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# Parental Perceptions of a Comprehensive Diagnostic Evaluation for Toddlers at Risk for Autism Spectrum Disorder

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Autism Spectrum Disorder

Dasal Jashar, Ph.D.

University of Connecticut [2017]

Comprehensive developmental and diagnostic evaluations for toddlers play an important role in identifying toddlers in need of early intervention. They may also provide parents with the support and resources needed to connect with early intervention service systems and providers. Therefore, it is important to develop a better understanding of how parents experience a comprehensive diagnostic evaluation, including how different aspects of the evaluation may impact parents' overall satisfaction as well as their intention to follow recommendations. The current study included 262 toddlers (192 males; 70 females) between the ages of 16 and 39 months ( $M=24.95$ ,  $SD=4.64$ ) who were given a comprehensive diagnostic and developmental evaluation after screening positive for autism risk. The parents of 190 of these toddlers responded to the Post-Evaluation Satisfaction Questionnaire (Questionnaire Group). An Exploratory Factor Analysis based on a polychoric correlation matrix was conducted to examine the presence and correlates of factors in the Satisfaction Questionnaire. Five factors (i.e., Collaboration/Checking in, Feedback Quality, Report Quality, Availability, and Cultural Understanding) were derived from the Post-Evaluation Satisfaction Questionnaire. All but the Cultural Understanding factor was positively correlated with overall satisfaction. Although most child characteristics were not correlated with parent satisfaction, a few cognitive and adaptive functioning skills were negatively correlated with Feedback Quality, Report Quality, and overall satisfaction. Analysis of qualitative responses to open ended

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questions in the Satisfaction Questionnaire provided themes that overlapped across various questions, including the importance of direct, clear, and honest feedback, and dissatisfaction with the wait time for diagnostic reports. These findings suggested ways in which clinicians can better support parents during diagnostic evaluations.

Parental Perceptions of a Comprehensive Diagnostic Evaluation for Toddlers at Risk for  
Autism Spectrum Disorder

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University of Connecticut

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[2017]

APPROVAL PAGE

Doctor of Philosophy Dissertation

Parental Perceptions of a Comprehensive Diagnostic Evaluation for Toddlers at Risk for  
Autism Spectrum Disorder

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## Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by a dyad of symptoms in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5), which are categorized by 1) persistent impairments in social communication and social interaction and 2) the presence of two or more restricted, repetitive patterns of behavior (RRB), interests, or activities (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association, 2013). Variations in symptom presentation are characterized through the use of severity level (i.e., Level 3 = “Requiring very substantial support,” Level 2 = “Requiring substantial support,” Level 1 = “Requiring support”), which is based on social communication impairments and RRBs (American Psychiatric Association, 2013). In addition to the presence of clinically significant impairment in at least one area of current functioning, symptoms must be “present in the early developmental period” (American Psychiatric Association, 2013).

Prior to the publication of the DSM-5 in 2013, ASD was conceptualized as a triad of symptoms, which included 1) social impairments, 2) communication impairments, and 3) RRBs (American Psychiatric Association, 2000). Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger’s Disorder were subcategories under the umbrella of ASD; Autistic Disorder reflected the greatest severity of symptoms. Due to the time period in which the current study was completed, DSM-IV or DSM-IV-TR’s autism diagnostic criteria were used (4<sup>th</sup> ed.; DSM-IV; American Psychiatric Association, 1994; 4<sup>th</sup> ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000; the DSM-IV-TR will be hereafter referred to as the DSM-IV).

As reflected by the concerns raised about the changes in the DSM-5, including diminished sensitivity of the diagnostic criteria for young children (Barton et al. 2013; Frazier et al. 2011; Gibbs et al. 2012), there is not a current consensus within the field on the boundaries or symptom clusters of autism. However, the importance of early detection and intervention for children with ASD and their relationship with positive outcomes has been well established (Howlin, 1998; Lord & McGee, 2001; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Myers & Johnson, 2007; Rogers & DiLalla, 1991; Rogers, Herbison, Lewis, Pantone, & Reis, 1986; Rogers & Lewis, 1989; Schopler, Reicheler, Bashford, Lansing, & Marcus, 1990; Strain, Kohler, & Goldstein, 1996). Therefore, when addressing the identification of children with ASD, the American Academy of Pediatrics promotes developmental surveillance (i.e., “ongoing process of identifying children who may be at risk of developmental delays”) of toddlers at well child visits as well as systematic screening (i.e., “the use of standardized tools at specific intervals to support and refine the risk”) (Johnson & Myers, 2007). Toddlers who screen positive for being at risk for ASD would be referred for a comprehensive diagnostic evaluation (Johnson & Myers, 2007).

A comprehensive developmental and diagnostic evaluation should consist of validated measures that examine various domains of functioning and behavior as well as providing appropriate diagnostic decisions. In addition to testing and observation, evaluations should include a parent interview to gather developmental history and information on current functioning (Huerta & Lord, 2012). Communication with the referring pediatrician following the evaluation and a detailed report that includes child specific recommendations is considered best practice (Huerta & Lord, 2012). Aside from

the pediatrician, results and recommendations from the diagnostic evaluation would be one of the few avenues through which parents could come to understand their child's symptoms and strengths, and the next appropriate steps if a diagnosis of ASD or another developmental condition is given. Since parents act as the gatekeepers to early intervention services in some regards (e.g., taking the steps to seek early intervention services, initiating and maintaining treatment) and their participation in their children's mental health services have shown to play a role in treatment success (Delaney & Engels-Scianna, 1996), it is important to understand how parents perceive and experience the diagnostic evaluation and how their experience and satisfaction with a diagnostic evaluation may impact their willingness to seek services or pursue recommendations.

Hart and colleagues (2007) examined parents' ratings of satisfaction on different aspects of their experience of communicating psychosocial concerns for their child to their primary care provider (PCP). Parent satisfaction was measured by responses to the question of "Overall, how satisfied are you with the care you have received you're your child's usual doctor/clinician?" Effective communication between parents and PCPs, which included collaboration on treatment planning between families and PCPs, parent report of mutual understanding, and PCPs asking parents about their own coping skills, resulted in parents reporting greater satisfaction with the care that they received (Hart, Kelleher, Drotar, & Scholle, 2007). Parents of toddlers who received a Speech and Language evaluation reported greater satisfaction with the evaluation when they had lower parenting stress scores and their child did not have health problems at birth (Bairati et al., 2011). Type of language delay (expressive or receptive) or the severity of the delay was not associated with parent satisfaction (Bairati et al., 2011). Additionally, self-report

of patient satisfaction has been linked to the three compliance behaviors: appointment keeping, medication use, and the intention to follow through with recommended treatment (Williams, 1994).

However, how parents/patients judge their own satisfaction and the factors that play a role in that rating are mostly unknown (Jackson et al., 2001). Galil and colleagues (2006) attempted to better understand the factors that play a role in satisfaction ratings by examining the factors in their study's 15-item satisfaction questionnaire. Parents of children with various disabilities (age ranging from 6 months to 6 years) who received rehabilitation services at a child developmental center filled out the satisfaction questionnaire. (The study categorized each child as having a "mild" (e.g., Attention Deficit Disorder, failure to thrive), "moderate" (e.g., cerebral palsy, mild to moderate learning disability), or "severe" (e.g., ASD, Angelman syndrome) disability.) Galil and colleagues (2006) found that their satisfaction questionnaire clustered into three factors: caring, collaboration, and interest. However, collaboration between parents and health care providers was the only factor that explained the variability on general satisfaction (Galil et al., 2006).

Information on parent satisfaction specific to ASD evaluations is very limited. One study found that parents of children who underwent an ASD evaluation reported that they felt heard, were treated with respect, and had confidence in the professionals' expertise (Hackett et al., 2009). Additionally, parents of children who underwent a neurodevelopmental evaluation, which included children who went on to get an ASD diagnosis, reported that identification of their child's deficits and a written report following the evaluation were important ways in which their needs were met (Giannoulis

et al., 2004). However, parents' needs were reportedly not met in the following areas: information on local services, explanation of treatment choices, what the future may hold for their child, being provided with reading material aside from the report on their child's diagnosis (e.g., book list), wait time before an appointment could be scheduled, and parking facilities (Giannoulis et al., 2004). Furthermore, when working with a multidisciplinary team, parents reported confusion about the role of each clinician (Hackett et al., 2009), especially the role of clinical psychologists (Giannoulis et al., 2004). This finding highlighted the importance of clear and detailed pre-assessment information on the assessment procedures and the clinicians who will be working with the family (Giannoulis et al., 2004; Hackett et al., 2009).

Open-ended questions allowed researchers to gather information on themes in parents' experiences of a diagnostic evaluation. The theme of the personal diagnostic journey that each family takes seemed to overlap with or impact all other themes (e.g., the professional-parent relationship, diagnostic assessment process, metaphor of a new life journey, provision of pre-assessment information, and parent needs for information) (Klein et al., 2011). For example, where families are in their diagnostic journey (e.g., expecting/suspecting a diagnosis of ASD or believing that their child is typically developing) may impact the relationship developed with the clinician, their need for additional information, and their ability to be emotionally and cognitively present during an assessment. These findings further highlighted the importance of clinicians assessing parents' stress level and reactions to the evaluation during the evaluation itself (Brown & Wissow, 2008; Klein et al., 2011).

The current study examined parents' or caregivers' experiences of a comprehensive developmental and diagnostic evaluation for their toddler who was identified as being at risk for ASD by examining their responses to a Post-Evaluation Satisfaction Questionnaire, which was developed for the purposes of a larger, multi-site study. (Parents and caregivers will be referred to as parents from here on.) The major aim of the current study was to examine the presence and correlates of factors within a Post-Evaluation Satisfaction Questionnaire. If factors were identified, factor scores would be calculated and higher factor scores would be considered more suggestive of a positive experience.

Similar to other satisfaction questionnaires, the Post-Evaluation Satisfaction Questionnaire directly asked parents how satisfied they were with the “help (they) and (their) child” received through their participation in the study as well their “overall satisfaction” with the service they received. The first hypothesis is that higher ratings of a positive experience, as defined by higher factor scores, would be correlated with greater study satisfaction and overall satisfaction. The Post-Evaluation Satisfaction Questionnaire also asked parents to rate the extent to which they felt their needs for evaluation and recommendations were met, to indicate the quality of the screening and evaluation, and to rate their intention of following recommendations given at the evaluation. The second hypothesis is that parental report of a positive experience would be correlated with greater likelihood of needs for evaluation and recommendations being met, higher ratings of screening and evaluation quality, and stronger intentions to follow recommendations provided by clinicians. The third hypothesis is that the diagnosis of the toddler at the time of the evaluation, cognitive and adaptive functioning of the toddler,



and parental stress would be associated with perceptions (negative/positive) of the diagnostic evaluation. An ASD diagnosis, which was the most severe of the diagnoses given, lower scores in the areas of cognitive and adaptive functioning, and higher parental stress are predicted to be associated with lower satisfaction and more negative perceptions of the diagnostic evaluation.

The current study will add to the sparse literature currently available on the factors impacting parent satisfaction with comprehensive developmental and diagnostic evaluations. Additionally, better understanding of parent satisfaction may provide health care providers with insight on how to best work with their patients' parents, and in turn, may positively impact treatment success (Delaney & Engels-Scianna, 1996) and patient compliance behaviors (e.g., appointment keeping, medication use, and the intention to follow through with recommended treatment) (Williams, 1994) since both treatment success and patient compliance behaviors have been linked with parent and patient satisfaction, respectively. Furthermore, both quantitative and qualitative data was collected from parents and analyzed in the current study, which is unique to this study.

## **Methods**

### **Participants and Procedure**

The current study included participants from a multi-site study examining the sensitivity and specificity of the Modified Checklist for Autism in Toddlers (from 2002 to 2009) (M-CHAT; Robins, Fein, Barton, & Green, 2001) and then the Modified Checklist for Autism in Toddlers, Revised (from 2010 to 2014) (M-CHAT-R; Robins et al., 2014). The M-CHAT (23 items) and its revised version, M-CHAT-R (20 items), are two stage parent-report screening tools used to assess risk for ASD in toddlers between

16 and 30 months of age. ("The M-CHAT or the M-CHAT-R" will be referred to as M-CHAT/-R from here on). In the first stage, parents completed the M-CHAT/-R during well child visits at their pediatricians' offices. The pediatrician sites then mailed the completed M-CHATs/-Rs to their collaborating research site. In the second stage, members of the research team contacted parents to complete follow-up phone calls when their responses to the M-CHAT/-R indicated that their children might be at risk for an ASD (i.e., failing two or more critical items, or any three items).

A sample of 288 families were offered and accepted a free developmental and diagnostic evaluation at the University of Connecticut because their responses to the follow-up interview questions continued to indicate ASD risk. On the phone, concerns raised by the M-CHAT/-R and M-CHAT/-R Follow-Up interview were described as developmental concerns about social interaction and communication rather than specifically ASD concerns to prevent further distress and to minimize reporting bias. The in person developmental/diagnostic evaluations were completed by a trained graduate student in a clinical psychology doctoral program and an experienced clinician (a licensed clinical psychologists or a developmental pediatrician) and lasted about three hours. The clinician interviewed the parent(s) and the graduate student clinician tested the toddler. Parents were interviewed simultaneously and in the same room as the graduate student clinician working with their toddler. If appropriate, a diagnosis and recommendations, including a referral to a local government funded early intervention provider, were related to parents at the end of the evaluation. The licensed clinical psychologist or the developmental pediatrician working with the family provided the diagnostic feedback. After the evaluation, parents were sent a detailed report with

recommendations tailored to the needs and strengths of their child. Along with the report, parents received a Post-Evaluation Satisfaction Questionnaire seeking feedback from parents on their participation in the study (see Appendix A). If parents did not return the questionnaire three to five weeks after the first mailing, it was sent a second time. A third and final mailing of the questionnaire was sent if it was not returned after the second mailing. A stamped and labeled return envelope was included in each mailing for the parent's convenience. Incentives were not provided for parents to return the Satisfaction Questionnaire.

Two hundred sixty-two toddlers (192 males; 70 females) between the ages of 16 and 39 months ( $M=24.95$ ,  $SD=4.64$ ) were included in the current study (see Table 1). Toddlers with missing data ( $n = 19$ ) or returned Satisfaction Questionnaires that were completed in Spanish ( $n = 7$ ) were not included in the current study. The group that returned the Satisfaction Questionnaire (Questionnaire Group) included 190 toddlers (146 males; 44 females) who received a diagnosis of Autistic Disorder ( $n = 62$ ) or PDD-NOS ( $n = 39$ ) as defined by DSM-IV or DSM-IV-TR diagnostic criteria, and Developmental Delay ( $n = 59$ ), Other Diagnosis ( $n = 4$ , 1 = Motor Delay, 1 = Expressive Language Delay, 1 = Reactive Attachment Disorder, 1 = Missing), No Diagnosis ( $n = 16$ ), or Typically Developing ( $n = 10$ ) as defined by the larger M-CHAT/-R study. For the purposes of the current study, the diagnoses of Autistic Disorder and PDD-NOS were grouped together into an ASD diagnosis ( $n = 101$ ). "No Diagnosis" was used in the larger, multi-site study to indicate the presence of development concerns that did not meet any diagnostic criteria but did not indicate typical development. In terms of the respondents in the Questionnaire Group, 90.5% were mothers ( $n = 172$ ), 6.8% were fathers ( $n = 13$ ), and

2.1% identified themselves as non-parent caregivers ( $n = 4$ ). Respondent information was missing for one participant (.5%).

The group that did not return the Satisfaction Questionnaire (Non-Questionnaire Group) after three mailings included 72 toddlers (46 males; 26 females) who received a diagnosis of Autistic Disorder ( $n = 16$ ) or PDD-NOS ( $n = 12$ ) as defined by DSM-IV or DSM-IV-TR diagnostic criteria, and Developmental Delay ( $n = 32$ ), Other Diagnosis ( $n = 1$ , specifically a previous diagnosis of Down Syndrome), No Diagnosis ( $n = 4$ ), or Typically Developing ( $n = 7$ ) as defined by the M-CHAT/-R study. For the purposes of the current study, the diagnoses of Autistic Disorder and PDD-NOS were grouped together into an ASD diagnosis ( $n = 28$ ).

The Questionnaire and Non-Questionnaire Groups did not differ significantly from each other in terms of evaluation diagnosis ( $\chi^2(4, n = 262) = 7.157, p = .13$ ) or sex ( $\chi^2(1, n = 262) = 3.84, p = .05$ , see Table 1), although there was a trend for the returned questionnaires to include a higher proportion of boys. The two groups differed significantly on ethnicity ( $\chi^2 = 16.31, p = .01$ ) and age ( $t(142.12) = 2.38, p = .02$ ). However, the differences between the Questionnaire and Non-Questionnaire Groups on ethnicity (Cramer's  $V = 0.23$ ) and age ( $r^2 = .04$  and a mean difference in age of less than 1.5 months) were small. In the Questionnaire Group, most participants were Caucasian ( $n = 144$ ; 75.8%) followed by Hispanic or Latino ( $n = 16$ ; 8.4%), Black or African American ( $n = 13$ ; 6.8%), Asian or Pacific Islander ( $n = 8$ ; 4.2%), Biracial ( $n = 3$ ; 1.6%), Other ( $n = 1$ ; 0.5%), and Native American ( $n = 1$ ; 0.5%). Four (2.1%) Questionnaire Group participants were missing ethnicity data. The majority of participants in the Non-Questionnaire group were Caucasian ( $n = 40$ ; 55.6%) followed by Hispanic or Latino ( $n$

= 15; 20.8%), Black or African American ( $n = 9$ ; 12.5%), Asian or Pacific Islander ( $n = 4$ ; 5.6%), Biracial ( $n = 3$ ; 4.2%), and Native American ( $n = 1$ ; 1.4%). Overall, there was a higher proportion of Caucasian families in the Questionnaire Group and of minority families in the Non-Questionnaire Group.

## **Measures**

The Post-Evaluation Satisfaction Questionnaire is a 30-item questionnaire created for the purposes of the M-CHAT/-R study. A majority (i.e., 23 items) of the questions were presented with a Likert scale (e.g., “No, definitely not,” “No, I don’t think so,” “Yes, I think so,” and “Yes, Definitely”). Some questions (i.e., 7 items) were open ended or asked for an explanation after choosing the Likert scale answer. The questionnaire was designed to seek information from parents about several aspects of their experiences in the study. Questions were asked about parents’ experiences filling out the M-CHAT/-R at the pediatrician’s office, the M-CHAT/-R Follow-Up phone interview, and the developmental and diagnostic evaluation. The questionnaire also asked for feedback about the detailed report that was sent. For the purposes of the current study, feedback about filling out the M-CHAT/-R at the pediatrician’s office and the M-CHAT/-R Follow-Up phone interview were not included because they were not considered components of a typical diagnostic evaluation. Additionally, parents’ responses about their intention to follow recommendations, satisfaction with study help, quality of screening and evaluation, study meeting needs, and overall satisfaction (a total of five questions) were identified as “key outcome questions” because of previous studies’ use of these variables to develop a better understanding of what parents/patients value and need

in evaluations or treatment (Bairati et al., 2011; Galil et al., 2006; Hart et al. 2007; Jackson et al., 2001).

The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) is a standardized semi-structured caregiver interview that assesses daily adaptive functioning in the following domains: Socialization, Communication, Daily Living, and Motor skills. The current study used the Standard Score (SS) from each domain to examine differences among groups. The interviewers were licensed clinical psychologists or a developmental pediatrician.

The Mullen Scales of Early Learning (Mullen, 1995) examines the child's functioning in the Expressive and Receptive Language, Fine Motor, and Visual Reception domains. The current study used the T-Score from each domain to examine differences among groups and correlations with parent satisfaction. Gross motor information was not collected as part of the larger multi-site study from which the current study derived participants. Experienced graduate students in a clinical psychology doctoral program completed the Mullen.

The Parenting Stress Index (Abidin, 1995) is a 36-item self-report questionnaire that examines parental stress on four subscales. On the Parental Distress (PD) subscale, parents are asked to report their stress level as a result of parenting. The Parent-Child Dysfunctional Interaction (P-CDI) subscale examines parents' perceptions of their child as not meeting expectations or the experience of interactions with their child when their role as a parent is not reinforced. The Difficult Child (DC) subscale asks parents to report on their child's temperament or behavioral tendencies that impact the parent-child

relationship. Finally, the Total Stress subscale computes respondents' overall parental stress.

Childhood Autism Rating Scale (CARS; Schopler et al. 1980) is a 15-item rating scale that was completed by the clinician and is based on direct observation as well as parent report. The measure requires clinicians to rate each individual on symptoms related to autism and higher scores indicate greater autism severity. The CARS Total Score leads to the categorization of each individual as "Non-Autistic," "Mildly-Moderately Autistic," and "Severely Autistic."

A total of six clinicians were involved in completing the comprehensive developmental and diagnostic evaluations reported in the current study. Five of the six clinicians were licensed clinical psychologists and one was a developmental pediatrician. All clinicians were females.

### **Data Analysis**

An exploratory factor analysis (EFA), which included all Likert scaled questions that were not considered key outcome questions (i.e., 22 questions), was conducted to determine if certain factors accounted for parental experience of a diagnostic evaluation. Due to the categorical nature of the items, the analyses were conducted using a polychoric correlation matrix (Holgado-Tello, Chacón-Moscoso, Barbero-García, & Vila-Abad, 2010). The initial EFA model resulted in a Heywood Case (where explained variance exceeded 1). In an attempt to address the Heywood Case, an EFA was run without the questionnaire items that did not load onto a factor in the initial EFA. A Heywood Case continued to be indicated. The content of the questions in the Satisfaction Questionnaire was then examined to determine which questions appeared to reflect

possible aspects of a parental experience. Questions that could be grouped together (i.e., two or more questions) to reflect certain aspects of parental experience of a diagnostic evaluation were included in an EFA (see Table 2). Questions that could not be grouped were removed from the EFA (see Table 3). This resulted in a set of 13 questions that were included in an EFA, which did not result in a Heywood Case.

The factors derived from the EFA were used to test the hypotheses of the current study. Factor scores were calculated for each participant in the Questionnaire Group. The factor scores were then used to examine if there was a correlation between the five factors and the key outcome questions, cognitive (Mullen Scales of Early Learning) and adaptive (Vineland Adaptive Behavior Scales) functioning of the toddler, autism severity score of the toddler (CARS total score), and parental stress (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score). Kruskal-Wallis H tests were also conducted to examine if factor scores differed by the toddler's diagnosis or the clinician conducting the evaluation.

Additional correlations were conducted to examine if there was a relationship between key outcome questions and cognitive (Mullen Scales of Early Learning) and adaptive (Vineland Adaptive Behavior Scales) functioning of the toddler, autism severity score of the toddler (CARS total score), and parental stress (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score). Kruskal-Wallis H tests were conducted to examine if key outcome questions differed by the toddler's diagnosis or the clinician conducting the evaluation.

Additionally, in order to comprehensively examine parents' experiences of diagnostic evaluations, a coding system was created from responses to open ended



questions (questions 11, 12, and 30) or questions that asked parents to further explain their responses to a Likert scaled question (i.e., questions 8, 16, and 25). Parents included in the current study did not provide a qualitative response to the question of whether or not they and their child were treated with respect (i.e., question 28). Therefore, it was not included in the coding system.

The current researcher (Rater 1) identified themes within each question and coded each response as present (1) or absent (0). Themes were grouped by question; for example, certain themes that were present in the responses to one question were not necessarily manifested for another question. The themes that did not manifest in any of the responses of a particular question were not coded to avoid overestimation of inter-rater reliability. Certain themes were present across two or more questions. In order to decrease bias in the identification of themes, a clinical psychology doctoral graduate student reviewed the themes identified by Rater 1. The graduate student agreed with the majority of the themes identified but also identified a few additional themes, which Rater 1 agreed with and added to the coding system. Once the coding system was established, an undergraduate research assistant coded the responses for all six questions. An inter-rater reliability of  $K=.60$  or higher was reached for each theme. Like the coding system created by Hilton and colleagues (2012), the responses were examined for themes indicating positive and negative experiences. These were then grouped into positive and negative experiences when presented in tables to allow for easier perusal of the data.

## **Results**

### **Factor Analysis**

As noted in the Methods section, an EFA based on a polychoric matrix was conducted on 22 items from the Satisfaction Questionnaire, which indicated a Heywood Case. After reviewing the content of the questions in the Satisfaction Questionnaire, an EFA based on a polychoric matrix was conducted on 13 out of the 22 items, which did not result in a Heywood Case.

Principal factor analysis revealed the presence of three components with eigenvalues exceeding 1. However, in the three-factor model, the factor with the most item loadings did not seem to reflect an identifiable aspect of the diagnostic evaluation or experience. A Parallel Analysis (Ledesma & Valero-Mora, 2007) indicated that a five-factor model, which seemed to best fit the questions from the Satisfaction Questionnaire, was acceptable (see Table 4). The first factor (“Collaboration/Checking in”) reflected collaboration between parents and staff by 1) staff seeking information from parents on their child’s development and 2) integrating this information into the report, and 3) staff putting in “effort to make (parents) comfortable” during the evaluation. Factor two, “Feedback Quality,” included questions that asked parents to rate 1) “the amount of information provided to (them) at the end of the evaluation,” 2) the clarity of the manner in which the diagnosis was explained to them, and 3) the clarity of the recommendation provided to them. Factor three, reflecting “Report Quality,” asked parents if the information provided in the report was 1) clear and 2) useful. The fourth factor, which reflected parents’ perception of the staff’s “Availability” to them, asked parents to rate 1) “the amount of time that was spend with (them) and (their) family,” and also 2) asked

parents if they had questions that they did not ask. The fifth and final factor reflected “Cultural Understanding.” The two questions included in this factor asked parents 1) how important it was to have the staff “understand (their) cultural background and values,” and 2) if they felt the staff working with them understood their “cultural background and values.”

### **Factor Scores Correlations**

Factor scores based on the five-factor model were calculated for each participant. The factor scores were then used to examine their relationship with key outcome questions, cognitive (Mullen Scales of Early Learning) and adaptive (Vineland Adaptive Behavior Scales) functioning of the toddler, autism severity score of the toddler (CARS total score), and parental stress (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score). Spearman’s Rank-Order correlation coefficient was used.

**Key Outcome Questions.** The relationship between key outcome questions (16, 20, 21, 22, 27) and factor scores was examined (see Table 5). There was a strong, positive correlation between a parent’s intention to follow through on recommendations (question 16) and Factor 3: Report Quality ( $r_s = .30, n = 157, p < .001$ ). Parents’ report on satisfaction with the help received from participation in the study was positively correlated with all five factors, Factor 1: Collaboration/Checking in ( $r_s = .32, n = 161, p < .001$ ), Factor 2: Feedback Quality ( $r_s = .45, n = 161, p < .001$ ), Factor 3: Report Quality ( $r_s = .51, n = 161, p < .001$ ), Factor 4: Availability ( $r_s = .40, n = 161, p < .001$ ), Factor 5: Cultural Understanding ( $r_s = .17, n = 161, p < .001$ ). Similarly, parents’ report on the quality of screening and evaluation was positively correlated with all five factors,

Factor 1: Collaboration/Checking in ( $r_s = .26, n = 162, p = .001$ ), Factor 2: Feedback Quality ( $r_s = .38, n = 162, p < .001$ ), Factor 3: Report Quality ( $r_s = .42, n = 162, p < .001$ ), Factor 4 : Availability ( $r_s = .39, n = 162, p < .001$ ), Factor 5: Cultural Understanding ( $r_s = .21, n = 162, p = .008$ ). Parents' report on the study meeting their needs for evaluation and recommendations was positively correlated with Factor 1: Collaboration/Checking in ( $r_s = .20, n = 161, p = .01$ ), Factor 2: Feedback Quality ( $r_s = .40, n = 161, p < .001$ ), Factor 3: Report Quality ( $r_s = .49, n = 161, p < .001$ ), Factor 4 : Availability ( $r_s = .29, n = 161, p = .06$ ). Parents' report on overall satisfaction was positively correlated with Factor 1: Collaboration/Checking in ( $r_s = .25, n = 159, p = .002$ ), Factor 2: Feedback Quality ( $r_s = .54, n = 159, p < .001$ ), Factor 3: Report Quality ( $r_s = .45, n = 159, p < .001$ ), Factor 4: Availability ( $r_s = .31, n = 159, p < .001$ ).

***Mullen Domains.*** There were no significant correlations between Mullen Domains (Visual Reception, Expressive Language, Receptive Language, Fine Motor) and factor scores (see Table 6).

***Vineland Domains.*** The relationship between Vineland domains (Communication, Socialization, Motor, Daily Living Skills) and factor scores was investigated (see Table 7). Vineland Communication Skills Domain was negatively correlated with Factor 2: Feedback Quality ( $r_s = -.23, n = 112, p = .013$ ) and Factor 3: Report Quality ( $r_s = -.19, n = 112, p = .046$ ), indicating more positive reports of feedback and report quality by parents of children with lower communication skills. Vineland Socialization Skills Domain was negatively correlated with Factor 3: Report Quality ( $r_s = -.21, n = 112, p = .027$ ), indicating higher Report Quality ratings by parents of children with lower socialization skills. Vineland Motor Skills Domain was negatively correlated

with Factor 2: Feedback Quality ( $r_s = -.30, n = 112, p = .001$ ) and Factor 3: Report Quality ( $r_s = -.25, n = 112, p = .027$ ), indicating more positive reports of Feedback and Report quality by parents of children with lower motor skills. Vineland Daily Living Skills Domain was negatively correlated with Factor 2: Feedback Quality ( $r_s = -.22, n = 112, p = .017$ ), Factor 3: Report Quality ( $r_s = -.22, n = 112, p = .018$ ), and Factor 5: Cultural Understanding ( $r_s = -.21, n = 112, p = .029$ ), which indicated higher ratings in Feedback and Report Quality, and Cultural Understanding by parents of children with lower daily living skills.

***CARS Total Score.*** There were no significant correlations between CARS Total Score and factor scores (see Table 8).

***Parent Stress Total Scores.*** There were no significant correlations between factor scores and PSI Total Scores (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score) (see Table 9).

#### ***Kruskal-Wallis H Tests Using Factor Scores***

Kruskal-Wallis H tests were conducted to examine the impact of diagnosis and clinician on factor scores.

***Diagnosis.*** There was not a statistically difference in diagnosis across the five factors, (Collaboration/Checking in:  $\chi^2(4, n = 162) = 2.69, p = .610$ ); Feedback Quality:  $\chi^2(4, n = 162) = 3.98, p = .409$ ; Report Quality:  $\chi^2(4, n = 162) = 1.87, p = .761$ ; Availability:  $\chi^2(4, n = 162) = 3.50, p = .477$ ; Cultural Understanding:  $\chi^2(4, n = 162) = 5.44, p = .25$ , see Table 10). “Other Diagnosis” was not included in the Kruskal Wallis H test because only one case was available for analysis.

**Clinician.** A Kruskal Wallis H Test was conducted to explore the impact of clinician on each of the factor scores (see Table 11). Clinician 7 was not included because only one case was available for analysis. There was a statistically significant difference on Factor 5: Cultural Understanding by clinician ( $\chi^2(4, n = 161) = 15.43, p = .004$ ). Mann-Whitney U tests were conducted to evaluate pairwise differences among the five clinicians, controlling for Type I error across tests using the Bonferroni approach. The results of these tests indicated a significant difference between Clinician 4 (mean rank = 108.11) and Clinician 1 (mean rank = 64.70). Cohen's effect size value ( $d = -.41$ ) indicated a moderate difference.

There was not a statistically difference in clinician across the four other factors, (Collaboration/Checking in:  $\chi^2(4, n = 161) = 5.47, p = .24$ ); Feedback Quality:  $\chi^2(4, n = 161) = .47, p = .976$ ; Report Quality:  $\chi^2(4, n = 161) = 5.05, p = .282$ ; Availability:  $\chi^2(4, n = 161) = 3.71, p = .447$ ).

### **Key Outcome Questions Correlations**

The relationship between parents' responses to the key outcome questions (16, 20, 21, 22, 27) and cognitive (Mullen Scales of Early Learning) and adaptive (Vineland Adaptive Behavior Scales) functioning of the toddler, autism severity score of the toddler (CARS total score), and parental stress (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score) was examined. Spearman's Rank-Order correlation coefficient was used.

**Mullen Domains.** The relationship between key outcome questions and Mullen Domains (Visual Reception, Expressive Language, Receptive Language, Fine Motor) was investigated (see Table 12). Parents' report on overall satisfaction was negatively

correlated with Mullen Expressive Language Skills Domain ( $r_s = -.20$ ,  $n = 179$ ,  $p = .007$ ).

There were no significant correlations between Mullen Domains and key outcome questions 16 (intention to follow recommendations), 20 (satisfaction with study help), 21 (quality of screening and evaluation), and 22 (study met needs).

***Vineland Domains.*** The relationship between key outcome questions and Vineland Domains (i.e., Communication, Socialization, Motor, Daily Living Skills) was examined (see Table 13). Parents' report on overall satisfaction (question 27) was negatively correlated with Vineland Communication Skills Domain ( $r_s = -.23$ ,  $n = 131$ ,  $p = .007$ ) and Vineland Motor Skills Domain ( $r_s = -.21$ ,  $n = 131$ ,  $p = .018$ ). There were no significant correlations between Vineland domains and key outcome questions 16 (intention to follow recommendations), 20 (satisfaction with study help), 21 (quality of screening and evaluation), and 22 (study met needs).

***CARS Total Score.*** There were no significant correlations between CARS Total Score and outcome questions (see Table 14).

***Parent Stress Total Scores.*** There were no significant correlations between any of the PSI Total Scores (Parental Distress, Parent and Child Dysfunctional Interaction, Difficult Child, Total Stress Score) and outcome questions (see Table 15).

### ***Kruskal-Wallis H Tests Using Key Outcome Questions***

Kruskal-Wallis H tests were conducted to examine the impact of diagnosis and clinician on outcome questions.

***Diagnosis.*** When examining the impact of diagnosis on key outcome questions (see Table 16), there was a statistically significant difference in responses to question 22 (the study's ability to meet needs for evaluation and recommendations,  $\chi^2(4, n = 186) =$

11.76,  $p = .019$ ) by diagnosis. Mann-Whitney U tests were conducted to evaluate pairwise differences among the five diagnoses, controlling for Type I error across tests using the Bonferroni approach. Due to the use of the Bonferroni approach to control for Type I error across tests, which prescribed  $p < .005$ , there was not significant difference between diagnoses on outcome questions.

There was not a statistically difference in diagnosis across the four other key outcome questions, (Intention to follow recommendation:  $\chi^2(4, n = 182) = 7.63, p = .106$ ); Satisfaction with study help:  $\chi^2(4, n = 187) = 4.75, p = .314$ ; Quality of study screening and evaluation:  $\chi^2(4, n = 188) = 6.88, p = .143$ ; Overall satisfaction:  $\chi^2(4, n = 187) = 8.13, p = .087$ ), see Table 16).

**Clinician.** There was not a statistically significant difference by clinician in any of the five key outcome questions: parents' reports of intention to follow recommendations ( $\chi^2(4, n = 181) = 2.48, p = .648$ ), satisfaction with study help ( $\chi^2(4, n = 186) = 3.08, p = .544$ ), the study's ability to meet needs for evaluations and recommendations ( $\chi^2(4, n = 187) = 5.30, p = .258$ ), quality of study screening and evaluation ( $\chi^2(4, n = 185) = 4.75, p = .314$ ) and overall satisfaction ( $\chi^2(4, n = 186) = 4.78, p = .311$ , see Table 17).

### **Coding of Open Ended Questions**

Themes were identified for each question. Each qualitative parent response to a question was then coded as being present or absent for the themes. With a few exceptions, only themes that were present in at least 10% of the responses were reported below due to presence of numerous themes. Certain themes reoccurred across questions and were indicated in the tables presenting the theme data.



***Question 8: Did you have questions at the time of the evaluation that you did not ask? Why didn't you ask?*** Twenty-three out of 190 parents (12%) responded to the question of why they did not ask questions they had (see Table 18). Of these, 12 parents were not prepared for the diagnosis, felt overwhelmed or shocked, and/or were overwhelmed by the amount of information provided during the feedback portion of the evaluation. Three parents noted that they forgot to ask their questions and three developed questions after the evaluation.

***Question 11: What specifically did you like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain.*** When asked about what parents liked about the way they were told about their child's diagnosis, 130 out of 190 (68%) participants responded (see Table 19). Of these, 45 parents reported that they appreciated the direct, clear, concrete, and/or honest manner in which they were given their child's diagnosis. Parents ( $n = 27$ ) also noted the care, sensitivity, patience, and/or friendliness demonstrated by the clinicians. Twenty-two parents expressed appreciation of the clinicians' explanation how they arrived at a diagnosis and/or the psychoeducation component of the feedback. Parents also commented on the helpfulness of the recommendations and referrals provided by the clinicians ( $n = 15$ ). Of note, a small number of parents ( $n = 3$ ) also provided responses to this questions that reflected aspects of the feedback that they did not appreciate, which included not receiving a diagnosis or not having a clear diagnosis.

***Question 12: What specifically did you not like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain.*** When parents were asked what they did not like about the way they were told about their child's diagnosis,

53 out of 190 participants (28%) provided a qualitative response (see Table 20). Of these, 10 parents noted that they would have liked more information/psychoeducation (e.g., “I wish someone could explain his odd obsessions”) from the clinician at the time of the diagnostic feedback. Nine parents reported dissatisfaction with not receiving a diagnosis or not receiving a clear indication of severity (e.g., “We weren’t told where on the Autism Spectrum he was.”). Six parents indicated that they were dissatisfied with the manner in which the feedback was delivered (e.g., “It was the first thing we were told- it could have been eased into...”). A few parents indicated that they were dissatisfied with the waiting time for a diagnosis ( $n = 1$ ) or report ( $n = 5$ ). Of note, parents also provided responses that reflected aspects of the feedback that they appreciated, which included the clinician’s professionalism and/or expertise ( $n = 2$ ; e.g., “No parent likes to learn their child is developmentally delayed, but we think it was tactfully and professionally presented.”).

***Question 16: To what extent do you intend to follow through with the recommendations for your child included in the report? Please explain.*** When asked about the extent to which parents intended to follow recommendations included in the report, 101 out of the 190 participants (53%) in the Questionnaire Group provided a qualitative response (see Table 21). Of these, 40 parents reported that they were receiving services and/or were enrolled in Birth-to-Three early intervention. Nineteen parents indicated that they used the evaluation report or the evaluation to get, maintain, or increase services for their child, and 16 parents noted that they were planning to follow through with all the recommendations given and/or wanted to seek as much help as possible for their child. A few parents noted disagreement with or uncertainty about the

need for certain recommendations ( $n = 4$ ; e.g., “We are receiving services from \_\_\_\_ . However, we don’t feel some of the suggested services are warranted such as the OT”) and some reported the decision to hold off or not follow through on a specific recommendation ( $n = 4$ ). Two parents reported the decision to hold off seeking any services (e.g., “At this time we won’t be contacting Birth-to-Three- giving CHILD NAME some time- she seems to be progressing fine.”).

***Question 25: If a friend’s child were in need of similar help, would you recommend participating in this study to him or her? ?*** Sixty out of 190 parents (32%) responded to the question regarding willingness to recommend the study to a friend (see Table 22). Of these, 8 parents reported that the evaluation was a helpful and/or a positive experience for them. Some parents ( $n = 8$ ) reported that they already recommended the study to someone else. Six parents responded by indicating the importance of early detection and diagnosis, and two parents reported dissatisfaction with the staff (e.g., “I feel I wasn’t heard enough or understood.”).

***Question 30: We would welcome any additional comments you might want to make. What specifically did you like or not like about your experiences in the Early Detection Study?*** When asked for additional comments, 100 of the 190 parents (53%) in the Questionnaire Group provided responses (see Table 23). Of these, 27 parents wrote “thank you.” Twenty-seven parents reported that they had a helpful and/or positive experience (e.g., “We had a very positive experience.”), 17 noted that they appreciated the clinicians’ care, sensitivity, patience, and/or friendliness, and 12 indicated an appreciation for the clinician’s professionalism and/or expertise. Some parents ( $n = 16$ ) reported dissatisfaction with the evaluation structure (e.g., “We felt the evaluation should

have taken place over several days or periodically throughout several months so that the evaluators could really get to know (Child Name).”). Eleven parents noted dissatisfaction about the wait time for the report after the evaluation (mean = 2.5 months) and 10 indicated that they would have liked more information.

## **Discussion**

The current study examined parent satisfaction of a comprehensive developmental and diagnostic evaluation for their toddler using a Post-Evaluation Satisfaction Questionnaire, which was developed for the purposes of larger multi-site study. Both parents who returned the Post-Evaluation Satisfaction Questionnaire (Questionnaire Group) and those who did not (Non-Questionnaire Group) were included in the current study. The Questionnaire and Non-Questionnaire Group differed significantly, with a small effect size, on ethnicity and age. There were more Caucasian families in the Questionnaire Group and more minority families in the Non-Questionnaire Group. This may have been partially due to the exclusion of Satisfaction Questionnaires completed in Spanish from the current study. Additionally, incentives or follow up phone calls encouraging the return of the satisfaction questionnaire may have led to the return of more satisfaction questionnaires, regardless of ethnicity. While the mean difference in age was less than 1.5 months, this significant difference in age may reflect parents of older children becoming more worried than parents of younger children about their children’s delays and therefore, more invested in the evaluation process, which would include the completion of the satisfaction questionnaire.

The major aim of the current study was to assess the factors present in parents’ experience of a comprehensive diagnostic evaluation by examining their responses to

Likert scaled questions in the Post-Evaluation Satisfaction Questionnaire (Questionnaire Group). Collaboration/Checking in, Feedback Quality, Report Quality, Availability, and Cultural Understanding were identified as the five factors present in the Satisfaction Questionnaire. The relationship between these identified factors and 1) key outcome questions relating to overall satisfaction, satisfaction with study help, willingness to follow recommendations, screening and evaluation quality, and needs met, 2) diagnosis, 3) autism severity, 4) cognitive and 5) adaptive functioning, 6) parental stress, and 7) clinician were investigated. Additionally, themes were identified in parents' responses to six open ended questions, which provided greater understanding of parents' experience of the evaluation process.

In support of the first hypothesis, satisfaction with the help provided through the evaluation was positively correlated with all five factors. Overall satisfaction was positively correlated with all factors except cultural understanding, which partially supported the hypothesis of a positive relationship between overall satisfaction and all five factors. The positive correlation between collaboration/checking in and overall satisfaction reflected the finding by Galil and colleagues (2006) as well as Hart and colleagues (2007) of the positive relationship between parent satisfaction and collaboration in treatment planning. It is not clear what may have led to the difference in Cultural Understanding correlation between overall satisfaction (not correlated) and satisfaction with study help (positively correlated). Replication of this result is warranted.

The second hypothesis, which predicted that parents' report of positive experiences would be positively correlated with greater likelihood of needs being met, higher ratings of screening and evaluation quality, and stronger intentions to follow

recommendations (key outcome questions), was also partially supported. Ratings on the quality of the screening and evaluation process were positively correlated with all five factors. The degree to which parents' needs for evaluation and recommendations were met was positively correlated with all factors except cultural understanding. Similar to the lack of a correlation between overall satisfaction and cultural understanding, there also was not a relationship between needs met and cultural understanding. It may be possible that cultural understanding, while important, was not always considered when parents evaluated certain aspects of a diagnostic evaluation. Interestingly, report quality was the only factor positively correlated with the key outcome question asking about their intention to follow recommendations. Report quality may have been the most salient way parents determined the importance and validity of the recommendations. The strong positive correlations between report quality and all outcome questions, particularly intention to follow recommendations, highlighted the importance of report quality.

The current study's third hypothesis about the relationship between parents' experience of the diagnostic evaluation, as measured by the five factors and the five key outcome questions, and the diagnosis of the toddler at the time of the evaluation and autism severity was not supported. There were no significant differences in any of the factors and the key outcome questions by diagnosis or autism severity. This suggested that the diagnosis provided at the end of the evaluation might not significantly color parents' experience of a diagnostic evaluation, which reflects Lawoko's and Soares' (2004) finding of no association between a child's disease severity and parent satisfaction. Additionally, some of the difficulty of receiving a diagnosis for one's child may have been eased by the support provided through recommendations and referrals.

Therefore, the support received may have been used to evaluate the diagnostic evaluation rather than the diagnosis itself.

The hypothesis that there would be a positive relationship between parents' report of positive experiences and their toddler's adaptive and cognitive functioning was partially contradicted. Some aspects of adaptive and cognitive functioning were negatively correlated with positive experiences. Vineland Communication, Motor, and Daily Living Skills Domains were negatively correlated with Feedback Quality and Report Quality. Vineland Socialization Skills Domain was also negatively correlated with Report Quality. Furthermore, there was a significant, negative relationship between overall satisfaction, and Vineland Communication and Motor Skills Domains. These results suggested that parents of toddlers with lower adaptive skills were more likely to report greater overall satisfaction and more positive experiences with Feedback (Communication, Motor, and Daily Living Skills) and Report (Communication, Socialization, Motor, and Daily Living Skills) quality. In terms of cognitive skills, there was a significant, negative correlation between overall satisfaction and the Mullen Expressive Language Skills Domain. This suggested that the parents of toddlers with weaker expressive language skills tended to report higher overall satisfaction.

The negative relationship of adaptive and cognitive functioning with positive experiences may further highlight the important role that the support provided by a diagnostic evaluation/clinicians might play for parents. Clinicians may have been able to provide more support in the form of more definite prognosis and recommendations for children with greater deficits in cognitive and adaptive functioning. For example, children with more delays were likely to qualify for more early intervention services and

therefore, receive more recommendations. Additionally, in line with the finding by Giannoulis and colleagues (2004) that identification of their child's deficits was an important way in which parents' needs were met, identification of deficits by a clinician in the current study may have validated concerns that parents already had, which may have been greater for parents of children with more impaired functioning. Explanations of their child's diagnosis may have also helped parents develop a better understanding of their child's behavior, especially for parents of children with more severe impairments (Giannoulis et al., 2006). For example, for a parent of a child with severe language impairments, the parent may now understand her child's tantrum as frustration at not being able to communicate his needs or wants.

There was not a significant relationship between any of the factors or key outcome questions and parental stress. This result does not contradict previous findings highlighting the importance of assessing parental stress level and reactions to the evaluation during the evaluation (Brown & Wissow, 2008; Klein et al., 2011) because parents filled out the parenting stress measure (Parenting Stress Index) used in the current study prior to the evaluation. The Parenting Stress Index was mailed home prior to the evaluation with a packet of other questionnaires and therefore, did not measure stress related to the evaluation. Results may have differed if parental stress was assessed during or after the diagnostic evaluation. Many parents' report of feeling unprepared, overwhelmed, shocked, and overloaded with information during the feedback process in the current study supported the importance of assessing parental stress level and reactions during the evaluation (Brown & Wissow, 2008; Klein et al., 2011).



Unique to the current study, the impact of clinician on differences in parents' experience of the evaluation was examined. There were significant differences in the Cultural Understanding factor between Clinician 1 and 4. Clinician 4 scored significantly higher than Clinician 1 on cultural understanding and effect size indicated a moderate difference. However, the clinicians did not differ significantly on parents' report of overall satisfaction, satisfaction with study help, the study's ability to meet needs, intention to follow recommendations, or quality of screening and evaluation quality. Clinician 1 averaged 3.04/4 (i.e., "Yes, I think so") on the question in the cultural understanding factor that asked parents how well the clinician understood their cultural background and values. Therefore, this significant result may reflect parents feeling very heard and understood by Clinician 4 rather than not being heard and understood by Clinician 1.

When parents were asked why they did not ask questions that they had, over half of the responders indicated that they were unprepared, overwhelmed, or in shock. A few also noted that they "forgot," or developed questions after the evaluation. These responses further supported overlapping themes (themes present in the responses of more than one question) of the need for written information after providing verbal feedback and for follow up after a diagnostic evaluation. (The larger, multi-site study has since implemented the practice of providing a brief written description of the diagnosis and recommendations immediately after the evaluation.) The parents' answers strongly suggest the advisability of a follow-up phone call or in-person visit during which parents can ask remaining questions. While the written information can be easily provided after the verbal feedback, the follow up after a diagnostic evaluation, most likely in the form of

phone calls, may be more difficult for clinicians to provide due to limited resources. If clinicians are able to make follow up phone calls, there is also the question of when the phone calls should be made (e.g., one month or two months after the evaluation).

Parents consistently noted that they appreciated feedback that was given in a clear, direct, concrete, and honest manner. Parents also appreciated feedback that provided psychoeducation on the diagnosis and explained how clinicians arrived at the diagnosis. Many parents also noted the staff's sensitivity, friendliness, care, and patience. Some parents, however, reported that they left the evaluation, which ended in a diagnostic feedback, without understanding if their child was given a diagnosis. This is valuable information and reminders for clinicians, particularly novice clinicians, on how to most effectively develop rapport and deliver a diagnostic feedback.

Consistent with findings by Hackett and colleagues (2009), some parents reported confusion about the structure of the evaluation. While some aspects of the evaluation structure (e.g., length of time, the staff involved, comprehensive developmental and diagnostic evaluation) were shared with parents over the phone during evaluation scheduling, parents were not told that their toddler might be at risk for autism due to the nature of the larger multi-site study. This finding suggests that the structure of the evaluation should be reviewed again in detail during the consent process (i.e., the beginning of the evaluation) to decrease confusion and potentially decrease feelings of being overwhelmed.

Parents also consistently noted dissatisfaction with the wait time for the evaluation report. It is important for clinicians to find ways to shorten the wait time for diagnostic evaluation reports. This is particularly important for toddlers who are

developing quickly and recommendations that were applicable the month of the evaluation may no longer be applicable or helpful a few months later. A strategy to accomplish this may be to shorten the length of reports without sacrificing the quality of the reports. The importance of shorter wait times for reports was further highlighted by responses that indicated how parents were able to use the report and the evaluation to enroll their child in services or to maintain or increase services, which reflects Giannoulis and colleagues' (2004) finding that a written report following an evaluation is one of the ways in parents' needs are met. Also, as noted earlier as a suggestion by parents, providing parents with a brief written description of the diagnosis and recommendations immediately after the evaluation, which they can share with providers, will allow parents to seek services while waiting for the full-length report.

While the qualitative responses provided by the parents have significant clinical implications, it is important to note that some suggestions made by parents did not reflect best clinical practice. For example, a parent suggested that an evaluation take place over several days. At such a young age, an evaluation of a toddler typically takes place over a course of a few hours and clinicians are able to develop a strong understanding of the toddler's functioning. Evaluation over a course of several days most likely would not have significantly added to that understanding.

### **Strengths and Limitations of the Study**

While parents were asked about their *intention* to follow recommendations, follow up information on the recommendations that were actually followed was not gathered. Various barriers (e.g., time, money) may have prevented parents from carrying out their intentions to follow recommendations. However, the information gathered by

the current study on parents' intentions and the reasons why certain parents decided not to follow all or specific recommendations, provides valuable information to clinicians and can help structure the way clinicians provide recommendations (e.g., highlighting the importance of early intervention and not taking the "wait and see" approach).

The current study had limited information on parent characteristics. While such data were requested from participants, it was inconsistently provided. Information on parent characteristics such as education level or family income may have helped to further understand the relationship between parent satisfaction with services provided and parent characteristics. Additionally, date of completion of the post-evaluation questionnaire may have impacted parents' report of satisfaction (Jackson et al., 2001). However, the exact date of completion was not available for the current study. Future research on the impact of time on satisfaction is warranted.

A significant strength of the study is the comparatively large sample size of parents who helped shed light on how they experienced their child's diagnostic evaluation. Another strength is the study's use of both qualitative and quantitative data to provide a more comprehensive understanding of the relationship between different aspects of the diagnostic evaluation and parent satisfaction. While not all-encompassing, the five factors identified through the current study may be used by clinicians as a guideline in providing a more positive experience for their clients and their families. The current study has attempted to voice some of the experiences of parents of children who have received a diagnostic evaluation and may act to further strengthen the relationships between clinicians and the families they serve. The following is a list of recommendations for clinicians developed from the results of the current study:

1. Explain clearly the structure of the evaluation (i.e., purpose, length, clinicians involved).
2. Demonstrate caring in the form of sensitivity, patience, and friendliness (e.g., asking parents if they had trouble finding parking, greeting the child by name, shaking hands with parents, asking parents if they have any questions about procedure before getting started).
3. Provide direct, clear, and honest feedback.
4. Provide a clear diagnosis or indicate that a diagnosis is not given, and in either case, explain why.
5. Check parents' understanding of what they have been told such as the diagnosis and major recommendations.
6. Provide clear recommendations and explain the importance of early intervention.
7. Check in with parents about their reactions during the evaluation process, particularly during the feedback.
8. Provide a brief written summary of the evaluation findings, which may include diagnosis and recommendations.
9. Conduct a follow up phone call to answer questions and/or provide support.
10. Provide a written report in a timely fashion.
11. Transition the families to community-based providers who can provide ongoing care.

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Table 1  
*Demographic Characteristic of Sample by Questionnaire Return*

	Groups		$\chi^2 (t)$	<i>P</i>
	Questionnaire ( <i>n</i> =190)	Non-Questionnaire ( <i>n</i> =72)		
Age, in months				
Mean (SD)	25.34 (4.74)	23.90 (4.24)	(2.26)	.02
Range	16.56-38.47	18.07-39.10		
Sex (Male: Female)	146:44	46:26	3.84	.05
Diagnosis				
Autism Spectrum Disorder	53.2%	38.9%	7.16	.13
Developmental Delay	31.1%	44.4%		
Other Diagnosis	2.1%	1.4%		
No Diagnosis	8.4%	5.6%		
Typical Development	5.3%	9.7%		
Ethnicity*, %			13.44	.009
Caucasian	75.8%	55.6%		
Black/African American	6.8%	12.5%		
Asian/Pacific Islander	4.2%	5.6%		
Hispanic/Latino	8.4%	20.8%		
Biracial	0.5%	4.2%		
Other	1.6%	0%		
Native American	0.5%	1.4%		

\*Data available for 186 out of 190 Satisfaction Questionnaire Group participants.

Table 2

*Grouping of Post-Evaluation Satisfaction Questionnaire Questions in Possible Factors*

Possible Factors	Post-Evaluation Satisfaction Questionnaire Questions
Collaboration/Checking In	<p>3. During the evaluation, did you feel like you were being listened to carefully and understood?</p> <p>4. During the evaluation, did the staff try hard enough to make you and your child feel comfortable?</p> <p>5. How would you rate the amount of <u>time</u> that was spent with you and your child during the evaluation?</p>
Diagnosis and Recommendations/ Psychoeducation	<p>6. How would you rate the amount of <u>information</u> provided to you at the end of the evaluation?</p> <p>7. Do you feel that the staff tried to answer all of your questions at the end of the evaluation?</p> <p>8. Did you have questions at the time of the evaluation that you did not ask?</p> <p>9. Was your <u>child's diagnosis</u> explained to you in a clear way?</p>
Report Clarity, Accuracy, and Usefulness	<p>10. Were the recommendations explained to you in a clear way?</p> <p>13. Do you feel that the information in the report was <u>clear</u>?</p> <p>14. Do you feel that the information in the report was <u>correct</u>?</p> <p>15. Do you feel that the information in the report was <u>useful</u>?</p>
Cultural Understanding and Its Importance	<p>18. Do you feel that it is important for the staff evaluating your child to understand your cultural background and values?</p> <p>19. Do you feel that those involved in your child's evaluation in the Early Detection study understood your cultural background and values?</p>

Table 3

*Post-Evaluation Satisfaction Questionnaire Questions Not Grouped into Possible Factors*

Post-Evaluation Satisfaction Questionnaire Questions
17. Do you feel that the staff who evaluated your child were knowledgeable?
23. To what extent do you agree with the diagnosis that was given for your child?
24. If you were to seek help again for <u>one of your children</u> , would you come back to our study?
25. If a <u>friend's child</u> were in need of similar help, would you recommend participating in this study to him or her?
26. Has participating in our study helped you to deal more effectively your child's problems?
28. Do you feel that you and your child were treated with respect?
29. Did the evaluation give an accurate picture of your child's behaviors and skills?

Table 4

*Summary of Exploratory Factor Analysis Results for Satisfaction Questionnaire Questions Using Principal Axis Factoring (n =162)*

Satisfaction Questionnaire Questions	Factor Loadings				
	Collaboration/ Checking in	Feedback Quality	Report Quality	Availability	Cultural Understanding
3. Listened to and understood	<b>0.7382</b>	0.0628	0.0832	0.1669	-0.0967
4. Effort to make participants comfortable	<b>0.9749</b>	-0.0030	-0.0395	-0.1326	0.1830
5. Time spent with participants	0.0080	-0.1319	0.1349	<b>0.8462</b>	0.1242
6. Amount of information provided	0.1010	<b>0.8855</b>	0.0996	-0.1373	0.0927
7. Effort to answer questions	0.4737	0.4578	-0.2520	-0.1099	-0.0940
8. Unasked questions	-0.0937	0.2765	-0.2846	<b>0.7207</b>	-0.1004
9. Clarity of diagnosis	0.1399	<b>0.6239</b>	0.1952	0.0988	-0.0220
10. Clarity of recommendations	0.0241	<b>0.7368</b>	0.1874	0.1200	0.0801
13. Clarity of report	-0.0900	0.2051	<b>0.7380</b>	-0.0025	-0.0285
14. Report information correct	<b>0.4412</b>	-0.1586	0.3785	0.2736	0.0161
15. Report information useful	0.0609	0.1814	<b>0.6742</b>	-0.0665	-0.0835
18. Importance of staff's cultural understanding	-0.0584	0.0600	-0.0887	0.0931	<b>0.7364</b>
19. Staff's cultural understanding	0.2139	0.0844	-0.0237	0.0093	<b>0.7718</b>
% of variance					

- *Note:* Factor loadings over .40 appear in bold.

Table 5  
*Bivariate Correlations Between Key Outcome Questions and Factor Scores*

Key Outcome Questions	Factors				
	Factor 1 Collaboration/ Checking in	Factor 2 Feedback Quality	Factor 3 Report Quality	Factor 4 Availability	Factor 5 Cultural Understanding
16. Intent to follow recommendations ( <i>n</i> =157)	-0.014	0.137	.303**	0.141	-0.011
20. Satisfaction with study help ( <i>n</i> =161)	.315**	.451**	.510**	.398**	.170*
21. Quality of screening and evaluation ( <i>n</i> =162)	.263**	.381**	.420**	.392**	.207**
22. Study met needs ( <i>n</i> =161)	.198*	.399**	.487**	.287**	0.147
27. Overall Satisfaction ( <i>n</i> =159)	.247**	.542**	.453**	.312**	0.11

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

Table 6  
*Bivariate Correlations Between Mullen Domains and Factor Scores*

Mullen Domains	Factors				
	Factor 1 Collaboration/ Checking in	Factor 2 Feedback Quality	Factor 3 Report Quality	Factor 4 Availability	Factor 5 Cultural Understanding
Visual Reception Skills ( <i>n</i> = 158)	-0.106	-0.117	-0.057	0.034	0.081
Expressive Language Skills ( <i>n</i> = 157)	-0.020	-0.077	-0.104	0.039	-0.012
Receptive Language Skills ( <i>n</i> = 157)	-0.045	0.009	0.019	0.099	0.080
Fine Motor Skills ( <i>n</i> = 157)	-0.037	-0.130	-0.049	-0.030	0.076



Table 7  
*Bivariate Correlations Between Vineland Domains and Factor Scores*

Vineland Domains	Factors				
	Factor 1 Collaboration/ Checking in	Factor 2 Feedback Quality	Factor 3 Report Quality	Factor 4 Availability	Factor 5 Cultural Understanding
Communication Skills ( <i>n</i> = 112)	-0.080	-.233*	-.189*	-0.071	0.139
Socialization Skills ( <i>n</i> = 112)	-0.092	-0.135	-.209*	-0.061	0.12
Motor Skills ( <i>n</i> = 112)	-0.126	-.300**	-.249**	-0.004	-0.045
Daily Living Skills ( <i>n</i> = 112)	-0.072	-.224*	-.222*	0.011	.207*

\* Correlation is significant at the 0.05 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

Table 8

*Bivariate Correlations Between CARS Total Score and Factors Scores*

	Factors				
	Factor 1 Collaboration/ Checking in	Factor 2 Feedback Quality	Factor 3 Report Quality	Factor 4 Availability	Factor 5 Cultural Understanding
CARS Total Score ( <i>n</i> = 158)	0.03	0.119	0.003	-0.064	-0.121

Table 9  
*Bivariate Correlations Between PSI Total Scores and Factor Scores*

PSI Score Domains	Factors				
	Factor 1 Collaboration/ Checking In	Factor 2 Feedback Quality	Factor 3 Report Quality	Factor 4 Availability	Factor 5 Cultural Understanding
Parental Distress ( <i>n</i> = 66)	0.134	-0.158	0.02	-0.145	0.068
Parent and Child Dysfunctional Interaction ( <i>n</i> = 66)	0.216	-0.087	-0.018	-0.109	0.213
Difficult Child ( <i>n</i> = 66)	-0.017	-0.024	0.041	-0.071	0.118
Total Stress Score ( <i>n</i> = 66)	0.118	-0.098	0.031	-0.123	0.176

Table 10

*Kruskal-Wallis H Test of Factor Scores by Diagnosis*

Factors	Mean Rank by Diagnosis				Chi-square	<i>p</i>
	ASD ( <i>n</i> = 89)	<i>DD</i> ( <i>n</i> = 51)	No Diagnosis ( <i>n</i> = 11)	Typical Development ( <i>n</i> = 10)		
Factor 1 Collaboration/Checking in	79.93	80.17	90.05	84.80	0.544	0.909
Factor 2 Feedback Quality	83.60	75.97	99.14	63.6	3.927	0.269
Factor 3 Report Quality	82.01	77.01	92.14	80.1	1.047	0.790
Factor 4 Availability	76.18	86.44	97.32	78.2	3.030	0.387
Factor 5 Cultural Understanding	77.03	86.95	97.95	67.3	3.794	0.285

Table 11  
*Kruskal-Wallis H Test of Factor Scores by Clinician*

Factors	Mean Rank by Clinician					Chi-square	<i>p</i>
	Clinician1 ( <i>n</i> = 41)	Clinician2 ( <i>n</i> = 23)	Clinician3 ( <i>n</i> = 12)	Clinician4 ( <i>n</i> = 18)	Clinician5 ( <i>n</i> = 67)		
Factor 1 Collaboration/Checking in	73.96	81.43	74.01	80.04	64.70	5.474	0.242
Factor 2 Feedback Quality	81.43	76.93	88.29	81.17	80.78	0.474	0.976
Factor 3 Report Quality	74.01	80.28	81.71	103.11	79.46	5.052	0.282
Factor 4 Availability	80.04	84.46	74.29	99.22	76.71	3.710	0.447
Factor 5 Cultural Understanding	64.70	92.72	59.04	108.11	83.6	15.427	0.004

Table 12

*Bivariate Correlations Between Mullen Domains and Key Outcome Questions*

Key Outcome Questions	Mullen Domains			
	Visual Reception Skills	Expressive Language Skills	Receptive Language Skills	Fine Motor Skills
16. Intent to follow recommendations	-0.049 ( <i>n</i> =177)	-0.003 ( <i>n</i> =176)	-0.059 ( <i>n</i> =177)	-0.064 ( <i>n</i> =176)
20. Satisfaction with study help	-0.075 ( <i>n</i> =180)	-0.142 ( <i>n</i> =179)	-0.029 ( <i>n</i> =179)	-0.016 ( <i>n</i> =179)
21. Quality of screening and evaluation	0.068 ( <i>n</i> =181)	0.066 ( <i>n</i> =180)	0.138 ( <i>n</i> =180)	0.062 ( <i>n</i> =180)
22. Study met needs	0.013 ( <i>n</i> =180)	0.04 ( <i>n</i> =179)	0.101 ( <i>n</i> =179)	0.034 ( <i>n</i> =179)
27. Overall Satisfaction	-0.089 ( <i>n</i> =180)	-.200** ( <i>n</i> =179)	-0.067 ( <i>n</i> =179)	-0.016 ( <i>n</i> =180)

\*\* Correlation is significant at the 0.01 level (2-tailed).

Table 13

*Bivariate Correlations Between Vineland Domains and Key Outcome Questions*

Key Outcome Questions	Vineland Domains			
	Communication Skills	Socialization Skills	Motor Skills	Daily Living Skills
16. Intent to follow recommendations ( <i>n</i> =130)	-0.079	-0.129	-0.012	-0.147
20. Satisfaction with study help ( <i>n</i> =131)	-0.15	-0.098	-0.15	-0.112
21. Quality of screening and evaluation ( <i>n</i> = 131)	0.01	-0.017	-0.104	-0.049
22. Study met needs ( <i>n</i> = 130)	0.01	-0.062	-0.09	-0.091
27. Overall Satisfaction ( <i>n</i> = 131)	-.233**	-0.153	-.206*	-0.165

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

Table 14

*Bivariate Correlations Between CARS Total Score and Key Outcome Questions*

Key Outcome Questions	CARS Total Score
16. Intent to follow recommendations ( <i>n</i> =179)	-0.049
20. Satisfaction with study help ( <i>n</i> =184)	0.031
21. Quality of screening and evaluation ( <i>n</i> =184)	-0.067
22. Study met needs ( <i>n</i> =182)	0.019
27. Overall Satisfaction ( <i>n</i> =183)	0.133



Table 15

*Bivariate Correlations Between PSI Score Domains and Key Outcome Questions*

Key Outcome Questions	PSI Score Domains			
	Parental Distress	Parent and Child Dysfunctional Interaction	Difficult Child	Total Stress Score
16. Intent to follow recommendations ( <i>n</i> =78)	-0.098	-0.121	-0.107	-0.124
20. Satisfaction with study help ( <i>n</i> =80)	-0.216	-0.06	-0.065	-0.14
21. Quality of screening and evaluation ( <i>n</i> =80)	0.002	0.078	0.193	0.118
22. Study met needs ( <i>n</i> =80)	-0.125	-0.097	-0.037	-0.097
27. Overall Satisfaction ( <i>n</i> =80)	-0.159	0.02	0.018	-0.054

Table 16

*Kruskal-Wallis H Test of Key Outcome Questions by Diagnosis*

Key Outcome Questions	Mean Rank by Diagnosis					Chi-square	<i>p</i>
	ASD	DD	Other Diagnosis	No Diagnosis	Typical Development		
16. Intent to follow recommendations	96.33 ( <i>n</i> = 98)	86.26 ( <i>n</i> = 57)	127.50 ( <i>n</i> = 2)	68.13 ( <i>n</i> = 15)	101.85 ( <i>n</i> = 10)	7.631	0.106
20. Satisfaction with study help	96.42 ( <i>n</i> = 99)	86.79 ( <i>n</i> = 58)	91.00 ( <i>n</i> = 4)	113.00 ( <i>n</i> = 16)	82.65 ( <i>n</i> = 10)	4.751	0.314
21. Quality of screening and evaluation	92.89 ( <i>n</i> = 99)	86.94 ( <i>n</i> = 59)	116.13 ( <i>n</i> = 4)	116.13 ( <i>n</i> = 16)	111.75 ( <i>n</i> = 10)	6.875	0.143
22. Study met needs for evaluation and recommendations	97.82 ( <i>n</i> = 99)	78.71 ( <i>n</i> = 58)	118.00 ( <i>n</i> = 3)	119.75 ( <i>n</i> = 16)	87.20 ( <i>n</i> = 10)	11.760	0.019
27. Overall satisfaction	99.47 ( <i>n</i> = 99)	86.27 ( <i>n</i> = 58)	90.75 ( <i>n</i> = 4)	107.53 ( <i>n</i> = 16)	64.35 ( <i>n</i> = 10)	8.134	0.087

Table 17

*Kruskal-Wallis H Test of Key Outcome Questions by Clinician*

Key Outcome Questions	Mean Rank by Clinician					Chi-square	<i>p</i>
	Clinician1	Clinician2	Clinician3	Clinician4	Clinician5		
16. Intent to follow recommendations	88.35 ( <i>n</i> = 50)	83.36 ( <i>n</i> = 25)	97.64 ( <i>n</i> = 14)	102.76 ( <i>n</i> = 19)	91.1 ( <i>n</i> = 73)	2.479	0.648
20. Satisfaction with study help	89.28 ( <i>n</i> = 51)	98.04 ( <i>n</i> = 24)	87.96 ( <i>n</i> = 14)	107.87 ( <i>n</i> = 23)	91.51 ( <i>n</i> = 74)	3.081	0.544
21. Quality of screening and evaluation	92.30 ( <i>n</i> = 51)	93.81 ( <i>n</i> = 24)	84.75 ( <i>n</i> = 14)	114.8 ( <i>n</i> = 23)	90.56 ( <i>n</i> = 75)	5.300	0.258
22. Study met needs for evaluation and recommendations	87.34 ( <i>n</i> = 51)	102.48 ( <i>n</i> = 24)	78.07 ( <i>n</i> = 14)	106.48 ( <i>n</i> = 23)	92.45 ( <i>n</i> = 73)	4.753	0.314
27. Overall satisfaction	86.21 ( <i>n</i> = 50)	83.54 ( <i>n</i> = 25)	106.68 ( <i>n</i> = 14)	104.04 ( <i>n</i> = 23)	96.02 ( <i>n</i> = 74)	4.781	0.311

Table 18

*Frequency of Themes within Question 8: Did you have questions at the time of the evaluation that you did not ask? Why didn't you ask?*

Theme (n=23; 12%)	Frequency (n)
Clinician Interaction-Positive	
Comfortable*	1
Diagnostic Feedback- Negative	
Dissatisfaction with Feedback Delivery*	2
Need for More Information- Negative	
Need for more information/Psychoeducation*	1
Need for Follow Up After Evaluation*	1
Evaluation Structure- Negative	
Confusion about structure of evaluation*	1
Unprepared/Overwhelmed/Shock/Information Overload*	12
Emotionality	2
Forgot	3
Developed questions after evaluation	3
Lack of Time/Desire for more time with clinician*	1
Other sources of Information	2
Other (misc.)	1

\*Themes overlapping across questions

Table 19

*Frequency of Themes within Question 11: What specifically did you like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain.*

Theme (n=130; 68%)	Frequency (n)
Information Delivery Manner- Positive	
Direct/Clear/Concrete/Honesty*	42
Detailed/Thoroughness*	10
Clinician Interaction- Positive	
Care/Sensitivity/Friendliness*	27
Parent/Clinician Expression of Hope/Optimism	5
Collaboration/Checking in*	6
Appreciated Availability of Clinicians	9
Highlighting of Child's Strengths	2
Feedback- Positive	
Appreciation of Explanation of how diagnosis was arrived at/Psychoeducation*	22
Professionalism/Expertise*	12
Confidence in Validity of Diagnosis*	1
Appreciated Having Diagnosis*	3
Appreciated Not Having a Diagnosis	7
Recommendations/Services- Positive	
Helpful Recommendations/Referral to Services*	15
Use of report/evaluation to inform providers of child's needs*	2
Appreciation of Report*	3
Validation- Positive	
Validation of concerns*	2
Process led to parent feeling empowered to seek more services*	1
Evaluation Structure- Positive	
Appreciated Structure of Evaluation*	2
Diagnostic Feedback- Negative	
No New Information Learned*	1
Lack of/Unclear diagnosis*	3
Dissatisfaction with Feedback Delivery Indirect*	4
Indirect*	1
Necessary Evaluation	1
Other (misc.)	8

\*Themes overlapping across questions

Table 20

*Frequency of Themes within Question 12: What specifically did you not like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain.*

Theme (n=53; 28%)	Frequency (n)
Feedback- Positive	
Appreciation of Explanation of how diagnosis was arrived at/Psychoeducation*	3
Professionalism/Expertise*	2
Evaluation Structure- Positive	
Appreciated Structure of Evaluation*	1
Diagnostic Feedback- Negative	
No New Information Learned*	1
Lack of/Unclear diagnosis*	9
Dissatisfaction with Feedback Delivery*	6
Use of Jargon	1
Poor Recommendations	1
Lack of Hope	1
Not happy to get a diagnosis (i.e., having a diagnosis for child)	2
Need for More Information- Negative	
Need for More Information/Psychoeducation*	10
Need for written information after feedback*	4
Evaluation Structure- Negative	
Confusion about structure of evaluation*	1
Dissatisfaction with Evaluation Structure*	2
Report- Negative	
Dissatisfaction with Waiting time for diagnosis/report*	6
Discrepancy in verbal feedback and report	1
Access to Services- Negative	
Difficulty receiving rec services/increased services*	2
Unprepared/Overwhelmed/Shock/Information Overload*	5
Lack of Time/Desire for time with clinician*	3
Disagreement with Diagnosis	2
Other (misc.)	3

\*Themes overlapping across questions

Table 21

*Frequency of Themes within Question 16: To what extent do you intend to follow through with this recommendations for your child included in the report? Please explain.*

Theme (n=101; 53%)	Frequency (n)
Clinician Interaction- Positive	
Collaboration/Checking in*	1
Recommendations/Services- Positive	
Enrollment in Birth -to-Three/receiving services*	40
Following through on specific recs	9
Use of Report/Evaluation to get/maintain/increase services*	19
Helpful Recommendations/Referral to Services*	3
Validation- Positive	
Process led to parent feeling empowered to seek more services*	1
Desire to seek as much help as possible/Following through on all recs*	16
Report- Negative	
Dissatisfaction with Waiting time for report*	3
Dissatisfaction with Written Report*	1
Recommendations- Negative	
Disagreement with/uncertainty about the need of certain recs	4
Recs irrelevant due to developmental changes*	2
Decision to hold off seeking any services	2
Decision to hold off or not follow through on a specific rec	4
Access to Services- Negative	
Concerned about receiving services	2
Money and Time Barriers to services	4
Difficulty receiving rec services/increased services*	3
Change in dx*	2
Other (misc.)	2

\*Themes overlapping across questions

Table 22

*Frequency of Themes within Question 25: If a friend's child were in need of similar help, would you recommend participating in this study to him or her?*

Theme (n=60; 32%)	Frequency (n)
Information Delivery Manner- Positive	
Detailed/Thoroughness*	3
Clinician Interaction- Positive	
Care/Sensitivity/Friendliness*	4
Helpful/Positive Experience*	8
Collaboration/Checking in*	1
Comfortable*	1
Feedback- Positive	
Professionalism/Expertise*	5
Confidence in Validity of Diagnosis*	5
Second Opinion	2
Recommendations/Services- Positive	
Helpful Recommendations/Referral to Services*	2
Appreciation of Report*	2
Use of report/evaluation to inform providers of child's needs*	1
Use of Report/Evaluation to maintain/increase services	3
Validation- Positive	
Validation of concerns*	1
Process led to parent feeling empowered to seek more services*	3
Evaluation Structure- Positive	
No Cost*	2
Appreciated Structure of Evaluation*	2
Already Recommended	8
Importance of early detection/diagnosis	6

\*Themes overlapping across questions



Table 22 (Continued)

*Frequency of Themes within Question 25: If a friend's child were in need of similar help, would you recommend participating in this study to him or her?*

Theme (n=60; 32%)	Frequency (n)
Evaluation Structure- Negative	
Dissatisfaction with Evaluation Structure*	1
Need for More Information- Negative	
Need for More Information/Psychoeducation*	1
Need for written information after feedback*	1
Report- Negative	
Dissatisfaction with Waiting time for report*	1
Clinician Interaction- Negative	
Dissatisfaction with Staff	2
Lack of collaboration	1
Stressful	1
Other (misc.)	12

\*Themes overlapping across questions

Table 23

*Frequency of Themes within Question 30: We would welcome any additional comments you might want to make. What specifically did you like or not like about your experiences in the Early Detection Study?*

Theme (n=100; 53%)	Frequency (n)
Information Delivery Manner- Positive	
Direct/Clear/Concrete/Honesty*	1
Detailed/Thoroughness*	7
Clinician Interaction- Positive	
Care/Sensitivity/Friendliness*	17
Helpful/Positive Experience*	22
Collaboration/Checking in*	5
Feedback- Positive	
Professionalism/Expertise*	12
Confidence in Validity of Diagnosis*	5
Appreciated Having Diagnosis*	3
Appreciation for Specific Staff	4
Differential Diagnosis	2
Recommendations/Services- Positive	
Enrollment in Birth -to-Three/receiving services*	4
Helpful Recommendations/Referral to Services*	5
Appreciation of Report*	2
Use of report/evaluation to inform providers of child's needs*	6
Use of Report/Evaluation to get/maintain/increase services*	1
Validation- Positive	
Validation of concerns*	1
Process led to parent feeling empowered to seek more services*	2
Evaluation Structure- Positive	
No Cost*	1
Appreciation of short wait time for appointment	2
Appreciated structure of evaluation*	3
Importance of diagnosis/early detection*	4
Looking forward to follow up visit	5
Thank you	27

\*Themes overlapping across questions

Table 23 (Continued)

*Frequency of Themes within Question 30: We would welcome any additional comments you might want to make. What specifically did you like or not like about your experiences in the Early Detection Study?*

Theme (n=100; 53%)	Frequency (n)
Diagnostic Feedback- Negative	
Dissatisfaction with feedback delivery	2
Need for More Information- Negative	
Need for more information/Psychoeducation*	10
Need for written information after feedback*	3
Need for Follow Up after Evaluation*	3
Need for more recommendations/support	7
Evaluation Structure- Negative	
Confusion about structure of evaluation*	1
Dissatisfaction with evaluation structure*	16
Dissatisfaction with Testing Environment	7
Did Not Capture Skills	2
Need to Account for other factors	1
Report- Negative	
Dissatisfaction with Waiting time for report*	11
Dissatisfaction with Written Report*	4
Recommendations- Negative	
Recs irrelevant due to developmental changes*	1
Access to Services- Negative	
Difficulty receiving rec services/increased services*	2
Change in dx*	4
Cultural Insensitivity	2
Other (misc.)	4

\*Themes overlapping across questions

## Appendix A

Date: \_\_\_\_\_

### Post-Evaluation Satisfaction Questionnaire

**Thank you for participating in the Early Detection Study. We would like to learn more about your experiences in this study as this will help us to improve our services. We are interested in your honest opinions, whether they are positive or negative. *Please circle an answer for every question.* We also welcome your comments and suggestions. Remember that the information you provide is confidential, and the clinicians who completed your child's evaluation will not have access to this information. We really appreciate your help.**

Relationship of person completing this form to the child evaluated:

*Mother*                      *Father*                      *Other* \_\_\_\_\_

Were you the person interviewed on the phone about your checklist answers?

*Yes*                      *No*

Were you present during the evaluation at the University of Connecticut?

*Yes*                      *No*

Have you read the entire report?

*Yes*                      *No*

**If you answered *No* to any of the above questions, please fill out what you can for the remainder of this questionnaire and have the appropriate person fill out the rest.**

1. Did you like filling out a form in your doctor's office or with your early intervention provider to check if your child's development (walking, talking, etc.) is going as it should for his/her age?  
*No, definitely not*      *No, I don't think so*      *Yes, I think so*      *Yes, Definitely*
2. How clear were the questions you were asked on the phone when the staff person called to go over the forms with you?  
*Confusing*                      *Not very clear*                      *Somewhat clear*                      *Very Clear*
3. During the evaluation, did you feel like you were being listened to carefully and understood?  
*No, definitely not*      *No, I don't think so*      *Yes, I think so*      *Yes, definitely*
4. During the evaluation, did the staff try hard enough to make you and your child feel comfortable?  
*No, definitely not*      *No, I don't think so*      *Yes, I think so*      *Yes, definitely*

5. How would you rate the amount of time that was spent with you and your child during the evaluation?  
*Not enough at all      Not quite enough      Enough      Too much*
6. How would you rate the amount of information provided to you at the end of the evaluation?  
*Not enough at all      No, I don't think so      Yes, I think so      Yes, definitely*
7. Do you feel that the staff tried to answer all of your questions at the end of the evaluation?  
*No, definitely not      Not quite enough      Enough      Too much*
8. Did you have questions at the time of the evaluation that you did not ask?  
*No      Yes*
- Why didn't you ask? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
9. Was your child's diagnosis explained to you in a clear way?  
*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*
10. Were the recommendations explained to you in a clear way?  
*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*
11. What specifically did you like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
12. What specifically did you not like about the way you were told of your child's diagnosis at the end of the evaluation? Please explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
13. Do you feel that the information in the report was clear?  
*Confusing      Not very clear      Somewhat clear      Very clear*
14. Do you feel that the information in the report was correct?  
*No, definitely not      No, not all of it      Most of it was      All of it was  
 correct      was correct      correct      correct*
15. Do you feel that the information in the report was useful?  
*Not useful at all      Not very useful      Somewhat useful      Very useful*

16. To what extent do you intend to follow through with this recommendations for your child included in the report?
- |   |                                       |                                       |                                      |
|---|---------------------------------------|---------------------------------------|--------------------------------------|
| <i>Do not plan to follow through on any</i> | <i>Plan to follow through on some</i> | <i>Plan to follow through on most</i> | <i>Plan to follow through on all</i> |
|---|---------------------------------------|---------------------------------------|--------------------------------------|

Please explain. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

17. Do you feel that the staff who evaluated your child were knowledgeable?
- |                   |                 |                 |                  |
|-------------------|-----------------|-----------------|------------------|
| <i>Not at all</i> | <i>A little</i> | <i>Somewhat</i> | <i>Very much</i> |
|-------------------|-----------------|-----------------|------------------|
18. Do you feel that it is important for the staff evaluating your child to understand your cultural background and values?
- |                          |                             |                        |                        |
|--------------------------|-----------------------------|------------------------|------------------------|
| <i>No definitely not</i> | <i>No, I don't think so</i> | <i>Yes, I think so</i> | <i>Yes, definitely</i> |
|--------------------------|-----------------------------|------------------------|------------------------|
19. Do you feel that those involved in your child's evaluation in the Early Detection study understood your cultural background and values?
- |                          |                             |                        |                        |
|--------------------------|-----------------------------|------------------------|------------------------|
| <i>No definitely not</i> | <i>No, I don't think so</i> | <i>Yes, I think so</i> | <i>Yes, definitely</i> |
|--------------------------|-----------------------------|------------------------|------------------------|

**Please think back over the entire screening and evaluation process...**

- **From filling out the forms in the doctor's office or with your early intervention provider**
- **To the telephone call you received at home from one of our researchers to go over the forms**
- **To the evaluation of your child by the staff**
- **To the report and recommendations you have received**

**Please circle an answer for every question.**

20. How satisfied are you with the amount of help you and your child have received from us through your participation in the Early Detection study?
- |                           |                            |                         |                       |
|---------------------------|----------------------------|-------------------------|-----------------------|
| <i>Quite dissatisfied</i> | <i>Mildly dissatisfied</i> | <i>Mostly satisfied</i> | <i>Very satisfied</i> |
|---------------------------|----------------------------|-------------------------|-----------------------|
21. How would you rate the quality of the screening and evaluation you have received as part of this study?
- |             |             |             |                  |
|-------------|-------------|-------------|------------------|
| <i>Poor</i> | <i>Fair</i> | <i>Good</i> | <i>Excellent</i> |
|-------------|-------------|-------------|------------------|
22. To what extent has our study met your and your child's needs for evaluation and recommendations?
- |                                       |   |                                       |                                      |
|---------------------------------------|---|---------------------------------------|--------------------------------------|
| <i>None of my needs have been met</i> | <i>Only a few of my needs have been met</i> | <i>Most of my needs have been met</i> | <i>All of my needs have been met</i> |
|---------------------------------------|---|---------------------------------------|--------------------------------------|
23. To what extent do you agree with the diagnosis that was given for your child?
- |                          |                 |              |                       |
|--------------------------|-----------------|--------------|-----------------------|
| <i>Strongly disagree</i> | <i>Disagree</i> | <i>Agree</i> | <i>Strongly agree</i> |
|--------------------------|-----------------|--------------|-----------------------|

24. If you were to seek help again for one of your children, would you come back to our study?

*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*

25. If a friend's child were in need of similar help, would you recommend participating in this study to him or her?

*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*

Please explain. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

26. Has participating in our study helped you to deal more effectively your child's problems?

*No, it seemed to      No, it didn't      Yes, it helped      Yes, it helped  
make things worse      really help      a great deal*

27. In an overall sense, how satisfied are you with the service you and your child have received through your participation in this study?

*Quite dissatisfied      Mildly dissatisfied      Mostly satisfied      Very satisfied*

28. Do you feel that you and your child were treated with respect?

*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*

If you feel you were not treated with respect, please help us to understand why you feel this way. What could we have done differently?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

29. Did the evaluation give an accurate picture of your child's behaviors and skills?

*No, definitely not      No, I don't think so      Yes, I think so      Yes, definitely*

30. We would welcome any additional comments you might want to make. What specifically did you like or not like about your experiences in the Early Detection Study?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_