North Dakota Department of Health and Human Services

Autism Spectrum Disorder (ASD) 2022 Survey Report

Autism Spectrum Disorder Task Force



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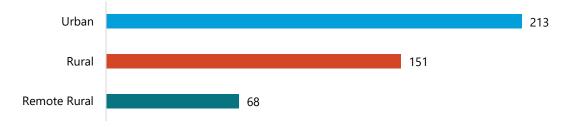
Report Summary and Details

This survey was taken by 499 individuals.

ASD Survey Respondents' Demographics

A majority of the 499 individuals who took the ASD survey were residing in an urban setting, with approximately 42.7% stating they resided in an urban setting, 30.3% residing in a rural setting, and only 13.6% residing in a remote rural location (*Figure 1*).





The geographic spread of survey respondents in the overall demographic report shows a higher concentration in Cass, Ward, and Burleigh counties with over 51% of the respondents residing in these three counties (*Figure 2*).

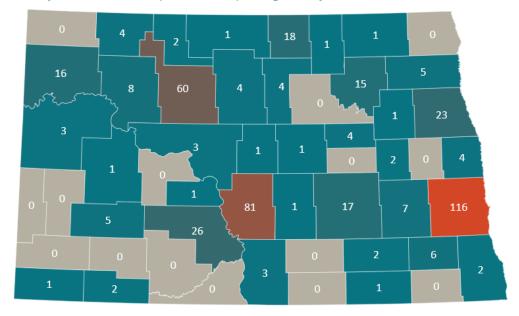
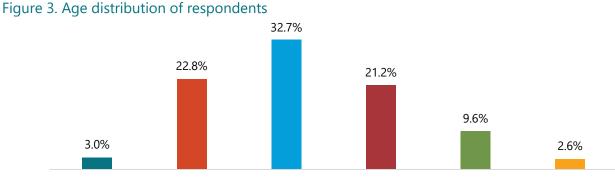


Figure 2. County of residence of person completing survey

The median age of respondents who took the ASD survey were within the age range of 35-44 years old. Only 3% of the respondents were under 25 years old and 2.6% of the respondents were 65 years old and older (*Figure 3*).



18-24 years old 25-34 years old 35-44 years old 45-54 years old 55-64 years old 65-74 years old

The survey respondents were overwhelmingly female identifying individuals at a rate of 82.4% of the respondents, followed by 7.6% identifying as male. Two respondents identified as gender nonconforming, and two identified as Two-Spirit (*Figure 4*).

There were 40 respondents who did not answer this question in the survey which would have the potential to alter these existing results.

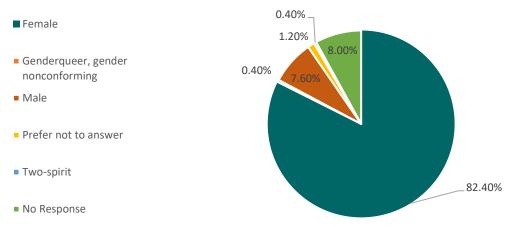
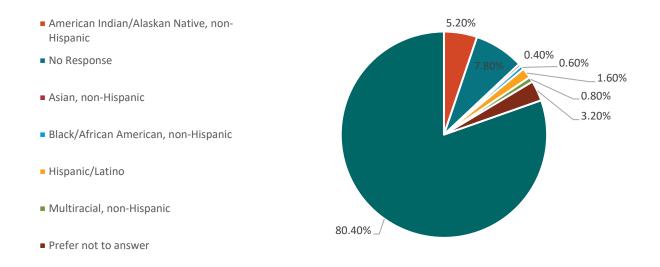


Figure 4. Gender distribution of respondents

Over 80% of the survey respondents were White, non-Hispanic individuals, followed by 5% of respondents identifying as American Indian/ Alaskan Native. Although these were the overwhelming response categories, individuals identifying as Asian, Black/ African American, Hispanic, and Multi-racial all comprise the survey respondents in this report (*Figure 5*).

Figure 5. Racial/ethnic distribution of survey respondents

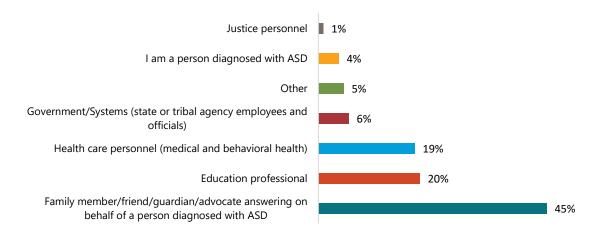


Respondents taking the survey on behalf of an individual with ASD were asked to identify their position with the ASD care community; 243 identified themselves as having a personal relationship being a friend, family, advocate, or guardian (*Figure 6*).

Following this, respondents identified themselves as having a relationship with ASD services through the education, healthcare, government, and justice systems. The individuals who responded to this question with "Other" were broken down into categories such as:

- o Parent
- o Guardian
- o Case Manager
- o Spouse
- o Sibling

Figure 6. Distribution of respondent's relationship to autism spectrum disorder



Completing the Survey on Behalf of Someone Diagnosed with ASD

Individuals who answered this section of the survey spoke to their relationship with an individual diagnosed with ASD. There were 233 respondents in this section, including people who identified as advocates, friends, family members, guardians, and parents of an individual diagnosed with ASD.

The distribution of individuals who answered this section of the survey is comprised of 183 parents, followed by the 15 advocates and 15 individuals who were classified as other. These were the highest-ranking groups followed by nine grandparents, seven friends and four guardians (*Figure 7*).

Figure 7. The respondent's relationship to the individual diagnosed with ASD

Advocate (non-family member)
Friend
Grandparent
Guardian
Other (specify)
Parent

The respondents identified that 74.2% of them were answering these questions on behalf of someone diagnosed with ASD who identified as male, followed by 22.3% responded that they were answering on behalf of a female who was diagnosed with ASD (*Figure 8*).

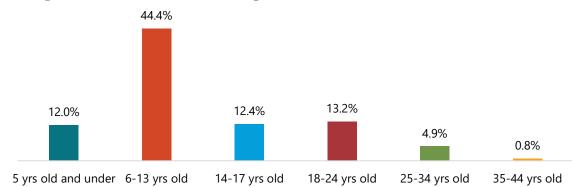
While it was found that 173 individuals were taking the survey for an individual with ASD who identifies as male, the survey itself was taken by overwhelmingly female respondents at 82.4%.

Figure 8. Gender demographics of individuals diagnosed with ASD



The highest age group of ASD individuals who were represented in the survey were those aged 6-13 years old at 44.4% of the survey respondents identifying this age range. There were similarly even distributions of around 12-13% of the respondents each selecting under five years old, 14-17 years old and 18-24 years old (*Figure 9*).

For this survey there were higher age ranges available for selection, but none of the 233 respondents selected these age ranges.





Of the survey respondents answering on behalf of an individual diagnosed with ASD, 82.8% identified that the individual was White, and non-Hispanic. This was followed by 7.3% identified the individual as American Indian/ Alaskan Native, and 3.9% of them as Multiracial (*Figure 10*).

These racial distributions were similar to what the survey respondents identified themselves as in the initial demographic section, showing similar distributions between those diagnosed with ASD and those who have a relationship with someone with ASD.

Figure 10. Racial distribution of individuals diagnosed with ASD

American Indian/Alaskan Native, non-Hispanic
Asian, non-Hispanic
Black/African American, non-Hispanic
Hispanic/Latino
Multiracial, non-Hispanic
White, non-Hispanic

Respondents were able to report what challenges they have seen that impact the ASD diagnosed individual and were able to report multiple challenges at once.

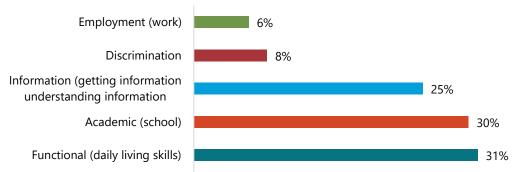
Daily life, or functional skills, were one of the most highlighted challenges for individuals with ASD, followed by challenged with Academia or school. Employment and discrimination were the least selected areas of challenge, but it does not discredit any need for improvement in these areas of service (*Figure 11*).

Limitations to Accessing Care:

- Awareness of services and resources
- Access to locally available services and resources
- Cost of Services
- o Eligibility Criteria

Survey respondents identified a host of existing limitations they were able to see for individuals with ASD in accessing services and care. The most prevalent are listed below, but the extensive list contains issues ranging from the transportation and travel barriers to slow or unreliable services as well as shortages in specialties that provide ASD services.

Figure 11. What challenges are faced by the individual diagnosed with ASD



Most individuals with ASD or families fall under private insurance plans that allow for a wider range of services and care programs to support ASD. Second to this, respondents identifies that the individual has Medicaid insurance to support their services. A lesser amount of the induvial fell into Medicare, Tricare or IHS insurance, and only two respondents identified no insurance (*Figure 12*).

Insurance accessibility is not one of the main service limitations for ASD diagnosed individuals.

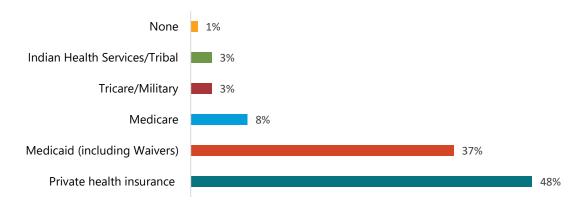


Figure 12. Insurance type of Individual with ASD or their family

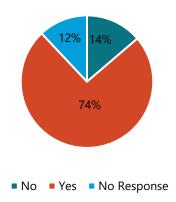
In the last 12 months, 74% of the individuals diagnosed with ASD received a well health screening, while 14% did not receive a health screening. The lack of well health screenings could be due to lack of availability of services, transportation barriers, financial barriers, no identified need for these services, or a host of other identified barriers (*Figure 13*).

Survey respondents identified a list of diagnosed comorbidities in the individuals they are responding on behalf of:

- o Anxiety
- o Depression
- o PTSD
- Sleep Disorder
- o Trauma

The list is not limited to these comorbidities, but these were the highest ranking by the respondents, and represent a need for comprehensive and more integrated healthcare for individuals with ASD.

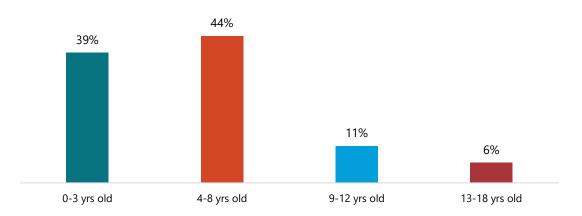




Individuals were more often diagnosed with autism spectrum disorder between the ages of 0-3 years old and 4-8 years old with 170 of the respondents identifying these ages. The diagnosis seems to decrease the older the individual was (*Figure 14*).

Out of the survey respondents, 27 did not respond, and these numbers could lend additional support for this trend, but there is no way to show.

Of the individuals diagnosed, there was a distribution who were diagnosed by a medical team, those who were diagnosed by an educational team, and individuals who were diagnosed through both.





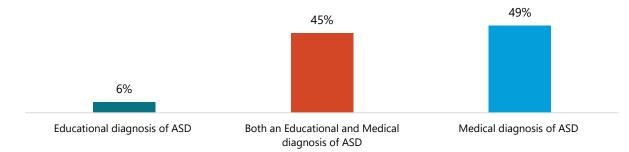
Survey respondents identified a higher rate of ASD diagnosis through medical services, followed by a diagnosis in both educational and medical settings. It was infrequently identified in strictly educational settings (*Figure 15*).

- o 69% were identified first in medical settings
- o 31% were identified first in educational settings

The most common practice for medical diagnosis consisted of one provider diagnosing with 106 respondents, followed by the practice of a team/interdisciplinary diagnosis approach with 75 respondents.

Respondents identified that between referral for ASD diagnosis and their medical diagnosis, 20.6% saw a 1-2 month wait period, and 14.6% saw a 3-4 month wait period. These delays are large barriers to seeking care and treatment post-diagnosis and can pose as limiting factors for individuals diagnosed with ASD.

Figure 15. What type of ASD diagnosis was received first?



The travel distance for individuals to receive their ASD diagnosis is under 10 miles for 47% of respondents, which supports the reduction of transportation as a barrier to care. Similarly, 16% only had to travel 11-25 miles to receive the medical diagnosis. Staggeringly, 25% of individuals had to travel 101 miles or more to receive their medical diagnosis, which is a large transportation, financial, and time barrier (*Figure 16*).

This limitation stands as a gap in care for most individuals and could prove a burden in adequate ASD diagnosis rates.

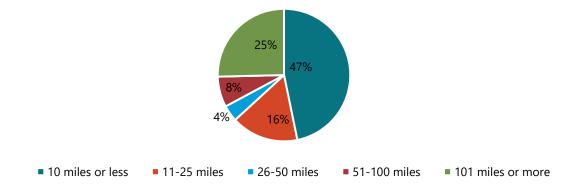


Figure 16. Distance traveled for ASD medical diagnosis

Similarly, most of the respondents traveled 30 minutes or less to receive their medical diagnosis, which would reduce the cost and barrier of travel in receiving care. As with the distance traveled question, 42 individuals noted that they had to drive 4+ hours to receive a medical diagnosis for ASD (*Figure 17*). Due to high amount of rural and remote-rural counties in North Dakota, the travel for medical ASD diagnosis may be higher on average than other states.

The survey respondent identified some integral support services that the individual they have a relationship with uses in their ASD care:

- Speech Language/ Therapy
- Occupational Therapy
- Emotional Support
- Physical Therapy
- o Case management

These were the most reported services to support ASD care and fall under a range of medical, educational, and behavioral health services that add to the ASD community.

With barriers identified like insurance, travel, and cost, some of these services may be harder to access and utilize for some individuals, identifying the need for more comprehensive services.

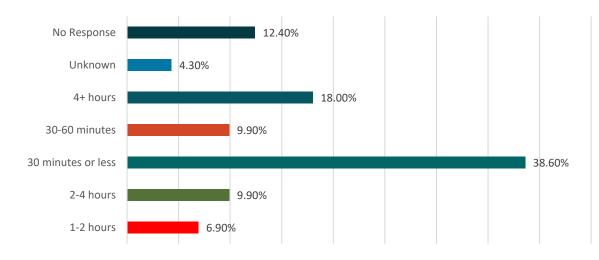


Figure 17. Time traveled for ASD medical diagnosis

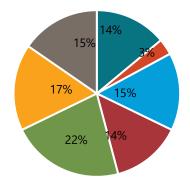
Individuals who identified having a relationship with someone diagnosed with ASD responded that they received trusted ASD information from (*Figure 18*):

- The internet, 77
- o Support Groups, 59
- o Family, Friends, or People with ASD, 54
- Medical Specialist, 53
- o State Provided Services, 49
- o School, 48
- Primary Physician, 11

Trusted sources and information were more likely to be identified as non-professional settings, whether it be organized like a support group, or personal like friends, family or people diagnosed with ASD.

Figure 18. Where did you get most of your trusted information about ASD?

- Through State Provided Services
- From Primary Physician
- From Medical Specialist
- From School
- From Internet



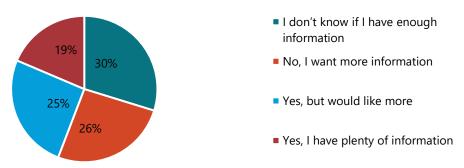
While 30% of the respondents agreed they did not know if they had enough information on ASD and ASD services, similarly, 26% of the respondents responded they did not have enough information and would like access to more. Only 19% of respondents who were answering on behalf of an individual with ASD felt confident that they had enough information on ASD and ASD services (*Figure 19*).

Respondents identified information that they would like more access to:

- o Communication Strategies
- o Behavioral Strategies
- o Sensory and Learning Strategies
- Social Skills
- Treatment/ Therapies

These were the highest-ranking information categories that respondents wish they had greater access too. This information, contrary to where respondents find trusted information, is mostly disseminated from medical behavioral health and education professionals.





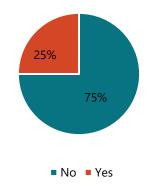
Completing the Survey as Someone Diagnosed with ASD

This section of the survey was completed by 20 individuals who took the survey and are themselves diagnosed with autism spectrum disorder. Their experiences and connection to the ASD services network in North Dakota provides an imperative perspective on ways to improve the ASD services in place.

Only 25% of the respondents of this survey said they receive services or treatment for their ASD diagnosis, and all five of those individuals answered they received these services in the county they reside in (*Figure 20*).

Three of these respondents who receive services stated they travel less than 10 miles to receive them, while the other two noted having to travel between 11-50 miles to receive this care. This trend was consistent, as three individuals responded that they travel less than 30 minutes to receive services, while the other two respondents must travel anywhere from more than 30 minutes to two hours to receive services.

Figure 20. Do you receive ASD services or treatment?

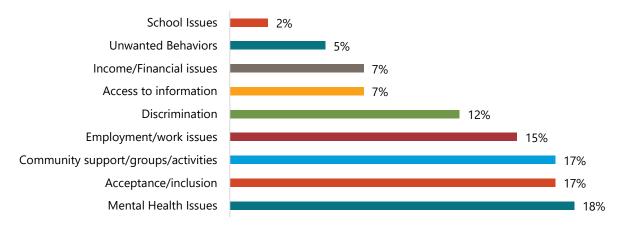


The most common challenges respondents noted facing were (Figure 21):

- o Mental Health Issues
- o Acceptance, or feeling included
- o Group and Social support activities
- Employment
- Discrimination

Fifteen respondents answered that they did not feel they received enough support in handling these challenges they faced, while only three felt they received adequate support. Only two of the respondents in this section said they had a court-appointed guardian or decision maker that helped them in receiving support. Sixteen responded they did not have a court-appointed guardian or a decision maker to aid them.

Figure 21. What are challenges that you face?

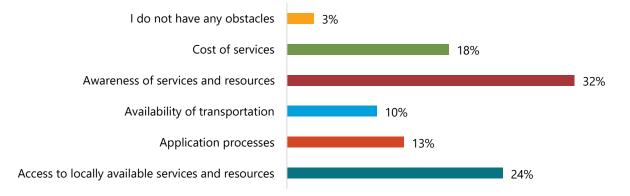


When trying to access care or services, some of the most faced obstacles include: the accessibility of local resources due to availability, the cost of services, and application costs. The trends of cost, transportation, availability, and application hurdles are barriers individuals with ASD face when attempting to seek services. These trends over time will impact individuals with ASD in their ability to seek out comprehensive ASD services and treatment (*Figure 22*). Some comorbidities that individuals diagnosed with ASD face include:

- o Anxiety
- o ADD/ADHD
- o Depression
- o PTSD
- o **Trauma**
- o Sleep Disorder

These reported comorbidities follow the same trend that respondents answered in other sections of this survey. This shows the need for comprehensive services to support individuals diagnosed with ASD in accessing treatment for their comorbidities as well.

Figure 22. What are some obstacles you have faced when trying to access care, support, or education services?



Eleven individuals answered they were diagnosed with their ASD when they were 25 years or older, while only six other respondents answered they were diagnosed younger than the age of 25. This trend varies from previous sections with the highest age group being 8 years old or younger at the time of diagnosis (*Figure 23*).

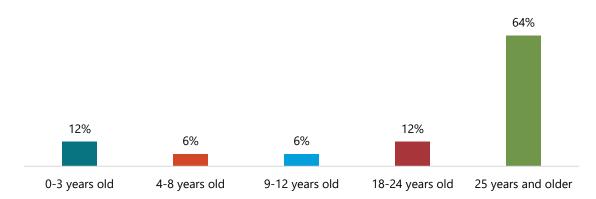


Figure 23. At what age were you diagnosed with ASD?

Only 29% of the respondents felt as though they have plenty of information on their ASD, and 24% felt as though they would like more information about their diagnosis (*Figure 24*).

More than half of the respondents felt they did not have enough information, which shows a lack of accessibility to medical and educational information regarding an ASD diagnosis. Most individuals responded they receive their information from sources including:

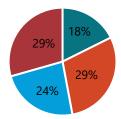
- The internet
- o Books
- o Counselors
- o Doctors

There was little information acquired from case managers, friends and family, and TV. This shows more information being disseminated from professional sources to individuals diagnosed with ASD, compared to those answering on behalf of an ASD individual.

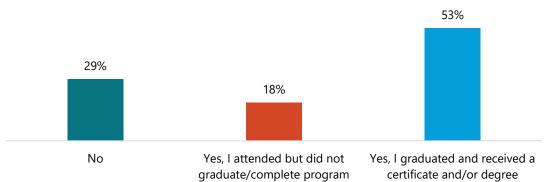
Most individuals found information regarding managing sensory triggers, social skill development, community activities and parenting support to be valuable in helping with their diagnosis.

Figure 24. Do you feel that you have access to enough information about your ASD?

- I don't know if I have enough information
- No, I want more information
- Yes, but I would like more
- Yes, I have plenty of information



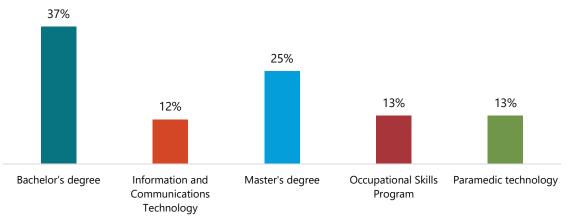
Most individuals diagnosed with ASD have attended a graduate program. Nine individuals completed or acquired a degree from a program, and five individuals reported not being involved in any college, trade school, or post-secondary programs (*Figure 25*).





Of the individuals who completed their program, three received a bachelor's degree, two completed a master's degree, and three individuals completed varying technical certification programs (*Figure 26*).





Of the respondents diagnosed with ASD, 11 work in full time positions, one is self-employed, and two are stay at home mothers. Three individuals identified not being employed in any positions (*Figure 27*).

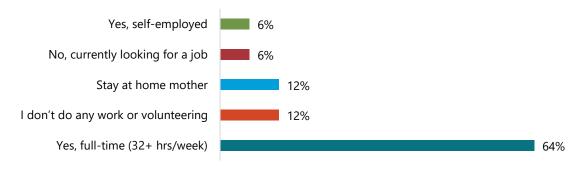
Among the employed respondents:

- One respondent makes \$11-15/hr.
- Four respondents make \$16-20/hr.
- One respondent makes \$21-25/hr.
- Four respondents make \$26+/hr.

Within these employed responses, workplace discrimination was discussed. Five individuals identified no experiences with workplace discrimination due to their ASD diagnosis. Three respondents identified discrimination with a current or previous employer, and two identified being unsure if they faced discrimination, but due to their diagnosis, they put in extra effort to exist in their place of work.

Respondents mentioned not having the proper workplace accommodations to support their diagnosis.

Figure 27. Are you currently employed?



The distribution of individuals who work shows that 11 individuals diagnosed with ASD drive themselves to work, three work from home, one has a hybrid work position, and one receives a ride from a friend or family member (*Figure 28*).

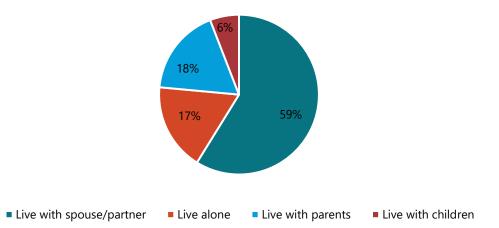
Figure 28. How do you get to work?

Drive Myself
Telework (work from home)
Drive Myself, Telework
Family member or friend

69% of individuals diagnosed with ASD identified living with their spouse or partner, 18% living with parents, 18% living alone, and 6% living with children (*Figure 29*). Of the respondents, ten identified having children of their own. Six responded no to having children, while one respondent did not answer.

Nine of these individuals responded they lived in a house, while eight of these respondents live in an apartment. Out of these respondents 10 individuals felt they were satisfied with their current living arrangement, and six felt unsatisfied with their current living arrangement.



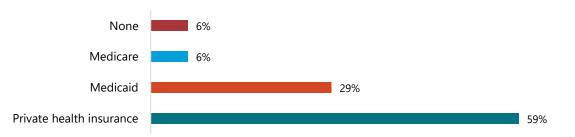


Most of the respondents have health coverage under private insurance plans, while five respondents were covered under Medicaid, and one respondent was covered under Medicare *(Figure 30)*.

Beyond health coverage, respondents identified receiving state resources:

- o 31% received the Supplemental Nutrition Assistance Program (SNAP)
- o 25% received food assistance from community meal programs
- o 25% received housing assistance
- 13% received behavioral support
- o 6% received Employment support through vocational rehabilitation.

Figure 30. What health coverage do you have?



Most respondents diagnosed with ASD saw a provider 1-2 times a year, followed by 1-2 times a month. Only three respondents identified seeing their provider 1-2 times a week (*Figure 31*).

Within the last year, only three respondents identified an emergency room visit, with 14 individuals not needing the emergency room.

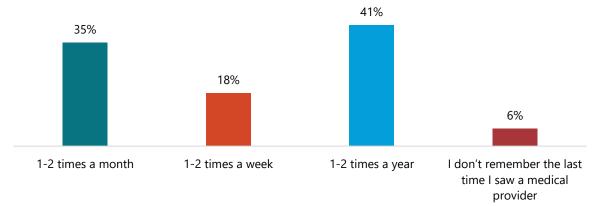
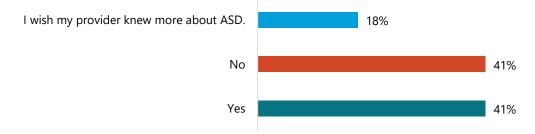


Figure 31. How often do you see a provider for physical, behavioral, or mental health needs?

Seven respondents felt their provider understood them and their diagnosis. Yet, 10 individuals identified they felt that their provider did not understand them, or that they did not understand them enough (*Figure 32*).

This shows the need for intensive provider education on ASD and other supported conditions to allow patients a greater sense of empathy and understanding throughout their treatment and services.

Figure 32. Do you feel that your medical provider(s) understands you and your ASD diagnosis?



Completing the Survey as an Education Professional

Education professionals work with the treatment, counseling, and education of individuals diagnosed with ASD. In this section of the survey, 104 education personnel responded commenting on their work in aiding the success and development of students diagnosed with ASD. This commentary also works to highlight areas of improvement needed to further bolster ASD services within the education arena.

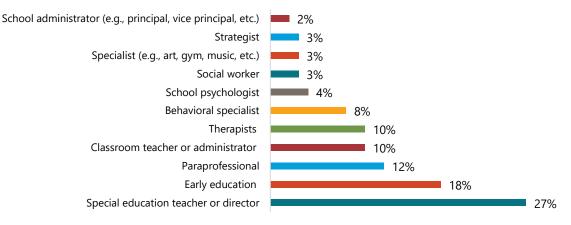
Most of the educational personnel identified as being a special education teacher, an early education worker, or a paraprofessional. But the list of educational professionals who responded to this survey encompasses a large range of specialists who have a direct relationship to supporting students with ASD (*Figure 33*).

Of these education professionals:

o 35% have a MS/MA degree

- o 28% have a M.Ed degree
- o 22% have a BS/BA degree
- o 6% have a bachelor's degree
- o 5% have a EdS degree
- o 4% have varying doctorate degrees

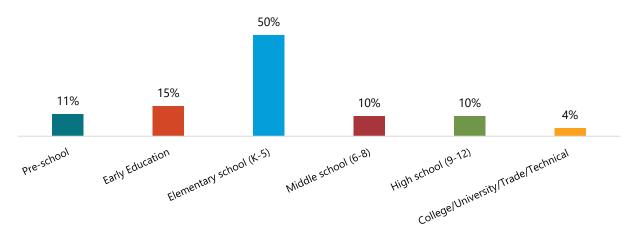
Figure 33. What is your primary role in the education system?



Most of the education professionals identified working with elementary school students in grades kindergarten through fifth, and in early education programs. There are substantially fewer education personnel in older academic settings including middle school, high school, and post-secondary school (*Figure 34*).

40 of these respondents work in a school with between 301-1000 students, while 42 respondents work at a school with between 50-300 students in their population. These population size differences greatly impact the available resources and services that support students with ASD.





Within those educational settings, professionals working with ASD have ranging experience from 27 respondents having worked 1-5 years, 26 respondents having worked 6-10 years, and 21 respondents working over 21 years. Additionally, 41% of education personals have 5-10 years of experience working with students diagnosed with ASD, and 24% have experience from 10-20 years. There are 17% of these professionals that have more than twenty years of experience working with ASD (*Figure 35*).

This shows remarkable field experience, and a store of prepared, dedicated educators supporting students with ASD.

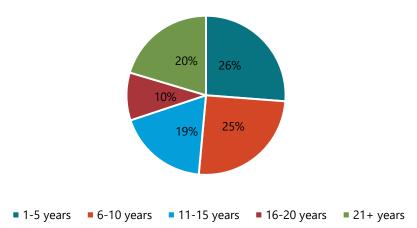
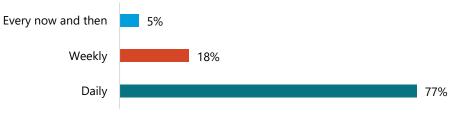


Figure 35. How many years have you spent in the identified educational setting?

Educational professionals work with students diagnosed with ASD daily, with only 22 respondents identifying that they work with ASD students more infrequently (*Figure 36*).

This again shows the need for a greater allocated set of resources for educational professionals to work with students diagnosed with ASD.





Out of educational professionals, 35% felt they had enough information, and 19% felt they had information but would like access to more information about ASD services. 45% of respondents felt they did not have enough information (*Figure 37*). This shows a disparity in the distribution of ASD information available throughout educational institutions.

Increased information for education professionals would benefit from targeting topics including:

- o Information to support working with differing behavioral needs
- o Information to benefit and support family's needs
- Trainings that aid education professionals in fostering a supportive learning environment for students with ASD.
- Information on support programs to bridge education institutes, individuals with ASD and community interventions
- Information on ways to advocate for students needs involving existing policies, legislature, and academic regulations

Educational professionals identified the most efficient ways they could receive trainings would be through web-based training, conference workshops, online downloadable resources, and accessible ASD toolkits.



Figure 37. Do you have enough information on ASD and how to access ASD services?

Completing the Survey as a Medical or Behavioral Health Professional

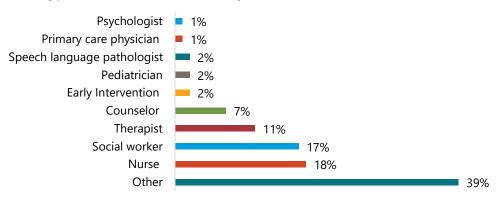
There were 90 respondents in this section. The respondents comprised of varying medical and behavioral health professionals who work closely with individuals diagnosed with ASD. These professionals are familiar with the diagnosing, treatment, and practices that go into supporting individuals with this diagnosis.

The distribution of healthcare workers shows respondents predominantly employed as nurses, social workers, therapists, and counselors (*Figure 38*).

For individuals who identified as "Other", the distributions show individuals identifying as Board-Certified Behavioral Analysts (BCBA), Registered Behavior Technicians, Audiologists and six other varying types of behavioral therapists.

For medical personnel, respondents identified anywhere from Certified Nursing Assistants, Pediatrician workers, Occupational therapists, and more.

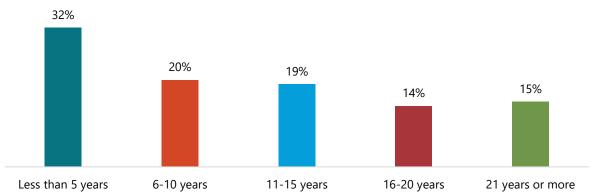
Figure 38. What type of healthcare worker are you?



Respondents identified that most individuals have less than five years of experience post school graduation, with varying healthcare professionals having practice experience anywhere from six to 21+ years post school (*Figure 39*).

Thirty of the individuals described working in a practice setting that was classified as a large group practice (>8), while 17 identified working in a private/ independent practice, 12 respondents identified working in a small group practice setting (1-7), and five identified working in a hospital setting.

When asked if they felt their practice setting had adequate workforce to meet the community's needs, 59% responded they were "nowhere near close enough", and only 9% felt they had an adequate and sufficient workforce for the community needs.

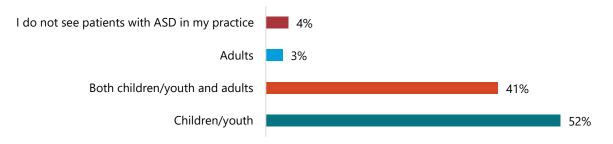




Many patients met with primarily children/youth in their clinics, and a similar amount saw children/youth as well as adults. Within these clinics, 62% provided telehealth and virtual services for their prospective patients, while 38% do not provide this accommodation (*Figure 40*). Virtual and telehealth services provide patients with an opportunity to speak to providers on their own comfort levels and maintain a level of flexibility for service.

Throughout the practices that saw children/youth on Medicaid, only 37% conduct the Health Tracks and Periodic Screening and Treatment. The additional 63% responded they do not conduct this screening and treatment tool within their practice.

Figure 40. Which of the following patients with ASD do you see in your practice?



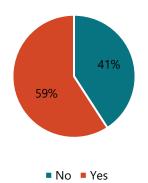
Throughout medical and behavioral health practices, 59% routinely screened for emotional or behavioral concerns in children (*Figure 41*). Some of the most common prompts they indicate the need for further ASD evaluations include:

- Social delays
- Communication delays
- Hypersensitivity
- Repetitive movements
- Limited eye contact
- Limited self-help skills

When a healthcare professional suspects their patient may have ASD, or needs further evaluation the most identified practices include:

- Providing information and resources on ASD
- o Evaluate further about a patient's development history
- o Refer a patient to specialty care
- Refer a patient to Early Intervention Programs

Figure 41. Do you routinely screen for emotional or behavioral concerns in children from birth to five years of age?



Commonly healthcare professionals will screen for ASD when concern is expressed by a patient, parents, or their caregiver. If there is no concern expressed, healthcare personnel will screen at growth markers, most commonly 18 months (*Figure 42*).

Some of the most common screening tools that healthcare professionals identified as part of their ASD services include:

- Modified-Checklist for Autism in Toddlers (M-CHAT)
- Relying on Clinical Observations
- Autism Behavioral Checklist (ABC)
- Childhood Autism Rating Scale (CARS)
- o Social Communication Questionnaire (SCQ)

Figure 42. When do you screen for ASD?

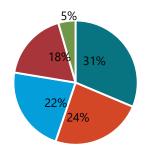


When asked if respondents felt they had all the necessary tools and resources to support people with ASD, only 49% of the healthcare professionals felt they had adequate accommodations. Almost half of the healthcare providers do not feel they have adequate support for individuals with ASD (*Figure 43*).

This shows a need for increased access to trainings and resources to bolster health services for this community.

Figure 43. Do you have adequate tools, resources, and practice models to accommodate people with ASD in your practice?

- Agree
- Neither agree nor disagree
- Disagree
- Strongly agree
- Strongly disagree



Between all the respondents who answered this survey question, 84% identified they do not currently diagnose patients with ASD (*Figure 44*). These providers cited reasons for not diagnosing including:

- Not being qualified to diagnose ASD
- They only refer to specialists for diagnosis
- o They are not familiar with the screening tools
- They lack sufficient training

Of the individuals who identified diagnosing patients with ASD, seven identified they make 11 or more ASD diagnosis a year, and two answered they also will travel to make ASD diagnosis for patients.





In North Dakota, autism spectrum disorder is a mandatory reportable condition as per the ND Century Code (23-01-41), yet 62% of healthcare providers were unaware of this code (*Figure 45*).

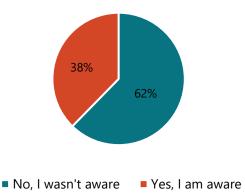
There is a gap in accessible information for individuals working in ASD services regarding policies and regulations that impact this condition. Healthcare personnel identified some ways that would be successful in disseminating information regarding ASD or other conditions would include:

- o Email, mail, or newsletters distributed through their institution
- o Trainings or continuing education with supported updates
- Webinars or supplemental online educations

Similarly, some specific trainings and resources that healthcare providers cited would be beneficial in supporting their knowledge and confidence include:

- o Checklist of community resources
- ASD Conferences/ Workshops
- ASD toolkit for screening and diagnosis
- Network of providers to consult with on ASD services
- Trainings on specific communication strategies with ASD patients

Figure 45. Are you aware that ASD is a mandatory reportable condition in North Dakota?



Most of the available resource providers have in their practices contact information for different support services within the ASD care network. The resources mentioned provide contacts within every sector of ASD services and support a large continuum of care throughout North Dakota (*Figure 46*).

Although providers have access to all these resources, only 45% view that their patients have access to adequate support to partner with their practice.

Within these respondents, 18% disagree they have adequate support for individuals with ASD partnering with their practice. Providers felt similarly about the support they can give caregivers of their patients with ASD in a resource partnership.

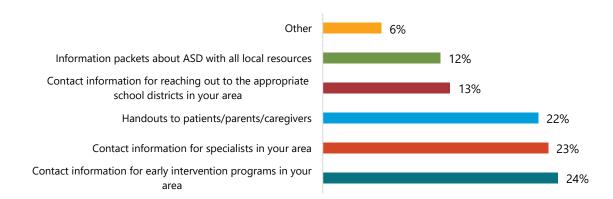


Figure 46. What resources does your practice have available for individuals diagnosed or suspected of having ASD?

Only 3% of providers felt they had poor knowledge or skills in providing care to individuals with ASD. Overwhelmingly, respondents agreed that they had good (42%), fair (24%) or excellent (31%) knowledge in providing care to their ASD patients (*Figure 47*).

In a similar trend of confidence, 36 respondents agreed they felt familiar with techniques for accommodating ASD patients, and 34 were comfortable with examining a patient diagnosed with ASD.

These trends of confidence in providing care, accommodating patients, and successfully examining them shows a level of comprehensive care that hopefully is translated into rewarding and competent patient interactions.

3% 42% 31% 42% 5 air 6 Good

Figure 47. How would you rate your knowledge and/or skills in providing care to people diagnosed with ASD?

24%

Completing the Survey as a Justice System Personnel

This section is comprised of justice personnel who have a relationship working with individuals diagnosed with ASD. There were only three respondents from this section. Two attorneys and one juvenile/district court representative participated in this survey (*Figure 48*). Of these respondents, two identified being somewhat familiar with recognizing signs and symptoms of ASD, and one identified being very familiar.

Two individuals identified being very confident with their abilities to communicate and interact with someone diagnosed with ASD.



Figure 48. What is your primary role in the justice system?

Poor

Accommodations that ASD individuals would be able to ask for in a justice setting include accommodations to help with sensory issues, including loud sounds, interpretations or communication needs, or the ability to access certain resources.

Only two of the justice personnel identified feeling comfortable with being able to provide accommodations, while one member did not feel comfortable. This could be due to lack of experience, training, or the system in place to support these needs (*Figure 49*).

Within the respondents, only two identified having received training on supporting ASD individuals within the justice system. Respondents identified getting information from:

- Medical providers
- Legal personnel
- Continuing education within the legal system
- Webinars, trainings, or educational sessions
- o Speaking with individuals diagnosed with ASD

Respondents indicated that more information to increase their disability awareness and more training to improve their communication skills when working with individuals diagnosed with ASD would support their work.

Figure 49. How confident do you feel in your ability to accommodate the needs of someone with autism?



Completing the Survey as a Government Systems Personnel

Government systems play an integral role in the support and access of services for individuals diagnosed with ASD. Personnel within these state and tribal government systems develop legislature, policies, and programs that directly impact the care continuum for ASD. 22 respondents from within this system commented on their experiences of the relationship between government systems and ASD care.

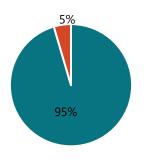
Most individuals responding to this section of the survey are government employees working for local or state agencies. Only one of the respondents identified working directly with policy making (*Figure 50*).

Ten of the respondents identified being very familiar with ASD, and 10 identified with only being somewhat familiar. Government personnel identified their familiarity with ASD came from:

- Working with individuals with ASD
- Personally, knowing people diagnosed with ASD
- Working in positions or with programs that support people with ASD.

Of the respondents, 16 identified they are aware of the needs of individuals with ASD within their community or system.

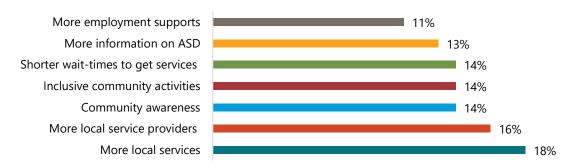




Government employee (state or local) Other policy maker (program director, administrator, etc.)

Government personnel identified the need for more ASD services and providers, increased community awareness, community activities, and more information to support ASD services (*Figure 51*). All these needs can be implemented with support from government systems and work within these systems.

Figure 51. What kinds of needs are you aware of?



Between all the respondents, only three identified they felt that the ASD- related policies and systems were effective for their community. Twelve of the respondents identified not having enough information to determine if they were effective in their community (*Figure 52*).

Government personnel identified some information that would benefit their work in supporting individuals diagnosed with ASD includes:

- Availability of community resources
- Development of increased community networking
- Information on community ASD providers
- Ways to connect with families to get information on their ASD needs
- Communication strategies for talking with people who have ASD
- o Training on different ways ASD impacts individuals

Figure 52. If you have ASD-related systems and policies in place, do you feel that they are effective for your system or community?

