

March 28, 2022

Senator Debbie Stabenow
731 Hart Senate Office Building
Washington, D.C. 20510-2204

Re: *Childhood Disability Fairness Act*

Dear Senator Stabenow:

The undersigned organizations thank you for your continued commitment to ensuring that individuals with disabilities receive much-needed services to participate in the community as valued citizens. Today we write to voice our support of the Special Needs Alliance's advocacy efforts to end the unfair and unintended situation created by the Supplemental Security Income (SSI) and Social Security Childhood Disability Benefits statute. The statutory flaw has a highly negative impact on some persons with disabilities due to no fault or actions of their own. We have seen this issue impact many of our own Michigan residents with disabilities and their families. We are joining the Special Needs Alliance in asking you to help us change the law and protect these families.

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 SSDI, formerly known as "DAC" benefits) for the CDB SSDI income to be disregarded for Medicaid qualification. Requiring SSI 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 before receiving CDB SSDI benefits, subject to a monthly Medicaid spenddown. These individuals desperately need Medicaid but find themselves without coverage and potentially without other resources for their basic needs. These Medicaid-covered services are essential to ensuring their health, safety, independence, and meaningful participation in the community.

The harm is not theoretical. In Michigan, this trap is in our Medicaid policy under the Department of Health and Human Services' Medicaid Bridges Eligibility Manual 158. Under this policy, our Department of Health and Human Services will deny the income disregard unless a child with CDB SSDI benefits received SSI before receiving CDB SSDI benefits. Then because that individual is not automatically qualified for Medicaid, increasingly Michigan Community Mental Health providers are denying that individual services.

Unfortunately, there is nothing advocates can do. The State of Michigan is following current federal law. Thus, we urge you to make a simple change to federal law.

What Does the Law Say?

42 USC §1383c(c) has a noble intent. It ensures individuals with disabilities retain their Medicaid benefits when they lose Supplemental Security Income (SSI) and receive CDB SSDI benefits because of a change in their parent's situation (e.g., death, disability or retirement). However, the current law has the unintended consequence of singling out certain individuals with disabilities simply because their parents die, retire, or become disabled because they automatically qualified for CDB SSDI benefits and never could 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 independently. Michael requires complete support due to severe physical and mental disabilities, including full assistance with basic activities like personal hygiene, bathing, and dressing. He relies on using 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 can communicate with him through eye raising and head shaking.

Michael did not become eligible for SSI benefits before receiving CDB SSDI benefits due to his father's passing when he was a child. As a result, Michael must first expend over half of his CDB SSDI monthly benefit (of \$915 from his monthly CDB SSDI benefits of \$1,343) on medical expenses to access Medicaid and related benefits, instead of using CDB SSDI benefits for his basic living expenses and other needs.

Unfortunately, Michael cannot pay this amount each month on medical expenses from his CDB SSDI benefits. Therefore, he cannot access Medicaid benefits such as obtaining incontinence briefs, formula for his feeding tube, orthotic braces, mobility equipment, and other needs typical of an individual with quadriplegia. Michael cannot access other Medicaid programs and mental health services to hire caregivers to assist him with his personal care and access meaningful activities in the community. He is denied these benefits simply because his father died of cancer when Michael was a child.

Michael's inability to access such Medicaid benefits and other services also unfortunately affects his mother, who continues to be his primary caregiver. Michael's mother, Marilyn, would like 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. Marilyn not only lost her husband, but she is also losing her career.

Other individuals with the exact same circumstances, but whose father had not passed away, would be eligible for Medicaid and would not face this difficult situation trying to pay for needed care, treatment and supplies.

Requested Correction

Fortunately, a simple amendment to 42 USC 1383c of the Social Security Act as proposed by the Special Needs Alliance would correct this unfortunate outcome:

(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.

As such, we are in support of and hope you will consider introducing and sponsoring the Childhood Disability Fairness Act as proposed by the Special Needs Alliance, reflecting the above amendment to 42 USC 1383c of the Social Security Act.

On behalf of Michael and many others that we serve in Michigan, we thank you for your time and consideration and your continued efforts to improve the lives of individuals with disabilities and their families.

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