



National Autism Indicators Report:

Children on the autism spectrum
and family financial hardship

May 2020



Mission

The A.J. Drexel Autism Institute is the first research organization built around a public health science approach to understanding and addressing the challenges of autism spectrum disorder (ASD) across the lifespan.

The Autism Institute's Life Course Outcomes Program (LCO) is working towards a future where people on the autism spectrum are valued as contributing members of our communities who have roles to play and dreams to pursue. LCO is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.

For more information about us, please visit our website: <http://drexel.edu/AutismOutcomes>

How to cite this report

Anderson, Kristy A., Rast, Jessica E., Roux, Anne M., Garfield, Tamara., and Shattuck, Paul T. *National Autism Indicators Report: children on the autism spectrum and family financial hardship*. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, May 2020.

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A publication of A.J. Drexel Autism Institute's Life Course Outcomes Program, Drexel University

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Funding Acknowledgement

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UJ2MC31073: Maternal and Health-ASD Transitions Research Project. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Letter from the Program Director

Paul T. Shattuck, PhD

Healthy food. Adequate clothing. Access to needed medical care. A roof overhead.

Parents are driven by love to provide their children with these basics. This can feel especially urgent when your child, or children, have special health needs. It is hard to devote attention to life-changing interventions and treatments for autism when meeting basic daily needs is a struggle. Many families of children with autism end up with terrible dilemmas when faced with the choice of putting food on the table or paying for services.

Our 2018 National Autism Indicators Report: High School Students on the Autism Spectrum revealed that roughly half of all teens on the autism spectrum live in very low-income households. About one in four autistic teens live in households below the federal poverty level. Approximately 100,000 youth with autism turn 18 each year. Thus, about 25,000 autistic youth entering adulthood each year with the added difficulties that come with deep poverty.

In 2016, the federal poverty level was \$24,300 for a household of four in the continental U.S. Imagine being a single parent of three children, one with autism, and trying to raise your family on this income. Our last Indicators Report also revealed that many families rely on federal safety net programs to help with things like health insurance and paying for food – yet, not all families who need help are able to access that help.

We decided to focus this Indicators Report on the financial hardships facing hundreds of thousands of families raising children on the autism spectrum. I have talked with countless families of children with autism over the past 20 years who are struggling with the dual challenge of parenting a child with special needs AND covering the basic needs of the entire family. These parents are hard-working and love their children as fiercely as any other parents. Tragically, many of these parents internalize a sense of shame and inadequacy, and inaccurately believe they are failing their children.

The truth is that raising a child with special needs is hard work and is often expensive. There are almost always extra expenses for medical care, educational supports, mental health care, special transportation, prescription medications and round-the-clock supervision for children who cannot be left alone safely.

Our hope for this Indicators Report is that it will raise awareness and spark discussion about the ways in which families are struggling and need our collective societal support. Many thanks to the dedicated team of authors and reviewers who made this Indicators Report possible.

A handwritten signature in black ink that reads "Paul Shattuck". The signature is written in a cursive, flowing style.

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A note about wording. In this report, we use the terms *autism and autism spectrum disorder*, or ASD, because it was the official wording in the survey and because it reflects the wide range of characteristics, impairments, and strengths seen in people with ASD.

Executive Summary

National Autism Indicators Report: Children on the autism spectrum and family financial hardship

May 2020

The challenge

Families of children with ASD face significant financial challenges due to their child's complex service needs and frequent out-of-pocket expenditures for community services and health care. They are more likely to report financial problems and to need additional income for their child's medical care compared to caregivers of children with other developmental disabilities and mental health conditions.^{1,2} As of 2016, an estimated one-third of children with ASD were living in poverty.³ However, we know few details about the characteristics, financial hardships and use of financial supports among households of children with ASD. Families living in poverty have fewer resources to spare and are especially vulnerable in the face of burdens like care-related expenses, reduced earnings from taking time off work to cope with caregiving, and disconnection from services and supports. Financial hardship may contribute to greater stress for families which, over time, could result in worse outcomes for youth on the autism spectrum.⁴ This report will inform policies aimed at promoting economic well-being of children with ASD and their families.

Findings from the broader field of disability highlight the bidirectional relationship of how disability and poverty affect each other. Disability increases risk for poverty through high costs of care and reduced access to earning opportunities. Poverty increases the risk for disability, poor health and co-occurring conditions by reducing access to health care and community services that can prevent conditions from becoming worse. Unfortunately, there is a lack of research that examines the interrelationships between disability, poverty and service use. Additionally, ASD research often fails to distinguish between the needs of low-income households of adolescents with ASD versus high-income households. This impedes our ability to identify strategies that could improve service access among youth from low-income households – a national priority stated in the 2017 Federal Strategic Plan for ASD research.⁵

The charge

This report describes financial hardship among families of children with ASD (ages 3-17 years) and their participation in safety net programs. This builds on our 2018 National Indicators Report which found that low-income and minority youth with ASD have greater impairment severity, poorer outcomes and less access to needed services compared to other disability groups.⁶ This current report focuses on indicators of financial need and supports across disability groups, federal poverty level, age and race. This report also fills an important knowledge gap by characterizing the subpopulation of children with ASD living in poverty.

Aims of this report

We aim to:

- Report levels of family financial hardship among households of children with autism.
- Describe the types of safety net programs being used by low-income households.
- Compare levels of family financial hardship between low-income households of children with autism that do and do not receive safety net benefits.

Data source

The combined 2016 and 2017 National Survey of Children's Health (NSCH) provides national and state-level data on the health and well-being of children in the United States, ages 3 to 17 years. The survey was funded by the Health Resources and Services Administration's Maternal and Child Health Bureau. Our report focuses on children whose parents reported their child had a current diagnosis of autism. More information about the NSCH is available elsewhere.^{7,8} A description about the study methods and data are outlined in the **Appendix**.

Key Findings

National Autism Indicators Report: Children on the autism spectrum and family financial hardship

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We used data from a federally funded national survey to study financial hardships experienced by families of children with ASD compared to those with and without special health care needs (SHCN). We summarize the main findings of our analyses below. Detailed information about each of these key findings can be found in the chapters that appear later in this report.

Key Abbreviations and Definitions

ASD	Autism Spectrum Disorder (as indicated by parent report)
Children	Ages 3-17 years
CSHCN	Children with Special Health Care Needs
FPL	Federal Poverty Level
Free/Reduced Lunch	Free or reduced-cost breakfasts or lunches at school
No SHCN	Children who did NOT have ASD or any other type of special health care need
School-age Children	Ages 6-11 years
SHCN	Special Health Care Needs (as indicated by increased need for health care, medication, or services compared to their peers – and no parent-reported autism)
SNAP	Food stamps or supplemental nutrition assistance program benefits
WIC	Woman infants and children program
Young Children	Ages 3-5 years
Youth	Ages 12-17 years

Demographics and Disability Characteristics

- Over half (56%) 56% of children with autism lived in low-income households (defined as households below 200% the federal poverty level). Children with autism were more likely to live in low-income households compared to children with SHCN (47%) and children with No SHCN (42%).
- Children with ASD had poorer health than children with special health care needs (SHCN). They also used and needed more services and were more often limited from doing things most children of the same age can do.

- Children with ASD from low-income households tended to have poorer health and higher parent-reported autism severity than their peers from higher-income households.
- Children with ASD from low-income households were more likely to be non-White, to live in a household headed by a single mother and to have at least one sibling with a special health care need.

Family Financial Hardship

- We examined three dimensions of family financial hardship in this report: household poverty, medical expenses and material hardship.
- Household Poverty. About 30% of children with autism lived in very low-income households (below 100% of the federal poverty level, or FPL) compared to 25% of children with SHCN, and 20% of children with no special needs.
- Medical expenses for medical, dental and vision care were lower among children with ASD from lower-income households.
- Material Hardship. We report on four key indicators of material hardship: 1) Difficulty paying for basics like food or housing, 2) Unable to afford adequate food, 3) Difficulty paying a child’s medical bills, and 4) Reducing work hours to care for their child.
 - › Parents of children on the autism spectrum experienced high rates of material hardship across all four indicators, and two-thirds of parents of children with ASD reported experiencing at least one type of material hardship.
 - › Parents of children with ASD experienced material hardships much more often than parents of children with SHCN and parents of children with No SHCN.
 - › Material hardship was higher among parents of Black and Hispanic children with ASD and younger children (ages 3-5 years).
 - › One in every five parents of children with ASD from low-income households said they sometimes or often could not afford enough food for the family to eat.

Safety Net Program Use

- We examined use of four safety net programs: 1) Cash assistance for poor families with children; 2) the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); 3) the Supplemental Nutrition Assistance Program (SNAP, also known as “food stamps”); 4) free and reduced-price meals in schools.
- More than two-thirds (86%) of children with ASD from low-income households participated in at least one of the following four safety net programs (cash assistance, WIC, SNAP, and free/reduced meals). Free/reduced lunch was the most common program among low-income children with ASD, followed by SNAP, cash assistance and WIC.
- Over half (58%) of low-income households with children with ASD participated in more than one safety net program and 28% of participated in three or more programs.

- Low-income families of children with ASD had the lowest rates of disconnection from safety net programs (14%) compared to children with other SHCN (24%) and children with no SHCN (29%).
- Children with ASD who participated in at least one safety net program scored higher on three indicators of material hardship (*difficulty paying bills, parents reduced/stopped work, and inability to afford food*) and had higher out-of-pocket expenditures than children who were disconnected from the safety net.
- Children with ASD from low-income households who received public health insurance had higher levels of safety net program use than children with ASD who were either uninsured or received private health insurance only.
- Families of children who had public health insurance reported lower out-of-pocket expenditures and were less likely to report problems paying for their child's medical care than children with private health insurance.

Demographics and Disability Characteristics

This chapter describes the demographics and disability characteristics of children on the autism spectrum, ages 3 to 17 years. We compare the statistics for children with autism spectrum disorder (ASD) to children with special health care needs who did not have autism (SHCN), and children who did not have a SHCN or autism (No SHCN). We also put a spotlight on the characteristics of children with ASD living in low-income households (below 200% of the federal poverty level, or FPL) compared to those in higher-income households.

Our key findings

- Over half (56%) 56% of children with autism lived in low-income households (defined as households below 200% the federal poverty level). Children with autism were more likely to live in low-income households compared to children with SHCN (47%) and children with No SHCN (42%).
- Children with ASD had poorer health than children with special health care needs (SHCN). They also used and needed more services and were more often limited from doing things most children of the same age can do.
- Children with ASD from low-income households tended to have poorer health and higher parent-reported autism severity than their peers from higher-income households.
- Children with ASD from low-income households were more likely to be non-White, to live in a household headed by a single mother and to have at least one sibling with a special health care need.

How do we know?

We used data from the National Survey of Children's Health 2016-2017 (NSCH 2016-2017) to study children on the autism spectrum ages 3-17 years. In this survey parents reported information about their child's health.

A word about age

For this report, we examined three age groups: **young children** (3-5 years), **school-age children** (6-11 years) and **youth** (12-17 years).

Key Abbreviations

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **SHCN:** Children who did NOT have ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to their peers
3. **No SHCN:** Children who did NOT have ASD or any other type of special health care need

Who are children with special health care needs?

Children with special health care needs (SHCN) are children who have (or are at risk of having) physical, developmental, behavioral or emotional conditions that require health and related services beyond that required by most other children.⁹ This definition is set by the federal Maternal Child Health Bureau.

The NSCH 2016-2017 identified children with SHCNs by asking parents whether their child had any of these characteristics:

1. Needs or uses medications prescribed by a doctor (other than vitamins),
2. Has an above-average need for, or use of, medical, mental health or educational services,
3. Is limited or prevented in any way in his or her ability to do things most children of the same age can do,

4. Needs or uses specialized therapies such as physical, occupational or speech therapy, or
5. Needs or gets treatment or counseling for an emotional, behavioral or developmental problem.

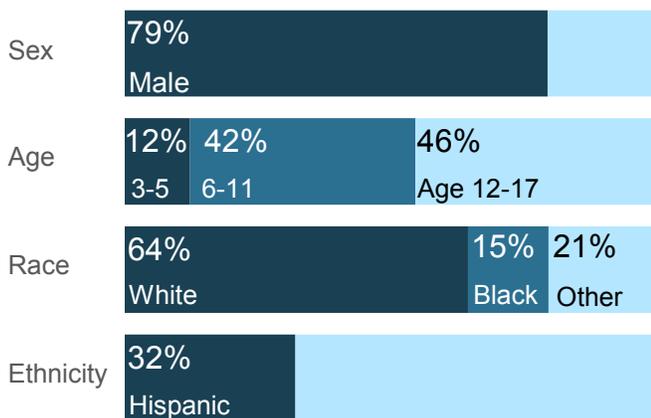
Children who experienced at least one of these characteristics met criteria for having a SHCN if the need was due to medical, behavioral, or other health conditions that lasted (or was expected to last) at least 12 months. Meeting criteria for having a SHCN in this survey is not based on diagnosis of any specific condition. However, children with diagnosed health conditions or disorders often meet the criteria for having a SHCN because they have heightened health care needs.

Most of the parents who reported their child has ASD also answered questions indicating their child has a SHCN. Roughly 8% of children with parent reported ASD did not also meet criteria for having a SHCN.

Child and household demographics

Most children with autism were male and White. Approximately one-third of children on the autism spectrum were Hispanic compared to 21% of children with other special health care needs (SHCN) and 26% of those with no SHCNs.

Most children with ASD were male, older than 5 years, white, and non-Hispanic.

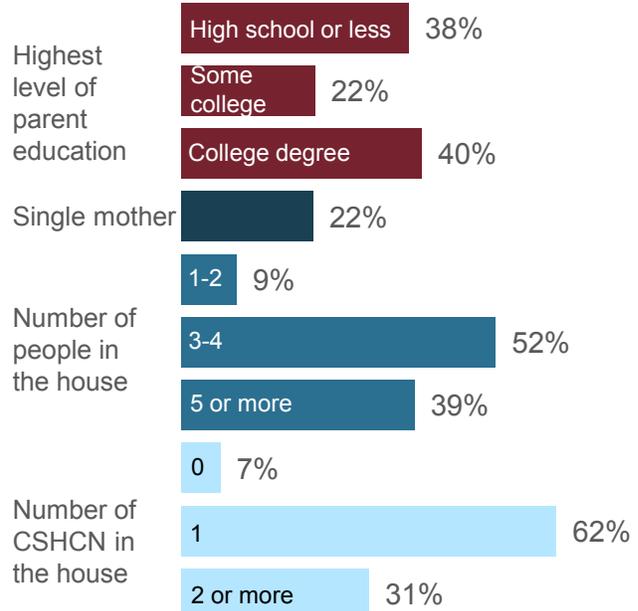


Source: National Survey of Children's Health 2016-17

Roughly one out of every three children with autism lived in households with two or more children with a SHCN. Approximately one in every five children with autism lived in households with a single mother, similar

to children with SHCN and those with No SHCN. Household education level was generally lower among children with autism, relative to children with SHCN and No SHCN.

Household characteristics of children with ASD.



Source: National Survey of Children's Health 2016-17

The importance of health insurance

Public health insurance generally includes Medicaid and the Children's Health Insurance Program (CHIP). We considered a family to have public health insurance if they used only public health care OR a combination of public and private health insurance.

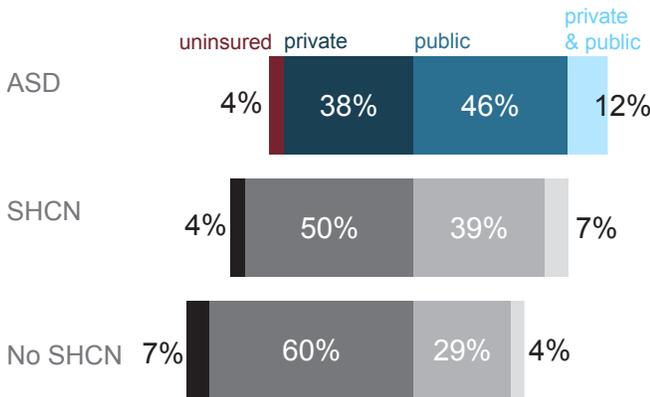
Health insurance is especially important to consider when examining the financial circumstances of families of children with ASD. First, children who have public health insurance – through Medicaid or CHIP – have greater awareness of safety net programs than children who do not have public health insurance and are more likely to use benefits.

Second, health insurance protects families of children with ASD against financial burden by offsetting the financial costs associated with caring for a child with autism. For instance, adolescents with ASD that are covered by any health insurance have lower financial burden and fewer unmet service needs compared to adolescents without any health insurance. The extent of financial burden and service receipt also varies by type of insurance. More specifically, research shows

that children with ASD who are enrolled in Medicaid – or public health insurance – have lower parent unemployment and out-of-pocket expenditures than children with private health insurance.^{10,11,12}

Children on the autism spectrum had higher rates of public health insurance (such as Medicaid) and lower rates of private insurance coverage, compared to children with SHCN and those with No SHCN. Only 4% of children with ASD were uninsured.

Children with ASD were more likely to have public insurance than children with SHCN or children with no SHCN.

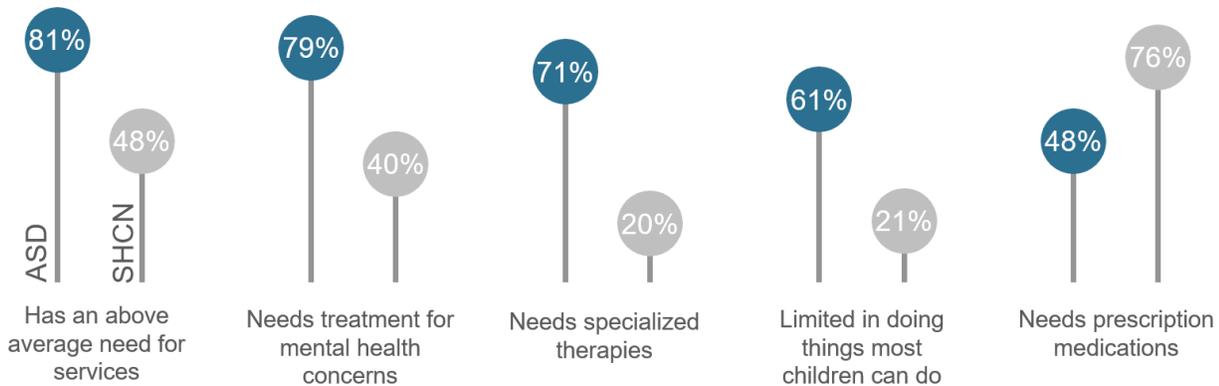


Source: National Survey of Children's Health 2016-17

Health conditions and service needs are common in children with ASD.

Overall, children on the autism spectrum used more services, and used services more often than children with special health care needs (SHCN) who did not have ASD. Most used medical, mental health, or educational services, and/or received treatment or counseling for an emotional, behavioral or developmental problem. About 60-70% needed specialized therapy like speech therapy or were limited in some way from doing things most children of the same age can do.

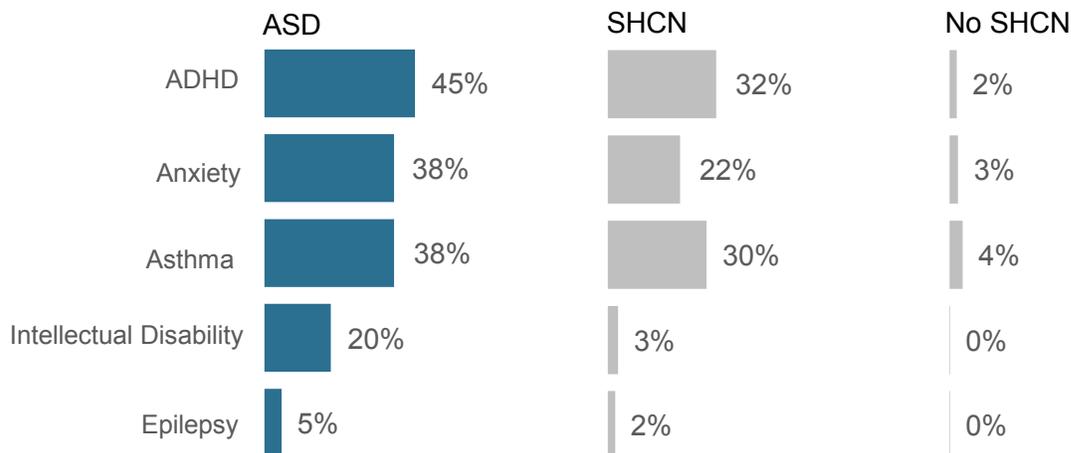
Children with ASD were more likely to have each special health care need than children with SHCN except medication use.



Source: National Survey of Children's Health 2016-17

More specifically, research shows that children with ASD who are enrolled in Medicaid – or public health insurance – have lower parent unemployment and out-of-pocket expenditures than children with private health insurance.

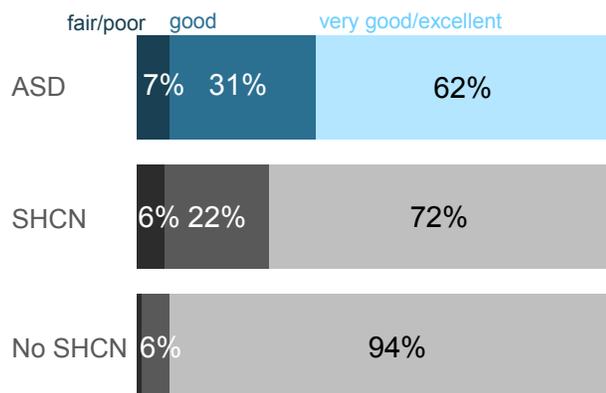
Co-occurring conditions were common in children with ASD.



Source: National Survey of Children's Health 2016-17

On average, the health of children on the autism spectrum was worse than the health of children with SHCN and children with No SHCN. A little over 60% of children on the autism spectrum had very good or excellent health, compared to over 70% of children with SHCN. Nearly all children with No SHCN had very good or excellent health.

Children with ASD had poorer health than children with SHCN and children with No SHCN.



Source: National Survey of Children's Health 2016-17

SPOTLIGHT on low-income households with children on the autism spectrum: Characteristics

A word about federal poverty guidelines

Each year, the U.S. Department of Health and Human Services (HHS) issues federal poverty guidelines (also known as the federal poverty level, or FPL) to determine household poverty status.¹³ These guidelines are based on the number of people living in the household as well as the household's income for the previous year. The NSCH uses HHS guidelines to determine household poverty level.

HHS poverty guidelines for a family of four within the 48 contiguous states and DC was 24,300 in 2016 and 24,600 in 2017. Separate HHS guidelines are issued for Alaska and Hawaii.

Several programs, including SNAP, CHIP, Medicare, WIC, national school lunch program for free and reduced-price meals, use HHS guidelines to determine financial eligibility for services. These programs typically limit their eligibility to a percentage of the FPL (such as 125%, 138 percent, 150 percent or 185 percent). These thresholds are calculated by multiplying that percentage by income. Table 1 shows the 2015-2016 household income for a family of four across four federal poverty thresholds.¹⁴ For instance, the income for a household of four at 100% of the FPL would be \$24,250.

Table 1
2015-2016 household income (in dollars) for a family of four, across federal poverty thresholds.*

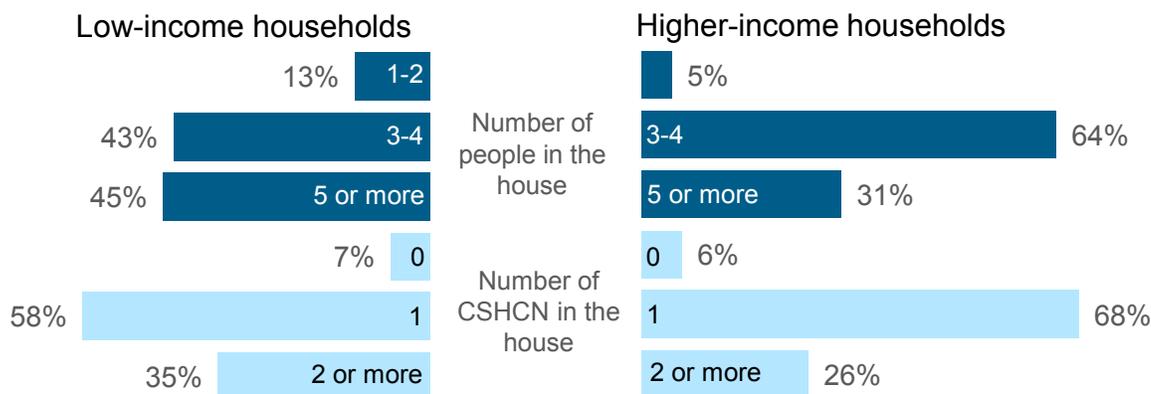
Poverty Threshold	Dollar Amount
100%	\$24,250
200%	\$48,500
300%	\$60,625
400%	\$97,000

Note: *These were the years of NSCH data collection

In this report, we discuss the characteristics and needs of families of children with autism from **low-income households** (combined income of all household members was below 200% of the FPL), compared to those from **higher-income households** (at or above 200% of the FPL). We chose 200% FPL because this number corresponds with the eligibility threshold for many safety net programs discussed in this report. The cutoff of 200% FPL has also been used in prior research about safety net program use among low-income populations.

Level of parent education varied significantly between the two income groups. Nineteen percent of parents of children on the spectrum from low-income households had a college degree, compared to 67% of parents from higher-income households. Nearly one-third (31%) of children on the autism spectrum from low-income households were from households with single mothers, versus 10% of children from higher-income households. Children with autism from low-income households also had a larger average number of family members and were more likely to have additional children with SHCN living in the home.

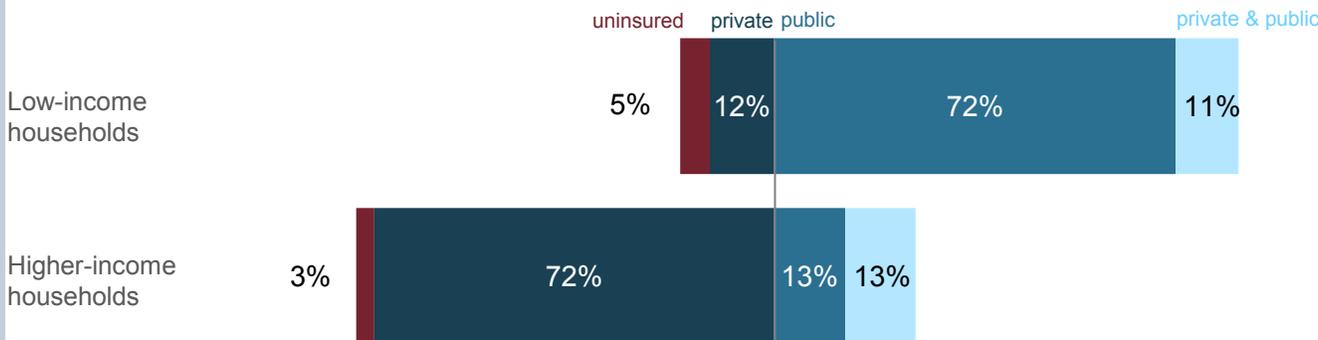
Low-income households had more total members and more children with special health care needs than higher-income households.



Source: National Survey of Children's Health 2016-17

Public health insurance was much more common for children with ASD from low-income households than for children from higher-income households. Eighty-three percent of children from low-income households had some kind of public insurance, while nearly three-quarters of children from higher-income households had private insurance only.

Children with ASD from low-income households most often had public health insurance, while children from higher-income households most often had private insurance.

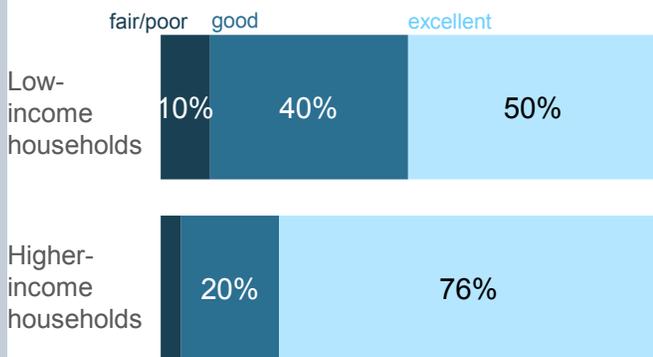


Source: National Survey of Children's Health 2016-17

Parent-rated disability characteristics are often more severe in children from low-income households.

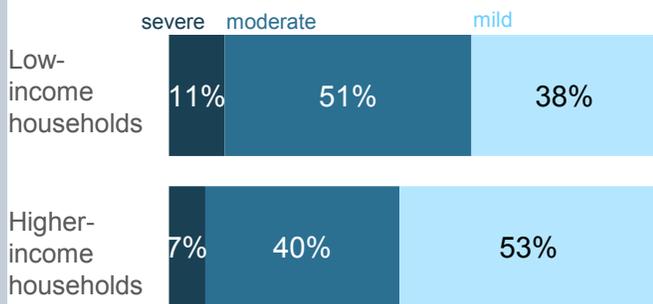
Children on the autism spectrum from low-income households tended to have poorer health and higher levels of parent-reported autism severity than their peers from higher-income households. However, rates of co-occurring health conditions, such as ADHD and anxiety, were about the same across the two income groups. Children with ASD from low-income and higher-income households also tended to use medical, therapy, and educational services and medication at about the same rates

Parents of children with ASD from low-income households were less likely to rate their child's health as excellent.



Source: National Survey of Children's Health 2016-17

Parents from low-income households more often rated their child's ASD as moderate or severe than parents from higher-income households.



Source: National Survey of Children's Health 2016-17

Family Financial Hardship

This chapter compares the financial hardships facing families of children with autism to families of children with special health care needs who did not have autism (SHCN), and families of children who did not have a SHCN or autism (No SHCN). We describe financial hardship among subgroups of children with autism by age, poverty level and race and ethnicity. We conclude with a detailed look at financial hardship in low-income households of children on the autism spectrum.

Our key findings

- We examined three dimensions of family financial hardship in this report: household poverty, medical expenses and material hardship.
- **Household Poverty.** About 30% of children with autism lived in very low-income households (below 100% of the federal poverty level, or FPL) compared to 25% of children with SHCN, and 20% of children with no special needs.
- **Medical expenses** for medical, dental and vision care were lower among children with ASD from lower-income households.
- **Material Hardship.** We report on four key indicators of material hardship: 1) Difficulty paying for basics like food or housing, 2) Unable to afford adequate food, 3) Difficulty paying a child’s medical bills, and 4) Reducing work hours to care for their child.
 - › Parents of children on the autism spectrum experienced high rates of material hardship across all four indicators, and two-thirds of parents of children with ASD reported experiencing at least one type of material hardship.
 - › Parents of children with ASD experienced material hardships much more often than parents of children with SHCN and parents of children with No SHCN.
 - › Material hardship was higher among parents of Black and Hispanic children with ASD and younger children (ages 3-5 years).
 - › One in every five parents of children with ASD from low-income households said they sometimes or often could not afford enough food for the family to eat.

How do we know?

We used data from the National Survey of Children’s Health 2016-2017 (NSCH 2016-2017) to study children on the autism spectrum ages 3-17 years. In this survey parents reported information about their child’s health.

What is family financial hardship and why is it important?

Family financial hardship refers to a wide range of economic challenges that can limit a family’s ability

to afford basic needs (e.g., food, housing and medical bills). Families of children on the autism spectrum may be especially vulnerable to hardship due to their child’s complex service needs and high out-of-pocket expenditures for services and health care.

Measuring family financial hardship helps us understand which types of financial need are the greatest for different groups of people. Policymakers can use this information to develop new programs and practices that target specific needs across vulnerable subgroups.

Understanding family financial hardship involves several aspects of a family’s economic situation including their financial resources, expenses, and whether they can make ends meet.

We report on three dimensions of family financial hardship:

- **Household poverty.** The NSCH uses the HHS federal poverty guidelines (commonly referred to as the federal poverty level, FPL) to assign poverty status. We report on low-income households which were below the threshold of 200% of the federal poverty level (FPL). The table below shows the 2015-2016 household income for a family of four across four federal poverty thresholds.¹⁴ For instance, the income for a household of four at 100% of the FPL would be \$24,250.

2015-2016 household income (in dollars) for a family of four, across federal poverty thresholds.*

Poverty Threshold	Dollar Amount
100%	\$24,250
200%	\$48,500
300%	\$60,625
400%	\$97,000

Note: *These were the years of NSCH data collection.

- **Medical Expenses.** Families pay out-of-pocket for their child’s medical expenses. We report on the actual dollar amount of these medical expenses.
- **Material hardship.** We report on four key indicators of material hardship: 1) Difficulty paying for basics like food or housing, 2) Unable to afford adequate food, 3) Difficulty paying a child’s medical bills, and 4) Reducing work hours to care for their child.

Combining these three indicators of financial hardship can help to identify whether a household has limited financial resources, and the extent to which families can get their basic needs met.

Why focus on three different types of family financial hardship?

To fully understand the financial circumstance of families, it is important to look at multiple measures of financial burden. First, we examine household poverty. However, it is likely that income-based measures of poverty – like household poverty - do not account for the financial demands and costs associated with caring for a child with a disability. In many instances, the high

support needs of children with ASD may greatly exceed available resources of family members. Even among wealthier households, families may need help to pay for their child’s medical care. Therefore, it is also important to measure material hardship.

The relationship between household poverty and medical expenses is also complicated. On the one hand, it is possible that low-income households experience greater financial burden due to a lack of resources. Indeed, studies have found that low-income families spend a substantially greater share of their income on out-of-pocket medical expenditures than higher-income families. However, there is also evidence that low-income households of children with ASD have fewer out-of-pocket expenditures for services compared to their more affluent counterparts. This may be due to high rates of participation in Medicaid among low-income households, which provides better financial coverage for health services than private insurance.¹¹

Household Poverty

Recall from Chapter 1 that more children on the autism spectrum lived in households that experienced poverty, compared to children with SHCN and those with No SHCN.

Key Abbreviations

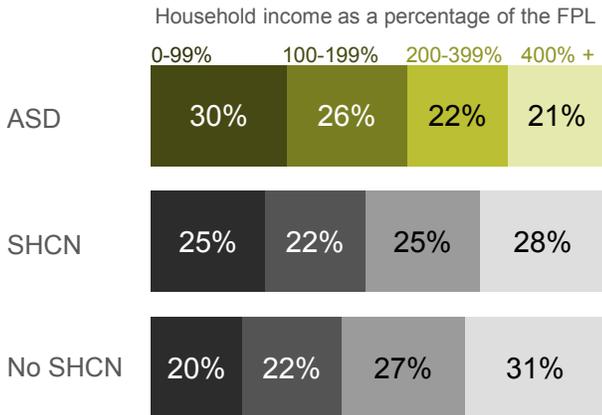
This report compares three groups of children:

4. **ASD:** Children with parent-reported autism spectrum disorder
5. **SHCN:** Children who did NOT have ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to their peers
6. **No SHCN:** Children who did NOT have ASD or any other type of special health care need

The data for this report came from the National Survey of Children’s Health (NSCH) for 2016-2017.

About 30% of children with autism lived in very low-income households (below 100% FPL) compared to 25% of children with SHCN, and 20% of children with no special needs.

More children with ASD lived in very low income households.



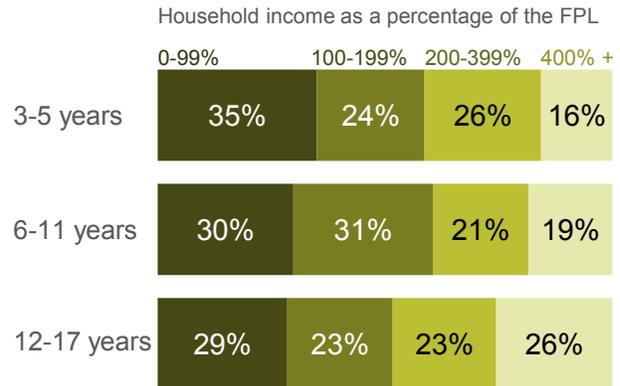
Source: National Survey of Children's Health 2016-17

Household income was higher among youth with autism. Approximately 59-61% of young children and school-age children with autism were living in low-income households (below 200% FPL), compared to 52% of youth. The percentage of children with autism who were living in very low-income households (less than 100% FPL) was highest in young children and lowest in youth. We do not know why income was higher among households with youth. Perhaps more parents were able to return to work as youth were older.

A word about age

For this report, we examined three age groups: **young children** (3-5 years), **school-age children** (6-11 years) and **youth** (12-17 years).

More young children with ASD lived in low-income households than older children with ASD.



Source: National Survey of Children's Health 2016-17

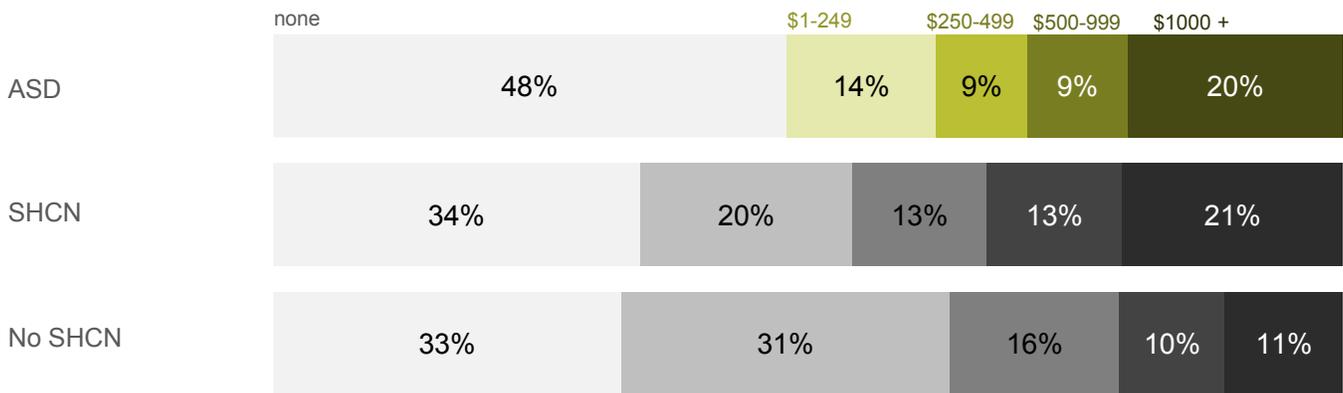
Half of households of children with ASD have medical expenses.

We can think about medical expenses in terms of money a family must spend out-of-pocket to provide for their child's needs. Out-of-pocket costs refer to the amount spent on care that is not covered by insurance or another source. Absolute levels of out-of-pocket costs are typically reported in dollar amounts.

About 20% of the households of children on the autism spectrum spent more than \$1,000 per year on out-of-pocket costs of care. This was similar to households of children with other special healthcare needs (SHCN). However, only 11% of households of children with No SHCN spent more than \$1,000 per year on out-of-pocket costs of care.

A larger percentage of households of children with ASD reported no medical expenses (48%) compared to other groups. We do not know why this is based on the survey data.

More families of children with ASD had no out-of-pocket medical costs than families of other children.



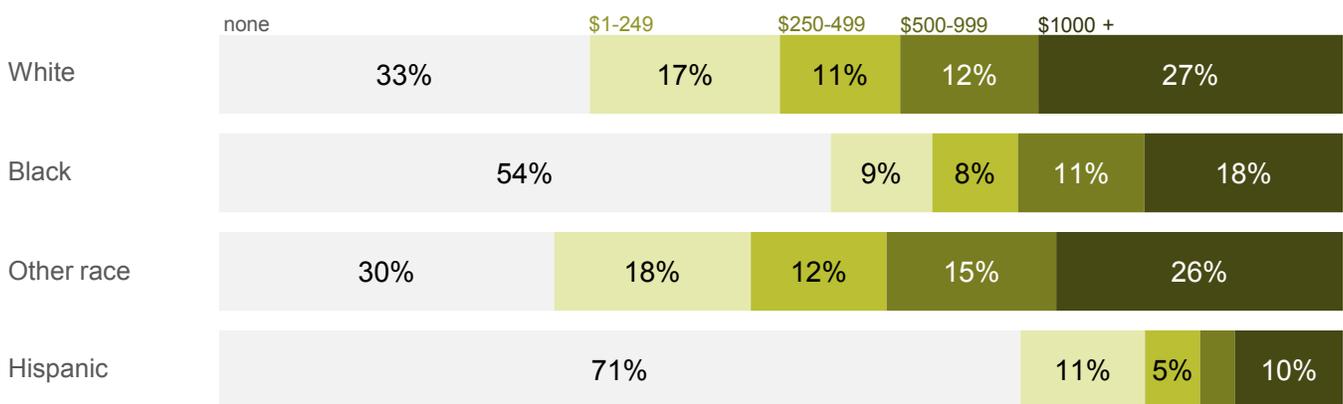
Source: National Survey of Children's Health 2016-17

Out-of-pocket costs were highest among young children with autism. About 25% of households of young children on the autism spectrum had more than \$1,000 per year in out-of-pocket costs of care, compared to 17% of school-age children and 21% of youth.

Six percent of ASD children from low-income households (below 200% FPL) had out-of-pocket costs of \$1,000 or more compared to 37% of higher-income households. This is likely due to higher receipt of Medicaid among the low-income group.

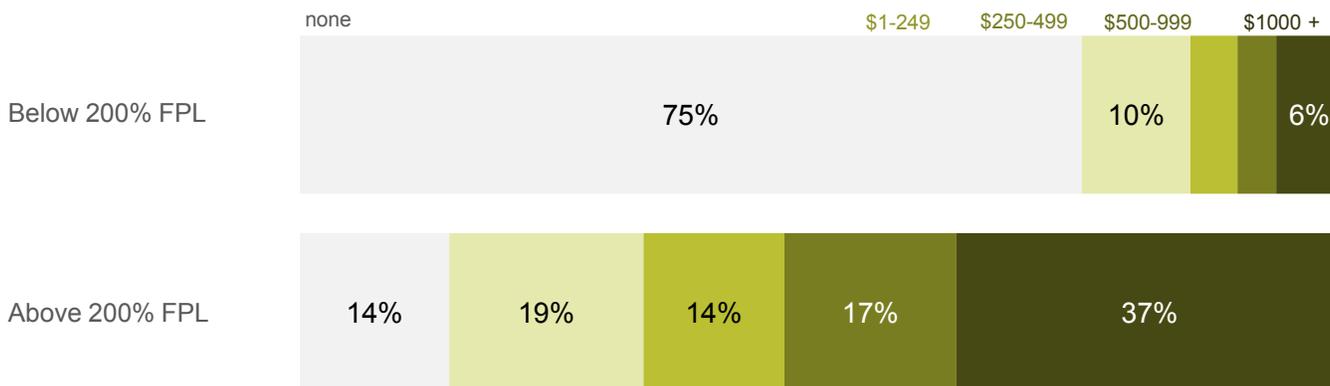
Out-of-pocket costs of care for children on the autism spectrum were different across racial and ethnic groups. Approximately 27% of households of children with autism who were White had at least \$1,000 per year in out-of-pocket costs of care, compared to 18% of Black children, 26% of children from another race, and 10% of children who were Hispanic. Hispanic children were mostly likely to have no medical payments (71%).

Families with Hispanic children with ASD were the most likely to have no out-of-pocket expenditures.



Source: National Survey of Children's Health 2016-17

Out-of-pocket expenditures for families of children with ASD varied by household income as a percentage of the FPL.



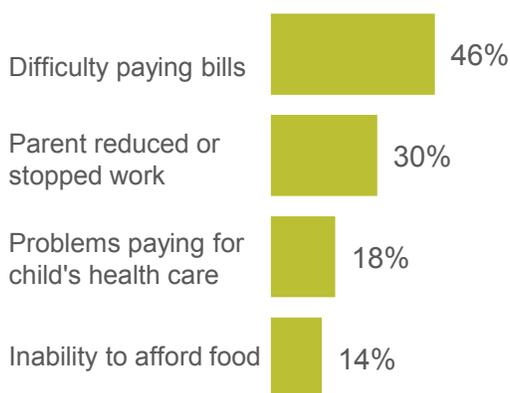
Source: National Survey of Children's Health 2016-17

Material Hardship, or difficulty paying for basic needs, is common in families of children with ASD.

Parents of children on the autism spectrum experienced high rates of hardship across all *four indicators of material hardship*. Nearly half reported *difficulty paying for basics* like food or housing. Nearly one-third had to *reduce work to care for their child* with autism. About one in five families had *problems paying for their child's health care*. Roughly 15 percent had *difficulty affording food for the family*.

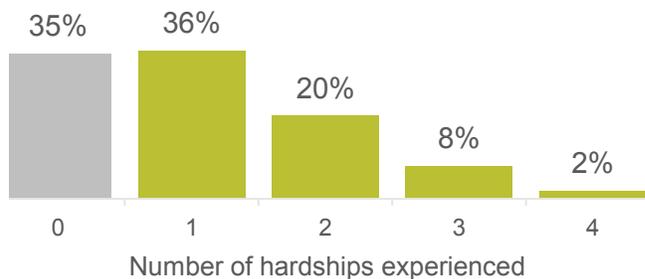
Two-thirds of parents of children with ASD reported experiencing at least one type of material hardship. Parents of children on the autism spectrum experienced material hardships much more often than parents of children with other special healthcare needs (SHCN) and parents of children with No SHCN. Only 35% of children with ASD reported no material hardship compared to 52% of children with SHCN and 73% of children with No SHCN. About one-third (30%) of parents of children with ASD reported two or more material hardships, compared to 20% of children with SHCN, and 8% of children with No SHCN.

Nearly half of parents of children with ASD had trouble paying bills.



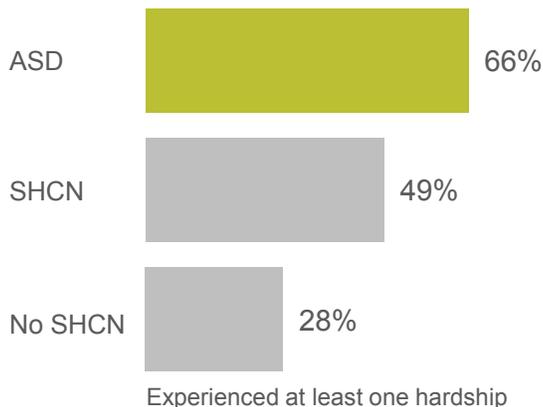
Source: National Survey of Children's Health 2016-17

One-third of parents of children with ASD reported no hardships.



Source: National Survey of Children's Health 2016-17

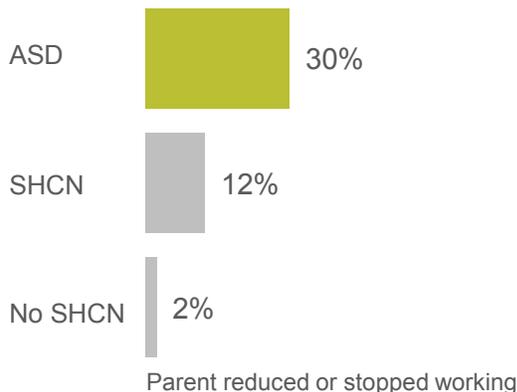
Households of children with ASD had a greater number of material hardships.



Source: National Survey of Children's Health 2016-17

Far more parents of children on the autism spectrum had to reduce their work hours to care for their child – approximately one-third - compared to parents of children with SHCN (12%) and parents of children with No SHCN (2%). The percentage of parents who reduced work hours to care for their child did not vary by household income in household with children on the autism spectrum.

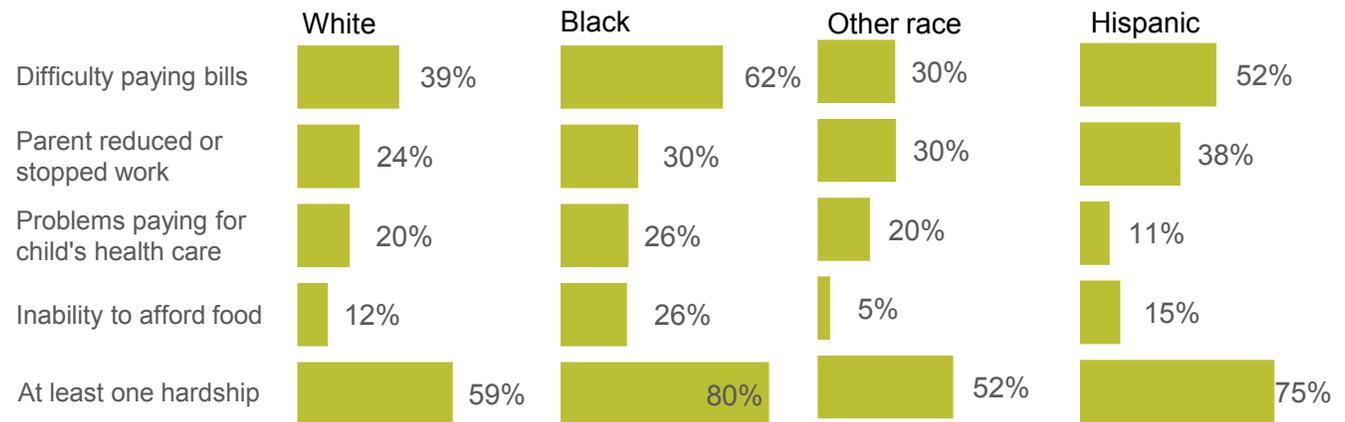
More parents of children with ASD had to reduce work hours or stop working to care for their child.



Source: National Survey of Children's Health 2016-17

Parents of Black and Hispanic children with autism had higher rates of experiencing at least one material hardship compared to White children. About 75-80% of these families experienced at least one material hardship compared to 59% of White children and 52% of children of another race. However, parents of Black children with autism were the least likely to quit work or reduce work hours to care for their child.

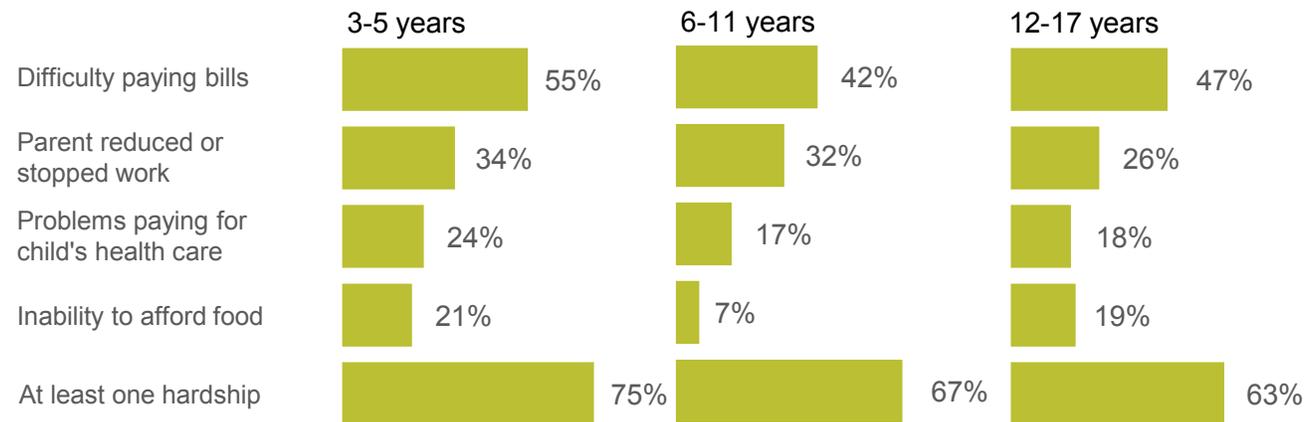
Material hardship was differentially experienced by race and ethnicity in households with children with ASD.



Source: National Survey of Children's Health 2016-17

Parents of young children with autism reported the highest levels of material hardship across all indicators. Levels of hardship were slightly lower in households of school-age children and youth on the spectrum. Over one-fourth of parents of youth reported needing to reduce work hours to care for their child, compared to one-third of parents of young children.

Difficulty paying bills was the most common material hardship across age groups in households with children with ASD.



Source: National Survey of Children's Health 2016-17

SPOTLIGHT on low-income households with children on the autism spectrum: levels of family financial hardship

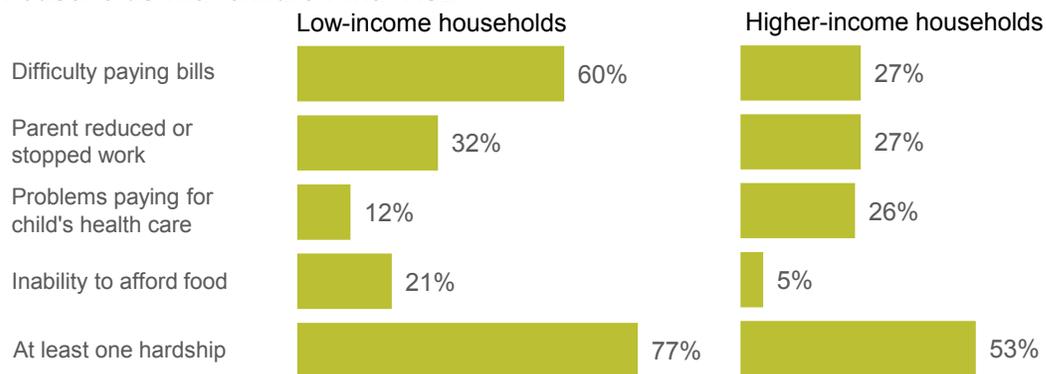
One out of every five parents of children on the autism spectrum from low-income households said they “sometimes” or “often” could not afford enough food for the family to eat.

Parents of children with autism from low-income households also reported more material hardships than higher-income households, except for difficulty paying for the child’s medical or health care bills.

What is a low-income household?

In this report, we discuss the characteristics and needs of families of children with autism from **low-income households** (the combined income of all household members was below 200% of the FPL), compared to those from **higher-income households** (at or above 200% of the FPL). We chose 200% FPL because this number corresponds with the eligibility threshold for many safety net programs discussed in this report. In 2015, 200% of the FPL for a family of four was \$48,500.

Difficulty paying bills was the most common material hardship across age groups in households with children with ASD.



Source: National Survey of Children's Health 2016-17

We note that most (75%) parents of children with autism from low-income households had no out-of-pocket medical expenses. However, these families also had higher rates of public health insurance coverage, which may have reduced their out-of-pocket costs. Only 14% of parents of children with autism from higher-income households had no out-of-pocket medical expenses.

The high rates of public health insurance receipt among low-income children with ASD may reflect changes in the Early Periodic Screening Diagnostic and Treatment (EPSDT) program, which entitles Medicaid-eligible children to health care services that are deemed medically necessary for the treatment of the child’s conditions.

Safety Net Program Use

This chapter examines the types of safety net programs low-income households of children with ASD report using. We first compare safety net program use between low-income families of children with autism to low-income families of children with special health care needs who did not have autism (SHCN), and families of children who did not have a SHCN or autism (No SHCN). Then, we compare safety net use among the ASD group by age groups. Finally, we compare family financial hardship among households of children with ASD that do and do not receive safety net benefits.

Measures of safety net programs were drawn from four yes/no survey questions. Participants were asked, “At any time during the past 12 months, even for one month, did anyone in your family receive: 1) cash assistance from a government welfare program; 2) food stamps or supplemental nutrition assistance program benefits (SNAP); 3) free or reduced-cost breakfasts or lunches at school (abbreviated as *free/reduced lunch*; or 4) benefits from the woman infants and children (WIC) program?”

Public health insurance generally includes Medicaid and the Children’s Health Insurance Program (CHIP). We considered a family to have public health insurance if they used only public health care OR a combination of public and private health insurance.

Our key findings

- We examined use of four safety net programs: 1) Cash assistance for poor families with children; 2) the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); 3) the Supplemental Nutrition Assistance Program (SNAP, also known as “food stamps”); 4) free and reduced-price meals in schools.
- More than two-thirds (86%) of children with ASD from low-income households participated in at least one of the following four safety net programs (cash assistance, WIC, SNAP, and free/reduced meals). Free/reduced lunch was the most common program among low-income children with ASD, followed by SNAP, cash assistance and WIC.
- Over half (58%) of low-income households with children with ASD participated in more than one safety net program and 28% of participated in three or more programs.
- Low-income families of children with ASD had the lowest rates of disconnection from safety net programs (14%) compared to children with other SHCN (24%) and children with no SHCN (29%).
- Children with ASD who participated in at least one safety net program scored higher on three indicators of material hardship (*difficulty paying bills, parents reduced/stopped work, and inability to afford food*) and had higher out-of-pocket expenditures than children who were disconnected from the safety net.
- Children with ASD from low-income households who received public health insurance had higher levels of safety net program use than children with ASD who were either uninsured or received private health insurance only.
- Families of children who had public health insurance reported lower out-of-pocket expenditures and were less likely to report problems paying for their child’s medical care than children with private health insurance.

Background

What are safety net programs and why are they important?

Safety net programs refer broadly to government-funded programs that provide material and financial support for people living in poverty. Findings suggest that safety net program benefits play a significant role in reducing poverty rates among households of children, including those with disabilities.^{15,16,17,18,19} Safety net benefit receipt is also shown to be associated with reduced material hardship and health-related spending.²⁰

What safety net programs are examined in this report?

This report considers two major categories of safety net programs: cash assistance and food assistance. Cash assistance programs include: 1) Temporary Assistance to Needy Families (TANF, formerly Aid to Families with Dependent Children or AFDC) - a federal-state block grant program that offers cash welfare for low-income families, - and 2) Supplemental Security Income (SSI) - a federally-funded income maintenance program that provides cash benefits for people with disabilities.

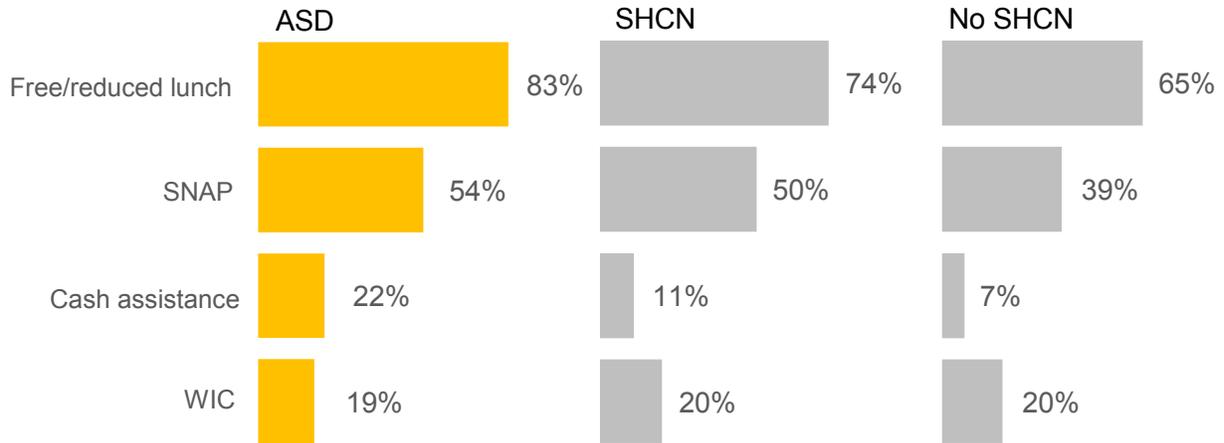
Food assistance can include: 1) Supplemental Nutrition Assistance Program (SNAP, previously referred to as “food stamps”), which provides food vouchers and nutritional assistance to eligible low-income individuals and families, 2) ; the National School Lunch Program (NSLP), which offsets the cost of lunch at school (free/reduced lunch); and 3) the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), which provides food packages to pregnant and postpartum women and young children.^{21,22}

Safety net programs in low-income households

Safety net program use was common in households of children with ASD.

We explored use of four safety net programs: cash assistance, free/reduced lunch, SNAP, and WIC. Low-income children with ASD had higher levels of safety net use across all four programs, except for WIC, compared to low-income children with other special health care needs (SHCN) and those with No SHCN.

Safety net program use was common in low-income families of children with ASD.



Source: National Survey of Children's Health 2016-17

Most children with ASD from low-income households (86%) received at least one safety net benefit, compared to 76% of children with SHCN from low-income households and 71% of children with no SHCN from low-income households.

Low-income families of children with ASD were the most likely to receive at least one safety net benefit.

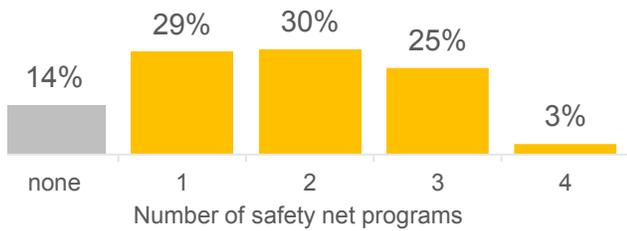


Source: National Survey of Children's Health 2016-17

Some families received more than one safety net benefit.

Only a small proportion of low-income children with ASD (3%) used all four safety net programs. About 30% of low-income children with ASD participated in two programs and one in four low-income children participated in three programs. This was similar to children with SHCN and children with no SHCN. However, children with SHCN or no SHCN were less likely to receive three or four benefits.

More than half of low-income families of children with ASD received at least two safety net benefits.

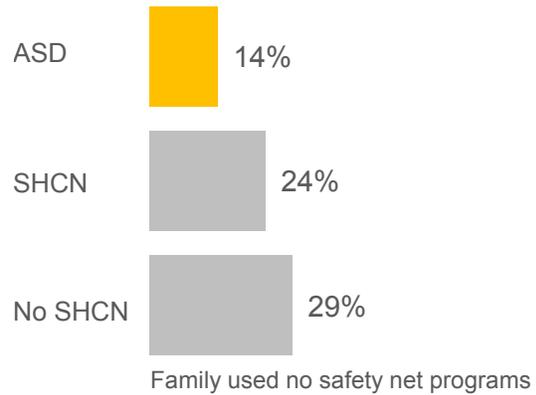


Source: National Survey of Children's Health 2016-17

The most common combination of safety net programs was the free/reduced lunch benefit plus SNAP, with nearly 95% of SNAP recipients also receiving free/reduced lunch benefits.

A bit of good news, while some low-income families are disconnected from needed benefits, low-income families of children with ASD had the lowest rates of disconnection from safety net programs.

Low-income families of children with ASD had the lowest rates of disconnection from safety net programs.



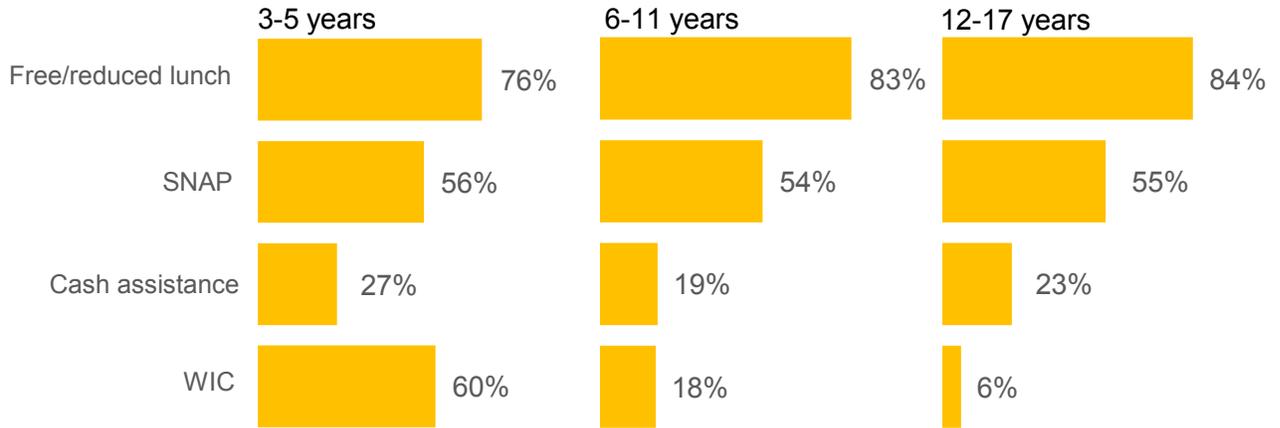
Source: National Survey of Children's Health 2016-17

Certain safety net programs were more common in households with younger children with ASD

We examined safety net program use according to age groups of children with ASD. The proportion of safety net use was consistent with the target population of each benefit program. For instance, more households of young children with ASD (3-5 years) received WIC, while more households of school-age children (6-11) and youth (12-17) received free/reduced lunch.

Some of the graphs in this section seem to have smaller font titles than in previous chapters.

Safety net program use in low-income families of children with ASD across age groups.

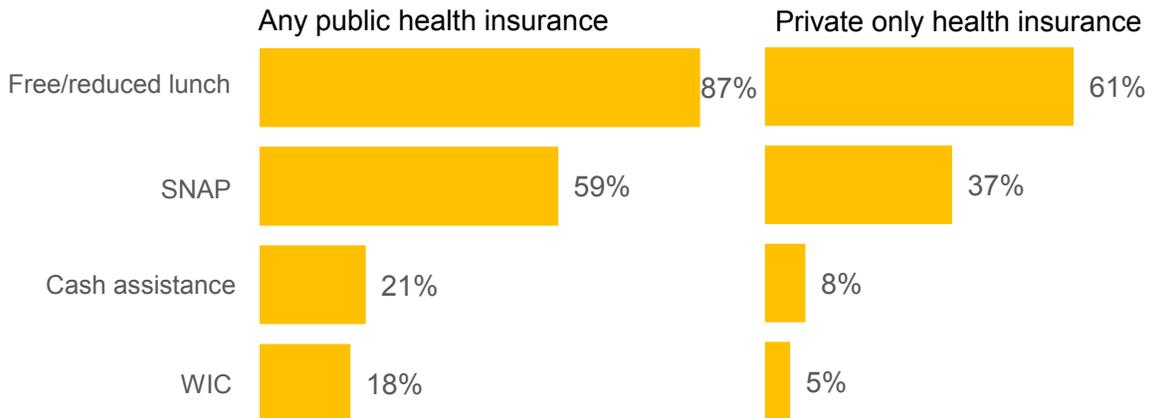


Source: National Survey of Children's Health 2016-17

Children with ASD with public health insurance often lived in households that received safety net benefits.

Children with ASD from low-income households who received public health insurance had higher levels of safety net program use than children with ASD from low-income households who were either uninsured or received private health insurance only.

Participation in safety net programs was more common in children with ASD from low-income families who had public health insurance than children who did not.



Source: National Survey of Children's Health 2016-17

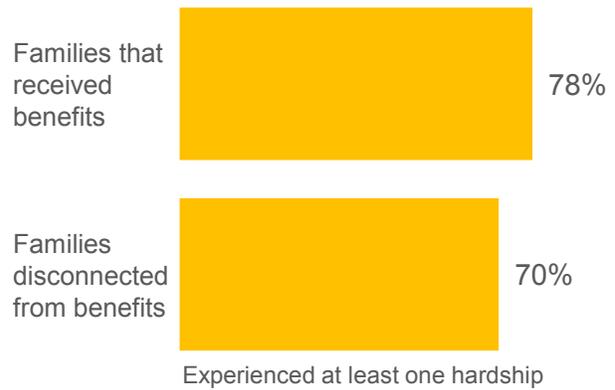
Family financial hardship by safety net use

What we know

Use of safety net programs can help to reduce the adverse consequences of poverty among people with disabilities. However, low-income safety net benefit users still experience higher rates of financial burden relative to those that do not receive benefits. This likely reflects the stringent eligibility criteria of safety net programs.

Material hardship was common in low-income households of children with ASD, regardless of whether families were connected to safety net benefits. Seventy percent of low-income families that were disconnected from safety net benefits reported at least one material hardship, as did 78% of families that received benefits.

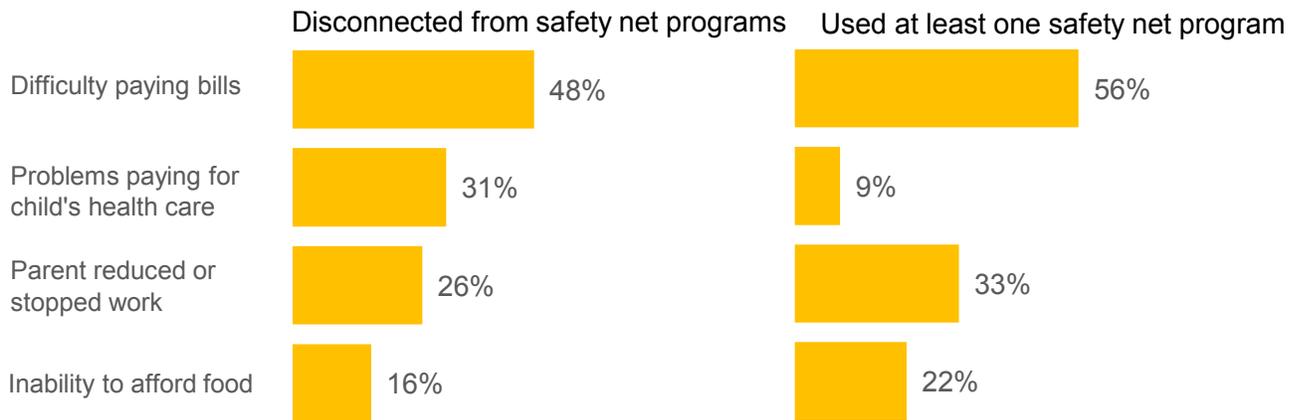
Low-income families of children with ASD had high rates of material hardship.



Source: National Survey of Children's Health 2016-17

Problems paying for health care were more common in families of children with ASD that were disconnected from safety net benefits, whereas difficulty paying bills was more common in families that were connected to benefits.

Difficulty paying bills was a common material hardship in low-income families of children with ASD even if they were connected to safety net programs.

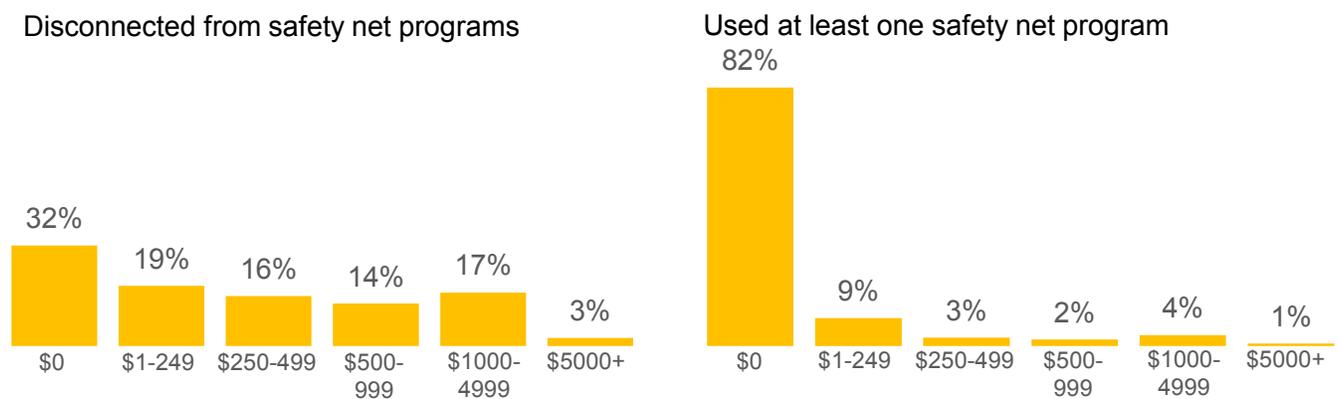


Source: National Survey of Children's Health 2016-17

About 14% of low-income households of children with ASD were disconnected from all four safety-net programs. Low-income households of children with ASD which were disconnected from benefits tended to have incomes right about the poverty level, compared to households that used safety net programs (67% versus 44%).

Higher out-of-pocket expenditures were reported for low-income families of children with ASD who were disconnected from safety net programs. Roughly one out of every five (20%) disconnected households of children with ASD reported out-of-pocket expenditures of \$1,000 or more per year, compared to just 4% of households that received at least one safety net benefit.

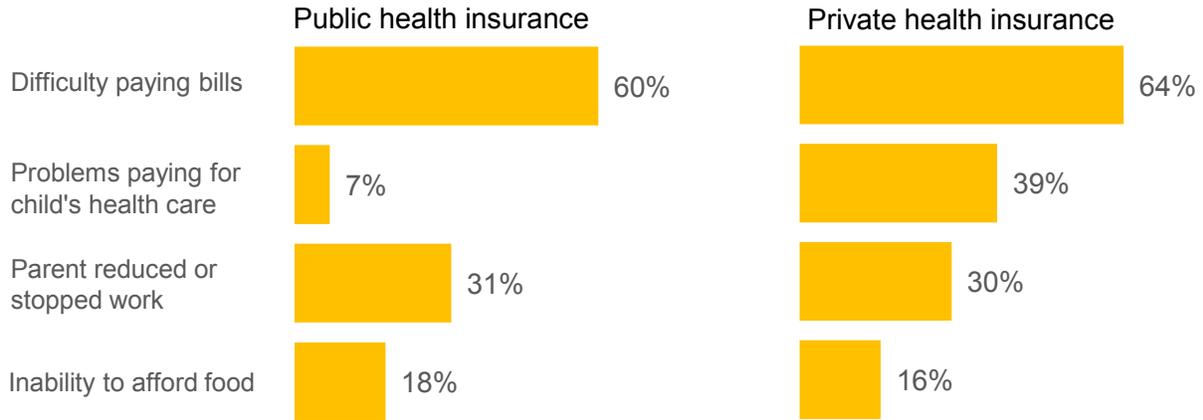
Low-income families of children with ASD who were disconnected from safety net programs had more out-of-pocket expenditures than families that were connected.



Source: National Survey of Children's Health 2016-17

Some types of family financial hardship were more common among low-income households of children with ASD with private health insurance than in children with public insurance.

Problems paying for child healthcare were lower among households of children with ASD with public health insurance.



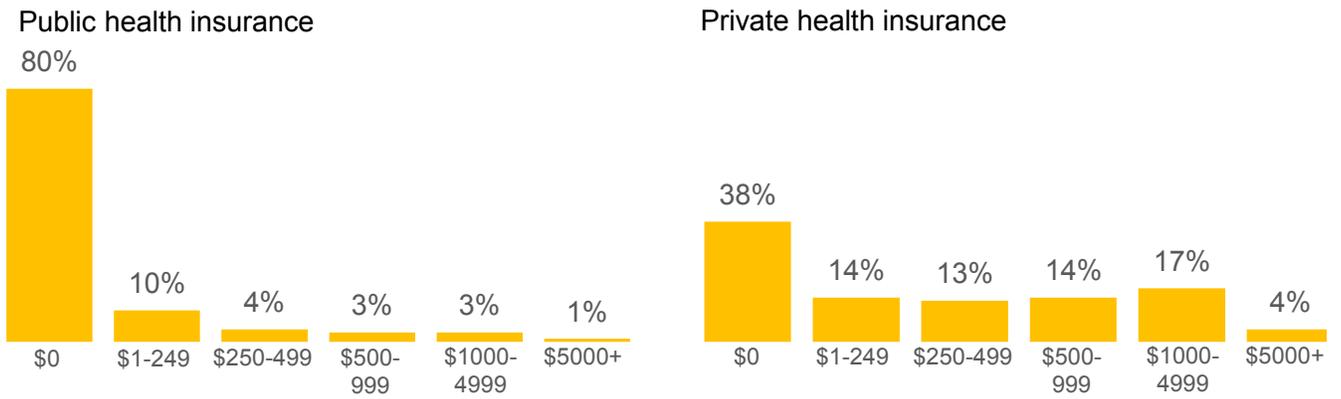
Source: National Survey of Children's Health 2016-17

Roughly eight in ten children with ASD from low-income households received public health insurance and two in ten received private health insurance. There were few differences in reported hardships by health insurance type, with the exception of medical hardship. Only 7% of children who had public health insurance had problems paying for child's health care, compared to 64% of children who had private health insurance.

Out-of-pocket expenditures were also lower among children who had public health insurance. Among low-income households, most families of children with ASD (80%) who had public health insurance reported no out-of-pocket expenditures, compared to 38% of families of children with ASD who received private health insurance.

Higher-income households are more likely to have some out-of-pockets costs than low-income households because they are more likely to have the discretionary funds needed to pay for healthcare. On the other hand, low-income households often do not have discretionary funds and may rely on public health insurance to offset medical expenses.^{23,24,25,26}

Families of low-income children with ASD who had public health insurance reported fewer out-of-pocket expenditures.



Source: National Survey of Children's Health 2016-17

What Next?... Looking Ahead

Conclusions and recommendations for future research

Families of children with ASD face significant financial challenges due to their child's complex service needs and frequent out-of-pocket expenditures for community services and health care. In many instances, the high support needs of children and adolescents with ASD may greatly exceed the available resources of family members and lead to financial strain, especially among families with low-income.^{27,28,29} As of 2016, an estimated one-third of children with ASD were living in poverty.³ However, until now, we knew few details about the characteristics, financial hardships and use of financial supports among households of children with ASD.

Using data from the 2016-2017 National Survey of Children's Health, this report described financial hardship among families of children with ASD (ages 3-17 years) in three areas: household poverty, material hardship (difficulty paying for basics like food or housing, unable to afford adequate food, difficulty paying a child's medical bills, and reducing work hours to care for their child) and medical expenses. We also assessed families' participation across four safety net programs: cash assistance from a government welfare program, food stamps or supplemental nutrition assistance program benefits (SNAP), free or reduced-cost breakfasts or lunches at school (free/reduced lunch), and benefits from the Women, Infants and children (WIC) program.

We found that households of children with ASD were more economically disadvantaged compared to households of other children and that they were more likely to receive safety net benefits. Children with ASD also had poorer health and were more often limited from doing things most children of the same age could do. They used or needed more services than children with other special health care needs.

This report provides new information about children with ASD from low-income households and population-level estimates of financial hardship and safety net program participation which were previously unexamined.

We conclude this report by noting seven needs for future research:

1. **Compare financial hardship across types of disability and health conditions.** Many studies examine financial hardship for children with special needs as a whole. This report found differences in family financial hardship between children with ASD, other SHCN and No SHCN. Given that the population of children with SHCN differ widely in severity, future research could build upon our findings by further disaggregating children with SHCN by diagnosis.³⁰
2. **Identify the factors that drive group differences in financial hardship.** Our findings suggest a link between ASD diagnosis and family financial hardship. We found that households of children with ASD experienced greater levels of poverty and material hardship than households of other children but were more likely to report having no medical expenses. One possible explanation for why more ASD families reported no medical expenses is related to higher rates of enrollment in public health insurance. Additionally, state-level mandates require private insurance to cover autism. Our report found that families of children with public health insurance had lower out-of-pocket medical costs. This is consistent with other studies of children with ASD that found significantly higher medical expenses among privately insured children relative to publicly insured children. These preliminary findings suggest that public health insurance might mitigate medical expenses for children with ASD. Further research should examine the role of public health insurance in households raising children with ASD and the possibility of raising the income threshold for qualifying for various means-tested programs.
3. **Analyze subpopulations of low-income children with ASD by age, race and ethnicity.** Our research suggests that young children from minority backgrounds might be particularly vulnerable to the effects of poverty and hardship. Among households of children with ASD, 80% of parents of Black children and 75% of Hispanic children reported at least one hardship, compared

with 59% of parents of White children. Household with young children (ages 3-5 years) with ASD had the highest rates of material hardship with 75% of households reporting at least one material hardship. The findings suggest that material hardship is a major problem for households of children with ASD, especially minority children and children ages 3-5 years. If policymakers want to target new resources and programs to subgroups to alleviate hardship, they should look to analysis of subpopulations of low-income children with ASD.

4. **Consider the subpopulation of children with ASD who do not receive safety net benefits despite being eligible.** This report compared the characteristics of children with ASD that do and do not use safety net programs among the subpopulation of low-income households. However, the data do not generally allow direct identification of the group of eligible individuals who are not receiving welfare because Federal Poverty Level is not a perfect indicator of safety net program eligibility (i.e., not everyone within the Federal Poverty guidelines are eligible to receive benefits). Future studies that include more accurate measures of program eligibility – including assets, household income, and immigration status – are needed.
5. **Estimate the direct and indirect consequences of financial hardship on child and family outcomes.** Families of children with ASD were more likely to live in low-income households, reported higher levels of material hardship, and had more medical expenses than families of children with other SHCN and no SHCN. However, no published research examines the effect of these adverse experiences on outcomes of children with ASD as they age into adulthood. This is an important avenue for future investigation.
6. **Assess how material hardship varies by household income.** Although families of children with ASD of all income levels experience material hardship, those who live in households with incomes under 200% FPL experience the most hardship. This suggests that policies to increase the financial and food security of households of children with ASD could have the greatest effect on alleviating hardship for the lowest-income families. Expanding support for low income families who are raising children with disabilities, particularly those under 100% FPL, would alleviate part of the burden these families

experience. However, budget cuts to nutritional programs - like SNAP and free/reduced lunch - are likely to increase the challenges of accessing safety net benefits among low-income ASD households.

7. **Examine the role that safety net programs play in ameliorating poverty and material hardship.** A major question facing policymakers is whether safety net programs help to reduce the adverse effects of poverty. A large proportion of low-income children with ASD report material hardships despite using safety net programs. This is an especially important fact given that safety net programs – notably SNAP and free/reduced lunch – have faced budget cuts in recent years.³¹ Our findings offer evidence that the use of safety net programs should be considered when family financial burden is investigated. To date, this issue has been largely ignored by ASD researchers and social welfare researchers. Further study with in-depth data on hardship and safety net use is needed.

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Appendix: Methods

Data Source

Funded by the Health Resources and Services Administration's Maternal and Child Health Bureau, the National Survey of Children's Health is a repeated cross-sectional design that provides national and state-level data on the health and well-being of United States children, ages 3 to 17 years.^{7,8} The data provide a wealth of information across a range of topics including: physical and emotional well-being, healthcare experiences, school activities and neighborhood safety. Earlier versions of the NSCH have served as a principal source of state-level information on children's health and has been widely used throughout the Maternal and Child Health Bureau to monitor federal and state Title V programs and Healthy People objective.

Who is represented in this report?

The NSCH 2016 and 2017 and sampling plans were designed to produce nationally representative samples that would generalize to United States children under the age of 18 living in mailable residential housing units. Therefore, it is important to note that these findings are representative of children with (parent-reported) ASD but not households of children with ASD.

The survey identifies children with ASD based on parent report. In this report, children were considered to have ASD if parents responded affirmatively to two survey questions: 1) has a doctor or other healthcare provider ever told you that this child had autism or autism spectrum disorder? and 2) does this child currently have the condition?

A note about CSHCN

The CSHCN screener was developed in 1998-2000 as part of the Child and Adolescent Health Measurement Initiative (CAHMI) to identify CSHCN in population-based surveys. The five-item parent-reported CSHCN screener is a widely used method for estimating the prevalence of CSHCN and has been validated as a population-based tool for comparing healthcare needs and performance across states and population subgroups.³² The screener relies on the Maternal Child Health Bureau's (MCHB) definition of CSHCN as children that "have or are at risk of a physical, developmental, behavioral or emotional condition

and require health and related services of a type or amount beyond that required by children generally."⁹ Note that this definition does not categorize health conditions according to diagnosis, but rather applies five qualifying criteria to all children with an ongoing medical, behavioral or other health condition regardless of their specific underlying diagnosis or health issue. As a result of this approach, CSHCN identified in the data are similar in terms of health needs and health-related consequences. It is important to note that children whose parents report separately the presence of a chronic condition or functional difficulties may not be identified as a CSHCN. Likewise, not all children who have been given a specific diagnosis will meet CSHCN criteria.

Data Analysis

Using data from the 2016-2017 National Survey of Children's Health, this report provides descriptive evidence on family financial hardship among children with ASD using a large national survey. The data collected in the surveys were based on caregiver report. The first set of analyses showed the percentages, across the three disability groups, of children with selected demographic and disability characteristics, and across indicators of family financial hardship and safety net use. The cases were weighted to ensure their representativeness in the national population. The second set of analyses focused on children with ASD and examined the characteristics and outcomes across strata of age, race and receipt of public health insurance. In addition to comparisons and demographic breakdowns, this report also includes a separate investigation of characteristics and outcomes among the subgroup of children with ASD from low-income households (those under 200% FPL). These "Spotlight" analyses are included in the report to stimulate further discussion and exploration of the data.

Group differences in the outcomes presented throughout this report – including financial hardship and safety net program use - do not control for other variables, like income, that could be driving, in part, some of these differences.

Study Strengths

- The 2016-2017 NSCH provide a unique opportunity to examine family financial hardship among a recent, nationally representative sample of children with ASD from low-income households.
- These data offer several measures of family financial burden and material hardship that are absent in other sources of data and provides an indicator of household federal poverty level (FPL).
- The survey has well-designed and tested data collection instruments and sampling design procedures.
- The NSCH2016-2017 includes weights for each child, which allows researchers to generalize findings to the population of all noninstitutionalized children in the United States who live in housing units (e.g. houses, apartments etc.). That said, it is important to note that these estimates do not generalize to parents, nor to households. Thus, we cannot state that our findings represent all households of children with ASD in the United States, which is the unit of analysis for the study.
- The estimates included in this report do not generalize to parents, nor to households and we cannot state that our findings represent all households of children with ASD. For example, weighted estimates based on the variable of SNAP receipt, can be interpreted as the proportion of children living in a household in which at least one family member received food stamps or supplemental nutrition assistance program benefits (SNAP). Findings cannot be interpreted as the proportion of households that receive SNAP.
- identify directly the group of eligible individuals who are not receiving welfare.
- The NSCH2016-2017 relies on parent reported ASD, which are not substantiated through clinical evaluation or educational records and are subject to imperfect parental recall. The questions used to identify ASD also lack specificity on method of diagnosis. ASD ascertainment relies on yes/no responses to just two questions. The questionnaire would not have identified all children on the autism spectrum, but rather those whom a health professional had categorized with the term autism. Because undiagnosed ASD could not be assessed, the prevalence of ASD may be underestimated, especially for younger children. Further, ASD questions are not the same as the definitions used by other major federal disability organizations and policies (like the social security administration and special education). Thus, the NSCH cannot reliability measure eligibility for such benefits using ASD data.
- The data is cross-sectional and observational in nature. We cannot infer causal relationships between variables (i.e., if safety net program use reduces family financial hardship). Rather, we can only assess if financial burden differs, on average, between safety net users and nonusers.

Study Limitations

- There is some evidence that safety net program use is underreported in national surveys, which suggests that the reported rates of safety net program participation may underestimate the true prevalence.³³³⁴³⁵
- Federal Poverty Level is not a perfect indicator of safety net program eligibility (i.e., not everyone within the Federal Poverty guidelines are eligible to receive benefits). In these surveys respondents are typically asked whether they receive any welfare benefit. However, the data do not generally allow to



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