

NATIONAL AUTISM INDICATORS REPORT:

Health and Health Care
November 2020



**Life Course
Outcomes Program**



DREXEL UNIVERSITY
A.J. Drexel

Autism Institute



Life Course Outcomes Program

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 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 website: <http://drexel.edu/AutismOutcomes>

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National Autism Indicators Report:

Health and Health Care

November 2020

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Foreword

Lindsay L. Shea, DrPH & Paul T. Shattuck, PhD

Our Life Course Outcomes Program is dedicated to the proposition that people on the autism spectrum have dreams to pursue and contributions to make. The point of effective services and supports is ultimately to unleash human potential.

Good health and access to needed care are gateways to quality of life and full community participation. However, this is a population where challenges in health and access to healthcare abound. Most scientific studies of these matters focus on one health condition, one type of healthcare or one age group at a time. Yet we all know from our own experience that our health evolves over time, health conditions co-occur, and health is intimately entangled with other areas of life like education and employment. The typical fragmented approach to studying health and healthcare access leaves us with a fragmented understanding of how these things unfold over time.

This report is our attempt to paint a holistic picture of what health and healthcare access and use look like across the life course. It is one of our most ambitious reports to date and we have stitched together data and statistics from a variety of sources. The picture is still incomplete and has notable gaps. However, it is an important step forward in our overall goal to emphasize the connectivity between issues and challenges that people face so that our solutions can be holistic and aimed at improving overall systems of care.

Linking data from healthcare systems to health status and outcomes is critical for informing policy and the evolution of the U.S. healthcare system. Healthcare is costly and unique, cross-system views of healthcare expenditures are needed to point to new opportunities for improvement. This report is built to support policy decisions to advance all types of healthcare for all individuals on the spectrum and their caregivers, including individuals from racial and ethnic minorities.

It remains unclear how our healthcare system will be reshaped by the challenges of COVID-19. This report presents stepping-stones to guide those changes to support the growing, aging group of autistic individuals who need care and their caregivers who support them.

The image shows two handwritten signatures in black ink. The first signature on the left is 'Lindsay L. Shea' and the second signature on the right is 'Paul T. Shattuck'.

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A note about wording. In this report, we use “person on the autism spectrum,” “person with autism,” and “person with an autism spectrum disorder” 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 Diagnostic and Statistical Manual (DSM-5), as well as the surveys used in this report (National Survey of Children’s Health, Medical Expenditure Panel Survey). Some adults with ASD report that they prefer the term “autistic”. We use the term “autistic” when presenting our findings about adults to acknowledge that identity first language (such as “autistic”) is an important tool in increasing neurodiversity awareness and acceptance. In cases where we present research from other studies, we mirror their language choices.

Executive Summary

The issues

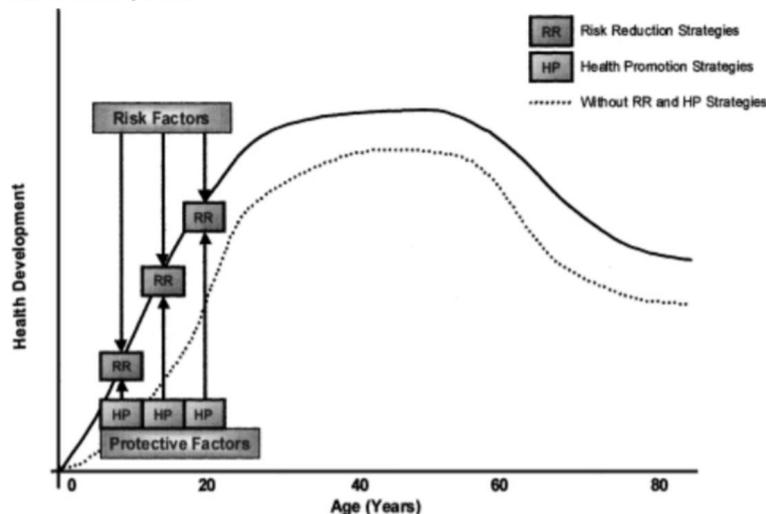
Health changes across the life course.

Health and healthcare needs change across the life course. A person's experiences and health earlier in life can influence later health outcomes. A person may be more vulnerable to developing health conditions or experiencing disruption in their health care at certain critical points in life, such as during the transition to adulthood. Furthermore, health is influenced by a complex host of biological, social, and societal factors that also may change across a person's life course. These are the basic tenets of a life course health perspective, which is the foundation of our work.

According to the life course health perspective, the path of each person's health is shaped by their health trajectory, risk factors, and exposures encountered throughout life, plus positive health experiences and improvements. These components accumulate from the time a person is conceived until the end of life (Halfon and Hochstein, 2002). If a person experiences less risk and more positive health, overall, this increases their ability to engage across employment, postsecondary education, and social participation opportunities. In turn, being employed, gaining education, and having healthy social connections can be positive influences on health and mental health in the context of adequate supports.

This idea is highlighted in Figure 1. The trajectory of a person's health is represented by the dotted line. Risk factors, such as genetic predisposition to certain diseases, limited economic resources, and chronic stress, may push the whole trajectory downward. Protective factors, such as preventive medicine, familial support, and access to services, push the whole trajectory up. Risk and protective factors experienced early in life can have a lifelong impact on health. Specific strategies to reduce risk and promote health across the life course can lead to better overall health. These strategies can be as focused as smoking cessation intervention and as encompassing as national policies on universal healthcare.

Figure 1. How risk reduction and health promotion strategies influence health development.



Source: Halfon, Inkelas, and Hochstein, 2000, pg 455.

The degree of disability that a person on the autism spectrum experiences is a result of a mix of factors: the extent of their service and support needs and access to those services; their abilities and strengths; and social influences such as the accommodations they receive and stigma they encounter (World Health Organization, 2001; Kapp, 2013). The degree of disability may also fluctuate across a person's lifetime as health status changes, they face different roles and challenges in life, and encounter shifts in the nature and availability of supportive services.

People on the autism spectrum often have complex health needs.

Health care for individuals on the autism spectrum can be highly complex. People with autism spectrum disorder (ASD) often have multiple health and mental health issues in addition to autism. Psychiatric issues may emerge during the early adult years, just as young people are transitioning into the adult health care system. Having several health conditions may mean having to see multiple healthcare providers. It is also common for individuals on the spectrum to take several medications to manage mental health conditions, and for them to report needing mental health services and supports.

The complexity of a person's health needs depends, in part, on the number of issues they need help with and whether they have access to the types and quality of care they need. The healthcare journey may be less complicated if people are able to access care that is integrated across health and mental health, if they have fewer unmet needs, and if their care is coordinated when needed. The patient-centered medical home is one model of care that aims to provide comprehensive, coordinated care to reduce complexity and improve quality of healthcare.

Emergency department visits and inpatient hospitalizations occur more often.

When individuals receive preventive and routine health and mental health care, the overall severity of their conditions may be reduced. Receipt of timely and effective health care services helps to prevent the need for emergency department visits and hospitalization. Preventive and primary medicine is more cost effective than emergency medicine, and prevention and treatment of chronic conditions leads to better health-related quality of life (Vanstone *et al.*, 2015). However, half of children with ASD visit the emergency department for treatment of conditions that could be prevented or cared for in a primary care setting (Carbone *et al.*, 2015). This enhanced usage may be a marker of inadequate primary care and condition management (Coller *et al.*, 2017). Conditions that can be prevented or treated in comprehensive primary or outpatient care are referred to as Ambulatory Care Sensitive Conditions (ACSCs) and sometimes used as markers of quality of outpatient care. The Agency for Healthcare Research and Quality (AHRQ) includes diabetes and diabetes related complications, hypertension, urinary tract infections, asthma, epilepsy, and others as ACSCs (AHRQ, 2020). Mental health conditions are often considered ACSCs as well (Carbone *et al.*, 2015).

Children and adults with autism are more likely to have emergency department visits than their peers without autism (Liu *et al.*, 2017; Vohra *et al.*, 2016; Deavenport-Saman *et al.*, 2016). The most common reasons for emergency department visits vary by age in people with autism. Young children with ASD often present with respiratory infection, viral infection, or otitis media (ear infection) (Deavenport-Saman *et al.*, 2016). Teens and adults most commonly present with epilepsy or psychiatric conditions (Ianuzzi *et al.*, 2015). Autistic adults who present to the emergency department are more likely than their peers to be admitted to an inpatient hospital stay (Vohra *et al.*, 2016).

Children and adults with autism are also more likely to have inpatient hospitalizations than their same

age peers. Inpatient stays are often longer and more expensive (Lockhandwala *et al.*, 2012), and children with autism are more likely to have an inpatient stay related to mental health or neurological conditions than their peers (Nayfack *et al.*, 2014).

People with autism may use health care more often and have higher health care costs.

One way to measure complexity and severity of health care needs is by counting how often a person accesses health care during a year. People who have frequent visits with health care providers usually have more complex or more severe health needs. Another way to measure complexity and severity is total health care costs for a person across a year. These may be costs that insurance covers and/or out-of-pocket costs for the patient.

Children and adults on the autism spectrum have greater health care utilization and higher health care expenditures than peers. Children with autism tend to have higher health care costs than children without autism or children with other special health care needs (Croen *et al.*, 2006; Kogan, 2008). Autistic adults also have greater amounts of health care use and higher costs than some of their peers with other conditions including attention deficit/hyperactivity disorder (Zerbo *et al.*, 2019).

Even when people on the spectrum access care, they have more unmet health care needs.

Unmet health care needs are more common in people with autism than in people without autism. While people with autism may access primary care, specialty care may be harder to access due to increased cost, limited provider availability, or inability to get needed referrals. Need for specialty visits and therapy are often greater than children with other special health care needs (Benevides *et al.*, 2016; Chiri *et al.*, 2012).

Some insurance coverage has proven effective at reducing unmet needs in people on the autism spectrum. Particularly, state implementation of Medicaid Home and Community-based Services (HCBS) waivers has shown reduction in unmet health care needs in children with autism (Leslie *et al.*, 2017). HCBS waivers expand eligibility and services covered in this population.

Health and health care in context

Differences between pediatric and adult health care may be challenging.

Health care in adulthood is different from pediatric care. When youth transition into adult health care around the age of 18, there is a new expectation that the patient will take the lead in communicating about their health and healthcare needs by initiating appointments, raising concerns, and taking responsibility for managing their care at home. As a result, some people on the autism spectrum, especially those with complex healthcare needs, may have more difficulty transitioning to a new health care provider or navigating an office space that is new to them, or they may experience anxiety about medical care. Even a routine health check may feel overwhelming.

Transition-age youth on the spectrum may have more positive experiences with the change to adult health care when they are prepared through a process known as health care transition. However, to improve this transition, we need to know more about what healthcare experiences are like for autistic adults – what is difficult and what helps.

Social and political factors influence health.

A person's health is not governed only by the healthcare system. Other factors known as social determinants impact health and health care experiences (World Health Organization, 2008). Social determinants include things like where a person lives, their neighborhood, income, access to resources, race and ethnicity, sexual orientation, and gender.

Policies and political views also shape health. Federal and state laws, judicial decisions, and executive orders impact population health by mandating insurance coverage, defining requirements for public program participation, distributing resources, and setting care priorities. Policies and political agendas are an important consideration in the discussion of population health (Kickbusch, 2015; Mishori, 2019). One example of state policy that impacts children with autism is coverage of applied behavior analysis through Medicaid, which most states now allow.

Why do we examine health by race and ethnicity?

In the United States, race is a consistent determinant of health. Race is thought to impact health through many pathways starting with racism and discrimination. People who experience racism may experience poorer health because of the stress of dealing with discrimination. Racism may also impact the relationship between a physician and patient. Most health care providers don't provide different care to different people on purpose. They are often not aware of how their unconscious attitudes and stereotypes, their implicit biases, may affect their decisions and recommendations to their patients. This lack of awareness increases the importance of placing focus on race and ethnicity when reporting on health.

Ethnicity and race are both social groups used to categorize people. Where race describes social groups based on physical characteristics, ethnicity captures geographic origin. In the context of this study and many U.S. data collection efforts, ethnicity refers to a person of Hispanic or Latinx origin. In much the same way that race impacts health, so does ethnicity. Ethnicity and race can overlap in any pattern: a Hispanic person can identify as white, black, Asian, or any other race.

Healthcare is also affected by institutional and structural racism - practices and policies that perpetuate racial inequality in access to goods and power (Jones, 2000; Smedley, 2012). Families with children on the spectrum in one part of a city may have access to many more autism services than families in an under-resourced part of a city where more minority families may live.

Because many forms of racial inequality are so pervasive in the United States, race is an important consideration in studying health. In fact, the Institute of Medicine recommends explicitly addressing race as a determinant of health and emphasizes the role that race plays in health above and beyond income, insurance, age, and severity of healthcare needs (Smedley, 2003). Race and ethnicity impact a person through individual experiences with discrimination and as a member of society that was built on racist ideals; race as a biological reason for health differences is largely unfounded.

Why do we compare to people with other health conditions?

Just as race shapes health, diagnosis may too. Access to services may be limited by inadequate health insurance, lack of providers that have knowledge about autism, and barriers to accessing specialty care. While autism may have little to do with certain physical health conditions, other factors may make health care harder for people on the spectrum. These include having inadequate insurance, waitlists

for disability-specific services, and lack of accommodations at a physician office for people with challenging behavior or anxieties about health care. For example, while there is no biological reason that a person with autism would be more likely to die from the flu, some people on the spectrum may be less likely receive health care when very ill because of anxieties about visiting the doctor – causing common conditions to spiral into health crises. Because people on the spectrum face unique challenges, it is important to understand how their health and health care compare to people with other health conditions and to people with no special needs.

Why do we compare different age groups?

Healthcare needs change throughout life as people and their environment change. Before age 18, a child experiences developmental changes across physical, social, and cognitive domains. As developmental changes occur, healthcare needs also evolve. Therefore, we present findings for younger (up to age 11) and older (age 12-17) children with ASD to examine how health and health care experiences may differ across childhood. We also present findings for young adults and all adults as available.

The charge

In summary, health and health care are critical issues for many children and adults on the autism spectrum. They may experience more frequent use of services and medications. They may need more types of routine and specialty health care. And their overall health and mental health care tends to be more complex than people with other types of disabilities and special health care needs.

Unfortunately, the current healthcare system often fails to adequately address the needs of people on the spectrum. As a result, there is more frequent need for emergency health care and hospitalization. The gaps in health care for people with autism, versus those with other disabilities, are important to address.

We need to understand health and healthcare needs across the life course so that recommendations can be made about how to improve health and health care at critical points in a person's life.

Considerations about the data used in this report

What data is used in this report?

We present findings about health and health care utilization for both children and adults on the autism spectrum. This report combines data from: 1) two national surveys about health, 2) one national sample of all-payer hospital inpatient stays, and 3) previously published findings from Kaiser Permanente Northern California (KPNC) patient records.

We use the National Survey of Children's Health (NSCH) to describe health and health care of children with autism, ages 3 to 17. The NSCH is a cross-sectional, nationally representative survey designed to provide national estimates on the health and well-being of United States children from parent or caregiver report. The NSCH is designed by the Health Resources and Services Administration's Maternal and Child Health Bureau and conducted by the U.S. Census Bureau. The NSCH asks about health, healthcare services, health insurance, and school and household activities.

We also use the Medical Expenditure Panel Survey (MEPS) to describe health service and medication

use in children with autism. The MEPS is a nationally representative survey of health, health service use, medical events, health insurance coverage, and pharmacy use in non-institutionalized children and adults in the U.S. It is conducted by the Agency for Healthcare Research and Quality (AHRQ) within the U.S. Department of Health and Human Services (HHS).

Information about the health and healthcare experiences of autistic adults is much less robust than information about children and adolescents. National surveys do exist to examine adult health; however, they do not typically have a way to note if a survey participant is autistic. Data collected through health systems or medical records is more common, but often inaccessible to unaffiliated researchers. One available source (for purchase) is the National Inpatient Sample (NIS). NIS is a nationally representative sample of hospital inpatient stays that collects information on diagnoses recorded during the stay. NIS is a project of the Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality (AHRQ). We use NIS hospital inpatient stays with an ASD diagnosis in the patient record to describe inpatient experiences such as cost, length of stay, and primary reasons for the hospital stay.

Finally, data on the health and health care of adults on the autism spectrum living in northern California from Kaiser Permanente Northern California (KPNC) patient records have been published in scientific journal articles but not packaged for dissemination to a broader nonscientific audience. While the KPNC findings are not national estimates of health and health care experiences of adults with autism, they do provide unique insights using data from a healthcare system that covers roughly four million patients and is largely representative of the greater northern California area.

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Key Findings

Health and Health Care

Overall Health

- When parents were asked about whether their child had certain health conditions, children with ASD had higher rates of every listed condition except asthma.
- Certain conditions varied in prevalence by race and ethnicity in children with ASD. 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 the most common in black, non-Hispanic children.
- Almost two-thirds of parents of children with ASD, ages 3-17, rated their child's health as very good or excellent. Parent-rated health for those with ASD was similar to other children with special health care needs (CSHCN), but worse than children with no SHCN.
- Just over half of parents of children with ASD reported that their child's teeth were in very good or excellent condition. This percentage was lower than other CSHCN (67%) and children with no SHCN (80%).
- KPNC spotlight findings: many psychiatric and medical conditions were more common in transition age youth (TAY) with ASD than in other TAY, including obesity, anxiety, and epilepsy.

Health Services

- Most (87%) children with ASD saw a doctor, nurse, or other healthcare provider in the past year. Health care visits were less common in Hispanic children with ASD than in non-Hispanic children of any race.
- Over half (53%) of older children with ASD (ages 12-17) received mental health treatment versus 38% of younger children with ASD (ages 3-11). Hispanic children with ASD were less likely to receive mental health treatment (34%) than non-Hispanic children (51% of white children, 46% of black children, and 44% of children of other or multiple races).
- The average total expenditures for all healthcare, excluding costs for prescriptions, in the past year was higher in children with ASD (\$13,000) than in CSHCN (\$11,000) and children with no SHCN (\$6,000). Out-of-pocket expenditures were also higher in children with ASD than in the other two groups.
- A little over half (58%) of parents of children with ASD reported their child had worked with their provider to gain health skills they would need when they transitioned to adult healthcare, compared to 75% of CSHCN.
- KPNC spotlight findings: While adults with ASD had higher rates of cholesterol and diabetes screenings, women with ASD had lower rates of cervical cancer screening.

Medication

- Children with ASD had an average yearly total expenditure for medications of \$2,740, with an average total out-of-pocket expenditure of \$158. Average expenditures for children with ASD were higher than for CSHCN or children with no SHCN.
- Over one-third (38%) of children with ASD took medication due to difficulties with their emotions, concentration, or behavior. This was more common in older and white, non-Hispanic children.

- KPNC spotlight findings: 80% of adults (ages 18 and older) with ASD had at least one prescription in a year, similar to adults with ADHD (79%) but more than adults in the general population (62%). The most common medications for adults with autism were psychotherapeutic medication, anti-infectives, and medications for respiratory or allergy needs.

Insurance

- Most children with ASD had insurance at the time of the survey and were continuously insured over the past 12 months (93%).
- Over half (56%) of children with ASD had public insurance (such as Medicaid or CHIP) or a mixture of public and private insurance. Younger children with ASD (ages 3-11) were more likely to have public insurance only (50%), versus 37% of older children with ASD (ages 12-17).
- Almost half (46%) of parents of children with ASD reported that their child's insurance did not always cover the services they needed.
- One-fifth of parents of children with ASD reported avoiding changing jobs because of concerns about maintaining health insurance for their child – five times the rate of parents of children with no SHCN.

Accessing Services

- Of parents whose child with ASD had more than one healthcare appointment in the past 12 months, 28% reported someone helped coordinate or arrange care among different providers. Another 30% reported they could use more help coordinating care - more than parents of CSHCN or children with no SHCN. The need for help coordinating care also varied by race and ethnicity; parents of black non-Hispanic children with ASD most often reported that they could use more help coordinating care.
- Half of parents of children with ASD who had an unmet healthcare need reported a need for mental health care.
- One-third of children with ASD received care within a medical home, compared to 44% of CSHCN and 49% of children with no SHCN. White children with ASD were more likely to receive care within a medical home (39%) than black (22%), Hispanic (30%), or children of another race (32%).
- KPNC spotlight findings: Three-quarters (77%) of adult health care providers rated their knowledge and skills for providing care to patients with ASD as poor or fair, according to a survey of 922 healthcare providers who worked for KPNC

Overall health

Co-occurring conditions are common in children with ASD and impact their functioning.

This chapter explores the physical and mental health of children and adults on the autism spectrum. Comparisons are made across ages, race and ethnicity, and comparison groups with or without conditions other than autism.

Our key findings

- When parents were asked about whether their child had certain health conditions, children with ASD had higher rates of every listed condition except asthma.
- Certain conditions varied in prevalence by race and ethnicity in children with ASD. 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 the most common in black, non-Hispanic children.
- Almost two-thirds of parents of children with ASD, ages 3-17, rated their child's health as very good or excellent. Parent-rated health for those with ASD was similar to other children with special health care needs (CSHCN), but worse than children with no SHCN.
- Just over half of parents of children with ASD reported that their child's teeth were in very good or excellent condition. This percentage was lower than other CSHCN (67%) and children with no SHCN (80%).
- KPNC spotlight findings: many psychiatric and medical conditions were more common in transition age youth (TAY) with ASD than in other TAY, including obesity, anxiety, and epilepsy.

How do we know?

The data about children in this chapter came from the National Survey of Children's Health (NSCH) 2016-2018. The NSCH is a nationally representative study of United States children with and without special health care needs, including children on the autism spectrum.

Because publicly available national data on the health of adults on the autism spectrum is scarce, we also summarize findings from studies published in scientific journals on adults enrolled in Kaiser Permanente Northern California (KPNC). More information on these data sources and how we conducted our analyses can be found in the **Methods**

KEY ABBREVIATIONS

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **CSHCN:** Children who did *not* have parent-reported ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to peers
3. **No SHCN:** Children who did *not* have parent-reported ASD nor any other type of special health care need as defined above

appendix.

Parents reported few concerns about their child's physical and dental health.

Almost two-thirds of parents of children with ASD ages 3-17 rated their child's health as very good or excellent. Parent-rated health for those with ASD was similar to other CSHCN, but worse than children with no SHCN. Nearly all (94%) parents of children with no SHCN rated their child's health as very good or excellent.

Parent-rated health for children with ASD did not vary between younger children (ages 3-11) compared to older children (12-17).

Just over half of parents of children with ASD reported that their child's teeth were in very good or excellent condition. This percentage was lower than other CSHCN and children with no SHCN. Reported dental health did not vary between younger (3-11 years) and older children (12-17 years) with ASD.

Gastrointestinal issues were the most common health problem.

Parents were asked about frequent or chronic difficulties their child experienced over the past 12 months.

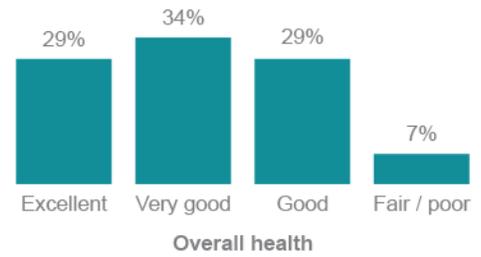
Parents of children with ASD reported similar levels of difficulty for many problems compared to other CSHCN, except that other CSHCN (28%) more often had difficulty breathing or other respiratory problems. Fewer than 5% of parents of children with no SHCN reported any health difficulties, with the exception of decayed teeth or cavities (12%).

Parents of children with ASD reported similar levels of health difficulty across age groups with the exception of chronic physical pain including headaches or back or body pain. Twenty three percent of older children with ASD (12-17 years) were reported to have chronic pain, compared to 11% of younger children (3-11 years) with ASD.

Health problems and their effects on functioning

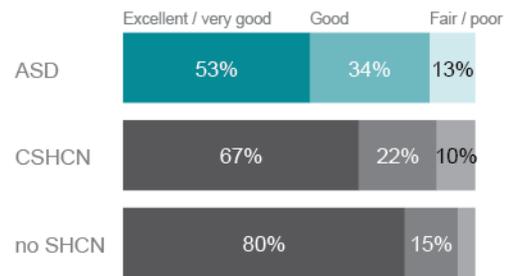
Children with ASD often had difficulty functioning due to their health and mental health conditions.

Most parents of children with ASD rated their overall health as very good or excellent.



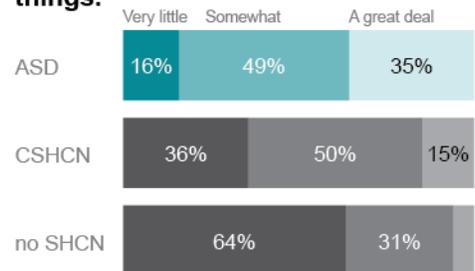
Source: National Survey of Children's Health 2016-18

Parents of children with ASD less often reported the condition of their child's teeth as excellent or very good



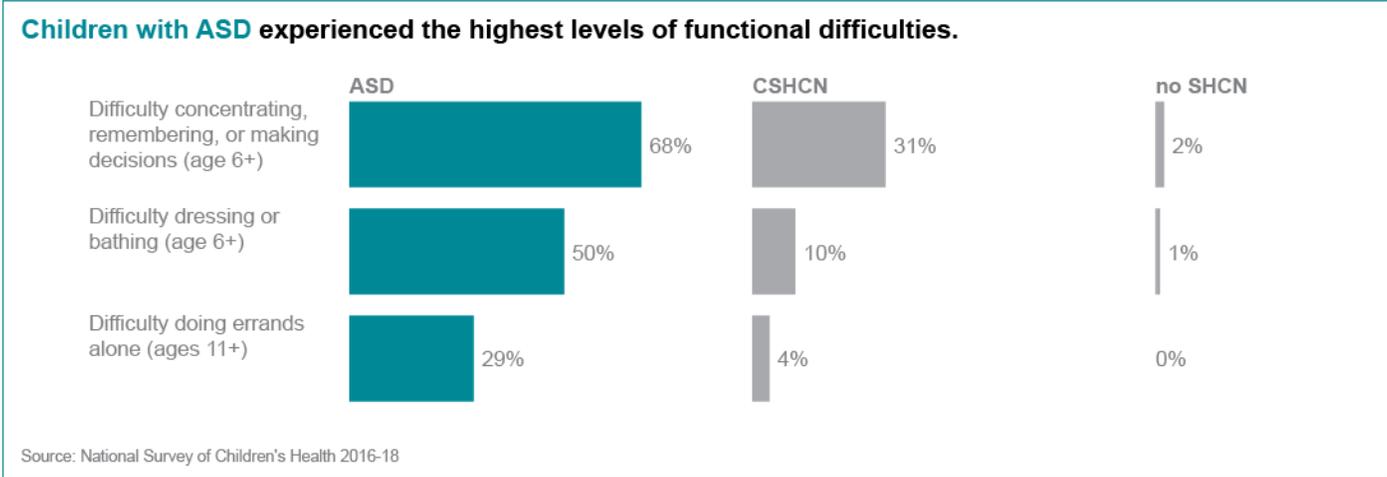
Source: National Survey of Children's Health 2016-18

Parents of children with ASD more often reported their child's condition greatly impacted their ability to do things.

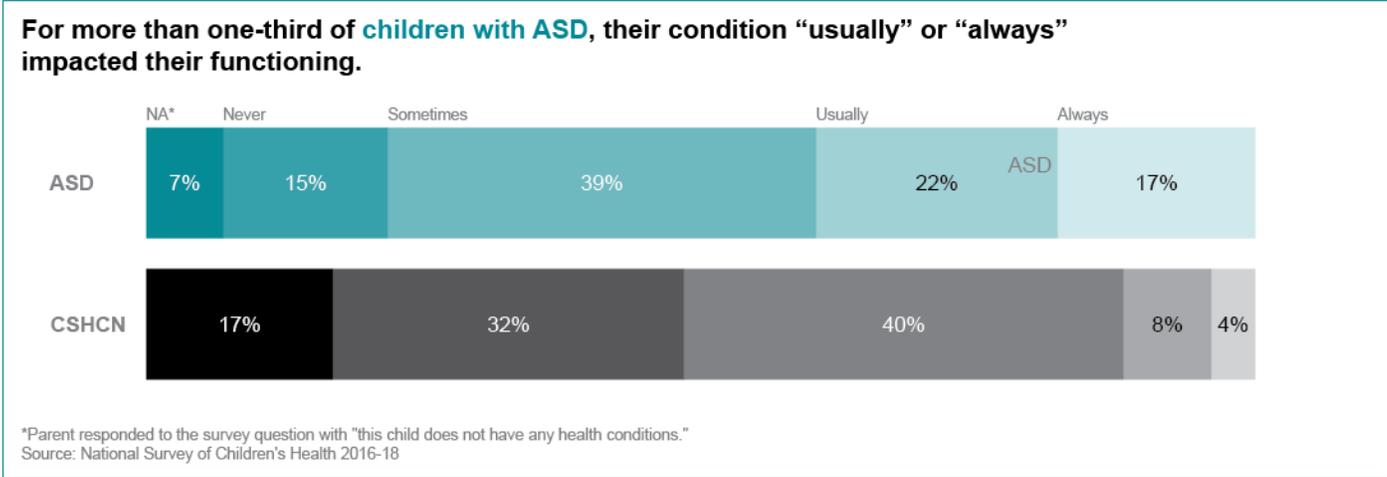


Source: National Survey of Children's Health 2016-18

Two-thirds of parents of children with ASD reported their child had difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition – more than twice the rate of CSHCN. For children ages 11 and up, 29% of parents of children with ASD reported that their child had difficulty completing errands alone because of a physical, mental, or emotional condition – seven times the rate of CSHCN (4%).



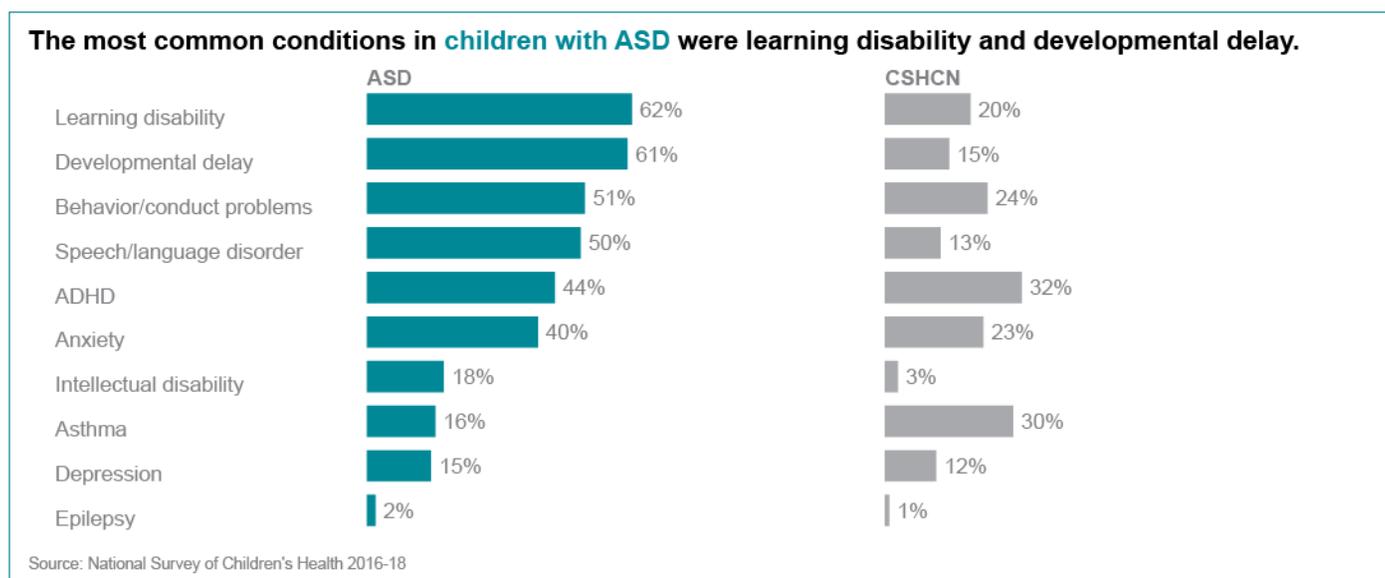
One-third of parents of children with ASD reported that their child's health conditions or problems usually or always affected their ability to do things other children their age can do. These difficulties were present for both younger and older children with ASD.



Of children with ASD who had a condition that “sometimes,” “usually,” or “always” affected their ability to do things other children their age could do, one-third of parents reported that the condition impacted the child a great deal. This rate was higher in children with ASD than for other CSHCN.

Learning disability was the most common co-occurring condition in children with ASD

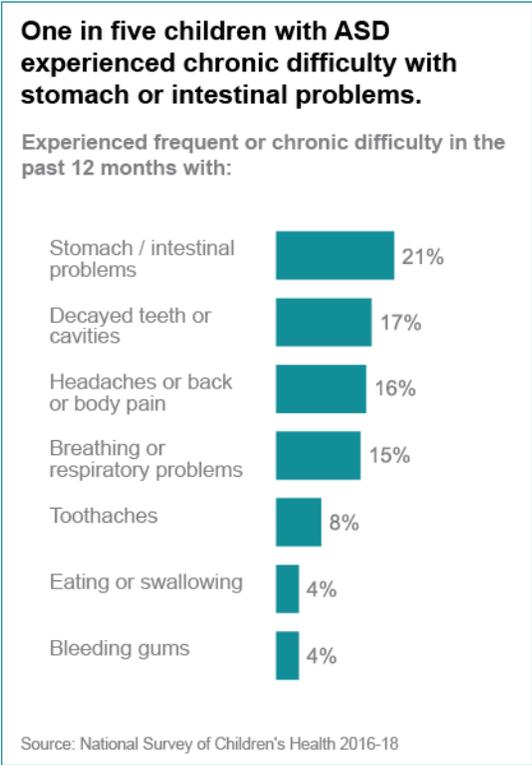
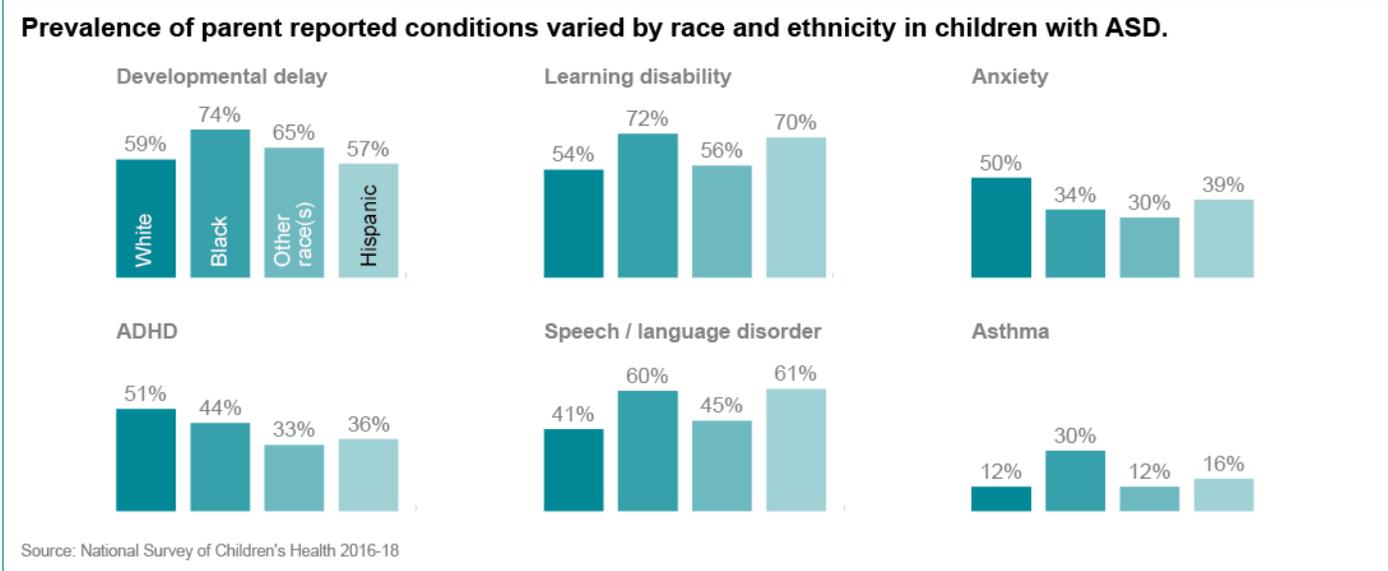
When parents were asked about whether their child had certain health conditions, children with ASD had higher rates of every single condition except for asthma. The most common conditions reported for children with ASD ages 3-17 were learning disability, developmental delay, and behavior or conduct problems. These were much more common in children with ASD than in other CSHCN.



Some conditions varied in prevalence by age. Older children with ASD (ages 12-17) were more likely to have anxiety (49% versus 33%) or depression (23% versus 8%) than younger children (ages 3-11). Younger children more often had behavioral or conduct problems (57% versus 45%), developmental delay (68% versus 53%), or speech or other language disorder (58% versus 39%) than older children with ASD.

Certain conditions varied in prevalence by race and ethnicity in children with ASD. 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.



Spotlight: Health of transition-age youth and adults

Two published studies used Kaiser Permanente Northern California (KPNC) member data to examine the health of transition age youth and adults with ASD.

Transition age youth with ASD (ages 14-25)

The first study examined 4,123 transition age youth (TAY) with ASD ages 14-25 who were members of KPNC for at least nine months of each year from 2013-2015 (Davignon *et al.*, 2018). Comparisons were made to a random sample of TAY with ADHD, a sample of TAY with diabetes mellitus, and a sample of TAY with none of the three conditions (other TAY).

Most psychiatric conditions were more common in TAY with ASD than in other TAY groups (e.g., anxiety, depression, bipolar), and most medical conditions were more common in TAY with ASD than TAY with ADHD or TAY with none of the conditions (e.g., obesity, gastrointestinal, epilepsy). Musculoskeletal conditions were more common in other TAY than in TAY with ASD.

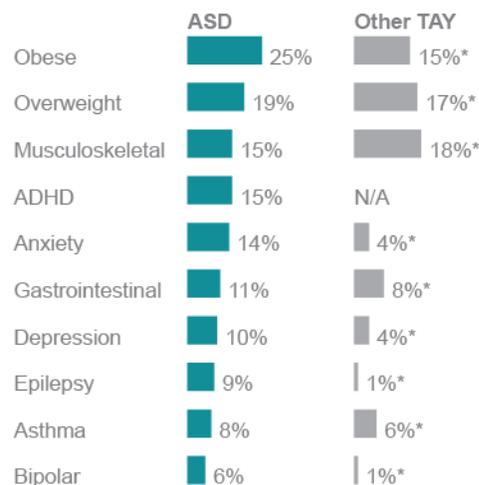
Adults with ASD (ages 18 and older)

A second study focused on 1,507 adults with ASD ages 18 and older who were members of KPNC for at least nine months in each year from 2008-2012 (Croen *et al.*, 2015). Comparisons were made to a randomly sampled selection of adult KPNC members who did not have ASD.

About one-third of adults with ASD in the Kaiser sample experienced gastrointestinal disorders, obesity, or anxiety disorder. About one-quarter had hypertension or depression. Adults with ASD were two to three times as likely to have depression or anxiety, compared to adults without ASD. Adults with ASD were also far more likely to have epilepsy, ADHD, bipolar disorder, or a type of schizophrenia.

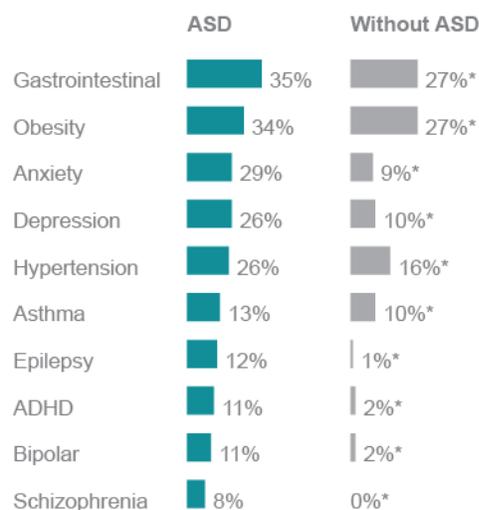
Some conditions were more common in female than male adults with ASD, including anxiety (36% versus 27%), depression (34% versus 23%), and epilepsy (19% versus 9%).

Prevalence of conditions in TAY with ASD and other TAY.



*Significantly different from the ASD group as tested using logistic regression controlling for age, race, sex, and months of KPNC membership
The Other TAY group comprises transition age youth (TAY) who had neither ASD, ADHD, nor diabetes; therefore the prevalence of ADHD in other TAY was 0%.
Source: Davignon, *et al.*, 2018

Prevalence of conditions in adults with ASD and a random sample other adults without ASD.



*Significantly different from the ASD group as tested using logistic regression controlling for age, race/ethnicity, and sex
Source: Croen *et al.*, 2015

Spotlight references

- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823. <https://doi-org.ezproxy2.library.drexel.edu/10.1177%2F1362361315577517>
- Davignon, M.N., Qian, Y., Massolo, M., Croen, L.A. (2018) Psychiatric and medication conditions in transition-aged individuals with ASD. *Pediatrics*, 141 (S4), S335-S345, <https://doi.org/10.1542/peds.2016-4300K>

Health Services

Children with ASD were likely to receive routine health care but experienced inadequate services when transitioning to adult care.

This chapter examines health care utilization in children and adults on the autism spectrum. Comparisons are made across ages, race and ethnicity, and comparison groups with or without conditions other than autism.

Our key findings

- Most (87%) children with ASD saw a doctor, nurse, or other healthcare provider in the past year. Health care visits were less common in Hispanic children with ASD than in non-Hispanic children of any race.
- Over half (53%) of older children with ASD (ages 12-17) received mental health treatment versus 38% of younger children with ASD (ages 3-11). Hispanic children with ASD were less likely to receive mental health treatment (34%) than non-Hispanic children (51% of white children, 46% of black children, and 44% of children of other or multiple races).
- The average total expenditures for all healthcare, excluding costs for prescriptions, in the past year was higher in children with ASD (\$13,000) than in CSHCN (\$11,000) and children with no SHCN (\$6,000). Out-of-pocket expenditures were also higher in children with ASD than in the other two groups.
- A little over half (58%) of parents of children with ASD reported their child had worked with their provider to gain health skills they would need when they transitioned to adult healthcare, compared to 75% of CSHCN.
- KPNC spotlight findings: While adults with ASD had higher rates of cholesterol and diabetes screenings, women with ASD had lower rates of cervical cancer screening.

How do we know?

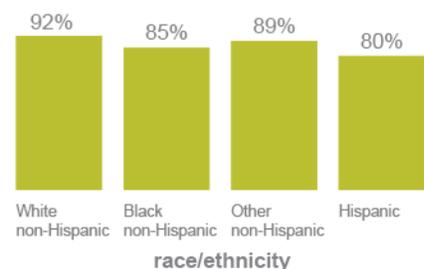
The data about children in this chapter came from the National Survey of Children's Health (NSCH) 2016-2018 and the Medical Expenditure Panel Survey (MEPS) 2013-2017. The NSCH is a nationally representative study of United States children with and without special health care needs, including children on the autism spectrum. MEPS is a nationally representative survey designed to elicit detailed information about health care in adults and children.

KEY ABBREVIATIONS

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **CSHCN:** Children who did *not* have parent-reported ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to peers
3. **No SHCN:** Children who did *not* have parent-reported ASD nor any other type of special health care need as defined above

Hispanic children with ASD were the least likely to report seeing a physician in the past year.



Source: National Survey of Children's Health 2016-18

Further data about hospital inpatient stays in patients of all ages came from the National Inpatient Sample (NIS) 2017. NIS is a nationally representative sample of all-payer inpatient hospital stays with information about diagnoses, procedures, and patient and hospital characteristics.

Because publicly available national data on the health of adults on the autism spectrum is scarce, we sought information from published studies which used Kaiser Permanente Northern California (KPNC) patient records for research. More information on all data and how we conducted our analyses can be found in the **Methods** appendix.

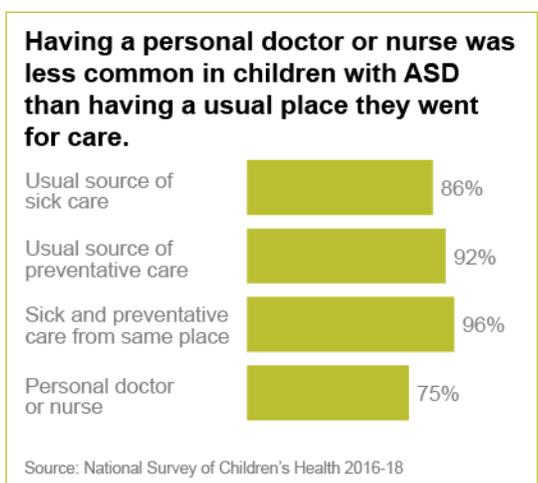
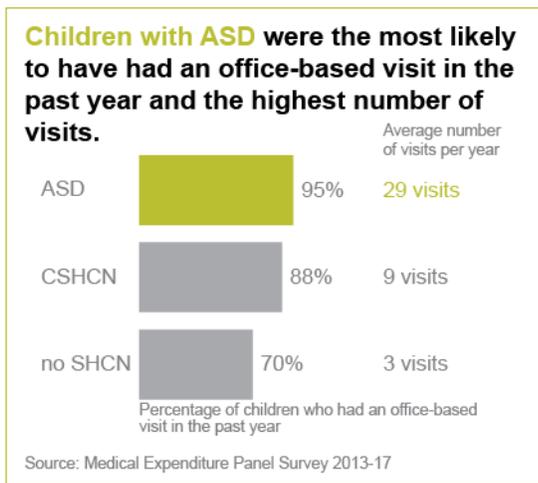
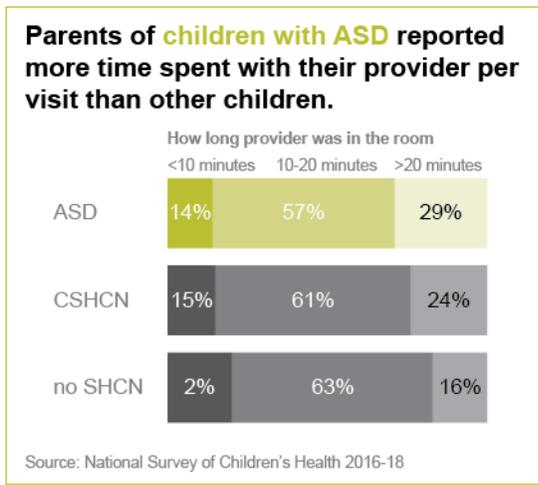
Most children with ASD saw a healthcare provider in the past year.

According to the NSCH, 87% of children with ASD saw a doctor, nurse, or other healthcare provider in the past year. Reasons for care included illness, well-child check-ups, physical exams, or hospitalizations. Health care visits were less common in Hispanic children with ASD than in non-Hispanic children of any race.

Most children with ASD (82%) had a preventive checkup in the past year. This rate was similar to CSHCN (86%) and children with no SHCN (74%) and did not vary by age in children with ASD. Hispanic children with ASD were the least likely to have a preventive visit; only 73% of parents reported a preventive visit in the past year, compared to 87% of white, 82% of black, and 86% of children with ASD of other or multiple races.

Of children with ASD who had a preventive visit, the majority (57%) spent 10-20 minutes with their provider. More children with ASD spent longer than 20 minutes with their provider than children with no SHCN.

According to MEPS, 95% of children with ASD had an office-based visit with a medical provider in the past year, similar to CSHCN (88%), but more than children with no SHCN (70%). The medical provider may have been a physician or other health care professional including a counselor, chiropractor, physician’s assistant, nurse, or psychologist. The average number of visits of children with ASD was 29 per year (median of 9), compared to 9 for CSHCN (median of 4) and 3 (median of 2) for children with no SHCN. The large difference between the mean and the median in children with ASD suggest that a few



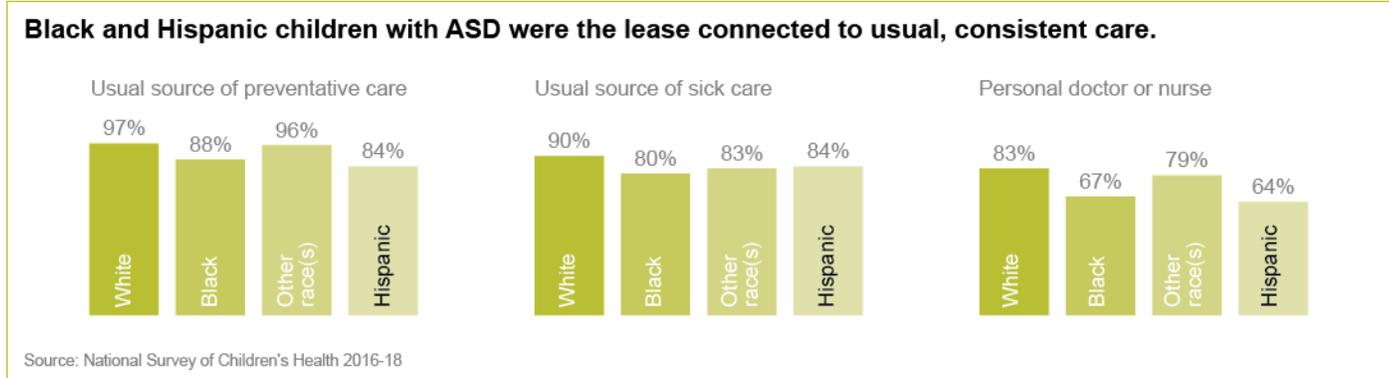
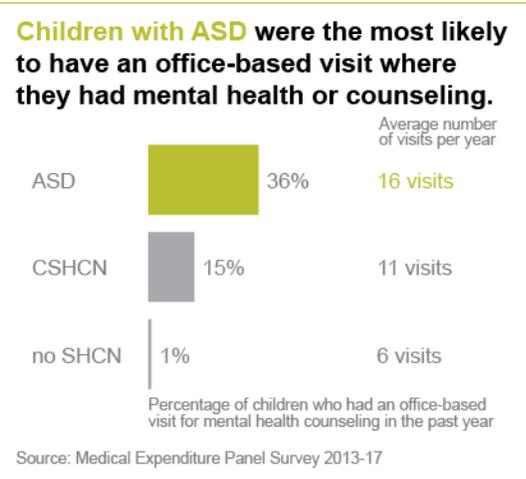
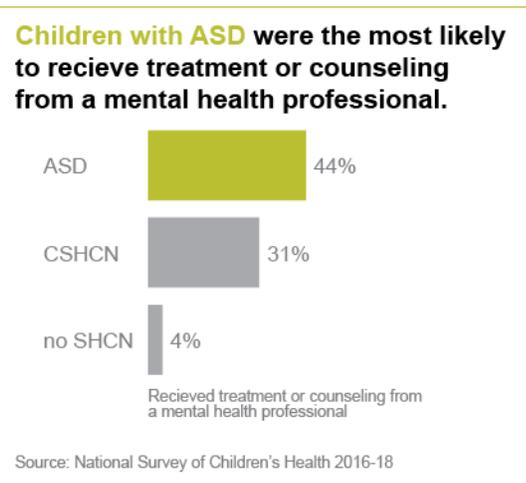
children had a large number of visits. The average total cost, including insurance payments and out-of-pocket payments, for children with ASD was \$160 per visit, and the average out-of-pocket expenditure was \$15 per visit. Cost was similar for CSHCN and children with no SHCN.

Most children with ASD had a place for routine care and a personal doctor.

Most children with ASD had a place they usually went when they needed routine preventive care, such as a physical exam or a well-child check-up. Similarly, most had a place they usually went for care when they were sick, or when a parent needed advice about the child’s health. Most children with ASD received their preventive and sick care from the same source.

Three-quarters of children with ASD had one or more personal providers; this was a person that knew the child well and was familiar with the child’s health history, and could be a general doctor, pediatrician, specialist doctor, nurse practitioner, or physician’s assistant.

White, non-Hispanic children were the most likely to have a usual source of preventive care and to have a personal doctor or nurse.



One third to one half of children with ASD received mental health care in the past year.

Almost half of children with ASD received treatment or counseling from a mental health professional (including psychiatrists, psychologists, psychiatric nurses, and clinical social workers) - more than CSHCN and children with no

SHCN. Older children with ASD (53% of children ages 12-17) were more likely to receive mental health treatment than younger children with ASD (38% of

children ages 3-11), and Hispanic children with ASD were less likely to receive mental health treatment (34%) than non-Hispanic children (51% of white children, 46% of black children, and 44% of children of other or multiple races).

In the MEPS data, 36% of children with ASD had an office-based appointment at which they received care for psychotherapy or mental health counseling - more than CSHCN (15%) and children with no SHCN (1%). Children with ASD had an average of 16 visits per year (and a median of 7), more than CSHCN (10 visits, median of 6) and children with no SHCN (6 visits, median of 3). Furthermore, total cost for these services was higher in children with ASD than in CSHCN and children with no SHCN.

Fifty-eight percent of children with ASD received behavioral treatment for ASD, such as intervention the child or their parent received to help with behavior. Younger children (ages 3-11) were more likely to receive ASD-specific behavioral treatment than older children (ages 12-17). There were no differences by race and ethnicity.

Fewer children with ASD saw specialists besides mental health professionals.

About one-third of children with ASD saw a specialist provider other than a mental health professional, similar to CSHCN but more than children with no SHCN. This did not vary by age or race and ethnicity.

Fewer children with ASD received alternative health care or treatment (14%). Alternative health care can include acupuncture, chiropractic care, and herbal supplements, and may be done with a healthcare provider or on one's own. Specialized diets may be considered an alternative treatment, but it is unclear if parents considered this in their answer as it was not explicitly mentioned in the survey. This was similar to CSHCN and children with no SHCN, and the proportion did not vary by age, race or ethnicity in children with ASD.

Most children with ASD received preventive dental and vision services.

More than three-quarters of children with ASD had a dental

Children with ASD had the highest average total expenditure per visit for outpatient mental treatment or counseling.

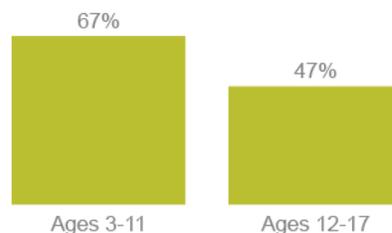


*this estimate has a RSE>30%
Source: Medical Expenditure Panel Survey 2013-17

What is an out-of-pocket expenditure?

Out-of-pocket, or OOP, expenditures are costs that the family pays for a healthcare visit or prescription. In the MEPS data, this includes the total dollar amount paid directly by the family for the service before any reimbursements that may be made by an insurer. Some other methods of measuring OOP expenditures exclude costs reimbursed by insurance companies.

Younger children with ASD were more likely to receive behavioral treatment.



Source: National Survey of Children's Health 2016-18

or oral health care appointment in the past year and vision testing in the past two years, similar to CSHCN and children with no SHCN. Preventive visits varied by race and ethnicity. Approximately 71% of Hispanic children with ASD had a dental appointment – a lower rate than non-Hispanic children (88% of white children, 87% of black children, and 85% of children of other or multiple races).

Outpatient and inpatient health care visits were less common than office-based visits.

Outpatient visits were more common and inpatient stays were less common for children with ASD. Sixteen percent of children with ASD had an outpatient visit and 3% had an inpatient stay. Outpatient visits capture appointments at a hospital outpatient department or special clinic. Children with ASD and CSHCN were more likely to have outpatient visits than children with no SHCN. The average number of outpatient visits for children with ASD was 2.5 (median of 1). For inpatient care, the average number of visits was 1.0 (median of 1).

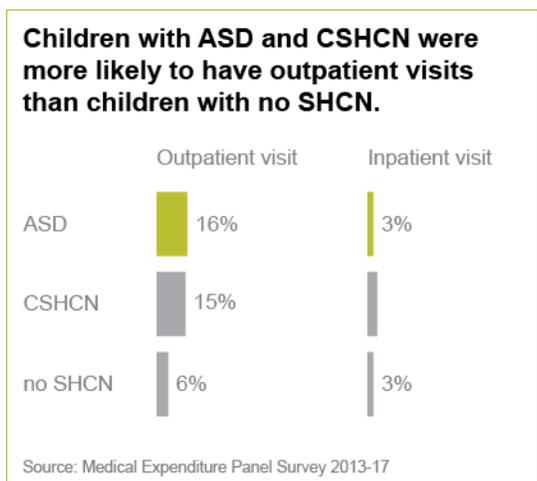
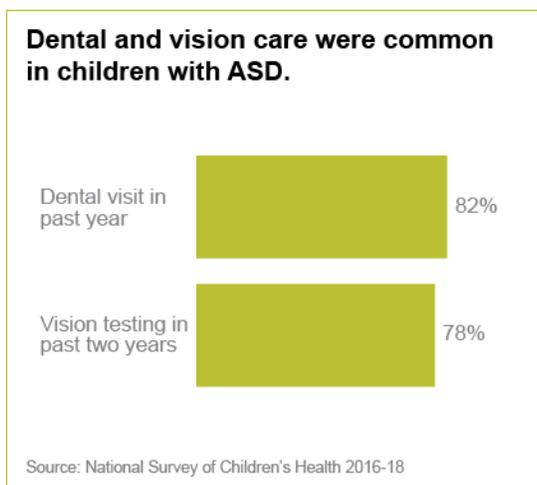
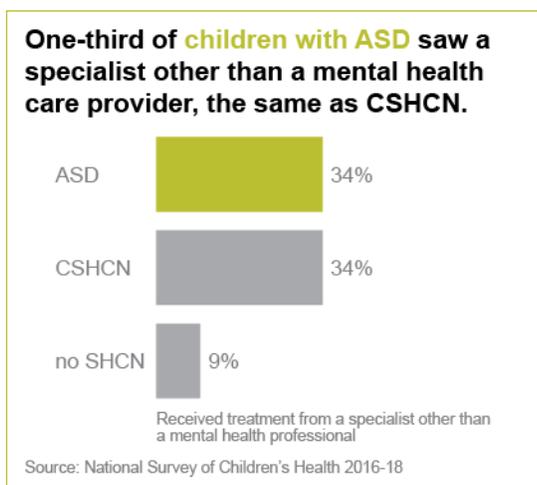
Children with ASD were no more likely to have emergency department visits.

According to the NSCH, about one-quarter (24%) of children with ASD visited a hospital emergency department in the past year. This did not vary by age or race and ethnicity. The rate was similar to the percentage of CSHCN and children with no SHCN who visited an emergency department in the past year.

According to MEPS data, 17% of children with ASD had an emergency department visit. The rate was similar to the percentage of CSHCN and children with no SHCN who had an emergency department in the past year. The average number of visits per year was 1.4 (median of 1), with a mean total cost of \$539 per visit. The mean total cost per visit was \$725 in CSHCN and \$692 in children with no SHCN.

Total healthcare expenditures were highest in children with ASD.

According to MEPS data, the average total expenditures per person, excluding costs for prescriptions, was higher in children with ASD than in CSHCN and children with no SHCN. Out-of-pocket expenditures were also higher in children with ASD than in the other two groups.

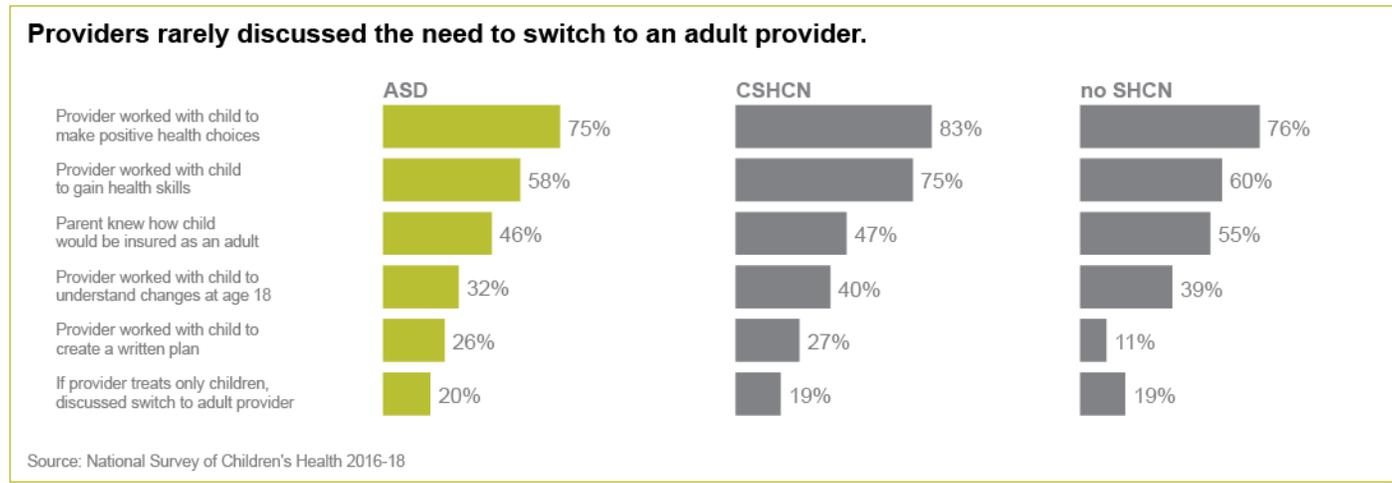
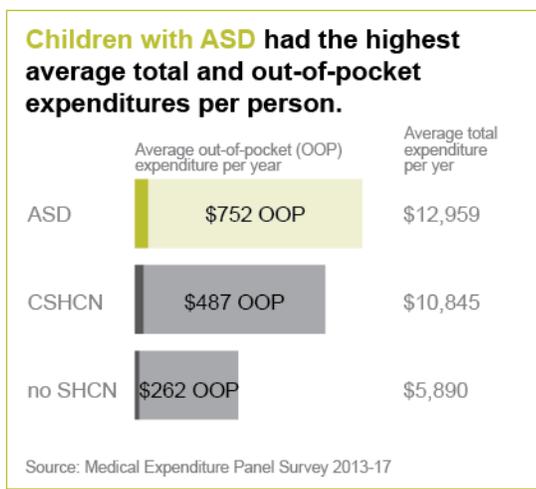
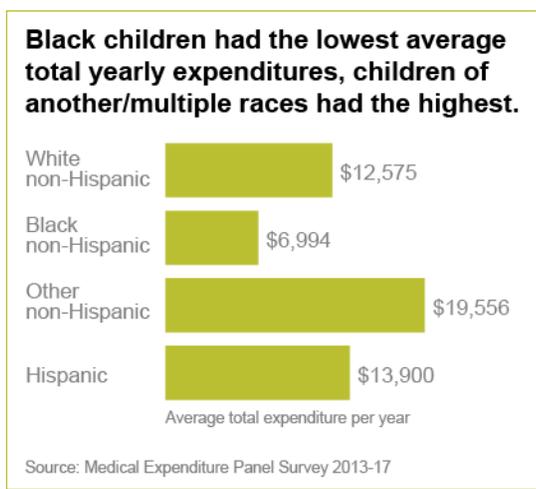


Total expenditures per person were the highest in non-Hispanic children who were of a race other than black or white or of multiple races (\$19,556). Total expenditures were the lowest in black, non-Hispanic children (\$6,994).

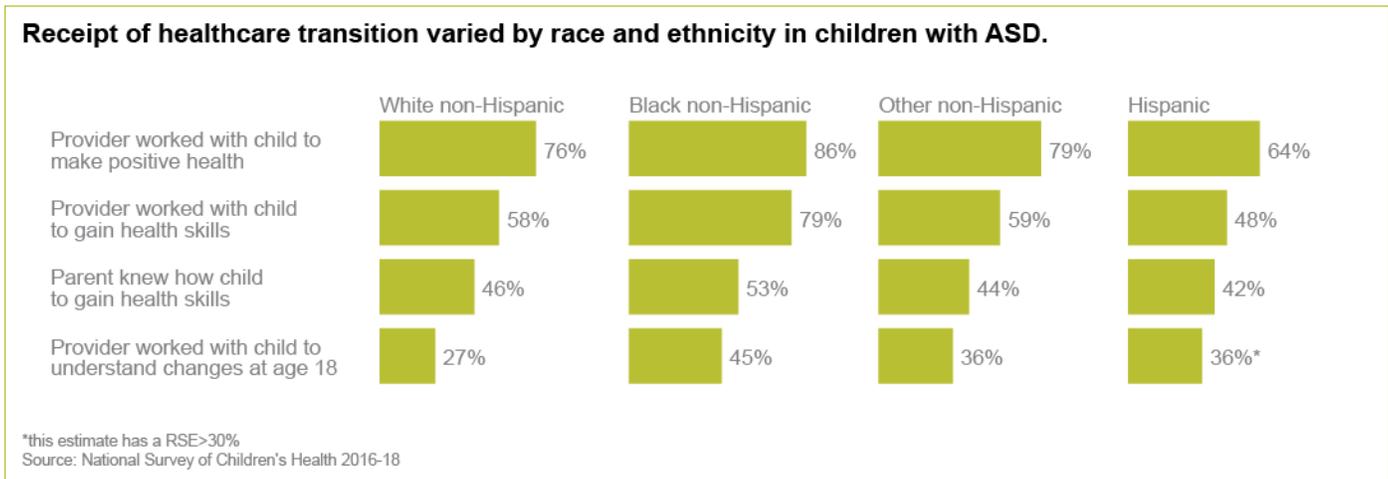
Healthcare transition services were not common in older children with ASD.

Healthcare transition (HCT) is the individualized process of addressing the comprehensive healthcare needs of children as they age into adulthood (AAP, 2011). HCT services are designed to maximize lifelong functioning and potential by providing patient-centered care during the transition (Cooley, *et al.*, 2009). HCT is increasingly recognized as a necessary process for all children, but especially for those with complex needs like children on the autism spectrum. Important components of HCT include switching to appropriate adult providers, taking more ownership over one’s own health care, and maintaining insurance coverage as coverage requirements change.

In the NSCH, questions about HCT were asked about children ages 12-17. One-fifth of families of children with ASD who saw a provider who treats only children had spoken to their provider about switching to a doctor who treats adults. Three-quarters of families of children with ASD had worked with their provider to make positive choices about their health, but fewer had spoken to their doctor about the healthcare changes that happen at age 18 or had a written plan to address healthcare goals and needs.



Receipt of healthcare transition tools and processes varied by race and ethnicity in children with ASD. Generally, black, non-Hispanic children had the highest reported receipt of healthcare transition components and Hispanic children generally had the lowest. However, white, non-Hispanic children were the least likely to have worked with their healthcare provider to understand the changes in health care that happen at age 18.



References

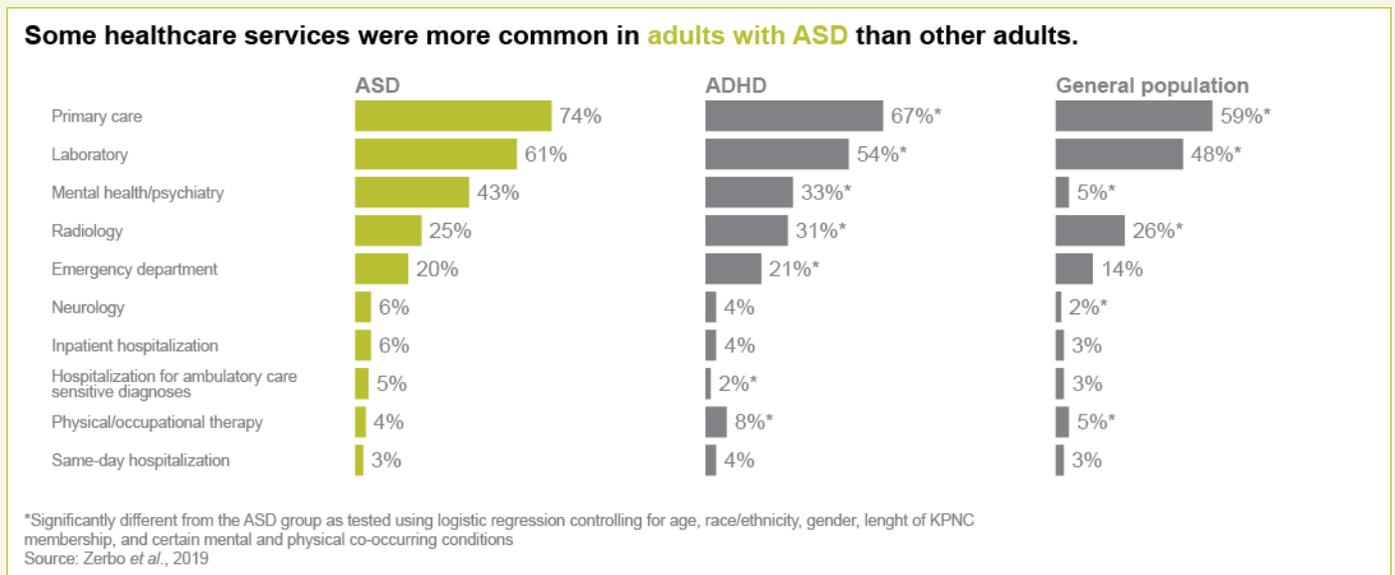
American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182-200. <https://doi.org/10.1542/peds.2011-0969>

Cooley, W. C., McAllister, J. W., Sherrieb, K., & Kuhlthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*, 124(1), 358-364. <https://doi.org/10.1542/peds.2008-260>

Spotlight: Health service use among adults with ASD.

A published study used Kaiser Permanente health data to examine the health service use of 1,507 adults with ASD ages 18 and older (Zerbo *et al.*, 2019). This study presented the percentage of adults with ASD who received several kinds of care and the average number of visits for each type of care in a year. Types of care included primary care, mental health care, neurology, speech therapy, radiology, and hospitalization. This study compared adults with ASD to adults with attention deficit/hyperactivity disorder (ADHD) and adults in the general population. The study sample came from Kaiser Permanente Northern California, which serves approximately four million people in the Sacramento and San Francisco areas.

Some healthcare services were more common in adults with ASD than in other adults, such as primary care visits, mental health care, and laboratory services. Other services, including radiology, were less common in adults with ASD than other adults.

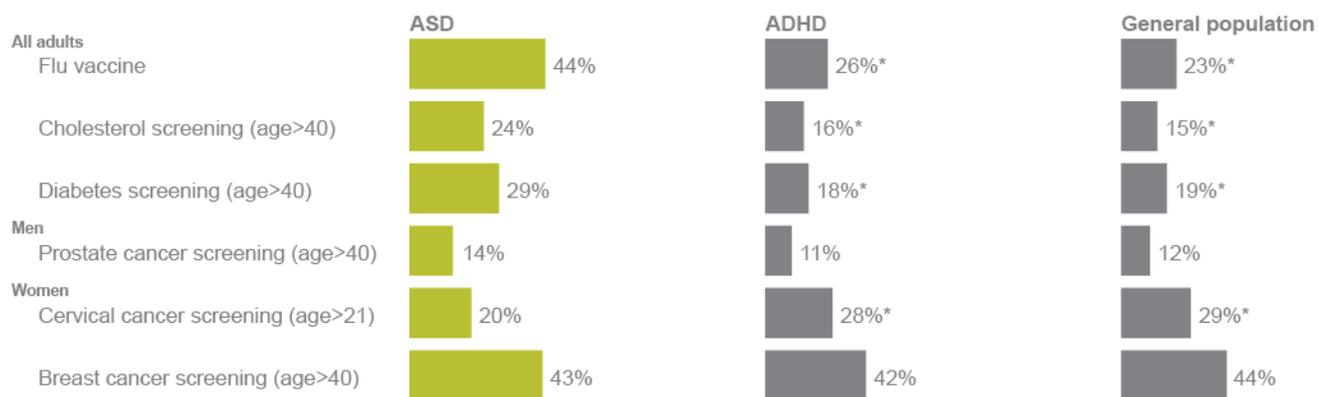


Mean overall healthcare costs were higher for adults with ASD than adults with ADHD or the general population comparison group. Adults with ASD had a mean overall cost of \$7118.70, while adults with ADHD had an average of \$5876.70, and the general population comparison had an average cost of \$3197.30. The comparison group

was significantly different from adults with ASD even after controlling for gender, age, race and ethnicity, length of KPNC membership, and certain mental and physical co-occurring conditions. Overall costs included hospitalizations, emergency room visits, outpatient visits, home health care, skilled nursing, and medications.

Zerbo and colleagues also reported on preventive services received by adults with ASD. The most common preventive service was receipt of a seasonal flu vaccination. More adults with ASD received a flu shot than adults with ADHD or adults in the general population. While adults with ASD had higher rates of cholesterol and diabetes screenings, women with ASD had lower rates of cervical cancer screening. Preventive services may be more common in Kaiser Permanente patients than in the general U.S. population because of the emphasis placed on preventive care through the managed care model.

Some preventive health services were more common in adults with ASD than other adults, cervical cancer screening in women with ASD was less common.



*Significantly different from the ASD group as tested using logistic regression controlling for age, race/ethnicity, gender, length of KPNC membership, and certain mental and physical co-occurring conditions
 Source: Zerbo et al., 2019

Spotlight references

Zerbo, O., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., & Croen, L. A. (2019). Health care service utilization and cost among adults with autism spectrum disorders in a US integrated health care system. *Autism in Adulthood*, 1(1), 27-36. <https://doi.org/10.1089/aut.2018.0004>

Spotlight: Inpatient hospital stays from the National Inpatient Sample

The National Inpatient Sample (NIS) is a database of U.S. hospital inpatient stays, weighted to estimate national inpatient utilization and experiences. It includes records of any care whether paid through insurance or private pay. The NIS is a project of the Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality (AHRQ) (NIS, 2017).

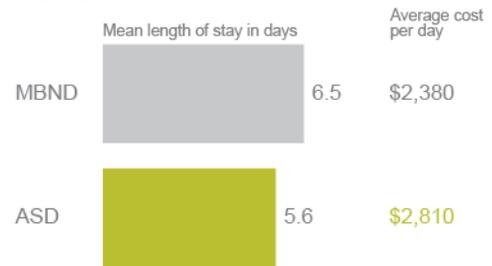
About 80,000 inpatient stays in 2017 involved a patient with ASD. In comparison, there were 12.6 million inpatient stays for patients with another mental, behavioral, or neurodevelopmental (MBND) diagnosis. The rate of ASD was 2.2 per 1000 inpatient stays and MBND was 352 per 1000 stays. The rate of ASD inpatient stays in children (ages 17 and younger) was 7.2 per 1000 stays, compared to a 1.3 per 1000 in adults (ages 18 and older). The rate of MBND inpatient stays in children was 65.2 per 1000 stays, compared to 402.4 per 1000 stays in adults.

Child inpatient stays

Average age was similar in child inpatient stays with ASD (11 years) and MBND (12 years). Mean length of stay was shorter by about a day for patients with ASD, but cost per day was \$400 more. Half of patients with ASD used the emergency department some time during their stay, as did nearly as many patients with MBND (48%). Admission was typically non-elective; only 23% of admissions for patients with ASD were elective.

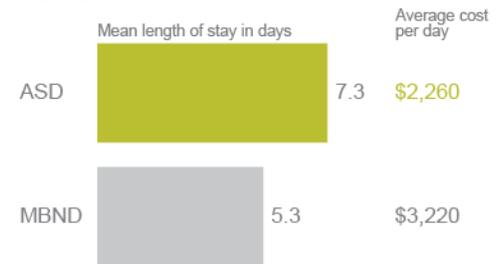
The 10 most common principal diagnoses for stay had some overlap for children with ASD and MBND. Mood disorders; epilepsy; stomach or intestinal diseases; disruptive, impulse-control and conduct disorders (including ADHD); and physical injury were among the most common in both groups. Many of the most common principal diagnoses were for hospitalizations considered avoidable or preventable. These conditions, known as ambulatory care sensitive conditions (ACSCs), could be successfully treated and managed with comprehensive outpatient care. The Agency for Healthcare Research and Quality (AHRQ) includes epilepsy, stomach or intestinal diseases, asthma, and diabetes as pediatric ACSCs (AHRQ, 2020). Mental health conditions, including mood disorders and ADHD, are also considered ACSCs because hospitalization could be avoided by quality

Child patients with ASD stayed in the hospital one day less, but had daily costs \$1600 greater than patients with MBND.



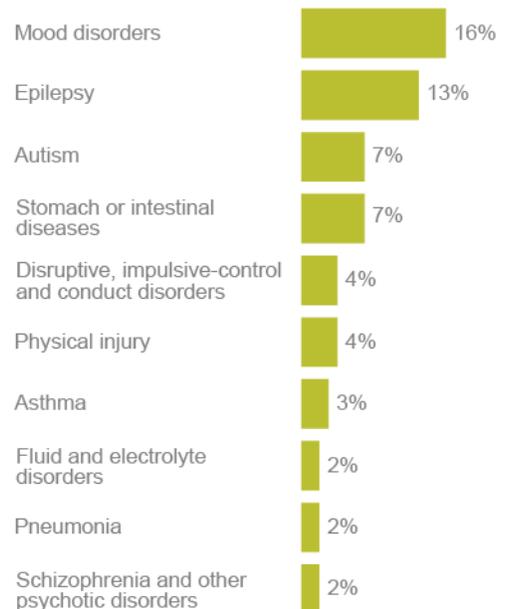
Source: National Inpatient Sample 2017

Adult autistic patients stayed in the hospital two days more, but had daily costs \$400 less than patients with MBND.



Source: National Inpatient Sample 2017

The most common principal diagnoses in stays of child patients with ASD.



Source: National Inpatient Sample 2017

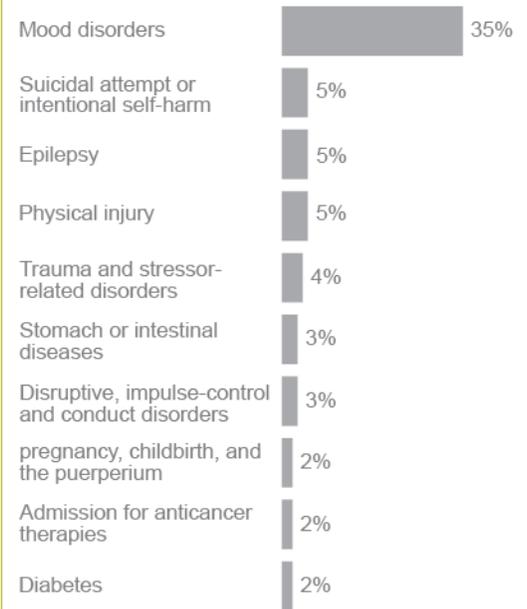
outpatient care (Carbone, *et al.*, 2015; Lavoie *et al.*, 2018).

Adult inpatient stays

Average age was older for adult patients with MBND (mean 56 years) than autistic patients (mean 34 years). Mean length of stay was longer by about two days for autistic patients, but charge per day was \$1000 less. Three-quarters of autistic patients used the emergency department at some time during their stay (67%), similar to patients with MBND (66%).

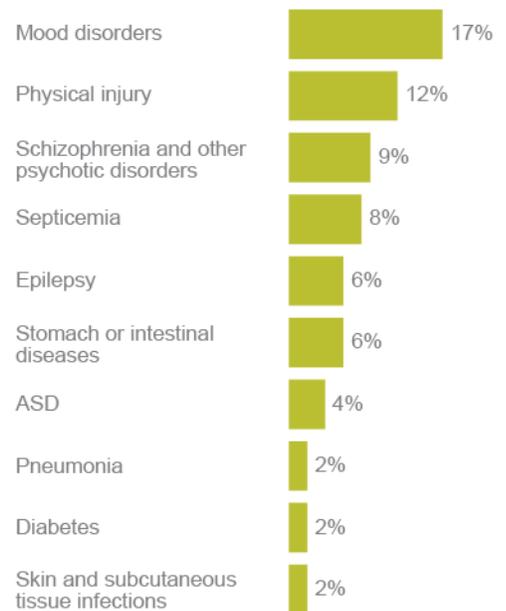
Five of the 10 most common principal diagnoses for stay were the same for adult stays with ASD and MBND. Physical injury, mood disorders, and septicemia were in the top four for both groups. Many ACSCs were present in autistic adults, including epilepsy, stomach or intestinal diseases, diabetes, and pneumonia (AHRQ, 2020). Mental health conditions, including mood disorders and schizophrenia, are also considered ACSCs.

The most common principal diagnoses in stays of child patients with MBND.



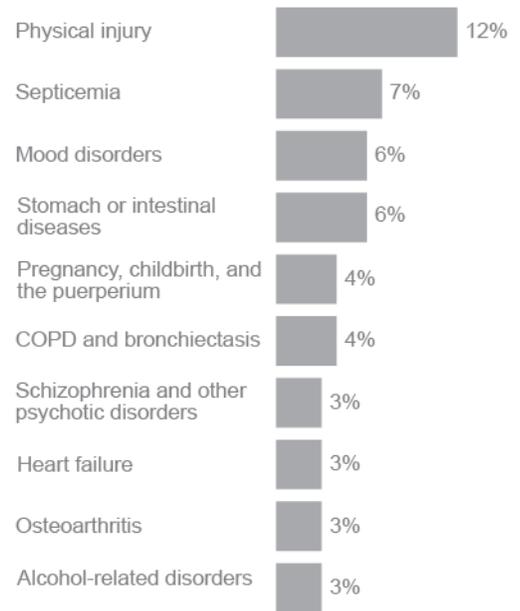
Source: National Inpatient Sample 2017

The most common principal diagnoses in stays of adult autistic patients.



Source: National Inpatient Sample 2017

The most common principal diagnoses in stays of adult patients with MBND.



Source: National Inpatient Sample 2017

Spotlight references

Agency for Healthcare Research and Quality (AHRQ). (2020). Quality Indicator User Guide: Pediatric Quality Indicators (PDI) Composite Measures. Retrieved August 13, 2020 from https://www.qualityindicators.ahrq.gov/Downloads/Modules/PDI/V2020/PDI_Composite_Development.pdf

Agency for Healthcare Research and Quality (AHRQ). (2020). Quality Indicator User Guide: Prevention Quality Indicators (PQI) Composite Measure Workgroup Final Report. Retrieved August 13, 2020 from https://www.qualityindicators.ahrq.gov/modules/pqi_resources.aspx

Carbone, P. S., Young, P. C., Stoddard, G. J., Wilkes, J., & Trasande, L. (2015). A comparison of ambulatory care sensitive hospitalizations among children with and without autism spectrum disorder. *Academic Pediatrics*, 15(6), 626–635. <https://doi.org/10.1016/j.acap.2015.07.006>

Lavoie, J. G., Ward, A., Wong, S. T., Ibrahim, N., Morton, D., O'Neil, J. D., & Green, M. (2018). Hospitalization for mental health related ambulatory care sensitive conditions: what are the trends for First Nations in British Columbia? *International journal for equity in health*, 17(1), 156. <https://doi.org/10.1186/s12939-018-0860-7>

National Inpatient Sample (NIS). Healthcare Cost and Utilization Project (HCUP). (2017). Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/nisoverview.jsp

Medication

Prescription medications were common and expenditures were higher for children with ASD than for peers.

This chapter examines medication use in children and adults on the autism spectrum. Comparisons are made across ages, race and ethnicity, and comparison groups with or without conditions other than autism.

Our key findings

- Children with ASD had an average yearly total expenditure for medications of \$2,740, with an average total out-of-pocket expenditure of \$158. Average expenditures for children with ASD were higher than for CSHCN or children with no SHCN.
- Over one-third (38%) of children with ASD took medication due to difficulties with their emotions, concentration, or behavior. This was more common in older and white, non-Hispanic children.
- KPNC spotlight findings: 80% of adults (ages 18 and older) with ASD had at least one prescription in a year, similar to adults with ADHD (79%) but more than adults in the general population (62%). The most common medications for adults with autism were psychotherapeutic medication, anti-infectives, and medications for respiratory or allergy needs.

How do we know?

The data about children in this chapter came from the National Survey of Children's Health 2016-2018 (NSCH) and the Medical Expenditure Panel Survey (MEPS) 2013-2017. The NSCH is a nationally representative study of children with and without special health care needs, including children on the autism spectrum. MEPS is a nationally representative survey designed to elicit detailed information about health care in adults and children.

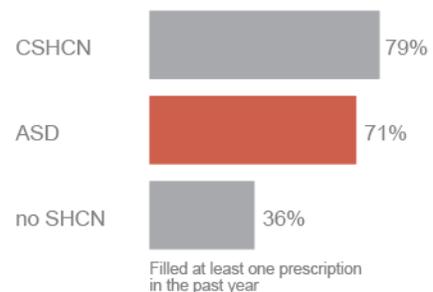
Because publicly available national data on the health of adults on the autism spectrum is scarce, we sought information from published studies which used Kaiser Permanente Northern California (KPNC) patient records for research. More information on all data and how we conducted our analyses can be found in the **Methods** appendix.

KEY ABBREVIATIONS

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **CSHCN:** Children who did *not* have parent-reported ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to peers
3. **No SHCN:** Children who did *not* have parent-reported ASD nor any other type of special health care need as defined above

Nearly three-quarters of children with ASD had a prescription filled in the past year.



Source: Medical Expenditure Panel Survey 2013-17

Most children with ASD had at least one prescription medication.

According to MEPS, 71% of children with ASD had at least one prescription filled in the past year, similar to CSHCN (79%) but more than children with no SHCN (36%). For children with ASD who had a prescription filled, the average number of prescriptions per year was 17 (median of 13), compared to 10 for CSHCN (median of 6) and three for children with no SHCN (median of 2). A larger average than the median suggests a few children had a lot of prescriptions filled. Average total cost per prescription was similar for children with ASD versus CSHCN.

White, non-Hispanic children were more likely than children of another race or ethnicity to have a prescription filled in the previous year.

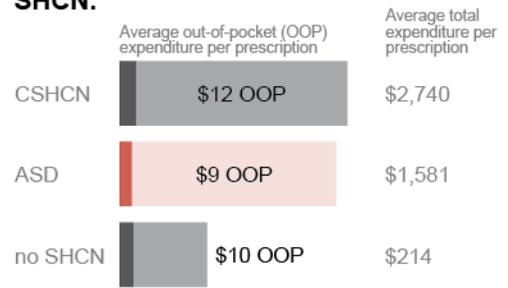
Children with ASD who had at least one prescription filled had an average yearly total expenditure for medications of \$2740, with an average total out-of-pocket expenditure of \$158. Average expenditures for children with ASD were higher than for CSHCN or children with no SHCN.

Parents of half of children with ASD reported current medication use.

According to the NSCH, 51% of children with ASD currently needed or used a prescription medication other than vitamins. Current medication use was more common in CSHCN (78%) but rare in children with no SHCN (4%). Parents of older children with ASD (ages 12-17) were more likely to report current medication use than parents of younger children with ASD (ages 3-11). Furthermore, white, non-Hispanic and black, non-Hispanic children with ASD were the most likely to have current medication use.

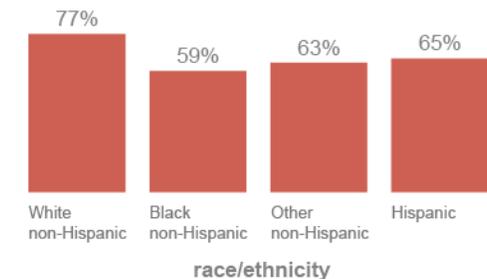
According to the NSCH, one in four children with ASD were currently taking medication for ASD, Asperger's Disorder or pervasive developmental disorder (PDD) (although these are not terms currently used in diagnostic practice, the survey included these terms in the question). Nearly one-third of older children with ASD were taking a medication for ASD, compared to one-fifth of younger children. Furthermore, white, non-Hispanic and black, non-Hispanic children with ASD were the most likely to currently use a medication for ASD.

Children with ASD and CSHCN had higher average spending per prescription than children with no SHCN.



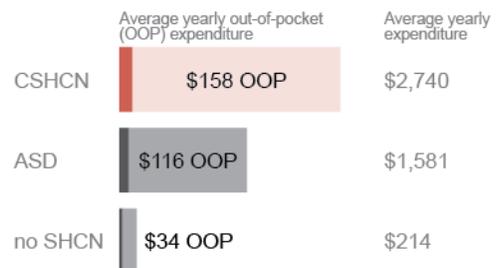
Source: Medical Expenditure Panel Survey 2013-17

White children with ASD were the more likely to have a prescription filled in the past year.



Source: Medical Expenditure Panel Survey 2013-17

Children with ASD had the highest average yearly total and out-of-pocket expenditure on prescriptions.



Source: Medical Expenditure Panel Survey 2013-17

Nearly 40% took medication for emotion, concentration, or behavior.

According to the NSCH, 38% of children with ASD took medication due to difficulties with their emotions, concentration, or behavior, similar to CSHCN (31%). Older children with ASD were much more likely to take medications for emotion, concentration, or behavior than younger children with ASD, and white, non-Hispanic children with ASD were more likely than children of another race or ethnicity.

Stimulant medications were the most common.

According to MEPS, nearly one-third (31%) of children with ASD had a prescription filled for a central nervous system (CNS) stimulant. CNS stimulants are used in conditions such as ADHD and include amphetamine, dextroamphetamine, and methylphenidate. For children with ASD, the average number of prescriptions filled for a CNS stimulant was nine (median of 9), compared to eight for CSHCN (median of 7).

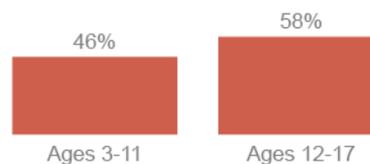
Anti-microbials were the next most common prescription class for children with ASD, with just over one-quarter filling at least one in a year. Anti-microbials are medications that kill organisms that cause infections. This includes antibiotics, antifungals, and antivirals. Children with ASD had an average of two anti-infective prescriptions filled per year (median of 1), the same as CSHCN and children with no SHCN.

Eighteen percent of children with ASD had an antidepressant prescription filled in the past year, filling an average of nine of these prescriptions (median of 11), versus seven for CSHCN (median of 7).

Fourteen percent of children with ASD had a prescription filled for respiratory or allergy medications in the past year, filling on average five prescriptions (median of 2), versus six for CSHCN filled an average (median of 3) and two for children with no SHCN (median of 1).

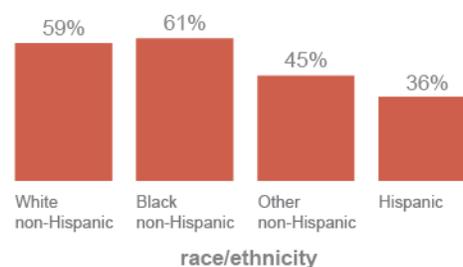
Nine percent of children with ASD had a prescription filled for an anxiolytic, sedative, or hypnotic in the past year, on average filling six (median of 6), versus four for CSHCN (median of 2). Examples of anxiolytics, sedatives, and hypnotics include benzodiazepines such as alprazolam and diazepam, hydroxyzine, barbiturates, and zolpidem.

Over half of older children with ASD currently needed or used a prescription, more than younger children with ASD.



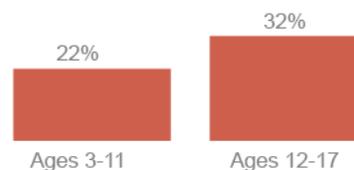
Source: National Survey of Children's Health 2016-18

White and black children with ASD were the most likely to currently need or use a prescription.



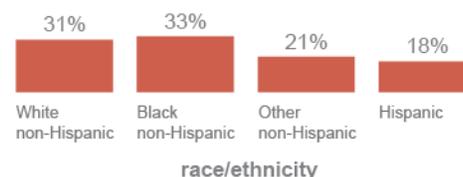
Source: National Survey of Children's Health 2016-18

One-third of older with ASD currently used a medication for ASD.



Source: National Survey of Children's Health 2016-18

White and black children with ASD were the most likely to currently use a medication for ASD.



Source: National Survey of Children's Health 2016-18

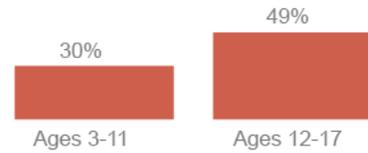
Anxiolytics are used to treat anxiety.

Prescription medications belong to one or more classes based on the conditions they are approved to treat. However, medications can be useful for conditions they are not approved for. This is referred to as off-label use. In these findings, we cannot tell if medications were used off-label, only what class they belong to.

Previous research has suggested that antipsychotic drugs, including risperidone and aripiprazole, are more common in children with ASD than our findings suggest. Previous studies have found that 10-20% of children with ASD who received treatment from a mental health professional took them (Anderson *et al.*, 2015; Madden *et al.*, 2017). However, fewer than 1% of children with ASD were found to use antipsychotics in this data. This discrepancy may be due to random variability in sampling, survey design, or actual differences in antipsychotic use. The sample of children from MEPS is also not limited to children who received treatment from a mental health professional; we found in Chapter 2 that 36% of children with ASD had an office-based appointment at which they received care for psychotherapy or mental health counseling. Since previous research and anecdotal evidence highlights this anomaly, we note it here.

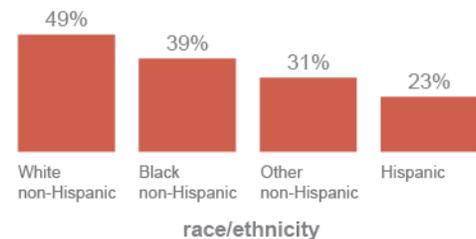
Expenditures are not reported for all medication classes due to small numbers of children taking those medications.

Half of older children with ASD took a medication in the past year because of difficulties with emotions, concentration, or behavior.



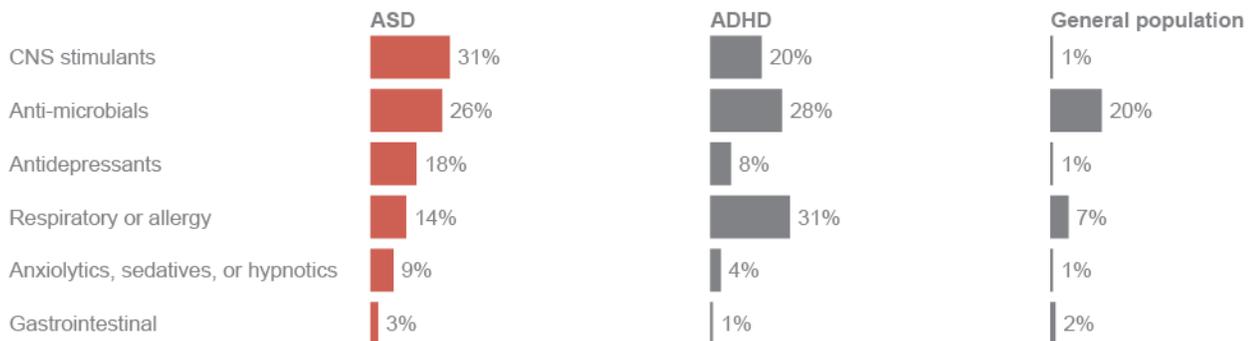
Source: National Survey of Children's Health 2016-18

White children with ASD were the most likely to have taken a medication for emotions, concentration, or behavior in past year.



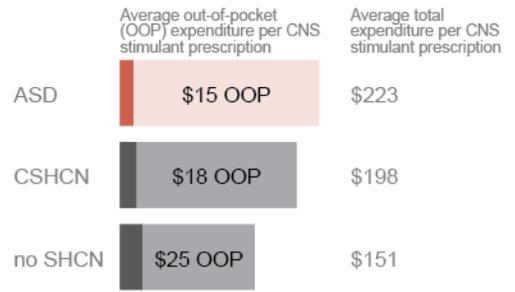
Source: National Survey of Children's Health 2016-18

CNS stimulants were the most common class of prescriptions in children with ASD.



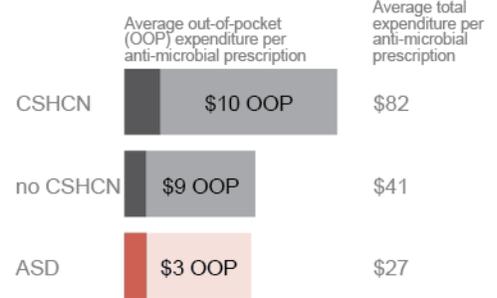
Source: Medical Expenditure Panel Survey 2013-2017

Children with ASD had the highest average total expenditure per prescription for CNS stimulants



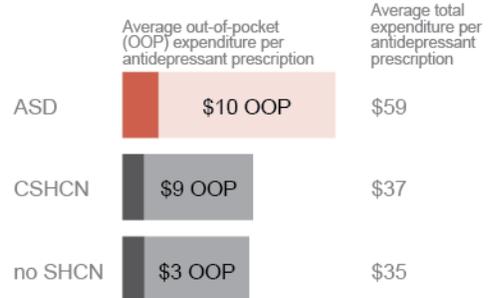
Source: Medical Expenditure Panel Survey 2013-17

Children with ASD had the lowest average total expenditure per prescription for anti-microbials.



Source: Medical Expenditure Panel Survey 2013-17

Children with ASD had the highest average total expenditure per prescription for antidepressants.



Source: Medical Expenditure Panel Survey 2013-17

References

Anderson, L. E., Chen, M. L., Perrin, J. M., & Van Cleave, J. (2015). Outpatient visits and medication prescribing for US children with mental health conditions. *Pediatrics*, 136(5), e1178-e1185. <https://doi.org/10.1542/peds.2015-0807>

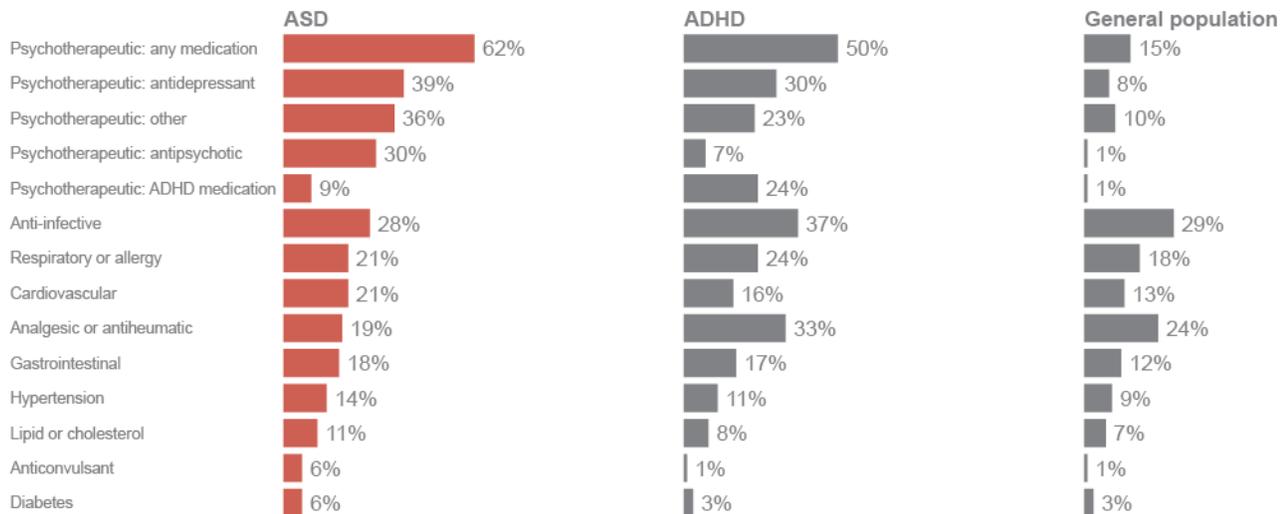
Madden, J. M., Lakoma, M. D., Lynch, F. L., Rusinak, D., Owen-Smith, A. A., Coleman, K. J., ... & Croen, L. A. (2017). Psychotropic medication use among insured children with autism spectrum disorder. *Journal of autism and developmental disorders*, 47(1), 144-154. <https://doi.org/10.1007/s10803-016-2946-7>

Spotlight: Medication use by adults with ASD

A published study used Kaiser Permanente health data to examine medication use among 1,507 adults with ASD ages 18 and older (Zerbo *et al.*, 2019). This study presented the percentage of adults with ASD with prescriptions for several classes of medication. Pharmacy costs were also presented, including annual average and median cost per person. Cost included only pharmacy costs, and no patient out-of-pocket payments. This study compared adults with ASD to adults with attention deficit/hyperactivity disorder (ADHD) and adults in the general population. The study sample came from Kaiser Permanente Northern California, which serves approximately four million people in the Sacramento and San Francisco areas.

In this study, 80% of adults with ASD had at least one prescription in a year, similar to adults with ADHD (79%) but more than adults in the general population (62%). The most common medications for adults with autism were psychotherapeutic medications, anti-infectives, and respiratory or allergy medications. Adults with ASD had higher utilization than peers of psychotherapeutic medications, cardiovascular medications, cholesterol medications, anticonvulsants, and diabetes medications. Analgesic medications were less common in adults with ASD than in adults with ADHD and in the general population, as was ADHD medication compared to adults with ADHD.

Some medications were more common in adults with ASD than other adults.



*Significantly different from the ASD group as tested using logistic regression controlling for age, race/ethnicity, gender, length of KPNC membership, and certain mental and physical co-occurring conditions
 Source: Zerbo *et al.*, 2019

For adults who had at least one prescription for any medication, the average yearly cost for all prescriptions was \$1857.90 (median of \$254). This was significantly more than adults with ADHD (average yearly cost of \$1200.50 median of \$181) and adults in the general population (average yearly costs of \$404.90 median of \$29). Adults with ASD also had higher yearly costs for psychotherapeutic agents.

References

Zerbo, O., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., & Croen, L. A. (2019). Health care service utilization and cost among adults with autism spectrum disorders in a US integrated health care system. *Autism in Adulthood*, 1(1), 27-36. <https://doi.org/10.1089/aut.2018.0004>

Insurance

While nearly all children with ASD had insurance, coverage often fell short.

This chapter examines insurance coverage and the services covered by insurance for children on the autism spectrum. Comparisons are made across ages, race and ethnicity, and comparison groups with or without conditions other than autism.

Our key findings

- Most children with ASD had insurance at the time of the survey and were continuously insured over the past 12 months (93%).
- Over half (56%) of children with ASD had public insurance (such as Medicaid or CHIP) or a mixture of public and private insurance. Younger children with ASD (ages 3-11) were more likely to have public insurance only (50%), versus 37% of older children with ASD (ages 12-17).
- Almost half (46%) of parents of children with ASD reported that their child's insurance did not always cover the services they needed.
- One-fifth of parents of children with ASD reported avoiding changing jobs because of concerns about maintaining health insurance for their child – five times the rate of parents of children with no SHCN.

How do we know?

The data about children in this chapter came from the National Survey of Children's Health (NSCH) 2016-2018. The NSCH is a nationally representative study of children with and without special health care needs, including children on the autism spectrum.

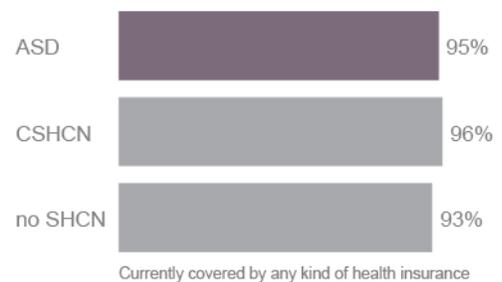
Further data about hospital inpatient stays in patients of all ages came from the National Inpatient Sample (NIS) 2017. NIS is a nationally representative sample of all-payer inpatient hospital stays with information about diagnoses, procedures, and patient and hospital characteristics. More information on all data and how we conducted our analyses can be found in the **Methods** appendix.

KEY ABBREVIATIONS

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **CSHCN:** Children who did *not* have parent-reported ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to peers
3. **No SHCN:** Children who did *not* have parent-reported ASD nor any other type of special health care need as defined above

Most children with ASD were insured at the time of survey.



Source: National Survey of Children's Health 2016-18

More children with ASD had public health insurance.

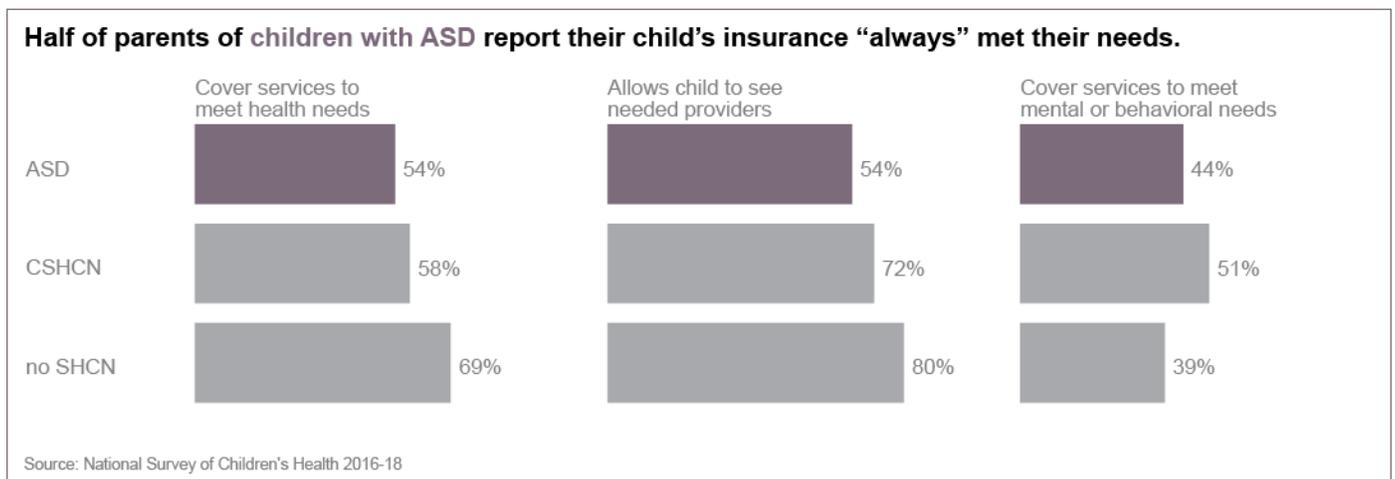
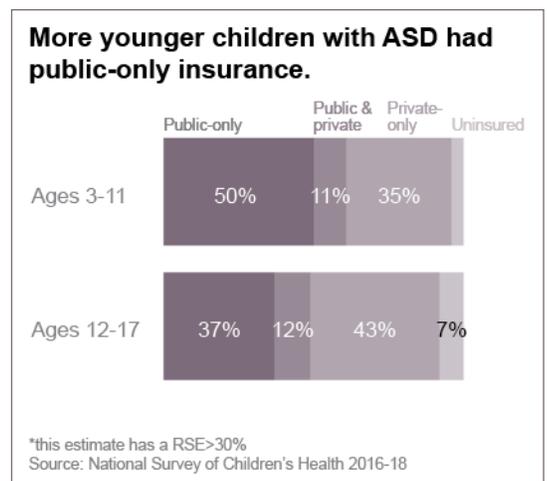
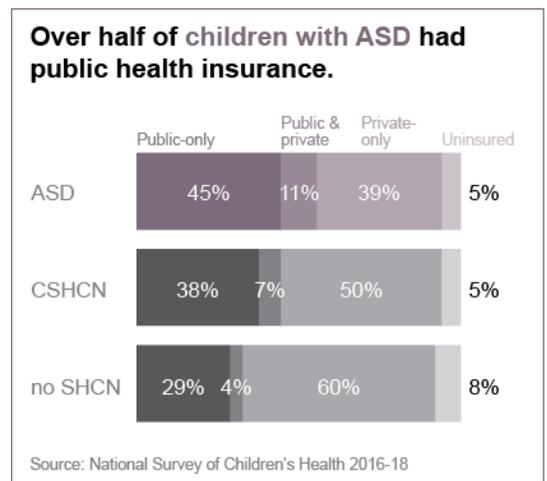
Most children with ASD had insurance at the time of the survey. Most (93%) were also continuously insured over the past 12 months. Very few (2.5%) had no insurance coverage over the past 12 months.

Over half (56%) of children with ASD had public insurance or a combination of public and private insurance. Children with ASD were the least likely to only have private insurance (39%), compared to 50% of CHSCN and 60% of children with no SHCN. Younger children with ASD (ages 3-11) were more likely to have public insurance only (50%), versus 37% of older children with ASD (ages 12-17).

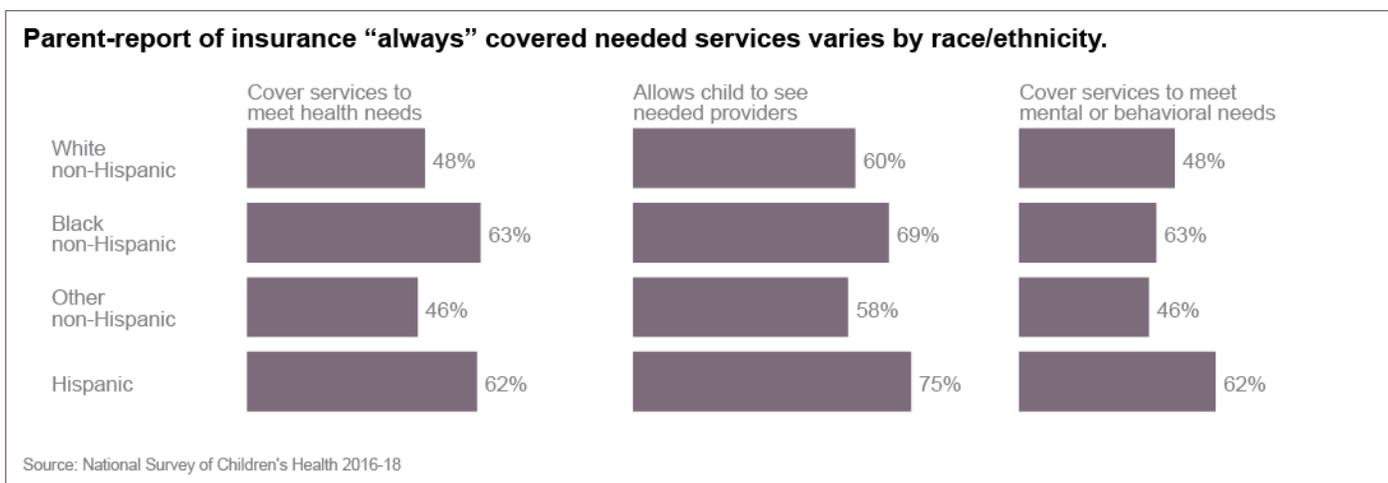
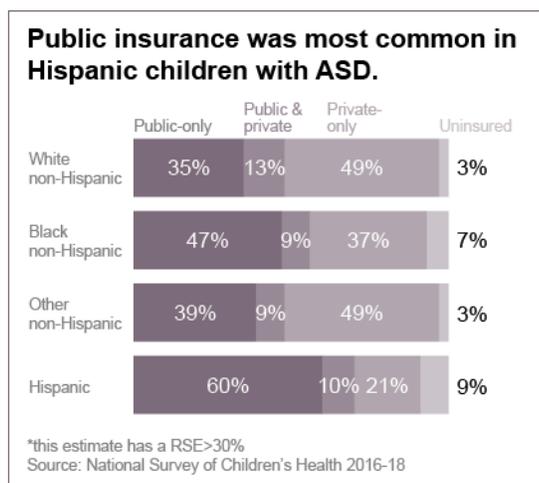
Hispanic and black, non-Hispanic children with ASD were the most likely to have public insurance only.

For most children, insurance covered needed services and providers.

Just over half of parents of children with ASD reported that their child's insurance always covered the services they needed - fewer than parents of CSHCN and those with no SHCN. Two-thirds of parents of children with ASD reported that their child's insurance always allowed them to see the providers they needed – fewer than parents of CSHCN and those with no SHCN. Less than half of parents of children with ASD reported their child's insurance always covered services to meet their child's mental or behavioral health needs.

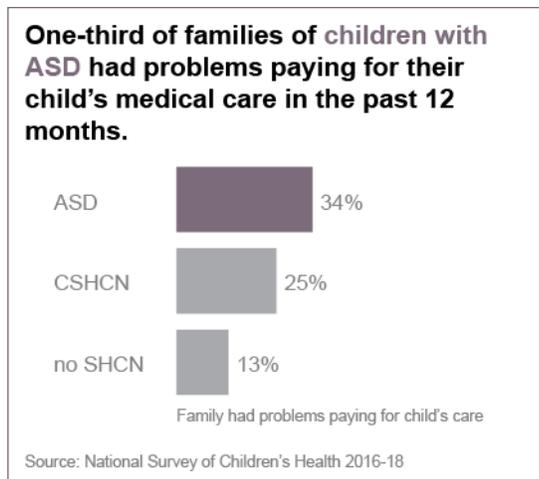


Over 60% of parents of black, non-Hispanic and Hispanic children with ASD reported that their child’s insurance always covered the services they needed, compared to less than half of white children and children of other races. Similarly, parents of black, non-Hispanic and Hispanic children were more likely to report their child’s insurance always allowed them to see the providers they needed. Parents of Hispanic children with ASD were the most likely to report their child’s insurance always covered services for mental or behavioral health needs. But findings in Chapter 2 showed that parents of Hispanic children with ASD were the least likely to report their child received mental health treatment.



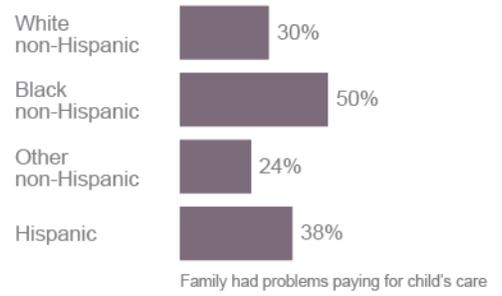
Cost of care and worries about maintaining insurance were more common in families of children with ASD.

One-third of parents of children with ASD reported having problems paying for their child’s health care in the past 12 months. This rate was higher than parents of CHSCN and parents of children with no SHCN. Problems paying for care varied by race and ethnicity in children with ASD. Half of parents of black, non-Hispanic children with ASD reported difficulty – a higher rate than parents of Hispanic children, white, non-Hispanic children, and non-Hispanic children of other or multiple races.



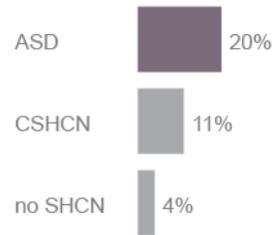
One-fifth of parents of children with ASD reported avoiding changing jobs because of concerns about maintaining health insurance for their child – five times the rate of parents of children with no SHCN. This largely did not vary by race and ethnicity in children with ASD.

Half of families of black children with ASD had problems paying for their child's medical care in the past year.



Source: National Survey of Children's Health 2016-18

One-fifth of parents of children with ASD avoided changing jobs for concern of keeping insurance.



Source: National Survey of Children's Health 2016-18

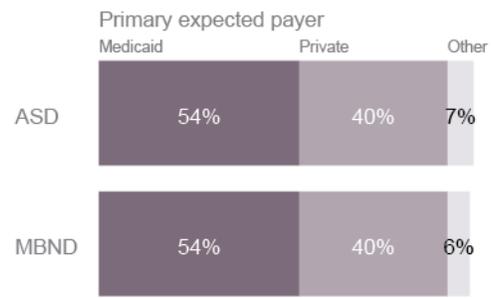
Spotlight: primary expected payer for inpatient hospital stays

The National Inpatient Sample (NIS) is an all-payer database of U.S. hospital inpatient stays each year. It includes records of any care whether paid through insurance or private pay. The primary expected payer of each inpatient stay is recorded as Medicare, Medicaid, private insurance, self-pay, no charge, or other. We compared the primary expected payer first for children (ages 0-17) with ASD and another mental, behavioral, or neurodevelopmental (MBND) diagnosis; and then for adults (ages 18+) with ASD and MBND.

Medicaid was the most common primary payer in children with ASD (ages 0-17) (54%) and MBND, followed by private insurance (40%). Fewer than 1%, of children with ASD had Medicare as their primary expected payer.

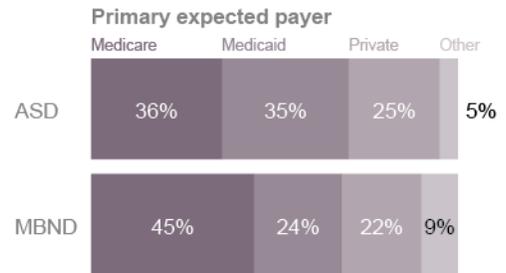
Medicare (36%) and Medicaid (35%) were the most common primary expected payer in adult autistic patients, while Medicare was more common in adults with MBND (45%).

Medicare was the primary payer for half of inpatient stays for child patients with ASD.



Source: National Inpatient Sample 2017

Medicaid and Medicare were the primary payer for two-thirds of inpatient stays for adult autistic patients.



Source: National Inpatient Sample 2017

Accessing Services

Parents of children with ASD reported higher need for care coordination but less often had a medical home.

This chapter examines access to services for children on the autism spectrum, including care coordination, the medical home, and unmet needs. Comparisons are made across ages, race and ethnicity, and comparison groups with or without conditions other than autism.

Our key findings

- Of parents whose child with ASD had more than one healthcare appointment in the past 12 months, 28% reported someone helped coordinate or arrange care among different providers. Another 30% reported they could use more help coordinating care - more than parents of CSHCN or children with no SHCN. The need for help coordinating care also varied by race and ethnicity; parents of black non-Hispanic children with ASD most often reported that they could use more help coordinating care.
- Half of parents of children with ASD who had an unmet healthcare need reported a need for mental health care.
- One-third of children with ASD received care within a medical home, compared to 44% of CSHCN and 49% of children with no SHCN. White children with ASD were more likely to receive care within a medical home (39%) than black (22%), Hispanic (30%), or children of another race (32%).
- KPNC spotlight findings: Three-quarters (77%) of adult health care providers rated their knowledge and skills for providing care to patients with ASD as poor or fair, according to a survey of 922 healthcare providers who worked for KPNC.

How do we know?

The data about children in this chapter came from the National Survey of Children’s Health (NSCH) 2016-2018. The NSCH is a nationally representative study of children with and without special health care needs, including children on the autism spectrum.

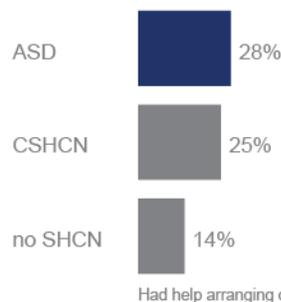
Because publicly available national data on the health of adults on the autism spectrum is scarce, we sought information from published studies which used Kaiser Permanente Northern California (KPNC) patient records for research. More information on all data and how we

KEY ABBREVIATIONS

This report compares three groups of children:

1. **ASD:** Children with parent-reported autism spectrum disorder
2. **CSHCN:** Children who did *not* have parent-reported ASD but did have a special health care need, as indicated by increased need for health care, medication, or services compared to peers
3. **No SHCN:** Children who did *not* have parent-reported ASD nor any other type of special health care need as defined above

Over one-quarter of parents of children with ASD who visited more than one provider had help coordinating care.



Source: National Survey of Children’s Health 2016-18

conducted our analyses can be found in the Methods appendix.

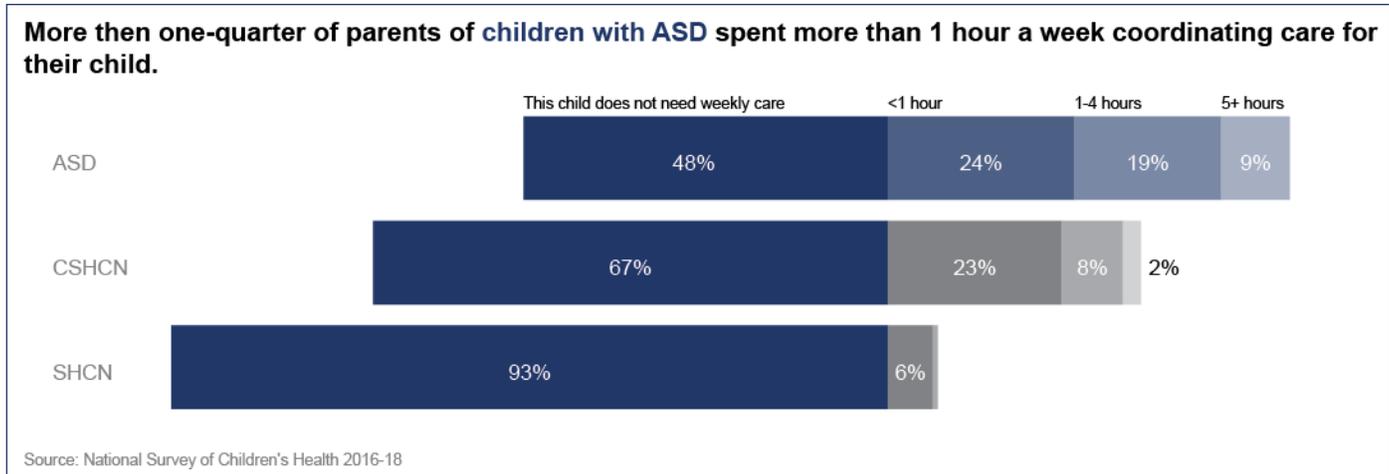
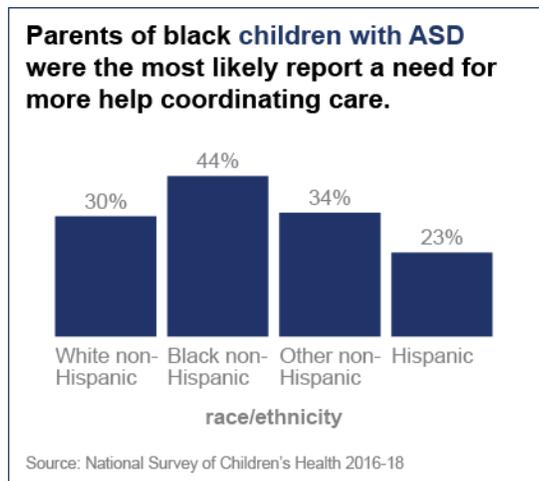
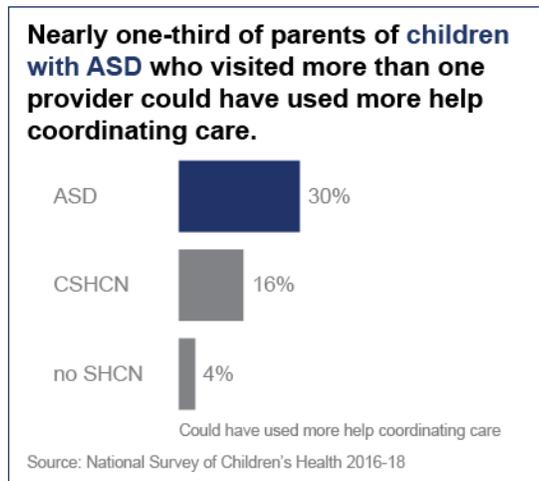
Parents of children with ASD more often needed help with coordinating care.

Many children with ASD and CSHCN see multiple providers of health and other types of care. Care coordination is the planned organization of care across providers, systems, and people. Good care coordination improves effectiveness, efficiency, and safety of care.

Twenty-eight percent of parents of children with ASD reported someone helped coordinate or arrange care among different providers, of those whose child had more than one healthcare appointment in the past 12 months. This was similar to CSHCN, but more than children with no SHCN.

Thirty percent of parents of children with ASD reported they could use more help coordinating care among different providers or services, for those parents whose child saw more than one healthcare provider in the past 12 months. This rate was higher than CSHCN and children with no SHCN. Need for help coordinating care also varied by race and ethnicity; parents of black, non-Hispanic children with ASD most often reported that they could use more help coordinating care.

One-quarter of parents of children with ASD spent at least one hour every week coordinating care and services for their child, more than parents of CSHCN and children with no SHCN.



More than one-third of children with ASD needed referrals, and almost as many reported it was difficult to get them.

Forty percent of parents of children with ASD reported their child needed a referral to see a doctor or receive services in the past 12 months, similar to CSHCN (35%) but more than children with no SHCN (13%). More parents of younger children with ASD (ages 3-11) reported a need for referrals (45%) compared to parents of older children with ASD (33%). Parents of black, non-Hispanic children with ASD were the most likely to report a need for referrals of all children with ASD.

For children who needed a referral, parents of children with ASD were more likely than children with no SHCN to report problems receiving the referral.

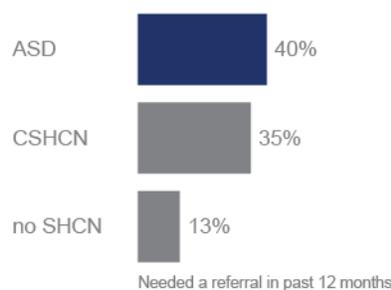
More than half of parents of children with ASD reported that, in the past 12 months, they were at least sometimes frustrated in their efforts to get services for their child. This was more common in children with ASD than in CSHCN and children with no SHCN. Furthermore, parents of younger children with ASD reported frustration more often than parents of older children with ASD.

The most common unmet healthcare need in children with ASD was mental health services.

Eleven percent of parents of children with ASD reported not receiving needed care at any time in the past 12 months. This did not vary by age or race and ethnicity in children with ASD.

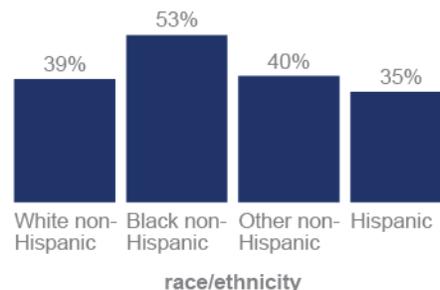
Of children who had an unmet need for care, the most commonly reported need was mental health services, followed by dental care. Children with ASD experienced more unmet need for mental health services and “other” services than CSHCN and children with no SHCN. Children with no SHCN had the highest reported unmet need for dental care.

Almost half of the parents of children with ASD reported their children needed a referral for care or services.



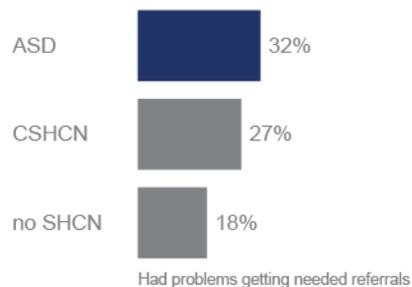
Source: National Survey of Children's Health 2016-18

Parents of black children with ASD were the most likely needing a referral for care in the past 12 months.



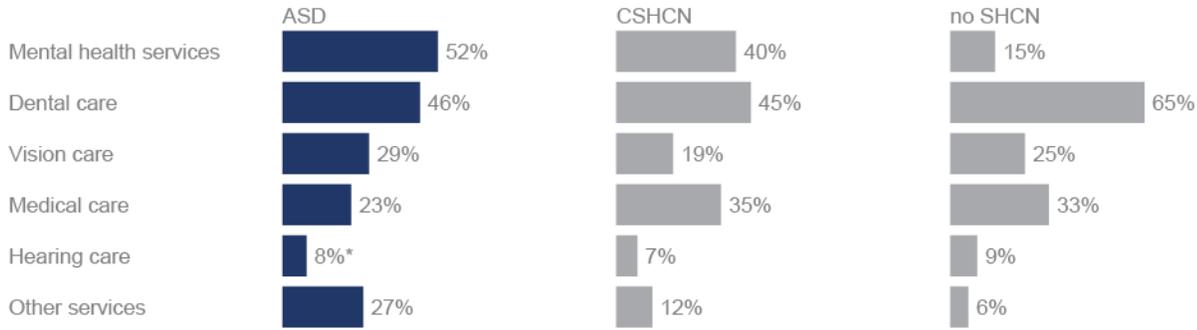
Source: National Survey of Children's Health 2016-18

One-third of parents of children with ASD who needed a referral reported it was a problem to get it.



Source: National Survey of Children's Health 2016-18

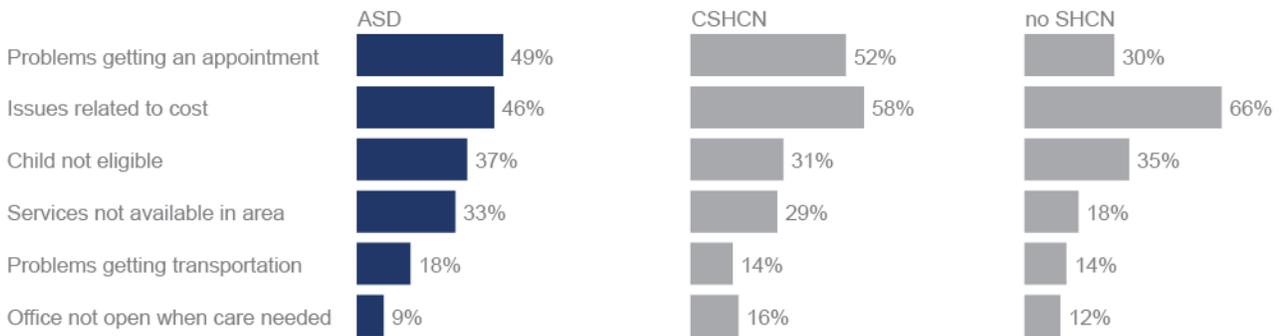
Half of parents of children with ASD who reported need for additional services reported need for mental health services.



*this estimate has a RSE>30%
Source: National Survey of Children's Health 2016-18

The most common reason children with ASD did not receive needed services was difficulty getting an appointment (49%), followed closely by issues related to cost (46%). More parents of CSHCN and children with no SHCN reported issues related to cost as a barrier to needed services. One-third of parents of children with ASD reported they could not get needed services because those services were not available in their area, more than children with no SHCN.

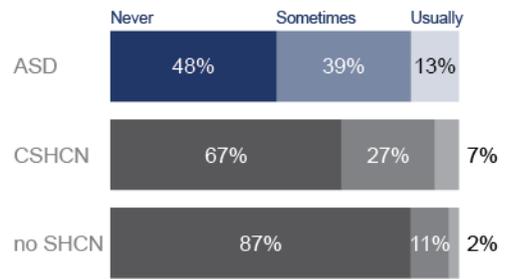
Almost half of parents of children with ASD who had unmet service needs reported difficulty getting appointments and issues related to cost.



Source: National Survey of Children's Health 2016-18

Reasons for unmet needs varied by age. Parents of younger children with ASD (ages 3-11) were more likely to report that their child was not eligible for services (47% compared to 27%), and issues related to cost (54% compared to 38%) than parents of older children with ASD (ages 12-17).

Half of parents of children with ASD were at least sometimes frustrated in their efforts to get services for their child.



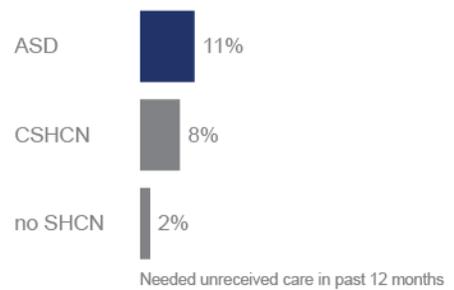
Source: National Survey of Children's Health 2016-18

Parents of older children with ASD more often reported frustrated in their efforts to get services.



Source: National Survey of Children's Health 2016-18

Some parents of children with ASD reported their child needed care in the past 12 months that was not received.



Source: National Survey of Children's Health 2016-18

Spotlight: Medical home use among children with ASD

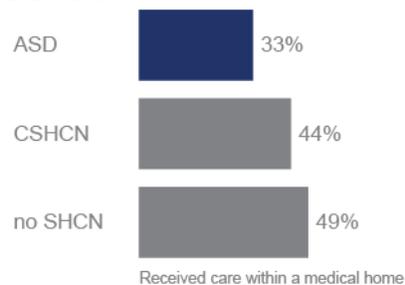
The patient centered medical home is a model of health care that aims to provide comprehensive, coordinated care to reduce complexity and improve healthcare quality. The American Academy of Pediatrics (AAP) states the medical care of children should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally competent (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002; American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association, 2007).

In an ideal world all children would have a medical home, but especially children with special health care needs (CSHCN) who have an increased need for services and resources beyond that of typically developing children (Damiano *et al.*, 2006; Long *et al.*, 2012; McPherson *et al.*, 1998). Families of children with ASD must navigate an array of systems and services that can be challenging and overwhelming (Cheak-Zamora & Teti, 2015). The medical home helps coordinate care across multiple services and systems that provide care for children with ASD (Turchi & Antonelli, 2014).

In the NSCH, a child is considered to have a medical home if the parent reports that their child has: 1) a personal doctor or nurse, 2) a usual source of sick care, 3) family-centered care, 4) received referrals if needed, and 5) effective care coordination if needed.

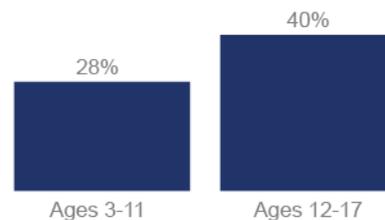
Most parents of children with ASD (84%) reported their child had a usual source of sick care. Three-quarters of children with ASD had a personal doctor or nurse, and 73% of children with ASD who had healthcare in the past year received family-centered care. Just over half of children with ASD who needed care coordination received it. Care coordination includes communication between doctors when the child saw more than one doctor in the past 12 months, communication between doctors and schools when needed, and getting help coordinating care when needed.

One-third of children with ASD received care within a medical home, fewer than CSHCN and children with no SHCN.



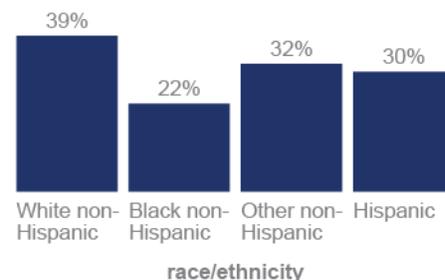
Source: National Survey of Children's Health 2016-18

Older children with ASD were more likely to receive care within a medical home than younger children.



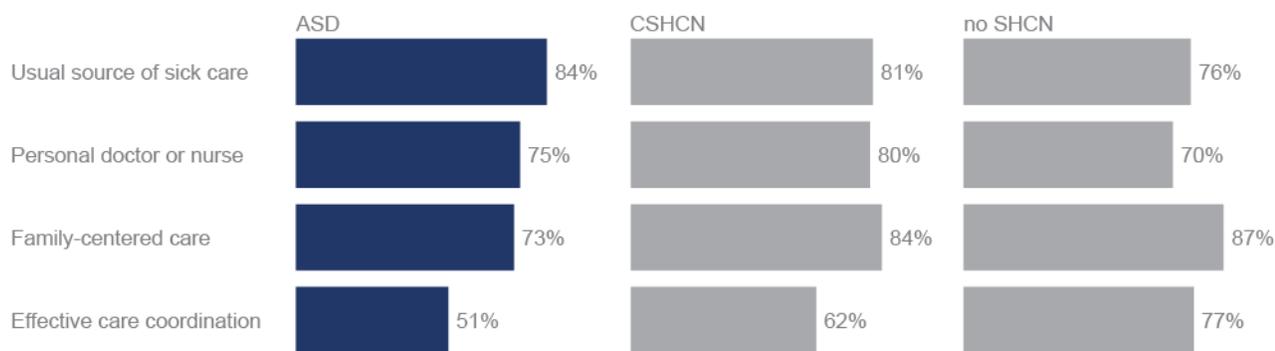
Source: National Survey of Children's Health 2016-18

White children with ASD were the most likely to receive care within a medical home.



Source: National Survey of Children's Health 2016-18

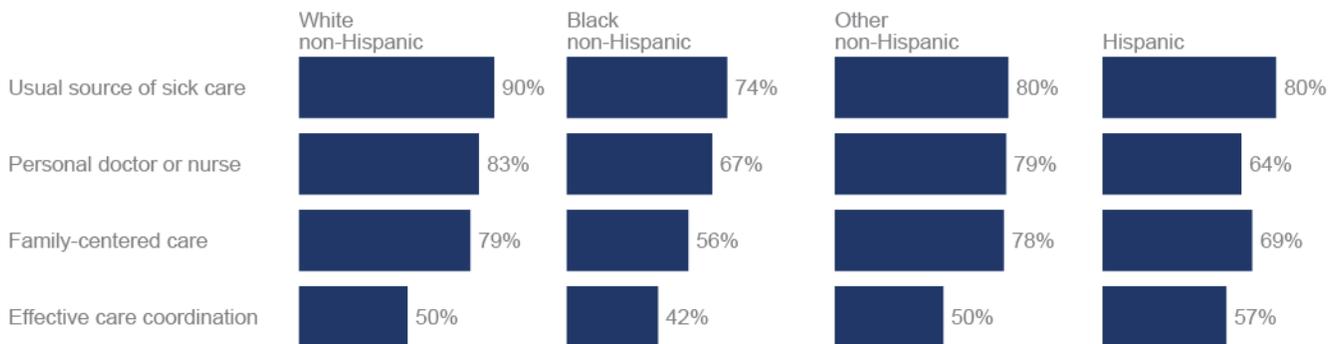
Most children with ASD had a usual source of sick care. Half received care coordination if they needed it.



Source: National Survey of Children's Health 2016-18

These findings varied by race and ethnicity in children with ASD. White, non-Hispanic children with ASD were the most likely to have a usual source of sick care (90% versus 74% of black, non-Hispanic children, 80% of Hispanic children, and 81% of non-Hispanic children of other or multiple races). Black, non-Hispanic children with ASD were the least likely to receive family-centered care and effective care coordination when needed.

Black children with ASD were the least likely to experience key components of a medical home.



Source: National Survey of Children's Health 2016-18

Overall, one-third of children with ASD received care within a medical home, compared to 44% of CSHCN and 49% of children with no SHCN. Older children with ASD (ages 12-17) more often received care within a medical home than younger children with ASD (40% compared to 28%). White, non-Hispanic children with ASD were more likely to receive care within a medical home (39%) than black, non-Hispanic (22%), Hispanic (30%), or non-Hispanic children of other or multiple races (32%).

Spotlight: Access to health services for adults with ASD

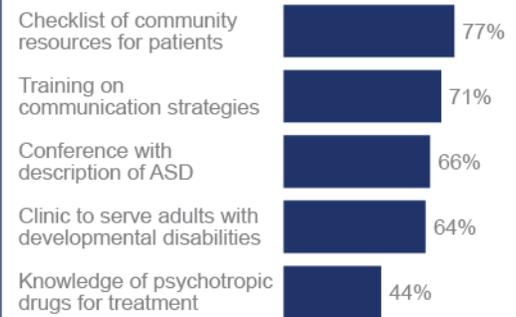
There are many reasons that people on the autism spectrum may have difficulty accessing services in their community. One is a lack of providers that have autism-specific knowledge to allow them to provide appropriate services. This is particularly problematic with providers of adult health services.

A survey of 922 healthcare providers who worked for Kaiser Permanente Northern California in the Sacramento and San Francisco areas found providers have insufficient skills and tools for providing healthcare to patients with ASD and need additional training (Zerbo *et al.*, 2015). The survey included physicians, psychologists, social workers, and nurses from several medical departments (e.g., family and internal medicine, adult mental health, and obstetrics/gynecology).

Three-fourths (77%) of healthcare providers rated their knowledge and skills for providing care to patients with ASD as poor or fair. Mental health providers were the least likely to report poor or fair skills (70%), followed by adult medicine providers (79%) and OB/GYN providers (88%). None of the physicians received formal training in screening or diagnosis of ASD.

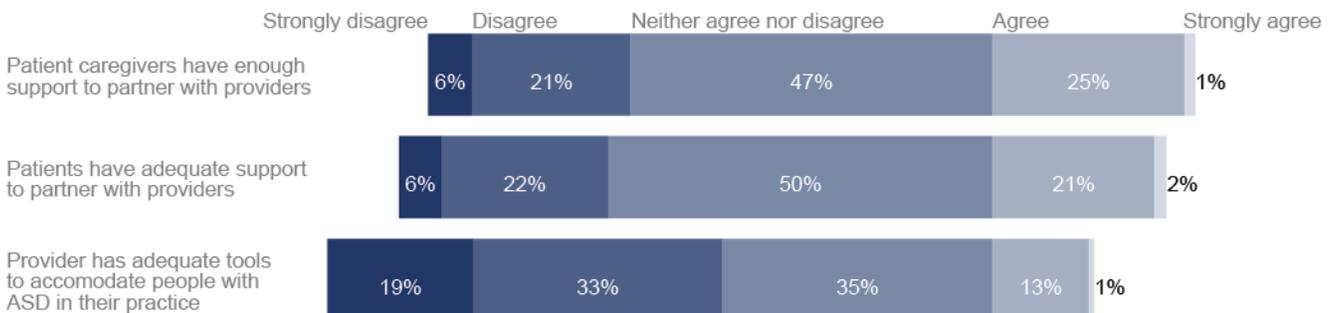
Similarly, only 13% of providers agreed that they had adequate tools, referral resources, or practice models to accommodate people with ASD in their practice.

Most providers said resources and training would be useful to them.



Source: Zerbo, *et al.*, 2015

Most providers feel they, their patients, and their patients' caregivers were not adequately supported to provide care.



Source: Zerbo, *et al.*, 2015

Most healthcare providers reported needing checklists of community resources for patients with ASD (77%) and training on effective communication strategies with patients with ASD (71%).

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Looking Ahead: Conclusions and Recommendations

Health is a vital aspect of life. It is related to quality of life and life satisfaction. Health can be impacted by many factors in positive and negative ways. While some people may be predisposed to worse health, preventive services and comprehensive healthcare can go a long way in improving the trajectory of health across the life course.

Health services and intervention can positively influence health, just as lack of these can lead to poor health. People on the autism spectrum face barriers to care that may cause their health to be worse than that of their peers.

Comprehensive care is harder to achieve for people on the autism spectrum because their healthcare needs are often more complex compared to peers with and without other disabilities. People with ASD receive more services, spend more on health care, and use more medications than peers with and without disabilities. People with ASD also face complex barriers to accessing certain types of care and to navigating all the services they rely upon to prevent and improve health needs. Providing more appropriate care and reducing barriers to accessing primary care can lead to better health and less emergency healthcare utilization.

This report highlights the need for improved health and health care in people on the autism spectrum across age groups. We present a holistic picture of health and health care across the lifespan for people on the autism spectrum. More work is needed to understand why health and health services are worse for people on the spectrum than their peers, and to determine how to improve systems and services to increase levels of health and decrease healthcare burden. With this in mind, we end with the following recommendations for research moving forward.

- First, we must begin by embracing the idea that all types of health are important. Primary care, dental care, vision care, mental health care, specialty healthcare... all of these and more are important health needs that impact life. All must be considered when assessing health and healthcare needs.
- Second, considering only physical health and health conditions is not enough. In people on the autism spectrum particularly, high rates of psychotropic medication use point to the need for behavioral supports, trained clinicians to manage the multifaceted impacts of psychotropic medications on health, and systems that support and prioritize behavioral health services. But even in comprehensive care approaches, such as the medical home as described in Chapter 5, mental health care is often not addressed.
- Third, we need more focus on coordinated care to improve health. Health care is complex. Take for example the report of poor dental health from Chapter 1. Reasons for poor dental health could be influenced by many factors: lack of insurance coverage, a need for behavioral supports for successful office visits and daily hygiene, dietary issues linked to dental health, or lack of accommodations at the dental office. If these all impact dental health, a truly comprehensive, interdisciplinary approach to health care would need to consider all these concerns.
- Fourth, we must do a better job of addressing persistent disparities. The health disparities seen by race and ethnicity in the U.S. are reflected in the population of people on the autism spectrum. Acknowledging these disparities is only the first step to combating them. Future research must work to reduce them. The reliance on public health insurance (Medicaid), especially among underserved and underrepresented groups, suggests that research focused on these systems should be an area

of emphasis. Economic disparities are also of particular concern in this population, where costly services and insurance inadequacies are common.

- Finally, we end by highlighting the need for more data. While this report examines health outcomes across multiple data sources, there is an obvious emphasis on child health. This emphasis is not by desire, but we are limited in what we can report on: comprehensive national data on adult health and healthcare is elusive. The data we have included comes from specific healthcare systems or segments. As a result, we do not have adequate nationally representative data that explores the multiple healthcare needs across the systems that serve adults with ASD.

Appendix: Methods

What data did we use for this report?

Data for this report came from: 1) two federally funded national surveys conducted in the United States, 2) one administrative database of hospital inpatient stays, and 3) previously published research findings from Kaiser Permanente Northern California (KPNC) patient records.

The **National Survey of Children's Health** (NSCH) is a cross-sectional, nationally representative survey designed to provide national estimates on the health and well-being of United States children from parent or caregiver report. The NSCH is designed by the Health Resources and Services Administration's Maternal and Child Health Bureau and conducted by the U.S. Census Bureau. The survey is conducted using a two-phase design; first sending a short screener to households and then offering a web-based in-depth topical survey to one child in each qualifying household. The NSCH asks about health, healthcare services, health insurance, and school and household activities. Parents or caregivers (both referred to as "parents" throughout this report) participated in the survey on behalf of their children ages 0-17. For this report, we combined the NSCH administered from years 2016-2018. More information about the NSCH can be found by visiting <https://www.census.gov/programs-surveys/nsch.html> or <https://www.childhealthdata.org/>.

The **Medical Expenditure Panel Survey** (MEPS) is a nationally representative survey of health, health service use, medical events, health insurance coverage, and pharmacy use in non-institutionalized children and adults in the U.S. It is conducted by the Agency for Healthcare Research and Quality (AHRQ) in the U.S. Department of Health and Human Services (HHS). MEPS participants are identified as participants from the previous years' National Health Interview Survey (NHIS), a national study conducted by the U.S. Census Bureau designed to present a yearly snapshot of the health of the nation. MEPS is a panel design survey, conducting five rounds of interviews with the same person over two years. Whole families were asked to participate in MEPS, and parents or caregivers (referred to as "parents") were interviewed about the health and healthcare experiences of their children ages 0-17. MEPS can be used to produce yearly national estimates of characteristics and experiences, or for longitudinal follow-up of change over a two-year period. MEPS has several components. The publicly available household component was used for this report, as well as household component event files for prescribed medicines, hospital inpatient stays, emergency room visits, outpatient visits, and office-based medical provider visits. For this report, we combined MEPS survey years 2013-2017. To learn more about MEPS, visit <https://www.meps.ahrq.gov/mepsweb/>.

Although MEPS is a household survey and includes information about adult health and healthcare use, we did not use the survey to explore health in adults with ASD. Over the survey years examined (2013-2017), there were fewer than 100 adults ASD associated with healthcare events surveyed. Small samples make estimates of indicators unstable, meaning we are unsure if they are an accurate representation of real experiences. Furthermore, the estimation of MEPS data assumes we have a sample of adults that is representative of experiences of adults nationally. It is questionable whether autistic adults who chose to or were able to participate in MEPS were representative of all adults in the U.S. who have autism. This not of concern with children because the survey was completed on their behalf by a parent.

The **National Inpatient Sample** (NIS) is a nationally representative sample discharge data from the Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality (AHRQ) (NIS, 2017). The NIS is an all-payer inpatient database of U.S. hospital inpatient stays,

weighted to estimate national inpatient utilization and experiences. NIS 2017 captured more than 7 million stays from 47 states plus the District of Columbia, covering 97% of the U.S. population. The NIS is sampled (an approximately 20% sample) from the State Inpatient Database, all inpatient data contributed from all participating states to HCUP. The NIS sample excludes rehabilitation and long-term acute care hospitals. NIS includes diagnosis codes, procedural codes, length of stay, stay cost, and characteristics of the hospital and patient. The unit of analysis in NIS is index stays, not individuals. For this report, we used NIS from the year 2017. More information about the NIS and HCUP can be found at www.hcup-us.ahrq.gov/nisoverview.jsp

Kaiser Permanente Northern California (KPNC) is an integrated health care delivery system that provides care to nearly four million residents in northern California, including San Francisco, Sacramento, and surrounding areas. While this is not a national snapshot of health and healthcare in adults on the spectrum, findings are valuable as they begin to paint a picture of health in this population. They also fill a void. There is no adequate adult complement to the national surveys used here to examine health and healthcare in children with ASD. National surveys do exist to examine adult health; however they do not typically have a way to note if a survey participant has autism. Furthermore, they likely do not capture a representative sample of this population.

Three manuscripts using the KPNC population were cited throughout this report to describe health and healthcare in adults with ASD (Croen *et al.*, 2015; Davignon *et al.*, 2018; Zerbo *et al.*, 2019). These studies presented findings for transition age youth and adults on the autism spectrum compared to various groups of people also insured by KPNC. A fourth study surveyed KPNC healthcare providers to assess their knowledge and capacity for caring for adults with autism (Zerbo *et al.*, 2015). Although a regional sample, studies have noted that the population covered by KPNC is socioeconomically very similar to the rest of the population in the same geographic area (Gordon, 2015).

Who is this report about?

Children with ASD

The NSCH and MEPS are both national surveys designed to yield results that are representative of health experiences of non-institutionalized children (and adults) in the United States (in 50 states and the District of Columbia) in housing units.

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

Children with ASD were identified in MEPS using the Medical Condition File. Parents can identify their child has ASD in several sections of the survey. First, parents were asked in an open-ended manner to identify any health conditions the child had in the condition enumeration section. Second, parents were asked to identify a condition associated with reported medical events in the medical events section, including medical provider office visits, emergency room visits, outpatient departments, hospital inpatient stays, prescribed medications, and home health providers. Third, parents were asked to identify conditions related to missed school or work in the disability days section. Responses from all these sections were combined in the Medical Condition File, and children with any recording of autism were included in analysis.

Children with special health care needs

The NSCH was designed to oversample children with special health care needs (CSHCN) to get a large sample by which to understand the health and healthcare needs of this population. In order to do this, a short screener survey was sent to selected households to ascertain SHCN status: children who needed more services than typical children, used medication, were prevented from doing things most children their age can do, or needed treatment or counseling were marked as having a SHCN. Families then complete the topical survey, which was much longer and gathered the rest of the information collected in the survey. This follow-up survey asked parents if their child had a current diagnosis from a healthcare provider or other professional from a list of 25 conditions, of which ASD is one. Not all children with parent-reported health conditions, including ASD, screen positive on the CSHCN screener.

MEPS also used the CSHCN questionnaire to identify CSHCH. The questionnaire is integrated into the survey, not used a screener. Information about the CSHCN screener and its use in national surveys is available (Bethell *et al.*, 2002; Bethell *et al.*, 2015). The screener is designed based on the following definition of CSHCN: “Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally,” (McPherson *et al.*, 1998).

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Findings from studies using KPNC describe the health and experiences of transition age youth and adults insured by KPNC during the study period (as defined by each study separately). These results are not representative of health and experiences of a larger, national population.

Inpatient hospital stays

The NIS is a national sample of hospital inpatient stays that provides a nationally representative view of stays in a given year. The NIS captures hospital stays. The number of stays may be greater than the number of individuals who experienced an inpatient stay, as patients may have had more than one stay in a year. NIS captures all inpatient stays regardless of age. NIS does not capture stays at a rehabilitation or long-term acute care hospital.

Patient diagnoses in 2017 were collected through the hospital recording using International Statistical Classification of Diseases and Related Health Problems, 10th revision, Clinical Modification (ICD-10-CM) codes. Up to 40 diagnoses could be reported for a patient. The first diagnosis is considered the primary diagnosis related to the index stay, also referred to as the principal diagnosis. Index stays with an ASD diagnosis in any of the 40 positions were considered ASD stays for this report. An ASD diagnosis is captured here by ICD-10-CM code F84.0, F84.5, or F84.9.

For NIS, patients with a diagnosis of another mental, behavioral, or neurodevelopmental disorder (MBND) were used as a comparison to ASD patients. This comparison group was created using Clinical Classifications Software Refined (CCSR) for ICD-10-CM-coded diagnoses version 2020.3. CCSR codes are curated and housed by HCUP to create clinically meaningful categories for analysis. CCSR aggregates ICD-10-CM diagnosis codes into smaller, clinically meaningful categories that generally align with ICD-10-CM diagnosis chapters. The CCSR body system for Mental, Behavioral, and Neurodevelopmental Disorders includes 32 subcategories. The MBND comparison group was created capturing any of the 32 subcategories in the primary or any secondary diagnosis position. Any

individual with an ASD diagnosis as previously defined was excluded.

The MBND group includes mental and behavioral disorders due to physiological conditions or psychoactive substances including schizophrenia and other non-mood psychotic disorders; mood [affective] disorders; anxiety, dissociative, stress-related, somatoform, and other nonpsychotic mental disorders; behavioral syndromes associated with physiological disturbances and physical factors; disorders of adult personality and behavior; neurodevelopmental disorders; and substance-related disorders.

Principal diagnoses for inpatient hospital stays were also categorized using the CCSR taxonomy. When appropriate for interpretation, CCSR categories were combined. Combined categories include mood disorders, physical injury, stomach or intestinal diseases, and pregnancy.

Data analysis

We presented descriptive data for key indicators in this report. We used percentages and means 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. However, we reported differences in indicators that seemed to have practical significance between groups. Differences of larger than 10% were generally reported between groups. To ensure adequate sample size for reliable inference, we calculated the relative standard error (RSE) by dividing the standard error by the proportion estimate (Parker *et al.*, 2017). The RSE is a measure of precision of an estimate and how much certainty there is that it represents actual experiences. Throughout the report, estimates with a RSE greater than 30% are noted. Estimates with a RSE greater than 50% are not reported.

For this report, race and ethnicity were broken into four groups: white, non-Hispanic; black, non-Hispanic; other or multiple races, non-Hispanic; and Hispanic. The grouping of non-white and non-black into an “other” category was done due to small numbers of people who identified as another race or multiple other races. Other races asked in NSCH included American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, and Other Pacific Islander.

All analyses were done incorporating the complex sample design information, including weights, from the NSCH 2016-2018, MEPS 2013-2017, and NIS 2017 in Stata 15 (Statacorp, 2017).

To read more about NSCH methods, visit <https://www.census.gov/programs-surveys/nsch/technical-documentation/methodology.html>.

To read more about MEPS methods, visit file-specific documentation found on https://www.meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp and the household component methodology report found https://www.meps.ahrq.gov/data_files/publications/annual_contractor_report/hc_ann_ctrct_methrpt.shtml.

To read more about NIS methods, visit <https://www.hcup-us.ahrq.gov/db/nation/nis/nisdbdocumentation.jsp>.

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.

Defining medical home in the NSCH

In the NSCH for each of the years 2016-2018, medical home presence was measured by a composite measure of five medical home components: presence of a personal doctor or nurse, a usual source of sick care, receipt of family-centered care, ability to get referrals if needed, and effective care coordination. In 2016, this construction was based on 14 survey questions; in 2017 and 2018, it was based on 16 survey questions. To meet the requirements for the presence of a medical home, a parent must report that their child has: a personal doctor or nurse, a usual source of sick care, and family-centered care. Furthermore, if the parent reports need for referrals, they must report they received all needed referrals and effective care coordination. Children who did not need referrals or care coordination could meet the requirements for receipt of care within a medical home if they met all three of the first five components.

Reporting on published results from KPNC

Findings presented from Kaiser Permanente Northern California (KPNC) are from previously published research. Croen *et al.* (2015) examined adults ages 18 and older who were KPNC members for at least nine months of the year from 2008-2012. They compared adults with ASD to a comparison population of adults who did not have ASD using frequency matching. This study examined the prevalence of medical and psychiatric conditions in these adults.

Davignon *et al.* (2018) examined transition-age youth and young adults ages 14-24 who were members of KPNC for at least nine months in a year from 2013-2015. They compared transition-age youth and young adults with autism to same-age peers with 1) ADHD, 2) diabetes mellitus, and 3) no ADHD or diabetes mellitus. This study examined the prevalence of medical and psychiatric conditions in these transition-age youth and young adults.

Zerbo *et al.* (2019) examined adults ages 18 and older who were KPNC members for nine months in each year from 2008-2012. Adults with ASD were compared to adults with ADHD and adults with neither ASD nor ADHD via frequency matching by age and gender. This study presented findings on healthcare utilization in these adults, including healthcare visits and medication use.

A final KPNC study by Zerbo *et al.* (2015) conducted a survey of adult healthcare providers at KPNC in the departments of family and internal medicine, adult mental health, and obstetrics/gynecology. Surveys were collected in 2013 from 922 healthcare providers. Topics included knowledge of autism, comfort in treating adult patients with autism, and available and needed training and resources to provide optimal care.

Strengths and limitations

The surveys used in this report (NSCH 2016-2018, MEPS 2013-2017) are large, nationally representative surveys that have information about health and health care in children with ASD. The NSCH and MEPS give insight into the health and healthcare utilization of children on the autism spectrum based on parent report across a variety of indicators. NIS 2017 provides a national picture of hospital inpatient stays for children and adults with a diagnostic code of ASD based on hospital records. Combining these three national sources gives an unprecedented look at health and health care across ages and indicators in a nationally representative population. While these surveys have less information regarding adult health care, our inclusion of health records for adults in the KPNC health

system helps to fill this gap. Together, this report presents an emerging picture of health and health care in people on the autism spectrum across the life course.

The typical limitations of surveys apply to the indicators presented in this report. The NSCH and MEPS rely on parent recall of past events and specific details about cost and healthcare usage. Information about healthcare costs from MEPS is validated when possible through medical and other event records, but validation is not always possible. Recall of specific information about past healthcare events is likely imperfect. In both surveys, small sample size is a problem when examining differences by race and ethnicity. Particularly in MEPS, the number of non-white children is small and uncertainty in estimates results. NSCH and MEPS (as the data is used in this report) are cross sectional and the complex relationships between many of the findings are not fully examined. For example, findings from NSCH showed that public insurance was common in Hispanic children, and they reported the lowest barriers to mental health care. However, they also reported the lowest use of these services and were the least likely to have a primary care provider. The reasons for these potentially discrepant findings are not evident. In NSCH, autism diagnosis is based on parent report of current ASD, not a clinical diagnosis. However, prevalence of parent reported ASD has been found to be similar to national estimates of prevalence from medical and educational records (Kogan *et al.*, 2009). MEPS also relies on parent report but does not specifically ask about ASD diagnosis; MEPS relies on parent to offer ASD as a condition during enumeration or as reason for a medical event.

The accuracy of NIS data relies on documentation of diagnoses in hospital records, either as a reason for hospitalization or a relevant diagnosis. Therefore, it is possible that persons on the autism spectrum experienced inpatient stays but did not have an ASD diagnosis in their records.

Finally, data from KPNC only captures experiences of patients receiving care through the KPNC health system in northern California. We chose to present these findings with the nationally representative findings from the other data sources because data on adult health and healthcare is limited. However, nationally representative data would create a clearer picture of health across the country.

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