

# National Autism Indicators Report

The Intersection of  
Autism, Health, Poverty  
and Racial Inequity

April 2022



**Life Course  
Outcomes Program**



DREXEL UNIVERSITY  
A.J. Drexel  
**Autism Institute**



## Mission

The A.J. Drexel Autism Institute's mission is to discover, develop, promote and disseminate population-level and community-based approaches that will prevent autism-associated morbidity and disability and improve the quality of life for individuals with autism of all ages.

The Policy and Analytics Center (PAC) seeks to utilize research methods and innovative analytic strategies to support the development of effective social and health policy in cities, states, and across the US.

The Autism Institute's Life Course Outcomes Program (LCO) is building a base of knowledge about the things other than clinical interventions that promote positive outcomes (and prevent negative ones) across the life course for people on the autism spectrum and their families and communities. As a result – advocates, policy makers and organizations will be empowered with trustworthy information that is useful in creating a world where people on the autism spectrum are valued and effectively supported as contributing members of our communities who have roles to play and dreams to pursue.

For more information about us, please visit our websites: <https://drexel.edu/autisminstitute/research/Policy-Analytics-Center/> and <http://drexel.edu/AutismOutcomes>

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# National Autism Indicators Report:

## The Intersection of Autism, Health, Poverty and Racial Inequity

APRIL 2022

A publication of the A.J. Drexel Autism Institute's Policy and Analytics Center  
and Life Course Outcomes Program, Drexel University

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# Letter from the Project Director

Alice Kuo, MD, PhD, MBA

As Director of the Autism Intervention Research Network on Physical Health (AIR-P), I am extremely pleased that our network was able to contribute to this very important report on the intersection of autism identity, health and poverty. We are only beginning to recognize and describe disparities in health care services, health outcomes and life outcomes for individuals who identify as autistic. Autistic individuals have higher rates of undiagnosed cancers and cardiovascular disease, higher rates of unintentional injuries and decreased life expectancy, compared to non-autistic individuals. Research should focus on exploring factors that contribute to these disparities, and social determinants are likely to be the key.

Autism research is struggling to catch up from decades of neglect in our understanding of how social determinants affect outcomes among autistic people. For example, while recent CDC surveillance data show signs of improvement in the gap in age of diagnosis between white and Black children, we know that disparities are often more significant at the local level. Most intervention studies in autism have not considered effectiveness, the ability to scale up to the entire population, making intervention programs often inaccessible to lower-income autistic individuals or those without the right type of insurance or disposable income. We question the ethics of health and health care for autistic individuals without considering the impact of social determinants of health.

One challenge with social determinants of health is that people rarely only experience one aspect of disparities (i.e., they are not singular). Autistic children often experience other vulnerabilities that can lead to worse health outcomes. In addition, co-occurring health and mental health conditions add to vulnerability, as do a host of other social characteristics. Future autism research studies should include social determinants in order to understand how best to provide services to autistic individuals that will maximize their potential.

We also recognize that the national conversation on Equity, Diversity and Inclusion (EDI) too often does not include disability as a type of diversity. In fact, the National Institute on Minority Health and Health Disparities (NIMHD) does not include disability in its definition of groups at risk for health disparities. For this reason, our report is a critical step toward highlighting the need for our nation to recognize disability as a critical characteristic that intersects with the types of diversity (race, ethnicity, income) that dominate the current conversation—just as the American with Disabilities Act (ADA) recognizes disability as a vulnerable group in need of accommodations.

In summary, this report is hopefully the first of many examining the important intersection of autism, health and poverty.

*Alice Kuo, MD, PhD, MBA*

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# National Autism Indicators Report:

## The Intersection of Autism, Health, Poverty and Racial Inequity

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A note about language. In this report, we use the phrases “child with autism,” “child with an autism spectrum disorder,” and “child on the autism spectrum” interchangeably. We use the specific term autism spectrum disorder, or ASD, because it reflects the wide range of characteristics, impairments, and strengths seen in people with ASD. It is the language used in the current version of the Diagnostic and Statistical Manual (DSM-5), as well as the survey used in this report (National Survey of Children’s Health, or NSCH). Some youth and adults with ASD report that they prefer the term “autistic.” We also use the term “autistic” in this report to acknowledge that identity-first language is an important tool in increasing awareness and acceptance of neurodiversity.

We use the term BIPOC (Black, Indigenous, and People of Color) to represent the diversity of racial and ethnic backgrounds among children with autism who are not identified as “white, non-Hispanic” in NSCH data. We seek to be inclusive with this terminology but acknowledge that preferences vary and that best practice for language used may change.

## Executive Summary

# National Autism Indicators Report:

## The Intersection of Autism, Health, Poverty and Racial Inequity

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### The Charge

Reducing socioeconomic and racial/ethnic disparities in health and health care is a national priority for autism research.<sup>1</sup> Yet, there is little evidence that examines health and healthcare measures by race/ethnicity and socioeconomic position at the population-level. This report begins to address this gap by examining autism-, racial/ethnic-, and income-based disparities in health and health care in U.S. children ages 3-17 using nationally representative data. This report builds upon our November 2020 *National Autism Indicators Report on Health and Health Care* which compared health outcomes of children with autism to those of children with and without other special healthcare needs using the same data.<sup>2</sup>

Findings from this report align with federal program efforts to reduce health disparities and promote health equity for vulnerable populations at the national level. This report will also help to address Healthy People 2030 plan of action to “provide accurate, timely, and accessible data that can drive targeted actions to address regions and populations that have poor health or are at high risk for poor health.”<sup>3</sup>

### Our Goals

This report examines income-based differences in health and health care among U.S. children and explores how children and teens (“children” for brevity), with and without caregiver-reported autism, vary by race/ethnicity. We also provide population benchmarks of income-based disparities in health among children with autism. We focus on the following two questions:

- Do income-based differences in health and health care outcomes look the same for children with and without autism?
- Do income-based differences in health and health care outcomes look the same for BIPOC children with autism and white children with autism?

Examining the health and healthcare outcomes of children with autism in combination with other social characteristics offers several advantages. First, we can illuminate how demographics alone, and in combination with other social characteristics of children, are associated with differences in the rates of health and healthcare outcomes they experience. This will offer clues as to which social groups appear to be at the greatest risk for poor health or reduced access to care. Second, it increases our understanding of the health-related experiences of social groups who are often neglected in research.

Our findings also provide current and comprehensive evidence on how children with autism experience relative disadvantages related to social determinants of health, which are aspects of the environment that affect health, functioning, and quality-of-life outcomes and risks. Social determinants of health are grouped into major categories of economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context.<sup>4</sup> Policymakers, decisionmakers, and advocates can use this information to better understand the needs of the autism population and guide the development of targeted programs and services.

## Our Data Source and Approach

We combined four years of annual data from the National Survey of Children’s Health (NSCH), for 2017 through 2020. This survey provides national and state-level data on the health and well-being of children ages three to 17 years in the United States and is funded by the federal Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB). It asks families to provide information on children’s physical and mental health, access to quality health care, and the child’s family, neighborhood, school, and social context. (Information was reported by caregivers or other adult caregivers in the household; we typically use the words “caregiver” or “parent” for brevity when discussing study findings.) More information about the NSCH is available at <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>.

In light of the fact that very little is known about the intersection of autism, income, and race/ethnicity, we focused on descriptive analyses, such as examining the percentage of children in a given group who were reported to have a specific characteristic or experience. We did not perform tests of statistical significance for this report, as is often done in scientific journal publications, but discuss differences that seemed to have practical or clinical significance between groups. In general, we focused on differences of at least 5 percentage points. We also discuss general trends. For example, even when differences between groups were small, there were often consistent patterns in the data that were notable and suggest that further inquiry is needed. Additional information about the study methods is available in the **Appendix** of this report.

- **Statistical significance** refers to the mathematical probability that an observed difference occurred solely by chance, rather than because of a true difference between groups.
- **Clinical significance** refers to whether an observed difference is thought to be meaningful, such as whether it might have an impact on health or well-being. We report group differences of five percentage points or more. A 10 percentage point difference was used as a criterion for evaluating a larger magnitude of difference between groups.

## How We Define Autism, Income, and Race/Ethnicity

In discussing findings from the National Survey on Child Health, we have focused on three groups and how they overlap and compare to one another.

1. The autism group is made up of children whose caregivers reported that their child had a current diagnosis of autism.
2. Income groups are defined based on household income relative to the federal poverty level, or FPL. The FPL is based on the number of people living in the household as well as the household’s income for the previous year. Federal poverty levels are used to determine eligibility for certain programs and benefits, including health insurance programs. These levels are defined each year by the U.S. Department of Health and Human Services.
3. Mutually exclusive race groups and the designation of Hispanic vs. non-Hispanic are based on information self-reported by families using categories in the survey (white, non-Hispanic; Black or African American, non-Hispanic; other or multiple races, non-Hispanic; and Hispanic or Latino).

In our income-based analyses, we examined differences across four federal poverty thresholds: *poor* (0%–99% of the FPL) *near-poor* (100%–199% of the FPL), *middle-income* (200%–399% of the FPL), and *high-income* (400% of the FPL or higher). In some cases, these subgroups were too small to allow for meaningful comparison. In those cases, we compared differences between children from *lower-income households* (combined income of under 200% of the FPL) to those from *higher-income households* (at or above 200% of the FPL). We chose this threshold (200% FPL) because it corresponds with the eligibility threshold for many of the safety net programs (including food stamps, social security, and free/reduced lunch). The cutoff of 200% FPL has also been used in prior research about safety net program use among lower-income populations.

In our analyses of race and ethnicity, we examined differences between white and BIPOC children with autism and also examined specific racial/ethnic groups. As with income, sometimes groups were too small to allow for comparison.

### **How this Report is Organized**

Chapter 1 of this report provides new estimates about the size and characteristics of the population of children with autism across different household incomes, and by key subgroups defined by race/ethnicity. The remainder of this report is divided into chapters focused on findings related to health status (Chapter 2), healthcare access and use (Chapter 3), and health insurance and expenditures (Chapter 4). We also provide new estimates about the size and characteristics of the population of children with autism living in lower-income

households overall, and by key subgroups (defined by race/ethnicity) who are at greater risk for poverty. We conclude the report with a discussion of policy and practice implications and provide recommendations for future research.

In each chapter, we start with an overview of relevant issues, review what's been found previously, and provide technical details about how we analyzed the data.

Each chapter contains two sections focused on our two main questions of interest: 1) income-based disparities among children with and without autism, and 2) income-based disparities among children with autism from different racial and ethnic backgrounds.

# National Autism Indicators Report:

## The Intersection of Autism, Health, Poverty and Racial Inequity

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### Key Findings

We found that household income appears to be a very important factor for understanding health disparities for people with autism, as it is associated with differences in health status, insurance coverage, medical expenditures, and healthcare access. The report also shows that autism, poverty, and race/ethnicity appear to be risk factors for poor health and healthcare outcomes individually and in combination.

We present key findings on income-based differences in health and health care between **children with autism versus those without autism** and between **white children with autism versus BIPOC children with autism**.

#### Findings by Chapter:

##### Household Income

###### Does household income look the same for children with autism versus children without autism?

- Over half of the children with autism lived in lower-income households and one in four were poor, which was higher than the percentage of children without autism who lived in lower-income and poor households.

###### Does household income look the same for BIPOC children with autism versus white children with autism?

- A larger percentage of children with autism from lower-income households were BIPOC, compared to the overall population of children with autism.

##### Health Status

###### Do income-based differences in health outcomes look the same for children with autism versus children without autism?

- Children with autism had poorer overall health and dental health, more chronic health difficulties, and more health conditions than children without autism, regardless of income.
- As household income increased, so too did the percentage of children with excellent health.
- Autism-based differences in excellent overall health and dental health were smallest among high-income households, with the proportion of high-income children with autism with excellent dental health exceeding those of high-income children without autism.

###### Do income-based differences in health look the same for BIPOC children with autism versus white children with autism?

- Across all income groups, a greater percentage of BIPOC children with autism had poorer overall health, poorer dental health, and more severe autism than white children with autism.
- A greater percentage of poor and near-poor BIPOC children had poorer health, compared with their middle- and high-income BIPOC counterparts.

## Health Care Access and Use

### Do income-based differences in healthcare use and access look the same for children with autism versus children without autism?

- The proportion of children with access to a usual source of care increased as household income increased, regardless of autism status.
- Caregivers of children with autism were four times more likely to report that their child did not receive needed healthcare in the past year, compared to caregivers of children without autism.
- Near-poor and middle-income children with autism were more likely to have an unmet healthcare need than their poor and high-income counterparts.

### Do income-based differences in healthcare use and access look the same for BIPOC children with autism versus white children with autism?

- Children of other race(s) had similar rates of health care use as white children except for mental health care services.
- Racial/ethnic differences in healthcare use were most evident among near-poor and middle-income households, with BIPOC children having lower rates of use.
- BIPOC children with autism had lower levels of access to a usual source of care than white children with autism. Hispanic children with autism were at the greatest risk for poor outcomes.
- There was a general decrease in unmet healthcare needs with income among white children with autism but not among BIPOC children with autism.

## Health Insurance and Expenditures

### Do income-based differences in health insurance and expenditures look the same for children with autism versus children without autism?

- Overall, 96% of children with autism had some type of health insurance coverage at the time of the survey. Poor children with autism were more likely to have some type of health insurance coverage than poor children without autism (95% versus 88%).
- Children with autism were more likely to have public health coverage and less likely to have private coverage than children without autism across income levels.
- Children with autism had similar rates of consistent insurance coverage than children without autism but were less likely to have adequate coverage, regardless of income.
- Children with autism who were poor were more likely to have adequate insurance coverage (61%) versus children from high-income households (41%) while poor and high-income children without autism were equally as likely to have adequate insurance.
- Middle and high-income caregivers of children with autism were more likely to report difficulty paying for their child's medical bills than caregivers from other income groups and those of middle-income children without autism.
- As income increased, so too did out-of-pocket medical expenses. Differences in out-of-pocket medical expenses between children with and without autism were the greatest among middle- and high-income groups relative to poor and near-poor groups.

### Do income-based differences in health insurance and expenditures look the same for BIPOC children with autism versus white children with autism?

- White and BIPOC children with autism were similarly likely to have some type of health insurance coverage. Among BIPOC children, only Hispanic children differed in insurance coverage from white children (93% versus 98%).
- Type of health insurance varied according to race/ethnicity. Across all income levels, Black (63%) and Hispanic (64%) children with autism were more likely to have public health insurance coverage than white children (47%) and children of other race(s) (45%).
- While consistency in health insurance coverage did not vary by race/ethnicity, BIPOC children with autism were more likely to have adequate health insurance coverage. Notably, Black (58%) and Hispanic (50%) children were more likely to have adequate health insurance coverage than white children (46%) and children of other race(s) (41%).
- Poor BIPOC children had the highest rates of reported insurance adequacy (66%) relative to their BIPOC and white peers in other income groups.
- Black children with autism and those in middle-income households were at the greatest risk for medical hardship.
- High-income BIPOC children with autism were the least likely to have no out-of-pocket medical expenses (5%) and most likely to have expenditures of \$500 or more (66%). Conversely, BIPOC and poor children had the lowest expenditures, with 77% reporting no expenses and just 6% reporting expenditures of \$500 or more.

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### Background

**Children with autism and their families face significant health challenges due to complex service needs and frequent out-of-pocket expenditures for health care.** <sup>5,6</sup>

In our November 2020 *National Autism Indicators Report on Health and Health Care*, we found differences in health and healthcare outcomes among children with autism relative to children with and without other special healthcare needs (as indicated by increased need for health care, medication, or services compared to peers).<sup>2</sup> Children with autism had poorer overall health and dental health than children without autism, and they also experienced higher levels of functional difficulties and had more health conditions than their peers without autism. We found differences in co-occurring health and mental health conditions, office visits, mental health care, and need for care coordination. Families of children with autism also had higher total healthcare expenditures than families of children with and without other special healthcare needs and paid more out-of-pocket for medications. We reported similar findings in our 2020 *National Autism Indicators Report on Family Financial Hardship*. That report revealed that families of children with autism had higher out-of-pocket medical expenses than children without special healthcare needs and were more likely to have difficulty paying for health care.<sup>7</sup>

**Children with autism, children from lower-income households, and children who are Black, Indigenous and People of Color (BIPOC) disproportionately experience poor health and healthcare access.** <sup>4,8-12</sup>

Our May 2020 *National Autism Indicators Report on Family Financial Hardship* demonstrated that children with autism from lower-income households were at

greater risk for poor health and health care relative to their more affluent peers with autism. Families of color are at a historical disadvantage of experiencing poverty because of systemic barriers such as discriminatory practices. As a result, racial and class inequalities are closely tied in the United States, further complicating pathways to stable health outcomes. Our 2020 *National Autism Indicators Report on Health and Health Care* found that BIPOC children with autism are more likely to report health and healthcare disparities than their white counterparts. We also found that healthcare visits were less common among Hispanic children with autism compared to their white counterparts. Likewise, caregivers of Black children with autism were the most likely to report needing help coordinating their child's care. According to our 2020 *National Autism Indicators Report on Family Financial Hardship*, the families of BIPOC children with autism were also at greater risk for material hardships (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), than their white, non-Hispanic peers. The report also found that BIPOC children with autism were at greater risk of living in lower-income households.

Autism research has a Eurocentric/white bias and has failed to include BIPOC researchers and study participants.<sup>13</sup> To date, there has been little research about how social identities “intersect” to impact health and health care for children with autism. For example, a BIPOC child with autism who lives in poverty might have different healthcare experiences than a white child with autism from a high-income household. We need to better understand the intersectionality of these multiple social characteristics to figure out how to target and tailor interventions and improve health outcomes.



## Chapter 1.

# Household Income

To better understand the economic situation of children with autism, this chapter provides new estimates about the size and characteristics of the population of children with autism living in lower-income households overall, and by key subgroups defined by race and ethnicity.

As noted earlier, we define income categories based on the federal poverty level. The federal poverty level for a family of four within the 48 contiguous states and DC was \$24,600 annual income in 2017 (the beginning time frame for our data set) and \$26,200 annual income in 2020 (the final year of our data set). Separate income thresholds are issued for Alaska and Hawaii.

This chapter is divided into two sections. Section 1 examines income-based differences in health status for children with and without autism. Section 2 focuses only on children with autism and examines income based differences by race/ethnicity.

# Section 1.1

## Does household income look the same for children with autism versus children without autism?

### WHAT WE KNOW:

Findings from our May 2020 National Autism Indicators Report on Family Financial Hardship.

- More children with autism lived in lower-income households, compared to children with other special healthcare needs and children with no special healthcare needs.
- More children with autism from lower-income households had poorer health and higher autism severity (by caregiver report) than their peers from higher-income households.

### WHAT THIS REPORT ADDS:

Our new analysis generated more recent population estimates of household income among the population of U.S. children with and without autism. We found:

- Over half of the children with autism lived in lower-income households and one in four were poor.

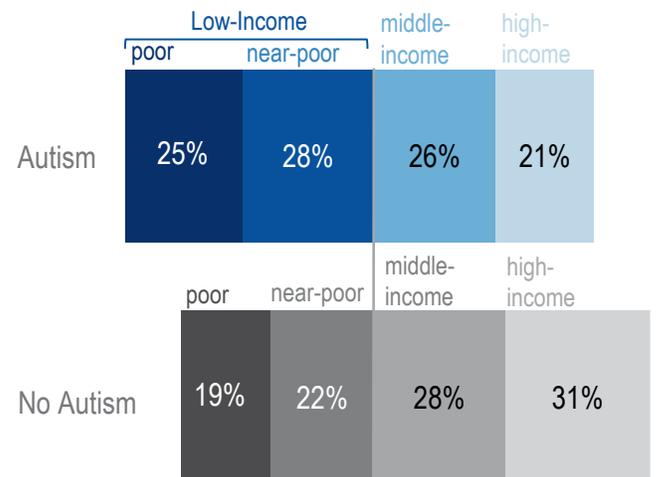
We define income categories based on the federal poverty level:

- *poor* (0%-99% of the FPL)
- *near-poor* (100%-199% of the FPL)
- *middle-income* (200%-399% of the FPL)
- *high-income* (400% of the FPL or higher).

More generally, lower-income households refer to income less than 200% of the FPL and higher-income households refer to income at or above 200% of the FPL.

More children with autism lived in poor households, compared to children without autism. One in four (25%) children with autism lived in poor households. More than half of children with autism (53%) lived in lower-income households, versus 41% of children without autism. Fewer children with autism lived higher-income households than their peers without autism (21% versus 31%). These findings are similar to those presented in our previous report on family financial burden.

### Over half of children with autism lived in low-income households and 1 in 4 lived in poor households.



Source: National Survey of Children's Health 2017-20

## Section 1.2

### Does household income look the same for BIPOC children with autism versus white children with autism?

#### WHAT WE KNOW:

Findings from our May 2020 *National Autism Indicators Report on Family Financial Hardship*.

- A greater proportion of children with autism from lower-income households were non-white, lived in a household headed by a single mother, and had at least one sibling with a special health care need.

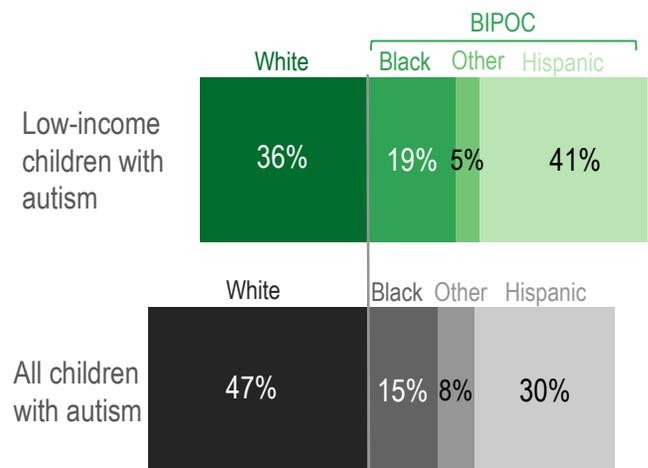
#### WHAT THIS REPORT ADDS:

Our new analysis examined whether household income varied according to race/ethnicity among the population of children with autism. We found:

- Two-thirds of children with autism from lower-income households were BIPOC, compared to about half of children with autism from all households.
- A larger percentage of children with autism from lower-income households were Hispanic and a smaller percentage were white relative to the total population of children with autism.

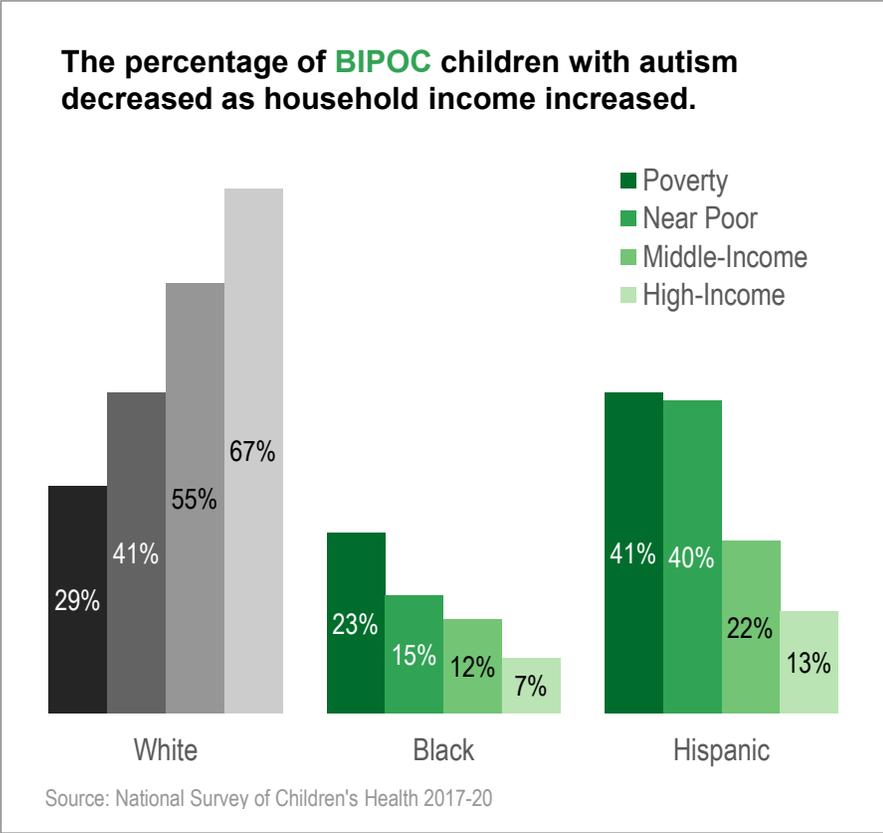
A larger proportion of lower-income children with autism were BIPOC in the lower-income group relative to the total population of children with autism. In particular, 41% of the population of lower-income children was Hispanic, whereas 30% of all children with autism were Hispanic. White children comprised 47% of the group of children with autism, but just 36% of the subpopulation of children with autism from lower-income households.

#### Low-income children with autism were more racially/ethnically diverse than all children with autism.



Source: National Survey of Children's Health 2017-20

As income increased, the percentage of white children in each income group increased. Similarly, the lower income groups had the highest percentages of BIPOC children with autism.





## Chapter 2.

# Health Status

The purpose of this chapter is to examine the health status of U.S. children with and without autism, with a spotlight on the intersection of an autism diagnosis, household income and race/ethnicity.

In this chapter, we focus on three health status measures for children: overall health, dental health, and caregiver-reported autism severity. We also examine the presence of a variety of chronic health difficulties and health conditions.

This chapter is divided into two sections. *Section 1* examines income-based differences in health status for children with and without autism. *Section 2* focuses only on children with autism and examines income-based differences by race/ethnicity.

## Section 2.1

### Do income-based differences in health outcomes look the same for children with autism versus children without autism?

#### WHAT WE KNOW:

Findings from our November 2020 *National Autism Indicators Report on Health and Health Care* and May 2020 *National Autism Indicators Report on Family Financial Hardship*.

Our past reports have shown that health status varies by autism diagnosis, although patterns differ between higher- and lower-income households:

- On average, the health of children on the autism spectrum was worse than the health of children with and without other special health care needs (SHCN).<sup>2</sup>
- Children with autism were more likely to have fair/poor dental health relative to children with other SHCN, but not relative to children with no SHCN.<sup>2</sup>
- Caregivers of children with autism generally reported similar levels of chronic health difficulties, compared to caregivers of children with other SHCN.<sup>2</sup>
- Based on parent report, children with autism had higher rates of every single condition listed, compared to children with other SHCN, with the exception of children with asthma.<sup>2</sup>
- A lower percentage of caregivers of children with autism from lower-income households rated their child's health as excellent, and a higher percentage rated their child's autism as severe, compared to caregivers of children with autism from higher-income households.<sup>7</sup>

#### WHAT THIS REPORT ADDS:

Our new analysis focuses on gathering more details on healthcare use and access across different income levels. We found:

- Across all income groups, children with autism were less likely to report excellent overall health and excellent dental health relative to children without autism. They also had more chronic health difficulties and more health conditions than children without autism, regardless of household income.
- Children from poor households generally experienced the most health issues and better health was observed in children in households with higher-income, for both children with and without autism.
- Differences in excellent overall health and dental health between children with and without autism were smallest among high-income households, with the proportion of high-income children with autism with excellent dental health exceeding those of high-income children without autism.

We define income categories based on the federal poverty level:

- *poor* (0%-99% of the FPL)
- *near-poor* (100%-199% of the FPL)
- *middle-income* (200%-399% of the FPL)
- *high-income* (400% of the FPL or higher).

More generally, lower-income households refer to income less than 200% of the FPL and higher-income households refer to income at or above 200% of the FPL.

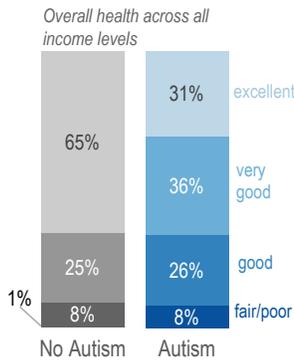
## Overall Health

Overall, a greater proportion of children with autism were rated as having fair/poor overall health, compared to their peers without autism (8% versus 1%), and only half as many were rated as being in excellent health (31% versus 65%).

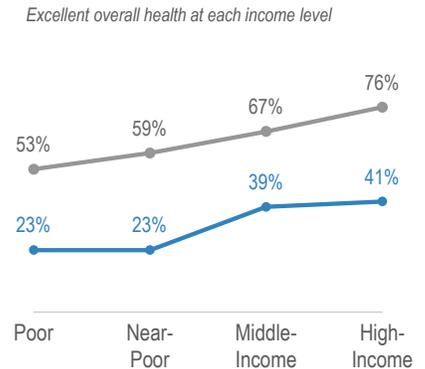
Autism-based differences in caregiver-reported overall health persisted across all income levels, with differences in overall health between children with and without autism ranging from 28 to 36 percentage points.

Health status increased with household income for both groups: 23% of poor children with autism had caregiver-reported excellent health, versus 41% of high-income children with autism.

Children with autism were more likely to have fair/poor overall health and less likely to have excellent health than children without autism.



Children with autism were less likely to have excellent health than children without autism, regardless of household income.

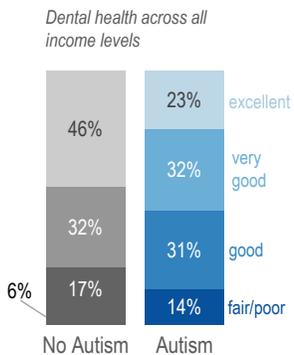


Source: National Survey of Children's Health 2017-20

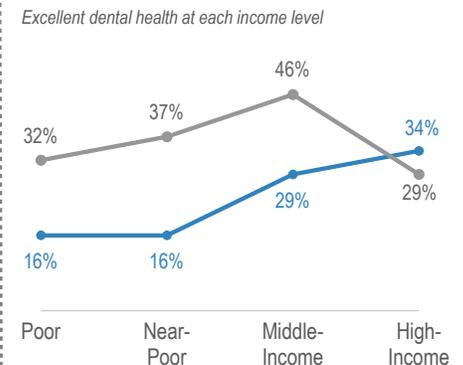
## Dental Health

Overall, the proportion of children with autism with caregiver-reported fair/poor dental health was more than twice that of children without autism (14% versus 6%). Likewise, the proportion of children with autism with excellent dental health was half that of children without autism (23% versus 46%). When examining specific income categories, poor and near-poor children with autism had the lowest percentage with excellent dental health with the proportion of children with excellent health increasing with household income. Notably, children with autism were much less likely to have excellent dental health than children without autism at every income level *except* the highest group. Among high-income households, parents of children with autism were more likely than parents of children without autism to report excellent dental health (34% versus 29%).

Across all income levels, more children with autism had fair/poor dental health than children without autism.



Children with autism were less likely to have excellent dental health than children without autism at every income level *except* the highest income group.



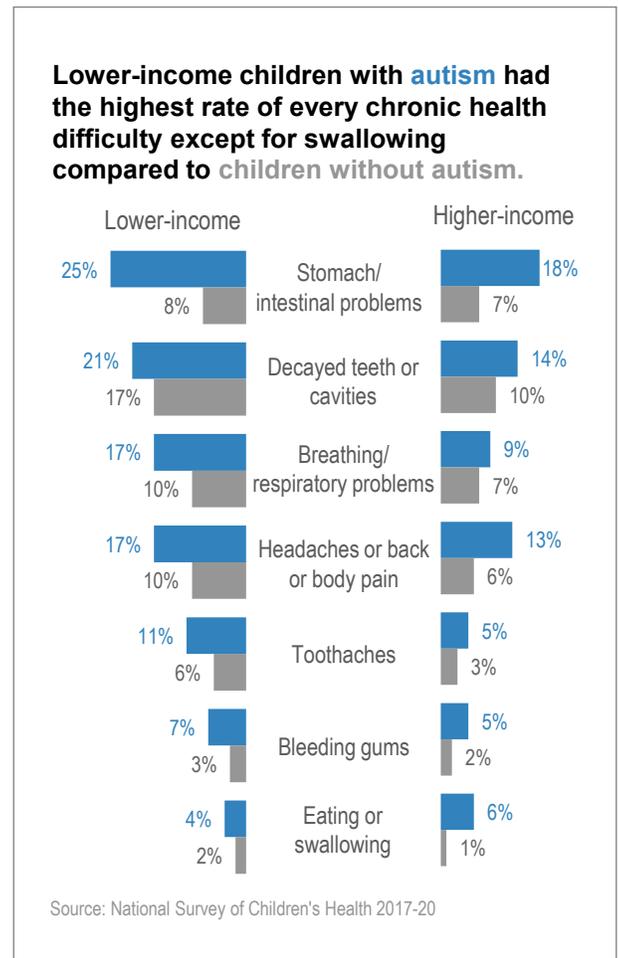
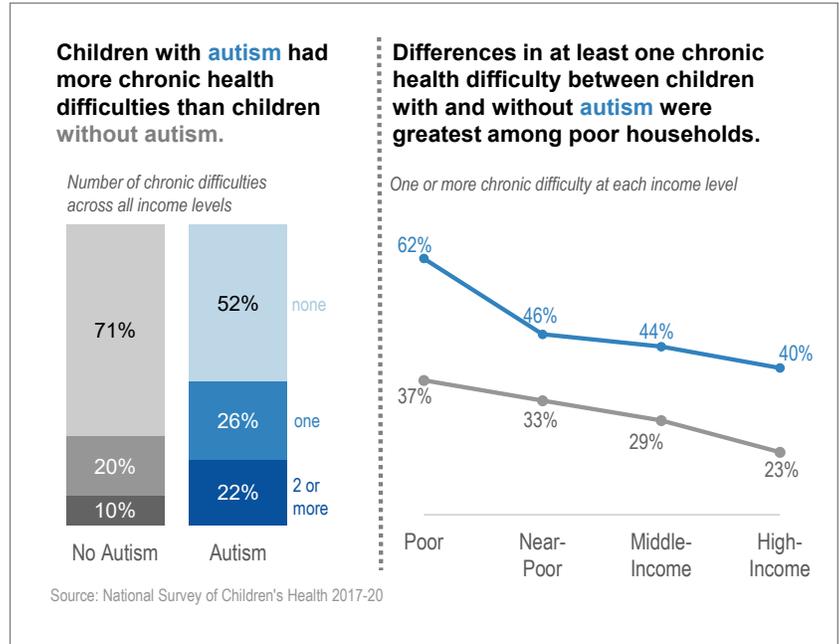
Source: National Survey of Children's Health 2017-20

## Chronic Health Difficulties

Caregiver-reported chronic health difficulties were more common among children with autism than children without autism. When caregivers were asked about frequent or chronic difficulties their child experienced over the past 12 months, about half (52%) of children with autism had no reported chronic health difficulties, versus 71% of children without autism; 26% had one difficulty (versus 20% of children without autism); and 23% had two or more difficulties (versus 10%).

Differences in chronic health difficulties between children with and without autism were evident at each level of income. Regardless of household income, children with autism were more likely to have at least one caregiver-reported chronic difficulty than children without autism. This disparity was most prominent among poor children, with a difference of 25 percentage points. The steepest difference in frequency of caregiver-reported chronic difficulties among children with autism occurred between poor (62%) and near-poor (46%) children with autism. This difference was much greater than that observed among children without autism.

The frequency of a wide variety of chronic health difficulties for children varied among income groups. Lower-income children with autism had the highest rates of every difficulty measured by the survey, except for swallowing.



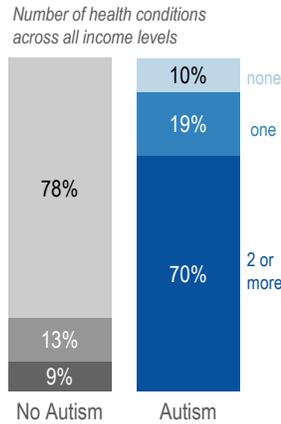
## Health Conditions

When the survey queried about nine different health conditions, a much higher percentage of children with autism across all income categories had at least one caregiver-reported health condition, compared to children without autism. One in ten (10%) children with autism had none of the listed health conditions, versus 78% of children without autism. Most children with autism (70%) had two or more health conditions (versus 9% of children without autism).

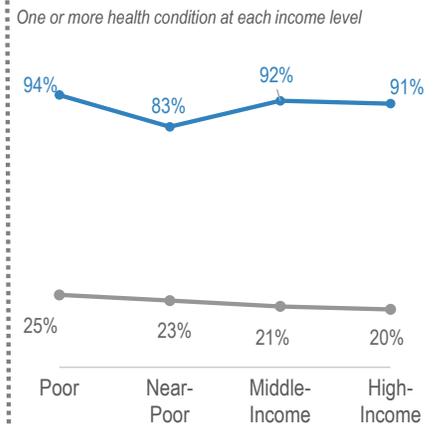
Although differences between income groups were fairly small within each diagnostic group, the differences between the autism and no autism groups were large, across all income groups.

Specific health conditions varied by autism status and household income. While lower-income children with autism had the highest rates of six of nine health conditions, higher-income children with autism were more likely to have anxiety (46% versus 40%) and behavior problems (54% versus 49%) than their peers with autism from lower-income households. The most common health conditions reported for lower-income children with autism were learning disability (71%), developmental delay (64%), and speech disorders (52%).

**Children with autism had more health conditions than children without autism.**

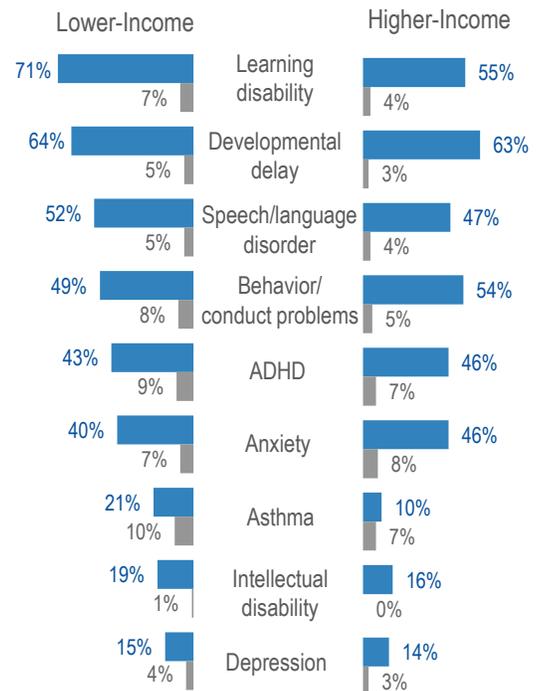


**Children with autism were more likely to have at least one health condition compared to children without autism, regardless of household income.**



Source: National Survey of Children's Health 2017-2020

**Children with autism had higher rates of all health conditions relative to children without autism.**



Source: National Survey of Children's Health 2017-20

## Section 2.2

### Do income-based disparities in health look the same for BIPOC children autism versus white children with autism?

#### WHAT WE KNOW:

Findings from our November 2020 *National Autism Indicators Report on Health and Health Care* and May 2020 *National Autism Indicators Report on Family Financial Hardship*.

Our past reports have shown that health status varies by race and ethnicity, although differences between higher-income and lower-income households was not examined. We found:

- BIPOC children with autism had poorer health than white children with autism.<sup>2</sup>
- Certain health conditions varied in prevalence by race and ethnicity in children with autism. ADHD and anxiety were more commonly reported in white, non-Hispanic children than in children of any other race or ethnicity. Asthma and developmental delay were more commonly reported in Black, non-Hispanic children.<sup>2</sup>
- Young BIPOC children might be particularly vulnerable to experiencing hardship. A majority (80%) of caregivers of Black children with autism and 75% of caregivers of Hispanic children with autism reported at least one hardship, compared with 59% of caregivers of white children with autism.<sup>7</sup>

#### WHAT THIS REPORT ADDS:

We found:

- Across all income groups, BIPOC children with autism were less likely to report excellent overall health and dental health (per caregiver report) than white children with autism. They were also more likely to have severe autism.
- Poor and near-poor BIPOC children generally had lower percentages of excellent health than their middle- and high-income BIPOC counterparts.
- The most disadvantaged group of children with autism (BIPOC poor children) had the poorest health outcomes across all measures.

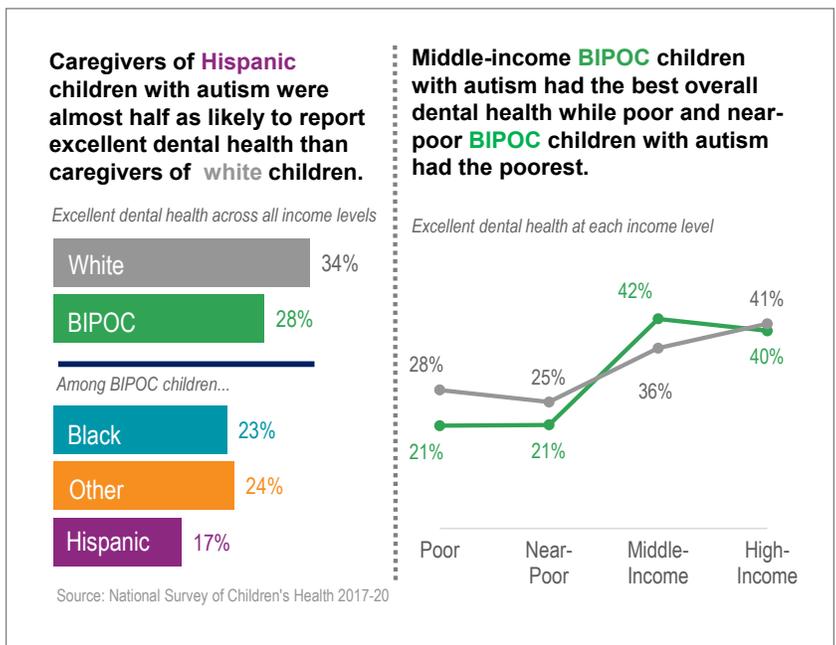
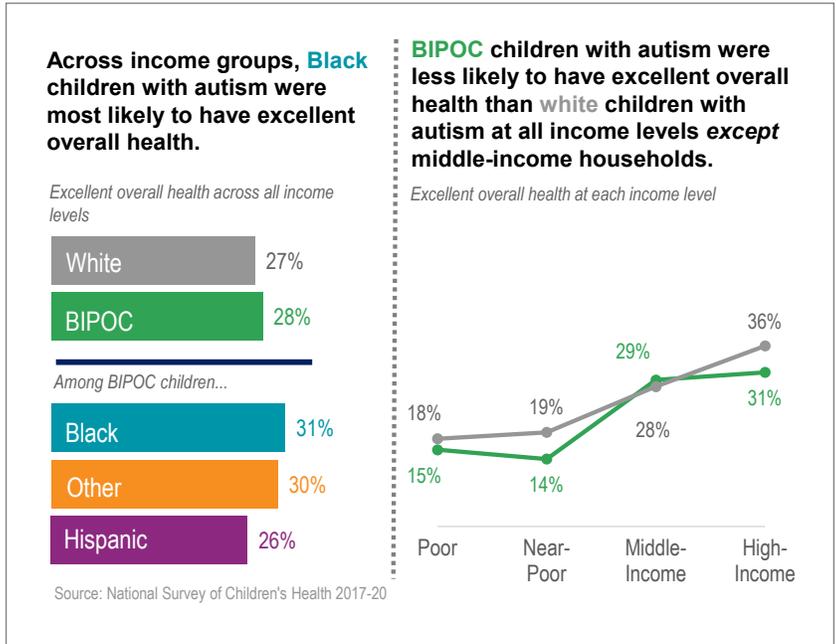
## Overall Health

The percentage of white children with autism with caregiver rated excellent overall health was similar to that of BIPOC children with autism. Among BIPOC children with autism, 31% of Black children, 30% of children of other race(s), and 26% of Hispanic children with autism were reported to have excellent overall health.

Examination of specific income groups revealed substantial differences within race/ethnicity subgroups. For example, 15% of poor BIPOC children with autism were reportedly in excellent health, versus 31% of their high-income BIPOC peers. Similarly, 18% of poor white children with autism were reportedly in excellent health, compared to 36% of their high-income white peers. There were only small between-group differences; within each income category, differences between white and BIPOC children ranged from one to five percentage points.

## Dental Health

Relative to white children with autism, a lower percentage of BIPOC children with autism had caregiver-rated excellent dental health (28% versus 34%). Among BIPOC children, Hispanic children had the lowest rate of excellent dental health (17%), followed by Black children (23%) and children of other race(s) (24%).



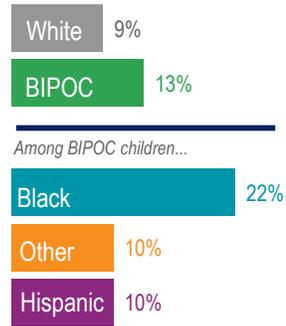
## Autism Severity

A similar percentage of caregivers of white and BIPOC children with autism rated their child's autism as severe. Examination of individual BIPOC groups showed that this reflected a comparatively high percentage of Black children (22%) with severe autism.

The gap in autism severity between white and BIPOC children was present in each income group except middle-income and was greatest among the lowest income group.

Caregivers of **Black** children with autism were much more likely to report severe autism than those of children from all other race/ethnic groups.

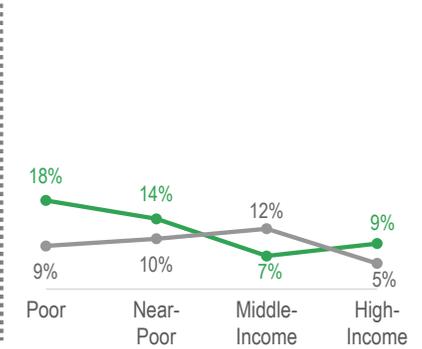
Severe autism across all income levels



Among BIPOC children...

Caregivers of **BIPOC** children were more likely to report severe autism, except among the middle-income group.

Severe autism at each income level



Source: National Survey of Children's Health 2017-20

## Chapter 3.

# Health care access and use

The purpose of this chapter is to examine health care use and access among children in the United States with and without autism, with a spotlight on the intersection of an autism diagnosis, race/ethnicity, and household income.

We report on three dimensions of health care use and access (based on caregiver report):

- ▶ **Health care use.** We include four indicators of health care use in the past 12 months: medical visits (including sick care and hospitalization), preventative visits, dental health care visits, and mental health care visits. We also report the number of times the child visited a hospital emergency room in the prior 12 months.
- ▶ **Usual source of care.** This includes three indicators of access to a usual source of care: whether the child had a usual source of sick care, whether the child had a usual source of preventative care, and whether the child had a personal doctor or nurse. The National Survey of Children's Health defines a personal doctor or nurse as a health professional who knows this child well and is familiar with this child's health history. This can be a general doctor (like an internist), a pediatrician, a specialist doctor (like a psychiatrist), a nurse practitioner, or a physician assistant.
- ▶ **Unmet health care needs.** We considered a child to have an unmet medical need if the caregiver reported that the child did not receive needed health care at any time in the past year. We focused on three types of health care: medical care, dental care, and mental health care. We also report if the child did not receive needed health care due to cost.

This chapter is divided into two sections. **Section 1** examines income-based differences of all United States children, ages 3-17, by autism status. **Section 2** focuses only on children with autism and examines income-based differences by race/ethnicity.

## Section 3.1

### Do income-based disparities in Health care access and use look the same for children with autism versus children without autism?

#### WHAT WE KNOW:

Findings from our November 2020 *National Autism Indicators Report on Health and Health Care*.

- Most children with autism (75% or higher) had a place for routine care and a personal doctor.
- The proportion of children with autism who had a usual source of preventative care was similar to that of other children with and without special health care needs.

We define income categories based on the federal poverty level:

- *poor* (0%-99% of the FPL)
- *near-poor* (100%-199% of the FPL)
- *middle-income* (200%-399% of the FPL)
- *high-income* (400% of the FPL or higher).

More generally, *lower-income households* refer to income less than 200% of the FPL and *higher-income households*

#### WHAT THIS REPORT ADDS:

Our new analysis focuses on gathering more details on health care use and access across different income levels. We found:

- Poor children with autism were the most likely to have had at least one visit to the emergency room in the past year relative to their higher-income peers and to their peers without autism.
- The proportion of children with access to a usual source of care increased as household income increased, regardless of autism status.
- Caregivers of children with autism were four times more likely to report that their child did not receive needed healthcare in the past year, compared to caregivers of children without autism.
- Near-poor and middle-income children with autism were more likely to have an unmet healthcare need than their poor and high-income counterparts.

## Health Care Use

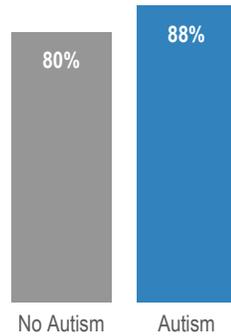
Children with autism more often had a medical visit (88%) in the past year than children without autism (80%). These patterns were consistent over income levels. Differences in medical visits between children with and without autism were largest among poor households (a percentage point difference of 18) and smallest in the highest-income group (a percentage point difference of four).

Across all income groups, children with and without autism had similar rates of preventative visits in the past year (86% versus 84%). When broken down by income, the gap in preventative care between children with and without autism was largest among those living in poor households (88% versus 74%). There were no differences in preventative care among the near-poor and high-income groups.

Of children with autism who had a preventive visit, 14% spent less than 20 minutes with their provider (versus 19% of children without autism), 55% spent 10–20 minutes (versus 64% of children without autism), and 31% spent more than 20 minutes with their provider (versus 17% of children without autism). For both children with and without autism, the proportion that spent over 20 minutes with their provider decreased as income rose. Data not shown.

**More children with autism had a medical visit in the past year than children without autism.**

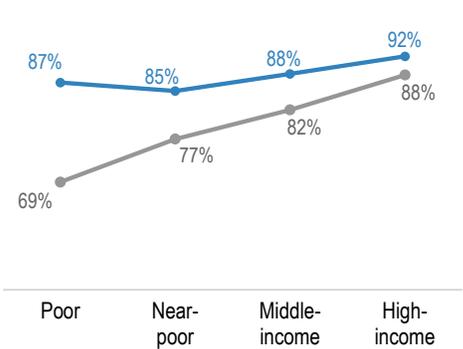
*Medical visit in the past year across all income levels*



Source: National Survey of Children's Health 2017-20

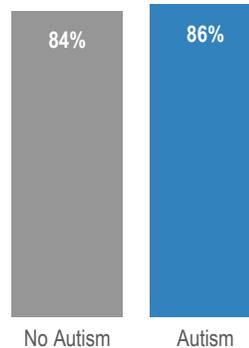
**Differences in medical visits between children with and without autism were widest among the lowest-income group and narrowed with increasing income.**

*Medical visit in the past year at each income level*



**Most children with and without autism had a preventative visit in the past year.**

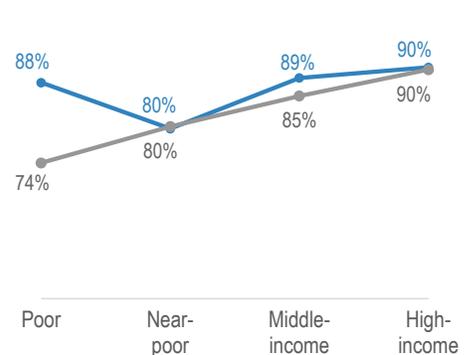
*Preventative visit in the past year across all income levels*



Source: National Survey of Children's Health 2017-20

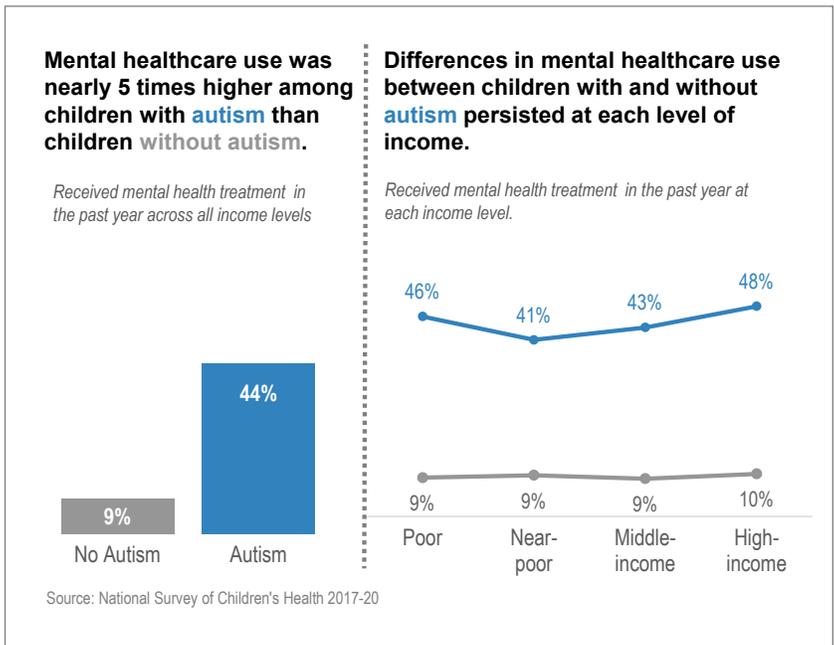
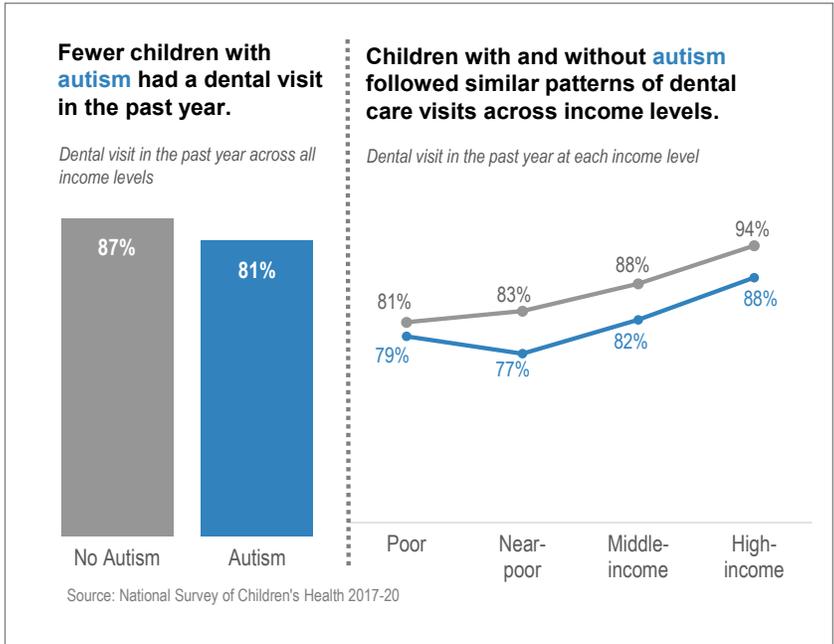
**Near-poor children with autism were the least likely to have had a preventative visit in the past year.**

*Preventative visit in the past year at each income level*



Across all income groups, children with autism were less likely to have had a dental visit in the past year than children without autism (81% versus 87%). This pattern persisted at each income level, with the percentage of children who had a dental visit in the past year generally increasing with household income. The income gradient for dental visits were similar for children with and without autism.

Overall, children with autism were nearly five times more likely to receive mental health care than children without autism (44% versus 9%). Differences in mental health care by income were minimal for both children with and without autism, ranging from 41%–48% among the autism group and from 9%–10% among children without autism.



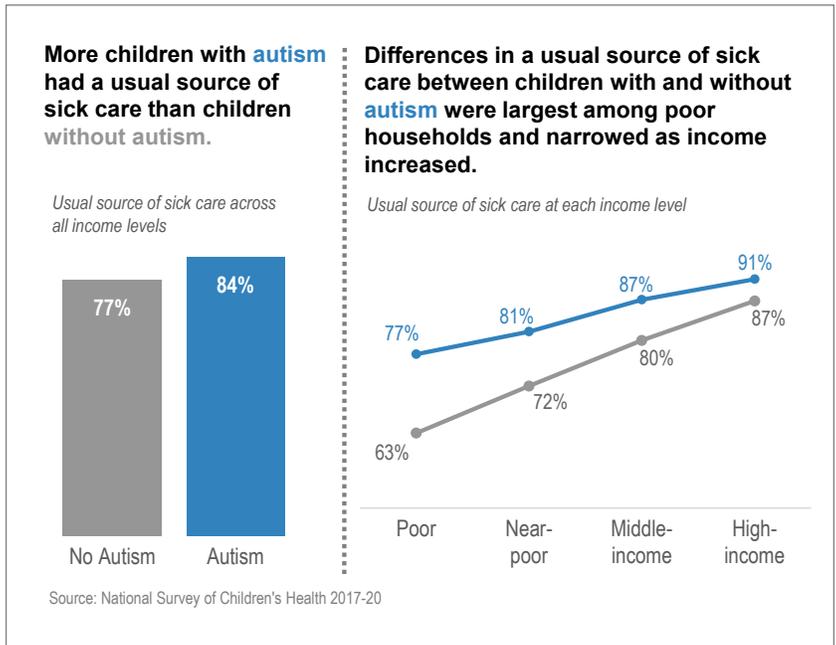
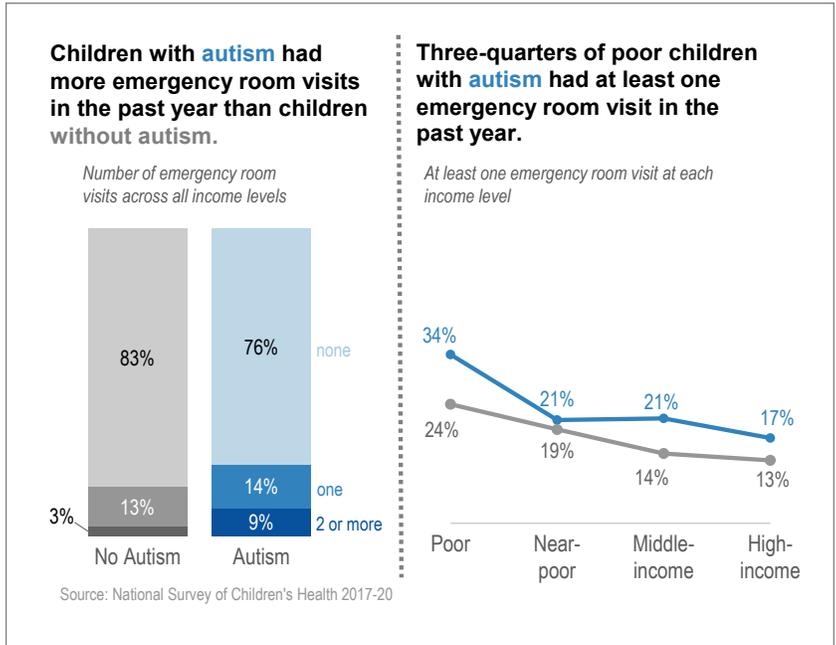
More than one in five autistic children had visited the emergency room in the last year: Fourteen percent of children with autism visited the emergency room one time in the past year and 9% visited the emergency room two or more times.

The percentage of children with autism who visited the emergency room at least one time during the past year generally declined with income; however, there were no differences in emergency room use between near-poor and middle-income households.

### Usual Source of Care

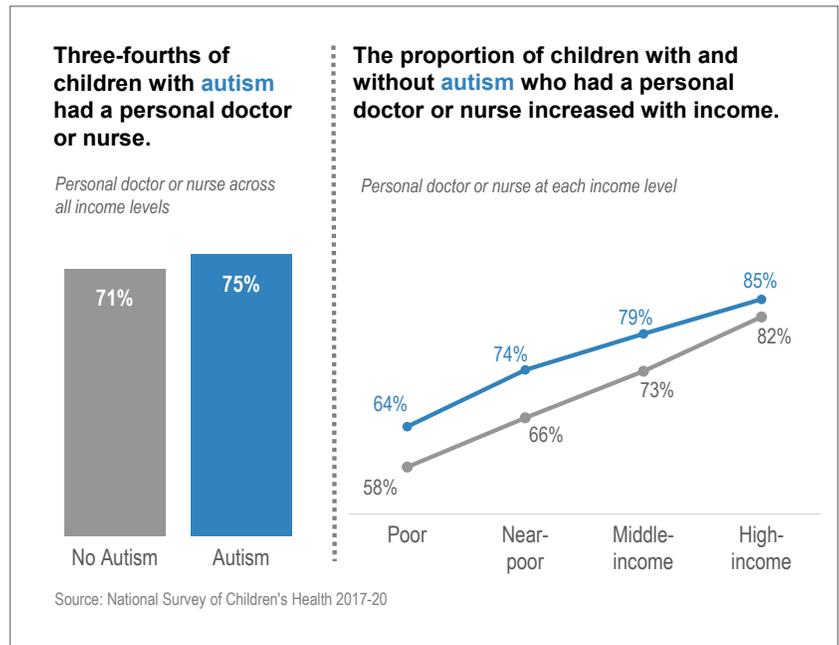
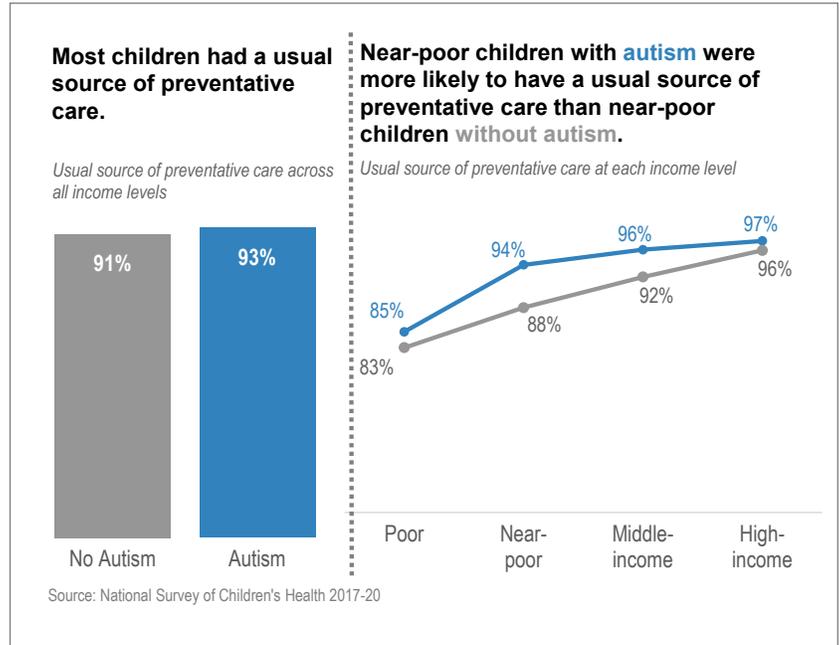
Across all income levels, 84% of children with autism had a usual source of sick care, versus 77% of children without autism. More children with autism had access to a usual source of sick care than their peers without autism at every income level; however, differences between children with and without autism were under five percentage points among the highest-income group.

Comparing income categories, there was a steeper increase in access to a usual source of sick care among children without autism as household income increased. The percentage of children without autism who had access to a usual source of sick care was 63% among the poorest group but 87% in the high-income group (a difference of 23 percentage points). In comparison, the corresponding difference was 13 percentage points among children with autism (77% of poor children vs. 91% of children in high-income households).



A majority (93%) of children with autism had a usual source of preventative care, as did a majority of children without autism (91%). For both groups, poor children had the lowest access to a usual source of preventative care, and access increased with rising income.

Overall, 75% of children with autism had a personal doctor or nurse. There was generally an increase in the percentage of children who had a personal doctor or nurse as income increased, for both children with and without autism. However, a greater percentage of children with autism had a personal doctor or nurse at all levels of income except high-income households.



## Unmet Health Care Needs

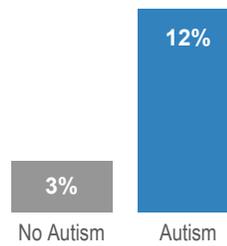
Across all income levels, children with autism were much more likely to report an unmet health care need than children without autism (12% versus 3%). These patterns persisted across income levels; however, the magnitude of autism-based differences varied substantially based on household income. The percentage point difference in unmet health care needs between children with and without autism ranged from a low of three points among poor households to 13 points among middle-income households.

Children with autism in middle-income households had the highest rates of unmet health care needs (16%), followed by children with autism in near-poor households (14%), poor households (9%) and high-income households (7%). The percentage of unmet health care needs generally declined with increases in household income.

Types of unmet health care need varied according to autism status and income level. Lower-income children with autism reported a greater need for medical care (22% versus 17%) and dental care (65% versus 33%) than their peers from higher-income households, but lower unmet need for mental health services (32% versus 48%). In the non-autism group, children from lower-income households were at greater risk for unmet medical care (36% versus 31%) and dental care (59% versus 47%) than their higher-income peers, but not for unmet mental health service needs (28% versus 31%).

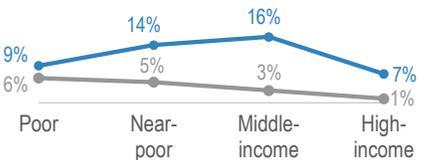
The percent of children with autism who did not receive needed health care in the past year was four times higher than that of children without autism.

*Did not receive needed health care across all income levels*



Children with autism from middle-income households were at the greatest risk of not receiving needed health care in the past year.

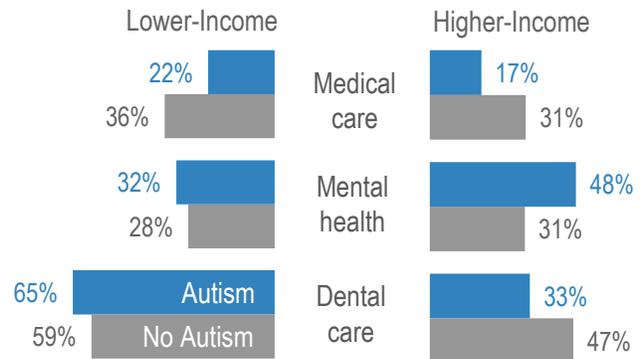
*Did not receive needed health care at each income level*



Source: National Survey of Children's Health 2017-2020

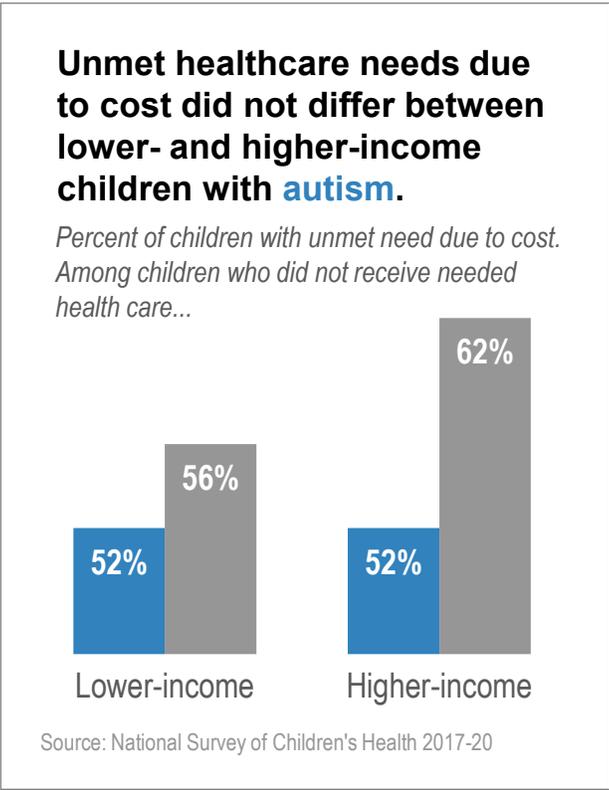
Low-income children with autism more often reported an unmet need for dental care than their higher-income peers, and less often reported an unmet need for mental health services.

*Percent of children with unmet needs of each type. Among children who did not receive needed health care...*



Source: National Survey of Children's Health 2017-20

Income-based differences in unmet health care needs due to cost varied according to autism status. The percentage of parents with a reported unmet health care need due to cost was the same for lower- and higher-income households among the autism group (52%) but not for children without autism, where 56% of lower-income children had an unmet need due to cost versus to 62% of higher-income children.



## Section 3.2

### Do income-based differences in health care access and use look the same for BIPOC children with autism versus white children with autism?

#### WHAT WE KNOW:

Findings from our *November 2020 National Autism Indicators Report on Health and Healthcare*

Findings from earlier chapters in this report show that BIPOC children with autism are at greater risk for poverty and that lower-income children face more risk for poor health. Our past reports have also shown that health care use and access vary by race and ethnicity, although patterns might differ between higher- and lower-income households:

- White, non-Hispanic children were the most likely to have a usual source of preventive care and to have a personal doctor or nurse. Black and Hispanic children with autism were the least connected to usual source of care.
- Hispanic children with autism were the least likely to report seeing a physician in the past year. Health care visits (including medical visits, preventative visits, and mental health counseling) were less common in Hispanic children with ASD than in non-Hispanic children of any race.
- Emergency room visits did not vary across race and ethnicity among children with autism.

#### WHAT THIS REPORT ADDS:

Our new analysis focuses on gathering more details on race/ethnic disparities in health care use and access across different income levels.

We found:

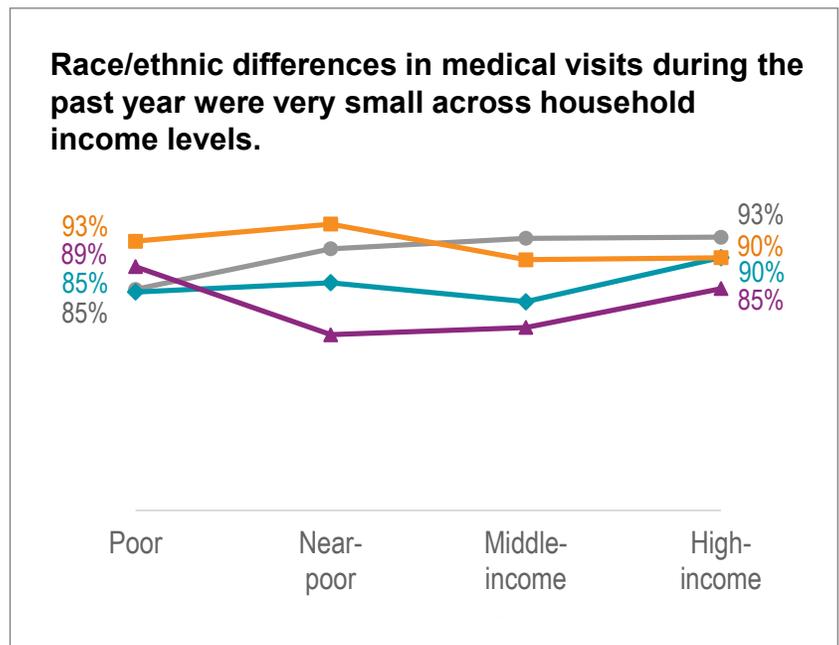
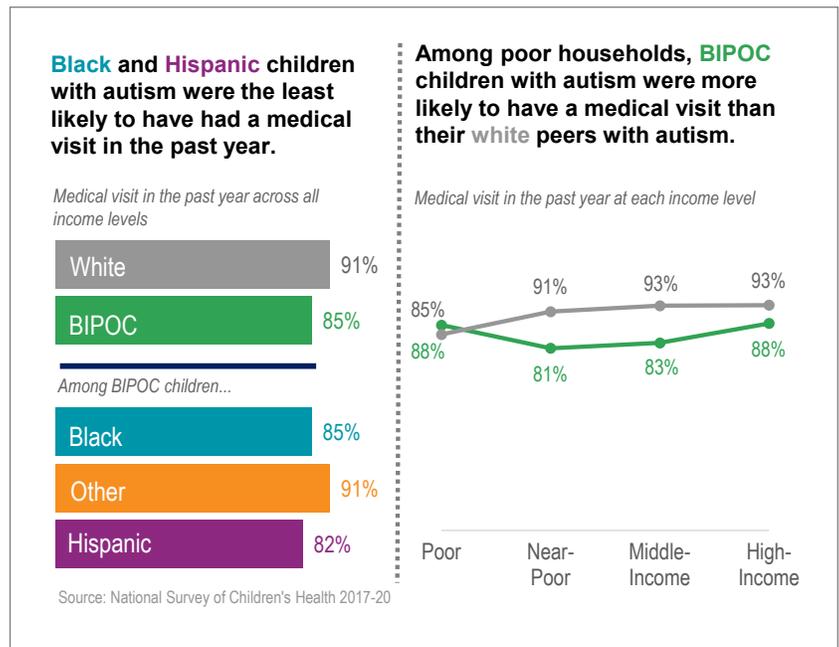
- BIPOC children had similar rates of health care use as white children except for mental health care services.
- Race/ethnic differences in health care use were most evident among near-poor and middle-income households, with BIPOC children having lower rates of use.
- BIPOC children with autism had lower levels of access to a usual source of care than white children with autism.
- Hispanic children with autism were at the greatest risk for poor outcomes. The white-Hispanic gap in access to a personal doctor or nurse was 14 percentage points and only 70% of Hispanic children had dental care in the past year, which was less than Black children and children from the other race(s) category.
- There was a general decrease in unmet healthcare needs with income among white children with autism but not among BIPOC children with autism. Notably, nearly one-fifth (19%) of BIPOC children with autism from middle-income households had an unmet need, a higher percentage than those of BIPOC children in poor (6%) and high-income (5%) households.

## Health Care Use

Most (91%) of white children and children of another race(s) with autism saw a doctor, nurse, or other health care professional for medical care in the past year, followed by 85% of Black children, and 82% of Hispanic children.

When broken down by income, BIPOC children were generally less likely to have had a medical visit than their white counterparts *except* among poor households.

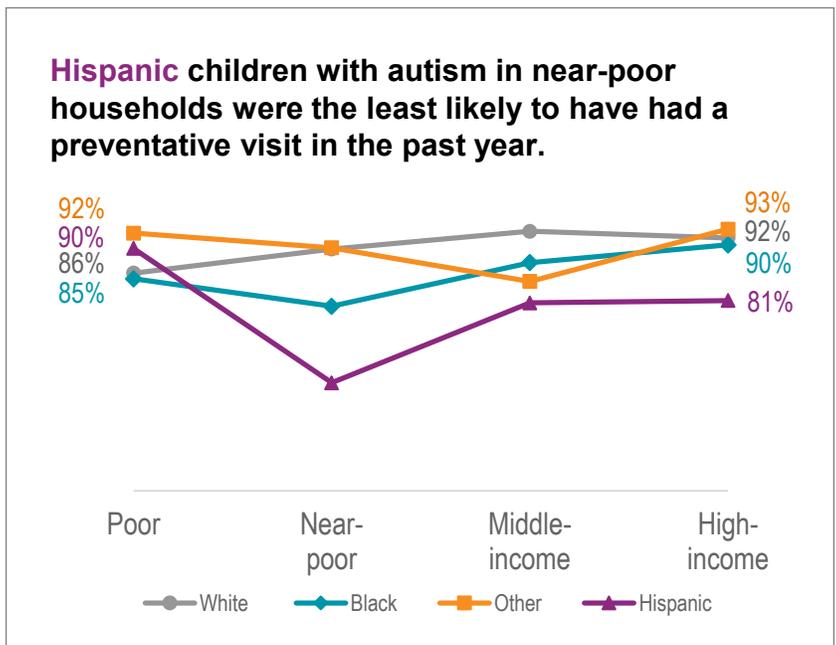
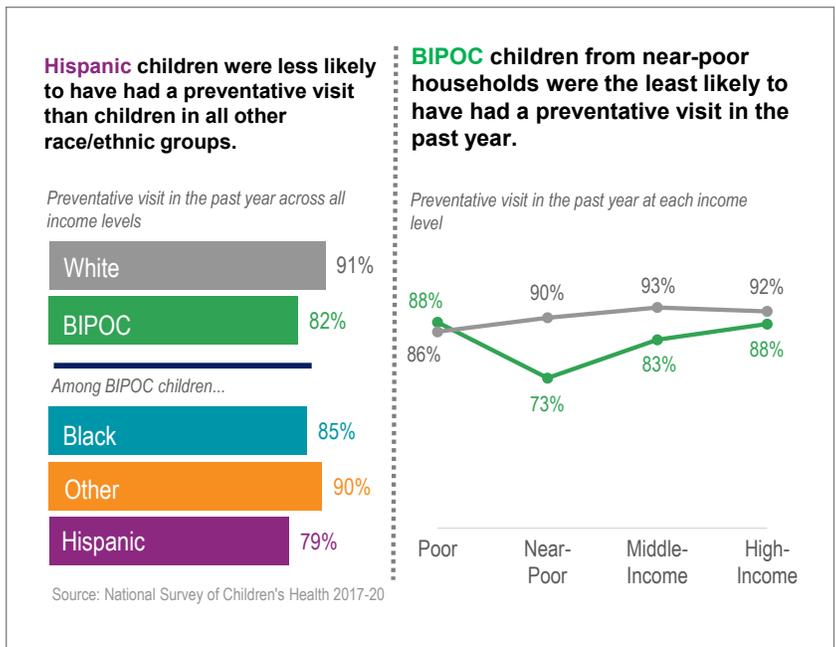
There was little variation in medical visits within BIPOC groups. Near-poor children of other race(s) were the most likely to have had medical visit in the past year while near-poor Hispanic children were the least likely.



The greatest racial/ethnic differences in preventative visits were between Hispanic (79%) and white (91%) children with autism (a percentage point difference of 12). The Black-white gap in preventative visits was six percentage points. There were no differences in preventative visits between white children and children of other race(s).

When broken out by income, BIPOC children with autism had lower rates of preventative care use than white children, *except* among the poorest group. Notably, BIPOC children in near-poor households were much less likely to have had a preventative visit relative to their BIPOC and white peers from all other income groups.

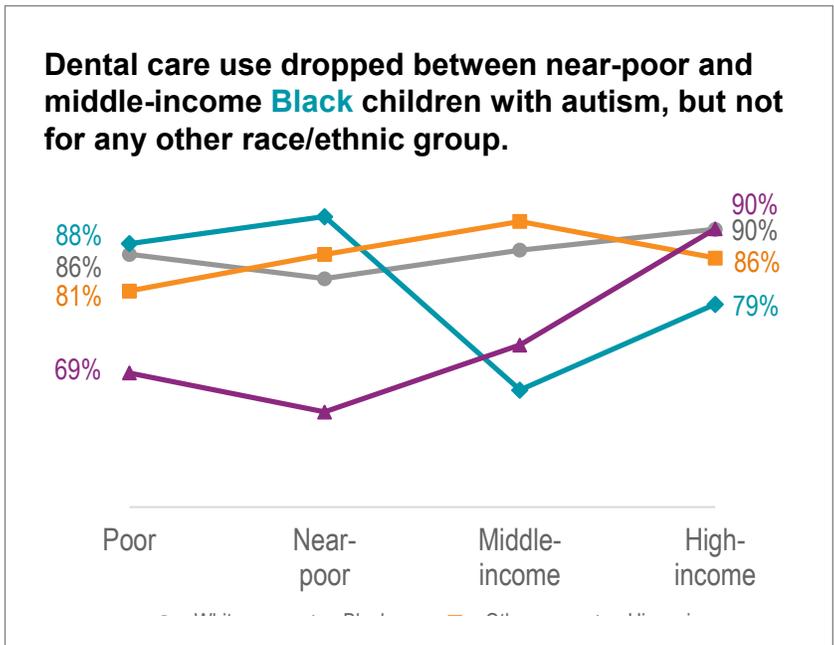
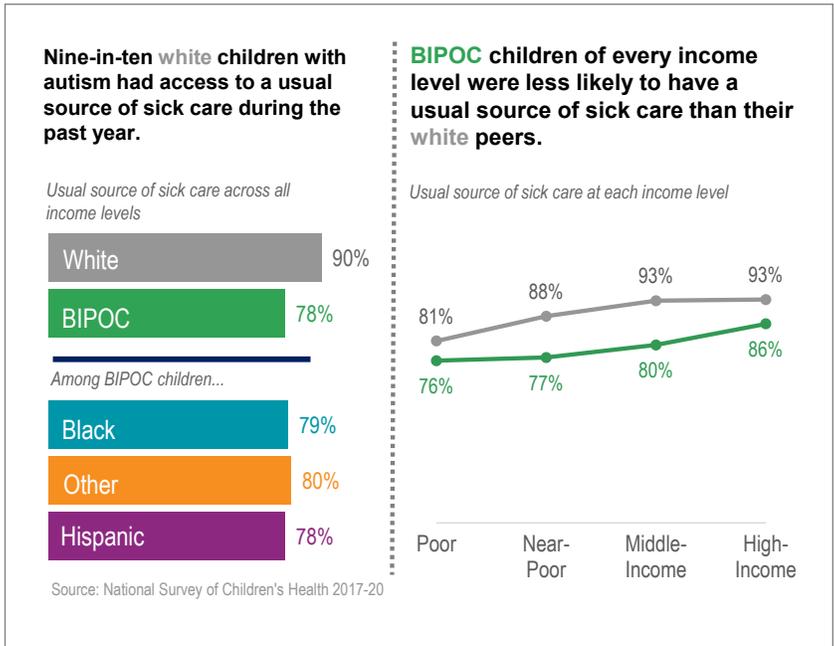
These patterns persisted when broken out by more detailed racial/ethnic categories. 68 % of Hispanic children from near-poor households had a preventative visit in the past year.



White children with autism more often had a dental visit than BIPOC children with autism (87% versus 76%). Within BIPOC children, 70% of Hispanic children had dental care in the past year compared to 83% of Black children and 87% of children of other race(s).

White children had higher dental care use than BIPOC children at each income level *except* the highest income group. The percentage point difference between white and BIPOC children decreased from 13 points in the poor group to just four percentage points in the high-income group.

The racial/ethnic gap among high-income households was the largest between Hispanic (79%) and white (90%) children (a 21 percentage point difference). Black children with autism from poor and near-poor household had the highest rates of dental care (88% and 92%). However, the percentage dropped substantially between near-poor and middle-income households (92% versus 67%, a 25 percentage point decrease). On the contrary, the rate of dental care use generally increased with income among all other race/ethnic groups.



About one-third (32%) of Black children, 20% of children from other race(s), and 19% of Hispanic children.

When broken out by income, differences in emergency room use between white and BIPOC children varied substantially based on income. BIPOC children had lower rates of emergency room use at all income levels *except* in the poorest group; however, racial/ethnic differences were under five percentage points among high-income households.

### Usual Source of Care

Children in the other race(s) category had similar rates of access to a usual source of sick care than white children across all measures except for access to sick care – in which access for children of other race(s) was 10 percentage points lower than white children.

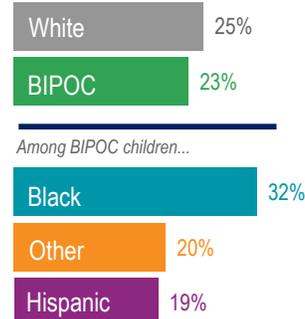
Differences among BIPOC groups were very small, with 79% of Black children, 80% of children of other race(s), and 78% of Hispanic children having a usual source of sick care.

At each income level, white children with autism were more likely to have a usual source of sick care than children of all other race/ethnicities.

The greatest racial/ethnic differences in access to a usual source of sick care were among the near-poor and middle-income groups.

**Black children were more likely to have had at least one emergency room visit in the past year than all BIPOC children.**

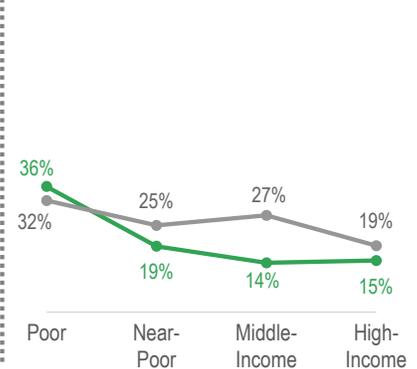
*At least one emergency room visit across all income levels*



Source: National Survey of Children's Health 2017-20

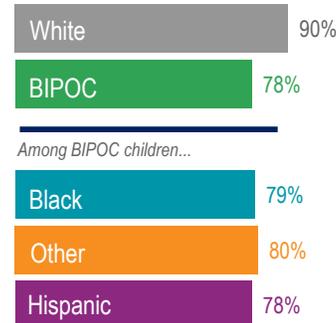
**The percentage of BIPOC children with at least one emergency room visit in the past year was smaller than those of white children, except among poor households.**

*At least one emergency room visit at each income level*



**Nine-in-ten white children with autism had access to a usual source of sick care during the past year.**

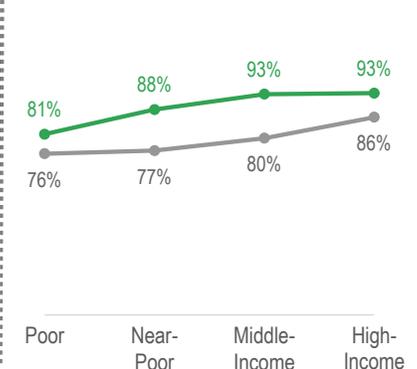
*Usual source of sick care across all income levels*



Source: National Survey of Children's Health 2017-20

**BIPOC children of every income level were less likely to have a usual source of sick care than their white peers.**

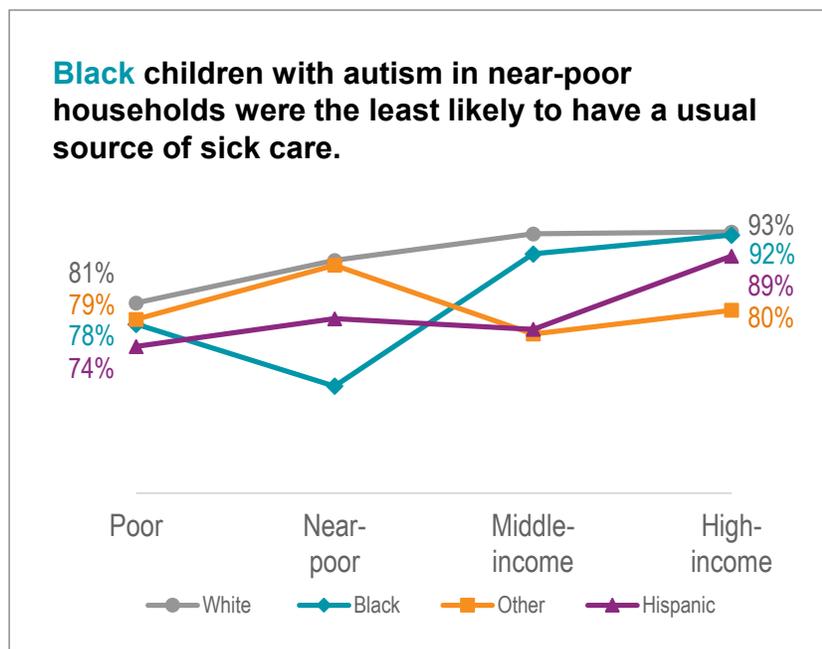
*Usual source of sick care at each income level*



There was an income gradient in access to a usual source of sick care with income for both white and BIPOC children. However, when examined by more detailed racial/ethnic categories, we found that clumping BIPOC children together hides heterogeneity within this group. For instance, access to a usual source of sick care was higher in near-poor households than those in poor households for all race/ethnic groups except for Black children. Black children in near-poor households were the least likely to have access to a usual source of sick care (68%), a 10 percentage point decline from poor Black children. Likewise, we found that Black children increased in access to sick care from near-poor to middle-income (22 percentage point increase) whereas access declined by only two percentage points among Hispanic children and 11 percentage points among children of other race(s).

The greatest differences between white and Black children in access to a usual source of sick care were in the near-poor group (with a Black-white gap of 22 percentage points) while greatest differences for Hispanic children and children of other race(s) were in the middle-income group, with percentage point differences of 16 for both.

Although the proportion of BIPOC children with a usual source of sick care increased with each level of income, disaggregated findings show differences in income-gradients within BIPOC groups. For instance, the proportion of Black children with a usual source of sick care dropped from 78% in the poverty group to 68% in the near-poor group (a 10 percentage point decline). Likewise, access also dropped between middle- and high-income households among Hispanic children and children of other race(s).



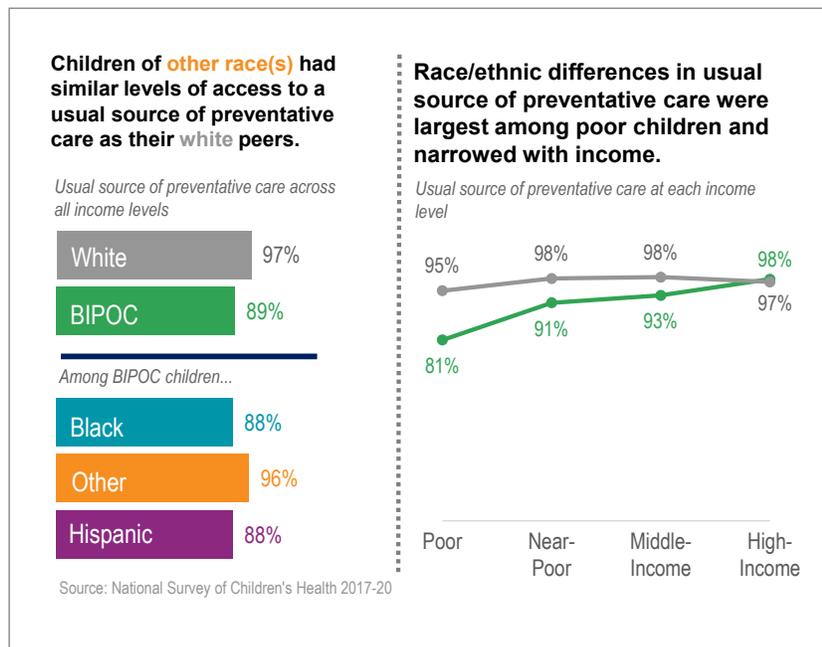
White children with autism were more likely to have a usual source of preventative care than BIPOC children (97% versus 89%).

Compared to white children, Black and Hispanic children were much less likely to have access to a usual source of preventative care (88% versus 97%, or nine percentage points). There were no differences between white children and children in the other race(s) category. This trend continued regardless of income, with white children generally reporting greater access to preventative care.

Income-based differences in access to a usual source of preventative care were observed among BIPOC children only. The percentage of BIPOC children with preventative care between the lowest- and highest-income group rose 17 percentage points (from 81% in poverty to 98% of high-income

households) compared to just a two percentage point increase among white children (from 95% among poor household to 98% of high-income households).

The gap in access to a usual source of preventative care between white and BIPOC children with autism was widest among those living in poor households and narrowed as income increased. For instance, among children with autism, 81% of BIPOC children and 95% of white children had access to a usual source of preventative care (a percentage point difference of 14%). This gap decreased to a seven- and five-percentage point difference among near-poor and middle-income households. Among high-income households, access to preventative care did not differ between white and BIPOC children with autism.

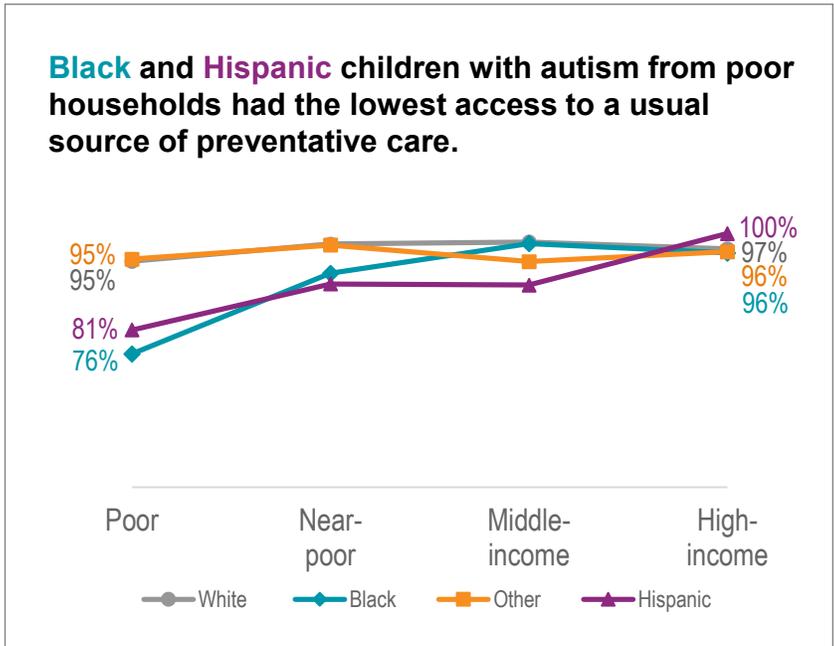


The Black-white and Hispanic-white gap in preventative care, was largest among poor households (percentage point differences of 18 and 14, respectively). These gaps generally decreased with income, reducing to a Black-white gap of one percentage point and a Hispanic-white gap of three percentage points among high-income households, with Hispanic surpassing white in the high-income group.

Black and Hispanic children in poor households had the least access to a usual source of preventative care (76% and 81%).

Among those in poor households, white children and children of other race(s) had higher access to a usual source of preventative care than Black and Hispanic children, whereas high-income households did not greatly vary in access by race/ethnicity.

Among those in poverty, white (74%) children and children of other race(s) (78%) had higher access to a usual source of preventative care than Black (61%) and Hispanic (56%) children, whereas high-income households did not greatly vary in access by race/ethnicity.



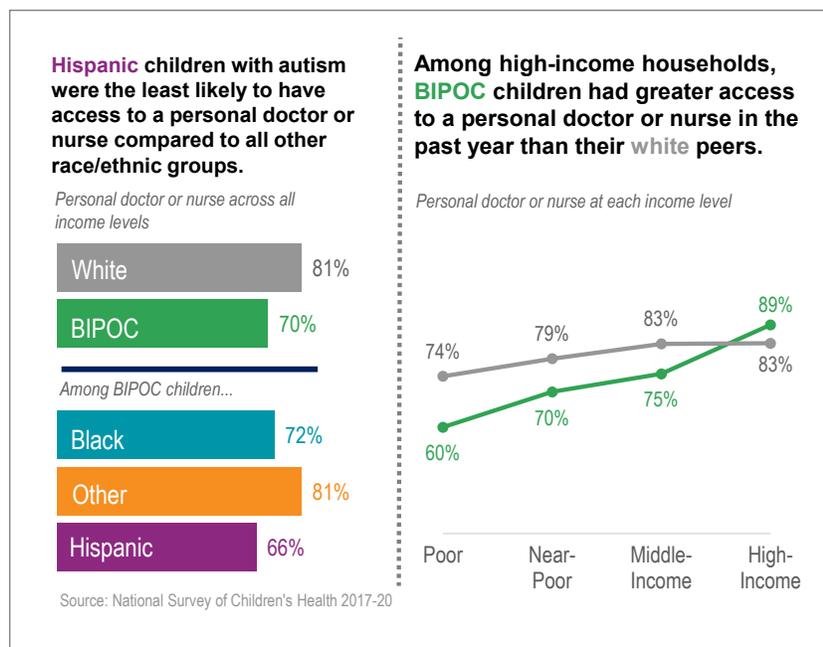
81% of white children and 70% of BIPOC children had a personal doctor or nurse. There were wide racial/ethnic differences among BIPOC children with autism: 81% of children of other race(s) had a personal doctor or nurse, followed by 72% of Black children and 66% of Hispanic children.

Within BIPOC categories, Black and Hispanic children with autism were much less likely to have a personal doctor or nurse than their white peers. Across all income levels, 72% of Black children had a personal doctor or nurse, compared to 81% of white children (a percentage point difference of nine). The gap between white and Hispanic children was even larger (14 percentage points).

Access to a personal doctor or nurse increased between middle- and high-income BIPOC children but either plateaued or decreased among white children. The percentage of BIPOC children with a personal doctor or nurse increased by 14

percentage points between middle- and high-income households but did not change among white children. Therefore, BIPOC children in high-income households had greater access than their white counterparts (89% versus 83%).

BIPOC children were less likely to have of having a personal doctor or nurse than white children at all income levels except the highest-income group. Among the high-income group, more BIPOC children had a personal doctor or nurse than white children (89% versus 83%). Differences between white and BIPOC children with autism were largest in poor income households, with 74% of white children having a personal doctor or nurse versus 60% of BIPOC children (a percentage point difference of 14). Racial/ethnic differences were smaller among near-poor and middle-income households.



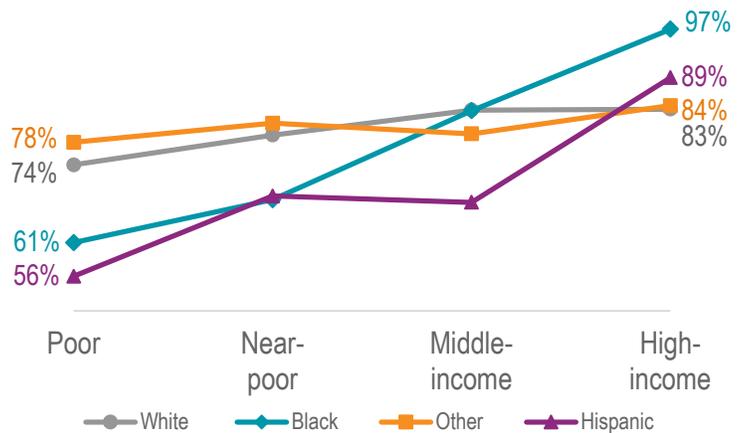
Patterns for access to a personal doctor or nurse by race look like other measures of access in several ways. Access to a personal doctor or nurse increased with income among white children and plateaued among middle- and high-income groups.

There was a steeper increase in access to a personal doctor or nurse among Black and Hispanic children with autism than white children, especially for access to a usual source of sick care. The percentage of children who had a personal doctor or nurse rose from 69% among poor households to 97% in the high-income group among Black children and from 56% to 89% among Hispanic children. Increases in access among white children and children of other race(s) were much smaller (a nine percentage point difference among white children and a six percentage point difference among children of other race(s)).

### Unmet Health Care Needs

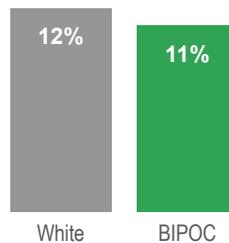
There was a general decrease in unmet health care needs with income among white children with autism but not among BIPOC children with autism. Notably, nearly one-fifth (19%) of BIPOC children with autism from middle-income households had an unmet need, a higher percentage than those of BIPOC children in poor (6%), and high-income (5%) households.

**Black and Hispanic children with autism had the greatest increase in access to a personal doctor or nurse than white and other children.**



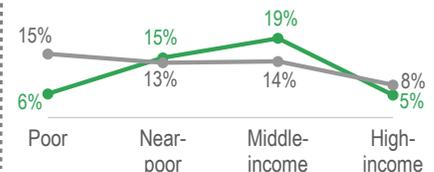
**Differences in the percent of children who did not receive needed health care between white and BIPOC children were small.**

*Did not receive needed health care across all income levels*



**Middle-income BIPOC children were more likely to have not received needed health care in the past year than white and BIPOC children.**

*Did not receive needed health care at each income level*



Source: National Survey of Children's Health 2017-2020

## Chapter 4.

# Health Insurance and Expenditures

The purpose of this chapter is to examine how autism diagnosis and race/ethnicity intersect with household income to affect health insurance and expenditures United States Children.

*Health insurance status* was based on parent reported coverage in the past 12 months and was broken into three categories: public, private, and uninsured. We also examined two dimensions of insurance quality. *Consistent insurance coverage*, which referred to insured for all twelve months during the past year. *Adequacy of insurance* (among insured children only) was based on two indicators: parent report that coverage 1) always meets their child's needs and 2) always allows child to see needed providers.

This chapter is divided into two sections. **Section 1** examines income-based differences of all United States children, ages 3-17, by autism status. **Section 2** focuses only on children with autism and examines income-based differences by race/ethnicity.

## Section 4.1

### Do income-based differences in health insurance and expenditures look the same for children with autism versus children without autism?

#### WHAT WE KNOW:

Findings from our November 2020 *National Autism Indicators Report on Health and Health Care* and May 2020 *Report on Family Financial Hardship*.

Our past reports have shown that health insurance and expenditures vary by autism diagnosis, although patterns might differ between higher- and lower-income households:

- Children with autism from lower-income households most often had public health insurance while children from higher-income households had private health insurance.<sup>7</sup>
- 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.<sup>7</sup>
- Most children with autism had insurance at the time of the survey and were continuously insured over the past 12 months (93%).<sup>2</sup>
- Almost half (46%) of caregivers of children with autism reported that their child's insurance did not always cover the services they needed.<sup>2</sup>
- Children with autism from lower-income households who received public health insurance had higher levels of safety net program use than children with autism who were either uninsured or received private health insurance only. Safety net programs refer broadly to government-funded programs that provide material and financial support for people living in poverty, and include programs like food stamps, cash assistance, or free/reduced cost lunch.<sup>7</sup>
- 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

#### WHAT THIS REPORT ADDS:

Our new analyses focused on gathering more details on different income levels. We found:

- Nearly all children with autism had some type of health insurance coverage at the time of the survey. Poor children with autism were more likely to have some type of health insurance coverage than poor children without autism.
- Children with autism were less likely to have public coverage and less likely to have private coverage than children without autism overall and within each income level.
- Among insured children, those with and without autism had similar rates of insurance consistency. However, differences in insurance consistency were observed among poor and near-poor households for children with autism only.
- Children with autism were less likely to have adequate coverage, both overall and within each income level.
- Income-based disparities in insurance adequacy were much more pronounced among children with autism than those without autism.
- Middle and high-income caregivers of children with autism were more likely to report difficulty paying for their child's medical bills than caregivers from other income groups and those of middle-income children without autism.
- As income increased, so too did out-of-pocket medical expenses. Autism-based differences in out-of-pocket medical expenses were the greatest among middle- and high-income groups relative to poor and near-poor groups.

We define income categories based on the federal poverty level:

- *poor* (0%-99% of the FPL)
- *near-poor* (100%-199% of the FPL)
- *middle-income* (200%-399% of the FPL)
- *high-income* (400% of the FPL or higher).

More generally, *lower-income households* refer to income less than 200% of the FPL and *higher-income households*

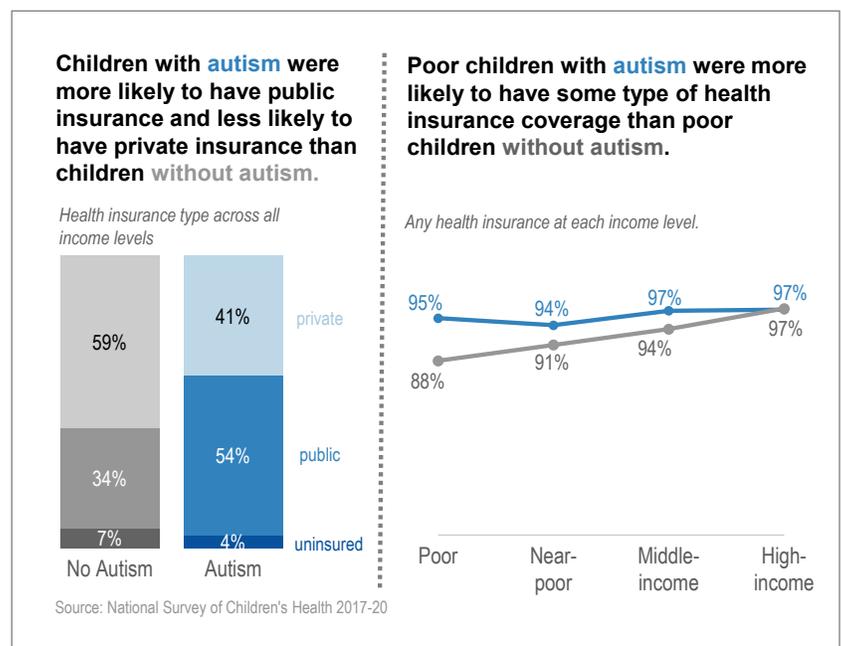
## How Did we Measure Health Insurance Coverage?

Type of health insurance was broken into three categories: public, private, and uninsured. The NSCH defined *public* health insurance as “Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability.” *Private* health insurance was defined as “insurance through a current or former employer or union, purchased directly from an insurance company, TRICARE or other military health care, or coverage through the Affordable Care Act or other private insurance.”

This study considered a child to have public health insurance if they used only public health care OR a combination of public and private health insurance.

## Insurance Status

Most children had health insurance coverage, regardless of household income. Overall, 96% of children with autism and 93% of children without autism had some type of health insurance coverage at the time of the survey. More than half (54%) of children with autism were covered by public health insurance (versus 34% of children without autism) and 41% were covered by private health insurance (versus 59% of children without autism).



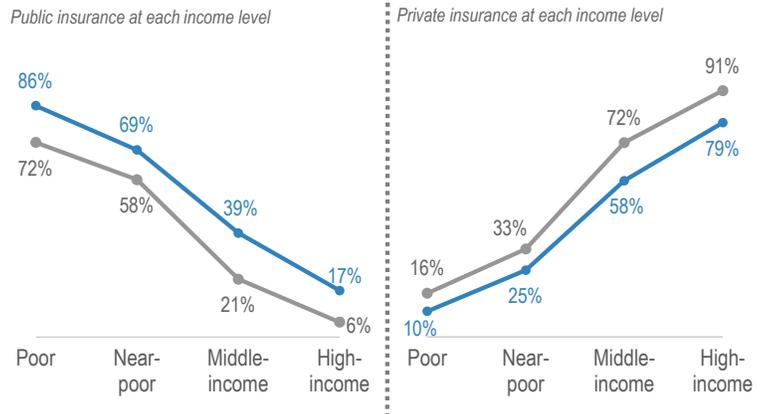
Among poor children, those with autism had higher rates of health insurance coverage than their peers without autism. Differences in health insurance coverage between children with and without autism were largest among poor households, in which 95% of children with autism were covered versus 88% of children without autism.

Despite high overall rates of health insurance coverage among children, disparities in type of insurance existed across the income distribution. A strong gradient for public and private health insurance coverage was visible for both children with and without autism. As household income increased, so too did the percentage of children with private health insurance, regardless of autism status. Likewise, the proportion of children with public health insurance decreased with rising income. Children in poor households were most likely to have public health insurance and least likely to have private health insurance, regardless of autism diagnosis.

### A note about household income and insurance.

The Medicaid and State Children’s Health Insurance Programs (SCHIP) in most states have income eligibility limited to < 200% of FPL. However several states have expanded eligibility to 250% or even 300% of FPL. Thus, the likelihood of being uninsured or publicly or private insured varies by state for this income group. These income thresholds also vary by age across the states for Medicaid eligibility for age groupings of infants, ages 1–5, ages 6–16, and ages 17–18. Some middle-income and most of the highest income groups are predominantly covered by private insurers.

For both children with and without autism, the percentage of children with public health insurance coverage decreased with income while the percentage of children with private coverage increased with income.



Source: National Survey of Children’s Health 2017-20

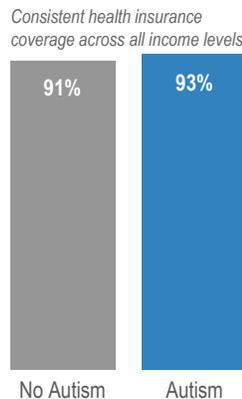
## Insurance Quality

### How did we measure insurance quality?

We used two measures of insurance quality, insurance consistency and insurance adequacy.

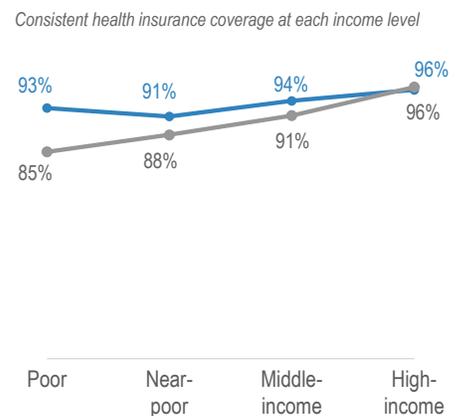
- **Consistent health insurance** means that the child was covered by any type of health insurance for all twelve months in the past year.
- **Adequate health insurance** means that caregivers reported that their child’s insurance always meets their child’s needs and always allows their child to see needed providers.

About nine in ten children with autism had consistent health insurance coverage.



Source: National Survey of Children’s Health 2017-20

Poor children with autism were more likely to have consistent health insurance coverage than poor children without autism.

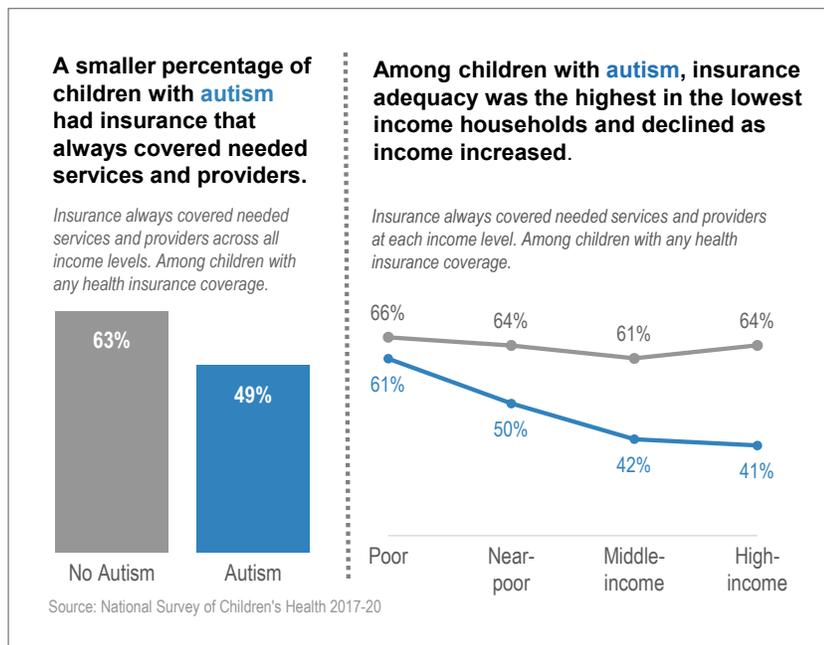


Overall, 93% of children with autism had consistent health insurance coverage.

A child was considered to have adequate health insurance coverage if their caregivers reported that their insurance always meets their child’s needs *and* always allows their child to see needed providers. Among the 96% of children with autism who received health insurance coverage, 49% had adequate coverage, versus 63% of insured children without autism.

Half (52%) of caregivers of children with autism reported that their insurance always meets their child’s needs (versus 66% of insured children without autism) and 64% reported their insurance always allows their child to see needed providers (versus 77% of insured children without autism).

Children with autism had lower rates of adequate coverage at each income level, with differences between children with and without autism widening as household income grew. Among poor households, 61% of children with autism had adequate health insurance coverage versus 66% of children without autism (a five percentage point difference). Among high-income households, the autism gap grew to 23 percentage points, with 41% of children with autism having adequate coverage versus 64% of children without autism. Income-based differences in adequate coverage were more pronounced among children with autism than for children without autism.



## Expenditures

Across all income groups, children with autism were much more likely than children without autism to have no medical expenses (39% versus 33%) and to have expenses of \$1,000 or more (22% versus 13%).

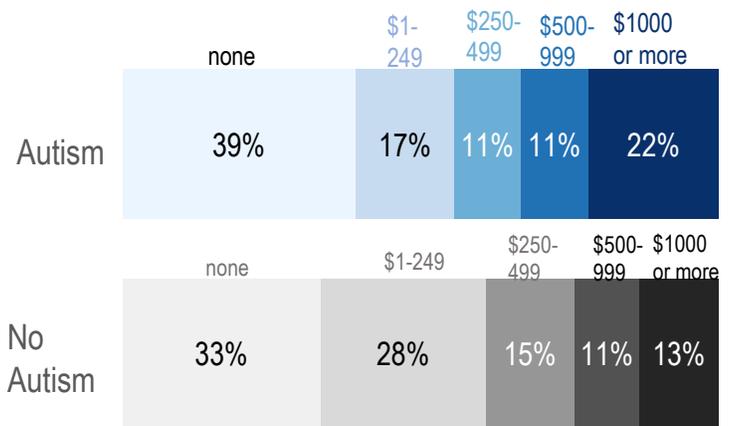
### What is an out-of-pocket medical expenditure?

In the NSCH, out-of-pocket medical expenditures (or OOP), are costs that a family paid for medical, health, dental, and vision care during the past 12 months, including co-pays and amounts from Health Savings Accounts and Flexible Spending Accounts.

*Does not include health insurance premiums or costs that were or will be reimbursed by insurance or another source.*

### Over one-fifth of families of children with autism had out-of-pocket medical expenses of \$1,000 or higher.

Across all income levels

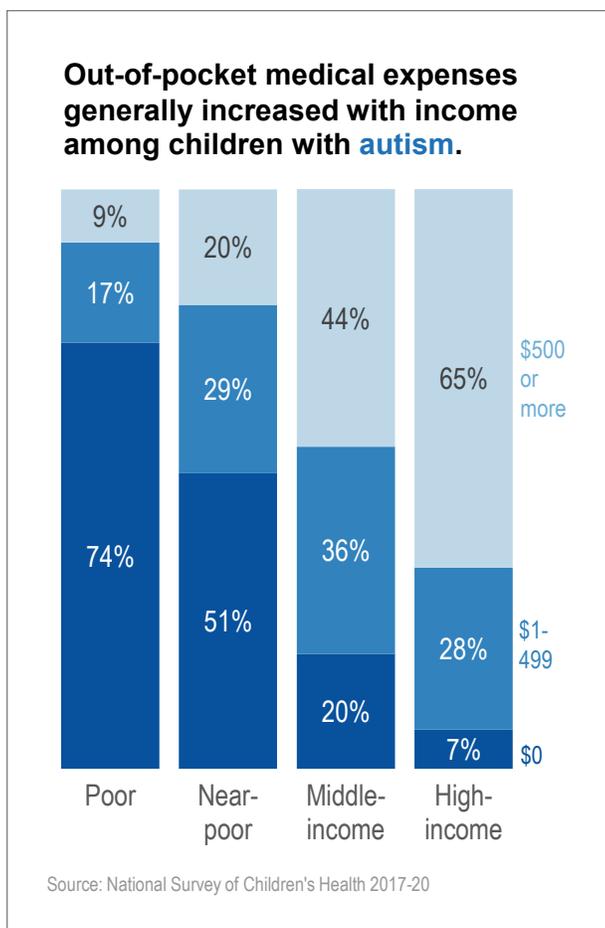


Source: National Survey of Children's Health 2017-20

Generally, there was an income gradient with out-of-pocket medical expenses. About three-fourths (74%) of children with autism from poor households had no out-of-pocket medical expenses, compared to 51% of children with autism from near-poor households, 20% from middle-income households, and 7% from high-income households.

As income increased, so too did the amount of out-of-pocket expenses. There was an increase in the proportion of children with autism who reported out-of-pocket expenses of \$500 or more and autism-based differences in out-of-pocket medical expenses were the greatest among middle-

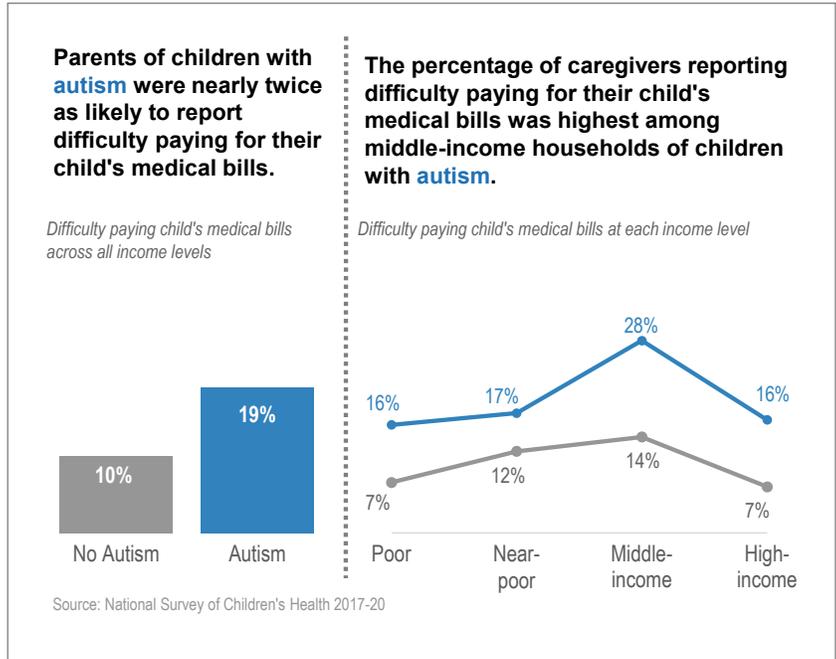
and high-income groups relative to poor and near-poor groups. For instance, 65% of high-income caregivers had out-of-pocket expenditures of \$500 or more in the autism group (versus 38% in the no autism group), followed by 44% of middle-income (versus 28%), 29% of near-poor (versus 14%), and 9% of poor caregivers of a children with autism (versus 8% of caregivers of children with no autism). This trend is likely due to the higher proportion of children who receive public health insurance in lower-income groups. Similar trends were reported for children without autism (data not shown).



Across all income levels, caregivers of children with autism had higher rates of medical hardship. Just under one-fifth (19%) of caregivers of children with autism reported problems paying for child’s medical bills (versus 10% of caregivers of children without autism).

Children with autism from middle-income households had the highest levels of medical hardship (28%), whereas the other income groups had similar levels to one another (16–17%).

Regardless of household income, caregivers of children with autism were more likely to report difficulty paying for their child’s medical bills than caregivers of children without autism. Differences in medical hardship between children with and without autism were greatest among the middle-income group (a percentage point difference of 14) and smallest among the near-poor group (a percentage point difference of five).



## Section 4.2

### Do income-based differences in health insurance and expenditures look the same for BIPOC children with autism versus white children with autism?

#### WHAT WE KNOW:

Findings from our November 2020 *National Autism Indicators Report on Health and Health Care* and May 2020 *Report on Family Financial Hardship*.

- Hispanic and Black, non-Hispanic children with autism were the most likely to have public insurance only.<sup>2</sup>
- Over 60% of caregivers of Black, non-Hispanic and Hispanic children with autism reported that their child's insurance always covered the services they needed, compared to less than half of white children and children of other races.
- Problems paying for care varied by race and ethnicity in children with autism. Half of caregivers of Black, non-Hispanic children with autism reported difficulty – a higher rate than caregivers of Hispanic children, white, non-Hispanic children, and non-Hispanic children of other races.<sup>2</sup>
- 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. Hispanic children were mostly likely to have no medical payments.<sup>7</sup>

#### WHAT THIS REPORT ADDS:

Our new analyses focused on gathering more details on different income levels. We found:

- White and BIPOC children with autism were similarly likely to have some type of health insurance coverage. Among BIPOC children, only Hispanic children differed in insurance coverage from white children.
- Type of health insurance varied according to race/ethnicity. Across all income levels, Black and Hispanic children with autism were more likely to have public health insurance coverage than white children and children of other race(s).
- Black and Hispanic children with autism were more likely to have adequate health insurance coverage than white children and children of other race(s).
- Poor BIPOC children had the highest rates of reported insurance adequacy relative to their BIPOC and white peers in other income groups. And Black children with autism and those in middle-income households were at the greatest risk for medical hardship.
- High-income BIPOC children with autism were the least likely to have no out-of-pocket medical expenses and most likely to have expenditures of \$500 or more. Conversely, BIPOC and poor children had the lowest expenditures

## Insurance Status

White and BIPOC children with autism were similarly likely to have some type of health insurance coverage (98% versus 94%). Among BIPOC children, only Hispanic children differed in insurance coverage from white children.

Near-poor and middle-income BIPOC children had lower levels of insurance than their white peers.

Insurance coverage generally increased with income for all race/ethnic categories.

**White children with autism were more likely to have some type of health insurance coverage than BIPOC children.**

Any health insurance across all income levels



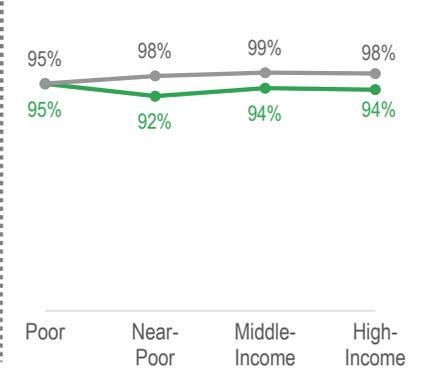
Among BIPOC children...



Source: National Survey of Children's Health 2017-20

**Race/ethnic differences in usual source of preventative care were largest among poor children and narrowed with income.**

Any health insurance at each income level



**Hispanic children with autism were the least likely to have access to a personal doctor or nurse compared to all other race/ethnic groups.**

Personal doctor or nurse across all income levels



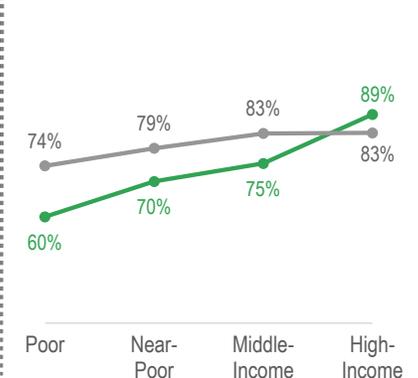
Among BIPOC children...



Source: National Survey of Children's Health 2017-20

**Among high-income households, BIPOC children had greater access to a personal doctor or nurse in the past year than their white peers.**

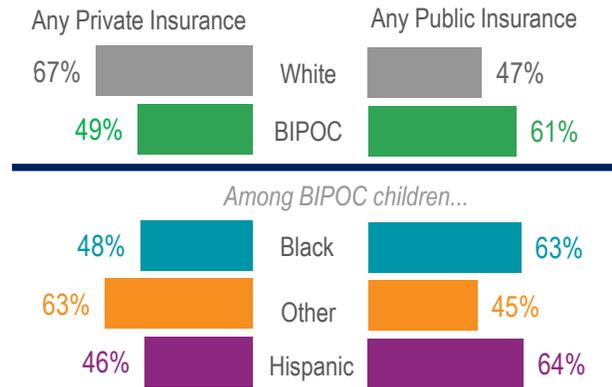
Personal doctor or nurse at each income level



Type of health insurance also varied according to race/ethnicity. Across all income levels, Black (63%) and Hispanic (64%) children with autism were more likely to have public health insurance coverage than white children (47%) and children of other race(s) (45%).

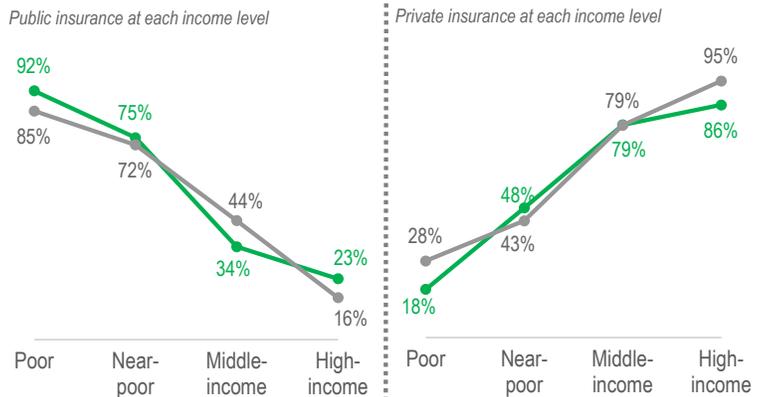
Public health insurance decreased with income while private coverage increased with income for both groups of children. Differences in type of health insurance between BIPOC and white children with autism were relatively small across income levels. The sharpest decrease in public coverage occurred among near-poor and middle-income households, with a percentage point decline of 36 among BIPOC children and 26 among white children.

**Black and Hispanic children with autism were more likely to have public health insurance coverage and less likely to have private coverage than white children and children of other race(s).**



Source: National Survey of Children's Health 2017-20

**For both white and BIPOC children with autism, public health insurance coverage decreased with income while private coverage increased with income.**



Source: National Survey of Children's Health 2017-20

## Insurance Quality

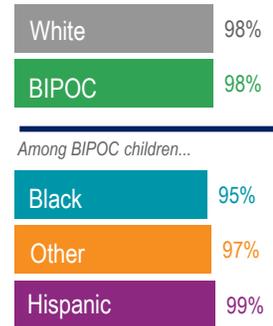
Consistency in health insurance coverage did not vary by race/ethnicity or household income.

There were differences in insurance adequacy within BIPOC groups. Notably, Black (58%) and Hispanic (50%) children were more likely to have adequate health insurance coverage than white children (46%) and children of other race(s) (41%).

Racial/ethnic differences in adequate coverage varied according to household income. For instance, near-poor BIPOC children with autism had lower rates of adequacy than their white and their poor and high-income BIPOC peers. Poor BIPOC children with autism reported the highest levels of adequate coverage (66%).

**Nearly all children who had health insurance were covered for all 12 months during the past year, regardless of race/ethnicity.**

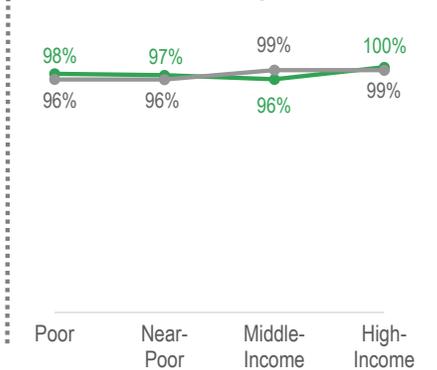
Consistent health insurance coverage across all income levels



Source: National Survey of Children's Health 2017-20

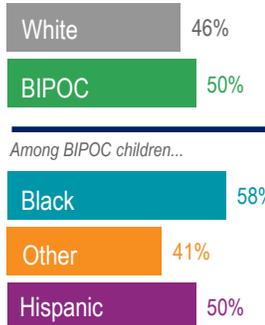
**There were little racial/ethnic differences in the percentage of children with consistent health insurance by household income.**

Consistent health insurance coverage at each income level



**The percentage of children with adequate insurance differed by race/ethnicity.**

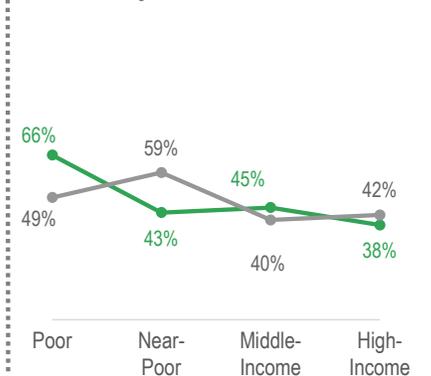
Insurance always covered needed services and providers across all income levels. Among children with any health insurance coverage.



Source: National Survey of Children's Health 2017-20

**Poor BIPOC children with autism were the most likely to report adequate health insurance coverage.**

Insurance always covered needed services and providers at each income level. Among children with any health insurance coverage.



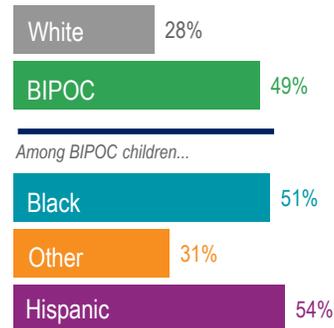
## Expenditures

Across all income levels, BIPOC children with autism were more likely to have no out-of-pocket medical expenses than white children (49% versus 28%) and less likely to have expenses of \$500 or more (25% versus 42%). Among BIPOC children, Black and Hispanic children with autism were more likely than children of other race(s) and white children to report no medical expenses. However, the percentage of BIPOC children with out-of-pocket expenses of \$500 or more did not vary within race/ethnic categories.

Race/ethnic differences in out-of-pocket expenditures of \$500 or more were only apparent among poor (a percentage point difference of 11) and near-poor households (a percentage point difference of 10). Similar findings were observed for no out-of-pocket expenditures, with race/ethnic differences of 13 percentage points among poor children and 14 points among near-poor children.

**BIPOC children with autism were much more likely to have no out-of-pocket medical expenditures than white children, overall.**

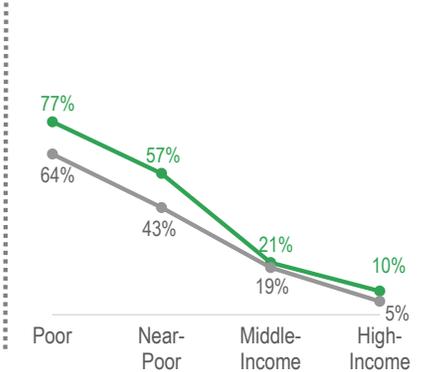
Medical expenditures of \$0 across all income levels



Source: National Survey of Children's Health 2017-20

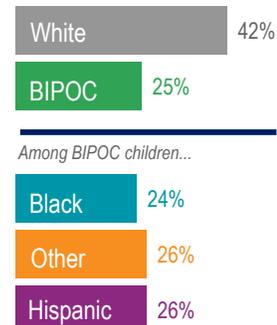
**Race/ethnic differences in no out-of-pocket medical expenditures were present among poor and near-poor households only.**

Medical expenditures of \$0 at each income level



**White children were more likely to have out-of-pocket medical expenditures of \$500 or more than BIPOC children.**

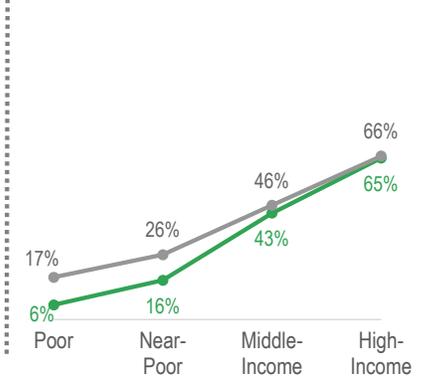
Medical expenditures of \$500 or more across all income levels



Source: National Survey of Children's Health 2017-20

**Race/ethnic differences in medical expenditures of \$500 or more were present among poor and near-poor households only.**

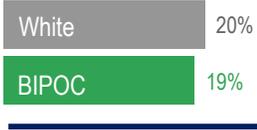
Medical expenditures of \$500 or more at each income level



Black children with autism and those in middle-income households were at the greatest risk for medical hardship.

**Caregivers of Black children were most likely to report difficulty paying their child's medical bills.**

*Difficulty paying child's medical bills across all income levels*



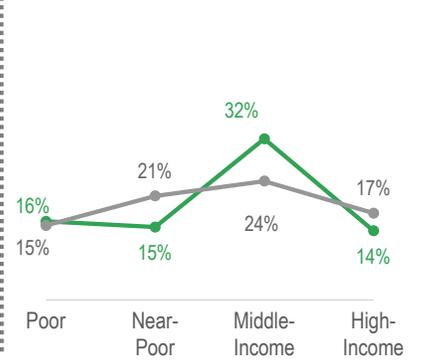
*Among BIPOC children...*



Source: National Survey of Children's Health 2017-20

**Middle-income caregivers of BIPOC children were most likely to report difficulty paying their child's medical bills.**

*Difficulty paying child's medical bills at each income level*



## Looking Forward

# Conclusions and recommendations for future research

### Findings

Reducing socioeconomic and racial/ethnic disparities in health and health care is a national priority for autism research.<sup>1</sup> Yet, there is little evidence that examines health and healthcare measures by race/ethnicity and socioeconomic position at the population-level. This report begins to address this gap by examining autism-, racial/ethnic-, and income-based disparities in health and health care in U.S. children ages 3-17 using nationally representative data. We focused on the following two questions:

1. Do income-based differences in health and health care outcomes look the same for children with and without autism?
2. Do income-based differences in health and health care outcomes look the same for BIPOC children with autism and white children with autism?

Below, we summarize how our findings offer initial answers to these questions and discuss research and policy implications.

We examined health and healthcare outcomes overall and by household income for U.S. children with autism and without autism. Health status, insurance coverage, medical expenditures, and health care access among children with autism

varied across income groups, with lower-income groups experiencing consistent disparities across categories. At the same time, poor children occasionally showed higher rates of health care access than their near-poor or middle-income peers, likely reflecting the importance of access to safety net programs and public health insurance.

This report also showed that autism, poverty, and non-white race/ethnicity appear to increase rates of health concerns and care challenges both individually and in combination. More work is needed to understand the complex ways in which autism, socioeconomic status (including educational and occupational factors, in addition to income), and race/ethnicity combine to affect health. To advance this understanding, we recommend that future research monitor disparities across a wide range of social determinants. For instance, Healthy People identifies four dimensions of social determinants of health (in addition to health and health care) including economic stability, education, social and community context, and neighborhood and built environment.<sup>10,12</sup> We also suggest that we turn our attention to understanding and addressing policies outside of healthcare – such as economic safety net policies like food stamps and Social Security – to address health equity among U.S. children with ASD.

## Do income-based differences in health and health care outcomes look the same for children with and without autism?

Key findings include:

- **Children with autism experienced more challenges than children without autism across a wide range of health outcomes.** Children with autism had poorer overall health and dental health, more chronic health difficulties, and more health conditions than children without autism. Caregivers of children with autism were also more likely to report difficulty paying for their child's medical bills and to have at least one unmet health care need due to cost.
- **Poor children with autism had the highest frequency of poor health outcomes.** Lower household income was associated with higher rates of poor outcomes on a range of health status measures including overall health, dental health, chronic difficulties, health conditions, and parent-reported autism severity. For health care access and unmet health care needs, higher household income was related to having access to a usual source of care and fewer unmet health care needs.
- **Higher rates of health-related challenges were evident not just among the poor but also in near-poor and middle-income groups, compared with high-income households.** Our findings revealed patterns suggesting incremental gradients (i.e., greater challenges as income decreased) for a range of health and health care outcomes among children with and without autism including health status, type of health insurance, and adequacy of coverage. That said, higher-income did not necessarily protect caregivers of children with autism from experiencing difficulties. We found that caregivers of children with autism from middle- and high-income households were more likely to report difficulty paying for medical bills than their lower-income peers. The proportion of middle-income caregivers reporting difficulty paying for their child's medical bills was higher in the autism group compared to the group without autism (28% versus 14%). This is likely due to the complex healthcare needs of children with autism, which can lead to higher medical use and expenditures, and not meeting income requirements to qualify for safety net programs.
- **Income-based disparities in health and health care differed between children with and without autism.** While poor children generally had the highest rates of health and healthcare challenges regardless of autism status, and rates typically decreased with each level of rising income, there were still notable differences in the relationship between income and health and health care among children with autism versus those without autism. For instance, the greatest difference in rates of overall health and chronic health difficulties was generally observed between poor and near-poor households for children with autism, but not for children without autism. The percentage of children with autism who had at least one chronic health difficulty was substantially higher in poor versus near-poor income groups (62% vs. 46%, a 15 percentage point difference). In comparison, the rate of chronic health difficulties between poor and near-poor children without autism were not different. This suggests that among lower-income groups, differences in income may have particular relevance for children with autism.

## Do income-based differences in health and healthcare outcomes look the same for white children with autism and BIPOC children with autism?

Key findings include:

- **We found differences between white and BIPOC children with autism on a broad set of health and health care measures.** Compared to white children with autism, BIPOC children with autism had lower rates of excellent dental health, access to a usual source of care, and health care use. BIPOC children were also more likely to be covered by public health insurance and to have inadequate coverage than white children and to report no out-of-pocket medical expenditures.
- **The observed differences between white and BIPOC children were also present across specific racial/ethnic categories.** Within BIPOC categories, Black and Hispanic children were especially vulnerable relative to children of other race(s). For example, Black and Hispanic children were less likely to have a usual source of preventative care and to have a personal doctor or nurse than white children and children of other race(s). Black and Hispanic children were, however, more likely to have adequate health insurance coverage than white children and children of other race(s). Hispanic children had the poorest overall health and dental health relative to all other race/ethnic groups while Black children were the most likely to have severe parent-reported autism. BIPOC children were also more likely to be poor than white children across all racial/ethnic subgroups. Relative to the total population of children with autism, poor children with autism were more likely to be Black (23% vs. 15%) and Hispanic (41% vs. 30%).
- **Racial/ethnic disparities remained even when we grouped children by household income.** One hypothesis might be that the racial differences we observed reflect patterns of socioeconomic inequality in the U.S. Indeed, BIPOC children from lower-income households had lower rates of excellent health and lower rates of access to a usual source of care than their higher-income peers. Many of these racial/ethnic differences persisted at each income level, suggesting that household income accounts for some but not all racial/ethnic disparities in health and health care. Although more research is needed in this area, this finding speaks to the importance of studying income and racial/ethnic disparities both separately and in combination.
- **Children from middle-income groups faced greater health challenges relative to their peers in other income categories.** Nearly one-fifth (19%) of BIPOC children with autism from middle-income households had an unmet health care need, a higher percentage than those of BIPOC children in poor (6%) and high-income (5%) households. Middle-income caregivers also had the greatest difficulty paying for their child's medical bills, regardless of child race/ethnicity. That said, it seems as though middle-income BIPOC children are especially vulnerable, with 32% reporting hardship versus 24% of white children in the same income group, even though middle-income BIPOC children had similar rates of excellent overall health as their white peers (29% versus 28%). These vulnerabilities among middle-income BIPOC children may be due to the lower rates of public health insurance coverage among middle-income BIPOC children.

## Research and Policy Recommendations

Although our findings are descriptive in nature and cannot determine causal relationships, we found that household income appears to be a very important factor in understanding health disparities for children with autism, with further investigation needed to determine the degree to which it might contribute to differences in health status, insurance coverage, medical expenditures, and health care access. The report also showed that autism, poverty, and race/ethnicity warrant additional study as potential risk factors for poor health and health care outcomes individually and in combination. More work is needed to understand the complex ways in which autism, socioeconomic status, and race/ethnicity combine to affect health. Future research should monitor disparities across a wide range of social determinants and incorporate policies outside of health care to address health equity among U.S. children with autism.

The growing commitment to create social and physical environments that promote health equity has led to widespread recognition of the importance of social determinants of health.<sup>14</sup> Social determinants are broadly defined as “the conditions in the environments in which people are born, live, learn, work, play, worship, and age.”<sup>15</sup> These determinants represent factors outside of medical care that influence health and can be grouped into five major areas: economic stability, education, social and community context, health and health care, and neighborhood and built environment. At present, much of our understanding of disparities among children with autism has concentrated on inequities in health and health care access; however, evidence shows that medical care only accounts for a small fraction of health disparities.<sup>16,17</sup> Therefore, it is imperative that researchers monitor disparities across a wide range of social determinants. Without this information, and data on how people enroll in health care and the services they receive, policymakers do not have the evidence needed to make decisions about health care policy.

Tracking both the rates of poor health and variation in rates across relevant social groups can help to identify areas in which to target policies and programs. Findings from empirical studies suggest that the unequal distribution of key health determinants (like economic resources, housing difficulties, and neighborhood deprivation) can lead to disparities in health across social groups.<sup>14,15,18,19</sup> Indeed, in this report, we found that groups who had multiple potential risk factors (poverty, autism, identifying as BIPOC) did show higher rates of poor health and health care outcomes. In some cases, the differences we observed between income groups were more substantial than the differences we observed between children with and without autism, or between white and BIPOC children. We conclude that efforts to reduce health inequities must be combined with efforts to improve the economic stability of children, especially those with autism and those who are BIPOC. Social policies outside of healthcare delivery (like cash assistance and nutrition programs) can reduce health disparities by ameliorating the adverse effects of poverty among children.<sup>20</sup> Future research aimed at understanding how social policies influence health disparities is needed.<sup>21</sup> Innovative policy approaches that combine health and social policy solutions are needed to address the health inequities we identified.

## Data Needs

Monitoring racial/ethnic and economic disparities in health and its determinants is a necessary step towards achieving Healthy People 2030’s goal of eliminating health disparities and achieving health equity. However, these efforts are impeded by data limitations. To move this area of research forward, we need to: 1) Include more detailed measures of socioeconomic status,<sup>22</sup> race/ethnicity, and social determinants of health in data collection efforts and analyses; and 2) Include underrepresented racial and ethnic groups; 3) Collect longitudinal data that include adults with autism.

This report monitored patterns in health and health care across four levels of household income, which allowed us to not only compare outcomes between lower- and higher-income households, but to also distinguish between subgroups of poor, near-poor, and middle-income children. While this approach helped to provide a more nuanced understanding of economic disparities in health, household income only measures one facet of socioeconomic status. Moreover, income-based measures may understate the economic conditions of households of children because they do not adjust for the financial demands and costs associated with caring for a child with a disability.<sup>23</sup> To address this shortcoming, future research needs to incorporate additional indicators of socioeconomic status, such as education, employment, and food insecurity, and measures of the communities that surround these children and families to better understand how socioeconomic status influences health.

If sampling of underrepresented groups is not adequate, we may miss the opportunity to identify populations of people with autism vulnerable to poor health outcomes and specific barriers to healthcare access. Qualitative research could also provide insight into the ways people with autism and their families from underserved groups navigate healthcare systems.

We also need longitudinal studies that include a focus on health and socioeconomic status for autistic people across the lifespan. This would allow for a better investigation of the cumulative impacts of poverty and racism on health and employment in this population. Mental health care needs were significantly greater for people with autism across racial/ethnic and income groups. Research should be conducted to determine how early adverse experiences and structural inequalities impact the health and mental health of autistic people differentially across income group and racial or ethnic groups over time.

# 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 (NSCH) has a repeated cross-sectional design and provides national and state-level data on the health and well-being of United States children, ages birth to 17 years. The questionnaire, which is administered in both web-based and paper formats or by telephone, is completed by an adult caregiver who is familiar with the health and health care of the child. The data provide a wealth of information across a range of topics including: physical and emotional well-being, health care 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 have been widely used throughout the Maternal and Child Health Bureau to monitor federal and state Title V Maternal and Child Health Services Block Grant programs and Healthy People objective.

For our analyses, we pooled data across four time periods (2017–2020) to produce a large enough sample to stratify findings across multiple indicators (i.e., race/ethnicity, household income).

## Who is represented in this report?

The NSCH was designed to produce nationally representative findings of non-institutionalized United States children under the age of 18 living in mailable residential housing units. Because sampling focused on the child as the sampling unit, study results are representative of children but not the overall population of caregivers or other household members.

The survey identifies children with autism based on caregiver report. In this report, a child was considered to have autism if the reporting caregiver

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?

## Subpopulation Groups

This report highlights disparities by household income and race/ethnicity.

### Household Income

Consistent with past studies,<sup>18,24</sup> we report household income based on federal poverty level (FPL) thresholds. We examined four categories of household income:

- *Poor* households refer to those under 100% FPL.
- *Near-poor* households are defined as those between 100% and 199% FPL.
- *Middle-income* households are between 200% FPL and 399% FPL.
- *High-income* households are those at 400% FPL or higher.

### Race and Ethnicity

We categorized children's race/ethnicity as follows:

- white, non-Hispanic
- Black, non-Hispanic
- Other race(s), non-Hispanic
- Hispanic

We also included a binary measure of race in which one group represented white, non-Hispanic children, and the BIPOC group included all other race/ethnicity categories.

We combined race and ethnicity to allow for comparison with other data sources and our previous reports. The grouping of non-white and non-Black and biracial/multiracial categories into an "other" category was done due to small numbers of people who identified as another race or multiple races.

### A Note about Race:

The basic racial and ethnic categories for federal statistics and program administrative reporting are defined as follows:

- **American Indian or Alaska Native (AI/AN).** A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.
- **Asian.** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- **Black or African American.** A person having origins in any of the Black racial groups of Africa. Terms such as “Haitian” can be used in addition to “Black or African American.”
- **Hispanic or Latino.** A person of Cuban, Mexican, Puerto Rican, Central or South American, or other Spanish culture or origin, regardless of race. The term “Spanish origin” can be used in addition to “Hispanic or Latino.”
- **Native Hawaiian/Pacific Islander (NHPI).** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White.** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

## Data Analysis

We presented descriptive data for key indicators in this report. We used percentages to convey how often and to what extent characteristics and experiences happened. We did not perform tests of statistical significance for this report, as is often done in scientific journal publications. We report group differences of five percentage points or more. A 10 percentage point difference was used as a criterion for evaluating a larger magnitude of difference between groups.

All analyses were done incorporating the complex sample design information from the NSCH 2017–2020 in Stata 16.<sup>25</sup> The estimates in this report may be slightly different from estimates reported in our previous work or in other published scientific articles or reports. These differences represent differing analytic approaches to analyzing the data, including how missing data is handled and who is included or excluded from analysis.

## Study Strengths

- ▶ The NSCH provides a unique opportunity to examine health and healthcare outcomes among a recent (2017–2020), nationally representative sample of children with autism across income gradients.
- ▶ These pooled data offer a large enough sample size to stratify outcomes across various racial/ethnic categories and across four levels of household income.
- ▶ The survey has well-designed and tested data collection instruments and sampling design procedures.

## Study Limitations

- ▶ The NSCH relies on caregiver-reported autism and does not confirm the diagnosis by other means, such as use of a screening instrument, clinical evaluation, or educational records. As a result, autism may have been underdiagnosed or overdiagnosed in some cases; especially for younger children, the prevalence of autism may be underestimated because it has not yet been recognized by a healthcare provider. Although caregivers' reports of autism diagnoses and severity were not clinically validated, recent epidemiological surveillance research in the United States reveal high concordance rates between parent reported autism diagnosis and Diagnostic criteria for autism.<sup>26</sup> Findings from past studies also reveal reliability in parent reported autism diagnoses of children when compared to clinical reports,<sup>27</sup> and across national surveys.<sup>26,28</sup>
- ▶ The data are cross-sectional and observational in nature. We cannot infer causal relationships between variables. For example, we cannot determine whether observed differences were directly attributable to group membership (e.g., lower-income). Rather, we can only assess if outcomes differ, on average, between different groups.
- ▶ Measures of race/ethnicity are based on parent-reported census categories, and do not represent how a specific child self-identifies or how that child might be perceived or categorized by others. This is an important metric for understanding stigma and racism at the structural level.
- ▶ Several other important indicators of social identity, including sexual orientation and gender identity, are not included in the NSCH and therefore could not be measured in this report. As a result, we are not able to examine all potentially vulnerable autism populations, such as young people who do not belong to cisgender or heterosexual groups.

# References

1. Interagency Autism Coordinating Committee (IACC). IACC Strategic Plan for Autism Spectrum Disorder (ASD) 2018–2019 Update. July 2020. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/strategic-plan/2019/>
2. Rast J, Roux A, Anderson K, et al. *National Autism Indicators Report: Health and Health Care* Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University; November 2020.
3. Kleinman DV, Pronk N, Gómez CA, et al. Addressing Health Equity and Social Determinants of Health Through Healthy People 2030. *Journal of Public Health Management and Practice: JPHMP*. 2021.
4. Morgan EH, Rodgers R, Tschida. Addressing intersectionality of race and disability to improve autism care. *Pediatrics*. Supplement 4, 2022.
5. Tregnago MK, Cheak-Zamora NC. Systematic review of disparities in health care for individuals with autism spectrum disorders in the United States. *Research in Autism Spectrum Disorders*. 2012;6(3):1023–1031.
6. Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: data from US national samples. *Journal of autism and developmental disorders*. 2006;36(7):871–879.
7. Anderson KA, Rast JE, Roux AM, Garfield T, Shattuck PT. *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.
8. Bishop-Fitzpatrick L, Kind AJ. A scoping review of health disparities in autism spectrum disorder. *Journal of autism and developmental disorders*. 2017;47(11):3380–3391.
9. Magaña S, Parish SL, Rose RA, Timberlake M, Swaine JG. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and developmental disabilities*. 2012;50(4):287–299.
10. Parish S, Magana S, Rose R, Timberlake M, Swaine JG. Health care of Latino children with autism and other developmental disabilities: Quality of provider interaction mediates utilization. *American Journal on Intellectual and Developmental Disabilities*. 2012;117(4):304–315.
11. Magaña S, Parish SL, Son E. Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American journal on intellectual and developmental disabilities*. 2015;120(6):504–513.
12. Liptak GS, Benzoni LB, Mruzek DW, et al. Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children’s Health. *Journal of Developmental & Behavioral Pediatrics*. 2008;29(3):152–160.
13. Jones DR, Mandell DS. To address racial disparities in autism research, we must think globally, act locally. In. Vol 24: SAGE Publications Sage UK: London, England; 2020:1587–1589.
14. Chang L, Stewart AM, Monuteaux MC, Fleegler EW. Neighborhood conditions and recurrent emergency department utilization by children in the United States. *The Journal of Pediatrics*. 2021;234:115–122. e111.
15. Chu MT, Williams DR, James Todd T, Coull BA, Adamkiewicz G. Social Determinants of Housing Quality for US Immigrants: Intersections of Nativity, Race, and Socioeconomic Status. Paper presented at: ISEE Conference Abstracts 2021.
16. McGinnis JM, Williams-Russo P, Knickman JR. The case for more active policy attention to health promotion. *Health affairs*. 2002;21(2):78–93.
17. Bunker JP, Frazier HS, Mosteller F. The role of medical care in determining health: creating an inventory of benefits. In: *Society and Health*. Oxford University Press, USA. 1995
18. U.S. Department of Health and Human Services HRaSA, Office of Health, Equity. *Health Equity Report 2019–2020: Special Feature on Housing and Health Inequalities*. Rockville, Maryland. 2020.
19. Beverly SG. Measures of material hardship: Rationale and recommendations. *Journal of Poverty*. 2001;5(1):23–41.
20. Waxman BS, Sherman A, Cox K. Income Support Associated With Improved Health Outcomes for Children, Many Studies Show. 2021.
21. DeSalvo KB, Gracia JN. Health is more than health care. *Annals of Internal Medicine*. 2020;172(2\_Supplement):S66–S67.
22. Braveman PA, Cubbin C, Egerter S, et al. Socioeconomic status in health research: one size does not fit all. *Jama*. 2005;294(22):2879–2888.
23. Parish SL, Rose RA, Grinstein-Weiss M, Richman EL, Andrews ME. Material hardship in US families raising children with disabilities. *Exceptional Children*. 2008;75(1):71–92.
24. Kennedy J, Wood E. Disability-Based disparities in social determinants of health among working-age adults: evidence from the 2018 National Health Interview Surveys. S Pullman, WA: CHRIL, 2020.
25. StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.
26. Kogan MD, Vladutiu CJ, Schieve LA, et al. The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*. 2018;142(6):e20174161.
27. Daniels AM, Rosenberg RE, Anderson C, Law JK, Marvin AR, Law PA. Verification of parent-report of child autism spectrum disorder diagnosis to a web-based autism registry. *Journal of autism and developmental disorders*. 2012;42(2):257–265.
28. Christensen D, Baio J, Van Naarden Braun K. Community Report on Autism. *CDC Community Rep Autism*. 2016;65:01–23.