

Policy Options for Improving SSI

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On Behalf for the Special Needs Alliance

Chairman Brown and Ranking Member Young, and members of the subcommittee, we first congratulate you on holding a hearing to identify ways to increase income and resource limits and other components used to determine Supplemental Security Income (SSI) eligibility and related benefits for individuals with disabilities. We appreciate the opportunity to provide written testimony to this subcommittee to express the gratitude and support of the Special Needs Alliance (SNA) regarding these efforts, as well advise on additional ways that SSI eligibility and related benefits can be improved for persons with disabilities.

We are co-chairs of the Public Policy Committee and Board members of the SNA. The SNA is a national, non-profit organization committed to helping individuals with disabilities, their families, and the professionals who serve them. Its members are attorneys representing the majority of states in the union, and the members regularly assist clients with disabilities and their families with eligibility for public benefit programs, guardianship/conservatorships, planning for disabilities, and special education issues. Many members also have family members who have disabilities. The SNA members contribute significant time to the special needs community and advocate for legislative and regulatory change to improve the quality of life and care for individuals with disabilities.

The SNA is one of approximately one hundred national organizations who are members of the Consortium for Citizens with Disabilities (CCD), working together to advocate for national public policy that promotes self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Improvements to the existing SSI eligibility requirements has been a public policy priority of the CCD, and hence also of the SNA. As such, the SNA greatly appreciates the work of this subcommittee and its efforts towards passage of bills that consist of various improvements to the SSI benefits program, which will have a meaningful impact on some of the most vulnerable in our society – children and adults with disabilities.

We would like to take the opportunity to voice SNA's support of the Supplemental Security Income Restoration Act of 2021, S.2065 introduced by Senator Brown and cosponsored by twenty other senators. The provisions in this bill will unquestionably improve the quality of life for individuals with disabilities.

As the subcommittee and full Finance Committee considers changes proposed in the SSI Restoration Act and other related legislation, we would like to draw your attention to another issue which is also a major priority of the SNA related to SSI benefits and Social Security Childhood Disability Benefits. The CCD also supports our position on this issue. The Social Security Act as currently drafted results in a fundamentally unfair outcome because it arises from circumstances the individual with disabilities cannot control, which can have a significant impact on access to much-needed care, treatment, and services.

What's the Problem?

Under Section 1634 of the Social Security Act (42 USC 1383c(c)), an individual with disabilities must receive Supplemental Security Income (SSI) before receiving Social Security's Childhood Disability Benefits (CDB, formerly known as "DAC" benefits) in order for the CDB income to be disregarded for Medicaid qualification. This creates an unintended trap of making individuals with disabilities whose parents die young, or are older and retire, or who otherwise fail to apply for SSI benefits prior to receiving CDB benefits, subject to a monthly Medicaid spenddown.

Medicaid eligibility for persons with disabilities is commonly linked to eligibility for SSI benefits. Depending on the state, these individuals with disabilities who received CDB benefits before receiving SSI benefits may not be able to qualify for or receive Medicaid benefits, including essential mental health services, simply by being unlucky in their uncontrollable personal life circumstances. These Medicaid covered services are essential to ensuring their health, safety, independence, and meaningful participation in the community.

What Does the Law Say?

The noble intent of 42 USC §1383c(c) is to ensure that individuals with disabilities who subsequently lost Supplemental Security Income (SSI) and Medicaid solely because the individual began receiving SSDI payments as a result of changes in a parent's situation (death, disability or retirement), continue to maintain their eligibility for Medicaid benefits without the imposition of a Medicaid deductible solely because of this change in the source of income.

However, the law as written has the unintended consequence of imposing a Medicaid spenddown prior to accessing Medicaid benefits and related services simply because their parents die, retire, or become disabled themselves before the child with disabilities can qualify for SSI. There appears to be no intended justification why there are more hurdles to access Medicaid benefits for these individuals.

An Introduction to Michael, a Person with Disabilities

Michael is a thirty-one (31) year old man from Michigan, born with spastic quadriplegia and cerebral palsy. When Michael was only six (6) years old, his father died from cancer leaving his mother, Marilyn, to raise him on her own. Michael requires complete support due to his severe physical and mental impairments, including full assistance with basic activities like personal hygiene, bathing, and dressing. He relies on the use of a wheelchair, receives nutrition through a feeding tube, and wears adult briefs due to incontinence. Michael is medically fragile and suffers from upper respiratory dysfunction and frequent pneumonia. Although Michael is nonverbal, his mother is able to communicate with him through eye raising and head shaking.

Michael did not become eligible for SSI benefits prior to receiving CDB benefits due to his father's passing when he was a child. As a result, Michael must first expend almost half of his CDB monthly benefit (or \$680 from his monthly CDB benefits of \$1343) in order to access Medicaid and related benefits instead of using CDB benefits for his basic living expenses and other needs.

Unfortunately, Michael is unable to pay this amount each month from his CDB benefits and therefore is unable to access Medicaid benefits, which can assist with obtaining incontinence briefs, formula for his feeding tube, orthotic braces, mobility equipment, and other needs typical of an individual with quadriplegia. Michael is also unable to access other Medicaid programs and mental health services which enables individuals to hire caregivers to assist him with his personal care, along with access to socialization and meaningful activities in the community.

Michael's inability to access such Medicaid benefits and other services also has an unfortunate impact on his mother, who continues to be his primary caregiver. Michael's mother, Marilyn, would like to be able to work outside the home but has found it difficult because Michael cannot be left alone, and she cannot afford to pay caregivers privately which causes the family to suffer financially. Marilyn, age 56, is also concerned about her continuing ability to care for Michael as she ages.

Requested correction

Fortunately, a simple amendment to 42 USC 1383c of the Social Security Act would correct this unfortunate outcome as follows:

(c) Entitlement to Medicaid Upon Receiving Child's Insurance Benefits Based on Disability

Any individual entitled to child's insurance benefits under section 402(d) of this shall be treated for purposes of subchapter XIX as receiving benefits under this subchapter so long as he or she would be eligible for benefits under this subchapter in the absence of such child's insurance benefits.

On behalf of Michael, the Special Needs Alliance, and the individuals with disabilities and families that we serve, we thank you for the opportunity to provide written testimony for your consideration, and for your continued efforts to improve the lives of individuals with disabilities.