NATIONAL AUTISM INDICATORS REPORT:

Mental Health

AUGUST 2021

Life Course Outcomes Program

PAC
POLICY & ANALYTICS CENTER

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Life Course Outcomes
Research Program

Mission

The A.J. Drexel Autism Institute is the first research organization built around a public health science approach to understanding and addressing the challenges of autism spectrum disorders. The Autism Institute's mission is to understand and address the challenges of autism by discovering, developing, and sharing population-level and community-based public health science.

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**

How to Cite This Report

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National Autism Indicators Report: Mental Health

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Letter from the Program Director

Lindsay L. Shea, DrPH, MS

Often health and mental health are described separately in reports and research. However, mental health is an integral but complex component of a healthy life. To ensure a focus on gaps and opportunities to address both individual and population-level mental health, this report extracts important findings about mental health among autistic individuals. We generated indicators that will help continue to track mental health outcomes and examine mental health within national systems. By studying these systems, our findings are exceptionally well poised to inform needed changes.

Mental health diagnoses are common: almost **800 million people** around the world had a diagnosed mental health condition in 2017. Mental health diagnoses occur at substantially higher rates among children, youth, and adults on the autism spectrum. However, studies estimating rates in autistic individuals are scattered across varying approaches. This report is among the first to compile data across multiple, robust sources to paint a thorough picture of where research, policy, and practice must push further.

This National Autism Indicators Report presents a series of important and timely mental health needs. Both detection of mental health diagnoses *and* linkages to effective treatment options for autistic individuals need substantial advancement. Autistic individuals who do not get the mental health services and supports they need are less likely to participate in relationships and in their communities in the ways they desire and that are aligned with their strengths. Consequently, our workforce and the communities we live in are missing out on tremendous assets that enrich and strengthen us.

Changing how we deliver mental health services is an incredible challenge. The system has been in place for so long and has a lot of moving parts. But recent events present a moment for change. The COVID-19 pandemic saw an increase in mental health concerns, but also new views on how people can be supported. In the wake of the pandemic, fresh opportunities to rethink approaches can and should be embraced. By using data and tracking indicators, we can drive toward change that puts mental health care at the forefront of the service delivery system for autistic individuals who need it.

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Report summary

This report focuses on mental health and mental health care in autistic children and adults. It is a follow-up of our previous report on health and healthcare. Mental health is an integral part of whole-person health and wellbeing. It is also a key component of community health.

The purpose of this report is to catalogue indicators of mental health and mental health care to highlight areas of needed improvement in practice and policy. To examine mental health, we used four main sources of data: 1) two federally funded national surveys conducted in the United States, 2) one administrative database of hospital inpatient stays, 3) Centers for Medicare & Medicaid Services (CMS) Medicaid Analytic eXtract (MAX) files, and 4) previously published research findings from Kaiser Permanente Northern California (KPNC) patient records.

We found high rates of co-occurring mental health conditions among autistic children and adults. Thirty nine percent of autistic children took medication in the past 12 months for difficulties with emotions, concentration, or behavior. This percentage was much higher for autistic children with certain co-occurring conditions, including depression (79%). In a study of adults enrolled in KPNC, autistic adults had higher utilization than peers of psychotropic medications, with nearly two-thirds of autistic adults (62%) taking a psychotropic medication in the past year. Autistic children with unmet need for mental health care were the least likely to participate in sports teams or lessons (25%) and in community service or volunteer work (12%) compared to children who had no unmet need for mental health care.

This report highlights mental health care as an urgent priority and documents barriers that individuals and families face when trying to access mental health care. There are many barriers to comprehensive mental health care and improved mental health that we did not measure, including availability of providers, providers who are trained and willing to treat autistic patients, financial and insurance hurdles, and stigma associated with both autism and mental health care. Good health and wellbeing require effective interventions and supportive policy to ensure that mental health needs of autistic children and adults are effectively addressed.

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Background

What is mental health?

Mental health is a spectrum. It refers to the way people think, feel, and behave, and how regulation of emotions and behaviors impact functioning, relationships, adapting to change, and coping with adversity. At one end is the presence of diagnosable mental health conditions. These conditions describe difficulties in thinking, feeling, or behavior that impact functioning and cause distress. Somewhere in the middle of the spectrum, people experience mental health problems that do not meet diagnostic criteria for specific psychiatric conditions. At the other end of the spectrum is a state of mental wellbeing that supports healthy functioning and quality of life. Across this spectrum, mental health challenges can significantly impact a person's ability to function in all life domains resulting in social isolation, strain on family members and relationships, financial hardship, housing insecurity, and loss of employment (Satcher, 2000).

One in five adults in the U.S. had a diagnosable mental illness in 2019 (SAMHSA, 2020). About half of people in the U.S. will experience a mental health condition at some point in their life (Kessler *et al.*, 2007). Some people experience mental health conditions that are temporary or cyclical, while others have serious and persistent mental illness.

Many adult mental health conditions begin during childhood and adolescence (Kessler *et al.*, 2007; Merikangas *et al.*, 2010). These conditions can cause cumulative harm as life progresses. But conditions that occur among children, such as anxiety and depression, may be successfully managed through early diagnosis and intervention (Bayer *et al.*, 2009; Cuiipers *et al.*, 2008). Rates of mental health conditions in children are high and have been increasing over time (Collishaw, 2015). Nearly one-quarter (22%) of children ages 3-17 in 2019 had at least one mental, emotional, developmental, or behavioral problem (CAHMI, 2021). Common mental health conditions include anxiety disorders, mood disorders such as depression and bipolar, psychotic disorders such as schizophrenia, impulse control and addiction disorders, attention deficit/hyperactivity disorder (ADHD), personality disorders, and post-traumatic stress disorder (PTSD).

Mental health and autism

This report examines mental health in autistic people. Autism is a developmental disability. Developmental disabilities can impact a person's ability to function but are different from mental health conditions. Developmental disabilities impact developmental milestones and developmental processes such as language, social, or motor development; tend to present consistently from early childhood; and do not necessarily involve emotional distress as part of their diagnostic criteria. The study of mental health in this population is a relatively recent phenomenon. Previously, mental health challenges experienced by autistic people often went unrecognized or were assumed to be due to autism (Whiteley *et al.*, 2021).

Autistic children and adults experience higher rates of co-occurring mental health conditions than their peers, impacting quality of life and increasing the complexity and cost of health care (Kerns *et al.*, 2020; Joshi *et al.*, 2010; Peacock *et al.*, 2012; Zablotsky *et al.*, 2016; Ahmedani and Hock, 2012). The higher rates of mental health conditions in autistic people may have genetic or social origins. Parents of autistic people have higher rates of anxiety and depression than peers (Daniels *et al.*, 2008; Micali *et al.*, 2004).

Experiences of adversity, isolation, and stigma may place autistic people at increased risk for mental health concerns (Botha & Frost, 2020; Kerns *et al.*, 2017). Some autistic people use "camouflaging" to act differently or repress actions to blend into social situations, which has recently been associated with increased depression and anxiety in autistic adults (Hull *et al.*, 2021). Heightened intolerance of uncertainty is also linked to increased anxiety in autistic and non-autistic people (Boulter *et al.*, 2014). Increasingly, clinicians and researchers note that stigma and lack of understanding, accommodations, and access to services contribute to mental health difficulties (Mitchell *et al.*, 2021).

Adverse childhood experiences and risk factors for poor mental health

Adverse childhood experiences (ACEs) are events that occur in childhood with a high likelihood of trauma. Common ACEs include experiences of violence, abuse, or neglect; witnessing violence; growing up in a household with substance use or mental health problems; and parental separation and incarceration. These events may impact child development and lead to worse physical and mental health. Mental health concerns are more common in children who have experienced ACEs, and experiencing more ACEs is associated with higher likelihood of mental health problems (CAHMI, 2021). Some children are more likely to experience ACEs than others. Exposure to many ACEs is more common in Black youth than in White youth, particularly exposure to community violence and police violence due to structural inequities (Maguire-Jack *et al.*, 2020).

Autistic youth are more likely to experience ACEs than non-autistic youth, and ACEs may disproportionally impact certain autistic youth (Berg *et al.*, 2016). Autistic youth from lower income households are more vulnerable to the long-term impacts of ACEs (Kerns, *et al.*, 2017), as are Black youth (Geller, 2021). The link between ACEs and mental health may be impacted by resilience – the capacity to adapt well in the face of adversity or trauma based on both individual and environmental factors. Pathways between ACEs, resilience, and mental health may be different in autistic people than peers without autism; autistic people may demonstrate resilience differently. However, the presence of co-occurring mental health conditions may undermine resilience and these conditions are common in autistic people.

While feeling accepted is related to lower depression and stress levels (Cage *et al.*, 2018), feelings of isolation, marginalization, and discrimination may all lead to stress that causes worsening mental health (Honey *et al.*, 2001; Emerson and Hatton, 2007). Non-autistic people of all ages tend to form negative impressions of autistic people, thinking of them in more negative terms and expressing less willingness to interact with autistic people (Sasson *et al.*, 2017), contributing to isolation. Autistic youth may also experience traumatic events, such as discrimination related to being autistic or peer victimization (Fuld, 2018; Hoover and Kaufman, 2018). Autistic adults report victimization and bullying in the workplace, community, and relationships (Weiss and Fardella, 2018; Fardella *et al.*, 2018). Trauma across the life course is understudied in this population (Kerns *et al.*, 2015; Baldwin and Costley, 2016).

Mental health services and support

Mental health services can play a key role in supporting people to cope with mental health concerns (Daniels *et al.*, 2008). Optimal management of mental health concerns can include both behavioral supports and use of medications (AACAP, 2009; AACAP, 2015). Primary care providers in the U.S. play a key role in identifying and managing mental health care needs. Primary care providers are the first point of contact to the medical system for most people. They are well positioned to have a holistic picture of their patients and identify emerging concerns. However, they often do not have expertise in providing mental health care directly.

When mental health is not adequately addressed, issues may escalate to crisis level. Without support, treatable mental health conditions may become more severe and disabling over time (Maddox *et al.*, 2020; Maddox & Gaus, 2019). There is no centralized mental health crisis system in the U.S. Without targeted mental health treatment, a person in crisis may end up in a hospital emergency department, in contact with law enforcement, in a psychiatric inpatient hospital, or at an increased risk of suicide or self-harm. Emergency departments and law enforcement are ill-suited to care for persons in mental health crisis, and psychiatric hospitals are expensive, overburdened, and under-resourced.

Barriers to accessing mental health care

Many autistic people experience barriers to mental health care. Many healthcare practitioners feel inadequately prepared to care for their autistic patients, particularly adult health and mental health care providers (Zerbo *et al.*, 2015). And most feel they do not have adequate tools and resources to accommodate autistic patients in their practice. In one study, half of mental health clinicians had no experience working with autistic clients, and clinicians' lack of knowledge and confidence related to working with this population were identified as a barrier to care for autistic adults (Maddox *et al.*, 2020). Mental health providers may lack understanding of autism and how autistic people experience and communicate about mental health issues. They may also hold biased assumptions that autistic people cannot make meaningful progress in improving their mental health and functioning (Maddox *et al.*, 2020; Camm-Crosbie *et al.*, 2019). This lack of understanding is a significant barrier to accessing treatment and attaining positive health outcomes. There is a particular lack of knowledge regarding trauma-related services for those with autism amongs providers despite notable demand for these services (Kerns *et al.*, 2020). Black or Latino autistic people experience additional barriers resulting in late diagnosis or misdiagnosis of autism and mental health conditions due to clinician bias, structural barriers, and a historical context of racism embedded in mental health care that engenders distrust (Dababnah *et al.*, 2018; Suite *et al.*, 2007; Mandell *et al.*, 2009).

Problems with the fragmentation of service systems contribute to lack of mental health care access for autistic people. Many autistic people lose access to services when they leave school-based service systems for youth and struggle to connect with adult community mental health services (Shattuck *et al.*, 2011). This problem is worse for Black youth and youth from low-income households. Mental health services are not integrated with the developmental disability (DD) service system so autistic adults who use DD services are referred back and forth between DD service providers who do not offer mental health support and community mental health services that are not inclusive of autistic people. This disconnect delays or entirely prevents access to care (Maddox & Gaus, 2019).

Cost is another notable barrier to care. Private insurance is required to cover mental health services by mental health parity legislation. But that insurance is typically obtained through employment, and employment outcomes among autistic individual are poor. Even among those who are insured, there are often substantial costs to receiving mental health care (Rowan *et al.*, 2013). In the Medicaid public health insurance system, mental and behavioral supports are more robust but often separate systems.

Stigma can prevent individuals and families from seeking care. Anticipated or experienced stigma about mental health care can prevent people from seeking support. Autistic individuals may feel stigma related to mental health conditions and autism. The stigma surrounding autism has historically led parents and families to keep their children from being diagnosed or seeking the care that they need. Autistic people report experiencing stigma and discrimination in clinical settings which could further contribute to hesitancy about accessing mental health services (Nicolaidis *et al.*, 2015).

The impact of poor mental health on people, families, and communities

Mental health impacts people, families, and communities. Poor mental health contributes to challenges in a variety of life areas, lower levels of well-being, and early mortality in adults with autism.

Underemployment. People with mental health conditions are more likely to experience periods of underemployment and unemployment than their peers (Butterworth *et al.*, 2012). This relationship goes both ways, with underemployment a known cause of worsening mental health. Adolescents with chronic mental health conditions experience a 60% greater risk of not participating in employment or postsecondary education in early adulthood compared to adolescents without mental health conditions (Rodwell *et al.*, 2018).

Worse physical health. People with mental health conditions are at higher risk for many physical health conditions, including cardiovascular disease (Newcomer and Hennekens, 2007). They are also more likely to die earlier from all causes (Lawrence *et al.*, 2010). Increased comorbidity and mortality may be partially caused by reduced healthcare use in people with mental health conditions. Autistic people report experiencing anxiety and depression-related barriers to participation in physical activity which may worsen physical health and reduce opportunities for socialization (Healy *et al.*, 2021).

Participation in the community. People with mental health conditions often face stigma and marginalization, reducing the time they spend interacting in their community. This reduces social capital, or the number and quality of relationships a person has available to call upon in many situations.

Relationships. People with better mental health are more likely to enter into romantic relationships, which are associated with strengthening mental health (Braithwaite and Hold-Lunstad, 2017). All types of relationships combat loneliness, which is common in people with mental health conditions and may cause worsening mental health (Duke, 2017).

Covering mental health in this report

In this report, we will examine the mental health and mental health care of autistic children and adults. Mental health includes many conditions and states of being. We will use mental health as a term to encompass conditions and disability alternatively referred to as behavioral, psychiatric, psychological, emotional, and substance use. This definition has been used in other reports and statements on the topic (Foy *et al.*, 2019).

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Chapter 1: Mental Health Conditions

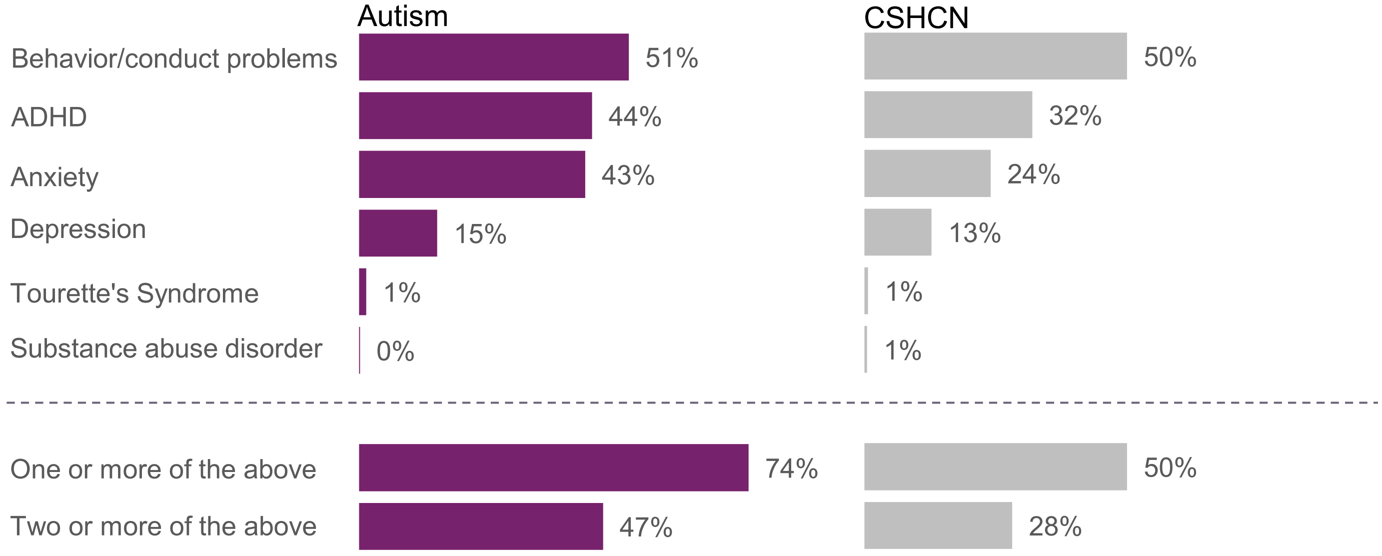
Mental health exists across a spectrum. Mental health concerns may be present without a diagnosed condition. Mental health concerns, whether a diagnosed condition or not, can significantly impact a person's ability to function across life domains resulting in social isolation, strain on family members, financial hardship, housing insecurity and loss of employment (Satcher, 2000). This chapter reports on the presence of mental health conditions in autistic children and adults.

Mental health conditions in children

How do we know?

Data on co-occurring conditions in children came from the National Survey of Children's Health (NSCH) years 2016-2019. Parents were asked if their child had ever been told by a doctor or health care provider that they had a list of conditions, including the mental health conditions reported here. We compared autistic children ages 3-17 to children with other special health care needs (CSHCN). CSHCN are children with more health service needs or use than peers.

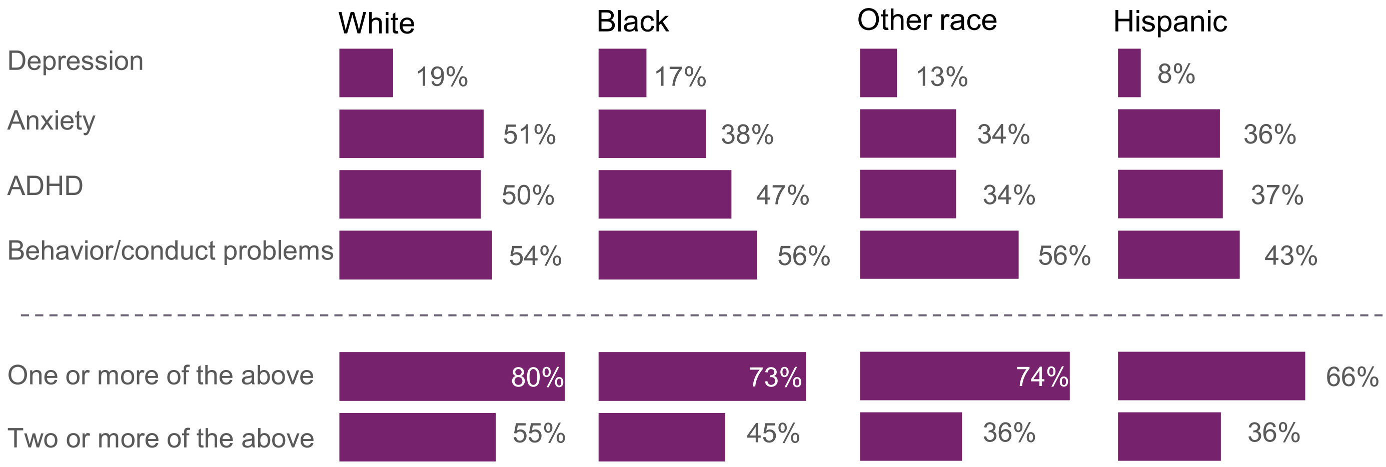
The most common co-occurring mental health conditions in autistic children were behavior and conduct problems, ADHD, and anxiety.



Source: National Survey of Children's Health 2016-19

Co-occurring mental health conditions were common in autistic children ages 3-17; three-quarters had at least one of the following mental health conditions: behavioral or conduct problems, ADHD, anxiety, depression, Tourette's syndrome, or substance abuse disorder (only asked for children ages 6-17). Nearly half had at least two of these conditions. Most of these conditions were more common in autistic children than in other CSHCN.

Prevalence of mental health conditions varied by race and ethnicity in autistic children.



Source: National Survey of Children's Health 2016-19

Some mental health conditions were more common in children based on race and ethnicity. ADHD was more common in White non-Hispanic and Black non-Hispanic autistic children than autistic children of another race or ethnicity. Hispanic autistic children had the fewest number of diagnoses, with two-thirds reporting one or more, and one-third reporting two or more of these conditions.

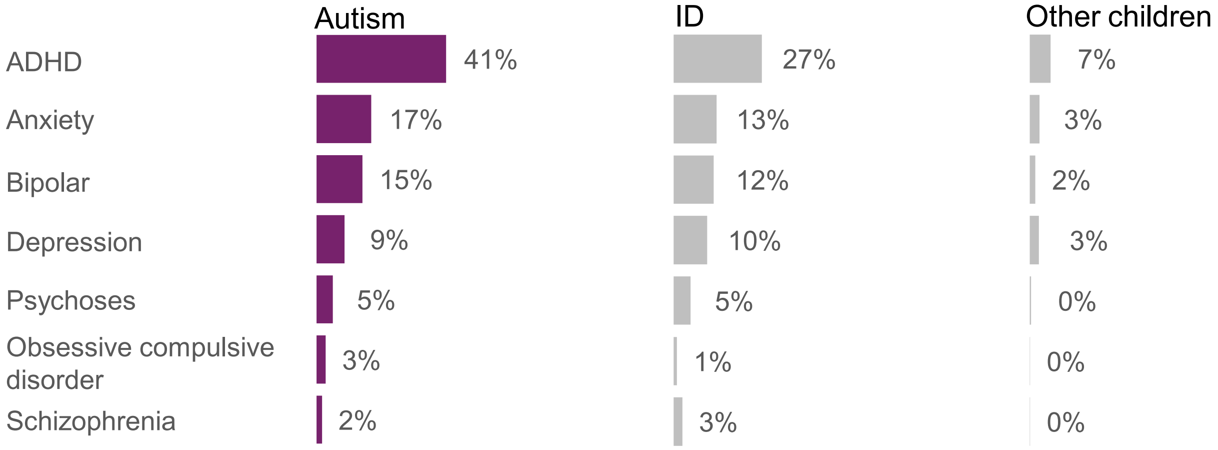
Mental health conditions: Children enrolled in Medicaid

How do we know?

The Centers for Medicare & Medicaid Services (CMS) Medicaid Analytic eXtract (MAX) data files include information about people enrolled in Medicaid between 2008-2012. Medicaid is a public provider of health insurance that is administered by states and funded by state and federal dollars. Medicaid covers children and adults with lower income, people with disabilities, pregnant women, and children in foster care. These estimates examine children ages 0-17 and adults ages 18-64 with autism, intellectual disability (ID) with no autism, and a random sample of all other Medicaid enrollees. MAX is an administrative data source of medical claims, not parent- or self-report like some of the other data sources used in this report including the NSCH. Conditions are captured by administrative records if they were attached to a billable service.

ADHD was the most common co-occurring mental health condition identified in medical records of autistic children enrolled in Medicaid. ADHD was more commonly identified in autistic children than in children with an intellectual disability (ID) without autism and in a random sample of other children. Anxiety was identified in 17% of autistic children. Lower rates of certain conditions in autistic children as identified in Medicaid data than national surveys like the NSCH are likely related to how conditions are identified in each source. In MAX data files, conditions are only captured if they are associated with a service the child received related to that condition that can be billed to Medicaid. Some conditions, like ADHD, may be more likely to have a billable service attached, including prescriptions and office visits. Other conditions, like anxiety in children, may be less likely to have an attached billable service, or they may have received services from non-Medicaid providers. National surveys, including the NSCH, often rely on a parent or individual disclosing that a provider told them they have a given condition.

ADHD and anxiety were common mental health conditions identified in medical records of autistic children enrolled in Medicaid.

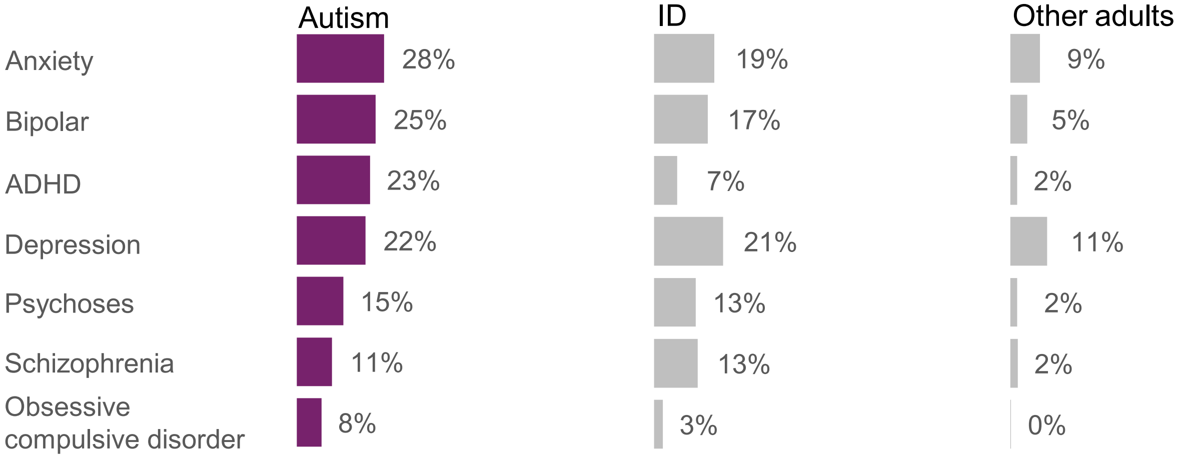


Source: Medicaid MAX 2008-2012

Mental health conditions: Adults enrolled in Medicaid

Anxiety was the most common co-occurring mental health condition identified from administrative Medicaid records in autistic adults ages 18-64 enrolled in Medicaid. Nearly one-quarter of autistic adults also had bipolar, ADHD, and depression indicated in records. Psychoses and schizophrenia were identified in 15% and 11% of autistic adults. Most conditions were more common in autistic adults than in peers. Depression was also common in adults with ID and no autism.

Anxiety and bipolar were common mental health conditions identified in medical records of autistic adults enrolled in Medicaid.



Source: Medicaid MAX 2008-2012

Mental health conditions: Transition age youth and adults in Kaiser

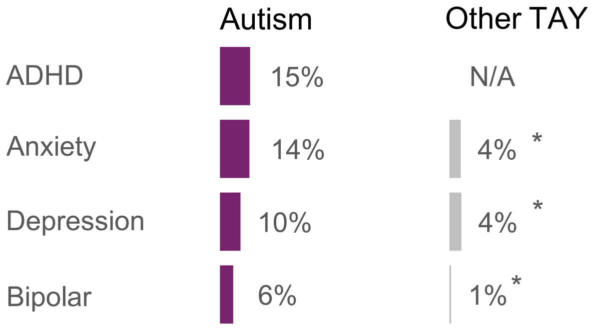
How do we know?

A study by Davignon *et al.* examined 4,123 transition age youth (TAY) with autism ages 14-25 who were members of Kaiser Permanente Northern California (KPNC) for at least nine months of each year from 2013-2015 (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). A second study focused on 1,507 autistic adults 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 autism. Kaiser data come from the medical records of KPNC patients.

Psychiatric conditions were more commonly identified in the medical records of transition age youth (TAY) with autism than in other TAY groups from KPNC. Fifteen percent of TAY with autism had ADHD, and 14% anxiety in their medical records, compared to 4% of a comparison group of peers.

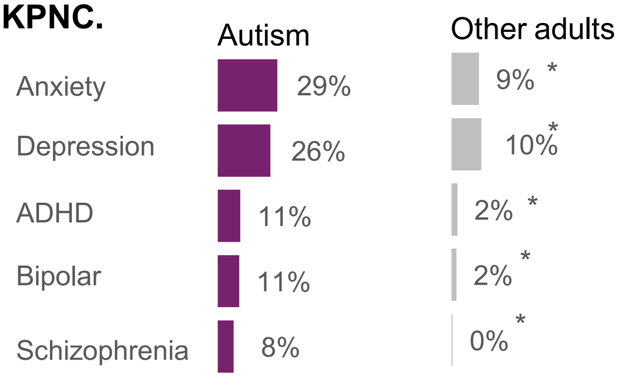
About one-third of autistic adults in the Kaiser sample had anxiety in their medical records, and about one-quarter had depression. Adults with autism were two to three times as likely to have depression or anxiety compared to adults without autism.

Prevalence of conditions in autistic TAY and other TAY in KPNC.



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

Co-occurring conditions in autistic adults and a random sample of other adults in KPNC.



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

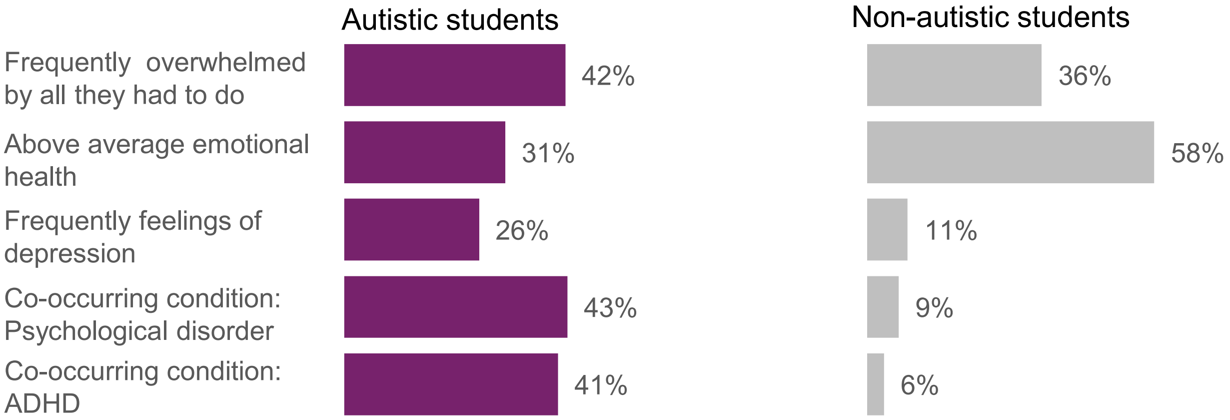
Mental health of college students

How do we know?

This study uses data from a national survey of freshman to examine student-reported mental health in autistic students and their peers. The freshman survey includes first-year college students at four-year nonprofit colleges and universities enrolled in the fall of 2012, 2014, 2016, and 2018. Autistic students represented 0.6% of full-time freshman during this time.

Autistic students reported lower emotional health than their peers. About a quarter of autistic students reported frequently feeling depressed, and closer to half (42%) reported feeling overwhelmed by all they had to do. Autistic students more likely to report they had a psychological disorder (43% compared to nine percent of peers), and 41% reported they had ADHD.

Autistic college students often felt overwhelmed and nearly half had a co-occurring psychological disorder or ADHD.

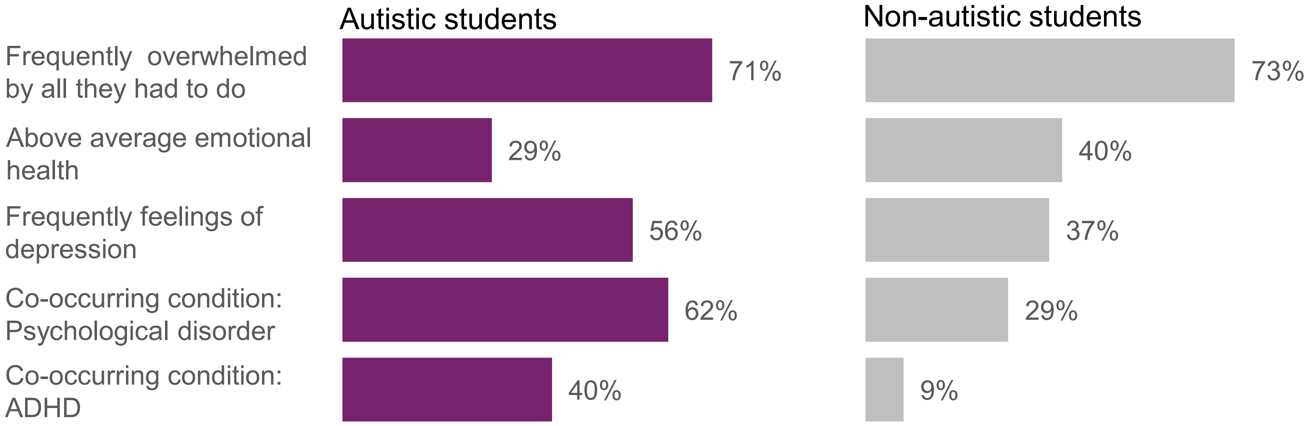


Source: Fernandes *et al*., 2021

Spotlight on autistic students with frequent anxiety or depression

Forty-four percent of autistic students reported frequent anxiety or depression in their freshman year. Twenty-two percent of all other freshman students reported the same. Autistic students with frequent anxiety or depression were more likely to rate their emotional health below average than their peers without autism (27% versus 16%). Nearly three-quarters of autistic students reported being overwhelmed by all they had to do. Mental health conditions were more common in this group than in the overall group of autistic students, with 62% reporting a psychological disorder. However, the rate of ADHD was the same, while still higher than peers without autism.

Autistic college students who had frequently feelings of anxiety or depression frequently felt overwhelmed, and nearly two-thirds had a co-occurring psychological disorder.



Sources: The Freshman Survey 2016, 2018, and 2019

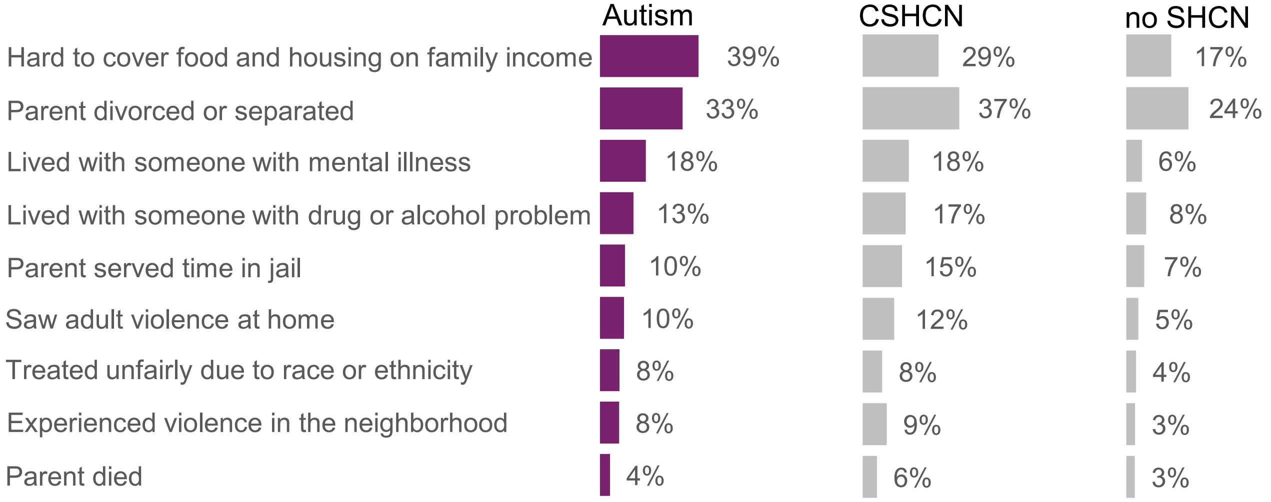
Adverse childhood experiences

How do we know?

Adverse childhood experiences (ACEs) are events that occur in childhood with a high likelihood of trauma. These events may impact child development and lead to worse physical and mental health. Mental health concerns are more common in children who have experienced ACEs, and experiencing more ACEs is associated with higher likelihood of mental health problems (CAHMI, 2021). Data on ACEs in children came from the National Survey of Children's Health (NSCH) years 2016-2019. The nine ACEs included in the NSCH can be seen in the graph below.

Over half (61%) of autistic children experienced at least one ACE, similar to other CSHCN but higher than children with no SHSN (41%). Approximately 12% of autistic children experienced at least four ACES, similar to other CSHCN but twice as high as children with no SHCN. The most common ACEs for all children were trouble covering the basics, including food and housing, on the family's income, and parent divorce or separation.

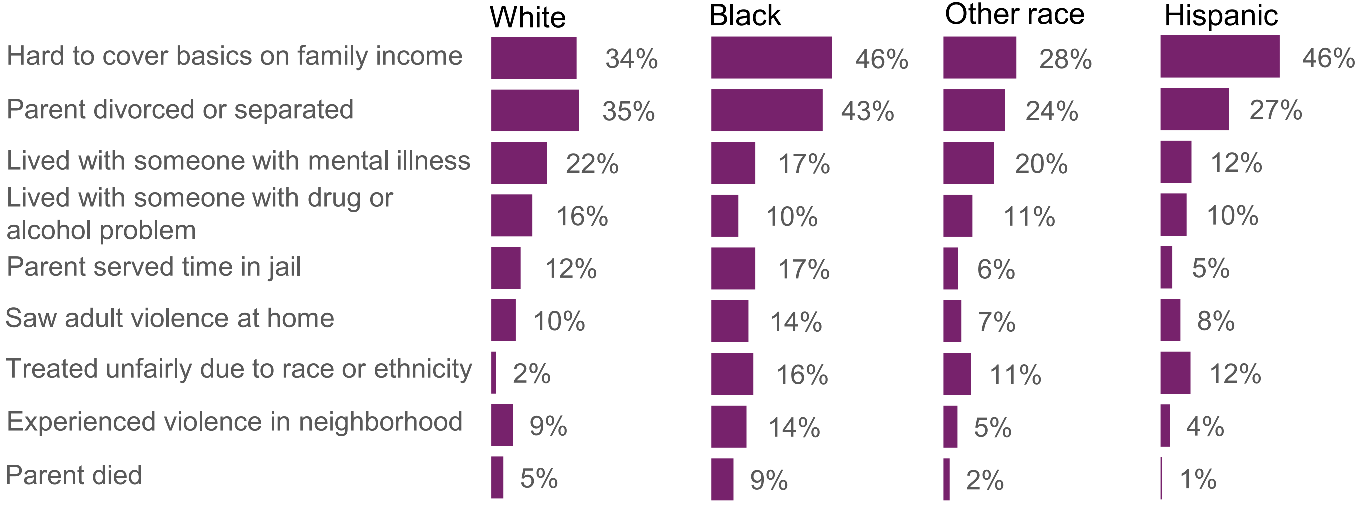
The most common ACEs experienced by autistic children was difficulty covering basics like food and housing on the household income.



Source: National Survey of Children's Health 2016-19

Most ACEs were more common in Black autistic children than in children of another race or ethnicity. Nearly half of Black autistic children experienced at least one ACE, compared to about a third of White children, children of another or multiple races, and Hispanic children. Eighteen percent of Black autistic children experienced four or more ACEs, as did 13% of White children, 8% of Hispanic children, and 10% of children of another race.

Many ACEs were more commonly experienced by Black autistic children than children of another race or ethnicity.



Source: National Survey of Children's Health 2016-19

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National Autism Indicators Report: Mental Health

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Chapter 2: Mental Health Services

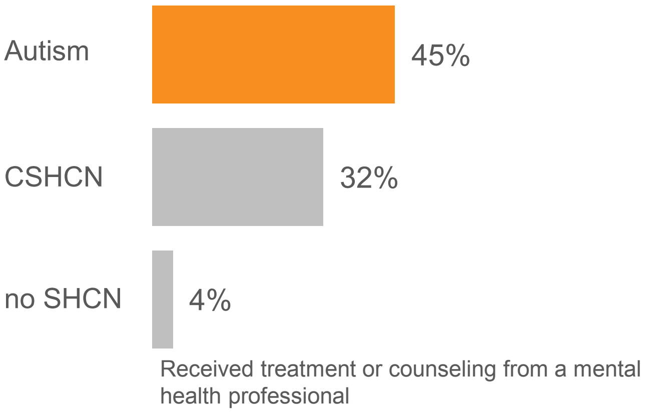
Management of mental health concerns and conditions are important for health, quality of life, safety, and most aspects of life. Mental health services can play a key role in supporting people to cope with mental health challenges. When primary treatment of mental health is not adequately addressed, behaviors may escalate to a crisis. Without support, treatable mental health conditions may become more severe and disabling over time (Maddox *et al.*, 2020; Maddox & Gaus, 2019). Many autistic children and adults end up in the hospital for mental health conditions. Mental health conditions are ambulatory care sensitive conditions (ACSCs), those which can be treated and maintained within primary care to prevent hospitalization (Carbone *et al.*, 2015). When a person is hospitalized for an ACSC, it maybe be a marker of inadequate primary care (Coller *et al.*, 2018).

Use of mental health services

How do we know?

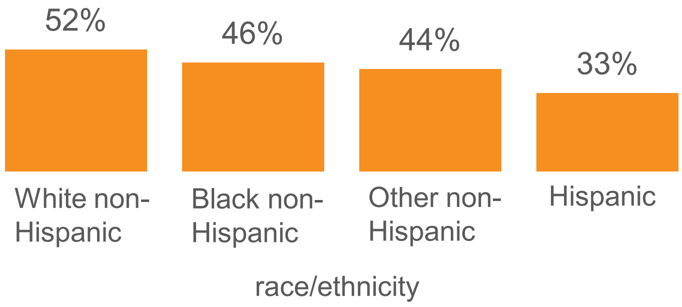
Data on service use in children came from the National Survey of Children's Health (NSCH) years 2016-2019. Parents were asked, "During the past 12 months, has this child received any treatment or counseling from a mental health professional?"

Autistic children were the most likely to receive treatment or counseling from a mental health professional.



Source: National Survey of Children's Health 2016-19

Hispanic autistic children were the least likely to receive treatment or counseling from a mental health professional.

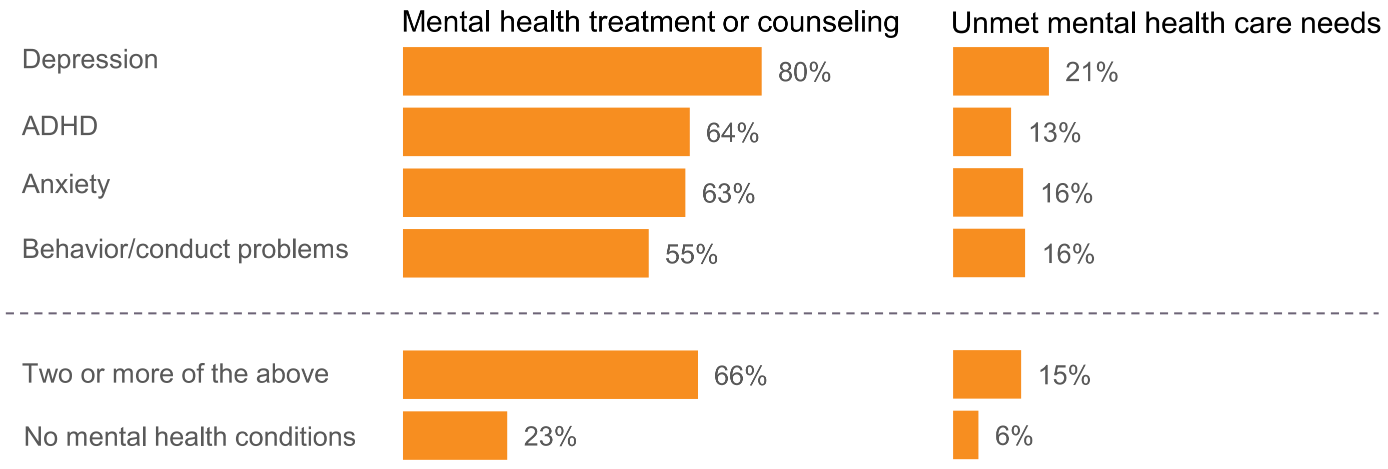


Source: National Survey of Children's Health 2016-19

Nearly half of autistic children received treatment or counseling from a mental health professional in the past year, compared to about one-third of CSHCN and four percent of children with no SHCN. Treatment or counseling was more common in older autistic children (age 12-17) (51%) than in younger ones ages 3-11 (40%). Hispanic autistic children were the least likely to receive treatment or counseling, with one-third of parents reporting this.

Autistic children with depression were the most likely to receive treatment or counseling from a mental health professional in the past year (80%) and children with no co-occurring mental health conditions were the least likely (23%). Autistic children without any co-occurring mental health conditions were the least likely to receive behavioral treatment for autism, and the least likely to have unmet mental health care needs.

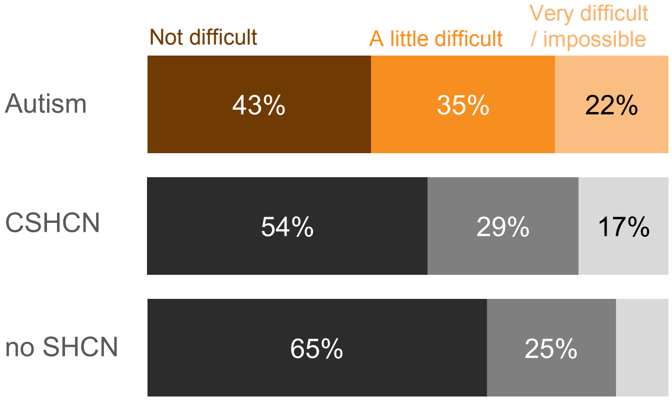
Autistic children with depression received the most, and had the most unmet need for, mental health care.



Source: National Survey of Children's Health 2016-19

Treatment or counseling was more difficult for autistic children to get than their peers, with one-fifth of parents of autistic children reporting it was very difficult or impossible to access needed services. Twelve percent of parents of autistic children reported their child needed mental health care that they did not receive in the past year.

Half of parents of autistic children had at least some difficulty getting the mental health services their child needed.



Source: National Survey of Children's Health 2016-19

Care in autistic adults: Kaiser spotlight

How do we know?

A published study used Kaiser Permanente Northern California (KPNC) health data to examine health care use among 1,507 adults with autism ages 18 and older (Zerbo *et al.*, 2019). This study presented the types of health care services that adults with autism received in 2012. The study compared adults with autism to adults with ADHD and adults in the general population. The study sample came from KPNC, which serves approximately four million people in the Sacramento and San Francisco areas.

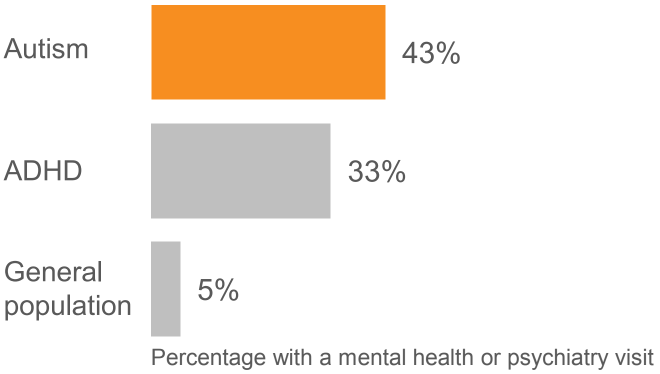
Almost half (43%) of autistic adults enrolled in KPNC had a mental health or psychiatry visit in the past year, compared to one-third of adults with ADHD and five percent of adults without autism or ADHD.

Cost of care for mental health visits

How do we know?

Information on care cost for children comes from the Medical Expenditure Panel Survey (MEPS) years 2013-2017. MEPS is a national sample of households, including those with autistic children.

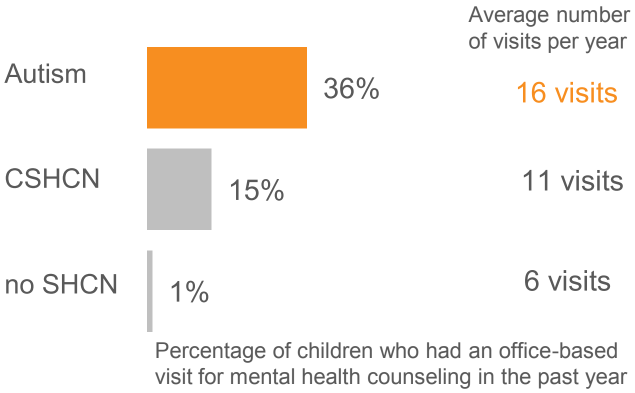
Autistic adults enrolled in KPNC were the most likely to have a mental health or psychiatry visit in the past year.



Source: Zerbo *et al.*, 2019

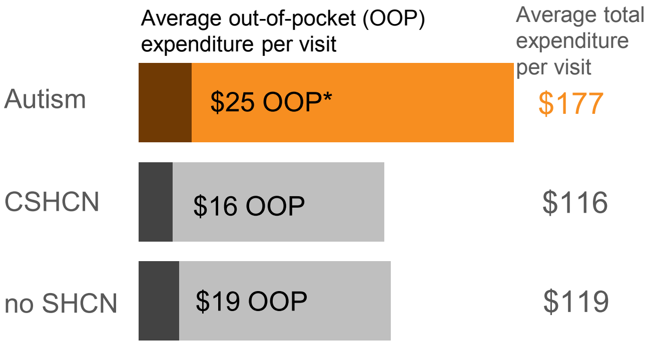
One-third of autistic children had an office visit for psychotherapy or mental health counseling in the past year, more than twice as many as CSHCN. Of autistic children who had a visit, the average number of visits per year was 16, with an average out-of-pocket expenditure of $25.

Autistic children were the most likely to have an office-based visit where they had mental health treatment or counseling.



Source: Medical Expenditure Panel Survey 2013-17

Autistic children had the highest average total expenditure per visit for outpatient mental health treatment or counseling.



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

Care in critical settings

How do we know?

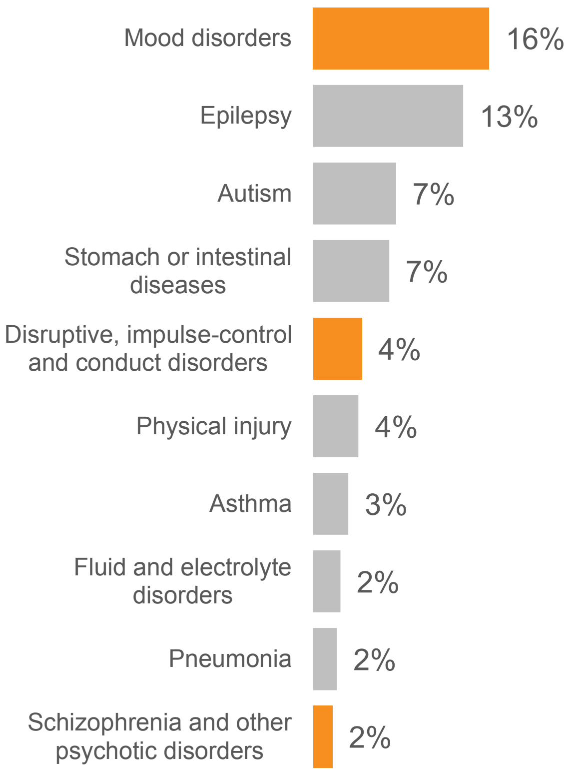
Data on inpatient hospitalizations came from the National Inpatient Sample (NIS) 2017. NIS captures hospital stays. Each stay has a principal diagnosis, the diagnosis that is noted in the record as the reason for hospitalization. Each stay can have up to 40 other diagnoses. We report on principal diagnosis for hospital stays of patients with an autism diagnosis in any point of their stay record.

Mental health conditions can be cared for in more acute settings when they escalate to a crisis situation or are not properly managed in primary care. For autistic children in 2017, three of the most common principal reasons for hospital admission were related to mental health. Mood disorders were the most common reasons for hospital admission in autistic children (16%); disruptive, impulse-control, and conduct disorders were the fifth most common reason (4%), and schizophrenia and other psychotic disorders were the 10th most common reason (2%).

Mood disorders were the most common principal diagnosis for admission of White (19%) and Black (13%) autistic children, but the third most common in Hispanic children (8%). Disruptive, impulse-control, and conduct disorders were similarly common regardless of race or ethnicity. However, schizophrenia and other psychotic disorders were more common in Black autistic children, with four percent having this as their principal diagnosis, the sixth most common reason for admission. Schizophrenia did not make the top 10 list in White or Hispanic autistic children.

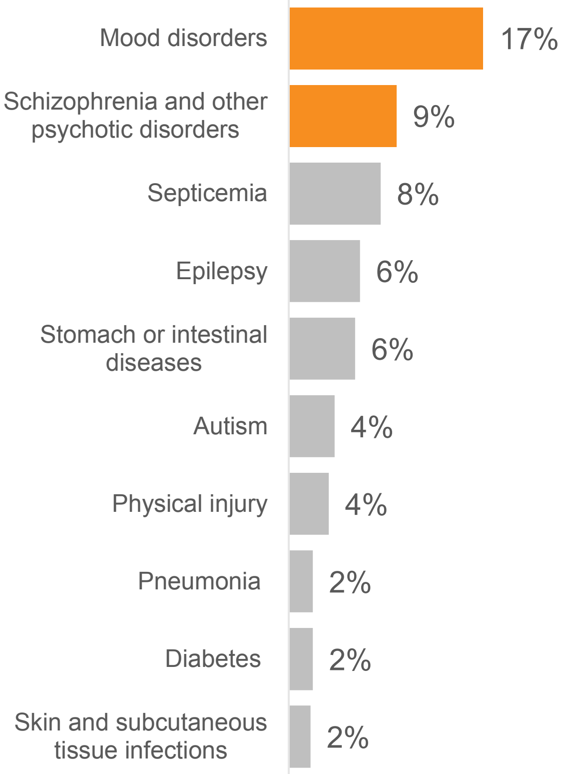
Mood disorders were also the most common principal diagnosis in autistic adults age 18 and up (17%), followed by schizophrenia (9%). Mood disorders were the most common principal diagnosis in White (19%) and Asian or Pacific Islander (10%) autistic adults, while schizophrenia was the most common principal diagnosis in Black (13%), Hispanic (15%) and autistic adults of another or multiple races (11%).

The most common principal diagnoses in stays of autistic child patients, including mental health conditions.



Source: National Inpatient Sample 2017

The most common principal diagnoses in stays of autistic adult patients, including mental health conditions.



Source: National Inpatient Sample 2017

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National Autism Indicators Report: Mental Health

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Chapter 3: Medication and Mental Health Care

As seen in chapter 1, co-occurring mental health conditions are common in autistic people. The use of psychotropic medication is an important consideration in the management of these conditions. Psychotropic medications describe a broad class of drugs used in the treatment of psychiatric and neurological disorders that affect behavior, mood, thoughts, or perception. Several classes of drugs are used to treat mental health conditions including antidepressants, antipsychotics, antianxiety medications, sedatives, hypnotics, stimulants, and antiseizure medications used as mood stabilizers.

Medications are often included in the management plan of mental health conditions and concerns. In autistic children and adults, the presentation of complex symptom profiles makes prescription and symptom management a difficult task that is often approached on a case-by-case and trial-and-error basis. The safety and efficacy of psychotropic medications in autistic populations is largely unknown (LeClerc and Easley, 2015).

Psychotropic medication should ideally be prescribed as part of a holistic management plan including evidence-based psychosocial interventions, a commitment to youth- and family-centered care, and the use of trauma-informed care principles (AACAP, 2015). Ongoing monitoring of symptoms, safety, and side effects is imperative. Overmedication is also a concern in autistic people. Experts appointed by the United Nations Human Rights Council issued a statement on discrimination and human rights violations related to mental health care for autistic people (2015). They identified an over-reliance on psychotropic medications and use of medications to restrain and sedate patients as practices that undermine the rights, health, and wellbeing of autistic people globally.

Medication use in autistic children

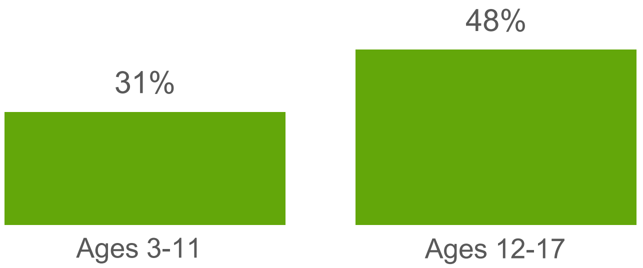
How do we know?

Parents who participated in the National Survey of Children's Health (NSCH) years 2016-2019 were asked if their child took medication for "difficulties with emotion, concentration, or behavior" in the past 12 months.

Over one-third of autistic children (39%) took medication in the past 12 months for difficulties with emotions, concentration, or behavior. Nearly half of older autistic children (ages 12-17) took medication, and about one-third of younger children (ages 3-11).

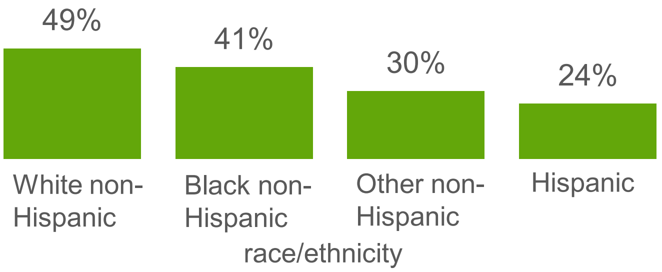
White and Black autistic children were more likely to take medication for emotions, concentration, or behavior than children of another race or Hispanic children.

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



Source: National Survey of Children's Health 2016-19

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



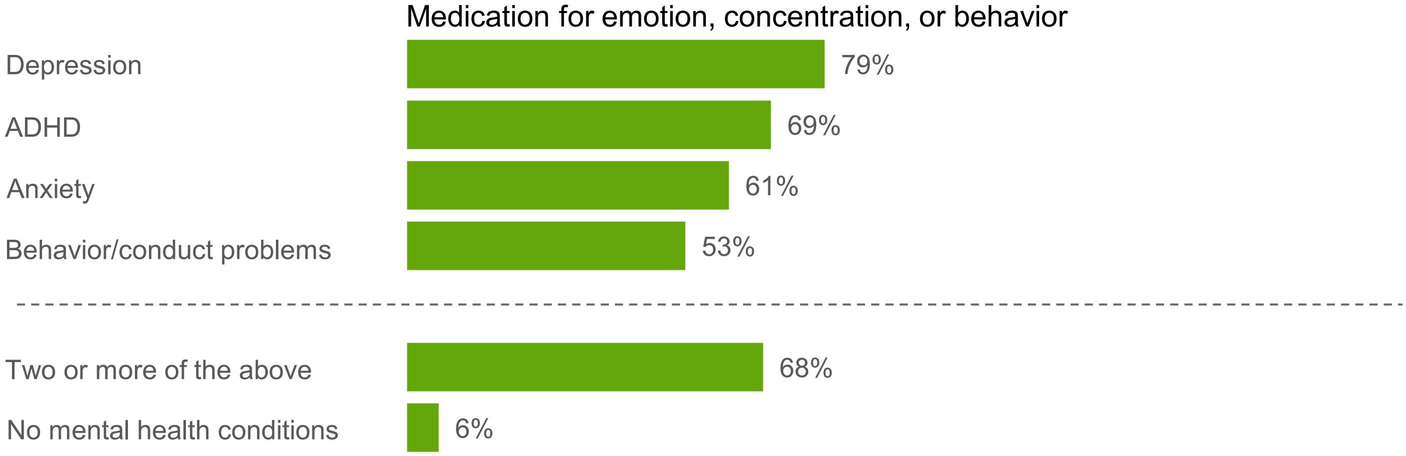
Source: National Survey of Children's Health 2016-19

Medication use by co-occurring condition

Autistic children with certain co-occurring mental health conditions were more likely to have parent-reported medication use. Children with depression were the most likely to be taking medication for emotions, concentration, or behavior.

Three-quarters of autistic children with at least two mental health conditions took medication for emotions, concentration, or behavior. Conditions include behavioral or conduct problems, ADD, anxiety, depression, Tourette's syndrome, or substance abuse disorder. Fewer than 10% of autistic children with none of those conditions took medication.

Medication use was more common in autistic children with certain conditions.



Source: National Survey of Children's Health 2016-19

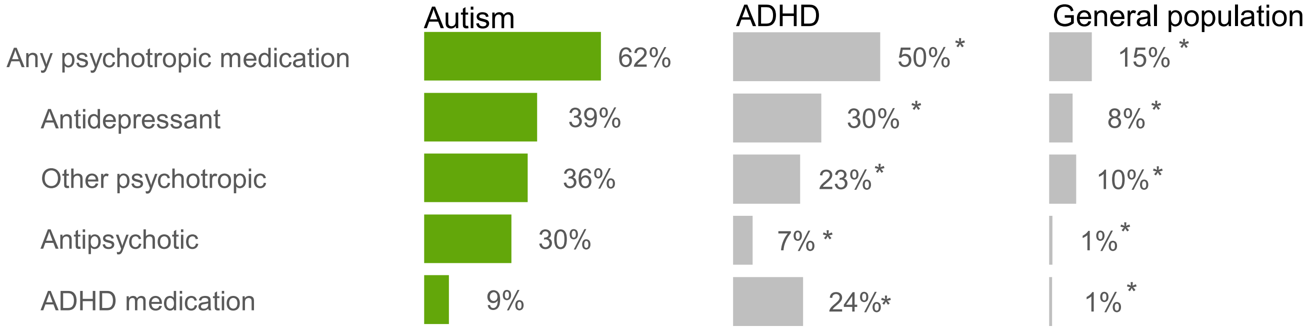
Adult medication use: Kaiser

How do we know?

A published study used Kaiser Permanente Northern California (KPNC) health data to examine medication use among 1,507 adults with autism ages 18 and older (Zerbo *et al.*, 2019). This study presented the percentage of adults with autism with prescriptions for several classes of medication and compared adults with autism to adults with ADHD and adults in the general population. The study sample came from medical records of KPNC, which serves about four million people near Sacramento and San Francisco.

The most common medications for adults with autism enrolled in KPNC were psychotropic medications. Adults with autism had higher utilization of psychotropic medications than peers, with nearly two-thirds of autistic adults (62%) taking a psychotropic medication in the past year.

Most psychotropic medications were more common in autistic adults than other adults.



*Significantly different from the autism 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

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National Autism Indicators Report: Mental Health

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Chapter 4: Mental health and community participation

As shown in Chapter 1, autistic youth have high rates of co-occurring mental health conditions and experience high rates of adverse childhood experiences (ACEs), especially financial hardship. These exposures can contribute to challenges related to mental health and engagement in activities and relationships.

With the right support, people with mental health challenges can improve their lives and become more resilient as a result of their experiences. Mental health providers may support youth and families in connecting with developmentally appropriate activities from playing sports and organized activities with peers to participating in community service and work activities. People with and without mental health conditions can benefit from professional support identifying and working toward goals related to career exploration and engaging in healthy relationships and activities particularly during the transition into adulthood.

Activities related to employment, sports, and other organized groups or activities may facilitate autistic people to be included and develop relationships within their communities and result in better health and wellbeing.

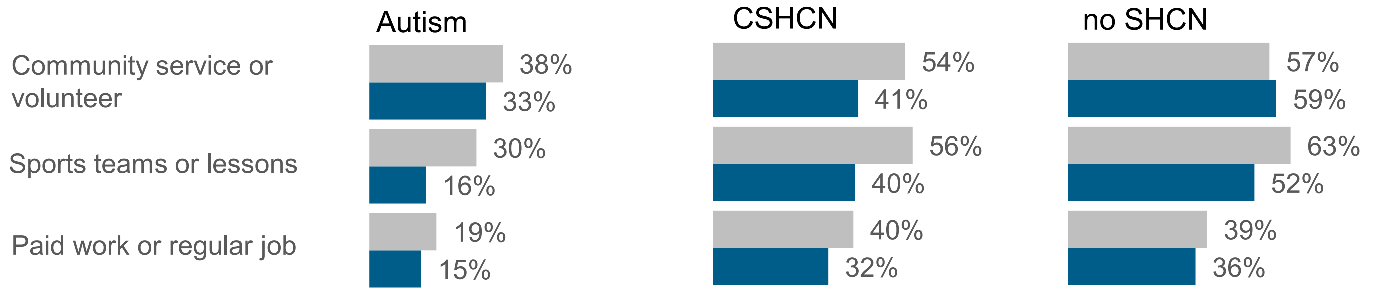
Participation and adverse childhood experiences

How do we know?

Data on community participation in children came from the National Survey of Children's Health (NSCH) years 2016-2019. Parents were asked if participated in any of the activities over the past 12 months. For this section, we included children ages 12-17.

For autistic children ages 12-17, experiencing financial hardship was associated with lower rates of participation in sports, unpaid work, and paid work. This was also true for CSHCN, but less so for children with no special health care needs (SHCN) where only participation in sports differed by financial hardship. Autistic children were less likely to participate in all of these activities than peers with and without SHCN.

Children (ages 12-17) who experienced financial hardship were less likely to participate in these activities, and autistic children less often participated than peers.

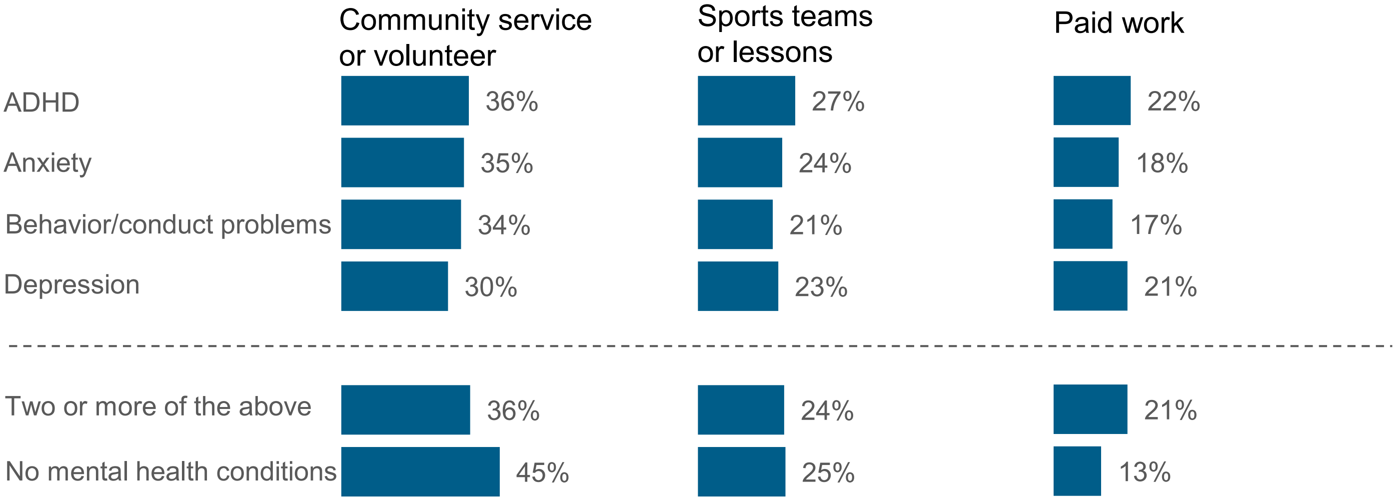


Source: National Survey of Children's Health 2016-19

Mental health and participation in early work and sports

Autistic youth ages 12-17 were more likely to participate in community service or volunteer if they did not have a mental health condition. However, there was not much difference in participation in sports or paid work based on the presence of a co-occurring mental health condition.

Autistic children with no co-occurring mental health conditions were the most likely to do community service or volunteer. Participation in sports or paid work did not vary as much.

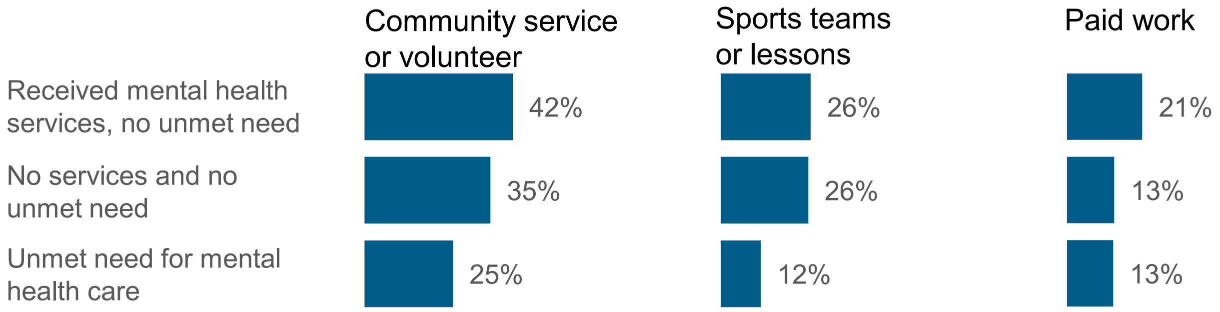


Source: National Survey of Children's Health 2016-19

Mental health care and social participation

Autistic youth ages 12-17 with unmet mental health care needs were less likely to participate in sports, unpaid work, or paid work activities than peers who received mental health services. Autistic youth who received mental health services and had no unmet mental health service needs participated at the same rate as autistic youth who did not receive or need any mental health services.

Autistic children who had unmet need for mental health care were the least likely to participate in community activities.



Source: National Survey of Children's Health 2016-19

Conclusions and recommendations for research and policy

Conclusions

Co-occurring mental health conditions are common in autistic children and adults. Three-quarters (74%) of autistic children had at least one mental health condition reported by parents including behavioral or conduct problems, ADHD, anxiety, and depression. Anxiety was a common condition in both autistic children and adults, as were ADHD and depression. Psychoses and schizophrenia were associated with billable services in 15% and 11% of autistic adults enrolled in Medicaid.

Many autistic children experienced adverse childhood experiences (ACEs) that are associated with mental health challenges in adulthood. Over half (61%) of autistic children experienced at least one ACE, while 12% experienced at least four. The most common ACE experienced by autistic children was trouble covering basics needs, including food and housing, on the household income. This was more common in autistic children than in their peers with or without special health care needs. Most ACEs were more common in Black autistic children than in children of another race or ethnicity.

The management of mental health conditions is imperative to healthier people and better quality of life. Nearly half (45%) of autistic children received treatment or counseling from a mental health professional in the past year. Treatment was most common in children with depression, with 80% receiving treatment or counseling in the past year. One in five parents of autistic children reported it was very difficult or impossible to access needed services, and 12% reported their child needed mental health care that they did not receive in the past year.

This report highlights the need for mental health care as an urgent priority and documents barriers that individuals and families face when trying to access mental health care. The top mental health priorities identified by autistic adults in a study by Benevides *et al.* (2020) included the impact of trauma, social isolation, stigma, and discrimination on mental health and mental health care; the role of self-managed interventions, like yoga, exercise, and meditation, in mental health; the negative impact of current therapies and intervention on autistic individuals across the lifespan; and developing better tools to measure mental health and quality of life in autistic adults. The U.S. Government Accountability Office convened a panel discussion in 2016 on the service needs of autistic youth and identified mental health services as a crucial component of improving independent living, education, community inclusion, and health outcomes for this population (US GAO, 2016). However, there are many barriers to comprehensive mental health care and improved mental health, including availability of providers, providers who are trained and willing to treat autistic patients, financial and insurance hurdles, and stigma associated with both autism and mental health care.

We end with a discussion of the role of research and policy that impacts mental health care, and suggestions to improve care and outcomes.

Research and policy to improve mental health care

The need for mental health services and supports is critical for autistic people. Addressing the needs of populations often requires changes to policies that impact access and provider training and resources. Policy changes can impact what is covered, who is covered, where and how.

What services are covered?

Mental health parity

The intention of mental health parity is to require that mental health services are covered to the same degree as, or in parity with, medical and surgical services. In 2008, the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity ACT (MHPAEA) was passed to enforce mental health service parity at the federal level. The MHPAEA advanced equal access to mental health services among certain types of insurance plans. Further state-level mental health parity laws and autism insurance mandates continue to seek to address gaps in mental health or autism insurance coverage. However, parity legislation at the federal or state levels does not ensure access to services (Bilaver and Jordan, 2013). In fact, many barriers to comprehensive coverage for needed services remain. Once a parity law is passed, the extent of the impact on an individual's access to mental health care varies by several factors including the state' implementation and enforcement of the legislation, provider availability, and reimbursement rates for providers by insurers. Learn more about mental health parity and state implementation in our **online supplement**.

How equitable is access?

Racialized communities

Historic disinvestment in non-White communities and their health care has resulted in unequal access to care, treatment effectiveness, and treatment relevance in racialized communities. Black people with mental health concerns are diagnosed differently than White people with the same symptoms, potentially resulting in improper care for their concerns and inadequate access to support (APA, 2017). Black people are also less likely to be insured, meaning they may be less likely to access or afford care (Ndugga and Artiga, 2021). Further, the mental health workforce is disproportionally White, making care from same-race providers difficult for many racialized people. Care from same-race providers may add a degree of cultural competence that improves care.

Unknown treatment success in diverse populations

Evidence-based practices are the standard of mental health care because they are supported by research and shown to be effective. However, evidence-based practices are not evidence-based in all populations. Evidence-based practices are not often studied in diverse populations. Therefore, it is unclear if these practices work for everyone. Autistic people are underrepresented in mental health research. A review of 300 randomized clinical trials published in high-impact medical journals found that people with intellectual and developmental disabilities were represented in only two percent of trials (Feldman *et al.*, 2014). Racialized groups are also underrepresented in mental health research. While some therapeutic approaches are proving at least somewhat effective in autistic people (Wood *et al.*, 2020), approaches to care may need to be different in different populations. Research into the practices in diverse populations is vital. In 2020, children of color became the majority of children in the U.S. (Children's Defense Fund, 2021). Research, policies, and programs must be reflective of the populations being served. The Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019 provides guidance and funding for autism research and services; further engagement across autistic stakeholders will continue to be needed to inform funding and policy priorities.

Where are people covered?

Telehealth and expanding access to care

Since the COVID-19 pandemic, there has been a documented expansion in the availability of, access to, and payment for services provided via telehealth. Telehealth services are not new, however the accessibility and implementation of these services were not as widely covered, reimbursed, or available before the COVID-19 pandemic mitigation efforts. Many activities, including mental and physical health care, have proved effective when delivered remotely both before and during the COVID-19 pandemic. Telehealth services may be an important solution to expand availability of mental health services. Telehealth removes barriers to access like travel and provider availability, providing a cost-effective way for patients to reach providers safely (The Commonwealth Fund, 2020). While the COVID-19 pandemic opened the doors for increased telehealth services, continued advancements will be needed to ensure that telehealth is equitably available across communities.

Portability

Portability is the ability for a licensed professional to provide services in a state other than the one in which they are licensed. Mental health providers are typically limited to practice within the state where they have been licensed, and laws and professional practice requirements limit the degree to which that licensure may be transferable to another state. However, during the COVID-19 pandemic many states eliminated portability restrictions for mental health services and telehealth providers. Permanently removing portability restrictions could benefit mental health providers and help autistic people and their families access specialized care that might not otherwise be available in their state. Continued examination of requirements for licensure and oversight of cross-state service provision will be critical to ensure quality and training requirements of service providers.

Integrating mental and behavioral health care into primary care

Many people access mental health care through referrals from their primary care physicians. Some people only ever see primary care physicians for their mental health concerns. But primary care physicians often do not have expertise to manage complex mental health concerns, especially in autistic patients. The integration of mental health care into a primary care setting can improve access to high quality mental health care for much of the population. Integration includes the co-location of primary and mental health care providers, as well as the integration of medical records, scheduling, billing, and care planning. Integration is necessary for a few reasons. Primary care and mental health care specialists often work in silos, where medical records, training, funding, care planning, and decision-making are handled separately (Todorow *et al.*, 2018). Most payment models and some insurance coverage options do not account for time needed to coordinate care between providers (Asarnow *et al.*, 2017; Kuo *et al.*, 2018). Insurance plans sometimes “carve out” mental health care, which means those services are contracted to another insurer that has its own network of providers. When these services are carved-out, primary care providers are not reimbursed for mental health diagnosis or care.

Many of these barriers to mental health integration can be addressed through policy changes. Care may be maximized by introducing pay-for-performance methods that incentivize identifying and treating mental health conditions, adjusting individual payments for care complexity, and rewarding practices with a higher degree of mental health integration (Bao *et al.*, 2013). Read more about mental health and primary care integration in Medicaid in our **online supplement**.

How comprehensive is coverage?

Connecting systems of care

Many systems through which autistic people may receive mental health care and support are isolated from each other. Children receive care through school, pediatric health care providers, and child-based services and supports. Many of these providers and systems do not talk to each other and lack the infrastructure to facilitate interaction. Adults face the same phenomenon, service systems isolate in silos, separate from one another. Many of the state services that fund programs for autistic individuals are separate from programs that support people with severe mental illness. Providers in each agency may little knowledge of the care needs of someone with both autism and mental illness from another agency. A new level of complexity is introduced when children must transition to adult service systems. The systems that serve people over a lifetime should be connected to allow for whole-person, continuous care (Kong *et al.*, 2020).

Mental health crisis care

The U.S. lacks an integrated mental health crisis system, so people in a crisis often do not end up getting the help they need. Some regions have behavioral crisis hotlines but in other areas, one of the only available options for a person in crisis is to call 911, which may prompt police involvement. A crisis care system should be part of a well-functioning mental health care system. The National Alliance on Mental Illness (NAMI) put forth three core elements of national guidelines for crisis care: crisis call centers, mobile crisis teams, and crisis receiving and stabilization programs. Crisis triaging and stabilization services should provide trauma-informed care aimed at stabilization and recovery. People should be able to access the crisis system in any way, include walk-ins and referrals from law enforcement or other emergency responders. Implementation of crisis systems includes shifting intervention from law-enforcement as the front line, to a trained mental health response professional.

Provider training

Provider training regarding the intersection of autism and mental health is a need consistently noted from advocates, policy makers, and providers. Provider training could be effectively incentivized through insurance reimbursement and governing bodies regulations. Training should also be inserted into curriculum for providers-in-training. There are several areas of provider training that could improve mental health care for autistic persons. Particularly among adult providers, there is a need for increased competence in accommodating autistic patients within practices. There is also a need for mental health providers who manage mental health conditions in autistic patients. Mental health care should be culturally and linguistically competent. This includes training in skills, attitudes, and approaches that value and respect such differences. Further, this includes training of a diverse mental health workforce.

U.S. policies focus on short-term mental health therapies without adequately addressing the needs of people with more complex or trauma-related challenges. This is particularly relevant to autistic people who are at increased risk for trauma and may have complex, ongoing psychosocial and mental health support needs across the life course. Providers should be trained in trauma-informed care, in which they recognize how common trauma is and how it impacts health and behavior. This understanding can then be translated to practices that avoid re-traumatization and emphasize patient-centered, compassionate care. Most providers who serve autistic children and young adults agree trauma-related concerns are important in serving autistic patients, but evidence-based guidelines and practices are lacking (Kerns *et al.*, 2020).

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Appendix A: Impact of COVID-19 on mental health—a call to action

The COVID-19 pandemic impacted the mental health of the overall population. Research is emerging from across the globe demonstrating the short-term mental health implications for autistic people and their families.

Studies conducted with families of autistic children during the COVID-19 pandemic in Ireland, the UK, China, Italy, and Saudi Arabia found several impacts on mental health of autistic children, adolescents, and their families. Children and adolescents experienced adverse mental health effects, including feelings of social isolation, depression, anxiety, and increases in problem behaviors (Colizzi *et al.*, 2020). Families with autistic children reported increased mental health difficulties during the pandemic due to changes to routine (O'Sullivan, *et al.*, 2021). Parent anxiety and feelings of being overwhelmed increased during the pandemic (Asbury, *et al.*, 2020), and families reported the need for more support, including medical, professional rehabilitation training, and in-home supports (Althiabi, 2021; Huang *et al.*, 2021; Colizzi *et al.*, 2020).

Autistic adults in Belgium, the Netherlands, and the UK also experienced an overall increase in depression and anxiety symptoms in response to the pandemic, a greater increase than non-autistic peers (Oomen *et al.*, 2021). There were some positive changes stated by autistic adults during the COVID-19 pandemic, including increases in solidarity and reduced sensory and social overload. But overall, autistic adults expressed a greater increase in worries about their pets, work, getting medication and food, loss of routines, and their own safety/security.

The Impact of COVID-19 on mental health highlights health inequities

COVID-19 not only exacerbated the significant inadequacies in our mental health care system, but disproportionately affected Black, Indigenous, and people of color. Households with children were more likely to experience hardship during the COVID-19 pandemic if they included a person of color, had income below the federal poverty level, or had special health care needs (Child Trends, 2021). Higher rates of depressive symptoms and other mental health conditions were found in Black and Hispanic populations than non-Hispanic White populations during the COVID-19 pandemic (Fitzpatrick *et al.*, 2020; Czeisler *et al.*, 2020).

The rate of infection of COVID-19 is higher in some racialized groups in the U.S., as are rates of hospitalization and death. Differences are likely driven by disparities in social determinants of health (CDC, 2020). Historical context and structural racism led to differences in the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks (Simmons *et al.*, 2021).

Pandemic mitigation strategies disproportionately impacted racial and ethnic minority groups. The rates of job loss and associated loss of health insurance, food insecurity, and housing instability were higher during the pandemic in Black households than in White households. The use of preventive health services decreased during the pandemic, more in racialized than White households.

Family hardship worsened during the COVID-19 pandemic. The combination of high poverty, limited school and social experiences, and lack of access to basics such as sufficient food or health care posed by COVID-19 threaten healthy development for this generation of children and adolescents (Hoagwood *et al.*, 2021).

Moving forward

The increased recognition of health inequity during the COVID-19 pandemic led to a strong response by the U.S. Federal Government and acknowledgment that promoting equity is essential to protecting the health of Americans and providing essential human services (E.O. 13985). Addressing issues of equity should include an understanding of how multiple forms of discrimination impact individuals' lived experiences. Disability is an important identity connected to discrimination and disenfranchisement.

While evidence of the short-term impacts of the COVID-19 pandemic are emerging, future surveillance on the long-term impact on mental health among all people, including autistic people, could provide evidence for focus areas and solutions. There are a few national studies in the U.S. under way to capture such information, but there is need for development of studies to understand the impact in autistic adults. Policy efforts for improving mental health may include financial stability and assistance, access to integrated health services that promote mental health, adequate emotional support from formal services and informal sources, and sick leave and personal time policies that support a focus on wellbeing (Fisher & Lombardi, 2021).

The differential impact of the COVID-19 pandemic on autistic people presents an important opportunity to expand, improve, and rethink our service delivery systems for this population. The solution may not require new initiatives and funding but will challenge health care providers and institutions to reimagine service delivery using virtual care platforms (Smile, 2020). Program delivery must be easily implemented and meet the needs of children and their families.

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Appendix B: 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, 3) Centers for Medicare & Medicaid Services (CMS) Medicaid administrative files, 4) previously published research findings from Kaiser Permanente Northern California (KPNC) patient records, and 5) a national survey of university freshman experiences. Some findings were previously published in the National Autism Indicators Report: Health and Healthcare. This report highlights some of those findings that focus on mental health and mental health care.

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 2016-2019. 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). 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. The publicly available household component was used for this report, as well as household component event files for outpatient visits and office-based medical provider visits. 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 autistic adults.

The N**ational 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 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. The unit of analysis in NIS is index stays, not individuals. More information about the NIS and HCUP can be found at www.hcup-us.ahrq.gov/nisoverview.jsp

We used administrative claims from the **Centers for Medicare & Medicaid Services (CMS) Medicaid Analytic eXtract (MAX)** data files, containing data from all 50 states. MAX data includes all individuals under the age 65 enrolled in Medicaid between 2008-2012. The claims data is collected by state on all Medicaid and Child Health

Insurance Program (CHIP) enrollees. Medicaid is a public provider of health insurance that is administered by states and funded by state and federal dollars. Medicaid covers children and adults with lower income, people with disabilities, pregnant women, and children in foster care. In January 2021, 80 million people were enrolled in Medicaid or CHIP. MAX files include information on enrollment, services, expenditures, and more.

Findings from our previous report, the National Autism Indicators Report: Health and Health Care (Rast *et al.*, 2020), that highlight mental health are included here. These including findings from two studies using **Kaiser Permanente Northern California (KPNC)** patient records for research. 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. 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.

The national freshman survey is part of a longitudinal study that collects data on incoming first-year college students' pre-college experiences; academic preparation; views on political and social issues; career, educational, and lifelong goals; college choice considerations; and expectations for college. More than 15 million students attending more than 1100 institutions have participated since the first administration in 1966. For this study, we included survey administration in 2016, 2018, and 2019. Findings also came from a previously published manuscript by Fernandes *et al.* (2021).

Who is this report about?

Autistic children

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).

Children and adults enrolled in Medicaid

Children and adults with autism were identified from Medicaid MAX data if they had at least one inpatient or two other claims containing a diagnosis of autism (International Classification of Diseases, Ninth Edition [ICD-9] codes 299.xx). There were 465,202 autistic children and 169,426 autistic adults during this time included in analysis. A comparison group of children and adults with intellectual disability (ID) without autism was created the same way; 272,924 children and 689,107 adults. A final comparison group was a random sample of the general medical population with no autism or ID diagnosis; 1,891,929 children and 1,698,861 adults. Co-occurring conditions were identified using ICD-9 codes and requirements of claims form the Chronic Condition Warehouse (CCW).

Kaiser Permanente Northern California Integrated Health Care Delivery System

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.

Patient diagnoses in 2017 were collected through hospital records 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 principal diagnosis related to the index stay. Index stays with an autism diagnosis in any of the 40 positions were considered autism stays for this report captured by ICD-10-CM code F84.0, F84.5, or F84.9.

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 if 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.

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.

All analyses were done incorporating the complex sample design information from the NSCH 2016-2019, MEPS 2013-1017, and NIS 2017 in Stata 16 (Statacorp, 2019).

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.

Strengths and limitations

The surveys used in this report (NSCH 2016-2019, 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 enrolled in Medicaid and adults in the KPNC health system helps to fill this gap. Together, this report presents an emerging picture of mental health in autistic people 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. 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.

Centers for Medicare & Medicaid Services (CMS) Medicaid Analytic eXtract (MAX) data is another administrative source of data, which is subject to billing and coding errors. MAX only includes Medicaid enrolled people, so does not describe autistic people with private health insurance. Finally, only fee-for-service claims were used for this report.

The freshman survey is a nationally representative sample of incoming four-year students, including those with autism. Self-report of student experiences is a strength of this data. The survey does not capture experiences of two-year college students, a common option for autistic students after graduating from secondary school (Roux *et al.*, 2015).

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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