



# Voices of Child Health in Chicago REPORT

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## REPORT HIGHLIGHTS

Seven percent of Chicago parents said they had a child with special health care needs (SHCN).

Parents with only boys, only girls, and boys and girls were equally likely to report having a child with SHCN.

Parents of children with SHCN were more likely to be in worse health themselves and to have experienced psychological distress.

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## Children with Special Health Care Needs in Chicago

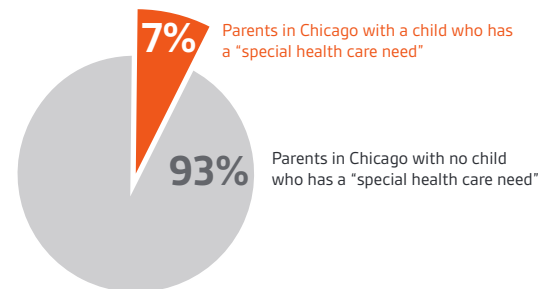
In this report, we explore the issue of children with special health care needs in Chicago. Researchers at Ann & Robert H. Lurie Children's Hospital of Chicago teamed up with the Chicago Department of Public Health (CDPH) on the 2018–19 Healthy Chicago Survey, Jr. to ask parents from all 77 community areas in Chicago about their children's health. Specifically, we asked parents, "Is your child/Are any of your children limited or prevented in any way in his or her/their ability to do the things most children of the same age can do?" We also asked parents questions about their own health. To learn more about children with special health care needs, visit [luriechildrens.org/SpecialHealthCareNeeds](http://luriechildrens.org/SpecialHealthCareNeeds).

### What proportion of children have special health care needs (SHCN)?

In Chicago, 7% of parents said that their child or children were limited or prevented in any way in their ability to do the things most children of the same age can do (Figure 1). In this report, we refer to this group as children with special health care needs (SHCN). However, our definition of SHCN differs from other researchers' definitions of this term.<sup>1</sup> Special health care needs for children can vary from conditions such as asthma to muscular dystrophy. The proportion of children with SHCN in Chicago reported through our survey is lower than national and state levels. Specifically, 19% of children in the United States and 19% of children in Illinois had SHCN in 2017-18.<sup>2</sup> The lower proportion of children with SHCN in Chicago may, for instance, be because parents did not consider their children to be limited in their abilities even if their children had various special health care needs.

We also asked parents about the health status of their children using a five-option scale. Children who were reported to be in "excellent" or "very good" health were grouped as having "better" health status. Children who were reported to be in "good," "fair" or "poor" health were grouped as having "worse" health status. Overall, 19% of families in our survey said they had at least one child in worse health. As we might expect, parents who said they had at least one child with SHCN were more likely to report having at least one child in worse health (51%) than parents who did not have a child with special health care needs (17%). Parents with only boys, only girls, or boys and girls were equally likely to report having a child with SHCN.

Figure 1. Proportion of parents with a child with SHCN in Chicago



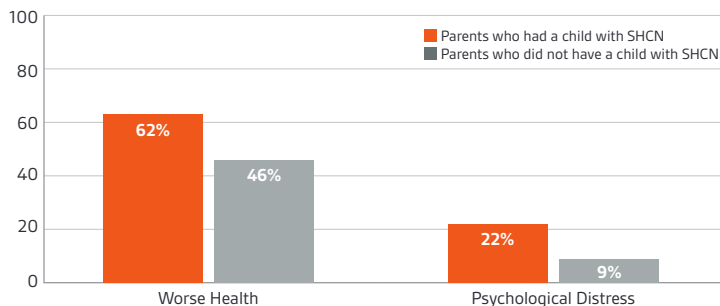
### How is having a child with SHCN associated with parents' health?

To examine how having a child with SHCN was associated with aspects of parents' health, we asked parents about their own health using the same "better" or "worse" groupings used for child health. Overall, 47% of parents were in worse health.

Parents with a child with SHCN were more likely to be in worse health themselves than parents who did not have a child with SHCN (62% vs. 46%, see Figure 2). Additionally, parents of children with SHCN were more likely to have experienced psychological distress in the last 30 days than parents with children who did not have SHCN (22% vs. 9%, see Figure 2). This is consistent with other research on the health of parents with children with SHCN. Parents of children with SHCN have been found to

be more likely to suffer from physical and mental health issues, to have higher rates of morbidity and mortality, to have lower quality of life, and to experience financial stress.<sup>3</sup> Parents also report being isolated from others and feeling guilt and fear related to their child's condition.<sup>4</sup>

**Figure 2.** Proportion of parents who had or did not have a child with SHCN who were in worse health themselves or who experienced psychological distress



## How to best support parents and families of children with SHCN

Other research has shown that families who had a child with a more severe health condition were more likely to report financial and employment problems due to the child's condition, as were families in which a family member provided home health care to the child.<sup>5</sup> Even low levels of annual health care expenditures have been associated with families' perceptions of financial burden, particularly for families with lower household income.<sup>6</sup> Furthermore, in the U.S., families with a child with SHCN collectively provide an estimated total of 1.5 billion hours of home health care each year.<sup>3</sup> This can result in lost income for the family and have negative psychosocial and health effects for the parents, especially for children with the most complex conditions.<sup>7,8</sup> Additionally, expenses related to long-term care and medical equipment that may not be covered by insurance can contribute to financial burden for families with a child with SHCN.<sup>9</sup>

However, research suggests that financial and employment problems can be reduced when health care providers coordinate care with other members of the child's care team and help the family feel like partners in their child's care.<sup>10</sup> This highlights the importance for the care team to treat the family as a whole unit of care and to understand how the family's financial burden may be affected.<sup>7</sup> Increasing access to medical homes and care coordination have also been shown to have a variety of positive outcomes for families of children with SHCN such as reduced financial problems, improved health outcomes for the child with SHCN and better family functioning.<sup>9,10,11,12</sup>

**Easterseals** offers a parent support group on a monthly basis for parents of children with SHCN.

**Family Voices** is a national organization of families and friends of youth with SHCN.

### HOW THE SURVEY WAS CONDUCTED

This report presents findings from the 2018–19 Healthy Chicago Survey, Jr., administered by the Chicago Department of Public Health in collaboration with Lurie Children's. The survey was administered via phone interviews from December 2018 through May 2019. The sample consisted of 2,982 adults in Chicago, 740 of whom were the parent, step-parent or guardian (referred to as "parents" in this report) of at least one child under 18 years old living in the household. The survey cooperation rate was 12%. All analyses were conducted with statistical weighting so that they are representative of the adult population of the City of Chicago during the time period of data collection. For more information about health in your community, visit [chicagohealthatlas.org](http://chicagohealthatlas.org).

Note that for some of the analyses presented in this report, the confidence intervals were wider than 20 due to the relatively small proportion of respondents with a child with SHCN. However, the relative standard error (RSE) was below 30%, suggesting adequate stability of the estimates reported.

### SUGGESTED CITATION

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