



# NATIONAL AUTISM INDICATORS REPORT:

Health and the COVID-19 Pandemic

JULY 2023





## Mission

The A.J. Drexel Autism Institute's mission is to pioneer research to better understand autism and drive impactful change in our communities and worldwide. The Policy and Analytics Center (PAC) is committed to advancing the equity, health, and well-being of the autism and disability communities by using data, conducting research, and centering community priorities to inform policy action.

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# National Autism Indicators Report: Health and the COVID-19 Pandemic

JULY 2023

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

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## A Note about Language

For the purposes of this National Autism Indicators Report, identity first language (i.e., autistic individual or individual on the spectrum vs. individual with autism) has been purposefully used per the preference and guidance from autistic communities. It is important to recognize that there is not a universal consensus in the autistic community about the use of either person-first or identity-first language as this community is not a monolith. However, in deference to documented stances on language-use from self-advocates, identify-language is the default for this report.

# Letter from the Project Director

Alice Kuo, MD, PhD, MBA

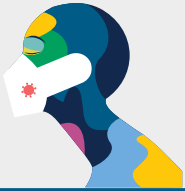
In December 2019, a cluster of patients in China experienced symptoms of an atypical pneumonia that would be later determined to be caused by Severe Acute Respiratory Syndrome Coronavirus (SARS-CoV-2). By January 2020, SARS-CoV-2 (renamed the 2019 Novel Coronavirus, or COVID-19) outbreaks had spread and cases were confirmed in countries outside of China. On March 11, 2020, the World Health Organization declared COVID-19 a pandemic, after 118,000 cases in 114 countries and 4,291 deaths.

The ensuing months to years after the pandemic have indelibly changed the landscape of health care delivery. Initially, during lockdown, people were hesitant to access healthcare, even with symptoms of potential stroke or heart attack, for fear of exposure to COVID-19. Health care workers began to leave the workforce, concerned for themselves and the potential to expose loved ones at home to COVID-19. As telehealth emerged as a widespread health care tool and vaccines were developed and became available, significant disparities were observed in underserved communities in which patients did not have access to the internet to participate in telehealth visits. People in these communities also were more likely to be essential workers and therefore exposed to COVID-19 at higher rates, and were also less likely to have access to vaccines or to be unvaccinated due to disinformation about vaccine safety and efficacy.

One notable marginalized population disproportionately impacted during the early months of the pandemic were individuals with intellectual and developmental disabilities (IDD), including autism. Despite clear evidence documenting their negative health outcomes across the lifespan, most of this population was not prioritized for COVID-19 vaccines. This was particularly concerning given the well-established body of literature indicating their compromised access to health-promoting services, supports, and resources that existed before the pandemic and increased their vulnerability to COVID-19 infection. Further, there was an absence of inclusive public health communication efforts tailored to the distinct needs, experiences, and priorities of IDD communities, which further compounded the negative health outcomes they experienced during the pandemic.

Now, in 2023, more than three years after the start of the pandemic, our health care system is still struggling to recover. Worsening chronic disease, mental health and overall physical health are evident in many populations after the pandemic, often due to delays in care for a variety of reasons. A diminishing health care workforce in the face of increased demands for care post-pandemic has led to exacerbations in accessing care with delays in appointments, refills, messages, lab tests and radiological studies.

This report highlights the impact that the COVID-19 pandemic has had on autistic individuals. As with other National Autism Indicator Reports, this report provides crucial information to better understand the health care experiences of autistic people, a marginalized population. By understanding the challenges they face, we can begin to develop interventions that will improve their health care outcomes.



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## Executive Summary

The COVID-19 pandemic changed how autistic people accessed services and engaged in their communities, ultimately impacting their quality of life. Access to appropriate services and accommodations help autistic individuals in maintaining employment, pursuing education, caring for their health, and establishing independence. Changes in access to services result in long-term consequences, which can be dire for autistic people. In an effort to improve policies and programs for autistic individuals, documentation of disruptions in accessing services during the COVID-19 pandemic informs better evidence-based practices for future public health emergencies.

This report examines the impact of the COVID-19 pandemic on health and healthcare among autistic children and adults. To build a comprehensive picture, we included various data sources, including health care claims and administrative records. We explored the availability of services for autistic children based on caregiver report from the National Survey of Children’s Health (NSCH). To understand hospitalization covered by both private and public health insurance, we used national emergency hospitalization records (via the National Emergency Department Sample [NEDS]) and hospital admissions data (via the National Inpatient Sample [NIS]). Finally, we used patient medical records from Kaiser Permanente Northern California (KPNC) to look at service utilization among adult autistic patients from Northern California over the same period. These data sources cover various populations. Some of the data provides nationally representative pictures of autistic children and adults. Other sources cover specific populations, but still cover diverse experiences in terms of income and race and ethnicity.

## Acronyms

There are several acronyms used in this report. Please see the following glossary for your use and understanding:

- COVID-19: Coronavirus Disease 2019
- CYSHCN: Children and Youth with Special Health Care Needs
- ED: Emergency Department
- KPNC: Kaiser Permanente Northern California
- NEDS: National Emergency Department Sample
- NIS: National Inpatient Sample
- NSCH: National Survey of Children’s Health

## Overview of main findings

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**Policies changed at the beginning of the COVID-19 pandemic to increase access to health care. However, public health insurance enrollment, like Medicaid, was equally as common in autistic children before (2019) as during the COVID-19 pandemic (2021). (Chapter 1)**

- There were differences in insurance coverage by race and ethnicity among autistic children.
- In 2021, more than three-fourths of Black non-Hispanic children were covered by public health insurance. Asian non-Hispanic children were the least likely to have public health insurance coverage (44%).

.....  
**Emergency department visits and inpatient hospital stays for COVID-19 were most common in older autistic adults as compared to other age groups. (Chapter 2)**

- In the U.S., COVID-19 cases started appearing rapidly in March 2020. Among older autistic adults (ages 45+), 13% of all ED visits in April 2020 were for COVID-19 as compared to less than 1% of children and 3% of adults ages 18-44.
- Among older autistic adults, 20% of all inpatient hospital stays in April 2020 were for COVID-19 (as compared to less than 1% for autistic children and 5% for autistic adults ages 18-44).
- Most COVID-19 hospitalizations and ED visits in 2020 were covered by public health insurance.

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**There were changes in the types of services that autistic individuals received from before to the first years of the COVID-19 pandemic. (Chapter 3)**

- From 2019 to 2021, there were small decreases in the percentage of autistic children who had any health care, including well-child visits, dental services, or emergency department visits in the past 12 months. About half of autistic children had a virtual or telehealth care visit in 2021, as did CYSHCN. Just over one-third of autistic children missed or delayed a well visit because of the COVID-19 pandemic.
- There was a large decrease in emergency department (ED) use midway through 2020. Starting in April 2020, ED use for autistic children (ages 0-17), adults ages 18-44, and older autistic adults (ages 45+) decreased.
- Similar to trends in emergency department usage, there were sharp decreases in April 2020 in the number of inpatient hospitalizations among autistic children and adults.
- Among autistic adults enrolled in Kaiser

Permanente Northern California (KPNC), there was a decline in the number of in-person primary care visits and a corresponding increase in the number of telehealth services received from 2019 to 2021.

.....

**There were not substantial changes in mental health care early on in the COVID-19 pandemic. (Chapter 4)**

- In 2019 and 2021, just under half of autistic children received mental health care, and about 10% had unmet need for mental health care each year (13% in 2021 and 9% in 2019).
- Visits for mental health conditions made up 13-18% of all ED visits for autistic children, 26-30% of visits for autistic adults, and 7-13% of visits among older autistic adults across all months of 2020.
- Inpatient hospitalizations for mental health conditions accounted for a large portion of visits in autistic children and adults: about one-quarter of inpatient hospitalizations in children, nearly half of hospitalizations in adults (ages 18-44), and about 10% of hospitalizations in older adults (45+).

# CHAPTER 1:

## Service environment changes

The COVID-19 pandemic resulted in restrictions to commonly accessible medical services for the U.S. population. For autistic children and adults, a lack of access to their usual health services may have led to an increase in crisis care, which is more expensive to individuals and costly to the system. The purpose of this chapter is to examine changes in health care in autistic children and adults. Information gleaned from this chapter may better prepare the U.S. healthcare system to support autistic people during a public health emergency.



**Data used in this chapter:** the National Survey of Children's Health includes information about health and health care for a nationally representative sample of children in the U.S.

### Insurance and policy changes during the COVID-19 pandemic:

- There were many changes to the health policy landscape to protect people and enable them to maintain health insurance and health care during the COVID-19 pandemic. Because there was increased job loss and unemployment, it resulted in a need to rely on public safety nets, including Medicaid and Children's Health Insurance Program (CHIP) for health insurance.
- The Families First Coronavirus Response Act (FFCRA) required continuous coverage in Medicaid and CHIP until the U.S. government lifts the COVID-19 pandemic classification. The FFCRA resulted in more and more people enrolling, and maintaining enrollment, in Medicaid during the COVID-19, without any disruptions that would limit their ability to access necessary health care services.
- Between April 2020 (with the enactment of the FFCRA) and December 2021, there was a 21.8% increase in Medicaid and CHIP enrollment. In March 2023, the FFCRA's continuous coverage requirement expired; states will resume pre-pandemic eligibility and enrollment procedures starting summer of 2023.

- The proportion of the U.S. population uninsured decreased during the COVID-19 pandemic. In all states, excluding North Dakota, there were lower uninsured rates in 2021 compared to 2019. Much of this can be attributed to the increased Medicaid-enrollment and stipulations of the FFCRA, in addition to other state and federal policies.

### Resources:

- <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-the-unwinding-of-the-medicaid-continuous-enrollment-provision/>
- <https://www.urban.org/research/publication/impact-covid-19-public-health-emergency-expiration-all-types-health-coverage>
- <https://policyimpactproject.org/unwinding-medicaid-unwinding/>
- <https://policyimpactproject.org/medicaid-unwinding-or-wind-down-impacts-on-the-autistic-community/>
- <https://www.census.gov/library/stories/2022/09/uninsured-rate-declined-in-28-states.html>

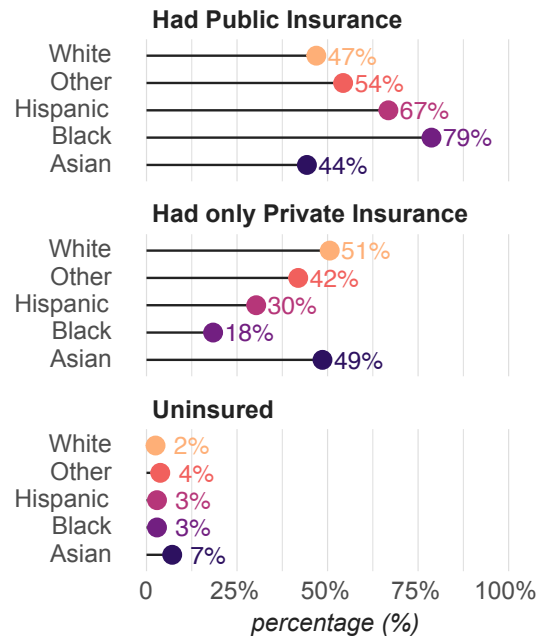


## Insurance coverage in autistic children

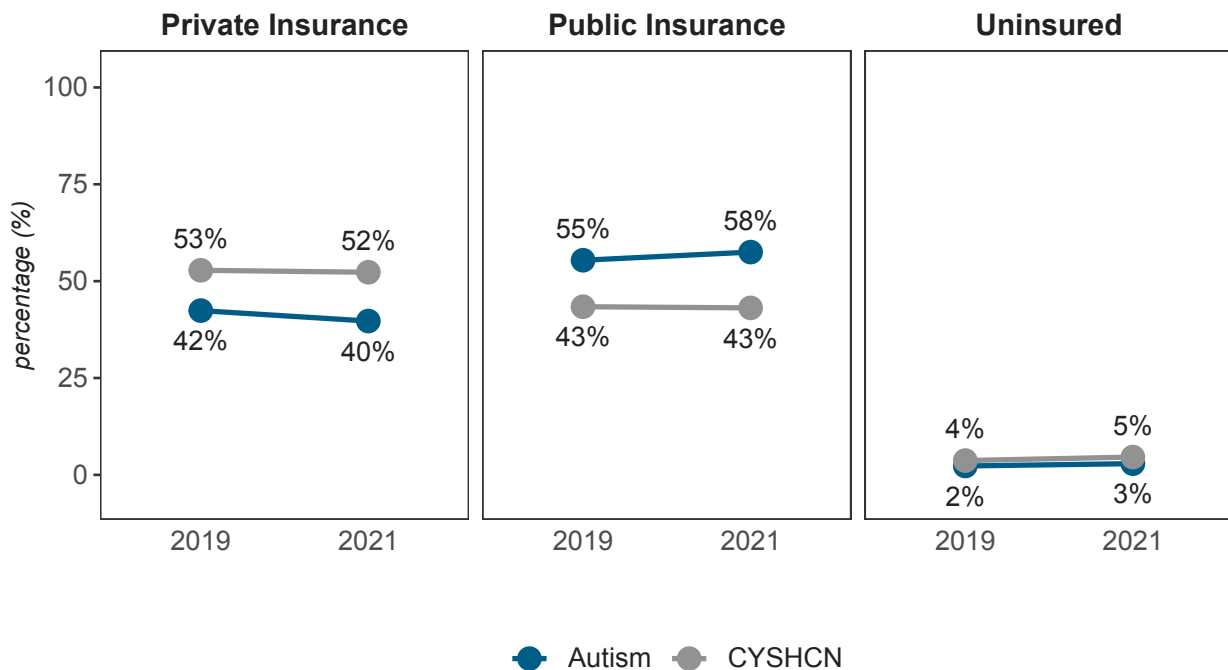
Nationally, more than half of autistic children have public health insurance, including Medicaid. This indicator came from the National Survey of Children’s Health. The proportion of autistic children with public health insurance has remained relatively consistent over the last decade and is mostly supported by the federal Children’s Health Insurance Program (CHIP). From 2019 to 2021, the number of autistic children enrolled in a public insurance program increased slightly and few autistic children were uninsured in either year. In comparison to CYSHCN, public health insurance enrollment was more common among autistic children.

There were notable differences in insurance type among autistic children by race and ethnicity. In 2021, more than three-quarters of Black non-Hispanic children were covered by public health insurance and Asian non-Hispanic children were the least likely to have public health insurance (44%).

### Insurance coverage varied by race and ethnicity in autistic children in 2021.



### More than half of children with autism have public insurance similar in 2019 and 2021.



Data source: National Survey of Children’s Health 2019 and 2021



## CHAPTER 2:

### Other health service utilization

The purpose of this chapter is to examine changes in preventive and other health services in autistic children and adults. The COVID-19 pandemic disrupted many health services, like well-care and dental care. Autistic children and adults often rely on health maintenance services more often than non-autistic people, therefore any lapse in health services may overly impact their health.



#### Data used in this chapter:

the National Survey of Children’s Health (NSCH) includes information about health and health care for a nationally representative sample of children in the U.S. The National Emergency Department Sample (NEDS) captures a nationally representative sample of emergency department visits in the U.S. for children and adults, regardless of how their visits is paid for (referred to as “all-payer” as it captures private insurance, public insurance, and uninsured patients). The National Inpatient Sample (NIS) captures a nationally representative sample of all inpatient hospitalizations in the U.S. for children and adults and is also all-payer. Kaiser Permanente Northern California (KPNC) includes information on adults covered by KPNC, an insurance provider and health care system in Northern California.

#### Emergency department visits for COVID-19

The following graphs show the rate of emergency department (ED) visits for COVID-19 in 2020 by age group. We separated this data by age because older adults were at greater risk for severe complications as a result of COVID-19 than younger people. In autistic children (ages 0-17), 3% of emergency department visits in December 2020 listed COVID-19 as the primary reason for the visit; December was the month with the most COVID-19 visits for this age group. Similarly, for autistic adults ages 18-44, the most COVID-19 ED visits were in December 2020 (6% of all ED visits were for COVID-19). Among older autistic adults (ages 45+), 11% of ED visits in December 2020 were for COVID-19, but April 2020 saw the most COVID-19 ED visits among older autistic adults (13%) in 2020. Overall, December 2020 saw the most COVID-19 ED visits for autistic children and adults. While an increase in ED visits for COVID-19 may seem surprising nine months after



#### What do we mean by “ED visits for COVID-19”?

When a person has a visit to the emergency department (ED), doctors record the main reason for the visit to the ED (like asthma, heart attack, stroke). ED visits for COVID-19 are those visits where the primary reason for the visit was COVID-19.

the start of the COVID-19 pandemic, a surge in ED visits correlates with inconsistent COVID-19 policies among states and a surge in the Delta variant across the country during that time frame.

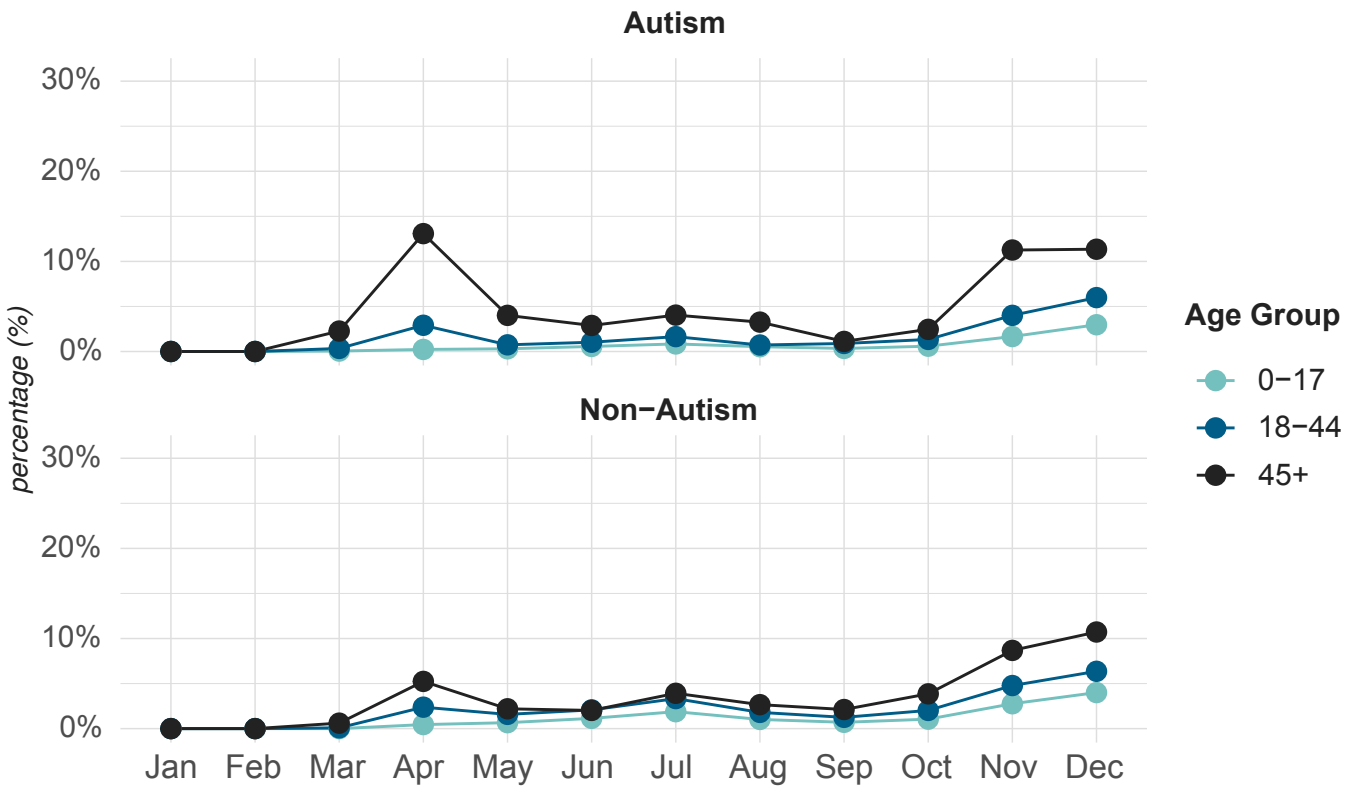
Among children and adults ages 18-44, rates of ED visits for COVID-19 were similar for autistic versus all other people. However, ED visits for COVID-19 were much more common in April 2020 among older autistic adults than older adults broadly. The

significant increase in ED visits among older autistic adults compared to other older adults in April 2020 demonstrates an area in which public health and healthcare policies need to consider strategies for maintaining usual health services for autistic individuals during public health emergencies.

Most COVID-19 ED visits for autistic people were covered by public insurance. Among autistic children, two-thirds of ED visits for COVID-19 in 2020 were paid for by Medicaid and about one-third were covered by private insurance. Among autistic adults

(18-44), just under half of COVID-19 ED visits were paid for by Medicaid and just over one-quarter were paid for by Medicare. Among older autistic adults (45+), most COVID-19 ED visits were covered by Medicare and very few were covered by private insurance (5%). Autistic people often have more than one type of insurance, for example both private health insurance and Medicaid. These results only report the insurance that was billed first at the hospital, referred to as the primary payer.

**Emergency department visits for COVID-19: in April 2020, 13% of ED visits in older autistic adults were for COVID-19.**



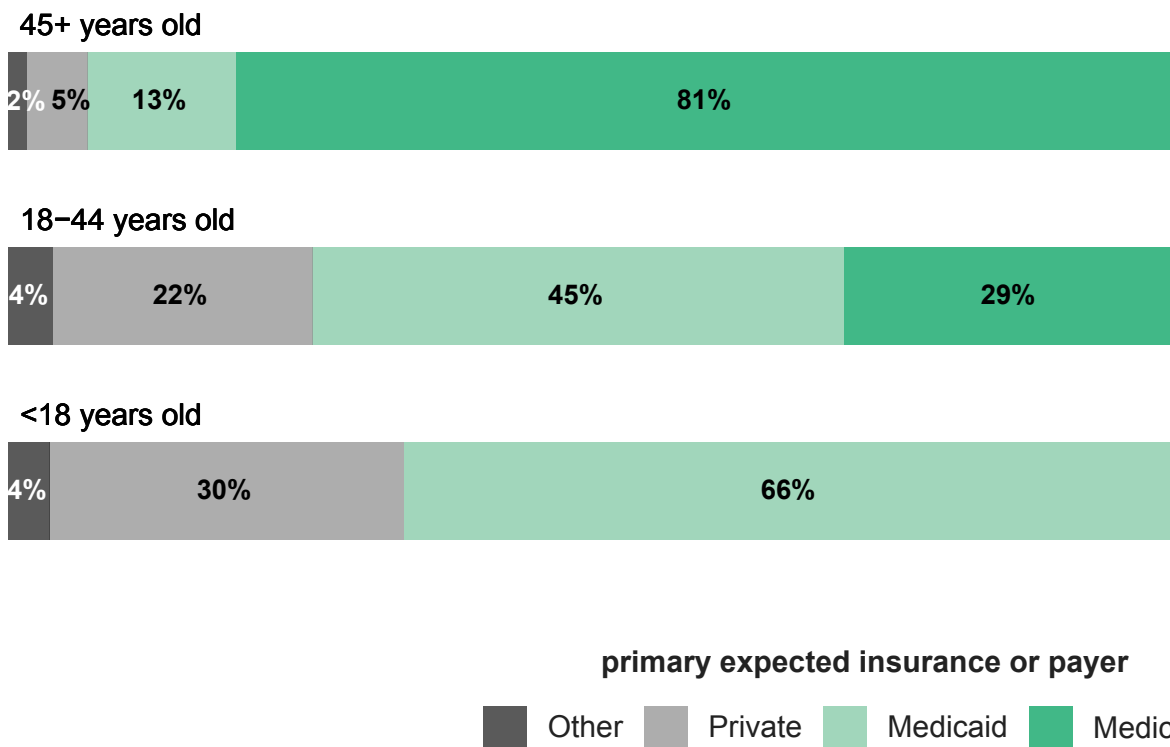
Data source: National Emergency Department Sample 2020

## Inpatient hospitalizations for COVID-19

Like the previous findings on ED visits, we examined the rate of inpatient hospitalizations for COVID-19 in each month of 2020. Examples of inpatient hospitalization include being treated for

severe illnesses (like an injury or a heart attack) or being in the hospital to deliver a baby. Inpatient hospitalization means a person was admitted to the hospital, whereas a visit to the ED may not result in a hospital admission.

### In autistic people of all ages, most COVID-19 ED visits were covered by public health insurance.



Data source: National Emergency Department Sample 2020

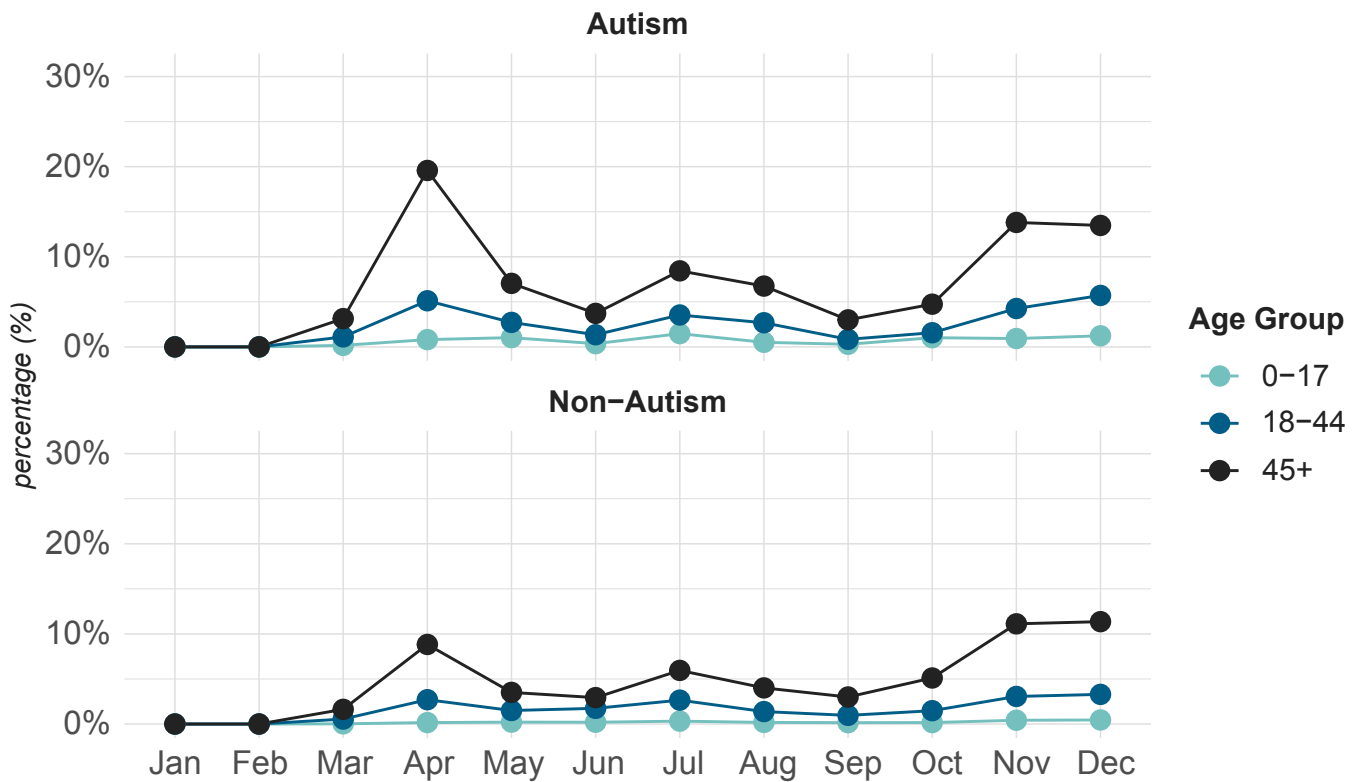
For autistic children, hospitalization for COVID-19 was uncommon. In most months, fewer than 1% of hospitalizations for autistic children were for COVID-19. Among autistic adults (18-44), COVID-19 hospitalizations were the most common in April (20%) and December (5%).

Among children and adults ages 18-44, rates of hospitalizations for COVID-19 were similar to the rest of the population. However, hospitalizations for

COVID-19 were much more common in April 2020 for older autistic adults than other older adults.

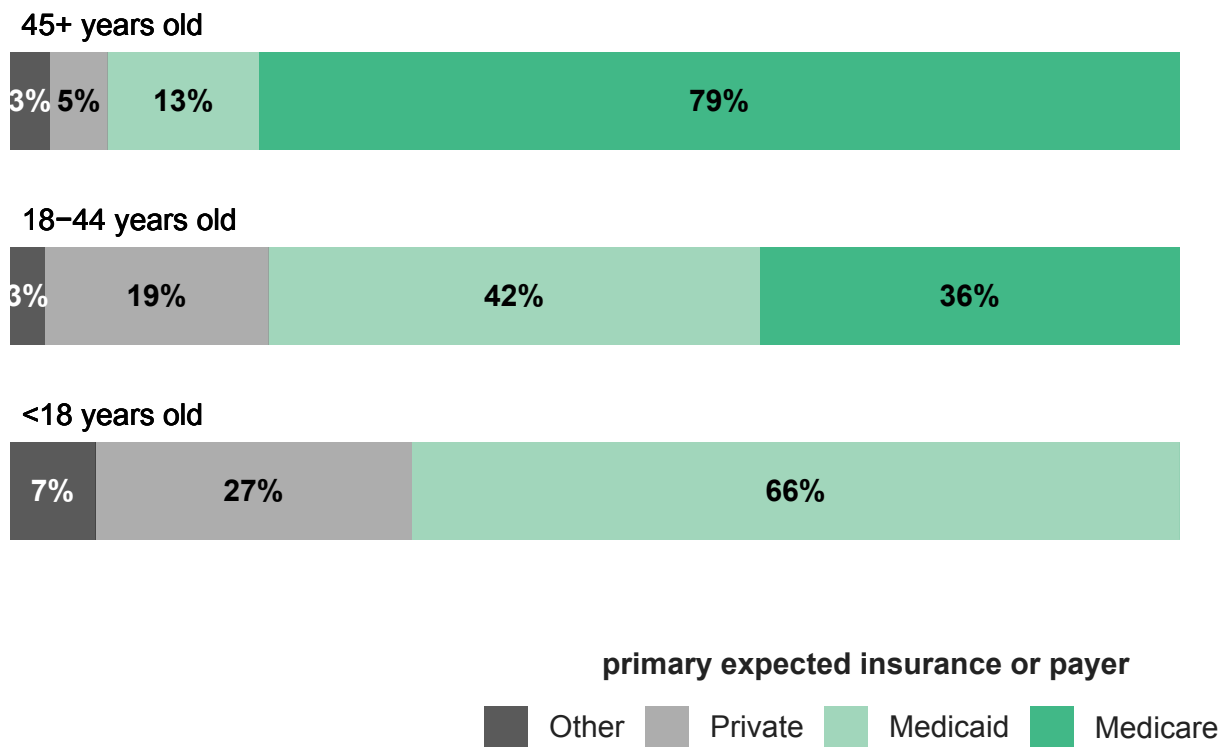
Most COVID-19 hospitalizations in 2020 were covered by public insurance. Among autistic children, two-thirds of COVID-19 hospitalizations were covered by Medicaid. Among autistic adults (18-44), most hospitalizations were covered by either Medicaid or Medicare. Among older autistic adults, more than three-quarters were covered by Medicare.

**Hospitalizations for COVID-19: in April 2020, 20% of hospitalizations in older autistic adults were for COVID-19.**



Data source: National Inpatient Sample 2020

## In autistic people of all ages, most COVID-19 hospitalizations were covered by Medicaid or Medicare.



Data source: National Inpatient Sample 2020

### ▶ Chapter conclusions and implications.

The findings in this chapter highlight increases in ED and inpatient hospitalizations for COVID-19 for everyone, but especially the oldest people. Autistic older adults saw bigger decreases in hospitalizations than their same-age peers. This may be reflective of increased risk factors for severe COVID-19 in autistic people, including higher rates of co-occurring health and mental health conditions and worse access to preventive health care than the general population. During emergency measures, policies should ensure equal access to appropriate care for all people, especially those who are the most vulnerable.

# CHAPTER 3:

## Other health service utilization

Most autistic children and adults have co-occurring health conditions that put them at increased risk of severe COVID-19 infection. The aim of this chapter is to describe emergency department and inpatient hospital visits for COVID-19 infection among autistic children and adults. Autistic children and adults, as well as people with developmental disabilities and underlying health issues, were at increased risk of hospitalizations for COVID-19.



### Data used in this chapter:

the National Survey of Children’s Health (NSCH) includes information about health and health care for a nationally representative sample of children in the U.S. The National Emergency Department Sample (NEDS) captures a nationally representative sample of emergency department visits in the U.S. for children and adults, regardless of how their visits is paid for (referred to as “all-payer” as it captures private insurance, public insurance, and uninsured patients). The National Inpatient Sample (NIS) captures a nationally representative sample of all inpatient hospitalizations in the U.S. for children and adults and is also all-payer. Kaiser Permanente Northern California (KPNC) includes information on adults covered by KPNC, an insurance provider and health care system in Northern California.

### Changes in health care receipt for children from the National Survey of Children’s Health

The COVID-19 pandemic interrupted access to health care services. We examined changes in use of services by children from 2019–2021.

From 2019 to 2021, there were small decreases in the percentage of autistic children and children and youth with special health care needs (CYSHCN) who had any health care services, preventive services, dental services, and emergency department visits in the past 12 months.



### How we captured healthcare:

The National Survey of Children’s Health (NSCH) asks parents/guardians about their child’s health care experiences in 1) any health care visits, 2) preventive health services, 3) emergency department visits, and 4) dental health services.

**Any health care visits:** “During the past 12 months, did the child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or any other kind of medical care?”

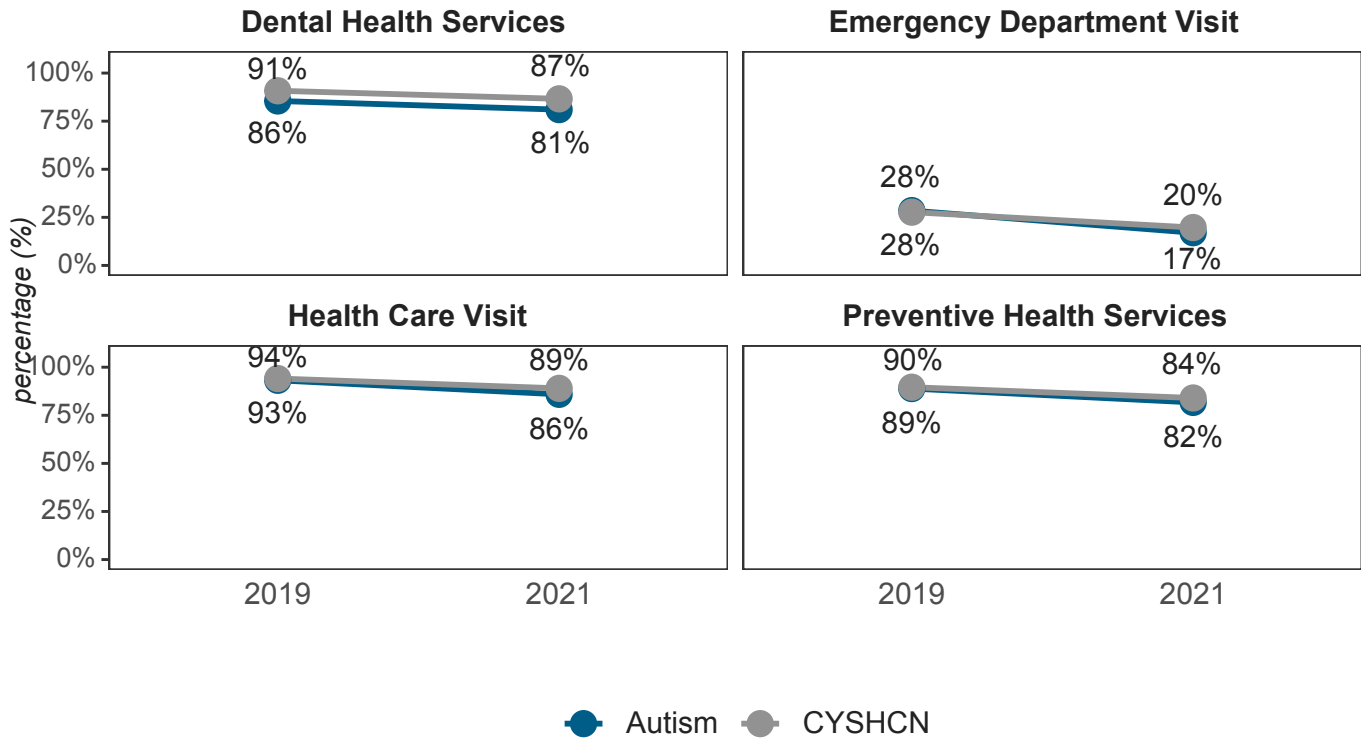
**Preventive health services:** “During the past 12 months, how many times did the child visit a doctor, nurse, or other health care professional to receive a preventive check-up? A preventive check-up is

when the child was not sick or injured, such as an annual or sports physical, or well-child visit.”

**Emergency department visits:** “During the past 12 months, how many times did this child visit a hospital emergency room?”

**Dental health services:** “During the past 12 months, did the child see a dentist or other oral health care provider for any kind of dental or oral health care?”

**Fewer autistic children visited the emergency department in 2021 than 2019; differences in preventive care over this time were smaller.**



Data source: National Survey of Children's Health 2019 and 2021

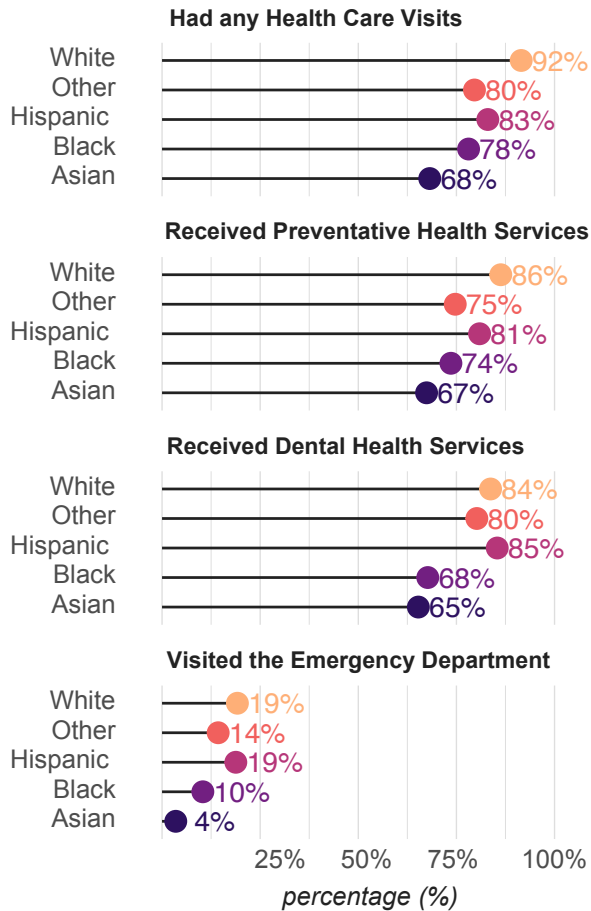
There were differences in the use of health care services among autistic children by race and ethnicity in 2021. Asian autistic children were the least likely to have had any health care service or any preventive services in the past 12 months (reported in 2021) while white children were the most likely to have used services during the same period.

Of all services, the biggest differences were in receipt of health care services: 68% of Asian children had a

health care visit in the past 12 months (reported in 2021) compared to 79% of Black children, 80% of children of another reported race, 83% of Hispanic children, and 92% of white children. Hispanic and white children were the most likely to have an ED visit. There was no notable difference in receipt of health care service by insurance status.



## Use of health services by autistic children varied by race and ethnicity in 2021.



Data source: National Survey of Children's Health 2021

### Access to health care services for children

Use of health care services may have decreased for many reasons like closed medical offices, restrictions on office visits for non-urgent conditions, lack of transportation options, or fewer people getting exposed to other germs and getting sick.

Findings from the National Survey of Children's Health (NSCH) also highlight changes in access to care that may have impacted how people were

getting services during the pandemic. Fewer autistic children received care coordination in 2021 as compared to 2019 (37% versus 42%). There was also more reported difficulty getting needed referrals, though fewer people reported needing referrals for their child (41% in 2021 versus 45% in 2019). Finally, the level of unmet health care was largely the same between 2019 and 2021 (14% in 2019 and 11% in 2021).

These patterns of change from 2019 to 2021 were mostly the same between autistic children and CYSHCN, though the need for referrals was more common in autistic children than in CYSHCN.

Receipt of care coordination for autistic children varied by race and ethnicity in 2021. One-quarter of Black children received care coordination, compared to two-thirds of Asian children. Use of referrals was also variable by race and ethnicity. Half of Hispanic children needed a referral as compared to 29% of Asian children. Difficulty getting needed referrals was greatest in children of another reported race or those who reported multiple races.

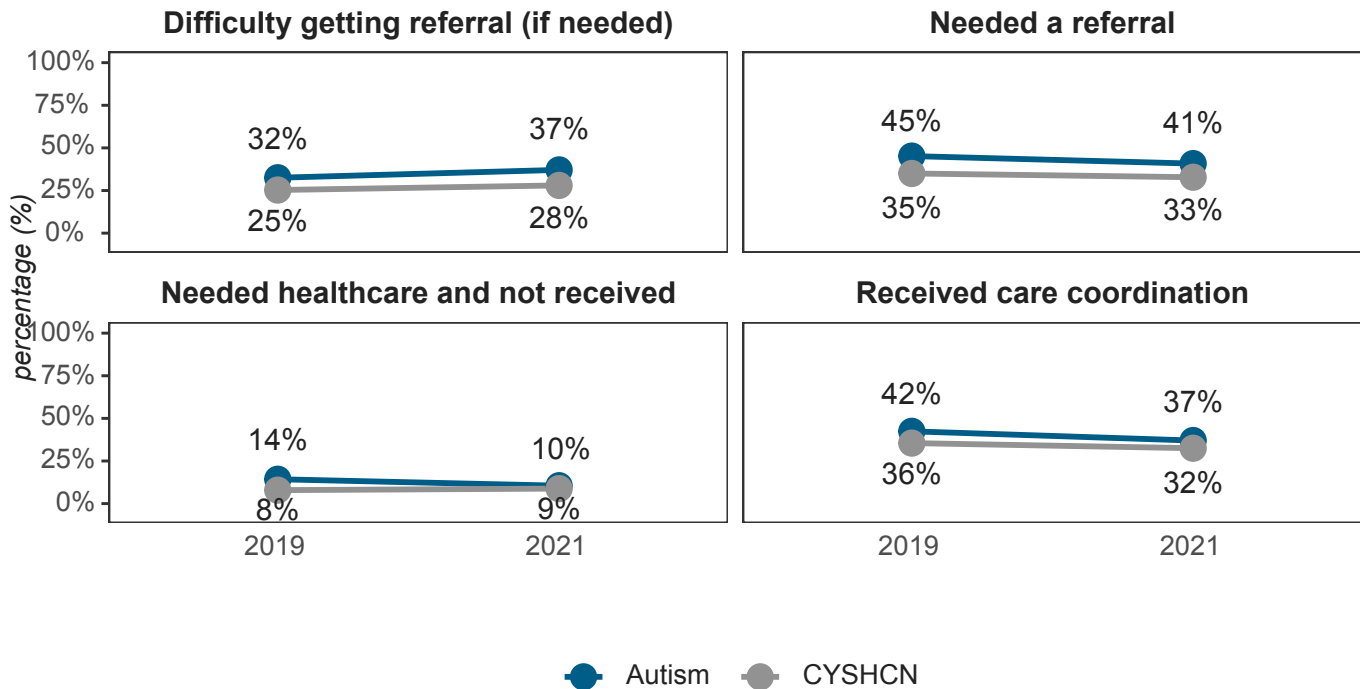
Receipt of care coordination was more common in children with public health insurance (43% of children with any public health insurance compared to 30% of children with only private health insurance). Referrals did not vary by insurance status.

### Impact of COVID-19 on health care and childcare in the National Survey of Children's Health

About half of autistic children and children and youth with special health care needs (CYSHCN) had a virtual health care visit in 2021. Among autistic children, virtual visits varied by race and ethnicity. Black children were the most likely to have a virtual visit (64%) and Hispanic children, the least (38%).

Just over one-third of autistic children missed (or delayed) a preventive checkup because of the COVID-19 pandemic, as did 36% of CYSHCN. Among

**There were small decreases in receipt of care coordination and referrals in autistic children from 2019 to 2021, while difficulty getting referrals increased.**



Data source: National Survey of Children's Health 2019 and 2021

autistic children, Asian and Black children were less likely to miss a visit than children of another race or ethnicity. There was no notable difference by insurance status.

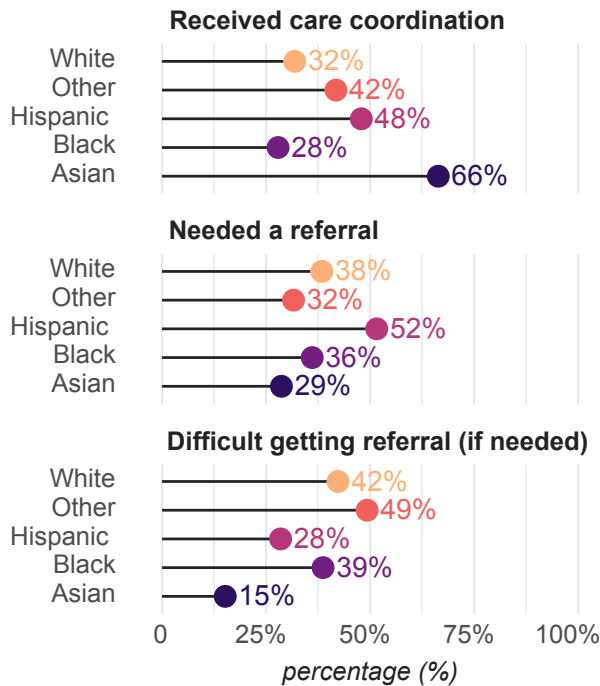
Finally, 42% of parents of autistic children (3-11) had a childcare arrangement closed due to the COVID-19 pandemic. This varied by age with half of parents of younger children (3-7) reporting closure, compared to 30% of parents of older children (8-11). Closed childcare also varied by race and ethnicity of autistic children. Parents of Hispanic children and white children were the least likely to experience closures of childcare arrangements as compared to parents of children of other races.

### Changes in national emergency department usage in 2020

There was a large decrease in emergency department (ED) use in the middle of 2020, as seen in the National Emergency Department Sample. Starting in April 2020, there were decreases in ED use for autistic children (0-17), adults (18-44), and older autistic adults (45+). The COVID-19 pandemic was declared in March 2020.

The number of ED visits returned to pre-pandemic levels in the fall of 2020 among older autistic adults with visits remaining low for autistic children. We saw greater decreases in ED use for non-autistic adults as compared to autistic adults.

### Receipt of care coordination and referrals varied by race and ethnicity in autistic children in 2021 (in the past 12 months).



Data source: National Survey of Children's Health 2021

### Changes in national inpatient hospitalizations in 2020

Like trends seen in emergency department visits, there were sharp decreases in April 2020 in the number of hospitalizations among autistic individuals of all ages. This data came from the National Inpatient Sample.

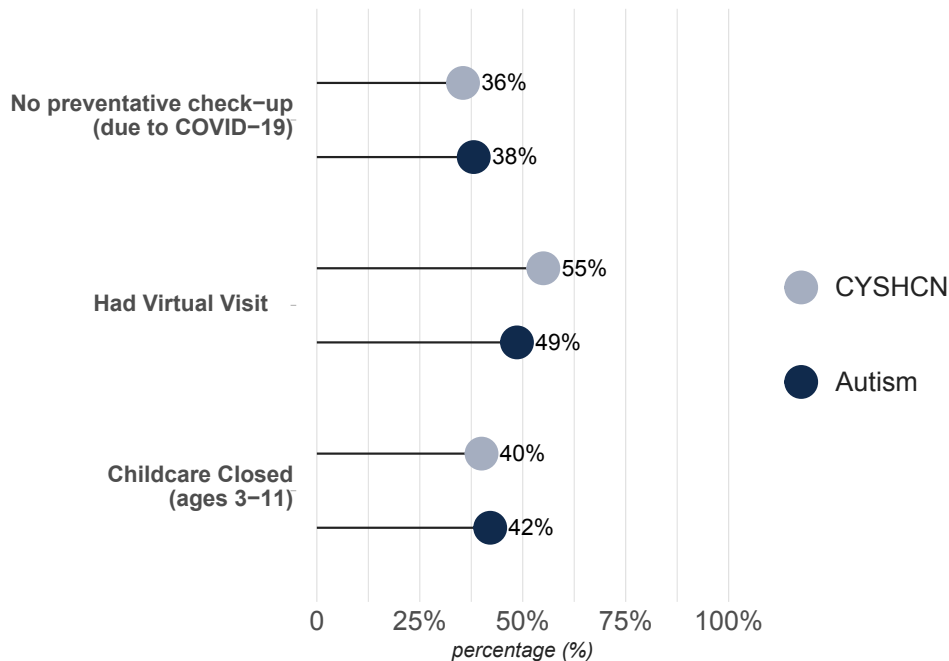
For autistic children, the number of hospitalizations did not increase to pre-pandemic levels in the rest of 2020. In autistic adults and older adults, hospitalization did increase to pre-pandemic levels by the end of 2020. There were smaller decreases in hospitalizations for all non-autistic individuals as compared to autistic individuals.

### Service changes in autistic adults insured by Kaiser Permanente Northern California

Finally, we focused on services received by autistic adults (ages 18+) enrolled in Kaiser Permanente Northern California (KPNC) (n=7750).

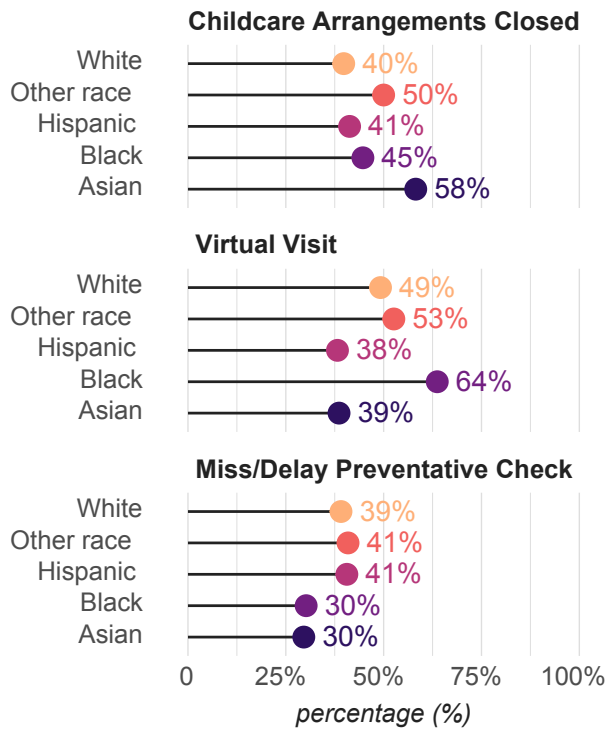
From March 2019 through February 2021, there was a decline in the number of in-person primary care

### Impact of the COVID-19 pandemic on children in 2021.



Data source: National Survey of Children's Health 2021

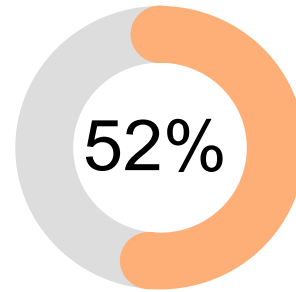
**The impact of the COVID-19 pandemic on autistic children varied by race and ethnicity.**



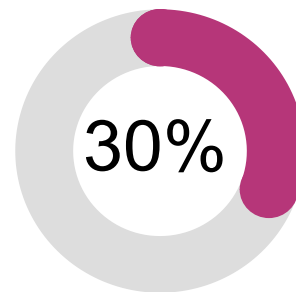
Data source: National Survey of Children's Health 2021

**Closure of childcare arrangement dues to COVID-19 were more common in younger autistic children, where half experienced closures in 2021.**

Ages 3-7



Ages 8-11



Data source: National Survey of Children's Health 2021

visits and a corresponding increase in the number of telehealth services received. In March-April 2020, the number of primary care visits (either in-person or via telehealth) declined, but visits started to increase again beginning in May 2020.

Nearly three-quarters of autistic adults had a primary care visit in the year preceding the COVID-19 pandemic (March 2019 to February 2020). In the following year (March 2020 to February 2021), 58% of autistic adults had a primary care visit.

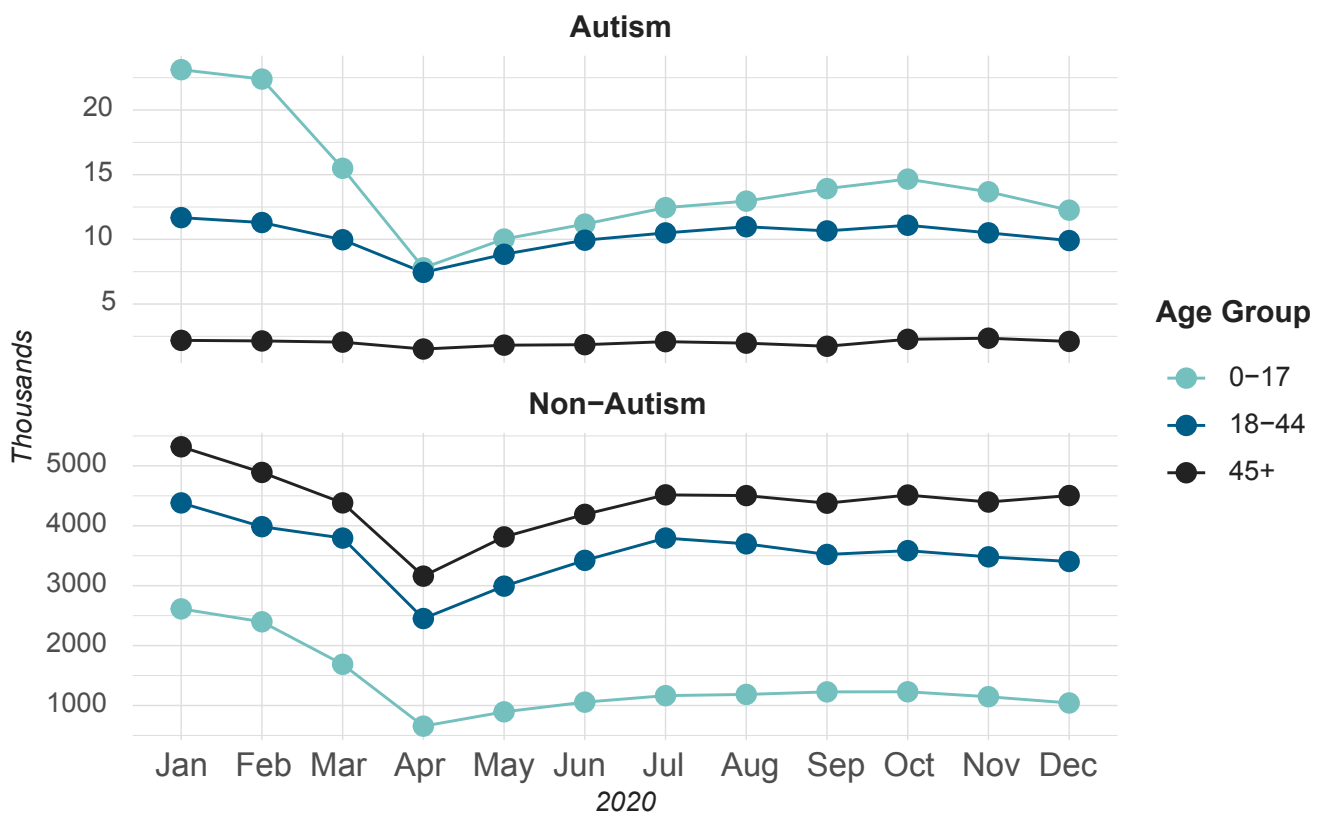
Older autistic adults were more likely to access primary care than younger adults. In the year before the pandemic, 66% of autistic young adults (18-24) had a primary care visit as compared to 95% of older adults (60+). In 2020, 52% of autistic young adults had a primary care visit as compared to 87% of older adults. While all age groups experienced a decline in primary care use between the pre-pandemic and early pandemic periods, the youngest group saw the largest decline.

Changes in primary care use by autistic adults from 2019 to 2020 varied by race and ethnicity. Asian autistic adults had the biggest decrease in primary care use from 2019 to 2021 (74% versus 51%) followed by Black adults (76% vs. 58%).

Use of urgent and emergency care also decreased from 2019 to 2021. There were large decreases in the

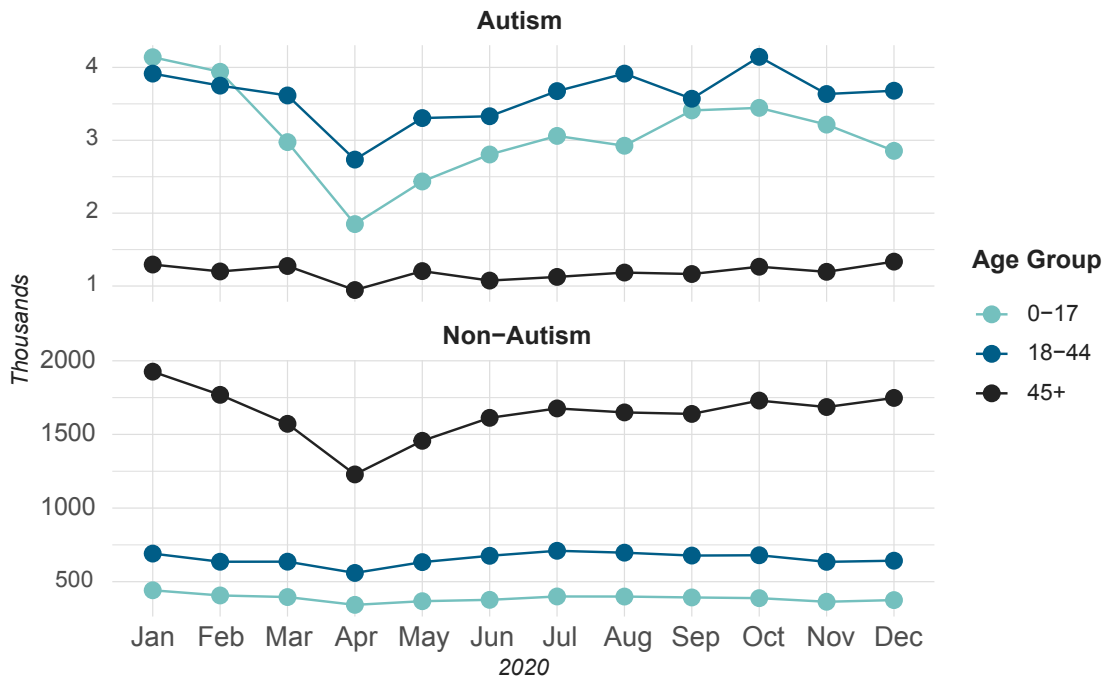
number of emergency department (ED) and urgent care visits in April-May 2020 and then subsequent increases through February 2021. From March 2019 to February 2020, 16% of autistic adults had an ED visit as compared to 11% from March 2020 to February 2021.

**Counts of emergency department visits in 2020 decreased the most for children, but decreases were seen in all ages.**



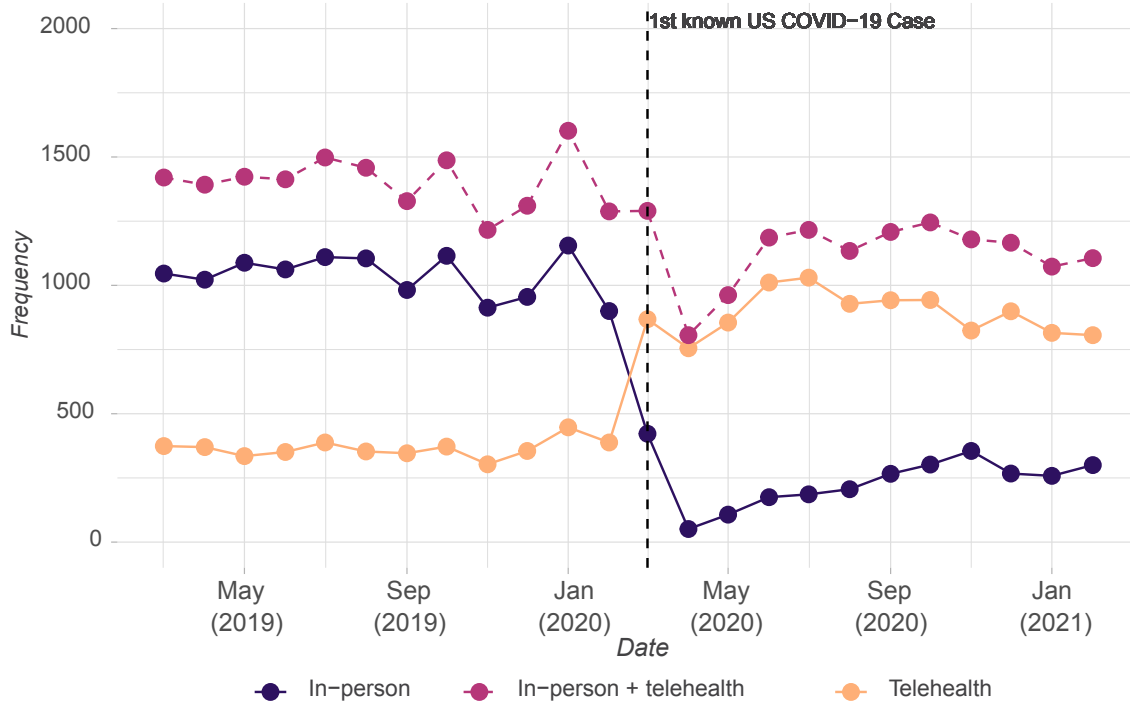
Data source: National Emergency Department Sample 2020

**The number of hospitalizations decreased the most in autistic children in 2020, but decreases were seen across all ages.**



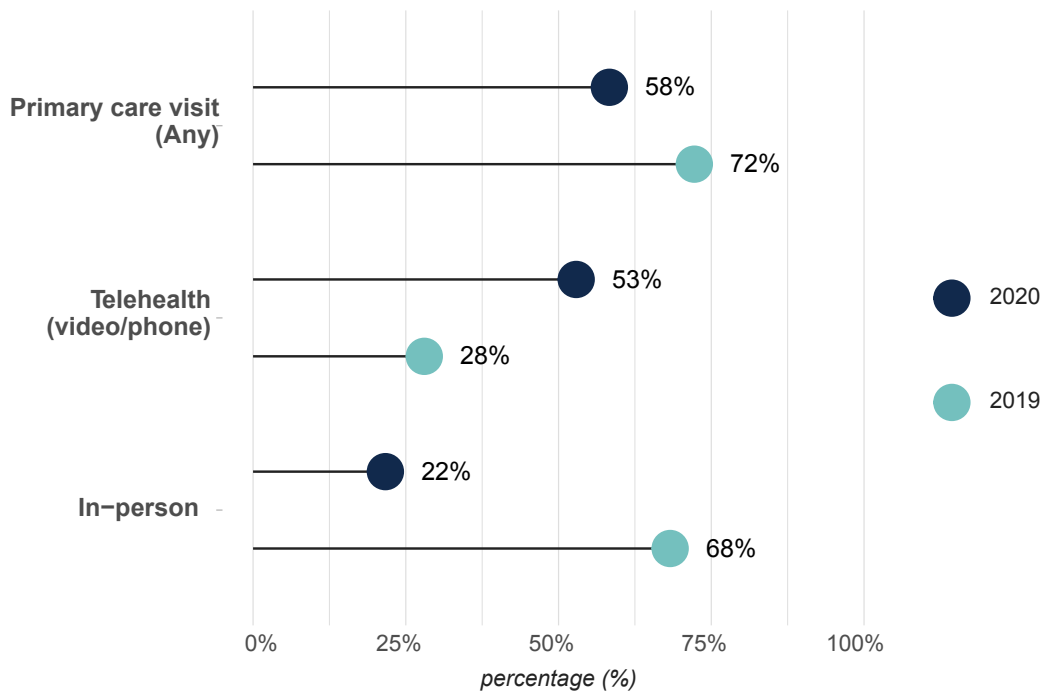
Data source: National Inpatient Sample 2020

**Primary care visits decreased in autistic adults in March 2020.**



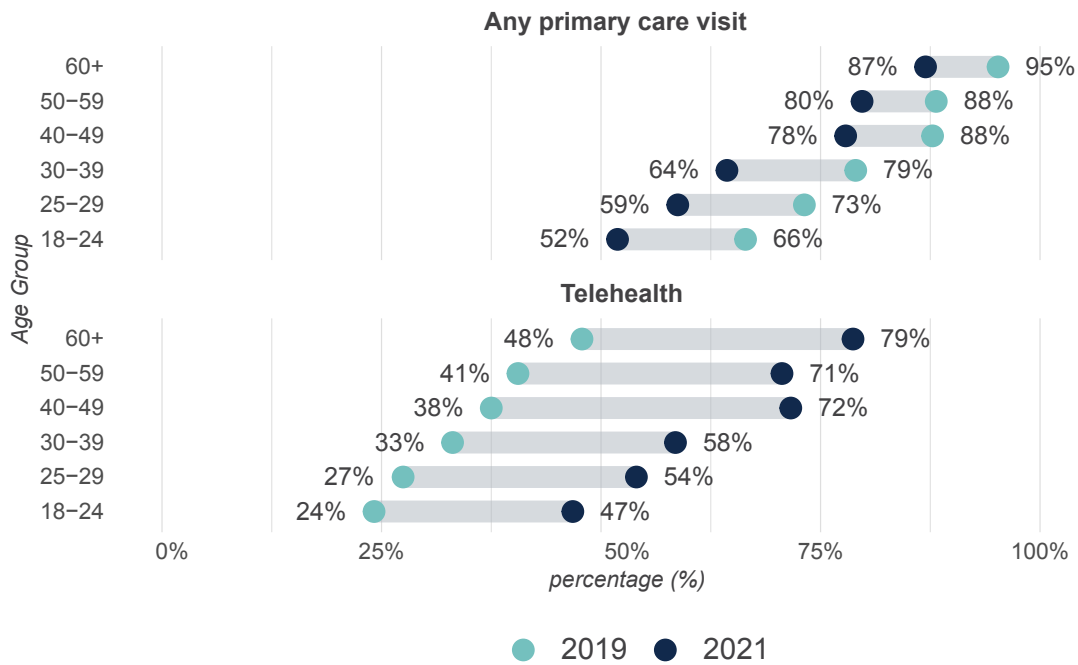
Data source: Kaiser Permanente Northern California 2019 to 2021

**In-person primary care visits were much less common in 2020 than 2019 for autistic adults, while rates of telehealth increased.**



Data source: Kaiser Permanente Northern California 2019 to 2021.

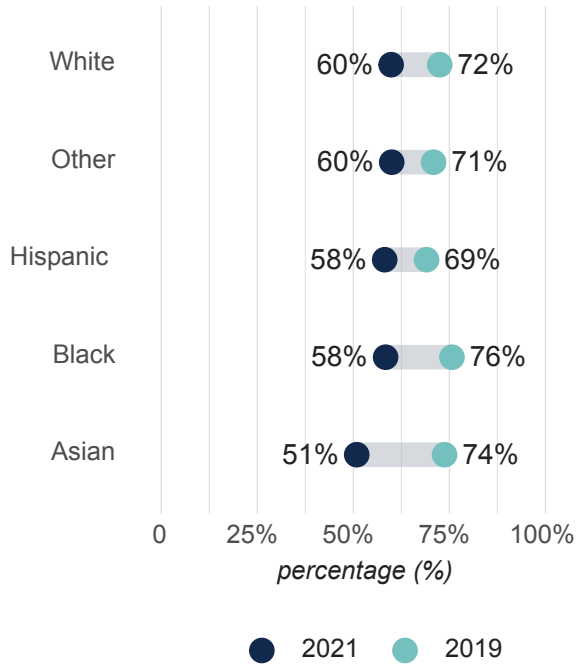
**Primary care visits decreased for all patients regardless of age, with the biggest decreases seen in younger patients.**



Data source: Kaiser Permanente Northern California 2019 to 2021

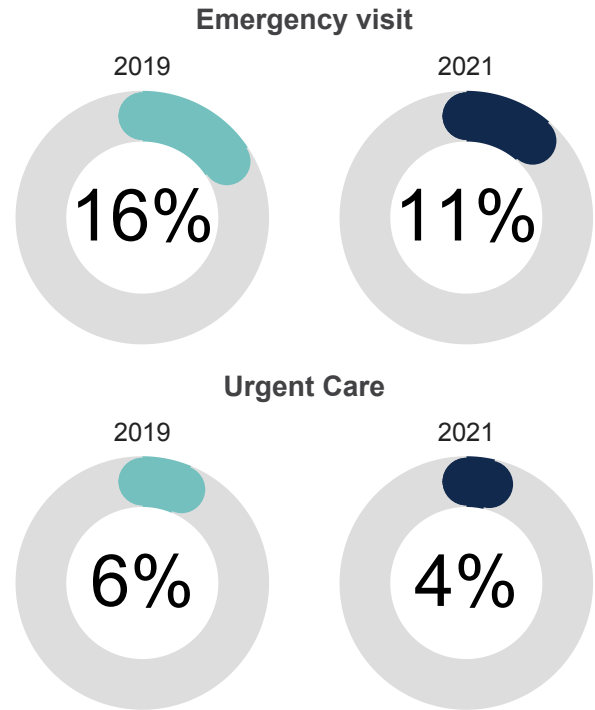


**Decreases in primary care visits from 2019 to 2021 were biggest for Black and Asian autistic adults.**



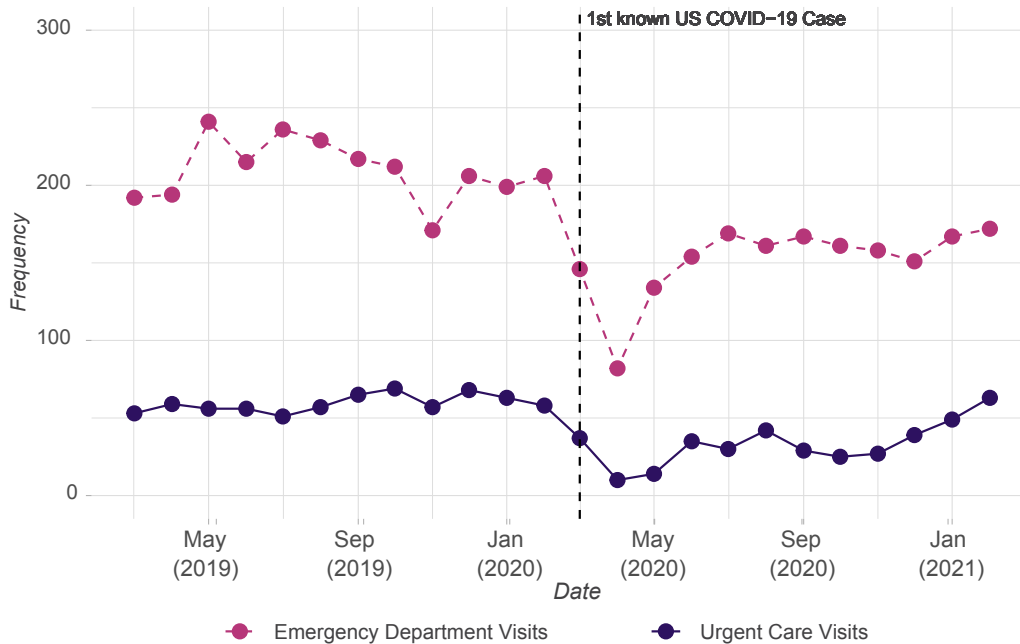
Data source: Kaiser Permanente Northern California 2019 to 2021

**Urgent care and emergency visits decreased from 2019 to 2021.**



Data source: Kaiser Permanente Northern California 2019 to 2021

**Monthly counts of emergency and urgent care visits in autistic adults.**



Data source: Kaiser Permanente Northern California 2019 to 2021

## Chapter conclusions and implications.

Efforts to reduce COVID-19 transmission and staffing shortages reduced access to health care services during the COVID-19 pandemic. People with chronic health conditions may have suffered from worsening health due to reduced access to care, which can lead to a need for more costly emergency care. We found decreases in access to services such as dental care, emergency department visits, and inpatient hospitalizations in 2020 and 2021 as compared to pre-pandemic years. Younger people experienced greater reductions in care. Black and Hispanic autistic children experienced larger decreases in care access as compared to white autistic children. Children with public health insurance, like CHIP and Medicaid, had better access to care, including virtual care and mental health care, than those with private insurance.

# CHAPTER 4:

## Mental health service utilization

The COVID-19 pandemic had a detrimental impact on the mental health of the entire U.S. population. Prior to the pandemic, autistic people were already at increased likelihood of having co-occurring mental health conditions. The purpose of this chapter is to understand the use of mental health services by autistic children and adults during the COVID-19 pandemic.



### Data used in this chapter:

the National Survey of Children’s Health (NSCH) includes information about health and health care for a nationally representative sample of children in the U.S. The National Emergency Department Sample (NEDS) captures a nationally representative sample of emergency department visits in the U.S. for children and adults, regardless of how their visits is paid for (referred to as all-payer as it captures private insurance, public insurance, and uninsured patients). The National Inpatient Sample (NIS) captures a nationally representative sample of all inpatient hospitalizations in the U.S. for children and adults and is also all-payer.

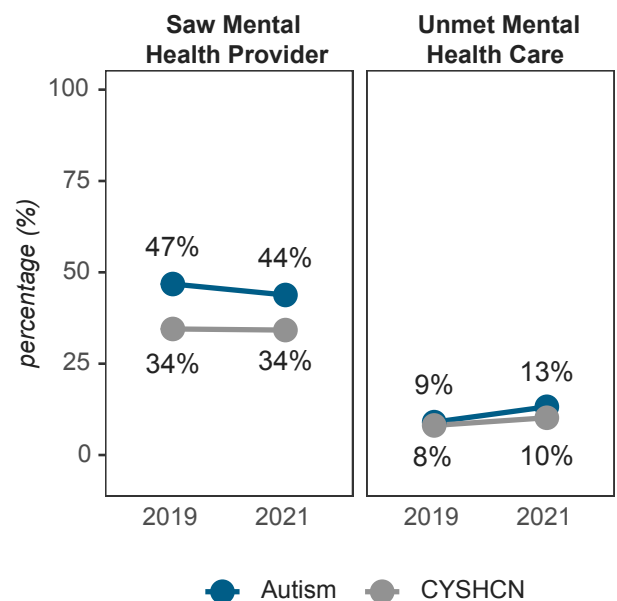
### Mental health care in autistic children from the National Survey of Children’s Health

In 2019 and 2021, just under half of autistic children (3-17) received mental health care. Parents of autistic children reported unmet need for mental health care; 13% in 2021 and 9% in 2019. Fewer children and youth with special health care needs (CYSHCN) received mental health care, but unmet need was similar to children with autism.

Among autistic children, there were differences in receipt of mental health care by race and ethnicity in 2021. About 20% of Black children received mental health care in 2021, compared to nearly 50% of children of all other races.

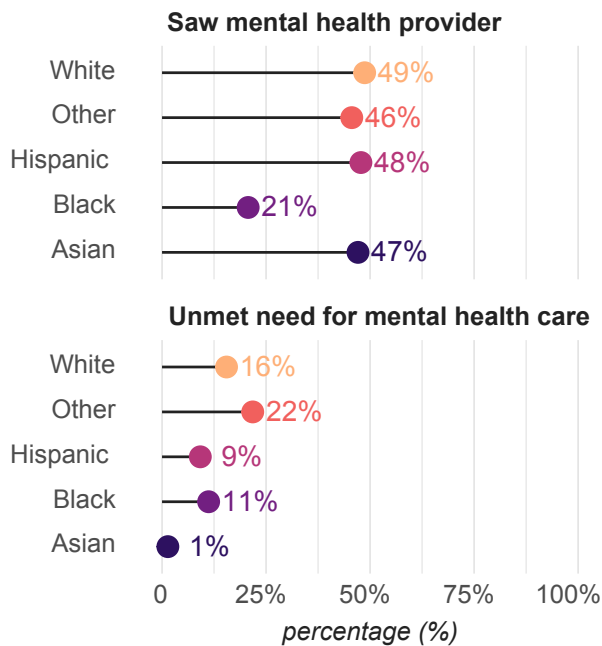
Asian children had the lowest reported unmet need for mental health care and parents of children of another reported race had the highest. There were also differences in mental health care by health insurance status: nearly half of children with public insurance received mental health care, while one-fifth of children with private insurance received mental health care. Unmet need was also

**There were not changes in receipt of mental health care from 2019 and 2021. Mental health care was more common in autistic children than CYSHCN.**



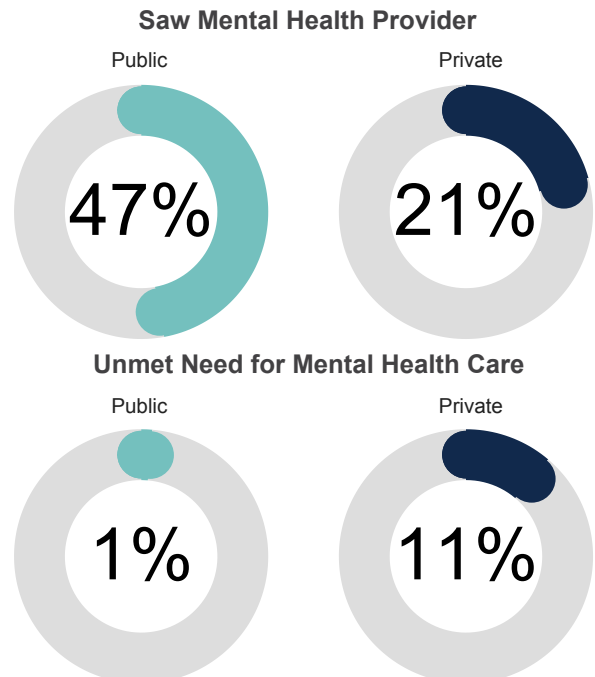
Data source: National Survey of Children’s Health 2019 and 2021

**Receipt of mental health care was least common in Black autistic children in 2021, while unmet need was highest in children of another or multiple races and white children.**



Data source: National Survey of Children's Health 2021

**Mental health care was more common in autistic children with public insurance than those with private insurance, while unmet need for mental health care was more common in children with private insurance in 2021.**



Data source: National Survey of Children's Health 2021

greater in children with private health insurance in 2021.

## National emergency department visits for mental health conditions

In chapter 3, we found that visits to the emergency department (ED) decreased in April and May 2020. Now we consider the reason for ED visits that did occur using the National Emergency Department Sample.

Among autistic children (0-17), visits for mental health conditions comprised 13-15% of all visits from January-March 2020, and 16-18% of all visits from April-December 2020. Among autistic adults (18-44), visits for mental health conditions comprised about one-quarter of ED visits across 2020. ED visits for mental health conditions were less common in older autistic adults than autistic individuals of other ages.

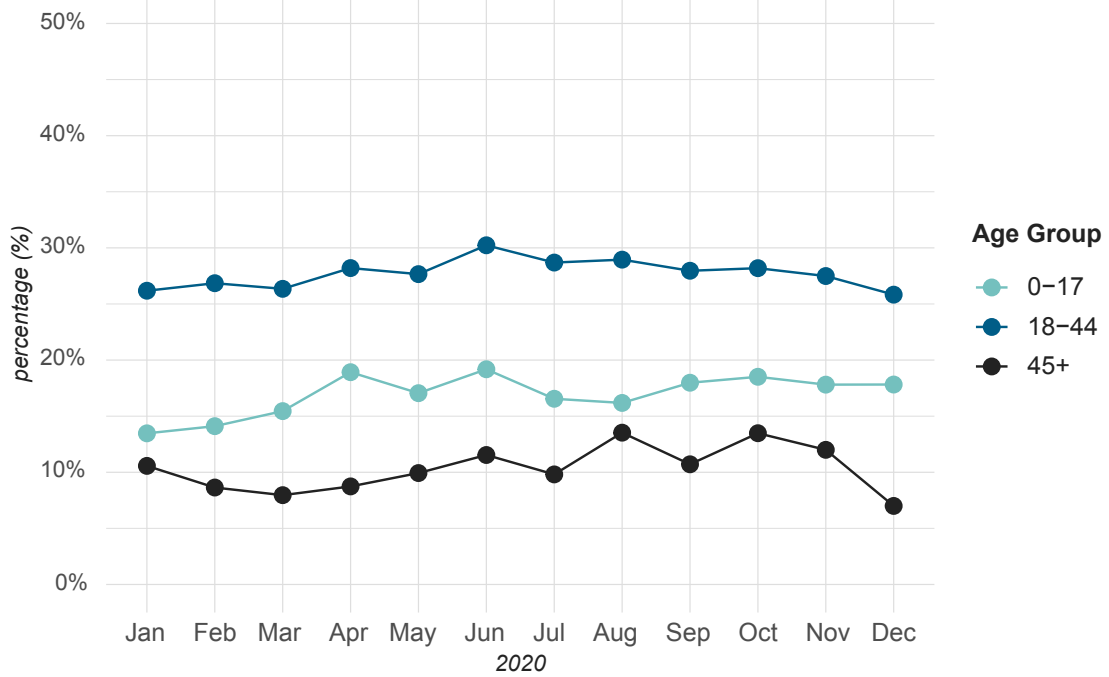
Among autistic children (0-17), there was a 5% increase in ED visits for mental health conditions from April 2019 to April 2020. There was a smaller increase in autistic adults (18-44) (2%) and a decrease in older autistic adults (-1%) for ED visits for mental health conditions.



### What do we mean by “ED visits for mental health conditions”?

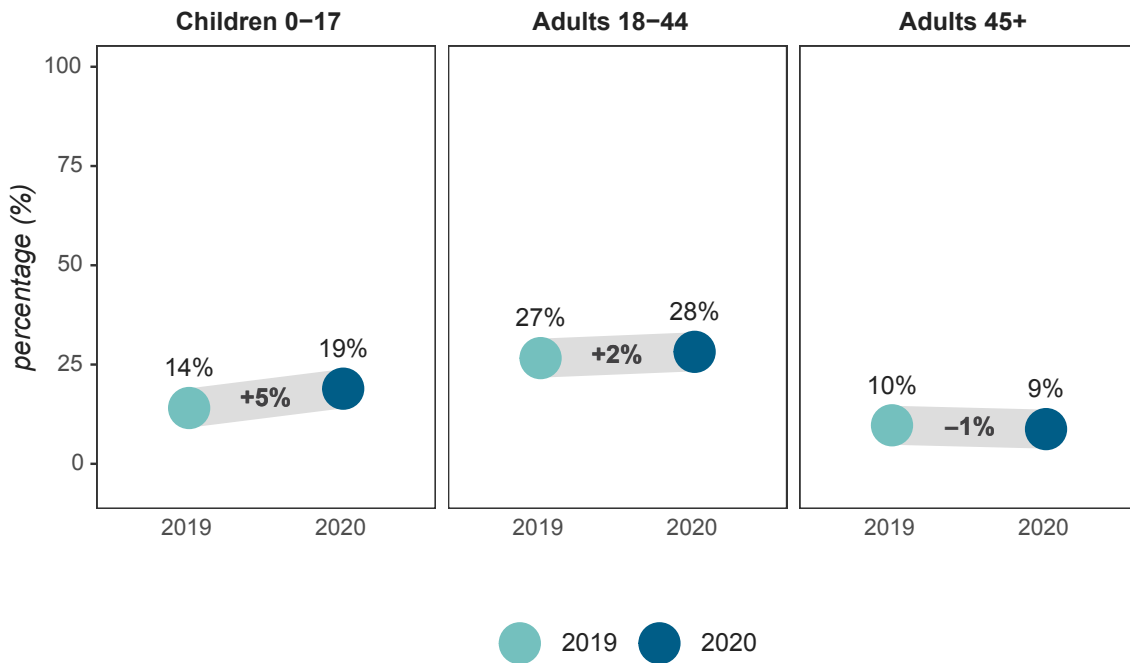
When a person has an emergency department (ED) visit, doctors record the primary reason for the visit to the ED. Visits for mental health conditions are those visits where the primary reason for the visit was recorded as any mental health disorder or condition.

**Visits for mental health conditions account for one-quarter to one-third of all ED visits for autistic adults ages 18–44 in 2020.**



Data source: National Emergency Department Sample 2020

**There was little change in the proportion of ED visits for mental health conditions from April 2019 to April 2020.**



Data source: National Emergency Department Sample 2019 and 2020

## National inpatient hospital admissions for mental health conditions

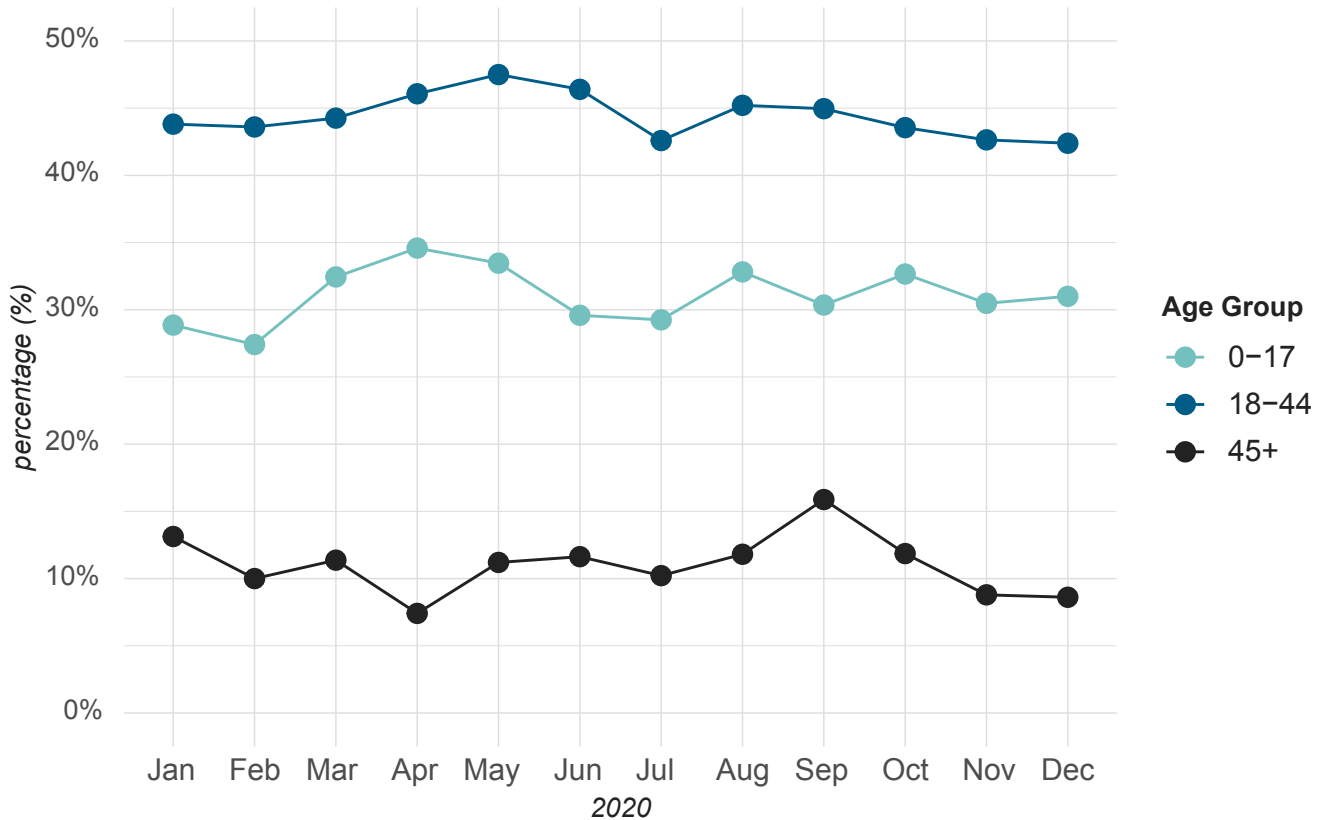
In 2020, one-quarter to one-third of inpatient hospitalizations in autistic children (0-17) were for mental health conditions. This was largely consistent over the year with slightly higher hospitalization rates in March, April, and May. Data came from the National Inpatient Sample.

Hospitalizations for mental health conditions were even more common in autistic adults (18-44). In May 2020, 48% of hospitalizations were for mental

health conditions. Older autistic adults had the fewest hospitalizations for mental health conditions (ranging from 7-16%).

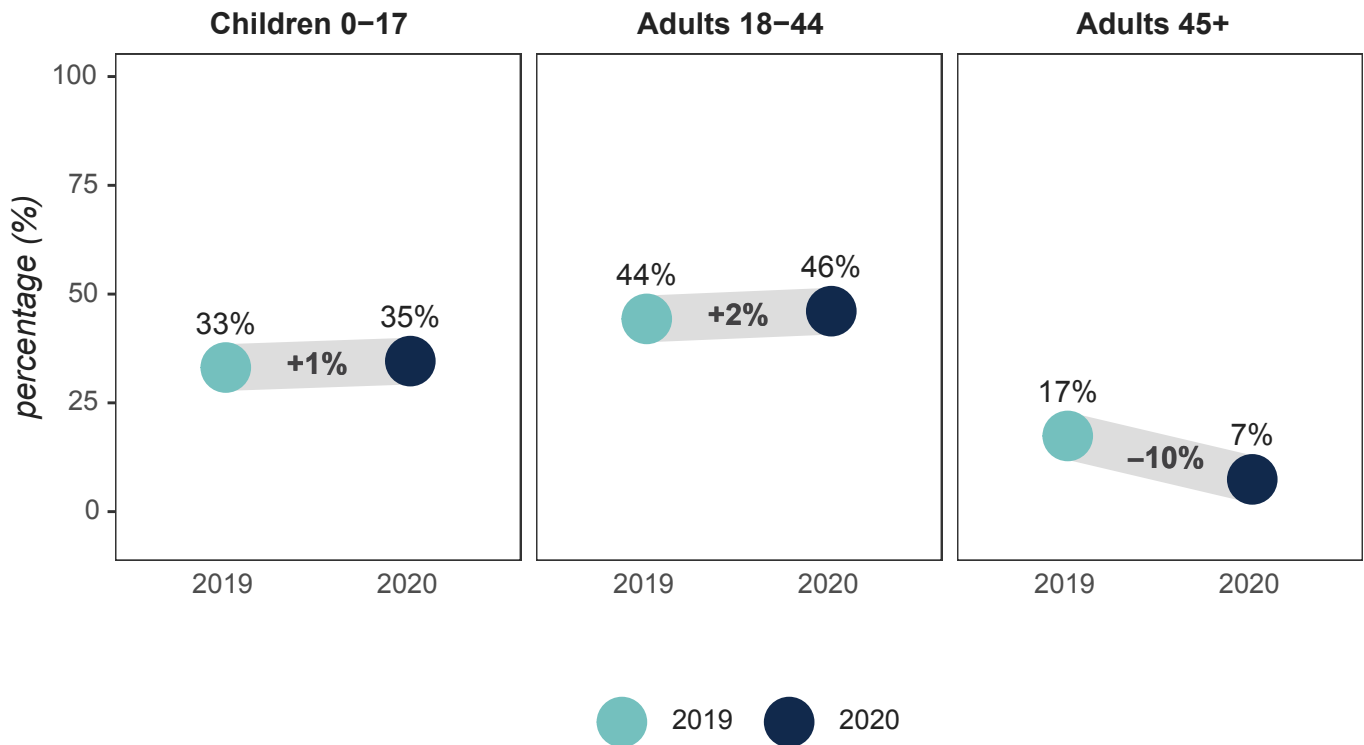
There were not significant increases in the percentage of hospitalizations for mental health conditions among autistic children and autistic adults (18-44) from April 2019 to April 2020. However, in older autistic adults, there was a 10% decrease in hospitalizations for mental health conditions during the same period.

### Hospitalizations for mental health conditions accounted for nearly half of hospitalizations for autistic adults ages 18-44 in 2020.



Data source: National Inpatient Sample 2020

**The proportion of hospitalizations that were for mental health conditions decreased by 10% in older autistic adults from April 2019 to April 2020.**



*Data source: National Inpatient Sample 2019 and 2020*

## ▶ Chapter conclusions and implications.

Emerging research on the impact of the COVID-19 pandemic on the general population highlights increases in mental health concerns among children and adults, including anxiety and depression. In this study, there were no apparent changes in receipt of mental health care among autistic children identified through 2021. There were noted differences in mental health care access by health insurance status. Nearly half of children with public insurance received mental health care, while only 1/5 of children with private insurance received mental health care. Unmet need for mental health care was also greater in children with private health insurance in 2021. To accommodate mental health care needs during the COVID-19 pandemic, many states changed regulations around use of telehealth for mental health care and eased restrictions that limit clinicians from practicing across state lines. Making these changes permanent could allow for increased access to appropriate mental health care and qualified mental health care providers. Increased accessibility of mental health care through public health insurance is of importance to examine to determine how private insurance may then also improve care access. Future work will be needed to examine changes in mental health in the years following the COVID-19 pandemic.



# Conclusions and recommendations for research and policy

## Takeaways from our findings:

- The COVID-19 pandemic significantly impacted the access to services and supports for autistic people, affecting their employment, education, health, and independence.
- Autistic adults had higher rates of visits to the emergency department (ED) and hospitalizations for COVID-19 compared to non-autistic adults.
- Certain risk factors for severe COVID-19, such as obesity, chronic lung disease, diabetes, and chronic kidney disease, are more common in autistic people, putting them at increased risk.
- Access to care decreased during the COVID-19 pandemic, including dental care, emergency department visits, and inpatient hospitalizations.
- Younger people experienced greater reductions in care, and Black and Hispanic autistic children experienced larger decreases compared to white children.

## Research recommendations:

- Further research is needed to examine the long-term mental health changes among autistic people in the years following the conclusion of the official COVID-19 Pandemic.
- Future studies should explore the effectiveness and impact of telehealth for mental health care among autistic individuals.
- We need to investigate disparities in mental health care access and utilization among different racial/ethnic groups and health insurance statuses.

## Policy actions:

- Healthcare providers and virtual platforms should ensure accessibility and high-quality services for all patients, including those on the autism spectrum. This can include creating physical and virtual environments that are sensory-friendly, minimizing overwhelming stimuli such as bright lights, loud noises, and crowded waiting areas. Provide options for individuals to request accommodations, such as quiet spaces or extended appointment times. Additionally, providers can use communication strategies that cater to diverse communication preferences. This may include using visual aids, written instructions, or simplified language to enhance understanding and ensuring any online platforms are user-friendly and accessible for individuals with diverse sensory and cognitive profiles.
- Health care policies should continue to support telehealth and virtual care options for mental health services, including easing portability restrictions and expanding coverage. This includes the need to ease portability restrictions, allowing mental health providers to deliver care across state lines, and expanding coverage to ensure equitable access for individuals in diverse geographic areas. By supporting telehealth and virtual care, individuals on the autism spectrum and other neurodivergent individuals can benefit from increased accessibility and convenience. It enables them to receive care from the comfort of their own homes, reducing barriers such as transportation challenges or sensory overload in clinical settings. Moreover, expanding coverage for telehealth services can enhance affordability and make mental health care more accessible to individuals with limited financial resources or those residing in underserved areas.

# Appendix: Methods

## What data did we use for this report?

Data for this report came from: 1) one federally funded national survey conducted in the United States, 2) one administrative database of emergency department visits and one of inpatient hospitalization, and 3) Kaiser Permanente Northern California (KPNC) patient medical 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 NSCH asks about health, health care 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 examined the NSCH administered in 2019 and 2021. More information about the NSCH can be found by visiting <https://www.census.gov/programs-surveys/nsch.html> or <https://www.childhealthdata.org/>

The **National Emergency Department Sample (NEDS)** is a nationally representative sample of emergency department visits from the Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality (AHRQ) (NEDS, 2020). NEDS is an all-payer database of U.S. emergency department visits. NEDS 2020 captured more than 120 million ED visits from 40 states and the District of Columbia, covering 85% of the U.S. population. The unit of analysis in NEDS is index visits, not individuals. More information about the NEDS and HCUP can be found at <https://hcup-us.ahrq.gov/nedsoverview.jsp>

The **National Inpatient Sample (NIS)** is a nationally representative sample discharge data also from HCUP (NIS, 2020). NIS is an all-payer inpatient database of U.S. hospital inpatient stays, weighted to estimate national inpatient utilization and experiences. NIS 2020 captured more than 7 million stays from 48 states plus the District of Columbia, covering 98% of the U.S. population. 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](http://www.hcup-us.ahrq.gov/nisoverview.jsp)

We used **Kaiser Permanente Northern California (KPNC)** patient medical records to examine health and services in the population of adults enrolled in KPNC in Northern California. KPNC is an integrated health care delivery system that provides care to 4.6 million residents in northern California, including San Francisco, Sacramento, and surrounding areas. Medical records include all patient visits to primary care, outpatient providers, and emergency and inpatient hospitalizations, as well as prescriptions.

## Who is this report about?

### Autistic children

The NSCH is national surveys designed to yield results that are representative of health experiences of non-institutionalized children 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 health care provider ever told you that this child had autism or autism spectrum disorder, and 2) does this child currently have the condition?

### **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 health care 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 (Bethell et al., 2002; Bethell et al., 2015). 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 health care provider or other professional from a list of 25 conditions, including ASD. Not all children with parent-reported health conditions, including ASD, screen positive on the CSHCN screener.

### **Kaiser Permanente Northern California Integrated Health Care Delivery System**

Findings from studies using KPNC data describe the health and healthcare utilization of autistic adults insured by KPNC in March 2019 through February 2021. Autistic adults were identified if they had a diagnosis of autism from a comprehensive assessment at a KPNC assessment center or had at least two diagnoses of autism in their KPNC record on separate occasions. They must have been at least 18 years old as of March 1, 2019, and have at least six months of KPNC membership between March 1, 2019 and February 28, 2021. Given the integrated health care model of KPNC differs from other health care models in the US, findings within KPNC are not necessarily representative of health and experiences of a larger, national population. Over half (59%) of adults enrolled in KPNC have privately paid health insurance, while 41% have public insurance, such as Medicaid. The sociodemographic of KPNC enrollees are broadly representative of the larger population of the Northern California area.

### **Emergency department visits and Inpatient hospital stays**

NEDS and NIS capture emergency department visits or inpatient hospital stays. The number of stays may be greater than the number of individuals who experienced an ED visit or inpatient stay, as patients may have had more than one stay in a year. Patient diagnoses in 2020 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. Index events with an autism diagnosis in any position were considered autism stays for this report captured by ICD-10-CM code F84.0, F84.5, or F84.9. Principal diagnoses for index events were also categorized using ICD-10-CM codes. The first diagnosis is considered the principal diagnosis related to the index event.

## **Data analysis**

This report presents descriptive statistics of health and health care experiences in the populations described above. Indicators are generally described as mean or proportions. We do not conduct tests of statistical significance or adjust for covariates in our presentation. However, we do examine indicators over several key strata, including age, race and ethnicity, and insurance type. We only report differences across these strata that are greater than 10% different, to focus on clinical difference rather than statistical difference.

Analyses using the NSCH were conducted in Stata 17 and controlled for the complex sampling design of the survey. Analysis using the NEDS and NIS were conducted in SAS 9.4 and controlled for the complex sampling design of these databases. Analysis of KPNC records was done in SAS 9.4.

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

This report gathered national and regional data to assess the health service impacts of the emergence of the COVID-19 pandemic on autistic people across the life course. A major strength is the combination of nationally representative data to present a wholistic picture of experiences during this time across geography, demographics, and service sectors. We also included a regional data source, KPNC, to add to the information available about services received by autistic adults, as the NSCH only includes children. Several of our data sources are all-payer, while one focus on a specific payer (KPNC). This allowed a comprehensive look across payers to examine varied populations.

A limitation to this report is the focus on health. We chose to focus this report on health and health services due to data availability. However, we know the COVID-19 pandemic impacted many aspects of life, including employment, community involvement, food, that also impact health. This report could not assess all factors associated with health during this time.

There are several limitations to the data sources to mention here. The NSCH is a survey of parents that relies on recall of past events and specific details about health experiences. In some cases, the sample size of autistic children in the NSCH is small, which makes analysis of certain subgroups difficult and estimates unstable. Diagnosis of autism is based on parent report of current diagnosis, not a clinical diagnosis. However, prevalence of parent reported ASD has been found to be close to national estimates of prevalence from medical and educational records (Kogan et al., 2009).

Data from NEDS and NIS rely on documentation of diagnoses in hospital records, either as a reason for hospitalization or a relevant diagnosis. Therefore, it is possible that autistic people experienced inpatient stays but did not have an autism diagnosis in their records.

Finally, data from KPNC only captures experiences of patients receiving care through the KPNC health system in northern California.

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