In Part I of this series of policy action briefs on increased hardships and barriers faced by families of children with SHCN, Children’s HealthWatch found that more families with young children with SHCN experienced more material hardships. Troubling advances in basic needs like food housing and utility costs than similar families of young children without SHCN.

In Part II of this series, we focus specifically on food insecurity, the inability to afford enough food for the whole family to eat. In addition to children with SHCN, this also affects other families with the most severe health challenges. Despite the assistance of families of children with SHCN who receive SSI at the highest risk of food insecurity when compared to children with SHCN, but no SSI and those who do not have SHCN. While seemingly contradictory, it is, in fact, logical given current policy.

The rationale for providing families cash assistance through SSI was outlined by the National Commission on Children and Families in 1994.

Successive administrations have adopted a policy of compensating for some of the lost wages when parents are out of work or work fewer hours while caring for a child who has a disability.

Help meet children’s basic needs for food, clothing, and shelter;

Help families care for children with severe special health care needs in their homes;

Supporting Young Children with Disabilities: Solutions for Improving Food Security

Millions of children in the United States experience serious physical, developmental, emotional, and behavioral conditions that require more health-related services than their peers, known as special health care needs (SHCN). A small proportion of children with SHCN have severe enough disabilities or impairments and live in households with low enough incomes to qualify them eligible for Title II of the Social Security Disability Insurance program (SSI). Among young children enrolling in the physical disabilities group, SSI are most prevalent. While the population of children with severe physical or cognitive disabilities is just a subset of those with SSI, all children with SSI require specialized medical and educational services, and, in the worst cases, often lose their ability to live independently.

The application process for SSI, for those considered to have a disability in any time spanning due to extensive medical documentation required to file multiple requests and documentation of household finances, including income and assets. Eligibility for the SSI program is determined by the Social Security Administration through the process of financial need and medical eligibility.

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Summary of Findings

High costs associated with caring for a child with disabilities can strain the family budget and health insurance. Sustained SSI benefit levels demonstrated that families of children with SHCN who receive SSI are even more likely to include an SSI payment among their income compared with families of children with SHCN living below the poverty line.

Recommended Policy Solutions:

• Maximizing benefit through SSI rules

• Combining benefit programs to reduce SSI eligibility

• Systematically enforcing families of children with SSI of the potential eligibility for medical expense deduction in calculating net income for determining SSI eligibility

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Children’s HealthWatch is a nonpartisan network of pediatricians, public health researchers, and children’s health and policy experts. Our network is dedicated to empowering parents and families of children with special health care needs (SHCN) to improve their children’s health and well-being.

Background

Steps Forward: Strengthening SSI for Children with Special Health Care Needs

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Supporting Young Children with Disabilities: Solutions for Improving Food Security

Billions of children in the United States experience chronic physical, developmental, emotional and/or behavioral conditions that require ongoing medical and/or developmental services. Every year, the health care system spends over $200 billion on the care of children with special health care needs (SHCN). A special characteristic of children with SHCN is severe enough disabilities that significantly impair daily functioning and are likely to persist into adulthood. Children with SHCN have higher levels of poverty, have higher rates of food insecurity and have more difficulty achieving economic stability than other children. Supporting young children with disabilities is critical to improving their health and future opportunities for healthy, successful lives.

Families of children with SHCN at high risk of food, housing, or energy insecurity

In part of this review, we focus specifically on food insecurity, the inability to afford enough food for a healthy diet for all members of a household. In the simulation of 120,000 children with SHCN, 80% also receive SSI, or other words those with the most severe health challenges. Despite the assistance of SSI, families of children with SHCN who receive SSI are at highest risk of food insecurity when compared to children with SSI but no SSI and those who do not have SSI. While seemingly counterintuitive, this is due to logical government policy; receipt of SSI is associated with significant disability related expenses that may compete with limited household income, including the food budget.

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Summary of Findings

High costs associated with caring for 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 are more likely to be in food insecure compared with families of children with SSI receiving other forms of cash assistance.

Recommended Policy Solutions:

• Maximizing Supplemental Security Income (SSI) benefits to ensure that children with disabilities continue to receive adequate support to meet basic needs.

• Liftgates for busses.

• Combining benefit programs to reduce disparity in income for SNAP eligibility.

• Systematically informing families of children with SHCN of the potential eligibility for medical expense deduction in calculating net income for determining SSI benefits.

The application process for SSI for those considered to have a disability is very time consuming due to extensive medical documentation required to file a multiple forms and the determination of household financial resources, including income and assets. Equally, a single SSI application may require an average of 10 forms. By year 2015, all children are expected to receive SSI.

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Increased risk of food insecurity among families of young children with disabilities

Food insecurity is directly connected to family income and wealth. Families of children enrolled in SSI are more likely to face food insecurity as an economic reality. Families of children with SHCN, specifically those managing higher levels of disability, are more vulnerable to food insecurity.23,24


greater awareness to the deduction will enable more families to know they are eligible for SSI income tax deduction and will help to alleviate the squeeze on household budgets for other basic needs like transportation.5

In addition, improving SNAP policies to further support the nutritional needs of these families is a crucial step to ensuring that children with SHCN are well-nourished and they and their families are able to thrive.

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Families of children with rare conditions may not face food insecurity as an economic reality, but it is a major concern for families of children with disabilities, including food insecurity.23

"I am a single mom of two children with special needs and even though my kids don't have any co-pays or deductibles, they 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 on medical equipment, I don't even have a co-pay on that because they don't have medical equipment."

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CHILDREN’S HEALTHWATCH

POLICY A BRIEF

AUG 2020

Increased risk of food insecurity among families of young children with disabilities

Children with and without special health care needs (SHCN) face higher risk of inadequate or at-risk food insecurity, with some children at even higher risk for extreme food insecurity. For example, families of children with SHCN are facing additional food insecurity challenges due to increased costs associated with medical expenses. This additional cost is exacerbated by food insecurity, which is a common issue for many children with disabilities. It is estimated that over 50% of children with disabilities are food insecure at some point during childhood.

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 allow policymakers to develop policies that are more targeted toward this group of children. For example, policies that provide additional financial support for families receiving SSI may help to reduce the risk of food insecurity for children with disabilities. Additionally, policies that provide additional support for children with disabilities, such as those that provide additional nutritional support, may help to reduce the risk of food insecurity for children with disabilities.

Complex SSI Application Process

Eligibility: To apply for SSI, individuals must meet both the financial and medical criteria. The child must have a medical condition that meets the Social Security Administration’s “severe disability” standard. The child must also have a low income, as defined by the state where they reside.

Example of Disability Severity

Disabling, in a SSI context, is determined by whether reasonable medical criteria exist to support application for SSI. For example, asthma may be classified as a disabling condition if it significantly limits the ability to participate in daily activities such as work or school. However, if the condition is medically severe but does not prevent the individual from performing all of the major life activities associated with daily living, it may not be considered a disability for SSI purposes.

Conclusion

SSI is a valuable benefit for children with special health care needs. However, the application process can be lengthy and complex, and families with children with disabilities may face additional barriers to accessing SSI. As a result, policymakers and stakeholders must continue to work towards improving the application process and ensuring that families with children with disabilities are able to access the support they need.

Figure 1: Rates of household food insecurity among children with and without SHCN

Household Food Insecurity:

Household food insecurity is defined as the inability of a household to acquire enough food for an active, healthy life because of insufficient income or resources to do so. Food insecurity can be mild, moderate, or severe, with severe food insecurity indicating a lack of access to food at any time over the past year.

Childhood Food Insecurity:

Childhood food insecurity occurs when children regularly go to bed hungry, are underweight, or fail to eat enough food to meet their nutritional needs. Childhood food insecurity can be mild, moderate, or severe, with severe childhood food insecurity indicating a lack of access to food at any time over the past year.

Increased food insecurity among families of young children with disabilities

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Improved food insecurity among families of young children with disabilities

Children with special health care needs (SHCN) are more likely to be food insecure. Food insecurity can have a significant impact on health and development. Children with SHCN may face a range of challenges that make it even more difficult to ensure that they are food-secure.

Figure 1: Rates of household and child food insecurity among children with and without SSI

<table>
<thead>
<tr>
<th>Household Food Insecurity</th>
<th>Child Food Insecurity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood with SSI</td>
<td>Childhood without SSI</td>
</tr>
<tr>
<td>30%</td>
<td>20%</td>
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</tbody>
</table>

The rates of food insecurity among children without SSI are significantly lower than those who receive SSI. The SSI program is intended to provide enough support to families to meet their basic needs, but the high prevalence of food insecurity among children with SHCN highlights the need for additional support.

Increased risk of food insecurity among families of young children with disabilities

Children with special health care needs are more likely to have difficulty accessing adequate food. This is due to a combination of factors, including:

- Limited access to nutrition education and resources
- Difficulty obtaining affordable, healthy food options
- Increased costs associated with special medical foods
- Limited ability to prepare meals
- Competition for resources within the family

The SSI program is designed to provide financial support to families of children with disabilities, but it may not be sufficient to meet the increased needs of these families. Therefore, additional support is needed to ensure that children with SHCN are able to access nutritious food and meet their basic needs.

Solution Policies to Support Children with SHCN Receiving SSI

An understanding of the unique challenges and successes faced by families of children receiving SSI should influence policy changes that seek to improve food security among these families. The following policy recommendations are based on the needs and experiences of families with children receiving SSI.

1. **Better coordination of SSI and SNAP to improve food security among families of young children with disabilities**

   - **Policy Solution:** Ensure that families of children receiving SSI are aware of the SNAP (Supplemental Nutrition Assistance Program) and understand how to apply for and receive benefits. This will help families access additional support to meet their food needs.

   - **Example:** The SNAP program provides food assistance to low-income individuals and families, which can help offset food insecurity among children with SHCN. By increasing awareness of the SNAP program, families can be better equipped to meet their nutritional needs.

2. **Addressing the increased costs associated with special medical foods**

   - **Policy Solution:** Implement policies that acknowledge the increased costs associated with special medical foods. This may include tax breaks or other supports to help families cover these costs.

   - **Example:** Children with special health care needs may require special medical foods to meet their nutritional needs. Providing tax incentives or other supports can help families afford these foods and improve overall nutrition.

3. **Improving the medical condition recognition process for Medicaid and SNAP eligibility**

   - **Policy Solution:** Streamline the Medicaid and SNAP eligibility process to ensure that children with special health care needs are recognized and receive the support they need.

   - **Example:** Children with special health care needs may have difficulty accessing Medicaid and SNAP due to the complexity of the application process. By simplifying these processes, families can more easily access the support they need to meet their nutritional needs.

Conclusion

SSI is a valuable program that provides support to children with special health care needs. However, additional support is needed to ensure that children with SHCN are able to access nutritious food and meet their basic needs. By implementing the policies outlined above, we can work towards providing the necessary support to ensure that all children, regardless of their health status, are able to access nutritious food and meet their basic needs.
Families of children with SHCN at high risk of food, housing, or energy insecurity

In Part II of this series of policy action briefs on increased hardships and barriers faced by families of children with SHCN, Children’s HealthWatch found that more families with young children with SHCN experienced more material hardships (struggling to afford basic needs like food and utility costs) than similar families of young children without SHCN.

In Part II of this series, we focus specifically on food insecurity, the inability to afford enough food for one’s household to eat adequately. Federal data on all income, race, and ethnicity groups show that all families of children with SHCN who receive SSI also receive SNAP. Focusing on food insecurity allows us to further explore and understand the trade-offs between basic needs.

While extremely counterintuitive, it is, in fact, logical given current policy: receipt of SSI is associated with significant disability-related expenses that may complicate hardship and resource allocation for families of children with SHCN. In contrast, receipt of SNAP is associated with increased hardship for families of children with SHCN who do not receive SSI.

The application process for SSI, for those considered to have a disability, is very time-consuming due to the application process. Applicants must complete a lengthy application and submit it within a strict time frame. Families who do not have adequate disabilities-related evidence may be denied coverage.

To address and alleviate economic hardships faced by families of children with SHCN, policies need to focus on the development of children with SHCN. By addressing the economic needs of families of children with SHCN, policymakers can improve the health and well-being of these children.

Summary of Findings

High costs associated with raising a child with disabilities can strain the family budget and health insurance

Findings

- Families of children with special health-care needs are more likely to experience food insecurity
- Families of children with special health-care needs are more likely to have lower income
- Families of children with special health-care needs are more likely to have higher medical costs

Recommendations

- Increase SNAP benefits to ensure that children with SSI continue to receive adequate support for basic needs
- Prioritize funding for SNAP eligibility and benefits

Conclusion

While the population of children with special health-care needs continues to grow, policymakers and other stakeholders must work to ensure that families of children with SHCN have access to the resources and support they need to thrive.

For additional information on policy action briefs, contact

patricia@childrenshealthwatch.org

To download this brief, please visit

www.childrenshealthwatch.org/

Supporting Young Children with Disabilities: Solutions for Improving Food Security

Millions of children in the United States experience chronic physical, developmental, emotional, and behavioral conditions that require medical-related services (that are greater than those known to be required for special health care needs). SSI is a program that provides children with special health-care needs (SHCN) with financial assistance. Children with special health-care needs are more likely to receive SSI than their peers.

SSI provides children with financial assistance, including:

- Help cover children’s basic needs: food, clothing, and shelter
- Refund for SNAP eligibility
- Medical benefits

The application process for SSI is often more complicated and time-consuming than other federal programs. Parents of children with special health-care needs often face significant challenges in the application process.

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