

Nurturing Children

Solutions to Alleviate Hardships and Barriers for Families of Children with Special Health Care Needs

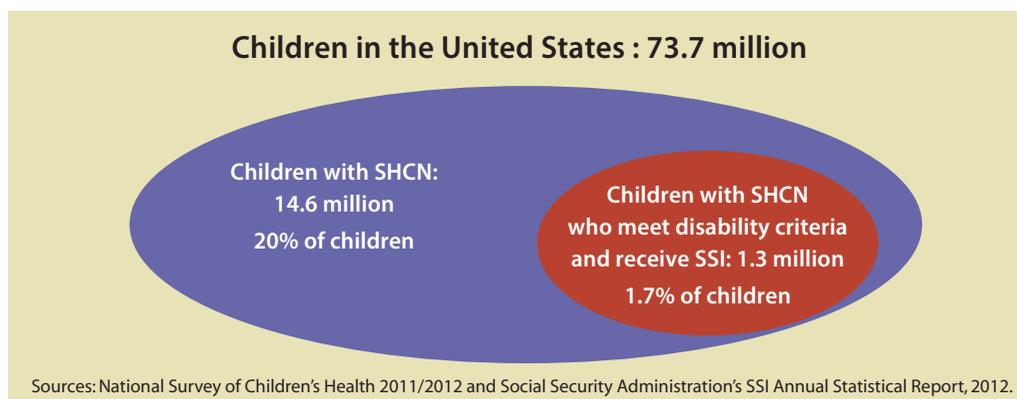
Part I of II

Over two million children in the United States under the age of 5 have special health care needs (SHCN) – experiencing chronic physical, developmental, emotional and behavioral conditions that require more health and related services than their peers.^{i,ii} This policy brief is the first in a two-part series exploring economic hardships faced by families with children with SHCN and relevant policy solutions.

Children with SHCN are identified using a validated, five-question screening tool. To meet SHCN criteria using the screener, a parent must report that their child has an ongoing (having lasted or expecting to last more than 12 months) health condition, which requires any of the following: (1) need or use of prescription medication; (2) need for medical care or educational services beyond routine services; (3) need or use of special treatment or therapies; (4) need or use of mental health counseling; (5) functional limitations due to medical, behavioral, or health conditions. Many children with SHCN meet more than one of these criteria. Health, behavioral, and emotional conditions of children with SHCN cover a wide range of severity levels. Use of this screening instrument may identify children with significant medical issues, but due to their young age or other factors, they may not yet have a clear medical diagnosis. However, 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. Health conditions might include: severe food allergies, asthma, cancer, heart problems, neurological conditions such as attention deficit and hyperactivity disorder, cerebral palsy, epilepsy, and serious developmental delay.

Some children with the most severe diagnoses associated with SHCN may also meet disability criteria, making them eligible for federal and state benefits not available to most children with SHCN. One federal program, Supplementary Security Income (SSI), for children is intended to offset some of the financial burden families low-income households face when raising children with severe SHCN. However, the bar for receiving SSI is very high; children eligible for SSI must have a medically determinable physical and/or mental impairment with marked or severe functional limitations that may cause death or are expected to last for at least 12 months.ⁱⁱⁱ The diagram below illustrates how many children with SHCN – both those who do and do not receive SSI – fit within the wider population of children.

Figure 1. One-fifth of U.S. children ages 0-18 have SHCN but just 1 in 50 have severe disabilities



Summary of Findings

Compared to families with young children without special health care needs, families with young children with special health care needs (SHCN) have higher rates of:

- Household food insecurity
- Child food insecurity
- Frequent moves
- Threatened utility shut-offs
- Actual utility shut-offs or use of a cooking stove to heat their home

Recommended Public Policy Solutions

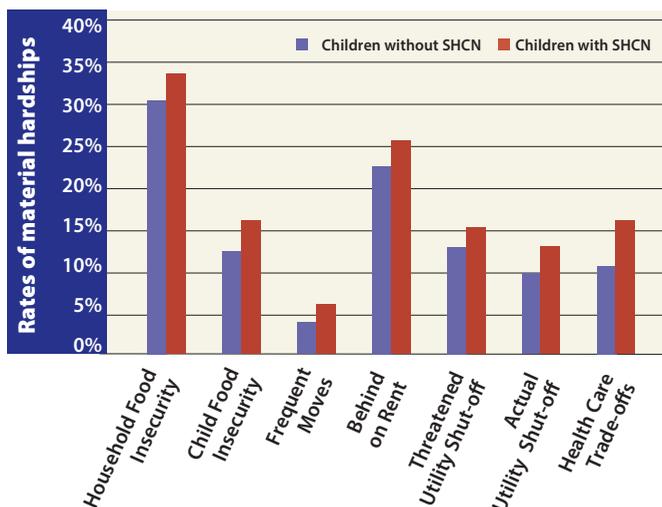
- Expand existing list of special medical foods for children with SHCN available through WIC
- Provide additional SNAP benefits for families with children with SHCN by broadening access to the medical deduction
- Expand funding for and number of housing subsidies available to low-income families, especially those with children with SHCN
- Broaden access to and/or implement utility shut-off protection policies for families of children with SHCN



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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.

Figure 2. Low-income families of young children with SHCN have higher rates of economic hardship than similar families whose young children do not have SHCN.



Source: Children's HealthWatch Data, June 2013-December 2014. All differences are significant at $p < 0.05$.

Families of young children with SHCN experience increased hardship

Taking care of a child with SHCN may require families to take more time off of work for medical appointments and/or to spend more money on medication, medical care, and specialized education and/or child care.^{iv,v} Additionally, children with SHCN may need specialized foods and formulas, which are often expensive and difficult to find.^{vi} These expenses can contribute to additional economic hardships, including the family's inability to afford enough rent, utilities, or food, for the child with SHCN, their other children, and the adults in the household.^{vii}

In a sample of 6,724 low-income families with children under age four who participated in the Children's HealthWatch survey during a visit to a primary care clinic or emergency room, 18.5 percent of children screened positive for SHCN and 3.7% of this medically at-risk group received SSI.

Families of young children with SHCN had higher rates of hardships, including household food insecurity, child food insecurity, frequent moves, being behind on rent, threatened or actual utility shut-off, and health care trade-offs, than families of children without SHCN.

Previous research shows that young children, whether with or without SHCN, whose families experience any of these hardships may suffer more negative health outcomes, including fair or poor health, increased hospitalizations, and developmental delays than children in families not experiencing these hardships.^{viii,ix,x,xi,xii,xiii} These hardships, however, rarely occur in isolation as families struggle to juggle competing expenses for food, rent, and utilities while also caring for children, especially those with SHCN.^{xiv}

Household Food Insecurity:

When families lack access to sufficient food for all members to lead active, healthy lives because of insufficient family resources.

Child Food Insecurity: (the most severe level of food insecurity)

When children experience reductions in the quality and/or quantity of meals because caregivers can no longer buffer them from inadequate household food resources

Frequent moves:

A severe level of housing insecurity when a family moves two or more times in one year.

Behind on Rent:

A form of housing insecurity when families are unable to pay their rent or mortgage on time.

Energy Insecurity:

- **Threatened shut-off:** When utility companies send a letter threatening to discontinue service due to missed bill payments.
- **Actual shut-off:** When utility companies shut off service to a family's home due to failure to pay bills. This may result in days without heating or cooling, and in extreme cases, caregivers may use a cooking stove to heat the home. Of the highest concern is when this situation occurs in households with children with SHCN who require electronic equipment for their care.

Health Care Trade-offs:

When families are unable to pay for basic living expenses, including rent, utilities, or food due to payment of medical expenses for any family member.

Alleviating hardship with safety-net supports

Public programs designed to alleviate these hardships can help eligible, low-income families. The Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) provide nutritious foods for families facing economic hardships and have been shown to improve child health.^{xv,xvi} Additionally, though more difficult to obtain due to limited availability, the Low Income Home Energy Assistance Program and subsidized or public housing help families keep the heat and lights on and maintain stable housing, both of which are proven solutions for improving the health of young children.^{xvii,xviii}

Policy Solutions

Alleviating hardships for all low-income families also benefits the health and well-being of children with SHCN. Federal and state assistance programs play a role in buffering families and children, as do workplace and employment policies, including raising the minimum wage and providing paid time off for employees. Recognition that families of children with SHCN experience increased financial burdens (whether or not the child's needs qualify for a disability-based benefit) is essential to designing policies that directly and effectively address the needs of these children.

Recommended policy solutions to address hardships include:

1. Expanding further the list of special medical foods for children with SHCN available through WIC

- WIC provides low-income pregnant, postpartum, and breastfeeding women, and children under the age of five with certain nutritious foods essential for growth and development. WIC could explore additions to the WIC food list, which may require amending food package regulations to allow more flexibility for special medical foods to meet packaging requirements and/or encouraging food companies to design medical/specialty foods to meet WIC packaging and nutrient guidelines (e.g. rice milk with higher protein content).

2. Broadening access to and boosting the benefits of SNAP by allowing families of children with SHCN to qualify for the medical deduction even if they do not meet disability criteria for SSI

- Households participating in SNAP who have a family member receiving federal or state disability benefits are able to deduct the monthly cost of medical expenses over \$35 in calculating net income for SNAP benefits. Allowing families of children with SHCN that may not receive state or federal disability benefits to qualify for the medical deduction would increase their monthly benefit, thus helping to offset some of the additional costs faced by families raising a child with SHCN.

3. Broadening access to and/or implementing utility shut-off protection policies for families with children with SHCN

- Shut-off protection policies vary widely from state to state and in some cases require threats of extreme danger before a family is protected from having their utilities shut off by the utility company. States should consider the dangers associated with utility shut-offs, especially for families of children with SHCN who may require refrigeration for special nutritional supplements and/or medical equipment powered by electricity, when reviewing or creating policies regarding the necessary severity of demonstrated need to qualify for protection.

4. Encouraging utility companies to provide modified payment plans or discounts for families of children with SHCN

- Some utility companies offer flexible or discount payment plans for low-income and disabled families. Encouraging utility companies to provide additional categories of eligibility for qualifying families will help families keep the heat and lights on and in the case of some children with SHCN, allow use of medical electrical equipment.

5. Increasing availability of rental subsidies as well as the subsidy amount for low-income families

- All children need safe, stable homes to ensure healthy development. This is especially true for children with SHCN who may be more sensitive to unsafe or unstable housing arrangements. Increasing not only the availability of rental subsidies but also subsidy amounts would help more families to find and stay in affordable housing appropriate for a child with SHCN.



"I have one daughter with celiac disease and severe food allergies and another daughter without. I have to shop for my daughter who requires specialized foods first. I travel to multiple stores and spend more money on groceries for her food and then have little left over to buy food for the rest of the family. I cannot buy food for my daughter with celiac disease at the same store as I purchase everything else because her food is so expensive. When SNAP gets low near the end of the month, I have to make up the difference with other benefits, making it difficult to pay rent or utility bills."

Photo and voice by Juell F., Witness to Hunger, Boston

Conclusions

For the millions of families in the United States caring for children classified as having a special health care need (SHCN), greater than average medical, educational, and therapeutic costs may directly affect a family's ability to afford food, rent, utilities and health care. Even though many children with SHCN do not meet criteria for a disability benefit or have severe functional limitations, their families may still face significant financial hardship. Addressing the needs of our children, regardless of disability status, is crucial to ensuring that all children have enough to eat and the health care they need; are kept warm in the winter and cool in the summer; and have a safe, steady place to sleep at night.

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- ⁱ National Survey of Children with Special Health Care Needs. NS-CSHCN 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [02/23/2015] from www.childhealthdata.org.
- ⁱⁱ McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102: 137-140.
- ⁱⁱⁱ 45 United States Code (U.S.C.) § 1381; 20 Code of Federal Regulations (C.F.R.) § 416.906.
- ^{iv} Newacheck, P.W. and Kim, S.E. (2004) A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatric Adolesc Med*. 159(1):10-17.
- ^v Knoche, L., Peterson, C.A., Pope Edwards, C., Jeon, H.J. (2006) Child care for children with and without disabilities; The provider, observer, and parent perspectives. *Early Childhood Research Quarterly*. 21(1): 93-109.
- ^{vi} Lucas B, Feucht SA, Grieger LE, eds. (2004) Children with special health care needs: Nutrition care handbook. Chicago, IL: Am Diet Assoc.
- ^{vii} Parish SL, Rose RA, Grinstein-Weiss M, et al. (2008) Material hardship in US families raising children with disabilities. *Except Child*. 75(1):71-92.
- ^{viii} Rose-Jacobs R, Black MM, Casey PH, et al. (2008) Household food insecurity: Associations with at-risk infant and toddler development. *Pediatrics*. 121(1):65-72.
- ^{ix} Cutts DB, Meyers AF, Black MM, Casey PH, Chilton M, Cook JT, et al. (2011) US Housing insecurity and the health of very young children. *Am J of Public Health* 101(8): 1508-1514
- ^x Cook JT, Frank DA, Casey PH, Rose-Jacobs R, Black MM, Chilton M, et al. (2008) A brief indicator of household energy security: Associations with food security, child health, and child development in US infants and toddlers. *Pediatrics*. 122:e-867-e875.
- ^{xi} March E, Ettinger de Cuba S, Cook JT, Bailey K, Cutts DB, Meyers AF, et al. (2011) Behind Closed Doors: The hidden health impact of being behind on rent. Children's HealthWatch. Retrieved from: http://www.childrenshealthwatch.org/wp-content/uploads/behindcloseddoors_report_jan11-.pdf.
- ^{xii} Jeng K, Ettinger de Cuba S, March EL, Meyers AF, Cook JT, and Coleman S. (2009) Affordable Health Care Keeps Children and Families Healthy. Children's HealthWatch. Retrieved from: http://www.childrenshealthwatch.org/wp-content/uploads/AffordableHealthCare_brief_July2009.pdf
- ^{xiii} Cook, JT and Frank, DA. (2008) Food security, poverty, and human development in the United States. *Annals of the New York Academy of Sciences*. 1136:193-209.
- ^{xiv} Frank, DA, Casey PH, Black MM, Rose-Jacobs R, Chilton M, Cutts DB, et al. (2010) Cumulative hardship and wellness of low-income, young children: Multisite surveillance study. *Pediatrics*, 125(5):1115-1123.
- ^{xv} Ettinger de Cuba S, Weiss I, Pasquariello J, Schiffmiller A, Frank D, Coleman S... Cook J. (2012) SNAP Vaccine. Children's HealthWatch, Retrieved from http://www.childrenshealthwatch.org/upload/resource/snapvaccine_report_feb12.jpg.pdf
- ^{xvi} Gayman, A., Ettinger de Cuba, S., Cook, J., March, E., & Coleman, S. Children's HealthWatch. (2010). WIC improves child health and school readiness. Available at: http://www.childrenshealthwatch.org/wp-content/uploads/WIC_brief_January2010.pdf
- ^{xvii} Meyers A, Cutts DB, Frank DA, Levenson S, Skalicky A, Heeren T, et al. (2005) Subsidized housing and children's national status: Data from a multisite surveillance study. *Arch Pediatr Adolesc Med*. 159: 551-556.
- ^{xviii} Frank DA, Neault NB, Skalicky A, Cook JT, Wilson JD, Levenson S, et al. (2006) Heat or eat: Low Income Energy Assistance Program and nutritional health risks among children less than 3 years of age. *Pediatrics*. 118:1293-1302.

