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Factors Associated with Parent Reactions to the Diagnosis of an Autism Spectrum Disorder

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A dissertation submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

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ABSTRACT

Factors Associated with Parent Reactions to a Diagnosis of Autism Spectrum Disorder

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Doctor of Philosophy

Receiving a diagnosis of autism spectrum disorder is often a pivotal moment for parents. The diagnostic feedback session can provide helpful information for moving forward with their child's care but can also be filled with conflicting emotions. A few studies have looked at common parent experiences and have suggested actions for providers, but there is little information about how providers can predict parent reactions to the diagnosis and adjust their feedback accordingly. This study investigated factors related to parent reactions to the diagnostic disclosure session using a) interviews with providers that commonly diagnose autism; b) a focus group with parents of children with autism; and c) a mixed-methods survey of 189 parents with autistic children diagnosed in the US in the past 3 years. Overall, providers seem to give more information to families who are already knowledgeable about autism, helping them leave even more prepared. However, families who come to feedback very anxious about receiving a diagnosis are most critically in need of a breadth of information and are at risk of leaving the session feeling lost and unprepared if they do not receive adequate resources during feedback. Providers should be aware of parent anxiety about diagnosis and prior autism knowledge, as these factors predict parent post-session preparedness, positive emotions, difficult emotions, and confusion. Providers can help promote positive emotional reactions for parents and prevent confusion by increasing their positivity, warmth, and respect towards the family, and by being clear and confident in their communications.

Keywords: autism spectrum disorder, autistic, diagnosis, disclosure, feedback, parents

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Factors Associated with Parent Reactions to the Diagnosis of an Autism Spectrum Disorder

Receiving a diagnosis of an autism spectrum disorder (ASD) is often an important event in the life of a family (Howlin & Moore, 1997). This diagnosis can produce strong emotions and stress (Mansell & Morris, 2004) but also can help families learn about and access helpful resources and understand their child's strengths (Moh & Magiati, 2012).

Physicians have long researched the disclosure of difficult diagnoses such as cancer, Down's syndrome, and physical disabilities (Cunningham, Morgan, & McGucken, 1984; Sloper & Turner, 1993). For example, Sloper and Turner (1993) found that parents were more satisfied with the disclosure of a physical disability if the professional was sympathetic, understanding, and direct, and if they had been given sufficient information and time to ask questions. However, autism spectrum disorder is a unique diagnosis because it is not life-threatening and, often, is an invisible disability (not obvious from physical appearance). Nonetheless, it still has lifelong implications and can drastically change a parent's vision for their child (Midence & O'Neill, 1999). Because there are not yet definitive physical or medical indications, ASD is also often a difficult disorder to diagnose (Gray, Msall, & Msall, 2008), leading to long delays between first concerns and a formal diagnosis (Goin-Kochel, Mackintosh, & Myers, 2006). Recent estimates from the US indicate that families have an average delay of 2.2 years between their first contact with a professional about their concerns and a final diagnosis, with an average diagnostic age of 4.4 years (Zuckerman, Lindly, & Chavez, 2016). Families also tend to see an average of 4-5 professionals before receiving an ASD diagnosis (Goin-Kochel et al., 2006) and may be told that their child will "grow out of it" or that nothing is wrong (Oswald, Haworth, Mackenzie, &

Willis, 2017). This prolonged diagnostic process can be quite stressful for families (Crane, Chester, Goddard, Henry, & Hill, 2015).

When the diagnostic process comes to a close and a family is finally told their child has ASD or is autistic, parents have a variety of reactions, both positive and negative (Mansell & Morris, 2004). The diagnosis can help them find information, access services, gain understanding and acceptance, and receive support (Moh & Magiati, 2012). However, the diagnosis can also lead families to despair about their child's future and leave them unsure of how to proceed (Mansell & Morris, 2004). Parents often cite that receiving the diagnosis was a turning point in their lives (Howlin & Moore, 1997). However, the existing literature is extremely mixed about parents' overall satisfaction with the diagnostic process, likely owing to different practices in different countries, as well as inconsistency in measurement methods. The majority of research in this area is qualitative in nature, often including loosely structured interviews with parents that have been through the diagnostic process. Only a very few studies to date have specifically studied the diagnostic disclosure (or diagnostic feedback) session. Several studies have used quantitative measures of parental satisfaction, though these often ask about satisfaction with the diagnostic process as a whole, which includes many complicating factors. Overall, the research indicates that a family's reaction to the diagnostic disclosure is likely to be affected by pre-existing characteristics of the family, the manner of the diagnosing professional, and the information conveyed during the diagnostic disclosure session.

Pre-Diagnosis Factors

Parents and their children come to the assessment process with a variety of factors which affect their reactions to the diagnosis. Previous studies have shown that families who have spent longer looking for a diagnosis, have seen more providers, and have children who are older at the time of the diagnosis tend to be less satisfied with the diagnostic process (Crane et al., 2015; Goin-Kochel et al., 2006; Moh & Magiati, 2012). These three factors tend to be correlated, as the longer it takes, the more providers you are likely to see during that time, and the older your child grows by the time you finally end the diagnostic process (Goin-Kochel et al., 2006). Children with higher functioning ASD (i.e., Asperger's Syndrome) tend to be diagnosed later than lower functioning children, likely due to their less clear symptoms (Crane et al., 2015; Goin-Kochel et al., 2006). Several studies have shown that parents of higher-functioning children are less satisfied, in line with the longer diagnostic process they endure (Brogan & Knussen, 2003; Howlin & Asgharian, 1999; Siklos & Kerns, 2007). However, other studies have shown mixed results, likely owing to the fact that many factors accompany high-functioning children besides the longer wait, such as better adaptive functioning and reduced need for intensive treatment (Goin-Kochel et al., 2006; Moh & Magiati, 2012).

Before coming to the assessment, parents have varying levels of knowledge about autism and varying degrees of certainty that their child will be diagnosed (Braiden, Bothwell, & Duffy, 2010). One study found that parent confidence in their knowledge of ASD prior to diagnosis predicted more positive feelings towards their child following diagnosis, compared to those with less knowledge of ASD (Tomiyama et al., 2018). Some parents are fairly certain that their child has ASD, are frustrated by long delays in receiving a final diagnosis, and feel quite relieved to have the diagnosis confirmed (Midence & O'Neill, 1999). Others report feeling blindsided and "shocked" by the diagnosis, noting that they came in largely unaware about the possibility of ASD (Abbott, Bernard, & Forge, 2013; Braiden et al., 2010). Professionals often hold the belief that it is more difficult to give a diagnosis to a parent if they are less certain that their child has ASD, and that these families react more negatively and require significantly more explanation of the diagnosis compared to those who are expecting the diagnosis (Nissenbaum, Tollefson, & Reese, 2002). Conversely, Hasnat and Graves (2000) found no association between parent suspicion of disability and satisfaction with the diagnostic process in their small sample. However, this study included only 13 families with a child with ASD, and the rest with other childhood disabilities (hearing disorders, genetic disorders, etc.), making it unclear whether an association may exist in the broader ASD population.

Manner of the Professional Delivering the Diagnosis

Delivering a diagnosis of ASD is a difficult process for professionals to navigate, especially if they are not accustomed to giving such diagnoses. Professionals report nervousness at giving the diagnosis, and some report dreading the diagnostic disclosure session because of the strong emotions it evokes in both parent and provider (Nissenbaum et al., 2002). Because some providers worry about the disclosure, they may try to hedge the diagnosis (Bartolo, 2002), though parents have mixed feelings on whether this is a good trait or not, with some wanting full information and some appreciating the news being softened (Quine & Pahl, 1986). When a diagnosis was given more tentatively, or the provider seemed unsure of the diagnosis, parents were less satisfied (Brogan & Knussen, 2003). In a study of provider perspectives, many felt that it was challenging to give the diagnostic information at the right level of technicality for the caregivers, make sure the family fully understood the diagnosis, and manage parent distress (Rogers, Goddard, Hill, Henry, & Crane, 2016).

Providers also try to express liking for the child and acknowledge what the parents have already been doing for the child (Bartolo, 2002; Nissenbaum et al., 2002). Abbott and colleagues (2013) found that over half of their parent sample cited clinician positivity about their child and their parenting as important determinants of their satisfaction. Providers also try to be hopeful

(Bartolo, 2002), and this is something parents report needing and appreciating greatly (Abbott et al., 2013; Nissenbaum et al., 2002).

Parents report increased satisfaction when the provider is supportive and sympathetic, clear and definite about the diagnosis, positive and open with the parent, understanding of parent concerns, and effective at communicating (Brogan & Knussen, 2003). Many parents report that they appreciate when a provider seems to see a child's strengths and recognize their individuality, instead of talking about their child in generalities (Abbott et al., 2013; Braiden et al., 2010; Crane et al., 2018, 2015). Parents notice whether their provider seems trustworthy and competent, and put a high value on these traits (Hackett, Shaikh, & Theodosiou, 2009). Finally, parents appreciate when the provider really listens to their concerns and gives them time to process the diagnosis (Abbott et al., 2013; Crane et al., 2018; Hackett et al., 2009).

Information Conveyed During the Diagnostic Disclosure

While the manner of the professional sets the stage for a successful diagnostic disclosure session, the information conveyed during the session is crucial for parents' satisfaction. Parent satisfaction with the quality of information given is correlated with their overall satisfaction with the diagnostic process (Crane et al., 2015). Similarly, Brogan and Knussen (2003) found that the measured quality of information shared by the provider was correlated with parent satisfaction. This study defined information quality by combining parent ratings of a) their understanding of the information, b) the amount of information given, c) the degree of technicality of the information, and d) the ease with which the information was remembered (Brogan & Knussen, 2003). Qualitative studies corroborate the importance of several of these factors. Parents often indicate that the information was too technical for them to understand (Abbott et al., 2013; Hackett et al., 2009). Hasnat and Graves (2000) found that parents who reported receiving an “overwhelming” amount of information were more satisfied than those receiving an adequate amount of information, indicating that more information may be better, even if it is more than a parent can absorb. However, some parents also indicated that they had trouble paying attention to information after the diagnosis was given, due to the emotional impact of the diagnosis (Abbott et al., 2013; Braiden et al., 2010). Parents greatly appreciated the opportunity to ask questions, and while many felt that they were given adequate opportunity during the session, many also felt that they were too overwhelmed to ask questions (Abbott et al., 2013; Brogan & Knussen, 2003).

In addition to the quality of information, the type of information given is also important to parents and predicts their satisfaction (Moh & Magiati, 2012). Parents express that they are looking for a prognosis for their child, and are frustrated if they do not receive one (Braiden et al., 2010; Mansell & Morris, 2004; Nissenbaum et al., 2002). However, many professionals avoid giving a prognosis because it is uncertain, or because they feel that the prognosis is not particularly hopeful (Nissenbaum et al., 2002). In their study of the diagnostic process in Singapore, Moh and Magiati (2012) found that 92% of parents in their study (total $n = 98$) reported receiving information about early intervention programs and 87% received information about speech and language therapy, while only 79% received an explanation of their child’s problems and 77% received general education on ASD. Many parents were also offered information about special education provisions, contact information for autism related organizations, practical child management skills, and personal support and counseling, among several other services (Moh & Magiati, 2012). Notably, 30% of participants indicated that they felt “no help was offered” (Moh & Magiati, 2012), and this trend was also evident in a sample from the UK, in which 60% of parents indicated dissatisfaction with the amount of support and information offered post-diagnosis (Crane et al., 2015). Parents frequently indicate that general information about ASD is helpful, but they would like more information about their own child's symptoms, and treatments that would be most helpful for their child's individual needs (Abbott et al., 2013; Braiden et al., 2010; Hackett et al., 2009; Mansell & Morris, 2004).

Common Reactions to the Diagnosis

Receiving a diagnosis of autism spectrum disorder is an impactful event for many families, but this impact can be positive or negative (Abbott et al., 2013; Mansell & Morris, 2004). Many parents report feeling a primary emotion of relief when they finally hear the diagnosis (Abbott et al., 2013; Braiden et al., 2010; Mansell & Morris, 2004; Midence & O'Neill, 1999; Osborne & Reed, 2008). Mansell and Morris (2004) found that 90% of parents surveyed were relieved that a diagnosis had been made. Osborne and Reed (2008) noted that a higher percentage of parents of school age children reported relief (44-52%) than parents of preschool aged children (19%). Some parents express that their relief is because they finally know what is going on with their child and can move forward (Midence & O'Neill, 1999). Many parents note that the diagnosis helped them gain acceptance and understanding of their child's behaviors (Mansell & Morris, 2004; Midence & O'Neill, 1999). Other parents describe feeling validated or vindicated by the diagnosis, because it confirmed that their suspicions were well founded and made them believe that they were not just "bad parents" (Abbott et al., 2013; Mansell & Morris, 2004; Midence & O'Neill, 1999; Osborne & Reed, 2008). Some parents also felt that the diagnosis helped them feel hopeful about their child's future, because they could now receive early intervention or other services (Nissenbaum et al., 2002).

In addition to positive emotional reactions, many parents expressed negative emotions as a result of receiving the diagnosis. Mansell and Morris (2004) found that 73% of parents reported worrying more about their child's future as a result of the evaluation. Parents also commonly describe feeling “shocked” or “in shock” after the diagnosis was given (Abbott et al., 2013; Braiden et al., 2010; Mansell & Morris, 2004; Nissenbaum et al., 2002). Many providers and parents have some sense that shock is more common for parents that are not expecting an ASD diagnosis (Braiden et al., 2010; Nissenbaum et al., 2002), though some parents report feeling shocked or upset even if they knew the diagnosis was coming (Abbott et al., 2013). Finally, parents often express feeling devastated, upset and hopeless about their child’s diagnosis (Abbott et al., 2013; Midence & O’Neill, 1999; Nissenbaum et al., 2002). Several studies have used the Reaction to Diagnosis Interview (RDI) to establish whether a parent’s overall reactions (thoughts and feelings) were “resolved” or “unresolved” following a diagnosis of one of various pediatric concerns (Marvin & Pianta, 1996). Studies using this measure in the autism diagnosis population have found that more severe ASD symptoms may predict more initial “unresolved” reactions (Poslawsky, Naber, Van Daalen, & Van Engeland, 2014) while a longer diagnostic process may actually predict more “resolved” reactions, as families have time to process the possibility of a diagnosis over several months (Reed, Giles, White, & Osborne, 2019).

Parents also come away from the diagnosis with varying levels of confidence about the information they received and about how to get help. Many parents felt they received an inadequate amount of information about where to go for help and were not offered any help by the diagnostician (Crane et al., 2015; Mansell & Morris, 2004; Osborne & Reed, 2008). This led some parents to wait a long period of time before getting help because they didn’t know where to go (Braiden et al., 2010). Parents also expressed that they left somewhat confused about the diagnosis or uncertain about what to tell others about the diagnosis (Abbott et al., 2013; Hackett et al., 2009; Mansell & Morris, 2004). Several parents felt that they came away with very little information about autism and had to get it from other sources (Mansell & Morris, 2004). Parents in two UK studies identified post-diagnostic support (including information, follow-up, and direction) to be a top research priority in the coming years, and many felt frustrated with leaving the feedback session feeling directionless, without necessary supports (Crane et al., 2018; Pellicano, Dinsmore, & Charman, 2014).

Provider Guidelines for Diagnostic Disclosure

Previous research has shown that some providers lack confidence in effectively sharing autism diagnoses (Nissenbaum et al., 2002) and would benefit from further training, as has been helpful in other diagnostic fields such as with Down syndrome (Kleinert, Lunney, Campbell, & Ferguson, 2009). Nissenbaum and colleagues (2002) developed nine recommendations for providers diagnosing autism, including becoming knowledgeable about autism, establishing a family-friendly setting, understanding the family's needs, communicating effectively, providing lists of resources, providing follow-up, discussing prognosis, providing hope, and accepting that giving diagnoses can be difficult for providers as well. A recent meta-analysis of UK parent diagnostic experiences identified several themes to parent needs, including emotional, informational, and relational needs (Legg & Tickle, 2019). Several organizations have developed guidelines for the delivery of autism diagnoses, including NICE (National Institute for Health and Care Excellence, 2011) and the Autism Speaks Autism Treatment Network (ATN/AIR-P, 2012). The latter summarizes the research on this topic well and gives tools and actionable steps for providers to learn high quality diagnostic feedback methods. However, current research and guidelines do not adequately describe how providers can predict which families may struggle after diagnosis, and how to adjust to these varied needs.

The Current Study

Research into diagnostic feedback sessions has been mostly qualitative in nature and has provided a solid foundation for effective clinical practice. However, there has been limited research on the quantitative predictors of parent experiences. The current study strives to determine factors that can help diagnosing professionals predict which clients are at risk for struggling most with the diagnosis and moving forward with their child’s care and discover what that these professionals can do during the diagnostic process to improve client outcomes. Specific aims are set forth as follows:

Aim 1. Understand parent and provider experiences with the diagnostic disclosure session in order to inform quantitative data collection and analysis.

Aim 2. Categorize the various types of parent reactions to diagnostic disclosure sessions, as well as pre-session parent factors and provider factors that may impact parent reactions.

Hypothesis 2.1. Parent reactions will cluster under positive emotions, negative emotions, and readiness for action.

Aim 3: Determine which parent and provider factors predict parent readiness to take action following diagnosis.

Hypothesis 3.1. Parents who received more information about resources and recommendations will leave feeling more prepared.

Hypothesis 3.2. Parents who know more information about autism and available resources before the disclosure will leave feeling more prepared.

Aim 4. Determine which parent and provider factors will predict positive and negative emotional reactions.

Hypothesis 4.1. Parents who were more certain that their child would be diagnosed with autism prior to feedback will have more positive emotional reactions and fewer negative emotional reactions.

Hypothesis 4.2. Parents who report that their diagnosing professional displayed a more positive manner will have more positive emotional reactions and fewer negative emotional reactions.

Aim 5. Integrate relationships between parent factors, provider factors, emotional outcomes, and readiness outcomes in one model.

Aim 6. Develop guidelines for professionals giving an autism spectrum disorder diagnosis.

Methods

This study included three distinct components: Provider interviews, a parent focus group, and a mixed-methods parent survey. See Appendix A for study flow chart. All recruiting and experimental procedures were approved by the university's Institutional Review Board in accordance with ethical standards.

Participants

Provider interviews. In the first portion of the study, six providers who regularly diagnose autism spectrum disorder were consulted by phone to receive input on a draft of our parent survey and to gain more information about their diagnostic processes. The survey draft was emailed to them prior to the phone call. These providers were recruited from the surrounding area and were intended to provide a sample of several professions that commonly diagnose autism spectrum disorders. See Table 1 for demographics of providers interviewed. Participating providers were offered a $50 Amazon gift card for their time.

Table 1.

Demographic characteristics of providers interviewed

Profession	Setting	ADOS Training	Evals/month	General Age Range
Psychologist (PhD)	Private practice, academic medical center	Research reliability	2-4	Teens and adults
Psychologist (PsyD)	Academic medical center	Clinical training	8	3 years – 5 years
Social Worker (LCSW)	Community mental health center	Clinical training	2	2 years - adult

Clinical/School Psychologist (PhD)	University Autism Clinic	Research reliability	20	1 year - adult
Pediatrician (MD)	Academic medical center	None	3-5	1 year - 10 years
Speech Pathologist (PhD, CCC-SLP, BCBA-D)	Private practice	Research reliability	2-5	2 years - 7 years

Parent Focus Group. Before the final research survey was sent out, a focus group of parents was convened to pilot the survey and discuss diagnostic experiences. The focus group consisted of 10 parents of children that have been diagnosed with autism spectrum disorder within the last three years, recruited from the surrounding area by word of mouth and a local autism parent group. Participating parents were offered free child care with trained child-care providers during the meeting and a $25 Amazon gift card for their time. The focus group consisted of 8 mothers and 2 fathers. See Table 2 for demographic breakdown of the focus group. The group was designed to include parents of children diagnosed at different ages. None of the participants had a child diagnosed by the focus group leader or other study staff, though several families were diagnosed by providers interviewed in the previous portion of the study. All parents had children diagnosed in the past three years in the United States.

Table 2.

Demographic Characteristics of Focus Group Participants

Relation	Child Gender	Age at Dx	Diagnosing Provider type
Mother	Male	5	Psychologist
Mother	Male	10	Social Worker
Mother	Male	3	Speech Pathologist
Mother	Female	3	Neurologist
Father	Female	3	Neurologist
Mother	Female	3	Psychologist
Father	Female	3	Psychologist
Mother	Female	6	Psychologist
Mother	Male	15	Psychologist
Mother	Male	12	Social Worker

Survey Sample. Parents of children diagnosed with autism spectrum disorders were recruited from autism-related service organizations and community groups from around the United States. Survey information was distributed to relevant organizations that serve families with ASD with a request to publicize the survey on their websites, social media, or by email. Organizations and individuals contacted include national autism research organizations, state and regional autism parent organizations in several parts of the country, university and hospital-based autism centers, and autism specialty private practice clinicians. Clinicians and researchers also shared the study on personal social media accounts to potentially reach parents that were not associated with any formal organizations.

Parents who completed the survey had a child that had been diagnosed with an autism spectrum disorder (ASD, Autistic Disorder/Autism, Asperger's Syndrome, Pervasive Developmental Disorder—Not Otherwise Specified [PDD-NOS]) within the prior three years. The three-year benchmark was chosen partially to generally increase accuracy of memories for this specific moment in time, but also to increase the likelihood of parents experiencing diagnosis after widespread implementation of DSM-5 diagnostic labels. This time frame also allows us to generalize findings to current diagnostic practices in the US. The survey consent requested that the parent filling out the survey was present (in person or by phone) when the ASD diagnosis was initially disclosed by a clinician following some level of assessment. Participants were offered a chance to enter a drawing for a $75 Amazon.com gift certificate. At the end of the survey, parents who wished to enter the drawing were routed to a separate page where they could enter an email address, to preserve confidentiality of responses on the main survey. The chances of winning were estimated to be 1 in 25. Winners were drawn randomly following closure of the survey.

Parents who completed the survey had children a wide range of ages at diagnosis (Min = 1 year, Max = 28 years), with the median age at diagnosis (4 years) and median first contact with a professional (2 years) matching closely with recent US averages (age of diagnosis 4.4 years, first contact 2.2 years; Zuckerman et al., 2016). Overall, 49% of families reported that their child was diagnosed with one or more additional conditions during the diagnostic feedback session. The most common co-diagnosed condition was attention-deficit/hyperactivity disorder (n = 43), followed by anxiety disorders (n = 37), intellectual/global developmental disorders (n = 16), depressive disorders (n = 13) and sensory processing disorders (n = 11). Due to a coding error, the question regarding child ethnicity status was omitted from most participants' surveys, making race/ethnicity data difficult to interpret. It is thus unclear how many participants identify as Hispanic/Latino. Participants' children were diagnosed in 24 U.S. states. The greatest number of participants were diagnosed in Utah (n = 100), followed by Oregon (n = 19), New York (n = 14), Washington State (n = 14), and California (n = 15), with the remaining 32 spread across 19 states. See Table 3 for further demographic information for children and Table 4 for information about parents.

Table 3.

Demographic Characteristics of Survey Respondents' Most Recently Diagnosed Children (n = 189)

Child Sex	
Male	77%
Female	23%
Age at First Concern	
Mean	2.61 years
Median	2.0 years
SD	2.70 years
Age at First Provider Contact	
Mean	3.12 years
Median	2.0 years
SD	3.27 years
Age at Diagnosis	
Mean	6.23 years
Median	4.0 years
SD	5.12 years
Diagnosis Given	
Autism Spectrum Disorder	79.4%
Asperger's Syndrome	8.5%
Autistic Disorder/Autism	6.3%
PDD-NOS	3.2%
Unsure	2.6%
Child Race	
White	85.7%
Black/ African- American	1.1%
Asian	4.8%
American Indian/Alaska Native	1.1%
Native Hawaiian/Pacific Islander	0.5%
Other	6.9%

Table 4.

Demographic Characteristics of Survey Respondents (n = 189)

Relationship to the Child	
Mother	90.5%
Father	6.9%
Other	2.6%
Respondent Marital Status	
Married	87.8%
Divorced/Separated	5.8%
Never Married	6.3%
Education	
Less than High School	2.1%
High School Graduate	5.8%
Some College	18.5%
2 Year Degree	9.5%
4 Year Degree	37.0%
Professional Degree	23.8%
Doctorate	3.2%
Family Income	
< $20,000	5.3%
$20,000 – 39,999	12.7%
$40,000 – 59,999	15.9%
$60,000 - 79,999	14.8%
$80,000 – 99,999	10.1%
$100,000 or more	41.3%

Procedures

Provider interviews. Providers were consulted about the draft survey questions and about their experiences giving diagnoses. Providers were asked to discuss their general diagnostic feedback process, modifications made to their process based on family characteristics, client factors that made diagnoses easier and harder to deliver, their assessment of client preparedness for feedback, and their use of follow-up communication post-feedback. They were also asked about their perceptions of their clients' experiences with feedback, including commonly seen emotional reactions, common questions asked, and common actions taken following feedback. Consultations were audio recorded. In response to provider feedback on the survey, questions were added and wording altered before sending the survey to focus group participants.

Parent focus group. The focus group participants were asked to complete the survey as pilot participants prior to the group meeting. In the focus group session, parents were asked general questions about their experiences with the diagnostic feedback session, including their knowledge of autism prior to diagnosis, their memories of the session and diagnosing provider, and their reactions to the diagnosis. Participants were also asked to comment on the clarity and appropriateness of the questions in the survey draft and give suggestions about questions or answer choices they deemed important that may have been missing from the survey. The focus group was audio and video recorded and was transcribed from recordings. Survey questions were adjusted and response options were added as a result of focus group feedback. These changes are reflected in the final survey presented to families (Appendix B).

Measures

The self-report survey used in the current study was combined and adapted from various interview questions presented in Sloper and Turner (1993) and Howlin and Moore (1997), as well as more recent updates of these questions (Brogan and Knusen, 2003; Crane et al., 2016; Moh and Magiati, 2011). New questions were developed from ideas found in the qualitative literature previously discussed and some were developed to directly address study aims. Questions were then altered based on provider and focus group feedback (see results section for further details about these changes).

Information about the child. This section asked about the child's diagnosis, age at diagnosis, age at parent's first concern, age at parent's first contact with a professional regarding their concerns, other diagnoses given during the appointment, US state in which diagnosis was given, and the child's sex at birth.

Information about the parent/family. This section requested information about the respondent's relationship to the child, education level, marital status, family income, and whether any other children in the family have been diagnosed with ASD.

Parent status before the feedback session. Parents were asked to rate their thoughts before the diagnostic feedback session on a 5-point Likert scale, ranging from strongly agree to strongly disagree. Parents were asked to report on how strongly they believed their child would be diagnosed with ASD, to what degree they wanted their child to receive an ASD diagnosis, to what degree they were nervous about receiving a diagnosis, how uncertain they were about what the professional would diagnosis, and how strongly they hoped the provider would not diagnose ASD. Parents were also asked to rate on a 5-point Likert scale how much they knew about autism spectrum disorder before the diagnosis, how much they knew about what treatments their child would benefit from, to what degree they had sought out services for their child already, and to what degree they had sought information to help their child at home. Parents were asked to record the reasons they were seeking an evaluation and what services (if any) their child was already receiving.

The diagnostic feedback session. Parents were asked to rate how clearly the diagnosing provider gave information about why their child had been given a diagnosis, ASD in general, the child's prognosis, treatment options, treatment goals, and strategies for helping the child at home. Parents were asked about their perceptions of the manner of the diagnosing provider. They were asked about the provider's competence, how confident the provider seemed in the diagnosis, how well the provider seemed to understand their child individually, how much the provider seemed to enjoy or like the child, how positive the provider was about their parenting, and how clearly the provider expressed the child's strengths.

After the diagnostic disclosure. The parents were asked about how strongly they felt a variety of common positive and negative emotions following the diagnostic disclosure session. Parents were given a short descriptive statement attached to each emotional label, to anchor parents on a common understanding of the question. This anchor was given in response to parent feedback that it was difficult to report on their complicated emotional experience without being clear about why they felt that emotion. For example, "worried about my child's future," rather than "worried," as there are many things a parent may be worried about during this process. These anchors were developed based on provider and focus group descriptions of their emotional experience, which matched well with past qualitative literature. Positive emotions include: relieved, validated, hopeful, and grateful. Negative emotions include: in shock, worried, upset, overwhelmed, confused, lost, alone, sad, and angry. The parents were also asked to indicate how competent they felt in a variety of domains following the feedback session, including perceived ability to locate help, knowledge about what treatments their child needs, knowledge about what goals the treatment providers should be working on, knowledge about how to help their child effectively at home, knowledge about why their child meets criteria for ASD, and knowledge about ASD in general. They were also asked about the time taken to begin seeking help following the diagnostic disclosure. Finally, parents were asked to rate their overall satisfaction with the diagnostic disclosure process on a 7-point Likert scale.

Data Analysis

Data cleaning. There was little missing quantitative data in this dataset, due in part to reminders for participants about missing items when the survey was advanced to the next page. Out of 189 total participants (those that filled out at least one question) only 11 participants did not complete the quantitative portion of the survey, with four terminating participation after demographic variables and before any questions about their feedback experience. Participants who discontinued the survey were overall similar to those who completed the survey, with a few notable exceptions. Participants that discontinued quantitative questions prematurely on average reported lower income and education than those that completed the survey. The group of 11 who did not complete the survey also included two grandparents (with zero grandparents represented in the completed survey group). The online nature of this data collection may have reduced access for some interested in participating. One outlier case was deleted due to an inattentive response style with uninterpretable results. In this study, listwise deletion of data was used for regression analyses and structural equation modeling, and pairwise deletion was used for correlations.

Aim 1 – Understand parent experiences. We first analyzed all qualitative data, in order to better inform quantitative analyses. The primary author analyzed transcripts from provider interviews, the parent focus group, and open-ended survey questions in NVivo software using a content analysis approach to identify themes. The primary author served as the coder for this study, and first read through all transcripts to understand the data more broadly. Because many participants answered questions with multiple thematically separate answers, we chose to code individual comments rather than whole heterogeneous answers. Within each question asked of participants, the primary author coded individual comments into content areas. Once all answers were coded by content, the primary author sorted related codes under broader themes. A second researcher naïve to the original coding process checked each category for face validity and overlapping of codes. Several themes were then reorganized by the primary coder to improve thematic efficiency.

Aim 2 – Categorize parent reactions, parent factors, and provider factors. We used principal-component factor analysis with the Likert survey data to identify natural groupings of the variables that could be combined into a smaller number of scale scores. We ran separate analyses for pre-session variables, in-session variables, and post-session variables. We extracted and explored factors with eigenvalues greater than 1. Factors that made conceptual sense were used to create a scale for the underlying latent variable by averaging relevant variables. Thus, scales all range from 1 to 5, but encompass more variability than their original component survey questions. See Tables 10, 11, and 12 for final scales and the variables used to create each scale.

Aim 3 – Factors related to parent preparedness. We ran Pearson’s correlations between parent, provider, and reaction variables to confirm the hypothesized relationships between variables. In order to investigate how pre-existing parent knowledge interacts with provider-delivered information to impact parent feelings of preparedness, we used a mediational analysis. We used moderation analysis to determine the relative impact of provider-delivered information at different levels of parent anxiety about receiving a diagnosis.

Aim 4 – Factors related to parent emotional reactions. We used simultaneous multiple regression analysis to determine how strongly provider factors influenced emotional outcomes, as previous literature is unclear about how provider actions directly affect parent emotions after diagnosis. We then included the strongest provider factor or factors in a simultaneous regression with parent pre-session factors, and then eliminated any factors that did not add significantly to model fit to improve model efficiency. This method was used for all three emotion factors individually. For difficult emotions and positive emotions, Shapiro-Wilk tests showed normality in the distributions of regression residuals (Thode, 2002), scatterplots of residuals against predicted/fitted variables did not show heteroscedasticity, and collinearity was within appropriate limits as the variance inflation factors (VIF) for all variables was < 2 (O'Brien, 2007). For the regression equation for *confusion post-feedback*, residuals were found to be affected by skew. To help correct for the effect of this non-normality on significance of results, a more rigorous cutoff for significance values was used.

Aim 5—Model factors associated with outcome. Finally, we used concepts from qualitative analysis and quantitative analyses to develop three path analysis models that may explain the relationships between pre-session factors, provider factors, emotional reactions, and preparedness. These models tested whether the data can best be explained by provider and parent factors feeding into preparedness which then affects parent emotions, or parent and provider factors leading to emotional reactions which then affects parent feelings of preparedness, or whether preparedness and emotional reactions are best understood as separate parallel processes.

Aim 6—Establish recommendations for providers. Results of qualitative and quantitative data were summarized and integrated to establish recommendations for providers, found in the discussion section.

Results

Provider Interviews

Providers who diagnose autism are faced with many decisions before and during feedback, which may differ significantly depending on the family's particular needs and situation. Providers were asked about their process of diagnosing a family from start to finish, in order to gain insight into how providers make these important decisions and where there may be room for improvement in the field. A summary of major findings can be found in Figure 2 at the end of this section.

Screening prior to disclosure. Starting when a family is scheduled for an appointment, providers typically begin preparing for a child's assessment and care. When asked if they have a formal process for collecting information about a parent's initial beliefs that their child has autism or understanding of the diagnosis prior to feedback, all providers interviewed stated that they did not have any such process. However, all six providers also noted that they try to informally pick up on cues to determine what the family believes about their child or how they may react to the diagnosis. One provider described it as "nothing formal. I think I get some sense of it on the interview portion, when you are spending 30 to 45 minutes, you can pick up on those clues." Providers noted that they pick up this information from comments on the intake form, from the interview, from how parent questionnaires match the child's presentation, or a parent's affect during the assessment.

Timing of delivery of diagnosis within assessment framework. Providers acknowledged that they carefully consider when to start the process of preparing the family for the diagnosis and when to deliver the final diagnosis. Three providers stated that they often try to warn the family throughout the assessment process that a diagnosis is coming, but they report doing this for different reasons. One provider stated that she will weave in comments about what diagnoses different symptoms might be pointing to throughout the assessment, so that parents are not surprised at the end. Another provider mentioned that she might focus on providing these diagnostic warning comments if the family seems to already know that their child has autism, because “we’re talking about it more openly throughout.” In contrast, the same provider mentioned that she will also give more warning if the family seems to know very little about autism. She states, “I’ll say something like…’I’ve seen a couple things that look like autism, but I really want to know how he looks at home’… where it’s not definitive, but it’s not confirming something that I don’t want them to think. Some people will say ‘oh, he did great’ and parents might take that the wrong way, while he may have done great, but he still has autism.” Another provider described that they will give more warning if the case seems particularly clear to them, diagnostically.

When discussing their diagnostic process, four providers mentioned having some flexibility about when they will deliver the final diagnosis within their assessment process. These providers report choosing between same-day delivery and waiting until after the assessment day and having the family return for feedback. The deciding factor for all four providers was their confidence in the diagnosis by the end of the final assessment session. They report delivering a diagnosis at the end of the session if they are certain of the diagnosis, and waiting if they are uncertain, usually taking the additional time to score assessment measures, review materials, communicate with other care providers, consolidate their thinking, or write the full written report. These providers expressed balancing worries about keeping the family waiting for a diagnosis (and subsequent treatment) with the desire to ensure accuracy of diagnosis.

General feedback session structure. Interviewed providers were asked to elaborate on their general outline for feedback sessions. They gave varying levels of detail, and some described having a formal outline that they use, with others describing no set structure. The structure usually consisted of reviewing test results, stating the diagnosis, leaving room for reaction and questions, and then discussing recommendations. See Figure 1 for provider session outlines.

Modifications to session structure. Providers noted that they may modify their general session outline depending on the qualities of participants, how ready they feel parents are to receive the diagnosis, and how much emotionality the parents are showing. Each is described below.

Qualities of participants. Providers noted that they are likely to modify their sessions to best fit the personal qualities of the participants including age, cognitive abilities, language, and co-parenting status. One provider noted that when small children are in the room, she tends to be more abbreviated, because while she prefers to take the whole allotted time, “when you have a screaming 2-year-old and a 4-year-old and a child with autism who is 6, that's just not possible.” Another provider mentioned that she tends to be more abbreviated and use simpler language when a parent seems to have reduced cognitive abilities or otherwise has difficulties with understanding. Alternately, when using interpretation services for non-English speaking families, one provider described needing either a longer session or to give less information during the session, as interpretation takes more time. Two providers mentioned that they tend to modify their sessions when parents either do not agree with each other or have different perspectives on their child’s difficulties. One provider noted that if two parents are separated she will offer to have the parents meet together or have two separate feedback sessions. These combined sessions are described as longer and more emotion-focused, as it is difficult to “hold all of those emotions at one time.”

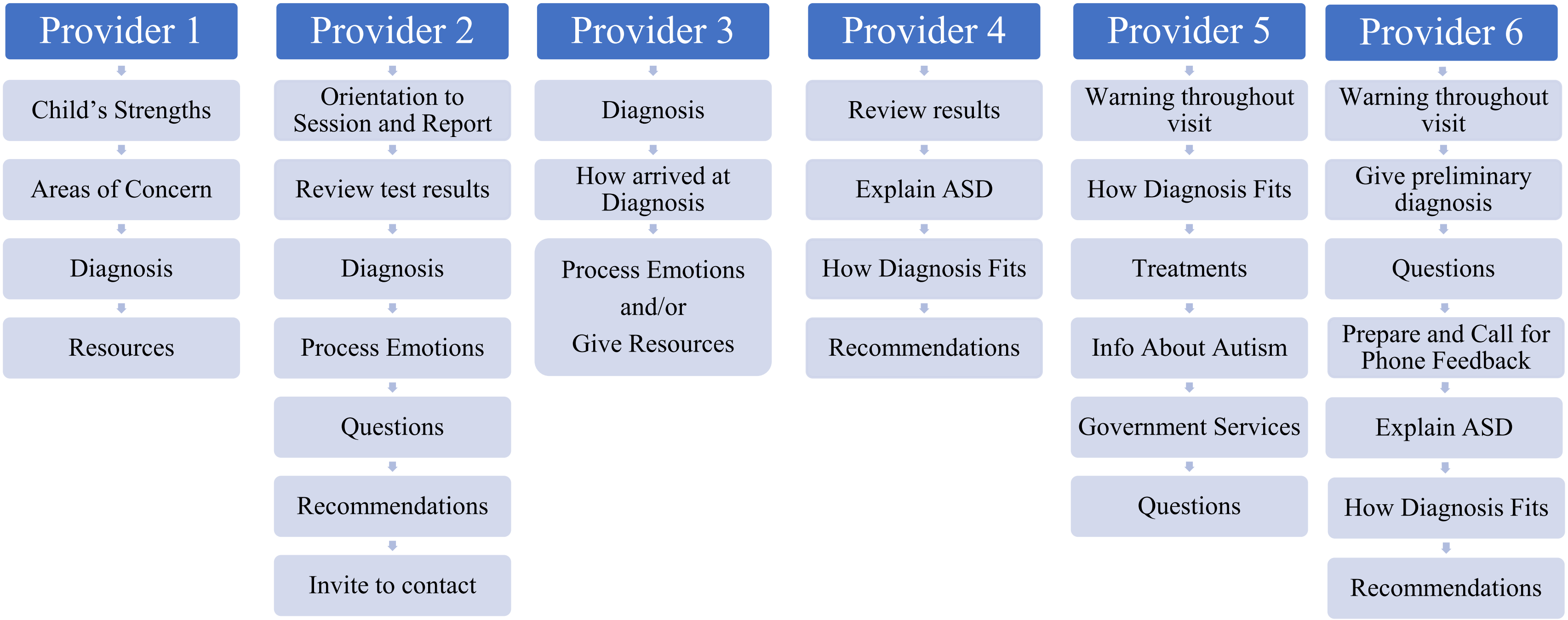

Figure 1. Feedback session outlines commonly used by interviewed providers.

Readiness for diagnosis. Several providers indicated that a family's readiness for the diagnosis leads them to modify their session structure. When families are expecting a diagnosis or are wanting a diagnosis, feedback sessions are described as shorter and more focused on answering specific questions rather than on processing emotions or giving education. One provider described that "it was usually families that came in pretty confident that it was autism…those were usually the ones who were 'thank you' and then they were gone." Several others described that when families are very uncertain of the diagnosis, seem to be "in denial," or are particularly shocked by the diagnosis, then they give less information and focus on emotions. One provider stated that when a family does not seem to be prepared, they will "focus a lot on the strengths that I'm seeing and then am more cautious about, I mean I will use the word autism but will be more cautious in the way that I talk and will try to look for parent reactions and try to adjust to that to not overwhelm them."

Emotionality. Though some providers indicated an overlap between emotionality and readiness for diagnosis, others noted that they modify their sessions when a family is emotional, regardless of the reason. Providers described low-emotionality sessions as focused on giving information and problem solving. In contrast, high emotionality sessions were reported as focused on processing the family's thoughts and feelings about the diagnosis, with less focus on information. One provider described that when the family expresses devastation, "sometimes the report gets set aside and we almost have more of a therapy session to help them come to some peace and some understanding of the diagnosis." Another provider noted that even if a family is wanting a diagnosis, an unexpected upset might cause them to focus more on emotional support than on information.

Difficult sessions. When asked under what conditions they find it hardest to deliver an autism diagnosis, provider answers separated into three themes: violation of expectations, parental disagreement, and lack of resources. Five providers noted that delivering diagnoses is the most difficult when the diagnosis given does not match the family's expectation. This includes when the family is very upset or angry about the diagnosis and when they are in denial about the diagnosis. Three providers also mentioned that the hardest feedback for them to give is when the parents were expecting an autism diagnosis, but the provider is not giving one. Providers expressed that these sessions are difficult because often "there aren't really good answers in terms of diagnosis" and families feel "a sense of devastation or hopelessness or just fear—like, 'I don't know where to go.'" Three providers also described that it is most difficult to give a diagnosis when two parents/caregivers disagree about the diagnosis in the room. They reported situations where two parents saw different symptoms, or "start blaming the other parent for the child's behaviors." Finally, two providers described that they find it very difficult to deliver an autism diagnosis when the family does not have sufficient resources, financial or otherwise, to carry out recommendations.

Least difficult sessions. When discussing what conditions make a diagnosis easier to give, providers largely described the same themes as were described as making a session difficult, with opposite valence. Two providers clarified that they always find it difficult to give a diagnosis to a family, with one provider describing that "I don't think there is anything that makes it easier." Four providers indicated that when a family is well prepared for the diagnosis, it tends to be easier to deliver. Similarly, three providers described that it is easier to diagnose when a family wants the diagnosis (e.g. to receive services). Sessions were also described as easier if both parents were in attendance, and if the family had ample resources to engage in treatment and advocate for their child.

Follow-up after disclosure. When asked whether they follow up with parents after the disclosure, five providers said that they do not do any formal follow-up but will give the parents their contact information and encourage them to reach out with questions. Though they reported genuinely wanting families to reach out, several providers stated that very few families seem to take advantage of their offer. One provider, a developmental pediatrician, stated that they try to schedule a 3-month follow-up with families. Several providers said that they wished they could follow up formally with families, but that it is difficult given their clinic structure.

Provider perceptions of parent reactions to diagnosis. Providers were specifically queried about emotions they commonly see, but also made note of client emotional reactions throughout the interview. Mentions of emotions and feelings were collected from throughout the interview. Common reactions to the diagnosis clustered into five themes: Struggling, sadness, anxiety, anger, and positive emotions.

Struggling with the information. Providers reported several different emotions and feelings that were described as related to a family's reception of the diagnostic label and information in the moment. Several providers emphasized that they frequently see families appear to be struggling to accept the diagnosis or look as if they are in denial. Other families were described as unsure or confused about the diagnosis. For example, one provider described that they frequently see "confusion, regarding Asperger's vs high functioning vs all the other names that people have tried to give to understand these characteristics." Providers frequently used the word "overwhelmed" to describe common parent reactions to the information.

Sadness reactions. Providers describe a wide range of reactions that represent a range of sadness about the news. Several providers used the words “sad” or “depressed” to describe common reactions. Others described that the family’s reaction seemed to be part of a larger process of grief and loss. For example, one provider described that families express grief over losing “their dream of having the kid that’s going to have it easy.” One provider described families as sometimes expressing hopelessness after hearing the news. Many providers used words of higher intensity unhappiness, including “distraught,” “devastated,” and “heartbroken” to describe parent reactions, such as one provider describing parents having a “devastating ‘I didn’t want this to be the answer’ experience.”

Fear reactions. When hearing a diagnosis, many families are described as looking forward with fear. A few providers simply described these reactions with the word “fear.” Others noted a more cognitive “anxiety” or “worry.” One described that they sometimes see a mild “concerned” reaction, while others report seeing a more significant “scared” or “terrified” reaction. Some providers specified why a parent was expressing fear, for example “worry, over what the future will be like, like if they're kid will be independent or not” and “fear—like ‘I don’t know where to go.’”

Anger reactions. A few providers mentioned that they see their clients express anger or direct their distress at a person or institution. For example, one provider noted that they sometimes see “parents blaming each other – ‘Well if you didn’t do this, he wouldn’t act like this.” Another mentioned that they have seen clients express anger at past providers who may have missed the diagnosis or not believed them. Two other providers noted anger and blaming, without specifying at whom these were directed.

Positively valanced reactions. While there is great variety of negative reactions described by providers, there are also several positive reactions that providers frequently see from parents at diagnosis. The most common positive reaction noted was relief. Parents express “relief to have an answer” and a sentiment of “finally! So now what do we do?” One provider specified that relief is likely the most common reaction they see to an autism diagnosis in their setting. One provider mentioned that their families sometimes express appreciation when the diagnosis is delivered. Other providers describe that families appear to feel “validated” when given the diagnosis. Looking forward to what they will do next, some families express feeling “hopeful” and “confident.”

Common parent questions. After receiving the diagnosis, parents often have questions for the provider. The providers interviewed described that common parent questions revolved around a) the diagnosis itself and b) treatment options. Three providers mentioned that they are frequently questioned about the child’s prognosis. For example, one provider described that the most common question they get is about prognosis, “their ability to live independently, get a job, get married, have kids.” Some providers noted that this is one of the hardest questions for them to field, because it is difficult to estimate what a child’s future will hold. One provider described that they are frequently asked “Where on the spectrum is my child?” Another provider said they commonly are asked about what autism is and where it “comes from.” Finally, one provider indicated that they are often asked for advice on how or when to disclose the diagnosis to the child.

When asking about treatment options, three providers said families are likely to ask about specific strategies they can use to help their child at home or in the community. Another three providers stated that families ask about the names of people or places that can help, especially seeking the provider's opinion on who in the community is skilled to treat their child's concerns. In reaction to this question, one provider said that she finds it difficult to give advice because "the resources are constantly changing. I tell them that other parents are usually the best source of current information and resources." Two providers said that parents often want to know what the next steps are in terms of treatment and ask for the clinician's opinion on how to prioritize their child's care. Similarly, one provider noted that they often hear requests for specific steps on how to access the resources recommended.

Perceived client actions following diagnosis. When they leave the provider's office, families often begin to take new steps to help their family thrive. Providers were asked what they believe their clients do first after the disclosure. However, three providers shared that they were not entirely sure where families start, as so few follow up with them. Several providers suspected that families may start by seeking services, such as contacting the school, applying for government services, or starting early intervention. Three providers have found that families often go online first, "googling, … going to different forums" or "looking for resources." Two providers felt that many clients may "shut down" or "become depressed" for a while after the disclosure, especially for teens or adult clients.

Provider hoped-for client actions. After recognizing that providers were unsure of what actions their clients performed, a question about desired client first steps was added to the interview, eventually being asked to 5 of the 6 providers. Almost all of the providers hoped that families would seek out support, either from their families or from existing autism support communities. Three providers said that they often hope their clients will get on waitlists or get started with treatment first. For example, one provider described that they hoped "if ABA is that primary recommendation, that they're able to contact their insurance or reach out to a provider and take that ABA letter and get on a waiting list or start that process." Another provider described that they usually recommend families talk to the school (for school age children), while one provider hopes many eligible families start with government processes such as applying for disability services. Providers generally described hoping families start with an important service that can take a long time to get into, either because of waitlists or paperwork. Finally, three providers hoped families would start by seeking as much information as possible, often from other families: "if they're not already educated on the resources, to start learning, talking to other parents."

Changes to survey based on provider feedback. Providers were each asked to read through the first draft of the survey and make suggestions. One provider suggested adding a question about parent feelings of validation when receiving the diagnosis. Another suggested adding a question about confusion, as she sees many families who seem confused about the diagnosis, especially about the new diagnostic labels as compared to Asperger's or Autistic Disorder. Another added that many parents seem overwhelmed at the amount of information and requested that a response option be added to this effect. Several providers suggested adding a qualitative question about what providers can do better in their feedback sessions, both in terms of information they would like to have received and what they would have changed. Finally, one provider asked that it be clarified when discussing information that it could have been received verbally or in writing, such as in a report given the same day or shortly afterwards.

- **Screening:** Many providers believe that parent knowledge, attitudes, and emotional preparedness is related to outcomes and should affect what the provider does during feedback. However, few formally collect information on these parent variables.

- **Timing of Diagnosis:** Providers often give families warning during session. Providers wait to disclose until they are reasonably certain of the diagnosis, sometimes for several weeks until reports are written, depending on clinic structure.

- **General feedback structure**: Review/strengths, explain ASD, how diagnosis fits, diagnose, process emotions, questions, recommendations.

- **Modifications to session, based on:** personal qualities of parents and children, their readiness for diagnosis (ready: short and recommendation-focused; not ready: longer and emotion-focused), and their emotionality (low expressed emotion: information-focused, high emotionality: emotion-focused.)

- **Most difficult feedback:** diagnosis violates parents' expectations, caregivers are not all present or in agreement, and when the family has limited resources.

- **Follow-up:** Providers want to follow up but are often constrained by clinic structure.

- **Common emotions seen**: Struggling/denial, sadness, fear, anger, positive emotions.

- **Common questions for providers**: a) diagnostic questions—prognosis, severity, cause, how to share diagnosis b) treatment questions—strategies for home, providers who can help, next steps, how to access services

- **Actions after diagnosis:** Providers are often unsure of what families do first. Providers hope families: seek social support, initiate treatments recommended, contact the school, apply for government services, seek information.

Figure 2. Summary of major findings from provider interviews

Parent Focus Group Results

The parent focus group discussed their experiences with diagnostic feedback, including how they felt before receiving the diagnosis that may have affected their reaction, their experiences during the feedback session, and their reactions shortly after feedback. They also provided input on the survey draft. See Figure 3 at the end of this section for summary of relevant findings from the focus group.

Factors leading to reaction. As parents in the focus group discussed their individual journeys from concern to diagnosis, several themes emerged. Parents described that there were elements of their journey that made it easier or harder to hear and process the final diagnosis. Several parents noted that if they were concerned about their child's development and were seeking answers, it was easier to hear the final diagnosis and that they were more likely to feel relieved. One parent described, "So my son, he was officially diagnosed when he was about 15. We suspected since he was 7. And we tried really hard. We had lots of providers tell us "no," so we had filled out surveys and surveys and surveys, so by the time we actually did get the diagnosis, we were like, 'Yes! Finally.'"

Other parents described that they had concerns about their child, but if they hadn't thought about autism specifically, it was a shock to hear the diagnosis. One parent described her experience as, "the first one blindsided us completely. She was just a hard child. We didn't have any family diagnoses known, so we had nothing pointing us in that direction. We went to a psychiatrist for a year and a half before we finally got the diagnosis."

Several parents in the group had other children or a spouse that had been diagnosed with autism before their most recent child was diagnosed. Most parents felt that having someone else in the family diagnosed made it easier to accept the next diagnosis because they knew more about autism and the benefits of a diagnosis. For example, the same parent who felt blindsided by the first diagnosis stated that, "[my daughter] was 9 when she was diagnosed. My son that reminded me very much of my daughter, we took him in at 3, and we were like, 'if she has it, then he has it too.' Our second time around was so much easier." Alternately, one parent described that having her spouse and child diagnosed in close succession was a steep learning curve, and it took quite a while to understand and accept the diagnosis. Other parents who had worked with or known people with autism reported that this did not necessarily help them identify their own child or make it easier to accept: "I thought I knew a lot, because I worked with autism kids for about 10 years…but when my own child had it, I was completely blind."

Finally, several parents indicated that their child's strengths or seemingly typical early development made it more of a shock to hear the diagnosis. For example, one parent described "I asked, 'why did I not see this?' And that's when she told me that reading by age 3 by themselves, that is a red flag. Why doesn't anybody tell you that?" Another parent mentioned that it was hard because "from a mom point of view, my child seemed perfectly fine. There was no indication. My mom [who was a therapist] didn't think that…there was nothing."

Information given during feedback. Parents offered several suggestions on improvements that can be made to the information given during the feedback session. Two parents felt that they didn't leave the feedback session with enough information. One indicated that the medical center was "overloaded" and could not provide anything beyond the diagnosis. Another mother felt that she was too overwhelmed to take in any information during the session and for a year afterwards and is now trying to catch up. For these parents, more information or lists that they could access later would have reportedly been helpful.

However, other families felt that there was actually too much information given. One parent described it as, “It’s like, I’m starving but you’re feeding me this huge thing and I have no idea where to start.” Several solutions were offered for this commonly experienced problem. Families agreed that it would be helpful to be given only resources that are applicable to your child: “It seems like it’s copied and pasted from somewhere…even to differentiate based on where your child falls [on the spectrum].” For example, parents wanted resources specific to their child’s age, developmental level, and areas of concern. Generally, parents of older children agreed that there are too few services available that target their child’s age and developmental level, and any resources the provider could give would be useful. Parents also discussed that it would be helpful to have their provider give guidance about where to start, or “the first three steps.” Instead of a “17-page document” that has options for every possible area of growth, one parent suggested saying “this the most major issue, so you should probably address this first and it will improve these other areas.” One father suggested a “tailored plan…your child is here, here, and here in these different areas, and here’s how you can advance—almost like a business plan.” Almost all families agreed that follow-up from the diagnosing professional or their team would be helpful, with ideas ranging from “an email that says a quick, ‘How are you doing?’”, to monthly check-ins, to a yearly update to address progress and resources.

Provider presentation. Almost all participants appreciated the manner in which their diagnosing professional interfaced with the family. The group appreciated when the provider was kind and sensitive in their delivery, and when they were responsive to their questions and later requests. One couple felt that the neurologist who gave the diagnosis was rather matter-of-fact, and would have liked him to be more sensitive to their needs. Several parents described that they appreciated when the provider paused to allow them to process the diagnosis, and checked in about how they were coping. Many parents expressed that they liked when the provider showed respect for their child by interacting with the child, expressing their strengths, and addressing older children directly.

Emotional Reactions. Parents described a variety of reactions to the diagnosis. On the positive side, several parents felt relieved to finally have an answer, validated (e.g. "see, I'm not crazy! Something *is* wrong."), or proud (e.g. "almost a fist pump, like 'yes, I'm so smart'…that I caught it earlier [than my other child]." Other parents reported experiencing worries about their child's future (e.g. "It's just so difficult. Life is hard enough without people immediately judging you, determining you, putting you in a box, bullying potentially," or "Because she was my 3rd child diagnosed, I was like 'who is going to take care of these kids when I'm gone?'"). A few parents experienced shock when the diagnosis was given, or initially felt they were in denial about the diagnosis or its implications. A few talked about trying to ward off self-blame or frustration. Several parents agreed that they felt some loss "of the child that you thought you'd have." Describing that "it just kind of sneaks up on you and then all of a sudden you're like 'oh no, my child may not talk to me like I expected her to.'"

Actions following disclosure. Participants described that they took actions to take care of themselves or to begin services quickly after the diagnosis. Several parents remembered securing services quickly, such as calling the school or making therapy appointments. Others started by reaching out for support: "The only thing I remember really is that I was alone, so I texted my husband and I reached out to one other friend who understands. I do not have much other family support. They don't agree with the diagnosis." One father commented that he initially wrote his thoughts on social media which helped him to process "her strengths, and how relieved I was to finally have an answer to what was going on with her, and what to do next."

Another parent bought books and started researching. Two parents reported that they told family but did not seek treatment right away, one citing that she was still "in denial about the diagnosis," and another held off because "I don't know what [to do]—because he's high functioning and because he's older. I don't know what is available."

Changes made to the survey based on focus group feedback. Parents in the focus group piloted the survey and provided helpful feedback, both on content and wording. Parents suggested changing data collection about child's birthdate and date of assessment to child age at assessment, as some parents felt uncomfortable putting their child's birthdate online in the survey. Parents also requested a clarification on the definition of the feedback session, as several were not sure what part of their process was considered the feedback, especially if they were told the diagnosis over the phone or in a normal physician appointment. In the emotional reactions section, parents felt that all of the current response options fit at least some of their experiences well but suggested the addition of an item discussing a feeling of sadness at the loss of the future they thought their child would have. The wording on two other items was changed very slightly based on parent feedback.

- **Easier to process diagnosis if:** already concerned and seeking answers, other family member already diagnosed.
- **Harder to process diagnosis if:** hadn't considered autism, child had significant strengths or seemingly typical early development, told 'not autism' by trusted person.
- **Parent suggestions for information:** a) Give enough information, but not an overwhelming amount. b) Ensure information is specific to child's age and functioning. c) Prioritize recommendations for families (e.g. first three steps) d) outline what to expect from treatment. e) Follow up with families.
- **Positive provider characteristics:** kind and sensitive, responsive to questions and requests, pauses to allow for processing, shows respect for child
- **Emotional reactions:** relieved, validated, proud; worried about the future, shocked, in denial, self-blaming, loss of expected future for child.
- **First actions taken following diagnosis:** Initiated services, contacted school, sought social support, researched, processed feelings.

Figure 3. Summary of major findings from parent focus group

Survey Open-Response Questions

In survey open-response questions, parents discussed their thoughts regarding their own diagnostic feedback process and their suggestions for how feedback can be improved. See Figure 4 at the end of this section for summary of relevant findings.

Specific Memories. Survey participants were asked to describe anything they remembered “almost word-for-word” from the feedback session. There were 90 responses to this question, with 5 of these answering that they did not remember anything specific. The remaining 85 responses were coded for themes. Many responses included multiple memories, or statements that fit more than one theme. Quotes that illustrate the themes are included in Table 5; some parents used language as if quoting the provider (displayed in quotes), while others summarized the remembered statements.

Diagnosis. The most commonly remembered statements pertained to the diagnoses given in the session. Many people remembered simple ASD diagnostic statements, such as “[Name] has autism.” Others remembered statements about the known or uncertain severity of their child’s autism. Many parents remembered statements about their provider’s certainty in the diagnosis, and conversely, other parents remembered when a provider stated uncertainty about the final diagnosis. Parents seemed to remember statements made about how their child’s presentation was unique in some way. A few families remembered statements about the speculated or unknown cause of their child’s autism. Many parents recollected hearing similar statements to the ones described above, but about other diagnoses (not ASD) given in the session. For example, one parent remembered a discussion of the severity of her child’s ADHD being unique.

Information. In addition to remembering statements about the diagnosis itself, families remembered information given about their child or their child's future care. The most common piece of information remembered was about the child's prognosis. Parents remembered prognostic statements that were positive, negative, and uncertain. Many families remembered a specific recommendation that was given, or what a provider thought about a certain recommendation. Several families remembered feeling upset at a recommendation, such as being referred to a colleague who didn't seem well trained or feeling unsettled by the philosophy of ABA. Families also seemed to remember explanations of a child's difficulties, such as understanding a new way of looking at their situation, or a summary of difficulties that well captured the parents' concerns. Areas of specific weakness, especially stated directly, seemed to stick with families as well.

Positive. Though many parts of the assessment can be difficult to hear or process, many parents still remember positive statements made during the disclosure. A large number remembered overtly hopeful statements about the child's future. Others remembered statements about the child's strengths or positive qualities. Several recalled positive comments the provider made about their parenting of their child or about the provider liking their child. Others remembered that the clinician offered to be a support for them, or that the provider reminded them that their child is the same child as before the diagnosis.

Negative. In contrast, a number of parents mentioned strong memories of unkind, unhelpful, or insensitive things that were said during the diagnostic feedback session. While there were many more comments that may have been taken negatively by a family, only those that were explicitly described as upsetting were coded under this theme, as every family's interpretation of statements can differ. A few parents mentioned that they did not like the tone that a provider used to convey information, including several that thought the provider’s tone was overly sad or pessimistic. Other parents were put off by statements that were seen as insensitive towards the child or family. Some parents took away that their provider was generally either unhelpful (not saying anything new to the family) or inaccurate in some of their statements. A few parents noted that they were upset when a provider made a snap judgement, either saying confidently that their child had autism before getting to know them or saying that the child didn’t have autism because of a single characteristic, then changing their minds.

Table 5.

Parent quotes regarding specific remembered statements from feedback, with direct provider quotes signified by quotation marks

Prompt: Some people remember things that were said during the diagnostic disclosure session, almost word-for-word. If something that was said during the session sticks out in your mind, write it below.

Category/Sub-Category	Count	Parent Quotes—Specific Memories
Diagnosis	**52**	
Diagnostic statement	14	“We believe your son is autistic” “[Name] has autism.”
Where on spectrum	8	“We try not to say high or low functioning” That ASD is a spectrum and she was on the mild end.
Certain about dx	7	“I'm 100% certain, no doubts in my mind, that he has Asperger’s.”
Other dx	7	That out of all the kids they have seen, he is the top 5 worst when it came to ADHD.
Unique presentation	7	That my son was unusually strong socially, and that it made it a less typical diagnosis
Unsure of dx	7	“If you had a gun to my head, I’d say he’s autistic. If not, I don’t know,”
Cause of autism	2	He said it came from my side of the family
Information about child		
Prognosis	14	“He will probably never live on his own or go to college. He may end up sorting items at the [thrift store]. But he also has jokes and music and love and will have a meaningful life.”
Recommendation	9	“Kids who do ABA are here (held her hand high) later in life, vs kids who don't (lowered her hand).”
Explanation for difficulties	7	Reminded me that my child isn't bad or difficult. But that he's rigid. Which does explain his issues.
Weaknesses	7	“he doesn’t know what a friend is” “I could find almost no motivation”
Positive	**30**	
Hopeful	11	“Let’s wait and see how many ways he can surprise us.”
Strengths	8	That my child was very bright and there was no reason she couldn't get a PhD if she wanted.
Good parenting	4	She said that she believed we were good parents and could tell that we loved him very much
Same child	3	“He is still the same child you have always known and loved”
Liked or got child	2	The diagnosing professional hit it off with my child right away and knew how to hold his attention.
Offered to help	2	Reassured me that they were going to help me get the right services for my son.
Negative	**12**	
Insensitive	4	“At least he doesn’t look like he has a syndrome” “We want you to have a diagnosis so if he becomes violent as a teenager, we know why.” She compared her hysterectomy to my child having autism.
Negative tone	3	Her tone was very sad as if she was telling me my daughter had cancer, she had an air of superiority as if she knew what was best for my daughter, and she seemed very pessimistic.
Unhelpful/untrue	3	“You can’t trust the school district. They don’t care about your child”— but our school is wonderful.
Snap judgment	2	She said she could tell even before we got started. I hated that. I felt like it was bias. He’s my child, and I couldn’t tell. How could a stranger?

Most helpful information received. When discussing the most helpful type of information they received during the feedback session, parents emphasized that they appreciated resources, the diagnosis, information about the child, and statements that imparted positive feelings. Overall, 137 families responded to this question, with 5 stating that they received no helpful information. See Table 6 for full coding frequencies and related parent quotes.

Resources and treatment. When discussing what information from the session they found most helpful, the majority of parents talked about resources. Many gave general statements about appreciating receiving lists of resources, knowing that there were places to go for help, or hearing about options. Others specified that information about ABA was very helpful. Many families found information about school supports and how to access them the most useful type of information they received. Some families cited that they appreciated hearing techniques that they could use at home or that they could suggest to the school. The remaining parents cited that a specific resource was very helpful, though the type of resource varied. For example, a few appreciated social skills groups, a mental health therapist, a specific website, a book recommendation, a research study, a group home, and others.

Diagnosis. A large number of families stated that simply receiving the official diagnosis was the most helpful part of the session. Some specified that they already knew their child had autism but needed documentation to receive certain services. Others noted that they already suspected the diagnosis but having it confirmed was the most helpful thing they took away from the session. A few families stated that, looking back, the diagnosis was the single most important thing they received, because it opened so many doors for them.

Information about child. Outside of the diagnostic label itself, many families described that they appreciated receiving information about their child and autism in general. Some families found information about their child's strengths and weaknesses to be the most helpful. Others appreciated a reframing of their child's difficulties or a new way of thinking about autism. Several families reported that a prognosis, whether more positive or limited than they were hoping, was the most helpful thing they took away.

Positive feelings. For quite a few families, the most helpful thing they took away was more of a feeling than a specific piece of information. Many families left with a feeling of hope that things could get better. Other families took away a feeling of being supported, like the were no longer alone in the journey of helping their child. Others stated that they appreciated being validated during the session, like their concerns were taken seriously and, in the end, proved to be correct.

Table 6.

Parent quotes and coding frequencies describing the most helpful information received during feedback

Prompt: What was the most helpful type of information that you got from the diagnostic disclosure session?

Category/Sub-Category	Count	Quote
Resources	**83**	
Other specific resources	16	Recommendation for 100 day toolkit
ABA	14	She told me to talk to his school ASAP and sign him up for ABA therapy. That the ABA would be his greatest help and would help me understand and teach him. She was right.
Lists of resources	14	Advice for books and on-line resources.
General info	13	References on where to go and what kind of therapies my son needed.
Techniques for home	12	List of activities to do at home to strengthen skills
School	7	A list of how school could accommodate him, helpful strategies, all of which helped us for his IEP.
Next steps	7	Information on what to do next
Diagnosis	**41**	
Diagnosis only	21	Gaining an autistic diagnosis has given us a clearer window into their mind and their world and has changed everything in our home.
For services	12	That he had ASD and we could get him into therapy to help him. Without that diagnosis we didn't have a lot of options.
Confirmation	8	Just knowing for certain what we already knew.
Positive Feelings	**28**	
Hope	16	He will succeed; it just may take him a little longer. That he could make a lot of progress with the right help.
Validation	9	Answers and validation for concerns we had as parents.
Support	3	That my son had an opportunity to have therapy and that with the help of doctors and family, I was not alone
Information about child	**28**	
General info	12	Ways to look at the diagnosis and remove stigma.
Strengths and weaknesses	12	I got detailed test information, so we had a good sense of strengths and weaknesses. Everything was well documented and ready to be presented to the school.
Prognosis	4	Prognosis information, about how much my child's life would be profoundly impacted. It was horrible news, but I needed to learn this so I could grieve.

Information parents would have liked to receive. Parents reported on information that they did not receive, but looking back, would have liked to receive during the feedback session. There were 125 responses to this question, with 22 respondents indicating that there was nothing additional they would have liked to receive. Many of the types of information that parents found most helpful are mirrored in their desires for what they would like to see more of in sessions. Answers focused on receiving more and better information about services, more information about their child and about autism, and more general guidance. See Table 7 for coding frequencies and parent quotes.

Resources and treatment. Looking back, though parents valued the information they received about resources most, they still would have liked to hear more specific information about resources and treatments. The most cited type of resource desired was ways to receive support for parents and families, such as support groups (online and in person), therapy for parents (grief counseling, mental health support, and marital therapy), and ways to connect with other parents. Other parents wished they would have received information about a specific service, often that they found out about later and wish they had known about up-front. Parents also wished they could be given specifics on how to access services, including the steps involved in applying for and paying for services. Some parents simply stated that they would have liked to hear about more services, or a broader range of services. Other families indicated that they were satisfied with the number of treatment recommendations offered, but wished they would have heard about specific therapists, companies, and groups that their provider knows of or trusts. In addition to outside treatments, many families would have liked to receive tips on how to help their child at home.

Information about child. Parents also indicated that they would have liked to receive more information about their child and about autism in general in the feedback session. Families indicated that they wished they would have received more information about their child's prognosis, though here parents focused more on their desire to know "what to expect" rather than a general prognosis. For example, parents described wanting to know what kinds of help their child might need when they reach school age, or how much they should expect their child to improve with a certain treatment. Parents also indicated that looking back, they wished their provider would have given more information about ASD. It seems that parents either found it difficult to access helpful information about autism once leaving the session or found helpful information later and wished that they had been given that knowledge at the beginning of their journey. Finally, some families noted that they wish they had left with a better conceptualization of how their child's difficulties and strengths fit together and what about their child led to the diagnosis.

Guidance. Additionally, many families wish they had walked away from the assessment with more general guidance on how to best help their child. Parents noted that while they may have been given a lot of information, they wish they had some professional advice on how to navigate the process. Many families wished they would have been given clear next steps, such as a suggested prioritization of treatments. These families indicated that lists of services were helpful, but were not enough, as they felt overwhelmed and unsure of how to proceed. Other families cited that they wish the provider had given them general advice, for example, on how to navigate the options and systems available. Finally, several parents cited that they wish they had been given some reassurance that they would be able to manage or that their child would be alright.

Table 7.

Parent quotes and coding frequencies of themes related to preferred information for feedback

Prompt: In hindsight, what information would you have liked to have received, that you did not, at the diagnostic disclosure session?

Category/Sub-Category	**Count**	***Parent Quotes***
Resources	**66**	
Social support	19	I would have liked to be informed about support opportunities for my family. Especially sibling supports since they struggle a lot because of their brother.
Specific service	15	More information about therapies and government helps that we can apply for. DDD, SSI, etc.
Generally more	14	What services, education to seek...what treatments available...websites and books
Where/who	10	I would have liked specific references for ABA therapists and other support professionals.
Strategies for home	8	More advice and techniques on how to help my son at home to cope with meltdowns and mental blocks.
Guidance	**35**	
Next steps	15	Maybe more direction of what type of help to seek out first—what help is most critical in their opinion
How to get services	13	More help with finding resources for my son rather than just a list of names.
General advice	4	Alternative therapies (play therapy, music therapy, hippotherapy, etc.), the concept that more therapies is not necessarily better, the concept that different is not inferior, autism acceptance information.
Reassurance	3	Some reassurance or hopeful comments would have helped.
Information about child	**29**	
Information about ASD	13	I would like to know what are some of the behaviors of autism. I'm still trying to figure out what about my son is "autistic" and what is not
Prognosis/what to expect	10	What would a realistic future for my son look like.
Explanation of child's difficulties	6	I would have liked a definition of how anxiety manifests itself in my son. Mental health issues and anxiety were foreign topics to me even though I had studied ADHD and autism issues for years.

What parents would change. Parents were asked what about the feedback session they would have changed. In total, 134 parents answered this question, with 29 stating that they would change nothing about the feedback session, 4 indicating that they would change everything about the session, and 5 stating that they are unsure of how it could be improved. See Table 8 for full coding frequencies and related parent quotes. Many parents indicated that they would change what information they were given, mirroring the themes in the previous question: many parents wanted more and better information about services and others wanted more information about their child or autism in general. These answers are included in Table 8 but will not be elaborated upon below. Besides desires related to information, parents indicated that they would change time and pacing associated with the session, how the provider delivered the information, and their own engagement with the session.

Timing. Parents recognize that there are limitations associated with the timing associated with feedback sessions, but also felt that there is much to be desired in this area. The largest number of parents indicated that they wished the feedback session was longer. They cited that it was difficult to cram all of the information, emotions, and questions into the short time allocated. Several felt that the session was rushed or that they were being pushed out the door. Other parents wished the feedback session had been sooner, either because they had a long wait to get into the assessment in the first place, or because they had a long wait between the assessment and the feedback. Several families stated a desire to have more follow-up after the session, because it was so difficult to process everything in that moment. Different solutions were offered for this problem, including a family coordinator to walk through the next steps with them, a check-up a year later to make new goals, or a second session a week later or when the paper report was finished. A few families indicated that they felt the time in the session was allocated poorly, or that they would have rather heard news in a different order during the session. Two families felt that the process was too long, citing that they were exhausted by the time they received feedback.

Provider delivery. Many families felt that their provider's way of delivering information and interacting with the family could have been improved. Many families would have liked their provider to appear warmer and more empathetic, feeling that they were sometimes overly formal or aloof. Families would also like their providers to be reassuring and hopeful. Some felt that they walked away feeling hopeless and thought their provider could have done more to reassure them that change was possible. Other families felt that their provider did not seem certain about some of the information or diagnoses they were conveying, and this was unsettling to families. The wanted their provider to be clear and concrete. A few families were concerned by how disengaged their provider seemed, and wished they would have made more of an effort to get to know their family and show that they were there to help.

Family engagement. Several families felt that they would have changed how they engaged with the session. Some parents wished that they would have had different individuals in the room during the feedback. For example, a few wished their young child had not been in the room during feedback, while others wished that their spouse had been present. Additionally, looking back some parents wish they had reacted differently to the news, such as worrying less or accepting the diagnosis more quickly.

Table 8.

Parent quotes and coding frequencies related to things parents would change about diagnostic feedback sessions

Prompt: What about the diagnostic disclosure session would you have changed?

Category/Sub-Category	Count	Quote
Timing	**32**	
More time	11	It felt fast, hard to digest the information being thrown at us. We were in shock.
Long wait	7	The wait time between referral and the first observation session
Follow-up	6	After all was communicated, I would have liked the opportunity to review things in a week to make sure I understood
Order of events	6	I would have preferred to get the Autism Diagnosis first instead of the ADHD. They started out by saying he has significant ADHD. For half a second I had a sigh of relief that it wasn't Autism.
Too long	2	It was a long visit. I was exhausted by the end of testing. I was emotionally unprepared.
Resources	**30**	
Resource details	13	I wish I would have had more resources on how to help my child at home and at daycare
Next steps	8	She was so vague about our next steps other than to tell us to set an appointment with the practices caseworker. I would have felt better if I had a better understanding of what steps to take
Parent support	5	Provide materials from parents who went through it years previous.
Written	3	Considering that I could probably qualify for ASD if I was evaluated, I would have loved a more compelling written presentation with illustrations, since that can really clarify what is most important
Provider Presentation	**25**	
Warm and empathetic	11	Empathy. Support. Less frustration with my child
Clear and certain	6	I feel like she wasn't sure. She gave him the diagnosis but left me thinking we were missing something.
Reassuring and hopeful	6	I wished the Dr. was more positive about my daughter's future.
Engaged and supportive	5	More interaction between my son and the clinician. More one on one communication and connection.
More Information	**11**	
Child’s diagnosis	5	Possibly some brief explanation about how the diagnosis works. Strengths or weaknesses of the process.
Assessment	3	More information about why the child was asked to do the tasks.
Autism	2	I would have wished for more information on Autism. I left with a diagnosis but with little understanding of what it was.
Parent Factors	**9**	
Who present	5	I would have had my toddler daughter (being diagnosed) in another room so that my full attention was on clinician.
Own reaction	4	I wish I reacted differently when she got the diagnosis of ASD1.

First actions following diagnosis. Parents were asked to describe the first thing they did following the diagnosis, to help their child or help themselves. Overall, 142 parents answered this question, with 5 indicating that they did nothing different following the diagnosis. The remaining answers fell into several broad themes including starting the process of seeking services for their child, seeking support for themselves as parents, processing their thoughts and feelings, seeking information about the diagnosis, or taking steps to support their child at home. The answers of many families blended two or more of these themes. Commonly, parents started the process of seeking services while simultaneously seeking support for themselves or trying to process their emotions. See Table 9 for coding frequencies and parent quotes.

Sought services. About half of parents stated that the first thing they remember doing was seeking services for their child. Many families contacted non-school service providers after the feedback session. This included calling around to various providers, getting on waitlists, and making appointments. Several parents reported that they went to a favored site to get on a wait list on their way home from the feedback session. Other families contacted their child's school or school district to work towards receiving appropriate supports. Depending on the child's age and existing services, this included requesting an IEP evaluation or meeting, informing the child's school or teacher of the child's diagnosis, working with the teacher to tailor classroom supports, or applying for special education preschool services. Several families immediately called their insurance company in order to determine which providers or services may be covered under their plan.

Sought support. After receiving the diagnosis, many parents described immediately reaching out for social support. Most parents sought support from family or friends. Many described calling their spouses following the disclosure, highlighting that they were not present at the meeting. Others reached out to a friend or family member to receive support and to tell them about the diagnosis. While many sought informal support, parents also reported joining formal support groups after the disclosure, either online or in person.

Sought information. Many parents report that after they heard the diagnosis, they went home and sought as much information as possible to aid in their understanding of autism. Some families felt that they did not have a good understanding of what providers would be able to help them or their child and went to work researching local providers. Some parents spoke about reading books about autism while others looked up information online. For some this search was prompted by feeling lost after the session with little information, while others described focused search, looking at toolkits or resources recommended by their provider. Other parents described seeking advice from other professionals or parents of children with autism, either with whom they were already connected or through a local organization.

Parent processing. Receiving the diagnosis is described as a momentous and emotional occasion, and parents reported that they took time after the session to care for themselves and their emotions. Many families report that the first thing they did after leaving the session was to cry. While this was a common first reaction, most parents mentioned that after crying they went and did another initial task, such as seeking services or support. Other parents described taking time to care for themselves or do something relaxing. Finally, parents took time to process their thoughts and feelings about the diagnosis. Families described either celebrating and talking about all of the positive things a diagnosis can bring to their family or mourning and wrestling with the implications of this diagnosis.

Caring for child. At the end of the day, many families note that the first thing they did to help their child was at home. Some parents describe that they went home and cared for their child’s daily needs, as they always do. They may have bought their child a favorite food, comforted their child after a long day, or took them to their next activity. Other families found themselves changing the way they interacted with their child after seeing them in a new light. In some instances, parents’ first action was to disclose the diagnosis to their child and help them process the news. Finally, a few families went home and soon implemented new strategies into their daily routines, such as schedules or rewards.

Table 9.

Parent quotes and coding frequencies regarding first actions taken by parents following diagnosis

Prompt: What was the first thing you did after receiving the diagnosis (either to help your child or yourself)?

Category/Sub-Category	Count	Quote
Services	**58**	
Contacted services	31	Made appointments for evaluations for PT and OT that the pediatrician suggested.
School	20	I worked with school district for a preschool IEP.
Insurance	7	Talked to the insurance agent about getting coverage for ABA therapy
Support	**54**	
Contacted support	43	Talked to family members for emotional support
Joined group	11	Joined several autism groups on Facebook (local and non-local) and read all the blogs and writings I could find written by autistic adults and teenagers.
Sought information	**42**	
Researched autism	27	Called my family, then went online and read everything I could about ASD.
Looked for resources	15	Search for someone vetted by the AS community as knowledgeable & kind to provide services and resource referrals.
Parent processing	**38**	
Cried	18	Cry and allow myself to try and accept that we would make it.
Self care	12	Take a break to recover and talk to spouse. / Seeking therapy for myself
Processing thoughts/ emotions	8	We just talked through the diagnosis and talked about what it meant for her and her life.
Child-centered	**20**	
Cared for child	10	Talked with him about his feelings. Encouraged him to come to us with any problems or when he was feeling down. Prayed together as a couple.
Disclosed dx to child	5	We've also been very up front with him about his diagnosis so he can self advocate.
Strategies	5	Prayed. Then organized a daily schedule and token chart so they would know the things they would get to do each day. I think some of their anxiety was the fear they wouldn't get to engage in interests.

- **Parents remember:** Diagnostic statements (severity, certainty/uncertainty, uniqueness of child, suspected cause); informational statements (prognosis, a specific recommendation, explanation of child's difficulties, child's weakness); positive statements (hopeful, child's strengths, parent strengths, provider liked child, offer of support); negative statements (tone, insensitive, snap judgements).

- **Most helpful information:** Resources (lists, options, ABA, school supports, techniques for home, other specific resource); diagnosis and documentation; information about child (strengths/weaknesses, new perspective, prognosis); positivity (hope, support, validation).

- **Parents want more information about:** Resources (family support, specific services, how to access services, broader range of services, where to go, strategies for home); information about child (prognosis, info about ASD, strengths/weaknesses); and general guidance (prioritized next steps, how to navigate systems, reassurance, general advice).

- **Parents would change:** Information given; timing (longer, sooner, follow-up, better flow, when less tired); provider delivery (more warm, empathetic, reassuring, hopeful, certain, clear, engaged); family engagement (toddlers out of room, spouse present, accept news quicker, less worry).

- **First actions following diagnosis:** Sought services, sought support, processed (cry, self-care, process thoughts, celebrate, mourn), sought information, cared for child (new strategies, disclosure, childcare).

Figure 4. Summary of major findings from parent survey open response questions

Quantitative Survey Results

Reasons for seeking evaluation. Parents have their child evaluated for a variety of reasons, and these reasons shape what they are expecting from a feedback session. Figure 5 shows the distributions of parent reasons for seeking an evaluation. Parents could select as many answers as were applicable to them (mean number of reasons indicated = 5.3, SD = 2.1). Most (86%) of parents were seeking an evaluation with a general goal of better understanding their child. Importantly, 75% of families say that they sought an evaluation to learn strategies to help their child at home. Other common reasons for evaluation include to see if a parent's concerns were valid, to understand what to expect for the child's future, and to receive ideas about what treatments would help their child. Many parents report seeking an evaluation in order to receive an official diagnosis that can help them access services, such as ABA therapy, school services, and more. When designing a feedback session that will be effective and meaningful for a client, it is important to understand what they are hoping to receive from the session.

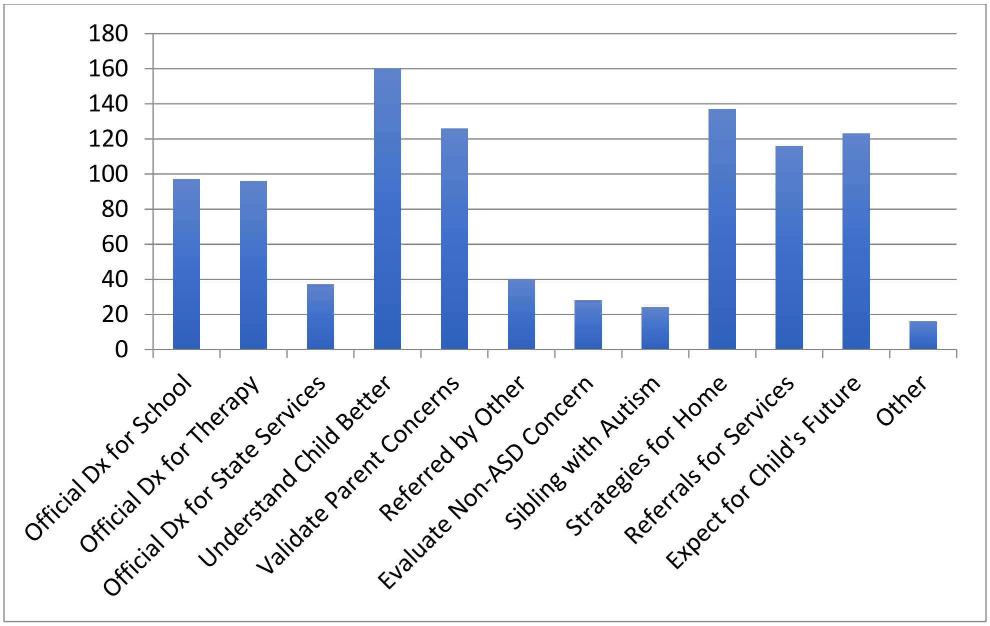

Figure 5. Number of parents reporting various reasons for pursuing a diagnostic evaluation for their child

Aim 2 – Understand and categorize pre-, during, and post-session variables. An exploratory factor analysis showed a four-factor solution for parent pre-session characteristics, including parent pre-session autism knowledge and help-seeking, parent belief and desire for an autism diagnosis, parent anxiety and resistance to an autism diagnosis, and a fourth factor that included only one variable (parent uncertainty that their child would be diagnosed) that was not used in analyses for this study due to its limited scope. See Table 10 for factor loadings.

Provider characteristics formed a three-factor solution, including provider engagement and positivity, provider informativeness, and perceived provider competence. See Table 11 for factor loadings.

Factor analysis showed a four-factor solution to parent reactions to diagnosis, including three factors that were hypothesized and one additional factor. Parent reactions as measured by our survey can be categorized as feelings of preparedness for action, positive emotional reactions, difficult emotional reactions, and confusion. See Table 12 for item loadings to these factors.

Table 10.

Factor Analysis of Parent Pre-session Parent Variables.

Prompt: The following questions are about how you felt and what you thought shortly before you were told your child had ASD. "Shortly before the diagnosis was given…"

Scale: Strongly agree (5), Somewhat agree (4), Neither agree nor disagree (3), Somewhat disagree (2), Strongly disagree (1)

	Factor Loading			
Item	**1**	**2**	**3**	**4**
Factor 1: Previous Autism Knowledge (α = .75)				
20.1 I knew a lot about ASD	.60	-.02	-.15	.58
20.2 I knew what treatments my child would benefit from	.65	.01	-.12	.51
20.3 I had sought out services to help my child's development	.83	.12	.13	-.07
20.4 I had sought out information to help my child at home	.81	.07	-.10	-.07
Factor 2: Previous Autism Expectations (α = .63)				
19.1. I believed my child had autism spectrum disorder	.06	.85	.08	.29
19.2. I wanted the professional to diagnose my child with ASD	.09	.79	-.36	-.07
Factor 3: Anxiety About Diagnosis (α = .66)				
19.3. I was nervous about receiving a diagnosis of ASD	-.00	.05	.89	-.20
19.5. I hoped the provider would not diagnose ASD	-.05	-.47	.75	.10
Factor 4: Uncertainty				
19.4. I was uncertain about what the professional would diagnose	.12	-.22	.09	-.80

Table 11.

Exploratory Factor Analysis of Provider Variables During Feedback.

Prompt: The following questions are about the professional that delivered the diagnoses of ASD to you. "During the diagnostic assessment and disclosure process, the professional…"

Scale: Strongly agree (5), Somewhat agree (4), Neither agree nor disagree (3), Somewhat disagree (2), Strongly disagree (1)

	Factor Loading		
Item	**1**	**2**	**3**
Factor 1: Professional was Informative (α = .90)			
22.2 gave me helpful information about ASD in general	.68	.21	.42
22.4 gave me helpful information about what kinds of treatments would help my child	.78	.21	.16
22.5 gave me helpful information about organizations or providers that could help me or my family adjust to the diagnosis	.81	.17	.16
22.6 gave me a good sense of what goals other treatment providers should be working on with my child	.82	.27	.05
22.7 expressed what I could expect for my child's future (prognosis)	,72	.29	-.09
20.3 gave me helpful strategies for how I could help my child at home	.80	.29	.15
Factor 2: Professional Was Engaging and Positive (α = .90)			
21.3 seemed to like/enjoy my child	.19	.82	.27
21.4 seemed to think I was a good parent	.21	.80	-.00
21.5 clearly expressed my child's strengths	.27	.77	.24
21.6 seemed to really "get" my child	.26	.80	.24
21.7 was warm and empathetic	.34	.71	.29
Factor 3: Professional Was Competent (α = .66)			
21.1. seemed competent in their evaluation	.14	.40	.76
21.2 seemed confident about the final diagnosis they gave	.06	.25	.78
22.1 explained why they thought my child had ASD	.41	.13	.52

Table 12.

Exploratory factor analysis of parent reactions post-feedback

Prompt: “Shortly after the diagnostic disclosure session, I felt…”

Scale: Strongly agree (5), Somewhat agree (4), Neither agree nor disagree (3), Somewhat disagree (2), Strongly disagree (1)

	Factor Loading			
Item	**1**	**2**	**3**	**4**
Factor 1: Parent Difficult Emotions (α = .85)				
24.5 in shock about the news	.70	-.02	-.09	.41
24.6 worried about my child's future	.82	-.06	-.08	.03
24.7 upset, struggling with the diagnosis	.79	.01	-.28	.22
24.9 overwhelmed by the amount of information	.60	.05	.21	.45
24.12 alone, left feeling isolated or unsupported	.63	-.48	-.20	.08
24.13 sad about the loss of the future I thought my child would have	.77	-.11	-.31	-.07
Factor 2: Parent Preparedness (α = .86)				
23.3 I knew about what kind of treatments my child would benefit from	-.07	.85	.16	-.14
23.4 I knew where to go to get my child help	-.05	.89	.13	-.03
23.5 I knew what goals treatment providers should be working on with my child	-.02	.87	.08	-.12
24.11 lost, not sure where to go from here	.58	-.57	-.00	.18
Factor 3: Parent Positive Emotions (α = .78)				
24.1 relieved to finally have a diagnosis	-.22	.07	.78	-.09
24.2 validated, like my concerns were valid all along	-.07	.08	.77	-.08
24.3 hopeful about my child's future now that we can get help	-.39	.33	.64	.00
24.4 grateful for the diagnosing professional(s)	-.11	.26	.75	-.31
Factor 4: Parent Confusion (α = .75)				
23.1 I knew what autism was, in general	-.08	.48	.27	-.62
23.2 I knew why my child was given an ASD diagnosis	-.00	.29	.43	-.59
24.8 angry or unhappy at the diagnosing professional(s)	.25	-.08	-.49	.47
24.10 confused about the diagnosis	.46	-.15	-.13	.68

Aim 3—Factors predicting parent preparedness for action following diagnosis. Mediation and moderation analyses were used to determine factors that best predict how prepared parents feel to move forward and seek services following diagnosis.

Mediation. The providers who were interviewed expressed a belief that family variables as well as provider variables contribute to the reactions that parents have following a diagnosis. Accordingly, we found that the relationship between the extent of parent knowledge and help seeking prior to feedback and how prepared parents felt following the session was partially mediated by how much information was given by their diagnosing professional. Direct and indirect effects were calculated using the Sobel test. Due to some multivariate non-normality in the model, a Satorra-Bentler correction was used to calculate final statistics. Overall, 28% of the total effect of pre-session parent knowledge on post-session parent preparedness was mediated by information given ($P_M = .16/.56 =.28$). While parents who are already informed and seeking help are more likely to leave the session feeling prepared to take action, they are also likely to receive a greater breadth and depth of information during their feedback session, which in turn increases their preparedness. Providers seem to give more treatment recommendations and information when a parent was coming into the session with a strong base of knowledge and had already begun to seek help, rather than when they were less far along in their process of information gathering. This pattern was mentioned by several providers interviewed in the qualitative portion of the study. Providers indicated that they often spend more time giving recommendations if the family seems like they are ready to move forward, and spend more time processing emotions if a family is newer to the diagnosis. This overall model (see Figure 6) accounts for about 61% of the variability in preparedness following feedback.

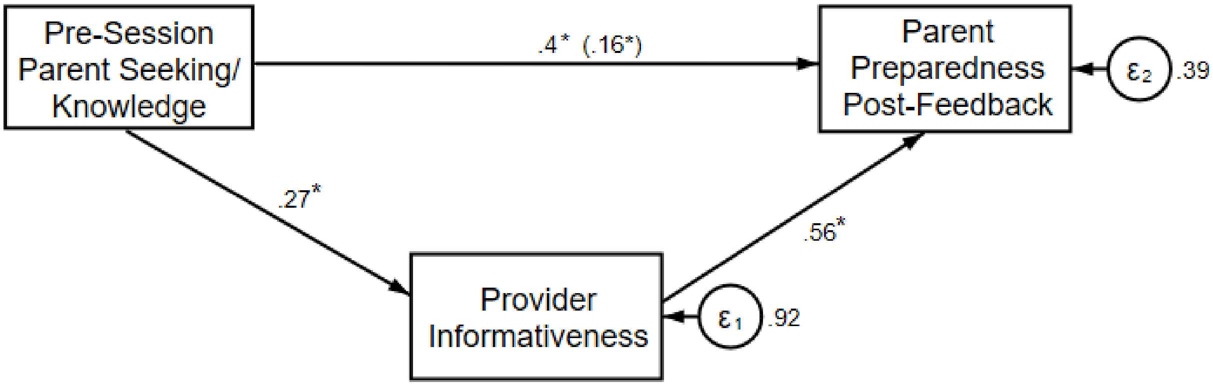

Figure 6. Standardized regression coefficients for the relationship between parent pre-session knowledge and post-session preparedness as mediated by provider informativeness. In parenthesis is the standardized coefficient for the relationship, controlling for informativeness. *$p < .05$.

Moderation. Providers tend to naturally give more information when a family has already begun seeking help, but it is unclear when it is most critical for providers to give this information. Provider informativeness during feedback was examined as a moderator of the relationship between pre-feedback anxiety and post-feedback preparedness. Provider informativeness and parent pre-session anxiety about diagnosis significantly predict parent preparedness following feedback ($R^2 = .47$, $F(2,174) = 79.35$, $p <.001$). To avoid potentially problematic high multicollinearity with the interaction term, the variables were centered and an interaction term between anxiety and informativeness was created and added to the model. The interaction between anxiety and information was found to have a significant effect on preparedness, increasing the amount of variance explained from the model without the interaction term ($\Delta R^2 = .02$, $F(2,173) = 55.20$, $p < .001$). See Table 13 for regression coefficients. While receiving more information always increases a parent's preparedness following the feedback, the amount of information received matters most for the outcome of parents who are very anxious about the diagnosis (Figure 7). Parents who are highly worried about the session and are resistant to hearing a diagnosis are at high risk for leaving unprepared, especially if they leave the feedback with little information. However, if they are able to gain a breadth of high-quality information during the session, they may still leave just as prepared as a low-anxiety parent.

Table 13.

Preparedness predicted by parent anxiety and provider informativeness

Predictor	β	*p*	95% CI	
Parent Anxiety	.49	.006*	-.853,	-.143
Provider Informativeness	.34	.065	-.021,	.711
Anxiety x Informative	.11	.045*	.002,	.201

*$p \leq .05$

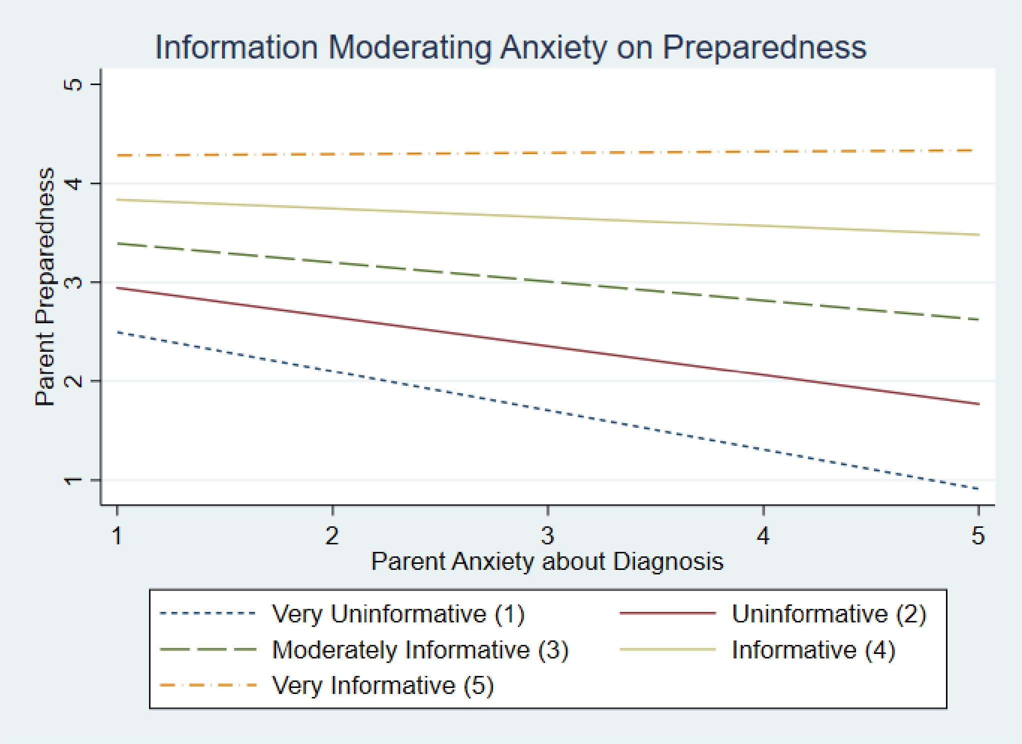

Figure 7. Moderation of the relationship of parent pre-feedback anxiety about diagnosis on post-feedback parent preparedness at different levels of provider informativeness

Actions following diagnosis. Following the feedback session, parents go back into their communities and begin to seek and secure help and support. Families were asked to rank order which actions they took first, second, and so on following diagnosis (see Figure 8). Overall, 41% of parents report seeking informal social support first, with 73% accessing informal social support at some point. About 72% of parents eventually accessed information on websites that they found on their own, while only 50% accessed information on websites recommended by their provider. This may indicate that families are wanting to look through helpful websites but aren't receiving adequate guidance on where to locate accurate and relevant information online. Providers may wish to give their clients lists of high-quality websites that are relevant for their child and for their geographic area. A similar pattern is found with books—parents are more likely to read books that they found on their own rather than ones recommended by providers. Encouragingly, 49% of parents reported that the first or second action they took was to seek services recommended by their provider. A smaller but significant number eventually sought services that they found on their own but were more likely to do this later in their process rather than first or second. Providers should ensure that they are listening to what kinds of services families want and helping them locate high-quality programs or providers that will meet their needs. Many families report seeking formal social support, such as through a support group or parent organization, with parents varying widely on the timing of seeking this support. On qualitative questions, parents reported wishing they had received more information about formal support during their feedback. Overall, in interviews providers described that they hope parents will leave the session, seek social support, seek recommended services, and share information with the school (if relevant). It appears that many families surveyed have indeed been equipped to take these actions following diagnosis.

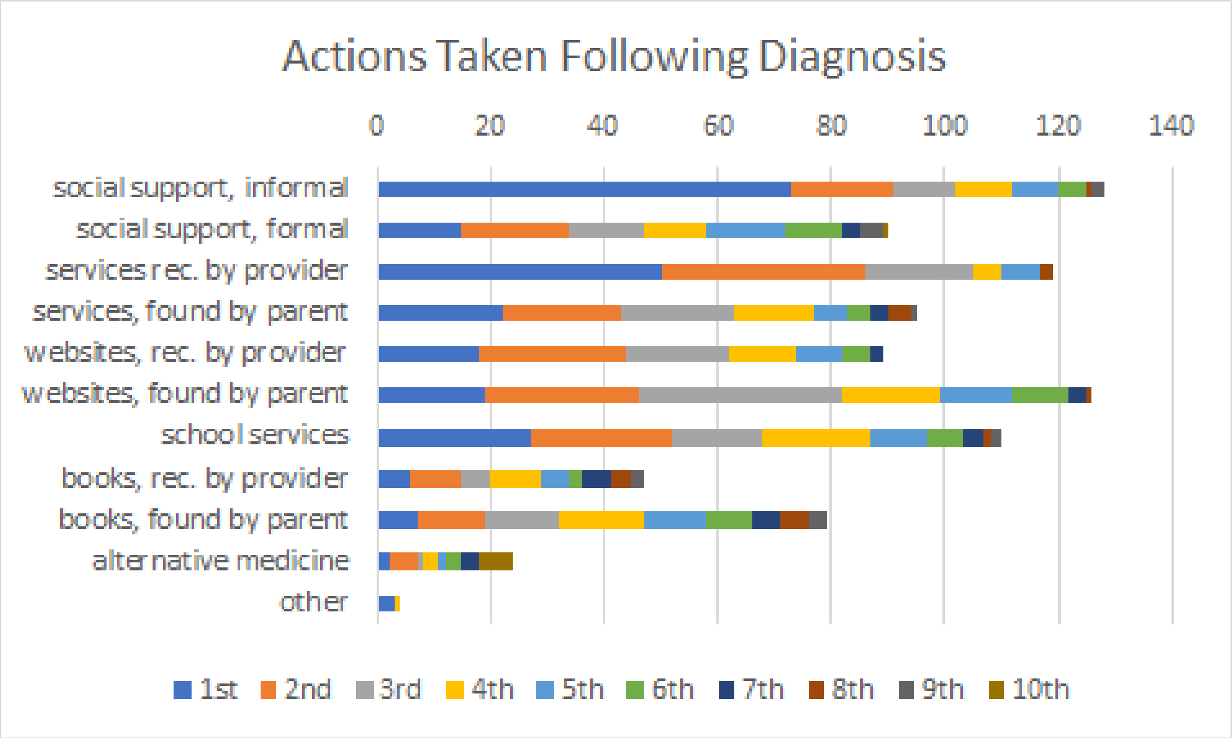

Figure 8. Parent survey report of order of actions taken following diagnosis, shown by frequency of response for each ordinal position (1st action, 2nd action, etc.)

Aim 4—Factors predicting parent emotional reactions following feedback. Several common emotional reactions to diagnosis were shown in our sample, including positive emotions, difficult emotions, and confusion. Factors that predict these reactions were investigated using regression analyses.

Positive emotions. In our sample, experiencing positive emotions following diagnosis was quite common (Figure 9). Experiencing positive emotions following feedback is not necessarily the inverse of struggling post-feedback. While they are correlated (r = -.52, p < .001), they are separate constructs, and it is possible to have both strong positive and strong negative emotions. Providers can help promote positive feelings post diagnosis. As might be expected, provider positivity (expressing positivity towards the child and family, being warm and empathetic, etc.) strongly influences parent positivity, itself explaining 39% of parent positive reactions to the session (F(1,175) = 113.48, p < .001). Additionally, the more a family is ready for a diagnosis, believing it to be accurate and wanting a provider to diagnose, the more they leave feeling positive. Similarly, the more anxious a family is about receiving a diagnosis, the less positive they are likely to feel at the end of the session. Overall, provider positivity, pre-session anxiety, and pre-session readiness together explain 59% of parent positive feelings following feedback (see Table 14*)*.

Table 14.

Regression predicting parent positive emotions post-session

Predictor	*b*	SE b	β	*t*	*p*
Pre-session anxiety	-.26	.04	-.32	-6.02	.000
Pre-session expectations	.16	.05	.19	3.52	.001
Provider positivity	.44	.06	.43	7.02	.000
Provider informativeness	.16	.05	.20	3.38	.001

Note. Fit for model $R^2 = .59$, Adjusted $R^2 = .58$, $F(4, 172) = 62.76$, $p < .000$.

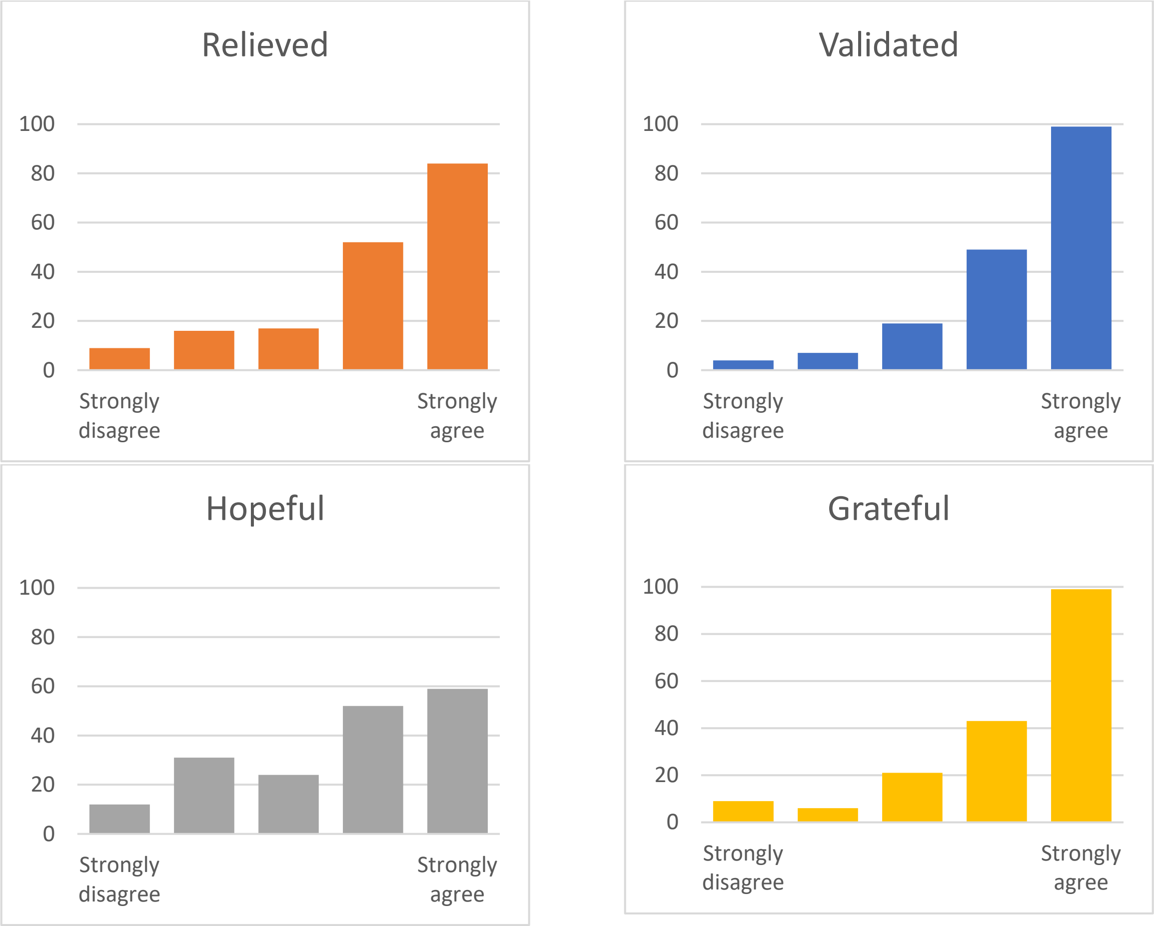

Figure 9. Distribution of number of parents surveyed reporting various positive emotional experiences.

Difficult emotions. Many providers feel that feedback sessions are more difficult when a parent or parents experience negative emotionality during the session. However, it should be noted that feeling sad, worried, upset, overwhelmed, lost, alone, and shocked are common experiences (see Figure 10) that are not strongly related to the quality of the provider or feedback session. In a regression analysis, provider positivity, provider perceived competence, and provider informativeness together explained only 8% of the variance in struggling ($F(3,173) = 4.82, p = .003$). When including pre-session factors, parents that come to the session anxious about receiving an autism diagnosis are more likely to struggle when the diagnosis is given, and parents who come in feeling knowledgeable and having sought information are less likely to struggle. A model that includes parent anxiety, parent knowledge and seeking, and provider positivity explains 54% of the variance in struggling following feedback (see Table 15).

Table 15.

Regression predicting parent difficult emotions post-session

Predictor	*b*	SE b	β	*t*	*p*
Pre-Session Knowledge	-.20	.06	-.18	-3.30	.001
Pre-Session Anxiety	.65	.05	.65	12.35	.000
Provider Positivity	-.13	.07	-.11	-2.04	.043

Note. Fit for model $R^2 = .54$, Adjusted $R^2 = .53$, $F(3, 173) = 66.69, p < .000$.

Parent confusion. Providers interviewed reported that they wanted parents to leave feeling prepared to move forward, and not feel confused, uninformed, or angry. To investigate what factors best predict confusion following feedback, we ran a simultaneous regression analysis, including relevant pre-session and provider factors. Overall, a confused response is best predicted by low pre-session parent belief and desire for the diagnosis, low pre-session experience with and knowledge about autism, high pre-session parent anxiety about the evaluation, and low levels of perceived provider competence and informativeness. See Table 16 for this model, which accounts for 48% of a confused response following feedback. This regression analysis did not meet the assumption of normality, so a more conservative *p* value of .01 was used to gauge significance. Overall, this reaction appears to be partially preventable by providers, as opposed to other difficult emotional experiences. While the majority of people surveyed found their provider to be very competent (M=4.7, SD =.61) those reporting an unprofessional provider were especially at risk for poor outcomes, as well as those with an uninformative provider.

Table 16.

Regression predicting parent confusion following diagnosis

Predictor	*b*	SE b	β	*t*	*p*
Pre-session expectations	-.12	.05	-.14	-2.37	.019
Pre-session knowledge	-.18	.05	-.20	-3.44	.001*
Pre-session anxiety	.22	.05	.28	4.69	.000*
Provider competence	-.44	.08	-.33	-5.12	.000*
Provider informativeness	-.13	.05	-.18	-2.72	.007*

Note. Fit for model $R^2 = .48$, Adjusted $R^2 = .46$, $F(5, 171) = 31.19$, $p < .000$; $*p < .01$

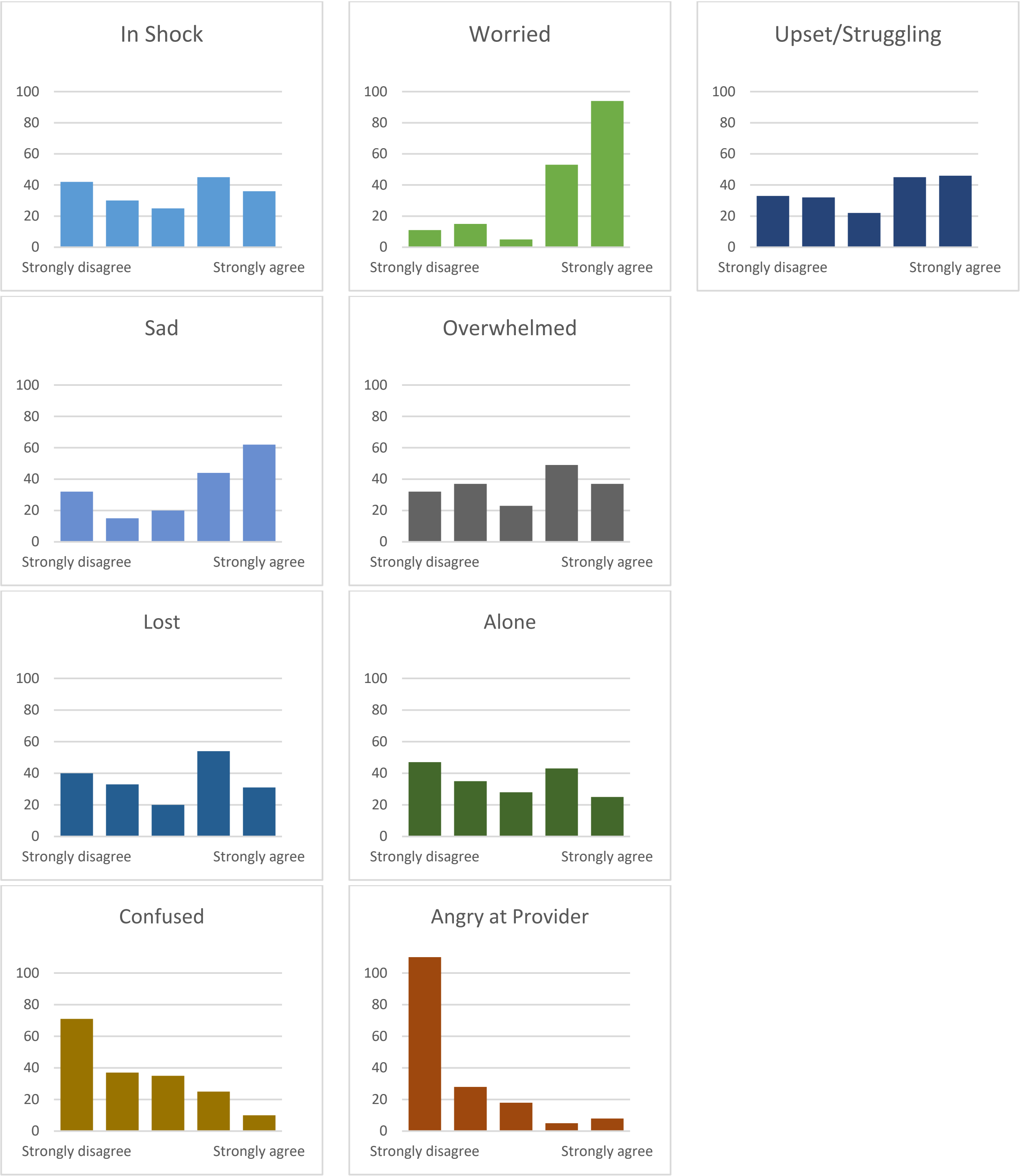

Figure 10. Distribution of survey responses for negative emotional experiences.

Aim 5—Model interactions between factors predicting outcome. Overall, provider informativeness, pre-session parent anxiousness, and pre-session parent help- and information-seeking well predict a variety of outcomes. As providers state hoping their clients leave prepared to move forward and with manageable levels of negative emotions, a model was created to best predict these two outcomes. Due to multivariate non-normality, in the model variables, a Satorra-Bentler correction was used to make chi squared and related values more robust to non-normality. See Figure 11. This model's fit is significant and strong ($\chi^2(2) = .950$, *p* = .622*; RMSEA* < .001*; SRMR* = .013*; CFI* = 1.00*; TLI* = 1.01*)*. The model indicates that when parents feel more prepared, they are less likely to struggle emotionally, though high pre-session anxiety still may lead a family to feel overwhelmed at the end of the session, no matter how prepared they were feeling.

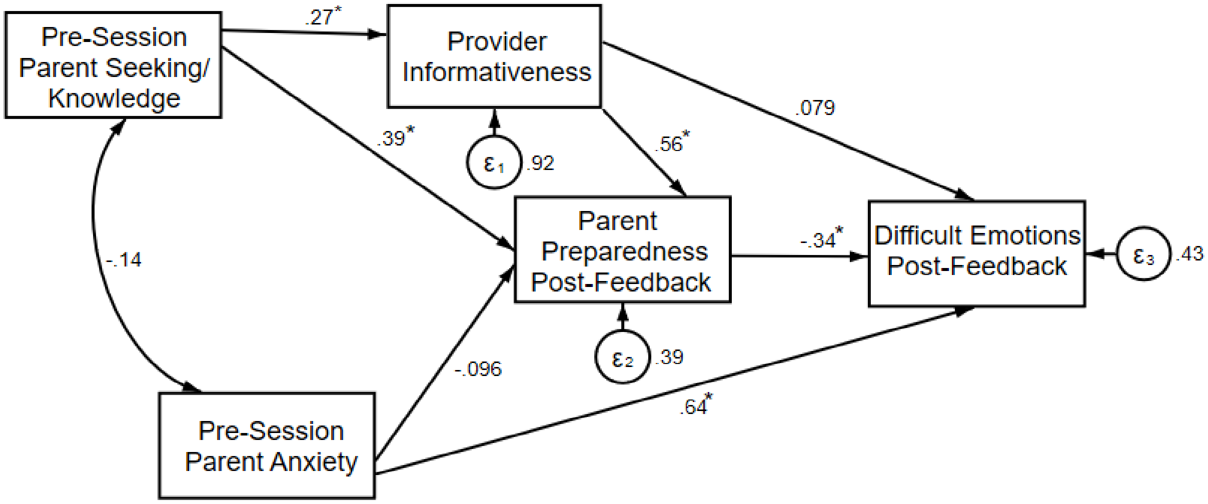

Figure 11. Structural equation model, with preparedness predicting difficult emotions, standardized coefficients, *p < .05

Alternate models showed weaker model fit. The first alternative model with the same variables, but with struggling and prepared in opposite positions, showed poor fit compared to null models

(Figure 12). This indicates that it is more helpful to think of families' preparedness affecting their overwhelmed feelings, rather than their overwhelmed feelings affecting their preparedness ($\chi^2(2) = 45.94$, $p < .001$; *RMSEA* = .352; *SRMR* = .077; *CFI* = .871; *TLI* = .421).

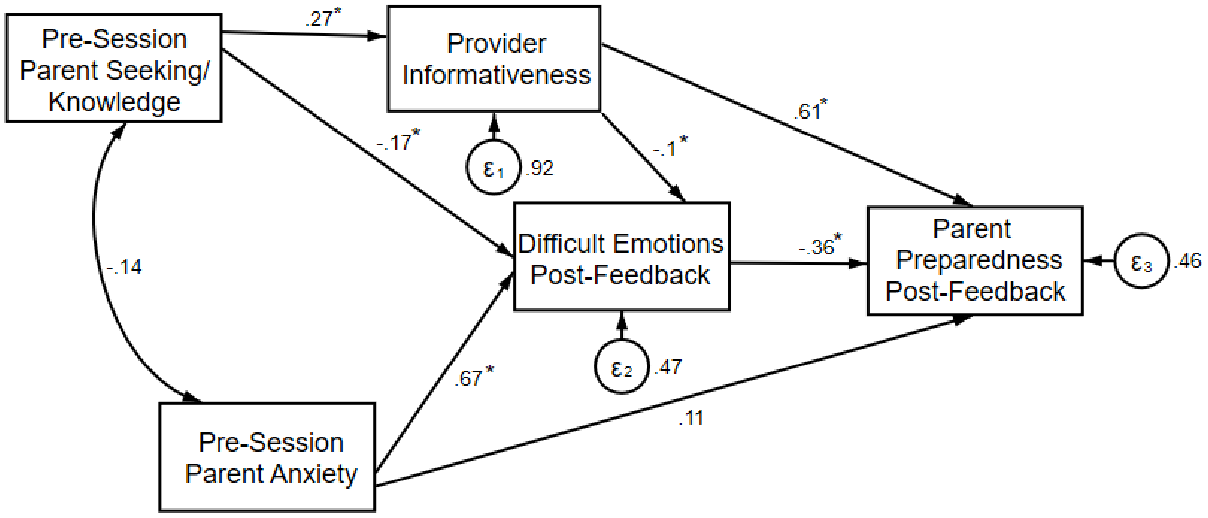

Figure 12. Structural equation model, with difficult emotions predicting preparedness, standardized coefficients, *p < .05

Figure 13 shows the second alternative model using the same variables predicting prepared and struggling, including both relationships between the outcomes ($\chi^2(2) = 3.48$, $p < .323$; *RMSEA* = .030; *SRMR* = .024; *CFI* = .999; *TLI* = .996). This model showed moderately good fit, though not as strong as the original model. This model further indicates that preparedness more strongly predicts struggling than does struggling predict preparedness.

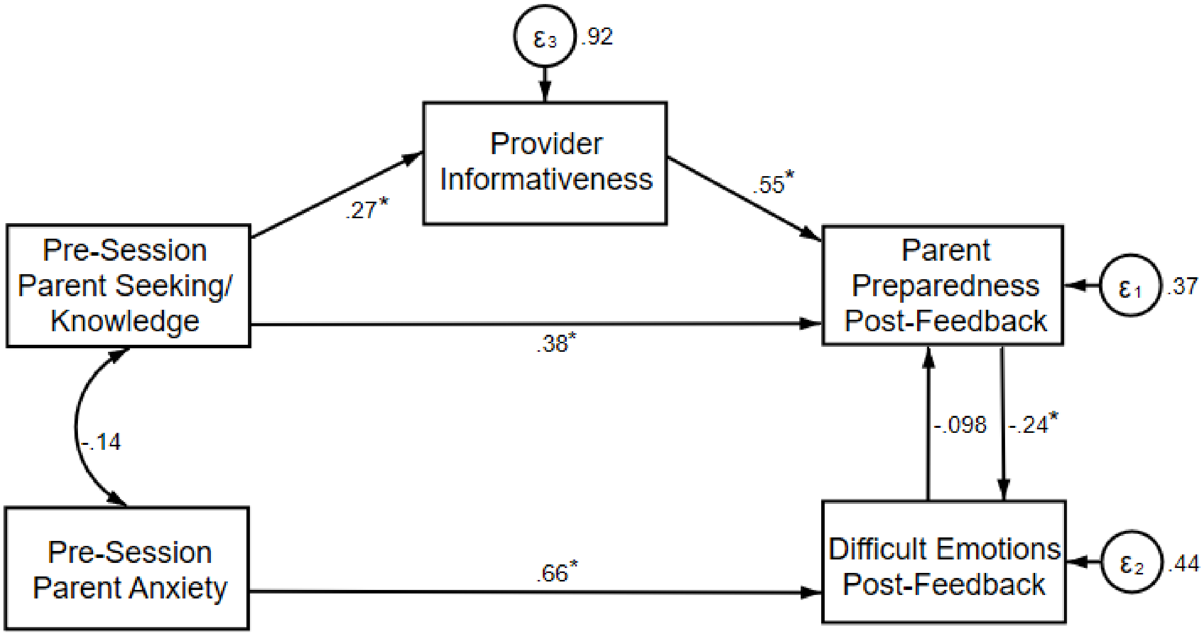

Figure 13. Structural equation model, with difficult emotions and preparedness predicting each other, standardized coefficients, *p < .05

Discussion

Summary

This study aimed to use both qualitative and quantitative methods, including provider interviews, a parent focus group, and a mixed-methods survey of parents, to understand parent experiences with autism diagnostic feedback sessions. To date, most research on this area has been qualitative in nature, and has yet to investigate which factors help predict parent reactions to diagnosis. This study focused on factors predicting parent reactions to diagnosis, in order to help providers understand which families are likely to struggle and how they can adjust to meet their needs. All hypotheses for this study were supported by the data. Parent reactions to diagnosis can be grouped into readiness to move forward, positive emotional reactions, and difficult emotional reactions, as well as confusion. Parent anxiety/uncertainty about the diagnosis and provider positivity were related to both positive and difficult emotional reactions, and pre-existing knowledge and provider informativeness were both related to parent feelings of readiness to take action following disclosure.

Our study found that feedback sessions can be both positive and difficult experiences for families. The feedback session can also allow families to move forward in their process of helping their child grow and thrive. Providers in our study reported trying to balance giving information to the family with helping the family process their conflicting emotions, and trend more towards emotional support when a family is anxious or upset by the diagnosis. However, the results of this study show that both information given during feedback and a positive demeanor are critical to outcomes, and families who are anxious about receiving a diagnosis may be most in need of high-quality information in order to feel prepared to move forward. Thus, providers should work to ensure they are preparing clients well for diagnosis, are aware when a family may be likely to struggle, are maximizing the information and recommendations they deliver, and are utilizing follow-up as much as possible. Clinical recommendations for these areas of practice are included below.

Clinical Applications

The results of this study are relevant for providers diagnosing autism in how they prepare families for the session, how they prepare themselves for the session, and how they conduct the session. Providers who infrequently diagnose autism may need to focus on ensuring they deliver helpful and accurate information sensitively, while larger autism or developmental clinics may think about specific clinic procedures that can help improve the experience of the many families that walk through their doors.

Preparing families. As feedback sessions are often impactful moments for families, it is important to prepare families adequately. Many clinics that are providing autism-specific evaluations will prepare the families for the type of testing that will be done or how many hours they will be at the clinic. However, based on our data, it also may be important to prepare families with a broader range of information about what to expect.

One simple piece of information providers can give to families when they schedule an appointment or before arriving is an idea of when feedback may be given. Some providers interviewed generally were certain about when diagnoses would be delivered (usually at the end of a long assessment day), while other providers had more flexibility and would decide according to their certainty about the diagnosis. It may be helpful to explicitly share with families the common possibilities, so they can make informed decisions about who should be at the session. Some mothers in our study mentioned that they wished their husband would have been at the session, or that the first thing they did was call their husband or another important family member. There is some recent evidence that fathers may struggle more with the diagnosis, partially because of their exclusion from the diagnostic process (Legg & Tickle, 2019). It may be helpful to let families know when they will be given assessment results and encourage them to include anyone whom they would want present when receiving important information. Other families in our study mentioned that they wish their younger children had not been in the room during feedback. Providers may help support family engagement and focus during the session by sharing information on timing so families can make arrangements or giving an option for brief childcare at the clinic.

Many providers interviewed noted that they try to prepare the families for the diagnosis by giving information throughout the assessment that communicates that the child is fitting diagnostic criteria. They also noted that feedback sessions seem to be most difficult when families' expectations were violated, and that giving families warning seemed to help offset this effect somewhat. Our study also showed that family knowledge about autism and belief that their child had autism affected emotional and preparedness outcomes. Giving families information throughout the session that would help them understand how their child may fit into the diagnosis may help them enter the session somewhat more informed and emotionally prepared.

Some level of information about autism and commonly co-occurring or differentially diagnosed conditions could also be given to families when they schedule the session while they are on a waitlist. This would hopefully help families enter more informed and better situated to receive the diagnosis or diagnoses during feedback. Giving information about common differential diagnoses for the child's age may also help set family expectations that they may or may not receive an autism diagnosis, as many providers reported finding it most difficult to give feedback when a family believes their child is autistic, but the child is not given an autism diagnosis.

It may also be helpful to prepare families for diagnosis by describing and normalizing common emotional experiences associated with the diagnostic process. Families may be able to experience and process their emotions most effectively if they feel they are normal and expected in this situation. Some providers mentioned that they see families apologize for their emotional experience and a few parents noted that they wish they had not had such a strong emotional reaction during feedback. Normalizing complex and conflicting emotions during feedback may help to reduce the functional impact of these emotions. It may also be important to help families waiting for a diagnosis to understand that there are ways we can help children with autism and other developmental concerns to grow and thrive. Giving families hope may reduce their fear of being given a diagnosis, which our study has shown is related to less optimal outcomes.

Overall, preparing families for the assessment and diagnostic feedback session may help families make appropriate decisions, but also feel more prepared and less anxious about the session. As anxiety about receiving a diagnosis is related to more negative emotionality and unpreparedness, if providers can influence this variable before the session they could significantly impact outcomes.

Preparing providers for feedback. Providers prepare for each individual's feedback session by collecting data, investigating differential diagnoses, and making diagnostic decisions. These things are critical, and our study showed that parents benefit when their provider appears competent and confident in the information they are sharing. However, providers can additionally prepare by formally evaluating the parent's current understanding of autism, preparedness for diagnosis, and reasons for seeking an evaluation.

Adding a few simple questions to intake paperwork or to the interview can help providers better plan feedback. Our study suggests that providers should ask about how nervous parents are about receiving a diagnosis, how much they are hoping or not hoping to receive a diagnosis, how much they believe their child has autism, and how much they already know about autism and treatment options. While most providers interviewed felt that some of these factors were important to how families react to feedback or inform how they tailor their sessions, none had yet established a formal system for collecting this information but rather attempted to pick up on these family beliefs and knowledge along the way. Formalizing what providers are already spending energy trying to gauge could help reduce unnecessary provider burden and decrease the possibility of misreading the family and being surprised by their reaction during the session. As our results suggest, knowing about the family's worries, beliefs, and knowledge can help predict how prepared they will feel when they leave the feedback session, as well as their positive and difficult emotional reactions. Recognizing high parent anxiety about the diagnosis can also help cue providers to make sure to take extra time to walk through resources with the family, as providing a strong amount of quality information to highly anxious families can help increase the likelihood that they will leave feeling prepared.

According to our sample, parents often pursue an evaluation for their child because they are hoping to learn more about their child and learn how they can best help them grow. While it is likely that many clinics already ask families why they are seeking an evaluation, it is imperative that providers carefully consider this information when planning their feedback. Parents often sacrifice much to bring their child to an assessment, and parents in our study noted that the wait for an evaluation can be difficult and confusing. Ensuring that the feedback session is focused on the family's goals is thus crucial to effectively serving them. In our sample, the most common reasons for pursuing an assessment were to understand their child better, to learn strategies that they could use at home to help their child, to validate parent concerns, to learn what to expect for their child's future, and to learn what services may help their child. If a family is most interested in learning strategies for home, it would likely be an unsatisfying feedback session if they were only told about school services and prognosis, while this session might be a perfect fit for another family. Generally, as almost all parents surveyed want to understand their child better, providers should consider how they can help put the child's behaviors into a broader context and help the parent see their child's strengths and difficulties in a new light.

Conducting an effective session. In evaluating parent experiences and factors that predict their responses, our study has shown how providers can help improve the feedback session for parents. This includes thinking about the provider's tone, information delivered and emphasized, and how to consider following up with families.

Families in our study emphasized that receiving diagnostic feedback can be difficult (even if it is also positive) and should be treated sensitively by providers. Many parents also clarified that they appreciated when providers were hopeful, rather than seeming to treat the diagnosis with the sad tone of telling someone of a life-threatening illness. Parents in our focus group and survey remembered statements of hope, caring, and understanding from their providers, and noted that these had a lasting impact on them. Additionally, our study found that a provider's positivity and warmth can help predict the parent positive emotional reactions following feedback. Setting a positive tone can include giving a hopeful prognosis, showing the family that you see the strengths of their child, letting parents know that you see their effort and their strengths as parents, taking the time to get to know the child and talking to and about them respectfully, and generally being warm and empathetic as you interact with the family. Both qualitative and quantitative results confirm that this warm and positive tone is important for family outcomes.

While tone is extremely valuable, the information shared during feedback is also critical for family success. Interviewed providers indicated that they usually share with families a bit about what autism is and why their child is diagnosed. Survey results showed that this type of basic information, along with a level of confidence and competence in the information being shared, is especially important to avoid families leaving confused. Beyond this basic information, parents would like providers to share what they can expect for their child's future. While providers do not know what exactly the future may hold, most parents surveyed noted that they would have appreciated a hopeful but accurate prognosis or a few likely scenarios for their child's growth and development.

In terms of resources, parents appreciate being pointed towards high quality resources, and every parent may need different resources based on their family's situation. Our survey data shows that having a satisfying breadth and depth of information is related to reduced negative emotionality and increased feelings of preparedness. In general, a few themes stood out of the qualitative data on resource needs. Families would like more information about how parents can be supported, whether that be support groups, connecting with a parent advisor, or even therapeutic services for parents, if desired. Parents also emphasized that the resources were helpful, but they needed assistance navigating these resources. This included wanting a provider to help prioritize next steps for the family. While some providers feel that they don't want to dictate a family's priorities, screening of family goals and interests, as mentioned previously, could help providers use their clinical knowledge to help the family reach their goals. It may be helpful to families to show this same prioritization in the written report, giving recommendations that are most related to families' immediate goals first, then following up with recommendations for less critical areas in an appendix or later in the report. Parents interviewed and surveyed also reported expecting that providers are the expert in local services, and would like their opinion on specific providers that may be a good fit for their child. Different providers may have different levels of comfort with providing specific recommendations and should be clear with families about their knowledge and comfort level. If the diagnosing provider does not have enough knowledge of relevant practitioners in the area, they should have information ready for families on how to evaluate possible practitioners or where they can receive more direct referrals. Several interviewed providers mentioned referring families to parent networks, as they have found that other parents are often the best source of information about community providers.

Finally, families in our study also wanted someone to walk them through resources and specifically outline how to access these resources. While it may not be feasible to spend time looking at websites with parents or filling out forms with them during the session, some organizations have thoughtfully employed family navigators to help with this. Providers who do not have this resource in their practice could find or develop handouts detailing how to go about accessing the services they have recommended, and can spend a few extra minutes discussing an important recommendation in the session. It is difficult for providers to expect families to follow up on a recommendation if they have not been given sufficient information to navigate the complicated systems. Employing these principles for every family can also help reduce the health disparities between families with more and fewer resources.

Looking at all the information it would be helpful to cover, providers may find that they do not have enough time to include all of this in the time allotted for feedback. Many families we spoke to expressed a strong desire for follow up with their diagnosing provider. While most providers interviewed gave families their contact information with an invitation to follow up, they generally reported that few families took advantage of this offer. Our focus group felt strongly that providers need to be the ones to reach out about follow-up. This desire was echoed in survey data. Follow up could be as simple as an email asking whether families needed any additional support, to a second session to go over resources once families have processed their initial reactions, to a one-year follow up to re-establish goals. Different practices may have different constraints and capabilities, but follow-up may be an important area of growth for the autism diagnostic field.

Limitations and Future Directions

This study constitutes a first look into the full experience of parents during diagnostic feedback sessions. It also has several limitations that affect the scope of application. The results of this study open possibilities for further investigation into the general themes discovered here. Due to the online nature of this study, it was difficult to ensure a representative sample. Our participants were predominantly wealthy, highly educated, and white, and the majority were diagnosed in one US state (though many other states were represented as well). While this population's perspective and experience will likely be similar in some ways to other populations, it is also likely to differ in many ways. The conclusions of our study thus primarily apply to this specific demographic group. However, it is likely that the recommendations for providers would benefit all individuals and universal application of these practices may especially benefit any populations that tend to receive less thorough or evidence-based care. Future research will need to collect similar data from other socioeconomic and racial/ethnic groups to determine exactly where these perspectives are similar or different. Our respondents were also mostly mothers of children diagnosed. While interviewed providers indicated that mothers are likely to attend feedback sessions more often than are fathers or other caregivers, research has shown that fathers have some areas of difference in their thoughts and concerns following diagnosis compared to mothers (Legg & Tickle, 2019). It is possible that fathers have different needs during feedback or different risk factors for difficult outcomes that are not adequately represented here.

In addition, the survey was sent to various types of autism organizations, including tertiary care center hospital diagnostic clinics and state parent support and advocacy groups. While there was some recruitment done by word of mouth across social media networks, it is likely that many of our participants were either diagnosed in an autism specialty diagnostic center that agreed to send out our survey or were well plugged into autism support networks and active in the communities that advertised the study. This likely skews our sample in the direction of parents who have had positive experiences and have been able to move forward effectively to help support their child and family. General satisfaction with the diagnostic feedback session was very high in our sample, lending credence to this theory. It is difficult to reach families that have not been directed to helpful services by their diagnosing provider, making this population difficult to capture. Future studies may wish to collect samples through the school system or through another program that may be most likely to capture families that are not well connected in the autism community.

Additionally, there is much about our study population that is not known, leaving room for further exploration. The study was sent to a variety of different groups and spread by word of mouth, in order to not pull from one type or quality of clinic. This means that we likely had quite a bit of variety in the type of provider, setting, and structure of the feedback session. However, in initial talks with focus group participants, it became clear that while they may have remembered the name of their specific clinic or provider, they were often unsure of the provider's professional qualifications or other details about the setting. Because parents are not intended to be experts in the complex medical and mental health systems, we did not attempt to collect these data for this study. However, our provider interviews clearly showed that different professionals have different perspectives and diagnostic routines. The feedback experience is very likely different for families who are diagnosed by their primary care provider, an interdisciplinary autism team, a psychologist in private practice, etc. In order to guide training efforts, it will be important for research to understand which areas are most critical for different professionals and practices to improve upon and which areas are going well already. Similarly, we do not know the general level of cognitive, adaptive, language, or social functioning of the children who were diagnosed, as we found it difficult to have parents report on this using the DSM-5 diagnostic labels. The majority of the families in our focus group were unsure what level of support (1-3) their provider put on their child's diagnostic paperwork, and there did not appear to be any other reliable indicator of functioning available in parent memories. Future research may wish to explore how different areas of child functioning may impact parent reactions to the diagnosis.

Similarly, in this study we only knew what families remembered from their diagnostic feedback sessions and could not definitively determine the full extent of what occurred during the session. Parents throughout our survey reported that at times they felt overwhelmed, and felt unable to focus and take everything in. The study was purposefully designed to capture the experience of parents, which was considered an important first step in this field of study. The next step will be to understand any differences between what actually occurs during the session and what parents remember. Providers would benefit from learning what helps parents remember the information given in the feedback session, and what they can do to help parents leave with the messages that are most important for them. Future studies could record or document feedback sessions and survey parents at a later date about their experiences, comparing the two. A randomized controlled study of parent reactions to different feedback session outlines would also be helpful in illuminating these concepts.

While this study used a moderately sized sample, some statistical analyses used, especially exploratory factor analysis and path analysis, are generally considered more robust with a larger sample that can be split into two or more separate samples to confirm conclusions. A larger sample size would be a logical next step for this study, especially to further validate the questions and measure for use in a clinical setting.

Finally, it is also possible that some correlations between variables are more affected by the retrospective self-report than by what actually occurred during the session. For example, it may be that parents who were happier about the diagnosis remembered the positive elements of their feedback session, while an overwhelmed parent may have remembered the same session and provider as less positive. The best way to overcome this bias may be to record feedback sessions and code for various provider factors to see if these connections with parent outcomes still hold true.

This study constitutes a first mixed-methods investigation into factors that affect parent reactions to feedback sessions. While previous research has focused on the diagnostic process as a whole, including wait times and the assessment process, this work narrows the focus to the diagnostic feedback session, which has the potential to serve as the end of a long journey of exploration and the beginning of a journey of acceptance and growth. Future work in the field of autism diagnostic feedback sessions should work towards continuing to understand factors that predict parent experiences and using these factors to design helpful protocols for various types of professionals. Feedback sessions are highly important for families and all would benefit from development and wide dissemination of evidenced based diagnostic care.

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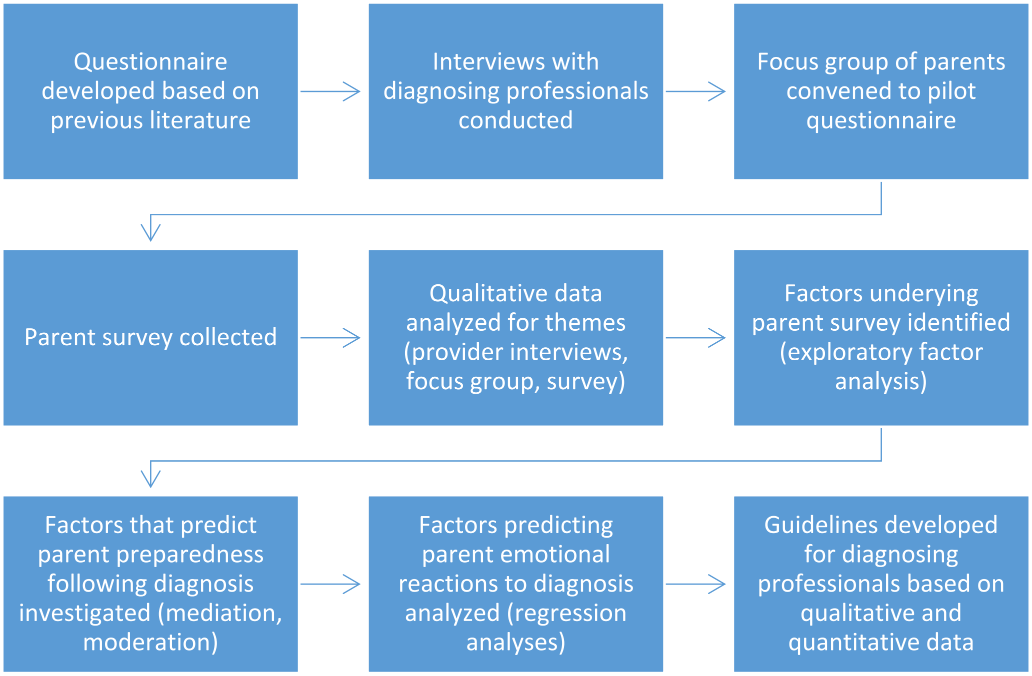
Appendix A

Study Flow Chart:



Appendix B

Q1 This survey will ask about **Parent Reactions to the Diagnosis of an Autism Spectrum Disorder.** We are interested in better understanding how parents react when their child receives a diagnosis of autism spectrum disorder and how their provider communicated this diagnosis.

Your participation in this study will require the completion of the attached survey. **In order to qualify for this survey,** you must be the **parent/guardian of a child diagnosed with an Autism Spectrum Disorder** (ASD, Asperger's Syndrome, Autistic Disorder, or Pervasive Developmental Disorder—Not Otherwise Specified [PDD-NOS]). Additionally, you must have **been present (in person or by phone) when this diagnosis was delivered** by a clinician**,** and the diagnosis must have been initially made within the **last 3 years.** Your child may have been any age when they were diagnosed.

This should take approximately 10-20 minutes of your time. Your participation will be anonymous and you will not be contacted again in the future. You will not be paid for being in this study, but may choose to enter a drawing to win a $75 gift card to Amazon.com (chances of winning are estimated to be 1 in 25). This survey involves minimal risk to you. The results of the research, however, may impact society by helping to increase knowledge about how parents experience the diagnostic process, and will result in guidelines for providers that may help them deliver the diagnosis in a way that is helpful to parents.

You do not have to be in this study if you do not want to be. You do not have to answer any question that you do not want to answer for any reason. We will be happy to answer any questions you have about this study. If you have further questions about this project or if you have a research-related problem you may contact me, Emily Anderberg, M.S. at emily.anderberg@byu.edu or my advisor, Mikle South, PhD at southlab@gmail.com.

If you have any questions about your rights as a research participant you may contact the IRB Administrator at A-285 ASB, Brigham Young University, Provo, UT 84602; irb@byu.edu; (801) 422-1461. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

The completion of this survey implies your consent to participate and your affirmation that you meet the study criteria as outlined above. **If you choose to participate, please continue on to complete the survey. Thank you for your participation!**

End of Block: Introduction

Start of Block: Demographic Information

Q5 What is your relationship to the child?

○ Mother (1)

○ Father (2)

○ Other (please specify): (3) ____

Q6 What sex was your child born?

○ Male (1)

○ Female (2)

Q9 Approximately how old was your child when you first became concerned about their development?

____

Q10 Approximately how old was your child when you first brought up your concerns with a professional of some type, like a doctor or teacher or counselor?

____

Q33 How old was your child when they received a diagnosis of an autism spectrum disorder?

____

Q4 In what US state was your child diagnosed?

____

Q3 Which autism spectrum disorder (ASD) was your child diagnosed with?

○ Autism Spectrum Disorder (1)

○ Asperger's Syndrome (2)

○ Autistic Disorder/ Autism (3)

○ Pervasive Developmental Disorder (PDD-NOS) (4)

○ I am unsure (5)

○ Other (please specify): (6) ____

Q11 Was your child diagnosed with another disorder(s) during the same diagnostic assessment? (e.g. Generalized Anxiety Disorder, ADHD, Intellectual Disability, etc.)

- ○ Yes (please specify): (1) ____
- ○ No (2)

Q12 Does your child have any siblings that were diagnosed with an Autism Spectrum Disorder prior to this child's diagnosis?

- ○ Yes (1)
- ○ No (2)

Q13 What is your child's ethnicity?

- ○ White (1)
- ○ Black or African American (2)
- ○ American Indian or Alaska Native (3)
- ○ Asian (4)
- ○ Native Hawaiian or Pacific Islander (5)
- ○ Hispanic/Latino (7)
- ○ Other (6)

Q16 What is the highest level of education you have completed?

- ○ Less than high school (1)
- ○ High school graduate (2)
- ○ Some college (3)
- ○ 2 year degree (4)
- ○ 4 year degree (5)
- ○ Professional degree (6)
- ○ Doctorate (7)

Q14 What is your approximate annual family income? (for classification purposes)

- ○ Less than $10,000 (1)
- ○ $10,000 - $19,999 (2)
- ○ $20,000 - $29,999 (3)
- ○ $30,000 - $39,999 (4)
- ○ $40,000 - $49,999 (5)
- ○ $50,000 - $59,999 (6)
- ○ $60,000 - $69,999 (7)
- ○ $70,000 - $79,999 (8)
- ○ $80,000 - $89,999 (9)
- ○ $90,000 - $99,999 (10)
- ○ $100,000 - $149,999 (11)
- ○ More than $150,000 (12)

Q15 What is your current marital status?

- ○ Married (1)
- ○ Widowed (2)
- ○ Divorced (3)
- ○ Separated (4)
- ○ Never married (5)

End of Block: Demographic Information

Start of Block: Before the Diagnostic Disclosure Session

The following survey will ask about your experience with the "diagnostic disclosure session." We define the diagnostic disclosure session as the time when, after doing an evaluation of some sort, a professional told you with some level of certainty that your child would be diagnosed with an autism spectrum disorder (ASD). This session may have been in person or over the phone, and it may have been a formally scheduled session some time after your assessment, or a few moments near the end of your assessment/appointment. Please answer these questions about whichever period of time you feel meets this definition most closely. Some people find it difficult to remember details about what they were thinking and feeling around this time. Please answer each question to the best of your ability. If you have more than one child who has been diagnosed with ASD in the last 3 years, please report on the most recent child's diagnostic disclosure session.

Q17 People often have many reasons for seeking a diagnostic evaluation for their child. **Select ALL of the following that apply**. "I wanted a diagnostic evaluation:

☐ to receive official documentation of Autism Spectrum Disorder (ASD) for services at school (Individualized Education Plan [IEP], 504 plan, etc.) (1)

☐ to receive official documentation of ASD for services outside of school (Applied Behavioral Analysis [ABA] therapy, early intervention etc.) (2)

☐ to receive official documentation for state/federal services or programs (Social Security [SSI], etc.) (3)

☐ to understand my child better (4)

☐ to determine whether my concerns were valid (5)

☐ because someone else told me to have my child evaluated (6)

☐ to get my child help for a different (non-ASD) problem (ADHD, anxiety, etc.) (7)

☐ because another child in my family has been diagnosed with ASD and I was worried about this child, too (8)

☐ to receive ideas for how to help my child at home (9)

☐ to receive referrals for other professionals that could help my child (10)

☐ to learn what to expect for my child's future (11)

☐ Other: (please specify) (12) ____

☐ Other: (please specify) (13) ____

Q18 Before the diagnostic disclosure session, my child was already receiving: (**Select ALL of the following that apply)**

- ☐ early intervention services (birth-to-3) (1)
- ☐ specialized services at school (504, Individualized Education Plan (IEP), special education preschool, therapies at school) (2)
- ☐ speech therapy, occupational therapy, and/or physical therapy from non-school providers (3)
- ☐ applied behavior analysis (ABA) therapy (4)
- ☐ other (please specify:) (5) ____
- ☐ my child was not receiving any services (6)

Q19 The following questions are about how you felt and what you thought in the days shortly **before** you were told your child had Autism Spectrum Disorder (ASD).
"Shortly before the diagnosis was given...

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I believed my child had autism spectrum disorder (1)	○	○	○	○	○
I wanted the professional to diagnose my child with ASD (2)	○	○	○	○	○
I was nervous about receiving a diagnosis of ASD (3)	○	○	○	○	○
I was uncertain about what the professional would diagnose (4)	○	○	○	○	○
I hoped the provider would not diagnose ASD (5)	○	○	○	○	○

Q20 "Shortly before the diagnostic disclosure session, I...

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
knew a lot about autism spectrum disorder (1)	○	○	○	○	○
knew what treatments my child would benefit from (2)	○	○	○	○	○
had sought out services to help my child's development (3)	○	○	○	○	○
had sought out information to help my child at home (4)	○	○	○	○	○
had social support to help me cope with my child's difficulties (5)	○	○	○	○	○

End of Block: Before the Diagnostic Disclosure Session

Start of Block: The diagnostic disclosure session

Q21
The following questions are about the **professional that delivered the diagnosis** of Autism Spectrum Disorder to you. This may have been a pediatrician, psychologist, speech pathologist, etc. If there was more than one professional involved in the assessment, please report on the one that most clearly told you

the diagnosis and gave you information. During the diagnostic assessment and diagnostic disclosure process the professional:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
seemed competent in their evaluation (1)	○	○	○	○	○
seemed confident about the final diagnosis they gave (2)	○	○	○	○	○
seemed to like/enjoy my child (3)	○	○	○	○	○
seemed to think I was working hard as a parent/was a good parent (4)	○	○	○	○	○
clearly expressed my child's strengths (5)	○	○	○	○	○
seemed to really "get" my child (6)	○	○	○	○	○
was warm and empathetic (7)	○	○	○	○	○

Q22 During the diagnostic disclosure session, the diagnosing professional:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
explained why they thought my child had autism spectrum disorder (1)	○	○	○	○	○
gave me (orally or in writing) helpful information about autism in general (2)	○	○	○	○	○
gave me useful strategies for how I could help my child at home (3)	○	○	○	○	○
gave me useful information about what kinds of treatments would help my child (4)	○	○	○	○	○
gave me useful information about organizations or providers that could help provide social support or advocacy (5)	○	○	○	○	○
gave me a good sense of what goals treatment providers should be working on with my child (6)	○	○	○	○	○
expressed what I could expect for my child's future (prognosis) (7)	○	○	○	○	○

End of Block: The diagnostic disclosure session

Start of Block: After the diagnostic disclosure

Q23 Following the diagnostic disclosure session, I felt like:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I knew what autism was, in general (1)	○	○	○	○	○
I knew why my child was given an autism spectrum disorder diagnosis (2)	○	○	○	○	○
I knew about what kind of treatments my child would benefit from (3)	○	○	○	○	○
I knew where to go to get my child help (4)	○	○	○	○	○
I knew what kinds of things treatment providers should be working on with my child (5)	○	○	○	○	○

Q24 Shortly after the diagnostic disclosure session, I felt:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
relieved to finally have a diagnosis (1)	○	○	○	○	○
validated, like my concerns were valid all along (2)	○	○	○	○	○
hopeful about my child's future now that we can get help (3)	○	○	○	○	○
grateful for the diagnosing professional(s) (4)	○	○	○	○	○
in shock about the news (5)	○	○	○	○	○
worried about my child's future (6)	○	○	○	○	○
upset, struggling with the diagnosis (7)	○	○	○	○	○
angry or unhappy with the diagnosing professional(s) (8)	○	○	○	○	○
overwhelmed by the amount of information (9)	○	○	○	○	○
confused about the diagnosis (10)	○	○	○	○	○
lost, not sure where to go from here (11)	○	○	○	○	○
alone, left feeling isolated or unsupported (12)	○	○	○	○	○
sad about the loss of the future I thought my child would have (13)	○	○	○	○	○

Q25 Many people seek help for their child as a result of the diagnostic disclosure. Approximately how long after the diagnostic disclosure session did you begin to seek services for your child (by contacting a provider, signing up for a treatment or waitlist, giving assent for your child to begin a new treatment, etc.)

○ less than a week (1)

○ 1-4 weeks (within a month) (2)

○ 1-3 months (3)

○ 4-6 months (4)

○ after more than 6 months (5)

○ I did not seek any help/services for my child (6)

Q33 What were the first types of help you sought in the days, weeks, or months following the diagnosis? (rank in the approximate order you sought them following the diagnosis [1 = first type of help you sought, 2 = second type, etc.], if you didn't seek this type of help, leave it blank)

______ Social support (informal, reaching out to friends and family) (1)
______ Social support (formal, like support groups or clubs) (2)
______ Services recommended by my diagnosing professional (therapies, medications, social services, groups, etc.) (3)
______ Services I found on my own (including therapies, medications, social services, groups, etc.) (4)
______ Online information, on websites recommended by my diagnosing professional (5)
______ Online information, on websites I found on my own (6)
______ School services (therapies, IEP, 504 plan, etc.) (7)
______ Books, recommended by my diagnosing professional (10)
______ Books, that I found on my own (11)
______ Alternative medicine (8)
______ Other: (9)

Q26 Overall, how satisfied were you with the diagnostic disclosure session?

○ Extremely satisfied (1)

○ Moderately satisfied (2)

○ Slightly satisfied (3)

○ Neither satisfied nor dissatisfied (4)

○ Slightly dissatisfied (5)

○ Moderately dissatisfied (6)

○ Extremely dissatisfied (7)

End of Block: After the diagnostic disclosure

Start of Block: Qualitative

Q27 Some people remember things that were said during the diagnostic disclosure session, almost word-for-word. If something that was said during the session sticks out in your mind, write it below:

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____

Q28 What was the most helpful type of information that you got from the diagnostic disclosure session?

____

____

Q29 What about the diagnostic disclosure session would you have changed?

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____

Q30 In hindsight, what information would you have liked to have received, but did not, at the diagnostic disclosure session?

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Q35 What was the first thing you did after receiving the diagnosis (to help your child or yourself)?

____

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Q34 If you would like to provide any other information that would help us understand your experience, please write us a note here:

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End of Block: Qualitative