



*For people with intellectual
and developmental disabilities*

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July 2, 2024

Senator Ron Wyden
Chairman
Senate Committee on Finance
221 Dirksen Senate Office Building
Washington, DC 20510

Senator Mike Crapo
Ranking Member
Senate Committee on Finance
239 Dirksen Senate Office Building
Washington, DC 20510

Via email: Statementsfortherecord@finance.senate.gov

**RE: June 18, 2024 Hearing on “Work and Social Security Disability Benefits:
Addressing Challenges and Creating Opportunities”**

Dear Chairman Wyden and Ranking Member Crapo,

Thank you for holding this hearing on the important topic of barriers to workforce participation for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries.¹

The Arc is the largest national community-based organization advocating for people with intellectual and/or developmental disabilities (IDD) and their families. Our nearly 600 state and local chapters across the United States provide a wide range of services for people with IDD, including individual and systems advocacy, public education, family support, systems navigation, support coordination services, employment, housing, support groups, and recreation. Nearly half of all SSI child beneficiaries and around one in three adults on SSI have an intellectual or developmental disability. As a result, protecting and improving SSI and other Social Security disability benefits has been a longstanding focus of The Arc’s advocacy work.

We often hear from our networks about how outdated rules and administrative burdens for both beneficiaries and employers can limit opportunities for people with disabilities to work. For example, the parent of a disabled person in Texas shared how navigating these requirements pose challenges for employers:

“My adult son received Social Security benefits as a young adult. He has autism. He graduated high school and then community college, but needed these benefits while he tried to get a full-time job.

Social Security's outdated rules made it almost impossible for him to do that. He worked part-time for a small, veteran-owned company for a while, but they let him go after Social Security sent the first batch of paperwork. They felt so badly, but it was just too much of a burden for them.”

Multifaceted approaches are needed to modernize Social Security disability programs to increase opportunities for work, to provide support to help people with disabilities remain attached to the labor force, and to deliver the training, services, and supports that people with disabilities may need to return to work. Our comments will focus on three key issues highlighted in the hearing, including: (1.) restrictions on work-related income faced by Disabled Adult Child (DAC) beneficiaries; (2.) the SSI program’s grievously outdated asset limits, income limits and earned-income disregards; and (3.) the impact of overpayments on both SSI and SSDI beneficiaries. We are grateful for the substantial bipartisan attention and action that members of the Senate Finance Committee have undertaken this Congress to address each of these issues. We also commend the steps that the Social Security Administration (SSA) has taken this year to reduce the burden of overpayments on beneficiaries. Advancing the SSA’s important work in this and other critical activities geared towards improving services for millions of Social Security beneficiaries will require sustained and increased administrative funding in the FY2025 budget.

1. Eliminate Harsh Work Disincentives Impacting Disabled Adult Child (DAC) Beneficiaries

Around 1.1 million Americans with disabilities rely on “Disabled Adult Child” (DAC) benefits for their basic needs and access to critical health services. DAC provides a monthly stipend and eligibility for Medicare. These crucial benefits allow people whose disabilities onset before age 22 to claim benefits on a parent’s record – allowing parents to continue to support their children with disabilities even after retirement, disability, or death. Unfortunately, navigating the program and its rules is extremely complex for people with disabilities and their families.

As Chairman Wyden mentioned in his remarks, DAC beneficiaries are subject to a strict and punitive restriction on the amount of earnings from work they can make each month. If a DAC beneficiary has countable earnings of even one dollar over the

substantial gainful activity (SGA) level (\$1550 a month in 2024) before receiving DAC benefits, they lose their eligibility for DAC benefits forever.ⁱⁱ This creates a harsh disincentive to work for young adults with disabilities, who may want to try and work, but who cannot risk losing these benefits. There are many circumstances in which a young person with a disability might be able to earn over SGA for a short period of time or a few times, but is unable to sustain that level of work in the long run. Families worry that the wrong amount of work will cause their family member to lose eligibility for DAC benefits and this fear may discourage young adults with disabilities from working at all, or to their full potential.

The Arc strongly supports the bipartisan Work Without Worry Act (S.2196), co-led by Chairman Wyden and Senator Cassidy. The Work Without Worry Act would eliminate this work disincentive by allowing young adults with disabilities to work and see if they can support themselves without losing eligibility for DAC benefits. Earnings from work over SGA will not prevent the individual from receiving DAC benefits from their parent's work history as long as the individual remains disabled by the same impairment from before age 22 and meets other eligibility conditions for benefits. The benefit amount will be either the benefit from the individual's parents or the benefit from the individual's own work history, whichever is higher.

We agree with Chairman Wyden's statement during the hearing that this policy change is "a no-brainer that will be life-changing for thousands of Americans who want to participate in the workforce but don't, out of fear that federal rules could hurt their ability to be financially secure in the future."ⁱⁱⁱ We look forward to continuing our work with your office to advance this legislation.

2. Remove Barriers to Work Related to SSI by Modernizing Asset and Income Limits

SSI provides an extremely modest cash benefit for low-income individuals with disabilities and older adults that meet the program's strict means-tested criteria. Around 7.6 million people rely on SSI to meet basic needs for food, clothing, and shelter – including 4.3 million working-age individuals with disabilities, 1 million children with disabilities, and 2.3 million older adults.^{iv} But the program's asset and income limits trap people in poverty, punish them for getting married, create barriers to work, and constrain their financial independence.

The Arc appreciates the solution-oriented discussion during the hearing on how updating the SSI asset limit would empower people with disabilities to save earnings from paid work and pursue their career goals. As Senator Brown noted in his remarks,

SSI's strict asset limits haven't been updated in nearly 40 years. An individual on SSI is not allowed to have more than \$2,000 in total financial resources at any time. Married couples are only allowed \$3,000. Resources that count towards the SSI asset limit include cash, money in bank accounts, most retirement accounts, stocks and bonds, the value of whole life insurance policies and burial funds over \$1,500, and some personal property. JPMorgan Chase recently noted that SSI's outdated asset limit makes it difficult for SSI beneficiaries to achieve any measure of economic security and called for it to be modernized.^v

Because they were never indexed to inflation, these limits have lost nearly all their value over the decades and have become a significant barrier to workforce participation.^{vi} Many individuals who receive SSI want to work and do in fact work. But the extremely low asset limit prevents people from saving money from paid work for fear that they could be kicked off of SSI if they save over \$2,000. The fear of disqualification is justified – tens of thousands of recipients see their benefits suspended or permanently revoked each year for exceeding the asset cap. The sibling of a person with a developmental disability in Texas recently sent a message to The Arc about how outdated SSI rules limit the number of hours her brother can work:

“My developmentally disabled brother has a job ... that he ADORES, but though he wants to work more, we have to keep his hours limited so he can continue to receive benefits. He doesn't make enough money to live off of, but loves the time to socialize and contribute to society.”

The bipartisan SSI Savings Penalty Elimination Act (S.2767) led by Senators Brown and Cassidy would significantly improve the lives of SSI beneficiaries by raising the asset limit to \$10,000 per individual and \$20,000 per married couple. The legislation also adjusts that number for inflation every year. The Arc strongly supports this legislation and joined a joint letter of endorsement from over 370 disability advocacy organizations.^{vii} We look forward to continuing our work with your offices to advance this legislation.

Another outdated SSI rule mentioned during the hearing that poses a significant barrier to work for beneficiaries is known as “earned income disregards” – which have been frozen in time for nearly five decades. As a CBPP report notes,

“SSA [exempts (or “disregards”)] the first \$65 per month of earnings; each \$1 of earnings above that level reduces SSI benefits by 50 cents. These rules

begin to reduce benefits even when a recipient's income is well below the poverty line. The amount of income that SSA disregards when calculating SSI benefits has not changed, even to account for inflation, since 1972. That has increasingly eroded the inflation-adjusted value of benefits for SSI recipients who work or receive Social Security or other income. For SSI beneficiaries who can work, the stringent disregard for earned income significantly diminishes any incentive to work. The dollar-for-dollar benefits reduction for non-wage income above \$20 does little to reward those who receive Social Security based on their past work, since the combined benefits that they receive are little different than the benefits received by those with no work history."^{viii}

The Arc recently received a message from a disabled self-advocate living in Washington State expressing how the rising cost of living has made SSI's income limits and earned-income disregards especially difficult to navigate:

"I am a member of The Arc and a person with a disability. ... I am working in a job that I am very passionate about. I constantly worry about going over income/work hours, and I do not want to lose my much-needed Medicaid benefits. The cost of living is much higher today and it gets more difficult to make ends meet than it ever has been. Please consider raising our income limits NOW."

Urgent action is needed to update SSI's income limits and disregards to relieve people with disabilities from harsh work penalties. In addition to increasing the disregards, they should also be indexed to inflation going forward or indexed with wages to keep up with rising living standards. We look forward to working with your offices to address this issue.

3. Update Overpayment Policy to Encourage Work

We appreciate the bipartisan discussion on work-related overpayments during this hearing and your attention to this issue this Congress. As Susan Wilschke, SSA's Associate Commissioner of the Office of Research, Demonstration, and Employment Support stated in her testimony, "[m]ultiple studies have found that, of the small fraction of beneficiaries with sustained earnings, large majorities experience work-related overpayments; these overpayments, in turn, can discourage work."^{ix} SSI and SSDI beneficiaries may also be wary of attempting a return to work out of fear that this may give rise to an overpayment when reported earnings are not properly recorded or monthly overpayments are not properly and promptly adjusted.

The Arc broadly supports the important steps that SSA Commissioner O'Malley and SSA staff have taken this year to reduce the frequency and financial burden of overpayments for beneficiaries.

A key driver of overpayments for SSI beneficiaries discussed during the hearing is the SSA asset limit. Susan Wilsche confirmed that the SSA has identified going over the SSI asset limit as the number one cause of overpayment.

The Arc regularly receives messages from our networks about how administrative challenges and SSI's low asset limit contribute to overpayments and undermine beneficiaries' financial security. For example, a parent in Ohio recently shared with us how the combination of SSI's asset limits, income limits, and overpayments effectively punish her daughter for working:

"My daughter was penalized [through] Social Security and has to pay \$14,000 back to Social Security. This is because [Social Security] counted my work checking/savings account and her sister's little bit of money she has in her own account while working and going to college. My daughter has money deducted from her [Social Security] payment each month to pay it back and continually has to pay money back if [SSA] deems she is paid too much in her \$163 bi-weekly paycheck from her part time job! She will never be able to afford to live on her own or own anything she dreams of owning because of [these] limits. She can't even save for an item, need, or want because of the [asset] limit. Please stop penalizing her and so many thousands who are trying to better themselves and work."

The Arc strongly supports the SSI Savings Penalty Elimination Act because it would support the participation of SSI beneficiaries in the workplace, and give them the freedom to build a more secure financial future for themselves.

4. SSA Needs Sufficient Administrative Funding to Improve Customer Service

The Social Security Administration is serving more customers than ever before with fewer staff than it has had in 27 years. Its administrative budget has been cut by 20 percent over the past nine years, and currently stands at less than one percent of benefits paid. By contrast, private insurance companies operate on well more than 10 percent of overhead compared to outlays. Until 2018, SSA operated on a budget of 1.2 percent of benefits paid, and its customer service and employee satisfaction were among the best of federal agencies. The subsequent decline in both of those

measures closely tracks the decline in spending authority as a percentage of benefits paid.

SSA already is making progress in reducing wait times and streamlining administrative processes. But continued progress will depend on Congress fully funding the President's request for FY 2025, and on restoring SSA's administrative budget to 1.2 percent of benefits paid in future years. We agree with Susan Wilschke's comment in her testimony that, "[w]hile modernization and other efficiencies have helped in some respects, there is no way around the fact that the agency cannot keep doing more with less."^x

The Arc urges Congress to fully fund the \$15.4 billion requested by the President for SSA in FY 2025 in order to give SSA the tools it needs to strengthen services and reduce excessive delays faced every day by Americans who are trying to access the benefits they have earned.^{xi}

Conclusion

The Arc supports new legislative and regulatory proposals that could increase employment opportunities for individuals with disabilities who receive Social Security disability benefits. We believe that any efforts to change SSDI and SSI must protect and expand these programs' effectiveness, as well as protect access to Medicare and Medicaid.

Thank you for your efforts on behalf of Social Security disability beneficiaries and the millions of others who interact with SSA. We stand ready to work with you, other members of Congress, and the SSA to improve services to the public.

Sincerely,
Darcy Milburn
Director, Social Security and Healthcare Policy
The Arc of the United States

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- ⁱ <https://www.finance.senate.gov/hearings/work-and-social-security-disability-benefits-addressing-challenges-and-creating-opportunities>
- ⁱⁱ <https://www.ssa.gov/oact/cola/sga.html>
- ⁱⁱⁱ https://www.finance.senate.gov/imo/media/doc/0618_wyden_statement.pdf
- ^{iv} https://www.ssa.gov/policy/docs/statcomps/ssi_monthly/index.html
- ^v <https://www.jpmorganchase.com/news-stories/expanding-economic-opportunities-and-mobility-for-people-with-disabilities>
- ^{vi} <https://www.cbpp.org/research/social-security/the-case-for-updating-ssi-asset-limits>
- ^{vii} https://thearc.org/wp-content/uploads/2023/09/SSI-SPEA_Letter-of-support_2023_Final.pdf
- ^{viii} <https://www.cbpp.org/research/social-security/policymakers-should-expand-and-simplify-supplemental-security-income>
- ^{ix} https://www.finance.senate.gov/imo/media/doc/0618_wilschke_testimony.pdf
- ^x https://www.finance.senate.gov/imo/media/doc/0618_wilschke_testimony.pdf
- ^{xi} https://www.c-c-d.org/fichiers/CCD-SSTF_FY25-SSA-Funding_4.26.24.pdf