

Difficulties in Diagnosing Autism Spectrum Disorder as Experienced by Parents and Families

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By

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Introduction

Autism spectrum disorder, or ASD, is a complex disorder that is characterized by social deficits and restrictive or repetitive patterns of behavior that are present in childhood and impair daily functioning. This is expressed differently in each individual and can vary widely from one person to the next. Some of the common traits associated with ASD include a lessened or heightened response to sensory input, strict adherence to routines, fixation on objects, delayed speech, difficulty forming and/or maintaining relationships, repetitive speech or behaviors, lack of eye contact in conversations, and a difficulty recognizing emotions. In order for a diagnosis of ASD to be made, many of these symptoms must be present in a child prior to the age of eight and must cause impairment in daily life. It is also necessary that these symptoms are observed across multiple contexts, often including different settings, like home and school (Carpenter 2013).

As of 2016, the Centers for Disease Control and Prevention (2020) (CDC) reported that approximately 1 in 54 eight-year-old children have autism spectrum disorder in the United States. This data, collected from a number of Autism and Developmental Disabilities Monitoring (ADDM) sites has shown a consistent increase in the number of children with an autism diagnosis since it was first recorded in 2000 (Centers for Disease Control and Prevention 2020). The most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), the DSM-V, removed subgroups of ASD that were present in the previous edition. These new criteria are regarded by some professionals as too restrictive compared to previous editions of the DSM. An estimated 60% of individuals diagnosed with autism using the DSM-IV criteria would be given a diagnosis using the updated DSM-V standards (Mazefsky et al. 2013). Even with the stricter diagnostic requirements, the prevalence of ASD in children continues to increase.

ASD is difficult to diagnose in children, in part because there is a broad range of potential symptoms, and autism may present differently in different children. To diagnose ASD, providers must interpret symptoms to fit the diagnostic criteria. Many cases are misdiagnosed or missed altogether, especially when symptoms differ from that of “classic” ASD. Parent involvement and consideration throughout the diagnostic process plays an important role in the quality and type of care a child receives. There is a plethora of research on autism, but little on how parents experience diagnosis. This research study examines factors that influence parent satisfaction in the ASD diagnostic process and explore weaknesses within it.

Background

One noted characteristic of ASD is social difficulty, which is sometimes caused by a speech delay or inability to communicate verbally. An early warning sign that a child may have ASD is that they do not hit typical developmental milestones, including speech. For children with developed speech, it can be significantly more difficult to receive a diagnosis, even if many other symptoms are present. Males and females who did not communicate verbally were the most likely group to receive an early diagnosis. Even among children who did communicate verbally, delays in verbal development warranted an earlier diagnosis. Children who used complex phrases when speaking were likely to be diagnosed with ASD much later than their peers (Salomone et al. 2015).

ASD can be difficult to diagnose because its symptoms may overlap with other diagnoses, including ADHD and anxiety. It is common that children receive more than one diagnosis, as multiple conditions present comorbidly with ASD. These conditions often can be reduced into clusters, or similar types of diseases or disorders, based on medical presentation. Doshi-Velez et al. (2014) divided comorbid conditions into seizures, multisystem disorders

including gastrointestinal issues, psychiatric disorders, and a fourth, undefined cluster. Epilepsy, defined as two or more unprovoked seizures, is often diagnosed in addition to ASD at drastically higher rates than what is found in the general population. Between 25-30% of those with ASD also have epilepsy, compared to 1-2% of the general population (Tye et al. 2019: para 4).

Sleep problems are generally common in children with a prevalence of 9-50%, but even more prevalent in children with ASD (Tye et al. 2019: para 16). Between 50-80% of children with an ASD diagnosis have some other condition affecting sleep, including insomnia, restless leg syndrome, and sleep disordered breathing conditions, like sleep apnea (Tye et al. 2019: para 16). Sleep is important and necessary for all people, especially children. Behavioral challenges can be worsened in children who do not get adequate sleep, which can be amplified in those with ASD. One of the other most commonly reported comorbid conditions are gastrointestinal dysfunctions. Prevalence estimates vary greatly, but GI disturbances can result from food selectivity and often include chronic constipation or diarrhea, gastro-esophageal reflux, and abdominal pain. Deficiencies in immune function are also reported at higher rates for children with ASD, which can lead to the development of conditions like asthma and psoriasis (Tye et al. 2019).

Many psychiatric conditions commonly co-exist in patients with ASD, with one of the most frequent being ADHD. It is estimated to be present in 30-80% of cases of ASD, with many overlapping symptoms, like repetitive movement of the body or objects (Belardinelli et al. 2016: para 23). Depression is also common, especially in high functioning individuals with diagnoses of mild ASD, with an estimate of up to 10% comorbidity (Belardinelli et al. 2016: para 37). Anxiety is another typical condition that occurs with ASD. Over 40% of children with ASD also qualify for some form of anxiety diagnosis (Belardinelli et al. 2016: para 42). Most often, this is

social anxiety, consistent with traits of ASD that impair typical social interactions. Another category often diagnosed is mood disorders, including bipolar disorder. Studies of the family histories of individuals diagnosed with ASD show that bipolar disorder and other mood disorders are commonly found in relatives. Bipolar disorder and ASD may share common genes.

Interestingly, eating disorders and ASD are related differently. Many people with ASD have food selectivity but do not qualify for an eating disorder. However, many individuals with an established eating disorder, specifically anorexia nervosa, would qualify for an ASD diagnosis (Belardinelli et al. 2016).

Many factors can influence a provider's likelihood to diagnose a child with ASD. Some of these factors have little to do with the child's condition and are instead related to the child's parents or family, including education level and income, race, gender, and access to healthcare. Studies find that children are more likely to receive an earlier diagnosis of ASD as the education levels of their parents increase (Goin-Kochel et al. 2006). Similarly, children from higher income families are more likely to receive an ASD diagnosis, although this difference may be due to greater access to medical specialists and providers (Durkin et al. 2010).

Of the nearly 2% of children with autism, there is approximately a 4:1 ratio of males to females. Presentation of ASD in males is often different than in females. The diagnostic criteria for ASD is based on typical male symptoms, so males are more likely to receive an ASD diagnosis than females. Among females, mild or moderate cases are more likely to be undetected. It is unclear whether this gender disparity is due to biased diagnostic criteria against females or the better ability of females to compensate for difficulties and mask them around others (Dworzynski et al. 2012). This implies that girls with a non-severe classification of ASD

may be misdiagnosed or not diagnosed at all. For families seeking a diagnosis for their daughter, this is a major obstacle.

It is well documented that minority groups face discrimination regularly, including in education and employment. These prejudices are not isolated and affect children in receiving a diagnosis that can help them access the services they need. In the case of ASD, it is more likely that a child belonging to a minority ethnic group will not receive the correct diagnosis upon initial assessment. Unlike the differences in presentation between males and females with ASD, there are no known racial differences in symptoms and presentation. Despite this, African American children received a diagnosis an average of 1.4 years later than white children and were required to attend more visits with specialists to obtain the same diagnosis. Additionally, compared to white children, African American children were nearly three times as likely to receive a different diagnosis before ASD, including attention deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), and oppositional defiant disorder (ODD) (Mandell et al. 2006). Many of the symptoms can overlap, but ASD was ultimately determined to be the most fitting diagnosis for these children. This indicates that these children were misdiagnosed, despite similar symptom presentation as compared to white children. Any differences noted were reduced to environmental differences between children, including parent responses and clinician assessment of the child. It is thought that this is due, in part, to prejudices held by clinicians (Mandell et al. 2006).

Differences in medical insurance coverage varies widely in its effects. Some states mandate that health policies cover services related to ASD and other developmental disorders, including diagnostic visits and treatments. In states where this was mandated, families were less likely to have to pay significant out of pocket costs related to their child's medical care (Parish et

al. 2012). As reported, children in low-income families are less likely to receive a diagnosis than children in higher income families. Requirements for insurance companies to cover ASD related medical expenses allows for more underprivileged children to have access to services they need. While most private insurance companies did have some coverage for ASD-related services, many limited the number of visits that were covered, and some companies excluded ASD-related care completely. This greatly disrupted medical care for children with ASD and burdened the parents and families of the children (Peele et al. 2002). Compared to the majority of private insurance, Medicaid, or another state-run insurance program had significantly better coverage of ASD services, including evaluation and diagnostic visits. Children having Medicaid or another state-run insurance is positively correlated with an increase in ASD diagnoses (Liptak et al. 2008).

Care for children cannot occur without parent involvement. Parents are the first and most important advocates for children, especially those with different and special needs. Parents effectively control the care their child receives, including the providers they see and treatments they get. Parent satisfaction with caregivers is associated with continuation of care and measures of parental well-being. Many different factors negatively affect parent satisfaction, including long wait times to see providers, personal medical issues, and low socioeconomic status of the family. Parents reported higher satisfaction levels when they were informed about familial supports and felt their doctors were knowledgeable. When parents were happy, they were more likely to continue allowing their child to receive care from providers. Those that were not satisfied were unlikely to continue, possibly losing valuable help for their child (Nik Adib et al. 2019). A positive experience with diagnosis leads to development of better coping mechanisms and lower stress levels of parents and families, while a delay in diagnosis can cause a lack of

trust for providers and can negatively impact the child long term (Crane et al. 2015). Some studies even claim that the care meant to help children is harming families because it does not always take them into account. The most effective care, as expressed by parents, is care that involves them in decisions and outcomes and considers their needs in addition to their child's (Parker and Killian 2020).

Research demonstrates that parent involvement in medical care is important to ensure quality care for children. Diagnosis of ASD differs based on age, gender, socioeconomic class, and race as a result of symptom presentation and/or perception by providers. Parent satisfaction with a child's medical care is a factor that affects a child's care but is not often considered. This research is intended to analyze parent satisfaction as it relates to other aspects of care. This is important to provide feedback to providers and identify weaknesses within the ASD diagnostic process that would improve parent satisfaction and overall care of children.

Methods

Research was conducted using an anonymous online survey, hosted by Qualtrics. Research protocol was approved by the Internal Review Board at SUNY Brockport. The survey had a combination of quantitative and qualitative measures to allow for closed-ended and open-ended written responses. Participants were recruited on the basis of being the parent or primary caregiver of a child with an established diagnosis of ASD. The survey and recruitment materials were posted in two different Facebook groups, "CNY Support Group for Autism and Special Needs" and "Autism Family Support Group." The survey was also distributed through my personal Facebook page and to other personal contacts. I work with many families who have children with autism. In discussing my study with these families, my personal connections likely

led to a number of participants responding to the survey on my personal page. The study was based out of Western New York, but participants were not required to be from this area.

Participants and individuals they discussed were given pseudonyms to protect anonymity.

The survey developed for this study was partially based on an existing survey, the Autism Family Experience Questionnaire (AFEQ). This was developed with the help of parents to ensure that it reflected values they found to be important in their child's care (Leadbitter et al. 2018). Questions that did not come from the AFEQ were designed to elicit thorough responses from participants and cover any information necessary to understand a complete picture of their diagnostic experience. Questions were divided into three sections: Introductory Questions, Diagnosis, and Post Diagnosis.

The introductory section addressed basic family demographics. This section included questions about the age, gender, and ethnicity of the child with ASD, type of school they attend, and the number of other children and family members in the household. Other questions included information about the primary caregiver, their transportation, and their work habits, as well as the education level of both of the child's parents and the annual household income.

Section two addressed specifics of the child's ASD diagnosis. This included the parent's first suspicions of ASD, the age of the child at the time of their diagnosis, the time required to wait between scheduling and attending diagnostic appointments, and the number of providers they saw to get a diagnosis. This section also addressed specifics about the diagnosis the child received, including the severity of their ASD, verbal ability, and any comorbid conditions. A series of questions asked the parent about their child's health insurance and how adequately it covered their needs while seeking a diagnosis.

The final section, Post Diagnosis, involved questions about required medical care since diagnosis and a number of factors that may hinder scheduling medical appointments, including work, financial strain, and other family obligations. A series of questions, adapted from the AFEQ, was included to address how parents have perceived their child's care since receiving an ASD diagnosis. This section of the survey allowed me to gauge parents' general satisfaction with care and include components like trust in professionals, confidence that the correct diagnosis was given, and sensitivity of providers to the needs of the family.

Findings

Several major themes emerged from the survey data. First, females seeking an ASD diagnosis saw more providers than males. Even among similar cases, females were required to attend more appointments than males to be diagnosed with ASD. Second, children, both male and female, who communicated verbally during a diagnosis were less likely to receive an ASD diagnosis in a timely manner. Children who were verbal saw more providers and were diagnosed at a later age than children who did not communicate verbally at the time of diagnosis. Third, parents often had to make significant sacrifices for their children with ASD. Many parents had to leave their jobs or careers in order to have the adequate time to take care of their children with ASD. The next sections detail each of these findings.

Females saw, on average, significantly more providers than males while seeking a diagnosis.

Of the 19 total responses, 14 parents detailed the experiences of their sons' diagnoses, while the other 5 explained the experiences of their daughters. A male seeking an ASD diagnosis saw an average of 2.1 providers to obtain that diagnosis, while females saw an average of 6.8.

This data is shown in Figure 1. One parent, Stephanie, reported her son having seen 5 providers for his diagnosis, which was the highest reported number of the males. He was the oldest of the male children detailed and had been diagnosed over 20 years prior, making it possible that he experienced different criteria than many of the younger children studied. Two parents reported that their daughters had seen 3 providers, which was the lowest of the females. This is higher than the average number of providers seen by the males. One parent reported that her daughter had seen “easily a dozen” providers while seeking a diagnosis. This particular female was also the oldest of the females reported but had not been diagnosed until 5 years prior.

Figure 1: Number of Providers seen to obtain an ASD diagnosis, by gender		
Number of Providers Seen, per Child	Males (14)	Females (5)
1-2	10 (71.4%)	0
3-4	3 (21.4%)	2 (40.0%)
5-6	1 (7.1%)	0
7-8	0	1 (20.0%)
9-10	0	1 (20.0%)
11 or more	0	1 (20.0%)
Average Number of Providers	2.1	6.8

Two examples illustrated this well. One parent was responding for their son, Jacob. Another respondent was discussing their daughter, Haley. Both children were 4 at the time of survey collection and had been diagnosed with ASD at age 2. Additionally, both children did not communicate verbally at the time of diagnosis, and both were diagnosed with severe ASD. Jacob saw just one provider, while Haley saw 3. The families report having only one child, their child with ASD, and list both parents as primary caregivers. The parents of each child have the same

educational background, total household incomes below \$60,000 per year, and have public health insurance for their child. Even with so many factors held constant, Haley saw two more providers than Jacob to receive a diagnosis.

Children who communicated verbally at the time of diagnosis had a harder time receiving an ASD diagnosis.

One of the possible criteria for diagnosing ASD is that a child has limited verbal ability, compared to other children their age. Many of the parents of children who communicated verbally at the time of their diagnosis had a more difficult time obtaining a diagnosis than children who did not communicate verbally. When asked how their child's verbal ability affected their diagnosis, one parent remarked that their "child is misunderstood by professionals because he has language." Providers may find that a child can talk and assume they are able to communicate everything that they need. According to one mother, professionals saw that her child had language skills, though limited, and were unable to look past that to understand his true abilities. Similarly, another parent responded that "people didn't listen to us when we voiced concern" and that their son was seen as "too typical." Neurotypical is a term often used to describe people who do not have ASD. Although the child did eventually get an ASD diagnosis, his ability to talk and communicate verbally led providers to view him as someone who did not have ASD and someone that was instead neurotypical.

Providers have a limited amount of time to observe a child and determine if they meet the criteria for an ASD diagnosis. Parents are around their children continuously and have a thorough understanding of what their language abilities truly are. One parent, when asked how their child's verbal communication affected his diagnosis, stated,

Often times the providers said he was expressing his needs as he should so there was no concern. The fact however is that he doesn't. His social communication lacks and he rarely expresses his own need[s] without prompting over and over.

Based on what the provider was seeing, this child did have language. He was able to express what he needed to his parents. His family felt that this was an inaccurate evaluation of their child and that he truly could not express what he needed independently. If someone was able to figure out what he needed and prompt him on what to say to express that, then he could communicate it. Otherwise, he was not able to communicate his needs. Additionally, his family felt that he could not talk to others in a social context, such as making friends at school. Social deficits are also considered an important part of an ASD diagnosis, but this is overshadowed regularly by verbal ability. It is clear that providers need to take time to listen to parents to develop a comprehensive understanding of the child's speech patterns and communication ability, instead of relying solely on what they observe in a short office visit.

This idea is further evidenced by another respondent, Stephanie, whose concerns were dismissed by her child's doctors.

First delay in getting diagnosis was when [I] expressed concern that at 2 he was not really talking. Pediatrician said "does he have 6 words?" I [said] yes. He said don't worry. One [developmental] pediatrician at first appointment declined to give ASD diagnosis because child had "communicative intent." Even though he was 3 and still speaking at best single words. All nouns.

This child's provider considered the child to have sufficient verbal ability, using the benchmark of him having and using 6 words. For a very young child, this is normal. Considering that he was 3 and still only able to use a few words, it is clear that he did not have the language skills that he

should have had at his age. To the provider, the child seemed to have sufficient verbal ability. For Stephanie, who is with the child every day, his lack of verbal communication was concerning. If providers were to take the experiences of parents and families into consideration when evaluating a child for a diagnosis, they would have a much more comprehensive understanding of the child's true nature and abilities.

Parent sacrifice

It is a parent's job to care for their children. At a basic level, this requires providing food, clothing, housing, and love. For parents of children with ASD, so much more is required. All parents agreed that their child needed to be their priority, but this could prove difficult for working parents. When asked how her ability to schedule appointments for her child was affected, one mother said that work did not interfere because "[her son] came first." Some parents had flexible work schedules that allowed them to schedule and attend appointments for their children when necessary. These jobs contributed to lower stress levels for parents, as they were able to both care for their children and manage their careers.

For jobs without as much flexibility, parents often had to compromise to be able to adequately care for their child's needs. This included taking positions with reduced hours or pay, compared to fulltime employment. One mother accounts that she "crafted work from home- at a severely reduced income despite my education- so that I can be available to meet my sons' needs." Despite having a doctoral degree, this mother had to take a position that was far below her experience level so she could work from home and have time for her child's needs. In finding a more flexible position, she was able to care for her child, but lost income that she would have made at a different job. Many accounts were similar to this, with parents losing or leaving jobs in

order to adequately care for their children. One parent regarded that they “had to give up my career to be able to care for him.” There was an overwhelming feeling of sacrifice that parents were describing in their responses. Parents are a vital part of medical care for their children and often have to make sacrifices and compromises to ensure that their children have access to quality care. Providers need to be aware of this and respect parents when treating their children. Parental needs should be taken into consideration almost as much as the needs of the child.

Some parents found themselves in situations that were caused not necessarily by their working, but by other institutions that they and their child were a part of. When asked if work interfered with her ability to schedule appointments for her child, Stephanie stated

I had left my career because even without diagnosis, daycare was clearly not working for my [son]. So work did not interfere with ability to schedule appointments, but my sons condition caused me to have to leave a 20yr career.

In this case, it was not flexibility for appointments that caused Stephanie to leave her job, but a school that did not work for her family. Stephanie’s son went to public schools and was enrolled in a daycare that she trusted to take care of him and manage his needs. She determined that the school was “not working” for him and would have preferred he be enrolled in a private school that was better equipped to handle his condition. She anticipated the school district denying her request for funding and could not afford to pay for private school herself. She did not want to “fight” the district for her son’s basic needs, so she felt that her only choice to provide what was best for him was to leave her career. In this case, Stephanie’s work did not directly cause difficulty, but was affected as a result. Her son’s school was not the right fit for him and there were limited options, so her work and career were ultimately sacrificed.

Epilepsy and other conditions commonly occur alongside ASD, causing parents of children with multiple medical issues to have more stress. For example, Amy's daughter was diagnosed with ASD at 17 months old. She also has epilepsy, which causes Amy to have to find around the clock care for her daughter's medical condition.

Her care and services have impacted how much I could work. I could only work part time when she was 0-5 and now I'm in the same predicament because of lack of CDPAP/respice workers.

Amy and her family are reliant on respice workers and home health care aides to care for her daughter. When care providers are unavailable, Amy and her husband take on the responsibilities themselves. Someone has to be with her daughter at all times, including overnight, leading to many sleepless nights and missed days at work. Amy has had to resign from her full-time position in order to care for her daughter and her medical needs. As seen with Stephanie, Amy's work was not the main problem. The limited availability of home healthcare aides affected her ability to work. Without reliable healthcare aides, Amy and her husband could not keep up with their daughter's medical needs while both working full time, so Amy gave up her career to stay home.

Discussion and Conclusions

ASD diagnosis can be stressful and difficult for parents. This study intended to determine which factors most predominantly interfered with the satisfaction of parents and determine potential solutions. The first suggestion is a revision of diagnostic criteria. It is apparent that there is a heavy reliance of providers on the verbal ability of children when diagnosing ASD. While it is regarded as one of the earliest signs, it is not the only one. Nearly every respondent

indicated that their child's ability or inability to communicate verbally affected their diagnosis. Verbal children typically saw more providers and were misdiagnosed more often than children who were not verbal. Those who could communicate verbally were seen as "too typical" for an ASD diagnosis and parent concerns were often dismissed or ignored, leading to higher levels of stress. Diagnostic criteria should be revised to better include children who can communicate verbally. A potential suggestion would be to have two sets of criteria, one for those who communicate verbally and one for those that do not. I elaborate on these suggestions below.

Diagnostic criteria for ASD, as with many other disorders, is based on male symptom experience. Females often have different symptoms and presentations than males and can more easily mask these symptoms to pass as neurotypical. As a result, females can easily be misdiagnosed or completely undetected by providers. For parents of girls, seeking an ASD diagnosis is even more stressful than for parents of boys. Parents experience many difficulties while seeking a diagnosis, but these problems are often exaggerated for parents of girls. It is common for parents to have to wait a few weeks to a few months after scheduling an appointment with a provider to actually take their child to the appointment. Females have to see more than three times as many providers as males, on average, to receive a diagnosis, which causes their parents to experience heightened stress and difficulty. Criteria to diagnose ASD should be revised to include female-predominant symptom presentation to help reduce the number of visits that females are required to make. This, in turn, would help to lower the stress level of parents of girls.

Parents are directly involved in ASD diagnosis and can easily become overly stressed during the process. The second suggestion, therefore, is to increase the level of parental support from providers and other professionals. Parents are constantly searching for the best resources

and help for their child and even with numerous resources available, navigating the system can become confusing. Research has shown that parents place more trust in providers when they feel supported as parents and caregivers. Group support sessions for parents of children with ASD may increase feelings of social support, especially for parents of newly diagnosed children. Sessions should be held by medical providers, community advocates, and other professionals to inform parents of the options and resources available. This may help some parents find resources like intervention services or home health care that would allow them to work full time, knowing their child was cared for. This also would provide a place for parents to share their own experiences and for their concerns and experiences to be heard by a group of people in a similar situation. The increased support and sense of community would decrease stress levels of parents and ultimately help them in best caring for their child.

This study was limited to 19 participants in upstate New York. Further research should include a larger population and larger geographic area from which greater conclusions could be drawn. Few studies focus on parent satisfaction, which research increasingly shows is important. Studies should focus on which aspects of care specifically lead to parent satisfaction or dissatisfaction during the diagnostic process.

The diagnostic process of ASD in children is far from perfect. This study gives insights into what specifically could be improved to help parents in the future receive a diagnosis for their child. Criteria and symptoms for ASD need to be revised to be more inclusive of females and of children who communicate verbally. Salomone et al. (2016) did note the effect of a child's verbal ability on their diagnosis. This was a major theme in my research but was limited by the small sample size. Future studies should research the correlations between children's verbal abilities, number of providers necessary to diagnose, and other symptoms exhibited by children.

Parent supports, possibly in the form of support groups, need to be more broadly integrated into the existing system to provide necessary help for parents and a place for them to be heard.

References:

- Belardinelli, Cecilia, Mahreen Raza, and Tolga Taneli. 2016. "Comorbid Behavioral Problems and Psychiatric Disorders in Autism Spectrum Disorders." *Journal of Childhood & Developmental Disorders* 2(2). doi: [10.4172/2472-1786.100019](https://doi.org/10.4172/2472-1786.100019).
- Bishop-Fitzpatrick, Lauren, and Amy J. H. Kind. 2017. "A Scoping Review of Health Disparities in Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 47(11):3380–91. doi: [10.1007/s10803-017-3251-9](https://doi.org/10.1007/s10803-017-3251-9).
- Carpenter, Laura. 2013. "DSM-V Autism Spectrum Disorder." Retrieved November 2, 2021. (<https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5%28ASD.Guidelines%29Feb2013.pdf>).
- Centers for Disease Control and Prevention. 2020. "Data and Statistics on Autism Spectrum Disorder | CDC." *Centers for Disease Control and Prevention*. Retrieved November 2, 2021 (<https://www.cdc.gov/ncbddd/autism/data.html>).
- Crane, Laura, James W. Chester, Lorna Goddard, Lucy A. Henry, and Elisabeth Hill. 2016. "Experiences of Autism Diagnosis: A Survey of over 1000 Parents in the United Kingdom." *Autism* 20(2):153–62. doi: [10.1177/1362361315573636](https://doi.org/10.1177/1362361315573636).
- Doshi-Velez, Finale, Yaorong Ge, and Isaac Kohane. 2014. "Comorbidity Clusters in Autism Spectrum Disorders: An Electronic Health Record Time-Series Analysis." *Pediatrics* 133(1):e54–63.
- Durkin, Maureen S., Matthew J. Maenner, F. John Meaney, Susan E. Levy, Carolyn DiGuseppi, Joyce S. Nicholas, Russell S. Kirby, Jennifer A. Pinto-Martin, and Laura A. Schieve. 2010. "Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study." *PLoS ONE* 5(7). doi: [10.1371/journal.pone.0011551](https://doi.org/10.1371/journal.pone.0011551).

- Dworzynski, Katharina, Angelica Ronald, Patrick Bolton, and Francesca Happé. 2012. "How Different Are Girls and Boys Above and Below the Diagnostic Threshold for Autism Spectrum Disorders?" *Journal of the American Academy of Child & Adolescent Psychiatry* 51(8):788–97. doi: [10.1016/j.jaac.2012.05.018](https://doi.org/10.1016/j.jaac.2012.05.018).
- Goin-Kochel, Robin P., Virginia H. Mackintosh, and Barbara J. Myers. 2006. "How Many Doctors Does It Take to Make an Autism Spectrum Diagnosis?" *Autism* 10(5):439–51. doi: [10.1177/1362361306066601](https://doi.org/10.1177/1362361306066601).
- Leadbitter, Kathy, Catherine Aldred, Helen McConachie, Ann Le Couteur, Dharmi Kapadia, Tony Charman, Wendy Macdonald, Erica Salomone, Richard Emsley, and Jonathan Green. 2018. "The Autism Family Experience Questionnaire (AFEQ): An Ecologically-Valid, Parent-Nominated Measure of Family Experience, Quality of Life and Prioritised Outcomes for Early Intervention." *Journal of Autism and Developmental Disorders* 48(4):1052–62. doi: [10.1007/s10803-017-3350-7](https://doi.org/10.1007/s10803-017-3350-7).
- Liptak, Gregory S., Lauren B. Benzoni, Daniel W. Mruzek, Karen W. Nolan, Melissa A. Thingvoll, Christine M. Wade, and G. Edgar Fryer. 2008. "Disparities in Diagnosis and Access to Health Services for Children with Autism: Data from the National Survey of Children's Health." *Journal of Developmental & Behavioral Pediatrics* 29(3):152–60. doi: [10.1097/DBP.0b013e318165c7a0](https://doi.org/10.1097/DBP.0b013e318165c7a0).
- Mandell, David S., Richard F. Ittenbach, Susan E. Levy, and Jennifer A. Pinto-Martin. 2007. "Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 37(9):1795–1802. doi: [10.1007/s10803-006-0314-8](https://doi.org/10.1007/s10803-006-0314-8).

- Mazefsky, C. A., J. C. McPartland, H. Z. Gastgeb, and N. J. Minshew. 2013. "Comparability of DSM-IV and DSM-5 ASD Research Samples." *Journal of Autism and Developmental Disorders* 43(5):1236–42. doi: [10.1007/s10803-012-1665-y](https://doi.org/10.1007/s10803-012-1665-y).
- Nik Adib, Nik Aida, Mohd Ismail Ibrahim, Azriani Ab Rahman, Raishan Shafini Bakar, Nor Azni Yahaya, Suria Hussin, and Wan Nor Arifin Wan Mansor. 2019. "Predictors of Caregivers' Satisfaction with the Management of Children with Autism Spectrum Disorder: A Study at Multiple Levels of Health Care." *International Journal of Environmental Research and Public Health* 16(10). doi: [10.3390/ijerph16101684](https://doi.org/10.3390/ijerph16101684).
- Parish, Susan, Kathleen Thomas, Roderick Rose, Mona Kilany, and Robert McConville. 2012. "State Insurance Parity Legislation for Autism Services and Family Financial Burden." *Intellectual and Developmental Disabilities* 50(3):190–98. doi: [10.1352/1934-9556-50.3.190](https://doi.org/10.1352/1934-9556-50.3.190).
- Parker, M. L., and Michael Killian. 2020. "Autism Spectrum Disorder and Complex Healthcare Needs: The Role of Healthcare Experiences." *Research in Autism Spectrum Disorders* 73. doi: [10.1016/j.rasd.2020.101535](https://doi.org/10.1016/j.rasd.2020.101535).
- Peele, Pamela B., Judith R. Lave, and Kelly J. Kelleher. 2002. "Exclusions and Limitations in Children's Behavioral Health Care Coverage." *Psychiatric Services* 53(5):591–94. doi: [10.1176/appi.ps.53.5.591](https://doi.org/10.1176/appi.ps.53.5.591).
- Salomone, E., T. Charman, H. McConachie, and P. Warreyn. 2016. "Child's Verbal Ability and Gender Are Associated with Age at Diagnosis in a Sample of Young Children with ASD in Europe." *Child: Care, Health and Development* 42(1):141–45. doi: [10.1111/cch.12261](https://doi.org/10.1111/cch.12261).
- Tye, Charlotte, Abigail K. Runicles, Andrew J. O. Whitehouse, and Gail A. Alvares. 2019. "Characterizing the Interplay Between Autism Spectrum Disorder and Comorbid Medical

Conditions: An Integrative Review.” *Frontiers in Psychiatry* 9. doi:

[10.3389/fpsy.2018.00751](https://doi.org/10.3389/fpsy.2018.00751).