



**AIR-P Presents:**

# **The National Autism Indicators Report (NAIR) on Health and Health Care**

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# Health and health care in autistic children and adults

January 21, 2021



Life Course Outcomes  
Research Program



DREXEL UNIVERSITY

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Autism Institute

# Note on language

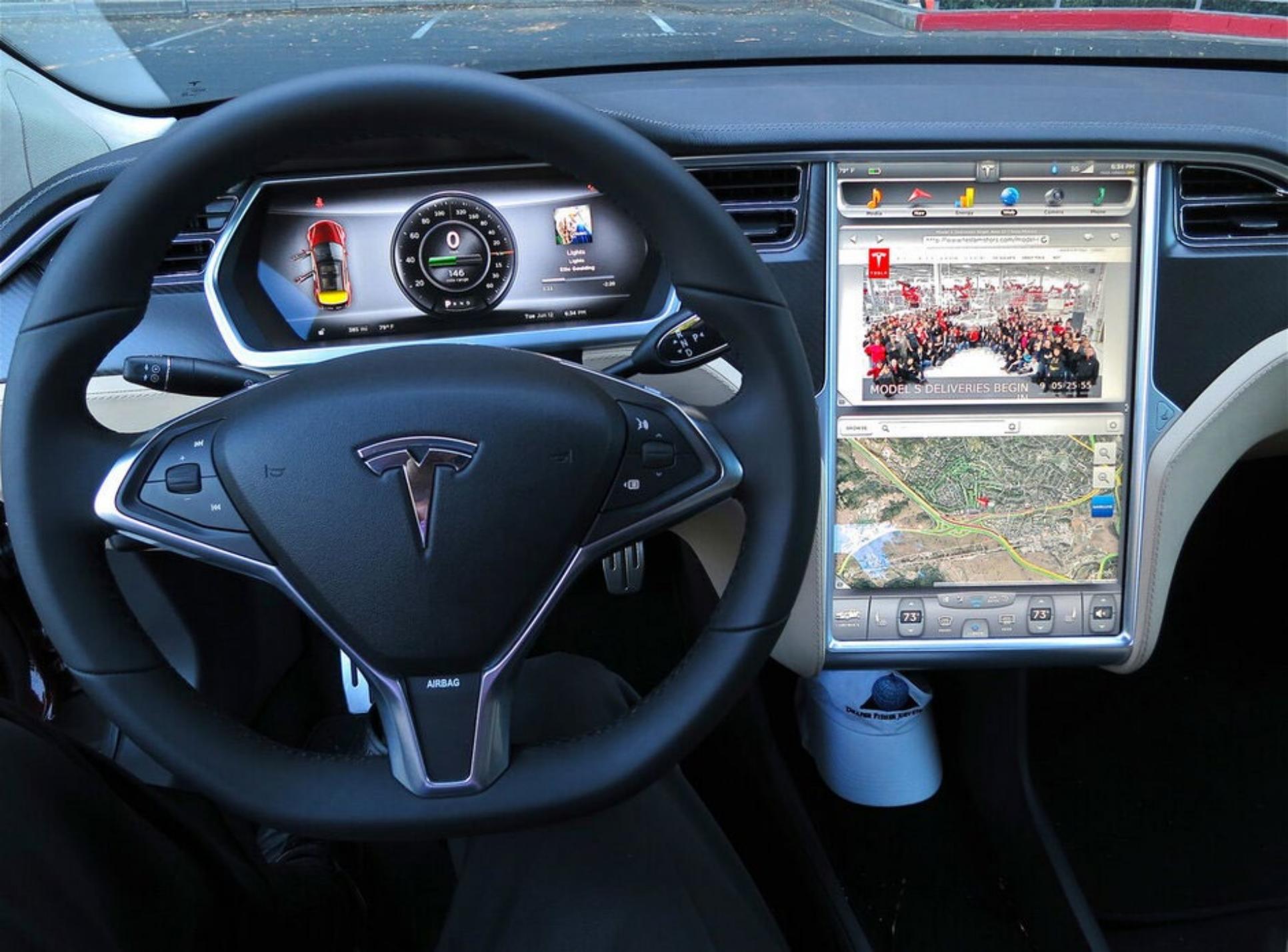
- Autistic
- ASD and the autism spectrum
- Current commentary on language
  - Bottema-Beutel *et al.*, 2020

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020).  
Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*.

# Life Course Outcomes Research

- Public health approach
  - Understand experiences and improve outcomes on a population level
- Life course science related to health
  - the path of each person's health is shaped by their health trajectory, risk factors, and exposures encountered throughout life, plus positive health experiences and improvements





# Building gauges

- Using existing national data, capitalizing on money already spent
- Creating information products that are accessible, understandable, and impactful
- Identifying gaps in data between available vs. needed

# NATIONAL AUTISM INDICATORS REPORT:

Health and Health Care  
November 2020

[drexel.edu/AutismOutcomes/NAIRhealth](https://drexel.edu/AutismOutcomes/NAIRhealth)



**Life Course  
Outcomes Program**



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# Why focus on health?



# Why focus on health care?

- Health care impacts health
- Health policies and insurance impact health care
- Health services and reimbursement patterns are not optimized for comprehensive care

# National attention on health

- HRSA re-investment in the AIR-P research network
- Autism CARES Act 2019 requires a report be submitted to congress on the health and well being of autistic people
- Interagency Autism Coordinating Committee (IACC) in the US Department of Health and Human Services convened a subcommittee to address the health needs of autistic people
- National research attention on health starting to identify the importance of the issue

# Need for this report

- Autistic people often have complex health needs.
- May use health care more often and have higher health care costs.
- Emergency department visits and inpatient hospitalizations occur more often.
- Even when autistic people access care, they have more unmet health care needs.

# Need for this report: context

- Social and political factors influence health and health services.
- Race and ethnicity influence health and health services.
- Health and healthcare needs change across the life course, experiences in early life have long-term impact.
- Differences between pediatric and adult health care may be challenging.

# Purpose

- Catalogue health and health care in autistic people across the lifespan
- Highlight inadequacies in current care systems
- Support recommendations for improvements in health and health care

# Topics covered

- Overall health
- Health services
- Medication
- Insurance
- Accessing services

# Findings highlighted

- Healthcare transition
- Primary care gaps
- Racial and ethnic disparities

# Data sources

- National Survey of Children's Health 2016-2018
- Medical Expenditure Panel Survey 2013-2017
- National Inpatient Sample 2017
- Kaiser Permanente Northern California previously published research—co author Lisa Croen

# Comparisons

- Throughout the results, you'll see comparisons to
  - Children with special health care needs (CSHCN)
  - Children with no special health care needs (SHCN)



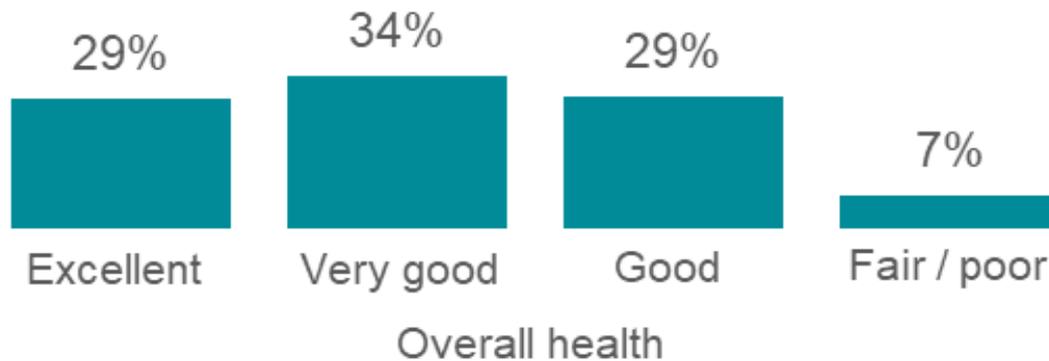
# Winding roads ahead

# Findings: Overall health



# Overall health

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



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

# Oral health

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

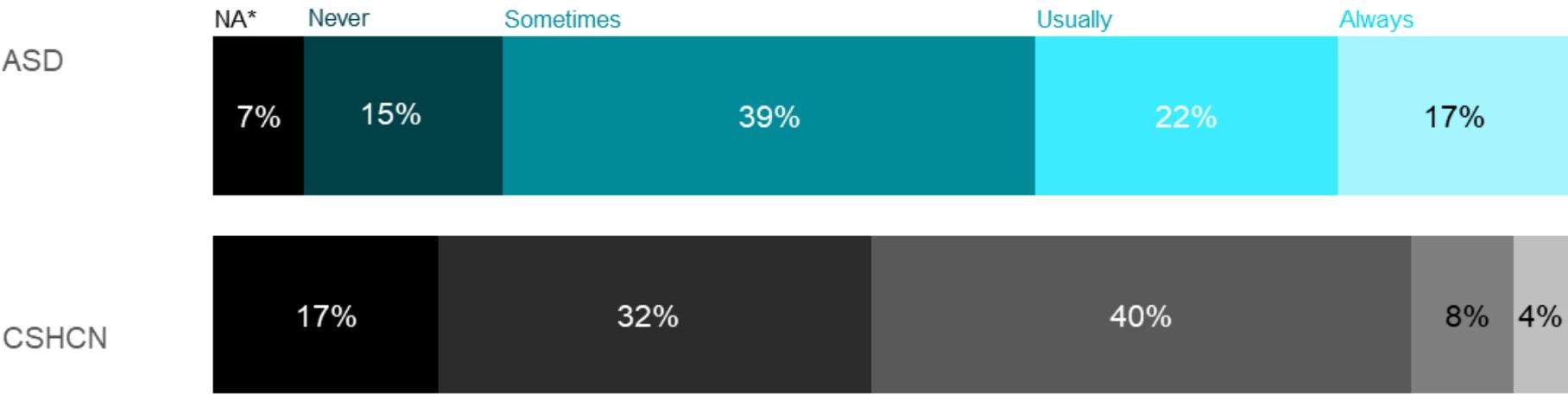


Source: National Survey of Children's Health 2016-18

**CSHCN** stands for children with special health care needs

# Impact on ability to things

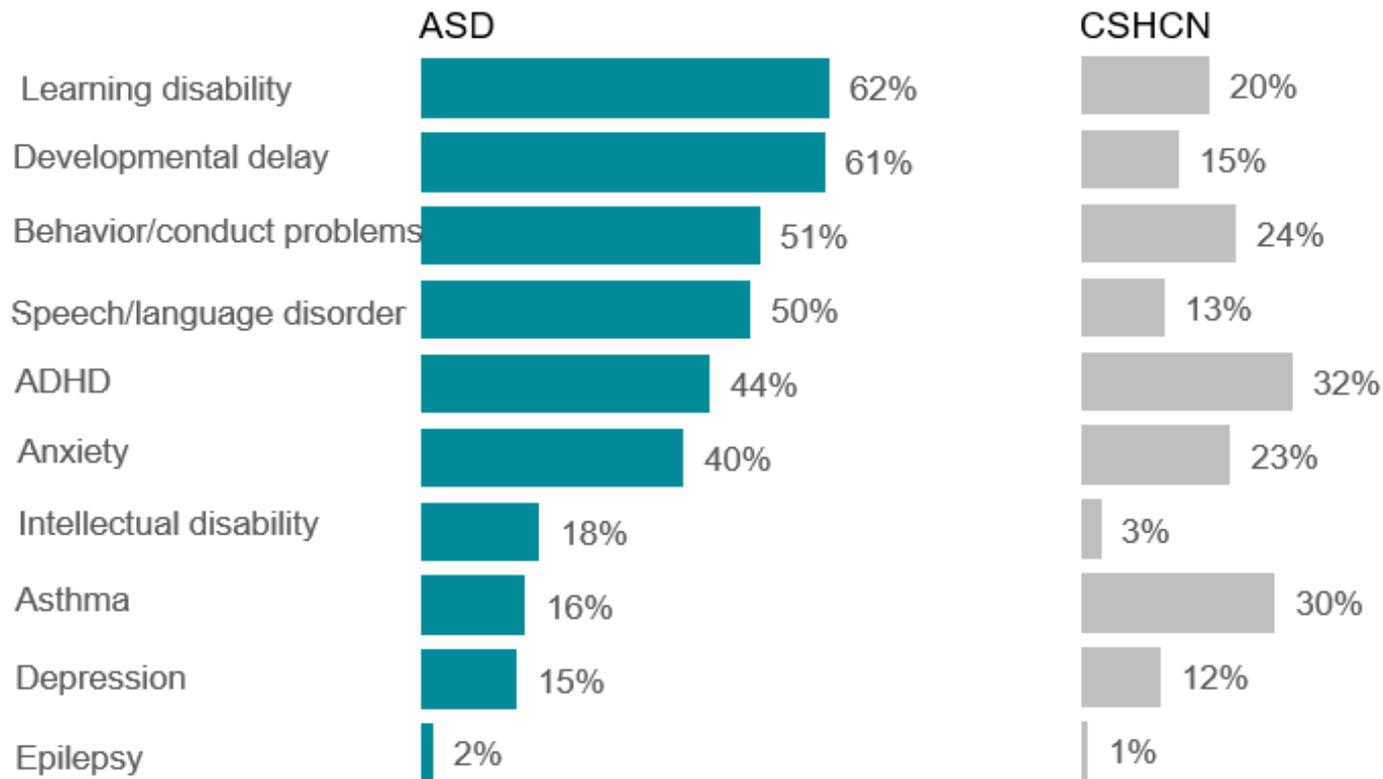
For more than one-third of **children with ASD**, their condition "usually" or "always" impacted their functioning.



\*Parent responded to the survey question with "this child does not have any health conditions."  
Source: National Survey of Children's Health 2016-18

# Co-occurring conditions

The most common conditions in **children with ASD** were learning disability and developmental delay.

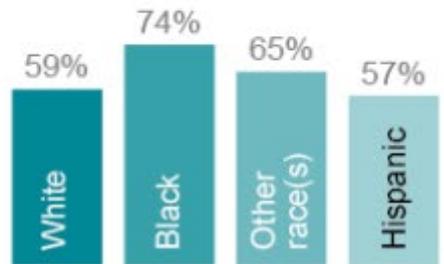


Source: National Survey of Children's Health 2016-18

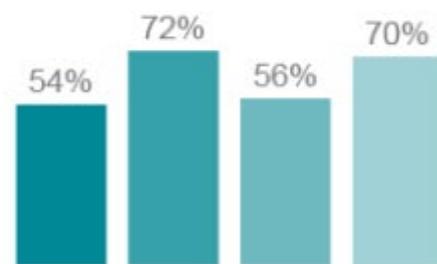
# Co-occurring conditions

Prevalence of parent reported conditions varied by race and ethnicity in children with ASD.

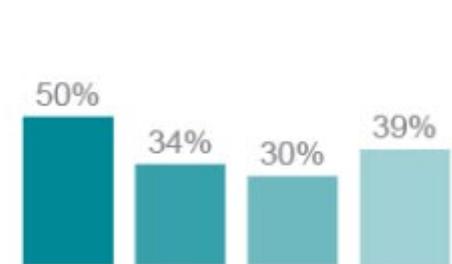
Developmental delay



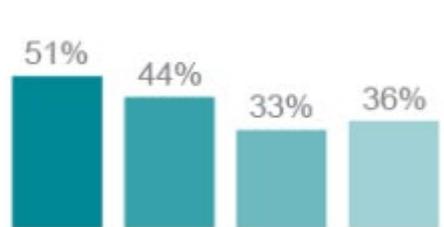
Learning disability



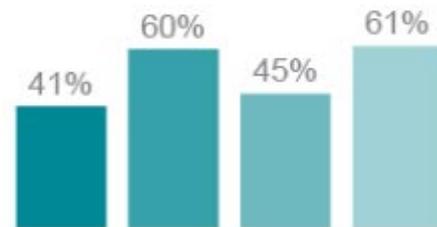
Anxiety



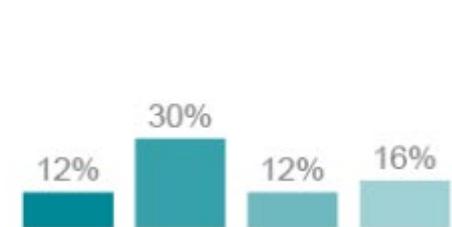
ADHD



Speech / language disorder



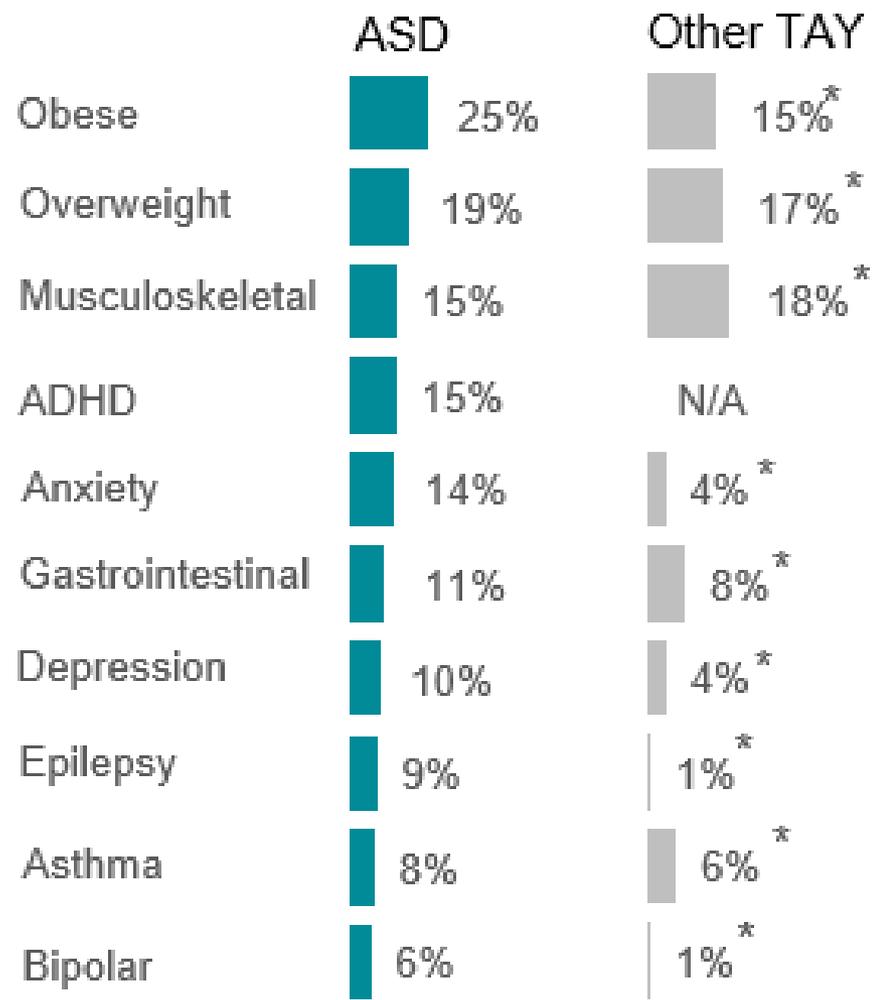
Asthma



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

# Kaiser: transition-age youth (TAY)

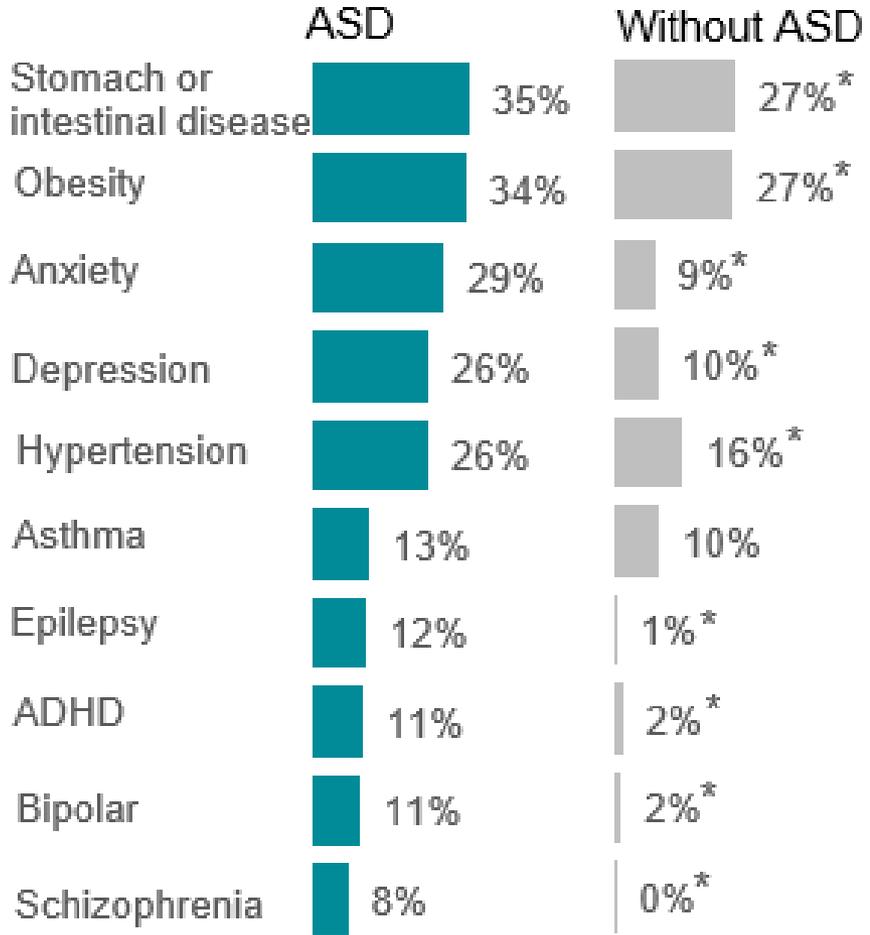
## Prevalence of conditions in TAY with ASD and other TAY.



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

# Kaiser: Adult co-occurring conditions

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

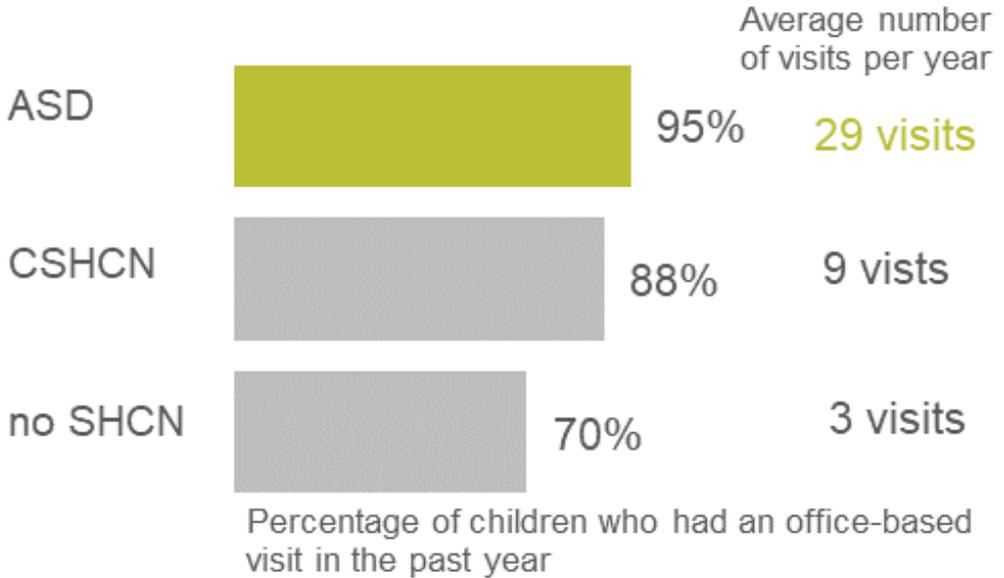


\*Significantly different from the ASD group as tested using logistic regression controlling for age, race/ethnicity, and sex  
Source: Croen et al., 2015

# Findings: Health Services

# Healthcare visits

**Children with ASD** were the most likely to have had an office-based visit in the past year and the highest number of visits.

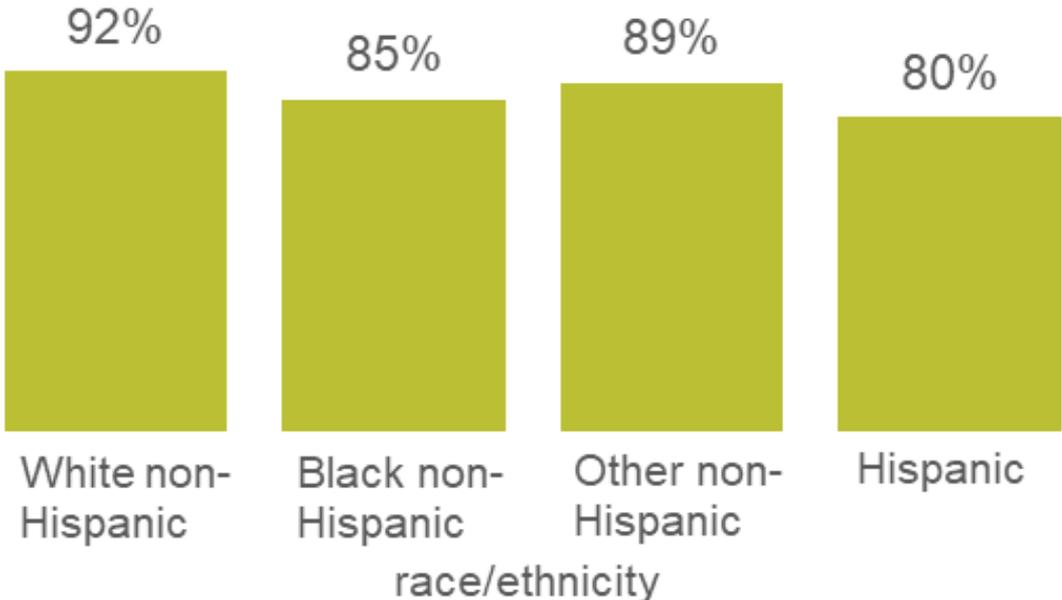


Source: Medical Expenditure Panel Survey 2013-17

**CSHCN** stands for children with special health care needs

# Healthcare visits

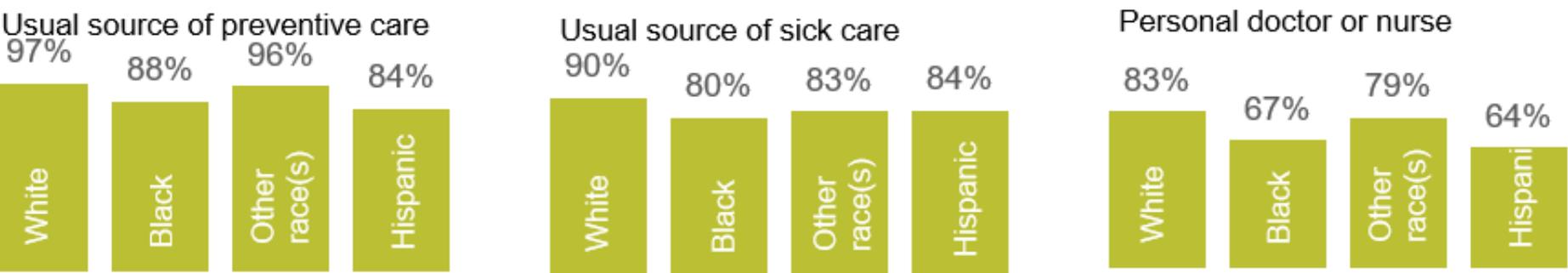
**Hispanic children with ASD were the least likely to report seeing a physician in the past year.**



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

# Usual care and a personal doctor

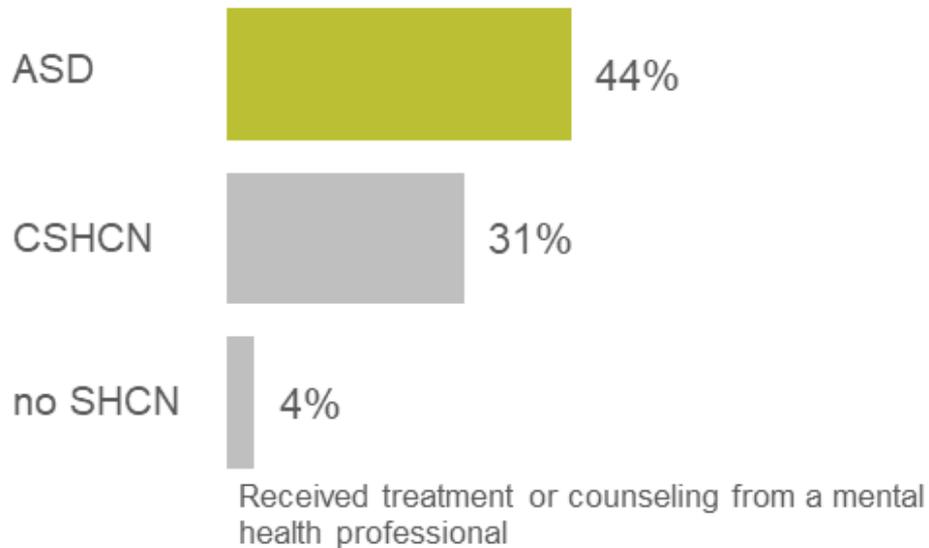
**Black and Hispanic children with ASD were the least connected to usual and consistent care.**



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

# Mental health care

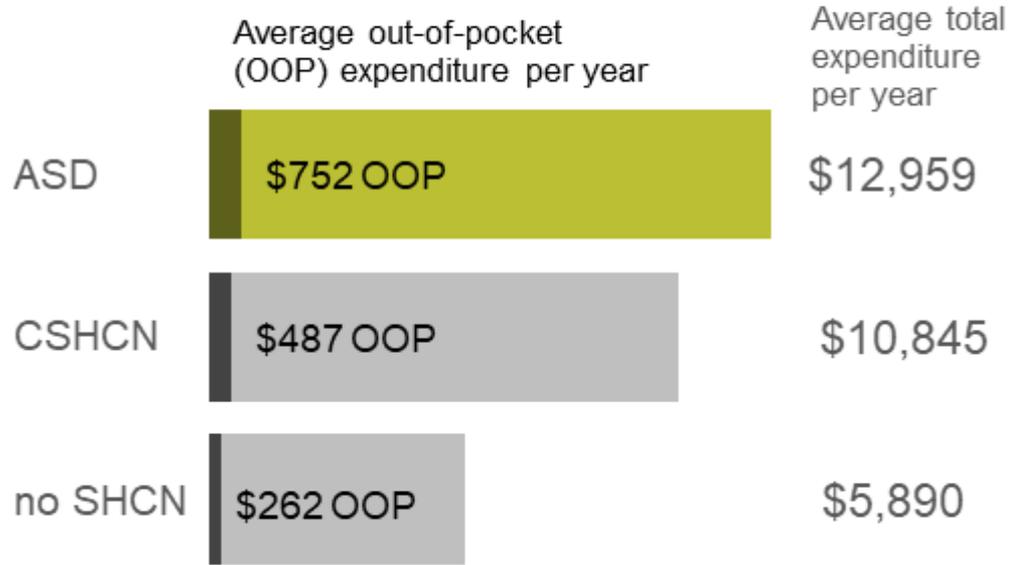
**Children with ASD** were the most likely to receive treatment or counseling from a mental health professional.



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

# Expenditures

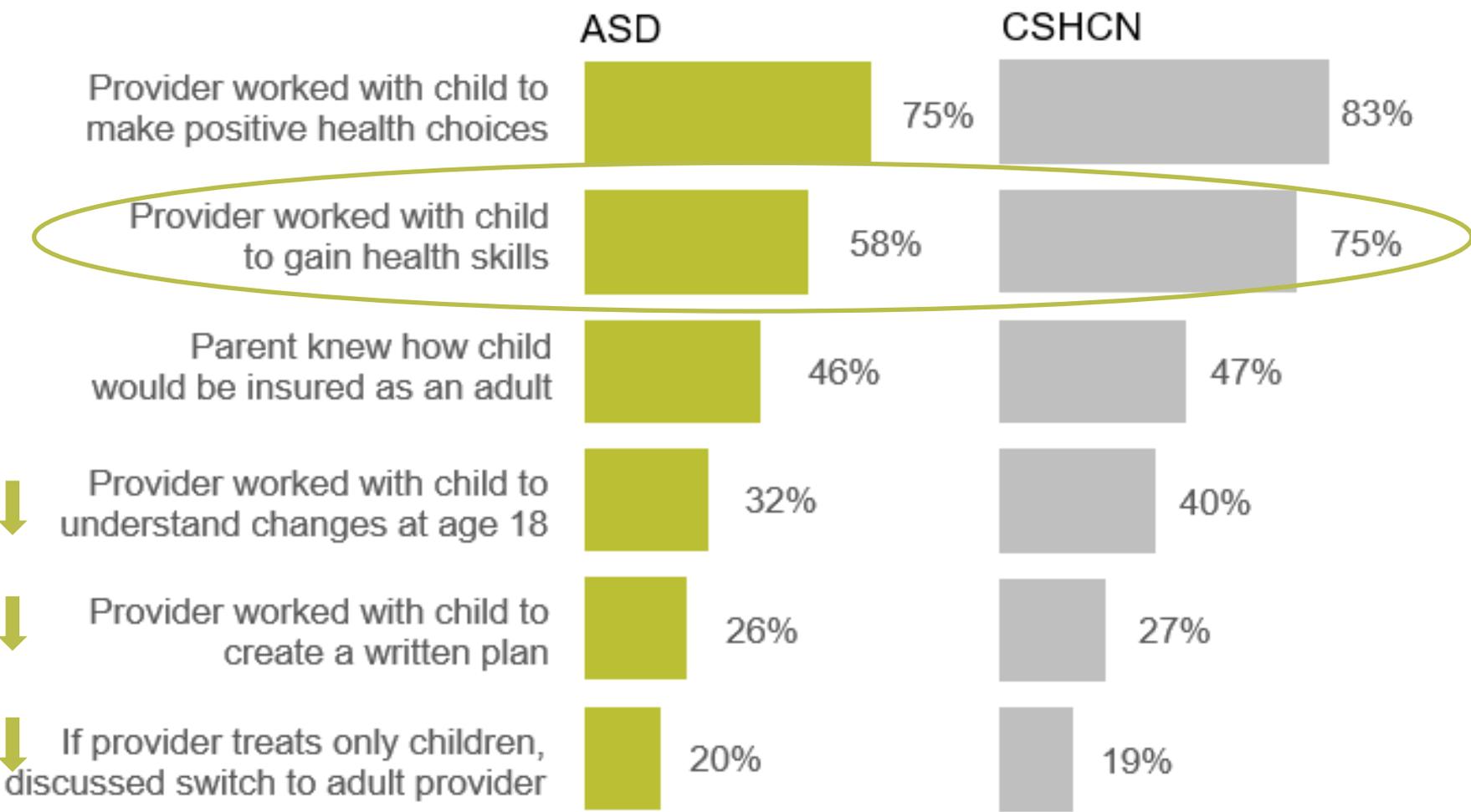
**Children with ASD had the highest average total and out-of-pocket expenditures per person.**



Source: Medical Expenditure Panel Survey 2013-17

# Healthcare transition

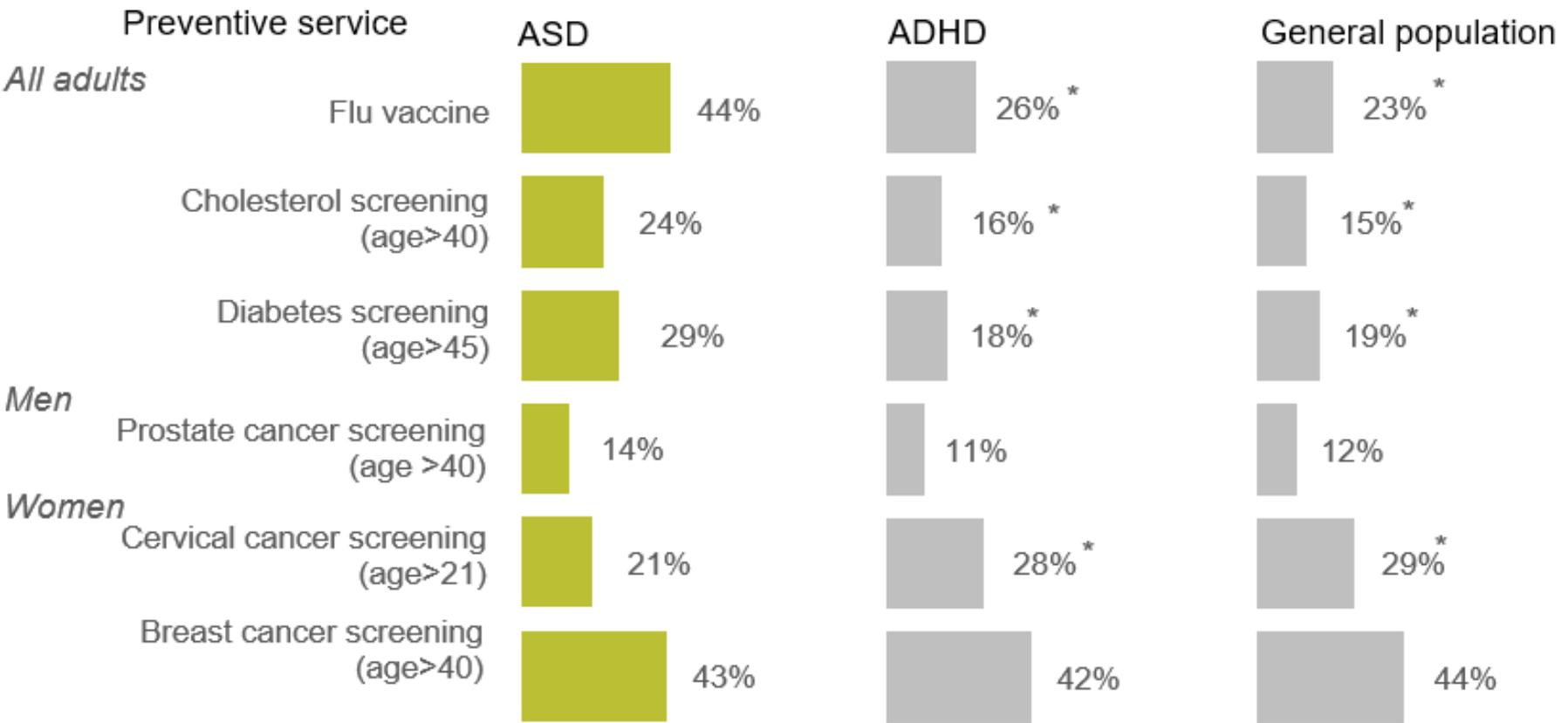
Providers rarely discussed the need to switch to an adult provider.



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

# Kaiser: Adult preventive services

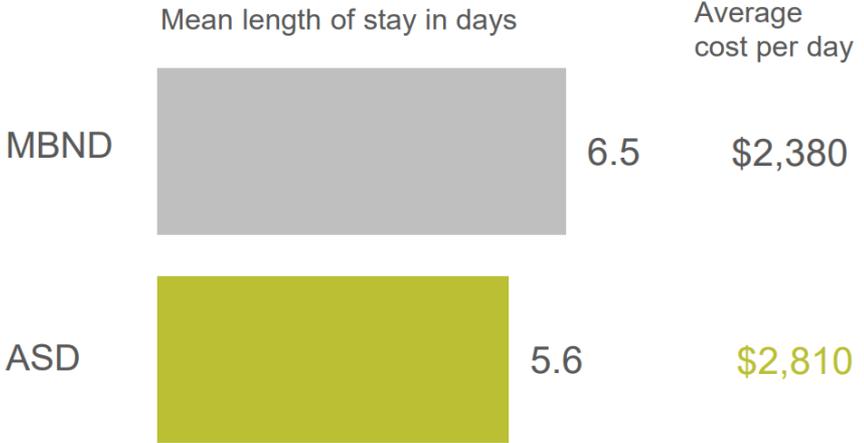
Some preventive health services were more common in **adults with ASD** than other adults.



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

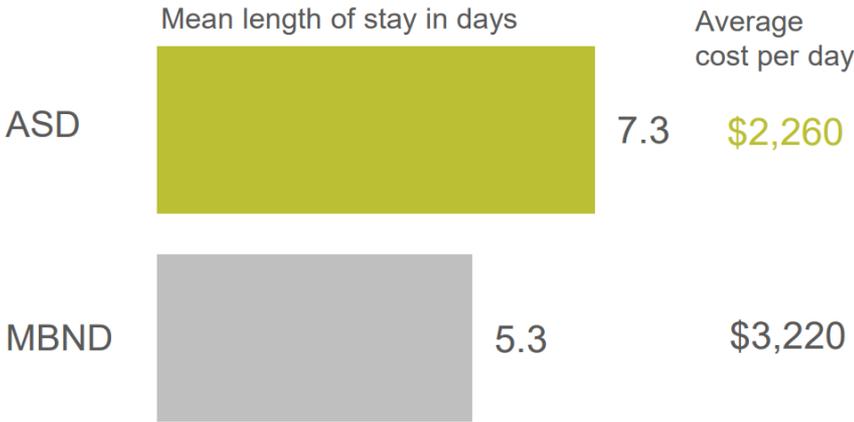
# Inpatient stays

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



Source: National Inpatient Sample 2017

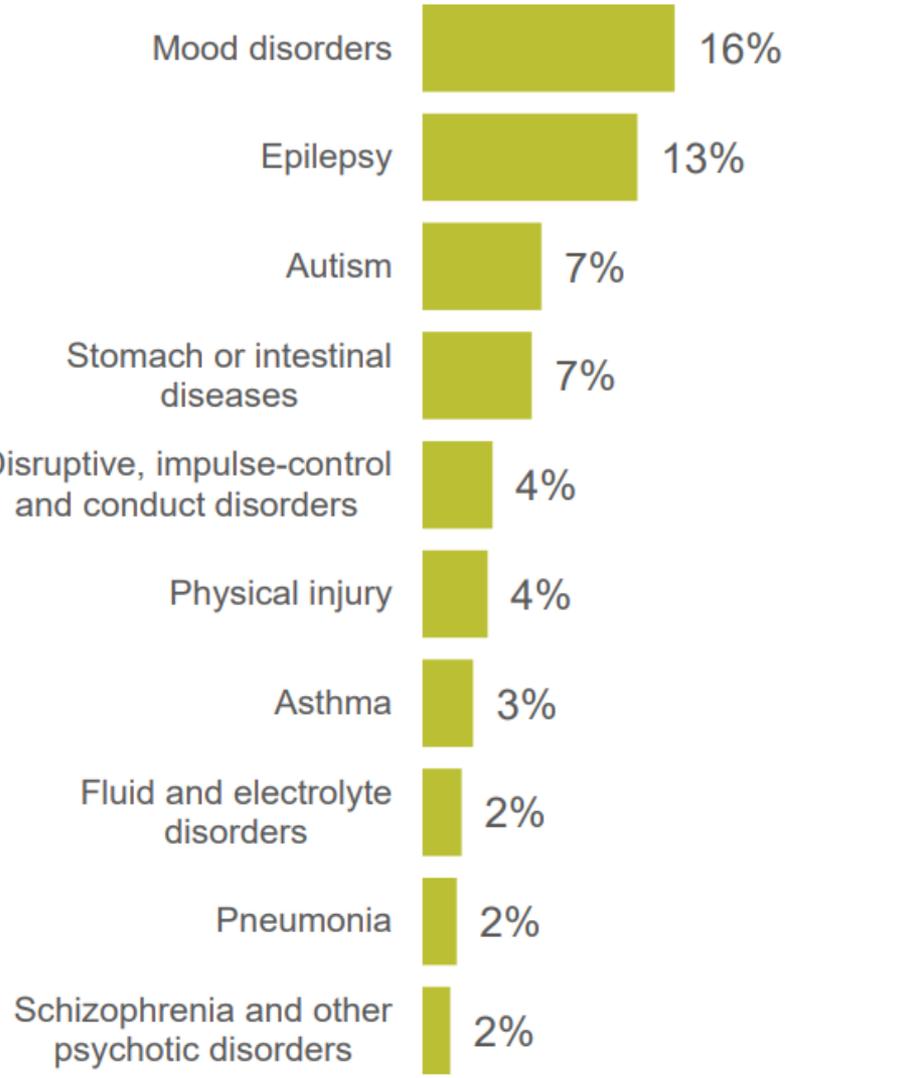
**Adult autistic patients** stayed in the hospital two days more, but had daily costs \$4000 less than patients with MBND.



Source: National Inpatient Sample 2017

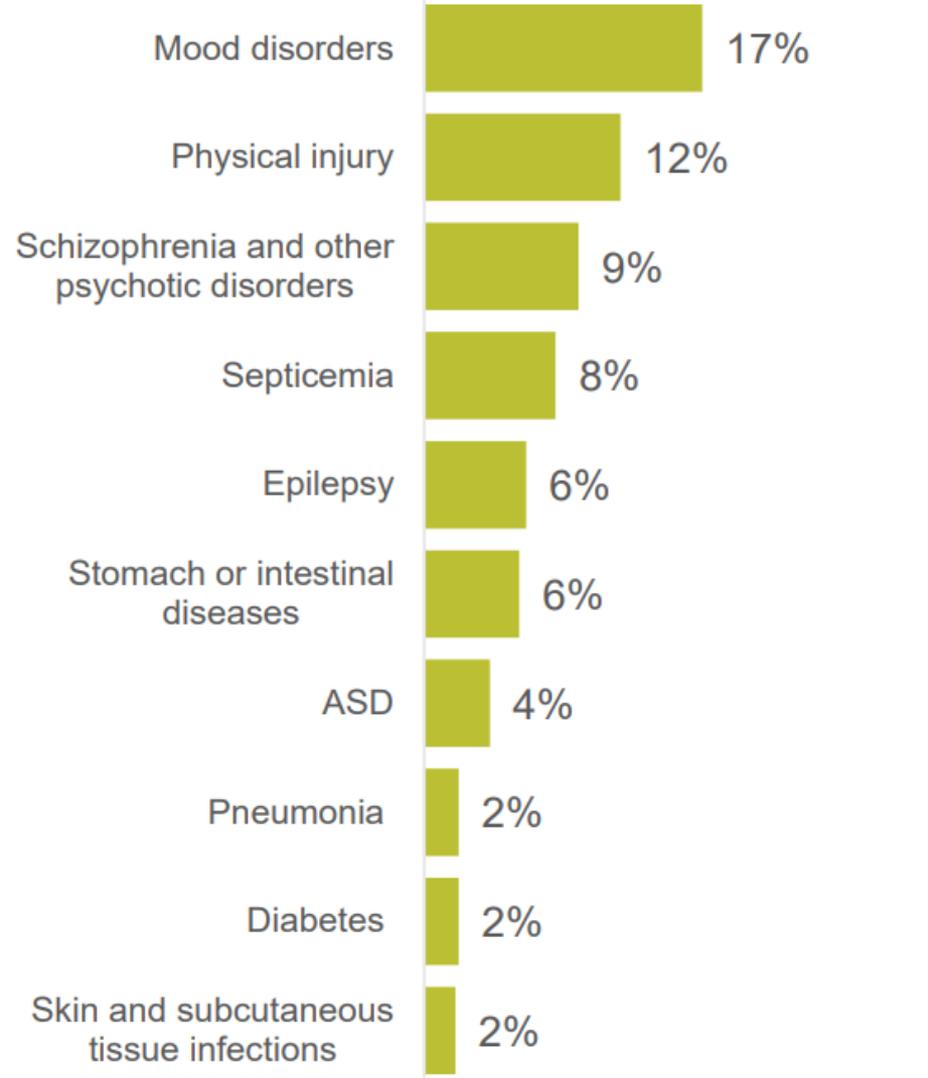
**MBND** stands for mental, behavioral, and developmental disabilities other than autism

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



Source: National Inpatient Sample 2017

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

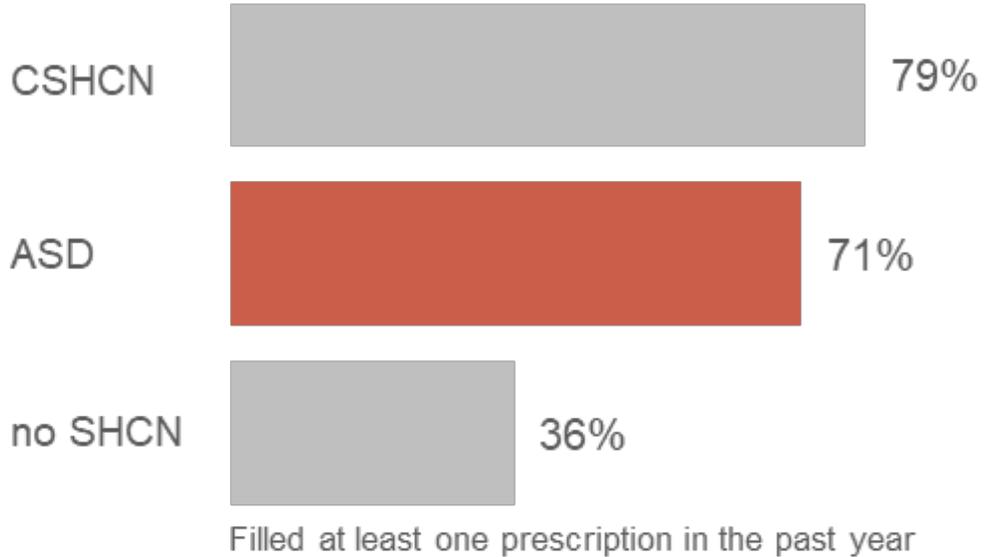


Source: National Inpatient Sample 2017

# Findings: Medication

# Prescription medications

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

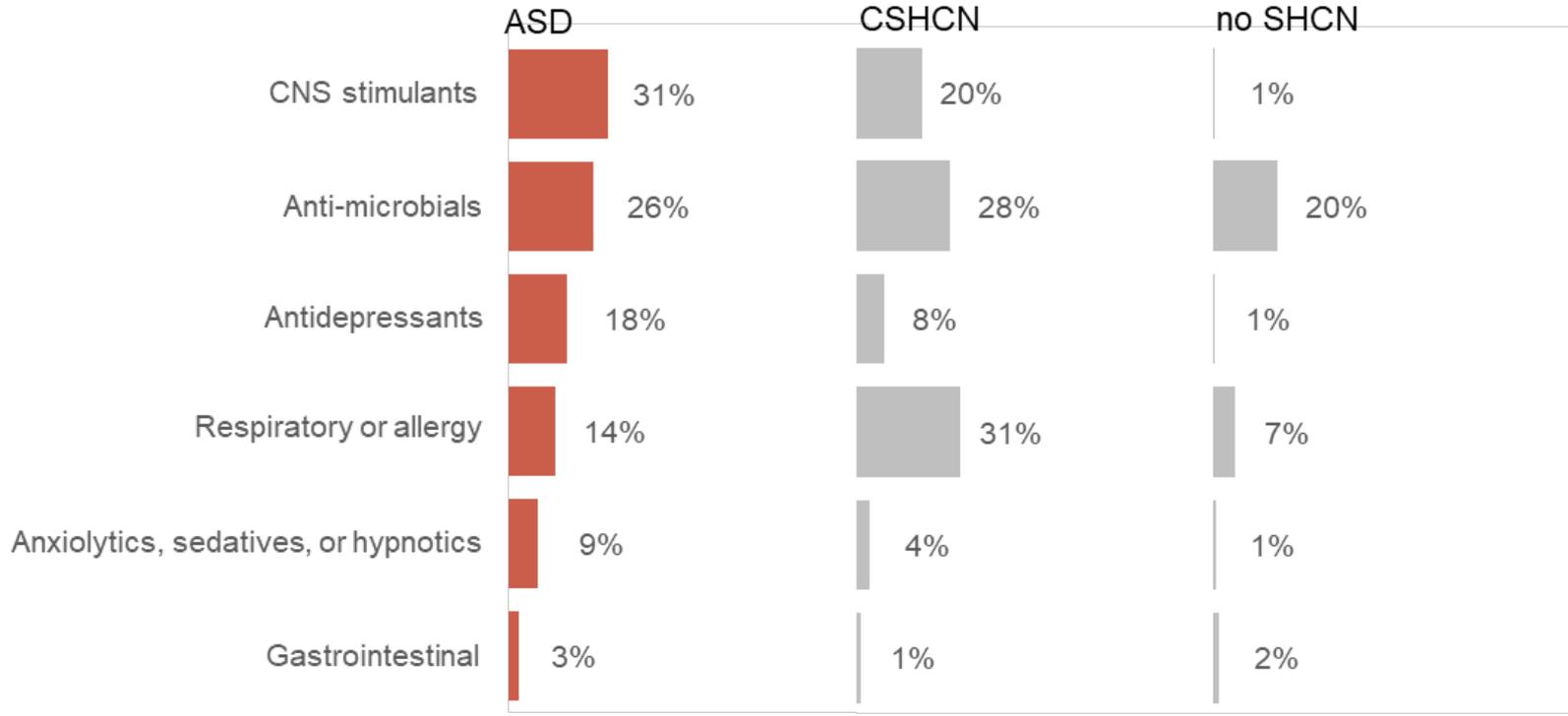


Source: Medical Expenditure Panel Survey 2013-17

**CSHCN** stands for children with special health care needs

# Prescription medications

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



Source: Medical Expenditure Panel Survey 2013-2017

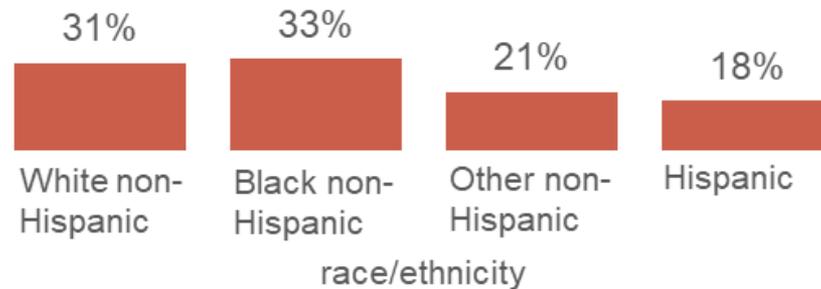
# Medications for autism

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



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

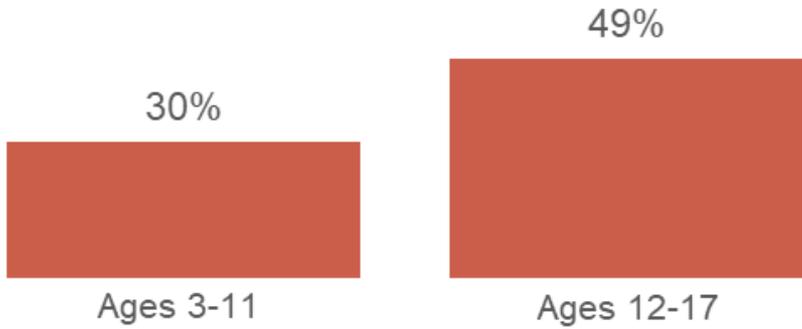
**White and black children with ASD were the most likely to currently use a medication for ASD.**



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

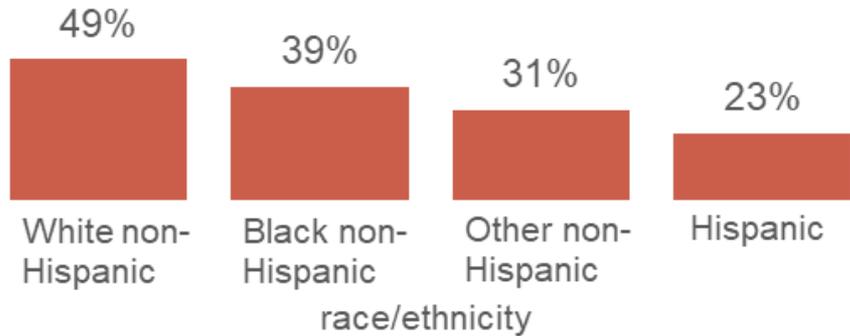
# Emotion, concentration, and behavior

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



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

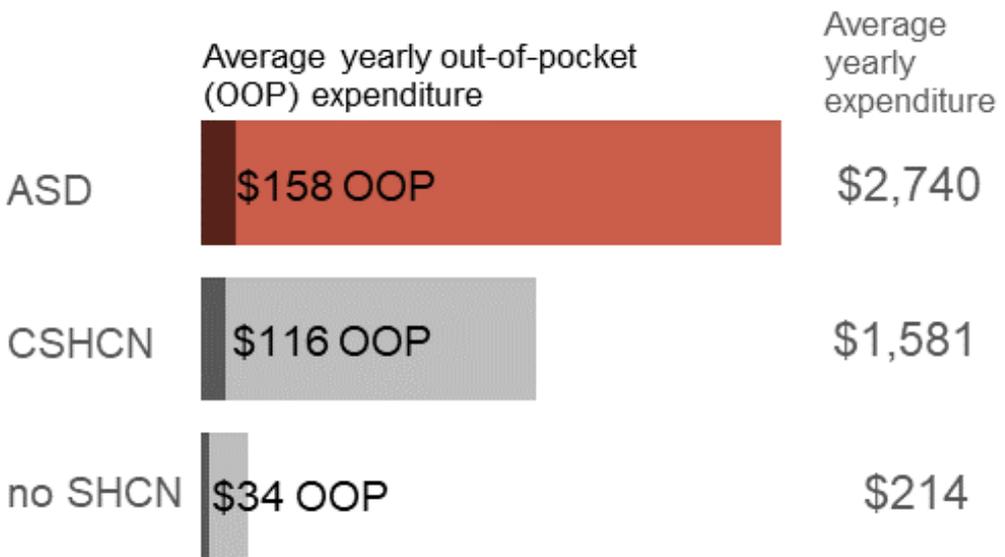
White children with ASD were the most likely to have taken a medication for emotions, concentration, or behavior in the past year.



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

# Expenditures

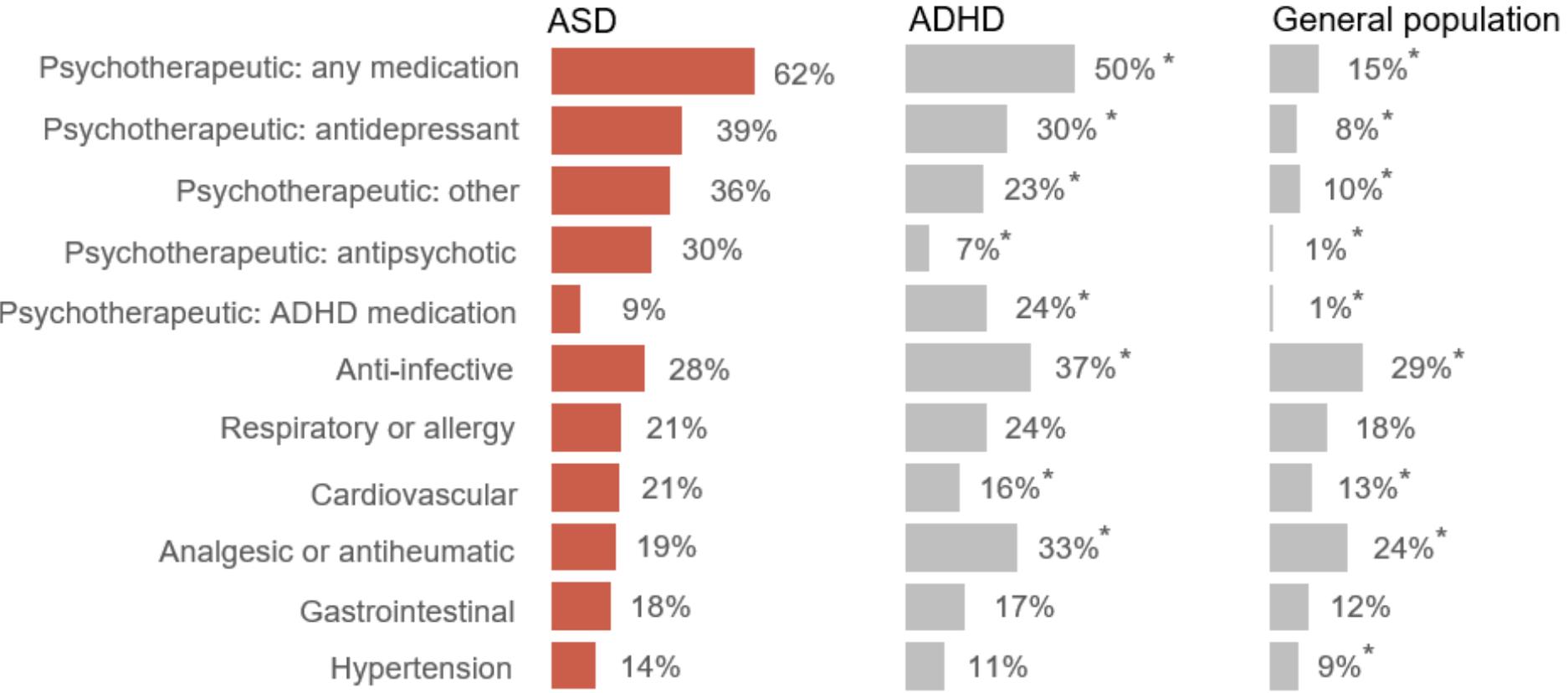
**Children with ASD had the highest average yearly total and out-of-pocket expenditure on prescriptions.**



Source: Medical Expenditure Panel Survey 2013-17

# Kaiser: Adult medication

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



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

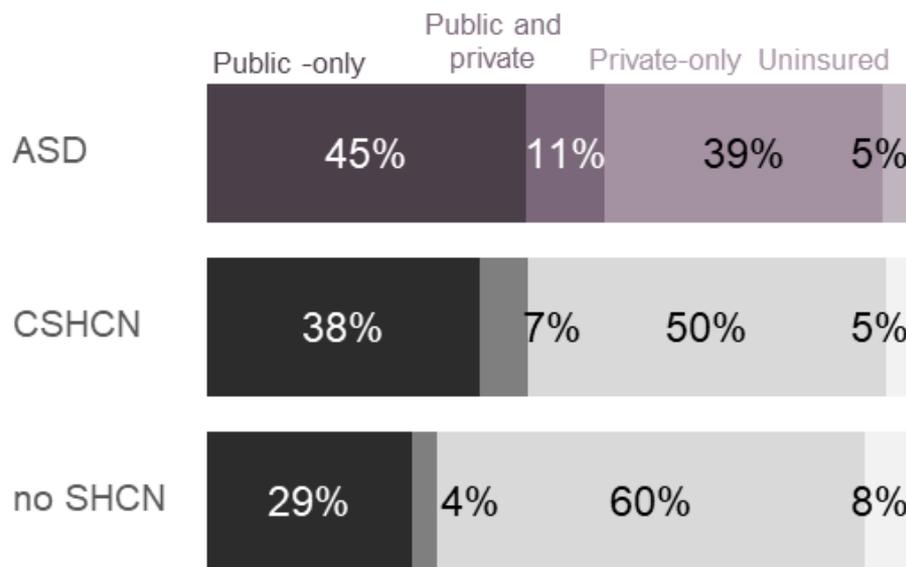
Source: Zerbo, et al., 2019

# Findings: Insurance



# Type of insurance

**Over half of children with ASD had public health insurance.**

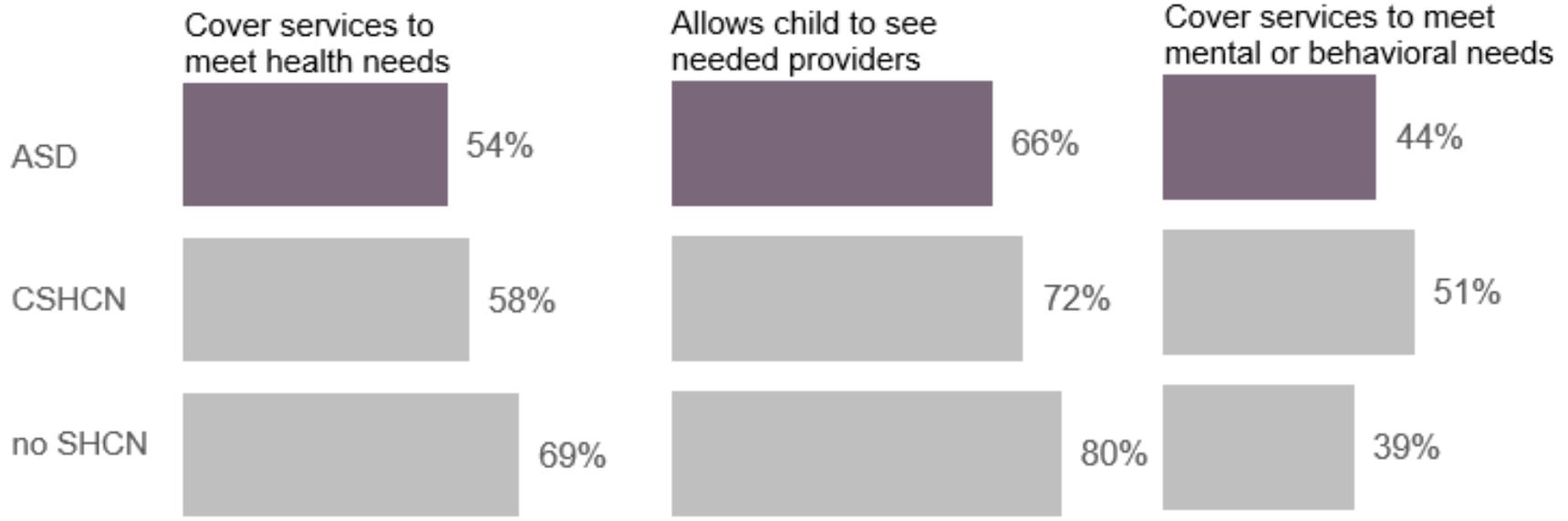


Source: National Survey of Children's Health 2016-18

**CSHCN** stands for children with special health care needs

# Insurance to meet needs

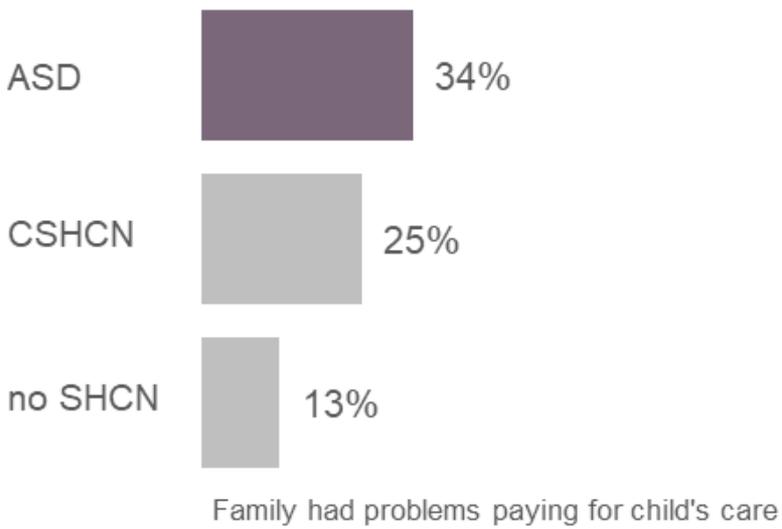
Half of parents of children with ASD report their child's insurance "always" met their needs.



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

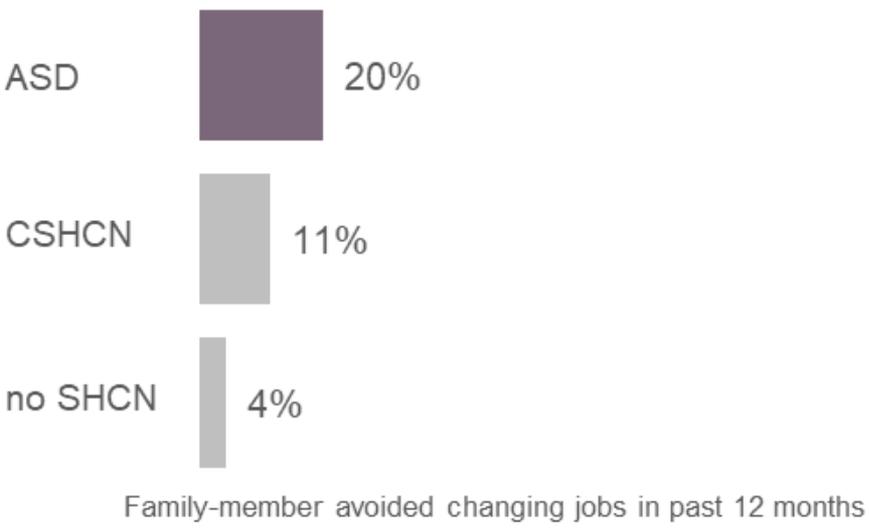
# Paying for healthcare

**One-third of families of children with ASD had problems paying for their child's medical care in the past 12 months.**



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

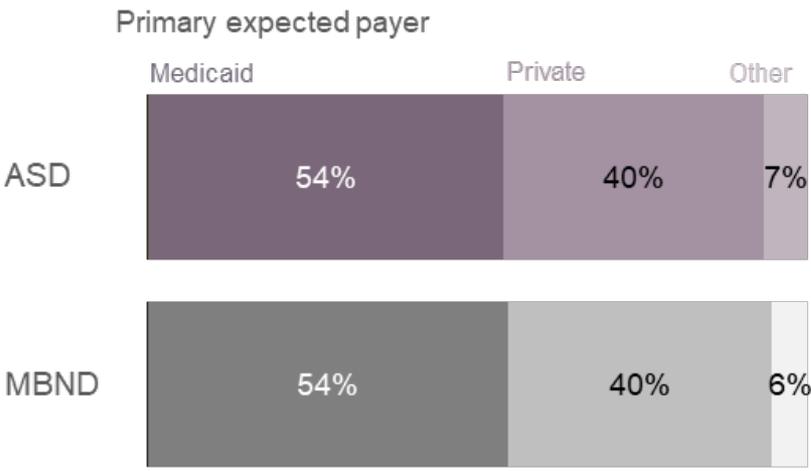
**One-fifth of parents of children with ASD avoided changing jobs for concern of keeping health insurance.**



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

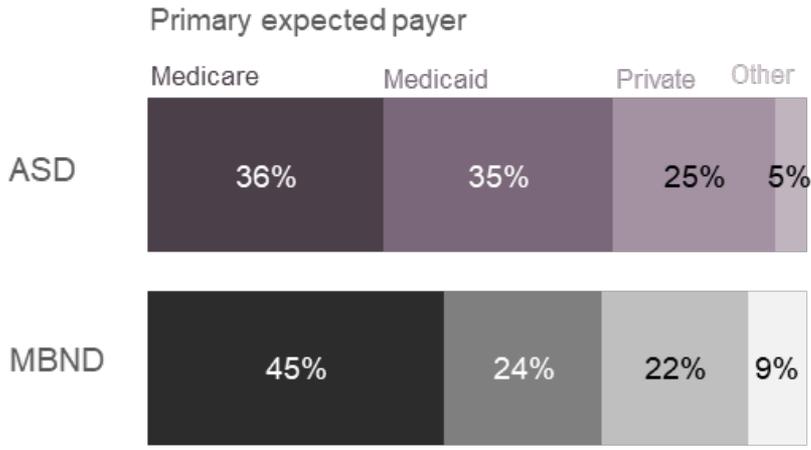
# Paying for hospital stays

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



Source: National Inpatient Sample 2017

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



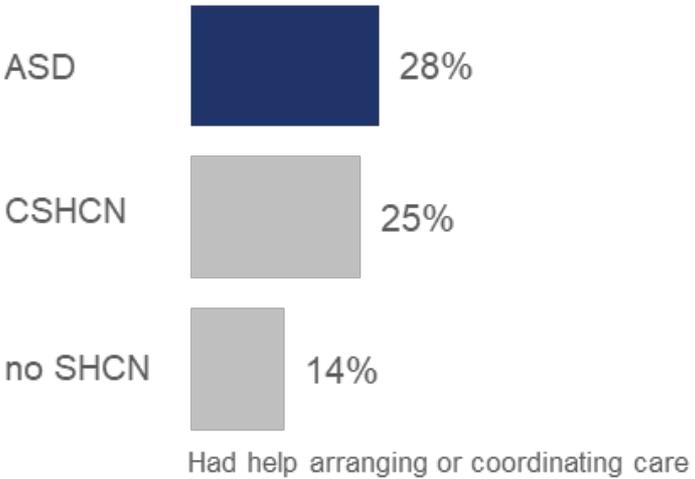
Source: National Inpatient Sample 2017

**MBND** stands for mental, behavioral, and developmental disabilities other than autism

# Findings: Accessing Services

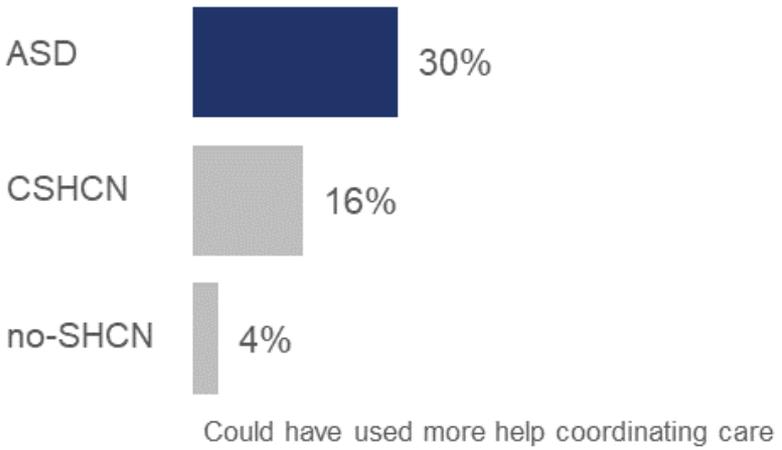
# Care coordination

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



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

Nearly one-third of parents of children with ASD who visited more than one provider could have used more help coordinating care.

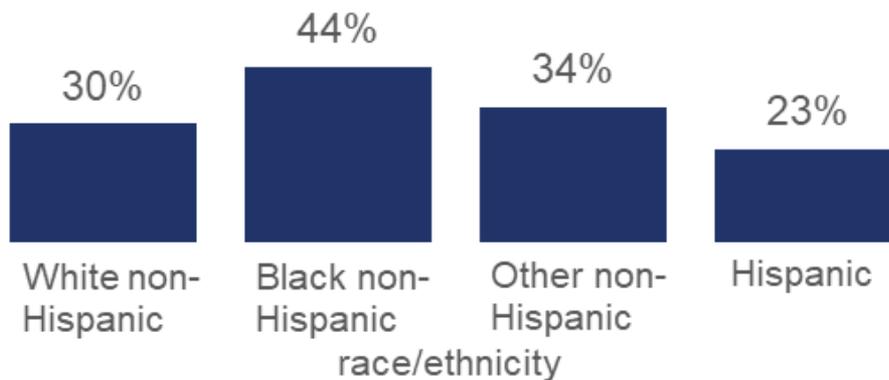


Source: National Survey of Children's Health 2016-18

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# Care coordination

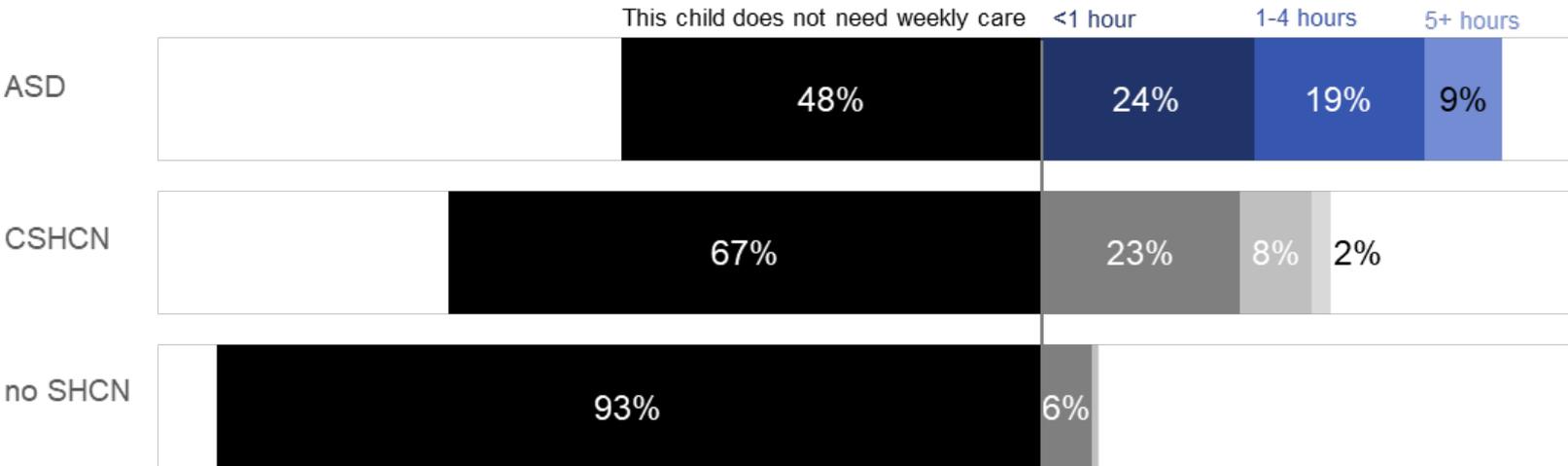
**Parents of black children with ASD were the most likely report a need for more help coordinating care.**



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

# Coordination efforts

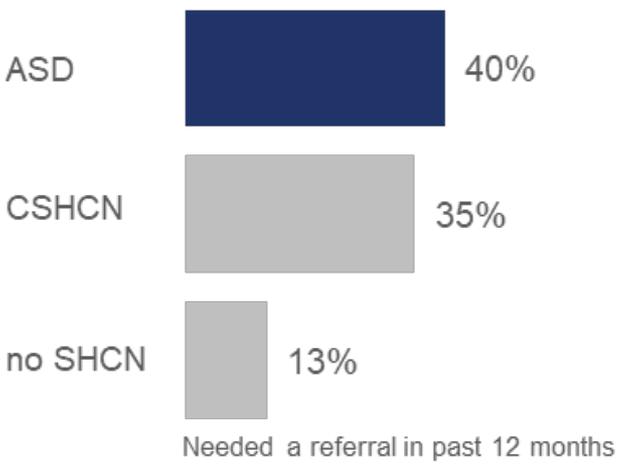
More than one-quarter of parents of children with ASD spent more than 1 hour a week coordinating care for their child.



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

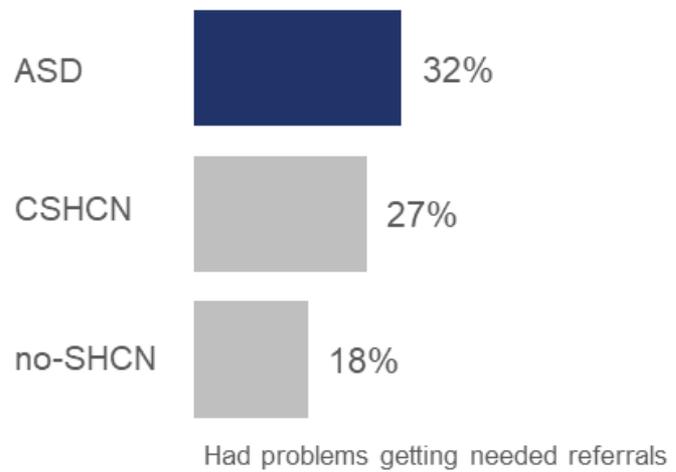
# Referrals

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



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

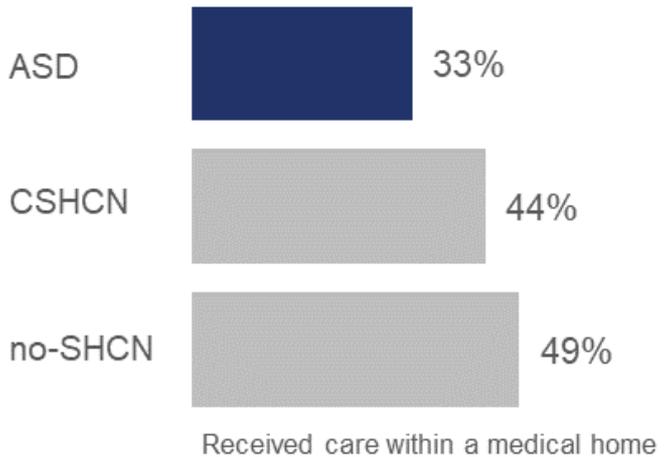
One-third of parents of **children with ASD** who needed a referral reported it was a problem to get it.



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

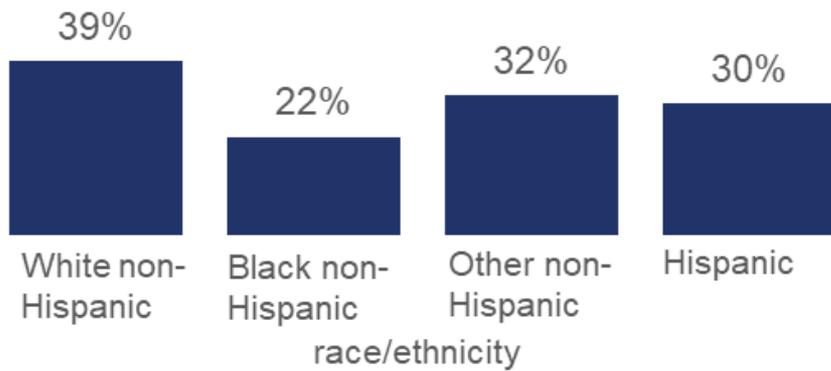
# Comprehensive care: medical home

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



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

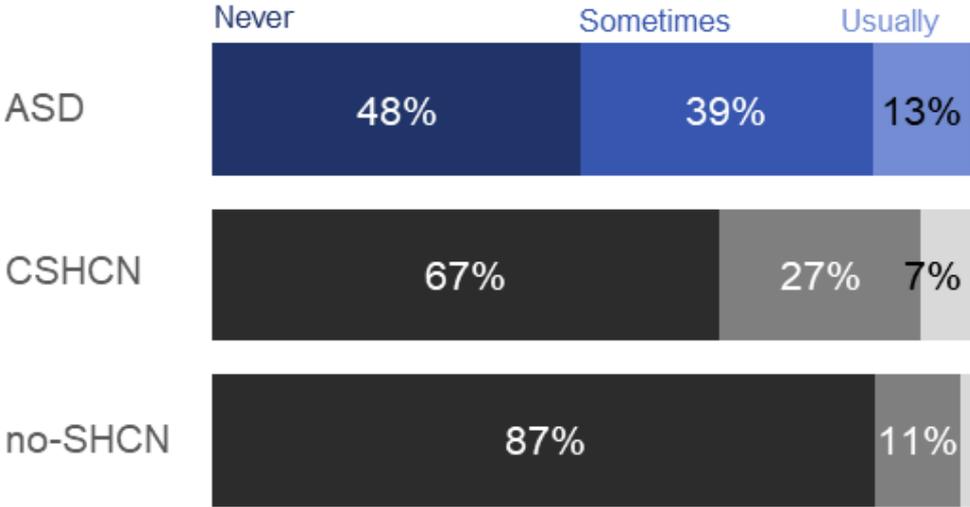
White children with ASD were the most likely to receive care within a medical home.



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

# Frustration in getting services

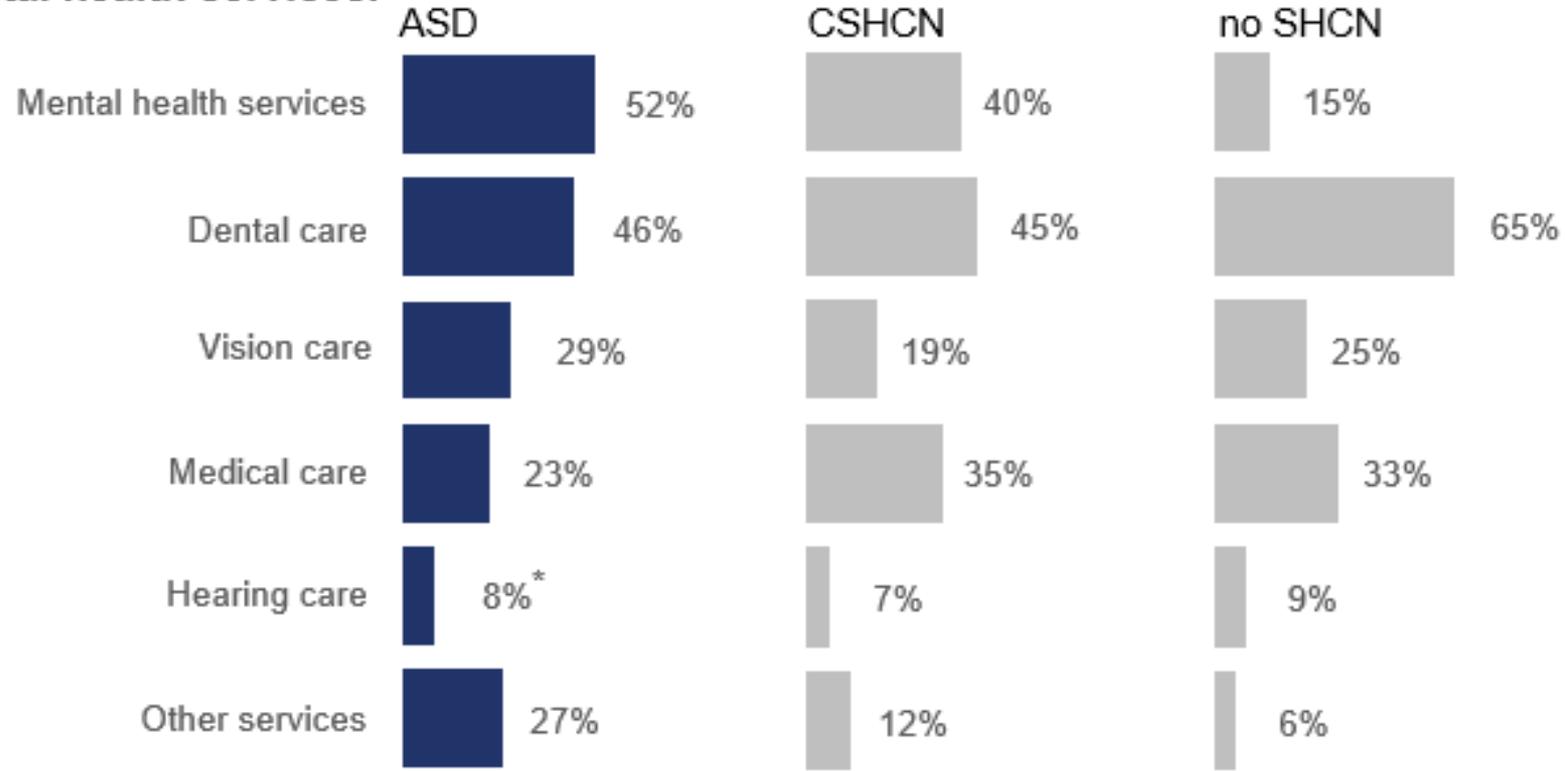
Half of parents of **children with ASD** were at least sometimes frustrated in their efforts to get services for their child.



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

# Need for more services

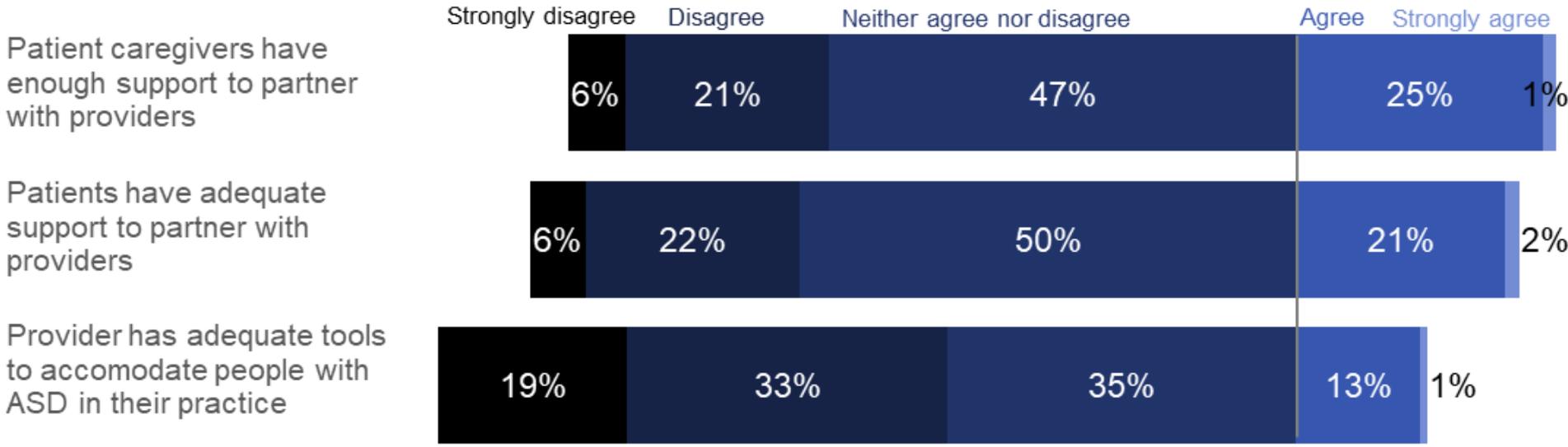
Half of parents of children with ASD who reported need for additional services reported need for mental health services.



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

# Kaiser: support for autistic patients

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



Source: Zerbo, et al., 2015



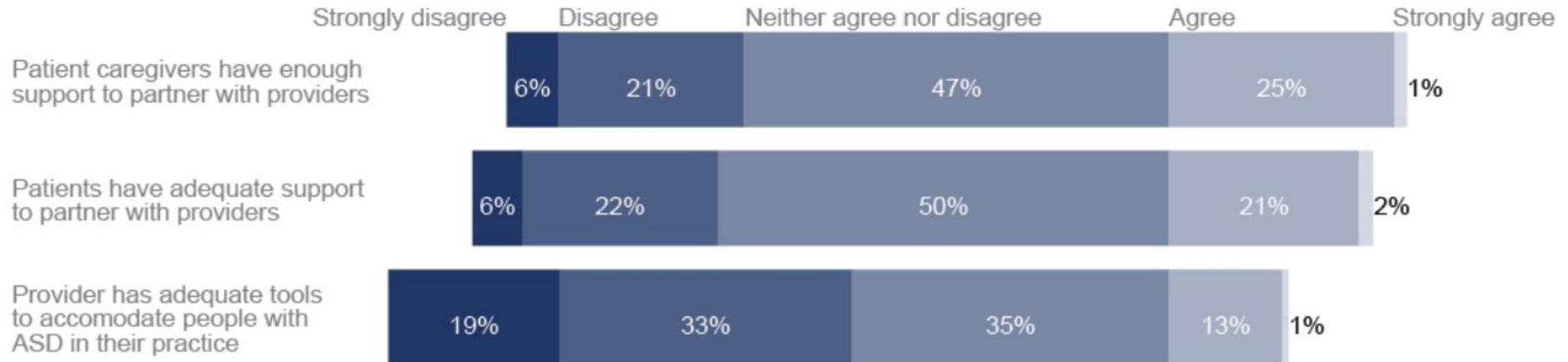
Examining a few key  
findings across topics

# Health care transition

- Fewer than 1/3 of autistic youth work with their provider to
  - Understand the changes at age 18
  - Create a written plan for transition
  - Discuss switch to an adult health care provider

# And who do they transition to?

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



Source: Zerbo, *et al.*, 2015

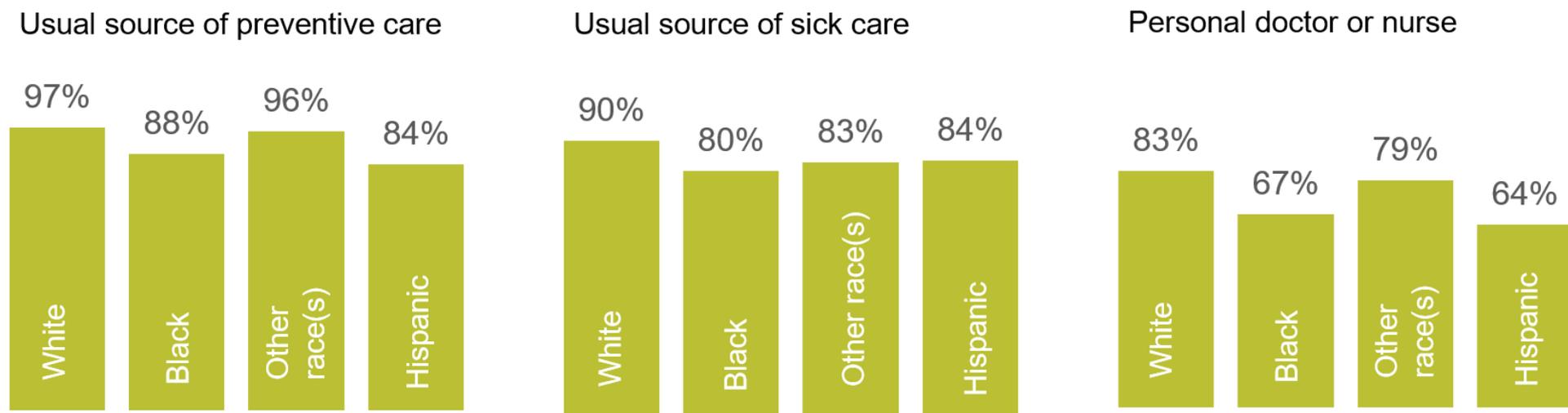
# Primary care gaps

- Unmet need for mental health services
- Cervical cancer screenings were less common in autistic women than in other women
- Emergency department and inpatient hospitalizations were not more common in autistic children than CSHCN
- But... the most common hospitalizations for autistic children and adults were for conditions that could be managed in primary care
  - Mood disorders
  - Epilepsy
  - Asthma

# Racial and ethnic disparities

- ADHD and anxiety were more commonly reported in white, non-Hispanic children than in children of any other race or ethnicity.
- Asthma and developmental delay were the most common in black, non-Hispanic children.

## Black and Hispanic children with ASD were the least connected to usual, consistent care.



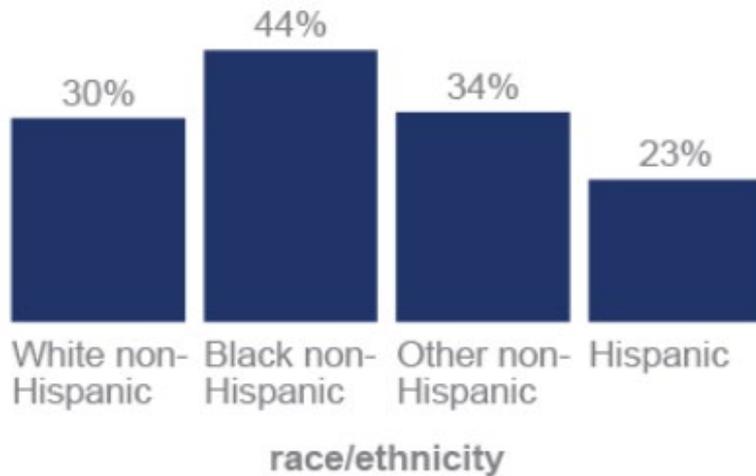
Source: National Survey of Children's Health 2016-18

# Racial and ethnic disparities

- Half of families of black autistic children had trouble paying for their medical care. Compared to 24-38% of other families

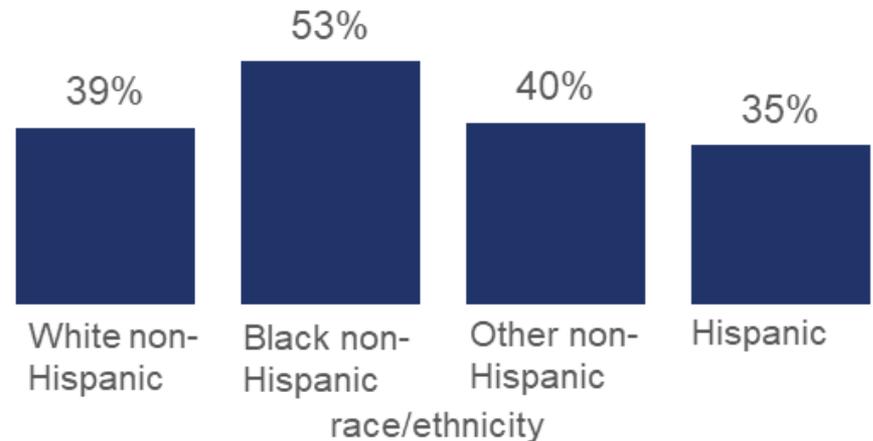
# Racial and ethnic disparities

**Parents of black children with ASD were the most likely report a need for more help coordinating care.**



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

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



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



# Conclusions

- Health services and intervention can positively influence health...just as lack of these can lead to poor health.
- This report highlights the need for improved health and health care in autistic people of all ages.
- Race and ethnicity are associated with worse health and poorer services in autistic children.
- The general trend was that autistic people receive more services, spend more on health care, and use more medications than peers.

# Conclusions

- Complex healthcare needs makes comprehensive care more important and more difficult for autistic people.
- Barriers to comprehensive care may cause worse health as seen compared to peers.
- Providing more appropriate care and reducing barriers to accessing care can lead to better health and less emergency health care utilization.

# Recommendations

More work is needed to understand why health and health services are worse for people on the spectrum than their peers, and to determine how to improve services to increase levels of health

# Recommendations

- First, we must begin by embracing the idea that all types of health are important.

# Recommendations

- Second, we need more focus on coordinated care to improve health.

# Recommendations

- Third, we must do a better job of addressing persistent racial and ethnic disparities.

# Recommendations

- Fourth, we need to assess the impact of healthcare disruptions and COVID-19 on autistic people.

# Recommendations

- Finally, we end by highlighting the need for more data.

# Co-authors



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Kristy Anderson, PhD, MSW

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# Full report available

[drexel.edu/AutismOutcomes/NAIRhealth](https://drexel.edu/AutismOutcomes/NAIRhealth)

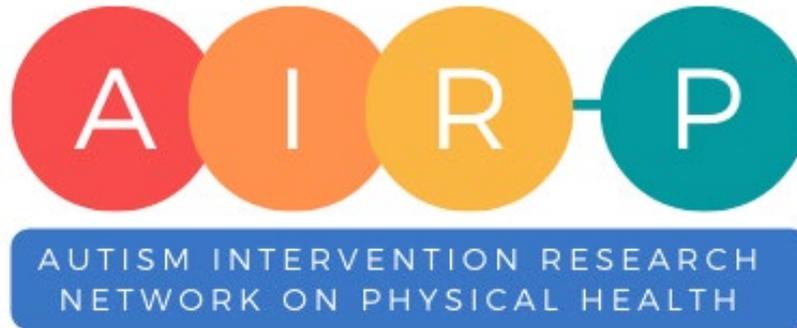


Life Course Outcomes  
Research Program



DREXEL UNIVERSITY  
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# Thank you!



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