

Disclosure of ASD Diagnosis to Children and Adolescents

Marcia Eckerd

Clinicians facing the challenge of disclosing the diagnosis of ASD Level 1 to a child or teen often struggle to determine whether or not this would benefit the patient and how best to do it. Considerations include when and what to disclose as well as effects of disclosure. Both parents and patients need help in processing this diagnosis, which can be seen as overwhelming and life changing.

Jason, age 15, sits fidgeting with his phone that he's reluctant to put down. He's been having difficulty in school settings since preschool, with teachers describing him as "marching to the beat of his own drum" and as having difficulty fitting in socially. These issues have continued through to the present. Jason's friendships tend not to last long, and he is often teased in school. He is frequently perceived as rude by teachers because of the lack of "respect" he displays when challenging assignments and rules. He is a black-and-white thinker, prone to rumination. He's very picky about food. He's extremely interested in World War II and can tell you in detail about specific battles, generals, and the dates of critical events. He has difficulty understanding others' points of view or describing his own feelings. He completely rejects his parents' points of view that there is something "wrong" with him, although he acknowledges wanting more friends. You have worked with him for a few months on the issue of his social understanding and his desire for friends, and in the process have concluded that Jason meets diagnostic criteria for Autism Spectrum Disorder Level 1. What issues should you consider in disclosing this diagnosis to Jason and his parents? Will it help him understand his experience or will he view you as just echoing his parents' views and opinions?

There is very little research on the reaction of children and adolescents to the disclosure of a diagnosis of an autism spectrum disorder (ASD). Most existing research on the disclosure of an ASD diagnosis has focused on (1) disclosure to parents, and (2) adults who retrospectively recall their response to getting a diagnosis of Asperger's Syndrome (now ASD Level 1) at an earlier age.

Prevalence of ASD

ASD is considered by DSM-5 as a neurodevelopmental disorder. The diagnosis of ASD has been rising significantly since 2000 (Eckerd, 2018). According to the Autism and Developmental



Marcia Eckerd, PhD, has been practicing as a clinical psychologist since 1985, specializing in consultation and therapy for patients with Asperger's Syndrome and similar cognitive, social, and emotional traits. She was appointed to the CT Autism Spectrum Disorder Advisory Council and serves on the Associate Staff in Psychiatry at Norwalk Hospital, where she participated in creating the Yale-Norwalk Hospital Collaborative Pediatric Development and Therapy Center.

Disabilities Monitoring (ADDM) Network, there was a continuous increase from 0.67% in 2000 to 1.47% in 2012 (Xu et al., 2018). The 2014 estimate of children with ASD, based on the ADDM and CDC data, was 1.68%. (Baio et al., 2018; CDC, 2014). The rates for ASD Level 1 (previously Asperger's) have not been differentiated from ASD in this research.

Disabilities Monitoring (ADDM) Network, there was a continuous increase from 0.67% in 2000 to 1.47% in 2012 (Xu et al., 2018). The 2014 estimate of children with ASD, based on the ADDM and CDC data, was 1.68%. (Baio et al., 2018; CDC, 2014). The rates for ASD Level 1 (previously Asperger's) have not been differentiated from ASD in this research.

Gender Distribution of ASD

There is a strong bias by gender in the diagnosis of ASD. Across 54 studies, the male-to-female ratio was approximately 4:1. However, in these studies diagnosis was made based on a male prototype of the presentation of ASD. When examining the presence and severity of autistic traits, rather than the diagnosis, a ratio of 3:1 was found. High-functioning girls tend to have obsessive interests that are more age appropriate (e.g., art, animals) and tend to be better at masking social deficits, seeming to fit in even when they lack genuine social reciprocity skills (Loomes et al., 2017). Some studies estimate the diagnosis ratio of males to females having ASD Level 1 to be 1:1 (Atwood, 2018).

Age of Diagnosis of ASD

The 2009–2010 National Survey of Children with Special Health Care Needs found that the age of diagnosis of ASD in the U.S. varied based on severity of symptoms, racial and ethnic factors, parent education, family income, and access to medical care. Higher functioning children with intact language were diagnosed later than children with lower verbal ability, as would be expected. The mean diagnosis age was comparable across racial/ethnic/language groups and was similar in 3- to 4-year-olds who were lower functioning. Among 15- to 17-year-olds, there was a significant difference in estimates of age at diagnosis based on different racial, ethnic, educational, and income groups (Jo et al., 2015). Another study found that the average age of diagnosis was 3.1 years old for children with more severe autistic features and 7.2 years old for children with Asperger’s disorder (Mandell et al., 2005). Several studies have suggested that ASD Level 1 is often not identified until age 11 or later, and some cases are not diagnosed until adulthood (Howlin & Asgharian, 1999; Jones et al., 2014) or not diagnosed at all (Eckerd, 2018).

Parental desire to find a diagnosis also influences differences in age at diagnosis. Some parents sense that something is wrong with their child and then spend years trying to get a diagnosis, while other parents fear that something might be wrong and resist taking a child to a professional (so symptoms of autism are not diagnosed). Parents are faced with a dilemma in seeking a diagnosis: Will the benefits of having a diagnosis outweigh the negatives of their child being diagnosed? Most parents do not want to needlessly stigmatize their child and many see an ASD diagnosis as stigmatizing and setting a child up for devaluation, losing the possibility to be seen as normal with normal life prospects. Some parents might feel that professionals want to pathologize and label their child as “disabled” instead of “different.” The diagnostic criteria for ASD focus on the way that a child’s behavior has a negative impact on daily functioning, which supports parental concern that a diagnosis will evoke a primarily negative view of their child. There is often a “tipping point” for parents where the negatives of having a diagnosis are outweighed by the positives: having resources to help their child, explaining their child’s behavior to others, reducing blame they receive for their child’s behavior, and obtaining professional support (Russell & Norwich, 2011).

Parent Satisfaction With ASD Diagnosis

Research on parent satisfaction with their child’s ASD diagnosis has shown mixed responses. In a survey in Scotland based on 22 families, 55% of parents were satisfied or very satisfied with the disclosure of the ASD diagnosis (Brogan & Knussen, 2003). Parents gave a higher rating if they were satisfied with the manner of the professional and the information provided; they appreciated being given written information and the opportunity to ask questions. They were more likely to be satisfied with a

higher functioning diagnosis (ASD Level 1 or Asperger’s) that was presented as a definite diagnosis.

Parent satisfaction was not related to the delay from the time of their initial concern to the time of diagnosis. Ninety percent of parents had been aware that there was something wrong. The average time between parent suspicions and diagnosis was approximately three years, ranging from no delay to 12.7 years. During the diagnostic process, parents could present opinions, observations, and fears; They were better able to tolerate the length of the diagnostic process if they felt these ideas and feelings were taken seriously and respected by professionals (Brogan & Knussen, 2003).

Controversy Over Disclosure and Presentation of Diagnosis

There is a diversity of opinion among clinicians as to whether disclosing a diagnosis of ASD is beneficial or detrimental, clarifying or stigmatizing to the individual with ASD. The issues of whether and when to disclose an ASD diagnosis are complex. Many clinicians dread sharing an ASD diagnosis (with the emphasis on the negative attributes that are the diagnostic criteria), although they believe it gives families realistic expectations of their child and gives the child a sense of not being alone with their experiences.

Differences in how the ASD diagnosis is presented reflect contrasting views of the diagnosis of ASD itself. The biomedical model of DSM-5 and ICD-10 holds that ASD is a pervasive developmental disorder. This model identifies ASD as a disability, a biologically based neurodevelopmental disorder. It emphasizes early intervention and rehabilitation to address the challenges of ASD. The psychosocial model holds that ASD is not a disorder but a differing cognitive style and developmental pathway. This model would define ASD as a neurological difference. This model acknowledges that impairments exist, but suggests that how these impairments are classified, treated, and defined by the world is socially constructed—that the designation of ASD as a disability is based on socially derived expectations of what is normal. The psychosocial model balances impairments with strengths and areas in which ASD individuals excel. It emphasizes educating society to accept neurodiversity and recognize the strengths of ASD individuals (Baron-Cohen, 2000; Malloy & Vasil, 2002). In my experience, the psychosocial model is applied to ASD individuals with no intellectual disability.

Investigators initially assumed the benefits of disclosing a diagnosis outweighed any disadvantages, but their studies revealed a more complex result. When children aged 9–16 years old with ASD (mean age 11.7 years) were interviewed, few of them felt there were advantages even when their parents identified advantages such as the ability to access services. All children interviewed found it difficult to think about the diagnosis and

Disclosure of ASD Diagnosis to Children and Adolescents

preferred to distance themselves from it. They reported that the diagnosis made them feel singled out as “not normal,” which differs from the reports of adults with ASD in retrospective studies who described feeling relief at the diagnosis. Most parents felt the diagnosis itself was of little utility in providing information about the child’s strengths and weakness, and that diagnosis did not provide schools enough information or understanding to help their child. All children felt the diagnosis had not given them understanding beyond their primary difficulty, such as “I know I have trouble making friends.” Most children found that teachers and relatives had a stereotyped understanding of ASD, consistent with their concern about stigmatization (Caldaza et al., 2012).

In a retrospective study, nine teenagers and young adults ranging in age from 16 to 21 with high-functioning autism (ASD with an IQ of 100 or above) attending college for young people with ASD were interviewed about memories of being given their diagnosis. Many issues and challenges were raised by the participants. Most individuals had been diagnosed as a young child, but disclosure to them was delayed until they were teenagers. The respondents had not been aware of having a significant problem before being informed of their diagnosis. A range of reactions were reported, including shock, disappointment, and disbelief. The diagnosis could be overwhelming, with some feeling it made their vision of their futures impossible; they wanted to avoid the idea of having autism. Others saw it as an opportunity for better outcomes. For all, it required a reworking of their sense of identity. Generally, in retrospect, the subjects felt the diagnosis ultimately helped them make sense of past experiences and gain insight into themselves (Huws & Jones, 2008).

Disclosure of the Diagnosis to Parents

The first disclosure must be to the parents if the child being diagnosed is under 18. As has been discussed, many clinicians try to balance the challenges reflected by the diagnostic criteria with the strengths suggested by the psychosocial model and the idea of neurodiversity. Research has indicated it is helpful to provide written materials and a discussion. A list of books for clinicians and for parents is provided in Table 1. In my experience, many but not all parents have already searched the topic of Asperger’s and have some degree of familiarity with the diagnosis.

An ASD diagnosis may be interpreted differently by each of the parents. Sometimes one parent (often the mother) is both saddened and relieved at having experiences and concerns validated, while the other parent (often the father) may disagree with the diagnosis as overly pathologizing behavior that will change with maturity. It may trigger recognition of these same characteristics in one of the parents, and the disclosure may evoke difficult memories. In many cases, there is grieving over the loss of visions the parents had for the family and for the child. It is critical that the parents have the opportunity to work through accepting the diagnosis and the idea of accepting their child, ASD and all (Sandler & Rosenthal, 2015).

The disclosure should be followed by a discussion of to whom else the diagnosis will be disclosed, and when such disclosure will occur (Jones, 2001). This decision is ultimately up to the parents.

As parents accept the diagnosis, they are better able to recognize the positives of a child’s ASD traits, such as attention to detail, depth of knowledge, truthfulness, and unique insight. Clinicians often use famous ASD people who have revealed their Asperger’s diagnosis, such as Tom Hanks, Andy Warhol, Susan Boyle, Dan Ackroyd, Darryl Hannah, Sir Anthony Hopkins, and Courtney Love. Many historical figures are suspected to have had Asperger’s, including Albert Einstein, Sir Isaac Newton, Steve Jobs, Charles Darwin, James Joyce, Michelangelo, and other high achievers in science, technology, and the arts. These individuals are referenced as role models to convey the message that people with ASD can be successful (Russell & Norwich, 2011).

Who Should Disclose the Diagnosis to the Child or Adolescent

It is up to parents to decide whether an ASD diagnosis should be shared with the patient, when it should be presented, and who should present the diagnosis of a child under 18. Sometimes parents may feel a diagnosis should be shared and the professional disagrees about the timing of disclosure. Such differences in opinion need to be resolved before disclosure occurs, and it provides another opportunity to clarify concerns about disclosure, possible emotional reactions to disclosure, and other issues.

Consideration of who will handle the disclosure and in what setting and conditions must be discussed. Many professionals feel they should take the lead on making the disclosure to the child and/or extended family, answering questions, and fielding any resentment. This leaves the parents free to be supportive of their child. If parents wish to make the initial disclosure to the child or adolescent, the clinician will want to discuss in depth what should be disclosed and how. In my experience, most parents have chosen to have the initial diagnosis shared by the professional, but if parents prefer to do it themselves, a follow-up appointment with the clinician could provide the opportunity for questions and clarification.

It can be important to discuss with parents what should be shared with siblings and the extended family, and to help them think through the best way to do it. A separate but related decision involves what should be shared with the school, and how best to engage the school to meet the child’s needs.

When to Disclose the Diagnosis

A child as young as 8 years old can understand ASD Level 1 if it’s presented in terms of their own experiences. Sometimes the child will provide openings for giving the diagnosis, such as asking questions about being different or having social problems.

Teenagers, however, are often very resistant to diagnosis; they want to fit in and be normal. They know that peers will reject them if they are different. It is not unusual for adolescents to become very angry and avoidant of the diagnosis and it can take an extended period of counseling to deal with this anger and resistance. This suggests that disclosure to adolescents might best be done when they raise questions about their experiences and seem more open to the suggestion of a diagnosis, rather than immediately after the diagnosis is made. In my discussions with other clinicians, most agree that timing is an important factor and readiness is a major concern. Discussions on the internet vary from opinions that diagnosis must be made immediately, even if there is an extremely negative response that takes years to work through, to beliefs that one should wait until the individual seems ready by asking questions or showing curiosity.

How to Disclose the Diagnosis

As has been discussed before, whether speaking to parents or the child, there is a movement away from using a purely medical model to one that stresses both the strengths and the challenges of ASD. If every aspect of the diagnostic criteria is not present, the patient still may have ASD traits. Books that will be useful with parents, younger children, and teens are included in Table 1.

Disclosure to parents. When disclosing to parents, labels have been found to have limited utility. It is most helpful if the disclosure not only provides a label and diagnostic criteria but also takes a phenomenological approach to the specific presentation of the child, including the positive attributes and the perceived problem areas. Clinicians need to recognize the pragmatic concerns of the parents and their experience of the challenges of the child.

For the parents, understanding why a child is insistent on doing routines in a particular way, and why changes often trigger meltdowns, is more useful than simply knowing that a diagnostic criterion is repetitive behavior. Learning why a child is unable to grasp what the parent views as normal behavior allows for a deeper understanding of the child's failure to appreciate others' points of view. Understanding that resistance to being in a large group of people might be due to the level of noise, or that resistance to brushing teeth might be related to the taste or texture of toothpaste or the feeling of the brush, is more helpful than only being told that children can have sensory hypersensitivities.

In my practice, I validate the experiences of the family, sharing the positives of the ASD cognitive style but also recognizing the difficulties the individual faces in navigating the neurotypical world and the challenges for the family. The extent of these difficulties varies greatly among ASD Level 1 individuals. Both the parents and the individual benefit from discussing a balance between fostering acceptance and accommodation and helping the individual with ASD develop skills and strategies to achieve desired outcomes. It is important for the clinician to recognize

this, especially with adolescents and young adults, because the desired outcome of the patient may differ from the desired outcome of parents and others.

It is important for clinicians and parents to understand that areas of intense interest often provide a safe and controllable respite from an overwhelming, challenging world. Children feel competent and comfortable when in the domain of their affinity or interest (Attwood, 2018). The interest may later translate into a career path. It may also provide a metaphor for the clinician to use in discussing issues with the patient. Being interested in the child's preoccupation may help parents relate positively to the child.

Disclosure to younger children (8-12). The amount of information disclosed to children is dictated by the age, capacity for understanding, and curiosity. Younger children need less information, and such information should be presented at an appropriate developmental level (in terms of language and content) and should incorporate specific examples they recognize. Children are less able to process abstract ideas. Linking the diagnosis to the child's experience is most helpful: "You know how you have trouble making friends?" or "You know how you can get stuck in school on doing things one way, even when your teacher tries to show you a different way?" The clinician can let the child know that many other children have this same problem/diagnosis, emphasizing that others also share many of the child's good qualities as well. The child needs to know that these problems can be helped. Further discussion would be gauged to the curiosity or interest of the child.

Disclosure to adolescents. For teenagers, individuals with ASD Level 1 still tend to be concrete. Developmentally, most want to be the same as peers and feel that any difference is a threat to their potential for future acceptance, even if they feel rejected by peers now. I find many are resistant to the idea that they have a problem and are hostile to the idea of being labeled or "fixed." In my practice, I wait until the teenager provides an opening by questioning behaviors or feelings. A teen might share that they feel different and will never fit in, and you can share that others have the same experience of being different in many of the same ways. You can also point to other specific ASD Level 1 traits. For example, "You know how it upsets you if the morning routine at home is different?" or "You know how you tend to feel things are right or wrong, and it's hard for you to consider someone else's way of thinking?" or "You know how it's hard for you to know how to join a group? There are a lot of people who have the same kind of problem, and other problems you have. It's a different way of thinking. If you want, most teens can have this issue improve." This type of framing is much less likely to be devastating to the self-esteem of the ASD child or teen.

It's important to keep in mind the problem as perceived by the adolescent. For example, although the parent may perceive the problem with the morning routine as a disruption for the fam-

Disclosure of ASD Diagnosis to Children and Adolescents

ily (e.g., meltdowns and difficulty getting to school on time), the adolescent may perceive the problems as being yelled at and starting the day with a negative experience.

The clinician must be literal and concrete not just in the disclosure but in the subsequent discussion. “You have difficulty understanding the point of view of others” is less helpful than “Remember when you thought that taking those pictures was OK, but your parents didn’t and it didn’t make sense to you?” As with disclosure, the clinician should work from the perspective of the adolescent. The clinician can use generalizations with bright teens, but it is important to remember that ASD Level 1 individuals tend not to generalize well. Even if you generalize to “It’s hard to know without asking, so it’s important to check out what others think or feel,” your patient may understand that parents have a different point of view about taking candid pictures of the family, but not that they have a different, valid point of

view about showing up for dinner or behavior around a sibling that must be considered.

A discussion of the teen’s interest might include the potential for development of expertise in that area, often suggesting possible career directions. Emphasis should be placed on the positive—not just the negative—features, such as attention to detail, verbal knowledge, unique insights, honesty, and expertise in areas of interest. Such a discussion may provide the opportunity to mention popular celebrities who self-disclosed having ASD to make the point that having ASD does not mean one cannot be successful.

Written Materials for Children and Adolescents

Some books are very helpful for ASD Level 1 children. Younger children might enjoy a book about a child who seems just like

Table 1. *List of Books*

<p>Literature for Clinicians</p>	<p>Attwood, T. (1998). <i>Asperger’s Syndrome: A Guide For Parents and Professionals</i>. Jessica Kingsley Publishers: London UK and Philadelphia PA</p> <p>Lynn, G, w/ Lynn, J. (2007). <i>The Asperger Plus Child: How to Identify and Help Children with Asperger Syndrome and Seven Common Coexisting Conditions</i>. Autism Asperger Publishing Company, Shawee Mission, KA</p> <p>Gerland, G. (2013). <i>Secrets to Success for Professionals in the Autism Field: An Insider’s Guide to Understanding the Autism Spectrum, the Environment and Your Role to Understanding the Autism Spectrum, the Environment and Your Role</i>. Jessica Kingsley Publishers, London UK and Philadelphia PA</p>
<p>Literature for Parents</p>	<p>Willey, L. (2001). <i>Asperger Syndrome in the Family: Redefining Normal</i>. Jessica Kingsley Publishers, London UK and Philadelphia PA</p> <p>Boyd, B. (2003). <i>Parenting A Child with Asperger Syndrome: 200 Tips and Strategies</i>. Jessica Kingsley Publishers, London UK and Philadelphia PA</p> <p>Moyes, R. (2002). <i>Addressing the Challenging Behavior of Children with High-Functioning Autism/Asperger Syndrome in the Classroom: A Guide for Teachers and Parents</i>. Jessica Kingsley Publishers, London UK and Philadelphia PA</p>
<p>Literature for Children and Teens</p>	<p>Kim, C, (2002). <i>Blue Bottle Mystery: An Asperger Adventure</i>. Kathy Hoopmann. Jessica Kingsley Publishers, London UK and Philadelphia PA</p> <p>Kim, C (2015). <i>Nerdy, Shy and Socially Inappropriate</i>. Jessica Kingsley Publishers London UK and Philadelphia PA</p> <p>Attwood, T. & Garnett M. (2016). <i>Exploring Depression and Beating the Blues: A CBT Self-Help Guide to Understanding and Coping with Depression in Asperger’s Syndrome</i>. Jessica Kingsley Publishers London UK and Philadelphia PA</p> <p>Wiley, L. H. (2015). <i>Pretending To Be Normal: Living With Asperger’s Syndrome</i>. Willey. Jessica Kingsley Publishers London UK and Philadelphia PA</p> <p>Scarpa A, Wells, A. & Attwood, T. (2013). <i>Exploring Feelings for Young Children with High-Functioning Autism or Asperger’s Disorder: The STAMP Treatment Manual</i>. Jessica Kingsley Publishers London UK and Philadelphia PA</p>

them, and it can be helpful to use a book in sessions and to share it with parents. Teens may not be ready—or they may take an interest in books on the experiences of Asperger’s teens, guides to social skills, and “how to” books. More scientifically minded teens who are less threatened by the idea of a diagnosis might benefit from looking together online or sharing articles about Asperger’s (since ASD Level 1 is a more recent diagnosis). A list of books for children and adolescents is in Table 1.

Other Considerations

Language Use and Presentation

Children and adolescents with ASD level 1 need time to process information. This is especially true for adolescents, for whom a diagnosis entails a reworking of identity and ideas about the future. It is important to gauge when a child or adolescent patient seems to have taken in as much as can be processed at the moment. It is important then to give them adequate time and space (if needed) to be quiet, do a preferred activity to self-calm, or change the topic in order to let them absorb and process the information.

When talking to children and teens with ASD, clinicians must be aware of the language they use. Word choice conveys an attitude toward what is being described and ASD children will take words literally. For example, describing something as an obsessive interest suggests that there’s something wrong with it, whereas describing it as an affinity that is intense and deep is more positive and less pejorative.

Some clinicians use a whiteboard to help parents and/or their child identify the positive and difficult aspects of ASD. These examples need to be specific for the child. Positive traits might include honesty, determination, noticing details and having ideas others miss, and the desire to do tasks to a high standard. Although many people assume those with ASD lack empathy and do not want friends, parents often describe their child as kind and caring when they understand difficulties of a family member—and as very much wanting to have friends. Difficulties might include making friends, handling emotional reactions, accepting a different way of doing things, making transitions, being teased, and understanding others’ feelings. Talking about the role models of high achievers with ASD Level 1 can help a child see that their unique qualities can be unique gifts as well. Some individuals with interest in technology or arts went on to have successful careers.

Disclosure to the Family Together

If telling the parents and child together, the time the parents need to process the implications of the diagnosis may differ from the time the child needs. It is important for the clinician to recognize

and monitor how much information the patient can take in. The patient needs time to process what is being said, too (Attwood, 2018). Providing more information than the patient can process can result in the patient shutting down or becoming upset. Pace the session accordingly. Even while presenting a positive outlook, discussing behaviors that result in an undesired outcome (e.g., current difficulties for the family or problems in school) is needed when the patient can tolerate the discussion. With understanding and compassion for the patient’s perspective, it is possible to develop insight into choices and strategies that can be developed.

Items to Keep in Mind When Disclosing Diagnosis

Disclosure of the diagnosis of ASD Level 1 can lead to feelings of loss and concerns about stigmatization, but it also can help parents have clearer expectations and a better understanding of their child, and help children understand their experiences as a different way of processing rather than being bad or inadequate.

There are basic ideas that a clinician disclosing an ASD Level 1 diagnosis must have in mind:

- A diagnosis of ASD can be experienced as an overwhelming, life-changing event by both parents and children. It is important to answer questions and to provide written material when appropriate.
- The impact of the ASD diagnosis on parents can vary widely. Parents need time to work through reactions and to accept the diagnosis.
- Both parents and children or teens find labels to be of limited usefulness. Relating the diagnostic criteria to a constellation of actual behaviors at home or in school facilitates productive understanding.
- In disclosing to children or teens, assessment of readiness and interest are important in deciding when and how much to disclose.
- When disclosing the diagnosis to children or adolescents, it is important to gauge how much information they can process and to allow adequate time for such processing.
- It’s important to emphasize the strengths as well as the challenges of the ASD diagnosis. Many children and teens with ASD Level 1 will live successful lives. This provides hope for both parents and patients.

References available at NationalRegister.org