

How Disabled Americans Are Pushing to Overhaul a Key Benefits Program

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Many older, blind and disabled Americans receive benefits from the Supplemental Security Income program. But it has been essentially unchanged since 1972, and its rules mean that many recipients must remain in poverty.



Felix Guzman, who has autism and schizoaffective disorder, is a recipient of Supplemental Security Income. Credit...Michelle V. Agins/The New York Times

By **Maggie Astor**

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When Congress created Supplemental Security Income in 1972, it left no question about its intentions. The program, [lawmakers wrote](#), was “designed to provide a positive assurance that the nation’s aged, blind and disabled people would no longer have to subsist on below-poverty-level incomes.”

Today, it helps ensure the opposite.

The maximum annual benefit is \$9,528, three-quarters of the federal poverty level. Payments decrease if recipients have more than \$85 a month in outside income, and are revoked if they exceed \$2,000 in savings. There are penalties for accepting groceries or even shelter from loved ones. The result is that it is structurally difficult to be on S.S.I. and not live in poverty.

The shift happened over nearly five decades in which Congress made no major changes to the program, which is run by the Social Security Administration and serves about eight million Americans. The outside income limits, for instance, have never been updated for inflation.

Now, as Democrats hash out the details of trillions of dollars in spending that they hope to pass through budget reconciliation with no need for Republican support, S.S.I. recipients and advocates see a rare opportunity to overhaul the program.

It is far from a guarantee. This Wednesday, Senator Kyrsten Sinema, Democrat of Arizona, said she would not support the full \$3.5 trillion package that her party has proposed — and because her support and that of Senator Joe Manchin III, Democrat of West Virginia, are essential, what stays in the package will depend on what they are willing to accept.

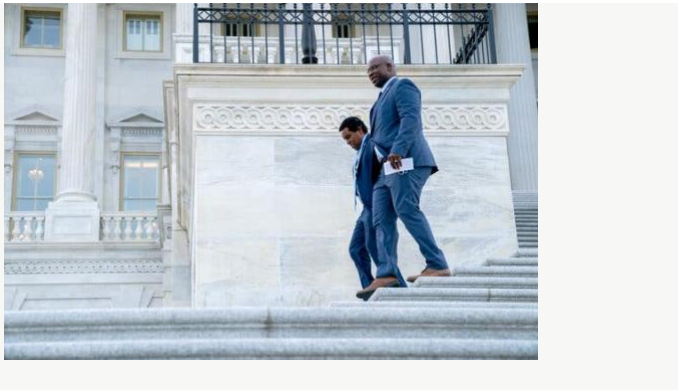
Republicans and some moderate Democrats oppose passing a package that would substantially increase the deficit, and if it has to be pared down to win 50 votes, a vast array of proposals — on education, health care, climate change and much more — will be competing for inclusion.

But “there is a shot,” Representative Jamaal Bowman, Democrat of New York, said in a virtual forum with advocates last week, calling the state of the S.S.I. program “a national scandal” and urging supporters to call the White House and congressional leaders “every single day.”

Mr. Bowman is a lead sponsor of the Supplemental Security Income Restoration Act, which advocates want included in the reconciliation bill and which the Social Security Chief Actuary [estimates would cost \\$46 billion in 2022](#) and a total of \$510 billion over the next decade. Among other things, it would increase S.S.I. payments to the federal poverty level and index them to inflation; allow more than \$500 per month in outside income with no penalty; raise the asset limit to \$10,000; and remove penalties for “in-kind support,” like a friend offering shelter.

In one sense, the bill is just another example of a measure that stopped being a nonstarter when Democrats took control. But it is also a culmination of years of work by people with disabilities, who have sought [to establish themselves](#) as a bloc capable of influencing elections and making demands of elected officials.

“We were agitating from the inside, but it was outside groups that really got it on the mainstream Democratic agenda,” said Senator Sherrod Brown, Democrat of Ohio, who is the lead Senate sponsor of the S.S.I. bill and has sponsored similar legislation for years alongside Representative Raúl Grijalva, Democrat of Arizona, and others. “They were less active when it was a Republican Senate and a president like Trump because they knew there wasn’t much at the end of the rainbow.”



Representative Jamaal Bowman, Democrat of New York, right, is a sponsor of the Supplemental Security Income Restoration Act. Credit...Stefani Reynolds for The New York Times

Last month, advocacy groups helped organize what they said was the first bicameral briefing on S.S.I. — essentially a presentation to congressional staff — in more than 30 years. Senator Bernie Sanders of Vermont included S.S.I. changes on a draft list of Democratic priorities. Mr. Bowman said that he had spoken with White House officials and that “all signs point to the president being supportive.”

The White House did not respond to a request for comment, but President Biden endorsed changes to S.S.I. during his election campaign, a move without which “I don’t think what we’ve seen on the Hill would have been possible,” said Matthew Cortland, a senior fellow at Data for Progress and leader of a campaign called #DemolishDisabledPoverty, of which the S.S.I. push is one part.

Other factors may be the pandemic’s outside impact on disabled and aging Americans and a growing collaboration between those groups.

Rebecca Vallas, a senior fellow at the Century Foundation and a leader of #DemolishDisabledPoverty, called the current effort “the logical next step of what we saw in 2017 and 2018, when the disability community and the senior community came together to fight in lock

step to protect the Affordable Care Act and Medicaid.”

A Century Foundation/Data for Progress [poll](#) in May found bipartisan support for increasing S.S.I. payments to the poverty level: 91 percent among Democrats and 70 percent among Republicans, with a margin of error of plus or minus three percentage points.

Republican lawmakers have been largely silent on the S.S.I. proposal, though they staunchly oppose the overall reconciliation bill.

Jeffrey Miron, an economist at the libertarian Cato Institute and at Harvard, said the measure was “completely rational given the objectives,” and that the main point of ideological contention was the objectives themselves. He added that S.S.I. was not a major contributor to the deficit.

“If you think that having insufficiently generous programs is a problem, then increasing the benefits indeed addresses the problem,” Mr. Miron said. “Whether it’s good overall and whether a broad range of people would agree we should make the programs more generous is a much harder question.”

Beyond organizers like Ms. Vallas and Mr. Cortland, himself a former S.S.I. recipient, current beneficiaries have begun speaking about how the program’s restrictions affect them.

Felix Guzman, an S.S.I. recipient with autism and schizoaffective disorder, said higher payments could cover speech therapy or communication devices for his 7-year-old son, who is autistic and nonverbal.

“The difference between waiting a month to two months for an item that might help him communicate can make the difference between him meeting a milestone for his disability or not,” Mr. Guzman, 39, said.

Other recipients say they can’t pursue meaningful work because it could cost them their S.S.I. and accompanying Medicaid coverage without providing enough income or insurance to compensate. Some want to test their ability to hold a job, but don’t want to risk having nothing to fall back on if they can’t.

“It can be very hard to get your S.S.I. or your Medicaid back once you do lose those benefits,”

said Mia Ives-Rublee, the director of the Disability Justice Initiative at the Center for American Progress, who uses a wheelchair and relied on S.S.I. in college. “There’s a real trap of having to balance your health needs versus your willingness and ability to work.”

The program can also discourage marriage, because a spouse’s assets — even a few thousand dollars in a retirement account — would count toward the asset limit of \$3,000 for couples.

“The amount of benefits that we lose is thousands — it’s not anything that a normal spouse can afford,” said a disabled S.S.I. recipient who spoke on the condition of anonymity because she fears retaliation for speaking against the rules of the program she relies on. “Most of us, myself included, are not getting married because I literally would die. I would lose everything.”



Melanie Waldman, 30, who has lupus, Ehlers-Danlos syndrome and an amputated arm, receives about \$800 a month from Social Security Disability Insurance. Credit...Michelle V. Agins/The New York Times

Once, that recipient said, she was too sick to leave her home for two months, and because her daily expenses fell, her bank account balance increased to \$2,135 from just under \$2,000 without her noticing. When the Social Security Administration found out, she had to repay her entire S.S.I. benefit for those months, which took two years.

Organizers of #DemolishDisabledPoverty also want Congress to increase funding for home- and community-based services; eliminate [a law](#) that lets companies pay some disabled employees far less than minimum wage; and update Social Security Disability Insurance, or S.S.D.I, which is distinct from S.S.I. but has many similar limitations.

Melanie Waldman, 30, who has lupus, Ehlers-Danlos syndrome and an amputated arm, has been unemployed since leaving a job that was, she said, “wrecking my body.” She receives about \$800 a month from S.S.D.I.

She has a background in theater and said she wanted to pursue roles, but would have to request lower pay. She is allowed \$10,000 per year in outside income and, before she was on S.S.D.I., earned about \$13,000 from acting. Even though S.S.D.I. pays less, she can’t afford to lose it because that would mean losing health care.

Mr. Cortland said the current push focused on S.S.I. because it can be changed through budget reconciliation, whereas S.S.D.I. cannot. But he emphasized at the virtual forum last week that advocates would also work to change S.S.D.I.

The forum, organized by the Century Foundation, included Mr. Bowman and Representative Ayanna Pressley, Democrat of Massachusetts, both of whom urged the roughly 17,000 people watching to pressure lawmakers.

“I know I’m preaching to the choir, and as the granddaughter of a Baptist preacher, there’s a reason why,” Ms. Pressley said. “It’s because I need the choir to sing.”