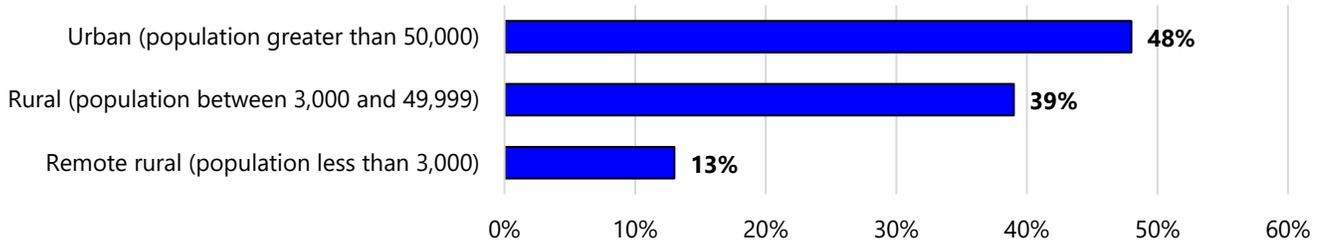


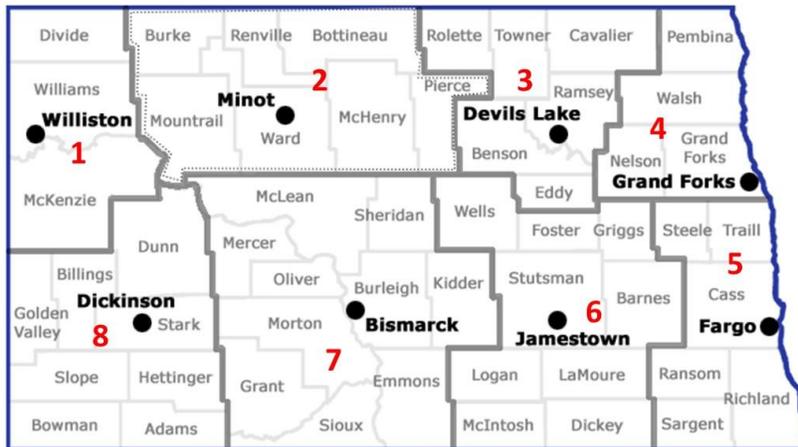
North Dakota Autism Spectrum Disorders (ASD) Survey

In March 2018, the Governor’s Appointed ASD Task Force composed an ASD Survey to assess service and training needs, gaps in care and to collect information from people living with ASD on how it impacts their lives. Everyone who had a connection to ASD was invited to take the survey. The 374 recorded responses will be used by the task force to make recommendations for state-level policies and services. The goal is to positively impact people with ASD and their families/communities.

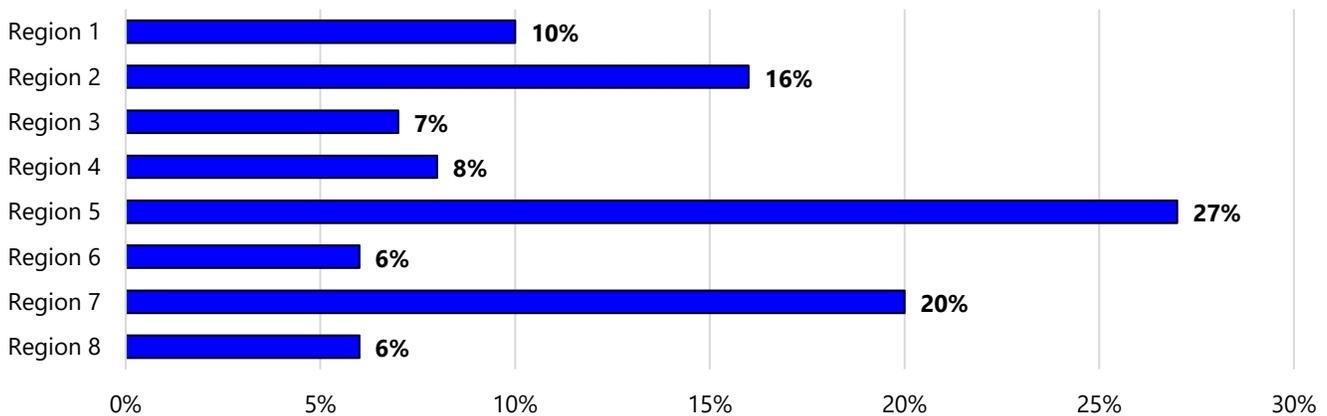
In what setting do you currently reside?



N=350

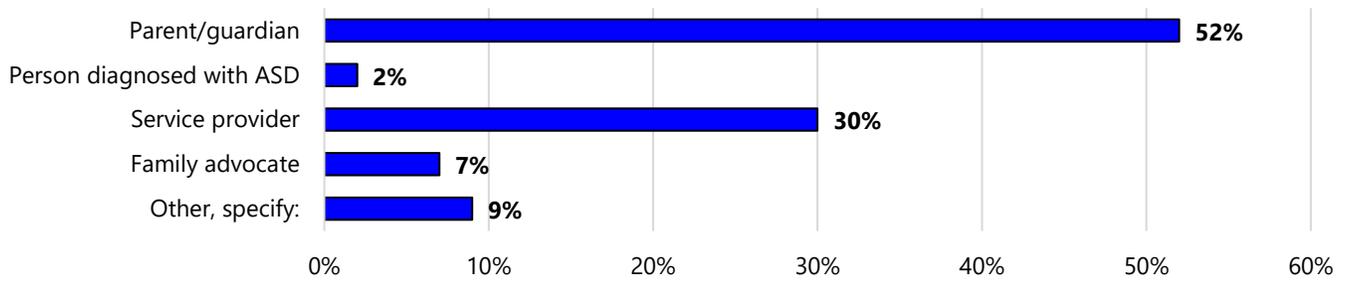


What is your region of residence?



N=354

Please select the response that best describes yourself:

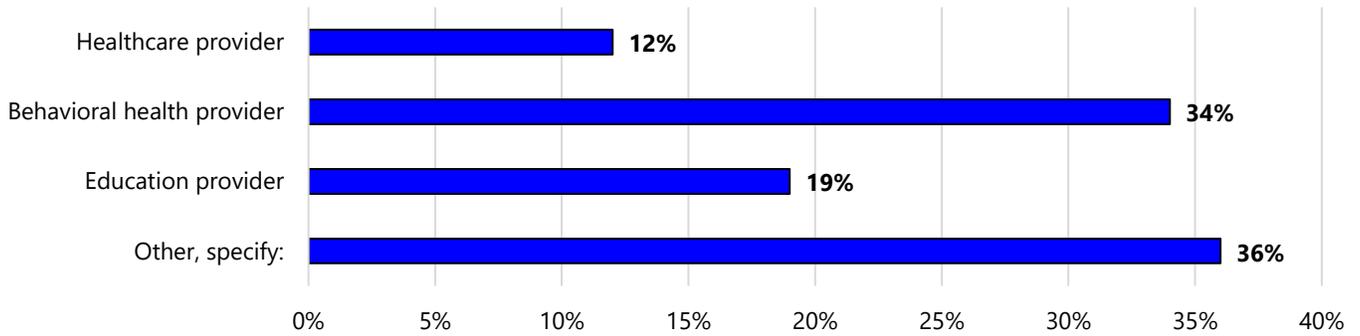


N=379 (Some respondents selected more than one)

Other, specify:

- | | |
|--|--|
| Education field. | Professional. |
| University instructor/ ASD professional. | Person with ASD, parent of child dx ASD, ECSE |
| Husband has ASD. | ASD para. |
| Spouse. | DDPA. |
| DD Program Manager. | Special Ed. Teacher. |
| Advocate. | Am retired but provided services to a family member and other clients. |
| DD Program Manager. | Grandmother. |
| Teacher. | DD Program Manager. |
| Professor. | Nurse Practitioner. |
| DD Program Manager. | Special Ed. Teacher. |
| Early intervention/autism diagnostic clinic team member. | DD Program Manager. |
| Teacher. | DD Program Manager. |
| Teacher. | DD Program Manager. |
| DD Program Manager. | Grandparent. |
| Teacher. | Health Educator. |
| Child welfare. | Stakeholder. |

Select one of the following that describes what kind of provider you are:



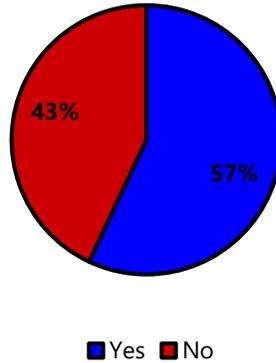
N=112

Other, specify:

- | | |
|---------------------------------|-------------------------------|
| Early intervention. | Autism Waiver. |
| LSTC - ICF Institutional Care. | Mental health. |
| DD Program Manager. | Residential in-home supports. |
| ABA. | Daycare provider. |
| Day Habilitation. | Early Interventionist. |
| Caregiver. | ICF/MR homes. |
| Residential and Vocational. | DSP. |
| Early intervention. | Developmental Disabilities. |
| Speech Language Pathologist. | In home care taker. |
| Occupational therapy assistant. | Therapy. |
| Family services. | Autism Services, DD Services. |
| VR. | Mental Health. |
| DSP. | Employment. |
| Occupational Therapist. | Occupational Therapist. |
| Mental health provider. | DD Provider. |
| DD Program Manager. | Speech/Language Pathologist. |
| Developmental Disabilities. | Occupational Therapist. |

Training:

I have access to training related to ASD.

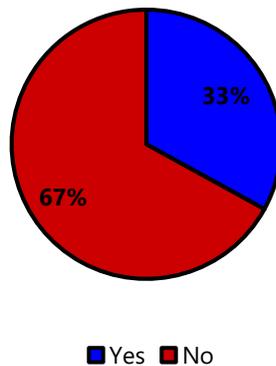


N=256

For the respondents that selected "No" to accessibility to training related to ASD, these are the regional breakouts:

- Region 1: 12%
- Region 2: 17%
- Region 3: 12%
- Region 4: 7%
- Region 5: 20%
- Region 6: 5%
- Region 7: 17%
- Region 8: 9%

The training is individualized to meet my needs.

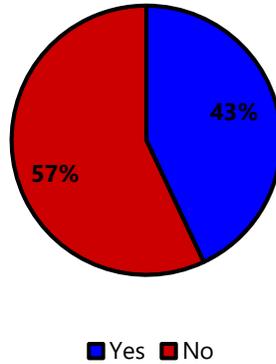


N=243

For the respondents that selected "No" to training that is individualized to meet needs, these are the regional breakouts:

- Region 1: 11%
- Region 2: 16%
- Region 3: 8%
- Region 4: 6%
- Region 5: 27%
- Region 6: 6%
- Region 7: 17%
- Region 8: 9%

The training is affordable.

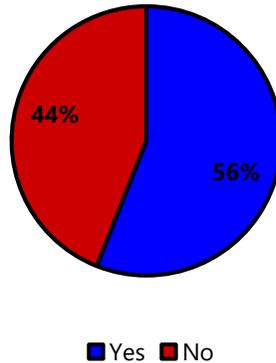


N=238

For the respondents that selected "No" to training that is affordable, these are the regional breakouts:

- Region 1: 9%
- Region 2: 14%
- Region 3: 9%
- Region 4: 4%
- Region 5: 28%
- Region 6: 6%
- Region 7: 18%
- Region 8: 12%

The training includes evidence-based strategies and promising practices.

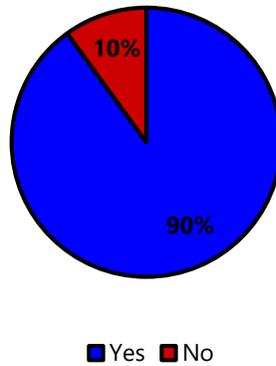


N=235

For the respondents that selected "No" to trainings that include evidence-based strategies and promising practices, these are the regional breakouts:

- Region 1: 13%
- Region 2: 14%
- Region 3: 9%
- Region 4: 3%
- Region 5: 26%
- Region 6: 6%
- Region 7: 21%
- Region 8: 9%

I am interested in more training on ASD.

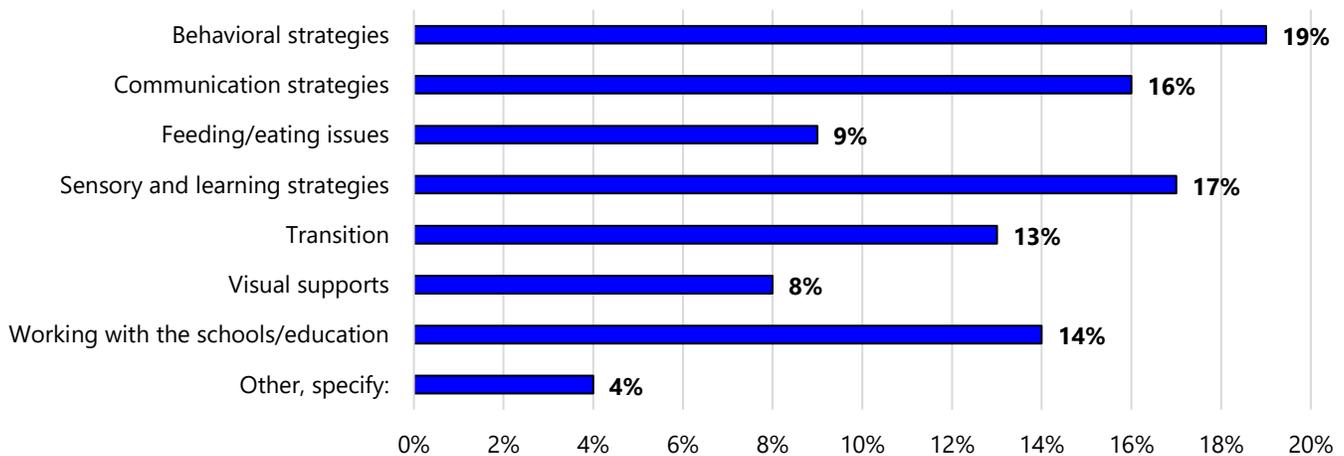


N=303

For the respondents that selected "No" to being interested in more training on ASD, these are the regional breakouts:

- Region 1: 8%
- Region 2: 16%
- Region 3: 7%
- Region 4: 6%
- Region 5: 29%
- Region 6: 7%
- Region 7: 20%
- Region 8: 7%

Please select which of the following topics you would like to learn more about: (Check all that apply)



Other, Specify:

Living skills when they move out.

Family support.

Autism and deafness.

Employment opportunities.

Special diet to help reduce allergic response.... there are many medical issues my child experiences, but doctors tell us "that's just autism" and nobody will help us with these issues.

Safety measures.

Social skills.

Social skills and chores.

Transitioning to independent adult.

Sleep.

Employment supports; addressing behaviors on the job site.

Funding for help.

My daughter doesn't qualify for SSI/SSDI and so I can't get services for her as an adult. What can I do?

ASD and puberty.

Anything that would help me be more supportive for my daughter, help her reach her full potential etc.

Therapies other than ABA.

Anxiety and its role in ASD.

Sibling, strict work schedule and working with traumatic brain injury parent.

Police in schools, Civil Rights reporting by schools.

Family supports; increasing access to services.

Adults needing financial guardian or planning.

Strengths of neurodiversity- looking at autistic individuals through a social model vs. medical model of neurodiversity, having actually autistic people give trainings to help with accommodations and sensory tips, training on orientations opposite of ABA (this will provide a much more rounded and diverse training, many autistics support other therapies, training on why Autism Speaks is negative and how to embrace the other 50 autism symbols instead of the puzzle piece, campaigns to go red instead of light it up blue.

Family care.

Employment.

Other ways to help my son rather than having to medicate my severely autistic child.

Physical education/gross motor strategies.

Social skills development.

Equine therapy.

High functioning ASD and mental health.

Family engagement.

Providing "real" social opportunities in rural communities for teens.

Sleep.

Teaching social, work, and daily living skills in the classroom setting.

Job placement.

Job training and placement.

Trauma.

Comorbidity, trauma and ASD, verbal de-escalation, anxiety interventions with ASD, floor time, RDI, other non-ABA interventions.

Parenting an adult child, secondary education and ASD.

Maintaining employment or having disability funds available.

Executive function skills.

Summer activities or day programs, respite care in remote areas.

Hospitals that treat psychiatric Autistic 9-year-old.

Employment.

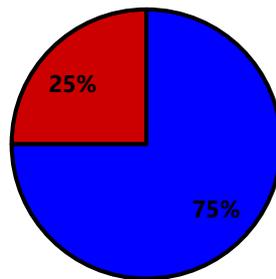
Realistic in-home not a study model.

Human service DDPM roles/expectations. Varies with different heads of these departments. Their staff do not seem to be kept updated.

Seizures associated with autism.

Information Resources:

I have access to resources about ASD.



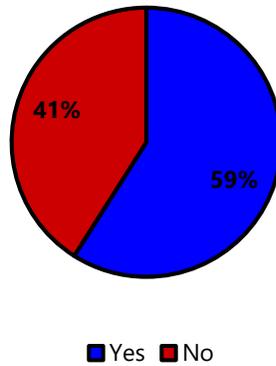
■ Yes ■ No

N=263

For the respondents that selected "No" to having access to resources about ASD, these are the regional breakouts:

- Region 1: 12%
- Region 2: 22%
- Region 3: 11%
- Region 4: 8%
- Region 5: 14%
- Region 6: 8%
- Region 7: 15%
- Region 8: 11%

I have access to resources on intervention strategies for people diagnosed with ASD.

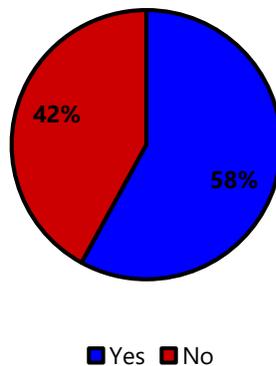


N=261

For the respondents that selected "No" to having access to resources on intervention strategies for people diagnosed with ASD, these are the regional breakouts:

- Region 1: 8%
- Region 2: 21%
- Region 3: 15%
- Region 4: 5%
- Region 5: 23%
- Region 6: 8%
- Region 7: 13%
- Region 8: 8%

The information in the resources is easily read and understood.

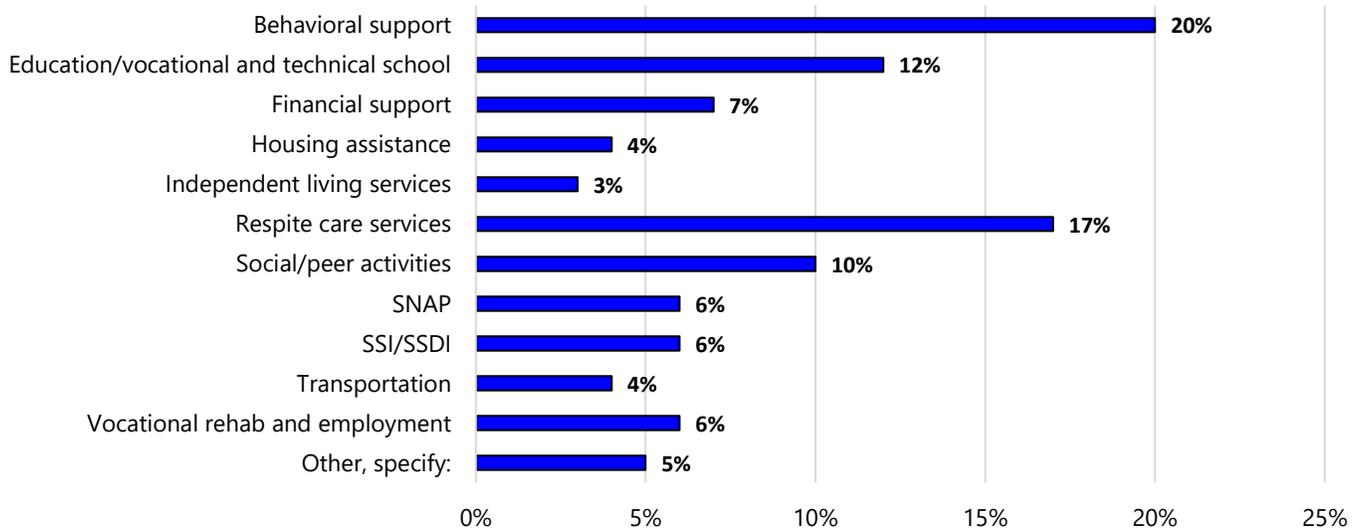


N=252

For the respondents that selected "No" to information in the resources being easy to read and understand, these are the regional breakouts:

- Region 1: 11%
- Region 2: 23%
- Region 3: 9%
- Region 4: 3%
- Region 5: 26%
- Region 6: 8%
- Region 7: 12%
- Region 8: 9%

Have you/or your child used any of the following supportive services?



Other, specify:

Day support services.

ABA therapy currently... note no physician or psychologist ever told us about this therapy. We researched it ourselves.

Partnership and the village.

Developmental Disabilities Program Management.

OT.

Early Intervention and special ed preschool.

Early Intervention and preschool special needs.

Need more information about group homes.

NA, provider.

Can't get SSI, we are just over the income levels which is ridiculous.

Early Intervention.

Medicaid, outpatient: occupational, speech and physical therapy. Kids program and DD services. In process of receiving respite and special education services for when she begins preschool.

OT, PT, CBT and talk therapy.

Guardianship.

Positive Sensory Support Therapy.

Occupational and speech therapy and family intervention through Anne Carlsen Center.

As a provider, I have provided behavioral support and social skills training.

He goes to different types of therapy.

Occupational therapy.

Day support services.

Outpatient therapy.

N/A but clients I have served say there are no service providers in most areas of our region and they are not using evidence-based practices.

ABA.

Voucher and waiver.

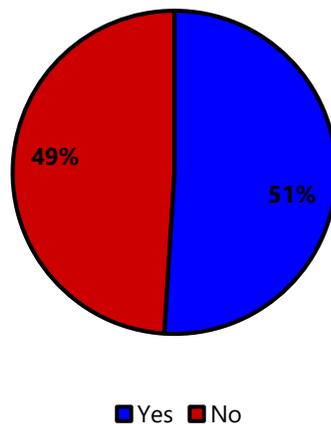
Occupational therapy and speech therapy.

DD Service Provider.

I'm a case manager.

Just what she gets through school.

Do you have tools to navigate ASD services?

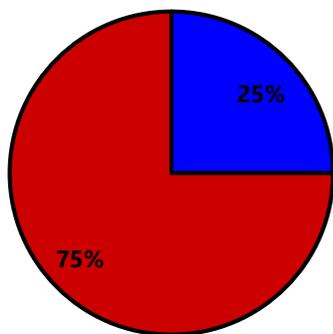


N=231

For the respondents that selected "No" to having the tools to navigate ASD services, these are the regional breakouts:

- Region 1: 11%
- Region 2: 20%
- Region 3: 7%
- Region 4: 4%
- Region 5: 27%
- Region 6: 6%
- Region 7: 16%
- Region 8: 10%

Are you satisfied with the services that are available?



■ Yes ■ No

N=225

For the respondents that selected “No” to feeling satisfied with the services that are available, these are the regional breakouts:

- Region 1: 11%
- Region 2: 18%
- Region 3: 6%
- Region 4: 5%
- Region 5: 24%
- Region 6: 7%
- Region 7: 19%
- Region 8: 9%

Please explain your satisfaction or dissatisfaction with the services that you have referred to, or used yourself, or as a family member?

I am dissatisfied with the autism waiver. First the waitlist. Then sending in the paperwork as requested by them. Asking them to call me back if they did not get the paperwork that was faxed to them. Then getting a letter in the mail 9 months later saying they closed my case because they didn't get his paperwork.

We don't have anything out here. We have to travel for everything.

We have tried to get involved with a behavioral therapist and there are minimal individuals for this need and we do not get the continued care to have this therapy to benefit my child with ASD. Making his school days and home days difficult to navigate with his behaviors.

Satisfied with ABA...less satisfied with speech, OT, and PT at Sanford.

They are ok and helpful but not enough. We need more services that aren't 50 miles away. Most of the services have income limits that are not realistic. When you pay copays, gas etc. we can't even buy food. Yet we don't qualify for things unless I quit working and hope we don't lose our home.

Use the North Dakota Autism Center for In Home Family Support and ABA Therapy. They are excellent.

Better access to evidence-based diagnosis and behavioral support as well as mental help support for parents is needed.

LSTC was diagnosing Autism in the 80's, when it wasn't the dx of the decade. We will continue to do so as appropriate. We see many ppl with Dx of Autism, where there is some professional disagreement.

There should be more training for staff who work for agencies that support and house individuals with autism.

Navigating ASD is a cumbersome process. It seems as if a diagnosis is given and then we are left to figure out the next steps and make amendments as we see fit.

What services? I really don't know of any in the Minot area. We were blessed with an amazing doctor who we worked with and the schools are great. As we are getting into High School, we don't know of anything that is available.

As a DDPM I am always looking for more information to assist my families. I would like more training, in the areas I have marked. The more the better. I can never have too much. Families look to me, others in my profession as a resource. Please offer more trainings. Thanks so much!!

We just got diagnosed so I am learning what is all available.

The services are very minimal. My health insurance is Tricare. Trying to find places that are Tricare approved is very hard to find. It took me most of a school year to find a place to do testing on my son. He has been struggling in school for over a year. The school is not equipped with ASD knowledge and most of the staff has had little to no training.

We have no therapy services in Rolette County, hire please. We went for 15 hours week therapy to none. Pay mileage for our regular therapist for Devils Lake, she was an amazing therapist.

We have a fantastic OT for our son. Other than that, we have no help. My husband is likely on the spectrum too and we have zero ideas for helping him, other than reading books.

I'm satisfied that ND Medicaid covers ABA services but there needs to be more ASD services covered also.

ABA therapy is limited in our area with months on a waiting list. Schools are not supportive of families in getting children to school when there are behavioral issues.

Very few staff to help care for adults who need support. Very few professionals who know about how to treat our kids medically without psych drugs. My "typical" kids had sleep problems and when treated for apnea, slept so much better. My child with ASD is ignored when presenting with the same issues. Doctors only want to medicate, medicate, medicate.

We have access to quality services that are unique to the Fargo area.

We live in a very remote area and I'm a single parent working full-time. Finding or utilizing what's available is extremely difficult. Trying to pay for what's necessary for his development and safety is not impossible. Instead of gifts for holidays - I ask family for help with costs associated with his care.

MSU and NDACP is a great resource. The ND Autism Center is great. As a PC at a provider in a rural community, PT, OT and speech/communication professionals is very lacking for our area. I feel with their expertise our services/supports could improve greatly.

Lack of assessment/Dx opportunities, lack of appropriately trained professionals, late diagnosis.

We applied to have our son enrolled through Badlands Behavioral Health here in Dickinson and we got a letter back stating that we did not qualify because of our insurance and we had amply access to services in Bismarck. Very difficult to constantly try to get to appointments and facilities hours away and take time off from work when my son needs to be seen.

ABA is run by bachelor level with only on the job training.

We lack services that are specialized in ASD in the small communities. In order to get providers who are specialized in working with kids on the spectrum, it requires families like ours to travel multiple times per

week to cities like Grand Forks or Fargo. Reimbursement for medical appointments was discontinued a few years ago so it's just another added expense that prevents people from seeking necessary services.

I have Partnerships and the DD program through West Central, PATH, Hit, Inc., Youth works. I have been extremely pleased with these organizations. They've all been very supportive.

I myself am concerned with finding good babysitters as I am a single parent...I've applied for respite care but there is not enough staff, or I hear funding is short. So, I get 2 hours to work in the day due to trust issues and past issues with sitters who aren't qualified enough to ease my anxiety about it

Resources are extremely limited where we live. We have to drive 2 hours or more for services.

Small amount of behavioral support. Also support to finance the therapies is limited!

Minimal tools to navigate ASD services.

Long waiting list for ABA therapy, supervisors are in Bismarck-makes supervising my daughter's case more challenging.

Services were good when he was younger. Unfortunately, it was VERY hard to find out about. Young mothers do not know where to turn when they suspect their child is on the spectrum. They do not have the information about the services like EI. Also, right now my son is high functioning and is doing well but could use some social skills support. I should be more educated than average about this and I have no idea what services are available the state would fully fund.

I feel satisfied as the parent because we do monthly meetings to see where or what else can be improved with my child. They ask for family input. They work with the family schedule for vacations and such. I feel if something comes up I can approach a staff member & let them know my concerns.

Need more behavior analysts across the remote and rural regions of the state.

There are not enough support services for young adults on the spectrum to lead an independent life.

I need to know more about the tools available to help my students and my own child with ASD.

My son refuses to be dealt with like a little child. He is 17 and sometimes defiant, which makes everything more complicated.

I've found other states offer more services both privately and publicly. There are no schools in our region focusing on ASD. There is little training for paras in school district.

There is litter stuff here on this side of the side, some stuff we don't get because of stipulation. Like respite care. Autism qualifies but since my son is not developmentally delayed, we all off a sudden don't get that help.

There isn't access to ABA therapy to meet needs of individuals with autism, especially once they transition out of school. Supports may be available in the day time settings, but not for individuals who choose employment. Need providers who are trained and ready to address these behaviors in a work setting.

I'm not sure if I know about all the services but we do use ABA therapy. We only get 4 hours a week because of limited scheduling time frame at the place. I wish there was something open for weekends. It also took me a long time to find help for my child. If I wasn't so eager and persistent to get help, my child probably still wouldn't have any help at all.

It's not that I'm dissatisfied with services in my area because I don't believe we are entitled to anything but there is one facility in Williston that helps families with autism, called Chatter. They focus on training parents in ABA therapy and we have chosen the Son-Rise program for our autistic daughter's therapy needs, which differs from ABA therapy. We have seen great success with the Son-Rise program when we

have time to implement it. Either therapy requires one on one work with the child for over 25 hours a week minimum. For my family because we live far away from any relatives, this requires a lot of help we can't afford to pay. Very little is known in my area about the Son-Rise Program or autism reversing diets like the GAPs diet. We are trying to raise awareness and educate families in these matters. We are working on fundraisers to be able to afford the full Son-Rise program, the GAPs diet (a lot of organic foods that are highly expensive and not available in this area) and time off work to work with our child. We have read of families applying for funds and grants in other areas to implement their Son-Rise programs in their homes and hire help through school districts, Medicaid, and ELWYN but I do not know what is available if anything in my region. We intend to research this. This is a quote from the Son-Rise Program Fundraising Guide: "In the U.S., federal law mandates that public schools must provide appropriate education for children with disabilities, starting at age three. Even though the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, the Surgeon General, and the National Academy of Sciences all have called for early intervention, including one-on-one therapy for children with autism (minimum 25 hours per week, 12 months per year), these programs are rare. The federal government paid only 17% of the mandated 40% of the cost for 2002. (See New York Times online October 22, 2002)." We are not entitled to it and our wonderful church is helping us as much as they can but if funding were available in our area, we would happily take it. We also want to see more of an awareness in our community that autism is indeed reversible. Doctors and parents have been completely reversing it for decades. Though it is still not widely accepted, it is gaining ground.

Limited placement options for those with high functioning ASD. Need group home options.

There are next to no resources available in Region 1. Would be wise to provide training to primary care providers throughout the region, and also to school staff, particularly the paras who work one on one with these kiddos.

I have always been able to find the services I have needed but I have found in my professional life that often those on the higher side of the spectrum can really fall between the cracks and they and their families have to fight harder to get services.

There are no clear ways to diagnose, I have had multiple doctors fight for years over if my son does or does not have autism and if he is not formally diagnosed he falls through all the cracks but if he is then it could be wrong. I feel like the system has been failing my child for years and ND does nothing to help.

Wish services were more readily available in school. While my child qualified for service by insurance guidelines, he did not qualify by school guidelines. Currently, he's been absent for 15+ days of school, mostly due to his therapy appointments. I had to seek out services on my own. The school doesn't acknowledge his diagnosed ASD. Behavior health, PT, and OT have been wonderful and provide him with skills necessary to become a successful adult.

Just not much help.

At first working with an advocate was helpful, but other than my word the school wasn't aware and when things got difficult the advocate quit returning my calls. We also worked with a psychologist who would tell me what to do but didn't engage much with my son.

Not enough services for people who have borderline intellectual functioning. Just because someone's IQ is not within a developmental disability range does not mean they can live independently if they have ASD. I feel like there are no services available for my daughter especially now that she is an adult.

ABA and respite services through Anne Carlsen have been great.

Lack of support for when she transitions and the seclusion going on in the schools, lack of help with funding, more opportunities for her as she gets older, we are moving to Minnesota...

Unclear as to the services that are available as the child enters adulthood and potentially the workforce.

As he's getting older there seems to be less available as he's on the high end of the spectrum. He's been through OT, PT, SLP outside of school is currently in Sanford Behavioral Health which is a huge help, but he still needs assistance with SPD, GAD, ADHD, severe separation anxiety, speech and needs a scribe for school work in class and out also.

The state of North Dakota's service structure for people and families with ASD is confusing and lacks the support and benefits to help with critical issues facing people with ASD and their families. There is a critical lack of support and understanding for providers and families, which these survey questions cannot effectively answer as currently written.

I have read that parent training is a part of autism waiver and now are currently on dd waiver. I have never been offered a training or told how to access training. Have been told crisis training is too expensive for families to receive it. Have been discouraged of using funds since we did not get our items even after following the protocol they told us to use. Also told things are not covered, difficult to access new things.

I wish there was not a wait to access the Autism Waiver/Voucher and ABA services and assessments. Also wish services could be more easily provided in the rural communities (allow reimbursement for time and travel).

Respite staff is hard to find. We lose hours every quarter due to staff. Not enough support for high functioning (Asperger's).

The waiver and ABA services that are available are not very accessible to people in our area, as they are mainly only available in the largest cities in the state.

I am a single mother with a child with Autism, ADHD, and OCD. She has been going to Red Door for therapy but due to my financial situation I have had to cut her therapy. I cannot afford to pay the bill and we do not qualify for any assistance. It is very frustrating for me that I am told I am low income but not low enough. Basically, if I want my child to get anymore services I need to quit my main job and go on welfare which I choose not to do.

Not satisfied at all, there are not enough services available in the state of ND and we need to catch up to other states. We have one center that specializes in daily 24/7 care and therapies for children with special needs/ASD and they are very hard to get into with a waiting list. Cost to families for supplies and supports are expensive, early intervention only goes so far, schools and family need more readily available training and services provided to help with the children.

I don't feel like I know all the tools or services that are available. Besides the ones I get told about or received since early intervention. Otherwise I have no idea which we would like to learn more to educate ourselves and help our daughter.

Not enough slots on ASD waiver. ABA services waitlist unacceptable - urgency of early intervention completely missed by the whole state. Autism level one not supported at all by DD waived services (no child at age three can show how they will end up without services/MA- left up to determination of eligibility committee, not all of which are trained in all levels of ASD and their differing needs). Parents who have worked hard to provide out of pocket services to their children because EARLY INTERVENTION IS IMPORTANT are not provided same access to services because their children are doing "too well." If we hadn't poured all our money and time and emotional labor into our children when they were young, they would be much worse now and certainly "qualify." It is backwards to wait until there is a problem. Invest in ALL children with ALL LEVELS of ASD and you will save money long term. It is beyond problematic to wait until there is a huge gap in skills to acknowledge there is a problem. And then to only prescribe ABA- that no child can access within a years' time in our state. We are failing families and children.

I am very satisfied with the staff that works with my daughter at rehab visions in Dickinson, ND. As well as the kids' program. My only dissatisfaction is how difficult it is to get my child the care and support she needs from these services. Due to expenses, paper work, testing, etc..

Because my child is high functioning and we don't qualify for Medicaid, we don't qualify for services. I even tried to access behavioral support/in home support via self-pay but could not. Instead, I had to hire untrained respite providers and teach them myself.

I just don't really know what's out there. My child's case is mild. I sought a diagnosis when it seemed her issues were being ignored. I think an IEP might be helpful, but I don't know where to start.

I love Red Door services - they were very helpful with both my kids. They helped them with school needs too.

ASD service providers/staff/coordinators are not available for families in our region of the state. ABA service providers are not available for families in our region of the state. Families report they do not receive calls back from the state office when they leave messages regarding ASD services and request a return call. It is difficult for families to access and navigate ASD services and there are limited coordination staff to assist families and staff are only located in the state office in Bismarck. There needs to be more slots for ASD Waiver services. We hear there is always a waiting list.

PCIT and school case worker are the only ASD services. We started seeing pediatric partners for some type of therapy for his sensory and impulse issues.

There is a shortage of providers who will diagnose children with ASD and the waiting list is long especially on the reservations and in the western part of the state. Also, limited social peer groups for children with disabilities to participate in and have typical children be a part of the group.

I think that more information needs to be communicated about the Autism Waivers/Vouchers.

The people that work with my son are I credible from his case manager to early intervention to school teachers to his therapists (speech, OT, ABA). The only issue I have is we were encouraged to apply for the DD Waiver because the Autism Waiver is too hard to qualify for and it is limited to how many people can use its services.

We have to travel 80 miles or more to get services and it is not easy nor affordable to do when both parents work full time jobs.

My son has fallen thru the cracks. In part because I have to work and so often unpacked to get to go to trainings. When he was a kid we were given every reason, he didn't qualify for services. So easier for not to use. Some of the services used didn't go well. The public-school system failed him. I failed my son by not challenging the school system. Such as when the instructor said she would not put herself out there as he spent too much one in restroom. That is one of my Son's issues OCD. Because of how he was treated at the Fargo public library when he got sick once, he won't go back. It's been several years since he last went to the library.

Limited services. Not enough guidance for parents. Feel alone dealing with my son.

All of the services and the people who run them have been amazing.

The 3-5-year-old program was amazing in getting my son the extra attention he needed to have a chance to be at a similar level as his peers! LaShan and Teresa literally worked miracles in my son's life! He is in a normal Kindergarten class at a private school and receives speech 2x/wk... I have however never received the ISP in writing that we sat down for at the beginning of the school year. Fortunately, his teachers go above and beyond with him! I would like help or information on eating/foods- that has been a barrier with starting school as he is so picky in what he will eat.

I have insurance that covers ABA, but no provider. Anne Carlson did offer it and would send a provider out to perform therapy, but the autism program was drastically reduced. Where we live I have zero access to any support. I have to drive 75min to take him to OT and speech.

Respite care is desperately needed with qualified caretakers. My son qualifies for the Autism Voucher, but the respite care is required through an agency. Since he has been injured by respite care workers, I would prefer to be able to choose his caretaker instead of depending on a company to pick who they think would be a good match or use my child as a guinea pig to train their staff on autism needs.

There is a great need for social and peer activities both in schools and in the community. There needs to be more training for teachers and most we have dealt with view this as a behavior/discipline issue and do not have the slightest idea what works--and they are often unwilling to listen to what does work. There are not enough services period. There should be other options than a residential setting for adolescents. The ones we do have in ND are often more punitive than therapeutic and are hundreds of miles from the families' home.

School based supports are below IDEA guidelines with poor openness to change.

What can we do to help our 30-yr. old son with ASD?

I am satisfied with our services right now. However, there is a lack of available professionals for the number of people who need the services. I know that we do not get our hours fulfilled for ABA and sometimes respite on none school days or summer because of the shortage of professionals. I believe this is due to how they are paid for one. I feel like my staff is trained well and works well with my son, but their shortage is an issue.

There are very few quality supports in my area. My son was sent to a school an hour away because even the schools here lack training.

Dissatisfied with access to Autism Waiver and its resources and access to ABA therapy services.

We went to chatter once and are still waiting for a call back for more appointments. It's been months. That's the only place like that in our area for kids that I've heard about.

I was not aware of early intervention. I was made aware of this program through my child's occupational therapist. If I would have known more about that program I most likely would have started my child in early intervention sooner. Also, there were programs available to help finance sensory equipment for my child and I was not made aware of that until much later into his therapy. I wish there was a package for parents that went over all off the resources available for children living with ASD. However, I am currently satisfied with the services my child is now receiving. I only wish I was made aware of the services much earlier on in this process.

We never received full autism waiver services. We also have to drive 100 miles one way for autism psych. therapy

Frustration with how to access supports for the families I work with. If they are not DD it is hard to find services unless they have extreme behaviors. Student under Educational Autism on IEP -Doctor diagnosed him Pragmatic Disorder -under the spectrum; however, does not allow for any supports in the home -behavior concerns.

It seems to take a long time for families to receive services. Some services being provided to families is not evidenced based and could be considered harmful.

When we got my son's diagnosis I had nothing and no one to turn to that could help. It has taken me 5 years to get the support team for him that I have in place now. Reading these questions, I have no idea where to get info on the ASD services or support information. I have researched my stuff online.

Shouldn't be a cut off for age limit. Need more support for adults who have transitioned from school but continue to need support.

I wish that this state offered more, I was born and raised here having my child have all the services that could be available to him and others here would be an amazing asset to have, one state away they have Autism schools where our children can go to ABA classes 8 hrs. a day vs mainstream school. There are states one state away where Medical Cannabis is available to them, but here we can't give our kids much, I am happy with his therapists that he does have and the teachers he has, but I wish there was more here.

We have not been aware of any of these tools or services that are available since our son has been diagnosed with Autism and was placed in a facility for about 6 months and the school is now again asking for placement.

There is a gap in services for children that are low functioning with a diagnosis of ASD and other mental health disorders. It has been my experience as a mental health professional that their mental health diagnosis tends to disqualify them for developmental disabilities services regardless of them being lower functioning and struggling with the cognitive ability to make lasting change in their behaviors. Region 2 needs more community-based services for children with autism and challenging behaviors.

Lack of diagnostic evaluations with long wait lists.

Need for early diagnosis and in-home services, especially in rural areas.

We have access to services, but understanding what services are available and to get the services seems very confusing and convoluted.

Do not have enough availability for ABA, in-home family therapy, social skills groups, family support groups. Some of what is available has very limited accessibility.

Due to high intellect, services are being disallowed from school to case management although need for support in emotional/social/financial is substantial.

The school is very supportive in sending professionals to train on ASD.

I feel I could use more training with these services to benefit my 2 daycare children in my care.

Not a lot of services in Williston and not many programs as not all meet our criteria for eligibility.

lack of access to early diagnosis, in home supports, behavioral/mental health support in schools both in urban, but especially rural areas, and critical shortages in SW corner of the state.

ND autism center is a great idea but follow through on their part and their ability to work with families is not good and needs extreme improvement.

The waiting list is long; the amount of time it takes to get services is unbelievable for families. And most of the services are basically ABA related, and do not incorporate adequate sensorimotor, or social opportunities.

As a new member to the community and state (within the last year), it has been really hard to figure out what supports are available and how to get them for my son. He has an awesome case worker and she's really helped us, but there's so much out there, we still feel lost.

Are there support groups available? Could a program be set up in schools/communities that function somewhat like 'Big Brother/Big Sister.' I believe there are lots of middle school/high school kids that would 'mentor' an autistic classmate if they were educated?!

I'm not aware of some of the services mentioned in this survey, so left them blank (because a "no" wasn't right because maybe I do have access?). There is a tremendous shortage of qualified, experienced professionals right now to meet the demand now that more services are being allowed/reimbursed.

For us, it's been fairly easy to navigate services as we have been able to access a DDPM. Others have not been so lucky. However, through some meetings, we find out about other services we did not know about such as Able accounts. So, we sometimes miss out on important things.

There is an underservice in Fargo-Moorhead for evaluating, diagnosing and referring those with ASD to effective and appropriate intervention services. There is an underservice of evidence-based practice for intervention for children with ASD such as ABA based services.

I do not work with children, I work with adults.

The new payment system in ND has caused several people to not be able to work as much as before.

no one has offered ASD services. I don't know what is available in the state and there is no coordination of programming/services in the state.

It seems like our young adult with autism doesn't not qualify for services, either due to family income or because she is living at home. I should not have to put my child in a situation she is unprepared to handle, in order for her to qualify for services.

Very limited to no services available in Minot. Social group settings for kid with autism and needing social help is very difficult and expensive to find.

The services I need aren't easily obtainable. It's extremely heartbreaking to not be able to balance work when my child has therapy multiple days a week and I have to choose between work or forced into staying home to ensure my child gets to speech and OT.

Families that I have worked with report that there are no service providers in their area, no staff to provide respite services, no ABA therapy without traveling a great distance and with their location, and the children being in school it is not feasible to travel that far for therapy. The schools do not have the resources to provide these students with the services/supports they need for their school experience to be successful. These kids are falling through the cracks.

Very little training and limited resources on ASD.

I think there is poor training for staff members that are hired for respite care/direct support.

Need more options for work vs. school.

Services are so limited in the state. My concern is that so often there is nobody to refer families to, especially in rural areas. In some areas, the only service available is service management, for example. This does not meet the most significant needs of the family most of the time. It's also frustrating when there is only one provider in an area of the state. This doesn't provide for families to make a choice of available options.

We've only had ABA available for less than a year after years on the waiting list, but it is worth the wait - our child is making good progress. I need to ask if they could train me in some of their techniques, it's been a very long time since I borrowed some old training videos. I chose "not satisfied" because of the waiting list - my son waited ten years, and I know plenty of people are still waiting.

I have been trying to get the school to help me find accommodations or ways to help him and us manage his ADHD diagnosis since he was 10 years old. We've been to doctors, psychology and even a psychiatrist. We even tried working with an advocate and all of them would tell what to do but none of them participated in assistance to accomplish anything. Only to find out after he was referred to Neuro psychologist that he has High Function ASD. Now that he's 17 and will be a senior next year. The school only offers vocational I repent living education. He's been talking online computer classes. One class wasn't offered during second semester, so he sat in first period class with the librarian until it took them over 2 weeks before they found a comparable class, which isn't completed until three weeks after

everyone else. My son has slipped through every crack one could imagine. My biggest mistake was relocating to a smaller town thinking the calmer it would be for my kids. He was only diagnosed the end of third grade with no plans in place for treatment and putting too much faith in others to provide documents therefore feeling like they thought I was crazy.

Even when funding is available, there are not enough services to provide easy access and parents don't have a choice of ABA or the 27 other strategies out there that have been shown to be effective, especially with high functioning autism/Asperger's.

When I can find assistance, it has been good.

Anne Carlsen have done a very nice job of working with our daughter and communicating well with us as parents.

I have two adult sons on the autism spectrum that have fallen through the cracks.

Having an educator or provider able to individualize and use evidence-based practices is still hard to find. Also, access to board-certified behavior specialists remains very low for our state.

North Dakota only recently required health insurance coverage of ASD services so the capacity to provide more service needs to increase and is still developing.

Metro area, big teams, services available.

Do parents have the necessary information provided to them at the time of ASD diagnosis? I find that parents are often confused as to what services are available, beyond school base services.

Services are hard to find.

The autism waiver is very confusing. It is difficult for me to know who to contact and how to get started. Information in brochures and handouts about the waiver is not clear. There should be an accessible list of providers who I can contact who provide the services available on the waiver. Other information and resources on ASD are good.

Families in our region, especially in the more remote location are not getting any services due to their location. They have not had consistent service providers in the past and when they did most of the families I either previously or currently work with said their staff did not consistently show up and when they did all they did was play with Legos. These families do not have access to ABA therapy due to their location and are unable to travel and hour or more to get to the nearest location that does offer the service. I have had a few kiddos that were on the ASD waiver who terminated the service and switch back to DDPM services to obtain referral to a children's group home due to the lack of support and available service options in their area. The parent felt that she has no other options to try and keep her kids in their home at this time.

I am satisfied as a parent with the services that we have been able to utilize throughout my son's life. He was in need and may again need ABA therapy, so it is a relief that it is now covered, that was a financial hurdle for us to get over but was necessary for our son and our family's quality of life.

As an autism parent I have never been informed about any services that may be available to use.

We used applied behavioral analysis for our son starting at age 3 1/2. We felt he made gains both in behavior and language during this intensive program. It was difficult to maintain throughout the years with so many educators and people interacting with different philosophies -not familiar with the techniques or training. Expensive to train everyone and impractical. So many different approaches and levels of expectations make life confusing for these kids.

Families need more options for ABA therapy. They have been approved but current providers don't have enough staff. Family are on a waiting list as they struggle with their child.

A lot of services that are out there we cannot get for our daughter. We make too much money by \$200 dollars to qualify for any assistance or aid. So whatever therapy we do have her in, we pay for. We have gone into serious debt paying for services for her. I cannot afford to quit my job, and that is what we need to be doing for her. But most likely would still not qualify for any aid for her. We never looked into assistance until almost 2 years ago. It is extremely disheartening that the things that she needs we cannot afford, or get help to put her in. We do not want to live off of the government, just would like some help to make her life as good as we can. It is taking a toll on me physically and mentally since I am the primary care giver for her. I love her, and just wish things were easier for her.

Insurance many times limits # of therapy visits. Such as Occupational, Speech, and Physical Therapy. Or it is broken down into for example 30 each calendar year. Well 39 visits aren't even 1 per week. Many kids such as mine needed weekly visits and some more. I would like to see specific caps removed from types of therapies and leave it broader like 90 therapy visits and then you choose the one that best suits the child. My son didn't need Speech. But he needed more OT visits. We ran out at 30 and had to quit because of no coverage. We started over the beginning of next year. That was a challenge having to re-acclimate him to the environment and start over. I would also like the option to choose how much therapy my son gets. I applied for waiver. I need help with things, but the requirements seem to be much more than what we needed. I didn't want a stranger in my home that much during the week doing respite.

Services for adults on the spectrum are non-existent.

The resources I have are online which everyone has access to. There isn't a formal support group in my area for parents of children with ASD. There aren't any actual services that I am aware of. We have direct providers (OT) and within our school (IEP) otherwise I feel on my own to find information. Family Voices has offered some trainings (not specific to autism) but I have figured this out on my own.

There is no psychiatric hospital for an Autistic 9-year old to go to when they need help in Fargo. There is no financial help for parents struggling to keep a job when they have to run them to appointments or go get them from school when behaviors get bad.

Employment services are only provided if the person has a funding source for ongoing supported employment. If the person does not qualify for Medicaid because medical recipient liability is too high, the person cannot access assistance in independent living, employment, and the list goes on. Basically, there is no services available. Pretty sad.

Very limited adaptive summer social activities or outside of school activities. Limited adaptive sports.

We have such limited resources in our region as our families have to travel to get ABA services and any interventions. There is not any service providers in our area. Regarding respite care, our service agencies have limited respite workers in our area to provide the service needed for families in our area. (Region III).

Behavioral support/ respite care is very hard to access in more rural areas. The families are often asked to drive to a larger populated area to seek services which in most cases is not financially possible. The service providers are not willing to travel which means a lot of families struggling with behavioral issues are left to struggle. The school services alone are not enough to help them at home or with daily living skills/transition problems.

My son does not qualify for any help for needed services though he has an ASD diagnosis. He needs OT and speech and we must pay out of pocket until we reach our high deductible. This means that instead of saving money or taking our family on small trips, or allowing our kids to be in extracurricular activities, we pay for therapy that he needs. This is a hardship on us even though with both parents working fulltime, we cannot do the things a middle-class family like ours worked so hard for. If he hadn't received these

services (that we paid for) he would be worse off and would likely then qualify. Why do we wait until children and families are drowning before offering help?

Fargo seems to offer many different support services for kids with ASD and if we want to sue any of these services to include therapies/social events/exercise options we have to commute or move.

My son is diagnosed with autism once known as Asperger's. He does not qualify nor has ever qualified for services because he's considered too high functioning. We have never had respite or other services available to us. I was for years afraid to leave my house because of the possible destruction to person or property due to a meltdown my other children may have caused. How my marriage survived is a miracle. Now that he is 15 the behaviors aren't as severe however I worry about his transition out of high school as he refuses to learn any of the skill necessary to take care of oneself i.e. laundry, cooking, driving, etc.

Parents need to be encouraged to use services. They don't bother.

We live in Watford City and services are nonexistent for people with autism. No access to OT/SLPs. We may be relocating because we need to get our child help.

Autism services are minimum in our community. I hope we may network to have autism services available for our community.

The DDPM services offered are very different between regions. GF, DL, & Fargo programs do not seem to be the same. It's like having to start over explaining to them what families need from them even when on referral the services listed come straight from the DHS website. There seems to be a real negative bias towards the families who reside/are living in tribal areas. DDPM do not seem to know what services they can or cannot offer and again, there is a real discrepancy between DL, Fargo and Grand Forks offices. When a referral is made, the referring agency is never contacted about who the DDPM will be for the family or what the status of the referral is. The DDPM do not seem to be in agreement that with the waiting list for the ASD waiver, they are to be helping family until they can get on waiver. No meetings being held between DHS and service providers in their areas so real disconnect. When changes to local programs made and DHS/DDPM supervisors are updated they do not seem to hand down the information to their employees. Very frustrating for providers. DDPM do not seem to offer or inform families of all services they can and should be contact for if family in need. Seems more training and communication needed. Never see DHS staff at the state autism conferences which is such a disservice to those families whose region do not attend.

There are no services available to help with school issues and so my son is seen as an unruly juvenile and gets thrown into the court system. I do lots of research and use zones of regulation and lots of distressing with scents, massage and music.

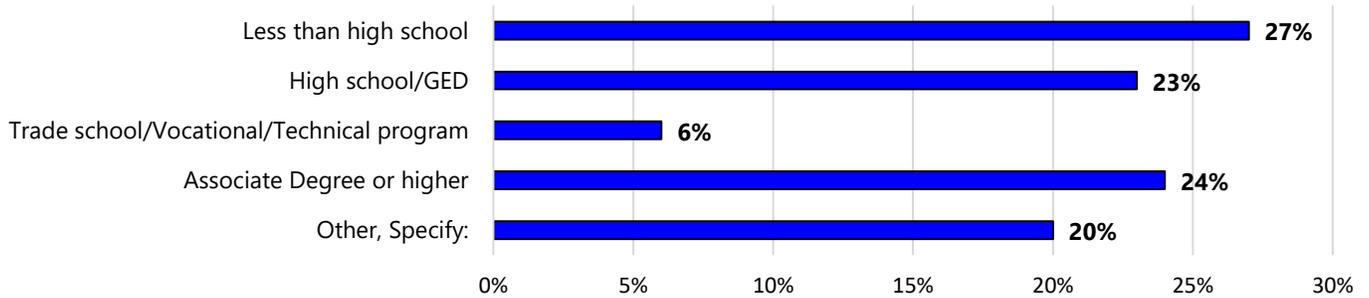
I can request further information about services and always told that there is a wait list and it will take several months.

No services.

I find services to be readily available when requested.

The following survey questions were answered by adults diagnosed with ASD or completed by the parents/guardians of an adult diagnosed with ASD.

What is the highest level of education you have completed?



N=102

Other, Specify:

Masters.

I'm in Middle School.

I'm the parent and my son is 15 yrs. old and a sophomore.

Child is 5 yrs. Old.

Some college, mom; pre-k at head start, son.

Some college.

Elementary.

MD.

BSA in Electrical Engineering.

Bachelor's Degrees.

Bachelors.

Kid with autism, not an adult.

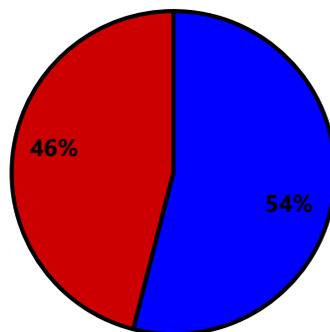
MBA.

Some college but did not graduate.

BS degree.

BSW.

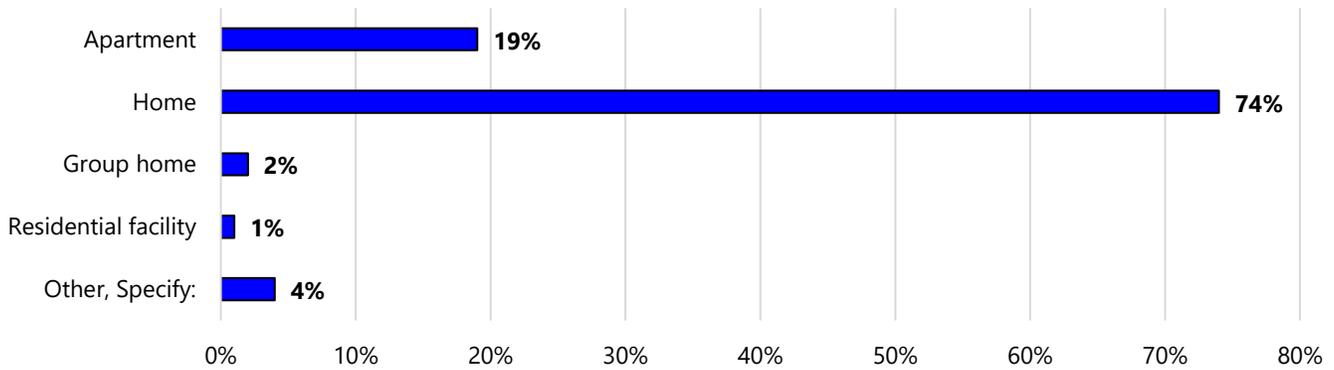
Are you currently attending school?



■ Yes ■ No

N=104

In what type of housing do you currently live?



N=103

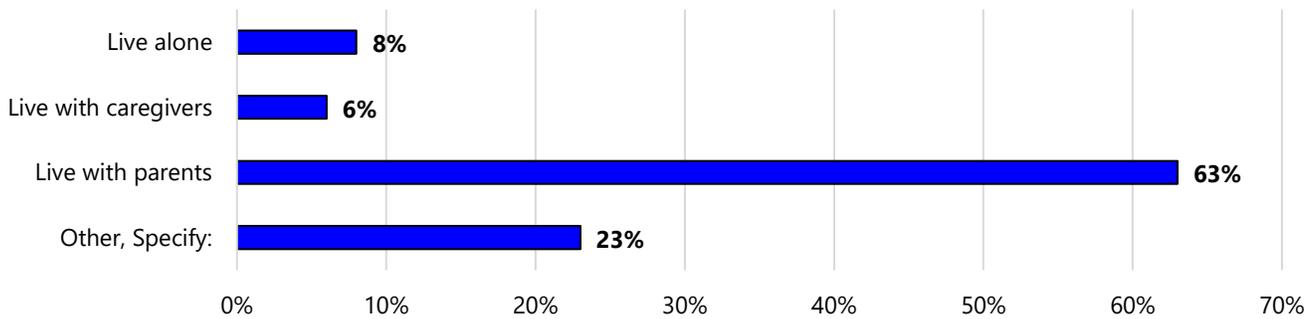
Other, Specify:

- Rent from a private owner.

- Dorm.

- Trailer.

What is your current living arrangement?



N=101

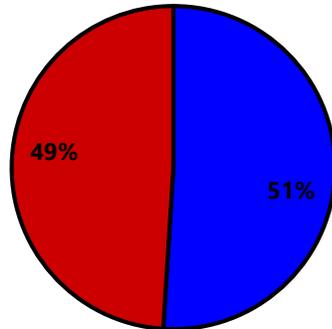
Other, Specify:

- | | |
|--|--|
| <ul style="list-style-type: none"> 1 on 1: 24/7. <hr/> I have child and husband with autism in my home. <hr/> ASD child lives with parent. <hr/> Live with wife and 3 kids. <hr/> With spouse and children. <hr/> Provo Canyon residential treatment. <hr/> Myself and my two children. <hr/> Dorm. <hr/> Live with family. | <ul style="list-style-type: none"> Husband and I, plus 3 kids. <hr/> My child and myself. <hr/> Live with girlfriend and baby. <hr/> Spouse and children (the fact that this isn't even an option is concerning about biases around autistic individuals). <hr/> Married living with wife. <hr/> Live with wife and child. <hr/> Spouse and children. <hr/> Lives with grandparents. |
|--|--|

Live with my husband.
Live with my husband and children.
Guardian.

Live with spouse and son.
Parent of child with autism. Married.

Are you currently employed?



■ Yes ■ No

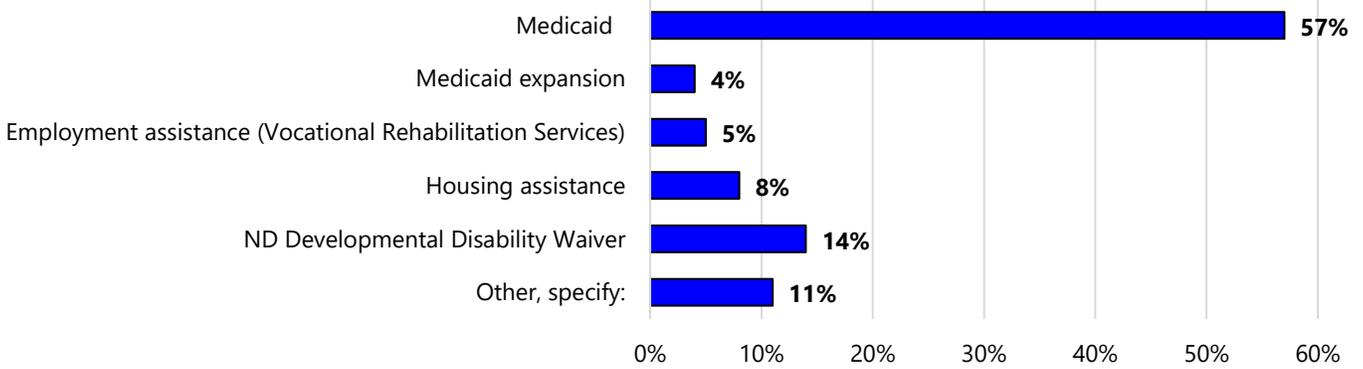
N=101

What is your hourly rate of pay?

\$10.00	\$0.00
Above minimum	\$27/hr. +SSDI
\$14.00	\$28.00
\$88,000/ year	As of this year, \$10.00-only works three to four hrs. per day
\$50 per hour	\$12.00
\$20.75	\$25.00
\$0.00	\$8.00
\$0.00	Student
\$75,000 per year	\$21.00
\$9.00	\$30/ hr.
\$34.39	\$16.00
\$1.00/hr. through Bismarck Public Schools Program	\$50/hr.
\$16	\$32.00
\$0.00	\$0.00
\$12.00	\$9.50
0. He's 5	\$27.00
She is only 15!	\$10.00 per hour
\$11.35	\$30/hr.

Piecemeal	\$25.00
\$14.00	\$0.00
\$0.00	\$0.00

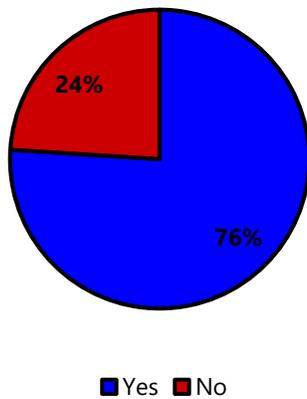
Do you currently receive any of the following? (Check all that apply)



Other, specify:

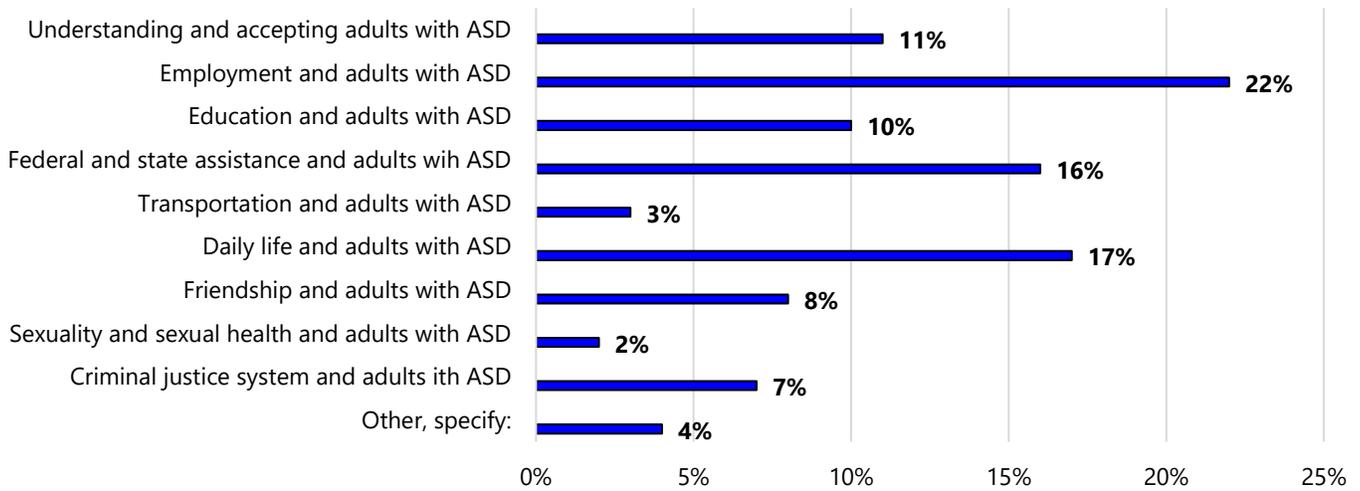
- The income cutoff and child's IQ disqualify all of this.
- Only Medicaid for child through DD waiver.
- Tricare.
- SSA.
- Respite aid.
- Only my 1 child qualifies.
- Snap and autism voucher.
- None.
- None.
- SSI.

Do you have private health insurance?



N=101

The ND ASD Task Force has developed this survey so that people better understand challenges faced by adults with ASD. Please select the top three topics that you find most important:



Other, specify:

ASD child.

Having doctors who are willing to look for medical explanations for some of the issues our children face...not everything is "just autism"... especially when a problem is not a symptom of autism (such as sleep issues) it shouldn't be said that it's "just autism" when it's not even a diagnostic criterion of the disorder.

Not sure, my son is 4. All of that is important, but we are trying to figure out now.

This says top 3: all the above are important! Without friends to support & understand them they are more at risk for depression & mental health issues. They need help to get around to jobs/education opportunities. They need more education on sexuality because people with special needs are at increased risk to be sexually assaulted or taken advantage of & in many cases by someone they know & trust. Every aspect of their daily life is affected by having ASD.

Diet, exercise, healthy choices, obtaining driver's license.

All of the above I find very important. Can't narrow down to only 3.

My 8-year-old son has autism.

Having gatekeepers training in positive, neuro-diverse strategies and belief systems.