A Brief History of the Politics of Child Disabilities Through the Lens of Medicaid, SSI, and CSHCN Policy

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Children and Youth with Disabilities: Health and Justice

I. Background

Defining Children with Special Health Care Needs

Trends in social and political perspectives regarding children with special health care needs (CSHCN) and disabilities have had major impact on the number of children and the conditions that make them eligible for Medicaid. With additional costs and need for services, health coverage is important to CSHCN, (Saper et al., 2023; Yu et al., 2022; Elinson et al., 1999) and Medicaid plays an important role. This brief explores: 1) how the macro political context has affected children's SSI and Medicaid eligibility, and 2) how advocacy by one parent changed the direction of health policy for children with disabilities.

An estimated 15 million children (21%) under age 18 have special health care needs.[1] (NSCH, 2023-24) Children with special health care needs (CSHCN) are defined as those who have chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally. (McPhearson et al., 1998) This group includes children with intellectual, physical, or developmental disabilities, as well as those with complex medical needs and other conditions. In addition, substantial overlap across different developmental disabilities and co-occurrence of conditions is common. This may be related to shared underlying factors, such as genetic, biological, environmental, neurodevelopmental, functional limitations, and other factors. (Zhou et al., 2026; Lin et al., 2024) prevalence and diagnoses vary by race ethnicity, geography, and age of child. (Gatewood et al., 2026; Li et al., 2023; Gandour et al., 2022; Pham et al., 2022; Shi et al., 2021; Zablotsky & Black, 2020; Zablotsky et al., 2019). National surveys and other studies show that children from certain historically disadvantaged groups (e.g., households with low-income or low parental education, Black or Hispanic, or uninsured) are disproportionally identified with developmental disabilities and as children with special health care needs. (Flasch, 2024; Black et al., 2024; Lin et al., 2024, Li et al., 2023) Disability-based discrimination in health care use is significantly more likely to be reported by families, particularly those with public insurance such as Medicaid. (Ames et al., 2025)

[1] To estimate CSHCN, the National Survey of Children Health (NSCH) uses the CSHCN Screener. This five item, parent-reported tool is designed to identify children across the range of childhood chronic conditions, functional capacity, and special needs requiring health and related services beyond that required by children generally.

Moreover, variation in definitions across states and public programs leads to wide variation in diagnosis, eligibility, and services. (Black et al., 2024; Davis & Brosco, 2007; Beers et al., 2003) For example, a national study of children ages 5 to 21 found that in 2023 the prevalence of developmental disability ranged from 4% using the narrowest definition to 16% using the broadest definition. (Ne'eman & Clark, 2025; Russell et al., 2024)

Medicaid's Vital Role in Coverage

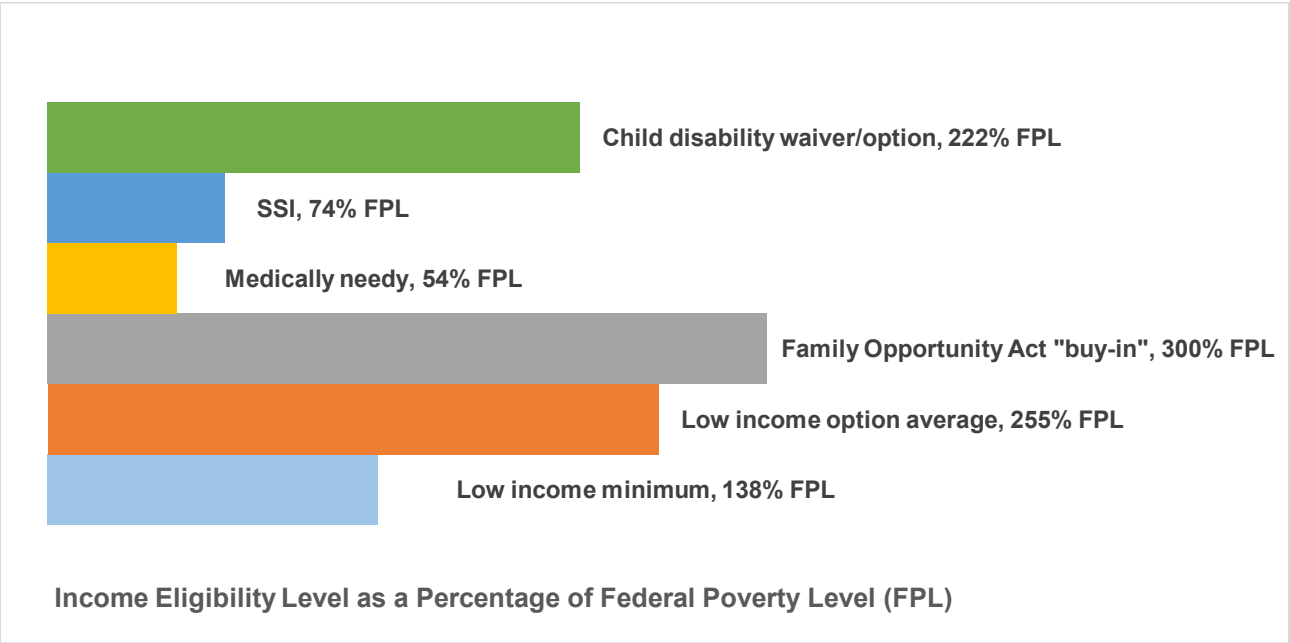
Medicaid and the Children's Health Insurance Program (CHIP)[2] provide health coverage for more than 4 in 10 CSHCN and disabilities. (Williams, 2025; Muscemci & Chidambaram, 2019) Reflecting variations in child poverty and state policy choices, the share of CSHCN covered by Medicaid varied from 22% to 65% in 2023. In recent years, most CSHCN enrolled in disability-related pathways remained enrolled in Medicaid as adults, particularly in ACA Medicaid expansion states. (Williams & Jennings, 2026)

CSHCN are more likely than other children to be eligible for Medicaid because they qualify under several eligibility pathways related to income and disability. (See Figure 1). Millions of CSHCN are eligible for Medicaid because of low-income status alone, with the minimum income eligibility level for children being 138% of the federal poverty level (FPL) and the average being 255% FPL.

Other CSHCN qualify on the basis of disability and income combined. Only about one in six (15%) children with disabilities has automatic Medicaid coverage because they receive federal Supplemental Security Income (SSI) benefits. (Muscemci & Chidambaram, 2019). Most of the Medicaid eligibility pathways for CSHCN and disabilities are optional, with about 1 in 5 children covered in a disability category enrolled at state option. (Rosenbaum et al., 2025) At the start of 2026, most states (43) use what is known as the TEFRA/ Katie Beckett option for children with significant disabilities who require an institutional level of care but are living at home. Some states use other types of waivers for covering home- and community-based services (HCBS). Only a few states (9) offer the optional Family Opportunity Act "buy-in" coverage for children with disabilities and family income up to 300% FPL. (KFF Survey of Medicaid Financial Eligibility for Older Adults and People, 2026)

[2] By 2026, 23 states used a CHIP-funded Medicaid approach (M-CHIP). Although not required to do so, 14 of 28 states with separate CHIP programs for children provide full Medicaid (EPSDT) benefits.

Figure 1. Medicaid Eligibility Pathways for Children with Special Health Care Needs and Disabilities



Data Sources: *KFF Survey of Medicaid Financial Eligibility & Enrollment Policies for Older Adults & People with Disabilities*. Issue Brief. April 2026; KFF State Health Facts Table "Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level. January 2026"; and KFF State Health Facts Table "Medicaid Eligibility for Katie Beckett Children with Significant Disabilities and Special Income Rule, 2026."

II. *What One Can Do:* How families of children with disabilities changed Medicaid's approach to coverage of home- and community-based services

Section 1902(e)(3) of the Social Security Act (the Act), permits states to extend Medicaid eligibility to certain children who are living at home, who require the level of care provided in an institution, and who would be Medicaid eligible if living in such an institution. Many individuals have income and/or resources too high to qualify for Medicaid unless they are living in an institution. Under this eligibility group, Medicaid eligibility may be granted to a child who would be eligible if institutionalized, but who can be cared for at home with no additional cost to Medicaid. This eligibility group is often called the Katie Beckett group because it was established as a result of the advocacy of Katie Beckett's mother, who wanted to care for her child at home. States can cover children in Katie Beckett group through a state plan amendment (SPA) and/or comparable waivers. In simple terms, the Katie Beckett option allows children with severe disabilities to qualify for Medicaid based solely on the child's income. By waiving the parents' income, it allows children requiring institutional-level care to live safely at home without bankrupting their families. Without parent advocacy, this option would not be available.

The Story of Julie and Katie Beckett

When she was an infant, Mary Katherine "Katie" Beckett contracted encephalitis, a viral brain infection. This condition and its complications affected Katie's central nervous system and permanently affected her ability to breathe and swallow without medical support. While she had

private coverage at the start, the family exhausted the $1 million cap in just three years. By age 3, Katie still needed a respirator to breathe, which was not covered as an in-home service under Medicaid. Federal law at the time would have required that Katie live in an institutional setting (e.g., hospital, intermediate care facility) in order to have Medicaid coverage. (McEnvoy, 2022; Catalyst Center, 2012; Family Voices, 2012).

Katie's mother, Juliann "Julie" Beckett was an indefatigable advocate for improving health care for CHSCN and disabilities for more than 35 years, beginning with her daughter. Julie fought successfully to give Katie the opportunity to grow up at home, rather than in a facility. This battle and its success began by talking to her Representative Thomas Tauke (R-IA-2). On a flight to Iowa with then Vice President George H.W. Bush, Rep. Tauke pleaded the Becketts' case. Mr. Bush was so moved that he immediately told President Ronald Reagan about the situation and the policy barrier. (New York Times, 2022)

In November 1981, Reagan singled out the Beckett's story in a news conference, saying: "Now, by what sense do we have a regulation in government that says we'll pay $6,000 a month to keep someone in a hospital that we believe would be better off at home?" Two days later, Secretary of Health and Human Services Richard S. Schweiker announced a waiver option for states, stating that Medicaid would in fact cover Katie's care at home. (McEnvoy, 2022; New York Times, 2022; Catalyst Center, 2012).

Photo caption: The White House paid attention to Ms. Beckett's advocacy. In 1984, President Ronald Reagan (seen holding Katie Beckett) met with the Beckett family on the tarmac of Cedar Rapids Municipal Airport in Iowa. Julie Beckett is on left, wearing a striped dress. Representative Tauke is standing behind the President. Credit: Courtesy of the Ronald Reagan Library.

In 1982, as part of the Tax Equity and Fiscal Responsibility Act (TEFRA, Public Law 97-248), Congress expanded what had been accomplished by the Reagan Administration by creating what is often referred to as the Katie Beckett waiver but is actually a state option. Additional types of home- and community-based waivers are also available to and used by states, some in the name of Katie Beckett. (KFF, 2026; MACPAC, 2018)

Thus, the determined advocacy efforts of one parent on behalf of her daughter resulted in the creation of the TEFRA/Katie Beckett option and led to other Medicaid home- and community-based waivers. While sometimes limited in numbers served, these waivers have allowed many thousands of families to care for their loved ones at home rather than in institutions. (Burns et al., 2023)

The story might have ended there, but Julie's advocacy was far from over. With Polly Arango and Josie Woll, Julie co-founded Family Voices to promote the inclusion of families' voices in all levels of health care decision-making for children. (Watch and earn more here https://www.youtube.com/watch?v=y_y1pal-KfE). In part, creation of Family Voices was stimulated by the fact that CSHCN were not guaranteed coverage in the Clinton health reform plan. Advocacy by Julie and other parent advocates from Family Voices helped to generate a broad definition of CSHCN and to create the federally-funded Family-to-Family Health Information Centers (F2Fs), which provide support to families of CSHCN in every state and DC. Hundreds of parents of CSHCN successfully fought against Medicaid block grants and repeal of the Affordable Care Act. The advocacy work of Family Voices continues more than 30 years later.

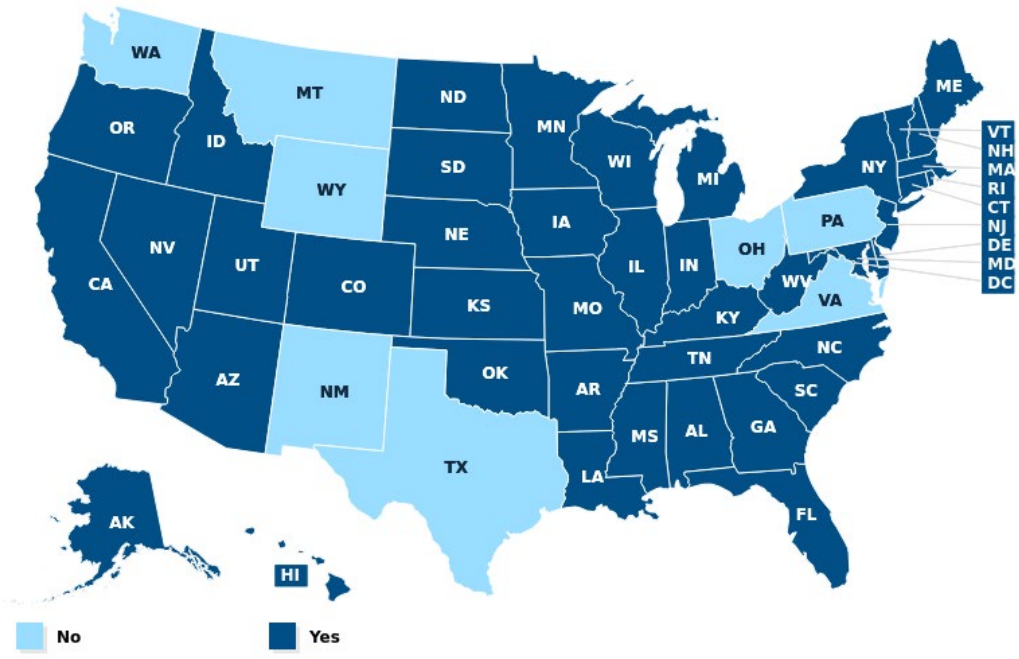
Notably, Katie —who grew up living at home, went on to graduate from college, and lived to age 34—also dedicated her life to advocating for disability rights. She was widely recognized for her motivating speeches and effective lobbying.

Current Policy Shows the Impact and Legacy of Julie Beckett's Action

Section 1902(e)(3) of the Social Security Act (the Act), permits states to extend Medicaid eligibility to certain children who are living at home, who require the level of care provided in an institution, and who would be Medicaid eligible if living in such an institution (e.g., hospital, nursing facility or intermediate care facility). (CMS) Under current policy, to qualify for Medicaid under either the TEFRA/Katie Beckett state plan option or a comparable waiver for home- and community-based services, a child must meet all of these criteria: a) be under age 19 b) have a disability, c) would be eligible for Medicaid if they were living in a medical institution, d) require an institutional level of care that can be safely provided outside of an institutional setting; and d) the estimated Medicaid cost of care at home is no more expensive than the estimated Medicaid cost of institutional care.

As shown in Figure 2, by 2026, 43 states had a Katie Beckett State Plan Option or comparable waiver in place. (States that do not have this policy in place include: MT, NM, OH, PA, TX, VA, WA, WY). (KFF, 2026)

Figure 2. Medicaid Eligibility under Katie Beckett State Plan Option or Comparable Waiver for Children with Disabilities, 2026



Source: KFF State Health Facts Table "Medicaid Eligibility for Katie Beckett Children with Significant Disabilities and Special Income Rule, 2026".

III. *Big P Politics for Children with Disabilities:* Why did the Supplemental Security Income (SSI) have multiple definitions of children with disabilities over a short period of years? Why did Congress override a Supreme Court decision? Who was harmed? Why does this matter today?

What is the SSI program and how does it define children with disabilities?

The Supplemental Security Income (SSI) program was enacted in 1972 (P. L. 92-603) and implemented by the Social Security Administration (SSA) in 1974 to provide cash assistance to certain low-income people considered aged, blind and disabled.[3] For children from birth to the 18th birthday to be eligible to receive SSI benefits, the child must have a severe medically determinable physical or mental impairment (disability) that results in marked and several functional limitations expected to last for at least 12 months or result in death. In addition, the individual must not be employed and must come from a household that does not exceed a certain level of income and resources. (SSA, 2026) The majority of children who are recipients of SSI benefits come from households at or below 200% FPL. In addition to cash benefits, children who qualify for SSI are automatically eligible for Medicaid coverage in most states. (SSA, 2026) Notably, given the fact that the child must have both severe disability and low income, less than 2% of the US child population receives SSI benefits. (NASEM, 2015)

[3] Social Security Act. Section 1604 (42 USC 1381). https://www.ssa.gov/OP_Home/ssact/title16b/1601.htm

Over its 50-year history, the program has evolved through four distinct phases of policy for children, as a result of legislative and judicial action. The larger social and political context influenced the program and its impact for children, including views about children, what constitutes a disability, and how generous cash assistance should be. (NASEM, 2015; Center on Budget and Policy Priorities, 2014; Haskins, 2012; Vallas and Fremstad, 2012).

In the first phase, from 1974-1990, the eligibility standards for children were based on the adult standards (related to employability). This so-called "comparable severity standard" used a list of conditions and did not include an assessment of a child's functioning and health status. Specifically, the statute stated that a child would be eligible for benefits "if he suffers from any medically determinable physical or mental impairment of comparable severity" to one that would disable an adult (SSA, 1991). Many observers found this approach unfair to children with disabilities. First, children don't work and their functional needs are different. Second, no list captures the hundreds of conditions affect children, which can be divided into four broad and overlapping categories: 1) children with developmental delays and disabilities (e.g., intellectual disability), 2) physical conditions (e.g., quadriplegia, spina bifida), 3) children with chronic conditions (e.g., cystic fibrosis, sickle cell anemia), and 4) children with mental/ emotional/ behavioral conditions (e.g., attention deficit hyperactivity disorder-ADHD, mood disorders).[4] These may be present from birth or be diagnosed as a child ages. (NASEM, 2015; Rupp et al. 2006)

The second phase was kicked off by a landmark US Supreme Court decision in 1990 (*Sullivan v. Zebley,* 493 US 521), which ruled that the SSI eligibility determination rules relying on "comparable severity" and a narrow list of conditions were unfair to children with disabilities and emphasized the importance of assessing a child's functioning. Fairness was the principle. As a result, from 1990-1996, based the determination of SSI eligibility for a child was based upon an individualized functional assessment, which measured a child's ability to function independently and effectively in an age-appropriate manner. (SSA, 1995) The SSA also updated medical listings to include seven additional mental health and developmental conditions (e.g., conditions such as ADHD, autism, infant mental health). Between 1991 and 1996, the number of SSI child beneficiaries more than doubled from 397,000 to 955,000, with a substantial portion of new awards being given to children with mental health and developmental conditions (NASEM, 2015, SSA, 1995).

The third policy phase has been from1996 to 2026. In 1996, the structure of the SSI program and its benefits for children was reconsidered at the same time as the national political discussion shifted toward "welfare reform" in the Clinton Administration. President Clinton appointed a National Commission on Childhood Disability, which voted to reduce benefits and made a recommendation for a new definition of childhood disability.

Enacted in 1996, the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA, Public Law 104-193) not only addressed "welfare reform" in terms of cash assistance, it also narrowed the definition of disability for children, including elimination of the requirement for functional assessment and new criteria for the determination of eligibility.

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[4] Social Security Administration. Listing of Impairments – Childhood Listings. Accessed July 23, 2026. Available at: https://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

(PRWORA also terminated SSI eligibility for most non-citizens and its provisions related to immigrants are being reinterpreted in 2026.) Following these changes to the childhood disability determination process and the stricter definition of disability,[5] a decline in the number of awards for new beneficiaries was documented. (Fremstad S & Vallas R, 2012; Bazelon Center, 2012; Loprest, 1999). In early implementation of PRWORA, child SSI recipients who were originally evaluated using functional assessment were reevaluated for eligibility based on the new criteria, which led to the termination of SSI benefits for more than 90,000 children. (Coe and Rutledge, 2013).

The fourth phase of policy for children in SSI began around 2010. The focus was on who was "deserving" and "fraud" – familiar themes in politics today. In part this was driven by an unprecedented rise in the number of applications, and the number of children found to meet the disability criteria between 2000 and 2010. (NASEM, 2015) By 2012, both political and media voices raised concerns about the number of children receiving SSI disability benefits (and Medicaid), with costs also rising. Misunderstandings and misimpressions grew. Speeches in Congress and opinion pieces in newspapers implied that parents were teaching children to pretend to have a disability (i.e., accusing parents of fraud), that children with "mild" disorders received benefits and children were "coached" by parents seeking income. Other critics said that children were being pulled out of school, that children were being given unnecessary psychotropic drugs, and that benefits were too generous. (Center for Budget and Policy Priorities, 2012; US Congress 2011) For example, in December 2010 the Boston Globe published a series of articles that described the experiences and challenges of families that either were currently receiving or else sought to become eligible to receive SSI benefits for their children. (Wen, 2010) An editorial article in the New York Times in December 2012 written by the influential opinion writer Nicholas Kristoff suggested that the growth in the SSI program for children not might be related to increases in the true prevalence of disability in children. (Kristoff, 2012).

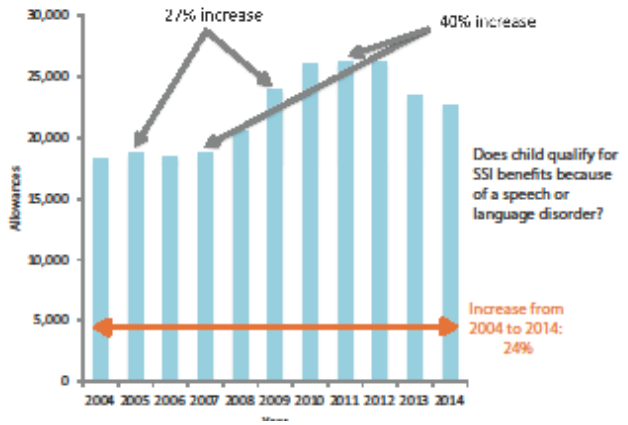
While the data about children in SSI do not support these critics' views, such allegations fueled public and Congressional sentiment. Members of Congress demand investigation and oversight of SSI child benefits in 2011-2015. (US Congress, 2011) Federal studies by the SSA, GAO and OIG indicated that the majority of the growth resulted not from the revised functional criteria, but from an increase in children with mental and other conditions who qualified.

A study by the National Academy of Sciences, Engineering, and Medicine helped to bring the facts forward in 2015. The panel concluded that "*many severely impaired or disabled children in the United States are recipients of SSI benefits. Most children who are recipients of the SSI benefits will have severe impairments and will come from an impoverished household*." Only

[5] Social Security Act Section 416.906. "Basic definition of disability for children. If you are under age 18, we will consider you disabled if you have a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months. Notwithstanding the preceding sentence, if you file a new application for benefits and you are engaging in substantial gainful activity, we will not consider you disabled. We discuss our rules for determining disability in children who file new applications in §§ 416.924 through 416.924b and §§ 416.925 through 416.926a. [62 FR 6421, Feb. 11, 1997, as amended at 65 FR 54777, Sept. 11, 2000]." Available at: https://www.ssa.gov/OP_Home/cfr20/416/416-0906.htm

about half had reported major mental disorders, with no significant increase between 2004 and 2013. The percentage of children who receive SSI benefits varied by state, in part related to patterns of diagnoses and in part related to state policies. (NASEM, 2015) Others found that SSI cash assistance and health coverage increased the likelihood that a family identifies and seeks services for chronic and disabling conditions. (Kubik, 1999) Having children receive needed services was seen by most as a positive result of policy; yet by others seen as too costly or fraudulent.

Figure 3. SSI Trend for Children with Speech and Language Disorders, 2004-2014



Source: National Academies of Sciences, Engineering, and Medicine. (Sara Rosenbaum and Patti Simon, editors.) Speech and Language Disorders in Children: Implications for the Social Security Administration's Supplemental Security Income Program. National Academies Press. 2016. DOI: 10.17226/21872.

FIGURE 5-1 Proportion of children with speech and language disorders in the general U.S. population based on the 2005-2006 and 2009-2010 National Survey of Children with Special Health Care Needs.

The changes in SSI definitions, eligibility criteria, and other policies for children led to fluctuations in the number of children who qualified for SSI benefits. For example, as shown in Figure 3, a special analysis of data regarding SSI enrollment of children with speech and language disorders shows increases and decreases between 2004 and 2014. As is generally true, these fluctuations are not mainly the result of changes in the prevalence of disabilities related to speech and language disorders. The variation in the trend is primarily related to the policies, processes, and criteria used to identify and enroll children eligible for SSI. The problem has been magnified at the state level.

In a positive turn, during the 118th Congress, Members of Congress introduced bills that would have changed certain eligibility criteria for childhood disability benefits. These various proposals would have allowed more individuals to establish or maintain their eligibility for childhood disability benefits but differed in terms of the specific eligibility criteria that would have been changed (e.g. extending benefits to age 22 or 26). (Congressional Research Service, 2025) However, none of these proposals was signed into law.

IV. Advocacy for Policies that Support CSHCN and Disabilities Must Continue

With access to modern medicine, quality pediatric care, and other supports, children with special needs and disabilities have the opportunity to grow, achieve optimal development, engage in school and community, and live for decades. The success of these efforts depends in large measure on strong and effective public policies.

SSI is beneficial for families, reducing stress, economic hardship, and pressure to use out-of-home, institutional care. Families of children with disabilities were almost twice as likely to experience financial hardships than families of children without disabilities. (Houtrow et al., 2025) The families of children with disabilities are more likely to have lower incomes, experience food insecurity, and have overall economic instability. (Constanzo and Reilly, 2023)

SSI Has Benefits for Children, Families, and Communities

- Supports ability to care for child at home, with family
- Replaces some of family Supplies income to help meet additional costs related to disability – reducing economic hardship
- Supplies income if parent(s) must reduce work hours
- Provides Medicaid coverage to increase access to needed health care
- Complements programs such as IDEA for educational success
- Reduces family stress

Public policies undergird the opportunity to thrive. Medicaid coverage and it's guarantee for medically necessary services under the EPSDT benefit is an essential support for nearly half of CSHCN. The SSI program is one pathway to ensure such coverage, as well as provide minimal income assistance. Public policies also support opportunities for inclusion in public schools through the Individuals with Disabilities Education Act (IDEA), and access to home- and community-based services and public accommodations protected under the Americans with Disabilities Act (ADA). All of these are essential for quality of life among people with disabilities, beginning at birth.

However, in the current political climate, the policy interpretation of PRWORA is being revisited. In 2026, revised rules have been proposed to more broadly apply the definition of "public charge" for immigrants. (Homeland Security Department, 2026) The potential for harm to children is great. In addition, pressure to reduce enrollment in Medicaid and other entitlement programs is growing. The One Big Beautiful Bill Act (OBBBA, Public Law 119-21), as passed in 2025, aims to cut approximately $1 trillion in federal funds for Medicaid, forcing states to make adjustments to budgets, eligibility rules, provider payments, and costs in the program. Additional rulemaking is further tightening the requirements for states and heightening the risk for lost coverage. People with disabilities, including children with disabilities, will feel the impact of these changes. (Alker & Kohler, 2026; Edwards, 2025; Vanneman et al, 2025)

Despite variations, much progress has been made. Today, Medicaid, nutrition programs, income assistance, and education programs for children with disabilities are all threatened by Congressional and administrative action. Vigilance by parents and other advocates remains essential to ensuring these public policies remain in place and are implemented effectively and efficiently.

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