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Examining the Role of Resolution to Diagnosis in Intervention Engagement for Early Diagnosed Children with ASD

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for Early Diagnosed Children with ASD

Cara Cordeaux, Ph.D.

University of Connecticut, 2019

A large body of research indicates that early intervention leads to better outcomes in children with Autism Spectrum Disorder (ASD); yet, research on parent factors that influence intervention engagement is sparse, though emphasized in recent literature that examines the impact of receiving a child's diagnosis on parents' mental health and well-being. Examination of the relationship between parent adaptation to a child's diagnosis (resolution to diagnosis) and intervention engagement as well as factors that may influence parent resolution provides important information about parent psychological processes and their impact on real-life behaviors. We examined these factors in parents of children diagnosed at 24 months and younger who participated in a study of ASD screening instruments. Approximately 12 weeks following evaluation, parents were contacted for a telephone interview to assess treatment engagement (e.g., contacting providers and beginning services) as well as resolution to the child's diagnosis through a semi-structured interview. Analyses indicate that parents had a high level of intervention engagement at follow-up regardless of resolution or lack of resolution to diagnosis. Consistent with previous literature on parent resolution, most parent and child demographic factors were not associated with parent resolution. Exploratory analyses identified trends in linguistic patterns between resolved and unresolved parents. Clinical implications are important to consider in the context of feedback and follow-up best practices and an increasing focus in the field on parent experiences during and after a child's diagnosis.

Examining the Role of Resolution to Diagnosis in Intervention Engagement
for Early Diagnosed Children with ASD

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Doctor of Philosophy Dissertation

Examining the Role of Resolution to Diagnosis in Intervention Engagement

for Early Diagnosed Children with ASD

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Examining the Role of Resolution to Diagnosis in Intervention Engagement for Early Diagnosed Children with ASD

Autism Spectrum Disorder (ASD) is a behaviorally defined and diagnosed disorder that includes deficits evident before the age of three in communication, play, attention, cognition, and sensory abilities (American Psychiatric Association, 2013). Current estimates place the rate of ASD at 1.7%, or one in 59, among school-aged children (Baio, Wiggins, Christenson, et al., 2014). ASD is generally considered a chronic diagnosis; affected children typically require consistent support and intervention as developmental needs change over time (Johnson et al., 2007), although a small number of children may make sufficient progress to lose their diagnosis over time. (Fein et al., 2014). More than a decade of evidence identifies early engagement with intervention services in the first 24 months of life as a means to shift the developmental trajectory for many children with ASD by facilitating improvements in social communication, play, and cognitive abilities (Dawson, 2008; Landa, 2008; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Orinstein et al., 2014; Rogers & Vismara, 2014). Indeed, research suggests that children diagnosed before age four who no longer meet criteria for an ASD diagnosis later in childhood received earlier and more intensive behavioral intervention compared to peers (Orinstein et al., 2014). The American Academy of Pediatrics recommends that children with suspected or diagnosed ASD receive 25 hours per week for 12 months per year of evidence-based intervention (Johnson et al., 2007).

Recent research suggests that early ASD diagnosis for children under 24 months is associated with an increase in intervention hours in the first six months following a diagnosis, even for children already receiving general early intervention (EI) (Suma, Adamson, Bakeman, Robins, & Abrams, 2016). Yet, beginning timely and time-intense intervention for children with

ASD can be impacted by a number of external factors, from person-level psychological processes such as parental acceptance and meaning-making in response to a diagnosis (Bonis, 2015; Edwards, Brebner, McCormack, & MacDougall, 2016; Gentles, Nicholas, Jack, McKibbon, & Szatmari, 2018) to system-level issues related to access to health care systems and care providers (Zuckerman et al., 2015). While the impact of system-level obstacles on intervention engagement is well documented in the literature, the role of person-level psychological factors (such as a parent's reaction to or acceptance of a diagnosis, coping strategies, or self-perceived competence to parent a special-needs child) on intervention-seeking behavior following early childhood diagnosis is less well understood.

The relative dearth of research on parent factors that influence intervention engagement is a notable gap in the literature, particularly as a growing body of research indicates that parents' experiences around diagnosis impact their well-being and functioning (Bonis, 2015; Reed & Osborne, 2012). To date, few studies have directly examined the relationship between parent adjustment to diagnosis and intervention engagement. Some evidence suggests that parent beliefs about the course or etiology of their child's autism influence what treatments they choose. A review of studies on intervention choices found that a child's trajectory impacted etiological beliefs and engagement with interventions. That is, if a child regressed, parents were more likely to believe vaccines were a causal factor and were less likely continue immunization schedules and more likely to use alternative interventions (Hebert & Koulouglioti, 2010). Parent beliefs about etiology have been shown to guide treatment choice; for example parents who believed a child's symptoms were due to sensory processing issues sought sensory therapies (Hebert, 2014) and parents who believed ASD was caused by food allergies were more likely to choose special diets, detoxification, or vitamin treatment over psychopharmacological treatment (Dardennes et

al., 2011). Existing literature on parent adjustment to diagnosis and intervention engagement suggests that parents experience urgent pressure to begin treatments (Edwards et al., 2016). One qualitative study of parent adjustment and intervention engagement proposed a model where multiple inter-related meaning-making processes impact parents' capacity and motivation for action (e.g., defining concerns, informing the self, seeing what is involved, and adapting emotionally) (Gentles, Nicholas, Jack, McKibbon, and Szatmari, 2018). In a hypothesized model, navigating intervention engagement begins with "coming to the understanding that the child has autism" followed by "going into high gear," with subsequent "easing off" of parent motivation for action, yet authors note that there is overlap among steps (Gentles, et al., 2018). However, this study did not collect objective data on intervention engagement (e.g., timelines or quantity of intervention hours). With the current strong emphasis on EI for children diagnosed with ASD, characterizing parents' psychological processes of adjustment to diagnosis in relationship to measurable intervention engagement for very young children may provide important information that can facilitate and support use of services (Rogers & Vismara, 2014).

Parent Reaction to ASD Diagnosis

A diagnosis of a chronic disorder (such as ASD) can elicit intense cognitive and emotional processes for parents in the time period after a child receives a diagnosis (Marvin & Pianta, 1996). Indeed, twenty percent of parents demonstrate posttraumatic stress symptoms following a child's diagnosis (Casey et al., 2012). A rich body of narrative research on parent adaptation to an ASD diagnosis notes prominent themes of grief and anger, relationship strain, and disappointment or doubt that occur before parents experience a revision of hopes for the child, meaning-making, and then begin seeking answers or taking action (DePape & Lindsay, 2014; Fleischmann, 2004; Huws, Braddock, & Ingledew, 2001; Lutz, Patterson, & Klein, 2012;

Mulligan, MacCulloch, Good, & Nicholas, 2012). One proposed way to conceptualize this process is through attachment theory, which posits two complementary systems: the attachment system in the infant and the caregiving system in the parent (Bowlby 1969, 1980). The caregiving system comprises both patterns of behavior as well as internal representations, including a representation of the parent as a caregiver, of the child, and of parental goals and the ways to achieve them (Bretherton & Munholland, 1999). Following from attachment theory, Marvin and Pianta (1996) proposed a model of “resolution” to a diagnosis to describe the process that occurs when a parent’s internal representation of their child must change to integrate the “loss of the perfect child” after a diagnosis. This process was first conceptualized through study of parents of children with cerebral palsy, a chronic childhood disease. When a child receives a diagnosis of a chronic illness, Marvin and Pianta (1996) posited that it acts as a trauma to the caregiving attachment system and requires adjustment to parents’ beliefs and expectations about a child and his or her future. The resolution process, though difficult, is hypothesized to help parents cope with their child’s changed reality and related challenges as it includes accepting the implications and possible outcomes of the diagnosis (Marvin & Pianta, 1996). For a diagnosis of ASD, possible implications and outcomes may include the expectation of a significant amount of resources devoted to a child’s needs in the immediate future and over time, as well as broader concerns about a child’s future ability to participate in age-appropriate milestones such as attending college, living independently, or forming successful social relationships.

The reaction to diagnosis interview (RDI; Pianta & Marvin, 1993) was developed to assess parents’ adjustment following a child’s medical diagnosis. The RDI is the only available published measure that assesses parent resolution to a child’s diagnosis. Within the coding system, parents are classified as “resolved” or “unresolved.” Within the resolved category,

parents are further classified by the type of coping strategies they endorse (action, thinking, or feeling). A parent is considered resolved to a diagnosis if they can orient to the child's new reality and regulate their own emotions; in other words, a resolved parent identifies a change in their feelings towards the diagnosis over time, and they move beyond the crisis of the diagnosis to focus on present or future-oriented problem solving (Pianta, Marvin, Britner, & Borowitz, 1996). An unresolved parent is characterized by disorientation and failure to move on from the crisis of the diagnosis; they are "stuck in the past" and may focus more on causality or hold unrealistic beliefs about their child's future (Marvin & Pianta, 1996; Pianta et al., 1996). Lack of resolution is associated with feelings of grief and confusion and may impact a parent's ability to meet a child's needs in an organized, effective way (Marvin & Pianta, 1996; Pianta et al., 1996).

The developers of the RDI note the importance of attending to the language of a parent's narrative (e.g., vocabulary choice, use of vague versus specific language, etc.) to guide classification (Pianta & Marvin, 1993). An important signifier of resolution to diagnosis is a parent's ability to access feelings and speak candidly about emotions (Pianta & Marvin, 1993). One exploratory principal components factor analysis of the RDI found that an "emotional resolution" factor (e.g., the extent to which parents have processed the complex feelings around child ASD diagnosis) was associated with more engaged parenting style and behavior (Wachtel & Carter, 2008). The authors posited that emotional resolution reflects the degree of emotional processing the parent has done since the child's diagnosis. In other words, it captures the psychological shift a parent has made that may allow them to make changes in their behavior (Wachtel & Carter, 2008). A growing body of linguistic research has demonstrated that language analysis tools can be highly informative when used in conjunction with other measures to understand complex psychological processes (McIsaac & Eich, 2004; Robbins, Mehl, Smith,

&Weihs, 2013). Recent research suggests a relationship between the use of emotion words and coping following a diagnosis of serious illness (cancer) for the self or for family members (Hexem, Miller, Carroll, et al., 2013; Robbins et al., 2012). Pronoun use is also associated with adjustment following diagnosis of serious illness (Robbins et al., 2012) as well as adjustment following trauma or loss (Kaplow et al., 2018). Given the emphasis on language in the RDI coding system, there may be utility in exploring RDI narratives with linguistic analysis tools. Understanding language patterns of resolution versus lack of resolution has potential clinical use in identifying parents who may benefit from additional follow-up or support.

Impact of Resolution to Diagnosis on Parent Functioning and Behavior

For parents of children with chronic disease, resolution to diagnosis has been associated with several psychological factors as well as real-life behaviors. Resolved parents of children with cerebral palsy had lower levels of parenting stress, better use of social support systems, and greater satisfaction in marital relationships (Sheeran, Pianta, & Marvin, 1997). Similarly, resolved parents of children with psychiatric disorders and phenylketonuria reported lower levels of stress (Kearney, Britner, Farrell, & Robinson, 2011; Lord, Ungerer, & Wastell, 2008). There is some evidence to suggest that parent resolution to a child's diagnosis relates to parenting behavior following diagnosis, such that resolved mothers of intellectually disabled children demonstrated more sensitivity to behavioral cues during play (Feniger-Schaal & Oppenheim, 2013). Unresolved parents of children with asthma or diabetes were more likely to endorse less emotion expressiveness in the family, lower family cohesion and greater family conflict than resolved parents, and the children of unresolved parents endorsed more family conflict (Popp, Robinson, Britner, & Blank, 2014). Marvin and Pianta (1996) originally posited that lack of resolution was a source of stress for parents that may impede appropriate caregiving. Taken

together, this evidence suggests that resolution to diagnosis as indexed by RDI classification has the potential for wide-reaching impact on parent and child outcomes following a child's diagnosis.

Several studies have utilized the RDI following an ASD diagnosis to examine parenting behavior, parenting stress, and the relationship between child or parent characteristics and RDI classification. Mothers resolved to a child's ASD diagnosis were found to demonstrate more sensitivity and engagement in play (Dolev, Sher-Censor, Baransi, Amara, & Said, 2016; Wachtel & Carter, 2008) and were more likely to have securely attached children (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). Resolved mothers of children with ASD had lower psychological distress and stress related to parenting (Dolev et al., 2016; Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010).

Additional Variables Associated with Parent Behavior Following Diagnosis

Resolution to diagnosis was conceptualized as a multi-faceted process with potential influence from both the parent's internal model of themselves and of their child. Parent self-efficacy is one variable that may impact resolution to diagnosis for parents following a child's ASD diagnosis. Bandura (1997) described parenting self-efficacy as parents' perceived feelings of competence in the parenting role, including their sense of ability to successfully raise their child, which is thought to contribute to actual parenting behaviors (Guimond, Wilcox, & Lamorey, 2008). Parent self-efficacy can be related to specific parenting tasks or challenges (Teti, O'Connell, & Reiner, 1996) as well as to the broader domain of general parenting ability (Guimond, et al., 2008). A central aspect of resolution is reorganization within the caregiving system, which includes a restructuring of parenting goals and ways to achieve them as well as a sense of the self as a caregiver. Self-efficacy may promote reorganization in a way that reflects a

parent's perception of their ability to competently parent their child and may potentially buffer some of the psychological impact of processing the diagnosis. That is, a parent with higher self-efficacy regarding their general and specific task competence prior to the crisis of diagnosis may be more readily resolved to a child's diagnosis compared to a parent with lower self-efficacy.

There is evidence that self-efficacy impacts parent experiences and behaviors. Parenting efficacy has been inversely associated with parenting stress for both typically developing children and children with clinical concerns (Kuhn & Carter, 2006; Teti et al., 1996). That is, parents who report greater self-efficacy also report less stress. Research also suggests that parents with greater self-efficacy are better able to adjust to the challenges and demands of raising a child with ASD (Bekhet, Johnson, & Zauszniewski, 2012; Pakenham, Sofronoff, & Samios, 2004). A greater sense of self-efficacy may also have a direct impact on parenting behaviors, with evidence suggesting that parents' sense of self-efficacy predicts use of intervention services following a child's ASD diagnosis independently of broader family demographics that have historically influenced service use (Siller et al., 2014). In addition, higher self-efficacy has been associated with taking a more active role in promoting child development, including liaising with interventionists (Kuhn & Carter, 2006).

The relationship between parent self-efficacy and resolution to diagnosis is relatively unexplored in the literature, though there is some evidence suggesting an association. One study that measured negative attitudes about parenting found that unresolved mothers reported more negative feelings about their child and reduced ability to cope with the impact of the disorder on the family functioning than resolved mothers (Milshtein et al., 2010). Another recent study found that a change over time from unresolved to resolved status was associated with increased parent self-efficacy, suggesting that parent self-efficacy may contribute to or influence the resolution

process (Poslawsky, Naber, Van Daalen, & Van Engeland et al., 2014). However, neither study measured parental self-efficacy before the child's diagnosis was made; thus, results represent parent attitudes and self-efficacy measured post-diagnosis. Thus, the relationship between pre-diagnosis self-efficacy and resolution is unknown. It is potentially valuable to understand what role, if any, pre-diagnosis self-efficacy plays in parent resolution to an ASD diagnosis. As self-efficacy has been shown to increase in response to brief parent-focused intervention (Sofronoff & Farbotko, 2002); characterizing the relationship between self-efficacy and resolution to diagnosis can inform potential points of support for parents of early diagnosed children.

RDI classification appears to reflect more internal psychological processes than objective parent or child characteristics among parents of children with ASD. RDI classification has not been associated with a parent's age, level of education, or socioeconomic status (Dolev et al., 2016; Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014; Wachtel & Carter, 2008), nor duration of time since receiving the diagnosis (Dolev et al., 2016; Hutman et al., 2009; Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014). Similarly, RDI classification has not been associated with a child's gender, age, birth order, cognitive development level, or adaptive functioning (Dolev et al., 2016, Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014; Wachtel & Carter, 2008). Research findings are mixed regarding the role of a child's symptom severity in parent RDI classification. Two studies found that resolved parents reported fewer ASD symptoms for their child (Dolev et al., 2016; Poslawsky et al., 2014) while two others found no association between reported ASD symptoms and parent RDI classification (Milshtein et al., 2010; Oppenheim et al., 2009). In use of the RDI in other groups, a study of children with cerebral palsy found that parents of children with less severe symptoms were more likely to be resolved (Schuengel, Rentinck, Stolk, et al., 2009). This

study's authors hypothesized that diagnosis is more easily processed when parents understand their child is less symptomatic, which may impart a sense of "mild" disability and thus greater expectation of positive outcome. In contrast, parents may experience difficulty adjusting to a diagnosis when they understand their child is more "severe" in symptoms or disability, with accompanying expectation of more pervasive limitations (Schuengel, Rentinck, Stolk, et al., 2009). Taken together, available research suggests that severity of ASD symptoms may impact a parent's resolution to the diagnosis in ways that remain poorly understood.

Current Study Aims

There is limited literature examining the relationship of resolution to diagnosis to other aspects of parental functioning and to intervention engagement after an initial diagnosis of ASD. The current study provides a unique opportunity to examine these variables in a sample of very young children (<24 months) receiving a first-time diagnosis of ASD. Research examining parental processes in the context of child diagnosis suggests that assessing parent RDI classification may be an important part of clinical treatment as well as a potential point of intervention, as parent mental health can influence child outcomes (Dolev et al., 2016; Reed & Osborne, 2012). A better understanding of the relationship between parental resolution and intervention engagement has important clinical implications for how clinicians may best serve families in order to facilitate use of intervention services following an ASD diagnosis. For example, working to facilitate parental resolution as a part of evaluation feedback may translate to higher rates of intervention engagement for children. Similarly, understanding of parent's resolution to the diagnosis could be used to tailor parental support planning to maximize healthy coping behavior. The current study seeks to better understand the relationship between parental resolution to diagnosis as indexed by RDI classification, parent and child characteristics, and

intervention engagement soon after a child's ASD diagnosis. See Figure 1 for a model of hypothesized relationships.

Primary Aim: First, the current study seeks to assess whether parent resolution to early diagnosis as measured by RDI classification is related to intervention engagement. We hypothesize that parents who are classified as resolved will have greater levels of intervention engagement relative to unresolved parents. As intervention engagement can often depend on system-level variables (e.g., availability of treatment providers in a family's geographic area, wait time for insurance approval), this variable was measured by assessing parent-initiated contact to EI and primary care providers rather than adherence to clinical recommendations.

Secondary Aims: Secondly, the study will assess whether parent and/or child-level factors are associated with resolution to early diagnosis as indexed by RDI classification. Consistent with prior research, no relationship is expected between parent age, education, family income and RDI classification. We hypothesize that parent self-efficacy prior to receiving a child's diagnosis will be related to resolution to diagnosis. Consistent with previous research, we hypothesize that symptom severity will be associated with resolution to diagnosis. We do not expect a relationship between RDI classification and other child factors (e.g., age, adaptive skill level, cognitive ability, birth order).

Exploratory Aim: Explore linguistic features of resolution to early diagnosis. Research on parent adjustment and reaction to a child's diagnosis suggests that linguistic content offers insight into psychological processes. More recent methods of linguistic analysis use empirically validated computerized tools to detect content words related to psychological processes, such as how parents of children with serious pediatric disorders experience and communicate about emotions (Hexem, Miller, Carroll, et al., 2013). Linguistic patterns have also been linked to

adjustment following serious illnesses (Owen et al., 2006; Robbins et al., 2012) and trauma processing (Kaplow, et al., 2018; McIssac & Eich, 2004). We examined parents' interviews using a linguistic analysis program to assess whether any patterns were associated with RDI classification.

Methods

Participants

Participants were parents drawn from a sample of children participating in the Early Detection Project, an ongoing population-based study to evaluate the ability of early childhood screeners to detect ASD risk in children aged 12-24 months across three sites (University of Connecticut, CT; AJ Drexel Autism Institute, PA; and Georgia State University, GA). All three states have public EI services for children under three years of age. Exclusion criteria for the broader study included significant sensory impairments (e.g., blindness) and deficits in motor functioning (e.g., severe cerebral palsy) that would impact a child's ability to complete testing. Children who had previously diagnosed co-morbid disorders (e.g., Down's syndrome, Fragile X Syndrome, seizure disorder) were further excluded from the current study. Non-fluent English speakers were also excluded from this study because most measures were normed on English-speaking samples. Recruitment ran from July 2017 through April 2018, with projected recruitment of 75 families over 10 months from all three sites. During the recruitment period, Georgia State University sites ended recruitment for the broader study. Due to declines in evaluation numbers in the broader study during the recruitment period as well as a higher than expected number of families who did not complete scheduled evaluations, overall participant numbers were lower than anticipated. This resulted in a smaller pool of families available for invitation to the current study. Parents who consented to the current study were contacted up to

six times over several weeks by research staff at different times of day to maximize response rate.

Thirty-nine parents of children who received a neurodevelopmental disorder diagnosis during the study recruitment period consented to be included in the current study (ASD diagnosis $n=27$, developmental delay diagnosis $n=9$, language disorder diagnosis $n=3$). A subset of parents ($n=20$; ASD $n=18$, developmental delay $n=2$) completed a full phone interview approximately 10 weeks after the evaluation. The majority of parents who responded were female ($n=19$, 95%). To establish whether parents who completed the interview (responders) differed from those who did not (non-responders), groups were compared on multiple demographic factors. Independent t -tests (two-sided) were performed to analyze continuous variables and chi-square tests of independence were used to analyze categorical data. There was no difference between responders and non-responder groups on child's age, race/ethnicity, birth order, eligibility for EI prior to evaluation, or hours of intervention received prior to evaluation. The relationship between child's gender and group was significant, with parents with male children more likely to be in the responder group ($\chi^2 (1, N=39) = 4.8, p=.03$). The relationship between diagnosis and group was also significant, with parents with children with an ASD diagnosis more likely to be in the responder group ($\chi^2 (2, N=39) = 8.8, p=.01$). There was no difference between groups on primary caregiver's years of education, marital status, or reported family income level. Parents in the responder group ($M=37, SD=6.4$) were older than non-responder parents ($M=30.5, SD=6.5; p=.004$). There was no difference between responders and non-responders on recruitment site. See Table 1 for a summary of responder and non-responder characteristics.

A final sample of 18 parents of children with ASD were included in further data analysis; two ICD-10 diagnoses (childhood autism and atypical autism) were collapsed into one category

(ASD) due to small cell numbers. Two parents of a child with a non-ASD diagnosis who completed the follow up interview were excluded from further analysis due to small cell size. Children of parents in the sample were 83% male ($n=15$), with a mean age of 24.5 months ($SD = 5.8$). For the purposes of this study, all minority races/ethnicities were collapsed into one category (non-White) due to small cell numbers. The majority of children in the sample were White (67%, $n=12$). Ten of the children were first-born (56%). Three children had older siblings with an ASD diagnosis. The majority of primary caregivers were female (94%, $n=17$). Caregivers included two adoptive mothers and one father. Two caregivers were single or divorced, and the median family income bracket was 84 to 96 thousand dollars. The time since receiving the diagnosis to follow-up interview ranged between 6 and 23 weeks.

Procedures

Children enrolled in the current study via pediatrician well-child visits where parents completed screening questionnaires and a pediatrician completed an ASD surveillance checklist; screening was completed by paper and electronically. If a child screened positive (i.e., failed a screener or a pediatrician noted ASD concerns), a graduate student contacted the primary caregiver via telephone to confirm failed items or to invite the child for a free developmental evaluation (in the case of pediatrician concerns). If a child was confirmed to screen positive during the follow-up phone interview, they were invited to attend a free developmental and diagnostic evaluation. A licensed clinical psychologist or developmental pediatrician and a graduate student in the clinical psychology program at the University of Connecticut, Drexel University, or Georgia State University conducted the evaluations; each evaluation consisted of parent interviews and child testing to assess the child's cognitive, adaptive, and language skills as well as ASD-specific measures. Caregivers received verbal diagnostic feedback and

recommendations for treatment at the conclusion of the evaluation and received a written report approximately six weeks later. Diagnoses were made based on the clinical judgment of experienced clinicians following ICD-10 criteria (World Health Organization, 1992). For the purposes of group analysis, ICD-10 diagnoses were coded into three groups in this study: ASD, developmental delay, and language disorder.

Parents of children who received a neurodevelopmental diagnosis during the study recruitment period were invited to participate in a follow-up phone interview approximately 10 weeks post-evaluation. The follow-up interview was conducted by a graduate student or trained research assistant and was designed to capture data about parents' intervention-seeking behaviors after evaluation. It included the RDI as well as questions about parents' experiences during the evaluation and feedback. The phone calls were audio-recorded and transcribed by trained research staff.

Studies examining factors related to RDI classification found associations between RDI classification and child symptom severity with effect sizes ranging from .5 to .8, and associations between RDI classification and parent efficacy with effect sizes ranging from .2 to .7. An a priori power analysis indicated a sample size of 75 (at least 37 subjects in each of the two groups) would have 0.9 power for detecting a medium effect size ($d= 0.50$) on the primary outcome variables of intervention engagement with dichotomous coding. In the context of unexpectedly low recruitment numbers, implied power was calculated for detecting a medium effect size for the final sample of 18 participants on the primary outcome variables of intervention engagement as assessed by Chi square tests (.79) and t-tests (.33).

Measures

Pre-evaluation Measures

History Form. A detailed history form was developed to gather information about children and families. On each form, caregivers indicated data such as age of first concern, concerns about regression, and provided demographic information (age, gender, race/ethnicity, birth order, maternal age, years of maternal education, yearly income).

Tool to Measure Parenting Self Efficacy (TOPSE). The TOPSE was developed from focus group narratives to assess parents' perceived ability to manage their children based on their experiences of challenges and difficulties raising a child under age six (Kendall & Bloomfield, 2004). It has good overall internal consistency reliability of .95, with Cronbach's alphas ranging from .81 to .93 for subscales. The TOPSE includes nine domain specific sub-scales of parenting; parents were administered subsections that ask about pressures (Cronbach's $\alpha=.87$), self-acceptance (Cronbach's $\alpha=.93$), and learning and knowledge (Cronbach's $\alpha=.81$). Items are scored on a ten-point Likert Scale ranging from "completely disagree" to "completely agree." Consistent with the measure's design, responses were summed within each subscale to produce domain-specific self-efficacy scores pre-evaluation. This measure was intended to capture general parent self-efficacy ratings related to broad parenting behavior.

Early Intervention Parenting Self-Efficacy Scale (EIPSES). The EIPSES is a questionnaire developed to assess parents' perception of self-efficacy and their ability to influence child outcomes in the context of EI (Guimond et al., 2008). Exploratory factor analysis indicated that the EIPSES has two factors, with the first related to parent perceptions of the ability to control EI outcomes for their children and the second related to parents' beliefs about their ability to affect positive change in the development of their child. It has an internal consistency estimate of .80. A subset of questions from the EIPSES was administered. The EIPSES items are scored on a five-point Likert Scale (1= strongly disagree, 2= disagree, 3=

neutral, 4= agree, 5= strongly agree). Items four, five, and eight are reverse coded. Consistent with the measure's design, responses were averaged across items to produce a mean self-efficacy score pre-evaluation. Higher scores indicate greater perceived self-efficacy. This measure was intended to capture aspects of task-level parent self-efficacy related to intervention.

Evaluation Measures

The Mullen Scales of Early Learning (MSEL). The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardized test of cognitive ability, intended to evaluate children between birth and 68 months. It has five subtests (Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language) that reflect domains of cognitive development. All subsets with the exception of the Gross Motor domain were administered in the current study; this domain is only available for children under 33 months (Mullen, 1995). Each subtest yields T-scores, percentile ranks, and age equivalents, which reflect the child's current level of development in comparison to same-aged peers. The MSEL has adequate concurrent validity with other measures of early childhood cognitive and development level, and median internal consistency was reported between .75 to .83 for all domains (Mullen, 1995). The MSEL is a frequently used measure of developmental level and cognitive functioning in both typically developing children and children with developmental delays. Due to many T-scores falling at more than three standard deviations below the mean, age-equivalent scores were transformed into developmental quotient scores to allow use of parametric statistical tests. A developmental quotient score was calculated according to the mental age formula: the age-equivalent divided by the chronological age, multiplied by 100 (Guthrie et al., 2012).

Vineland Adaptive Behavior Scales-Interview- Second Edition, (VABS-II). The Vineland Adaptive Behavior Scales (Sparrow, Cicchetti, & Balla, 2005) is a semi-structured,

standardized parent report interview that assesses adaptive function across domains of Communication, Daily Living, Socialization, and Motor Skills. The measure yields domain scores, standard scores for individual subscales, and an overall Adaptive Behavior Composite (ABC) score, which is used to compare a child's skills to same-aged peers. Domain standard scores range from 20-160, with higher scores indicating higher functioning or skill level. For the current study, caregivers were administered the VABS-II, a revised version (Sparrow, Cicchetti, & Balla, 2005). The VABS-II is considered a valid instrument when assessing children with developmental delays and ASD and has good established reliability and validity with internal consistency ranging from .79 to .95 across domains (Sparrow, Cicchetti, & Balla, 2005).

Autism Diagnostic Observation Schedule-Second Edition (ADOS-2). The Autism Diagnostic Observation Schedule, 2nd Edition (Lord, Luyster, Gotham, & Guthrie, 2012; Lord, Rutter et al., 2012) is a semi-structured, standardized, play-based assessment that measures individual performance in two domains (Social Affect and Restricted Repetitive Behavior) and provides a total score. Inter-rater reliability and test-retest reliability is reported as good, and the content and concurrent validity for the revised measure are adequate (McCrimmon & Rostad, 2013). Children are administered one of five modules based on language level. Each module consists of a series of unstructured and structured situations or activities that provide a hierarchy of presses for the behaviors of interest. Higher scores indicate greater autism severity. The ADOS-2 Toddler Module was administered to all participants. This module has good internal consistency, with Cronbach's alpha for Social Affect ranging from .88 to .90 and reaching .50 in the Repetitive Restrictive Behavior domain (McCrimmon, Rostad, 2013).

The Childhood Autism Rating Scale-Second Edition (CARS 2). The CARS (Schopler, 1980) is a 15-item observation-based rating scale designed to differentiate children with autism

from those with developmental delays without features of autism. Ratings are assigned based on parent report as well as clinician observation. Each item is a sub-domain (e.g., “verbal communication”) that is rated on a seven-point scale ranging from “within normal limits for that age” to “severely abnormal for that age.” The total score provides a classification of *non-autistic*, *mild autism* or *severe autism* based on established cutoff scores. Higher scores indicate greater autism severity. The current study will use the CARS-2, the most recent revision of the measure, which has internal consistency reported at .93 with good inter-rater reliability and adequate concurrent validity (Schopler, Van Bourgondien, Wellman, & Love, 2010).

Post-Evaluation Measures

Follow-up interview. This interview was developed to gather information about parents’ level of engagement with recommended treatments after evaluation. It also included questions to assess parents’ satisfaction with evaluation and feedback. To assess the construct of interest in the current study (“intervention engagement”), the interview contained questions about when parents began services and whether they had. The outcome of interest, intervention engagement, was measured in several ways: a dichotomous variable (contacted services or providers, yes or no) and a continuous variable (time from evaluation to contact services) that was captured by parent report and by multiple-choice categorical time periods (e.g., within days of the evaluation, within a week of the evaluation). See Appendix C for the follow-up interview.

Reaction to Diagnosis Interview. The follow-up interview also included the RDI, used with permission from the authors, with language slightly modified to be appropriate to developmental disorders (e.g. “developmental disorder” replaced “medical problem”). The RDI (Marvin & Pianta, 1996; Pianta et al., 1996) is a semi-structured interview that elicits parents’ reactions to their child’s diagnosis through a series of narrative questions, developed for use in

populations of parents with chronically ill children. According to the RDI manual (Pianta & Marvin, 1993), interviews are coded as “resolved” (evidence of emotional/cognitive or behavioral change with regard to the disorder and the child since the diagnosis) or “unresolved” (evidence of unrealistic perceptions of the child or disorder, ongoing search for cause, attention bias to the past, being cut off from experience; and/or confusion and disorientation with subcategory classification. In the resolved category, subcategory classifications include action, thinking, or feeling oriented coping. In the unresolved category, subcategory classifications include emotionally overwhelmed, angrily preoccupied, neutralizing, depressed/passive, cognitive distortion, and disorganized/confused. Classification of the RDI is based on the pattern that predominates, as parents can demonstrate elements of both resolution and lack of resolution. The reliability of the RDI has been confirmed across many different studies and populations, with overall very good inter-rater agreement (κ ranging from .73-1) (Dolev et al., 2014; Milshtein et al., 2010; Oppenheim & Yirmiya; Poslawsky et al., 2014)

The RDI was developed for use with video recording; we used digital audio recording consistent with published modified protocols for administering the RDI (Leblond, Achille, Beliveau, Clermont, & Blydt-Hansen, 2013; Lord, Ungerer, & Wastell, 2008). Interviews were transcribed and coded after identifying information was removed. Due to technical errors, two interviews were incomplete and were coded based on interviewer notes and partial recordings, consistent with previous research (Lord, Ungerer, & Wastell, 2008). A subset of interviews (31%, including several from each participating site) were independently coded by a graduate student and trained research assistant to establish inter-rater reliability. There was perfect agreement between raters’ judgment on resolved/unresolved status, $\kappa=1.00$ ($p=.014$). There was

moderate agreement between raters' judgment on resolution subtype, $\kappa=.77$ ($p=.001$), 95% CI [.45-1.18]. All discrepancies were discussed and resolved.

Data Analysis

All statistical analyses were performed using IBM SPSS Statistics for Windows, Version 22.0.

Primary Analyses. The relationship between parent RDI classification and intervention engagement variables was assessed by Fisher's Exact Test or Chi square tests within each group (resolved, unresolved). Intervention engagement variables included whether parents had read the report (coded as yes or no), contacted EI at the time of follow-up (coded as yes or no), whether parents had discussed evaluation results with the child's primary care provider (coded as yes or no), and the number of days from evaluation to EI contact. Exact dates were provided by 10 parents; for all parents, time to contact EI was captured through multiple choice options on interview. Primary outcome variables also included total number of intervention hours at time of interview and change in intervention hours from baseline.

Secondary Analyses. The relationship between parent level factors and RDI classification was examined with independent t-tests (two-sided) and Chi square or Fisher's exact tests within each group (resolved, unresolved). Parent level factors included years of education, age, marital status, and family income as well as general (TOPSE) and task-specific self-efficacy (EIPSES), measured in mean scores in accordance with scoring guidelines (Kendall & Bloomfield, 2004; Guimond et al., 2008). Similarly, the relationship between child level factors and RDI classification was examined with independent t-tests (two-sided) and Chi square or Fisher's exact tests within each group (resolved, unresolved). Child level factors included age at evaluation, gender, race/ethnicity, history of EI and hours of intervention prior to evaluation,

birth order, cognitive measures (MSEL), adaptive skill measures (VABS-II), and ASD symptom severity measures (CARS, ADOS-2).

Exploratory Aims. Exploratory qualitative analyses were also conducted to evaluate the relationship between linguistic patterns and RDI classification. Transcribed interviews were analyzed for emotion-related words (e.g., positive and negative affect), third person pronouns (e.g., he, she, they), and “evaluation” word content, defined as words that pertain to evaluation procedures and psychoeducation about autism. As noted above, the evaluation itself and information about ASD provided in the evaluation is associated with adaptation to a child’s diagnosis (Hasnat & Graves, 2000; Lutz, Patterson, & Klein, 2012; Siklos & Kerns, 2007).

Sixteen complete transcribed narratives were analyzed using the Linguistic Inquiry and Word Count (LIWC) text analysis program (Pennebaker, Boyd, Jordan, & Blackburn, 2015). The LIWC program analyzes text word by word and classifies words according to a comprehensive list of word categories that capture multiple linguistic and psychological constructs such as “personal pronouns or “positive emotions” (e.g., sweet, happy, likes). The percentage of total words in each category is reported relative to total words used in a narrative. The LIWC is a well-validated text analysis program that has demonstrated strong internal consistency across several psychological domains (Tausczik & Pennebaker, 2010). Overall word count and percentage of emotion, pronoun, and evaluation words use were calculated for each participant. Prior to RDI classification coding, evaluation target words were added to a study-specific dictionary, which was developed by analyzing word frequency tables for vocabulary pertaining to the evaluation and psycho-education typically provided during feedback (e.g., spectrum, symptoms, criteria). The word category percentages between the resolution groups were

compared using independent t-tests. See Appendix D for evaluation word dictionary and Appendix E for samples of Resolved and Unresolved coded interviews.

Results

Preliminary Analyses

Based on the manual, interviews ($n=18$) in the current study were classified into two groups: resolved to diagnosis ($n=12$) and unresolved to diagnosis ($n=6$). Parents with a resolved RDI-classification comprised 61% of the sample. Resolved parents were mostly characterized by an action orientation (55%, $n=7$), followed by emotion (18%, $n=2$) and thinking (18%, $n=2$) orientations. Unresolved parents ($n=7$) were characterized by neutralizing (71%, $n=5$) orientations, followed by emotionally overwhelmed (14%, $n=1$) and angrily preoccupied (14%, $n=1$) orientations. Consistent with previous research, there were no differences between resolved and unresolved parents on time from evaluation to interview or site of evaluation.

Primary Analyses

Relationship between parent resolution and intervention engagement variables. No differences were found on main intervention outcome variables by RDI classification group, including whether parents had read the evaluation report, contacted primary care providers, or contacted EI providers. Of note, nearly half of the unresolved group reported that they had not yet read the report (43%). The time it took for parents to contact intervention providers also did not vary by RDI classification. A majority of parents had made an initial contact with intervention providers within a week of the evaluation (82%) and nearly all children (94%) had begun or increased intervention hours at the time of follow-up. There was no difference in the total number of intervention hours or change in intervention hours by parent resolution group. The average number of intervention hours ($M=10.1$, $SD=7.9$) increased for nearly all children

following evaluation, though the change in number of hours was variable ($M=8.5$, $SD=8.25$). Half (50%) of parents reported being waitlisted for services, though the relationship between waitlist status and RDI classification was not significant. See Table 2 for a summary of RDI classification group differences.

Secondary Analyses.

Relationship between parent characteristics and RDI classification. No relationship was found between parent RDI classification and primary caregiver age, marital status, or income. Resolved parents had fewer years of education ($M=14.8$, $SD=2.5$) than unresolved parents ($M=17.1$, $SD=1.6$), $t(15)=1.12$, $p=.05$, $g=1$. Parent self-efficacy pre-evaluation was also examined for a relationship to RDI classification following diagnosis. Overall scores for measures of general self-efficacy (TOPSE) and task-specific self-efficacy (EIPSES) did not differ by RDI classification. See Table 3 for a summary of parent characteristics by resolution group.

Relationship between child characteristics and RDI classification. No relationship was found between parent RDI classification groups on child's chronological age at evaluation, child's EI eligibility, hours of intervention received prior to evaluation, child's race/ethnicity, or child's birth order. Similarly, no differences were found between groups on measures of child's cognitive ability (MSEL), adaptive measures of communication skills, daily living skills, and social skills (VABS-II), or on measures of symptom severity (CARS-2, ADOS-2). Children of resolved parents trended towards higher scores on a measure of adaptive motor skills ($M=95.9$, $SD=10.7$) than children of unresolved parents ($M=86.7$, $SD=10.3$), $t(16)=1.78$, $p=.09$. See Table 4 for a summary of child characteristics by resolution group.

Exploratory Analyses.

Explore linguistic patterns of RDI classification. The distributions of variables of interest (word count, use of “they”, emotion words, and use of evaluation words) were assessed. Of the linguistic variables assessed, the emotion words category had an outlier in the higher range in the Unresolved group (4.9%). The evaluation words category had an outlier in the higher range in the Resolved group (3.4%) and an outlier in the lower range in the Unresolved group (0.7%). Comparison of trimmed means to original means did not indicate meaningful difference and thus all data points were included in further analysis. Resolved parents used overall fewer words to describe their experiences ($M=545$, $SD=233$) than unresolved parents ($M=1029$, $SD=557$), $t(14) = -2.45$, $p=.03$, $g= -1.1$. Resolved parents used the third person plural (“they”) less ($M=.45$, $SD=.46$) than unresolved parents ($M=1.39$, $SD=.58$), $t(14) = -3.59$, $p=.003$, $g= -1.7$. This pronoun was typically used in reference to the professionals conducting evaluations across the total sample (e.g., “they only spent...two hours with him in a room,” “they already had their minds made up,” “when they did say [ASD] we were pretty upset,” “they told us he had autism,” “they gave us the diagnosis”) Resolved parents also used more emotion words ($M=4.32$, $SD=.93$) than unresolved parents ($M=3.22$, $SD=.94$), $t(14) = 2.26$, $p=.05$, $g= -1.2$. There was no difference between resolved and unresolved parents on percentage of evaluation words used. See Table 5 for a summary of linguistic characteristics by resolution group.

Discussion

In the present study, we explored the potential relationship between parent resolution to a child’s early ASD diagnosis and intervention engagement in the context of an early screening model. Previous research suggests that understanding the impact of parent resolution to diagnosis as indexed by RDI classification may be an important part of clinical treatment as well as a potential point of intervention, as parent adjustment to diagnosis can influence child outcomes.

Primary Aims: Relationship between parent resolution and intervention

engagement variables. There were no differences on intervention engagement variables by parent RDI classification. All parents in the current sample had contacted EI providers at the time of follow-up, though there was some variation in whether parents had read the evaluation report or discussed the diagnosis with the child's primary care provider.

Person-level psychological factors that may influence parents' intervention engagement have been long discussed and speculated about in ASD research (Bonis, 2015; Reed & Osborne, 2012; Rogers & Vismara, 2014). As parents of children with ASD endorse stress and related psychological impacts at a higher rate, understanding parents' ability to cope and adapt to a child's diagnosis has emerged as an important facet of research around best practices for communicating diagnoses and facilitating treatment follow-through. We found that unresolved parents in the current sample initiated and pursued interventions as much as resolved parents. Importantly, resolved and unresolved parents did not differ on average hours of intervention for their children following evaluation. Taken together, these findings highlight the utility of providing sufficient information and a rationale for interventions at feedback or evaluation follow-up so that parents may pursue them.

Some patterns within the outcome variables were notable. Though 100% of the sample was engaged in intervention, 50% of children were concurrently waitlisted for further services due to system-level barriers (cited impediments included limited availability of EI personnel, difficulty coordinating with insurance for EI coverage and eligibility, and difficulty managing the number of recommended intervention hours). Families in the current sample were located in states with well-established, publicly funded EI programs (Connecticut and Pennsylvania), and most families were engaged in EI prior to the ASD diagnosis. Within these programs, children

are required to begin receiving services within 45 days of initial intervention planning in Connecticut, and within 14 days of initial intervention planning in Pennsylvania. The availability of publicly funded and readily accessible intervention programs may have made it easier for all parents to engage in treatment and might therefore have obscured the potential impact of parental factors. Even under these ideal circumstances, however families in the current sample faced delays and barriers to obtaining the recommended number of intervention hours.

Secondary Aims: Relationship between parent characteristics and RDI

classification. Previous literature suggests that parent demographic factors are largely unassociated with RDI classification. Consistent with other studies examining ASD and parent resolution to the diagnosis, no relationship was found between RDI classification and parent age or marital status (Dolev et al., 2016; Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014; Wachtel & Carter, 2008). However, the current study findings indicated that parents differed on years of education by RDI classification. Previous literature largely suggests that RDI classification does not vary by parent education or income, in contrast to current study findings that unresolved parents had more years of education than resolved parents. Due to the small sample size and relative homogeneity of parent education level in the current study, the current finding may not be supported in a larger sample with broader range in parent education. Most parents in the current sample had at least a college education, and thus differ from samples in the literature that found no relationship between RDI classification and parent education level (Feniger-Schaal & Oppenheim, 2013; Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014).

The hypothesized relationship between parents' pre-evaluation self-efficacy and RDI classification was not supported. This suggests that the resolution to diagnosis process may

unfold separately from the influence of parent self-efficacy, though some previous studies suggested a potential relationship (Milshtein et al., 2010; Poslawsky et al., 2014). Poslawsky and colleagues (2014) measured the parent RDI classification and self-efficacy over time and noted that parents who changed classification also had changes in self-efficacy. It may be that parents' self-efficacy functions in parallel to the resolution process; and that levels of self-efficacy pre-diagnosis do not influence the process of resolution, as hypothesized in the current study.

Consistent with prior research, RDI classification was not related to child demographic factors, including hours of intervention or EI eligibility prior to evaluation, nor child adaptive skills or cognitive ability (Dolev et al., 2016, Milshtein et al., 2010; Oppenheim et al., 2009; Poslawsky et al., 2014; Wachtel & Carter, 2008). Contrary to the hypothesized relationship between symptom severity and RDI classification, more direct measures of child symptom severity were not related to parent resolution. There was a trend-level finding that unresolved parents had children with lower adaptive motor skills as measured by the VABS-II. It is possible that the measure of adaptive motor skills may capture some of the symptom severity construct, as more impaired children tend to demonstrate deficits across more domains of functioning. In this sample, where children were evenly matched in terms of symptom severity across groups by CARS-2 and ADOS-2 scores, VABS-II adaptive motor skill scores may reflect the broader symptom severity construct.

Exploratory Aims: Explore linguistic patterns of RDI classification. Exploratory results suggest that resolved parents were better able to access emotions and express them during the interview, based on the higher frequency of affect-related words relative to total word count. Resolved parents also had less volume of words in their narratives. In other words, resolved parents had less to say about their resolution process, but communicated emotionally rich

content. This finding is consistent with the resolution model proposed by Marvin and Pianta, (1996), where access to emotions is an important aspect of the trauma resolution process. Unresolved parents, in contrast, talked more but did not communicate emotions as frequently. These findings are also consistent with the relative proportions of RDI classification subtypes in the current sample, with a majority of “action oriented” resolved parents and “neutralizing” unresolved parents. Pianta & Marvin (1993) note that resolution occurs when the crisis of diagnosis is “over” and parents move on to the demands of parenting their child. Current findings suggest that resolved parents in this sample were able to acknowledge the crisis (access more related emotions) and move forward to parenting actions (higher proportion of action-oriented sub-classification). In contrast, unresolved parents had higher proportion of neutralizing sub-classification, associated with denial or distancing from their feelings about the diagnosis.

In this sample, use of third person plural (they) was higher for unresolved parents. However, use of professionals’ titles (e.g., doctor, psychologist, clinician; measured in the evaluation words category) did not differ by RDI classification group. Linguistic studies of trauma processing suggest that pronoun use may provide insight into coping and adjustment (Kaplow et al., 2018; McIsaac & Eich, 2004). In particular, use of the third person singular (e.g., he, she) has been shown to act as a psychological distancing strategy that aids in processing of emotions following a traumatic event, and may act as a mechanism to help people make meaning of negative experiences without becoming overwhelmed by affect (Kaplow et al., 2018; McIsaac & Eich, 2004). It may be that use of the third person pronoun rather than the title of the professional allowed unresolved parents to create a psychological distance from the distress of the evaluation events, and may signify ongoing processing of the diagnosis. On the other hand, use of third person pronouns has also been posited to reflect negative coping (e.g., cognitive

avoidance) and may exacerbate the associated psychological distress (Kaplow et al., 2018). Use of “they” for unresolved parents in this context may be related to parents’ emotional distress and reflect active challenges in coping with their child’s diagnosis. Analysis in a larger sample may clarify the role of this pattern of pronoun use.

Taken together, linguistic analysis suggests that parents may demonstrate objective word use patterns that can be harnessed to inform best practices during clinical evaluation feedback and follow-up. Current results suggest that unresolved parents use fewer emotion words and more pronouns to denote evaluation professionals. It may be possible for parent narrative in response to open-ended follow-up questions from clinic staff to be monitored for emotion words and use of specific pronouns (they) to then prompt further attention to parent emotional functioning or to offer additional support.

Strengths and Limitations of the Current Study

The current study offered a unique opportunity to examine how the person-level variable of resolution to diagnosis relates to intervention engagement in a sample of very young children (<30 months) receiving a first-time diagnosis of ASD. The inclusion of both objective variables, variables measured before and after diagnosis, and variables derived from parent report allowed thorough examination of the impact of parent resolution to diagnosis on child outcomes. ASD research on parent psychological processes around a child’s diagnosis has long speculated about a possible relationship between these constructs, and findings from the present study add to the knowledge currently available in the literature and can potentially contribute to clinical best practice guidance.

In addition, a strength of the current study was the first-time use of a linguistic analysis tool to examine word patterns related to RDI classification. Linguistic analysis offers a strategy

to connect everyday word use to real-world behavior and psychological processes (Tausczik & Pennebaker, 2010). Findings from the current study suggest that attending to patterns of linguistic cues during evaluation feedback, follow-up interviews or initial intervention sessions can potentially guide professionals in addressing parents' psychological adjustment to a child's diagnosis.

A primary limitation of the study was the small sample size of the responder group, as half of the recruited sample did not complete study procedures. This limits the accuracy of the estimates and the generalizability of the findings. Overall, power was low and thus there was a greater chance of having a large effect size for findings that are not statistically significant. In particular, type I error may result in rejection of a hypothesis that did not appear statistically significant, even with a large effect size.

Results in the current study primarily serve to illuminate potential avenues for future exploration in a larger, more heterogeneous sample. Child characteristics in the sample were relatively homogeneous, as were parent demographics, which limited exploration of the contributions of these variables. While differences were found by resolution group related to parent education, findings may not be generalizable to a broader population with greater socio-economic heterogeneity.

Another limitation of the study was the reliance on voluntary, retrospective parent report. It is important to note that parents are sharing a "metabolized, highly processed" version of their story (Pianta & Marvin, 1993). While the RDI was designed as a retrospective interview, parents may have suppressed or refrained from sharing more challenging emotions that may have influenced RDI classification coding. Similarly, primary outcome variables were coded based on

parent report. This method may have compromised the accuracy of the data in some cases, particularly for parents who may have had to recall several weeks in the past.

The current study was limited by the response bias inherent to the nature of the study procedures. Participation in the study was voluntary and parents with more difficulty accessing or following through on intervention engagement may have avoided the follow-up interview. Thus, parents who had high intervention engagement may be over-represented in this sample. Similarly, the study timeline contacted parents of young children during a busy period following the evaluation while they may have been busier than usual with less availability to respond to phone calls (e.g., navigating stress associated with a new diagnosis and lining up services). Parents with greater resources or fewer stressors to manage may be over-represented in this sample.

Clinical Implications and Future Directions

Understanding parent psychological processes around diagnosis and patterns of treatment engagement for children who are diagnosed with ASD at early ages can inform best practices for evaluation, feedback, and referral. The current study findings suggest that it may be important for professionals conducting feedback to focus on providing parents information about accessing intervention services as well as other aspects of the evaluation (such as differential diagnosis, potential causes, etc). A limited body of research examining professionals' experiences of diagnosis indicates a number of concerns to manage in an evaluation (Rogers, Goddard, Hill, Henry, & Crane, 2016). In one study from the National Health Service in the United Kingdom, the top three challenges reported by professionals included making sure caregivers understand the diagnosis, providing medical information at the appropriate level, and managing caregiver distress; the introduction of support services and/or information ranked eighth out of ten primary concerns. The current results add to evidence that despite distress or emotional reactions in the moment, parents can benefit from clear communication about intervention recommendations,

which may serve to reduce parental stress and facilitate positive coping over time (Hasnat & Graves, 2000; Mulligan et al., 2012; Siklos & Kerns, 2007).

Patterns of intervention engagement in the current study suggest areas for more exploration. In the available literature examining parent perspectives on EI, there is some evidence that parents experience intense pressure and stress to engage with services “as soon as possible” (Edwards et al., 2016). Gentles and colleagues (2018) hypothesized that parent meaning-making around a child’s ASD diagnosis may overlap with the motivation to take action. It may be that for the current sample, the push towards intervention engagement occurred concurrently with the resolution process; that is, parents initiated services regardless of where they were in processing the child’s diagnosis. Given the range in intervention hours and the high proportion of the sample on waitlists for additional intervention in the current sample, it is possible that this dynamic may have a down-stream negative impact on decision-making despite parent awareness of EI importance. That is, as the initial pressure and stress to find intervention wanes, parents may decrease in their motivation to continue to seek the recommended hours and types of interventions. Indeed, parents report confusion, exhaustion, and frustration as they become de facto case managers and struggle to navigate the complex web of intervention services options and insurance coverage following an evaluation (Mulligan et al., 2012). It may be that a two-step model of initial feedback and later clinical follow-up offers parents an additional opportunity to receive information about ASD and interventions, while also allowing clinical professionals to assess parent resolution and potential need for parent supports. A matched sample longitudinal study with a follow-up group condition would clarify whether such a model increases intervention engagement.

Appendix A

Table 1.
Results of Responder and Non-Responder Differences

Variable	Responder				Non-Responder				<i>p</i>	g or ϕ
	N	%	M	SD	N		M	SD		
<i>Parent Demographics</i>										
Primary Caregiver Age (years)	19	-	36.59	6.43	19		30.47	6.49	.04	.94
Years of Caregiver Education	19	-	15.37	2.59	19		14.74	2.92	.49	.22
Household Income (tens of thousands)	19	-	7.21	3.05	17		6.18	3.03	.36	.33
Marital Status (% partnered)	20	80%	-	-	19	68%	-	-	.41	
<i>Child Demographics</i>										
Child Age (months)	20	-	24.33	5.67	19	-	23.24	7.67	.62	.16
Gender (% Male)	20	85%	-	-	19	53%	-	-	.04	.35
Ethnicity (% White)	20	60%	-	-		37%	-	-	.25	.27
Eligibility for EI pre-evaluation (% yes)	20	65%	-	-	19	47%	-	-	.27	-.18
Intervention Hours pre-evaluation	20	-	1.4	2.36	19	-	0.45	0.83	.11	.53
Child's birth order (% firstborn)	20	50%	-	-	17	47%	-	-	.91	.13
Diagnosis (% ASD)	20	90%	-	-	19	47%	-	-	.01	.48
<i>Recruitment</i>										
Site (% UConn)	20	45%	-	-	19	47.4%	-	-	.47	.17
Note: EI=Early Intervention										

Table 2.
Differences by RDI Classification Group on Intervention Engagement Variables Characteristics

Variable	Resolved					Unresolved					p	g or φ
	N	%	M	SD	Range	N	%	M	SD	Range		
<i>Preliminary Analyses</i>												
Evaluation Site (% UConn)	11	54.5%	-	-	-	7	28.6%	-	-	-	.37	-.26
Time from Evaluation to Interview (days)	11	-	89.73	34.37	50-160	7	-	84.14	46.31	43-161	.77	.14
<i>Primary Analyses</i>												
Read Report (% yes)	11	81.1%	-	-	-	7	57.1%	-	-	-	.33	-.27
Contacted PCP (% yes)	11	72.7%	-	-	-	7	42.9%	-	-	-	.33	-.30
Contacted EI Provider (% yes)	11	100%	-	-	-	7	100%	-	-	-	-	.26
Time to contact EI from Evaluation	5	-	6.40	8.05	1-19	5	-	10.20	15.45	0-37	.64	.31
Time to contact EI from Evaluation (% within 1 week)	11	81.8%	-	-	-	7	57.1%	-	-	-	.63	.26
Begun or Increased Intervention (% yes)	11	90.9%			-	7	100%			-	1.00	.19
Intervention Hours post-evaluation	11	-	10.27	7.03	3-25	7	-	9.86	9.72	2-26.5	.92	.05
Change in Intervention Hours	11	-	8.84	7.57	1.25-25	7	-	8.11	9.86	-1.5-25.5	.86	.09
Waitlisted for Intervention (%)	11	36.3%	-	-	-	7	71.4%	-	-	-	.34	.53
Note: EI=Early Intervention, PCP=Primary Care Provider												

Table 3.
 Secondary Analyses: Differences by RDI Classification on Parent Characteristics

Variable	Resolved					Unresolved					<i>p</i>	g or ϕ
	N	%	M	SD	Range	N	%	M	SD	Range		
<i>Parent Demographics</i>												
Primary Caregiver Age (years)	10	-	38.9	7.36	31-56	7	-	35.29	5.02	30-45	.28	.55
Years of Caregiver Education	10	-	14.80	2.53	12-20	7	-	17.14	1.57	16-20	.05	1.07
Household Income (tens of thousands)	10	-	7.10	2.96	2-10	7	-	8.71	1.98	5-10	.23	.62
Marital Status (% partnered)	11	81.8%	-	-	-	7	100%	-	-	-	.50	-.27
<i>Parent Self-Efficacy</i>												
EIPSES	10	-	3.75	.46	3-5	7	-	3.87	.31	3-4	.55	.30
TOPSE: Pressures Total	10	-	41.10	11.22	22-58	7	-	49.00	9.17	35-60	.15	.76
TOPSE: Self-acceptance Total	10	-	48.50	9.97	31-60	7	-	51.00	6.68	44-60	.57	.28
TOPSE: Learning and Knowledge Total	10	-	50.80	7.85	37-60	7	-	51.43	7.83	42-60	.87	.08
Note: EIPSES=Early Intervention Parenting Self-Efficacy Scale, TOPSE = Tool to Measure Parenting Self Efficacy												

Table 4.
Secondary Analyses: Differences by RDI Classification on Child Characteristics

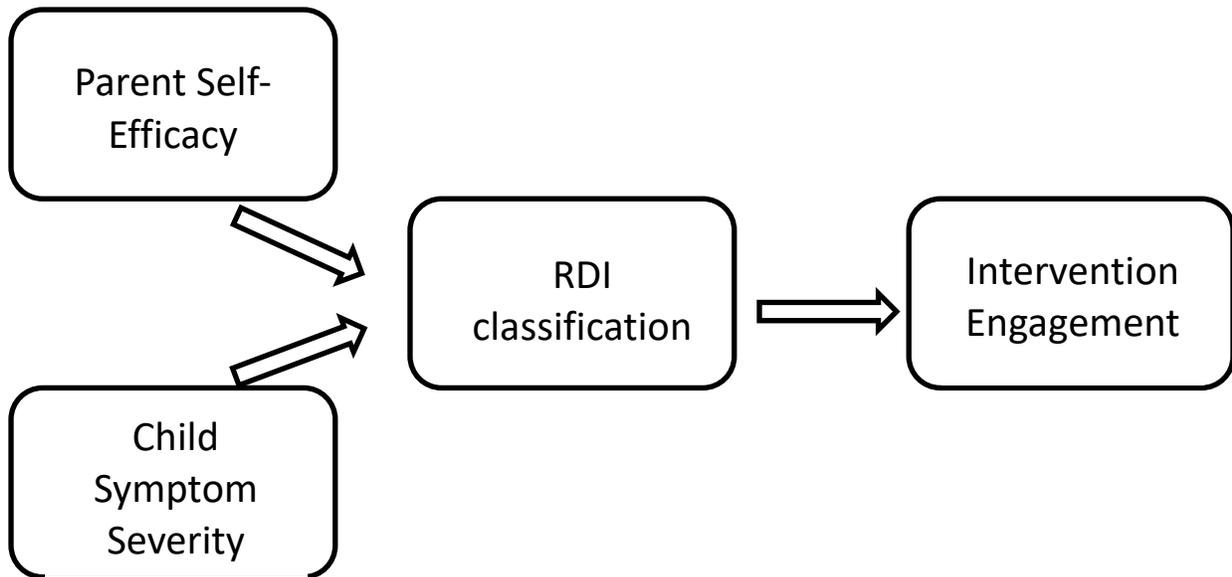
Variable	Resolved					Unresolved					<i>p</i>	g or ϕ
	N	%	M	SD	Range	N	%	M	SD	Range		
<i>Child Demographics</i>												
Child Age (months)	11	-	24.05	4.08	17.23-32.9	7	-	26.72	7.61	19.11-41.09	.20	.47
Ethnicity (% White)	11	63.6%	-	-	-	7	36.4%	-	-	-	1.0	.56
Eligibility for EI pre-evaluation (% yes)	11	63.6%	-	-	-	7	85.7%	-	-	-	.57	.24
Hours of Intervention pre-evaluation	11	-	1.43	2.62	0-9	7	-	1.75	2.32	0-6.5	.80	.13
Child's birth order (% firstborn)	11	54.5%	-	-	-	7	57.1%	-	-	-	.45	.45
<i>Cognitive</i>												
MSEL Expressive Language	11	-	50.58	17.54	22.65-75.75	7	-	58.05	23.16	36.63-107.47	.48	.38
MSEL Receptive Language	11	-	55.14	26.21	28.12-116.15	7	-	63.39	18.80	38.94-92.12	.48	.35
MSEL Visual Reception	11	-	80.14	28.94	21.02-121.20	7	-	76.62	23.78	46.59-111.83	.79	.13
MSEL Fine Motor	11	-	81.40	17.77	54.72-111.09	7	-	79.36	16.91	62.12-103.54	.81	.12
<i>Adaptive</i>												
VABS-II Communication Skills	11	-	77.55	12.29	62-97	7	-	84.43	14.86	58-100	.96	.52
VABS-II Daily Living Skills	11	-	85.09	10.30	71-98	7	-	85.00	13.55	71-105	.98	.01
VABS-II Socialization Skills	11	-	77.73	7.56	68-90	7	-	78.71	7.78	68-87	.79	.13
VABS-II Motor Skills	11	-	95.91	10.73	77-108	7	-	86.71	10.34	74-100	.09	.87
VABS-II Total Score	11	-	81.09	9.12	68-92	7	-	80.86	10.51	58-100	.96	.02
<i>ASD Symptom Severity</i>												
CARS-2 Total Score	11	-	32.32	6.49	23-41.5	7	-	29.50	5.02	23-38	.34	.47
ADOS-2 SA	10	-	16.90	2.13	13-20	5	-	14.20	5.56	7-19	.18	.76
ADOS-2 RRB	10	-	4.20	2.44	0-7	5	-	5.00	0.71	4-6	.49	.39
ADOS-2 Total Score	10	-	21.10	4.07	13-26	5	-	19.20	5.07	12-24	.45	.43
Note: EI=Early Intervention; MSEL=Mullen Scales of Early Learning, VABS-II=Vineland Adaptive Behavior Scale, 2 nd Ed., CARS-2=Childhood Autism Rating Scale, 2 nd Ed., ADOS-2=Autism Diagnostic Observation Schedule, 2 nd Ed. Means and standard deviations calculated from MSEL developmental quotient (DQ) scores ($M = 100$, $SD = 15$); DAS-II, VABS and VABS-II standard scores ($M = 100$, $SD = 15$); ADOS domain scores, and CARS-2 total scores.												

Table 5.
Exploratory Analyses: Linguistic Patterns Differences by RDI Classification

Variable	Responder				Non-Responder				p	g
	N	M	SD	Range	N	M	SD	Range		
<i>Linguistic Categories</i>										
Total word count	10	545.10	233.15	248-973	6	1028.67	557.46	266-1944	.03	1.27
Affective expression (% of all words)	10	4.32	0.93	3.07-5.58	6	3.22	.94	2.26-4.94	.04	1.18
Pronouns-he/she (% of all words)	10	4.99	2.59	1.12-9.68	6	5.04	1.37	3.17-6.67	.97	.02
Pronouns-they (% of all words)	10	0.45	0.46	0-1.34	6	1.39	0.58	.81-2.14	>.01	1.86
Evaluation terms (% of all words)	10	1.51	.81	.49-3.24	6	1.49	.56	.39-1.90	.92	.03

Appendix B

Figure 1. Hypothesized Relationships Between Variables



Appendix C

EDP Follow-up Phone Call

Hello. My name is _____ from the Early Detection Project. I'm calling from UConn, as part of the Early Detection Project. Your child [name] was evaluated at [site] as part of that project in [month]. We wanted to check in with you to see how things have gone since the evaluation and your thoughts about the evaluation itself. It will take about 15 minutes. Do you have time now to talk?

1. Have you been able to speak with your doctor about your child's evaluation? **YES**
NO

2. Have you been able to contact [Early Intervention] about (child's name's) services?
YES NO

3. **IF YES:** Do you remember when you made the first call? For example, was it after the evaluation, or did you call after receiving the report? (*ask for date if they can remember, prompt to check their phone call log*)

AFTER EVAL AFTER REPORT

- i. Date contact initiated _____
- ii. Name/type of service/provider contacted _____

- b. *If they can't remember date:* OK, which of these options best describes your actions?
 - i. I called within a day of [eval / report]
 - ii. I called within a week of [eval / report]
 - iii. I called several weeks after [eval / report]

4. Has your child begun therapy or any other types of treatment? **YES NO**

a. *IF NO:* Are you on a [waitlist for services / have you made an intake appointment]? **YES NO**

b. *IF YES:* Can you tell me about what services your child [is getting/will get]? **YES NO**
(prompt from table)

Type of Therapy	# of Hours/week	Provider (e.g. private, B23, state program)	intake appt. made/ waitlist/ Start Date
Birth to Three/Babies Can't Wait/PA EI			
Speech-Language Services			
Occupational Therapy			
Physical Therapy			

ABA or Behaviorally based therapy			
Play Therapy			
PECs			
Family Support Services (e.g., ChildFIRST)			
Special Education			
Parent-Child groups			

OTHER/NOTES:

5. *IF NO:* “We know that It can be hard to find or begin services. We’re trying to find out what barriers parents experience when they go through this process. Which of the following best describes your situation?
 - a. Do not think services are necessary
 - b. Services are too expensive
 - c. Services conflict with parent work schedule
 - d. Difficult to manage transportation demands
 - e. Confusion around finding services
 - f. Other _____
 - g.

REACTION TO DIAGNOSIS:

Now I’d like to ask a few questions about your reactions to the evaluation process.

1. When did you first realize that your child had developmental concerns (*probe for details*)?
2. What were your feelings at the time that you realized that?
3. Have your feelings changed over time? If so, how?
4. I’d like to ask about when you learned of [name’s] diagnosis. Where were you? Was anyone there with you? Can you tell me about your thoughts and feelings at that time?
5. Parents sometimes wonder or have ideas about why their child has special needs. Do you have anything like that that you wonder about? (*Prompt if necessary. For example, some parents feel that they might have done something to cause their child’s condition; others believe that God or fate must have a reason for giving them this child.*)

6. Who else have you talked about the diagnosis with (e.g., family members, people in the community)?

Circle all that apply

- a. I have not yet talked about the diagnosis with anyone

- b. Immediate family
 - c. Extended family
 - d. Friends
 - e. Members of community
 - f. Other health care or service providers
 - g. Other_____
-

Now I'd like to ask you some questions about your experiences during the evaluation. Please rate the following statements using this scale:

1=Strongly Disagree 2=Disagree 3= Neutral 4=Agree 5= Strongly Agree

1. I left the evaluation feeling confused.	1	2	3	4	5
2. I had time to ask questions during the evaluation.	1	2	3	4	5
3. The evaluation was carried out in a professional manner.	1	2	3	4	5
4. I was upset about the results of the evaluation.	1	2	3	4	5
5. I felt relieved after hearing a diagnosis.	1	2	3	4	5
6. The information I received was individualized to my child.	1	2	3	4	5
7. Having study staff follow up with me after the evaluation is helpful.	1	2	3	4	5

Finding useful services for young children can be difficult, and we appreciate you sharing your experience with us. How could the process of finding services for your child be improved?

This is the end of our follow up interview. Thank you so much for taking the time to speak with me today. Is there anything we haven't talked about that you would like me to know? Can I answer any questions?

Appendix D: LIWC Evaluation Terms Dictionary

%

Evaluation terms 1

%

provider* 1

therap* 1

service* 1

symptom* 1

autis* 1

intervention* 1

diagnos* 1

develop* 1

spectrum 1

criteria 1

qualify 1

evaluation 1

doctor* 1

learn* 1

inform* 1

Appendix E

Transcript of Resolved, action-oriented example.

When did you first realize that your child had developmental concerns?

Um, it was back when we noticed he was doing things um a little later than let's say my daughter did when she was a baby. Um it took him longer rlike to learn to sit up by himself uhh took him longer to learn to walk. Obviously he wasn't talking um and still non-verbal um and I rrjust could tell rlike seeing him around other kids that he wasn't on the same level as where he should be. Um rlike he didn't want to interact with any other kids. He wasn't curious about what they were doing. Um he wasn't making eye contact with us. Uh so things like that. I started noticing some things.

What were your feelings at the time that you realized that?

Um it took me a while to come to the realization. I rrjust kept telling myself rroh he's just a late bloomer. Um youknow my friends would tell me rlike their boys youknow developed late and youknow he'll be fine and and things like that and I rrjust saw it getting, not worse but the older he got rlike I could notice it more that he wasn't like other kids his age. Um I think for a long time I was in denial that it was actually true um and I know the same was for my husband. Um we rrjust didn't want to think that there could be something wrong um with him. So it was really um upsetting but then I finally came to a point after talking to our speech therapist rlike it finally rrjust dawned on me that youknow there is something going on and it's rrjust time to accept it and move forward and do whatever we can to help him.

Have your feelings changed over time? If so, how?

Yeahyeah she's, they've both been very helpful but his his speech therapist and I have grown really close and she's been really helpful um to me over the last couple months that she's been working with us. So now I've youknow we've accepted it and we're rrjust trying to navigate through this new world of autism because we we haven't ever had anyone in our family or friends youknow that have kids with autism so it was a brand new world for us.

I'd like to ask about when you learned of [name's] diagnosis. Where were you? Was anyone there with you? Can you tell me about your thoughts and feelings at that time?

Uh yes my husband was there. Um I mean I I know, I knew what they were going to say I mean it was pretty obvious that he was on the spectrum um but I rlike I think I was rrjust hoping that by the end of the evaluation that they were going to be rlike oh he's fine he's just developing late um it's nothing to worry about um so I think it was rrjust wishful thinking um but then rlike when they gave us the results then it was pretty it was pretty upsetting and uh I did get pretty upset towards the end um. It was rrjust a lot to take in because all you ever want is your kid to be ok and so it was and it was scary I mean cause we've never dealt with youknow that before so it was rrjust a lot of emotions.

Parents sometimes wonder or have ideas about why their child has special needs. Do you have anything like that that you wonder about?

Um I mean sometimes I wonder rlike youknow how this happened or why this happened umm but youknow they I've done some research and youknow there's no proven facts for what causes autism so I've justkindof learned to youknow accept this is what it is and it's not about what I could have done better or if I did something wrong.

Transcript of Unresolved, neutralizing example.

When did you first realize that your child had developmental concerns?

Um uh well I I had brought several concerns to the physician. Um I mean he he he's been late with all of his milestones. But but they I I didn't not um walk away from those visits with the physician thinking that it was anything other than um I guess crazy mom. Um so uh uh I mean I I've sort of suspected since he was I don't know 6 months. Um I rrjust you know rrwell and and I don't know that it it that I thought it was autism I just knew that he wasn't meeting his milestones. You know he didn't sit up when other kids sat up. He didn't um crawl.

What were your feelings at the time that you realized that?

Um I rrjust I'm a registered nurse so um you know I brought my concerns to the doctor um and they were just like you know uh I remember the first time I brought my concerns um she said rrwell you can contact early intervention if you want to and they gave me a brochure. But it wasn't "we're concerned about this too" so I was a little frustrated because, frustrated but I have enough, I had enough clinical knowledge to know that yes he wasn't sitting up yet but he was um an active, normal, functioning child. Um so I wasn't I was rrlike sort of watchful waiting. Um and he didn't crawl appropriately. He would drag the one leg but again the doctor was just like hmm rrwell let's watch and wait and so you know he was he was definitely getting around um and he was pulling himself up and trying to walk and he eventually did start crawling appropriately. So I I guess I was I would say I was confused, frustrated, concerned um but I wasn't I wasn't concerned to the point that I that it wasn't something I couldn't manage I guess. I wasn't overwhelmed. If that makes sense.

Have your feelings changed over time? If so, how?

Um well only because looking back I wish that I had known to be I guess more persistent but I rrjust you know I'm a I'm a new mom I'm an older I waited a long time you know um I just sort of trusted the doctors that it was just me being worried. Um I don't know if if anything could have been done differently at 6 months I don't know but um. I I'll be honest with you and and say that I know that my son has challenges. I'm not convinced he has autism but I'm going to give him all the support that he needs. Um I I understood the report that they sent and I think that it's um clear but I'm a little concerned uh I guess I don't understand the significance of some of the things that the doctor felt was significant. Um I they rrjust seem like normal childhood behaviors and like things a baby would do.

I'd like to ask about when you learned of [name's] diagnosis. Where were you? Was anyone there with you? Can you tell me about your thoughts and feelings at that time?

Um they came out to me. Yes I was there I so um yes. We had um I had a concern that he wasn't talking so I knew that there was something wrong um and the the physician did the M-CHAT screen and at the M-CHAT screen is when she said to me why haven't you contacted early intervention and I said rrwell I nobody told me to. You the last time we talked about it you know it was just like it just might make you feel better but it wasn't a you need to do this type of conversation. Um so she didn't say autism um but she did say you know she suggested the Drexel autism study so I knew that's where they were headed. Um and you know of course I was there during the evaluation and um the doctor called me afterwards and and told me you know that he she felt that he was autistic and I understand her report and I understand that he meets all the all of the um criteria. Um I guess maybe there's a delay somehow. I rrjust don't rrwell I I feel like I feel like he he also had um some hearing problems and once we had tubes put in his ears then he started talking because he could hear. So I I think that you know he a lot of some of that communication

deficit might have been impacted by the hearing. But I I think time youknow time reveals everything. I feel that I rrjust I I want to get him all the support he needs and youknow we'll see what happens.

No it was just me and Aiden and the ladies from Drexel. Um so she the doctor didn't tell me there in person she called me later that evening and um told me over the phone and um I was sad. I was um it wasn't a shock but I don't lmean I was a little sad.

Parents sometimes wonder or have ideas about why their child has special needs. Do you have anything like that that you wonder about?

rrWell I do because um he's adopted and um his mother has an intellectual disability and his birth father is unknown um and his his birth mother has a lot of other diagnoses. I don't know if they're all correct but she has a laundry list of them. Um so I do worry about youknow whether this is genetic or or the fact that she didn't get prenatal care um that she was on um antipsychotics throughout her entire pregnancy um I don't know what other if any street drugs that she was on I and like I said I don't have any history of the birth father um and then youknow I worry about youknow did I did I give him the right formula did did he get the right youknow did he get enough of whatever he needed because he didn't get breast milk um so. Youknow I I've thought about all of those things.

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