



NATIONAL AUTISM INDICATORS REPORT:

Family Perspectives on Services and Supports

MAY 2021



**Life Course
Outcomes Program**



DREXEL UNIVERSITY
A.J. Drexel

Autism Institute



Life Course Outcomes Research Program

Mission

The **A.J. Drexel Autism Institute** is the first research organization built around a public health science approach to understanding and addressing the challenges of autism spectrum 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>

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National Autism Indicators Report: Family Perspectives on Services and Supports

MAY 2021

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

Program Director

Lindsay L. Shea, DrPH, MS

Authors

Anne M. Roux, MPH, MA¹; Jessica E. Rast, MPH¹; Tamara Garfield, MSW¹; Shattuck, Paul T²;
and Lindsay L. Shea, DrPH, MS¹

¹Drexel University, A.J. Drexel Autism Institute, Philadelphia, PA, USA

²Mathematica Research, Princeton, NJ, USA

Acknowledgements

Graphic Design: Chisa Merriweather

Report Advisory Panel

Jiwon Lee, PhD, RN, MPH, Georgia State University

Valarie Oulds, J.D., Philadelphia Department of Behavioral Health and Intellectual disAbility Services

Maura Sullivan, MPA, The Arc of Massachusetts

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Letter from the Program Director

Lindsay L. Shea, DrPH, MS

Service providers, health professionals, educators, direct support staff and others continually change across the lifetimes of people on the autism spectrum. But family members are a constant – a vital source of stability, encouragement, coaching and resources for their emerging adult. As such, families are important supporters toward independence.

But family members have their own needs for support as well, especially when the service system has failed. Among these needs is the always-present question of who will care for my child when I am gone. Will my son or daughter be safe? Will they be happy and feel loved? Who will watch over them? Families need help to plan for the future and opportunities to shape service plans to best meet the needs of the adult and their own needs as well.

Many young adults on the spectrum remain living at home with family members through their early 20s, while others move into other types of living arrangements. Regardless of where the adult is living, state developmental disability (DD) services, typically funded by Medicaid, are often a critical source of services and supports.

Because families often remain so involved with their loved ones on the spectrum, they often have a valuable inside perspective about how well DD services are working. The experiences and insights of these family members are helpful for monitoring the quality, safety, and effectiveness of services their loved one receives. National and state level DD service administrators look to families as a valuable source of info and obtain this info via family surveys.

Autistic adults who receive DD services tend to be younger than adults with other disorders. This means that they tend to enter DD services earlier, and likely remain in services longer, which is critical information for policy planning.

This National Autism Indicators Report explores what families think about the DD services their family member on the spectrum is receiving, how they are involved in these services, and how well their own support needs are met during the adult portion of the lifespan. This is our first report that focuses on families. We hope this report will shine a spotlight on places where family supports need improvement. We also recognize the importance of continuing to track these needs and associated outcomes as we see more youth aging into adulthood.

We dedicate this report to the family members who participated in the surveys that informed this report and to those who strive to meet the needs of their loved ones every day. We also wish to express sincere gratitude to the family advisors who helped to shape this report.





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A note about wording. In this report, we primarily use the term autistic, because we are discussing adults on the autism spectrum who often prefer identity-first language. We also use 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 on the autism spectrum. The National Core Indicators Adult Family Survey (AFS) and the Family/Guardian Survey (FGS) use the term “autism spectrum disorder (for example, Autism, Asperger Syndrome, Pervasive Developmental Disorder)” as does the most recent edition of the Diagnostic and Statistical Manual (DSM-V).

In this report, we use the term distressed behavior instead of challenging behavior. The National Core Indicators Adult Family Survey (AFS) and the Family/Guardian Survey (FGS) inquire about “self-injurious, disruptive or destructive” behavior. These are behaviors which typically occur in response to physical or mental stress – such as pain, discomfort, sensory overload, confusion, or intense anxiety. Adults on the autism spectrum express that it is most respectful to use specific descriptions of behaviors which occur in response to stress. However, it is impossible to know the exact nature of behaviors when analyzing responses to survey questions. In cases like this, we use the term distressed to indicate the subjective perspective of the autistic person, versus challenging which expresses the perspective of someone observing the behavior. Some behaviors are extreme – resulting in harm to self or others, and even death, and can impact the mental health of all involved. Families need timely access to services and supports to help assess the causes of behaviors in an attempt to prevent their occurrence, to plan for safety and to train the family in de-escalation techniques, and to manage all levels of intensity of distressed behaviors.



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Executive Summary

You can go so long not knowing what you need. No one [school staff] talks about it. ...I just wanted a little job to keep him busy and have a purpose. I just wanted it [services] to continue. How do you go five years and have nothing in place?

– Philadelphia area mom of a 25-year old on the autism spectrum who has been on a waiting list for DD services for five years since leaving high school.

Families are the main support system within our society. Yet there is no comprehensive family support system in the U.S.

For families who are supporting individuals with intellectual and developmental disabilities, including autism, these two competing truths are a daily reality. Many adults on the autism spectrum sit on waiting lists for developmental disability (DD) services or may not qualify for services due to a lack of available autism-specific adult programs. Meanwhile, their family members also have no formal supports, or breaks from caregiving, and often cannot work because of the need to provide supervision and care for their loved one. The lack of supports for families diminishes opportunities for building successful long-term outcomes as individuals navigate toward adulthood.

Families are the main providers of support for their autistic family member, and yet their role is not recognized or supported as it should be.

Paired with this lack of support is another truth... America is aging. Thus, aging caregivers spend too many fretful hours wondering what will happen to their loved one when they are no longer able to provide for their care.

The Joint Position Statement on Family Supports from the American Association on Intellectual and Developmental Disabilities and The Arc says that “Family support services and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and developmental disabilities (IDD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.”

At this point in time, access to supports is not equal across families, as this parent points out.

I am convinced that the success any family has obtaining information and supports for their loved one with autism hinges almost entirely on how well-networked and tenacious they are. Information I am convinced that the success any family has obtaining information and supports for their loved one with autism hinges almost entirely on how well-networked and tenacious they are. Information is siloed at all levels. Schools, community, state and federal systems do not often refer parents to needed resources. Parent support groups are vital so that those who have discovered how to navigate SSI or accommodations in post-secondary ed, for example, share this knowledge to others facing it. Families that are disadvantaged for socioeconomic or situational reasons may not have the time, funds, internet, to obtain info and services on their own. I was fortunate to have the time and funds and knowledge to seek out groups who could help me grasp what I didn't know.

–North Carolina mom of a 23 year-old autistic son

This report set out to learn more about how families of adults on the autism spectrum are faring.

The Charge

Increasing numbers of individuals identified with autism are using state DD services,[1] but we know little about their experiences. Our 2017 National Autism Indicators Report focused on describing the DD services that adults with autism receive and the outcomes of these services.[2] This 2021 report delves further into the roles that family members play in the lives of adults with autism who receive DD services. These families have unique lived experience and can offer crucial insight into how well autistic adults are faring in our communities and how systems of care could be improved to support both autistic adults and family members.

The families of youth and adults on the autism spectrum provide vital supports across the lifespan. Family members of autistic people may function as advocates, coaches, teachers, navigators, care coordinators, organizers, record keepers, healthcare providers, communicators, safety monitors, transportation providers, and much more. They often do these jobs without adequate information or support or pay. Thus, their importance may go unrecognized, even though they are essential to the wellbeing of individuals with autism.

The term “family members” often refer to people who are biologically or legally related to the person with a developmental disability but can also include adoptive or foster family members or people who are “chosen” family. Chosen family are people who maintain close, supportive relationships with each other by choice, not because they are biologically or legally related to each other. Chosen family may provide important support for an individual with autism, stepping in when other family members are not present/available or can no longer provide care. Chosen family members can include friends, other self-advocates, neighbors, care workers or anyone else that the person with the disability considers as family.

This report explores what family members report about autistic adults: the settings they live in, their access to services, opportunities to participate in their communities, and the choices they have about their services and supports. We also look at the characteristics of family members themselves, how they participate in decision-making and choices about services and providers, and the types of supports they may need themselves to identify and coordinate quality care and to best meet the needs of the autistic adult.

Aims of this report

In this report we will:

- Describe key characteristics of autistic adults who use state DD services and indicators about their access to services and community participation, as reported by family members.
- Describe key characteristics of the family members of these autistic adults including how they are included and supported in the care of their loved one on the spectrum, how satisfied they feel with the services their loved one receives, and their opportunities to collaborate as care partners.
- Explore how experiences with services and supports differ across subgroups of autistic adults and their family members.
- Provide research and policy recommendations to further investigate and address the support needs of families with autistic adults who receive DD services.

Data for this report

Some autistic adults live with family members, and others live apart from family members – perhaps in a group home or independently in the community. We analyzed data from two surveys to learn more about both groups of family members. Family members of adults who received DD services within participating states provided all demographic information and survey responses.

Both surveys are part of 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 (HSRI) to collect data to help improve the quality of state DD services. We did not conduct these surveys ourselves. We are reporting results based on our independent analyses of the survey data.

Information in this report about autistic adults living with family members came from the 2018–2019 **Adult Family Survey (AFS)**. The AFS was administered to people with a family member on the autism spectrum who lived in the family home and received at least one DD services besides case management. Information from the AFS in this report is color-coded blue.

Data about autistic adults living apart from family members came from the 2018–2019 **Family/Guardian Survey (FGS)**. The FGS was administered to people with a family member on the autism spectrum who lived outside the family home, most commonly in a group home setting. Information from the FGS in this report is color-coded purple.

The AFS and FGS surveys measure indicators about individuals who use services and their family members. In addition to collecting information about the demographic characteristics of individuals and

their families, and the services and supports they receive, the survey questions measure:

- **Information and Planning:** Do families and family members with disabilities have the information and support necessary to plan for their services and supports?
- **Access and Delivery of Services and Supports:** Do families and family members with disabilities get the services and supports they need?
- **Choice, Decision Making and Control:** Do families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them?
- **Involvement in the Community:** Do family members with disabilities use integrated community services and participate in everyday community activities?
- **Satisfaction with Services and Supports:** Do families and family members with disabilities receive adequate and satisfactory supports?
- **Outcomes:** How can individual and family services be supported to make a positive difference in the lives of families?

More background about the data is available in the **Methods** appendix.

What is a developmental disability (DD)?

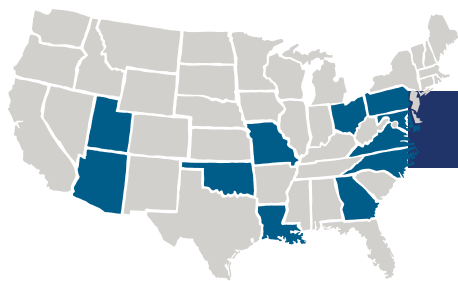
According to federal law, developmental disabilities are severe, chronic disabilities attributable to mental and/or physical impairments which manifest before age 22 and are likely to continue indefinitely. These impairments result in substantial limitations in three or more areas: self-care, receptive 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 may qualify as having a DD and might receive services through a DD agency.

What are DD services?

Individuals with intellectual or developmental disabilities (I/DD) might receive specialized services – called DD services – to maximize their well-being and participation in the community. Most state DD agencies offer employment supports, respite, transportation, and residential supports. These services are administered through DD agencies which are local agencies that provide services for people with DDs.

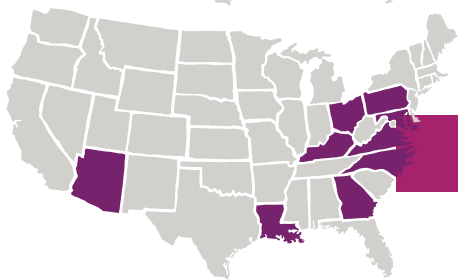
Who is represented in this report?

The Adult Family Survey and the Family/Guardian Survey provide valuable information about an important and growing group of autistic adults who use DD services. However, we cannot say that our findings generalize to the general population of adults on the autism spectrum across the nation. This is because the AFS and the FGS were designed to be representative of families with adults who received state DD services within the states that participated in the surveys.



11 states participated in the NCI Adult Family Survey 2018-19

The Adult Family Survey included family members of adults who used DD services in Arizona, Georgia, Louisiana, Maryland, Missouri, North Carolina, Ohio, Oklahoma, Pennsylvania, Utah and Virginia.



9 states participated in the NCI Family Guardian Survey 2018-19

The Family/Guardian Survey included family members of adults who used DD services in Arizona, Georgia, Kentucky, Louisiana, Maryland, North Carolina, Ohio, Pennsylvania and Virginia.

Second, our findings only represent people who were able to access DD services, were eligible for DD services in their state, and they (or their caregivers) were able to take the necessary steps to get services.

The needs of adults with ASD vary widely across the spectrum. DD service eligibility criteria vary by state, but in general, autistic adults who receive DD services are more likely to also have an intellectual disability (ID) compared to the overall population of people on the spectrum. Therefore, the findings in this report represent people with a greater level of challenges and functional impairments than all individuals with

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 indicators reported by 2,266 family members of adults on the autism spectrum (ages 18 or older) who were receiving at least one service (besides case management) from their state's developmental disability (DD) agency in 2018-2019. These indicators only reflect a subset of 11 states that implemented two standardized family surveys.

ASD. They may also have different needs than their peers with other types of DDs. This report examines the experiences of adults on the autism spectrum who use DD services and explores how their service use compares to other DD service users.

References

1. Hiersteiner D, Bradley V, Ne'eman A, Bershadsky J, and Bonardi A. (2017). Putting the research in context: The life experience and outcomes of adults on the autism spectrum receiving services in 29 states. *Inclusion*: 5(1), 45-59.
2. 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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▶ Key Findings

Among all families:

- **Autistic adults who received DD services were more likely to have co-occurring intellectual disability (ID).** About 60% of adults on the spectrum who lived with family had ID, and 75% of those who did not live with family. This means autistic adults who received DD services were more than twice as likely to have co-occurring ID as the overall population of people on the spectrum – about one-third of whom have ID.
- **High levels of co-occurring health and mental health conditions.** Like the general population of adults on the spectrum, those who received DD services experienced higher rates of many health conditions and mood/psychiatric disorders which can contribute to earlier mortality and poorer quality of life.
- **There is a need for more employment supports.** Although DD services are a key source of support for employment, only about one-third of adults on the autism spectrum had paid daytime activities. Families also reported that about one in three adults did not have enough supports to be able to work or volunteer in the community.
- **Families report inadequate planning for emergencies.** About four in 10 families did not discuss a plan for handling crises and emergencies at their last person-centered planning meeting. Thus, many families may have been unprepared for managing emergencies as they headed into the COVID-19 pandemic.

Families with an autistic adult who lived with them were more likely to report:

- **Financial hardship.** 22% of families reported an income of \$25,000 or less, signaling possible financial burden. But only 37% of all families with an adult living at home received payment for the care they provided
- **Need for additional support.** 27% of families felt they didn't have enough supports and services for themselves. Over half of these families needed respite services so they could take a break from caregiving. And 40% said they needed more information about public benefits the adult might qualify for.
- **Need for information and training.** 70% of these families managed the staff who provided support for the adult in their home. 30% said that the information they were given about services and supports was seldom or never easy to understand.

Families whose autistic adult did not live with them were more likely to report:

- **Less empowerment.** Only 45% of these families said they usually or always had a choice of the staff who supported their autistic adult. And 22% felt they could not change their service coordinator.
- **Safety concerns.** 10% of families with an autistic adult who did not live with family said they reported abuse or neglect within the past year.

We present findings from two surveys that asked the same questions with a few exceptions. However, the same states did not participate in both surveys. While we have organized key findings from these surveys by topics, **we caution that statistics from the two surveys cannot be directly compared.**

Adult Family Survey

We used data from the National Core Indicators® (NCI®) Adult Family Survey to learn more about autistic adults who lived in the family home and used DD services and the family members who supported them.

1,551 family members of adults with ASD who lived at home with family members participated in the 2018-19 AFS.

Family/Guardian Survey

We used data from the National Core Indicators® (NCI®) Family/Guardian Survey, to learn more about autistic adults who lived outside the family home and used DD services, and the family members who supported them.

715 family members of adults with ASD who lived at home with family members participated in the 2018-19 FGS.

CHARACTERISTICS OF AUTISTIC ADULTS

Among those who lived with family:

- More than six in every 10 adults with autism (64%) also had intellectual disability –almost double the rate found in the overall population of people on the autism spectrum.
- Most autistic adults who lived with family were male (73%) and non-Hispanic white (73%). A higher percentage were non-Hispanic Black (15%) compared to the general population (13%), but a lower percentage were Hispanic (6%), compared to 19% in the general population.
- 24% of autistic adults needed extensive supports for managing distressed behavior, compared to 10% of adults with other types of disabilities.
- Nearly 80% of families reported the autistic adult had extensive needs for support with daily activities like scheduling, managing money and shopping.
- While many families reported their loved one had activities in the community, only 33% had any type of paid daytime activities, and nearly 40% were doing some type of facility-based work in settings that do not include people without disabilities. Autistic adults who were Hispanic were less likely to participate in community-based activities compared to non-Hispanic White adults.

Among those who do not live with family:

- More than seven in every 10 adults with autism also had intellectual disability – more than double the rate found in the overall population of people on the autism spectrum.
- Autistic adults who did not live with family were primarily male (78%) and were more likely to be non-Hispanic White (79%) than the U.S. general population. Approximately 12% were non-Hispanic Black - roughly equivalent to the general population. A lower percentage were Hispanic (3%), compared to 19% in the general population.
- 42% of autistic adults needed extensive supports for managing distressed behavior, compared to 24% of adults with other types of disabilities.
- 88% of families reported the autistic adult had extensive needs for support with daily activities like scheduling, managing money and shopping.
- While many families reported their loved one participated in activities in the community, only 30% had any type of paid daytime activities, and nearly 60% were doing some type of facility-based work in settings that do not include people without disabilities. Autistic adults who were Hispanic were less likely to have any type of paid work compared to those who were non-Hispanic White, Black, or Other/Mixed race.
- Nearly 70% of adults with autism who did not live with family members were in group home or agency-operated apartment settings. Nearly 12% were in specialized facilities for people with I/DDs, and 9% lived in independent homes or apartments.

CHARACTERISTICS OF FAMILY MEMBERS AND HOUSEHOLDS

Among families whose autistic adult lived with them:

- 91% of survey respondents were parents, and 5% were grandparents.
- Nearly half (48%) of family members had a college education, and 61% were between 55-74 years old at the time of the survey.
- 22% of families reported annual household income of \$25,000 or less. Approximately 37% received pay for providing supports for their loved one.

Among families whose autistic adult did not live with them:

- 75% of survey respondents were parents, and 9% were siblings.
- 68% of family members were between 55-74 years old at the time of the survey, and 15% were age 75 or older. Over half (55%) had a college education or higher.
- 20% of families reported annual household income of \$25,000 or less.

SERVICES AND SUPPORTS FOR ADULTS WITH AUTISM AND THEIR FAMILIES

Among families whose autistic adult lived with them:

- A little over half of families living with autistic adults reported that their family member received transportation services (58%) and/or supports for daytime activities or employment (51%), and a little less than half received in-home supports (44%).
- 92% received Supplemental Security Income (SSI).
- 88% of families felt the DD service plan generally included all the services and supports the adult with autism needed.
- But 38% of families felt the person wasn't receiving enough supports to be able to work or volunteer in the community.
- Over one-quarter (27%) of family members felt they were not receiving enough supports and services for themselves and 55% indicated a need for respite care. Nearly 40% appeared to need more information about public benefits their loved one might qualify for.

Among families whose autistic adult did not live with them:

- Almost all autistic adults who did not live with family received transportation services (94%) and residential supports (93%). 75% received supports for daytime activities or employment and a little less than half received in-home supports (45%).
- 98% received Supplemental Security Income (SSI).
- 92% of families felt the DD service plan generally included all the services and supports the adult with autism needed
- Nearly 30% of families felt the adult wasn't receiving enough supports to be able to work or volunteer in the community.
- Most (90%) family members felt they were receiving enough supports and services for themselves. Others reported needs for regular support for the autistic adult, homemaker services, counseling, and family-to-family networks.

COMMUNICATION AND COLLABORATION WITH FAMILIES

Among families whose autistic adult lived with them:

- 86% of families reported that they participated in making the service plan for their family member. Over 80% also reported having a choice about support workers who are on the team that supports the autistic adult. However, 15% said they did not choose and cannot change the service coordinator.
- About 30% of families of autistic adults felt that information about services and supports was seldom or never easy to understand.
- 70% of families directly managed the support staff who provided services for the autistic adult in their home and in the community.

Among families whose autistic adult did not live with them:

- 82% of families reported that they participated in making a service plan for their family member. Most also reported having a choice about which agency they used for services (84%), but only 45% said they usually or always had a choice regarding which staff members provided supports for the autistic adult. 22% said they did not choose and cannot change the service coordinator.
- About 15% of families of autistic adults felt that information about services and supports was seldom or never easy to understand.
- Less than 10% of families directly managed support staff who provide services for the autistic adult in their home and in the community, even though 23% of families said the autistic adult (or their family representative) received assistance to self-direct their services.

EDUCATING AND SUPPORTING FAMILIES TO PARTICIPATE AS CARE PARTNERS

Among families whose autistic adult lived with them:

- Families most often reported need for help with planning around housing (for example, "Where will my son or daughter live when I can no longer provide care?"), but also reported need for help planning for future social relationships and recreation, financial and legal matters, and employment.
- Only six in every 10 family members said they discussed a plan for handling crises and emergencies at the last person-centered planning meeting.
- Most families (83%) said they knew how to report abuse and neglect when needed, but only 65% said they knew how to file a complaint or grievance about provider agencies or staff.

Among families whose autistic adult did not live with them:

- Families most often reported need for help with planning for the family member's medical care, but also reported need for help planning for future housing, social relationships and recreation, and financial matters.
- Only six in every 10 family members said they discussed a plan for handling crises and emergencies at the last person-centered planning meeting.
- Most families (79%) said they knew how to report abuse and neglect when needed, and 10% of families with an autistic adult who did not live with family said they reported abuse or neglect within the past year.



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Background The issues

Families are a primary support for many adults on the spectrum.

Most people on the autism spectrum (87%) continue to live with their families after they finish high school and enter their twenties. Young adults with autism are more likely to live with a family member or guardian compared to youth with other types of disabilities (learning disability, intellectual disability, or emotional disturbances).[1] Individuals with intellectual and developmental disabilities (I/DD), including those on the autism spectrum, also have higher rates of living with parents into middle age and early old age.[2] This means that family members are often serve as built-in, or natural, supports for adults on the spectrum.

Family members often play a central role in supporting the transition to adulthood, coordinating with providers as their children shift from receiving school-based services to receiving community-based adult services.[3] Many families struggle to access supports and services after their youth leaves high school. Parents must often navigate a broken and complex service system that lacks coordination as they attempt to help their young adult access Vocational Rehabilitation, Developmental Disability Services, mental and behavioral health services and others. Families often report that finding therapeutic and medical care, from providers who understand autism, can be daunting.

Families of individuals on the autism spectrum face extra challenges.

In our last report, we found that parents of youth on the spectrum experience higher rates of poverty and material hardships. They report more difficulty paying for essentials like food, housing and healthcare, compared to parents of children with or without other special healthcare needs.[4] Almost one-third of parents of children on the spectrum had to cut back on work hours to meet caregiving demands compared to only 2% of children without special health care needs.

Family financial challenges may persist as transition-age youth with autism enter adulthood. Parents of adults with I/DDs (including autism) who continued to live at home, earned less than parents of adults with I/DD who live outside the home,[2] possibly due to ongoing need for caregiving.

Families of people with autism may also experience elevated rates of stress and depression. This stress may take a physical toll, resulting in higher rates of health problems for parents of children with autism. Parents who live with their adult children on the spectrum may be particularly vulnerable to poor physical and mental health outcomes in older age.[2,5] The health and wellbeing of people with autism and their parents appear to be closely related, suggesting that a family-centered approach to service delivery may benefit people on the spectrum and their families.

An approach that considers the needs of the entire family is also critical given that families may have more than one member on the spectrum. As one autism researcher expressed:

I'm an autistic adult and I have two adult brothers on the spectrum who still need a lot of support. There are times I wonder if they will ever be able to live independently. I often worry about how I will take care of them if and when our mother no longer can, and if I will have to compromise on my dreams, on my career, and on my own happiness to support them.

– Kevin J. Carroll

We are not implying that youth and adults with autism are the cause of increased family burden. Rather, the difficulty families have in accessing supports to help them meet the demands of extra and extended caregiving, combined with a lack of family-centered care, may be the root of the problem. It is also important to recognize that challenges are not equal across families. We know that families of color and those with lower incomes face additional difficulty and stressors when trying to access services and supports and locate quality care due to systemic racism and unequal health care opportunities.

Why is it critical to examine family perspectives on DD services?

This report explores family perspectives on service delivery for individuals on the autism spectrum. Families offer a critical lens for viewing the quality of services and opportunities for improving systems.

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). The DD Act 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, 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.”[6]

At its heart, this report examines whether family members perceive that these rights are being fulfilled for their adult family member with autism – whether they live in the family’s home or elsewhere.

State Developmental Disability Services at a glance

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. There is no official tally of how many adults on the autism spectrum get services from state DD agencies. Approximately 7.38 million people in the U.S. had an I/DD in 2017. Of these, an estimated 1.48 million were individuals known to or served by state DD agencies in 2017, and roughly 1.28 million were receiving at least one long-term support service from a state DD agency.[7] These figures indicate that 17% of people with an I/DD received DD services in 2017. Autistic adults who do not 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 590,000 people with I/DD were on state waiting lists for Medicaid Home and Community Based Services (HCBS) waivers alone in 2018,[8] and Medicaid waivers are a primary funder of DD services.

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 fund services in the areas of employment, 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. [7]

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. Further, 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 is 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** Different departments house the DD program in each state. Services are typically administered through a system of local 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 with autism-even if they don't have an ID.
- 3** Each state decides what services are available under the DD program. Services are similar across states but do vary.
- 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.

What do the Adult Family Survey and the Family/Guardian Survey have to do with DD Services?

States use these surveys to track the quality of their public services for adults with I/DD. In fact, state DD agency directors and program managers report that the AFS and the FGS are among the most helpful survey information they gather for purposes of quality assurance and improving service provision. [10] The data from these surveys is especially helpful in guiding progress to make sure that services and supports that meet the criteria that Medicaid expects for quality service delivery. Read more about the survey in the Methods appendix.

What policy guides family involvement in DD services?

In general, there is little legislated guidance surrounding the involvement of families in DD services. 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.”[6] 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.

- Within the DD Act, The Families of Children with Disabilities Support Act aims to strengthen state systems of supports for family members providing care to children with disabilities at home, citing that most families do not have access to family-centered care or family-directed supports for care.
- This act also applies to individuals with DDs who are over the age of 18 if they have a significant physical or mental impairment as defined by the state, and if they are residing with and receiving assistance from a family member.
- The act provides funding for promoting leadership by families in planning, policy development, implementation, and evaluation of support services for families of people with DDs, and to increase the availability of funding for, access to, and provision of services to support families in caring for their child at home.

However, within this act, references to specific services or activities aimed at supporting family members of adults with I/DD are limited.

References

1. Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M. & Wagner, M. 2014. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*; 18(5): 562-570.
2. Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American journal on intellectual and developmental disabilities*, 116(6), 479-499.
3. Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2017). “Leaps of faith”: parents’ and professionals’ viewpoints on preparing adolescents on the autism spectrum for leaving school. *Journal of Research in Special Educational Needs*, 17(3), 187-197.
4. Anderson, Kristy A., Rast, Jessica E., Roux, Anne M., Garfield, Tamara., and Shattuck, Paul T. National Autism Indicators Report: Children on the Autism Spectrum and Family Financial Burden. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, May 2020.
5. Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(9), 1836-1846.
6. DD Act, section 101, 42 U.S.C. 15001 (b) (2006). https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf
7. Larson, S.A., Eschenbacher, H.J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M.L. (2020). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
8. Kaiser Family Foundation. Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-based Services Waivers. kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers
9. Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S, Sowers, M, & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
10. National Core Indicators. (2012, May). Using National Core Indicators (NCI) Data for Quality Improvement Initiatives. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. <https://www.nationalcoreindicators.org/>



Chapter 1 Characteristics of Autistic Adults Who Live with Family

▶ Our Key Findings

- Six in every 10 adults with autism (64%), who lived with family also had intellectual disability. This rate was almost double the rate found in the overall population of people on the autism spectrum.
- Most autistic adults in the AFS were male (73%) and non-Hispanic White (73%). A higher percentage were non-Hispanic Black (15%) compared to the general population (13%), but a lower percentage were Hispanic (6%), compared to 19% in the general population, according to U.S. Census estimates for 2019.
- One-fourth of autistic adults (24%) who lived with family needed extensive supports for managing distressed behavior, compared to 10% of adults with other types of disabilities who lived with family.
- Nearly 80% of families of autistic adults who lived at home reported the adult had extensive needs for support with daily activities like scheduling, managing money and shopping.
- While many families reported their loved one had activities in the community, only 33% had any type of paid daytime activities, and nearly 40% were doing some type of facility-based work in settings that do not include people without disabilities. Autistic adults who were Hispanic were less likely to participate in community-based activities compared to non-Hispanic Whites.

Family members of 1,551 adults on the autism spectrum who were over the age of 18 and lived at home with family members, provided information about these adults in the 2018-19 Adult Family Survey (AFS). Each of these adults received at least one DD service in addition to case management. For more information on who is included in these analyses, see the Methods appendix.

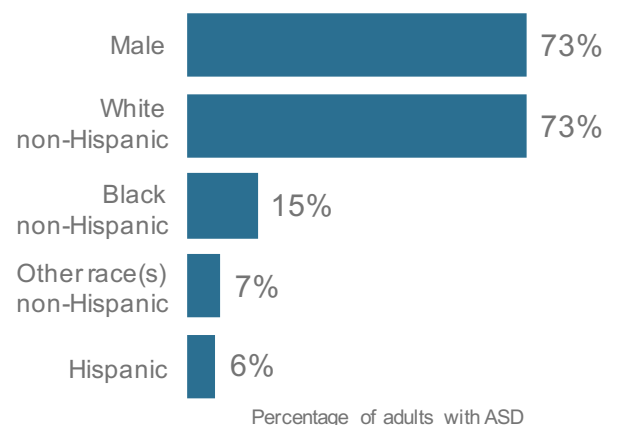
Autistic adults who lived at home with the family respondent and used state Developmental Disability services

Demographic characteristics

Autistic adults who lived with family members averaged 28 years of age at the time of the AFS 2018-2019 survey - younger than adults with other disabilities who averaged 36 years of age. Approximately 67% of these autistic adults were under the age of 30 years at the time their family member completed the AFS, compared to 35% of adults with other types of disabilities.

Most autistic adults in the AFS were male and non-Hispanic White. A higher percentage were non-Hispanic Black (15%) compared to the general population (13%), but a lower percentage were Hispanic (6%) compared to 19% in the general population, according to U.S. Census estimates for 2019.

Most adults with autism who received DD services and lived with family were male, white, and non-Hispanic.

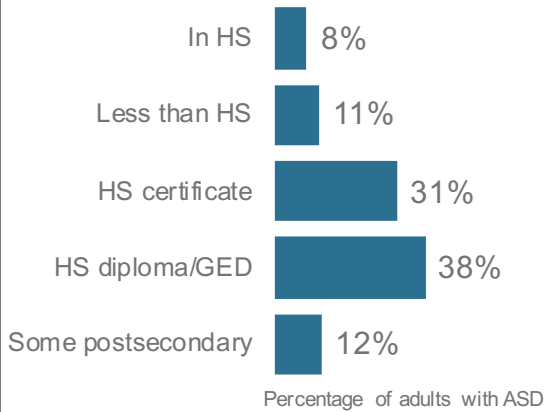


Source: NCI Adult Family Survey 2018-19



Half of autistic adults in the AFS had a high school diploma or GED, and 12% of these had some postsecondary education.

Half of adults with autism attained a high school diploma or GED.



(HS = high school)

Source: NCI Adult Family Survey 2018-19

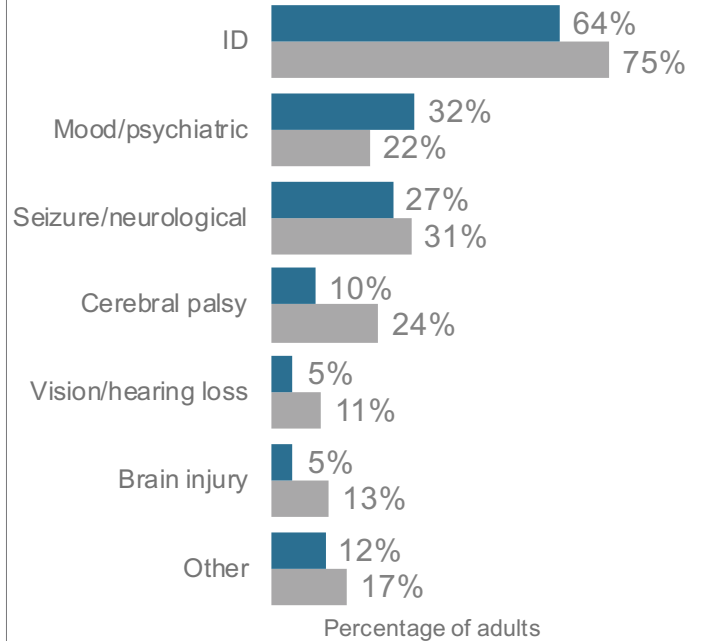
Co-occurring conditions

Many have disabilities in addition to autism.

Families reported diagnoses the adult had in addition to autism. Sixty-four percent of autistic adults who received DD services and lived with family members had co-occurring Intellectual Disability (ID). The prevalence of co-occurring ID among youth on the spectrum has generally decreased over time and is currently estimated at around one-third of children with ASD.[1] Adults on the autism spectrum who receive DD services, however, tend to have a much higher rate of ID, because having ID is sometimes linked to eligibility criteria for DD services. Because of this higher rate of co-occurring ID, the findings in this report represent people with a greater level of functional impairments than the overall population of individuals on the autism spectrum who often don't qualify for DD services.

Compared to adults with other disabilities who lived at home with family, adults with autism had significantly higher rates of mood/psychiatric

Adults with autism who used DD services and lived with family had mood/psychiatric disabilities more often than other adults.



Source: NCI Adult Family Survey 2018-19

disorders, but lower rates of ID or seizure disorder and vision/hearing loss. Other reported disabilities included hydrocephalus, microcephaly, spina bifida, genetic disorders (including fragile X syndrome and Williams syndrome), and musculoskeletal disorders such as scoliosis.

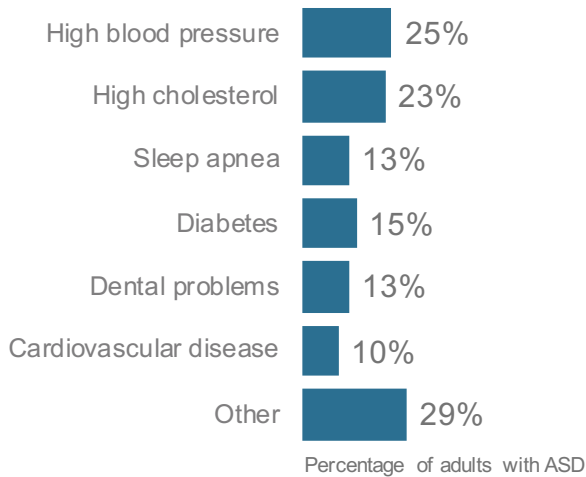
Some had additional health conditions.

Families were asked whether the adult had ever been diagnosed with any health conditions (from a list of 10 conditions that might occur more commonly in people with DDs). Among this list of conditions, approximately one-quarter of adult autistics in the AFS had high blood pressure and/or high cholesterol. Nearly 20% had sleep apnea. Rates of co-occurring health conditions among autistic adults were slightly lower than those of adults with other types of disabilities for all conditions except for dental problems. But nearly one-third of families reported



“other” health issues. Other types of commonly reported health conditions included thyroid conditions, gastrointestinal conditions (e.g., gastro-esophageal reflux, constipation), heart conditions, sleep disorders, and scoliosis.

High blood pressure and high cholesterol were the most common health conditions in autistic adults who received DD services.



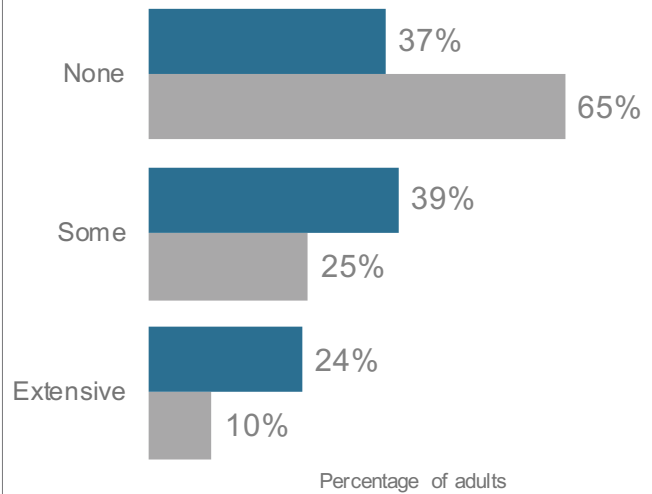
Source: NCI Adult Family Survey 2018-19

Functional skills

Approximately 72% of autistic adults in the AFS used spoken language to communicate, while 28% used gestures, body language, or another form of communication. For those who did not communicate with spoken language, family members reported that support staff could “sometimes” (19%) or “seldom/never” (11%) communicate with their loved one.

Adults on the autism spectrum who lived at home with family members had more need for help with self-injurious or other distressed behavior than adults with other types of disabilities. Nearly one-quarter of those on the autism spectrum had “extensive” needs for supports with regulating behavior – over twice the rate of those with other disabilities.

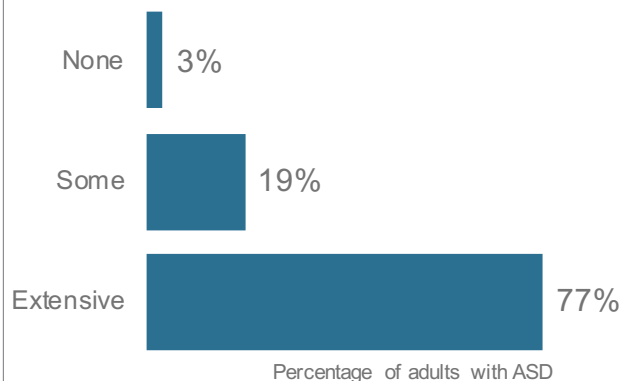
Autistic adults who lived with family needed more frequent supports for managing distressed behavior than other adults.



Source: NCI Adult Family Survey 2018-19

About 37% of family members reported their loved one with autism needed extensive help with personal care activities like bathing, dressing or eating, other daily activities; and another 40% required some help. Need for assistance with daily activities was even more common. Over 77% of families of autistic adults who lived at home reported the adult had extensive needs for support with daily activities like scheduling, managing money and shopping.

Most adults with autism who used DD services and lived with family needed extensive support to do daily activities.



Source: NCI Adult Family Survey 2018-19



The importance of supports for managing behavioral crises

In this report, we use the term distressed behavior instead of challenging behavior. The National Core Indicators Adult Family Survey (AFS) and the Family/Guardian Survey (FGS) inquire about “self-injurious, disruptive or destructive” behavior. These are behaviors which typically occur in response to physical or mental stress – such as pain, discomfort, sensory overload, confusion, or intense anxiety. Adults on the autism spectrum express that it is most respectful to use specific descriptions of behaviors which occur in response to stress. However, it is impossible to know the exact nature of behaviors when analyzing responses to survey questions. In cases like this, we use the term distressed to indicate the subjective perspective of the autistic person, versus challenging which expresses the perspective of someone observing the behavior.

Some behaviors are very extreme – resulting in serious harm to self or others, and even death. Behavioral crises are alarming and can impact the mental health of all who are involved including parents, siblings, grandparents, pets and friends. Without support, parents are left bearing an intense fear about managing this potential for distressed behavior, which may be stigmatizing in their social circles and communities. They may become increasingly isolated from social participation and support if family and friends are not understanding

and become distant or judgmental. Neighbors and community members may react negatively if the adult wanders onto their property or if police involvement occurs. Behavioral crises can also be traumatizing for the autistic adult because it may lead to interaction with police, forced hospitalization or institutionalization, and physical or chemical restraints – all of which are highly stressful.

Sometimes, behavior may become dangerous despite the best efforts of the family. If families do not have the resources or training to handle volatile situations, they can result in injury, and the adult may no longer be able to live in the home. This is especially true as parents age, if they experience health or mobility challenges, or if they are the sole care provider in the home. Families need timely access to services and supports to help assess the causes of behaviors in an attempt to prevent their occurrence, to plan for safety and to train the family in de-escalation techniques, and to manage all levels of intensity of distressed behaviors. Additional information and resources can be found here: <https://www.autism.org.uk/advice-and-guidance/topics/behaviour/distressed-behaviour/all-audiences> and here: <http://www.thinkingautismguide.com/2016/08/when-autistic-children-are-aggressive.html>

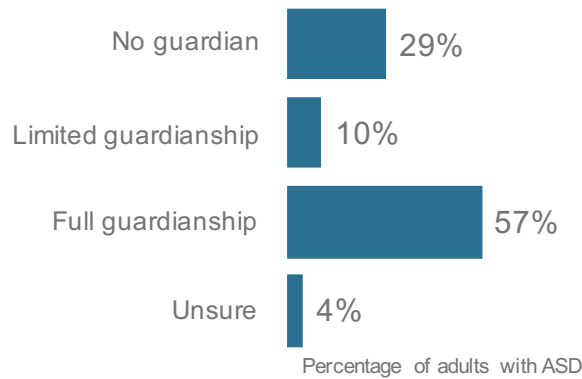
Families were asked whether the autistic adult was legally (presumed) competent with no guardian/conservator; had a limited guardian (person with authority over certain decisions, such as medical procedures); had a full guardian; or had a guardian but unsure to what extent. Families reported that nearly 57% of adults with autism who lived at home had full guardianship. In nearly all cases (98%) of people who had a full guardian, a family member served as the guardian. Rates of guardianship for

those with autism was comparable to those with other disability types.

We note that the survey did not ask about alternatives to guardianship. For example, supported decision-making is a newer option in some states that allows adults with disabilities to get support for legal and medical decisions without having to give up their legal rights, such as their right to vote. States are beginning to construct and recognize supported decision-making agreement documents.[2]



Most adults with autism who used DD services and lived with family had a full guardian.

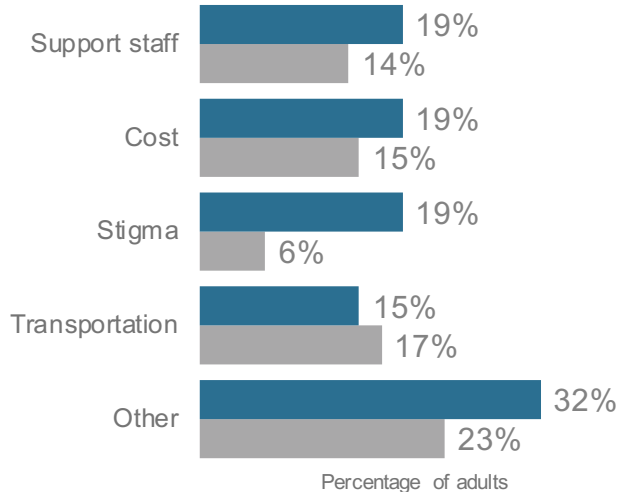


Source: NCI Adult Family Survey 2018-19

community, adults with autism were more likely to experience lack of support staff, costs and stigma (negative attitudes or reactions in the community) as barriers to participation. Other reported barriers included anxiety, distressed behavior, difficulties with social interactions, sensitivity to certain stimuli (including sounds, crowds, or unfamiliar situations), lack of interest and few opportunities to engage in activities.

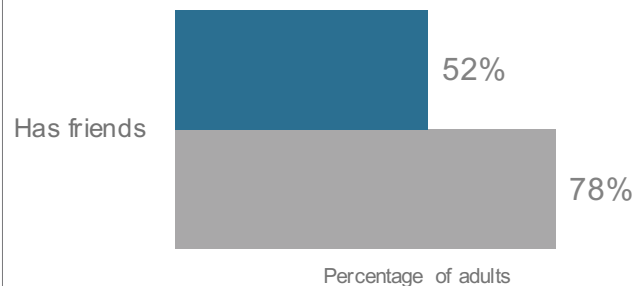
Friendships were also different among those with autism who lived at home. Only half of those with autism had friends other than paid support workers or family member, compared to over three-quarters with other disabilities.

Stigma was a more common barrier to participating in community activities for adults with autism than other adults.



Source: NCI Adult Family Survey 2018-19

Fewer adults with autism had friends (other than paid staff and family) than other adults.



Source: NCI Adult Family Survey 2018-19

Activities of adults with autism who live at home with family members

Almost all (88%) families reported “yes” when asked whether their family member with autism takes part in activities in the community. This was comparable to rates of those with other types of disabilities. However, for those who did not participate in the

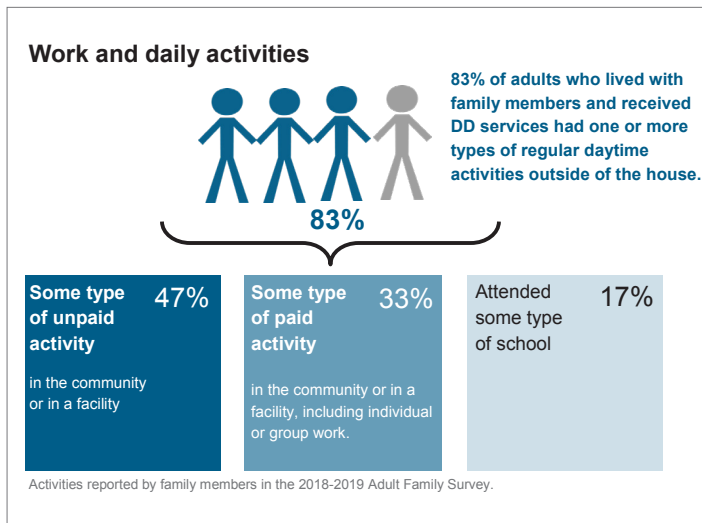


What did autistic adults who lived with family do during the day?

Family members reported ALL the types of activities their loved one did during the daytime over the previous two weeks. They could report more than one type of activity. So, it is possible that people had some community-based work and some facility-based work, or some paid work and some unpaid work. Or maybe they went to school sometimes and stayed at home sometimes. Our graphs may add up to more than 100% of people, because people may have been counted in more than one category.

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

Overall, 83% of adults with ASD participated in some type of work or daily activity. Remember that some adults may have participated in more than one type of job or activity.

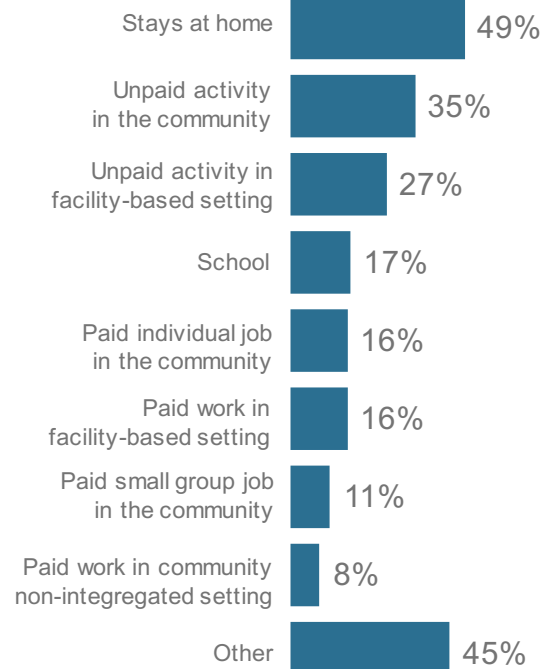


The fact that most people with ASD had some type of day activity sounds positive, but what were these people doing? Nearly half of adults on the autism spectrum who had DD services and lived with family were engaged in unpaid activity of some type, while one-third had some type of paid activity. Their activities were like those with other types of

disabilities, but autistic adults were over twice as likely to be attending some type of school – 17% versus 8% of adults with other disabilities, possibly related to the younger age of those on the spectrum and the fact that some were still in high school.

What specific activities were autistic adults doing? Nearly half of family members reported their loved one with autism stayed at home during the day. Others did unpaid (volunteer) work in the community or unpaid work in facility-based settings. About 45% of family members reported other activities including attending day programs, participating in church/faith-based activities, volunteering in a variety of settings, visiting service providers, engaging in physical activity, spending time with family, going on outings in the community, and engaging in recreational activities like art, music, and bowling.

Adults with autism who lived with family were most often doing unpaid activities or staying at home during the day.



Percentage of adults with ASD

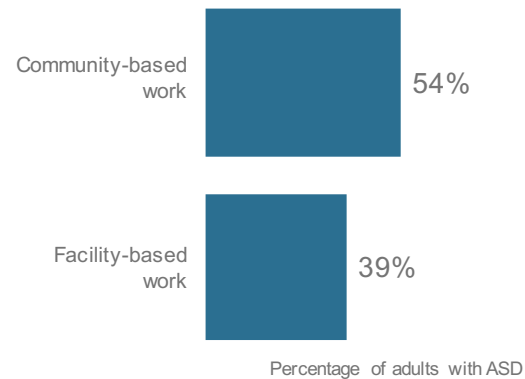
Source: NCI Adult Family Survey 2018-19



Over half of adults with autism engaged in community-based activity during the day. Fewer had paid activities.

Among adults with autism who lived at home with family members, over half had some type of community-based work (paid or unpaid), while fewer had facility-based work (paid or unpaid). Rates of community-based work among adults with autism was only slightly higher than that of adults with other types of disabilities. Overall, paid work of any type was far less common (33%) than unpaid work activities of any type (47%).

Over half of adults with autism who used DD services and lived with family worked in community-based settings.



Source: NCI Adult Family Survey 2018-19

Types of daytime activities among adults who receive DD services

State DD services are a key source of public funding for long-term supports and services for the daytime activities of people with disabilities. These services support people support work and other activities in two main settings – communities and facilities. In the AFS, 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, such as in a sheltered workshop setting. In either setting, sometimes people earned pay, but not always. Some people only engaged in paid work or unpaid activities, but other people’s days consisted of a combination of paid and unpaid work and other activities that were often supported by state DD services. More examples are provided in the table.

Community-based versus Facility-based: What does this mean?

Type of activity

What does this mean?

COMMUNITY-BASED

Paid individual job in the community	Works at an individual job in a local business alongside peers who do not have disabilities. The job is part of the typical labor market (for example, competitive employment).
Paid small group job in a community-based setting	Works in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).
Unpaid activity in the community	Examples: Volunteering, skills training, and staff-supported community connections
Paid work in a community business that primarily hires people with disabilities	Works in a setting where s/he interacts with the non-disabled population. This is NOT in a traditional sheltered workshop and NOT enclave. Examples include bakeries, car washes, thrift stores.

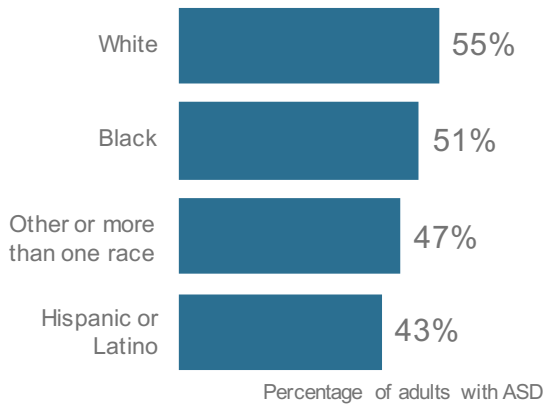
FACILITY-BASED

Paid work performed in a facility-based setting	Works at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.
Unpaid activity in a facility-based setting	Examples include day habilitation, senior programs, or drop-in centers



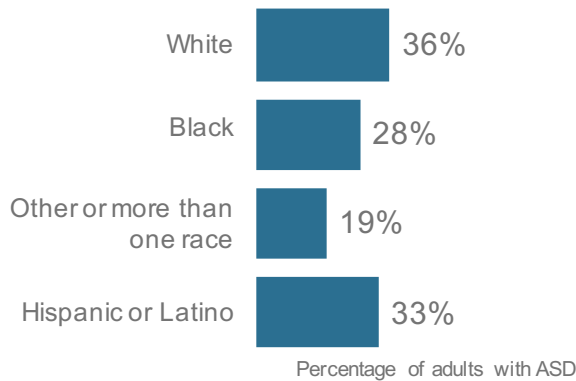
There were minimal differences in paid work and community-based work by age. Approximately 56% of family members of adults with ASD under age 30 reported any community-based activities and 33% reported any paid work. In comparison, approximately 49% of family members of adults with ASD age 30 and older reported any community-based activities and 34% reported any paid work.

White adults with autism were most likely to participate in community-based activities.



Source: NCI Adult Family Survey 2018-19

Fewer adults with autism who were Black or other/mixed race participated in any paid work.

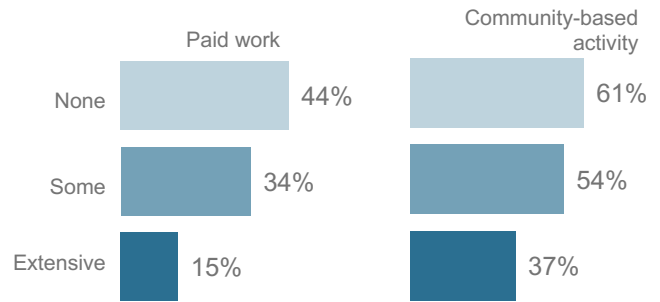


Source: NCI Adult Family Survey 2018-19

However, there were differences by race and ethnicity. Autistic adults who were Hispanic were less likely to participate in community-based activities compared to non-Hispanic White adults. Autistic adults who were non-Hispanic other/mixed race were less likely to participate in paid work, compared to non-Hispanic White adults.

Participation in paid work and community-based activities also depended on the level of support people with autism needed for managing distressed behavior. Those with extensive support needs were far less likely to have any paid work or community-based activities.

Far fewer adults with autism who lived with family and had extensive needs for behavior support engaged in any paid work or community-based activity.



Source: NCI Adult Family Survey 2018-19

Almost one in five autistic adults had no work or daytime activities.

17% of adults on the spectrum had no work or daily activities within the previous two weeks.* This rate was slightly lower than the 21% of adults with other disabilities who had no daytime activities.

*NOTE: Adults who had missing information on participation in employment or daily 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 indicator. For this reason, the percentage of adults with ASD who had no work or daily activities and the percentage of adults with any type of work or daily activity do not sum to 100%. About 4% of adults with ASD had unknown responses for all four types of work or daily activity.

References

1. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summary* 2018;67(No. SS-6):1–23. DOI: <http://dx.doi.org/10.15585/mmwr.ss6706a1external icon>.
2. Allen, Z., & Pogach. D. "More State Pass Supported Decision-Making Agreement Laws." American Bar Association, October 1, 2019. Accessed at americanbar.org



Chapter 2

Characteristics of family members and households

Family members of autistic adults who lived at home and used state Developmental Disability services

Our Key Findings

- Among family members who responded to the Adult Family Survey and had an adult on the autism spectrum living with them, nearly half (48%) had a college education, and 61% were between 55-74 years old at the time of the survey.
- Among families with an autistic adult living with them, 22% of families reported \$25,000 or less in annual household income.

- Of households with autistic adults living at home, approximately 37% received pay for providing supports for their loved one.

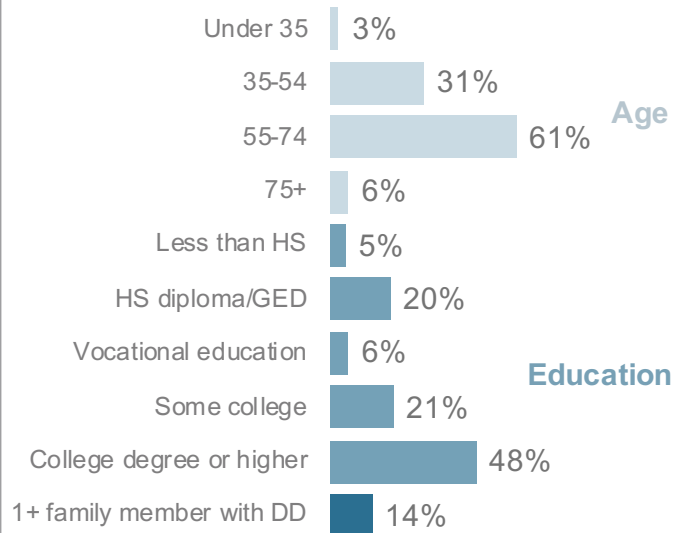
A total of 1,551 family members of adults on the autism spectrum, who lived at home with family members, participated in the 2018-19 Adult Family Survey (AFS). In addition to reporting information about the autistic adult, they reported information about themselves and their households.

Demographic characteristics of family members

Most family members of adults on the autism spectrum, who lived with family, were parents (91%) and about 5% were grandparents. These family members were most often between ages 55-74 years old. Overall, the family members of adults on the autism spectrum were younger than the family members of adults with other disabilities. One-third (31%) of family members were between 35-54 years of age, compared to 19% of family members with other types of disabilities. This was not surprising since adults with autism in this survey tended to be younger than adults with other types of disabilities.

Overall, these family members had higher rates of college education than family members of adults with other types of disabilities who lived at home with family members. Nearly half (48%) of family respondents of autistic adults had a college education or beyond, compared to 34% of family members of people with other types of disabilities.

Of family members who took the survey and had an autistic adult who lived at home, most had at least some college education.



Percentage of family members of adults with ASD (HS = high school)

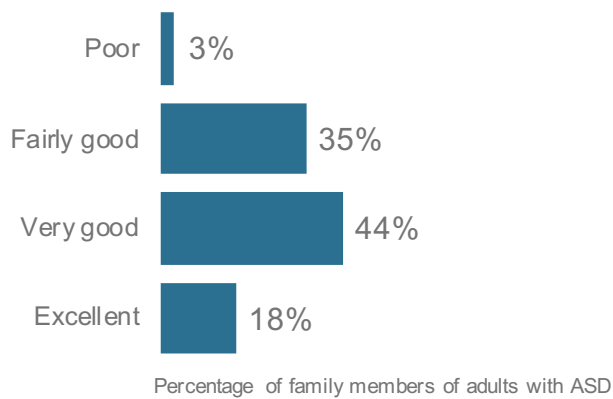
Source: NCI Adult Family Survey 2018-19



Approximately 14% of these family members reported having more than one adult with an intellectual or developmental disability in the home, like households with adults who had other types of disabilities.

The health status of family members of adults with autism who lived at home was similar to that of families with adults with other types of disabilities with very few reporting poor health at the time of the survey.

Most family members of DD service users with autism who lived at home were in fair to very good health.



Source: NCI Adult Family Survey 2018-19

Household characteristics

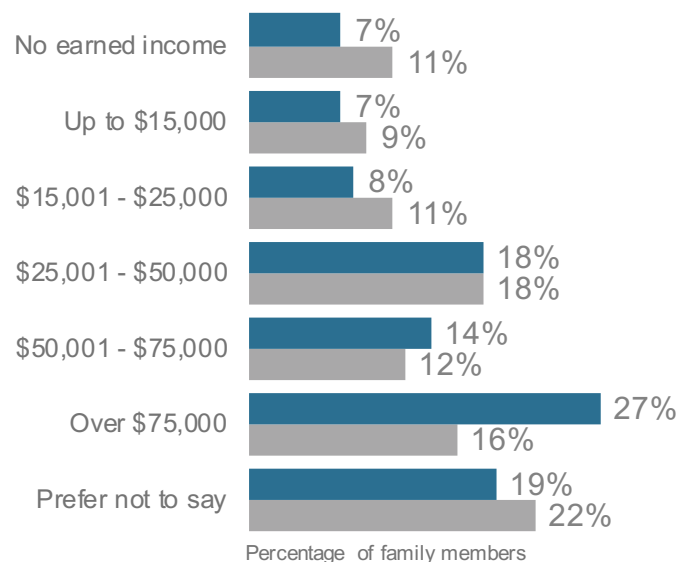
About 68% of family members who completed the AFS, and who had an adult with autism who lived at home, lived in urban areas, and 98% said that English was usually spoken at home. These rates were similar to families of adults with other types of disabilities who took this survey.

However, in the general population, approximately 22% of individuals speak languages other than English at home,[1] and in the nation’s top five cities, nearly half of people speak a language other than English at home.[2]

Approximately 20% of households had four or more adults in the home, and around 17% had at least one child in the home. The survey did not ask whether the household was led by a single parent and did not distinguish between experiences of mothers versus fathers.

Among families with an autistic adult living with them, who reported their total taxable household income, 59% earned less than 50,000 per year, with 22% reporting less than \$25,000 per year in earnings. It is important to note that 19% of families with an autistic adult and 22% of families with an adult with another type of disability said they preferred to not report their household income.

Nearly one-quarter of families with autistic adults who lived at home reported household incomes of \$25,000 or less.



Source: NCI Adult Family Survey 2018-19

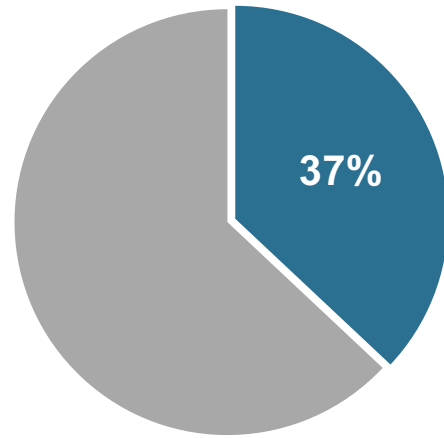


Approximately 37% of family members of autistic adults who lived at home received pay for providing supports for their loved one, compared to 32% of family members of adults with other types of disabilities.

References

1. United States Census Bureau. "Selected social characteristics in the United States. 2019: ACS 5-year estimates data profiles." Table DP02. Accessed at <https://data.census.gov>
2. Zeigler, K and Camarota, S.A. "67.3 Million in the United States Spoke a Foreign Language at Home in 2018." Center for Immigration Studies; October 29, 2019. Accessed at cis.org

Over one-third of family members were paid support providers for the person with autism.



Source: NCI Adult Family Survey 2018-19



Chapter 3

Services and supports for the adult with autism and the family

▶ Our Key Findings

- A little over half of autistic adults received transportation services (58%) and/or supports for daytime activities or employment (51%), and a little less than half received in-home supports (44%).
- Adults with autism who lived at home and received DD services relied heavily on cash benefits – with 92% receiving Supplemental Security Income (SSI).
- Many (88%) of families felt the DD service plan included all the services and supports the adult with autism needed
- But, when specifically asked about supports for daytime activities, 38% of families felt the person wasn't receiving enough supports to be able to work or volunteer in the community.
- Family members of autistic adults who lived at home reported on supports and services family members needed for themselves.
 - Over one-quarter (27%) of family members felt they were not receiving enough supports and services for themselves, and 55% indicated a need for respite care.
 - Nearly 40% appeared to need more information about public benefits their loved one might qualify for.

Services and supports for autistic adults who lived at home and used state Developmental Disability services

Services and supports for the adult on the autism spectrum who lives with family members

87% of family members who responded to the AFS indicated that the adult with autism who lived with them had a service plan, and 58% of these individuals said the autistic adult was involved with making the plan compared to 67% of adults who had other types of disabilities.

Types of services autistic adults might receive if they live with family

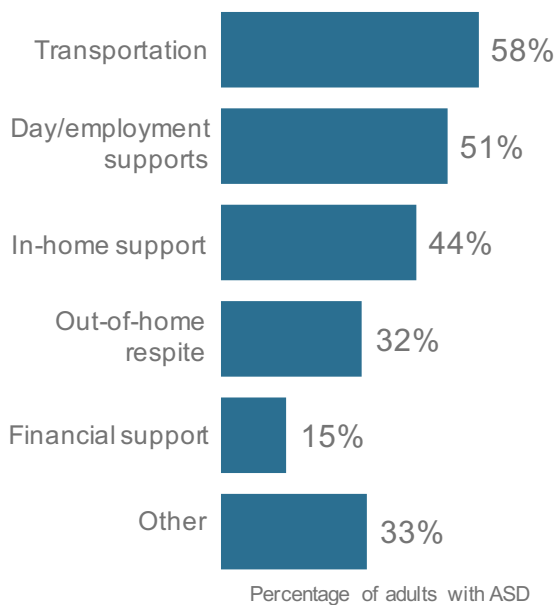
Day/employment supports	The family member with autism attends a day program, sheltered workshop, or receives vocational supports such as job training or job coaching at a job in the community.
Financial support	The adult family member receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for him/herself. Not including SSI payments
In-home support	People are paid to come to the home to assist the autistic adult with things like activities of daily living
Other services/supports	The family member with autism receives mental/behavioral health care and/or other treatments or therapies like physical therapy, occupational therapy, speech therapy or recreational therapy).
Out-of-home respite care	Someone takes care of the autistic adult outside of the home to give the family a break. Includes recreational respite care such as camp.
Transportation	Someone arranges or provides transportation for the family member with autism to go to a day program, work, medical appointments, and other places.



ADULT FAMILY SURVEY

Family respondents reported on the types of services the autistic adult received from DD Services. More than half received transportation services, and/or day or employment supports. Less than half received in-home supports, and fewer received out-of-home respite or other types of services. Approximately 15% received some financial support from DD Services, but the exact types of support were not specified. These rates of service receipt were all comparable to adults with other types of disabilities who were living with family members.

Autistic adults who used DD services and lived at home were most likely to receive support for transportation and employment.

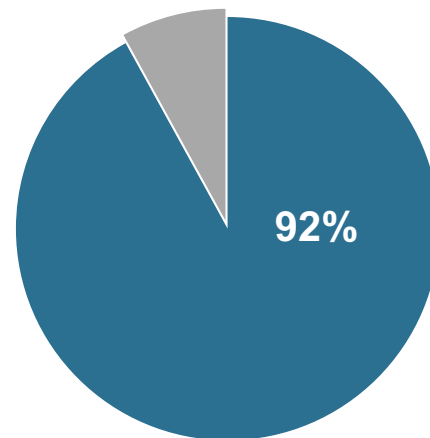


What are respite services?

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.

Additionally, almost all autistic adults who were living at home and receiving DD services were also receiving financial benefits from the Social Security Administration, such as Supplemental Security Income (SSI).

Nearly all autistic adults were receiving Social Security (SSI) benefits.



Source: NCI Adult Family Survey 2018-19

Self-directed supports

Approximately 44% of family respondents said the autistic adult (or a representative family member) received self-direction/fiscal intermediary services from the I/DD agency, slightly higher than the 39% of adults with other disabilities who live with family.

What are self-directed supports?

Adults with DDs, or their legal representatives, who self-direct their supports manage some or all of their services. For example, participants are allowed to hire or fire their support workers and are allowed to control how their budget is spent. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. The availability of this option varies across states. Source: Centers for Medicare and Medicaid Services.

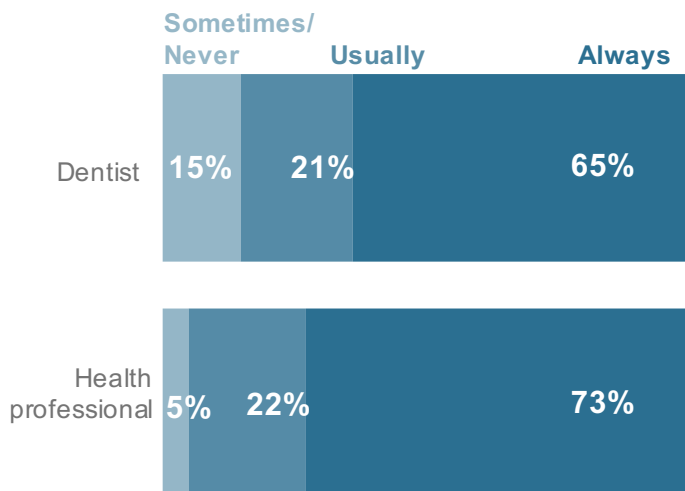


More adults with autism received additional services and supports from other agencies and organizations outside of DD services – 36% versus 28% of adults with other disabilities. The survey did not specify exactly what types of other services this included.

Access to health and dental care

Nearly 95% of family members reported that the autistic adult was usually or always able to see health professionals when needed, which was comparable to adults who lived with family and had other types of disabilities. However, only about 86% of autistic adults who lived at home were able to see a dentist when needed, with 7% seldom/never able to see a dentist when needed.

Many adults with autism can see a health professional when needed, but fewer usually or always have access to a dentist.



Source: NCI Adult Family Survey 2018-19

Changes in intensity of services over past year

Over 20% of family members reported that services for the autistic adult who lived with them had increased during the past year. Over 12% of families reported that the services or supports the family member with autism received during the past year had been reduced, suspended or terminated. Of people

whose services were reduced or ended, 72% of their family members said this resulted in a negative effect for the autistic adult. The reasons for why services were increased or reduced were not given in the survey.

One possible reason for increases in intensity of services is medical or behavioral crises or emergencies that the adult with autism or family experience. Of families who did ask for crisis or emergency services, only 52% received these services.

On the other hand, of families who said they experienced changes in family needs, nearly 80% of families felt that services usually or always changed in response. However, we note that there were many families who did not answer this question.

Family perspectives on services and supports for the family member with autism

Family perspectives are an important gauge of the quality of DD services. As we stated at the beginning of this report, DD agency administrators often turn to the opinions of family members in the AFS survey to monitor the effectiveness of service implementation.

Most families felt the autistic adult was receiving all needed services and supports, except in regard to services and supports needed to work or volunteer.

When families of adults with autism who lived at home were asked whether the DD service plan included all the services and supports the autistic adult needed, 88% said yes, which was comparable to family members of adults with other disabilities. Even among families of autistic adults who had no daytime activities, 91% of families felt the plan included enough supports and supports to meet their family members' needs.



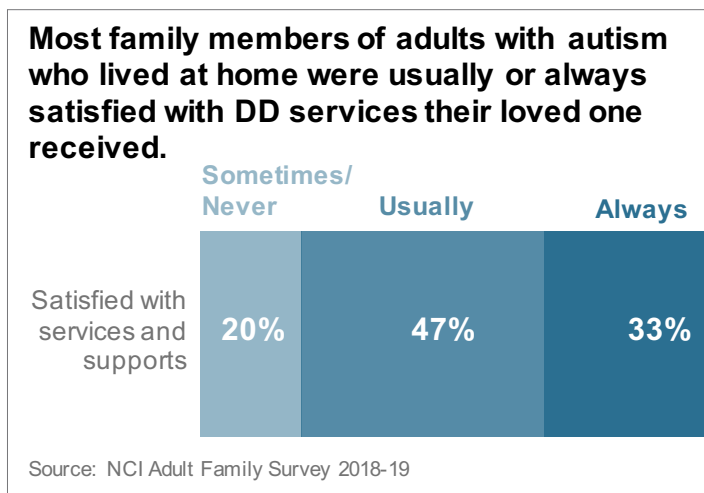
More than one in three families felt the autistic adult did not have enough support to work or volunteer in the community.

However, when asked whether the family member had enough support to work or volunteer in the community, 38% of people on the autism spectrum said no, versus 30% of those with other disabilities. When asked whether the family member with autism always or usually had special equipment or accommodations (if needed), only 79% of families said yes. Only 9% said the person seldom or never has needed equipment or accommodations, compared to 5% of persons with other types of disabilities who live with family.

Most families (80%) with an adult on the autism spectrum living with them reported always or usually feeling satisfied with the services and supports the adult received; although over 20% said they felt satisfied sometimes or seldom/never. These satisfaction rates were slightly lower than those of families with adults with other types of disabilities.

Satisfaction levels did not differ significantly based on whether the family member was paid to provide support for the autistic adult or not.

Approximately 73% of families said services and supports their loved one received were helpful in

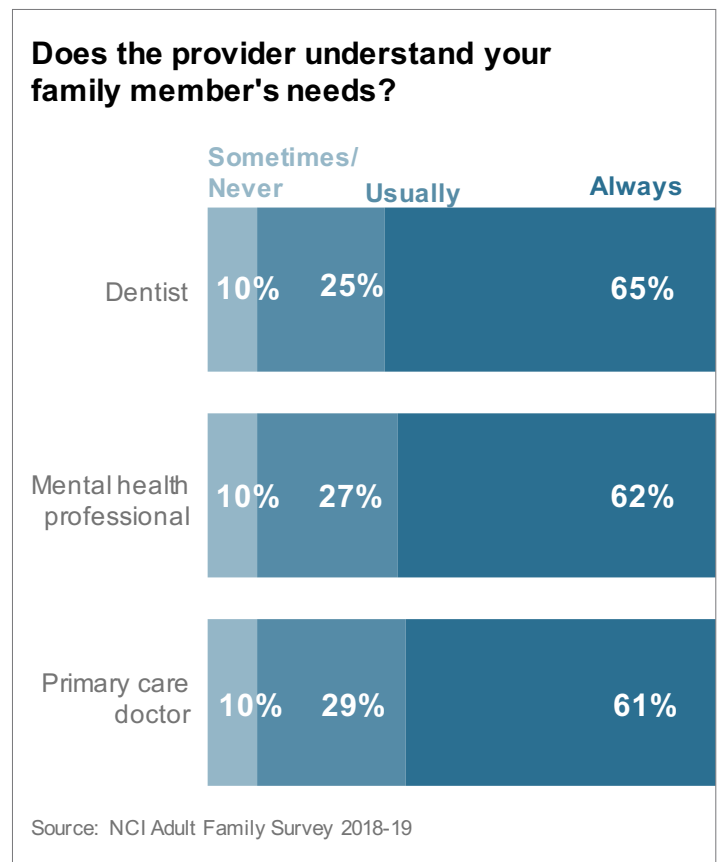


reducing the family’s out-of-pocket expenses for the family member’s care. And 94% said that the services and supports the adult with autism received were helping the adult to live a good life.

Perspectives on knowledge of professionals

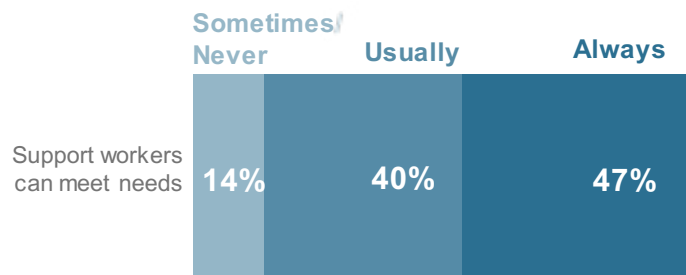
Family members reported their opinions on how well different health professionals understood needs related to the autistic adult’s disability. Approximately 90% of respondents felt that primary care doctors, dentists and mental health care professionals (for people who used mental health services) usually or always understood the person with autism’s disability.

When asked whether support workers (for adults who used this support) had the right information and skills to meet the family’s needs, most families again said that support workers were usually or always competent in these areas.



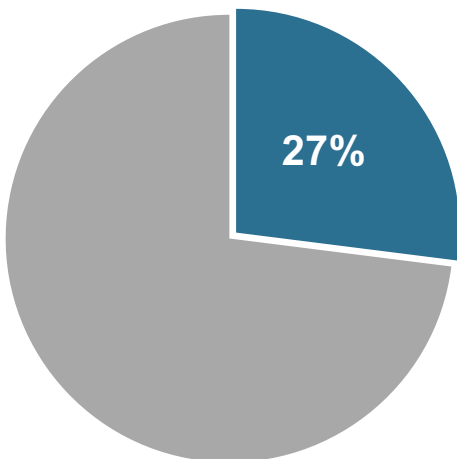


Most families of adults with autism who lived at home said support workers usually or always had needed information and skills.



Source: NCI Adult Family Survey 2018-19

One-quarter of families of adults who receive DD services and live at home don't get needed supports and services.

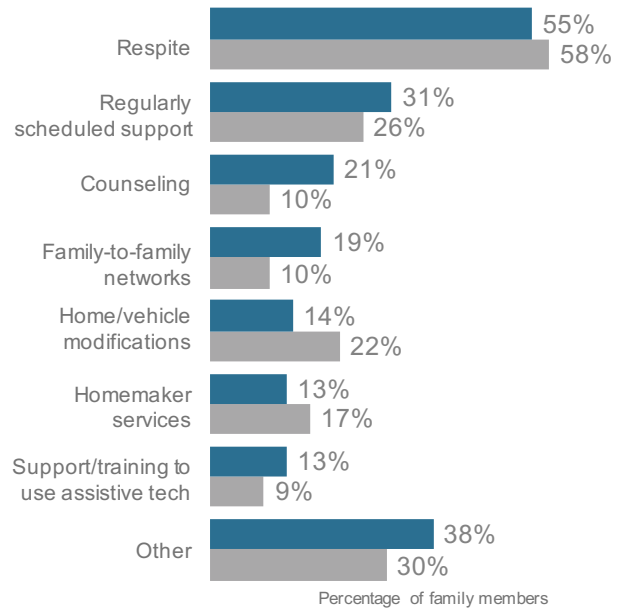


Source: NCI Adult Family Survey 2018-19

Services and supports for the family

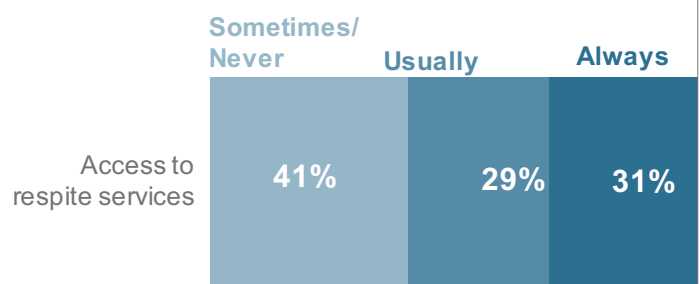
More than one-quarter of families said they did not get the supports and services they need for themselves. This means that while families often felt their loved one was getting needed services, they did not always feel that they were getting enough support themselves. We note that we only included people who answered this question, because some families (13%) did not provide an answer.

Families of adults with autism who lived at home were more likely to report needing in-home support, counseling, and family-to-family networks.



Source: NCI Adult Family Survey 2018-19

Nearly one-quarter of families of adults with autism who lived at home were seldom or never able to get needed respite services.



Source: NCI Adult Family Survey 2018-19

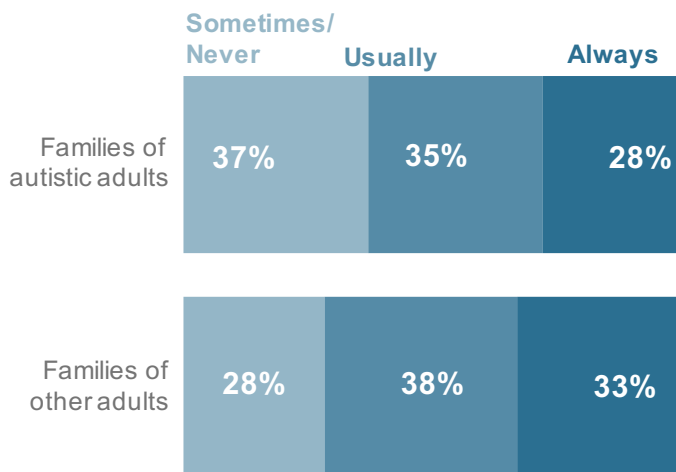
Those who reported that their needs were not met were asked about their additional service needs. Over half of these families said they needed respite care, and one-third said they needed regularly scheduled support for the family member. About 20% said they needed counseling and/or family-to-family networking.



ADULT FAMILY SURVEY

Families were asked if they were able to get and use respite services if they needed this type of support. Four in 10 families of adults with autism who lived at home said they were only sometimes or seldom/never able to get/use respite care, like families whose adult had other disabilities. However, 88% of families of adults with autism who lived at home reported feeling satisfied with the quality of respite services, if they used this service in the past year. Satisfaction with quality of respite services did not differ significantly by race of the family.

More families of adults with autism indicated needs for information about other public services.*



(*Examples = food stamps, SSI, housing subsidies)

Source: NCI Adult Family Survey 2018-19

When asked whether they had enough information about other public services the adult with autism might be eligible for, such as food stamps, SSI, and housing subsidies, 20% said sometimes and 17% said never. This information gap appeared more significant for families of autistic adults than it did for those with family members with other disabilities. There was little difference by race or ethnicity in whether families reported having enough information.



Chapter 4

Communication and collaboration with families

Interactions with family members of autistic adults who lived at home and used state Developmental Disability services

▶ Our Key Findings

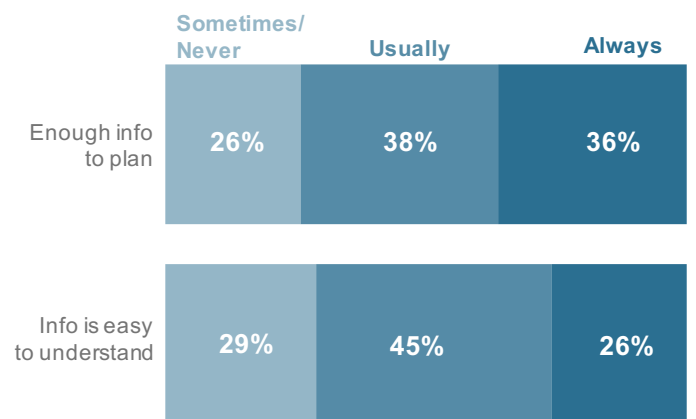
- 86% of families of autistic adults reported that they participated in making the service plan for their family member. Over 80% also reported having a choice about support workers who are on the team that supports the autistic adult. However, 15% said they did not choose and cannot change the service coordinator.
- About 30% of families of autistic adults felt that information about services and supports was seldom or never easy to understand. Families need understandable information about services and supports to support planning meetings and service delivery for their family member who receives DD services.
- 70% of families directly managed the support staff who provided services for the autistic adult in their home and in the community.

Communication with family members

Person-centered planning meetings are ideally held on an annual basis, or more often, to discuss the service and support needs of the individual who receives DD services. This team may include the family members who support the adult. About three-quarters of families felt they usually or always had enough information to participate in planning meetings, but nearly 30% sometimes or never felt the information about services and supports was easy to understand.

Families of autistic adults were positive about their interactions with support workers and their

Families of adults with autism who lived at home often said they had enough info to plan services, but fewer felt the info was easy to understand.



Source: NCI Adult Family Survey 2018-19

communication. Nearly all families (97%) of autistic adults who live at home reported that support workers usually or always speak to them in a way they can understand, and 94% felt the service coordinator usually or always respected their choices and opinion. Almost all families said that they or the family member could usually or always contact support workers when needed (92%) or the service coordinator (92%).

Collaboration, choice, decision-making

Of families who reported that the autistic adult had a DD service plan in place, 86% of family members said they helped make the service plan.

Consistency is important when supporting autistic individuals, as changes in routines and new faces can be unsettling. Families were overall positive in their reports about consistency and collaboration



with support workers. Almost all (94%) said support workers usually or always come and go when they are supposed to, and 82% said that support workers collaborate to provide support if there was more than one worker.

When problems arise, or direct support workers are not well-matched to the needs of the individual with disabilities, families should be able to request a change or support their family member in requesting a change in workers. Most families said they usually or always can choose or change the autistic adult's support workers when needed (83%) or the service coordinator (85%). It was notable that 15% said they did not choose and cannot change the service coordinator.

Across these indicators, families of adults with autism who lived at home had similar responses to families with members who had other types of disabilities.

What are self-directed supports?

Adults with DDs, or their legal representatives, who self-direct their supports have to manage some or all of their services. For example, participants are allowed to hire or fire their support workers and are allowed to control how their budget is spent. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. The availability of this option varies across states. Source: Centers for Medicare and Medicaid Services.

Self-directed supports

Some individuals with disabilities and their family members take on the responsibility of managing staff – hiring them, dismissing or changing them when needed, and handling communication needs. When asked whether the family directly manages the support staff, 70% said they usually or always do this, versus sometimes (11%) or seldom/never (20%).

Respect for family culture

Almost all (98%) of families felt that services were usually or always delivered in a way that was respectful of their family's culture. We note here that the sample of families, however, did not reflect the diversity of the general population. As we said in the Family Characteristics chapter, a lower percentage of family participants were Hispanic, and more were primarily English speakers, compared to the U.S. population around the time of the survey. Of the 10 states with the largest percentages of non-English speakers,[1] only one (Arizona) participated in this survey.

Across these indicators, families of adults with autism who lived at home had similar responses to families with members who had other types of disabilities.

References

1. Zeigler, K and Camarota, S.A. "67.3 Million in the United States Spoke a Foreign Language at Home in 2018." Center for Immigration Studies; October 29, 2019. Accessed at cis.org



Chapter 5

Educating and supporting families to participate as care partners

Education and support for family members of autistic adults who lived at home and used state Developmental Disability services

▶ Our Key Findings

- Families of autistic adults most often reported need for help with planning around housing, but also reported need for help planning for future social relationships and recreation, financial and legal matters, and employment.
- Only six in every 10 family members of autistic adults who live with them said they discussed a plan for handling crises and emergencies at their last person-centered planning meeting.
- Most families (83%) said they knew how to report abuse and neglect when needed, but only 65% said they knew how to file a complaint or grievance about provider agencies or staff.

Education and planning needs

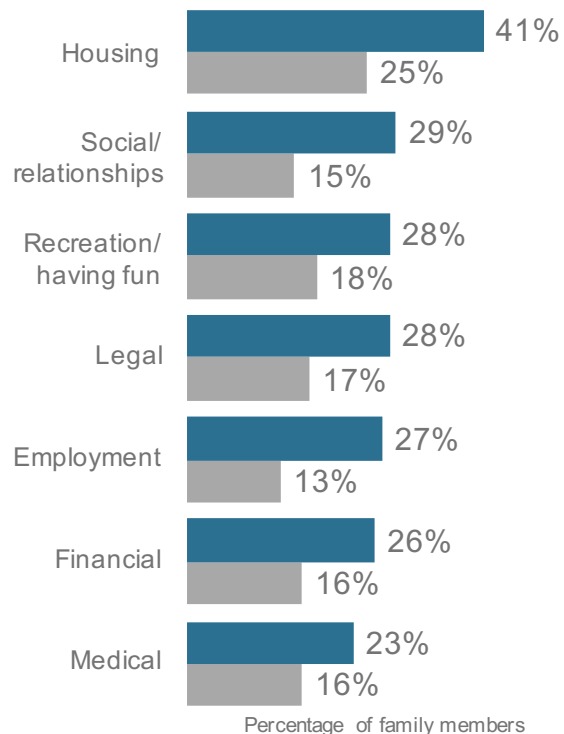
Among the top reported concerns of family members is the fear of what will happen to the autistic adult when parents are no longer able to provide care for them. In some cases, siblings may play an important role in caregiving. For families whose adult has been living at home with them, planning for the future is even more critical.

Families were asked whether they needed help planning for the family member’s future across a variety of topics. Families of adults with autism who lived with family reported more need for help than families of adults with other disabilities, across all topics. Families of autistic adults most often reported need for help with planning around housing. This

kind of planning often addresses a question that weighs heavily on parents’ minds, “Where will my child live and who will take care of them when I am gone?” Families also reported need for help planning for future social relationships and recreation, financial and legal matters, and employment.

Nearly all families (98%) reported that they usually or always knew what the autistic adults’ medications were for and how to take them safely.

Families of adults with autism who lived at home needed more help planning for the future than other families, across all topics.



Source: NCI Adult Family Survey 2018-19



Crisis and emergencies

Natural disasters, family emergencies (like a caregiver getting ill with, or dying from, COVID-19), and mental health crises are examples of unexpected events that can wreak havoc for adults with disabilities unless a plan for handling emergencies is in place. It is critical that families understand the resources available to them during crises and emergencies, including the ability to request additional services and supports if family members are unable to care for the autistic adult who is living within them.

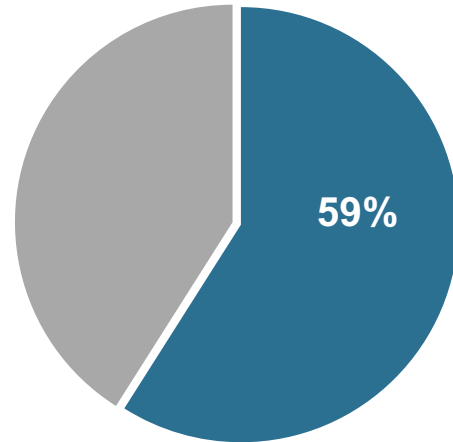
Approximately six in every 10 families said they discussed how to handle emergencies at the last service planning meeting. Most (86%) said they did feel prepared to handle the needs of the family member in case of medical emergency or a natural disaster. Approximately 90% of families with adults who did not need any additional support to manage behavior said they felt prepared to handle emergencies or natural disasters, compared to 81% of families with adults who needed extensive support to manage behavior. We note that this survey was conducted prior to the COVID-19 outbreak, and families may now feel differently about their preparation for emergencies given their experiences during the pandemic.

Safety and quality assurance

Understanding how to address safety and compliance issues is critical for maintaining the safety of vulnerable persons with disabilities. Families were asked if they knew how to report abuse or neglect related to the adult with autism who was living with family, and 83% reported knowing how to do this. Within the year before the survey, 34 families of adults with autism (2% of all families of adults with autism) said they reported abuse or neglect.

However, when families were asked if they knew how to file a complaint or grievance about provider agencies or staff only 65% reported that they knew how to do this. Of families who filed a grievance, only 62% felt satisfied with how the situation was resolved

59% of families of adults with autism reported discussing emergency planning at the last service planning meeting.



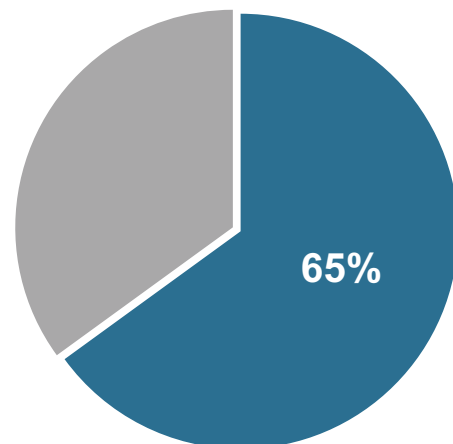
Source: NCI Adult Family Survey 2018-19

or handled (of only 80 families with autistic family members reporting).

There were too few responses to be able to reliably report on how responsive administrators were to any complaints or filed reports regarding abuse or neglect.

The survey also did not explore other serious safety issues that some autistic adults experience including running or wandering away (elopement), sexual victimization, and financial vulnerability, for example.

Only six in 10 families of adults with autism who lived at home said they knew how to file a complaint or a grievance.



Source: NCI Adult Family Survey 2018-19



Chapter 6

Characteristics of Autistic Adults Who Do Not Live with Family

Autistic adults who used state Developmental Disability services and did not live with family

▶ Our Key Findings

- More than seven in every 10 adults with autism (74%) who did not live with family also had intellectual disability. This rate was more than double that of the overall population of people on the autism spectrum.
- Autistic adults who did not live with family were primarily male (78%) and were more likely to be White (81%) than the U.S. general population according to U.S. Census estimates for 2019. Approximately 12% were Black – roughly equivalent to the general population. A lower percentage were Hispanic (3%), compared to 19% in the general population.
- Nearly 70% of adults with autism who did not live with family members were in group home or agency-operated apartment settings. Nearly 12% were in specialized facilities for people with I/DDs, and 9% lived in independent homes or apartments.
- Four in 10 autistic adults (42%) who did not live with family needed extensive supports for managing distressed behaviors, compared to 24% of adults with other types of disabilities who did not live with family.
- Most (88%) families of autistic adults who did not live at home reported the autistic adult had extensive needs for support with daily activities like scheduling, managing money and shopping.
- While many families reported their loved one had activities in the community, only 30% had any type of paid daytime activities, and nearly 60% were doing some type of facility-based work in settings that do not include people without disabilities. Autistic adults who were Hispanic were less likely to have any type of paid work compared to those who were non-Hispanic White, Black, or Other/Mixed race.

Family members of 715 adults on the autism spectrum who were over the age of 18 and did not live with family members, provided information about these adults in the 2018-19 Family/Guardian Survey (FGS). Each of these adults received at least one DD service in addition to case management. For more information on who is included in these analyses, see the **Methods** appendix.

Demographic characteristics

Autistic adults who did not live with family members averaged 38 years of age at the time of the FGS 2018-2019 survey – younger than adults with other disabilities who averaged 51 years of age. Approximately 68% of these autistic adults were over the age of 30 years at the time their family member

completed the FGS, compared to 93% of adults with other types of disabilities.

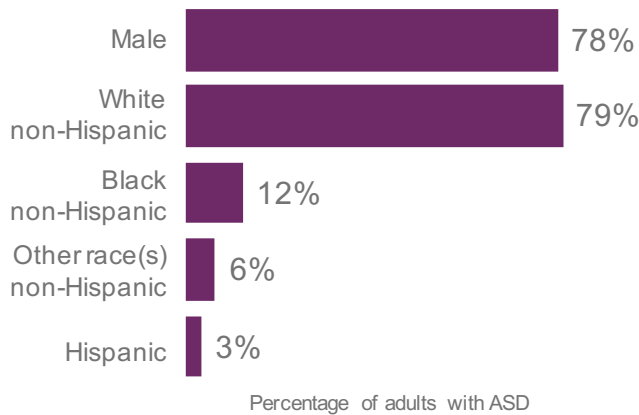
Most autistic adults in the FGS were male and non-Hispanic White. The percentage of autistic adults who did not live with family and received DD services who were non-Hispanic White (79%) was slightly



higher than the general population (76%) But those who were non-Hispanic Black was roughly equivalent to the general population, according to the U.S. Census estimates for 2019. A lower percentage were Hispanic (3%), compared to 19% in the general population.

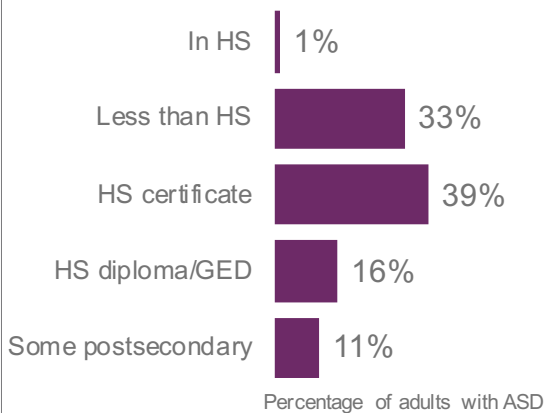
Approximately 34% of autistic adults in the FGS had less than a high school education, and another 39% left high school with a certificate instead of a diploma.

Most adults with autism who received DD services and lived outside of the family home were male, white, and non-Hispanic.



Source: NCI Family/Guardian Survey 2018-19

Less than one-third of adults with autism attained a high school diploma or GED.



(HS = high school)

Source: NCI Family/Guardian Survey 2018-19

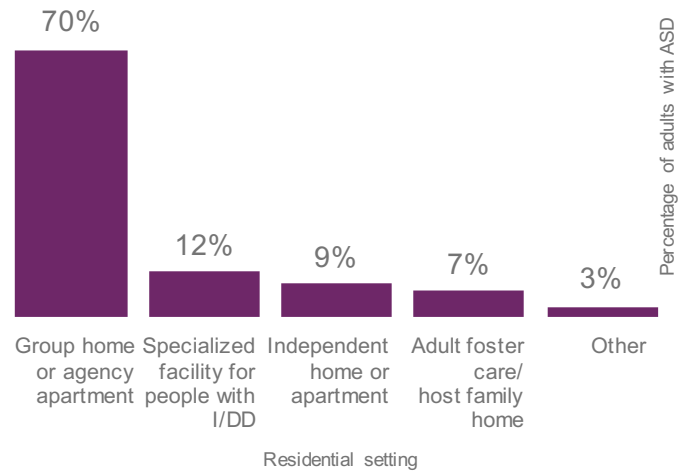
Living arrangements

Most autistic adults who lived apart from family were in group home or agency-operated apartment settings.

Nearly 70% of adults with autism who did not live with family members were in group home or agency-operated apartment settings. Nearly 12% were in specialized facilities for people with I/DDs, 9% in independent homes or apartments, 7% in adult foster care or host family homes, and 2.5% in other settings like nursing homes.

About 67% of families visited the autistic adult more than once a month, compared to 53% families of adults with other types of disabilities.

Most adults with autism who do not live with family were in group home or apartment settings.



Source: NCI Family/Guardian Survey 2018-19

Co-occurring conditions

Many have disabilities in addition to autism, and three-fourths have intellectual disability.

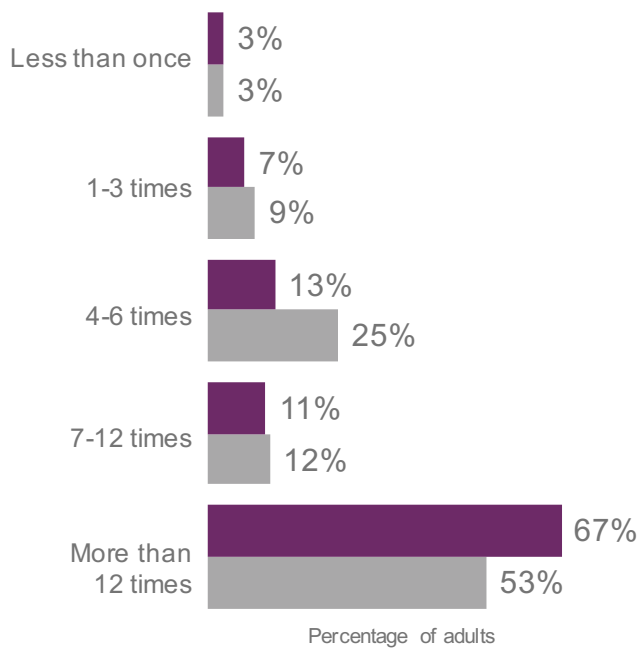
Families reported diagnoses the adult had in addition to autism. Nearly three-fourths of autistic adults who received DD services and lived outside of the family home had co-occurring Intellectual Disability (ID). The prevalence of co-occurring ID among youth on



the spectrum has generally decreased over time and is currently estimated at around one-third of children with ASD.[1] Adults on the autism spectrum who receive DD services, however, tend to have a much higher rate of ID, because having ID is sometimes linked to eligibility criteria for DD services. Because of this higher rate of co-occurring ID, the findings in this report represent people with a greater level of functional impairments than the overall population of individuals on the autism spectrum who often don't qualify for DD services.

Alzheimer's, dementia, Tourette's and tic disorders), genetic and chromosomal disorders (Fragile X syndrome, Angelman syndrome, tuberous sclerosis, Williams syndrome, and many other rare disorders), mitochondrial disorders, swallowing and feeding issues, and mobility issues. Families commonly mentioned intermittent explosive disorder and personality disorders.

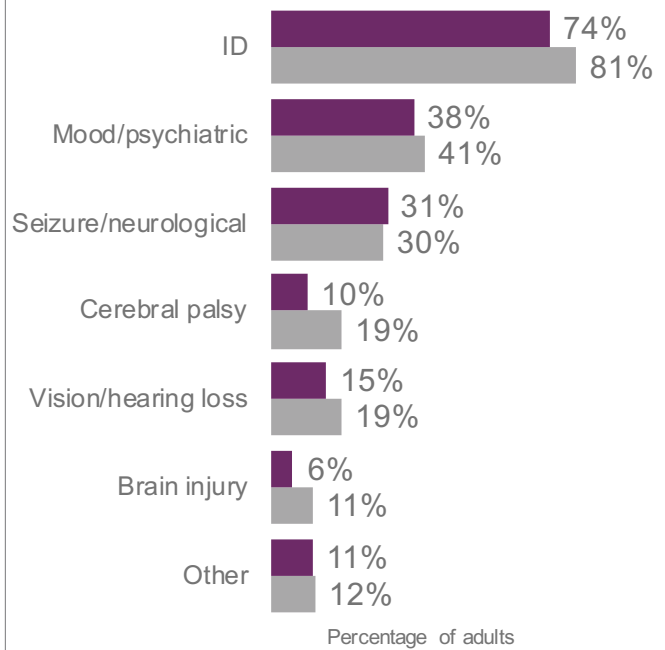
Families of adults with autism were more likely to visit at least 12 times a year compared to families of other adults.



Source: NCI Family/Guardian Survey 2018-19

Compared to adults with other disabilities who did not live with family, adults with autism had about the same rates of mood/psychiatric disorder, but lower rates across all co-occurring disorders with exception of seizure/neurological disorder. Other reported disabilities included specific brain malformations (hydrocephalus, microcephaly), neurological conditions (paralysis, hemiparesis, Parkinson's, early

Adults with autism who used DD services and lived outside of the family home had similar rates of disabilities as other adults.



Source: NCI Family/Guardian Survey 2018-19

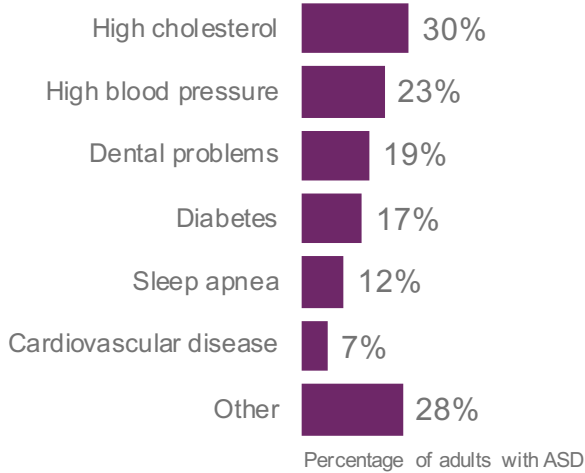
Some had additional health conditions.

Families were asked whether the adult had ever been diagnosed with any health conditions (from a list of 10 conditions that might occur more commonly in people with DDs). Among this list of conditions, nearly one-third of adult autistics had high cholesterol and one-quarter had high blood pressure. Approximately 12% had sleep apnea. Rates of co-occurring health conditions among autistic adults were slightly lower than those of adults with other types of disabilities for all conditions except



for dental problems. But over one-quarter reported “other” health issues including thyroid conditions, gastrointestinal conditions (e.g., gastro-esophageal reflux, constipation), musculoskeletal conditions (e.g., arthritis, osteoporosis, scoliosis), heart conditions, obesity, allergies, asthma, and sleep disorders.

High blood pressure and high cholesterol were the most common health conditions in autistic adults who received DD services.



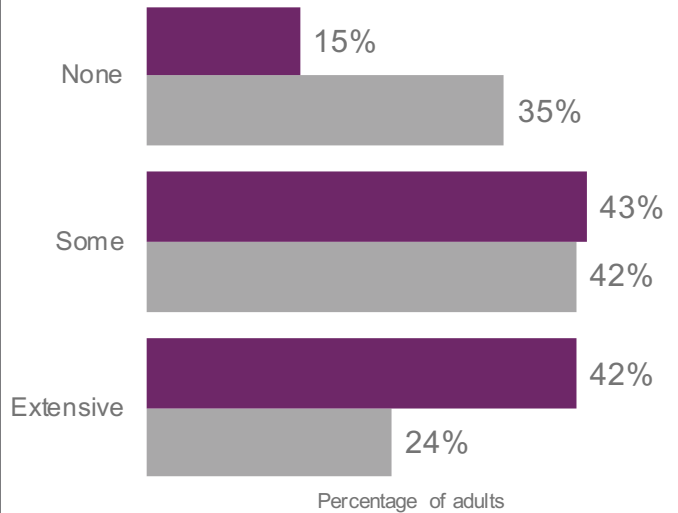
Source: NCI Family/Guardian Survey 2018-19

Functional skills

Approximately 60% of autistic adults in the FGS used spoken language to communicate, while 31% used gestures, body language, or another form of communication. For those who did not communicate with spoken language, family members reported that support staff could “sometimes” (11%) or “seldom/never” (5%) communicate with their loved one.

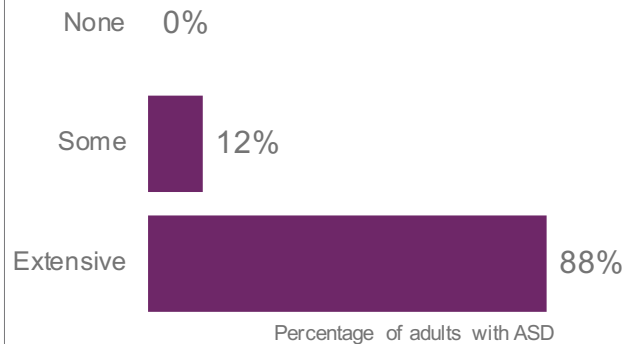
Adults on the autism spectrum who did not live at home with family members were almost twice as likely to need extensive help with self-injurious, disruptive and/or destructive behavior than adults with other types of disabilities. Four in 10 adults on the autism spectrum who lived outside the family home had extensive need for supports with regulating behavior.

Autistic adults who did not live with family needed more frequent supports for managing distressed behavior than other adults.



Source: NCI Family/Guardian Survey 2018-19

Most autistic adults who used DD services and did not live with family needed extensive support to do daily activities.



Source: NCI Family/Guardian Survey 2018-19

Nearly 4% of family members reported their loved one with autism needed extensive help with personal care activities like bathing, dressing or eating, other daily activities; and another 41% required some help. Need for assistance with daily activities was even more common. Most (88%) families of autistic adults who did not live with family reported the adult had

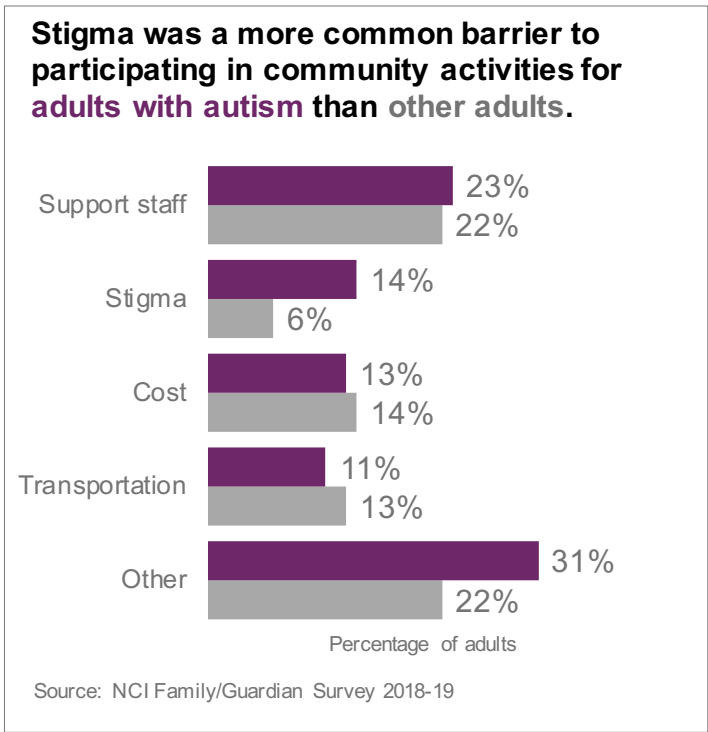


extensive needs for support with daily activities like scheduling, managing money and shopping.

Families reported that over 60% of adults with autism who did not live with family had full guardianship – similar to adults with other types of disabilities who did not live with family. In most cases (85%), a family member served as the guardian, while an employee of the state or guardianship agency was the guardian in 10% of cases. Family members were more likely to be the guardian for autistic adults who did not live at home compared to adults with other disabilities, and it was less likely that an employee of the state was the guardian. This could be related to the fact that family members of those with autism were generally younger than family members of adults with other types of disabilities who lived outside the family home.

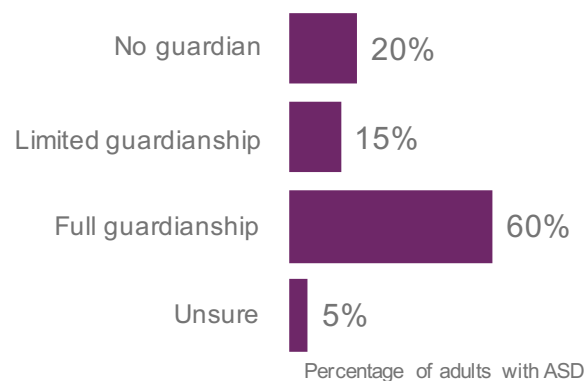
Activities of adults with autism who did not live at home with family members

Almost all (91%) families reported “yes” when asked whether their family member with autism took part in activities in the community. This was comparable to rates of those with other types of disabilities. However, for those who did not participate in the community, adults with autism were more likely



to experience stigma as a barrier to participation (negative attitudes or reactions in the community). Other reported barriers included lack of adequate staffing (such as need for one-to-one supervision), challenges related to other disabilities (such as mobility impairments and physical conditions that contributed to difficulty walking) or level of disability-related support needs, distressed behavior, sensory sensitivity, and lack of interest. Others reported that lack of time was a barrier.

Most adults with autism who used DD services and lived outside of the family home had a full guardian.



Source: NCI Family/Guardian Survey 2018-19

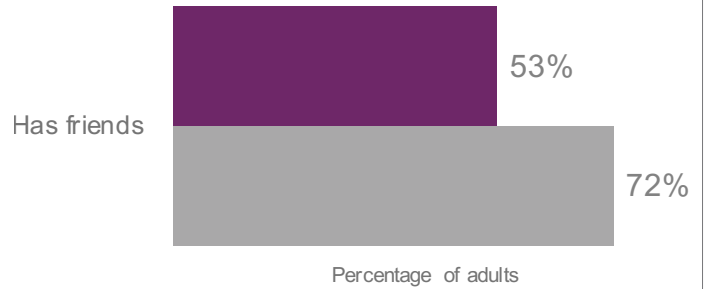


Friendships were also different among those with autism who did not live with family. Only half of those with autism had friends other than paid support workers or family member, compared to over three-quarters with other disabilities.

What did autistic adults who lived with family do during the day?

Family members reported ALL the types of activities their loved one did during the daytime over the previous two weeks. They could report more than one type of activity. So, it is possible that people had some community-based work and some facility-based

Fewer adults with autism had friends (other than paid staff and family) than other adults.



Source: NCI Family/Guardian Survey 2018-19

Types of daytime activities among adults who receive DD services

State DD services are a key source of public funding for long-term supports and services for the daytime activities of people with disabilities. These services support people support work and other activities in two main settings – communities and facilities. In the AFS, 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, such as in a sheltered workshop setting. In either setting, sometimes people earned pay, but not always. Some people only engaged in paid work or unpaid activities, but other people’s days consisted of a combination of paid and unpaid work and other activities that were often supported by state DD services. More examples are provided in the table.

Community-based versus Facility-based: What does this mean?

Type of activity

What does this mean?

COMMUNITY-BASED

Paid individual job in the community

Works at an individual job in a local business alongside peers who do not have disabilities. The job is part of the typical labor market (for example, competitive employment).

Paid small group job in a community-based setting

Works in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

Unpaid activity in the community

Examples: Volunteering, skills training, and staff-supported community connections

Paid work in a community business that primarily hires people with disabilities

Works in a setting where s/he interacts with the non-disabled population. This is NOT in a traditional sheltered workshop and NOT enclave (group work crews). Examples include bakeries, car washes, thrift stores.

FACILITY-BASED

Paid work performed in a facility-based setting

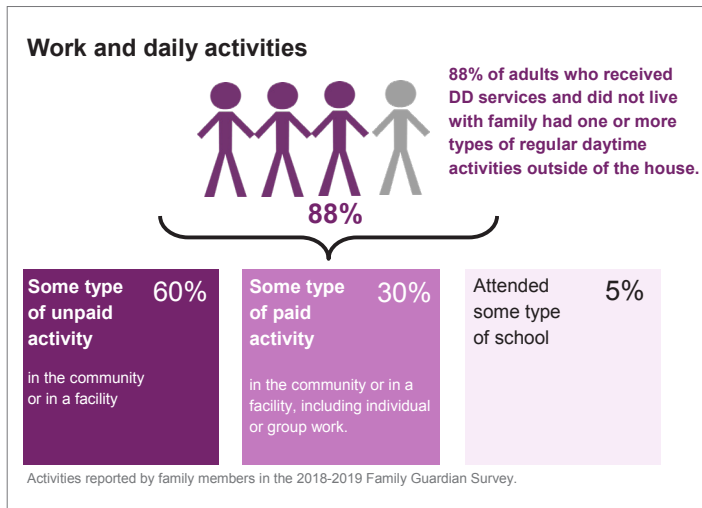
Works at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

Unpaid activity in a facility-based setting

Examples include day habilitation, senior programs, or drop-in centers



work, or some paid work and some unpaid work. Or maybe they went to school sometimes and stayed at home sometimes. Our graphs may add up to more than 100% of people, because people may have been counted in more than one category.



Most adults with autism who did not live with family currently had some type of work or day activity.

Overall, 88% of adults with ASD participated in some type of work or daily activity. Remember that some adults may have participated in more than one type of job or activity.

The fact that most people with ASD had some type of day activity sounds positive, but what were these people doing? Six in 10 adults on the autism spectrum who had DD services and did not live with family were engaged in unpaid activity of some type, while three in 10 had some type of paid activity. Their overall rates of unpaid activities, paid activities and school were like adults with other types of disabilities.

What specific activities were autistic adults doing? About half of family members reported their loved one on the spectrum did unpaid work in facility-based settings during the day, and 35% were doing unpaid activities in the community. Family members often

reported that the autistic adult was engaging in other daytime activities including attending day programs or a senior center, volunteering in a variety of settings, going to medical or therapy appointments, engaging in fitness programs, going on outings in the community, engaging in recreational activities and classes like art and music, and attending church/fair-based activities. Some respondents noted that the adult does not leave the group home or other residential setting – either because the adult is unable to or does not want to do community activities.

Autistic adults were more likely to be engaged in unpaid activity in the community (35% versus 26% of people with other disabilities) and less likely to be engaged in paid work in a facility-based setting (17% versus 25% of adults with other disabilities).

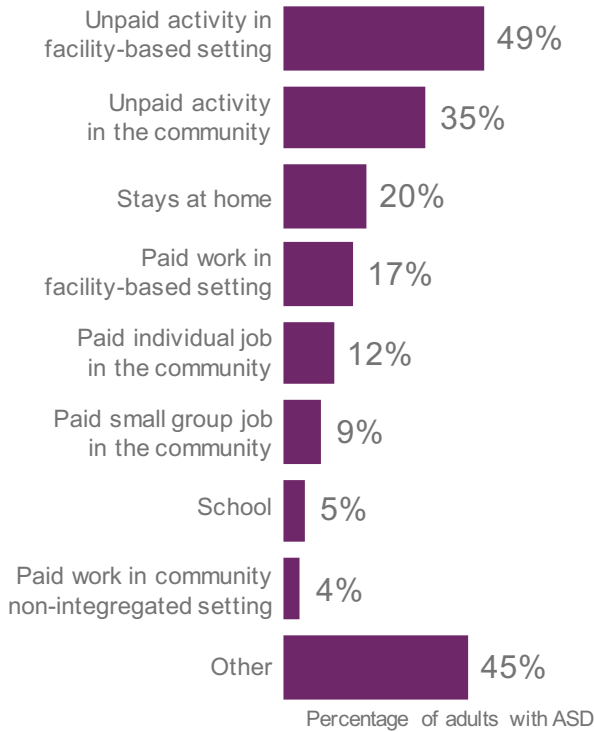
Half of adults with autism who did not live with family engaged in community-based activity during the day, but this was usually unpaid work of some type.

Among adults with autism who did not live with family members, more were doing facility-based work (paid or unpaid), which about half had some type of community-based work (paid or unpaid). Rates of community-based work among adults with autism were slightly higher than that of adults with other types of disabilities (50% versus 43%), but rates of any paid activities were slightly lower (30% versus 35%). Overall, unpaid work of any type was far more common (60%) than paid work activities of any type (30%).

There were minimal differences in paid work and community-based work by age. Approximately 55% of family members of adults with ASD under age 30 reported any community-based activities and 27% reported any paid work. In comparison, approximately 47% of family members of adults with ASD age 30 and older reported any community-based activities and 32% reported any paid work.

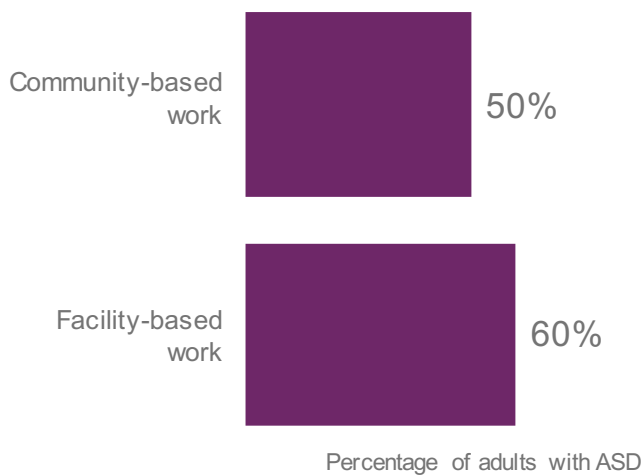


Adults with autism who lived outside of the family home were most often doing unpaid activities or staying at home.



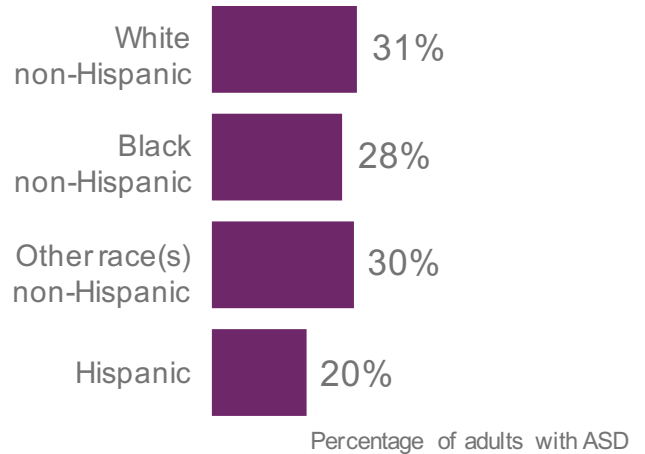
Source: NCI Family/Guardian Survey 2018-19

Half of adults with autism who used DD services and did not live with family worked in facility-based settings.



Source: NCI Family/Guardian Survey 2018-19

Fewer adults with autism who were Hispanic or Latino participated in any paid work.



Source: NCI Family/Guardian Survey 2018-19

There was little difference in community-based activities by race and ethnicity. However, fewer adults with autism who were Hispanic/Latin-x and lived outside of the family home had any paid work compared to those who were non-Hispanic White, Black, or Other/Mixed race.

Participation in paid work and community-based activities also depended on the level of support people with autism needed for managing distressed behavior. Those with extensive support needs were far less likely to have any paid work or community-based activities.

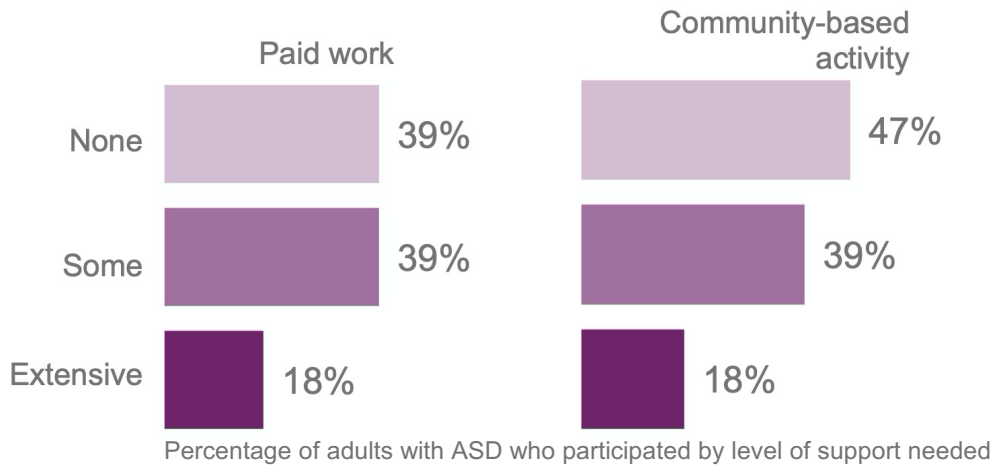
Few autistic adults had no work or daytime activities.

12% of adults on the spectrum had no work or daily activities within the previous two weeks.* This rate was slightly lower than the 16% of adults with other disabilities who had no daytime activities.

*NOTE: Adults who had missing information on participation in employment or daily activities were not considered for this indicator. For example, if it was recorded that a person did not have paid or



Far fewer adults with autism who did not live with family and had extensive needs for behavior support engaged in any paid work or community-based activity.



Source: NCI Family Survey 2018-19

unpaid community employment, but information on paid or unpaid facility-based employment was unknown, we excluded this person from consideration for this indicator. For this reason, the percentage of adults with ASD who had no work or daily activities and the percentage of adults with any type of work or daily activity do not sum to 100%.

References

1. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summary* 2018;67(No. SS-6):1–23. DOI: <http://dx.doi.org/10.15585/mmwr.ss6706a1external icon>.



Chapter 7

Characteristics of family members and households

Family members of autistic adults who did not live at home and used state Developmental Disability services

▶ Our Key Findings

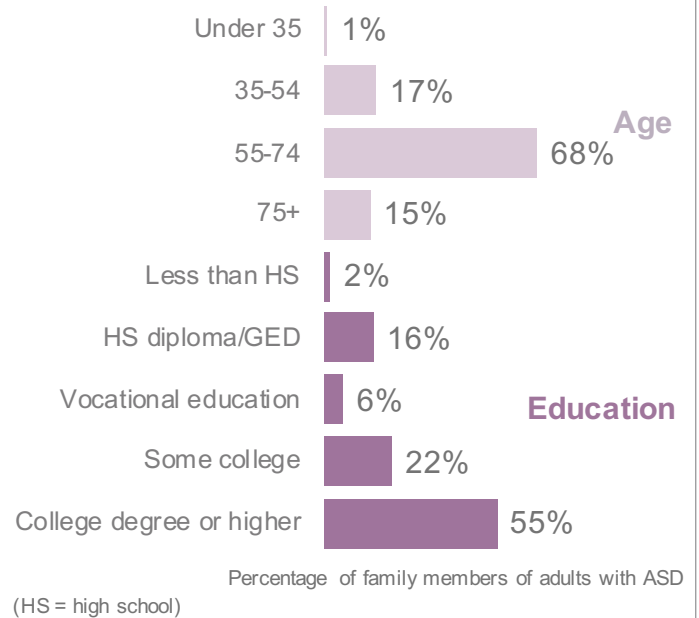
- Of family members with an adult on the spectrum who did not live at home, 75% of survey respondents were parents, and 9% were siblings.
- 68% of family members who had an adult on the autism spectrum who did not live with family were between 55-74 years old at the time of the survey, and 15% were age 75 or older. Over half (55%) had a college education or higher.
- 20% of family members with an autistic adult who did not live at home reported household income of \$25,000 or less.

A total of 715 family members of adults on the autism spectrum, who did not live with family, participated in the 2018-19 Family/Guardian Survey (FGS). In addition to reporting information about the autistic adult, they reported information about themselves and their households.

Demographic characteristics

Nearly 75% of survey respondents whose adult on the autism spectrum did not live with them were parents, and about 9% were siblings. Nearly 5% of family respondents in the FGS were public guardians, and 5% had some other relationship to the family member with autism. Family members who responded to the survey were most often between ages 55-74 years old. Nearly 15% of family members of adults on the spectrum were over 75 years of age, compared to 21% of family members with other types of disabilities.

Of family members who took the survey and had an autistic adult who did not live at home, half had some college education.

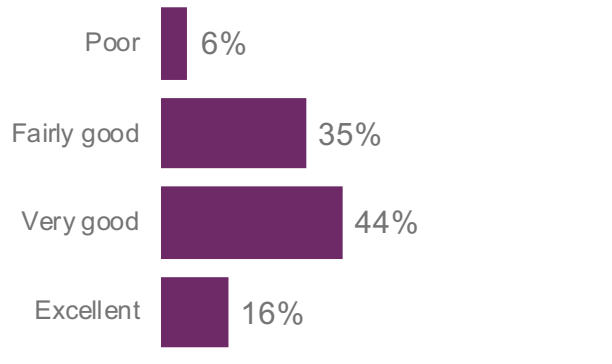


Overall, these family members had similar types of education as family members of adults with other types of disabilities who did not live with family. Over half of family respondents of autistic adults had a college education or higher.

The health status of family members of adults with autism who did not lived with family was like that of families with adults with other types of disabilities - with very few reporting poor health at the time of the survey.

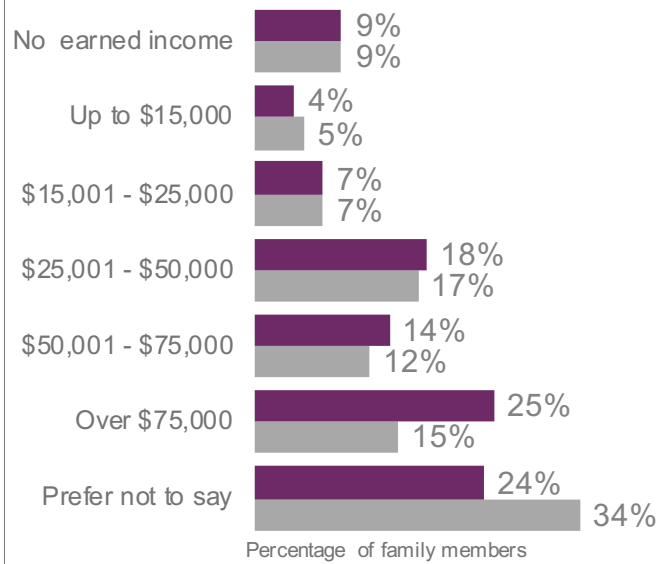


Most family members of DD service users with autism who did not live at home were in fair to very good health.



Source: NCI Family/Guardian Survey 2018-19

One in five households with an autistic adult who did not live at home reported annual household income of \$25,000 or less.



Source: NCI Family/Guardian Survey 2018-19

Household characteristics

About 80% of family members, who had an adult with autism who did not live at home, lived in urban areas, and 98% said that English was usually spoken at home. These rates were similar to families of adults with other types of disabilities.

However, in the general population, approximately 22% of individuals speak languages other than English at home,[1] and in the nation’s top five cities, nearly half of people speak a language other than English at home.[2]

Among families with an autistic adult who did not live with them, who reported their total taxable household income, 59% earned less than 50,000 per year, with 20% reporting \$25,000 or less per year in household earnings. It is important to note that 24% of family members of adult with autism, and 34% of families with an adult with another type of disability, said they preferred to not report their household income.

We note that the survey didn’t differentiate between experiences of mothers versus fathers, or households led by single parents versus parents versus two-parent households.

References

1. United States Census Bureau. “Selected social characteristics in the United States. 2019: ACS 5-year estimates data profiles.” Table DP02. Accessed at <https://data.census.gov>
2. Zeigler, K and Camarota, S.A. “67.3 Million in the United States Spoke a Foreign Language at Home in 2018.” Center for Immigration Studies; October 29, 2019. Accessed at cis.org



Chapter 8

Services and supports for the adult with autism and the family

Services and supports for autistic adults who did not live with family and used state Developmental Disability services

▶ Our Key Findings

- Almost all autistic adults who did not live with family received transportation services (94%) and residential supports (93%). 75% received supports for daytime activities or employment and a little less than half received in-home supports (45%).
- Almost all adults with autism who did not live with family and received DD services received cash benefits – with 98% receiving Supplemental Security Income (SSI).
- Most (92%) of families felt the DD service plan generally included all the services and supports the adult with autism needed.
- But when specifically asked about daytime supports, nearly 30% of families felt the adult wasn't receiving enough supports to be able to work or volunteer in the community.
- Most (90%) family members felt they were receiving enough supports and services for themselves. Others reported needs for regular support for the autistic adult, homemaker services, counseling, and family-to-family networks.

Types of services autistic adults might receive if they live with family

Day/employment supports	The family member with autism attends a day program, sheltered workshop, or receives vocational supports such as job training or job coaching at a job in the community.
Financial support	The adult family member receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for him/herself. Not including SSI payments
In-home support	People are paid to go to the family member's house to assist with things like activities of daily living
Residential supports	The family member with autism receives mental/behavioral health care and/or other treatments or therapies like physical therapy, occupational therapy, speech therapy or recreational therapy).
Out-of-home respite care	The family member with autism receives care and support in a residence outside of the family's home.
Transportation	Someone arranges or provides transportation for the family member with autism to go to a day program, work, medical appointments, and other places.

Services and supports for the adult on the autism spectrum who does not live with family members

94% of family members who responded to the FGS indicated that the adult with autism who did not live with them had a service plan. Only half (53%) of these

individuals said the autistic adult was involved with making the plan compared to 66% of adults who had other types of disabilities.

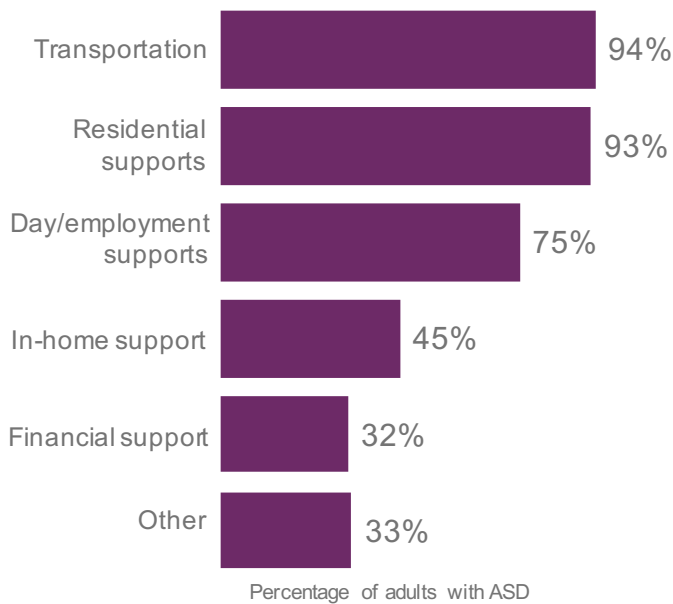
Family respondents reported on the types of services the autistic adult received from DD Services. Almost all received transportation services and residential supports. Three-quarters received day or employment supports or other types of services. Less than half receives in-home supports or any financial



support from DD Services. These rates of service receipt were all comparable to adults with other types of disabilities who did not live with family members.

Additionally, almost all autistic adults who did not live at home and received DD services were also receiving financial benefits from the Social Security Administration, such as Supplemental Security Income (SSI).

Autistic adults who used DD services and lived outside of the family home were most likely to receive supports for transportation.

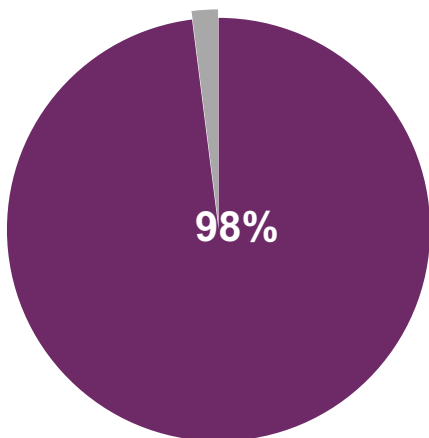


Source: NCI Family/Guardian Survey 2018-19

What are self-directed supports?

Adults with DDs, or their legal representatives, who self-direct their supports manage some or all of their own services. For example, participants are allowed to hire or fire their support workers and are allowed to control how their budget is spent. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. The availability of this option varies across states. Source: Centers for Medicare and Medicaid Services, www.medicaid.gov/medicaid/ltss/self-directed

Nearly all autistic adults were receiving Social Security (SSI) benefits.



Source: NCI Family/Guardian Survey 2018-19

Self-directed supports

Approximately 23% of family respondents said the autistic adult (or a representative family member) received self-direction/fiscal intermediary services from the I/DD agency, similar to adults with other disabilities who did not live with family.

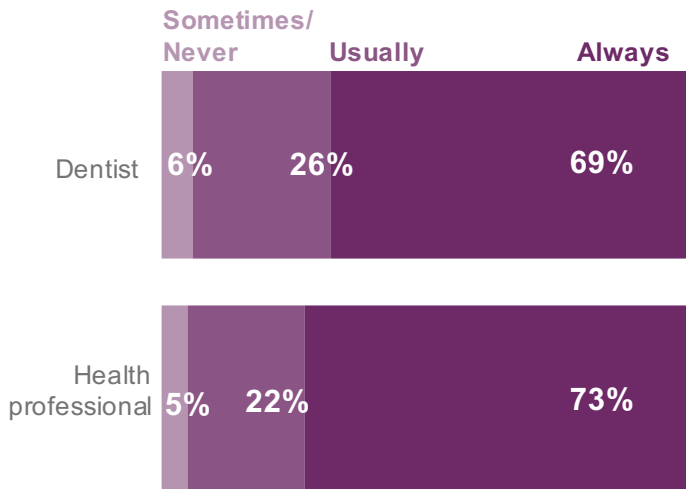
Approximately one-third of adults with autism who did not live with family received additional services and supports from other agencies and organizations outside of DD services (32%), similar to adults with other disabilities. The survey did not specify exactly what types of other services this included.

Access to health and dental care

Approximately 95% of family members reported that the autistic adult was usually or always able to see health professionals or a dentist when needed, which was comparable to adults who did not live with family and had other types of disabilities.

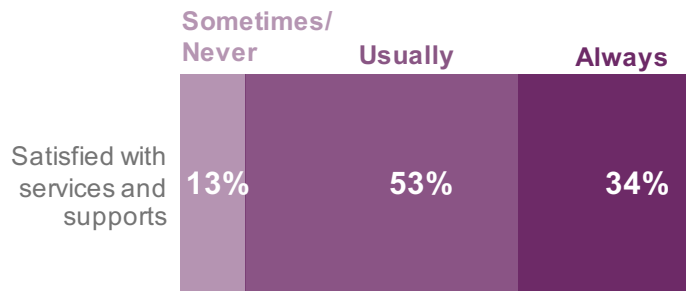


Most adults with autism who lived outside the family home could see a health professional or dentist when needed.



Source: NCI Family/Guardian Survey 2018-19

Most family members of adults with autism who did not live at home were usually or always satisfied with DD services their loved one received.



Source: NCI Family/Guardian Survey 2018-19

Changes in intensity of services over past year

Approximately 19% of family members reported that services for the autistic adult who did not live with them had increased during the past year. Less than 10% of families reported that the services or supports the family member with autism received during the past year had been reduced, suspended or terminated. Of people whose services were reduced or ended, 62% of their family members said this resulted in

a negative effect for the autistic adult. The reasons for why services were increased or reduced were not given in the survey.

Over 80% of families of autistic adults who did not live with family felt that services and supports changed in response to changes in family needs. However, over 35% of respondents either did not answer this question or reported that their needs rarely changed.

Family perspectives on services and supports for the family member with autism

Family perspectives are an important gauge of the quality of DD services. As we stated at the beginning of this report, DD agency administrators often turn to the opinions of family members in the FGS survey to monitor the effectiveness of service implementation.

Most families felt the autistic adult was receiving all needed services and supports, but one in three families felt the person did not have enough services and supports needed to work or volunteer in the community.

When families of adults with autism who did not live with them were asked whether the DD service plan included all the services and supports the autistic adult needed, 92% said yes, which was comparable to family members of adults with other disabilities. Even among families of autistic adults who had no daytime activities, 92% of families felt the plan included enough supports and supports to meet their family members' needs.

However, when asked whether the family member had enough support to work or volunteer in the community, nearly one in three (29%) families of people on the autism spectrum said no, versus 24% of those with other disabilities. When asked whether the family member with autism always or usually had special equipment or accommodations (if needed), 11% said the person seldom or never had needed equipment or accommodations, compared to 6% of



persons with other types of disabilities who did not live with family members.

Most families (87%) with an adult on the autism spectrum who did not live with them reported always or usually feeling satisfied with the services and supports the adult received, while 13% said they felt satisfied sometimes or seldom/never. These satisfaction rates were slightly lower than those of families with adults with other types of disabilities.

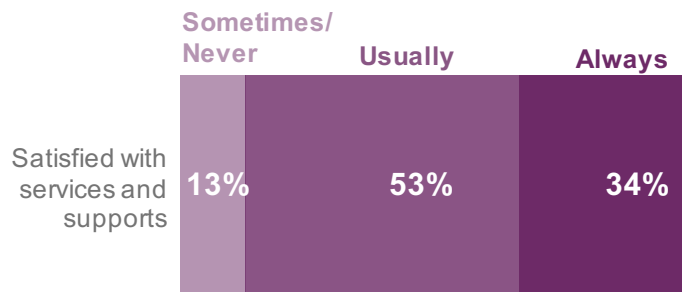
Less than 10% of families said services and supports their loved one received were helpful in reducing the family’s out-of-pocket expenses for the family member’s care. And 95% said that the services and supports the adult with autism received were helping the adult to live a good life.

and skills to meet the family’s needs, most families again said that support workers were usually or always competent in these areas. However, over 17% said that support workers only sometimes or seldom/never had the right information and skills. This finding conflicts with family reports regarding barriers to community participation with included lack of adequate staffing and lack of motivation among support workers. It is possible that questions about skills and information are less relevant if there aren’t enough staff or the staff don’t seem motivated to provide excellent care.

Services and supports for the family

Among families whose autistic adult did not live with them, nearly 90% of families said they get the supports and services they need for themselves, while 10% reported they did not. This means that these families most often felt that both the family and the autistic adult were getting needed service and supports.

Most family members of adults with autism who did not live at home were usually or always satisfied with DD services their loved one received.



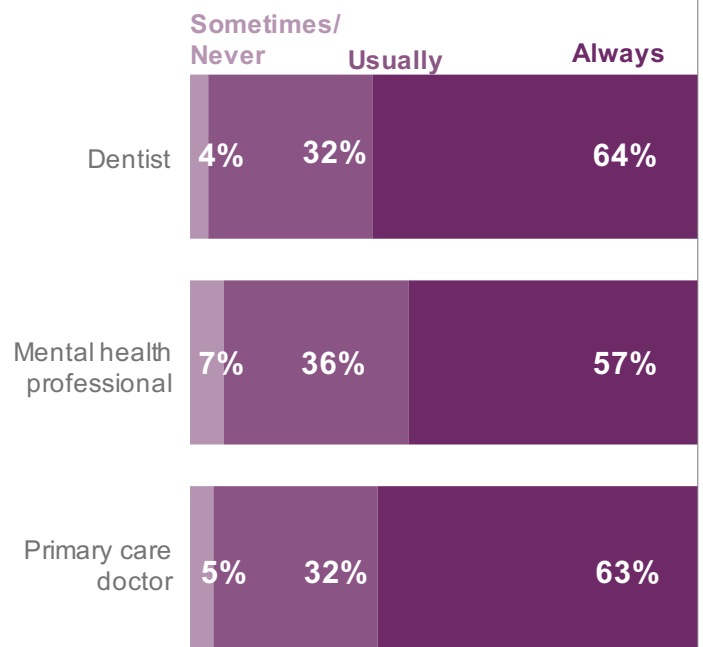
Source: NCI Family/Guardian Survey 2018-19

Perspectives on knowledge of professionals

Family members reported their opinions on how well different health professionals understood needs related to the autistic adult’s disability (for those who did not live with family). Approximately 95% of respondents felt that primary care doctors, dentists and mental health care professionals (for people who used mental health services) usually or always understood the person with autism’s disability.

When asked whether support workers (for adults who used this support) had the right information

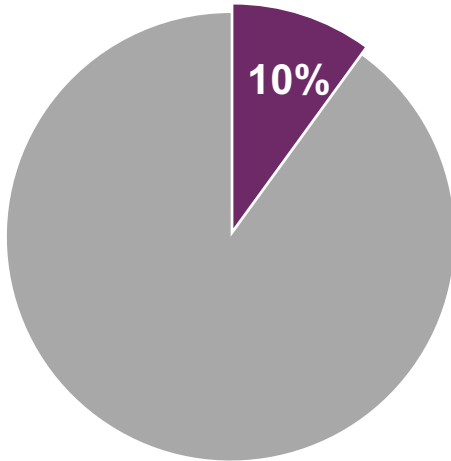
Does the provider understand your family member's needs?



Source: NCI Family/Guardian Survey 2018-19



One-tenth of families of adults who receive DD services and did not live at home don't get needed supports and services.

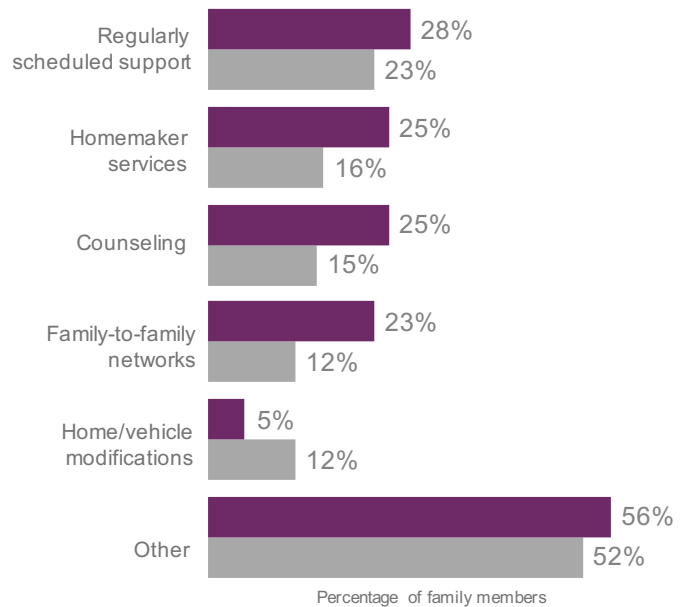


Source: NCI Family/Guardian Survey 2018-19

Those who reported that their needs were not met were asked about their additional service needs. Over one-quarter of families with an autistic adult who did not live with them said they needed more regularly scheduled support for the autistic adult, or homemaker services – presumably to support the autistic adult in taking care of their home. Family members of autistic adults were more likely to report that they needed counseling and family-to-family support networks, compared to families of adults with other types of disabilities.

Other supports that families said they needed included more staff, engagement in activities, communication with families, and assistance with oral hygiene. Families in the FGS were not asked about their need for respite or whether they needed information about other public services the adults with autism might be eligible for, presumably because these needs were being met outside of the family's home.

Families of adults with autism who lived outside the home were more likely to report needing regularly scheduled support and homemaker services.



Source: NCI Family/Guardian Survey 2018-19



Chapter 9

Communication and collaboration with families

Interactions with family members of autistic adults who did not live with family and used state Developmental Disability services

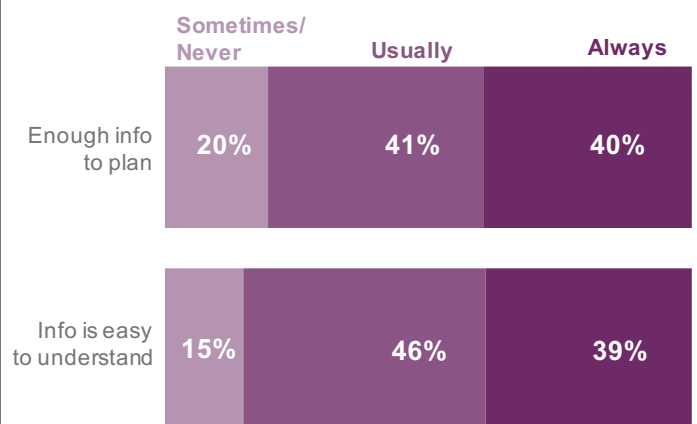
▶ Our Key Findings

- 82% of families of autistic adults reported that they participated in making a service plan for their family member. Most also reported having a choice about which agency they used for services (84%), but only 45% said they usually or always had a choice regarding which staff members provided supports for the autistic adult. 22% said they did not choose and cannot change the service coordinator.
- Families need to have information about services and supports to support planning meetings and service delivery for their family member who receives DD services. About 15% of families of autistic adults felt that the information about services and supports was seldom or never easy to understand.
- Less than 10% of families directly managed support staff who provide services for the autistic adult in their home and in the community, even though 23% of families said the autistic adult (or their family representative) received assistance to self-direct their services.

Communication with family members

Person-centered planning meetings are ideally held on an annual basis, or more often, to discuss the service and support needs of the individual who receives DD services. This team may include the family members who support the adult. About 80% of families felt they usually or always had enough information to participate in planning meetings, but nearly 15% sometimes or never felt the information about services and supports was easy to understand.

Families of adults with autism who did not live at home often said they had enough info to plan and the info was easy to understand.



Source: NCI Family Guardian Survey 2018-19

Families of autistic adults were positive about their interactions with support workers and their communication. Nearly all families (96%) of autistic adults who live at home reported that support workers usually or always speak to them in a way they can understand, and 91% felt the service coordinator usually or always respected their choices and opinion. Almost all families said that they or the family member could usually or always contact support workers when needed (90%) or the service coordinator (92%).

Collaboration, choice, decision-making

Of families who reported that the autistic adult had a DD service plan in place, 82% of family members said they helped make the service plan.

Consistency is important when supporting autistic individuals, as changes in routines and new faces can be unsettling. Families were overall positive in



their reports about consistency and collaboration with support workers. Almost all (96%) said support workers usually or always come and go when they are supposed to, and 94% said that support workers collaborate to provide support if there was more than one worker.

When problems arise, or direct support workers are not well-matched to the needs of the individual with disabilities, families should be able to request a change or support their family member in requesting a change in workers. Most families (84%) said they could usually or always choose or change the agency that provides services for the family member with autism. However, less than half of families (45%) said they usually or always can choose or change the autistic adult's support workers when needed. More indicated they could request a change of the service coordinator (78%). It was notable that 22% said they did not choose and cannot change the service coordinator.

Across these indicators, families of adults with autism who did not live with family had similar responses to families with members who had other types of disabilities.

Self-directed supports

Some individuals with disabilities and their family members take on the responsibility of managing staff – hiring them, dismissing or changing them when needed, and handling communication needs. In the previous chapter we reported that 23% of families said the autistic adult (or their family representative) received assistance to self-direct their services. However, when asked whether the family directly manages the support staff, less than 10% said they usually or always do this, versus sometimes (5%) or seldom/never (86%).

Respect for family culture

Almost all (98%) of families felt that services were usually or always delivered in a way that was respectful of their family's culture. We note here that the sample of families, however, did not reflect the diversity of the general population. As we said in the Family Characteristics chapter, a lower percentage of family participants were Hispanic, and more were primarily English speakers, compared to the U.S. population around the time of the survey. Of the 10 states with the largest percentages of non-English speakers,[1] only one (Arizona) participated in this survey.

Across these indicators, families of adults with autism who lived at home had similar responses to families with members who had other types of disabilities.

References

- ¹ Zeigler, K and Camarota, S.A. "67.3 Million in the United States Spoke a Foreign Language at Home in 2018." Center for Immigration Studies; October 29, 2019. Accessed at cis.org



Chapter 10

Educating and supporting families to participate as care partners

Education and support for family members of autistic adults who did not live with family and used state Developmental Disability services

▶ Our Key Findings

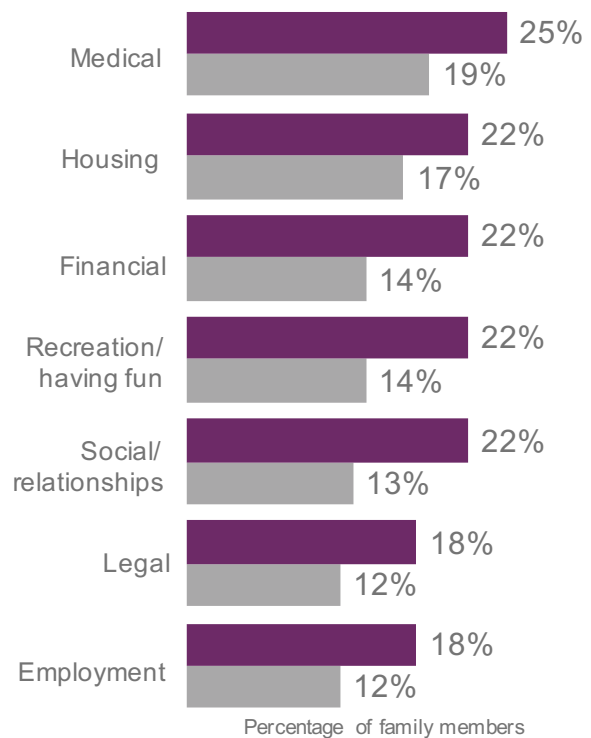
- Families of autistic adults who did not live with the family most often reported need for help with planning for the family member’s medical care, but also reported need for help planning for future housing, social relationships and recreation, and financial matters.
- Only six in every 10 family members of autistic adults who live with them said they discussed a plan for handling crises and emergencies at their last person-centered planning meeting.
- Most families (79%) said they knew how to report abuse and neglect when needed, and 10% of families with an autistic adult who did not live with family said they reported abuse or neglect within the past year.

Education and planning needs

Among the top reported concerns of family members is the fear of what will happen to the autistic adult when family members, especially aging parents, are no longer able to participate as care partners.

Families were asked whether they needed help planning for the family member’s future across a variety of topics. Families of adults with autism who did not live with family reported more need for help than families of adults with other disabilities, across all topics. Families of autistic adults most often reported need for help with planning around medical care, housing, finances, recreation and social relationships. Families also reported need for

Families of autistic adults who did not live at home needed more help planning for the future than other families, across all topics.



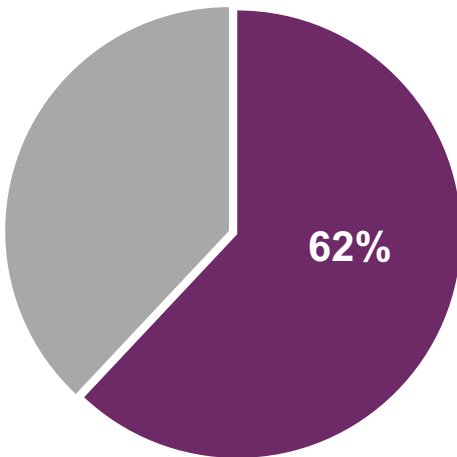
Source: NCI Family/Guardian Survey 2018-19

help around planning for the future needs related to burial services, plans for care after guardians die, and residential support. These kinds of planning often address a question that weighs heavily on parents’ minds, “Where will my child live and who will take care of them when I am gone?”

Nearly all families (94%) reported that they usually or always knew what the autistic adults’ medications were for and how to take them safely.

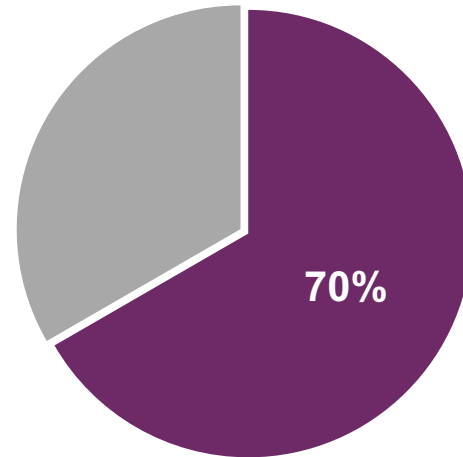


62% of families of adults with autism reported discussing emergency planning at the last service planning meeting.



Source: NCI Family/Guardian Survey 2018-19

Only seven in 10 families said they knew how to file a complaint or a grievance.



Source: NCI Family/Guardian Survey 2018-19

Crisis and emergencies

Natural disasters, family emergencies (like a caregiver getting ill with, or dying from, COVID-19), and mental health crises are examples of unexpected events that can wreak havoc for adults with disabilities unless a plan for handling emergencies is in place. It is critical that families understand the resources available to them during crises and emergencies, including the ability to request additional services and supports if needed.

Approximately six in every 10 families said they discussed how to handle emergencies at the last service planning meeting, if they took part in the meeting. About three-quarters (72%) said they did feel prepared to handle the needs of the family member in case of medical emergency or a natural disaster. We note that this survey was conducted prior to the COVID-19 outbreak, and families may now feel differently about their preparation for emergencies given their experiences during the pandemic.

Safety and quality assurance

Understanding how to address safety and compliance issues is critical for maintaining the safety of vulnerable persons with disabilities. Families were

asked if they knew how to report abuse or neglect related to the adult with autism who was living with family, and 79% reported knowing how to do this. **10% of families of adults with autism who did not live with them said they reported abuse or neglect of the adult within the year preceding the survey**, compared to 6.7% of families of persons with other types of disabilities. Recall that in the previous chapter on Services and Supports, we reported that 17% of families felt the support staff was lacking in information or skills needed to support the adult on the spectrum.

However, when families were asked if they knew how to file a complaint or grievance about provider agencies or staff only 70% reported that they knew how to do this. Of families who filed a grievance, only 70% felt satisfied with how the situation was resolved or handled.

The survey did not explore other serious safety issues that some autistic adults experience including running or wandering away (elopement), sexual victimization, and financial vulnerability, for example.



National Autism Indicators Report: Family Perspectives on Services and Supports

MAY 2021

Looking Ahead

Conclusions and Recommendations

This 2021 report on Family Perspectives on Services and Supports focused on the roles that family members play in the lives of adults with autism who receive DD services. Some of our key findings were:

- High levels of co-occurring intellectual disability among autistic adults who qualified for DD services, and a high need for supports with managing distressed behavior and daily life activities.
- High level of co-occurring health and mental health conditions which can contribute to risk of early mortality and lowered quality of life.
- Low levels of paid employment and a need for services and programs focused on work and volunteering in the community.
- Inadequate planning for handling crises and emergencies – topics which should be discussed at least yearly in person-centered planning with input from the medical team.
- Financial hardship, especially among families whose autistic adult lived with them, with few families receiving pay for the valuable supports they provide.
- Need for more supports and services for families with adults living with them – especially respite care to allow them to recharge and meet their own needs.
- Need for clear, understandable information about services, so that families can better participate in care and support the adult in self-directing their services.

- Lowered ability to ensure care aligned with the needs of autistic adults who lived apart from family and need for opportunities to support staffing and service provider selection and changes when care is inadequate.
- Concerning rates of reported abuse and neglect of autistic adults who did not live with family.

In response to these findings and other insights, we share policy and research recommendations.

Policy Recommendations

- **Expand qualification criteria.** We know that adults on the spectrum are more likely to qualify for DD services if they have ID and high levels of traditionally defined support needs. In the broader population of autistic adults, only about one-quarter have ID, but social, communication and sensory impairments, and co-occurring health and mental health issues, can also greatly impact ability to work and daily functioning. Many segments of the autism population need services beyond those with co-occurring ID, and eligibility for services should be responsive to the spectrum of needs among autistic adults by including adults who may have an above-average IQ but require services and supports due to a host of needs that impact their ability to work and function in the community. It is unacceptable for autistic adults who have a justifiable need for services to remain on waiting lists for 5-10 years before accessing the supports they need to function in the community. When people's needs are not met, it can result in costly, avoidable crises.

- **Expand and increase direct supports for families.** Even prior to the COVID-19 pandemic, families whose autistic adult lived with them were providing nearly all needed in-home care, with greater financial hardship but little financial assistance, and indicated need for additional support. Recent expansions to DD services and HCBS funding to states through the American Rescue Plan could possibly help bolster families who are providing for adults with I/DD, by providing expanded payment to families and increased funding for respite care.
- **Enhanced supports for behavioral crises.** As our societal response to crises shifts away from police interventions and toward improving mental health resources, there is an urgent need for updated policy solutions tailored to crisis care for persons on the spectrum, along with accompanying funding to implement programming. Availability of appropriate crisis response services is another critical need even within larger urban areas
- **Provide family-focused information and training.** Families often are left to navigate the service system and find services and supports for themselves and their family members on their own. All families need culturally competent, accessible information appropriately geared to stages of life of the adult and their family members and provided in ways they can understand. Families also need opportunities for counseling and to connect with other families for support. A lack of access to information and training is likely disproportionately experienced by families lacking internet access, who do not speak English, who have low health literacy, or who experience other barriers to health information. The need for accessible and understandable information is especially true for siblings who are navigating new caregiver roles and for grandparents who are caregivers.
- **Improve employment supports.** Adults on the spectrum want meaningful daytime activities and want to be valued for their contributions. They deserve to be paid for their work at equitable levels. Families believed that adults were able to work and participate in the community if only they had more assistance. There is a need for greater funding of DD services and HCBS waivers that include employment support, from job assessment to on-the-job supports, to achieve the level and quality of supports needed to foster and sustain more paid work opportunities.
- **Require annual planning for crises and emergencies.** People with I/DD and autism contracted COVID-19 at twice the rate of people without disabilities and were twice as likely to die of COVID-19 as the general population. Their caregivers, who are often aging, were also at much higher risk, and may have had difficulty caring for the adult with I/DD while they were ill themselves. Adults on the spectrum and families also experienced great disruptions and stress due to schedule disruptions, inability to work and difficulty finding safe respite care options. Lessons learned from the COVID-19 pandemic are just one example of how planning for crises and emergencies should be mandated in an attempt to save lives and prevent setbacks.
- **Acknowledge family dynamics.** Families may have complicated dynamics and policies need to be written to support service providers in assessing and navigating those differences to help adults and families navigate communities and relationships. Quality metrics must be generated and implemented that monitor providers who deliver supports that wrap around families to ensure that families are receiving effective care that is respectful to the unique contexts of individual families.

- **System cohesion and communication.** Adults and families are often navigating Medicaid, Vocational Rehabilitation, the end of special education services, and insurance requirements. The lack of coordination and information sharing across systems places a burden on adults and families to track assessments, communication, and complex policy requirements across multiple systems. Policies that support cross-system communication, care coordination, and record sharing could ease family burden and reduce system redundancies and inefficiencies.
- **Improve levels of community acceptance.** Stigma appears to be a key barrier to participation in community activities among families of autistic adults. Strategies for reducing stigma and promoting inclusive communities need to be discussed at the local level.
- **Improve and monitor early detection of health and mental health issues.** The multiple, co-occurring health conditions noted for autistic adults are especially concerning among those who live with family given their average age of 28 years. For example, 25% of these young adults had high blood pressure, compared to 7.5% of young adults in the general population per CDC statistics. Families who are providing care for young adults may need additional assistance to ensure that routine screening and preventive health care needs are being met. Monitoring health care and addressing barriers to preventive care should be an important focus of case management for this population, in addition to obtaining more information about what families need to better manage the health and mental health needs of the autistic adults who live with them.
- **Increase supported residential options.** It is developmentally appropriate for adults on the autism spectrum to want to live as independently as possible, apart from family, with opportunities for them to exercise choice and privacy in their

lives. Only 9% of adults in the FGS were living in non-group settings apart from family. It is imperative that more supported housing options, such as HUD subsidies and vouchers, be made available for those who wish to live more independently in the community with supports from DD services.

Research Recommendations

We conclude this report by noting significant gaps in knowledge and priorities for future research based on our evaluation of the findings and input from our advisors.

- The information we present in this report is uniquely important, because few surveys of state-funded services specifically look at the perspectives of family members. However, there are gaps in knowledge that should be addressed in future iterations of surveys of DD services and supports for autistic adults and their family members. For example:
 - **Funding.** We need more information about how the DD services that were the subject of this report were funded, so we know where to focus efforts aimed at improvements. For example, if we knew that 95% of the services in this report were funded by Medicaid waivers, we would know that improvements to Medicaid regulations are critical for improving the lives of autistic adults and their families.
 - **Access to DD services.** We also need data to assess how difficult it was to get DD services in the first place. There is a critical need for research to monitor enrollment in DD services, differences in access to services across programs and states, and to pinpoint recommendations for improving service provision.
 - **Tailoring questions better reflect the needs of adults on the autism spectrum.** We need questions that are better tailored to adults on

the autism spectrum. Throughout this report, high numbers of family members of autistic adults reported “other” conditions. When many people choose “other” and write in their own responses this signals concern that the survey questions may not do a great job of representing the experiences of that group. It’s crucial that researchers continue to develop and refine instruments so that they actually capture meaningful differences in adults on the spectrum. Understanding the details about what adults and family members are experiencing is important for understanding their unique needs and how well services are working.

We also need questions that better reflect health conditions that commonly co-occur in autistic adults – like gastrointestinal issues, or anxiety disorder. We cannot over-emphasize the roles that co-occurring health and mental health conditions play in how life turns out for autistic adults. If you don’t feel physically comfortable... if your body and mind are in a heightened state of alert all the time... it’s difficult to interact with others, work, and enjoy life. We need a better understanding of how health conditions impact outcomes and service use.

- **Understanding use of additional community services.** Similarly, we need more information about how adults who use DD services also use other services in the community. Health services are a great example. We know that rates of emergency department visits, and hospitalization for conditions that could be better managed through primary care, are elevated among people with I/DD (and autism, in particular), but there are no survey questions that specifically look at how people are accessing health services and whether their health care is coordinated across providers, including DD service providers. This is a critical missed opportunity given recent studies of early mortality among adults on the spectrum.

- **Better capturing unique family situations.** Families often have more than one member on the autism spectrum, or more than one member with related disabilities. These surveys do not capture that nuance or the additional challenges this poses for families who play multiple roles in the daily supports they provide. Nor does they capture how siblings, grandparents or chosen family manage when supporting multiple family members on the autism spectrum. Finally, the needs of single parent families and families in which parents have health and mental health needs, or have disabilities themselves, need additional focus. We need to better understand the needs of these families in order to identify policy solutions.
- **Identifying service disparities among people of color.** Data that is not nationally representative, including all or most states, may underestimate disparities among people of color. We did identify disparities in services and supports among marginalized communities within this report. However, there are likely many more areas of needed attention. In particular, Hispanic families are under-represented in this report, as are non-English speaking families. Because family supports have such a strong cultural component to them, it is vital that we better assess how well the needs of families are being met. It is critical that surveys better measure and address response bias in which families may report inflated levels of satisfaction with care and under-report their concerns.

Additional priority topics for research include the following:

- **Minimally verbal autistic adults.** Minimally verbal autistic adults are one subgroup that warrants additional research focus. It is unclear how adequately their communication needs are being addressed in terms of technology access and training of the people who support them. Further,

it is unclear how their community participation is affected by their verbal abilities and what recommendations could be made to improve supports for this group.

- **Safety and vulnerability in the community.** Another common concern raised by families of adults with autism is safety in the community. Issues range from wandering away, to risk of sexual assault, to involvement in the criminal justice system, to being taken advantage of financially, and experiencing bullying. Research into specific risks and how to develop community programs to mitigate risk is critical.

- **Unique needs of maternal care partners.** In general, mothers bear an unproportionate share of caretaking responsibilities, affecting their ability to work, and possibility contributing to increased levels of stress and maternal depression in this population. It is critical to identify unique needs of mothers as they age and identify tailored recommendations for policy solutions that could be implemented to meet the unique needs of mothers who are care partners for adults on the spectrum.

Appendix A: The importance of family-centered care

What is family-centered care?

You may have heard of person-centered care, which is also called patient-centered care when talking about health care. Person-centered care focuses on the needs, preferences and strengths of the person who is receiving care. Family-centered care, on the other hand, focuses on the needs and preferences of families and emphasizes respect for family customs and values. Family-centered care also focuses on the family-professional partnerships and collaboration needed to implement care and to improve care for persons with special health care needs like autism.[1]

The need for family-centered care across the lifespan

Most models of family-centered care are aimed at pediatric populations, but there is growing acknowledgment of the importance of a family-centered care approach for adults with complex and chronic conditions including those whose care is delivered within home and community-based settings.[1]

There is emerging evidence that use of patient and family-centered care models increases the self-determination and self-efficacy of young adults with chronic health conditions.[2] Many of these studies have focused on use of patient- and family-centered care with young adults with mental health conditions.

When a family member has a chronic health condition, regardless of their age, it can affect all members of the family. Increased stress levels in the home can reduce the family's ability to assist their loved one and to support their decision-making.[3] Listening to family's needs, views, and preferences can help to reduce this family stress. In theory, when providers understand families' wishes and priorities, this results in the development of better care plans that families are more likely to support.

For adults with chronic conditions, patient and family-centered care involves:[2]

- providing opportunities for the individual, provider, and family to work together
- empowering the individual and the family to make choices
- working toward outcomes as defined by the individual and their family

How does family-centered care work?

Family-centered care models focus on developing plans for care within the context of the family. The process of family-centered care occurs in conjunction with person-centered planning that is meant to be led by the person with a developmental disability. Family-centered care approaches weave the family into the planning with the individual.

Here are the key elements of family-centered care:[1]



Collaboration and communication with families.

The goal of a family-centered approach is to create a person-centered care plan that can be implemented within the context of the family's unique situation. This planning process is led by the individual with a disability, when possible, and supported by the family and the providers. Open communication with families about the issues they identify as important is key, as is understanding the day-to-day lives of the individual with a disability and their family members. Open communication helps match care options to the needs and values of the individual and their family members.



Family Education and Support.

Families function best when they receive the support they need. A family-centered approach recognizes that caregivers are experts on what they need to achieve their own well-being and that they experience their own set of stressors and needs. Making sure families have adequate emotional support, perhaps through making connections with other families who have dealt with similar challenges, is critical. It is also important to make sure families have access to information about their loved one's disability and about different approaches to providing care. Topics that are important to cover include mental health, home care, insurance and financing, transportation, public health, housing, vocational services, education and social services.



Consideration of family context.

Family members play vital roles on the care team. Each family has unique strengths, challenges and circumstances, and the family member's care plan should fit that. The individual with the disability (and/or their representatives, when appropriate) should also be the ones who define who is included as their family, as this word means different things to different people. Effective care planning incorporates the perspectives of these family members regarding priorities, needs, concerns, and their ability to provide care within their daily life and home routines. Care is also influenced by family members' social and religious views, cultural backgrounds, practices, and values. Creating culturally sensitive care plans requires open discussion around these topics.



Policies and procedures.

Families participate in care most effectively when policies and procedures support their role. For families whose loved one lives outside of the family home, this means having reliable and comprehensive services and supports as needed, flexible visiting hours and accessible facilities. Family voices are also critical in policy and program development. Families offer critical perspectives necessary for systems level change ranging from legislation to the policies and procedures of facilities and medical providers, to the education of service providers. For example, Title V Maternal and Child Health programs actively involve the voices of family partners in program development and evaluation, peer supports, and policies.[4] Families may need supports to actively participate in these processes.

Flexibility is key, so that families can provide feedback to inform policies and procedures online, if in-person events and interactions with policymakers present scheduling and communication demands.



Strategies to support families

In 2011, a group of family advocates and professionals from across the U.S. met at the Wingspread Family Support Summit to identify key supports and strategies that families often need to effectively support an individual with disabilities across their lifespan.[5] Although this summit occurred a decade ago, the strategies remain critical for families today.

Summit participants talked about the need to support families “to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.”

To achieve this goal, families need:

Information, education, and training on best practices for disability services and for informal supports. They need to know how to access and coordinate community supports. Families may also desire advocacy and leadership skills.

- **Opportunities to connect and network with other families**, including parents with disabilities, self-advocates and siblings, grandparents and other guardians for mutual support.
- **Access to services and tools needed for daily support and/or caregiving** for the person with the disability. This includes planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.

The Wingspread conference group later evolved to form the National Community of Practice on Supporting Families of Individuals with Intellectual & Developmental Disabilities funded through a partnership with the University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS). Further resources to assist families in **Charting the LifeCourse** to support their family member with a disability are available at www.lifecoursetools.com

References

1. Kokorelias, K. M., Gignac, M. A. M., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: A scoping review. *BMC Health Services Research*. <https://doi.org/10.1186/s12913-019-4394-5>
2. Allen, D., Scarinci, N., & Hickson, L. (2018). The nature of patient and family-centered care for young adults living with chronic disease and their family members: A systematic review. *International Journal of Integrated Care*, 18. doi:10.5334/ijic.3110/
3. Hickman, R. L., Jr., & Douglas, S. L. (2010). Impact of chronic critical illness on the psychological outcomes of family members. *AACN Advanced Critical Care*, 21, 80–91. doi:10.1097/NCI.0b013e3181c930a3
4. Association of Maternal & Child Health Programs. (October 2010). *AMCHP Issue Brief: State Profiles in Comprehensive Family Participation*. amchp.org
5. Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation. <http://supportstofamilies.org/wingspread-final-report/>

Appendix B: Methods

Data sources

Data for this report came from the National Core Indicators® (NCI®) Adult Family Survey (AFS) and Family/Guardian Survey (FGS) administered in fiscal year 2018–2019. NCI is a collaborative effort 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 AFS and FGS are surveys performed annually by a subset of NCI states who choose to participate. In fiscal year 2018–2019, 12 states participated in the AFS and nine participated in the FGS. Surveys were mailed to eligible participants and completed between July 1, 2018 and June 30, 2019. Sampling was conducted based on those receiving services during this timeframe.

Sampling: Who was included in this report?

This report presents indicators for autistic adults ages 18 and up who used at least one state DD service besides case management. Autism was identified through family report in both surveys.

For the AFS, families were eligible to participate if they had an adult family member with an intellectual or developmental disability (IDD) living in the home. Adult family members must have received at least one state developmental disability (DD) services in addition to case management. For the FGS, families were eligible to participate if they had an adult family member with an IDD who did not live at home and received at least one DD service in addition to case management.

For both the AFS and the FGS, states were advised to select a random sample of 1000 qualifying families to send the survey to with the expectation of a 40% response rate. States could choose who and how many they sampled. States with fewer than 1000 qualifying service recipients were advised to send the survey to all participants.

Additional sampling information is available in the AFS and FGS 2018–2019 reports at www.nationalcoreindicators.org.

Understanding outcomes for groups

There were two comparison groups in this report. The first group was composed of individuals who had family reported ASD. The second group was individuals with other types of intellectual or developmental disabilities (I/DDs) other than ASD. Both groups included adults ages 18 and over.

How was the data collected and evaluated?

Depending on the state, families were either sent a mailed paper survey or a link to complete a survey online. More information on how the family survey data was collected is available in this document:

https://www.nationalcoreindicators.org/upload/core-indicators/UsingNCIDataforQualityImprovementInitiatives__2017.pdf

Data analysis

We presented descriptive data for key indicators in this report. These indicators represent state averages for participating NCI states, reflecting a weighted average relative to the population and sample size of participating states. 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 AFS and the FGS, and instances of don't know responses. For this report, most don't know responses were included with missing data. In these cases, missing values were not considered in the denominator. Where relevant, we reported the percentage of don't know responses.

Strengths and Limitations

The AFS and the FGS provide a unique view of the services and experiences of autistic adults who use state DD services in select states. They capture both adults living at a family home, and those living away from the family home, examining experiences of two often under-studied groups.

There are several limitations to use of AFS and FGS 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 only select states participated in each survey.
- States were asked to draw a random sample of at least 1,000 families for administration of each survey, but it was up to states how sampling was done. Response rates varied by state but averaged around 27% for the AFS and 20% for the FGS. 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 family report of autism. Diagnoses were not clinically verified, and notation of ASD may have been less likely for middle-aged adults.

The general limitations of surveys apply here as well. The AFS and FGS relied on recall of events that happened over the previous year, which may have been difficult for some respondents. It may also be harder for families not living with their adult family member to describe the autistic adult's experiences and services over the past year.

NCI surveys were designed as quality assurance measures - not as research tools.