

# Supporting Young Children with Disabilities:

## *Solutions for Improving Food Security*

Millions of children in the United States experience chronic physical, developmental, emotional and/or behavioral conditions that require more health-related services than their peers, known as special health care needs (SHCN).<sup>1</sup> A small proportion of children with SHCN have severe enough disabilities or impairments and live in households with low enough incomes to make them eligible for state and/or federal disability benefits, particularly the Supplemental Security Income program (SSI).<sup>2</sup> Among young children receiving SSI, physical disabilities are most prominent.<sup>3</sup> While the population of children with severe physical or cognitive disabilities is just a subset of those with SHCN, all children with SHCN require specialized medical and educational services and/or other supports that often can stress family resources.



The application process for SSI, for those considered to have a disability, is very time-consuming due to extensive medical documentation required from multiple sources and documentation of household finances, including income and assets. Eligibility criteria for SSI receipt are stringent; 60 percent of applicants are denied.<sup>4</sup> Only 1.7 percent of all children in the United States and 3.9 percent of all children in low income families receive SSI.<sup>5</sup>

The rationale for providing families cash assistance through SSI was outlined by the National Commission on Childhood Disability in 1995. The goals of SSI are to:

- Help families care for children with severe special health care needs in their homes;
- Help meet children's basic needs for food, clothing, and shelter;
- Compensate for some of the lost wages when parents are out of work or work fewer hours while caring for a disabled child;
- Offset additional costs associated with raising a disabled child;
- Enhance the child's opportunity to achieve an independent, rewarding, and productive life.<sup>6</sup>

### Summary of Findings

High costs associated with raising a child with disabilities can strain the family budget and lead to trade-offs between basic needs. Children's HealthWatch research demonstrated that families of children with SHCN who receive SSI were more likely to be food insecure compared with families of children with SHCN not receiving SSI.

### Recommended Policy Solutions:

- Sustaining SSI benefit levels to ensure that children with SHCN continue to receive adequate support for medically complex needs
- Lifting asset limits for SSI
- Coordinating benefit program rules & discounting SSI income for SNAP eligibility
- Systematically informing families of children with SHCN of their potential eligibility for medical expense deduction in calculating net income for determining SNAP benefits.



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*Children's HealthWatch is a nonpartisan network of pediatricians and public health researchers with the mission to improve the health and development of young children by informing policies that address and alleviate economic hardships.*





SNAP has been shown to decrease food insecurity across many populations.<sup>20,21,22</sup> The higher risk of food insecurity among families of children receiving SSI, even for those also receiving SNAP, may be due in part to the complex eligibility relationship between SSI and SNAP.<sup>5</sup> What is not widely known is that families who begin to receive SSI may experience a reduction or loss of SNAP benefits, because SSI (unlike income from jobs up to a certain level) is considered fully countable income for the purposes of calculating SNAP benefits (when income is higher, SNAP benefits are generally lower).

Moreover, competing needs present in all families—food, rent, utilities, health care—may be more expensive overall than normal for a family with a child receiving SSI. Some of these increased costs may be due to necessities like special medical foods, medical equipment that may exceed Medicaid coverage, extra electricity costs for equipment, or special housing or housing modifications necessary for those with physical disabilities. Previous research has shown that SNAP benefit levels are not enough to purchase an ordinary healthy diet, regardless of whether the household includes a child with SHCN.<sup>23</sup> Therefore, given that special medical foods are often more expensive than other foods, the SNAP benefit is also insufficient to cover the extra cost for the affected child and simultaneously meet the needs of all other household members. Though a child receiving SSI may qualify for the medical deduction in SNAP, theoretically allowing the family ‘credit’ for all of the increased costs by deducting them from their income, eligible families may not be aware that they can access this deduction or know what it covers.

“I am a single mom of two children with special needs and even though my kids don’t have any co-pays or deductibles, there are still plenty of expenses related to their care that make it tough to make ends meet. When you look at how much I spend for things insurance doesn’t cover, like gas to all the appointments, parking fees, over the counter medications, etc. it is frustrating to hear that you don’t qualify for any financial help. Working more hours or changing jobs would not help as the cost of child care for older special needs children is not affordable, and starting over at a new job would not work with all the time I need to take off for appointments. I’m stuck at the financial level where I am with no hope of getting out.”

Angela Sitter, Parent Health Leader for Children and Youth with Special Health Care Needs, Maryland

## Policy Solutions to Support Children with SHCN Receiving SSI

An understanding of the unique challenges and barriers faced by families of children receiving SSI should inform policy changes that improve the financial stability of these families. Potential policy solutions include:

### 1. Sustaining SSI benefit levels to ensure that children continue to receive support for medically complex needs

- The SSI benefit offsets a portion of the costly medical, therapeutic, and/or education needs of families with children with SHCN. Without this support, families would face even more severe material hardships.

### 2. Modifying the asset limit for SSI and indexing it to inflation

- Families of children with disabilities receiving SSI cannot accrue more than \$3,000 in assets, making it difficult for them to absorb financial hardships that may arise suddenly. Additionally, asset limits impede families from saving money in order to exit poverty. Lifting the asset limits would allow such families to better stabilize themselves financially.

### 3. Partially discounting SSI income for SNAP eligibility

- Currently, SSI is counted as unearned income for SNAP eligibility and is not subject to the income discount applied to earned income. Discounting SSI income in the SNAP calculation to acknowledge the increased needs and costs associated with raising a child with SHCN would provide families with more nutritional support and help to alleviate the squeeze on household budgets for other basic needs like rent, utilities, and health care expenses.

### 4. Simplifying the verification process for medical expense deduction for SNAP

- To receive the medical expense deduction, families with children on SSI are able to deduct the monthly cost of medical expenses over \$35 in calculating their net income for SNAP benefits. Simplifying this process for families and bringing greater awareness to the deduction will enable more families to maximize their SNAP benefits.

Future research should explore similar policy solutions in other non-nutrition programs designed to support families experiencing economic hardships, including for unemployment, worker’s compensation, and child support.

## Complex SSI Application Process

Eligibility for SSI relies on two major factors: severity of medical condition and financial need. The Social Security Administration's definition of disability for children is very strict. The child must have a physical or mental condition(s) seriously limiting activities and lasting, or expected to last, at least one year or result in death.

The SSI application for children is very complex and even after all the required paperwork is submitted, notification of SSI determination takes three to five months. If the state agency is unable to make a determination based on the information provided, the agency may request an additional examination of the child. The Social Security Administration rejects about 60% of the applications submitted for SSI for children.<sup>24</sup> Even after a child is approved to receive SSI, the law requires periodic reviews of the medical condition to verify that the condition still meets criteria for disability benefits.

Caregivers must attend multiple interviews with Disability Determination Services where they must provide detailed information about their child's medical condition and grant the agency permission to contact qualified medical professionals to submit evidence of a medical or mental condition meeting disability criteria. To qualify for the SSI income eligibility criteria, a family's countable income and assets/resources cannot exceed the federal benefit rate, which represents both the SSI income limit and the maximum federal monthly SSI payment.<sup>25</sup> For example, a one parent household with only one child eligible for SSI and no other child must earn less than \$3,057 in earned income (i.e. wages) or \$1,873 in unearned income (i.e. Social Security benefits, pensions, unemployment compensation) per month.<sup>26</sup> Additionally, families with children cannot accrue more than \$3,000 in assets such as savings accounts, life insurance cash values, cars, and savings bonds to retain eligibility for SSI.

This already complex application process is further complicated by access limitations such as the need for multiple face-to-face interviews at locations not necessarily accessible by public transportation for families with a child with severe disabilities.



## Example of Disability Severity

Documenting a child's disability requires verification from physicians who must follow guidelines established by the Social Security Administration. For example, asthma is the most frequently reported health condition among children with special health care needs with or without SSI in the Children's HealthWatch dataset. To qualify for SSI, however, a child's asthma must be severe enough to result in asthma attacks that require physician intervention, despite prescribed treatment, at least once every two months or at least six times in one year. This determination may only be made after an evaluation period of at least 12 consecutive months to determine the frequency of asthma attacks. Alternatively the child must have persistent low-grade wheezing between acute attacks that requires daytime and nocturnal use of medical equipment to manage.<sup>27</sup> Managing asthma is difficult and often requires additional non-medical expenses to improve housing quality, such as purchasing air filters for a child's home. Because of these stringent medical criteria, only children with the most severe asthma diagnoses qualify for SSI.

## Conclusion

SSI for children serves those with severe special health care needs and is a crucial resource for low-income families caring for them. However, financial support from SSI may not be enough to buffer families from food insecurity, putting children's health at risk. Ensuring that benefit levels for SSI provide enough resources to address the increased financial burdens placed on families of children with SHCN is important for alleviating hardships. Additionally, improving SNAP policies to further support the nutritional needs of these families is a crucial step to ensuring that children are well-nourished and they and their families are able to thrive.

**About Children's HealthWatch** Children's HealthWatch is a nonpartisan network of pediatricians, public health researchers, and children's health and policy experts. Our network is committed to improving children's health in America. We do that by first collecting data in urban hospitals across the country on infants and toddlers from families facing economic hardship. We then analyze and share our findings with academics, legislators, and the public. These efforts help inform public policies and practices that can give all children equal opportunities for healthy, successful lives.

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