



SNA Public Policy: Advocating for Adult Children

*The Voice® is prepared and distributed by the [Special Needs Alliance \(SNA\)](#). This installment was written by a consortium of members of the SNA's Public Policy Committee. The Public Policy Committee through our public policy consultant, Brian Lindberg, work with members of Congress and congressional staff to educate and advocate on issues of importance to individuals with disabilities and their families. The Public Policy Committee will author periodic issues of the *The Voice®* to introduce our readers to the Public Policy efforts the SNA is directly involved in.*

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As part of its public policy efforts, the Special Needs Alliance spent much of 2021 advocating to make the Social Security system fair for children with disabilities who are entitled Social Security benefits based on a parent's work record. These are known as Childhood Disability Benefits (CDB, formerly known as Disabled Adult Child or "DAC" benefits). Adult children with disabilities that arose before the age of twenty-two years may be eligible for CDB benefits and collect Social Security Disability Insurance (SSDI) on a parent's work record when the parent begins to collect Social Security Retirement or Disability Insurance benefits, or when the parent passes away. In addition to SSDI, the child will be eligible for Medicare benefits after receiving SSDI for 24 months.

Yet there are some unfortunate traps in Social Security's CDB eligibility requirements. Some of these traps can include when a child never received Supplemental Security Income (SSI), a child earned too much even in a single month, or a child marries. The SNA's Public Policy Committee is working for changes to all these traps.

Childhood Disability Benefit Fairness Act

The SNA's proactive focus has been on getting what we are calling the Child Disability Benefit Fairness Act introduced. This would fix an unintended issue where a child could be denied crucial Medicaid and related medical benefits because they never received SSI before being eligible for Social Security's CDB benefit.

What is the Problem?

Under Section 1634 of the Social Security Act (42 USC 1383c(c)), an individual with disabilities must receive SSI before receiving CDB benefits 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 before 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 life circumstances beyond their control. These Medicaid-covered services are essential to ensuring their health, safety, independence, and meaningful participation in the community.

What Does the Law Currently 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.

Fixing the Problem

Fortunately, a simple amendment to 42 USC 1383c of the Social Security Act would correct this unfortunate outcome. The SNA is actively advocating for the introduction of the Child Disability Benefit Fairness Act with the suggested language included with our issue paper that can be found [here](#) on our website.

We also know that compelling personal stories can be the key to successful legislative change. If you or a family member have been hurt by this issue and you would like to help us in our legislative efforts, please contact us at info@specialneedsalliance.org.

Other Childhood Disability Benefit Efforts

Additionally, SNA supports its allies (many of whom are members of the Consortium for Citizens with Disabilities (CCD)) on two other important fixes that need to be made to the CDB eligibility requirements.

Work Without Worry. Under current Social Security law, a child must be under a disability that began before age 22 in order to receive the CDB benefit. Because the Social Security definition of “disability” is based on whether an individual can engage in substantial gainful activity, a child who works may not be able to establish their disability as existing before age 22. But what if a child tries to work and is ultimately unsuccessful? Instead of applauding that child for trying to be successful in the workforce, that child could be forever ineligible for the CDB benefit by simply having one month of substantial gainful activity earnings (\$1,350 of income in 2022). By ensuring that past earnings will not impair a child’s eligibility for CDB benefits, Work Without Worry would eliminate a child having to choose between trying to work and CDB benefits. The introduced bill can be found [here](#).

Marriage Access for People with Special Abilities (MAPSA). Unless a CDB beneficiary marries another individual with CDB benefits, that marriage will end the individual’s CDB benefits. And those benefits are not coming back if the individual is married or widowed. Often more crucially, that individual will lose access to crucial Medicaid supported services simply by marrying. MAPSA would ensure that when an individual with disabilities gets married, Social Security will not consider the spouse’s income or assets when determining eligibility for SSI or CDB. The introduced bill can be found [here](#).

Looking to 2022

In addition to the above proposals, the SNA’s Public Policy committee continues to proactively advocate for changes to the SECURE Act to ensure that parents and other loved ones have the freedom to leave retirement plans to special needs trusts without worrying about the residual beneficiaries of the trusts. You can read more about this issue by reading our Issue Alert located [here](#).

The SNA will also continue to initiate other legislative efforts, as well as collaborate with and support the efforts of other disability advocacy organizations, to improve the lives of individuals with disabilities and their families. Other areas of advocacy being explored by the Public Policy Committee include:

- Changes in eligibility for government benefits, such as Supplemental Security Insurance, Childhood Disability Benefits, housing assistance, and military benefits;
- Broadening eligibility criteria for individuals with disabilities to access ABLE accounts;
- Changes to permit the use of special needs trusts for child support payments; and,
- The promotion of supported decision-making models for persons with disabilities.

We will continue to share our progress with our existing advocacy efforts, as well as any new efforts, on the Special Needs Alliance Public Policy Page on our website found [here](#). We invite you to visit our site for updates on these important initiatives and look forward to another exciting and productive year!

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