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Helping Parents with the Initial Diagnosis of Autism: Parent-Informed Guidance for Clinicians

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ABSTRACT
Thousands of parents each year inform their child about a diagnosis of autism spectrum disorder, and most parents feel unprepared for this task. Although we are now able to reliably diagnose ASD very early in life, almost no empirical literature exists for clinicians on how to help parents educate their diagnosed child. This process must be conducted in a way that is sensitive to the child’s developmental needs while promoting an accepting and non-stigmatizing stance toward the diagnosis. This commentary is offered to help clinicians guide parents through this process. Rooted in a prior review of the literature as well as clinical experience on this topic and input from a parent of a child with ASD, we outline various factors parents may wish to consider in preparing to disclose ASD diagnoses, including rehearsal or practice of disclosure conversations, tailoring language to their child’s presentation, providing concise and accurate information, anticipating and providing space for children to react and process, and framing the discussion as a starting point for further conversation.

“Do I have to tell her?”
Caught off-guard by this question posed to me by the parent during an assessment feedback session, I recalled the particulars of the case and the questions my supervisors and I had wrestled with when preparing our case formulation. Katie, \(^1\) an 11-year-old female, had been “cuspy” in every sense of the word: her score on the ADOS-2 \((\text{Lord et al., 2012})\) fell below the clinical cutoff, she exceeded cutoffs in only some domains of the ADI-R \((\text{Le Couteur, 2003})\) and demonstrated similarly equivocal evidence on SRS-2 \((\text{Constantino & Gruber, 2012})\) and other questionnaires. Her cognitive ability was in the superior range and she demonstrated no evidence of comorbid behavior problems. Nevertheless, she rarely engaged in social interactions with peers, demonstrated clear verbal rituals, and much of her speech consisted of stereotyped language. On the whole, she met diagnostic criteria for ASD. In responding to the mother, I knew I needed to emphasize that these factors ought to be taken into consideration in any conversation with the daughter about what ASD was and how it might – or might not – affect her. Apart from that, I had little advice to offer on how she might facilitate such a conversation with her daughter.

The current estimated prevalence of autism spectrum disorder (ASD) is 1 in 59 youth in the United States \((\text{Baio et al., 2018})\) and there are thousands of children newly diagnosed each year. As a neurodevelopmental disorder, ASD symptoms persist throughout the lifespan, although manifestation can change with development. Regardless of age at diagnosis, most individuals should become aware of their diagnosis and its impact. Available literature suggests that parents of diagnosed children are most often told about their child’s diagnosis without their child present \((\text{Brogan & Knussen, 2003})\). Therefore, parents are typically responsible for the complex task of informing their child that they have a diagnosis of ASD. This process of disclosure must include concise and accurate information about what ASD is, how it affects their child, and what it means for

\(^1\)Pseudonym used to protect privacy.
the child’s activities and experiences throughout the lifespan. Further, the delivery must be tailored to each child’s age, cognitive ability, and anticipated reactions, which may be affected by difficulties with emotion regulation often present in individuals with ASD (Mazefsky et al., 2013). In our recent systematic review (Smith, Edelstein, Cox, & White, 2018), we identified factors implicated in parents’ decisions regarding whether, when, and how to disclose ASD diagnosis to their children. We also considered common reactions of children and potential strategies that might contribute to productive disclosure conversations. Here, we aim to apply these findings, as well as our experience conducting comprehensive ASD evaluations, to provide guidance to clinicians, trainees, and supervisors on discussing disclosure with parents. Our discussion aims to address the process from the perspective of a parent asking a clinician, “When and how should I tell my child about this?” Our suggestions are presented alongside personal reflections on the disclosure process from the second author, a parent of a child with ASD. As such, the suggestions that are offered to clinicians come from both clinical experience and a growing research base, whereas the parental reflections are a singular perspective, meant to illustrate the ‘felt experience’ of one parent.

**Issues for parents to consider**

Child-specific factors influence how the parent talks about the diagnosis (see Figure 1). The most obvious factor is probably the child’s age. Although the median age of first known ASD diagnosis is less than five years old based on recent prevalence estimates (Baio et al., 2018), many are diagnosed much later in life, and even into adulthood (White, Ollendick, & Bray, 2011). Diagnosis is often made later for children from racial/ethnic minorities and for those living in poverty or in rural areas (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017; Durkin et al., 2017; Mandell et al., 2009). Individuals with higher cognitive ability (often termed “high-functioning”) may also be diagnosed later (Shattuck et al., 2009). It is often not practical to disclose the diagnosis to very young children. With many children, parents may wish to describe a diagnosis in terms of behavioral differences that affect their child’s relationships with others, rather than use the formal diagnostic label. Once a child is in school, however, the label can be helpful. For practical reasons, it is preferred that the student know of their diagnosis, before they overhear it or some third party (e.g., a well-intentioned teacher) addresses it with them. An older child or teenager will likely have more questions than will a young child, about issues such as what the future holds and why s/he has the disorder.

Many individuals with ASD view the ASD label as part of their holistic identity, more so than a problem or label to be treated. Helping older youth learn about neurodiversity (e.g., Woods, Milton, Arnold, & Graby, 2018), and the social movements to promote a more inclusive and accommodating environment can be quite helpful. Within this framework, ASD might well be presented as a manifestation of behaviors that vary from a neurotypical population as a matter of degree and not of kind. That is, social communication deficits and restricted and repetitive behaviors are visible to an extent in broad swaths of the population, even when they do not approach a diagnostic level.

In order to be sensitive to the needs of the child one must also consider cognitive ability and ASD-specific communication impairment. Estimated prevalence of intellectual disability (ID) in ASD has decreased substantially from early descriptions in which ID was assumed to be present in the majority of individuals with ASD (Goin-Kochel, Peters, & Treadwell-Deering, 2008), and ID-level IQs are now estimated to be present in less than one-third of cases (Baio et al., 2018). For the minority of individuals with ASD and comorbid ID, special considerations might be made with regard to the language used and how much information about the diagnosis is provided (e.g., a more gradual process with information shared in stages). Even for children without ID, parents and clinicians should make efforts to respect that ASD is by definition a social communication disorder. Abstract and nonliteral language may therefore contribute to a child’s difficulty understanding a decontextualized and overly complex description of an ASD diagnosis (Tager-Flusberg, Paul, & Lord, 2013). One potential workaround might be for parents to contextualize descriptions of ASD in terms of behaviors the child actually demonstrates. For example, a parent might refer to the intensity of a circumscribed interest, sensory symptoms such as sensitivity
Clinical Guidance: Parent Considerations

- Disclosure conversations should begin as soon as is feasible to respect the child’s autonomy.
- Encourage parents to consider their child’s age, cognitive ability, and language use in determining how and when to disclose.
  - Diagnosis may be framed in more positive terms, using terminology related to ‘differences’ as opposed to ‘deficiencies’, as well as just one piece of a child’s holistic identity.
  - Parents may wish to cite specific examples of their child’s behavior as a means of understanding what it means to have ASD;
  - Parents might also use popular stories or characters to illustrate concepts (e.g., Inside Out (2015) to illustrate emotion regulation).
- Problems often associated with ASD (e.g., emotion regulation difficulty, alexithymia) might complicate disclosure conversations, and likely child reactions should be considered (e.g., allowing enough time and space for child’s reaction).
- Two-parent families should ensure that both parents are in agreement regarding the information to be delivered; in cases with separated or divorced parents, avoiding the presentation of conflicting information is essential.
- Parent Perspective:
  Although our son was diagnosed at age 3, we delayed the formal disclosure conversation until we thought he was developmentally ready at age 6. It was also around this time that his autism-related behaviors were becoming recognizable by other parents, teachers, and peers. By then, we also had lots of real-world examples we could reference when describing how autism manifests in him. We tried to be very conscious of our language. Although our son’s vocabulary has always been a year or two ahead of his peers, we knew he wouldn’t understand words like ‘echolalia.’ But would he know what we meant by ‘diagnosis’ or ‘cognition’? Throughout the disclosure conversation, we did frequent check-ins with him to confirm his understanding. We only used the word ‘disorder’ when giving the condition a label, and used ‘disability’ only when we linked his autism to the various therapies, groups, and school-based interventions in which he was involved. Otherwise, we emphasized how autism was a ‘difference’ in how his brain works – one that made some things easy and other things hard for him.

Figure 1. Parent considerations.

to textures, or specific social interactions that may have been affected by poor theory of mind. A child may be better able to understand what it means to be diagnosed if they are able to attach the label to their own behaviors.

Manifestations of autism within a particular child may also affect the manner in which the diagnosis is received. Specifically, difficulty with emotion regulation is well-documented within individuals with ASD (Mazefsky et al., 2013; Mazefsky & White, 2014; White et al., 2014). Especially for older individuals of average or above average cognitive ability who may have had previous negative exposure to the ASD label (e.g., from movies, or from experience with a more impaired or lower functioning student with the same diagnosis), there exists the potential for strong and negative reactions that are compounded by difficulty managing affect (Konstantareas & Stewart, 2006).
Processing evolving reactions may be further complicated by alexithymia, or difficulty identifying one’s own emotions, a common phenomenon in individuals with ASD (Berthoz & Hill, 2005; Rieffe, Meerum Terwogt, & Kotronopoulou, 2007). Therefore, clinicians should highlight the necessity of parents considering their child’s likely reaction and preparing accordingly. Space and time should be provided for the child to react in a manner consistent with their feelings.

Despite the daunting nature of preparing to disclose a diagnosis of ASD, clinicians should emphasize to parents that disclosure ought to be prioritized in all cases where it is feasible (i.e., child is of an age and developmental level that they are likely to understand information presented). There are a number of ethical and practical considerations that render it advantageous for children to know immediately about their diagnosis. First, disclosing a diagnosis to a child respects their autonomy. In addition to being included in APA’s ethical principles and code of conduct (American Psychological Association, 2017), advocates in the disability community have called attention to the need to respect the autonomy of individuals with disabilities, starting with the seminal work Nothing About Us Without Us (Charlton, 1998). An active self-advocacy community has supported this movement with regard to ASD, including the Autistic Self-Advocacy Network (Autistic Self Advocacy Network (ASAN), 2018). Parents who hold diagnoses for an extended period of time without disclosing to their children – a common phenomenon based on the results of our prior review – fail to respect the autonomy of their child, which may affect the child’s trust in his parent and ultimately contribute to negative feelings when disclosure does occur. Second, children and adolescents who are aware of their diagnoses are better able to engage in productive discussions regarding what they need and how they would like to coordinate access to services. Children are unlikely to effectively demonstrate self-determination (i.e., use knowledge and beliefs about oneself to advocate and engage in goal-directed behavior) without knowledge of their diagnosis (Field & Hoffman, 2015). Finally, knowledge of one’s own diagnosis is necessary in order for individuals to begin to decide whether and how to share that information with peers, teachers, or other adults.

**Child reactions**

In the studies included in our original review, parents cited concern about their child’s potential reaction as a reason to avoid or delay telling the child about the diagnosis. These reactions are likely to be idiosyncratic, varying as a function of the individual’s presentation of ASD and temperamental characteristics, as well as the way in which the diagnosis is communicated. Although parents may delay or elect not to disclose due to concern that the child may be angry or upset when told, they may neglect to consider possible positive reactions. Offering the child time and space to process, predicting and preparing for reactions stemming from symptoms associated with ASD, and ensuring that responses are based on accurate perceptions of ASD are critical (see Figure 3). The necessity of taking time to process a diagnosis was evident in the results of our review. Parents may therefore wish to preface disclosure conversations by letting their child know that discussions can be paused, to be revisited when the child feels ready or has questions.

Regardless of the valence of a child’s reaction, the sensitivity with which the diagnosis was disclosed, or the child’s understanding, their feelings about their ASD diagnosis are likely to evolve over time. Our review indicated that initial reactions might include anger, fear and denial; however, in many cases, these feelings reportedly gave way to a sense of “explanation” or the idea that symptoms “made sense” when considered retrospectively (Huws & Jones, 2008; Mogensen & Mason, 2015; Smith et al., 2018). However, even if symptoms provide a satisfactory means of understanding one’s own behavior, parents and children alike are likely to be wary of the extent to which a diagnosis might carry a degree of stigma. This fear was evident across all articles included in our systematic review. Parents might therefore emphasize that a diagnostic label is the child’s own information that they are entitled to share or withhold as they see fit. Additionally, parents should be prepared to provide – after an appropriate period of processing – information geared toward the child, to help them understand their diagnosis and begin to consider if and how to tell others. See Figure 2 for a list of these types of resources.
Diagnostic uncertainty

Although this update is focused on helping parents tell their child about an ASD diagnosis, the complexities of non-diagnosis should be touched upon (Figure 4). Clinicians may find themselves in a situation in which the diagnosis is not warranted. This can be difficult when the child previously held the diagnosis or when the parent is emotionally invested in ‘owning’ the diagnostic label. In such a scenario, the child may have developed effective strategies and adaptive behaviors that mitigate the presentation of autism-related characteristics. Conversely, perhaps the initial diagnosis was wrong. This is arguably a more perplexing situation, especially if a different problem has gone unaddressed due to misdiagnosis. Somewhat different from this is the situation in which a child is not diagnosed, but the parent is emotionally invested in the diagnosis for one or more reasons (e.g., connections to a social/parent network, securing services). We have worked with parents who are very active in local ASD activism groups or demonstrate investment in other forms (e.g., puzzle piece jewelry, tattoos) come to have their child re-evaluated. In such situations, when the child does not have the diagnosis, we encourage clinicians to balance empathy and understanding with fact-based feedback and information-providing. The parent may be frustrated, even angry. The clinician needs to respond appropriately without becoming defensive, or inadvertently undermining the authority or judgment of prior diagnosticians. Feedback conversations may need to include brief psychoeducation regarding the fact that even best-practice diagnostic instruments are never 100% accurate, especially considering potential changes in symptoms throughout the developmental trajectory (Pugliese et al., 2015). The clinician who can empathize with the parent’s perspective and reflect the (likely) confusion that such information brings, whilst being prepared to answer questions about the validity of the diagnosis, will more likely be trusted by the family.

Even in cases where initial evidence supports a diagnosis of ASD, the disclosure process may be complicated by a perceived need for a follow-up evaluation or by the presence of co-occurring conditions which cloud the diagnostic picture. Evidence suggests many parents consult several groups of professionals and undergo multiple diagnostic processes (Moh & Magiati, 2012). Further, diagnostic agreement across settings (e.g., school-based, hospital, community clinic) for ASD may be under 50% (Williams, Atkins, & Soles, 2009). Parents who are provided with a diagnosis they have little confidence in, or who have been provided with conflicting diagnoses, may understandably be confused about whether to disclose to their child. In these instances, transparency is warranted. Parents may wish to tell their child that they are trying to find out how best to help them with

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**Clinical guidance: Resources for Parents**


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**Figure 2. Resources.**
difficulties they may be experiencing. This might be particularly helpful in encouraging children to participate actively in multiple assessment processes. The potential for competing comorbid diagnoses may also render it difficult for families to understand behaviors attributable to ASD. The majority of individuals with ASD meet diagnostic criteria for other disorders; anxiety disorders, ADHD, and oppositional defiant disorder are particularly prevalent (Simonoff et al., 2008). Depending on the symptomatology of each disorder in a given individual, these comorbid diagnoses may be more prominent or have a greater impact on day-to-day functioning. Disentangling the symptoms of each disorder may be difficult.

Clinician disclosure to child

Alongside guidance to parents who will ultimately disclose ASD diagnoses to their children, an alternative format merits consideration. Instead, clinicians may wish to include the child in the initial feedback session, with the clinician delivering the diagnosis to parents and children together. Prior literature has suggested that this strategy may offer advantages, especially when the information contained in the feedback is creatively altered so as to be understood and processed by the child (Becker, Yehia, Donatelli, & Ewerton Santiago, 2002; Tharinger et al., 2008). However, this work was not specific to children with ASD. The vast majority of diagnoses are delivered to parents without children present; this approach likely predominates in clinical practice (Smith et al., 2018). Nevertheless, we discuss factors clinicians favoring inclusion of the child during feedback may wish to consider below (see Figure 5).

Delivery of a diagnosis from a clinician directly to a child with a parent present offers a number of advantages. First, clinician expertise can be utilized both to deliver information in a developmentally

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**Clinical Guidance: Child Reactions**

- Delivering concise and accurate information is essential.
- Disclosure need not take place in a single sitting; it may be better framed as an ongoing conversation, with further discussion when manifestation of ASD symptoms calls for it.
- Offer the child time and space to process their diagnosis; these feelings will likely evolve over time.
- Parent Perspective:

> Although we worried that he might not understand or respond positively to parts of the conversation, he was inquisitive and upbeat throughout. At times, he exhibited surprising self-reflection and would excitedly tell us about specific incidents/thoughts he had experienced that corresponded with autism-related characteristics. It was quite powerful to watch him make sense of autism by recognizing his own autistic behaviors. Nonetheless, we took too long during the actual disclosure conversation. It took us over 30 minutes to have the entire conversation. About the 20 minute mark, he was literally rolling around on the floor and jumping up and down like a frog, unable to sit still while we got to some of the more important points in the conversation. Thankfully, we framed our disclosure discussion as part of an ongoing conversation, one that our son could choose to restart or step away from at any time. In the years since, however, we (the parents) have generally prompted subsequent conversations connected to specific behaviors or situations where his autism was most apparent; but he doesn’t always make the link between autism and his own behaviors or others’ responses.

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**Figure 3.** Child reactions.
Clinical Guidance: Diagnostic Uncertainty

- Clinicians may need to navigate feedback situations in which parents demonstrate investment in an ASD diagnosis.
- Clinicians should acknowledge the confusion that may be present when parents receive conflicting information.
- Parent Perspective:

> By the time of our disclosure conversation, our son had undergone six diagnostic and evaluation processes. The four conducted by independent psychologists yielded consistent autism diagnoses; but initial reviews by the local school district and state agency for people with disabilities concluded otherwise. We successfully challenged both those rulings, but only because the first four evaluations yielded extensive and consistent evidence of an ASD diagnosis. Our son had been diagnosed with ADHD in addition to ASD. Because the conditions overlap somewhat, we introduced both diagnoses in the same conversation. It was easier for him to latch onto the ADHD diagnosis than the language surrounding autism, so we’ve had several follow-up conversations trying to disentangle ADHD and autism - with little success.

**Figure 4.** Diagnostic uncertainty.

appropriate manner and to ensure that the information relayed to the child is accurate. The latter of these points may be especially important considering that parents frequently rely on the results of internet searches for information, and the quality of online information varies widely (Reichow, Shefcyk, & Bruder, 2013). Joint disclosure by the clinician to parents and children together also encourages the child to take ownership and play a role in future decisions about their own care and treatment. In conducting feedback in this way, the clinician also helps set the precedent of respect for the individual, in keeping with the well-known “nothing about us without us” movement of disability advocates (Charlton, 1998). Finally, clinicians delivering diagnoses directly preclude the possibility that parents might delay disclosure to their child due to their fear about the child’s reaction or uncertainty regarding how to conduct the conversation. Both of these factors were found to contribute to non-disclosure in our initial review.

Despite these potential benefits, disclosure directly to the child with parents present may be undesirable or simply not useful for a number of reasons. First, the child’s age and cognitive ability may render direct disclosure inappropriate. Attempting to inform a 2-year-old or a child with severe or profound intellectual disability would likely be impractical, regardless of efforts made to adapt delivery of information. Second, parents’ emotional reactions to their child’s diagnosis should be considered. Although literature on this topic was purposely excluded from our initial review, parents have been shown to exhibit a wide variety of reactions, and may need time to process the diagnosis before considering how to deliver it to their child (Mulligan, MacCulloch, Good, & Nicholas, 2012). Parents’ reactions may include fear, guilt, frustration, or relief (Calzada, Pistrang, & Mandy, 2012; Midence & O’Neill, 1999; Ward, 2014). Third, regardless of the child’s ability to understand the diagnosis or the parent’s emotional reaction to it, parents may wish to control whether and how much information is provided to the child. As an example of this, a parent in our clinic expressed a desire for their child not to know about their diagnosis due to fear that their child would be stigmatized or treated differently. Another
Clinical Guidance: Inclusion of Child in Feedback

- We typically recommend that clinicians provide diagnoses first to parents, without children present; this decision is made easier when children are very young or their cognitive ability may interfere with their participation in the feedback.
- In cases where parents wish for clinicians to discuss diagnoses with the child, clinicians should ensure parents are in agreement regarding how much and what type of information is presented to the child.
- Parent Perspective:

  Our son was too young (3) to be included in the initial feedback session with the diagnosing psychologist, and we are thankful that was the case. Hearing the diagnosis for the first time instantly filled us with wildly fluctuating emotions that would have severely limited our ability to attend to our child’s needs at that moment. Now that our son has gained a foundational knowledge about his autism, we can envision a time in his teen years where he would join us for discussions with clinicians following any subsequent assessment processes.

Figure 5. Inclusion of child in feedback.

adult client presenting for therapy reported that his mother had told him that his ASD diagnosis simply meant that he was “just like everyone else, only a little bit smarter.” Although these parents were well-intentioned in attempting to protect their children, withholding or misrepresentation of information about a diagnosis may contribute to confusion for the child. For example, children may not understand that their symptoms are part of a larger, named entity; receipt of special services may also be confusing if they do not know why.

Conclusion and recommendations

The process of having a child diagnosed with autism is fraught with a host of potential complications. Long, difficult, expensive, and potentially conflicting assessment processes compound the emotional weight of having one’s child diagnosed with a lifelong disorder that is likely to affect their social relationships, education, and quality of life as adults (Howlin, Goode, Hutton, & Rutter, 2004). Mental health and quality of life issues for parents of children with ASD can be problematic in their own right (Davis & Carter, 2008). Nevertheless, evidence suggests that disclosure is ultimately a positive process. Children report being satisfied that they have been told about their diagnosis, and their awareness may help them to better understand symptoms they have experienced their entire lives (Smith et al., 2018).

Encouraging parents to disclose diagnoses as soon as possible is therefore incumbent upon clinicians who provide those diagnoses. Further, they should employ their awareness of ASD symptomatology and their familiarity with the evidence base to provide all parents with the tools necessary to conduct a disclosure conversation in a manner that is compassionate, easily understood, and scientifically accurate. To that end, we have synthesized the recommended considerations for language use, setting, parent resources, and content delivery in the figures included throughout this text. Finally, we present sample language below that the clinician in the introductory vignette might have used with the mother who reported being reluctant to disclose their daughter’s diagnosis to her.
Following supervision and consultation with the literature, I have a better idea regarding how I might have framed the disclosure discussion with Katie’s mother.

**Prepare/rehearse conversation**

“Choose a place and time to have this conversation with Katie. You might do some additional reading to make sure you know everything you would like to know and are able to answer potential questions. Additionally, you might direct her to resources where she can discover more about ASD on her own and connect with others going through this experience.”

**Consider child’s unique presentation and ability to comprehend information**

“Katie is extremely bright, uses sophisticated language, and has relatively mild symptoms. Therefore, you can describe ASD and what it means in relatively straightforward terms, without having to adapt your language too much to ensure she understands.”

**Provide necessary and accurate information**

“Make sure you and your husband are prepared to provide concise, accurate information about what ASD is and how it might affect Katie. You may wish to point out behaviors Katie demonstrates that are typical of individuals with ASD. For example, in your assessment you indicated that she often engages in verbal rituals and asks you to respond to her language in a certain way. By connecting specific behaviors with symptoms of ASD, she may gain a more complete understanding of what the diagnosis means.”

**Provide time/space for processing**

“Take time to process your own feelings and reactions before preparing to have this conversation with Katie. However, discuss this with her as soon as possible; it is her diagnosis and will in all likelihood be with her for the rest of her life. The sooner you tell her, the sooner she will be able to come to a clear understanding of the way ASD affects her and play a role in decisions regarding services and care. You may be nervous about Katie’s potential reaction. As her parents, you know Katie best and how she might react and may wish to prepare accordingly. Even if you anticipate a negative reaction, research suggests that many children told about their diagnoses are relieved to know that there is a name for the symptoms they experience that make them different from other kids.”

**Emphasizing conversation as a starting point**

“Let Katie know that you are willing to discuss ASD and what it means at any point, that you will answer any questions she has, and that you will find the answers if you do not. Emphasize that both your and her understanding of what ASD is and how it affects your family will evolve over time, and it is best to talk about it when necessary.”

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