



## Childhood Disability Benefit Fairness Act

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Earlier this year, I joined fellow members of the [Special Needs Alliance](#) in Washington, D.C. to meet with our Senators and Representatives to discuss the **Childhood Disability Benefit Fairness Act**. The Special Needs Alliance has crafted a [legislative solution](#) to a significant problem facing disabled adult children.

The Childhood Disability Benefit Fairness Act addresses the issue where disabled adult children are denied crucial Medicaid and related medical benefits because they never received SSI before becoming eligible for Social Security's [Childhood Disability Benefit](#) (CDB) (formerly Disabled Adult Child or DAC benefit).

### Benefits for Individuals with Disabilities

[Supplemental Security Income \(SSI\)](#) is a means-tested financial benefit for individuals who are unable to work due to disability. In 2025, individuals can receive up to \$967 per month in SSI benefits to cover their food and shelter expenses. Individuals who qualify for SSI automatically receive Medicaid to help with their medical expenses. Most children with disabilities do not qualify for SSI when they are under the age of 18 due to their parents' assets and income. However, once the disabled individual attains the age of 18, the parents' income and assets are no longer counted and the individual can become eligible for SSI and Medicaid benefits.

### Special Benefit for Individuals Disabled Before Age 22 - the Disabled Adult Child

In addition, the child may be eligible to collect the Child Disability Benefit, which is tied to their parents' Social Security earnings. The Child Disability Benefit is an insured benefit under Title II of the Social Security Act and is one of three types of benefits collectively known as Social Security Disability Insurance (SSDI) benefits. An individual who becomes disabled prior to age 22 and continues to be disabled can receive the Child Disability Benefit when his or her parent retires, becomes disabled themselves, or upon a parent's death. The child can receive up to 50% of the parent's full retirement or disability benefits and up to 75% of the parent's basic Social Security benefit upon the parent's death. In addition, a disabled adult child can receive Medicare to help cover the cost of his or her medical care.

Once a disabled adult child begins receiving the Childhood Disability Benefit, they typically lose SSI benefits because the income from the Childhood Disability Benefit exceeds the SSI benefit. However, recognizing that disabled adult children will likely never be able to be self-supporting through no fault of their own, Section 1634 of the Social Security Act (42 USC 1383c(c)) provides that an individual who receives SSI before receiving Childhood Disability Benefits can have his or her Childhood Disability Benefit income disregarded for Medicaid qualification. This allows the disabled adult child to receive the higher CDB benefit, Medicare for their primary health insurance, and Medicaid to cover those services not covered by Medicare, such as supported living services that can make it possible for a disabled adult child to live more independently in the community.

### But Wait...What's the Problem?

This all sounds great, but unfortunately, members of the Special Needs Alliance have discovered that the current statutory requirement creates an unintended trap for individuals whose parents died young, are older and retired, or who did not apply for SSI before the adult child began receiving Childhood Disability Benefits.

Take this example of two disabled children from the same family:

- Jill is 23 years old. She was born with Down syndrome and qualified for SSI benefits and Medicaid when she turned 18. Her mom passed away when Jill was 19 years old and Jill began receiving the Childhood Disability Benefit and Medicare. Jill no longer receives SSI because the Childhood Disability Benefit income is greater than the SSI benefit. However, she is able to disregard the CDB income for purposes of Medicaid eligibility and therefore she can keep her full Medicaid benefits without having to "spend down" her monthly income on medical expenses.
- Jill has a sister, Jamie, who is 21 years old and also has Down syndrome. Jamie was 17 when Jamie and Jill's mother passed away. Since she was not yet 18, she did not qualify for SSI because her parents' income and assets prevented her from being eligible. Jamie has never received SSI, but, like her sister, Jill, she qualified for Childhood Disability Benefits. Unfortunately, unlike her sister, Jamie's disability income is not disregarded and she must spend this income on her medical expenses before she can gain access to Medicaid benefits.

Jill and Jamie are similar in just about every way, but Jamie is able to keep **less** of her disability income just because her mom died before Jamie turned 18 and applied for SSI.

We don't believe this was the intent of 42 USC §1383c(c), which aims to ensure that individuals with disabilities who lose SSI and Medicaid because they begin receiving CDB payments can continue to maintain their eligibility for Medicaid benefits. Unfortunately, the law as currently written creates an **unintended trap** for individuals with disabilities whose parents **die young, are older and retire, become disabled themselves, or fail to apply to SSI in time**. Depending on the state, these individuals, through no fault of their own, may not be able to afford or receive Medicaid benefits due to circumstances beyond their control.

### **That's Not Fair...How do We Fix This?**

The Special Needs Alliance is requesting an amendment to 42 USC 1383c to read:

#### **(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.

This correction will allow **all** disabled adult children to have their Childhood Disability Benefit income disregarded for purposes of Medicaid eligibility regardless of whether they were receiving SSI prior to receiving CDB benefits, so long as they would have been eligible for SSI, but for the CDB income.

If this issue is important to you, I urge you to reach out to your [Senators](#) and [Representatives](#) to let them know about this issue and the proposed correction. For more information on the Special Needs Alliance's advocacy around this issue and to download a one page advocacy tool that you can provide to your [Senators](#) and [Representatives](#), click [HERE](#).