# 2018
# NATIONAL AUTISM INDICATORS REPORT

## *High School Students on the Autism Spectrum*

Life Course Outcomes Program

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Life Course
Outcomes Program

## Mission

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

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

For more information about us, please visit our website: *drexel.edu/AutismOutcomes*

## How to cite this report

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# National Autism Indicators Report

## *High School Students on the Autism Spectrum*

2018

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

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# Letter from the Program Director

*Paul T. Shattuck, PhD*

## What is an Indicator?

We rely on statistics and indicators to understand issues and make sound decisions – health statistics, crime rates, opinion polls, the unemployment rate, and demographic trends are just a few. Billions are spent yearly on services and research related to autism. National statistics about autism can inform decision making and highlight areas where more resources and investigation are needed.

This report continues our work to produce trustworthy, useful statistics about the kinds of challenges people are facing, the kinds of help people are getting, and how health and quality of life outcomes are looking across the life span for people on the autism spectrum.

This report focuses on teens and young adults who are about to finish high school. Being prepared for a healthy transition can set the stage for years of positive development. Inadequate preparation during the last few years of high school can hinder success on many fronts: health and mental health, employment, continued education, friendships and integration into community life.

This report includes information from the National Longitudinal Transition Study 2012 (NLTS-2012) – a national survey that provides a window into the lives of high school students on the autism spectrum, youth with other disabilities, and those without disabilities. We also include the latest data on health and healthcare access among youth with autism from the National Survey of Children's Health (NSCH 2016).

This year's report highlights the challenges facing minority youth and those from low-income households. Autism occurs in children from all backgrounds. But the impacts of autism are not felt equally across all groups. Youth from poorer households have fewer choices for services, fewer opportunities for work experiences and generally worse outcomes across a wide range of indicators. Minority youth often face obstacles accessing needed care and experience worse outcomes in many realms.

Our work identifies risk and protective factors that can influence how lives turn out. As individuals age into adulthood, outcomes are influenced by factors from multiple levels: individual, family, community, and society. This report can inform the improvement of policies and community services that support the goal of an inclusive and just society where all persons have the ability to participate in meaningful life activities.

Paul Shattuck

Paul Shattuck

# National Autism Indicators Report

*High School Students*

2018

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**What do we know about teens and young adults?**

**What services do youth and young adults receive during the transition years?**

### A note about language

In this report, we use "teens on the autism spectrum," "teens with autism" and, "teens with an autism spectrum disorder" interchangeably. The term spectrum reflects the fact that characteristics, impairments, and strengths range widely in this population. Autism spectrum disorder (ASD) is the term used in the Diagnostic and Statistical Manual (DSM-5), as well as the surveys this report is based one (the National Longitudinal Transition Study-2012 and the National Survey of Children's Health 2016).

# Executive Summary

## *High School Students*

## 2018

### Where we stand today

High school students identified as being on the autism spectrum today are different from their counterparts who had the same label 10 or more years ago. Today's youth are less likely to also have an intellectual disability and are growing up in a world where awareness of autism and expectations for full inclusion in society are rapidly changing. However, we have few current national statistics about the characteristics and needs of this growing and changing population. Such statistics are needed to ensure policies and programs are appropriately matched to the evolving needs of youth on the autism spectrum.

### The charge

In 2015, we published the first National Autism Indicators Report, describing the characteristics and postsecondary outcomes of teens and young adults with autism spectrum disorder (ASD) (Roux *et al.*, 2015) available at https://drexel.edu/autismoutcomes/publications-and-reports/nat-autism-indicators-report/ (Roux *et al.*, 2015). That report provided a comprehensive picture of the disconnections youth on the spectrum encountered after exiting special education and entering adulthood. The report spurred national conversation about services and research priorities to move the needle on adult outcomes
for those with ASD. That report was based on national survey data that was conducted from 2001 to 2011.

This 2018 report on high school students updates what we know about the changing demographic and disability characteristics of teens and young adults on the autism spectrum and their services experiences. There was no new data available on postsecondary outcomes for this new report.

There are several important differences between our 2015 and 2018 reports.

| **Report name** | **2015: Transition into Young Adulthood** | **2018: High School Students** |
|---|---|---|
| **Source of data** | National Longitudinal Transition Study 2 (NLTS2) – Wave 5* | National Longitudinal Transition Study 2012 (NLTS-2012)** |
| **Ages of youth in the report** | Youth at age 17 and in young adulthood after leaving high school | Youth still in high school broken out by two age groups: ages 12-18 and ages 19-23 |
| **Timing of survey data collection** | During high school and<br>Following high school | During high school (only) |
| **Special education classification** | Only included youth with ASD as the primary special education category | Included youth in the ASD special education category. Also included youth in other categories of special education (e.g., intellectual disability, emotional disturbance, or other health impairments) whose parents reported they had autism |
| **Includes general education students as a comparison group?** | No | Yes |
| **What other topics does the report cover?** | Additional indicators of health, mental health, and services for youth ages 15-17 years. | Additional indicators of health, mental health, services, and characteristics of youth ages 12-17. |
| **Survey used to cover other topics** | 2011 Survey of Pathways to Diagnosis and Services. | National Survey of Children's Health 2016. |

* The NLTS2 surveyed teens during secondary school. In later waves, youth were asked about their experiences and outcomes following high school up through ages 21-25.

**The NLTS-2012 does not include any information on what happened to youth following high school. Young adults who were ages 19-23 in this report were still in secondary school. This report includes young adults up to age 23. Age was ascertained at the time of the survey, which happened up to a year and a half after the time of sampling, at which point youth were last known to be in school.

## Aims of this report

- Characterize the demographics, disability characteristics and adaptive behaviors of teens and young adults ages 12-23 on the autism spectrum in secondary school.
- Describe education and healthcare services use of teens and young adults on the autism spectrum in secondary school ages 12-23.

## Data sources

We used data from two publicaly available sources in this report - the National Longitudinal Transition Study-2012 (NLTS-2012) and the National Survey of Children's Health 2016 (NSCH 2016). We analyzed data from these surveys to create this report but we did not design or conduct these surveys ourselves. Both were large, nationally representative surveys of youth and their parents or guardians. They used different approaches to define and recruit eligible participants. The NLTS-2012 included high school students aged 12-23. The NSCH 2016 included youth ages 12-17.

The NLTS-2012 and the NSCH 2016 covered different, but complementary, sets of topics. We used data from both studies to achieve a thorough description of characteristics and service experiences. More information about these data sources and our analyses is in the **Methods** appendix, but a brief overview of is provided below.

### National Longitudinal Transition Study 2012 (NLTS-2012)

- The NLTS-2012 included high school students who were ages 12-23 years at the time of survey sampling in 2012-2013.
- The NLTS-2012 sampling design included youth who were enrolled in school as of December of 2011. Therefore, young adults with autism ages 19-23 were still in secondary school, or just recently exited, at the time of interviews which were conducted in 2012 and 2013.
- The NLTS-2012 focused on youth who were receiving special education services at the time of the survey. The study also included a comparison group of youth in general education who did not receive services under an individualized education program (IEP) or a 504 plan.
- All parents were asked if their child had a current diagnosis of autism from a healthcare provider or other professional. In this report, we included youth as having autism if: 1) they received services through an IEP under the autism special education classification, *or* 2) their parent reported the youth currently had an autism diagnosis from a professional *and* they were receiving special education services under a classification other than autism *or* were getting support via Section 504 of the Rehabilitation Act (usually known as a "504 plan").

### National Survey of Children's Health 2016 (NSCH 2016)

- The NSCH 2016 included children in the U.S. with special health care needs regardless of whether they were enrolled in special education. It did not include children living in institutional settings like group homes, detention centers or jails, or other types of residential facilities.
- Our analyses for this report focused on youth who were ages 12-17 years at the time of survey administration (2016-2017).

# Key Findings

## *High School Students*

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We summarize key issues below and present top-level findings from our analyses. Detailed information about each of these key findings is in the chapters that follow.

The end of this section includes special spotlights on youth from low-income households and minority youth.

### Understanding differences between teen and young adult high school students

Many of the findings below from the NLTS-2012 survey data are broken out into two groups: teenage students with ASD (ages 12-18) versus young adult students with ASD (ages 19-23). Youth are eligible to continue receiving special education services through age 21, if continued services are deemed necessary. Students who continue past four years of high school sometimes receive a special education completion certificate instead of a high school diploma. In practice, the IEP team must decide that the student requires these extended services, and those who exercise this option are typically students with more-severe impairments. Therefore, it is not surprising that this older group of young adult students has different characteristics compared to teenage students.

### Individual and household demographics

- Teenage students with ASD in the NLTS-2012 were most often male, white and from households with incomes above 185% of the federal poverty level.
- Teens with ASD received Supplemental Security Income (SSI) benefits at lower rates than teens with an intellectual disability (ID). Teens with ASD who were black or African American were more likely to receive SSI benefits than teens with ASD of other races/ethnicity.
- Young adult high school students with ASD had similar demographic characteristics to teen students with autism but were more likely to receive SSI benefits.

## Disability characteristics and adaptive behaviors

- Activities of daily living:
    - Most teens with ASD could perform basic activities of daily living very well, such as dressing and eating.
- Communication:
    - Thirty-two percent of teens with ASD had great difficulty holding a conversation or were unable to do so. Seventy percent also had some trouble or a lot of trouble understanding what was said to them. However, nearly 70% were able to communicate in some manner about the things that really mattered to them somewhat or very well.
    - Young adult students with ASD had more trouble communicating, speaking, understanding, and conversing than teens with ASD.
- Social participation:
    - More than half of teens with ASD (57%) had a lot of difficulty making and keeping friends.
- Community mobility:
    - About one in three teens with ASD could not get to places outside the home very well, or were not allowed to do so at all.

## Special education services and transition planning

- Nearly half (45%) of parents of teens with ASD did not participate in IEP transition planning.
- One-quarter of teens with ASD themselves did not participate in IEP transition planning. Teens with ASD from higher-income households were the most likely to participate.

## Health, mental health, and healthcare services

- Almost two-thirds (64%) of teens with ASD were taking prescription medications, and nearly half (48%) were taking medications for attention, behavior, or mood. These rates were much higher than teens with ID.
- Teens with ASD were more likely than teens with ID to be diagnosed with ADHD, anxiety, or depression. Three quarters (76%) of teens with ASD were diagnosed with ADHD, anxiety, and/or depression.
- Over half (57%) of teens with ASD received mental health treatment or counseling in the previous year.
- Nearly half of parents of teens with ASD spent several hours weekly arranging and coordinating health care compared to 37% of parents of teens with ID.

## Focus on youth from low-income households

### Ranges represent findings from both surveys

- For this report we define low-income as households with income below 185% of the federal poverty level. For a household of four in the continental U.S., this was $42,643 in 2012.
- Forty to forty-six percent of teens and young adults on the autism spectrum live in households with low incomes (below 185% of the federal poverty level). This is compared to 40% of all teens in the U.S.
- In NLTS-2012, 39% of households had incomes of $0-$40,000 per year, 30% were $40,001-$80,000, 15% had incomes of $80,001-$120,000, and 16% had incomes of $120,000 or more.
- In NSCH 2016, 27% of teens were from households with incomes below the federal poverty level. For a household of four in the continental U.S., this was $24,300 in 2016. This is compared to 21% of all teens in the U.S.
- One in four households of teens with ASD received at least one form of public assistance.
  - » More than one in four (30%) households of teens with ASD received Supplemental Security Income (SSI) payments in the previous two years.
  - » Twenty-three to thirty-three percent of teens with ASD lived in a household that received Supplemental Nutrition Assistance Program (SNAP, also known as food stamps) within the previous two years.
  - » Seven percent of teens with ASD lived in households receiving Temporary Assistance for Needy Families (TANF).
- Teens from households with income below the poverty level had the lowest rate of being able to share ideas or talk about things that really matter.
- The rates of serious difficulty with concentrating, remembering and making decisions were highest among teens from low-income households.
- Teens with ASD from lower-income households were more likely to have trouble getting to places outside of the home.
- High school students from low-income households were less likely to participate in transition planning.
- Teens from low-income households were more likely to have health rated as fair or poor and were more likely to have unmet health care needs.

## Focus on minority youth

**Ranges represent findings from both surveys**

- Twenty to twenty six percent of teens on the autism spectrum were non-white and 11-15% were Hispanic. By comparison, U.S. Census statistics indicate that 26% of all 18-year olds were non-white in 2016 and 22% were Hispanic.
- Fourteen percent of teens and 16% of young adults with ASD lived in a household where a language other than English was regularly used.
- Low-income and minority status are highly correlated – minority youth with autism were much more likely to be living in low-income households compared to white, non-Hispanic youth.
- Black or African American teens were more likely to have difficulty than their peers in several areas:
  - » Communication
  - » Self-care and adaptive behaviors
  - » Independently getting to places outside the home
- Hispanic teens with ASD were more likely to participate in their transition planning than other youth.
- Black or African American teens had the highest rate of taking medication for emotion, concentration or behavior.
- Black or African American teens had the highest rate of unmet health care needs.
- Hispanic and black or African American teens were the most likely to have public health insurance.

# Key Findings

*Highlights*

| | | |
|---|---|---|
| **Youth from households with low income** | **Struggling financially**<br>**40-46%**<br>lived in households with income below 185% of the federal poverty level | **Received public benefits**<br>**1 in 4**<br>lived in a home that received at least one form of public assistance |
| **Minority youth** | **Highest rate of unmet needs**<br>**27%**<br>of black or African American teens had unmet healthcare needs | **Language minority**<br>**14%**<br>lived in a home where a language other than English was regularly used |
| **Special education** | **Most common therapy**<br>**47%**<br>received speech therapy from special education | **Youth participation in transition planning**<br>**1 in 4**<br>did not participate at all |
| **Mental health** | **Co-occurring conditions**<br>**76%**<br>were diagnosed with at least one of the following: ADHD, anxiety or depression | **Used psychiatric medications**<br>**55%**<br>took medication because of difficulties with emotions, concentration, or behavior |
| **Health care services** | **Went without health care**<br>**16%**<br>did not receive needed health care | **Talked about transition**<br>**18%**<br>of pediatricians talked with families about finding a doctor who treats adults |

# Background

## The issues

One in 59 children today has an autism spectrum disorder according to the most recent report from the Centers for Disease Control and Prevention (Baio, *et al.*, 2018). Multiplying that rate by the Census Bureau estimate for the number of 17-year-olds in the population in 2017 suggests that approximately 72,800 youth on the autism spectrum turned 18-years old in 2018. That means that roughly 728,000 youth with autism will enter adulthood in the next decade.

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder. The effects of autism on cognition, emotional regulation, language and social communication, and relationship skills are present across the lifespan. No two youth with ASD are alike. Their service, health care and support needs also continually change as they age.

About six million children ages 6-21 were in special education in 2017. Of these, around 611,000 (10%) had a primary disability of autism. However, not all students with ASD receive special education services. Some do not qualify. Others may receive special education services under categories other than autism.

## The secondary school years

### Special education in high school

Many high school students on the autism spectrum get help through special education services. According to the Individuals with Disabilities Education Act (IDEA), the purpose of special education is to prepare students for employment, further education and independent living after high school. Youth are eligible to continue receiving special education services through age 21 if continued services are deemed necessary. Students who continue past four years of high school sometimes receive a special education completion certificate instead of a high school diploma. In practice, the option to remain in school beyond four years is usually used by students with more severe impairments.

Youth are eligible to continue receiving special education services through age 21, if continued services are deemed necessary. Students who continue past four years of high school sometimes receive a special education completion certificate instead of a high school diploma.

In practice, the IEP team must decide that the student requires these extended services, and those who remain are typically students with more severe impairments. Therefore, it is not surprising that this older group of young adult students has different characteristics compared to teenage students.

### Transition planning: Preparing to leave secondary school

IDEA requires every student who receives special education to have a transition plan that supports achieving postsecondary education, employment and/or independent living upon leaving high school. Planning is supposed to begin at age 16 if not earlier. The services a student receives should support specific goals for transitioning to employment and/or postsecondary education as well as connection to non-school support services and public benefits.

Transition planning is supposed to include a determination of student strengths and interests, assessing possible target outcomes that match these strengths and interests, and setting goals for building skills necessary to attain the targeted outcomes.

Each student's special education team creates a transition plan and decides what services are needed to prepare them for young adulthood. Planning may be a more in-depth process for some students depending on levels of need. By law, planning should actively involve parents, students and non-school agencies (such as Vocational Rehabilitation services).

Students do not always receive transition planning, or sometimes it begins too late in high school to allow for adequate preparation. Community-based help is not always available after high school. This leaves many families struggling to navigate on their own and results in too many youth failing to launch successfully into adulthood.

### Health care transition planning

Health care services during the transition years can be complicated. More youth with autism also have co-occurring physical and mental health conditions than is seen in youth without autism (Peacock *et al.*, 2012), and complicated profiles of medication use are common (Esbensen *et al.*, 2009; Spencer *et al.*, 2013). Youth on the autism spectrum are also at increased risk for developing new health and mental health conditions during adolescence and early adulthood. Difficulties with communication, sensory issues, and coping with change can all affect health care.

Health care transition is the process of moving from pediatric to adult health care. The transition in health care involves many components such as choosing adult providers, possible changes in insurance, educating youth and family members about changing health issues, and helping youth make positive choices about caring for their health. Just as youth and their families receive help to plan for an exit from special education, assistance with planning for future health care is also vitally important.

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# Individual and Household Demographics

## *Characteristics of teens (ages 12-18) and young adults (ages 19-23)*

### Our key findings

- Teens with an autism spectrum disorder (teens with ASD) in the NLTS-2012 (ages 12-18) were most often male, white and from households above 185% of the federal poverty level.
- Teens with ASD received SSI benefits at lower rates than teens with an intellectual disability (teens with ID). Teens with ASD who were black or African American were more likely to receive SSI benefits than teens with ASD of other races/ethnicity.
- Young adult high school students with ASD (ages 19-23) shared similar demographic characteristics with teens with autism, but young adults were more likely to receive SSI benefits.

This chapter describes the characteristics of teenagers (ages 12-18) and young adults (ages 19-23) separately. The first sections focus on teens on the autism spectrum (teens with ASD) and make comparisons to teens with intellectual disability (teens with ID) and teens in general education. For data from NSCH 2016, teens without a special health care need are also included as a comparison group. Teens from the NSCH 2016 were ages 12-17 while teens from the NLTS-2012 were ages 12-18. The last section reports on the individual and household demographics of young adult high school students on the autism spectrum.

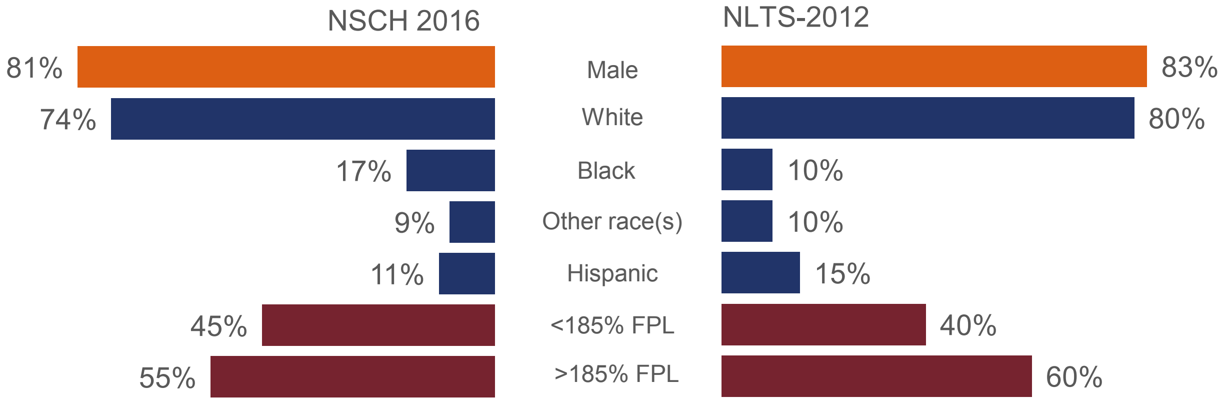
### How do we know?

We used data from the National Longitudinal Transition Study-2012 (NLTS-2012) and the National Survey of Children's Health 2016 (NSCH 2016) to study teens and young adults on the autism spectrum ages 12-23 years. When using the NLTS-2012 data, we only report on students with ASD who were receiving special education services.

### A word about age

For this report, we defined "**teens**" as those ages **12-18 years**, and "**young adults**" as those ages **19-23 years**. There is no perfect consensus among researchers and policy makers on these terms or where to set the boundaries for age groups.

**Most teens with ASD were male, white, and in households above 185% of the federal poverty level.**



Source: National Survey of Children's Health 2016

Source: National Longitudinal Transition Study-2012

## Demographics of teens on the autism spectrum (teens with ASD)

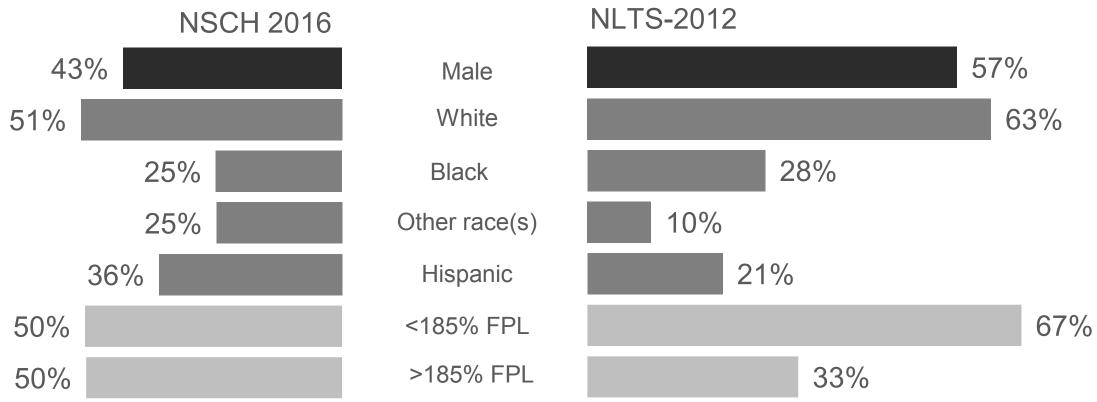
For both the NLTS-2012 and the NSCH 2016, teens with ASD were primarily male, white, and from households with income above 185% of the federal poverty level (FPL). There were few differences in demographic indicators between youth in the two surveys.

In NLTS-2012, 39% of households had incomes of $0-$40,000 per year, 30% were $40,001-$80,000, 15% had incomes of $80,001-$120,000, and 16% had incomes of $120,000 or more. In the NSCH 2016, 27% of teens were from households with incomes below 100% of the federal poverty level (FPL), 21% were from households with incomes from 100-199% FPL, 23% lived in households with incomes from 200-399% FPL, and 29% were in households with incomes at or above 400% FPL.

According to results from the NLTS-2012, 14% of teens with ASD lived in a household where a language other than English *was regularly used*. In the NSCH 2016, 5% of teens with ASD lived in a household where a language other than English *was the primary language* in the household.

We sometimes compare teens with autism to their peers. For NLTS-2012 indicators, we compared those with autism to a) students with an intellectual disability (ID) who did not also have autism and who had an IEP or 504 plan and, b) students who did not receive special education services or any type of accommodations. For the NSCH 2016, we compared teens with autism to a) teens with an intellectual disability (ID) who did not also have autism and, b) teens without special health care needs.

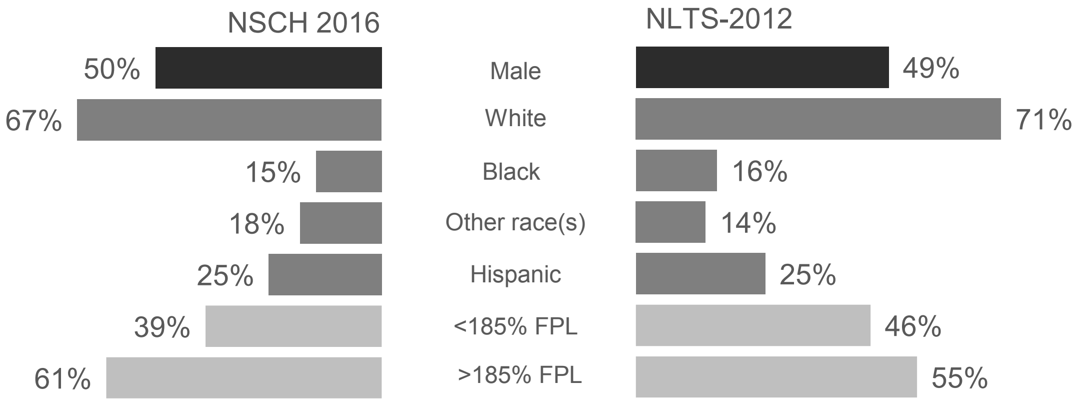
**Most teens with ID were male, white, and from lower income households.**



Source: National Survey of Children's Health 2016

Source: National Longitudinal Transition Study-2012

**Most teens without disabilities were white and from higher income households.**



Source: National Survey of Children's Health 2016

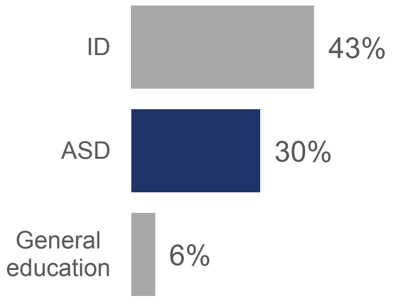
Source: National Longitudinal Transition Study-2012

## One in four households of teens with ASD received public assistance.

Public assistance is any kind of program that provides either cash or in-kind benefits from any government agency (local, state or federal) (United States Census Bureau, 2017). More than one in four households of teens with ASD received Supplemental Security Income (SSI) payments in the previous two years, and 7% received Temporary Assistance for Needy Families (TANF), as measured in NLTS-2012. SSI is a cash benefit provided to people who are both severely disabled and meet a low-income threshold. About one-quarter of teens with ASD lived in a household that received Supplemental Nutrition Assistance Program (SNAP) within the previous two years, as seen in NLTS-2012. One-third of teens with ASD ages 12-17 were in households receiving SNAP as measured in the NSCH 2016.

**Fewer teens with ASD were from households that received SSI in the past two years, compared to teens with ID.**

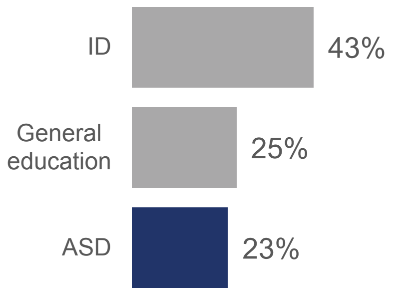
NLTS-2012



Source: National Longitudinal Transition Study-2012

**Fewer teens with ASD were from households that received SNAP in the past two years, compared to teens with ID.**

NLTS-2012



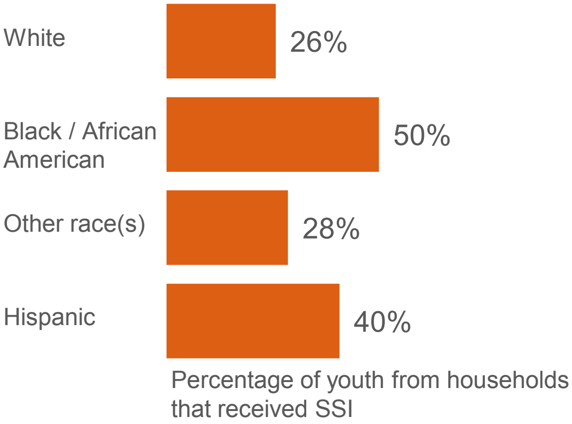
Source: National Longitudinal Transition Study-2012

## More teens with ASD from lower income households were minorities compared to higher income households.

We examined the income levels for households with teens with ASD. The NLTS-2012 measured total income per year, while the NSCH 2016 reported household income as a percent of the federal poverty level (FPL). According to the NLTS-2012, 72% of teens with ASD from the lowest income households ($0-$40,000 per year) were white, and 21% were Hispanic; whereas 86% of teens with ASD from higher income households ($120,000+ per year) were white and 5% were Hispanic. Black or African American teens with ASD were the most likely to live in households that received SSI. Estimates from the NSCH 2016 showed a similar demographic pattern. Sixty-two percent of teens with ASD ages 12-17 from the lowest income households (50%-99% of the federal poverty level) were white, and 18% were Hispanic; whereas 83% of teens with ASD from the highest income households (above 400% FPL) were white and 7% were Hispanic.

**Half of black teens with ASD were from households that received SSI.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

## SPOTLIGHT on young adult high school students on the autism spectrum: Demographics

In this section, we focus on the demographics of young adult high school students ages 19-23 years using NLTS-2012 data. Service provision often shifts once youth complete four years of high school and are continuing to receive special education services. Young adult high school students over age 18 are more likely to receive services through other systems. Examples of these systems include Medicaid, state developmental disability services, Vocational Rehabilitation, and community mental health.

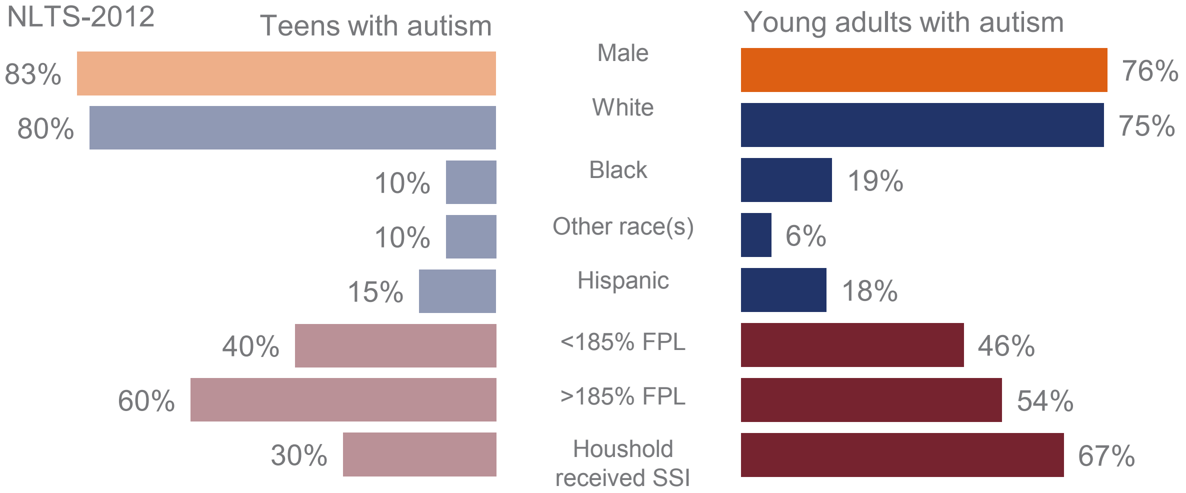
Most (78%) young adult high school students with ASD were from households that earned less than $80,000 a year. Nearly half (48%) were from the lowest income households ($0-$40,000 per year). About one-third (31%) were from households with incomes from $40,001-$80,000, while 13% were from higher income households ($80,001-$120,000), and 9% from those households earning more than $120,000. Compared to teens with ASD, young adults with ASD were more likely to receive SSI benefits.

Sixteen percent of young adults lived in a home where a language other than English was spoken.

### A word about age

For this report, we defined "**teens**" as those ages **12-18 years**, and "**young adults**" as those ages **19-23 years**. There is no perfect consensus among researchers and policy makers on these terms or where to set the boundaries for age groups.

**The majority of young adults with ASD were male, white, and from households that received SSI.**



Source: National Longitudinal Transition Study-2012

## References

United States Census Bureau, (2017, October 3). *Public Assistance*. Retrieved from *https://www.census.gov/topics/income-poverty/public-assistance/about.html*

# Disability Characteristics and Adaptive Behaviors

*Teens (ages 12-18) and young adults (ages 19-23)*

## Our key findings

- Communication:
  - » Thirty-two percent of teens with ASD had great difficulty in carrying a conversation or were unable to do so. Seventy percent also had some trouble or a lot of trouble understanding what was said to them. However, nearly 70% were able to communicate in some manner about the things that really mattered to them somewhat or very well.
  - » Teens with ASD who were black or African American had more difficulty with speech and language skills than teens with ASD of other races/ethnicity.
  - » Young adults with ASD had more trouble communicating, speaking, understanding, and conversing than teens with ASD.
- Activities of daily living:
  - » Most teens with ASD could perform basic activities of daily living very well, such as dressing and eating. More had trouble with counting change and using the telephone.
- Social participation:
  - » More than half of teens with ASD (57%) had a lot of difficulty making and keeping friends.
- Community mobility:
  - » While teens with ASD had less difficulty with adaptive behaviors than teens with ID, over one-third of teens with ASD were not able to get to places outside the home very well, or were not allowed to do so.
  - » Teens with ASD who were black or African American had more difficulty with adaptive skills than teens with ASD of other races/ethnicity.

## How do we know?

We used data from the National Longitudinal Transition Study-2012 (NLTS-2012) and the National Survey of Children's Health 2016 (NSCH 2016) to study teens and young adults on the autism spectrum ages 12-23 years. When using the NLTS-2012 data, we only report on students with ASD who were receiving special education services.

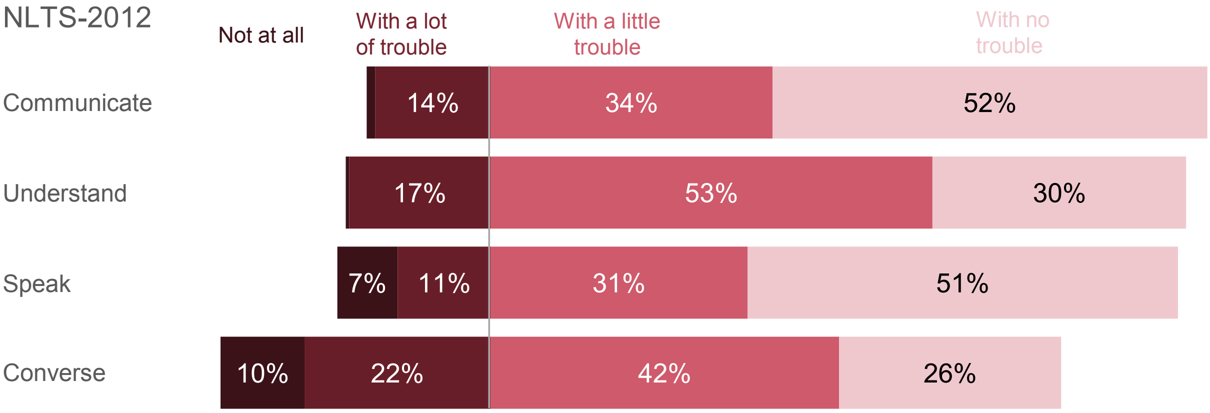
## Teens with ASD and teens with ID had similar speech and language abilities.

Difficulty with communication is one of the core diagnostic criteria for autism spectrum disorder. The NLTS-2012 asked four questions about communication abilities: 1) "How well does youth communicate by any means?"; 2) "How well does youth understand what people say to him/her?"; 3) "How clearly does youth speak?"; and 4) "How well does youth carry on an oral conversation?" Each question had the response options: "has no trouble," "has a little trouble," "has a lot of trouble," or "does not at all."

Among these four aspects of communication, difficulty with oral conversational skills affected the highest percentage. Twenty-two percent were unable to converse orally or had a lot of trouble.

Among those who had a lot of trouble speaking, or who could not speak, 6% could not communicate at all, and most (72%) had a lot of trouble communicating. Fewer communicated with little trouble (18%) or no trouble (5%).

**Teens with ASD had the most difficulty with conversational abilities.**



Source: National Longitudinal Transition Study-2012

## A note about communication

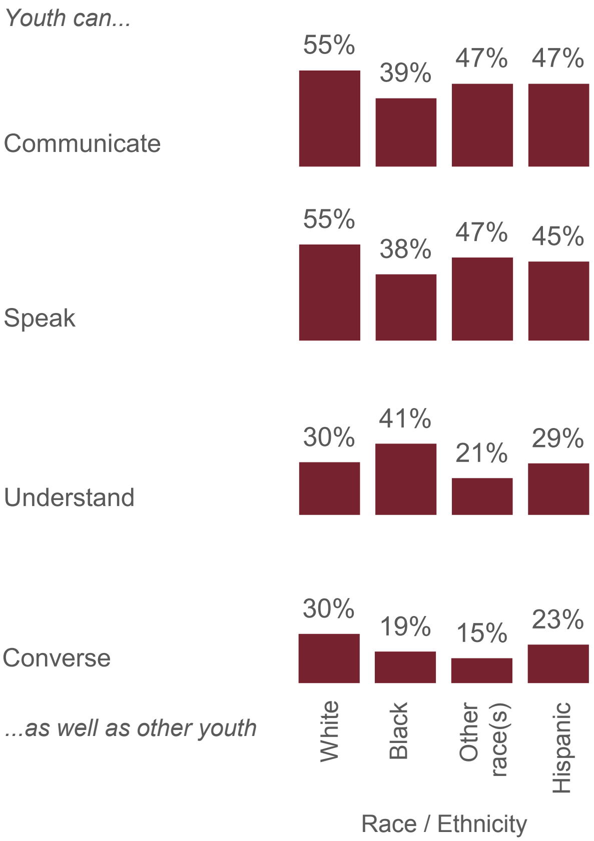
The indicators here are based on questions from the NLTS-2012 where parents were asked to describe the speech and communication abilities of their children receiving special education services. We report results from the survey's questions about speaking and conversing. We wish to note that the NLTS-2012 asked few questions about non-spoken communication. However, some people with autism do communicate without using spoken language.

Teens with ASD generally had more difficulty conversing than teens with ID. One quarter (26%) of teens with ASD conversed as well as other youth, compared to 43% of teens with ID; and 22% of teens with ASD had a lot of trouble conversing, compared to 12% of teens with ID. Teens in general education largely had no problems with speech and language abilities.

Black or African American teens with ASD had more difficulty with conversation and adaptive abilities than youth of other races; the percentage of teens with ASD who could not converse was 8% in white teens and Hispanic teens, and 25% in black or African American teens.

**Black teens with ASD had more difficulty with language expression and conversation than many of their peers.**

NLTS-2012

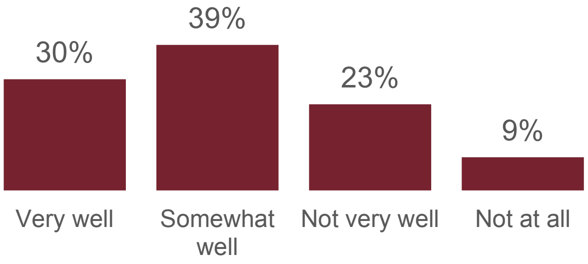


Source: National Longitudinal Transition Study-2012

The NSCH 2016 asked how well teens could share ideas or talk about things that matter. Some teens with ASD could do this very well (30%) or somewhat well (39%). Teens with ASD were more likely to have difficulty sharing ideas or talking about things that really mattered compared to teens with ID. Almost half of teens with ID (44%) could share ideas very well, and nearly one-quarter (24%) could share ideas somewhat well.

**One-third of teens with ASD had great difficulty sharing ideas or talking about things that really mattered.**

NSCH 2016



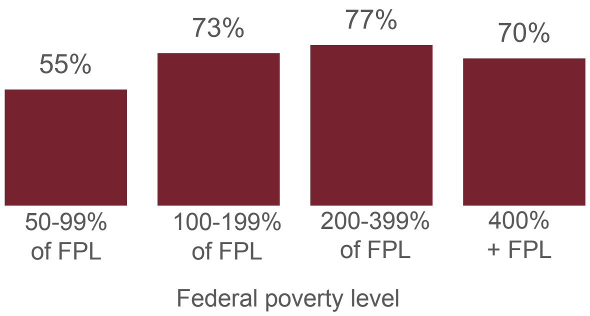
Source: National Survey of Children's Health 2016

In the NSCH 2016, black or African American teens with ASD had more problems sharing ideas or talking about things that really mattered than teens with ASD of any other race or ethnicity. Fifteen percent of black or African American teens with ASD could do this very well, compared to their peers who were white (32%), Hispanic (35%), or of other or multiple races (34%). Similarly, about one-fifth of black or African American (22%) and Hispanic (18%) teens with ASD could not do this at all, compared to 5% of white teens and 3% of teens of other or multiple races.

As seen in the NSCH 2016, teens with ASD who lived in households below the federal poverty level (FPL) had more trouble sharing ideas or talking about things that really matter than teens from households above the FPL. About half (55%) of teens from lower income households could do this very well or somewhat well.

**Only half of teens with ASD from the poorest households were able to share ideas or talk about things that matter.**

NSCH 2016

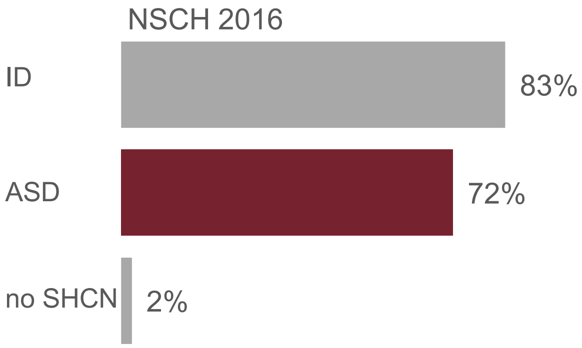


Source: National Survey of Children's Health 2016

## Many teens with ASD had trouble concentrating

Nearly three-fourths of teens with ASD had serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition according to NSCH 2016 data.

**Teens with ID had more difficulty with concentration than teens with ASD.**

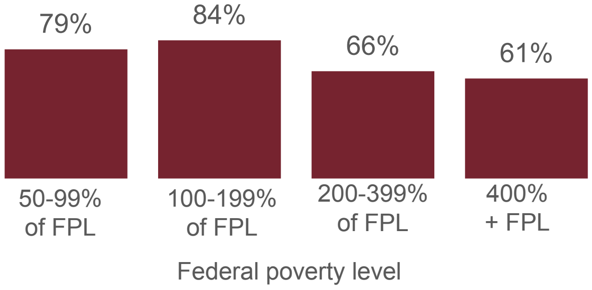


Source: National Survey of Children's Health 2016

More teens with ASD from households with income below or slightly above the FPL had serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition than teens with ASD from households with higher incomes.

**Teens with ASD from households with lower income were more likely to have serious difficulty concentrating, remembering, or making decisions.**

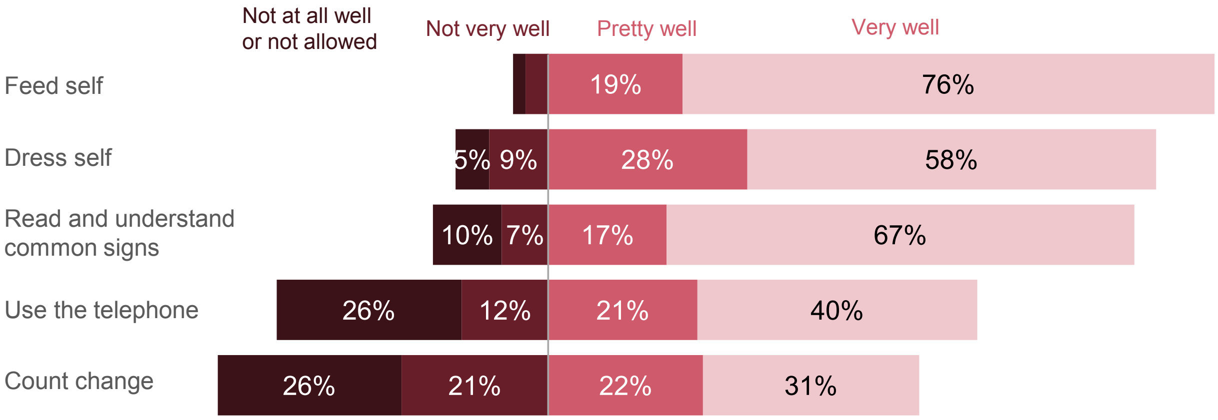
NSCH 2016



Source: National Survey of Children's Health 2016

**Most teens with ASD could perform adaptive tasks very well, some had trouble using the telephone or looking up phone numbers or counting change.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

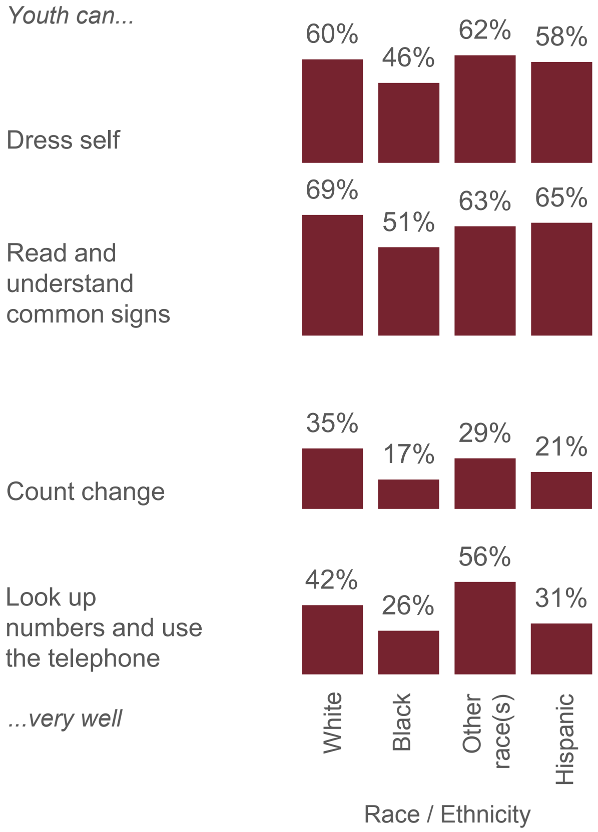
## Adaptive ability levels varied across types of skills

Most teens with ASD could perform basic activities of daily living very well, such as dressing and eating. More had trouble with counting change, using the telephone, and getting to places outside of the home.

Black or African American teens with ASD often had more trouble with these adaptive abilities than teens with ASD of any other race or ethnicity.

**Black teens with ASD were the least likely to be able to perform adaptive functions "very well."**

NLTS-2012

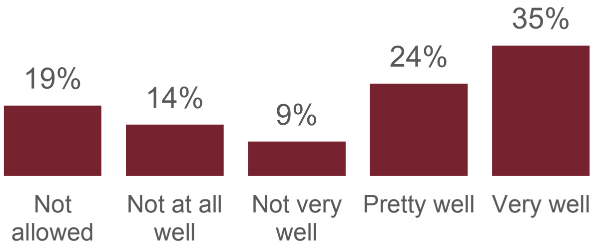


Source: National Longitudinal Transition Study-2012

Approximately 85% of teens in general education could get to places outside of the home very well compared to teens with ASD (35%) or teens with ID (46%).

**Over one-third of teens with ASD could not get to places outside the home very well, or were not allowed to do so.**

NTLS-2012

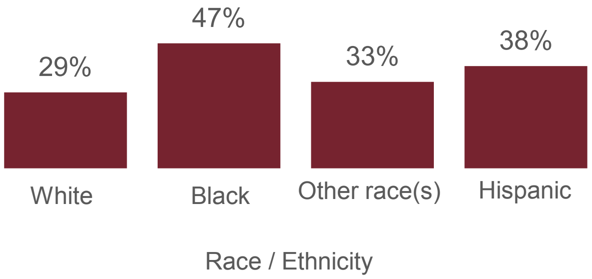


Source: National Longitudinal Transition Study-2012

Almost half of black or African American teens with ASD were not allowed to get to places outside of the home on their own. This percentage was higher than for teens with ASD of any other race or ethnicity.

**Almost half of black teens with ASD could not or were not allowed to get to places outside of the home.**

NLTS-2012

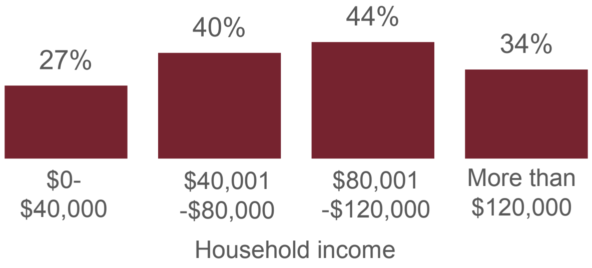


Source: National Longitudinal Transition Study-2012

Teens with ASD from higher income households had less trouble getting to places outside of the home. About one-fifth of teens with ASD from lower and middle income homes were not allowed to get to places outside of the home on their own (23% of teens in households lower than $40,000 and 19% of teens in households between $40,000 and $80,000). Thirteen percent of teens from households with an income between $80,000 and $120,000 and 14% of teens in households more than $120,000 were not allowed.

**Teens with ASD from the lowest income households were the least likely to be able to get to places outside of the home very well.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

One-fifth of teens with ASD had difficulty dressing or bathing according to NSCH 2016 data. A smaller percentage of teens with ASD reported these difficulties than teens with ID (31%). Fewer than 1% of teens with no special health care needs (SHCN) had difficulty bathing or dressing. About half (54%) of teens with ASD had serious difficulty doing errands alone, such as visiting a doctor's office or shopping, because of a physical, mental, or emotional condition. Two-thirds of teens with ID had serious difficulty doing errands alone, and fewer than 1% of teens with no SHCN had serious difficulty doing errands. Many parents of teens with ASD (67%) reported that their child was limited or prevented in some way from doing the things most children the same age can do. This was very similar to teens with ID (66%), but much higher than teens with no SHCN (1%).

## Restraints are sometimes used in schools for managing behavior of teens with ASD.

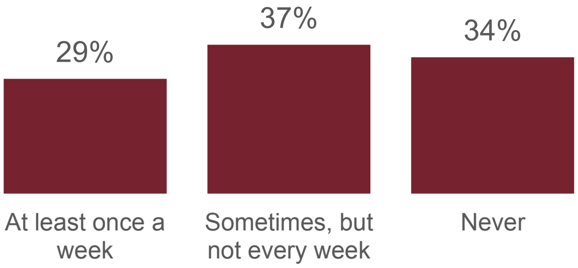
The NLTS-2012 asked parents "How often was youth held or restrained by a teacher or classroom aid because he/she was misbehaving in class?" Most teens with ASD were reportedly never restrained in the classroom because they were misbehaving (87%). Some were restrained a few times (11%), and 3% were restrained once a week or more. These rates were similar to teens with ID and teens in general education.

## Teens with ASD had more difficulty with friendships compared to teens in general education.

Less than one-third of teens with ASD got together with friends at least once a week, while over one-third saw friends sometimes but not every week. Another third of teens with ASD never got together with friends during the past year. These rates were similar to how often teens with ID saw friends. However, teens in general education tended to see friends at least once a week (67%) or sometimes (28%).

**Two-thirds of teens with ASD got together with friends at least sometimes.**

NTLS-2012

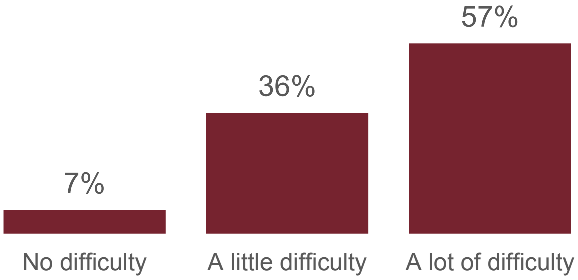


Source: National Longitudinal Transition Study-2012

According to the NSCH 2016, most teens with ASD had a lot of difficulty keeping friends compared to other youth their age. Well over half of teens with ASD had a lot of difficulty making and keeping friends compared to 27% of teens with ID and 1% of teens with no SHCN. Most teens with no SHCN (85%) had no difficulty making or keeping friends, and about one-third (31%) of teens with ID had no difficulty.

**More than half of teens with ASD had a lot of difficulty making and keeping friends.**

NSCH 2016



Source: National Survey of Children's Health 2016

## SPOTLIGHT on young adult high school students with ASD: Adaptive skills

Young adult high school students with ASD overall had more trouble communicating, speaking, understanding, and conversing than teens with ASD.

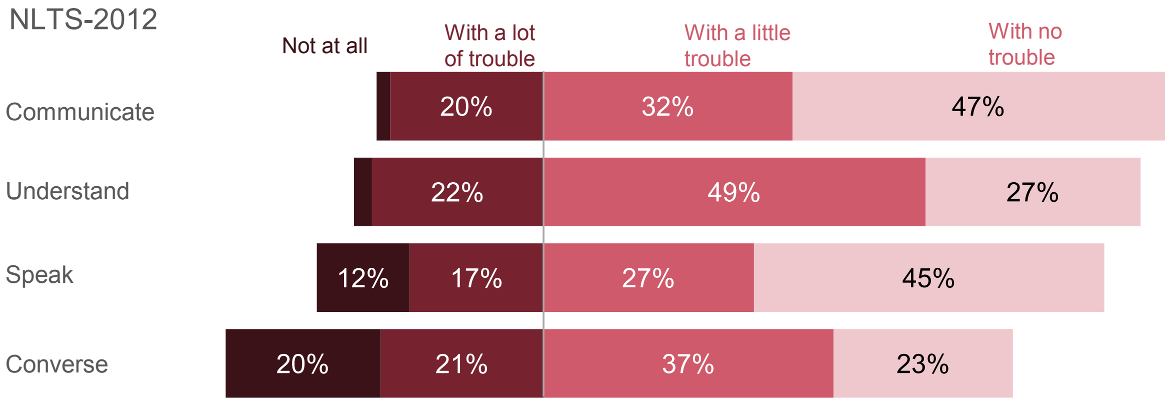
Young adults with ASD had more trouble across all of the adaptive skills than teens with ASD. Notably, 39% of young adults with ASD could not count change well at all (or were not allowed to do so), and 42% could not use the telephone well at all (or were not allowed to do so).

Approximately 86% of students in general education could get to places outside of the home very well compared to teens with ASD (37%) or teens with ID (46%). Young adults with ASD had more trouble than teens with ASD in getting to places outside of the home. Only 25% could get to places outside of the home very well. Thirty percent of young adults with ASD were not able to get to places outside the home at all, and 22% were not allowed.

### A word about age

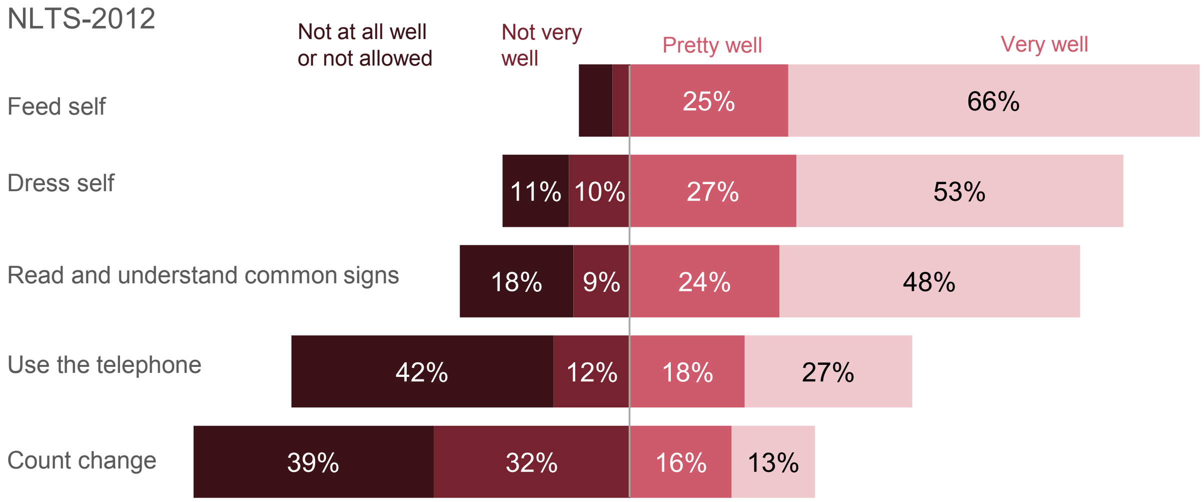
For this report, we defined "**teens**" as those ages **12-18 years**, and "**young adults**" as those ages **19-23 years.** There is no perfect consensus among researchers and policy makers on these terms or where to set the boundaries for age groups. We chose age 18 because the majority of youth with ASD leave special education at this point and may seek assistance through adult services.

**Young adult high shool students with ASD had great difficulty with conversation skills.**



Source: National Longitudinal Transition Study-2012

**Over half of young adults with ASD had great difficulty with at least one adaptive skill.**



Source: National Longitudinal Transition Study-2012

# Special Education Services and Transition Planning

*Most teens with ASD received special education. Less than half experienced transition planning.*

## Our key findings

- Nearly all teens with ASD received special education services to meet their education needs at some point, compared to two-thirds of teens with ID.
- Over half (55%) of parents of teens with ASD, who were ages 16-18, participated in IEP transition planning. Parents of teens with ASD who were Hispanic were the most likely to participate in transition planning.
- Three-quarters of teens with ASD themselves (ages 16-18) participated in IEP transition planning. Participation was highest among youth from higher-income households.

## How do we know?

We used data from the National Longitudinal Transition Study-2012 (NLTS-2012) and the National Survey of Children's Health 2016 (NSCH 2016) to study teens and young adults on the autism spectrum ages 12-23 years. When using the NLTS-2012 data, we only report on students with ASD who were receiving special education services.

## Enrollment in special education

In the United States, thirteen percent of children age 3-21 received special education services during the 2014-15 school year (Snyder, Brey, & Dillow, 2018). According to the NSCH 2016, 16% of all transition age youth (ages 12-17) ever received special education or early intervention services per parent report, and 10% were currently receiving those services.

Most teens with ASD (70%) were in special education at some point, according to the NSCH 2016. The mean age when they first received special education services was 5.1 years. Similarly, 73% of teens with ID were ever enrolled in special education with a mean first age of special education services of 4.9 years.

In comparison, the NLTS-2012 mainly focused on youth receiving special education services and parents reported that teens with ASD first received special education services at 5.3 years, on average.

## Services received in school

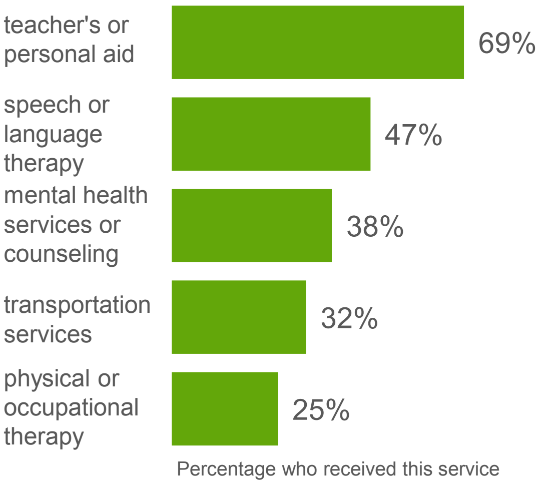
Ninety percent of teens with ASD in the NSCH 2016 had ever received special services to meet their educational needs, such as speech, occupational, or behavioral therapy. The services asked about in NSCH may have been delivered within the context of special education or outside of school. In comparison, two- thirds of teens with ID ever received special services.

As reported by parents in NLTS-2012, the most common services or accommodations teens with ASD received in the last 12 months were a teacher's aide or personal assistant (69%), speech or language therapy (47%), and psychological or mental health services or counseling (38%).

Most parents of teens with ASD attended a meeting about an Individualized Education Program (IEP) for their child's special education services in the past year (93%). About one third (37%) of parents of teens with ASD received classes or counseling on their child's rights and responsibilities under disability-related laws during the school year. Almost two-thirds of teens with ASD attended their own IEP meeting in the past year (62%).

**Teacher's or personal aid was the most common service received by teens with ASD.**

NLTS-2012

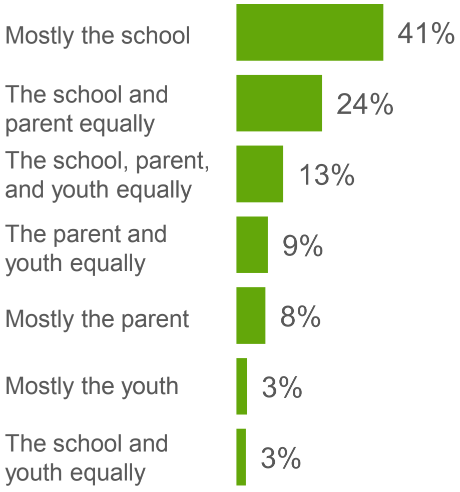


Source: National Longitudinal Transition Study-2012

## Parent participation in transition planning

About half (55%) of parents of teens with ASD (ages 16-18) met with teachers to set goals for what their child would do after high school. This process is called transition planning or IEP transition planning.

In nearly half of the cases, parents reported that the transition goals or plan were mostly created by the school. Sometimes both the parent and the school created the transition goals, or a combination of the parent, the school, and the youth equally.



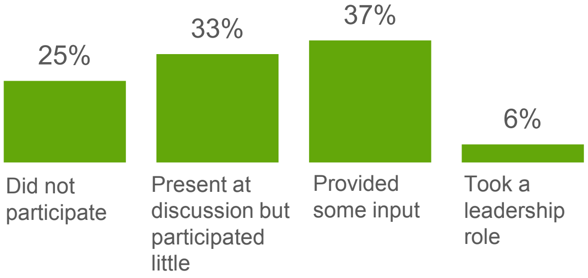
**Nearly half of parents of teens with ASD reported that the school mostly came up with the goals for the transition plan.**

NTLS-2012

Source: National Longitudinal Transition Study-2012

## Youth participation in transition planning

One-quarter of teens with ASD (ages 16-18) themselves had no participation in the IEP transition planning process. Another third were present for the meeting but did not participate much.



**One-quarter of teens with ASD ages 16-18 did not participate in transition planning.**

NLTS-2012

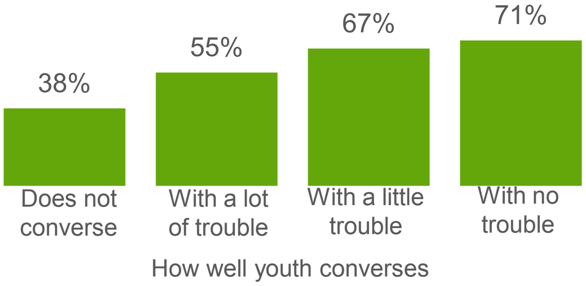
Source: National Longitudinal Transition Study-2012

## Transition planning varied by conversation ability.

Youth participation in IEP meetings was more common among teens with ASD who had little or no trouble conversing versus teens with ASD who could not converse.

**Teens with ASD who could not converse were more the least likely to attend an IEP meeting.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

Most teens with ASD who could not converse did not participate in the IEP transition planning process, while most students who could converse with no problem provided at least some input.

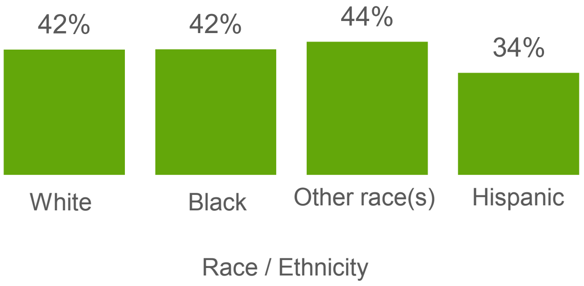
## Hispanic teens with ASD and their parents participated in the transition planning process more often.

Across youth of different races and ethnicity, Hispanic teens with ASD were the most likely to participate in the transition process or have a parent that participated in the process. Nearly three-quarters of parents of Hispanic teens with ASD attended a transition planning meeting, compared to 51% of parents of white teens with ASD, 52% of black or African American, and 64% of other parents.

More Hispanic teens with ASD played a role in transition planning than other youth. Parents of Hispanic teens with ASD were the least likely to report that the school mostly came up with the transition goals, compared to parents of teens of other ethnicities.

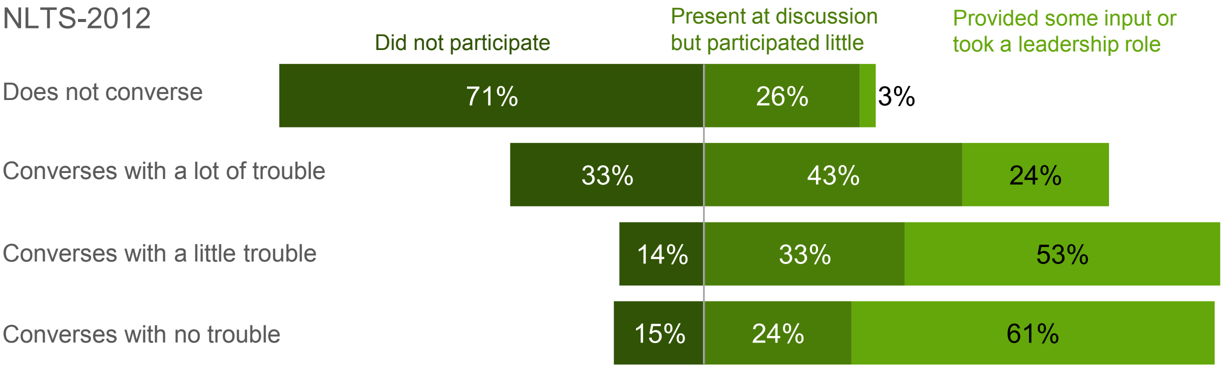
**Parents of Hispanic teens with ASD were the least likely to report that the school mostly came up with the transition goals.**

NLTS-2012



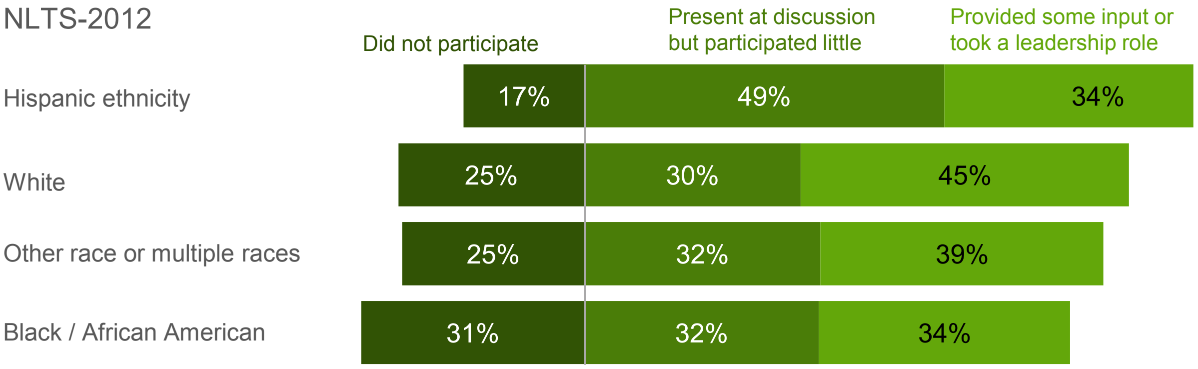
Source: National Longitudinal Transition Study-2012

## Teens with ASD ages 16-18 who could not converse were the least likely to participate in transition planning.



Source: National Longitudinal Transition Study-2012

## Hispanic teens with ASD ages 16-18 were the most likely to participate in transition planning.



Source: National Longitudinal Transition Study-2012

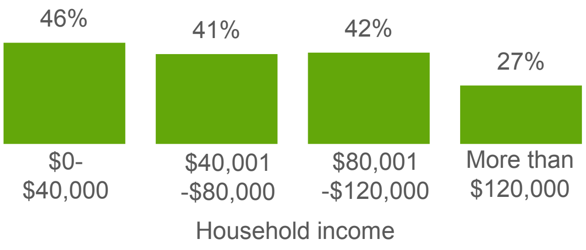
## Teens with ASD from higher income households took a more active role in transition.

Parents of teens with ASD from households with an annual income over $120,000 were the least likely to have the school mostly in charge of coming up with transition goals. Youth from households with the highest incomes were also more likely to participate in transition planning.

More than half of teens with ASD from households with the highest incomes participated in IEP transition planning, and fewer than one-fifth did not participate at all.

**Teens with ASD from the highest income households were the least likely to have transition goals set mostly by the school.**

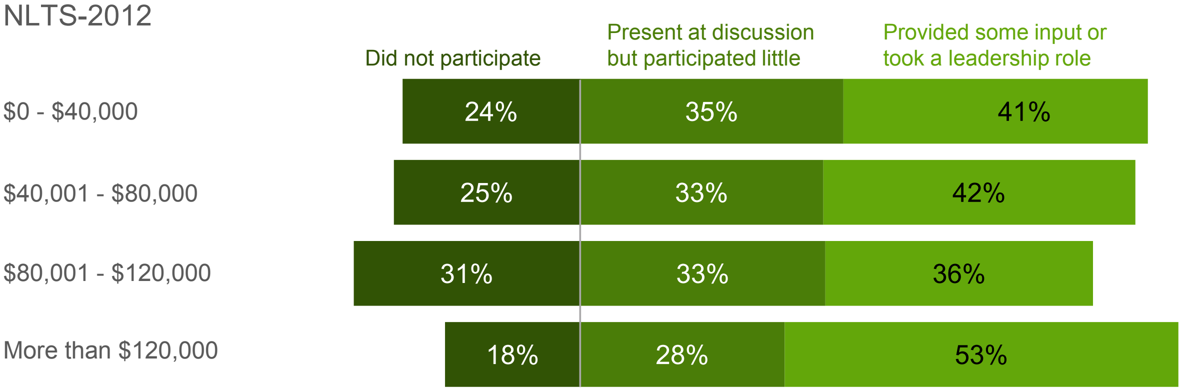
NLTS-2012



Source: National Longitudinal Transition Study-2012

**Teens with ASD ages 16-18 from the highest income households were most likely to participate in transition planning.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

## SPOTLIGHT on young adult high school students with ASD in special education

Young adult high school students with ASD who are still receiving special education services past the age of 18 likely have a higher level of special needs. Young adults with ASD were younger on average when they first started receiving special education services from a professional than teens with ASD (4.7 years versus 5.3 years). Young adults with ASD who were still in school received school services at similar rates to teens with ASD with the exception of transportation services; 43% of young adults with ASD received transportation compared to 32% of teens with ASD.

Young adults with ASD were more likely to have attended their own IEP meeting in the past year than teens with ASD. Nearly three-quarters (74%) of parents of young adults with ASD attended a transition planning meeting–much higher than the rate of parents of teens with ASD (55%).

### A word about age

For this report, we defined "**teens**" as those ages **12-18 years**, and "**young adults**" as those ages **19-23 years.** There is no perfect consensus among researchers and policy makers on these terms or where to set the boundaries for age groups. We chose age 18 because the majority of youth with ASD leave special education at this point and may seek assistance through adult services.

## References

Snyder, T.D., de Brey, C., and Dillow, S.A. (2018). Digest of Education Statistics 2016 (NCES 2017-094). National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education. Washington, DC.

# Health, Mental Health, and Healthcare Services

*Teens with ASD used many health services, but they were not prepared for the transition to adult healthcare.*

## Our key findings

- Well over half (64%) of teens with ASD were taking prescription medications, and nearly half (48%) were taking medications for attention, behavior, or mood. These rates were much higher than teens with ID.
- Teens with ASD were more likely than teens with ID to also have ADHD, anxiety, or depression. Over half (57%) of teens with ASD received mental health treatment or counseling in the previous year.
- Nearly half of parents of teens with ASD spent several hours weekly arranging and coordinating health care compared to 37% of parents of teens with ID.
- Teens with ASD from lower income households were more likely to be in fair/poor health or have unmet health care needs. Teens with ASD who were black or African American were more likely to have unmet health care needs than teens with ASD of other races/ethnicity.

## Overall health

Teens with ASD overall had better parent-rated health than teens with ID but worse health compared to teens in general education and teens with no special health care needs (SHCN).

Two-thirds of teens with ASD reported very good or excellent overall health in both the NLTS-2012 and the NSCH 2016.

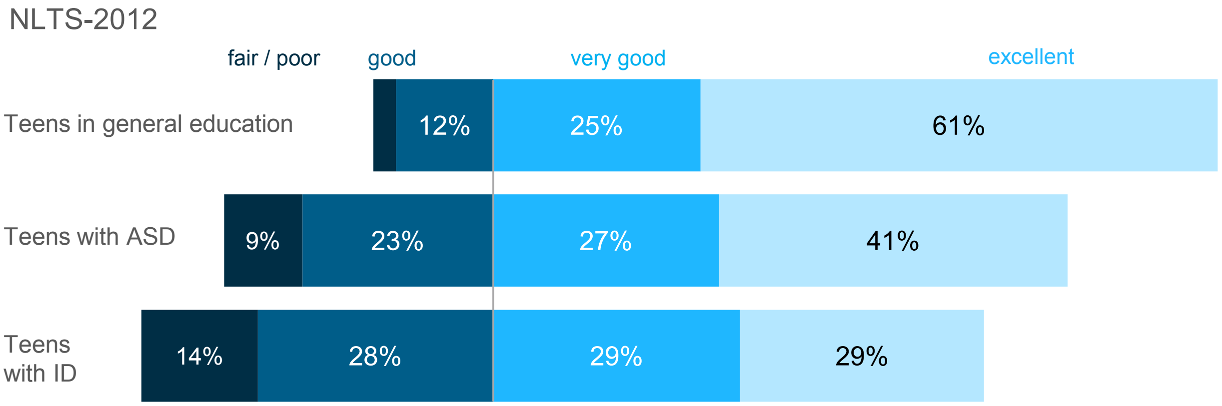
As seen in the NSCH 2016, teens with ASD from higher income households were more likely to have excellent health than teens with ASD from lower income households.

According to NSCH 2016 data, three quarters (79%) of teens with ASD needed more medical care, mental health services, or educational services than is usual for most children of the same age. This was similar to teens with ID (77%), but much more common than in teens with no SHCN (2%).

## How do we know?

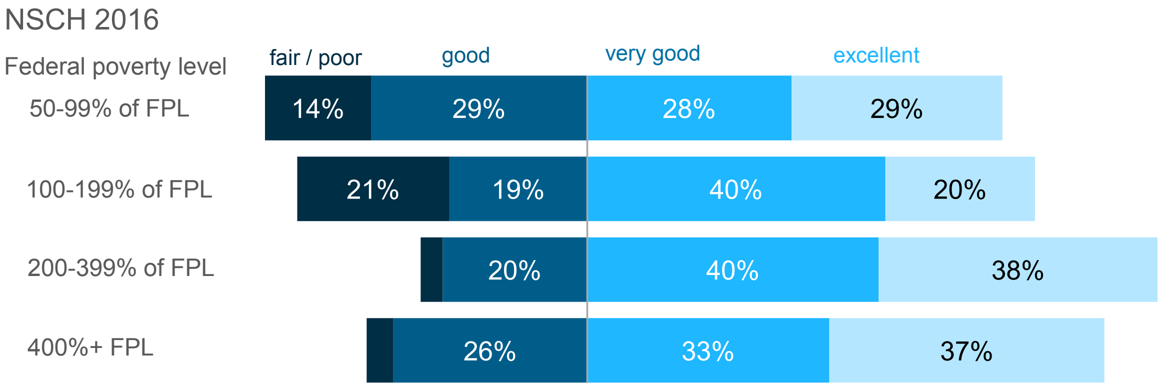
We used data from the National Longitudinal Transition Study-2012 (NLTS-2012) and the National Survey of Children's Health 2016 (NSCH 2016) to study teens and young adults on the autism spectrum ages 12-23 years. When using the NLTS-2012 data, we only report on students with ASD who were receiving special education services.

**Two-thirds of teens with ASD were in excellent or very good health.**



Source: National Longitudinal Transition Study-2012

**More teens with ASD from households near or below the federal poverty level had poor health.**

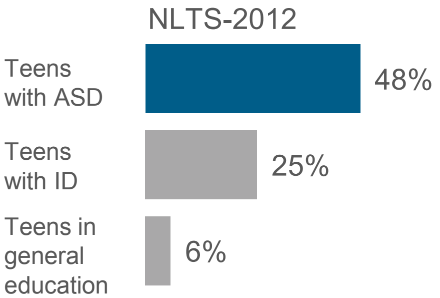


Source: National Survey of Children's Health 2016

## Medication use

Almost half of teens with ASD in special education were currently taking a prescription medicine that controlled attention, behavior, activity level, or mood, such as Ritalin or an antidepressant. Teens with ASD were nearly twice as likely to use these medications than teens with ID and eight times as likely as teens in general education according to NLTS-2012 data.

**More teens with ASD took medication for attention, behavior, or mood than teens with ID or teens in general education.**

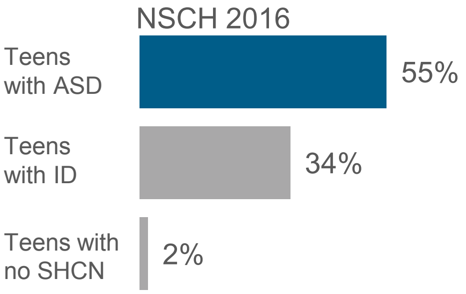


Percentage of teens who took prescription medication for attention, behavior, activity level, or changes in mood.

Source: National Longitudinal Transition Study-2012

Just over half of teens with ASD took medication because of difficulties with emotions, concentration, or behavior in the past 12 months according to the NSCH 2016.

**Over half of teens with ASD took medication because of difficulties with behavior.**

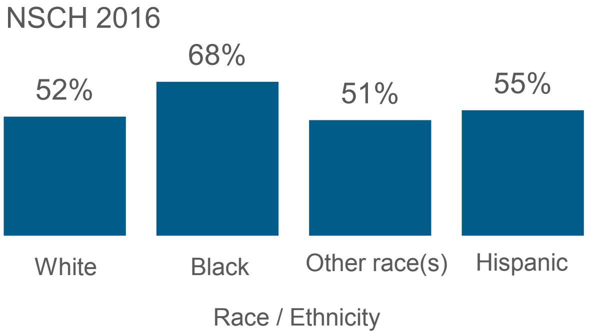


Percentage of teens who took medication because of difficulties with emotions, concentration, or behavior.

Source: National Survey of Children's Health 2016

According to the NSCH 2016, black or African American teens with ASD were the most likely to be taking medication because of difficulties with emotions, concentration, or behavior.

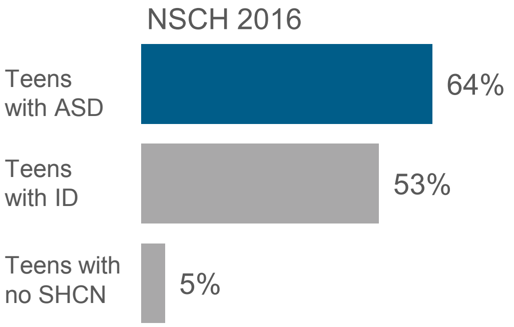
**Black teens with ASD were the most likely to take medication for emotion, concentration, or behavior.**



Source: National Survey of Children's Health 2016

Almost two-thirds of teens with ASD currently took a medication prescribed by a doctor (other than vitamins) in comparison to a little over half of teens with ID. Very few teens with no SHCN used prescription medication.

**Well over half of teens with ASD were taking prescription medication.**



Percentage of teens who need or use medication prescribed by a doctor other than vitamins.

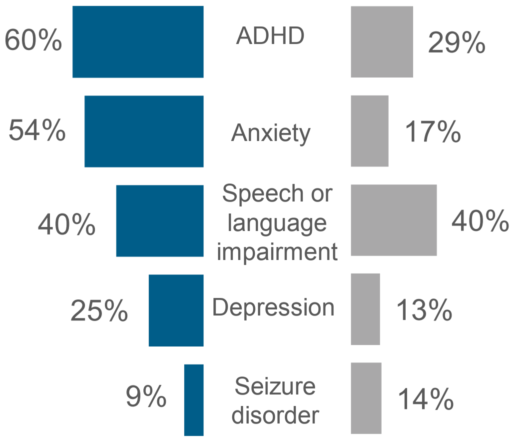
Source: National Survey of Children's Health 2016

## Co-occurring health and mental health conditions

According to the NSCH 2016, teens with ASD were more likely than teens with ID to have a current diagnosis of ADHD, anxiety, or depression from a health care provider. Over half had diagnoses of ADHD or anxiety disorder. Three-quarters (76%) of teens with ASD had a current diagnosis of at least one of the following: ADHD, anxiety, or depression.

**Teens with ASD were more likely to be diagnosed by a health care professional with ADHD, anxiety, or depression than teens with ID.**

NSCH 2016



Source: National Survey of Children's Health 2016

Rates of ADHD and speech-language impairments were very different across the two surveys. In the NLTS-2012, about one-quarter (29%) of teens with ASD had a diagnosis of ADHD, and only 12% of teens with ASD were diagnosed with speech-language impairment. These rates were similar to those of teens with ID. Only 5% of teens in general education had an ADHD diagnosis, and only 1% had a speech-language impairment. The surveys took different approaches to asking these questions, which may explain some of the differences. In the NSCH 2016, parents were asked to confirm if their child had a diagnosis from a health care professional from a list of 25 disabilities, disorders, or conditions. In the NLTS-2012, parents were asked if their child had any physical, sensory, learning, or other disability or problem identified by a professional. If so, the parent had to supply the name of the condition, not respond to a specific question about each possible disability or problem.

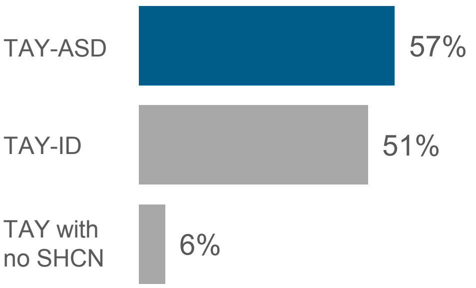
## Healthcare services

According to the NSCH 2016, nearly all (94%) teens with ASD had seen a doctor, nurse, or other health care professional for sickness or well-care in the past 12 months. Teens with ASD were more likely to have seen a health care provider than teens with ID (83%) or teens with no SHCN (80%).

Over half of teens with ASD had received any treatment or counseling from a mental health professional in the past 12 months, similar to teens with ID. Teens with ASD were more likely to receive mental health treatment or counseling than teens with no SHCN. Mental health professionals included psychiatrists, psychologists, psychiatric nurses, or clinical social workers.

**Well over half of teens with ASD received mental health treatment or counseling.**

NSCH 2016



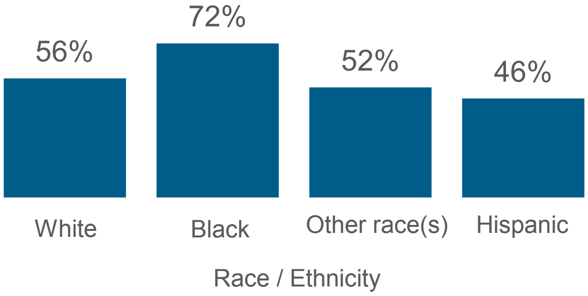
Percentage of teens who received treatment from a mental health professional in the past 12 months.

Source: National Survey of Children's Health 2016

Over one-third (38%) of teens with ASD visited a specialist besides a mental health professional in the past 12 months, similar to teens with ID (36%). Teens with ASD were more likely to receive specialty care than teens with no SHCN (11%). Black or African American teens with ASD were more likely to receive treatment from a mental health professional than teens of any other race or ethnicity.

**Black teens with ASD were the most likely to receive mental health counseling or treatment.**

NSCH 2016

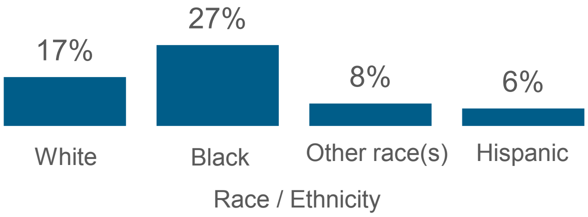


Source: National Survey of Children's Health 2016

Sixteen percent of parents of teens with ASD reported that there was a time over the last 12 months when their child did not receive needed healthcare. This included medical care, dental care, vision care, and mental health services. Far fewer teens with ID (7%) or teens without special health care needs (3%) went without needed care. Black or African American teens with ASD were more likely to have other unmet health care needs in the past 12 months.

**Black teens with ASD were most likely to have unmet health care needs.**

NSCH 2016

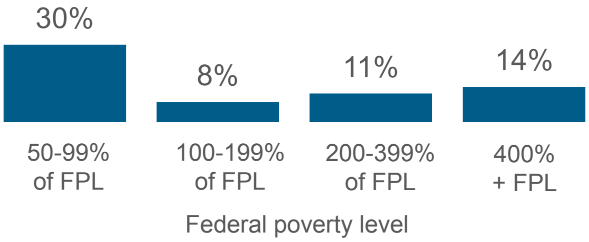


Source: National Survey of Children's Health 2016

Teens with ASD from the lowest income households were the most likely to report a time when the youth did not receive needed health care.

**Teens with ASD from the lowest income households were the most likely to have unmet health care needs.**

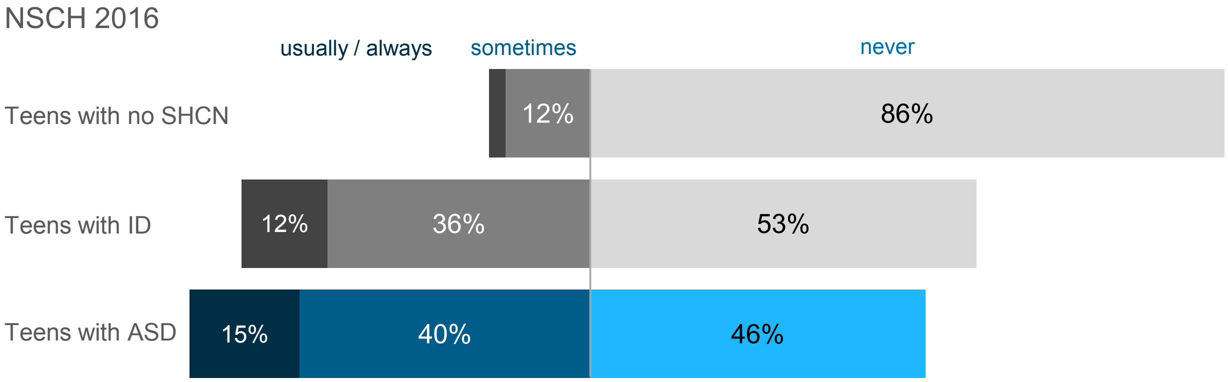
NSCH 2016



Source: National Survey of Children's Health 2016

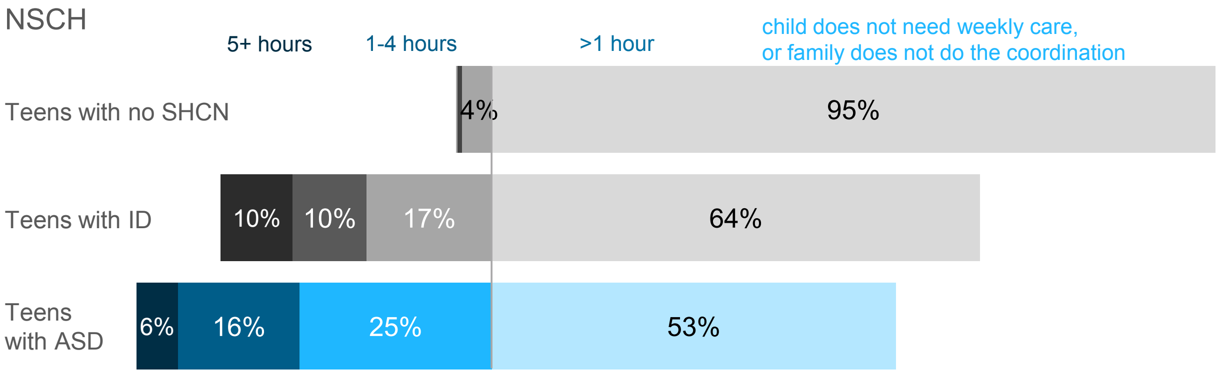
Parents of teens with ASD spent much more time coordinating and arranging health or medical care for their child than parents of teens with no SHCN.

**Over half of parents of teens ASD reported they usually or sometimes were frustrated in their efforts to get services.**



Source: National Survey of Children's Health 2016

**Almost half of parents of teens with ASD spent at least some time arranging or coordinating health care each week.**



Source: National Survey of Children's Health 2016

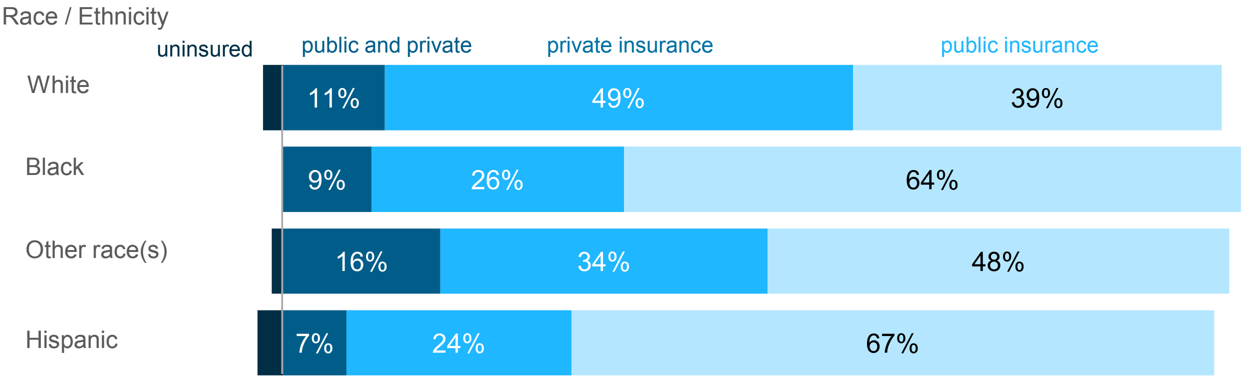
## Health insurance

According to the NSCH 2016, 98% of teens with ASD had some type of insurance. About half of teens with ASD had public health insurance only (46%), while nearly as many had private insurance only (42%). Fewer (10%) had both public and private insurance, and 2% were uninsured. Teens with ID were more likely than teens with ASD to have public insurance (55%), or both public and private insurance (25%). Teens with ID were far less likely to have private insurance (16%), and slightly more likely to be uninsured (4%). Teens with no SHCN were more likely to be insured through private insurance only (63%), compared to public insurance (26%), both public and private (4%), or uninsured (8%).

In the NSCH 2016, Hispanic and black or African American teens with ASD were the most likely to have public health insurance, while white teens with ASD were the most likely to have only private insurance. Youth were no less likely to be uninsured depending on their race.

**Hispanic and black teens with ASD were the most likely to have public insurance.**

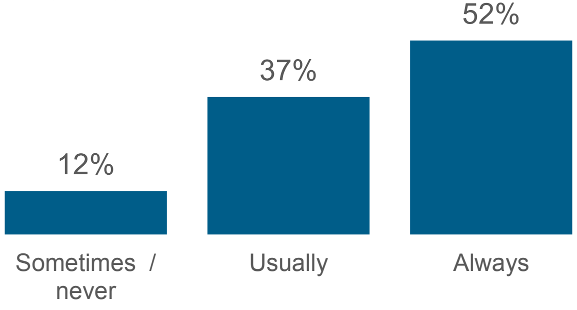
NSCH 2016



Source: National Survey of Children's Health 2016

### Half of teens with ASD who had health insurance said it always covered needed services.

NSCH 2016

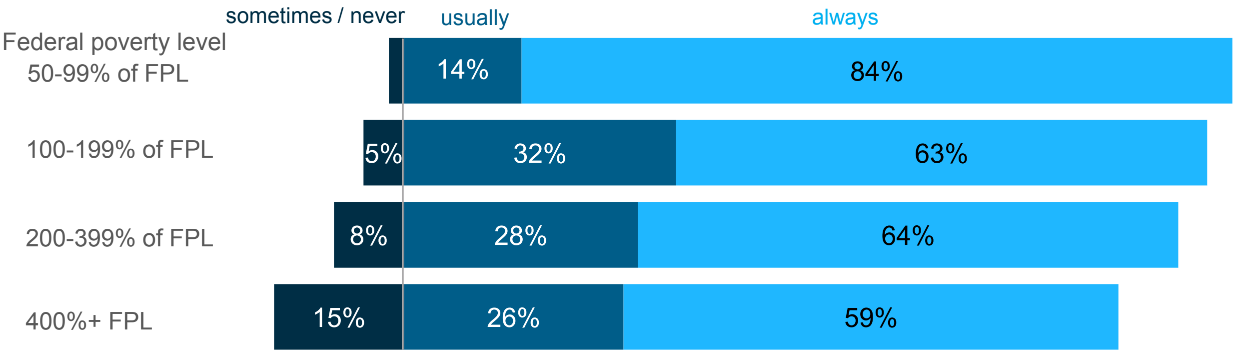


Source: National Survey of Children's Health 2016

Of teens with ASD who had any type of health insurance, about half had insurance that offered benefits or always covered services that met their needs.

### Teens with ASD from high income households were the most likely to report their insurance would not allow them to see needed providers.

NSCH 2016



Source: National Survey of Children's Health 2016

Just over two-thirds (68%) of teens with ASD had insurance that always allowed them to see the providers they needed, while 8% had insurance that only sometimes or never allowed them to see the providers they needed. Less than half of teens with ID (49%) had insurance that always allowed them to see the providers they needed, and 49% reported they could usually see the providers they needed.

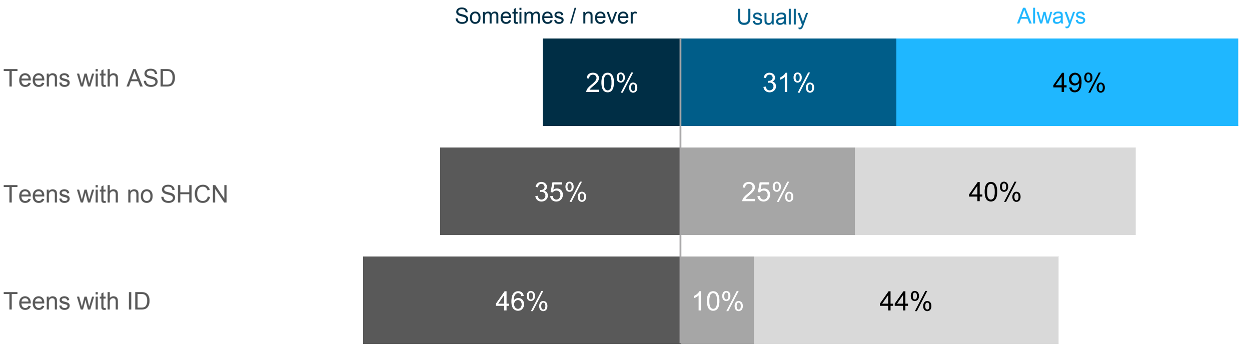
Few teens with ASD were uninsured even among lower income households. Teens with ASD from higher income households were the least likely to report that their insurance always allowed them to see the health care providers they needed.

Almost half of teens with ASD had insurance that always covered their mental or behavioral health needs. Teens with ID and teens with no SHCN were more likely to have insurance that sometimes or never covered their needed mental or behavioral health services. Insurance coverage may change in young adulthood. Teens with ASD were less likely to know how they would be insured in adulthood (39%) compared to teens with ID (54%) or teens without special health care needs (56%).

Over half (54%) of teens with ASD from households with incomes over 400% of the FPL reported knowing how they would be insured as they became an adult, compared to 38% of teens with ASD from households with incomes at 200%-399% of the FPL, 26% of teens with ASD at 100%-199% of the FPL, and 33% of teens with ASD below 100% of the FPL.

**Nearly half of teens with ASD with health insurance always had mental or behavioral health needs covered by their insurance.**

NSCH 2016



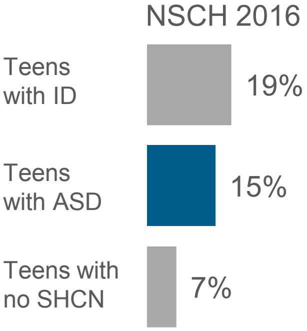
Source: National Survey of Children's Health 2016

## Health care transition planning

Health care transition is the process of moving from a pediatric to an adult health care model. In the NSCH 2016, 18% of teens with ASD who had pediatric care talked to their doctor about eventually seeing a doctor who treats adults. This was similar to teens with ID and teens with no SHCN. Teens with ASD were more likely to be seeing a pediatric provider (75%) than teens with ID (45%) and teens with no SHCN (58%).

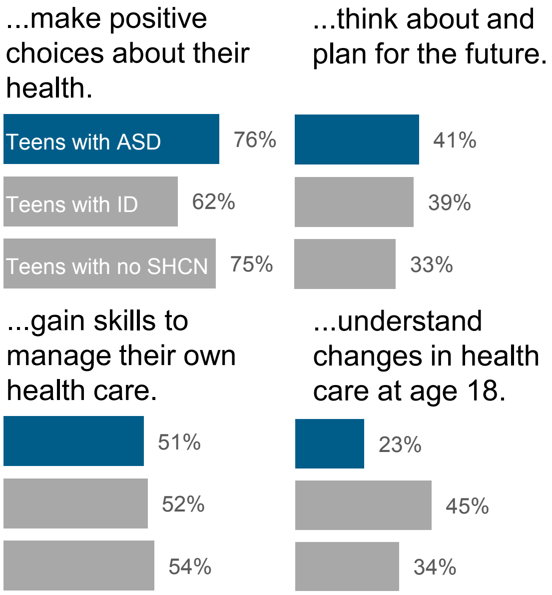
We explored whether youth experienced various components of effective health care transition. Most teens with ASD (76%) had a health care provider who actively worked with them to make positive choices about health. Half (51%) had a health care provider who actively worked with them to gain skills to manage their own health. Less than half (41%) had a health care provider who actively worked with them to think about and plan for their future or helped them understand the changes in health care that may happen at age 18 (23%). Few teens with ASD (15%) had health care providers who worked with them to create a written plan to meet their health goals and needs.

**Working with the health care provider to create a written plan to meet health goals and needs was not common.**



Source: National Survey of Children's Health 2016

**To aid in health care transition, the teens health care provider actively worked with them to...**



Source: National Survey of Children's Health 2016

Teens with ASD from households with incomes 100%-199% of the FPL were the most likely to talk to their doctor about eventually seeing health care providers who treat adults (37%), compared to 13% of teens with ASD from households with incomes under 100% of the FPL, 14% of teens with ASD from households with income from 200%-399% of the FPL, and 10% of teens with ASD from households with income above 400% of the FPL.

## SPOTLIGHT on the health of young adult high school students with autism

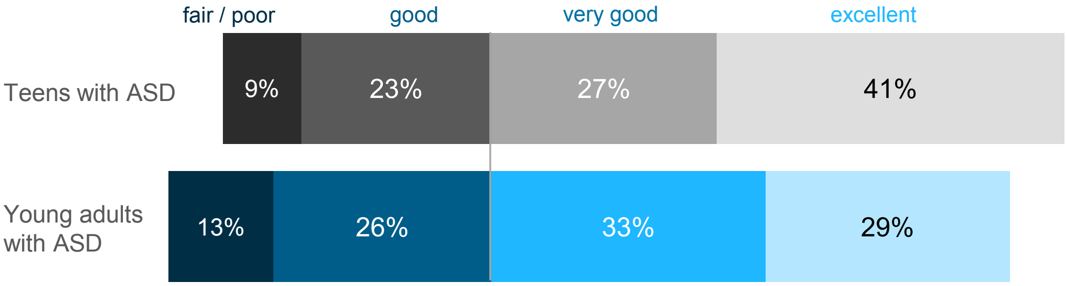
Health of young adult high school students with ASD was poorer than teens with ASD as reported by parents.

Just over half of young adults with ASD (54%) took prescription medications to control attention, behavior, activity level, or changes in mood. This was similar to 48% of teens with ASD who took prescription medication for these purposes.

Nearly all young adults with ASD had health insurance (95%), and most (92%) reported that their insurance covered any of the cost of mental health care. These rates were similar to teens with ASD.

**Young adults with ASD generally had poorer health than teens with ASD.**

NLTS-2012



Source: National Longitudinal Transition Study-2012

### A word about age

For this report, we defined "**teens**" as those ages **12-18 years**, and "**young adults**" as those ages **19-23 years.** There is no perfect consensus among researchers and policy makers on these terms or where to set the boundaries for age groups. We chose age 18 because the majority of youth with ASD leave special education at this point and may seek assistance through adult services.

# What's next? ...looking ahead

## Conclusions, research gaps, and recommendations for future research

This report characterized the demographics, disability characteristics, health, adaptive behaviors and service use patterns among teens and young adults on the autism spectrum ages 12-23. We used national data to describe the kinds of help people need versus the kinds of help people get coupled with data about related life course outcomes. These statistics will inform the improvement of programs and policies that aim to meet the needs of today's youth on the autism spectrum. As with past reports, we conclude by noting significant research gaps.

Many of our findings were broken out by income, race and ethnicity. Minority youth (about one in four youth with ASD) and those from low-income households (nearly half of all youth with ASD) generally have more-severe impairments, worse outcomes and poorer access to needed services across a wide range of indicators. These findings highlight the fact that these subpopulations face disproportionately large challenges. However, research on services and treatments for adults is often based on small samples that fail to include minorities and those from low-income households (Shattuck *et al.*, 2012). Much of what we think we know about evidence-based care for adults has been developed without careful attention to understanding how challenges, strengths and feasible solutions differ by race and class. Unfortunately, only 1% of all U.S. autism research funding focuses on adults. Hopefully, research on adulthood will begin to expand. We also need a dramatic increase in research aimed at understanding the unique needs of minority and low-income youth, and how to tailor services to their unique circumstances.

Several major evidence gaps persist. We have no recent sources of data about services received after high school, postsecondary education or employment outcomes, or indicators of social and community engagement. We also have no national information on issues of abuse, trauma, and vulnerability. Similarly, we have limited information on issues that are important to teens and adults like dating, relationships, and sexual health. Furthermore, we do not have much information on how teens and young adults feel about their lives and what they want for themselves.

This report does not directly compare recent findings to those reported in our 2015 National Autism Transition Report on Transition into Adulthood. Future publications will make detailed comparisons between cohorts. However, overall we can note some key differences versus the earlier generation of youth we reported on in 2015.

- Teens in 2012 were less likely to have difficulty across all indicators of communication and adaptive behaviors than teens in the early 2000's.
- Teens in 2012 were more likely to be white, less likely to be black, and more likely to come from lower income households.
- Rates of co-occurring conditions were similar across cohorts, with ADHD being the most common co-occurring condition in teens with autism.

There are many steps needed to move this research forward. We need more population-level data on teens and adults with autism. One way to accomplish this would be to use existing national data collection platforms to gather information about the outcomes of individuals on the spectrum. For example, the National Health Interview Survey is conducted annually and asks about a wide range of health topics. While this survey likely includes some adults with autism, we cannot identify them because there is no question that asks about autism diagnosis. Adding a question about the presence or history of an autism diagnosis could greatly expand what we know about adults with ASD in the US. However, we must acknowledge the likely underrepresentation of adults with autism in in-person and phone interviews. These rely on spoken communication, and we do not intend to negate the importance of non-spoken communication. The fields of autism research and service provision need better ways to support the provision and evaluation of assistive-augmentative communication that can support individuals to communicate without using speech.

Other opportunities include studying how outcomes are changing over time. Current survey infrastructure allows this to be done in teens with autism, particularly using the National Survey of Children's Health. The NSCH is administered yearly, allowing for future comparisons to build an understanding of how experiences are changing over time at a national level.

## References

Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J. F. (2012). Services for Adults with an Autism Spectrum Disorder. *The Canadian Journal of Psychiatry*, 57(5), 284-291.

# Appendix: Methods

## Data sources

**What data did we use for this report?**
All data for this report came from two federally funded national surveys conducted in the United States.

The **National Longitudinal Transition Study-2012** (NLTS-2012) is a study of the experiences of students receiving special education services. It was funded by the U.S. Department of Education and conducted by Mathematica, a private research company. The NLTS-2012 phone and web-based surveys collected information from parents and youth who were in school in the 2011/12 school year. Youth were either in grades 7-12 or age 13 or older in an ungraded classroom. The survey asked about school experiences, parent involvement in the youth's school, disability characteristics, school services, and school and extracurricular experiences. To read more about the NTLS-2012, visit https://www.mathematica-mpr.com/our-publications-and-findings/projects/national-longitudinal-transition-study.

The **National Survey of Children's Health 2016** (NSCH 2016) is a cross-sectional, nationally representative survey designed to provide national estimates on the health and well-being of 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 qualifying households. The NSCH 2016 asked about health, health care services, health insurance, and school and household activities. To read more about the NSCH 2016, visit http://www.childhealthdata.org/learn-about-the-nsch/topics_questions or https://www.census.gov/programs-surveys/nsch.html. Parents or caregivers provided reports for these surveys. We refer to both as "parents" in this report.

## Who is this report about?

**Who was included in this report?**
The NLTS-2012 and NSCH 2016 are representative of different populations of youth with ASD. Findings about teens with ASD from the NLTS-2012 are representative of teens with ASD ages 12-18 who received special education services. We included teens with ASD who had an individualized education program (IEP) under the autism category as well as teens with ASD whose parents reported they had a current diagnosis of ASD and were receiving special education services. Similarly, teens with ID are representative of teens with ID ages 12-18 who received special education services. However, the ID group excluded teens whose parents reported they had a current diagnosis of ASD from a healthcare or other provider. Teens in general education are a representative sample of teens who received no special education services and did not have a 504 plan. Young adult high school students with ASD are students ages 19-23 who had an IEP under the autism category as well as young adults with ASD whose parents reported they had a current diagnosis of ASD and were receiving special education services.

We analyzed young adults with ASD separately from teens with ASD in order to examine the differences in characteristics and experiences between these groups. Young adults with ASD who are still in special education past the age of 18 likely differed from teens with ASD who are in special education. This group of young adults is fairly large in number, but there is not much data about them.

The NSCH 2016 sampled all children in the U.S., regardless of special education status. The survey focuses on health and healthcare, so it was designed to oversample children with special health care needs (SHCN). In order to do this, a short screener survey was sent to selected households that ascertained 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. A longer follow-up survey was then sent to families, with a focus on families with children with SHCNs. 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 was one.

Teens with ASD from the NSCH are representative of all teens ages 12-17 in the US who were not institutionalized and had a parent report of a current diagnosis of ASD from a healthcare provider or other professional. Teens with ID are ages 12-17 with current parent report of ID but no parent report of ASD. Teens with no SHCN are those who screened negative on the SHCN screener described above.

## 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 happen. 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. All analyses were done incorporating the complex sample design information, including weights, from both the NLTS-2012 and the NSCH 2016.
To read more about NTLS-2012 methods, visit https://www.mathematica-mpr.com/our-publications-and-findings/publications/national-longitudinal-transition-study-2012-design-documentation.

To read more about NSCH 2016 methods, visit https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/methodology/2016-NSCH-Methodology-Report.pdf.

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 NLTS-2012 and the NSCH 2016 are large, nationally representative surveys that have information about teens and young adults with ASD. These surveys illuminate characteristics and service use at the national le comprehensive picture of experiences. Furthermore, they address different populations, allowing for an understanding of experiences of teens with ASD in general in addition to those receiving special education services - an important and very large subgroup.

The general limitations of surveys apply to the indicators presented in this report. These surveys rely on parents or individuals recalling events that happened over the previous year or two, which may be difficult.

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