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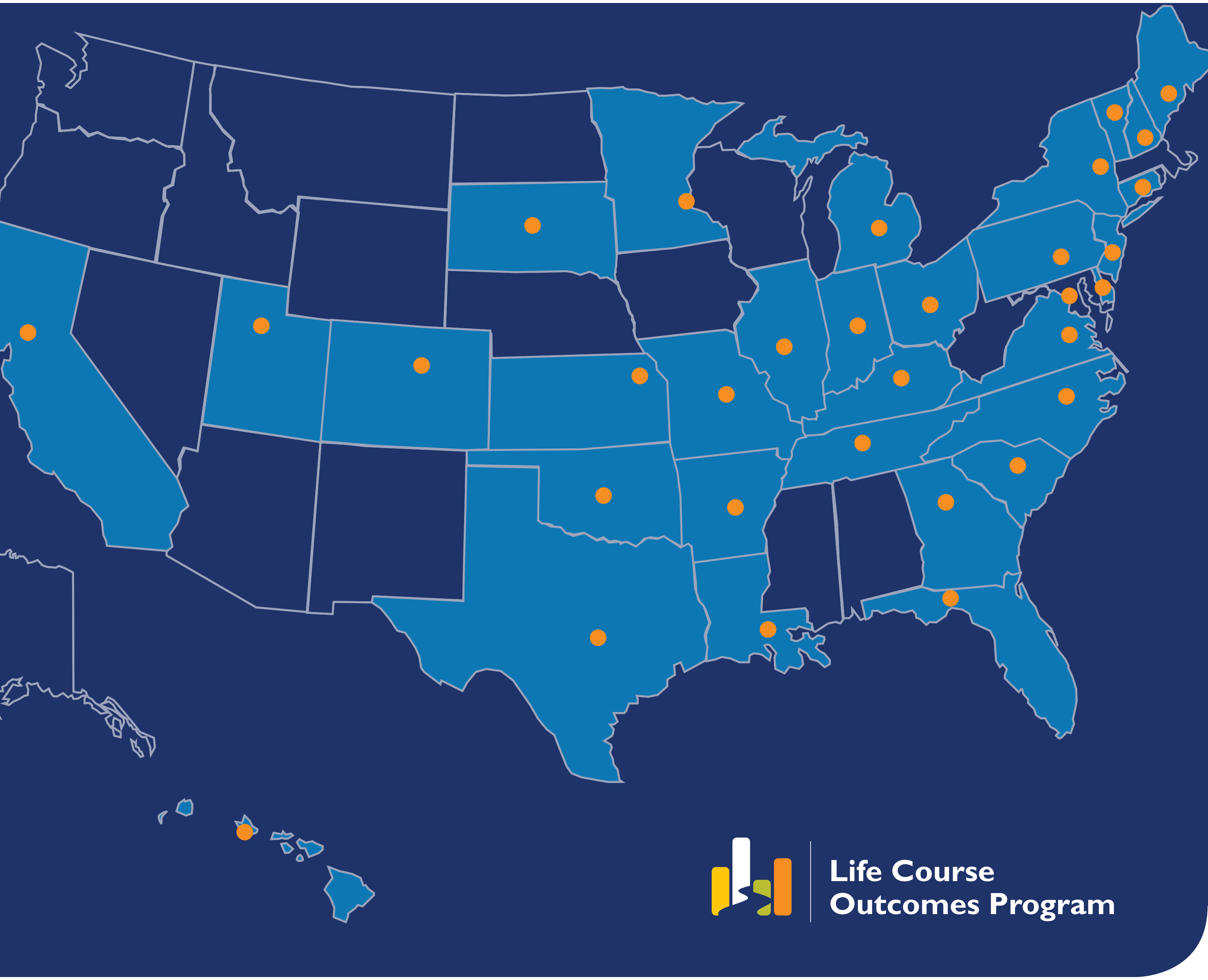
Autism Institute

National Autism Indicators Report

Developmental Disability Services and Outcomes in Adulthood

2017



Life Course
Outcomes Program

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Outcomes Program

A.J. DREXEL AUTISM INSTITUTE, DREXEL UNIVERSITY

Mission

The A.J. Drexel Autism Institute is the first research organization built around a public health science approach to understanding and addressing the challenges of autism spectrum disorder (ASD) across the lifespan.

The Autism Institute's Life Course Outcomes Program (LCO) envisions a future where people on the autism spectrum are valued as contributing members of our communities who have roles to play and dreams to pursue. LCO is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.

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

How to cite this report

Roux, Anne M., Rast, Jessica E., Anderson, Kristy A., and Shattuck, Paul T. *National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood*. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2017.

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National Autism Indicators Report:

Developmental Disability Services and Outcomes in Adulthood

2017

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

Program Director Paul T. Shattuck, PhD

Authors Anne M. Roux, MPH, MA; Jessica E. Rast, MPH; Kristy A. Anderson, MSW; and Paul T. Shattuck, PhD, MSSW

Acknowledgements

Graphic Design: Lisa Cain
Data Visualization: Stephanie Evergreen
Editing: Bushraa Khatib
Student Intern: Vijay Murthy

Report Advisory Panel

Samantha Crane, JD, Director of Public Policy, Autistic Self Advocacy Network
Tonia Ferguson, Esq., Vice President of Public Policy and Advocacy, Autism Society of America
Angela Lello, MPAff, Senior Director for Public Policy, Autism Speaks
Katy Beh Neas, Vice President of Government Relation, Easter Seals Office of Public Affairs
Kelly Nye-Lengerman, PhD, Institute on Community Integration, University of Minnesota
Robert Schmus, MSW, A.J. Drexel Autism Institute Community Advisory Board
Jan Serak, MA, CEO of WI FACETS; Co-Director, WI Parent Training & Information Center
Michael Shor, MSW, The Mental and Social Health Center

A special thank you to Dorothy Hiersteiner and Alexandra Bonardi at the Human Services Research Institute (HSRI) who provided technical assistance regarding the ACS survey and dataset, as well as reviewing and providing feedback on drafts.

Funding Acknowledgement: This report was made possible by a generous private donation to the Life Course Outcomes Research Program. This project was also supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number, UA6MC27364, and title, Health Care Transitions Research Network for Youth and Young Adults with Autism Spectrum Disorders for the grant amount of $900,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Letter from the Program Director

Paul T. Shattuck, PhD

Responding to the urgent need for research across the life course

Pressing facts surround this National Autism Indicators Report:

- About half a million youth on the autism spectrum will age into adulthood over the next decade.
- The majority of a typical life occurs in adulthood.
- Only 1% of all autism research funding supports investigation of topics related to adulthood and aging, according to a 2017 report from the Interagency Autism Coordinating Committee.
- Adulthood is the stage of life we know least about with respect to autism research, policy and practice.

In this Indicators Report, we focus on the needs of a subgroup of adults we know very little about -- those with more severe challenges, who are least able to speak for themselves and who depend on essential public services. This report includes adults who have just left the special education system, and others who are at the end of their working years - enabling us to look at differences in services and outcomes across the life course for people in over half of our nation's states.

State Developmental Disability (DD) agencies combine federal and state dollars to provide services that are supposed to foster community participation and access to vital healthcare and employment services. Major legislative changes affecting employment and residential services have recently occurred and more potential changes are being discussed related to health care and community-based supports. However, we are unaware of any significant investments to assess whether these changes "move the needle" on outcomes. Thus, we need state- and national-level statistics like the ones in this report now more than ever.

We aim to raise awareness about the kinds of services people need, the kinds of services they get and how life is turning out for people across the life course and across different types of community settings. Because this range of topics is so under-studied this report raises more questions than it answers. Our findings highlight the urgent need for additional research to understand how to support quality of life across the life course. A common saying is "What gets measured gets done." Billions are spent each year on services for people on the autism spectrum. If we are not measuring outcomes that matter at a community level then it is hard to set meaningful goals for improvement or to know if things are getting better or worse over time.

Paul T. Shattuck

National Autism Indicators Report:

Developmental Disability Services and Outcomes in Adulthood

2017

Table of Contents

Executive Summary

DD Service Utilization and Outcomes

A note about wording. In this report, we use the term autism *spectrum disorder*, or ASD, because it was the official wording in the survey and because it reflects the wide range of characteristics, impairments, and strengths seen in people with ASD. The National Core Indicators Adult Consumer Survey (ACS) asked whether "**autism spectrum disorder** (e.g., Autism, Asperger Syndrome, Pervasive Developmental Disorder)" was recorded in an individual's state records. The most recent edition of the Diagnostic and Statistical Manual (DSM-5) also uses *autism spectrum disorder* and discontinued the use of *Asperger's Disorder* and *Autistic Disorder*.

Executive Summary

Developmental Disability Services and Outcomes in Adulthood

2017

The charge

Changes in diagnostic definitions and public awareness over the past few decades have contributed to dramatic growth in the number of children identified as having an autism spectrum disorder (ASD). A growing body of research shows how youth with ASD fare as they enter adulthood. As seen in our 2015 and 2016 National Autism Indicators Reports, many adults with ASD have a difficult time achieving employment, continued education, and independent living. This year's report adds to what we know about the characteristics of adults with ASD, the quality of their lives, the opportunities they have to participate in their communities, their ability to exercise choice in their lives, and their access to needed services.

Aims of this report

- Describe key characteristics of adults with ASD who use state DD services and key indicators about their service experiences and outcomes.
- Understand how service use and outcomes differ across subgroups of people with ASD.
- Compare experiences and outcomes of adults with ASD versus adults with other types of developmental disabilities.

The importance of indicators

Indicators are like gauges. They help us understand the status or condition of something. Indicators research helps us understand the scope and magnitude of problems, resources needed to fix problems, and whether we are making progress toward solving them. This report is an almanac of currently available national indicators detailing the experiences of adults with ASD who use Developmental Disability (DD) services. These indicators come from a survey of people from 31 states who were receiving services from their state's DD agency in 2014-15.

Data for this report

Here are some things you should know about the data before reading this report. More background about the data is available in the **Methods** chapter.

- Data in this report came from the Adult Consumer Survey (ACS), which is part of the National Core Indicators (NCI). NCI is a collaborative effort of the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute.
- We did not conduct this survey ourselves. We are reporting results based on our independent analyses of ACS survey data.
- Our findings describe the 3,520 working-age adults (18-64 years) with ASD, who were no longer in high school, and were using DD services when they participated in the 2014-2015 ACS survey between July 1, 2014, and June 30, 2015.
- In each state (or smaller region), the survey sampled a subset of adults from people who received at least one service (in addition to case management) from their state DD agency.
- ACS information was collected through review of state documents, interviews with people who received DD services, and/or interviews with someone who knew the person well if needed.
- The ACS is not a nationally representative survey of all adults with ASD. Findings cannot be used to make inferences to the general population of individuals on the autism spectrum.

Who is represented in this report?

The people with ASD in this report do not represent all adults with ASD. This report's findings only represent people who were able to access DD services because they had a significant level of functional impairment, were eligible for DD services in their state, and they (or their caregivers) were able to navigate the steps to get services. This report includes people with ASD who used DD services in 31 states, Washington DC, and the Mid-East Ohio Regional Council (MEORC).

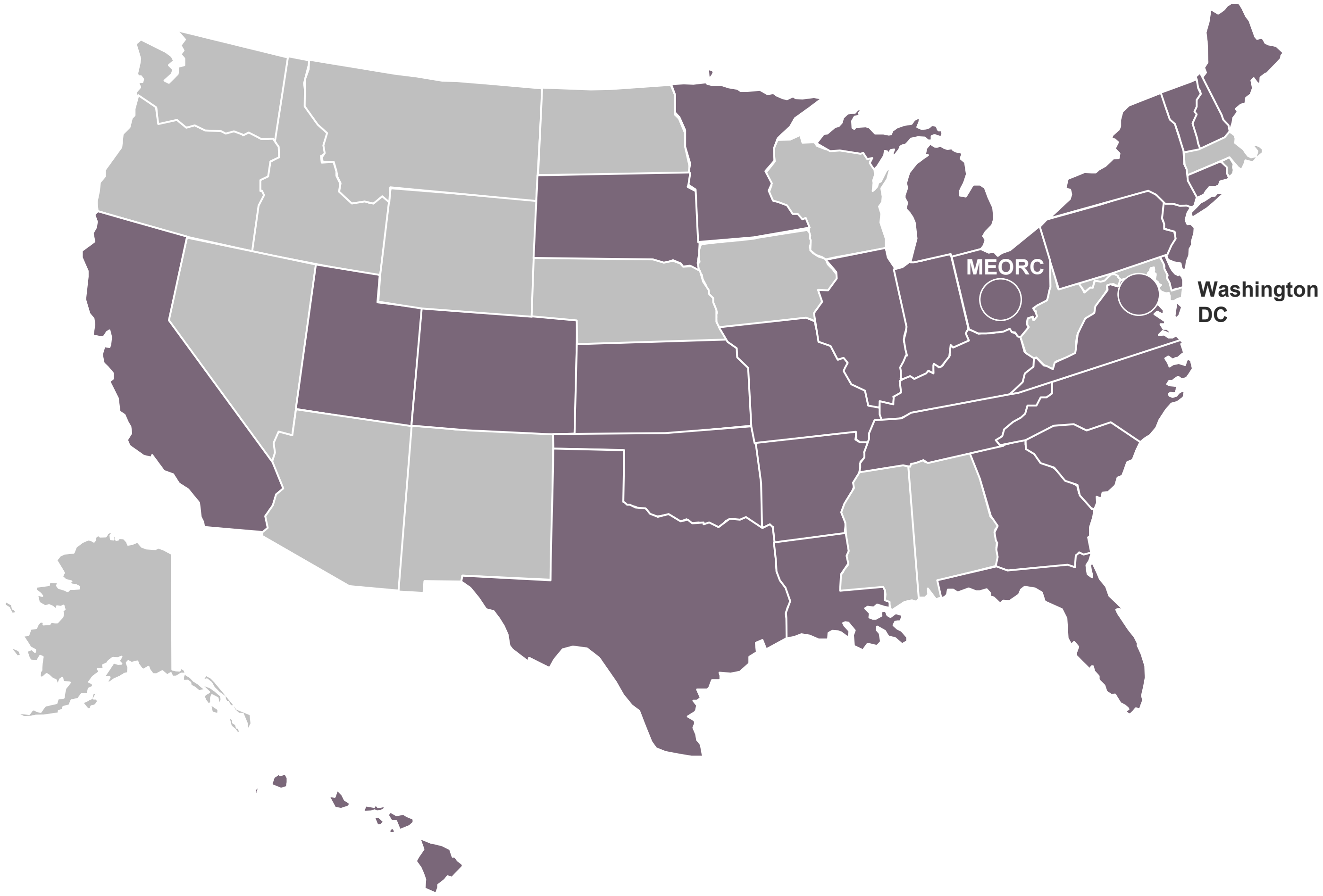
What is a developmental disability (DD)?

According to federal law, developmental disabilities are severe, chronic disabilities attributable to mental and/or physical impairment which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services. (Source: Developmental Disabilities Assistance and Bill of Rights Act of 2000). People with autism spectrum disorder (ASD) may qualify as having a DD and might receive services through a **DD agency**.

What are DD services?

DD services are services individuals with **intellectual or developmental disabilities (I/DD)** might receive to maximize their well-being and participation in the community. These services are administered through DD agencies which are local agencies that provide services for people with DDs. Read more about DD services in the **Background** chapter.

Thirty one states, the District of Columbia, and the Mid-East Ohio Regional Council (MEORC) **participated in the ACS 2014-15**.



Key Findings

Developmental Disability Services and Outcomes in Adulthood

2017

We used data from the National Core Indicators - Adult Consumer Survey (ACS) to study the services experiences and outcomes of adults with autism spectrum disorder (ASD) who used state Developmental Disability (DD) services during the 2014/2015 survey cycle. We summarize key issues and findings. **Detailed information and citations to related research can be found in the chapters that follow in this report**.

Characteristics

A total of 3,520 adults with ASD who were ages 18-64 and not in public school participated in the 2014-2015 ACS survey. If an adult with ASD did not want to respond to the survey or was unable to respond, a proxy who knew them well could respond to a portion of the survey on their behalf. We note that the group of people with ASD who received DD services were more likely to also have an intellectual disability (ID) compared to the overall population of people with autism. Therefore, the findings in this report represent people with a greater level of challenges and impairments than all individuals with ASD.

Our key findings:

- The average age of adults with ASD who participated in the survey was 34 years - eight years younger than DD service users who did not have ASD.
- **Half (51%) of middle-aged adults (45-64 years) with ASD had severe or profound intellectual disability (ID), compared to only 16% of young adults (18-24 years) with ASD.**
- In some states all adults with ASD also had ID, while in other states approximately half had ID - likely reflecting differences in state policy about who qualifies for DD services.
- Younger adults with ASD were more likely to use spoken language as their primary means of expression than middle-aged adults with ASD.

By the numbers: Autism spectrum disorder in the Adult Consumer Survey

Survey participants with ASD (n=4,187)

Who were ages 18-64 (n=4,089)

Who had valid answers to survey questions (n=4,060)

Who were no longer in public school (n=3,520)

ACS participants used services funded by a state DD agency and completed a survey during fiscal year 2014-2015.

Valid answers meant that the respondent answered at least one question and, if an adult with ASD answered the questions, the surveyor felt the person understood the questions and gave consistent answers. Read more about this in the **Methods appendix**.

Adapted from infographic by Nye-Lengerman, K.M. (2015). Doctoral dissertation.

Use of DD Services

We already know that youth with ASD lose access to the services that they may have had through special education once they leave high school. Services and programs available through state and local DD agencies vary widely. Compared to the overall ASD population, those who qualify for state DD services as adults tend to have higher levels of cognitive and functional impairments. They may also have different needs than their peers with other types of DDs.

Our key findings:

- Of the services that the ACS asked about, the most common services adults with ASD received were health care, dental care, and transportation. About half of adults with ASD received information about benefits or insurance (54%), and services for social relationships or meeting people (49%).
- **Almost half (49%) of adults with ASD used six or more services funded by a state DD agency.** Those with ASD used the same types of DD services, and at the same rate, as other DD service users who did not have ASD.
- Half (51%) of adults with ASD who lived with parents or relatives received respite care services. Younger participants with ASD (18-24 years) were more likely to receive respite care than middle-aged individuals (45-64 years).
- **Overall, 25% of ACS participants with ASD reported that they did not receive all of the services they needed.**

Health and Health Care

There is a growing body of knowledge about the health of adults with ASD. Recent studies have found high rates of many chronic health conditions among adults with ASD including epilepsy, high cholesterol, hypertension, and others. Medication rates and use of an emergency department are also higher compared to adults without ASD. There is a known need for physician education and strategies for assisting adults with ASD in their health care encounters.

Our key findings:

- **Half (51%) of adults with ASD had at least one health condition in addition to ASD** from a list of 11 conditions.
- More than half (58%) of adults with ASD had a Body Mass Index that placed them in the overweight or obese category. Those with ASD who had severe or profound ID or who used nonverbal communication were less likely to engage in moderate physical activity.
- Most had annual health and dental check-ups, but vision checks, cancer screenings, and flu vaccination were less common for those with ASD than among other DD service users.

Key Findings (continued)

Mental Health and Health Care

We already know that rates of co-occurring mental health conditions are higher in people with ASD compared to the general population, particularly in regard to anxiety, depression, and schizophrenia. The challenges posed by these additional conditions can make it more difficult to work, live independently, and participate in the community. Medications are often used to address co-occurring mental health conditions.

Our key findings:

- **Over half (54%) of adults with ASD had at least one mental health condition (including anxiety, mood disorder, psychotic disorder, and/or other mental illness) in addition to ASD.**
- Almost half (46%) of adults with ASD had behavioral challenges including disruptive, self-injurious, and/or destructive behaviors.
- **Six in 10 adults with ASD (64%) took medication for mood disorders, anxiety and/or psychotic disorder, and/or behavioral challenges.** This rate was much higher than among other DD service users.
- 44% of adults with ASD took medications for behavioral challenges - almost twice the rate of other DD service users.

Employment and Other Day Activities

Finding and keeping a job is hard for many people with ASD. Navigating the social dynamics of the workplace, coping with sensory overload, organizing and completing tasks, and communicating with coworkers may be challenging. State DD services are a key source of public funding for the long-term supports and services that people with ASD may need to participate in work and other types of day activities.

Our key findings:

- **Paid, community-based employment was the least common outcome for adults with autism spectrum disorder (ASD). Only 14% held a job for pay in the community.** About one-fourth of adults with ASD had community employment as a goal in their service plan.
- Over half (54%) participated in an unpaid activity in a facility (where most other workers had disabilities).
- One-fourth (27%) had no work or day activities, in either community-based or facility-based settings, in the two weeks prior to the ACS.

Key Findings (continued)

Living Arrangements

Where people with intellectual or developmental disabilities (I/DD) tend to live has changed dramatically over the last 50 years. More people with I/DD now live in the community in a home or a group home. They may receive assistance from direct support staff in their home, but few live in large institutional settings that are directly operated by states.

Our key findings:

- **Almost half (49%) of adults with ASD lived in the home of a parent or relative.** Many of those who lived with their families had been there for more than 5 years.
- Nearly four in ten adults with ASD who lived with parents or relatives received no paid in-home supports. Of these, 37% indicated they needed some type of supports or services.
- One-fourth (27%) lived in group homes with up to 15 people who also had disabilities. It was uncommon for adults with ASD to live in institutions.

Social and Community Participation

We know that adults with ASD report a strong desire for acceptance within their communities at large, paired with opportunities to connect with other people who share their common interests. There is no single level or type of social and community inclusion that is the right fit for all adults with ASD. Federal laws and Supreme Court decisions affirm the belief that people should be able to participate in their communities and have meaningful relationships and friendships to the extent that they choose and in the ways that they prefer.

Our key findings:

- Most adults with ASD (over 80%) got out at least monthly to shop, eat out, run errands, or for entertainment. Almost half had been on vacation during the last year.
- Most self-respondents with ASD (84%) said they always had a way to get to where they wanted to go - usually getting a ride from family or friends.
- **Less than half (43%) of adults chose their daily schedule on their own in regard to when they woke up, ate, or went to sleep; 40% could choose how to spend their money on their own.**
- Three-fourths of self-respondents (72%) said they had a friend who was not a family member or staff. However, 41% also reported feeling lonely sometimes.

Independence and Rights

This final chapter explores the rights of adults with ASD who participated in the ACS and their experiences with independence.

Our key findings:

- **Over half (53%) of adults in the ACS with ASD had a limited or full legal (court-appointed) guardian.**
- Almost three quarters (74%) of adults with ASD could be alone with guests or visitors in their home.

Read our thoughts about these findings and our research recommendations in the **Looking Ahead** chapter (page 75).

At a glance — Outcomes of adults with ASD (18-64 years) who received DD services

DD Service Access

Did not receive all needed services

25%

Reportedly did not receive all the services they felt they needed.

Received respite services

51%

Received respite care if they lived in the home of a parent or relative.

Average number of services received

6

Was the average number of services funded by state or county agencies from a list of 13.

Health and Mental Health

Had co-occurring health conditions

51%

Had at least one additional health condition from a list of 11 common conditions.

Had co-occurring mental health conditions

54%

Had anxiety, mood disorder, psychotic disorder, or "other mental illness/psychiatric diagnosis" in addition to ASD.

Took medication to treat mental health conditions

64%

Took medication for either mood disorders, anxiety, and/or psychotic disorder, and/or behavioral challenges.

Employment and Other Day Activities

Had a paid job in the community

14%

Worked in the community for pay in settings that also employed people without disabilities.

Were in unpaid, activities in facilities

42%

Participated in unpaid activities in facilities with others with disabilities (sometimes called day programs).

Had no work or activity

27%

Had no work or activities in the previous two weeks in community or facility-based settings.

Living Arrangements

Lived with a parent or family

49%

Lived in the home of parents or other relatives. Of these, **81%** had been there over 5 years.

Lived in a group home

27%

Lived in a group home consisting of 1 to 15 people with disabilities. **31%** of these were in 1-3 person homes.

No funding for services in a parent or relative's home

38%

Of those who lived with parents or relatives received no paid in-home supports.

Social and Community Participation

Got out in the community

80%

Shopped, dined out, or did errands in the community at least once a month.

Had a friend

72%

Of the subset of adults who could self-report answers to questions said they had a friend who was not a family member or a staff person.

Chose their schedule for themselves

43%

Made their own choices about when to get up, when to eat, and when to go to sleep. **40%** chose what to do with their spending money.

Independence and Rights

Had a guardian (limited or full)

53%

Had a court-appointed guardian on a limited or full basis.

Had some social independence

74%

Could be alone with friends or visitors in their home.

Read more about each of these indicators in the chapters that follow.

Background

The issues

Growing service needs

Young adults with autism spectrum disorder (ASD) often want the same things as their peers without ASD after high school - to live away from their parent's home, earn a living, and have opportunities for additional education. In our 2015 National Autism Indicators Report, we told you about the 50,000 youth with ASD who exit high school each year in the U.S.[1] During high school, many received special education services with a goal of finding employment, continuing their education, and/or living independently during adulthood. But over one-third of transition-age youth with ASD did not get a job or continue their education between high school and their early twenties.

We also reported on the "services cliff" that many youth experience after high school, when they lose access to the services they had through special education. In general, a far lower percentage of adults with ASD receive services compared to those who received services through special education during high school.[1-3] One in four of those who had no job or continued schooling after high school also received no services during that same period - services that might have helped them connect to jobs or schooling.[1] Our 2015 Indicators Report also noted that outcomes were generally worse for young adults with more severe challenges and that our knowledge base virtually ends at the age of 25. This new report was designed to help fill those voids.

Importance of holistic, lifespan services

When we think about services and outcomes, it is important to consider them holistically, as the various parts of our lives are all interconnected. Education impacts employment... Employment impacts living arrangements… Living arrangements impact social participation… and so on. Very few studies have holistically explored related domains of life - like where people live, their level of satisfaction and well-being, and opportunities for choice in the lives of adults with ASD.[4]

Our report examines indicators across many of the domains identified as priorities in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), which specifies that "...the goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to—

- make informed choices and decisions about their lives;
- live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;
- pursue meaningful and productive lives;
- contribute to their families, communities, and States, and the Nation;
- have interdependent friendships and relationships with other persons;
- live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and
- achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual."[5]

What are the main sources of services and funding to support adults with ASD?

Even though there is no single source of regulation and oversight of developmental disabilities (DD) services at the federal level, there are several key agencies that provide assistance to adults with DDs after they leave high school

- We reported on the **Vocational Rehabilitation (VR)** service system in our 2016 National Autism Indicators Report. VR provides short-term supports to help people find and keep a job.[6]
- State **Developmental Disability (DD)** agencies are a source of short and long-term services and service coordination to support employment, community living, relationships (socialization), transportation, and other needs.[7] Types of services available through DD agencies vary across states. DD services are often funded by Medicaid. (More on this below.)
- The **Social Security Administration (SSA)** provides cash supports to assist some adults with DDs who have financial needs through the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs. SSA also funds incentives to help people with disabilities work without risking the loss of their medical and financial public benefits.

These agencies operate independently - each with their own eligibility criteria and services. This results in a fragmented and incomplete system of supports for individuals with intellectual or developmental disabilities (I/DD) and their families. Individuals and their families often have to apply to attempt applying to many different places to find the help they need, and may encounter long waiting lists for services even after they qualify.

This report focuses on how adults with ASD use DD services. Increasing numbers of individuals identified with ASD are using state DD services,[8] but we know precious little about their experiences.

There is no official tally of how many adults with ASD get services from state DD agencies. Of the estimated 1.4 million individuals known to or served by state DD agencies in 2014, roughly 1.2 million were receiving at least one long-term support service from a state DD agency, and 840,000 were age 22 or older.[9] Using these figures and data from the National Core Indicators - Adult Consumer Survey (ACS), **we estimated that 111,400 working-aged adults (18 to 64 years) with ASD nationwide received services and/or funding through state DD agencies in 2014**. This estimated number likely does not come close to the overall number of people who need services. People with ASD who do not also have an intellectual disability (ID) may not qualify for DD services in some states. Other states have long wait lists which preclude access to DD services. Nearly 317,000 people with I/DD were on state waiting lists for Medicaid Home and Community Based Services (HCBS) waivers alone in 2014,[10] and Medicaid waivers are a primary funder of DD services.

Developmental Disability Services at a glance

What are DD services?

State DD services aim to improve well-being and participation in the community. Services might be provided directly through local governmental DD offices or by contracted nonprofit organizations, private businesses, and others.

Most state DD agencies offer employment supports, respite, transportation, and residential supports. The names of the services may vary depending on where one lives, and services with similar names may look very different across states. For example, in some states family support services might consist of small cash supports for families to pay for respite providers, while in others it might include funding for round-the-clock, in-home care.[9] For more information on DD services, see the **Use and Coordination of DD Services** chapter.

It may be more accurate to think of 'DD services' as 'services funded through state DD agencies', for several reasons. Many of the services people get are not designed specifically for people with DDs. For instance, DD agencies fund services (e.g., vocational, mental health, transportation) which can also be provided to people who have severe mental illness, substance abuse, or other conditions that are not DDs. Services funded through DD agencies are often also provided by other non-DD agencies. Many DD services are funded with federal/state DD dollars but are provided by local nonprofit agencies. Finally, there are many streams of funding that merge into DD services (e.g., Medicaid, state general revenue, local funding). Despite the varied streams of funding, services are still collectively referred to as DD services.

It is critical to understand that states are given flexibility to decide what services they provide, how the services are defined, who is eligible for services, how data about these services are collected and reported, and how services are funded. Because each state administers their DD services differently, the system of state DD services is varied and complex.[9] These services, and the ways in which they are provided, have changed dramatically over time - moving toward more community-based and consumer-directed approaches with attention to person-centered planning and fostering self-determination.

DD services look different in every state.

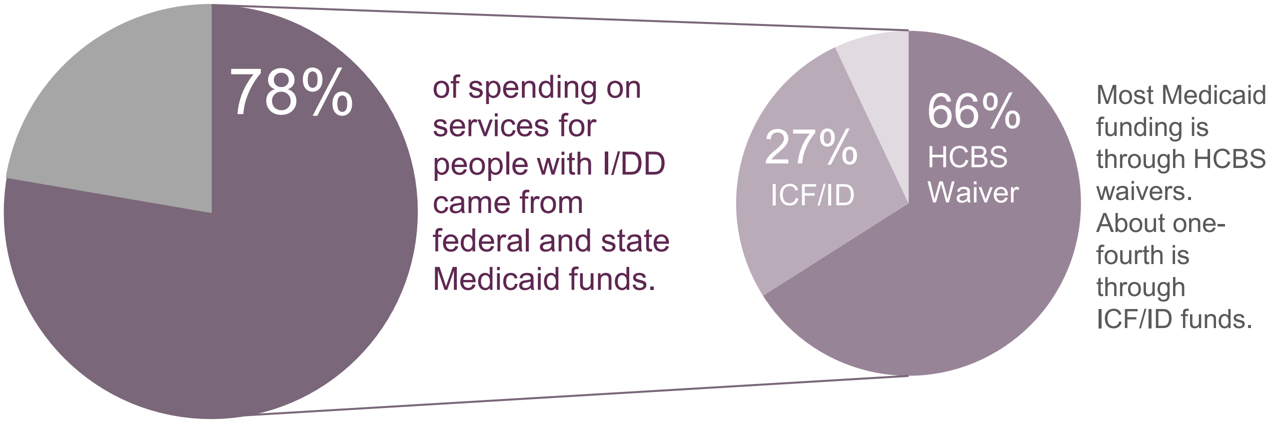
1. State DD agencies are embedded in various divisions or departments across states. Most services are administered through local government or nonprofit offices.
2. Eligibility criteria differs across states. Some states limit their DD services to people with intellectual disability (ID), and others include people with related conditions like autism - even if they don't have an ID.
3. Each state decides what services are available under the DD program. The names of the services may vary depending on where one lives, and services with similar names may look very different across states.
4. Funding for state DD programs is a complicated mixture of state and federal sources and looks different in each state. The two main sources of DD funds for states are Medicaid HCBS funds and state general revenue.(7)
5. States vary in the proportion of funding they direct toward community-based versus facility-based services.
6. There is no single source of regulation and oversight of DD services at the federal level. Guidance for state DD systems comes from DD State Plans, Medicaid HCBS waiver regulations, legislation and Department of Justice rulings, and various advisory bodies such as the DD state councils.

How are DD services funded?

State DD agencies combine federal and state dollars to fund services for people with I/DD. However, in many states, Medicaid funds the majority of services provided to children and adults with DD. In FY 2013, 78% of spending on services for children and adults with I/DD came from federal and state Medicaid funds for Long Term Services and Supports (LTSS) - ranging from 55% to 91% across states.[11] An additional 12% came from other state funds and 10% from other federal funds. The bulk (66%) of these Medicaid funds came from Home and Community Based Services (HCBS) waivers, 27% from ICF/ID funding (read more below), and 7% from other Medicaid related funds. In other words, some states fund almost all of their DD services through Medicaid waivers with the exception of family-directed services like respite and family supports. In some states, the DD agency is actually part of the state Medicaid agency.[12]

- **Medicaid Home and Community Based Services (HCBS) waivers** are used to fund LTSS for people with I/DD who live and function in community-based settings. In 2014, 53% of the people with IDD known to state DD agencies received funding from an HCBS or other Medicaid Waiver (including demonstration projects and managed care waivers).[13] States vary in which types of HCBS waivers they utilize and eligibility criteria to qualify for this funding. A few states have autism-specific waivers in place for adults.
- **Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID)** funding is a Medicaid program that primarily allows provision of services to people with I/DD in state-run residential facilities. This is generally the most restrictive type of residential care and is reserved for those who need active treatment, which means the individual requires constant attention and has limited independence. In contrast to HCBS programs, ICF/ID programs have no waiting list and states are not allowed to restrict enrollment. ICF/ID funding preceded HCBS waivers, and the use of this type of funding has been decreasing as the use of HCBS waivers has increased. In 2014, 6% of people with IDD known to state DD agencies had ICF/ID funding.[13] The cost of provision of services under ICF/ID is much higher than through HCBS waivers. The average annual per person expenditures for ICF/ID was 3.1 times higher ($133,582 average per recipient) than for HCBS and other Medicaid waiver recipients ($43,154 average per recipient).[13]

Most spending for DD services in 2013 was funded through federal and state Medicaid dollars. The majority were funded through HCBS waivers.



Adapted from Source: Broddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

Historical context

The provision of state DD services has been influenced by a variety of federal legislation and judicial rulings, including:

- The **Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (PL 106-402), commonly referred to as "the DD Act**", authorizes funds to assure that individuals with developmental disabilities and their families "have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."[5] The DD Act set up mechanisms for guiding systems change efforts, protecting and advocating for individuals' rights, conducting research and training, providing technical assistance, and funding national data collection initiatives about DD services.

- In 1999, the U.S. Supreme Court's "**Olmstead Decision**" ruled on a portion of the **Americans with Disabilities Act (ADA) of 1990** and clarified that public entities must provide community-based services to persons with disabilities when the services are appropriate, the persons involved do not oppose community-based treatment, and when community-based services can be reasonably accommodated.[14] Some states have an Olmstead Plan to help them meet these standards of integration. The Department of Justice (DOJ) enforces the Olmstead Decision, especially as it applies to housing, home and community based services, and employment. Testimony by a DOJ official in 2012 summarized the continued importance of Olmstead by saying that people with DDs should have:
    - Opportunities to live life like people without disabilities;
    - Opportunities for true integration, independence, recovery, choice and self-determination in all aspects of life including where they live, spend their days, work, or participate in their community; and
    - Quality services that meet their individual needs.[15]

Considerations about DD services data in this report

What is the purpose of the Adult Consumer Survey (ACS)?

States use the ACS to track the quality of their public services for adults with I/DD. Key indicators can be used to compare performance of DD service systems across states. Topics that fall outside of the DD service system - like postsecondary education - are not included. We were unable to examine how services and outcomes were related to household income as this was not measured in the survey. Read more about the survey in the **Methods** chapter.

How was the ACS data collected?

The information from the ACS is collected in three parts:

- **Background section** - Information gathered from state records by a survey administrator who did not know the participant. Example topics include health and mental history, where the person lives, recent employment history, and services received.
- **Section I** - A series of subjective questions about satisfaction levels or personal experiences that can only be completed by the adult service user in a face-to-face interview. Example topics include satisfaction with one's employment and living arrangement, and safety.
- **Section II** - A combination of objective and subjective questions completed by the adult service user if possible, or a **proxy** respondent if the individual was unable to participate on their own. Example topics include access to needed services, how the person spends their leisure time, and opportunities to make choices in one's life.

What is a proxy?

Some individuals were unable to understand and answer survey questions independently. In this case, a proxy respondent was allowed to answer questions for the individual (except for the questions in Section I about satisfaction and personal experiences). A **proxy** is a person who knows the person well, such as a family member, friend, staff person, guardian or advocate. Service coordinators or case managers were not allowed to serve as a proxy. Proxies answered questions face-to-face or by the phone (as a last resort).

About self-respondents

Half (50%) of the individuals with ASD self-reported information about their personal experiences. We refer to this group as self-respondents throughout this report in sections marked **In Their Own Voices.** We found that, on average, people who self-reported survey answers had less intellectual impairment and were more likely to use spoken language than those who were not able to report answers for themselves. However, some adults with severe and profound intellectual disability did self-report responses. Note: We did not analyze self-reported information if the interviewer indicated that a person was unreliable in understanding or answering survey questions.

People with I/DD want to be heard.

While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

In general, while self-reported data offers highly valuable insights about DD service users who have ASD, we caution that: 1) self-reporters represent only a subset of people on the autism spectrum who used DD services, and who were able to communicate for themselves, and 2) caution should be used when interpreting data that is reportedly from persons with severe and profound ID. For more information on self-respondents, see the **Characteristics** chapter.

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Characteristics

Adults with ASD who use state Developmental Disability services.

Our key findings

- The average age of adults with autism spectrum disorder (ASD) who participated in the survey was 34 years - eight years younger than DD service users who did not have ASD.
- **Half (51%) of middle-aged adults (45-64 years) with ASD had severe or profound intellectual disability (ID), compared to only 16% of young adults (18-24 years) with ASD**.
- In some states all adults with ASD also had ID, while in other states approximately half had ID - likely reflecting differences in state policy about who qualifies for DD services.
- Younger adults with ASD were more likely to use spoken language as their primary means of expression than middle-aged adults with ASD.

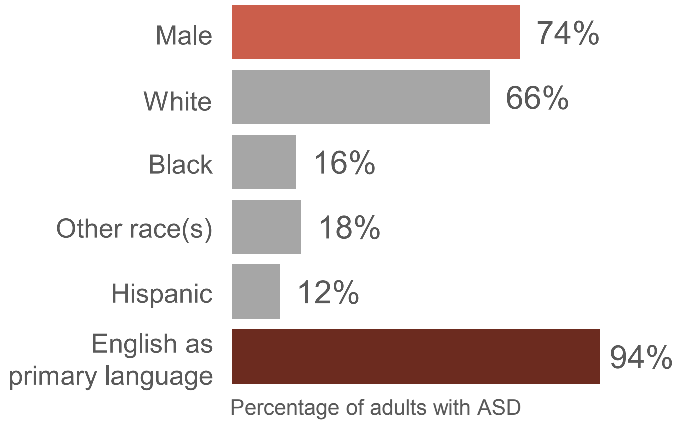
A total of 3,520 adults with ASD who were ages 18-64 and not in public school participated in the 2014-2015 Adult Consumer Survey (ACS). If an adult with ASD did not want to respond to the survey or was unable to respond, a proxy who knew them well could respond to a portion of the survey on their behalf. For more information on who is included in these analyses, see the **Methods** appendix.

Demographic characteristics

Throughout this report, we frequently refer to **younger adults (18-24 years) versus middle-aged adults (45-64 years)**, as there tend to be differences in their outcomes.

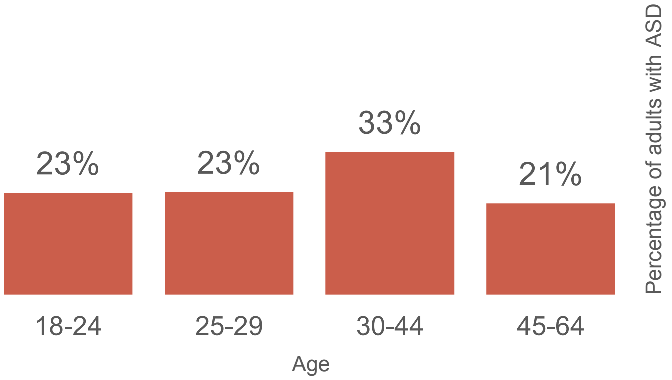
Adults with ASD in this report averaged 34 years of age at the time of the ACS 2014-2015 survey. While more people were between 30-44 years, participant ages were fairly evenly distributed across the working years (18-64 years). Most were male, white, and non-Hispanic. In comparison, the composition of the U.S. population in 2015 was female (51%), White (77%), Black (13%), Hispanic (18%), who used English as a primary language at home (79%).[1] Participants with ASD in the ACS were more likely to use English as a primary language.

Most ACS participants with ASD were male, white, and primarily used English.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD used DD services across their working years.



Source: NCI Adult Consumer Survey 2014-15

Impairment characteristics

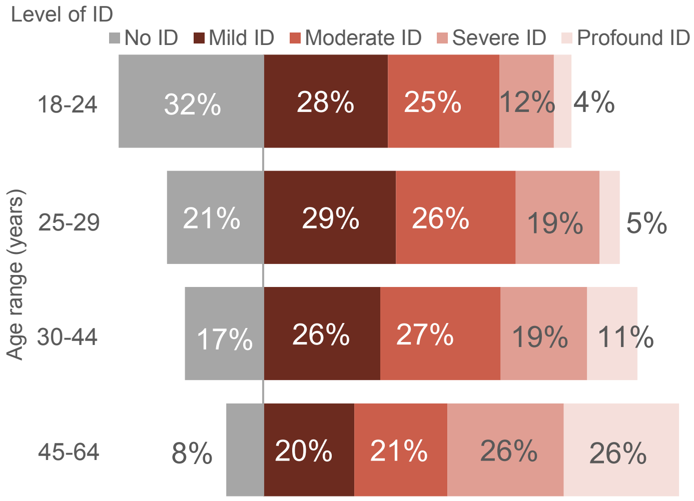
Intellectual Disability (ID). The proportion of youth with ASD who also have ID has generally decreased since 2002, and is currently estimated at around 30% of children with ASD.[2] The group of people with ASD who receive DD services, however, tend to have a much higher rate of ID. The findings in this report represent people with a greater level of functional impairments than the overall population of individuals with ASD.

ACS surveyors were asked "Does this person have an intellectual disability? If yes, what level?" Based on state records, about 80% of ACS participants with ASD reportedly also had ID, which refers to having significant deficits in intellectual and adaptive functioning that began in childhood. Impairments in intellectual functioning are generally defined using a person's IQ score and classified as mild (IQ 50-70), moderate (IQ 40-55) severe (IQ 25-40) or profound (IQ less than 25). Adaptive functioning refers to things such as how a person manages activities of daily living like dressing, cooking, and getting around.[3]

Intellectual Disability rates vary by age. Over half of those with ASD under the age of 30 had no or mild ID, compared to 28% of people over the age of 45. Over half of middle-aged adults (45-64 years) had severe or profound ID, compared to 16% in the youngest age group (18-24 years).

Later, we report that there are significant differences in the rates of many outcomes when broken out by age groups. It is important to remember that the **rate of ID varies by age**. Differences in outcomes across age groups might simply reflect the fact that older individuals in this survey were more likely to have ID.

Older adults with ASD were more likely to have severe or profound ID than younger adults with ASD.

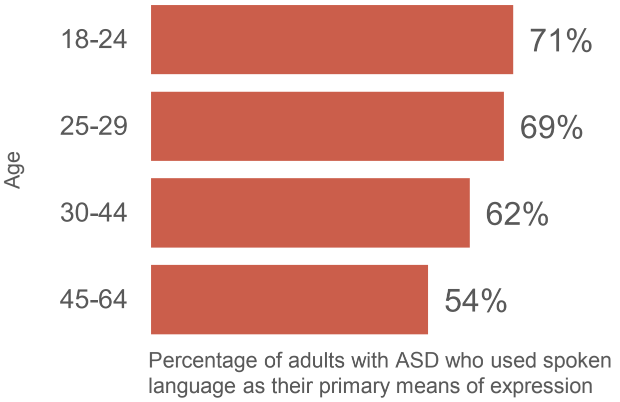


Source: NCI Adult Consumer Survey 2014-15

Communication abilities. ACS surveyors used state records to answer, "What is this person's primary means of expression?" We organized the answers into spoken versus nonverbal communication (gestures/body language, sign language or finger spelling, communication aid/device, or other). Spoken language was the primary means of expression for 64% of survey participants with ASD. Younger adults reported spoken language as their primary means of expression more often than middle-aged adults.

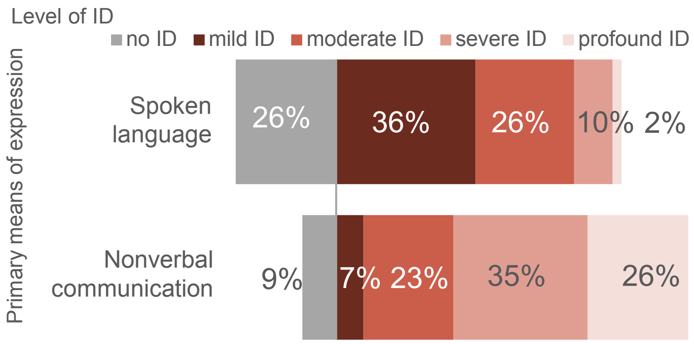
Use of nonverbal communication was more common in people with moderate to profound ID. It is important to remember that communication abilities and ID are highly correlated. People who cannot use spoken language are more likely to have higher levels of ID; although this is not always the case. Some people cannot speak but do have average to above average intelligence and may rely on electronic communication devices for communication.

Younger adults with ASD were more likely to use spoken language as their primary means of expression.



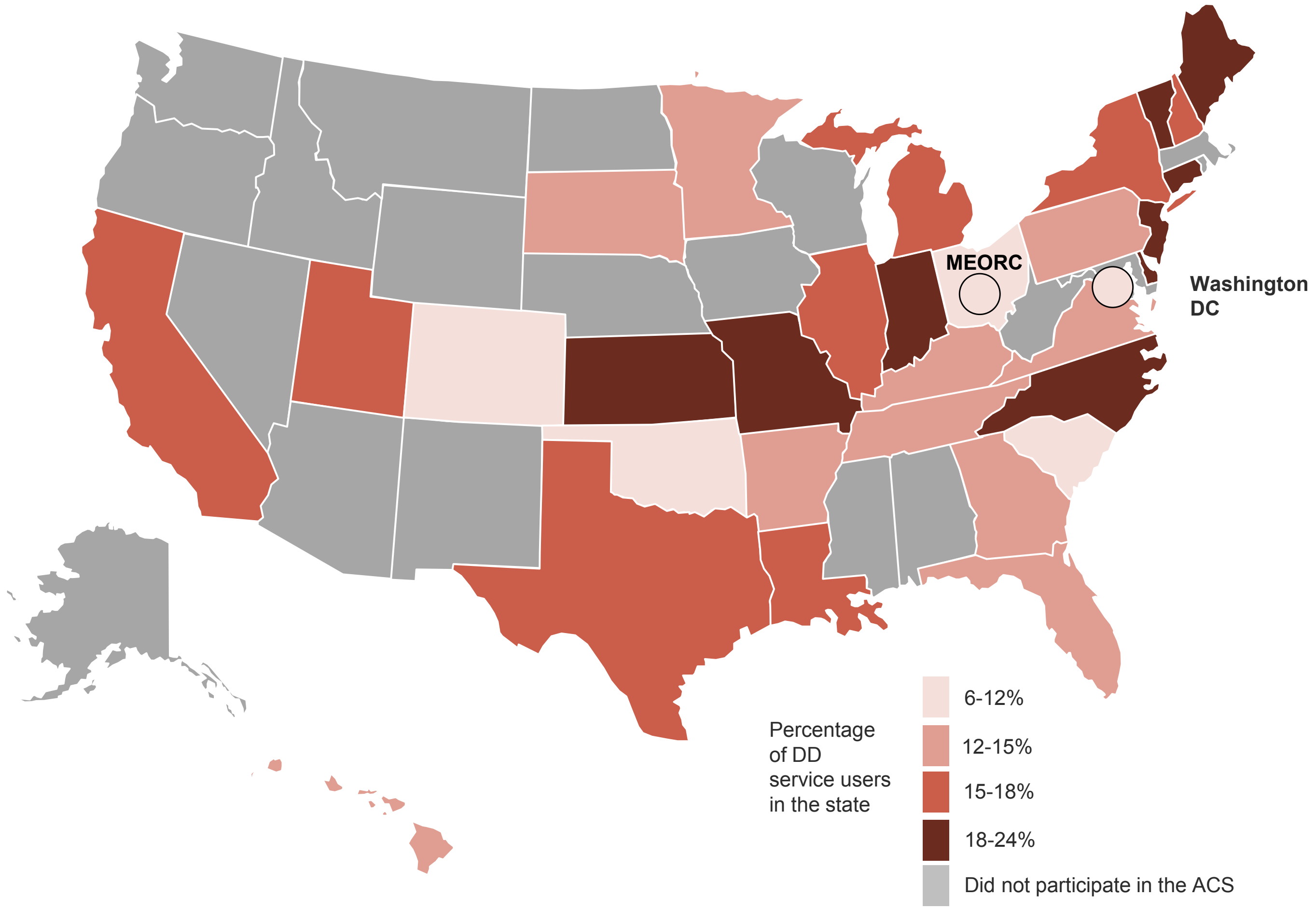
Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who primarily used spoken language were less likely to have an ID than adults who primarily used nonverbal expression.



Source: NCI Adult Consumer Survey 2014-15

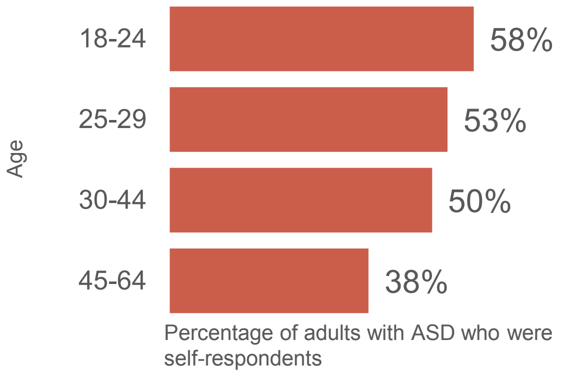
What percentage of DD service users in states had ASD?



Characteristics of self-respondents

Half of participants with ASD answered some or all questions in the ACS for themselves. More young adults participated independently compared to middle-aged adults. This may have been related to their abilities, as middle-aged participants were more likely to have ID.

Younger adults with ASD were more likely to self-respond to questions than middle-aged adults.



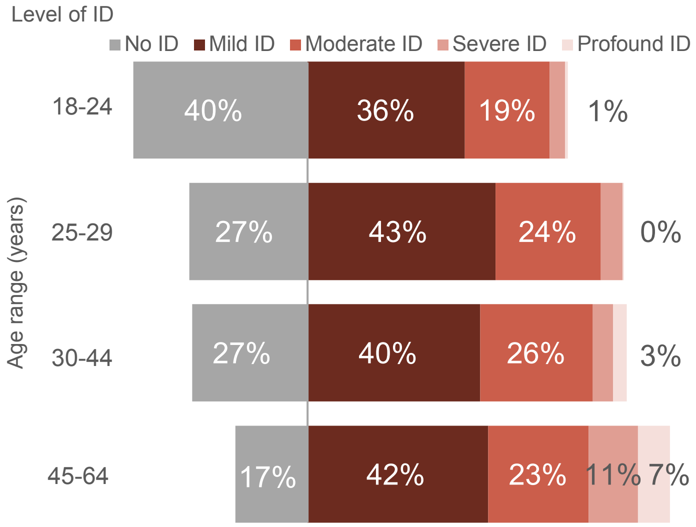
Source: NCI Adult Consumer Survey 2014-15

There were no differences in sex, race or and ethnicity for those who self-responded to survey questions compared to those who were unable to participate on their own. Self-respondents more often had no ID, or mild to moderate ID, compared to those who were unable to participate in the survey independently. The vast majority (90%) of self-respondents used spoken language as their primary means of communication, compared to 39% of those who needed a proxy.

Characteristics of other DD service users

Throughout this report, we compare the experiences of adults with ASD with other adults who used DD services. The average DD service user (who did not have ASD) was 42 years old - eight years older than the average DD service user with ASD. Most adults with ASD were male, compared to half (54%) of other adult DD service users. Racial and ethnic distribution was similar between the two groups, as was the use of English as a primary language. DD service users who did not have ASD were more likely to use spoken language as their primary means of expression (76%), compared to 64% of adults with ASD in the ACS.

Self-respondents with ASD were unlikely to have severe or profound ID.

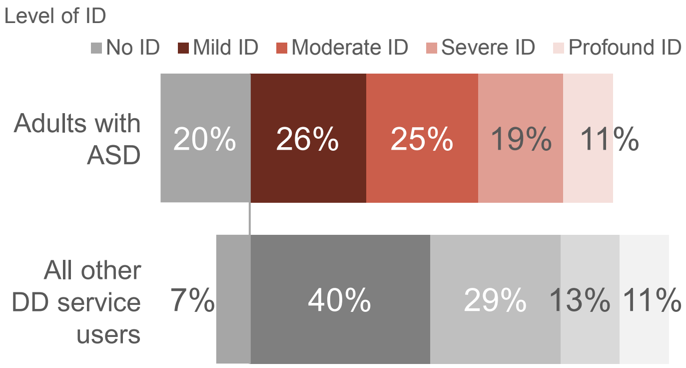


Source: NCI Adult Consumer Survey 2014-15

Some states had a higher percentage of adults with ASD with intellectual disability

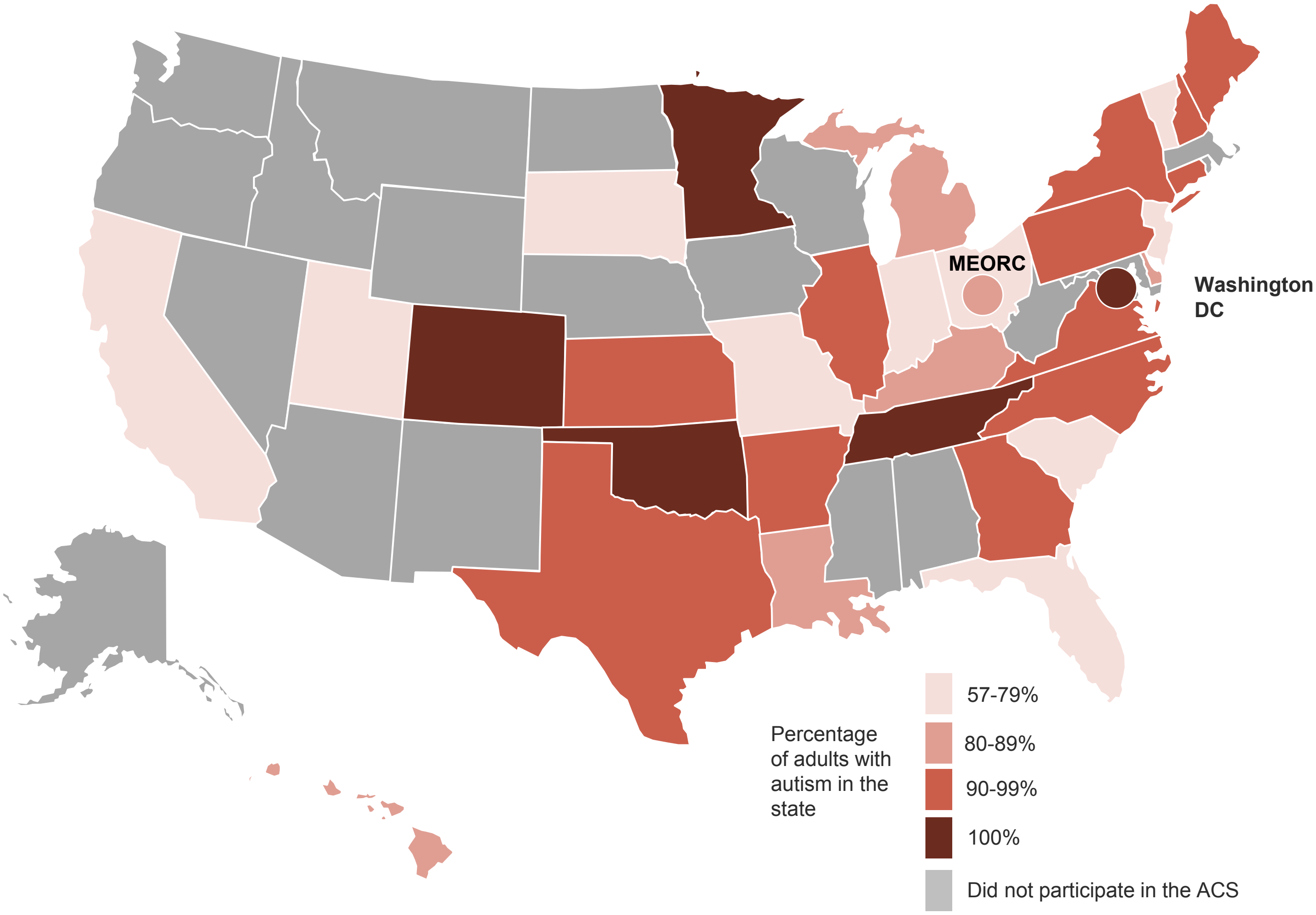
The percentage of working-aged adults with ASD who also had ID varied across participating states. Four states and Washington, D.C. reported 100% of their survey participants had ID, while Vermont and South Carolina reported that only 57% of their participants with ASD had an ID. This finding likely reflects differences in state policy regarding who can access DD services. **In some states, people without an ID are less likely to qualify as eligible for support even though they may be developmentally disabled or experience a high level of impairment related to their autism spectrum condition**.

Adults with ASD were less likely to have an intellectual disability (ID) than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

States differed in the percentage of adults with ASD in the ACS who also had an intellectual disability (ID).



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Use of DD Services

Half used at least six services funded by a DD agency.

Our key findings

- Of the services that the Adult Consumer Survey (ACS) asked about, the most common services adults with autism spectrum disorder (ASD) received were health care, dental care, and transportation. About half of adults with ASD received information about benefits or insurance (54%), and services for social relationships or meeting people (49%).
- **Almost half (49%) of adults with ASD used six or more services funded by a state developmental disability (DD) agency**. Those with ASD used the same types of DD services, and at the same rate, as other DD service users who did not have ASD.
- Half (51%) of adults with ASD who lived with parents or relatives received respite care services. Younger participants with ASD (18-24 years) were more likely to receive respite care than middle-aged individuals (45-64 years).
- **Overall, 25% of ACS participants with ASD reported that they *did not* receive all of the services they needed**.

Why DD Services matter

In our 2015 National Autism Indicators Report: Transition into Young Adulthood we told you about the "services cliff" - the drop-off in services that some youth experience after high school when they lose access to the services that they may have had through special education. Even if they had state DD services during childhood, they may need to requalify for help as adults upon reaching a specified age (18 in many states) and could encounter lengthy wait lists for services. Funding sources for supports in adulthood, such as the Medicaid waivers that often fund DD services, also require qualification.

The needs of adults with ASD vary widely across the spectrum. Those who qualify for state DD services tend to have higher levels of cognitive and functional impairments. They may also have different needs than their peers with other types of DDs. This chapter examines the experiences of adults with ASD who use DD services and explores how their service use compares to other DD service users.

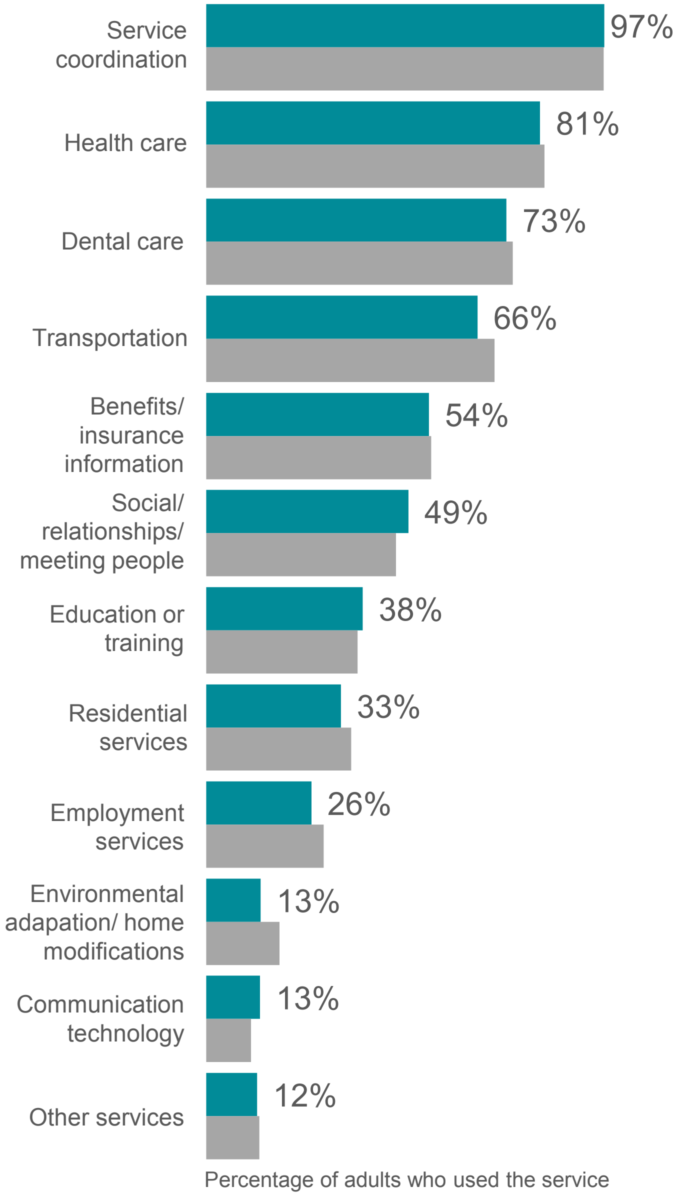
What types of services were included in the survey?

The services shown in the graphs below include only the services asked about in the ACS. There are many additional services adults with ASD might need including behavioral supports, personal care supports, services to support day activities other than employment, and services to help people self-direct their care. You can read more about DD services in the **Background** chapter.

Which DD services did adults with ASD receive?

The question, "Which of the following services/supports funded by the state (or county) agency does this person receive?" was answered using state records based on a list of potential services. Nearly all ACS participants with ASD received service coordination, and most used health care services. Over two-thirds of participants used dental services and transportation services. About half of participants with ASD received information about benefits or insurance, and services for social relationships or meeting people. One-third received educational or training services, respite or family support services, or residential services. Overall, about one-fourth received employment services to help them find, maintain, or change jobs. Adults with ASD used the same types of DD services, at the same rate, as other DD service users who did not have ASD.

Adults with ASD received services at about the same rates as other DD service users.



Source: NCI Adult Consumer Survey 2014-15

On average, adults with ASD received six services that were funded by state or county agencies from a list of 13 services (including an "other" category) asked about in the ACS. **Most (89%) adults with ASD received three or more services that were funded through the state (or county) agency; half (49%) had at least six**. This was the same in all other DD service users.

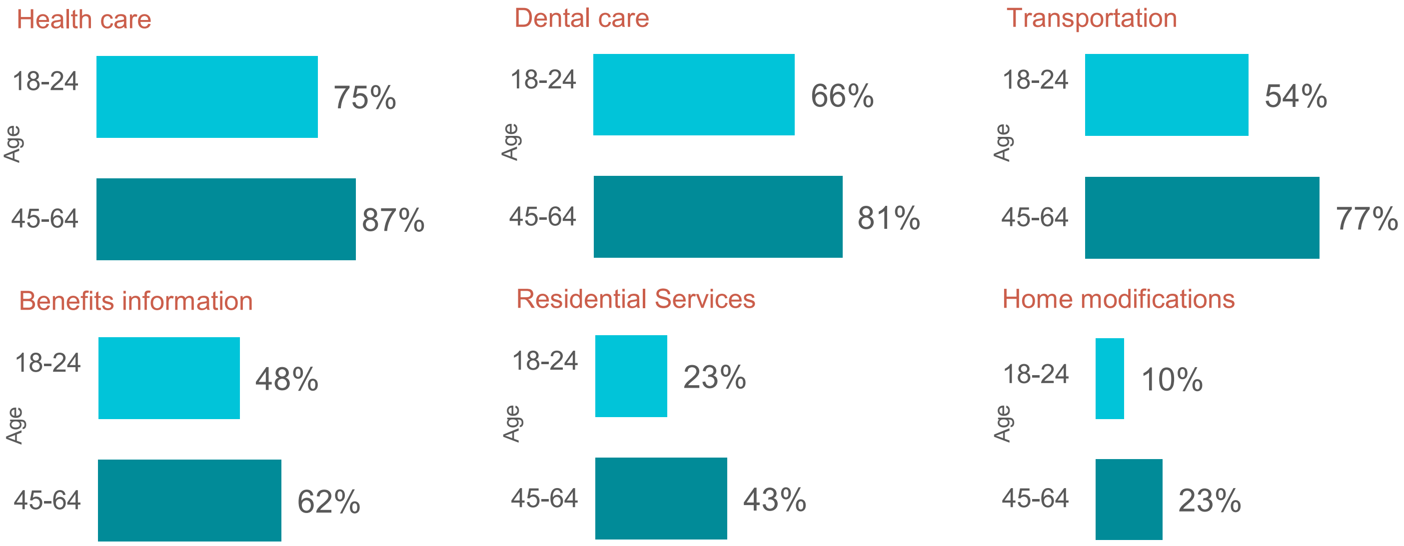
The use of most services was higher among middle-aged individuals (45-64 years) with the exception of respite services. Younger participants (18-24 years) were more likely to receive respite care than middle-aged individuals. Middle-aged participants were more likely to receive services for health care, dental care, transportation, benefits and insurance information, residential services (to find, maintain, or change housing), and environmental adaptations/home modifications than younger adults.

It is important to remember that the **rate of ID varies by age**. Differences in outcomes across age groups might simply reflect the fact older individuals in this survey were more likely to have ID.

What are home modifications and environmental adaptations?

Home modifications and environmental adaptations are changes that enable an individual to live safely and successfully within their home environment. Examples of modifications and adaptations for a person with ASD include creation of a private bedroom, a safe space, security or tracking devices to prevent wandering, or tools to support organization of the home environment to support independence.

Middle-aged adults with ASD were more likely to use many services than younger adults.



Source: NCI Adult Consumer Survey 2014-15

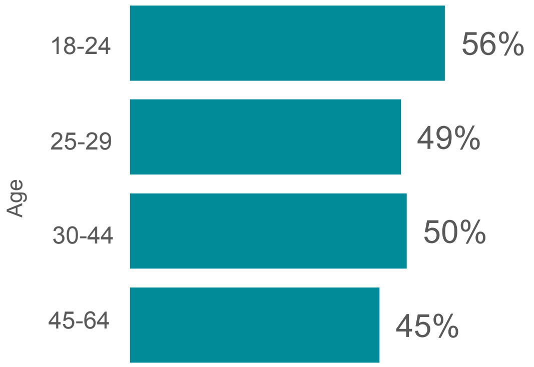
SPOTLIGHT:
Respite care

We examined the use of respite care services for caregivers of adults with ASD who lived in the home of a parent or relative. Just over half (51%) of adults with ASD who lived in the home of a parent or relative received respite care. This varied by age, and more young adults with ASD used this service than middle-aged adults with ASD.

What are respite services?

Respite is a type of family support service which provides temporary relief for caregivers, offering a break from usual care duties to help relieve stress. Respite services might be provided inside or outside one's home, and could be a planned break from care or assistance given during an emergency.

Receipt of respite care was more common for younger adults with ASD.



Percentage of adults with ASD who received respite services

Source: NCI Adult Consumer Survey 2014-15

Service needs

ACS participants were asked, "Do you get all the services you need?" Proxy respondents could also answer this question ("Does this person get the services and supports s/he needs?"). Those who responded with *no, sometimes*, or *not enough* were considered to have unmet service needs. If additional services were needed, people indicated which services were needed from a given list. People could also write in other types of needed services. **Three out of four (75%) participants with ASD reportedly received all the services they needed**.

Whether the person received needed services did not vary by race or ethnicity, but did vary by age. A higher percentage of middle-aged adults reportedly received the services they needed compared to younger adults. There were no differences in receiving needed services based on whether the person used spoken language or not.

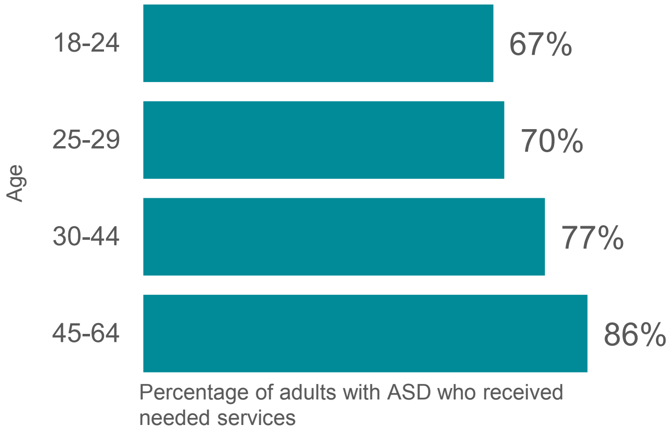
Those with ASD who had no ID were less likely to get the services they needed compared to adults who had ASD and ID. Adults with ASD were just as likely to receive needed services compared to other DD service users.

Potential sources of bias in survey responses about services, satisfaction and choice

Responses to questions about satisfaction with services and staff might be influenced by who answered the survey questions (e.g., an adult with ASD versus a proxy) and what these individuals were thinking when they answered the questions. Findings might be influenced in the following ways:

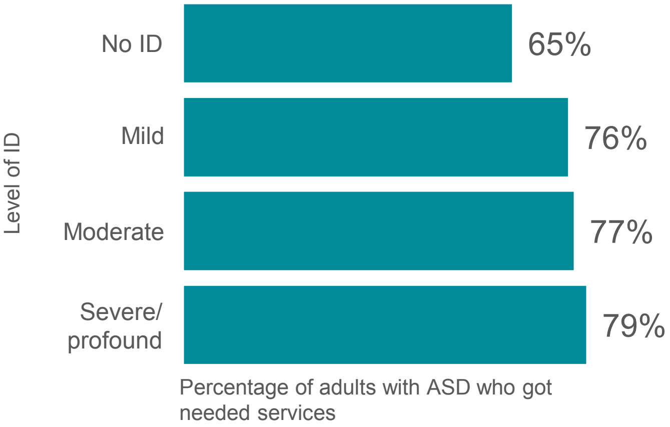
- A participant might give a more positive response to please the interviewer or to avoid displeasing staff who deliver their services. This issue of "socially desirable" responses is well known in DD research.[1]
- People who were dissatisfied with particular services may have discontinued them by the time of the survey. So, there might have been fewer dissatisfied service users who participated in the ACS. This could lead to an underestimation of service dissatisfaction.
- People who report not needing additional services or having all their service needs met might not be fully aware of services they could access which might be beneficial in helping them reach their desired outcomes.
- We don't know whether people truly had choices of service providers. It is impossible to know how many people actually knew it was possible to change their staff if necessary, or how many people would have felt empowered to ask to change staff.

Young adults with ASD were less likely to receive the services they felt they needed.



Source: NCI Adult Consumer Survey 2014-15

It was less common for adults with ASD with no ID to get the services they needed.

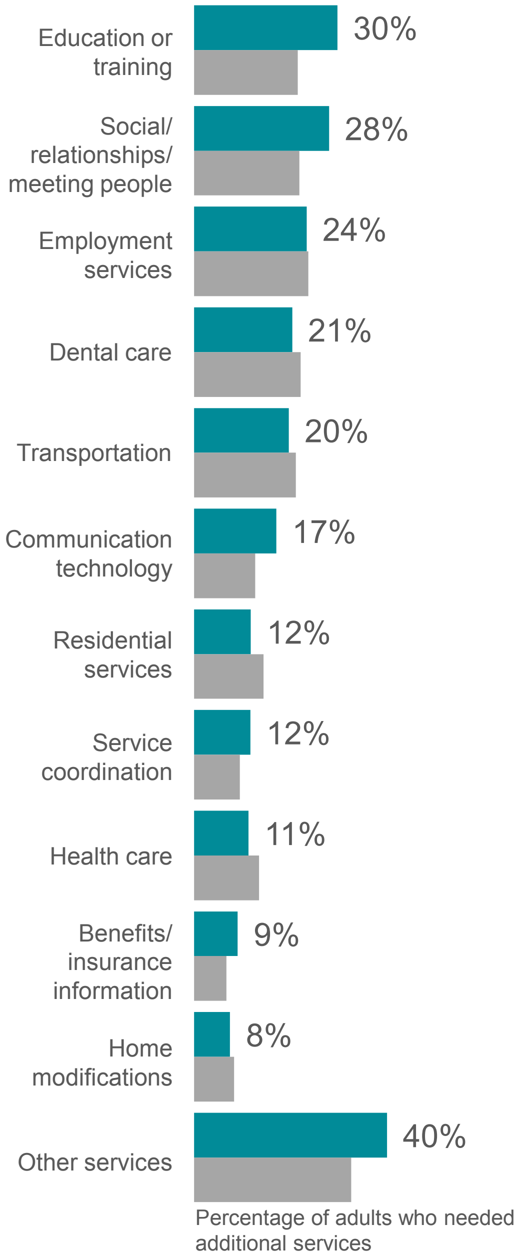


Source: NCI Adult Consumer Survey 2014-15

Overall, 25% of ACS participants with ASD reportedly did not receive all, or enough of, the services they needed. Respondents who said *no* or *sometimes, or doesn't get enough of the services needed* were considered to not receive all of the serviced needed. The most commonly reported unmet service needs were education or training, socialization and relationships, respite care, family supports, and job assistance. Types and rates of needed services were similar between people with ASD compared to other DD services users.

Young adults more often needed education or training services (30% of adults age 18-24 and 39% of adults age 25-29), compared to 19% of middle-aged participants. While 33% of young adults felt they needed services for relationships and meeting people only 18% of middle-aged adults reportedly needed this. Younger adults were more likely to report needing service coordination (10% of younger adults ages 18-24 and 19% of younger adults ages 24-29 years) compared to 2% of middle-aged adults. We note that while 96% of adults with ASD were reported to have service coordination, the 12% who indicated a need for service coordination might not have known that they had a service coordinator (or case manager), or may have felt they needed additional service coordination.

Adults with ASD had higher rates of unmet service needs than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

Unmet needs in the *Other Services* category were strikingly higher for those with ASD. When asked about the *Other Services* they needed, participants (or their proxies) most commonly mentioned: Speech/Occupational/Physical or other therapies; direct care staff and more hours of direct care; more available staff and providers in the community; day programs, funding for day programs, and more day programming hours; behavior supports, analysis, and services; and recreation, activities, and opportunities for socialization. Additional needs included: financial supports for individuals and their caregivers; daily living skills; transportation; housing options and funding for housing; employment supports and job opportunities; in-home supports and funding for in-home supports; information on services and referrals to providers; and exercise and weight management.

Among those adults with ASD who lived in the home of a parent or relative and reported a need for additional services, 33% reported a need for respite services. This varied little by age.

In their own voices

Self-respondents were able to answer questions about services using *yes, maybe*, or *not sure*. Similarly, some questions allowed for responses of *sometimes*. For this *In Their Own Voices* section, those who answered *maybe* or *sometimes* were included as responding *yes*.

People with I/DD want to be heard. While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

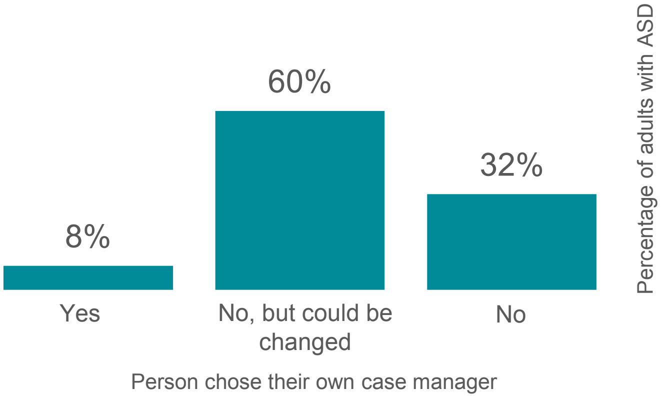
Experiences with service provision

Self-respondents with ASD expressed overall positive experiences with service provision. Almost all participants reported that they had a service plan (97%), and 94% reported helping make it. A service plan is the document that specifies individualized goals to be achieved through the services that are provided.

Service choices

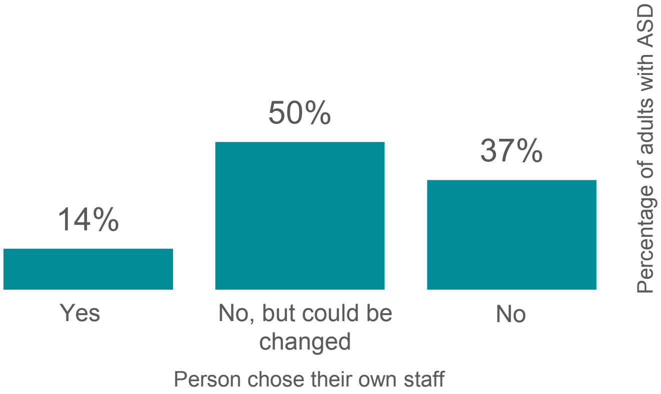
Surveyors asked ASD participants (or their proxies), "Did you choose or pick your case manager/service coordinator?" (or "Did this person choose his/her case manager/service coordinator?") and "Did you choose (or pick) your staff?" (or "Did this person choose his/her staff?") It was very uncommon for adults with ASD to choose their own case manager/service coordinator or their own staff. A little over half said that their case manager or staff was assigned but could be changed if requested.

Most adults with ASD did not choose their case manager, but over half could change their case manager if needed.



Source: NCI Adult Consumer Survey 2014-15

Most adults with ASD did not choose their staff, but about half could change staff if needed.



Source: NCI Adult Consumer Survey 2014-15

Over half (57%) of ACS participants with ASD (or their proxies) felt their staff had the right training to meet their needs, while 40% indicated uncertainty and 3% explicitly said no. There were few differences in choice-making across age groups.

Self-directed supports

Some DD service users who participate in Medicaid waivers choose to **self-direct** their supports, defined in the ACS as "the opportunity to manage some or all of their services" including hiring/firing support workers and controlling how their budget is spent. The availability of this option varies across states. Self-direction is often done with the support of family members to hire, supervise, and pay providers.

Using background records, surveyors answered whether the person was currently using self-directed supports. Overall, 13% of survey participants with ASD used self-directed supports - most commonly among younger participants. Of those who used self-directed supports, 35% were their own legal guardians; while 59% had a full guardian, and 6% had a limited guardian (See **Independence and Rights** chapter.)

Using background records, the surveyor reported who employed the person's support workers. More than half of those who were self-directing their supports (63%) employed their own workers.

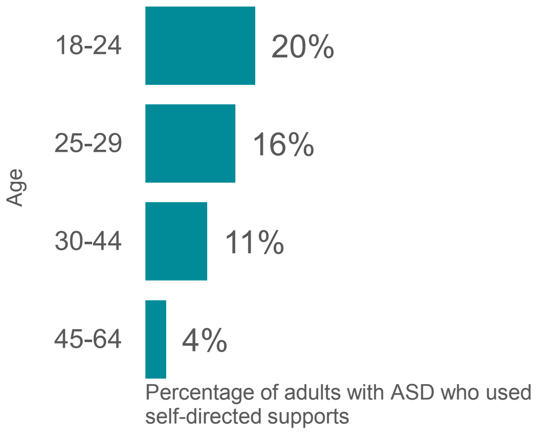
There were no significant differences in how often adults with ASD self-directed their services compared to other DD service users. Rates of use of self-directed supports were no different in those who used spoken language versus nonverbal communication, and also did not vary based on race or ethnicity. Younger adults with ASD were more likely to self-direct services, perhaps reflecting the contemporary push for self-direction. Note: There was no information about the use of self-directed supports for participants from the state of California.

What are self-directed supports?

Adults with DDs, or their legal representatives, who self-direct their supports have decision-making authority over certain services and take direct responsibility to manage their services with some assistance, within a person-centered planning process. For example, participants are allowed to recruit, hire, train and supervise individuals to provide services. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model.

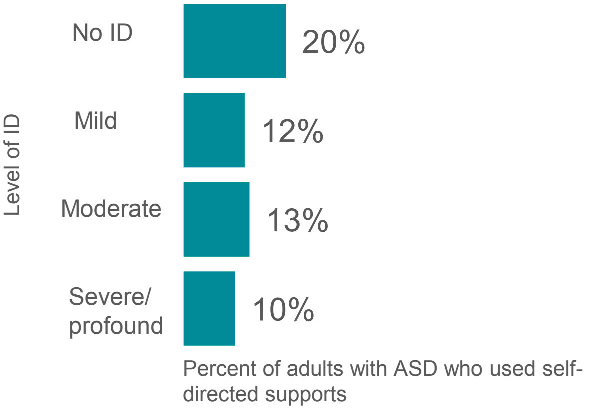
Source: Centers for Medicare and Medicaid Services, www.medicaid.gov/medicaid/ltss/self-directed

Younger adults with ASD were more likely to use self-directed supports.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who did not have ID were most likely to use self-directed supports.



Source: NCI Adult Consumer Survey 2014-15

Funding for services in the community

Funding information was collected differently across states (see **Methods**). Of the 29 states (plus Washington, D.C. and the Mid-East Ohio Regional Council) that reported this information, 93% of ACS participants with ASD received some type of Medicaid funding - either Home and Community Based Services (HCBS) waivers or Intermediate Care Facility for the Intellectually Disabled (ICF/ID) funding. The most common type of funding came from Medicaid Home and Community Based Services (HCBS) waivers, with nearly half of participants receiving this type of funding (48%). Recall that HCBS waivers are primarily used to meet the needs of people who receive long-term services and supports in their home or community versus in an institutional setting. For more information on funding, see the **Background** chapter.

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Health and Health Care and other topics.

Reference

1. Heal, LW, and Sigelman CK. (1995). Response Biases in Interviews of Individuals with Limited Mental Ability. *Journal of Intellectual Disability Research* 39(4): 331-340.

Health and Health Care

Half had at least one health condition in addition to ASD.

Our key findings

- **Half (51%) of adults with autism spectrum disorder (ASD) had at least one health condition in addition to ASD** from a list of 11 conditions.
- More than half (58%) of adults with ASD had a Body Mass Index that placed them in the overweight or obese category. Those with ASD who had severe or profound intellectual disability (ID) or who used nonverbal communication were less likely to engage in moderate physical activity.
- Most had annual health and dental check-ups, but vision checks, cancer screenings, and flu vaccination were less common for those with ASD than among other developmental disability (DD) service users.

Why health and health care matter

There is a growing body of knowledge about the health of adults with ASD. Recent studies have found exceptionally high rates of epilepsy, high cholesterol, hypertension, gastrointestinal disorders, diabetes, obesity, thyroid disease, inflammatory bowel disease, sleep disorders, musculoskeletal conditions, nutritional deficiencies, hearing and vision problems, stroke, Parkinson's disease, and genetic disorders including Down syndrome, among others in adults with ASD.[1-4] Adults with ASD are also twice as likely to use the emergency department (ED),[5] are more likely to be admitted to the hospital from the ED and incur higher costs of hospitalization,[6] and have more outpatient visits and more prescription drug use,[4] compared to adults without ASD.

There is also a known need for physician education about ASD and tools to help them provide care for this adult population.[7-8] Office and hospital visits can be challenging for individuals with ASD given difficulty adjusting to new environments, sensory issues with lights and noise, and encounters with healthcare providers who may be unfamiliar with how to best interact with people with ASD. These issues may contribute to higher levels of unmet healthcare needs and lower use of preventive services reported by adults with ASD.[5] Adults with ASD also report low levels of satisfaction about their communication with providers during healthcare visits compared to adults without ASD.[5]

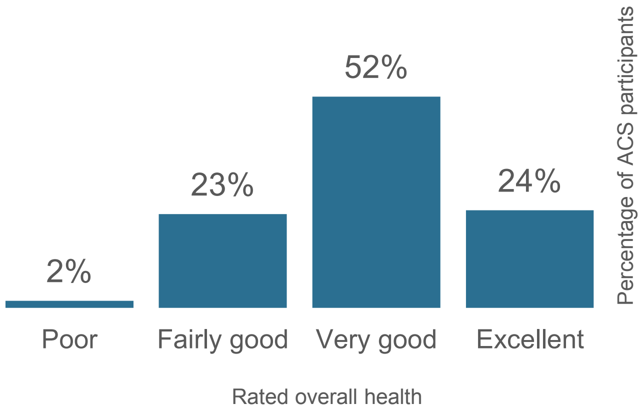
Special note: Almost all data on health conditions and health care in the 2014-15 Adult Consumer Survey (ACS) came from background information in state records. The only information on health reported by survey participants with ASD or their proxies was a question about overall health. Caution should be used in interpreting the data in this chapter, as some health information may not have been recorded in state records. We can also only report on conditions that were asked about in the survey.

Information about other health conditions, such as gastrointestinal problems, that are common in those with ASD, was not collected. There may be a systematic bias in this dataset toward under-reporting how common health difficulties are. That said, these statistics still provide important, baseline data about health and health care for adults with ASD.

Overall health

ACS participants (or their proxies) were asked "Overall, how would you describe your health?" (or "Overall, how would you describe this person's health?") given a rating scale of *excellent, very good, fairly good*, or *poor*. In contrast to the higher prevalence of health conditions found in many recent studies of adults with ASD, most who participated in the ACS reportedly had *very good* or *excellent* health. Ratings of overall health did not differ greatly across age groups.

Many adults with ASD were reportedly in good health.

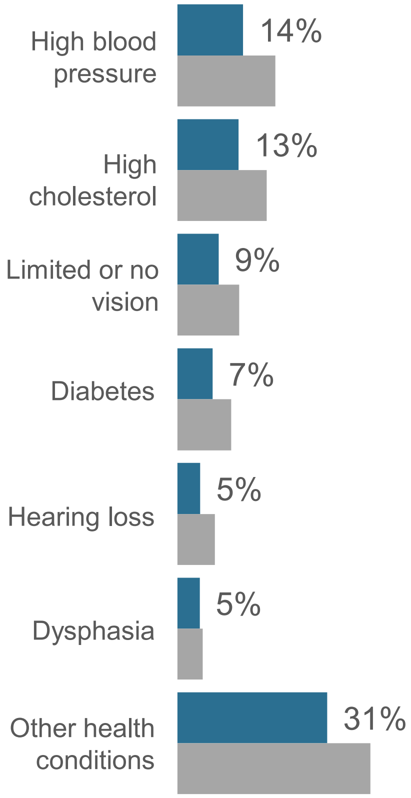


Source: NCI Adult Consumer Survey 2014-15

Physical health conditions

Surveyors used background records to answer, "What health conditions are noted in this person's record?" given a list of the following health conditions: cardiovascular disease, diabetes (types 1 and 2), cancer, high blood pressure, high cholesterol, dysphasia, pressure ulcers, limited or no vision - legally blind, hearing loss - severe or profound, Alzheimer's disease or other dementia, or other (with a write-in response option).
Half (51%) of adults with ASD had at least one of these listed conditions - lower than the 64% of all other DD service users. The rate of having at least one health condition varied by age - 37% among young adults (18-24 years) and 70% in middle-aged adults (45-64 years).

Health conditions reported in adults with ASD and all other DD service users.



Source: NCI Adult Consumer Survey 2014-15

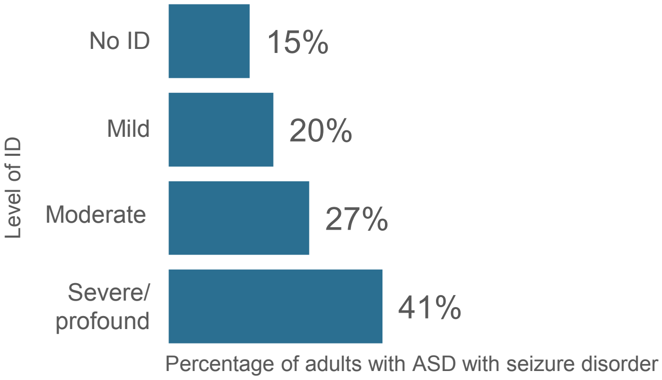
The most common physical health conditions reported in ACS participants with ASD were high blood pressure (hypertension) and high cholesterol. These conditions varied by age, with fewer young adults (4-5%) reporting high blood pressure or high cholesterol than middle-aged adults (25%). Hypertension was slightly more common among young adults with ASD than in the general population (as reported in the 2012 National Health Interview Survey), but less common than among middle-aged adults in the general population who had hypertension.[9] Nine percent of adults with ASD had limited or no vision. Seven percent had diabetes, and 31% had at least one additional health condition, including cardiovascular disease, cancer, hearing loss, or others. These rates were not different than other DD service users.

Other reported health conditions in the records of those with ASD commonly included: thyroid disorder, gastroesophageal/acid reflux, constipation, allergies, asthma, obesity, epilepsy, seizure disorder, eczema and other skin conditions, and others.

One-fourth of adults with ASD had seizure disorder.

About one-fourth (27%) of adults with ASD had a record of a seizure disorder (epilepsy) or neurological problem - about the same rate as seen in other DD service users. Seizure disorder was more common in adults with ASD with severe to profound ID and among those who used nonverbal communication. The rate of seizure disorder in a broader population sample of adults with ASD (who were not necessarily getting services funded through a state DD agency) was 12%.[1]

Seizure disorder and neurological problems were more likely in adults who had moderate ID or severe to profound ID.

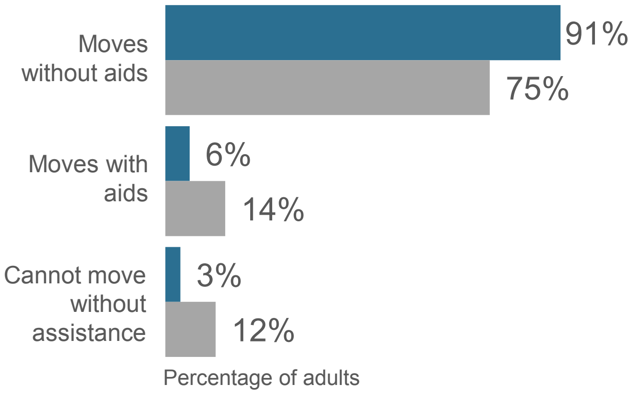


Source: NCI Adult Consumer Survey 2014-15

Mobility

ACS surveyors reviewed state records to answer, “How would you describe this person’s mobility?” Most adults with ASD were reported to move around their environment without assistance. Adults with ASD were more likely to be able to independently move around than other DD service users.

Adults with ASD were more likely to move around their environment without aids than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

Health risk behaviors

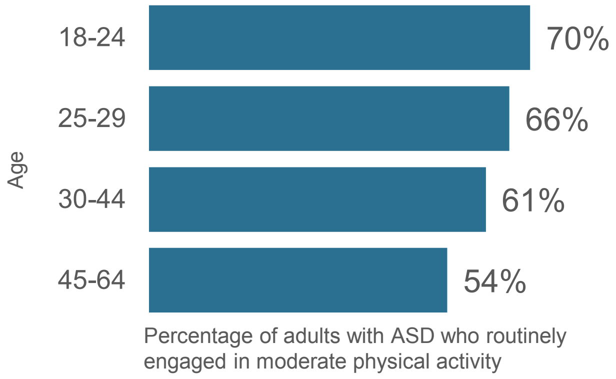
Tobacco use. Very few adults with ASD (2%) smoked or chewed tobacco. Tobacco use was low across age groups. Reported rates of smoking were much lower than the rate of cigarette smoking in adults across age groups in the general population (19-20%),[9] which is consistent with lower rates of smoking and alcohol use reported for adults with ASD in a large health care system.[1]

It is important to remember that the **rate of ID varies by age**. Differences in outcomes across age groups might simply reflect the fact that older individuals in this survey were more likely to have ID.

Exercise. Surveyors reviewed state records to determine, “Does this person routinely engage in any moderate physical activity?” which was defined as “an activity that causes some increase in breathing or heart rate” such as “brisk walking, swimming, bicycling, cleaning, and gardening.” Two-thirds (63%) of adults with ASD routinely engaged in moderate physical activity. More young adults engaged in moderate levels of physical activity, compared to middle-aged adults.

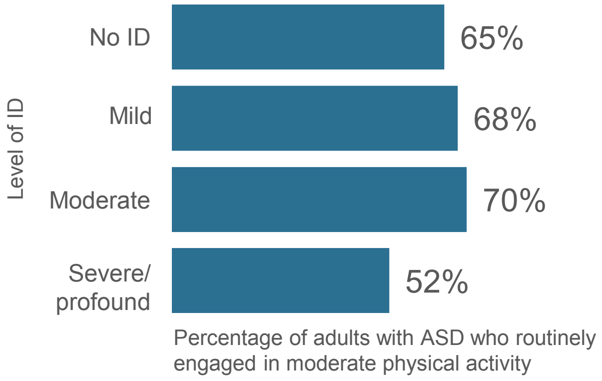
Far fewer adults with ASD who had severe or profound ID engaged in regular exercise compared to those with no ID or mild/moderate ID. Those who used nonverbal communication were also less likely to engage in regular exercise versus those who used spoken language.

Younger adults with ASD more commonly engaged in regular physical activity than middle-aged adults.



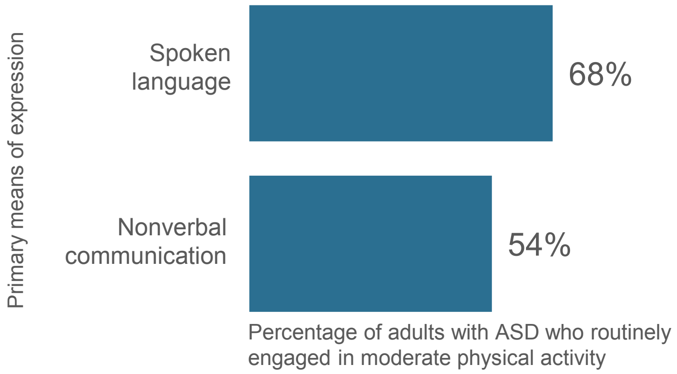
Source: NCI Adult Consumer Survey 2014-15

Adults with severe or profound ID were less likely to engage in moderate physical activity.



Source: NCI Adults Consumer Survey 2014-15

Adults with ASD who used nonverbal communication were less likely to participate in regular exercise.

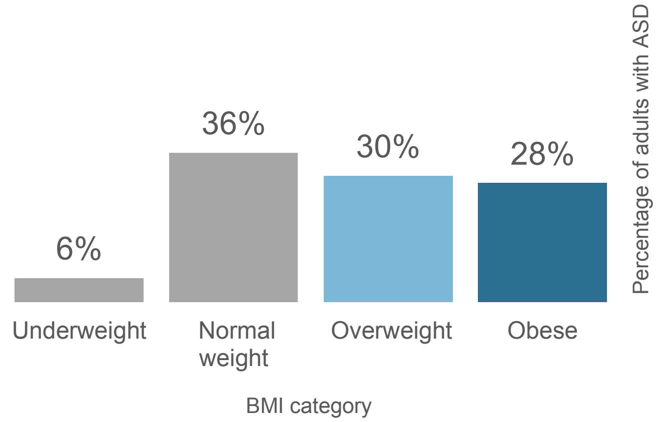


Source: NCI Adult Consumer Survey 2014-15

Weight management. More than half of adults with ASD had a body mass index (BMI) that placed them in the overweight or obese category. (Note: The ACS used weight categories defined by the CDC.) About one- third had a normal BMI, and 6% were underweight. Rates of being overweight increased with age. Fewer young adults were overweight (26%) compared to 36% of middle-aged adults. Rates were similar to general population adults across age groups and weight categories.[9]

Weight gain is a well-known side effect of some psychotropic medications used in both children and adults.[10] Maintaining healthy weight and getting regular exercise are important in this population, because psychotropic medication use is higher among people with ASD (see **Mental Health** chapter).

More than half of adults with ASD were overweight or obese.

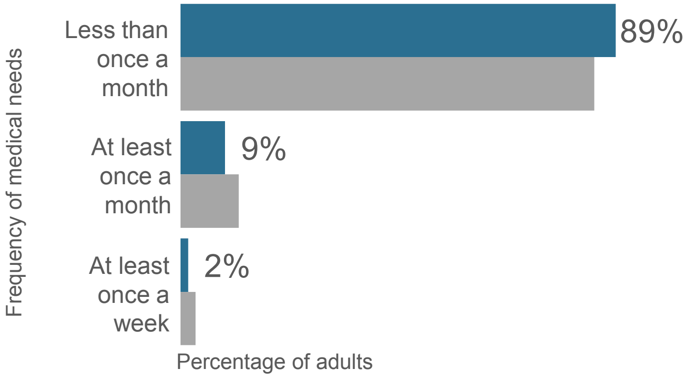


Source: NCI Adult Consumer Survey 2014-15

Health services

Reported need for medical care. Very few adults with ASD reportedly needed medical care more than once a week, and most needed it less than once a month. The need for medical care did not vary greatly by age. Need for medical care was not more frequent in adults with ASD compared to other DD service users. Other researchers have found higher rates of unmet health care needs in samples of adults with ASD who were able to self-report about their health care use.[5]

Most adults with ASD reportedly needed medical care less than once a month - the same as other DD service users.

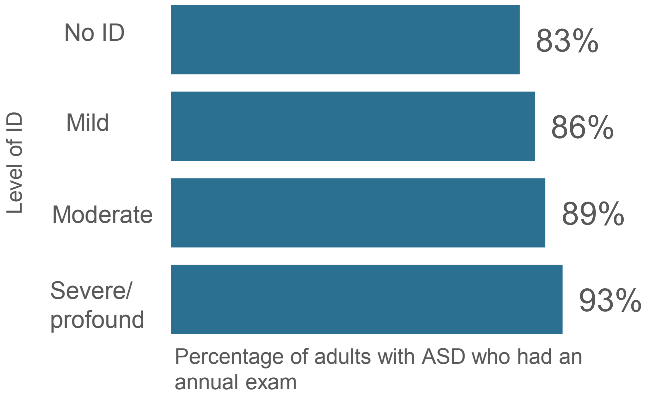


Source: NCI Adult Consumer Survey 2014-15

Primary care doctor. The vast majority of adults with ASD had a primary care doctor (97%), and this did not vary much by age group. Adults with ASD were more likely to have a usual place of health care compared to adults in the general population in which 76% of adults ages 18-44 had a usual place of care, and 88% of adults ages 45-64.[9]

Annual health exam. Most (88%) adults with ASD had a health exam in the previous 12 months. Fewer of those who did not have ID had an annual health exam, compared to those with severe/profound ID. Rates of having an annual health exam were fairly similar for those who used spoken language (86%) versus nonverbal communication (92%).

Adults with ASD who did not have ID were less likely to have an annual exam.



Source: NCI Adult Consumer Survey 2014-15

Annual dental and vision checks. Most (81%) adults with ASD had a dental visit in the previous 12 months, and this was consistent across age groups. Adults with ASD who received DD services were more likely to have had a dental visit than adults in the general population - approximately 60% of whom saw a dentist within the past year.[9]

Almost half (43%) of those with ASD had a vision screening within the previous 12 months. Use of annual vision screenings increased with age (39% of adults ages 18-24, 38% of adults ages 25-29, 42% of adults ages 30-44, and 53% of adults ages 45-64).

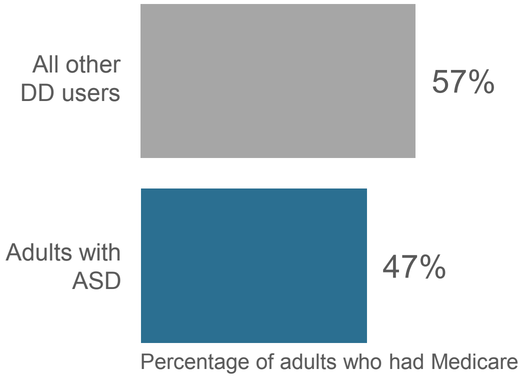
Cancer screenings. Recommendations from the U.S. Preventive Services Task Force state that most women age 18-64 should get Pap tests every three years. About half (52%) of the women with ASD in this study had a Pap test within the three years prior to the survey. This varied by age (38% of women ages 18-24, 39% of women ages 30-44, 62% of women ages 24-29, and 62% of women ages 45-64). Other researchers have found lower odds of Pap tests in adult females with ASD.[5]

The U.S. Preventive Services Task Force recommends that women ages 50-74 get mammograms every two years. Seventy-four percent of the women with ASD over the age of 50 had a mammogram in the previous two years.

Vaccinations. Over two thirds (69%) of those with ASD had a flu vaccine in the previous 12 months. Receipt of flu vaccine increased with age: 58% of adults ages 18-24, 61% of adults ages 25-29, 70% of adults ages 30-44, and 87% of adults ages 45-64.

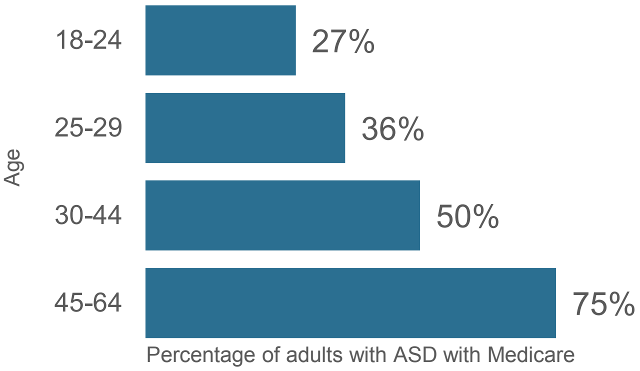
Public health insurance. Adults with disabilities automatically qualify for Medicare prior to age 65 IF they have received SSDI benefits for at least 24 months.[11] Less than half (47%) of adults with ASD in the ACS received Medicare funding - a lower rate than other DD service users. These rates were similar across adults who used spoken versus nonverbal communication. Many more middle-aged adults received Medicare than younger adults. Fewer adults with ASD received Medicare if they did not also have ID. Note that the ACS did not ask about whether a person had Medicaid funding, private insurance, or lack of insurance.

Adults with ASD were slightly less likely to have Medicare funding than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

Middle-aged adults with ASD were more likely to have Medicare funding than younger adults.



Source: NCI Adult Consumer Survey 2014-15

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Health and Health Care and other topics.

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Mental Health and Health Care

Many had co-occurring mental health conditions and behavioral challenges which were often treated with medications.

Our key findings

- **Over half (54%) of adults with autism spectrum disorder (ASD) had at least one mental health condition (including anxiety, mood disorder, psychotic disorder, and/or other mental illness) in addition to ASD.**
- Almost half (46%) of adults with ASD had behavioral challenges including disruptive, self-injurious and/or destructive behaviors.
- **Six in 10 adults with ASD (64%) took medication for mood disorders, anxiety and/or psychotic disorder, and/or behavioral challenges.** This rate was much higher than among other developmental disability (DD) service users.
- 44% of adults with ASD took medications for behavioral challenges - almost twice the rate of other DD service users.

Why mental health matters

Rates of co-occurring mental health conditions are higher in people with ASD compared to the general population, particularly in regard to anxiety, depression, and schizophrenia.[1-2] The challenges posed by these additional conditions can make it more difficult to work, live independently, and participate in the community.

Medications are often used to address co-occurring mental health conditions. An earlier survey of National Core Indicator (NCI) survey participants found that adults with ASD took psychotropic medications at higher rates than those without ASD - with 42% of those with ASD taking medications for mood, 41% for anxiety, and 49% for behavioral challenges. However, even though medication rates were higher, those with ASD were less likely to have a diagnosed mental illness.[3]

Special note: All data on mental health conditions in NCI's 2014-15 Adult Consumer Survey (ACS) came from background information in state records. Caution should be used in interpreting the data in this chapter, as other diagnoses or information about medications may not have been recorded in state records. That said, these statistics are still important, especially given that we don't know whether DD services in general are well-designed for meeting the unique needs of adults with ASD who have co-occurring mental health issues.

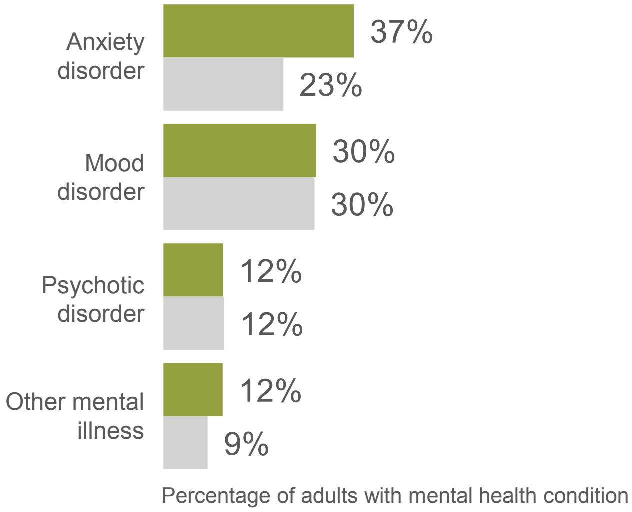
Mental health conditions

Surveyors used background records to answer, "What other disabilities are noted in this person's record?" given a list of the following mental or neurological health conditions: mood disorder (e.g., depression, mania, bipolar), anxiety disorder (e.g., obsessive disorders, panic disorders), behavior challenges (e.g., aggression, self-injurious behavior), psychotic disorder (e.g., schizophrenia, hallucinations), other mental illness/psychiatric diagnosis, cerebral palsy, brain injury, seizure disorder/neurological problem, chemical dependency, Down syndrome, Prader-Willi syndrome, or other disabilities. (Note: Seizure disorder and neurological problems are discussed in the Health and Health Care chapter.)

Adults with ASD who participated in the 2014-15 ACS reportedly had a variety of mental health conditions in addition to ASD. These included anxiety, mood disorders, psychotic disorder, and other mental illnesses. The only condition that varied by age was psychotic disorder, which was less common among young adults (ages 18-24) than among middle-aged adults (ages 45-64). Rates of the most common condition, anxiety, did not vary by age, or by whether the individual used spoken or nonverbal communication. However, anxiety was more common in the records of those with ASD compared to other DD service users.

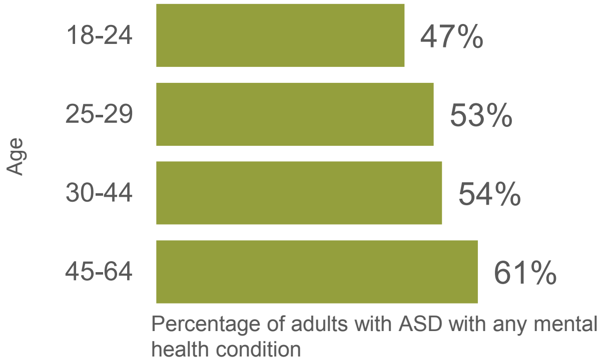
Over half (54%) of adults with ASD had at least one of these mental health conditions in addition to ASD, and co-occurrence of mental health conditions increased with age.

Mental health conditions in adults with ASD versus other DD service users.



Source: NCI Adult Consumer Survey 2014-15

The presence of other mental health conditions in adults with ASD increased with age.

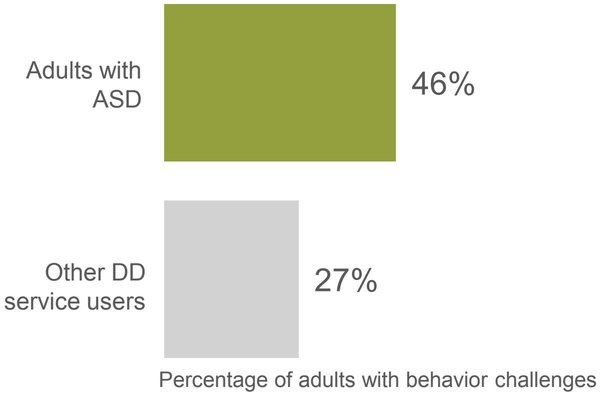


Source: NCI Adult Consumer Survey 2014-15

Challenging behavior was more common in adults with ASD.

Almost half (46%) of adults with ASD had behavioral challenges (defined below) - across age groups. The rate of behavioral challenges in those with ASD was higher than that of other DD service users.

Behavior challenges were more common in adults with ASD than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

Types of challenging behaviors

Self-injurious behavior: attempts to cause harm to one's own body, for example, by hitting or biting self, banging head, scratching or puncturing skin, ingesting inedible substances, or attempting suicide

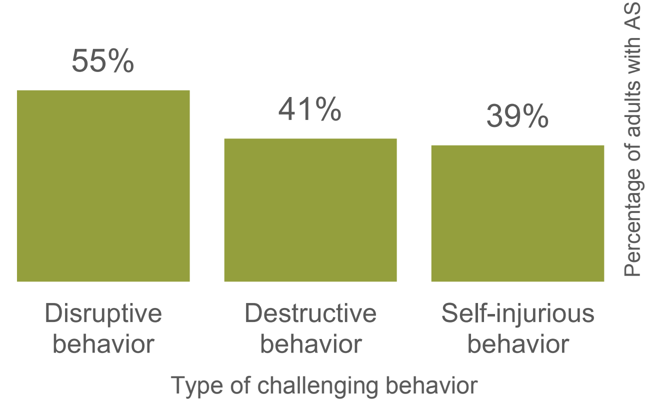
Disruptive behavior: interferes with the activities of others, for example, by laughing or crying without apparent reason, yelling or screaming, cursing, or threatening violence

Destructive behavior: externally-directed, defiant behavior, for example, taking other people's property, property destruction, stealing, or assaults and injuries to others

Source: NCI Adult Consumer Survey 2014-15

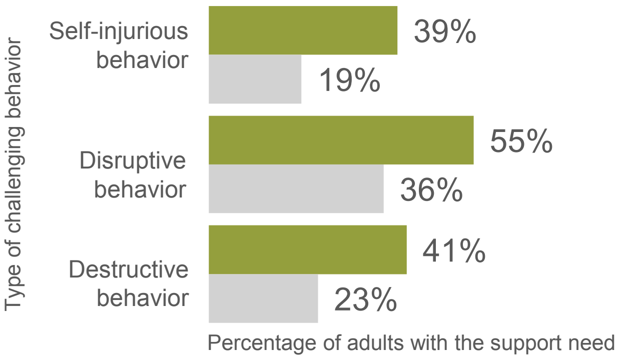
Over half (55%) of adults with ASD needed some support or extensive support to manage disruptive behavior, while others needed support to manage destructive behavior or self-injurious behavior. These rates did not differ by age. We don't know how many actually received this help or what the nature of this support was. The high rate of self-injurious behavior stands in contrast with the high rates of people who reported very good to excellent general health.

Over half of adults with ASD needed some or extensive support to manage disruptive behaviors.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD were more likely to need support to manage challenging behaviors than other DD service users.



Source: NCI Adult Consumer Survey 2014-15

Less than half of adults with ASD who used DD services had a behavior plan.

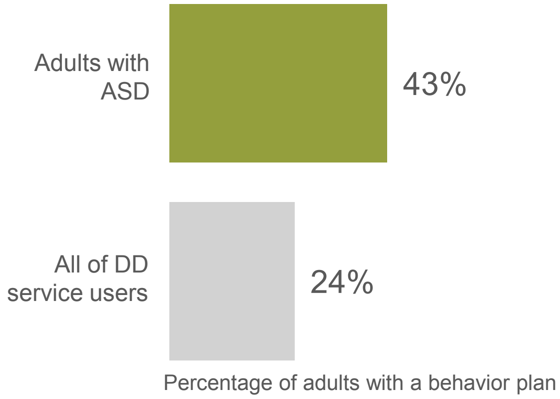
About four in 10 adults with ASD (43%) who used DD services had a behavior plan for challenging behaviors. Fewer younger adults had a **behavior plan** than middle-aged adults. Of those adults who had behavioral challenges, 68% had a behavior plan.

What is a behavior plan?

A behavior plan is based on an assessment of an individual's challenging behavior. The plan includes a description of the individual's strengths, preferences and interests, the goal(s) related to diminishing/eliminating the behavior, and applicable information about the nature of the behavior and potential triggering events. The plan should describe the interventions and accommodations that will contribute to the goal(s). It should also include the ways in which progress will be monitored, the staff who will be responsible for the interventions, and the length of time that the plan will be in place.

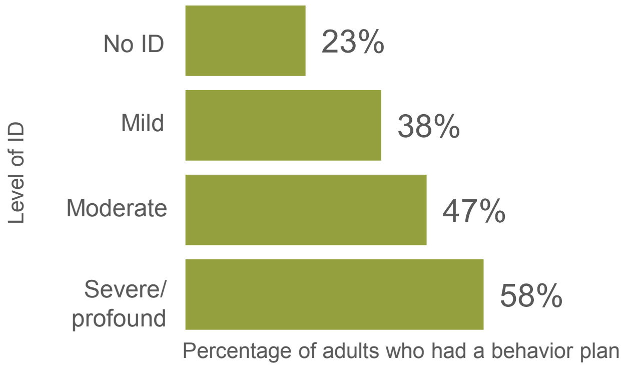
Source: NCI Adult Consumer Survey 2014-2015

Adults with ASD were more likely to have a behavior plan than other DD service users.



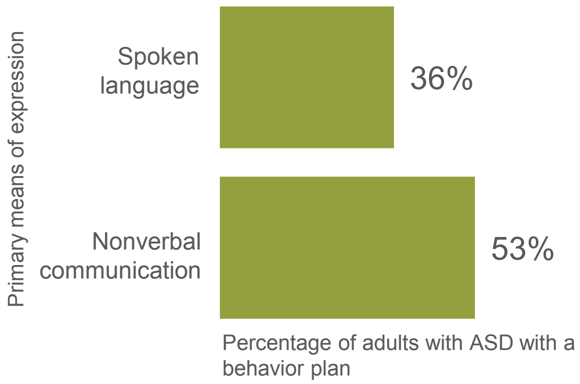
Source: NCI Adult Consumer Survey 2014-15

Adults with ASD with severe or profound ID were more likely to have a behavior plan than those with lower levels of ID.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who used nonverbal communication were more likely to have a behavior plan.



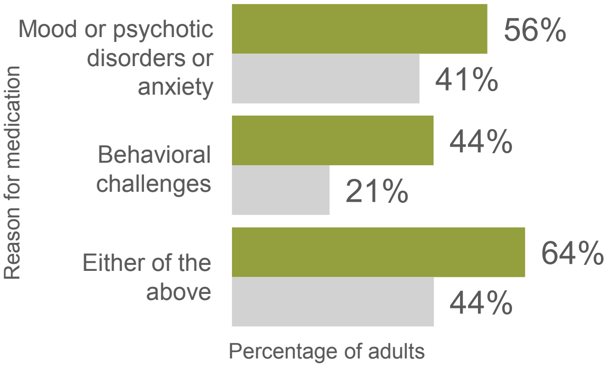
Source: NCI Adult Consumer Survey 2014-15

Psychotropic medication use was fairly common in adults with ASD.

ACS surveyors used background records to answer, “Does this person currently take medication to treat mood disorders, anxiety, and/or psychotic disorders?” and “Does this person currently take medications for behavioral challenges?” **Overall, six in 10 adults in the ACS with ASD took medication for mood disorders, anxiety and/or psychotic disorder, and/or behavioral challenges. This rate was much higher compared to all other DD service users.**

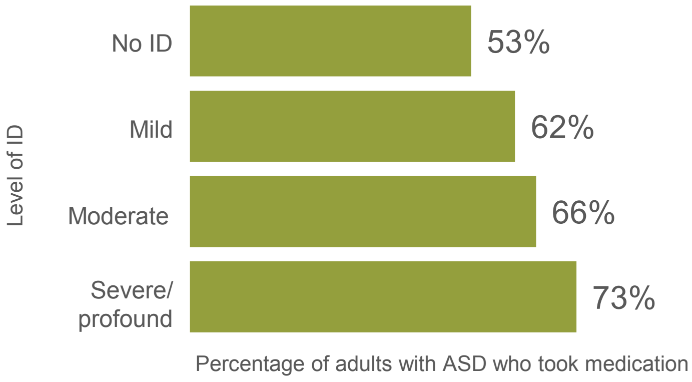
Overall rates of medication use varied by age; 55% of adults age 18-24, 63% of adults age 25-29, 67% of adults age 30-44, and 71% of adults age 45-64 had either medication use reported in their record.

Medication use was more common in adults with ASD than in all other DD service users.



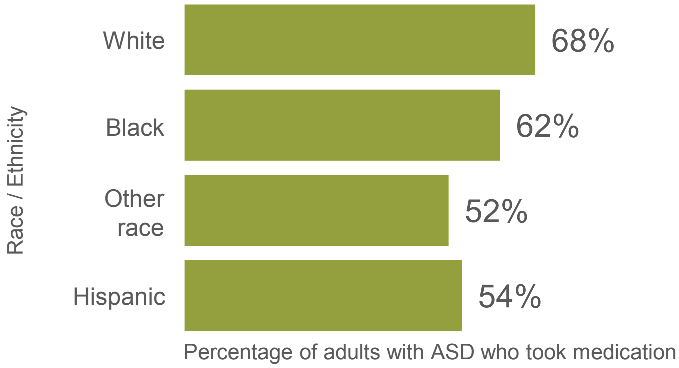
Source: NCI Adult Consumer Survey 2014-15

Adults with ASD with severe or profound ID were more likely to take medication for mood disorders *and/or* behavior problems.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who were white were the most likely to take medication for mood disorders *and/or* behavior problems.

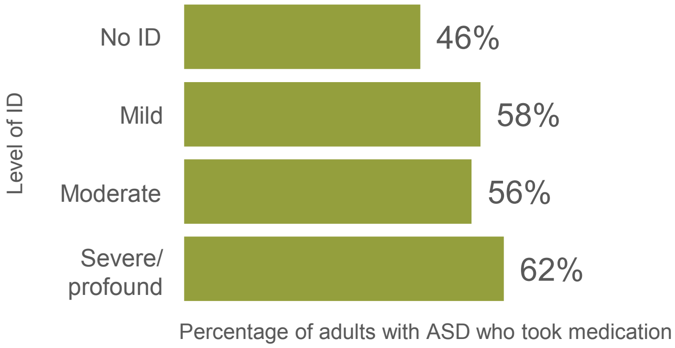


Source: NCI Adult Consumer Survey 2014-15

Use of medication to treat mood disorders

Over half (56%) of adults with ASD reportedly took medication for mood disorders, anxiety, and/or psychotic disorders. This varied by age, with fewer young adults taking medications than middle-aged adults. Of those who took medication for mood disorders, anxiety, and/or psychotic disorders, 68% reportedly took 1-2 medications, 26% took 3-4 medications, and 6% took five or more medications. These rates did not vary by age. More of those with severe or profound ID took medication for mood disorders compared to those with no or milder ID. Medication for mood disorders did not vary by whether they person used spoken language or nonverbal communication.

Adults with ASD with severe or profound ID more commonly took medication for mood disorders than adults with lower levels of ID.



Source: NCI Adult Consumer Survey 2014-15

This is how the ACS defined medications for:

Mood disorders: any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.

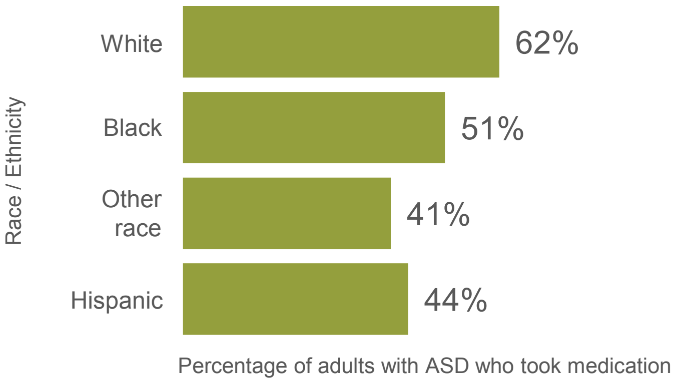
Anxiety: any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.

Psychotic disorders: any drug (e.g., anti-psychotic or "neuroleptic") used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.

Behavioral challenges: any drug prescribed for a behavior modification purpose (e.g., such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior.

Source: NCI Adult Consumer Survey 2014-2015

Adults with ASD who were white more commonly took medication for mood disorders than other adults.

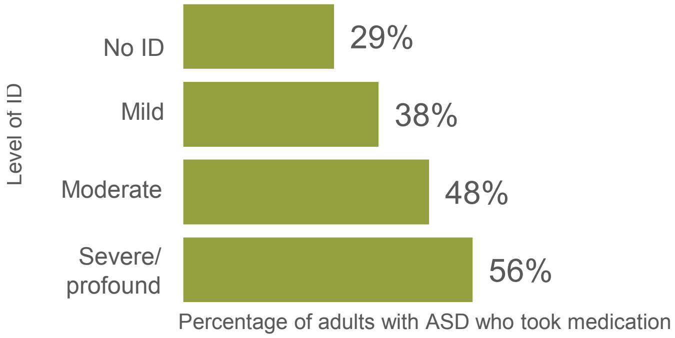


Source: NCI Adult Consumer Survey 2014-15

Use of medication to treat behavioral challenges

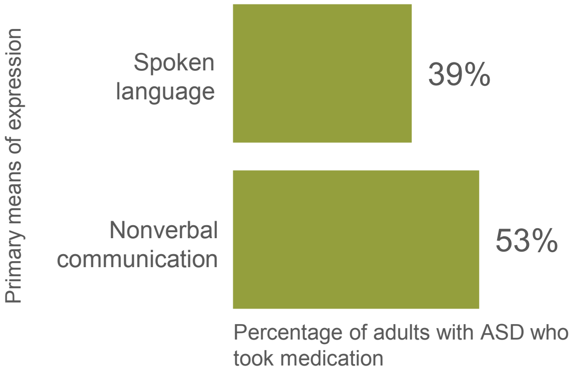
Overall, 44% of adults with ASD took medications for behavioral challenges - almost twice the rate of other DD service users. Use of medication for behavioral challenges was less likely than use of medication for mood disorders, anxiety, and/or psychotic disorders. Of those who took medication for behavioral challenges, 76% took 1-2 medications, 21% took 3-4 medications, and 4% took five or more medications. Use of medication for behavior challenges was higher among those with severe or profound ID and those who used nonverbal communication.

Adults with ASD with severe or profound ID were more likely to take medication for behavior problems than those with lower levels of ID.



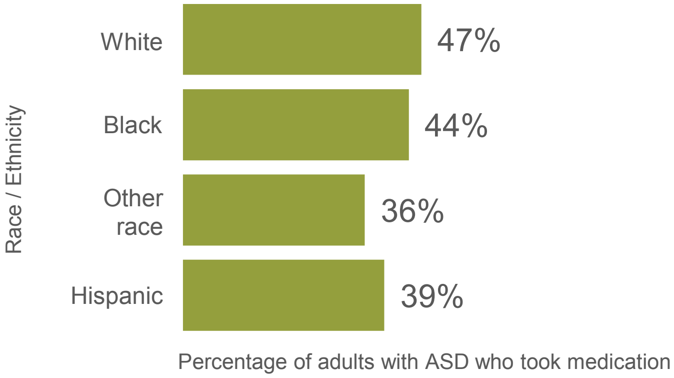
Source: NCI Adult Consumer Survey 2014-15

Use of medication for behavior problems was more likely in adults with ASD who used nonverbal communication.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who were white were the most likely to take medication for behavior problems.



Source: NCI Adult Consumer Survey 2014-15

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Mental Health and other topics.

References

1. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich, S, Sidney S, and Kripke C. (2015). The health status of adults on the autism spectrum. *Autism* 19(7): 814-823.
2. Kohane IS, McMurry, Weber G, MacFadden D, et al. (2012). The co-morbidity burden of children and young adults with autism spectrum disorders. *Plos One* 7(4): e33224.
3. Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. (April 2011). What does NCI tell us about people with autism? - An update. NCI Data Brief. Issue 3.

Employment and Other Day Activities

Most spent their days in unpaid, facility-based activities.

Our key findings

- **Paid, community-based employment was the least common outcome for adults with autism spectrum disorder (ASD). Only 14% held a job for pay in the community.** About one-fourth of adults with ASD had community employment as a goal in their service plan.
- Over half (54%) participated in an unpaid activity in a facility (where most other workers had disabilities).
- One-fourth (27%) had no work or activities, in either community-based or facility-based settings, in the two weeks prior to the survey.

Why what people do during their day matters

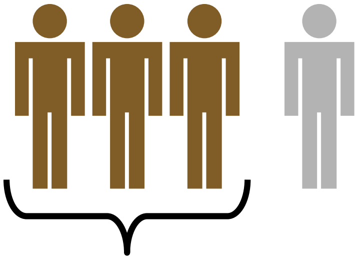
State developmental disability (DD) services are a key source of public funding for long-term supports and services for people with disabilities. These services support people in their place of living (See **Living Arrangements** chapter), but they also support the work and activities that people do during the daytime. Work and activities occur in two main settings. In the Adult Consumer Survey (ACS), a **community-based** setting was defined as a place where most people did not have disabilities. A **facility-based** setting was a place where most people had disabilities. (See examples below). In both settings, work and activities sometimes earn pay, but not always. Some people only engage in paid work or only do unpaid activities, but other people's days consist of a combination of paid and unpaid work and other activities that are often supported by state DD services.

While paid employment is a desired outcome for many, finding and keeping a job is hard for many people with ASD. Navigating the social dynamics of the workplace, coping with sensory overload, organizing and completing tasks, and communicating with coworkers may be challenging. How well a person handles these challenges may be related to whether the job is a good match for their interests and abilities, whether the employer knows how to successfully include employees with disabilities and whether co-workers are kind and know how to successfully work alongside someone with ASD. Having a job also does not mean that a person is on a path to building a career. Both job match and career potential are further influenced by whether jobs are available in one's community.

What were adults with ASD doing during the day?

Information about employment and day activities was gathered from state records. The ACS asked surveyors whether participants engaged in paid work or unpaid activities in community-based or facility-based settings within the last two weeks. Some participated in more than one type of work or activity.

At a glance: Work and day activities



72% **of all adults with ASD** participated in at least one work or day activity in the **two weeks prior** to participating in the ACS.

Work and day activities

Of adults with ASD who participated in the ACS, work and activities were reported for the two weeks prior to the survey. Some participated in more than one type of work or activity.

		What is that?	What does it look like?
32% were in **Community-based** settings	**14%** **Worked** in paid jobs in the community	Work done in the community (with or without supports) for pay, in settings that have people with and without disabilities	Any individual paid job in the community, or a job as part of a work crew (people with disabilities working together in a community-based setting, such as a group that stocks shelves in the grocery store)
	22% participated in **unpaid activities** in the community	Services and supports that are not paid work, but instead focus on community involvement such as recreational, educational, or volunteer activities, often identified as community integration or community participation services. [1] This service is referred to as Community-Based Day Services, Community-Based Non-work, or Community Life Engagement.	Volunteer work, community education, going to the library, going to the gym, running errands, dining out, exploring the community[2]
51% were in **Facility-based** settings	**15%** **Worked** in paid jobs in facilities	Job services provided in a setting "where the majority of people have a disability and receive continuous job-related supports and supervision. Facility-based work services are also referred to as sheltered work, work activity services, or extended employment programs.[3]	A job in a sheltered workshop
	42% participated in **unpaid activities** in facilities	Facility-based non-work activities are adult training services provided for persons with developmental disabilities (non-integrated) in a facility that is often owned by an agency. These services provide training and education to build skills needed to work or participate in the community.	Activities (in a non-integrated setting run by an agency sometimes called a day program or day habilitation center) designed to work on daily living skills, social skills, or prevocational training

Source: NCI Adult Consumer Survey 2014-2015. Additional sources as cited.

Most adults with ASD currently had some type of work or other day activity.

Overall, three out of four adults with ASD (72%) in the ACS were participating in some type of work or other day activity – with some adults participating in more than one type of job or activity. The fact that three out of four people with ASD had some type of day activity sounds positive, but what were these people doing? When you break down the numbers, a different story emerges.

Of those who participated in any type of work or other day activity...

- 78% **participated in unpaid activities**, either community-based or facility-based.
- 70% participated were in facility-based work or activities.
- Only 44% were in community-based work or activities.
- Only 38% participated in **paid work**, either community-based or facility-based.

What about those who had no work or activities?

One in four adults with ASD (27%) had no work or other day activities within the previous two weeks.* This rate was very similar to that of all other DD service users (26%). Adults with ASD in the ACS were less likely to have employment or other day activities if they were younger, had either no intellectual disability (ID) or severe or profound ID, primarily used nonverbal communication, and had poor or fairly good overall health. Of those who had no work or other day activity, 22% reported that they needed some type of service. Those needs included employment services (21%), education or training (29%), or transportation (18%)

*NOTE: Adults who had missing information on participation in employment or other day activities were not considered for this indicator. For example, if it was recorded that a person did not have paid or unpaid community employment, but information on paid or unpaid facility-based employment was unknown, we excluded this person from consideration for this particular indicator. For this reason, the percentage of adults with ASD who had no work or other day activities and the percentage of adults with any type of work or other day activity do not sum to 100%. About 1% of adults with ASD had unknown responses for all four types of work or day activity.

What DD services are offered to support work and activities?

DD services are delivered in community-based or facility-based settings. Which services a person receives is supposed to be determined through a person-centered planning process and written into an individualized plan called a person-centered services and supports plan. The services listed below are primarily funded through Medicaid Home and Community-Based Services (HCBS) waivers (see **Background** chapter). They are provided to help people achieve employment-related goals in their service plan.[4]

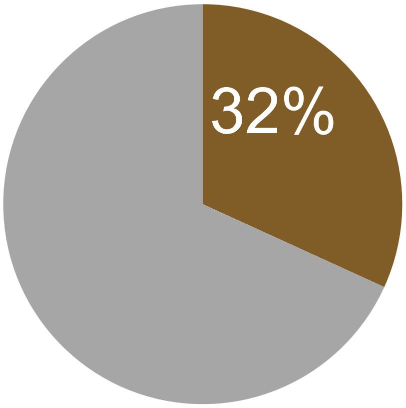
Habilitation services are supposed to assist individuals acquire, retain and improve the self-help, socialization, and adaptive skills needed to successfully live in home and community-based settings. Little research has evaluated the quality or effectiveness of habilitation services. **Expanded Habilitation services related to employment** include:

- **Pre-vocational services.** These are general learning and work-like experiences, including volunteer work and are primarily delivered in a setting that only includes people with disabilities. These services do not teach job-specific skills, but instead teach general skills to prepare a person for a future job such as completing tasks, workplace safety, getting along with others and attendance. Pre-vocational services are provided to people who are not able to work in the community or participate in sheltered workshops, and who are unlikely to achieve competitive employment at or above minimum wage. Pre-vocational services are different than vocational services funded through state Vocational Rehabilitation (VR) agencies. VR services are designed to help people get and keep a community-based job, and teach job-specific skills.

- **Supported Employment services.** These services include “supervisory services, training, transportation, and adaptive equipment” needed to perform a paid job in an integrated setting for compensation at or above minimum wage. People who receive supported employment services need intensive supports in order to work - such as job discovery or assessment to help find a job, coaching provided at the job to teach job tasks, or transportation to a job. Supported employment does not include volunteer work and cannot duplicate supported employment services available through VR. VR typically provides time-limited supported employment services, but supported employment through DD services can be longer-term.

Community-based employment or other day activities

One in three adults with ASD participated in community-based settings.



had a paid job or unpaid activity in the community in the two weeks prior to the ACS.

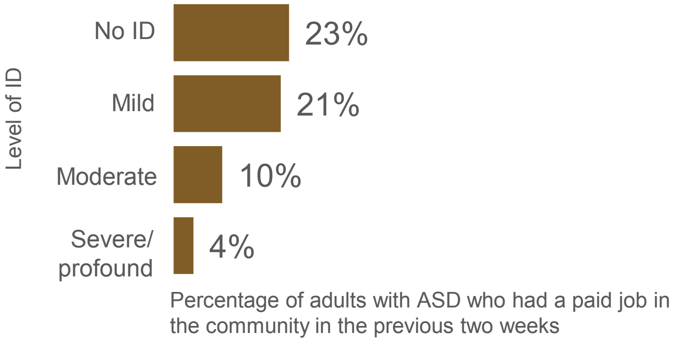
Source: NCI Adult Consumer Survey 2014-15

What do we know about…paid work in the community?

Of all adults with ASD… Only 14% held a paid job in the community in the two weeks prior to participating in the ACS. This did not vary by age group, or by race/ethnicity, and was essentially the same rate as other DD service users (16%).

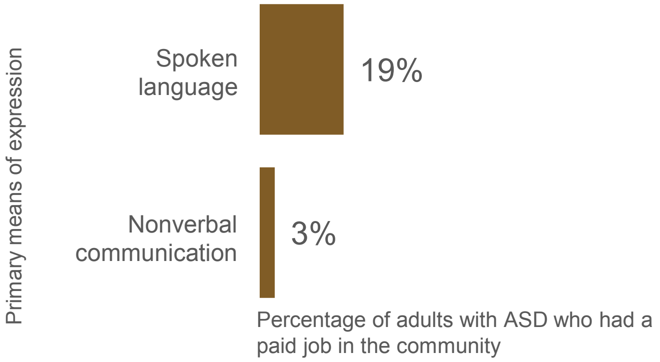
Adults with no ID or with mild ID more often had paid jobs in the community than those with more severe levels of ID. Adults who used spoken language as their primary means of expression were more likely to have paid jobs in the community than adults who primarily used nonverbal communication

Adults with ASD who had no ID or mild ID were more likely to have a paid job in the community than those with more significant ID.



Source: NCI Adult Consumer Survey 2014-15

Those who used spoken language were more likely to have a paid job in the community.



Source: NCI Adult Consumer Survey 2014-15

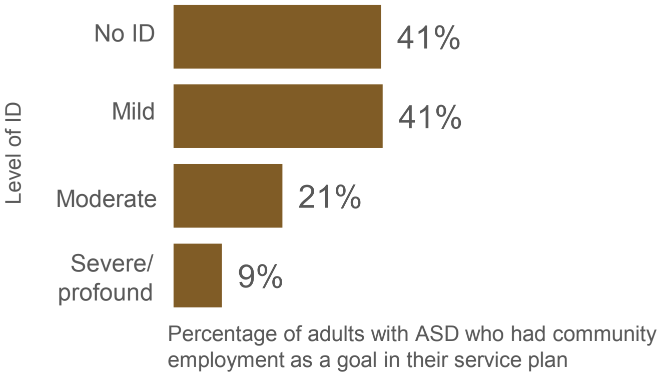
Of those who had a paid job in the community… Nearly two-thirds (62%) received publicly funded services to facilitate their employment, and 34% were working in a job done primarily by a group of people with disabilities. Most adults experienced continuity in their current employment, having worked 10 of the last 12 months in the same position (84%). The average length of time spent in this position was 5 years (range: 1 month to 33 years).

Few had community-based employment as a goal in their service plan.

According to background records, **about one-fourth (27%) of adults with ASD had community employment as a goal in their service plan.** This did not vary by race/ethnicity, but did vary by age (36% of adults age 18-24, 31% of adults age 25-29, 23% of adults age 30-44, and 17% of adults age 45-64). More adults with no ID or mild ID had community employment in their service goals than adults with moderate or severe/profound ID. More adults who used spoken language as their primary means of expression had community employment as a goal in their service plan than adults who primarily used nonverbal communication. An equal number of other adult DD service users had community employment as a goal in their service plan.

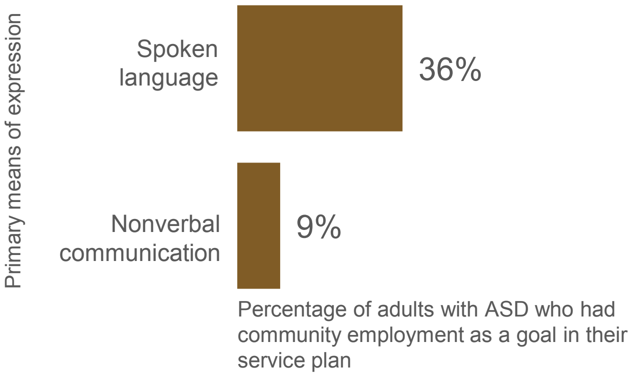
It is important to remember that the **rate of ID varies by age**. Differences in outcomes across age groups might simply reflect the fact that older individuals in this survey were more likely to have ID.

Adults with ASD who had no ID or mild ID were more likely to have community employment as a goal.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who used spoken language were more likely to have community employment as a goal.



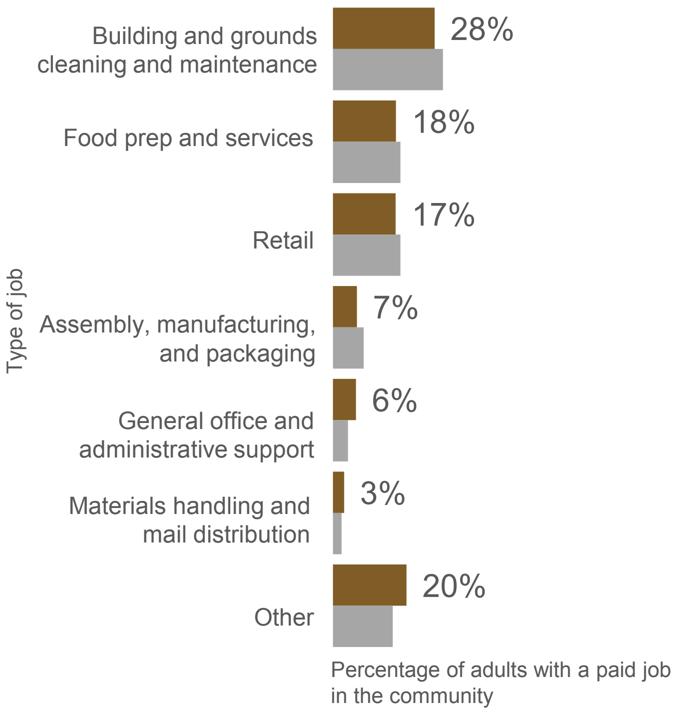
Source: NCI Adult Consumer Survey 2014-15

What types of paid jobs did people have in the community?

Of those who had a paid job in the community…. People spent an average of 30 hours working in the prior two-week period, earning a median wage of $194 (total over the two week period). Almost one-fourth (23%) got vacation or sick time at their job.

The most common job types were building and grounds cleaning and maintenance; and "other" types of jobs. (Note: There was no additional data about what these "other" jobs were.) Food preparation or food services jobs, and retail jobs, were the next most common, followed by assembly, manufacturing, or packaging; and general office support and administration jobs. The most common jobs in adults with ASD were the same as those of other DD service users. Comparatively, people with ASD who exited VR during FFY 2014 most commonly worked in office and administrative support (22%), food preparation and serving (16%), and building and grounds cleaning and maintenance (10%).[5]

Common job types in adults with ASD versus all other DD service users.



Source: NCI Adult Consumer Survey 2014-15

In their own voices

Self-respondents were able to answer questions about employment using yes, *in-between*, or *no*. Similarly, some questions allowed for responses of *sometimes*. For this I*n Their Own Voices section*, those who answered *in-between* were included as responding *no*, and those who answered *sometimes* were included as responding *yes*.

Opinions about community-based employment

Twenty-nine percent of self-respondents with ASD reported that they had a paid job in the community. This did not vary greatly by age. Most (87%) liked where they worked, but about a third (36%) reported that they would like to work somewhere else.

Of self-respondents who did not have a paid job in the community, **half said they would like to have a community-based job. But, only 52% of these self-respondents actually had community employment as a goal in their service plan**. More young adults (18-24 years) reported wanting a paid job than middle-aged adults (45-64 years) with ASD.

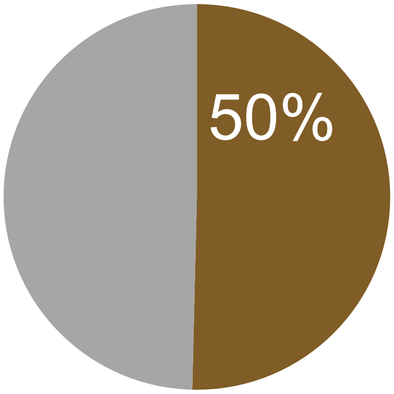
Opinions about day activities

Two thirds (65%) of self-respondents with ASD said they participated in a day activity that did not include community-based employment. Of those who participated in day activities, 89% said they liked doing that activity, and 29% said they would like to go somewhere else or do something else.

In regard to **safety in the community**, many (88%) self-respondents reported that they were ever scared at work or in their day activities.

People with I/DD want to be heard. While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

It is important to know what adults want, so it can be reflected in their service plan.



of self-respondents with ASD who were unemployed said that they would like to have a job.

Source: NCI Adult Consumer Survey 2014-15

Self-report on paid community employment mostly concurred with what was noted about paid community-based employment in people's state records. Of self-respondents with ASD who had a note in their state records of paid community employment in the two weeks prior to participation in the ACS, 93% self-reported that they had a paid community job. Similarly, 79% of self-respondents with ASD who said they had a paid job in the community had a notation of paid community employment in their state record.

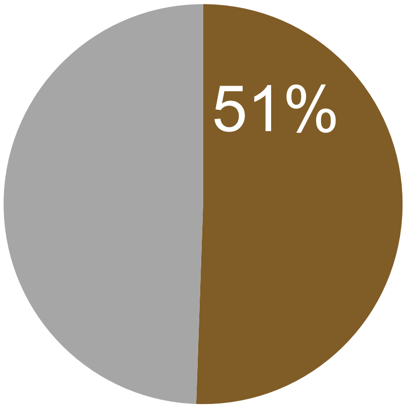
What do we know about… unpaid activities in the community?

Of all adults with ASD... Nearly one-fourth (22%) had an unpaid activity in the community (often referred to as community-based non-work) in the two weeks prior to participating in the ACS. This did not vary greatly by age. Participation in unpaid activities in the community did not vary greatly by race/ethnicity, level of ID or by primary means of expression. Eighteen percent of all other DD service users had an unpaid job in the community.

Of those who participated in unpaid activities in the community… Those with an unpaid community-based activity participated an average of 27 hours over the previous two weeks. Almost three-fourths (73%) received publicly funded services or supports to facilitate participation in this activity. Over half of these unpaid community activities (60%) occurred in segregated settings (mostly people with disabilities).

Facility-based employment or other day activities

Federal policies discourage participation in facility-based settings.



of adults with ASD in the ACS had a paid job or unpaid acitvity in a **facility** in the prior two weeks.

Source: NCI Adult Consumer Survey 2014-15

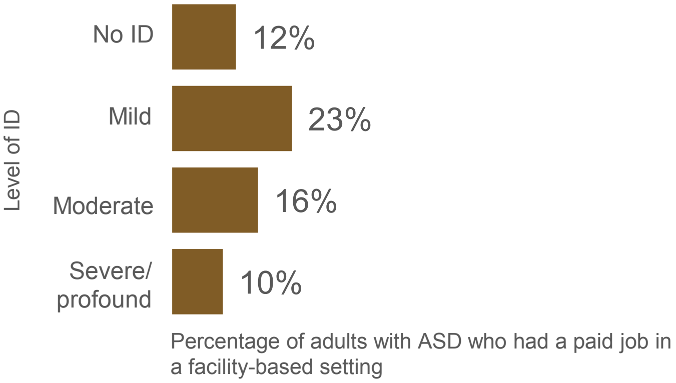
Of all adults with ASD... Over half (51%) had any type of facility-based employment or day activity, either paid or unpaid, in the two weeks prior to the ACS. Recall that a facility-based setting is one in which most of the workers or participants have a disability. Examples include sheltered workshops or activity centers (sometimes called day programs or day habilitation centers) that teach skills to prepare people with disabilities for community living. A person in a paid facility-based job may work primarily with co-workers with disabilities on simple, repetitive activities, such as packing produced goods, often for well below minimum wage. A person in an unpaid facility-based activity may spend time learning computer skills, money skills, and going on community outings such as trips to the store. The emphasis of this activity is skill building to promote independent functioning.

What do we know about… paid work in facilities?

Of all adults with ASD... About 15% had paid work in a facility-based position in the two weeks prior to participating in the ACS. This did not vary greatly by age or by race/ethnicity. Adults with mild ID were the most likely to participate in a paid facility-based position, and those with severe or profound ID or with no ID were less likely to have a paid facility-based position. Participation in a paid facility-based position did not vary by the primary means of expression in adults with ASD. Those with ASD were less likely to have a paid facility-based job compared to 22% of other DD service users.

Of those who had paid work in facilities… On average, adults worked 33 hours in their position in the prior two weeks. The median wage earned over that two week period was $37 (total over the two week period).

Adults with ASD who had mild ID were the most likely to have a paid facility-based job.



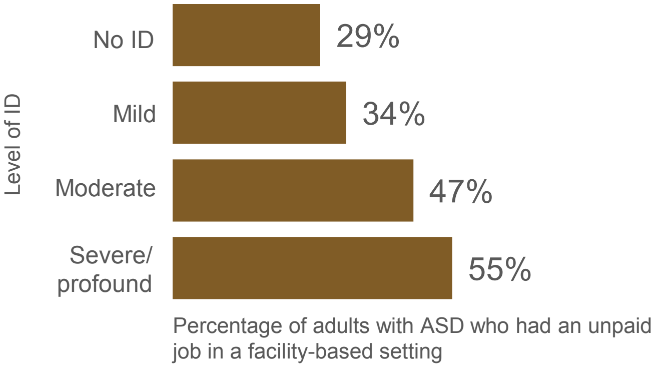
Source: NCI Adult Consumer Survey 2014-15

What do we know about… unpaid activities in facilities?

Of all adults with ASD… 42% participated in an unpaid facility-based activity in the two weeks prior to participation in the ACS. Adults with severe or profound ID were the most likely to participate in an unpaid facility-based activity, followed by those with moderate ID. Adults who used spoken language as their primary means of expression were less likely to participate in unpaid facility-based activities than those who used nonverbal communication. Adults with ASD participated in unpaid facility-based activities at the same rate as other DD service users. Participation in unpaid facility-based activities did not vary by race/ethnicity.

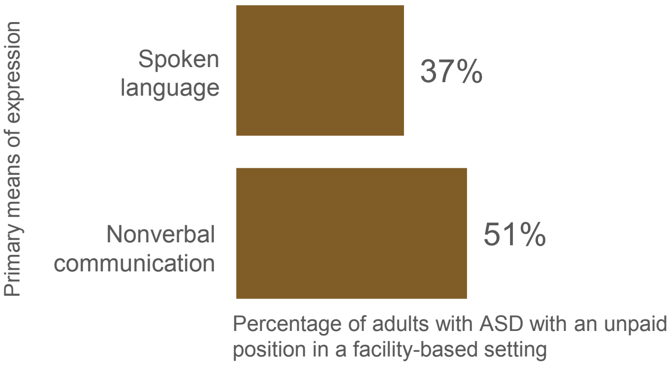
Of those who had unpaid activities in facilities… On average, adults participated 45 hours in their activity during the prior two weeks.

Participation in unpaid, facility-based activities increased with more significant levels of ID.



Source: NCI Adult Consumer Survey 2014-15

Those who used nonverbal communication were more likely to participate in unpaid, facility-based activities.



Source: NCI Adult Consumer Survey 2014-15

SPOTLIGHT: Opportunities for Choice

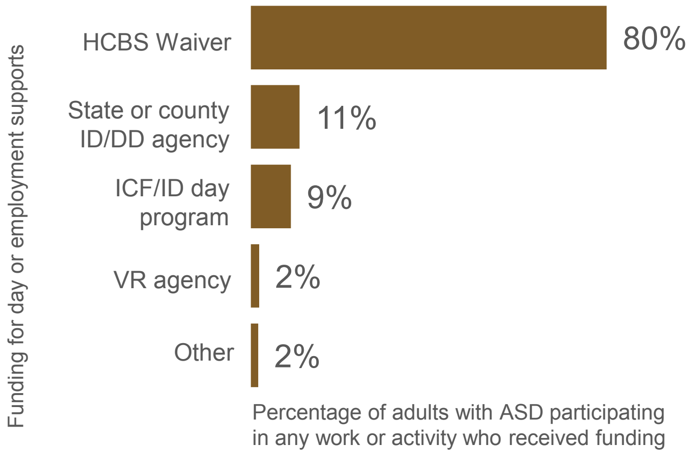
ACS participants (or their proxies) were asked, “Who chose (or picked) the place where you work? Did you help make the choice?” (or “Who chose the place where s/he works? Did s/he have any input in making the decision?”) Of adults with ASD with a paid job in the community, 35% chose the place they work, while 36% had some help in deciding, and 29% had the decision made for them. Of adults with ASD who had a facility-based job or day activities, or community-based (non-work) activities, 20% chose the place for themselves, while 32% had some help in deciding, and almost half (48%) had this place chosen for them. We don’t know the degree to which people felt they could actually make employment decisions for themselves.

SPOTLIGHT: Current Trends in Funding for Services

The bulk of the funding for state DD services comes from Medicaid Home and Community Based Services (HCBS) funds (see **Background** chapter). Therefore, guidance from the Centers for Medicare and Medicaid Services (CMS) has an effect on state DD services. CMS says that integrated, community-based employment is a priority for how services funded through Medicaid waivers are implemented in states.[4] Despite this, the number of people with I/DD who spend their days doing non-work activities has continued to grow over time.[6] When states were directed to focus their services on community-based settings, community-based non-work was initially used by states as a substitute for community employment. More recently, “States are starting to move from an exclusive focus on employment to thinking about how other community engagement activities relate to and can promote employment.”[7]

Home and Community Based Services (HCBS) Medicaid waivers funded most of the services used to support adults with ASD in their work and day activities. To be clear, waivers pay for services. They do not pay the wages people earn. Also remember that some states only included people in their ACS sample who received HCBS funding, which affects our findings about funding.

Most adults with ASD who had any type of work or activity and received funding for work supports and services got them from an HCBS waiver program.

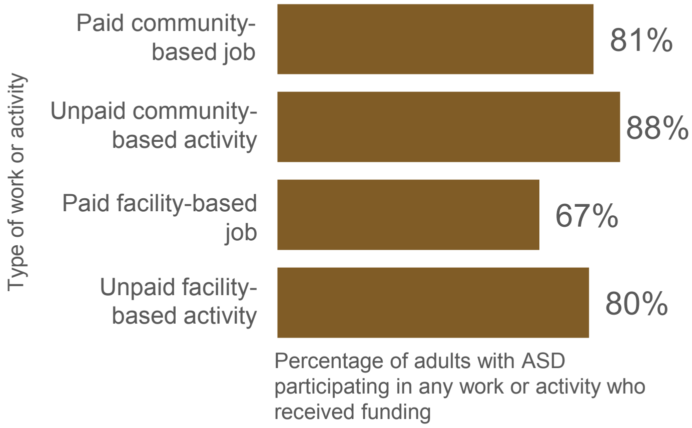


Note: the state of California did not report on the source of support for employment or day programs.

Source: NCI Adult Consumer Survey 2014-15

HCBS waivers paid for services to support people across all four types of employment or day activities:

HCBS waivers paid for services to support people across all four types of employment and day activities.



Note: the state of California did not report on the source of support for employment or day programs.

Source: NCI Adult Consumer Survey 2014-15

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Employment and Other Day Activities and other topics.

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Living Arrangements

Many adults resided with parents or relatives.

Our key findings

- **Almost half (49%) of adults with autism spectrum disorder (ASD) lived in the home of a parent or relative.** Many of those who lived with their families had been there for more than 5 years.
- Nearly four in ten adults with ASD who lived with parents or relatives received no paid in-home supports. Of these, 37% indicated they needed some type of supports or services.
- One-fourth (27%) lived in group homes with up to 15 people who also had disabilities. It was uncommon for adults with ASD to live in institutions.

Why living arrangements matter

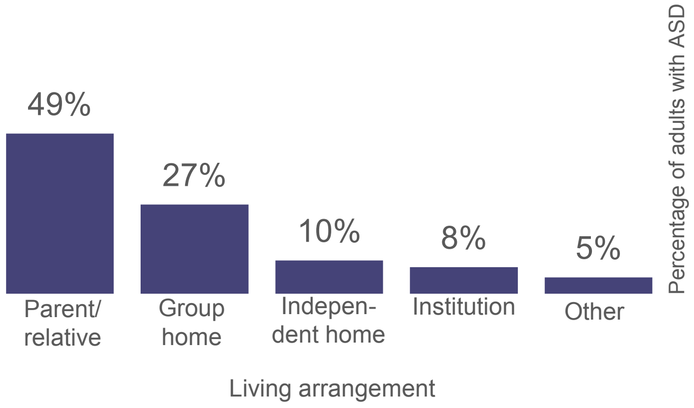
For all people, where we live and the supports we receive in that living situation impacts our quality of life. Where people with intellectual or developmental disabilities (I/DD) tend to live has changed dramatically over the last 50 years. Prior to the deinstitutionalization movement in the late 1970's, 84% of people with I/DD who received state-funded residential services lived in large institutional settings. By 2010, 75% lived in settings with 6 or fewer people.[1] More people with I/DD now live in the community in a home or a group home. They may receive assistance from direct support staff in their home, but fewer live in large institutional settings that are directly operated by states.

Whereas youth with I/DD transition into a variety of community-based living arrangements, most young adults with ASD continue living with their family members in the early years after leaving high school.[2-3] A study of NCI participants found that 38% of DD service users with ASD lived at home with family - a rate higher than participants who did not have ASD (29%).[4]

Nearly half of adults with ASD lived with a parent or relative.

Information about where people lived came from state records and reflected where people were living at the time of the Adult Consumer Survey (ACS). Overall, **almost half (49%) of adults with ASD lived in the home of a parent or relative**.

Adults with ASD were most likely to be living with family members.

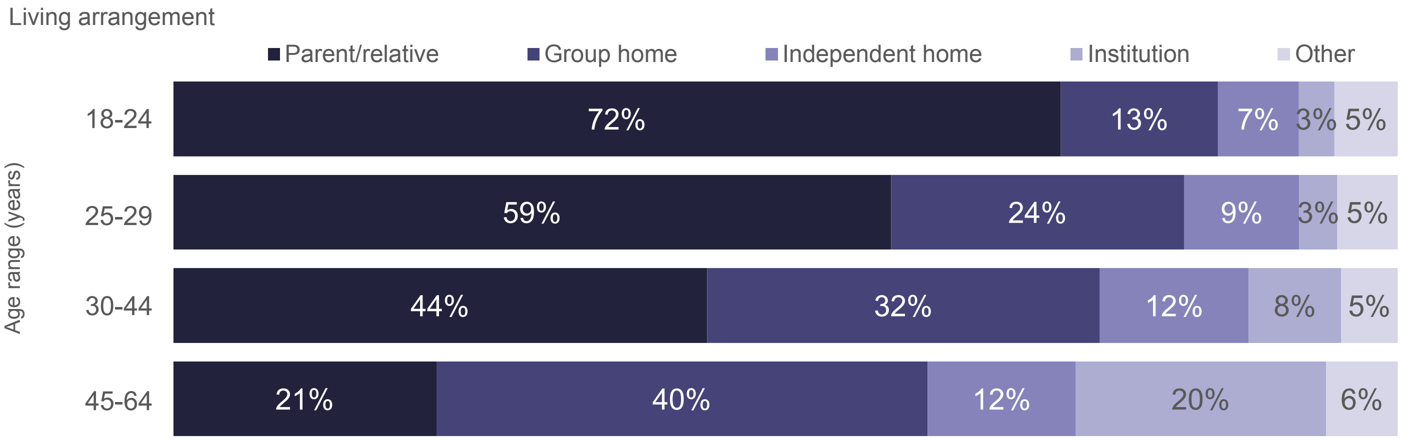


Source: NCI Adult Consmer Survey 2014-15

The percentage of adults with ASD who lived with a parent or relative varied widely by age. Three-quarters of young adults (18-24 years) lived at home and half of those ages 25-29 years, but this declined dramatically in the middle-aged (45-64 year) group. It also varied by level of ID, with more adults with no ID living in the home of a parent or relative (64%) than adults with mild ID (52%), moderate ID (50%) or severe or profound ID (33%). Adults with ASD who used spoken language as their primary means of communication were more likely to live in the home or a parent or relative (53%) than adults who primarily used nonverbal communication (42%). Adults with other DDs were less likely to live in the home of a parent or relative (41%).

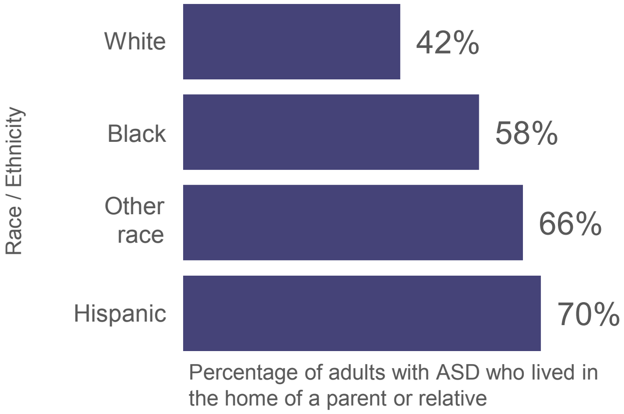
It is important to remember that the **rate of ID varies by age**. Differences in outcomes across age groups might simply reflect the fact older individuals in this survey were more likely to have ID.

Young adults with ASD were more likely to live with family than middle-aged adults.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD of Hispanic ethnicity were most likely to live in the home of a parent or relative.



Source: NCI Adults Consumer Survey 2014-15

Very few lived on their own. One in ten adults with ASD who participated in the ACS lived independently in a home or apartment, compared to 15% of adults with other DDs. This rate did not vary greatly by age. Of those adults with ASD who lived in an independent home or apartment, 62% owned or rented their own home; while 16% had a family, guardian, or friend who owned the home; and 14% lived in a home owned by a private agency.

One-fourth lived in group homes.

One in four (27%) adults with ASD in the ACS lived in a group home, with middle-aged adults more likely to live in a group home than young adults. Adults with ASD who used spoken language as their primary means of communication were less likely to live in a group home (24%) than adults who used non-verbal communication (34%). The overall rate was similar to the percentage of adults with other DDs who lived in a group home (28%). Of adults with ASD who lived in a group home, over half (57%) lived in a group home with 4-6 residents with disabilities, while 31% lived in group home with 1-3 residents with disabilities, and 12% lived in group home with 7-15 residents with disabilities. Sizes of group homes that people with ASD lived in were similar to group homes for people with other DDs.

What is a group home?

A group home is a home or apartment where a group of people with disabilities live, usually owned and staffed by an agency. Sizes of group homes vary between 1-15 residents with smaller group homes being more common.

Only a small percentage lived in institutional care settings.

Eight percent of adults with ASD lived in an institutional care setting - the same rate as adults with other DDs. Institutional long term care settings, as defined by Medicaid, include intermediate care facilities for people with I/DD (called ICF/IDs). ICF/IDs are residential facilities that deliver care to people who require high levels of supervision and "active treatment programs" defined as "aggressive, consistent implementation of a program of specialized and generic training, treatment and health services." These facilities are primarily funded with ICF/ID funds. Read more about funding at the end of this chapter.

Middle-aged adults with ASD were more likely to live in an institutional setting than younger adults (20% versus 3%). Of adults with ASD who lived in an institutional setting, 44% lived with 16 or more people, while 24% lived with 4-6 people, and 9% lived with 1-3 people. Another 8% lived in a different type of specialized institution. This was similar to adults with other DDs.

Note: California and New Hampshire did not report on the size of the institutions for their residents, so those residents are not included in these statistics.

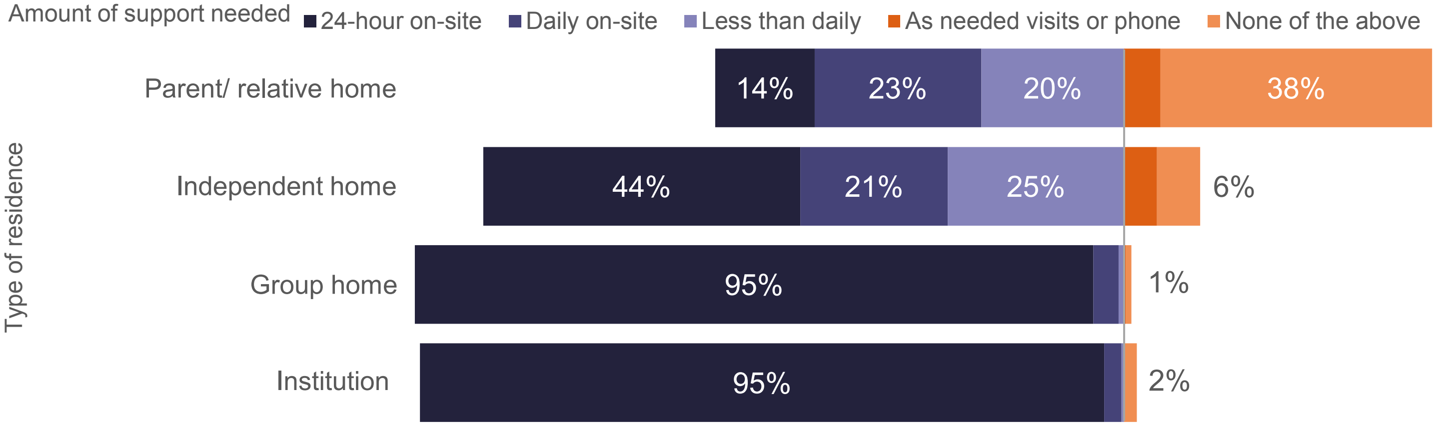
Adults tended to remain living with parents or relatives.

Nearly two-thirds (64%) of adults with ASD had lived in their current home for more than five years. This did not vary greatly by age. Adults with ASD who lived in the same place for more than five years, more commonly lived in the home of a parent or relative (81%) versus an institution (61%), in a group home (49%), or in an independent home or apartment (33%).

Support in the home

Background records were used to answer, "What amount of paid support does this person receive at home?" The levels of support provided to adults with ASD varied from continuous (24-hour) on-site care, to daily or less than daily support, to as-needed visits or phone calls to check in. Nearly half (49%) of adults with ASD received 24-hour on-site support in their home. This varied by living arrangement. For example, nearly all adults in institutions or in group homes had round-the-clock supports, but this was less common for adults in independent homes or apartments, or for adults living in the home of a parent or relative. **Overall, nearly four in ten adults with ASD (38%) who lived with parents or relatives received no paid in-home supports.** Of these, 37% indicated they needed services or supports. Their most frequent support needs were education or training services (43%), social or relationship services (37%), and respite services (31%).

Adults with ASD who lived in group homes or institutions were more likely to receive intensive hours of in-home supports.



Source: NCI Adult Consumer Survey 2014-15

In their own voices

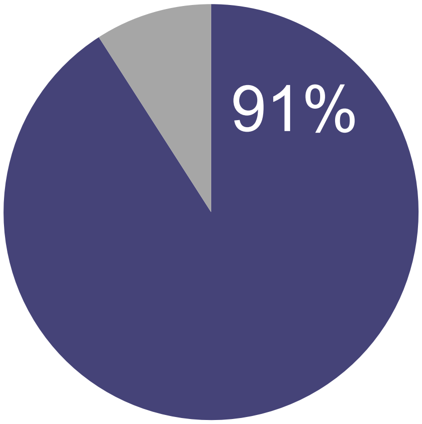
Self-respondents were able to answer questions about living arrangements using yes, *in-between*, or *no*. Similarly, some questions allowed for responses of *sometimes*. For this *In Their Own Voices* section, those who answered *in-between* included as responding *no*, and those who answered *sometimes* were included as responding *yes*.

Most liked where they lived.

Adults with ASD who were able to self-respond to survey questions were asked, “Do you like your home or where you live?” Most reported that they liked their home. This did not vary greatly by age or the type of home, level of ID, or primary means of expression. Most adults with other DDs who answered this survey question on their own also said they liked their home (90%).

People with I/DD want to be heard. While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

Self-respondents were asked whether they liked where they lived.



of self-respondents with ASD said they liked their home.

Source: NCI Adult Consumer Survey 2014-15

Some interacted with neighbors.

Questions about safety and neighborhood interactions were only asked to self-respondents. Over half (59%) of adults with ASD reported that they ever talked to their neighbors (either speaking to them sometimes or regularly). This varied by the type of living arrangement. More adults who lived in an independent home or apartment (68%) or in the home of a parent or relative (61%) spoke to their neighbors than those living in group homes (50%) or institutions (39%).

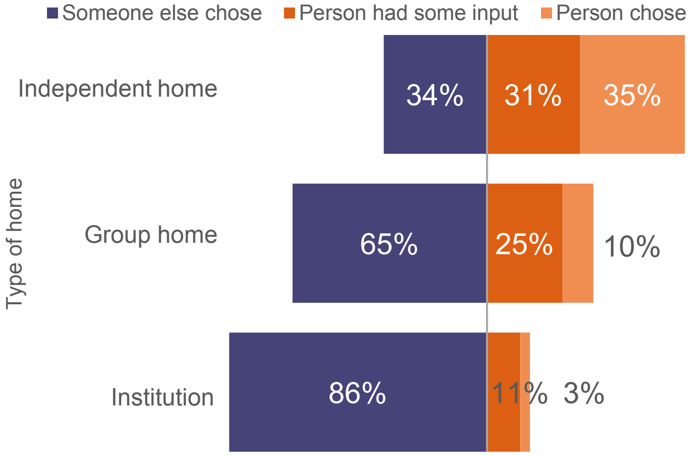
Few with ASD chose their own home or who lived with them.

ACS participants (or their proxies) were asked “Who chose (or picked) the place where you live? Did you help pick the place where you live?” (or “Who chose the place where s/he lives? Did s/he have any input in making the decision?”) Sixteen percent of adults with ASD reportedly chose their own home. Nearly one fourth (24%) had some input in choosing, but 60% had the choice made for them. This did not vary greatly by age, but did vary by type of living arrangement. Adults with ASD who lived in an institution rarely chose the place they lived, or gave input about it. About one-fourth of those who lived in a group home had some input in the choice of living arrangement. About two-thirds of those who lived in an independent home or apartment chose their home, or had some input about it. This question was not asked to those who lived in the home of a parent or relative.

ACS participants (or their proxies) were then asked “Did you choose (or pick) the people you live with (or did you choose to live by yourself)?” (or “Did this person choose any of the people s/he lives with?”) Seventeen percent of adults with ASD reportedly choose their roommates, while 14% had some input in the choice. But 68% did not have a choice about roommates. The level of input in this choice varied by living arrangement. It was rare that adults with ASD who lived in an institution chose their roommates (3%) or had some input in the choice (7%). It was also uncommon for adults who lived in a group home to choose their roommates (7%) or to have some input in the choice (14%). Half (51%) of adults who lived in an independent home or apartment chose their roommates, or had some input in the choice (18%). This question was also not asked to those who lived in the home of a parent or relative.

Two-thirds of adults with ASD who lived in a home on their own had at least some input about where they lived.

Who chose the person's home?



Source: NCI Adult Consumer Survey 2014-15

Funding for Long Term Services and Supports

There are two main types of funding for long term supports within different living arrangements.

Recall that **Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID) funding** is primarily used to provide services to people with I/DD in state-run residential facilities. Most (82%) adults with ASD who lived in a residential facility (institution) received ICF/ID funding, while 9% received HCBS waiver funding, and 11% received some other type of funding. We note here that ACS data indicates there are people who live in an ICF who do not get ICF funding. There are also a very few people who do not live in an ICF who get ICF funding.

Receipt of this type of funding varied by age, with 4% of adults ages 18-24 receiving ICF/ID funding, 5% of those ages 25-29, 8% of those ages 30-44, and 20% of those ages 45-64.

Home and Community Based Services (HCBS) Medicaid waivers fund Long Term Services and Supports (LTSS) that support adults with ASD in their living arrangement. To be clear, waivers pay for services. They do not pay rent or mortgages. Most (93%) adults with ASD who lived in a group home received HCBS waiver funding, 4% received ICF/ID funding, and 3% receiving some funding that was not ICF/ID or HCBS waiver funding. Similarly, 93% of adults who lived in an independent home or apartment received HCBS waiver funding and 3% received some other type of funding. Most (89%) adults with ASD who lived in the home of a parent or relative received HCBS waiver funding, and 9% received some other type of funding. Note: Recall that we told you earlier that four in every 10 adults who lived with parents had no in-home paid supports, but they may have had other HCBS funding to pay for services like employment or health care.

Also remember that some states only included people in their ACS sample who received HCBS funding, which affects our statistics about funding. Additionally, we do not have any information about HCBS or ICF funding from California or New Hampshire.

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Employment and Other Day Activities and other topics.

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Social and Community Participation

Most adults reportedly got out in the community monthly, but less than half chose their daily schedule.

Our key findings

- Most adults (over 80%) with autism spectrum disorder (ASD) got out at least monthly to shop, eat out, run errands, or for entertainment. Almost half had been on vacation during the last year.
- Most self-respondents with ASD (84%) said they always had a way to get to where they wanted to go - usually getting a ride from family or friends.
- **Less than half (43%) of adults chose their daily schedule on their own in regard to when they woke up, ate, or went to sleep; 40% could choose how to spend their money on their own.**
- About three-fourths of self-respondents (72%) said they had a friend who was not a family member or staff. However, 41% also reported feeling lonely sometimes.

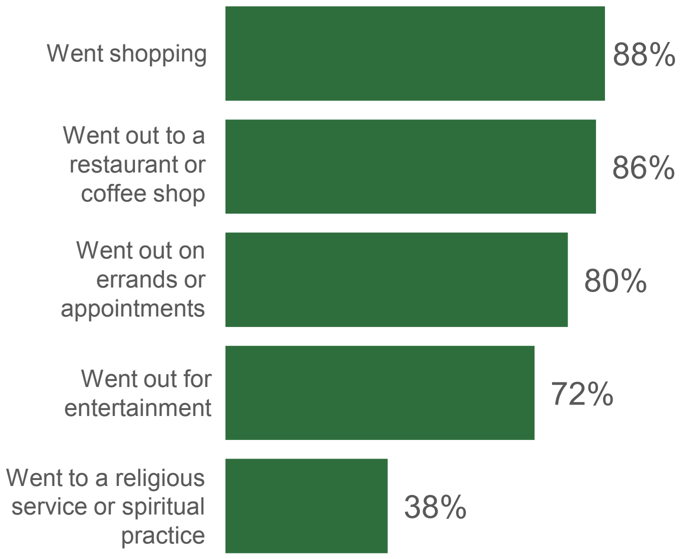
Social and community participation matter.

Adults with ASD report a strong desire for acceptance within their communities at large,[1] paired with opportunities to connect with other people who share their common interests. There is no single level or type of social and community inclusion that is the right fit for all adults with ASD. People should be able to participate in their communities and have meaningful relationships and friendships to the extent that they choose and in the ways that they prefer. The ACS does not fully capture all the ways that people interact with friends, participate in their communities or the choices they have in their lives. However, it does provide some important baseline information about social and community participation of adults with ASD who received developmental disability (DD) services.

Most adults with ASD participated at least monthly in shopping and dining out.

Adults with ASD (or their proxies) were asked about activities in the community. On a monthly basis, most adults with ASD had been shopping (88%), out to a restaurant or coffee shop (86%), out on errands or to appointments (80%), or out for entertainment (72%) in the month prior to the survey. About a third had been to a religious service or spiritual practice in the month prior to the survey (38%). These did not vary by age. Two percent of adults with ASD had done none of those activities in the prior month. Responses were scored as *no* if they occurred in a non-integrated setting (settings that included only people with disabilities).

Most adults with ASD had been shopping, out to a restaurant, or on errands in the month prior to participating in the ACS.

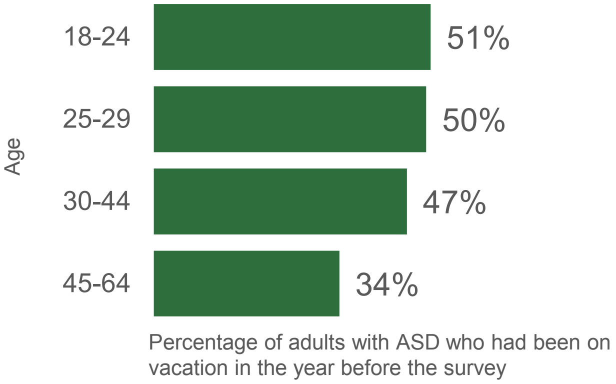


Source: NCI Adults Consumer Survey 2014-15

Getting out into the community to do shopping or errands varied by functioning level. More adults with ASD who had been shopping in the previous month had mild intellectual disability (ID) (93%), moderate ID (91%), or no ID (90%), than those with severe or profound ID (81%). More adults with ASD who primarily used spoken language had been out shopping in the previous month (92%) than those who primarily used nonverbal communication (82%). A similar pattern was seen in those who had been out on errands in the previous month (84% of adults with mild ID, 82% of those with no ID, 80% of those with moderate ID, and 72% of those with severe or profound ID).

Almost half (46%) of adults with ASD went away on vacation in the year prior to the survey. Over half of young adults (18-24 years) took a vacation compared to one-third of middle-aged adults (45-64 years). Adults who lived in the home of a parent or relative (54%) or independently (58%) were the most likely to have been on a vacation in the previous year. Those who lived in a group home (39%) or an institution (18%) were the least likely.

Young adults with ASD were more likely to have been on a vacation in the previous year than middle-aged adults with ASD.



Source: NCI Adult Consumer Survey 2014-15

In their own voices

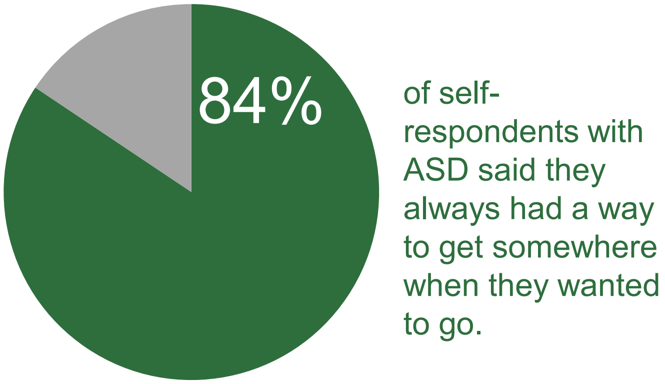
Self-respondents were able to answer questions about social and community participation using *yes, sometimes*, or *no*. For this *In Their Own Voices* section, those who answered *sometimes* were included as responding *no*.

People with I/DD want to be heard.
While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

Getting around in the community

Adults with ASD who could respond to survey questions on their own were asked, “When you want to go somewhere, do you always have a way to get there?” and “How do you usually get to the places you need to go?” A checklist was used to record the most frequent ways the person got around town. (Note: More than one box could be checked). **Most self-respondents with ASD said they always had a way to get to where they wanted to go.** This did not vary by age, level of ID, or primary means of expression, and was similar to the rate for other DD service users who were self-respondents (85%).

Having reliable means of transportation is important for both employment and community living.



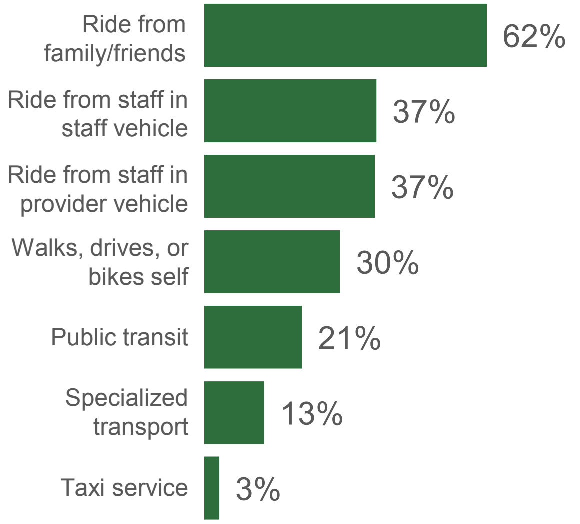
Source: NCI Adult Consumer Survey 2014-15

Nearly two-thirds of self-respondents with ASD said they usually got a ride from family or friends to get to where they needed to go. More than one-third used rides from staff (in the staff member's car or in a provider van or vehicle), and another third used their own form of transportation (e.g., bike, walk, drive). Adults with ASD less commonly used public transportation, specialized transportation such as paratransit service, or a taxi service.

About 16% of self-respondents with ASD said they did not always have a way to get to places they wanted to go, or only sometimes had a way. Of those, one-third said they needed additional services (36%); one-fourth citing that they needed transportation services (25%). This is important since having a consistent mode of transportation is key for employment in the community.

Young adults who self-responded to survey questions were more likely to get rides from family or friends (72%) than middle-aged adults (43%). Middle-aged adults were more likely to get rides from staff in a provider's vehicle (47%) than younger adults (25%).

The most common mode of transportation for self-respondents with ASD was getting a ride from family or friends.



Percentage of self-respondents with ASD who usually used this form of transportation

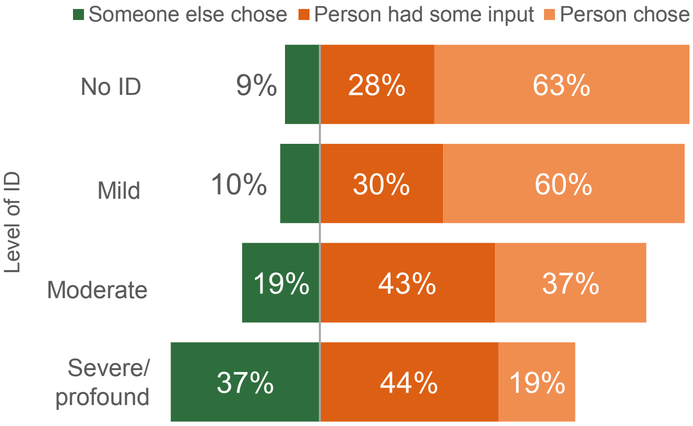
Source: NCI Adults Consumer Survey 2014-15

Decision making and choice of activities

ACS participants (or their proxies) were asked, "Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?" (or "Who decides this person's daily schedule?") **Less than half (43%) reportedly decided their schedule for themselves, while 37% had some help in deciding, and 20% had no choice about their schedule.** Young adults with ASD were more likely to decide their schedule (46%) than middle-aged adults (36%). Those who did not have ID or who had mild ID were more likely to choose their schedule than those with moderate, severe, or profound ID. Those who used spoken language were more likely to choose their own schedule than those who used nonverbal communication. Adults with ASD chose their own schedule at about the same rate as other DD service users.

Adults with ASD who did not have ID or had mild ID were more likely to choose their own schedule.

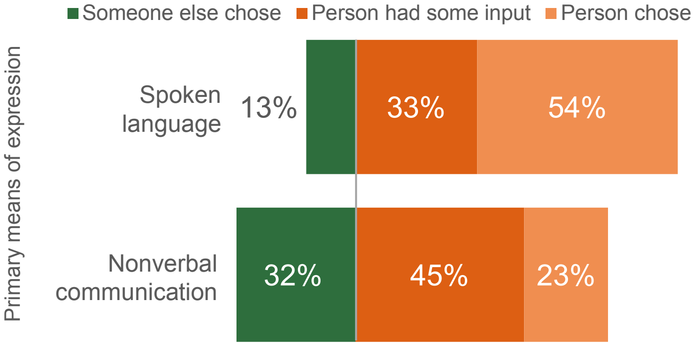
Who chose the person's daily schedule?



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who primarily used spoken language were more likely to choose their own daily schedule.

Who chose the person's daily schedule?



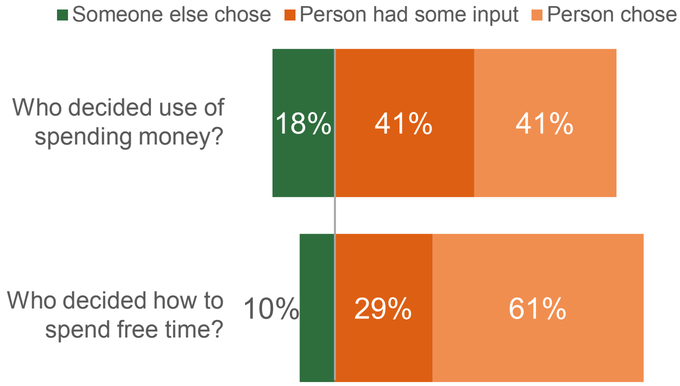
Source: NCI Adult Consumer Survey 2014-15

ACS participants (or their proxies) were also asked, "Who decides how you spend your free time (when you are not working, in school or at the day program)?" (or "Who decides how this person spends his/her free time?") **Over 40% of adults with ASD reportedly could choose what to do with their spending money (excluding money for rent, groceries, or other living expenses), while an equal number had some help in deciding, and adults less commonly had spending choices made for them.** Young adults with ASD were more likely to decide what to do with their spending money (46%) than middle-aged adults (34%). Nearly two-thirds of adults with ASD made their own decisions about how to spend their free time, while one-third had some help in deciding. Others had the choice made for them.

Only 6% of adults with ASD had no say in their daily schedule, how they spent their free time, or how they used their spending money.

Most adults with ASD had choice in how they spent their money and their free time.

Who chose each of the following?



Source: NCI Adult Consumer Survey 2014-15

In their own voices

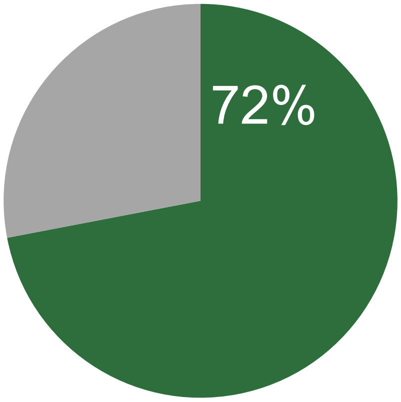
Self-respondents were able to answer questions about loneliness using *yes, sometimes*, or *no*. For this *In Their Own Voices* section, those who answered *sometimes* were included as responding *yes*.

Relationships: Friendships and Family

Self-respondents were asked "Do you have friends you like to talk to or do things with?" and "Do you have a best friend, or someone you are really close to?" Nearly three-quarters reported they had friends who were not staff, and an equal number said they had a best friend. About 14% of self-respondents with ASD said they had no friends who were not staff and no one they were really close to.

Self-respondents with ASD who had no ID, mild, or moderate ID were more likely to report having friends than adults with severe or profound ID. Adults with ASD who used spoken communication were more likely to report having friends (73%) than adults with ASD who primarily used nonverbal communication (62%).

Self-respondents were asked whether they had friends to talk to or do things with.



of self-respondents with ASD said they had a friend who was not family or a staff member.

Source: NCI Adult Consumer Survey 2014-15

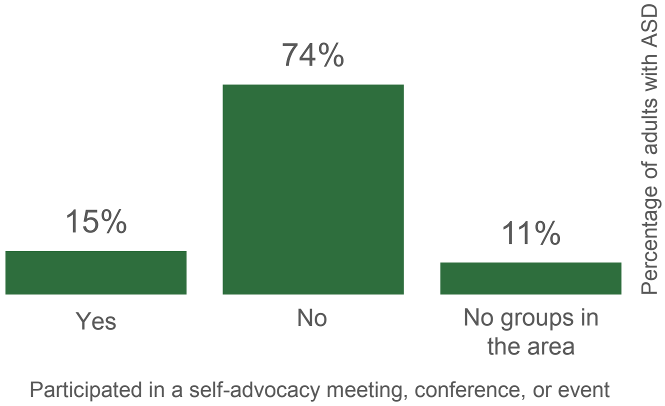
Most self-respondents with ASD (91%) said they had family they see. Young adults were more likely (95%) to report seeing family than middle-aged adults (84%). (Note: If the self-respondent was living with a parent or relative, they were asked if they had other family members that they saw.)
Self-respondents were also asked, "Do you ever feel lonely?" They were able to answer questions about loneliness using *yes, sometimes*, or *no*. For this question, those who answered *sometimes* were included as responding *yes*. Forty-one percent of self-respondents with ASD said that they ever feel lonely.

More self-respondents with ASD who did not have ID said they were ever lonely (44%) than adults with mild (41%) or moderate ID (41%) or severe or profound ID (24%). Self-respondents who primarily used spoken language were more likely to feel lonely (42%) than self-respondents who primarily used non-verbal communication (25%). Other DD service users who self-responded reported feeling lonely at about the same rate (37%) as adults with ASD.

Self-advocacy

Adults with ASD (or their proxies) were asked, “Have you ever participated in a self-advocacy group meeting, conference, or event?” (or “Has this person ever attended a self-advocacy group meeting or event?”) A self-advocacy group was defined as “where people with disabilities meet together to talk about things in their lives that are important to them” and People First was used as one example. Fifteen percent of adults with ASD had ever participated in this type of meeting. Nearly three-fourths (74%) never had, and 11% lived in an area where they did not have access to a self-advocacy group.

Few said they had ever participated in a self-advocacy meeting or event.



Source: NCI Adult Consumer Survey 2014-15

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Employment and Other Day Activities and other topics.

Reference

1. Gotham K, Marvin AR, Taylor JL, Warren Z, Anderson CM, Law PA, Law JK, and Lipkin PH. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, epub.

Independence and Rights

Nearly half were legally independent.

Our key findings

- **Over half (53%) of adults with autism spectrum disorder (ASD) in the Adult Consumer Survey (ACS) had a limited or full legal (court-appointed) guardian.**
- Almost three quarters (74%) of adults with ASD could be alone with guests or visitors in their home.

Why independence and rights matter

National Core Indicators (NCI) uses surveys like the ACS to track whether people receive the same respect and protections as others in the community - primarily in regard to their privacy and legal rights. This final chapter explores the rights of adults with ASD who participated in the ACS and their experiences with privacy.

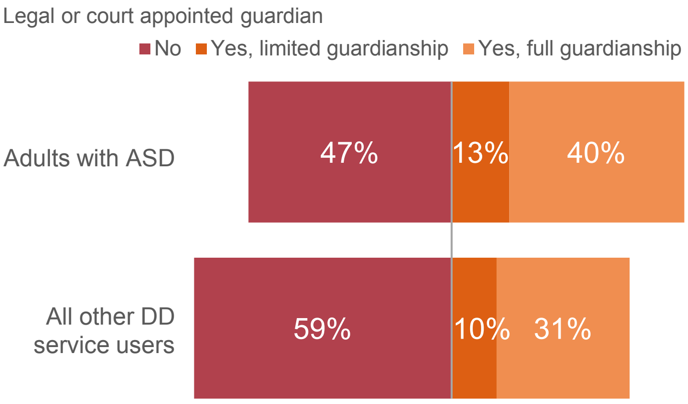
Legal guardianship

Guardianship refers to a legal arrangement in which one person is given authority over decisions and care for a person who is deemed unable (incompetent) to make decisions on their own. There are two types of guardianship asked about in the ACS: limited and full. Limited guardianship means that the court-appointed guardian has control over some areas of the individual's life – such as medical consent and health care decisions. Full guardianship refers to a broad decision-making authority over an individual. The process of establishing guardianship often requires families to hire an attorney.

Whether a person has a legal guardian or not does not necessarily correspond with presence of intellectual disability or other functional impairments, and may have more to do with individual circumstances and which state a person lives in. Having a guardian, however, can be associated with outcomes. For example, people who have a legal guardian are less likely to have community-based employment.[1]

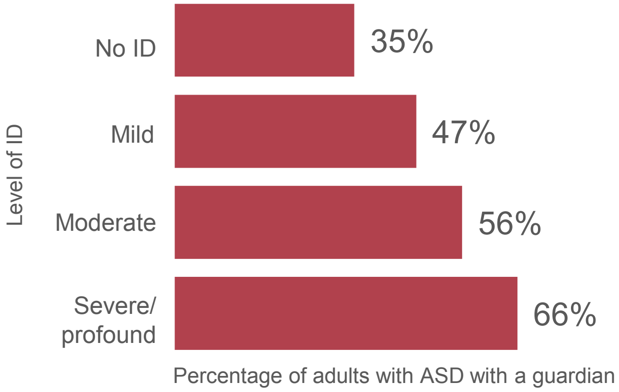
Information on guardianship came from state records. Almost half of adults with ASD in the ACS were legally independent adults, while just over half had a limited or full legal/court-appointed guardian. Guardianship varied based on race/ethnicity. Individuals who were white were more likely to have a limited or full legal guardian. Adults with ASD who did not have intellectual disability (ID) less often had a legal guardian than those with ID. Those who primarily used spoken language were also less likely to have a legal guardian, compared to those who primarily used nonverbal communication. More adults with ASD had a legal guardian than developmental disability (DD) service users with other disability types.

Adults with ASD were more likely to have a guardian than other DD service users.



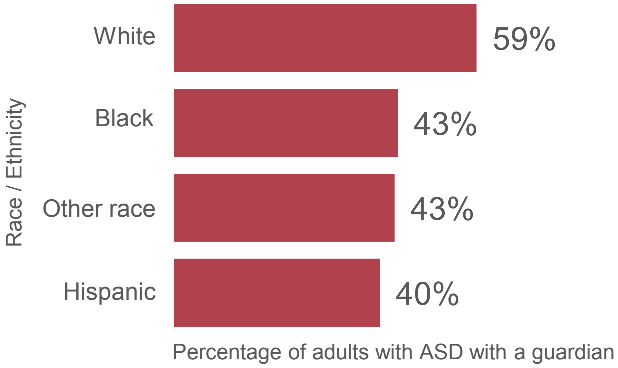
Source: NCI Adult Consumer Survey 2014-15

The likelihood of having a limited or full guardian increased across levels of ID.



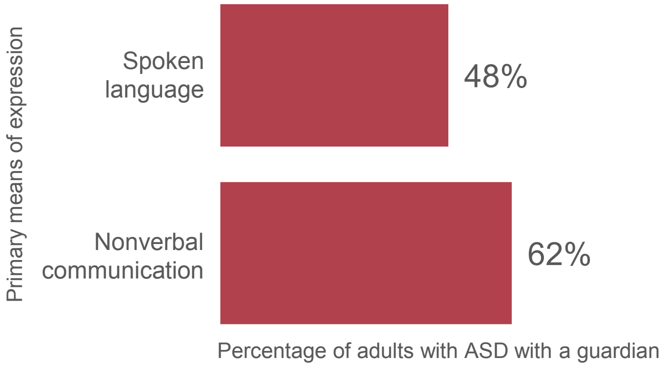
Source: NCI Adult Consumer Survey 2014-15

The likelihood of having a limited or full guardian was highest in adults with ASD who were white.



Source: NCI Adult Consumer Survey 2014-15

Adults with ASD who used nonverbal communication were more likely to have a limited or full legal guardian.



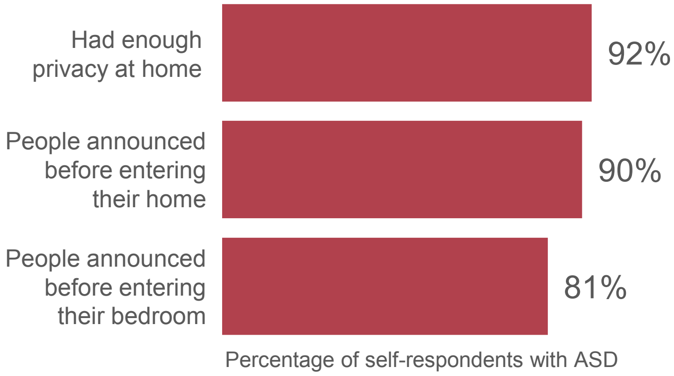
Source: NCI Adult Consumer Survey 2014-15

In their own voices

Independence and rights

Most self-respondents with ASD (92%) who did not live alone said they had enough privacy at home. Most self-respondents with ASD (90%) said people always let them know before entering their home, and 81% said that people always let them know before entering their bedroom. This did not vary by age, level of ID, or primary means of communication, and was similar to DD service users with other disabilities.

Most self-respondents with ASD had enough privacy, and had warning before someone entered their home or bedroom.



Source: NCI Adults Consumer Survey 2014-15

People with I/DD want to be heard. While self-report measures are never flawless, they are an important attempt at measuring the opinions and satisfaction levels of people whose quality of life may be related to the services they receive. Results may be influenced by who asked the questions, how they were asked, who else was in the room, and how well the person understood. Despite these concerns, we present self-responses for people who reportedly understood the questions and gave consistent responses (per the surveyor), to honor their voices. Half of the individuals with ASD in the ACS self-reported information about their personal experiences.

Some experienced social independence

ACS survey participants were asked, “Can you be alone with friends or visitors at your home, or does someone have to be with you?” Almost three quarters (74%) of adults with ASD could be alone with guests or visitors in their home. This did not vary greatly by age, but did vary by level of ID. It was more likely that adults with ASD who did not have ID were allowed to be alone with visitors (83%) than adults with mild ID (76%), moderate ID (73%) or severe or profound ID (68%). Other adult DD service users could be alone with guests or visitors in their home at about the same rate (81%).

Most adults with ASD could use the phone or internet whenever they wanted (89%). Some (14%) sometimes or often had people read their mail or email without asking.

Looking Ahead

Please refer to the **Looking Ahead** chapter for discussion of research gaps and next steps for learning more about Employment and Other Day Activities and other topics.

Reference

1. Nye-Lengerman K, Narby C, and Pettingell S. (in press). How is guardianship status related to employment status for people with IDD? *Bringing Employment First to Scale series*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

What next?... Looking Ahead

Conclusions and recommendations for future research

As recently as 50 years ago, many adults with developmental disabilities, including autism spectrum disorder (ASD), lived in large institutional settings or were at home but very isolated - shut away from society and thought to be incapable of attaining adult social roles like having a job, continuing their education or living in a place of their choosing. Decades of disability rights advocacy by people with disabilities and their families led to federal legislation, legal rulings and changing societal norms. Together, these have pushed us toward what President George W. Bush termed a "New Freedom" - a goal of supporting more people with developmental disabilities (DDs) to live and work in their communities. This shift to community-based inclusion and services has been accompanied by some positive changes in expectations and outcomes. However, today's services are dispersed services are dispersed across neighborhoods and providers, and there is no comprehensive or integrated system of collecting data about the supports people need, the services they end up getting or the results of those services.

In this report series, we continue to point to the need for useful national indicators that can inform the improvement of policies and practices aimed at helping people with ASD. This National Autism Indicators Report raises many questions that need further investigation. The ACS is just one source of data on these topics related to services and outcomes. This Report's findings do not always align neatly with findings from other research studies and data sources.

We conclude this report by noting several significant gaps in knowledge and priorities for future research:

- **A common theme in this report is a discrepancy between what we know from other research about how adults with ASD are faring versus the statistics derived from the Adult Consumer Survey (ACS) data.** For example, a study of the medical records of approximately 1,500 people on the autism spectrum found high rates of poor health and complex medical needs that are not well managed.[1] The ACS data in this report also found high rates of medication and also co-occurring health and mental health conditions. However, the self- and proxy-report ACS data suggests many adults with ASD are in *very good* to *excellent* overall health. Further research is needed to reconcile these kinds of discrepancies and to better understand the health and health care experiences of DD service users.
- The bulk of public funding for the services people with ASD say they need comes through local and state DD agencies. **We still know very little about which types of DD services work best for whom, or which related state policies result in the best outcomes.**
- Because adults with ASD often have several health and mental health conditions in addition to ASD, they often need different types of help from providers with different areas of expertise. These supports may all come from different providers who are funded through different state agencies. We often hear that services for people with intellectual or developmental disabilities (I/DDs) are not well coordinated, and that agencies aren't reimbursed for collaborating when addressing complex needs. The importance of interagency coordination is highlighted in the recent Workforce Innovation and Opportunity Act, but few measures of interagency coordination regarding service delivery to people with ASD or I/DD exist. **How can we improve the coordination of state DD services with other state and local services such as Vocational Rehabilitation, mental health, health, and special education?**
- **It is difficult to reconcile the ACS statistics about high levels of services satisfaction with anecdotal reports to the contrary.** There is little research to help us know how well people with significant intellectual impairment comprehend questions about abstract concepts embedded in questions like "Did you help make your service plan?" Nor do we know what helps them feel safe and empowered to answer candidly without fear of repercussions for voicing dissatisfaction.
- **Many who are potentially eligible for DD services do not get the help they need.** Many people are on waiting lists. How can we better understand the needs and outcomes of people who have high enough levels of need that they qualify for services, yet cannot receive them in a timely manner?
- Some states are just beginning to understand and respond to the fact that many adults with ASD who do not have ID may nonetheless have other disabling impairments that prevent their full participation in the community. State level variation is likely related to differences in whether states require adults with ASD to have an ID in order to be eligible for services. **How can we identify, evaluate and promote emerging state policies that appropriately recognize and adequately meet the unique needs of adults with ASD who do not also have ID?**

We believe that people with ASD are valuable members of our communities. We urge the creation of a better system of population-level indicators that can track whether our nation is making meaningful progress to help people with ASD achieve social roles and fulfill their potential to be contributing members of society.

Reference

1. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich, S, Sidney S, and Kripke C. (2015). The health status of adults on the autism spectrum. *Autism* 19(7): 814-823.

Appendix: Methods

Data sources

What data did we use for this report?

Data for this report came from the National Core Indicators (NCI) Adult Consumer Survey (ACS) 2014-15. NCI is a project of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The primary purpose of NCI data collection is to help states track their performance on key indicators of performance and compare their progress to other states.

The ACS is a survey performed annually by a subset of NCI states who choose to participate. In survey year 2014-15, 31 states, one regional council, and Washington DC participated. Surveys were completed between July 1, 2014 and June 30, 2015. Sampling was conducted based on those receiving services during this timeframe.

Adults with intellectual disability (ID) or developmental disability (DD) were eligible to participate if they received at least one service in addition to case management from the state developmental disability (DD) agency. States that participated in the ACS targeted a random sample of adult service users to interview, aiming for a minimum of 400 participants per state. Additional sampling information is available in the ACS 2014-15 report at www.nationalcoreindicators.org.

Who is this report about?

Who was included in this report?

This report presents indicators for individuals with autism spectrum disorder (ASD) who used state DD services and who were no longer secondary school students. These individuals all had ASD noted in their state records, and participated in (or had a proxy participate in) at least one section of the survey.

Many states chose who participated in the ACS based on the types of funding people received for services. For example, Utah randomly sampled adults who received Medicaid Home and Community Based Supports (HCBS) or Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID) supports. Other states included only certain types of HCBS waiver participants, or excluded individuals receiving certain funding types, like ICF/ID supports. Furthermore, some states did not include consideration of participation of these waivers at all when they selected their sample. Additionally, two states (California and New Hampshire) did not collect information about HCBS funding receipt in the 2014-15 ACS, so those individuals for these states were not included in the indicators presented in the Services chapter regarding receipt of HCBS funding or use of self-directed supports options.

Understanding outcomes for groups

There were two comparison groups in this report. The first group was composed of individuals who had a recorded diagnosis of ASD in their state records. The second group was individuals with other types of intellectual or developmental disabilities (I/DDs) other than ASD. Both groups were limited to working-aged adults who were not in public school at the time of the survey.

How was the data collected and evaluated?

Recall that the information from the ACS is collected in three parts:

- Background section - Information gathered from state records by a survey administrator who did not know the participant. Example topics include health and mental history, where the person lives, recent employment history, and services received.
- Section I - A series of subjective questions about satisfaction levels or personal experiences that can only be completed by the adult service user in a face-to-face interview. Example topics include satisfaction with one's employment and living arrangement, privacy and safety.
- Section II - A combination of objective and subjective questions completed by the adult service user if possible, or a proxy respondent if the individual was unable to participate on their own. Example topics include access to needed services, how the person spends their leisure time, and opportunities to make choices in one's life.

Survey questions were answered directly by the individual with ASD when possible. Otherwise, information came from proxy reporters - people who knew the individual and could report answers.

Following NCI analysis procedures, survey responses were considered invalid IF:

- A person had background information that was filled in from a review of state records, but had no answers to survey questions. None of these people were included in our analysis.
- No questions were answered in section I. These people were excluded from analysis of questions gathered in section I.
- The surveyor noted that the person did not seem to understand the questions or give consistent and valid answers in section I. These people were excluded from analysis of questions gathered in section I.
- No questions were answered in section II. None of these people were included in our analysis.

If a self-respondent's answers in section I were deemed invalid because the person did not seem to understand the questions or give consistent answers, and they did not have a proxy respondent for section II, then their responses to section II questions were also deemed invalid. None of these people were included in our analysis.

We did not include responses in our analyses if they were deemed invalid.

Validity of proxy reports

We note here that questions exist about the accuracy of proxy reports in DD research,[1-4] and research efforts are underway to better understand how to best gather information regarding people with significant difficulties participating in surveys. We don't know the extent of knowledge a proxy had regarding the individual they were representing, and it is likely that there were differences in the quality of proxy respondents. Some proxies may have an intimate knowledge of the person they are reporting about, while others may not have known an individual well enough to answer some questions. In general, caution should be used when interpreting proxy reports, since we cannot assess the validity of answers given by a proxy. In the absence of guidelines for how to handle these issues, we chose to handle these concerns by reporting results from all questions answered by proxies, as is standard for how NCI reports results.

Reliability

While NCI has designed a standard process for ACS interviews, there may have been differences in how interviews were conducted across states and across interviewers.

Data analysis

We presented descriptive data for key indicators in this report. We used percentages, means, and medians to convey how often and to what extent characteristics, experiences, and outcomes happen. Unlike scientific journal publications, we did not perform tests of statistical significance for this report. However, we reported differences that had practical significance.

Handling missing data

There were instances of missing data from the ACS, and instances of *don't know* responses. For this report, most *don't know* responses were set to be missing. In these cases, missing values were not considered in the denominator. Where relevant, we reported the percentage of *don't know* responses.

The proportion of the total ACS population who had a specific disability was calculated based on the entire ACS population that had at least one type of developmental disability listed. Those who had missing information on all disability categories were excluded from the denominator when calculating percentages.

State differences

Some indicators were missing information from some states. These are noted throughout the report. Missing information must be considered when interpreting the results for these states.

- There was no information about the use of self-directed supports or Medicaid waivers for ACS participants from the state of **California**. California did not offer self-directed support option at the time of this survey. Medicaid waiver information was collected differently in California.
- **New Hampshire** conducted the ACS on a two-year cycle, and for this administration of the ACS, they used the survey instrument that was administered in the 2013-14 administration cycle. For that reason, they did not have information on some of the questions presented in this report.
- A little over one-third of the adults with ASD in the **Delaware** sample were missing information on student status. We did not include these individuals in our analysis, because we only included those who responded that they were not a public school student at the time of survey administration.

How our analyses differ from other ACS publications

Estimates from this report may not exactly match estimates produced by NCI or other researchers. Official reports from NCI present statistics calculated using an "average of averages" approach which first averages data for participants within a state, and then averages these state-level average numbers across participating states. This method is used so states can compare their results to a summary total that is not swayed by states with a large number of participants.

For purposes of this report, we calculated point estimates by averaging all ACS participants, and did not perform an average of the averages. We chose not to present an average of averages because the main goal of this report was to produce indicators of adults with ASD across all participating states. Unlike the NCI reports, we did not aim to help state DD agencies compare their performance against other states. However, for informational purposes, we did present state averages in the maps in each chapter.

To learn more about NCI and the ACS, visit the NCI website at www.NationalCoreIndicators.org

Strengths and Limitations

The ACS provides a sizeable dataset with participants from many states including a large number of adults with ASD. The inclusion of adults with ID or a DD who require assistance to participate in the survey is an additional strength. The ACS also contains information about rights and decision making, which is not often assessed in large surveys despite their importance.

There are several limitations to use of ACS data that are important to note.

- Regulations for DD services and programs differed by state and may affect the averages we present for adults with ASD.
- Findings were not nationally-representative as not all states participated in the survey.
- States were asked to draw a random sample for participation in the ACS, but it was left to each state to decide how to do this and some of the samples are not truly random. Therefore, the samples from each state may not have been truly representative of all adult DD service users in that state.
- Adults were coded as having ASD based on notations in state DD service records. Diagnoses were not clinically verified, and notation of ASD may have been less likely for middle-aged adults. It is possible that more adults in the ACS had ASD than was identified via state records.
- We were unable to examine how services and outcomes were related to household income as this was not measured in the survey.

The general limitations of surveys apply here as well. The ACS relied on recall of events that happened over the previous year, which may have been difficult for some participants. Furthermore, the method of interviewing individuals with ID was not fully described, and therefore, may not have been easily replicable.

The Consent Process

The process of consent for adults who participated in this survey varied by state. The ACS was designed as a quality assurance measure - not as a research tool. Administration was subject to state regulations regarding consent for participation - not university IRB regulations. Consent processes were only approved by an IRB in states that contracted with a UCEDD for survey administration.

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A.J. DREXEL AUTISM INSTITUTE, DREXEL UNIVERSITY

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Life Course Outcomes Program
A.J. Drexel Autism Institute
3020 Market St., Suite 560
Philadelphia, PA 19104-3734
drexel.edu/autisminstitute/LCO/
www.facebook.com/autismlco
@autismlco