EXAUTISM SOCIETY Improving the Lives of All Affected by Autism Wisconsin

Autism in Wisconsin 2017 Report



ACKNOWLEDGEMENTS

The 2017 Report is a publication of the Autism Society of Wisconsin. We are grateful to the members of the Autism Society of Wisconsin Program Services Committee who contributed to the design of the survey and analysis of the open ended survey questions. A special thank you to the Treffert Center for their assistance with data analysis. We are also extremely grateful to the individuals with autism, parents/caregivers, and professionals who took time to provide their thoughts and experiences by participating in the survey.



"Everyone has heard of autism now. Now we need education about how it affects those without autism and how to interact appropriately, or understand the social cues."

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INTRODUCTION

At the time of the survey, the prevalence of autism was estimated to be about 1 in 92 in Wisconsin and 1 in 68 nationally. Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) showed that even though ASD can be diagnosed as early as 2 years, about half of children were diagnosed with ASD by age 4 years and 2 months. Boys were 4.2 times more likely to be identified than girls and white children were more likely to be identified with ASD than black or Hispanic children.

The purpose of the Autism in Wisconsin survey was to collect and compile data on the experiences of people affected by autism in Wisconsin to 1) influence Autism Society programming priorities 2) influence policies and legislation 3) document how experiences and attitudes change over time. As this was the first survey done, the data collected here will serve as a baseline for future surveys.

Individuals with autism, parents/caregivers, and professionals who work with individuals with autism were invited to participate in the survey. All survey respondents were entered into a drawing to win a \$50 Amazon gift card. The survey received 1,011 total responses, of which 780 were complete responses.

The survey included a mix of multiple choice, rating scale, and short answer questions.

DATA COLLECTION

The survey was conducted from April 7, 2016 through June 13, 2016. Collection methods included a link in Autism Society of Wisconsin Annual Conference app, Facebook posts, emails, and requests to local affiliates and other autism-related partners to distribute among their networks.

Methods:

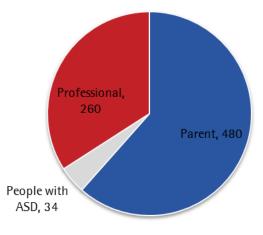
- 59% of responses came directly from Autism Society of Wisconsin email requests
- 28% of responses were a result of partner email requests (Community of Practice on ASD/DD)
- 5% of responses were from Autism Society of Wisconsin Facebook page
- 5% of responses came from local Affiliates sharing the survey link
- 3% of responses were from Autism Society of Wisconsin website

"Professionals do no not understand anything about autism in adults, especially those with Aspergers. I can only think of one therapist who "gets it," but she does not take my insurance. We (adults) need services, not just children."

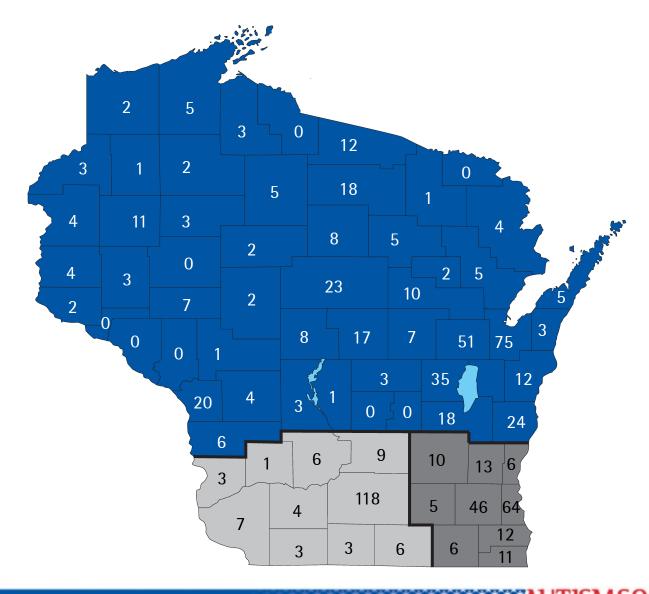
DEMOGRAPHICS

Of the 780 complete responses, 4% were completed by individuals with autism, 62% were parents/caregivers of those with autism, and 34% were from professionals that work with those affected by autism.

Eleven percent (11%) of the respondents identified as male, 87% as female, and 1% as transgender, agender or gender Q.

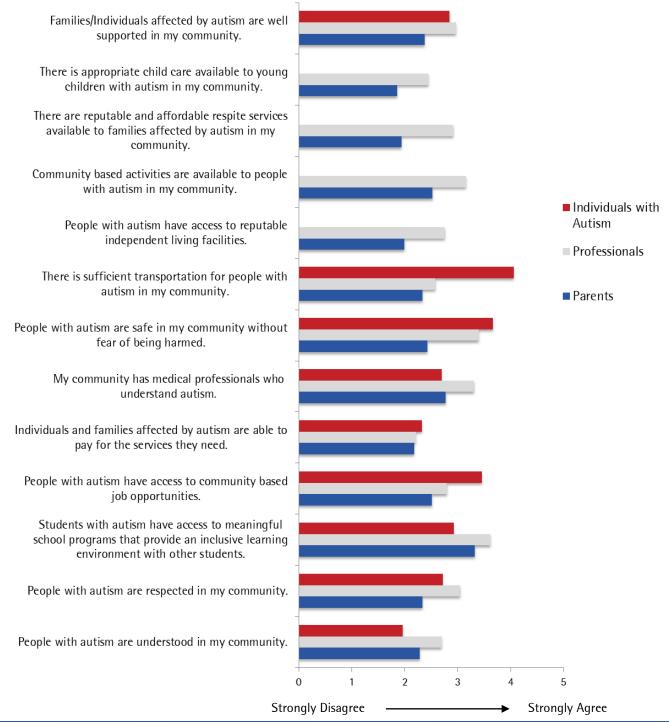


Geographical Representation of Survey Respondents



AUTISM IN WISCONSIN TODAY

The survey asked participants to respond to the statements below by rating how well they agreed with the statement. Respondents had the option of choosing Strongly Disagree (1), Disagree (2), Agree (4) or Strongly Agree (5). Individuals with autism were not asked about either respite care or childcare. Instead of asking individuals with autism generally if people with autism have access to independent living facilities, the survey asked more specific questions about their living situation, which is reported on page 16.



WHAT TYPES OF SERVICES DO YOU FEEL ARE MOST LACKING FROM YOUR COMMUNITY?

All groups that took the survey were asked what types of services are most lacking from their community. We received 714 answers to this question. This was one of two open ended survey questions.

1. Adult Services | 32%

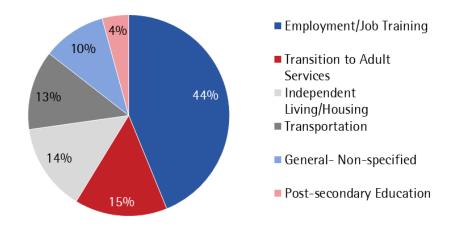
2. Caregiver/Parent Support | 27%

- 3. Access to Quality Treatment & Therapy | 22%
- 4. Social Opportunities/Peer Support | 19%
 - 5. Community Awareness, Acceptance and Inclusion | 11%
 - 6. Trained Professionals | 9%
 - 7. Quality Educational Services | 7%
 - 8. Financial Support | 3%

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ADULT SERVICES

The most common answer to this question was related to adult services, with 232 or 32% of respondents with an answer that fell in this category. Of those that indicated adult services were most lacking, 44% of those specifically mentioned employment or job training, 15% mentioned transition to adult services and 14% mentioned independent living or housing services. Other common answers were transportation and post-secondary opportunities services.



"Although individuals on the spectrum continue to develop through 20's, there is a relative scarcity of meaningful programming for young ASD adults."

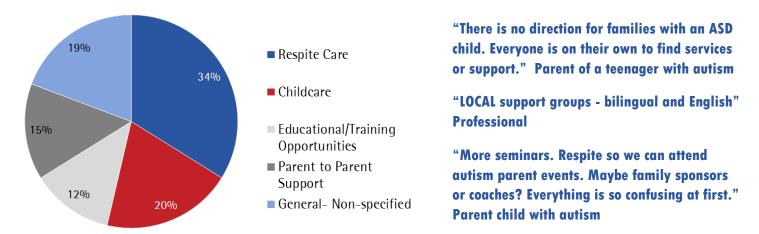
"Resources for adults who were not diagnosed as children, but should have been." Person with Autism

"Transition services from High School to independence." Parent of an Adult with Autism

"Job opportunities will likely be our biggest challenge once our child reaches adulthood." Parent of 0-12 year old

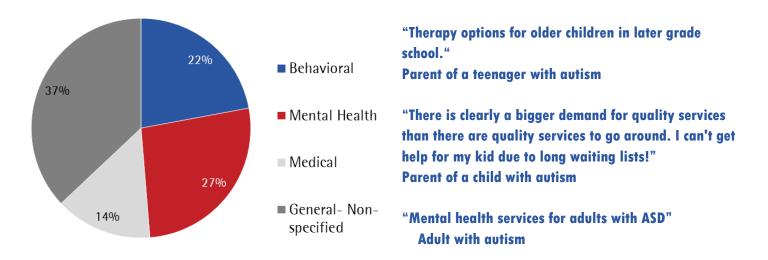
2 CAREGIVER/PARENT SUPPORT SERVICES

The next most common response, with 192 or 27% of responses, indicated a need for caregiver/parent support services. Of the 192 responses, 65 (34%) specifically mentioned a lack of respite care, 38 (20%) mentioned a lack of childcare for children on the spectrum, 28 (15%) wrote about a lack of parent support groups/ opportunities, and 26 (12%) discussed a lack of autism-related educational opportunities for parents and caregivers. The other 39 (19%) were general and did not specify a particular kind of caregiver/parent support service.



ACCESS TO QUALITY THERAPY & TREATMENT

One-hundred and sixty (160) or 22% of total responses to the question of what services are most lacking discussed a lack of access to quality therapy or treatment. Of those, 27% specified mental health treatment, 22% specified behavioral treatment, 14% specified medical treatment, and the other 37% did not specify a type of therapy or treatment.



4 SOCIAL OPPORTUNITIES/PEER SUPPORT/RECREATIONAL ACTIVITIES

Nineteen percent (19%) or 131 of total responses indicated a lack of social opportunities, peer supports or recreational activities for children, teen and/or adults with autism.

"Services for adults and opportunities to interact with others who are similar to myself." Person with autism

"Any services which would help alleviate the isolation, loneliness and despair our son experiences daily." Parent/Caregiver of an adult with autism

"Recreation/community activities with neurotypical kids and instructors who can work with a child who has autism." Parent/Caregiver of child with autism

5 COMMUNITY AWARENESS, ACCEPTANCE & INCLUSION

Eleven percent (78) of those taking the survey mentioned a lack of community awareness, acceptance and/or inclusion in their answer to this question. These types of answers included mention of the need for more sensory friendly environments, better inclusion supports across all community settings, and the need for better community understanding and acceptance of autism.

"Inclusion supports across all community settings." Parent/Caregiver of a teenager with autism

"Education that 3/4 of the spectrum does not look like Rainman. Quiet spaces to decompress at public buildings and events." Person with Autism

"Acceptance campaigns that are not based in fear." Parent/Caregiver of child with autism

"Keep trying to inform people - people who are directly affected and those who are not. I know awareness has increased a LOT in the past decade or so, and my hope is that if this keeps increasing as quickly as it has been, there will be more providers, resources, and community support. I found that even though there is more knowledge available about what autism is, information to take me beyond those basics (where to go for a diagnosis, treatment options, support groups, etc) was REALLY lacking, at least where I live (Sheboygan County)."



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6 TRAINED PROFESSIONALS

Nine percent (62) of the answers to this question indicated a need for more trained professionals who understand the autism spectrum and are trained to support those affected by autism. Examples included educators/para-educators, therapy staff, medical providers, counselors, law enforcement, among others.

"I think all educators need to have a better understanding of ASD." Parent/Caregiver of teenager with autism

"Trained, caring, trusted personal care workers knowledgeable about individuals with ASD." Parent/Caregiver of an adult with autism

"Educate the police about Autism" Person with autism

QUALITY EDUCATIONAL SERVICES

Seven percent (49) of those taking the survey mentioned quality educational services as the type of service most lacking from their community.

"Specialized care at the school district level. The special education program seems to be geared more towards maintenance (call it public childcare) rather than working to let my son grow towards who he is and what he can do. The focus is rather limited to pacifying him and ensuring he doesn't interfere with the other children's educational needs." Parent/Caregiver of child with autism

"Understanding from school districts on ASD & getting them to realize if they'd take the time to learn more, it would help them w/all students." Parent/Caregiver of teenager with autism

8 FINANCIAL SUPPORT

Three percent (21) of those who took the survey mentioned the need for better financial support for individuals and families affected by autism.

"Accessibility to sufficient funding opportunities." Parent/Caregiver of child with autism

"More funding to help pay for treatment." Parent/Caregiver of child with autism

PLEASE LIST THE TOP 3 CHALLENGES FACED BY INDIVIDUALS AND FAMILES AFFECTED BY AUTISM

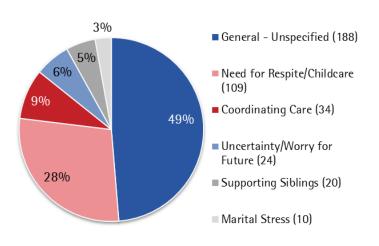
All groups that took the survey were asked to list the top three challenges facing individuals and families affected by autism. We received 749 answers to this question. This was the second of two open ended survey questions.

- 1. Stress/Need for Support | 52%
- 2. Accessing Services | 41%
- 3. Lack of Community Acceptance, Understanding & Inclusion | 34%
- 4. Lack of Adult Services | 30%
- 5. Issues with Educational System | 27%
- 6. Social Challenges | 26%

STRESS/NEED FOR SUPPORT

The most frequent answer to this question was in regards to individual, family, or caregiver stress and the need for more support. Fifty-two (52%) percent of all respondents listed this as a challenge and this answer accounted for 18% of all challenges reported. As the graph shows, 28% of the answers falling in this category were categorized as a need for more support in the form of better respite or childcare options, 9% discussed the

- 7. Financial Stress | 25%
- 8. Behavioral Support | 24%
- 9. Lack of Quality Providers & Professionals | 15%
- 10. Challenges Receiving Diagnosis | 5%
- 11. Mental Health Services | 5%



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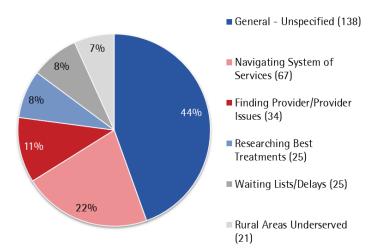
difficulties in coordinating care/appointments, 6% mentioned a worry and uncertainty for the future, 5% discussed the need for supporting siblings of children with autism as a challenge, 3% cited marital stress, and the other 49% answered generally about stress and/or the need for better support.

"Feeling isolated and alone because former friends don't understand what our family is going through."

- "Inability to support self due to complex paperwork."
- "Extreme parental fatigue and stress prior to receiving support services."
- "Juggling job, family responsibilities & therapy/treatment is a huge struggle."
- "Questioning what we need to worry about next."
- "Coordination of care/goals between school/providers."
- "Affordable, trustworthy respite we have no family in the area."
- "High degree of marital discord or disengagement; overall family stress."

2 ACCESSING SERVICES

The second most frequently listed challenge was accessing services. Forty-one (41%) percent of all respondents listed this as a challenge, while it accounted for 15% of all challenges reported. Twenty-two percent of the answers in this category pointed to the challenges of navigating the service system and understanding what was available to their family, 11% discussed difficulty finding specific providers or having issues with providers, 8% of answers reflected waiting lists and delays, and 7% about difficult finding services in rural areas.



"Finding resources. Yes, a lot of information was eventually given to us but only after asking around or stumbling on the right person."

"No providers of Medicaid funded Behavioral Focused Treatment."

"Too many hoops to jump through to find services & care."

"We as parents have to do all of the research ourselves...we have no one to go to. Pediatricians are not experts. We have to seek out the treatments and specialized Doctors around the world that can help our kids."

"Knowing what your child needs but put on a wait list to receive those needs. Example: ABA waiver we waited 3 and a half years"

"Rural families do not have resources or access to professionals."

"The hardest thing for me right now is that I fit right in the gap between people with disabilities and people without disabilities. That makes socializing with people and trying to get into a relationship difficult. I have tried joining many groups with people with disabilities, but in most of them I have a hard time connecting with the participants because my situation is so different."



3 LACK OF COMMUNITY ACCEPTANCE, UNDERTANDING & INCLUSION

Thirty-four (34%) of all respondents mentioned challenges and difficulty related to community acceptance, understanding, and inclusion. Many individuals with autism and their families reported discrimination, being misunderstood and/or not being included or feeling welcome at community events and activities.

"Misinformation by family and community about autism."

"The general public does not understand or even recognize when there is a problem, that it might be anything more than bad parenting, rotten kid, or misbehaving."

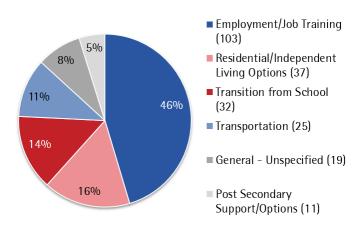
"Feeling welcome everywhere."

- "Having others in the community understand the unique needs of people on the autism spectrum."
- "Respect and understanding from a majority of community members."

"People think you just need to 'try harder' to be sociable instead of accepting I am not made that way."

4 ADULT SERVICES

Challenges related to adult services were the fourth most common answer. Thirty percent (30%) of all respondents mentioned challenges relating to adult services and 15% of the total challenges listed were related to adult services. In this category, employment and job training challenges were most frequent, making up for 46% of the answers. Residential/independent living options challenges accounted for 16% of answers in this category and transition from high school as a



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challenge accounted for 14% of answers. Challenges in transportation and post secondary support were also mentioned.

"After my two children were diagnosed, I realized that I am likely on the spectrum. I reached out to people involved in my children's treatment, but they didn't know of any resources for adults."

"Lack of employers to connect with that are willing to take a chance and hire a person with autism (focusing on their abilities instead of their autism)."

"Job training other than sheltered workshops."

"Lack of transition to adult care clinicians."

"Inadequate public transportation. The buses stop running early on Saturdays and do not run at all on Sundays. Many places he'd like to go are not on a bus route. This factors limit his ability to have a social life and attend church."

"Underemployed and underpayed."

"Getting information on how to help him in the future as he becomes an adult."

5 EDUCATIONAL SYSTEM

Twenty-seven percent (27%) of all respondents mentioned issues within the educational system as one of the top three challenges facing individuals and families affected by autism. These answers also accounted for 9% of total challenges listed. Many of the challenges related to the educational system were related to either the IEP process and/or lack of appropriate school programming for children and youth with autism.

- "School- defining "least restrictive" environment for my child. The district and I disagree."
- "Educational & emotional support at school fighting for services in a system stretched too thin."
- "School telling me they couldn't meet his needs and sending him home everyday."
- "Schools that understand autism as diversity."
- "Understanding parent rights and student rights in the schools."



"More autism programs are needed to help children pursue their passions and amplify their strengths at their own pace and in sensory appropriate environments."

SOCIAL CHALLENGES

Social challenges were listed by 26% of respondents and accounted for 9% of all challenges listed. Many answers in this categories discussed isolation of both individuals and families affected by autism, lack of meaningful social opportunities, the need for more social skills classes and training, and bullying as challenges.

- "Isolation/ finding support group that works with our schedule."
- "Making friends and doing things outside of school with them."
- "Limited options/time for family members to socialize."
- "Isolation socially from other parents/families."
- "My son is socially isolated despite his and our best efforts."
- "Finding social events/programs accepting of/willing to work with."
- "School bullying by teachers and students."
- "No groups that provide skills training, like social skills."

FINANCIAL STRESS

A quarter (25%) of all those who responded to the survey mentioned financial stress as one of the top three challenges, and this accounted for 8% of all challenges listed.

"Paying for treatment (copays) and other necessities that come with a diagnosis."

"One income home due to full time treatment schedule."

"Trying to get grandson help and services denied by insurance and MA."

"Funding for those kids that don't qualify for services if they are higher functioning."

"Insurance issues....especially finding services that cover what our child needs and/or what would be convenient for our family and affordable."

"Lack of access of funding for autism services that are done in normal community settings like child care centers or after school programs."

8 BEHAVIORAL SUPPORT

Twenty-four percent of those who took the survey responded that one of the biggest challenges facing individuals and families affected by autism was lack of support with behaviors. These answers accounted for 8% of all challenges listed in the survey. Respondents reported challenges with understanding and/or managing behaviors, accessing behavioral support, and safety concerns.

"Limited behavioral supports when my son had major incidents at home."

"Dealing with my son's meltdowns, both figuring out what triggered them and how to keep him and others safe."

9 LACK OF QUALITY PROVIDERS/PROFESSIONALS

Fifteen percent of respondents reported a lack of quality providers or professionals as one of the top three challenges and this answer accounted for 5% of total challenges listed. Providers and professionals specifically mentioned were medical professionals, mental health providers, caregivers, teachers and behavioral health professionals, among others.

"Lack/shortage of professional providers."

"Access to health professionals that had knowledge of autism or how to provide services for us (we needed to educate ourselves before appointments)."

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"Finding doctors/providers trained with/know autism."

"Finding a local counselor who acknowledges ASD in adults."

10 DIAGNOSIS

Five percent of respondents mentioned diagnosis related challenges and this accounted for 2% of the total challenges listed. Diagnosis related challenges included difficulty getting an autism diagnosis, getting an autism diagnosis too late, receiving the wrong diagnosis, and challenges related to receiving dual diagnoses.

"Unrecognized diagnosis/Falsely - ADD/ADHD."

"Dual diagnosis of autism/down syndrome, diagnosed later in life though highly suspicious while he was growing up. Hence services are poor. D/N fit in with Down Syndrome or autism."

"My son was diagnosed with autism at age 9. Therefore he was too old to receive help from the Katie Beckett program."

"Lack of rural area diagnosticians."

MENTAL HEALTH

Five percent of respondents mentioned accessing mental health services as one of the top 3 challenges facing families and individuals with autism. Mental health challenges were listed in 2% of the total challenges.

"Finding mental health services."

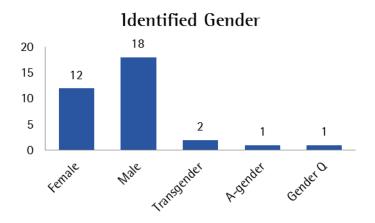
"Support for underlying issues including mental health concerns, trauma, etc."

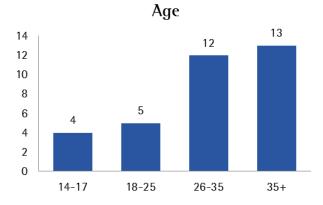
"Day to day struggles related to autism and other mental health disorders."

"The 18+ aged individuals need programs/supports for college and partnerships with businesses/ professionals to place them in meaningful jobs to the level of their ability. They also need health care professionals who are knowledgeable about ASDs and can treat/counsel them. They need a louder voice advocating for them. They need hope for a fulfilling life. Autism doesn't end at 18."



DEMOGRAPHICS





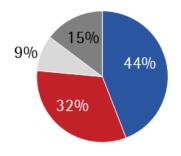
LIVING ARRANGEMENTS

Forty-four percent (15) of individuals with autism reported they are currently living independently with no support. Although the question did not specifically ask about marital status, a handful of respondents also mentioned that they are married with or without children. Thirty-two percent (11) of individuals with autism reported they are currently living with parents, with an additional 9% (3) living with other family members. Fifteen percent (5) indicated that they are living independently with supports.

A majority (56%, 19/34) of individuals with autism agreed with the statement "I am satisfied where I am living" and 18% (6) strongly agreed with the statement. Conversely, 21% (7) disagreed with the statement and 3% (1) strongly disagreed. One person did not rate the statement.

Living Arrangements

- Independently
- Living with Parents
- Living with Family Members
- Independently with Supports



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EDUCATION

Of the respondents who indicated they were 18 or older, all had received a high school diploma or GED and 87% (26) had started some type of post-secondary education. Seventeen percent (5) had received a graduate level degree, 23% (7) received a 4 year college degree, and 7% (2) received a 2 year college degree. Forty percent (12) of those who responded attended some college but had not received a degree yet.

Forty-one percent felt that their education is preparing them or did prepare them well for employment. Twenty -nine percent felt it is somewhat preparing them or had prepared them. Fifteen percent felt that their education is not or did not prepare them for employment and another fifteen percent was not sure.

EMPLOYMENT

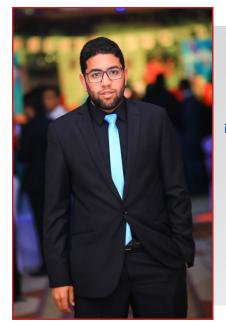
Fifty-six percent of individuals with autism surveyed indicated they are currently employed. Forty-one percent were employed and 3% reported they currently volunteer in the community. Of those employed, 42% were employed with no supports while 37% used supports. Eleven percent were selfemployed.

Over half (64%) of those employed reported working full time, though 55% (5 of 9) of those working full time indicated they would like to work less. Thirty-five percent reported working part time and 60% (3 of 5) of those working part time would like to work more.

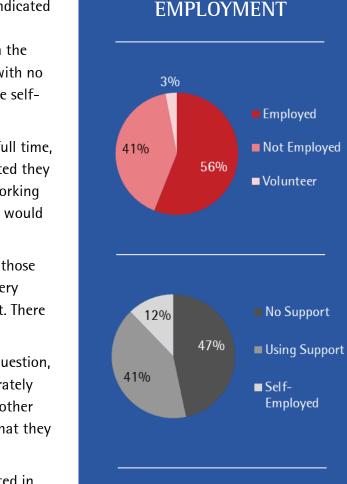
When asked if they enjoyed their job, forty percent of those who answered the question said they enjoy their job very much. 60% who answered said they enjoy it somewhat. There were none that chose the "not at all" answer choice.

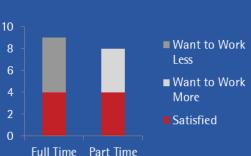
Forty-two percent of those responding to the survey question, "How well are you paid for your job?" answered moderately well. Twenty-one percent answered "very well" and another 21% answered "slightly well". Fourteen percent said that they are not paid well at all.

Individuals with autism were asked if they feel supported in the workplace. Fifty-seven percent answered they felt supported sometimes, 26% felt supported, and 7% did not feel supported.

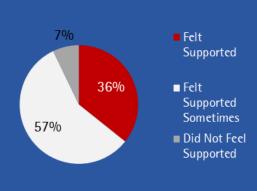


"Our community has come a long way since we moved here in the late 1990s, but access to college and meaningful work for a 30 year old, high functioning ASD person still feels like the impossible dream."



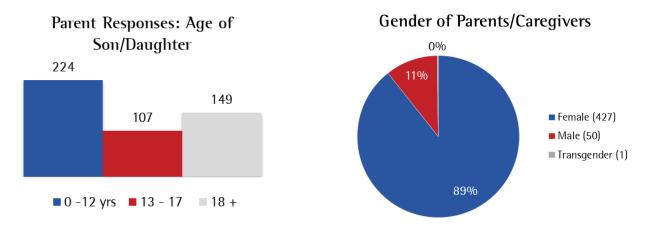


Employed



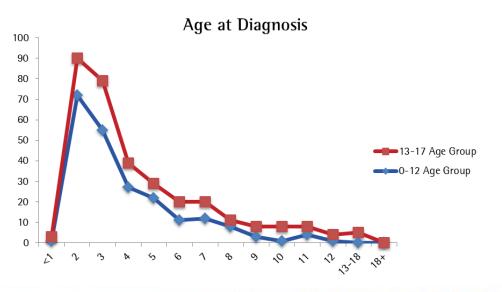
DEMOGRAPHICS

Parents and/or caregivers were grouped into three different categories based on the age of their son or daughter with autism. The age categories were parents/caregivers of children (0-12 years old), parents/ caregivers of teens (13-17 years old), and parents/caregivers of adults (18+). All parents and caregivers answered a set of standard questions and then were asked a series of questions based on the age of their child. Of the 480 parent/caregiver responses, 224 of these were from parents/caregivers of children aged 0-12, 107 were from parents of teens, and 149 were parents of an adult on the spectrum. The survey was completed by mostly mothers or female caregivers (89%), with 11% of responses from fathers or male caregivers and 1 response from a transgender parent/caregiver.



AGE AT DIAGNOSIS

Parents of children aged 0-12 and 13-17 were asked how old their child was at the time of their diagnosis. For parents of younger children (0-12) the average age of diagnosis was 3.74 years old. For parents of teens, the average age of diagnosis was slightly older at 5.6 years old, indicating that the average age of diagnosis may be declining over time.

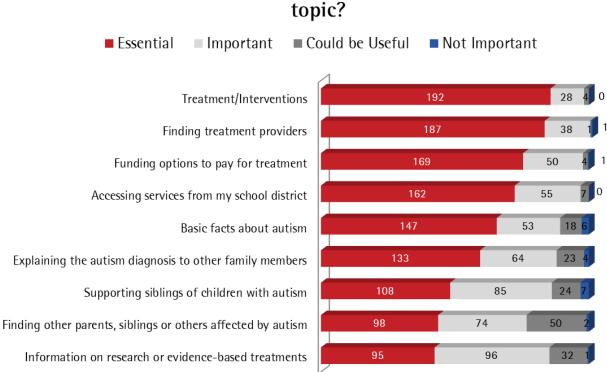


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Of the 224 responses from parents of children aged 0 - 12 years old, 218 of the children had received a medical diagnosis of autism, whereas 110 had an educational determination.

Parents/caregivers of this age group were given a list of topics and asked how important it is for families to receive information on each of the topics and whether or not they received the information when they needed it. A summary of the responses can be found in the figures below.

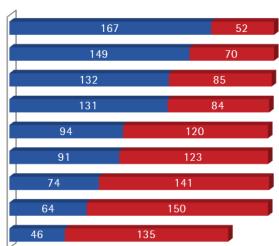
How important is it to receive information on this



Did you receive information on this topic when you needed it?

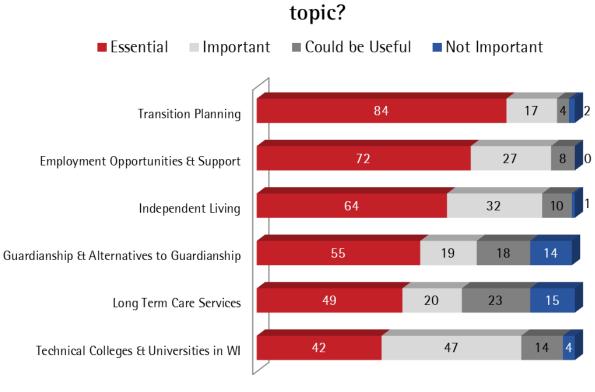
Received Did not Receive

Basic facts about autism Treatment/Interventions Finding treatment providers Accessing services from my school district Finding other parents, siblings or others affected by autism Funding options to pay for treatment Information on research or evidence-based treatments Explaining the autism diagnosis to other family members Supporting siblings of children with autism



Parents/caregivers of youth aged 13 to 18 were given a list of topics and asked how important it is for families to receive information on each of the topics and whether or not they received the information when they needed it. A summary of the responses can be found in the figures below.

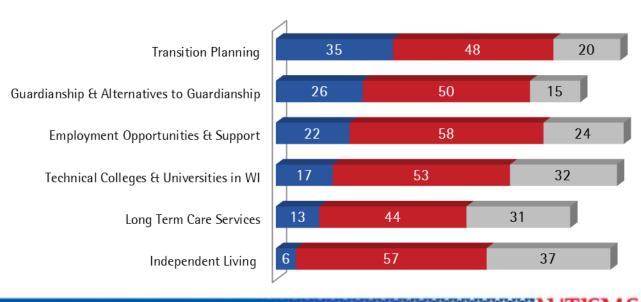
How important is it to receive information on this



Did you receive information on this topic when you needed it?

We don't need this information

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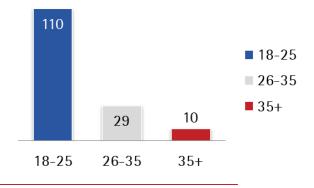


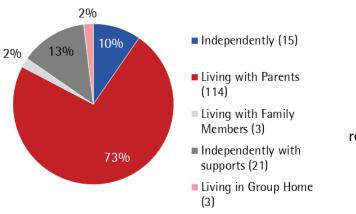
Did not Receive

Received

AGE OF SON/DAUGHTER

Of the 149 parents in this category, the majority of parents/ caregivers (74%) had a son/daughter aged 18-25. Nineteen percent of parents/caregivers had a child aged 26-35 and 7% had a son/daughter aged 35 or older.



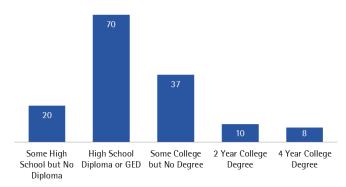


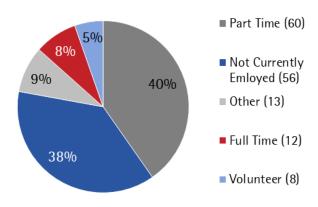
LIVING ARRANGEMENTS

These parents/caregivers were asked about the living arrangements of their son or daughter with autism. Seventy-three percent of parents/caregivers reported their son/daughter is currently living with them, 13% reported that their son/daughter is living independently with supports, and 10% reported that their son/ daughter is living independently with no supports in place.

EDUCATION

A majority of parents/caregivers (47%) reported that their son/daughter had received a high school diploma or GED as their highest level of education whereas 13% of parents reported that their son/daughter had completed some high school but had not received a diploma yet. Twenty-five percent of parents/caregivers reported their son/daughter had completed some college but had not received degree yet and 7% had received a 2 year college degree and 5% had received a 4 year college degree.



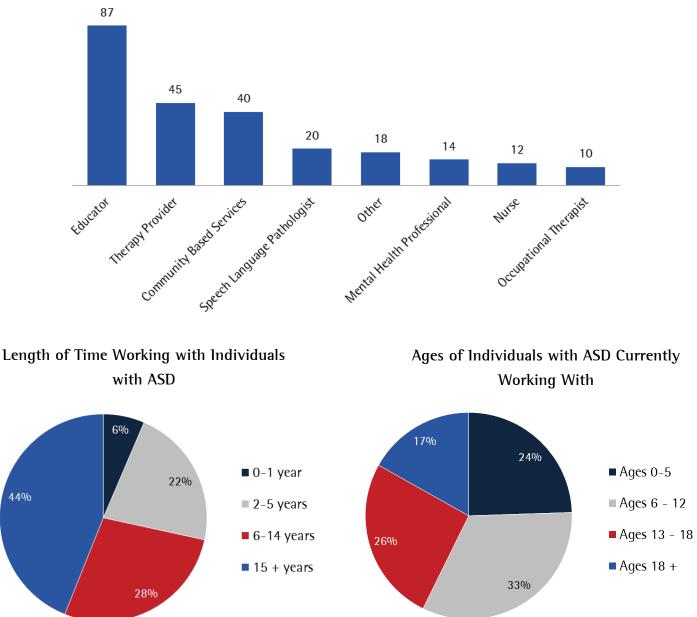


EMPLOYMENT

Of the 149 parents/caregivers surveyed, 40% reported that their son/daughter is employed part time and 38% reported their son/daughter is not currently employed. Nine percent are currently volunteering and 8% are employed full time. Another 9% of parents/caregivers reported another situation such as their son/daughter still being in high school or college, or just starting the employment process through DVR.

PROFESSIONALS

A variety of professionals who work with individuals with autism completed the survey. Educators were the biggest group of professionals, making up for 33% of the responses. Of these, most were special education teachers, with a handful of general education teachers (4) and para-educators (8) responding as well. Therapy providers and other community based service providers were also a large group of respondents. Most of the professionals who responded have been working with individuals and/or families affected by autism for over 15 years. A large percentage (33%) of these professionals work with individuals affected by autism aged 6–12, 26% work with ages 13–18, 24% work with ages 0–5, and 17% work with ages over 18.



Improving the Lives of All Affected by Autism

Professional Category

EXAUTISM SOCIETY Improving the Lives of All Affected by Autism Wisconsin

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