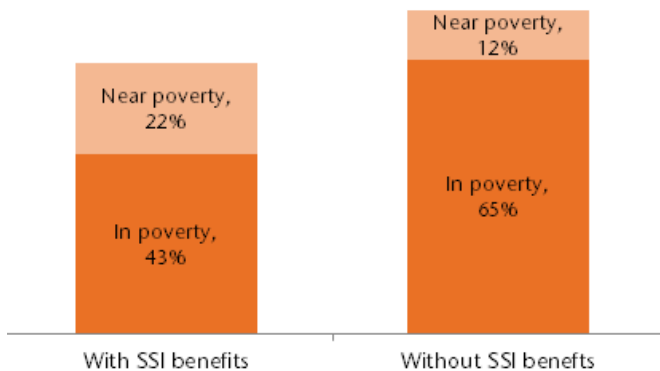


In poverty: Total household income <100% of the Federal Poverty Level (FPL)

Near poverty: Total household income 100% to 150% of FPL

With federal SSI payments set at no more than \$733 per month or \$8,796 per year (in 2015), unsurprisingly research has found that about 2 in 5 SSI beneficiaries live in poverty and 3 in 5 live under 150% of poverty. But if SSI were excluded from total household income, nearly 8 in 10 beneficiaries would live in or near poverty.

SSI Beneficiaries Living in or Near Poverty: With and Without SSI



In poverty: Total household income <100% of the Federal Poverty Level (FPL)

Near poverty: Total household income 100% to 150% of FPL

■ Access to Health Insurance and Long-Term Services and Supports

The health insurance under Medicaid and Medicare, and the long-term services and supports under Medicaid that are associated with Social Security and SSI are often essential for the very survival of many people with I/DD. People with significant disabilities, including people with I/DD, often lack access to employer-based or other private coverage, generally have greater medical needs than people without disabilities, and often require assistance with activities of daily living throughout their lifetimes.

Medicaid and Medicare offer primary sources of health insurance for many people with I/DD and provide needed health care services such as prescription drugs, dental, physical therapy, speech therapy, prosthetic devices, wheelchairs, and other health care services.

Through Medicaid's home and community-based services, many people with I/DD receive assistance with living in the community, as well as help with daily living such as help getting dressed, taking medication, preparing meals, managing money, and getting in and out of bed. Nationwide, state and federal Medicaid together provide over 75% of the funding for services for people with I/DD (see "[State of the States in Developmental Disabilities](#)").

How do Social Security, SSI, Medicare, and Medicaid support future planning for people with I/DD and their families?

Medicaid also supports many families caring for minor and adult children with I/DD by providing these types of in-home supports for the individual, as well as respite services for family caregivers.

Social Security and SSI disability benefits, along with health insurance and supports under Medicare and Medicaid, can be central to future planning for people with I/DD and their families, particularly for adults with I/DD living with aging caregivers. Visit [The Arc's Center for Future Planning](#) to learn more.

An understanding of current and future benefit

eligibility can assist people with I/DD, their parents and siblings to identify the kinds of community living arrangements that are financially sustainable and to secure supports and services to enable an individual to live as independently as possible.

Individuals and families need to consider both the benefits that a person currently qualifies for, as well as potential future eligibility. Examples include individuals who receive SSI and then acquire eligibility for Social Security (and, after 24 months, Medicare) by earning coverage through work, as well as individual who acquire eligibility for Social Security DAC benefits after a parent retires, dies, or begins receiving SSDI.

What current policy proposals for Social Security and SSI do people with I/DD and their families need to know about?

Individuals and families also need to consider the impact of a range of other events on benefits and eligibility, including work, marriage, savings, and living arrangements.

Many policies proposed over the last several years would cut Social Security, SSI, or both. In many cases, proposed cuts could have a disproportionate negative impact on many people with I/DD. A wide variety of proposals have been the subject of significant debate in recent years. Examples include:

- Adoption of the “chained” [Consumer Price Index](#) (chained CPI), which would cut Social Security and SSI benefits by reducing annual benefit cost-of-living increases. Cuts under the chained CPI grow larger with each passing year, and would be particularly harmful for people with disabilities who often rely on benefits for many years;
- Cutting or eliminating SSDI benefits for people who also qualify for [Unemployment Insurance](#) benefits because they have attempted to work but lost their job through no fault of their own;
- Raising Social Security’s retirement age, which would cut Social Security benefits by reducing retired workers’ lifetime benefits—including workers with I/DD who retire—and by reducing benefits for people receiving family benefits from a retired worker, including people receiving DAC benefits; and
- Converting all or part of the federal SSI program into [smaller state block grants](#), an option which, according to the [Congressional Budget Office](#),

“would almost certainly eliminate benefits for some people who would have otherwise received them, as well as significantly reduce the benefits of some people who remained in the programs.”

Additionally, Congress will need to act by the end of 2016 to ensure that Social Security’s Disability Insurance Trust Fund can continue to pay full benefits after 2016. Currently, the Social Security system as a whole is operating large surpluses and is expected to be fully-funded through 2034. However, by itself, the Disability Insurance fund is projected to be fully-funded only through the end of 2016. In or around the last few months of 2016, the Disability Insurance fund’s reserves are projected to become depleted. After that, unless Congress acts, SSDI would only be able to pay about 80 percent of scheduled benefits, based on incoming payroll taxes.

The need to adjust SSDI’s funding by 2016 has been anticipated for several decades, after Congress last passed major legislation on Social Security’s financing

in 1994.

Fortunately, Congress has never failed to act to shore up Social Security’s finances. Traditionally, Congress has addressed these kinds of shortfalls by rebalancing the allocation of existing payroll tax revenues between Social Security’s trust funds. Congress has made this adjustment, called “reallocation,” about 11 times. About half the time, Congress has increased the share of existing payroll taxes going into the retirement fund, and about half the time, Congress has increased the share of existing payroll taxes going into the disability fund.

According to Social Security’s Chief Actuary, a modest, temporary increase in the share of payroll taxes going into the Disability Insurance fund would allow both programs to pay full scheduled benefits through 2034— their current combined full-funding date.

Reallocation does not require raising taxes, and is a routine, [commonsense solution](#).

Do Americans support strengthening Social Security?

Yes. National surveys have repeatedly shown that Americans overwhelmingly support preserving Social Security and strengthening benefits, and oppose benefit cuts. In a [recent survey](#) by the National Academy of Social Insurance (NASI), respondents shared their strong beliefs:

- 85% believe that “Social Security benefits now are more important than ever...”;
- 81% don’t “mind paying Social Security taxes because it provides security and stability to millions of retired Americans, disabled individuals, and the children and widowed spouses of deceased workers”;

- 72% believe that “we should consider increasing Social Security benefits”; and
- 55% believe that the average Social Security disability benefit is too low.

NASI asked people to consider possible policy packages to strengthen Social Security. The packages had different combinations of cutting or increasing benefits and reducing or increasing Social Security’s funding. The most favored package—supported by 7 in 10 respondents—would eliminate Social Security’s long-term financing gap by raising revenues and enhancing benefits, with no benefit cuts.

What is The Arc's response?

The Arc knows that Social Security and SSI—along with health insurance and home and community-based services under Medicare and Medicaid—are lifelines for people with disabilities, including children and adults with I/DD, as well as women, low-income seniors, veterans, and many other Americans.

The Arc strongly opposes cuts to these and other vital supports. Benefits are minimal, and many people cannot afford any cuts in their basic income, which goes to pay for essential housing, food, and medical costs. The Arc knows that the impact of any cuts to benefits or eligibility would be real and painful, and we firmly believe this is not the way to balance the budget.

The Arc also has [many proposals](#) to make Social Security, SSI, Medicare, and Medicaid work better for people with I/DD and their families. These include strengthening benefits, improving opportunities for work and savings, and eliminating marriage penalties.



*DON'T CUT OUR
LIFELINE*

The Arc is working hard to educate policymakers about the importance of Social Security and SSI to people with disabilities, including people with I/DD. We have joined with other national groups and coalitions to urge policymakers to reject cuts to coverage, benefits, or eligibility and to act promptly to strengthen the finances and structure of these lifelines.

Additional Resources:

- [State Fact Sheets: Medicaid, Medicare, Social Security, and SSI are Lifelines](#)
- The Arc's [Center for Future Planning](#)

This edition of National Policy Matters and the associated State Fact Sheets were made possible in part due to a generous grant from AARP Washington.

Who Are People with I/DD?

People with I/DD have intellectual disability, a developmental disability, or both.

People with intellectual disability experience “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.” (*American Association on Intellectual and Developmental Disabilities (AAIDD), Intellectual Disability: Definition, Classification, and Systems of Supports (Schalock et al., 2010) and American Psychiatric Association (2013), Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).*)

People with developmental disabilities experience “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care., (II) Receptive and expressive language., (III) Learning., (IV) Mobility., (V) Self-direction., (VI) Capacity for independent living., (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,”. (*Developmental Disabilities Assistance and Bill of Rights Act of 2000.*)

How Does Social Security Report Data About People with I/DD?

For the Social Security and SSI disability programs, SSA provides statistical reports that use the agency’s own “diagnostic group” categories. SSA reports one diagnosis per person as the “primary” disability, and does not report data on other disabilities that a person may have.

SSA in some, but not all, cases reports data about the number of people who qualify for disability benefits due to a “primary” diagnosis of intellectual disability. SSA does not have a diagnostic group for “developmental disability”. As a result, people with developmental disabilities may be counted under many SSA diagnostic groups. These include categories likely to include many people with developmental disabilities, such as intellectual disability, autistic disorders, congenital anomalies (includes Down syndrome), and developmental disorders. These also include categories likely to include a mix of people with and without developmental disabilities. For example, people who have cerebral palsy may be counted under the “neurological disorders” diagnostic group—a category which also includes many people who acquired neurological disorders as adults (such as, Parkinson’s disease).

Additionally, because SSA only reports one impairment per person, some people with I/DD who have co-occurring disabilities may be reported as having other “primary” disabilities.

Finally, SSA does not track or report on disability for people with I/DD who receive Social Security, SSI, or both for reasons unrelated to their disability—including people who receive Social Security survivors’ benefits, Social Security spousal benefits, Social Security retirement benefits, or SSI benefits for seniors.

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