

Children with Special Health Care Needs and Disabilities: Solutions for Stable Homes

Young children with special health care needs (SHCN) are those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services beyond those required by children of similar ages.¹ Children with SHCN may or may not have a diagnosed disability. Children with special health care needs require stable homes as they are particularly vulnerable to the harmful health effects of material hardships. Raising a child with SHCN often strains a family's budget, due to increased costs linked to lost parental work time. This is associated with caring for the child; taking them to medical and educational appointments; home modifications; and out-of-pocket medical expenses.² Indeed, families of children with SHCN have higher rates of poverty and are at increased risk of food insecurity and housing instability.³⁻⁶

Health, behavioral, and emotional conditions of children with SHCN cover a wide range of severity levels. Screening children for SHCN through parental report may identify children with significant medical issues, but due to their young age or other factors, they cannot yet have a clear medical diagnosis. Even prior to a child receiving a formal medical diagnosis, families still may deal with considerable expenses trying to meet their child's increased medical needs.



Screening for Special Health Care Needs

Children with SHCN are identified using a validated, five-question parent-reported Special Health Care Needs screening tool. Children with SHCN have an ongoing (having lasted or expected to last more than 12 months) health condition, which requires any one or more of the following criteria:

1. Need for use of prescription medication;
2. Need for medical care or educational services beyond routine services;
3. Need for use of special treatment or therapies;
4. Need or use of mental health counseling;
5. Functional limitations due to medical, behavioral, or health conditions.

Health conditions might include: severe allergies, asthma, cancer, heart problems, neurological conditions such as cerebral palsy, epilepsy, and serious developmental delay.

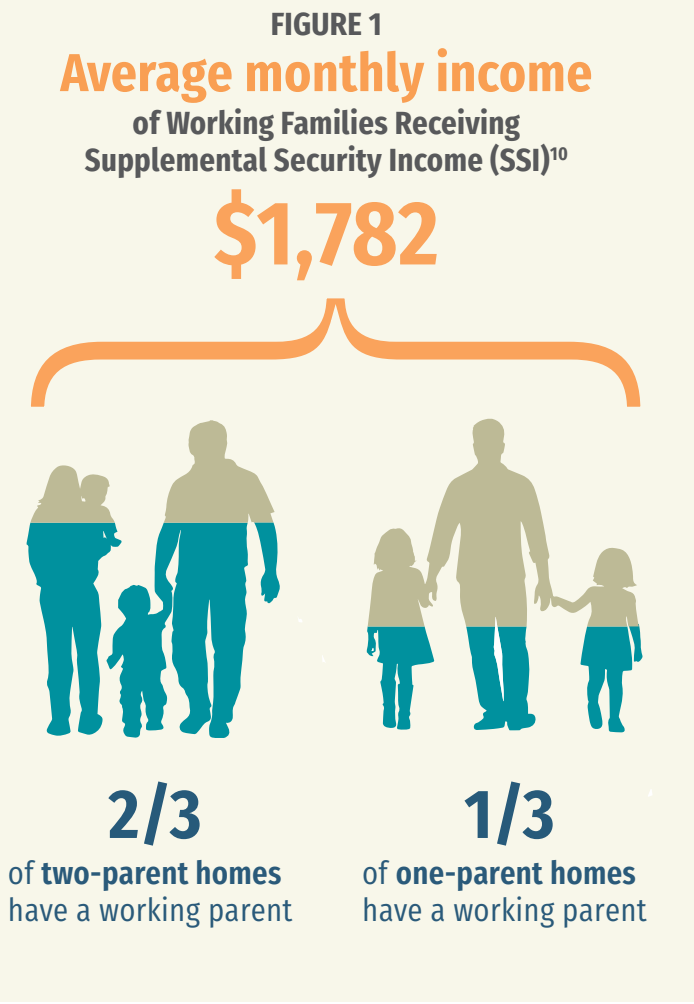
Children diagnosed with severe special health care needs may also be considered disabled. Some children with disabilities qualify for SSI. Families of children with disabilities may apply for the federal Supplemental Security Income (SSI) childhood disability benefits if 1) the child meets rigorous documented medical disability qualifications (i.e. has a medically determinable impairment resulting in “marked and severe functional limitations” expected to last at least 1 year or result in death) and

2) the family meets stringent low income qualifications.^{7,8} Currently, fewer than 2 percent of children are eligible for SSI or any other state or federal disability benefit.⁹ SSI is intended to 1) offset some of the significant medical costs related to the care of the child and 2) partially compensate for lost wages when parents need to truncate their work hours in order to care for their child.

Families of Children with SHCN Are Particularly Vulnerable to Housing Instability

All families of young children experiencing housing instability are at risk of poor child health and development and poor maternal physical and mental health. They also face greater economic hardships.¹¹ Maintaining housing stability for families with children is important and is strongly linked to healthy child development.¹² Housing stability is especially important for children with SHCN because establishment of daily routines within a home environment and proximity to social, familial, medical, and educational support networks are necessary to ensure children’s health and emotional needs are met.¹³ Moving frequently, or especially experiencing homelessness, may disrupt these supports.

Currently, there is limited research on potential risks of housing instability among families of young children with special health care needs, whether or not they are considered to have a disability. If they have a disability and receive SSI there is also little information regarding whether SSI receipt might help decrease risks of housing instability by helping to offset some of the medical and educational expenses. This study aimed to examine these connections.



Summary of Findings

All children need stable homes to thrive. High costs associated with raising a young child with special health care needs (SHCN) may strain a family's budget and impact their ability to afford housing expenses. Children's HealthWatch research demonstrates that compared to children without SHCN, children with SHCN are more likely to live in families who:

- were behind on rent in the past year
- moved two or more times in the past year
- were homeless during the child's lifetime

In this study, we found that for those children qualifying medically and financially for SSI, SSI may help to mitigate housing instability and may protect their families from disruptions that accompany frequent moves or homelessness, the most physically disruptive types of housing instability.

Recommended Policy Solutions

1. Increase Department of Housing and Urban Development (HUD) funding for affordable homes
2. Reduce barriers to non-housing assistance programs that improve housing stability
3. Screen for and respond to housing instability in clinical settings that serve all children, but especially those with SHCN
4. Maintain SSI structure
5. Increase income limit for SSI and index to inflation
6. Modify asset limits for SSI and index to inflation





Housing Instability:

When families experience any one or more of the following adverse housing conditions: unable to pay rent or mortgage on time, moved two or more times in the previous year, or have a history of homelessness in the child's lifetime.



Food Insecurity:

When families are unable to afford enough food for all members to lead active, healthy lives.



Families of Young Children with Special Health Care Needs are at Increased Risk of Living in Unstable Housing

Children's HealthWatch has previously shown that families of young children with special health care needs, with and without SSI benefits, were more likely to experience food insecurity.¹⁴

This new research examines the linkages between housing instability and families with low incomes who have young children with special health care needs with and without SSI. In a sample of 14,188 low-income children whose caregivers participated in the Children's HealthWatch interview during their child's visit to the emergency department or primary care clinic, 80.4% of children were identified as not having SHCN, 15.5% did have SHCN but did not receive SSI, and 4.1% of children have SHCN and received SSI.

Compared to families with children without SHCN, families of children with SHCN were at greater risk of housing instability. Specifically, families of children with SHCN were:

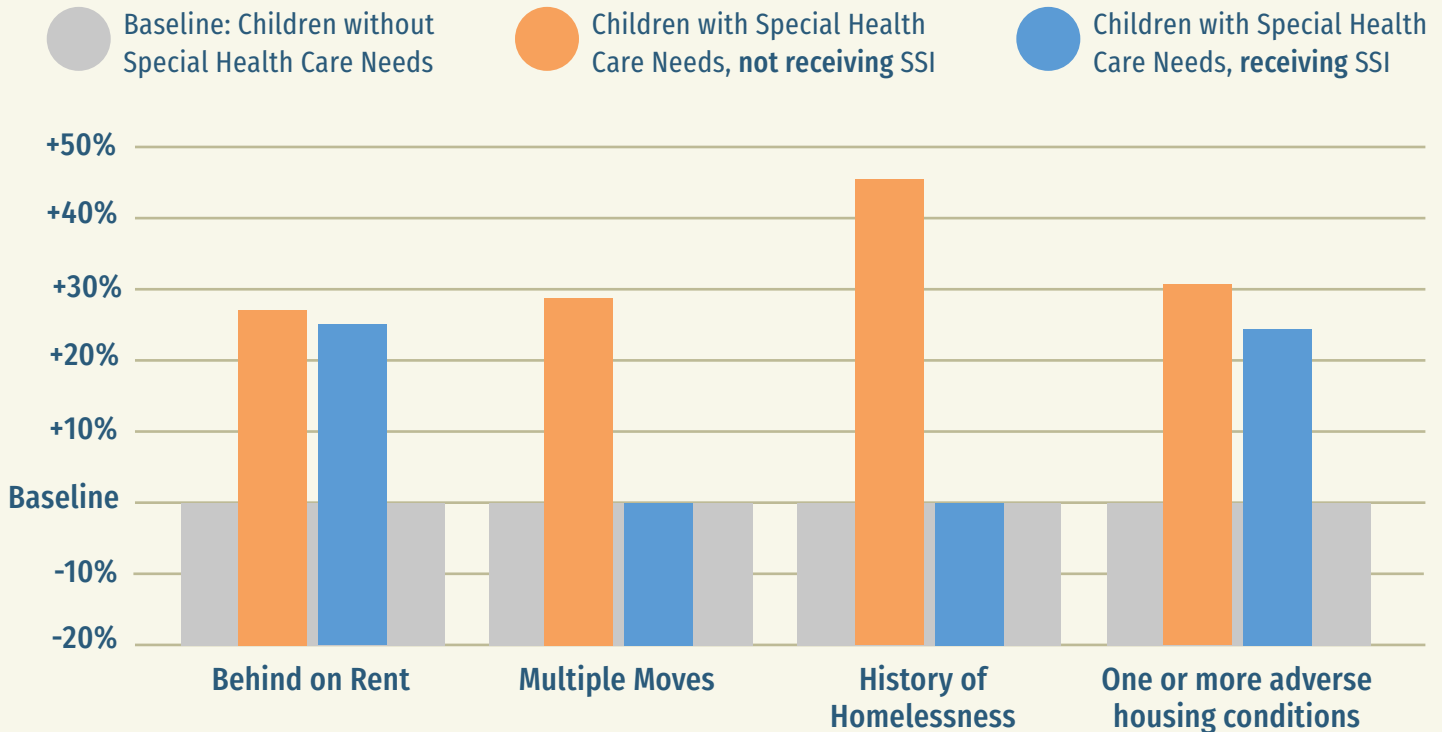
- 27 percent more likely to have been behind on rent in the previous year
- 21 percent more likely to have moved two or more times in the previous year
- 42 percent more likely to have experienced homelessness during the child's lifetime

SSI Decreases Risk of Some Adverse Housing Conditions

We also statistically compared housing instability among families of children a) without SHCN, b) with SHCN who did not receive SSI, and c) with SHCN who received SSI. Most children in the sample had either public or no health insurance: 91 percent of children without SHCN, 92 percent with SHCN not receiving SSI and 95 percent of children receiving SSI.

FIGURE 2

Children with SHCN who receive SSI may be protected from some adverse housing conditions



We found that SSI may help to mitigate housing instability and may protect families of children with SHCN from disruptions that accompany frequent moves or homelessness, the most disruptive types of housing instability.

Compared to families of children without SHCN:

Families of children with SHCN but not receiving SSI were at greater risk of experiencing all three conditions of housing instability. They were:

- 27 percent more likely to be behind on rent in the previous year
- 29 percent more likely to move two or more times in the previous year
- 46 percent more likely to have experienced homelessness in the child’s lifetime
- 31 percent more likely to have experienced one or more adverse housing conditions

Compared to families of children without SHCN, families of children with SHCN receiving SSI were:

- 25 percent more likely to be behind on rent in the previous year
- 25 percent more likely to report one or more adverse housing condition

There were no significant differences in reports of a history of homelessness or multiple moves between families of children with SHCN receiving SSI and children without SHCN.

Conclusion

Stable housing is critical for optimal health in early childhood and is especially necessary for children with SHCN. Increased costs associated with raising a child with SHCN, regardless of the severity of the child's health needs, places families at greater risk of material hardships, including housing instability. For families of children with disabilities with low

incomes, SSI is a critically important resource. SSI may also help buffer families from moving frequently or experiencing homelessness. However, policies and programs that help families of children with SHCN, regardless of SSI eligibility, are necessary to ensure all children thrive.



Policy Recommendations

Helping children with SHCN to thrive is achieved by providing resources that help families afford the necessary additional medical and related expenses for the child without excessively burdening the family budget and economic stability. In this way SSI mitigates some risks of housing instability. Improvements to SSI and increased access to affordable homes will improve the health and well-being of children with SHCN. We recommend the following policy solutions:

- 1. Increase Department of Housing and Urban Development (HUD) funding for affordable homes:** Communities across the country lack enough affordable homes for families with children, regardless of SHCN. Improved funding and access to HUD programs such as the Section 8 Housing Voucher Program, the National Housing Trust Fund, and HOME Investment Partnership Program are necessary to meet the needs of families. Policy makers should also create a mechanism for providing families flexible funds for emergency stabilization and eviction prevention as strategies for preventing homelessness, especially for children with SHCN.
- 2. Reduce barriers to non-housing assistance programs that improve housing stability:** Previous Children's HealthWatch research shows that families who participate in nutrition assistance programs as well as housing support programs are more likely to live in stable housing.¹⁵ Providing families with streamlined access to multiple benefits is key to ensuring that children, especially those with SHCN, live in stable housing.
- 3. Screen and respond to housing instability in clinical settings:** Unstable housing is a known health risk for all families. Screening for housing instability using validated measures and providing referrals and supports for families experiencing hardship is important to ensure children with SHCN and all children are able to achieve optimal health.¹¹
- 4. Identify children likely eligible for SSI in clinical settings:** In addition to screening for housing instability, pediatric providers should also identify children who are likely eligible for, but not receiving, SSI and refer them to the program as appropriate.
- 5. Maintain SSI structure:** The SSI benefit offsets a portion of the costly medical, therapeutic, and/or educational needs of children with SHCN. Without the ability to financially offset some of these expenses and choose what is best for their child, families would face even more severe material hardships.
- 6. Increase income limit for SSI and index to inflation:** Raising the SSI income limit and indexing it to inflation ensures families are able to maintain work in current labor markets and would help families earn wages necessary to better support their children.
- 7. Lift asset limits for SSI and index to inflation:** Lifting asset limits will help families save for when unexpected events happen without losing benefits necessary to care for their child with disabilities. Raising limits would allow families to better stabilize themselves financially while also caring for a child with SHCN.

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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