

Childhood Disability Benefit Fairness Act

What's the Problem?

- Certain children with disabilities are being placed in financial hardship and may forgo essential supports and services due to the sequencing of federal program eligibility. Although the number of affected individuals may be small, the impact is significant:
 - Disabled individuals go without needed Medicaid services that help them stay in the community,
 - Thousands of hours of unnecessary paperwork are conducted by families and government officials each month, and
 - Unnecessary health care spending due to higher acuity from forgone care.
- Currently, under Section 1634 of the Social Security Act (42 USC 1383c(c)) an individual 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 statutory requirement creates an unintended trap where individuals with disabilities may be subject to a Medicaid deductible if their parents die young, are older and retire, become disabled themselves, or fail to apply to SSI in time. Depending on the state, these faultless individuals with disabilities may not be able to afford or receive Medicaid benefits simply by being unlucky in their uncontrollable personal life circumstances.

What Does the Law Say?

- The noble intent of 42 USC §1383c(c) is to ensure that individuals with disabilities who lose SSI and Medicaid because they begin receiving SSDI payments can continue to maintain their eligibility for Medicaid benefits. However, the law as written inadvertently excludes children whose parents die, retire, or become disabled themselves before the child with disabilities can qualify for SSI. This creates unnecessary barriers to accessing Medicaid benefits, with no apparent justification for the added hurdles faced by these individuals.

An Example:

- Jessica resides in Michigan and has a severe genetic disorder that causes severe physical and intellectual disabilities from birth. She is entitled to \$1,380/month in CDB benefits. If Jessica had received SSI before CDB benefits, she would be able to keep the \$1,380/month for living expenses and also receive vital Medicaid benefits that she could not afford on her own.
- However, Jessica's father retired before she turned 18. This uncontrollable circumstance means Jessica must elect the higher CDB benefit and does not qualify for SSI. Consequently, she cannot benefit from the income disregard under 42 USC §1383c(c). As a result, each month Jessica has \$597 less to pay for her needs because that amount must be used for her Medicaid "spend down" simply due to the fact she had an older father. Jessica should not be penalized because she was young when her dad retired.

Requested Correction:

Amend current law (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.

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