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BRIDGING EARLY DIAGNOSIS AND INTERVENTION: ENHANCING  
RECOMMENDATIONS AND FACILITATING ACCESS TO EARLY INTERVENTION

by

BIANCA A. BROOKS

Under the Direction of Lisa Armistead & Diana L. Robins

ABSTRACT

Early detection facilitates early intervention (EI), which optimizes outcomes in autism spectrum disorders (ASD) and other developmental delays. However, facilitating the transition between receiving a diagnosis of ASD and other delays and accessing care has received little attention. When families first receive a diagnosis, they often experience grief, confusion, heightened stress, and difficulty accessing appropriate and affordable services, further increasing the disadvantages and disparity experienced by underrepresented populations. This feasibility study will focus on ways providers can better facilitate access to EI services for families following an initial diagnosis. Forty-nine diverse parents with children (16-32 m) diagnosed with ASD and other developmental delays were recruited from a larger screening study. During

feedback, all families were provided with a provider list (treatment as usual) of therapeutic services. Half of the families were randomly assigned to receive a DVD/ Youtube Link (treatment plus video) that describes the diagnosis as well as common therapeutic options for children with developmental delays. Parents were asked questions regarding their use of materials (video vs. provider list) following feedback and their ability to access EI services. Study retention, demand and satisfaction were assessed to evaluate the use of video recommendations and the provider list. Demand, satisfaction and completion rates were assessed to evaluate the use of video recommendations as a feasible intervention following diagnosis. Additionally, differences in post measures of parental sense of competence, parental stress and access to the EI system were used to assess the potential efficacy of the intervention. Seventy-five percent of parents (across both treatment groups) used the provider list, whereas only 29% of parents who were randomized to the video condition reported that they viewed the video recommendations. Qualitative reactions from parents in the current investigation suggest a need for interdisciplinary care and coordination between mothers. Challenges to delivering a brief intervention following diagnosis are explored.

INDEX WORDS: Autism Spectrum Disorders, Access to early intervention services,

Assessment feedback, Brief video-intervention, Parental stress, Parental sense of competence

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RECOMMENDATIONS AND FACILITATING ACCESS TO EARLY INTERVENTION

by

BIANCA A. BROOKS

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2016

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Bianca A. Brooks  
2016

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RECOMMENDATIONS AND FACILITATING ACCESS TO EARLY INTERVENTION

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## 1 INTRODUCTION

Research continues to emphasize the importance of early detection and early intervention (EI) in optimizing outcomes in Autism Spectrum Disorders (ASD; Warren et al., 2011; Zwaigenbaum, et al., 2015). EI is typically defined as treatment that occurs between birth and 3 years of age with the goal of preventing the development of additional deficits and treating existing deficits (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Boyd, Odom, Humphreys & Sam, 2010; C. Ramey & Ramey, 1998). Children who receive EI prior to their third birthday generally experience greater gains in skill development than those who receive intervention after the age of three (Bradshaw, Steiner, Gengoux, & Koegel, 2015; Landa & Kalb, 2012; McGee, Morrier, & Daly, 1999; Woods & Wetherby 2003). Given the importance of EI in childhood development, federal legislation such as the Individuals with Disabilities Education Act (IDEA) has been enacted to ensure that all infants and toddlers with diagnosed developmental disabilities qualify for EI (C. Ramey & Ramey, 1998).

EI research primarily focuses on the effectiveness of EI treatments; facilitating the transition between receiving a diagnosis of ASD and accessing care has received little attention. When families first receive a diagnosis, they experience a diverse range of emotional reactions. Some parents may be relieved upon confirming a diagnosis (Midence & O'Neil, 1999), whereas others may experience grief, confusion, and heightened stress (Davis & Carter, 2008; Osborne & Reed, 2008). Based on survey findings (Gaspar de Alba & Bodfish, 2011; Mansell & Morris, 2004), when first receiving a diagnosis parents wished to learn more about their child's core ASD symptoms, therapeutic options, prognosis and where to find further information on diagnosis. Additionally, oral feedback sessions after assessment that offer a supportive environment and allow parents a chance to ask questions resulted in higher ratings of parent

satisfaction (Brogan & Knussen, 2003). Parents also identified receiving comprehensive written reports with appropriate recommendations as valuable aspects of the assessment process (Farmer & Brazeal, 1998). Despite what is known from evaluation satisfaction measures, it is often difficult for providers to offer adequate support and education for distressed parents within the confines of a single feedback session. This further increases the disadvantages and disparity experienced by families from underrepresented populations who may struggle to advocate for their child. Therefore, the interim period between diagnosis and intervention may be an ideal time to motivate and begin to prepare parents for caring for a child with ASD.

### *1.1 ASD and Challenges to Access to EI*

Generally, children with ASD are likely to have unmet therapeutic needs (Chiri & Warfield, 2012; Montes, Halterman, & Magyar, 2009), and families often experience difficulty accessing services (Kohler, 1999; Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007). Before exploring why children with ASD tend to have unmet therapeutic needs, it is necessary to understand the context of early detection and general EI procedures. Although there is variation between U.S. states, ASD is often first detected by screening measures and parental concerns during pediatrician visits (Bailey et al., 2004). In the more recent past, identification of ASD in the first two years of life has been facilitated by validated screening measures such as the Modified Checklist for Autism in Toddlers, Revised with Follow up (M-CHAT-R/F; Robins et al., 2014). Children flagged by the M-CHAT-R/F ideally receive a formal diagnostic assessment from a licensed provider, inclusive of oral feedback and a written report with appropriate recommendations. From this point, the onus is placed on parents to navigate EI services and manage their emotional experiences related to their child receiving a diagnosis. The current

investigation focuses on the relationship between parental stress, parental self-efficacy, and possible systemic barriers to accessing EI services.

### *1.2 Systemic Challenges to Accessing EI*

Research has highlighted the delay between first parental concerns and receiving a formal diagnosis of ASD (Siklos & Kerns, 2007; Wiggins, Baio, & Rice, 2006; Zuckerman, Lindly & Sinche, 2015). This has propelled research and clinical initiatives to emphasize early diagnosis of ASD in toddlers. Intervention programs are then presented with the additional challenge of providing services to very young children (Boyd et al., 2010). Bailey and colleagues (2004) interviewed a sample of parents who had recently entered an EI program. Parents who were interviewed retrospectively reported experiencing more difficulty finding services between diagnosis and onset of EI services compared to the time between initial parent concerns and diagnosis. Additionally, parents of children with ASD are more likely to experience difficulty accessing services in comparison to parents of children with other developmental delays (Krauss, Gulley, Sciegaj, & Wells, 2003). In a retrospective study of parents' reactions to the diagnostic process, a majority of parents endorsed that they were dissatisfied with the diagnostic experience; particularly due to difficulty obtaining services for their children (Siklos & Kerns, 2007). Parents have also reported high levels of stress related to managing the costs and effort necessary to access appropriate services (Mackintosh, Goin-Kochel, & Myers, 2012).

Delays in entering EI services have been attributed to numerous causes including how parents perceive the diagnosis (Abrams & Goodman, 1998) and coordination of intervention services (Bailey et al., 2004). Although there are typically government agencies (e.g., Part C of Individuals with Disabilities Education Act, Medicaid) that offer services to young children with developmental delays (Boyd et al., 2010; Roberts, Innocenti, & Goetze, 1999), these systems are

often overtaxed and are unable to provide every child with appropriate care due to budget constraints and a high volume of consumers (Ruble, Heflinger, Renfrew & Saunders, 2005; Woods & Wetherby, 2003). In a national longitudinal study of EI services (Hebbeler et al., 2007), according to parent report the median weekly hours of EI services was 1.5 hours, a number far below the recommended 25 hours per week (National Research Council, 2001; Myers & Johnson, 2007). Even though some families are able to rely on private health insurance or Medicaid to pay for EI services, it is often difficult to locate available providers within network who have openings. In certain states, select families may be fortunate enough to receive a waiver from the government to help pay for behavioral treatments (Boyd et al., 2010). Other families have the additional challenge of having to pay out-of-pocket for expensive intervention services.

The process of early diagnosis may contribute to disparities in EI for families from racial minority and/or low socioeconomic (SES) status backgrounds. On average, African American children are diagnosed later than Caucasian children (Mandell, Listerud, Levy & Pinto-Martin, 2002). These families may have additional barriers to overcome in order to access ASD-specific EI for their children. Mandell and Novak (2005) suggest that culture intertwined with socioeconomic status may influence a family's ability to access specialty care for their child with ASD. Lack of familiarity with the majority culture and fear of stigma have been cited as factors preventing racial minorities from accessing services (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). Additionally, research indicates that racial minorities, lower income families and parents with lower levels of education tend to report having more difficulty entering EI services than more affluent or educated families (Bailey et al., 2004). Also, research suggests that parents from racial minority groups and lower SES are often less likely to participate in support groups for ASD (Mackintosh, Myers & Goin-Kochel, 2005; Mandell & Salzer, 2007).

### *1.3 Parenting Stress and Children with Developmental Delays*

Parents often play a primary role as a co-therapist and an advocate for children with ASD (Boyd et al., 2010). In a recent review of EI services and recommendations for children with ASD, Zwaigenbaum and colleagues (2015) found that EI programs for children under the age of three are more likely to intensively involve parents. Furthermore, they highlighted that appropriate parent supervision, training and monitoring should be incorporated within the intervention. Included within their recommendations, they also suggested that interventions should help caregivers locate needed support (Zwaigenbaum et al., 2015). This coincides with the integration of family-centered principles, or the idea of respecting a family's preferences and their role within ASD assessment and intervention (Woods & Wetherby, 2003). Although research has continuously cited elevated parental stress levels in parents of children with ASD (Davis & Carter, 2008; Estes et al., 2009; Hayes & Watson 2013; Pisula, 2007), little is known regarding the impact of parenting stress on intervention access.

When considering parenting stress in individuals from underrepresented populations, various trends have emerged. Generally, racial minorities endorse higher levels of parenting stress in comparison to Caucasian parents who have a child with a disability. For example, DeLambo, Chung and Huang (2011) found that in comparison to non-Asian parents, Asian American parents had significantly higher levels of parenting stress related to behaviors of their children with developmental delays. Similarly, Phetrasuwan and Miles (2009) observed higher ratings of parental stress in mothers of young children with ASD with less education and lower SES, which may have been attributed to limited social and financial resources. Conversely, Carr and Lord (2013) investigated perceived negative impact of having an adolescent with ASD on families. They found that African American mothers with lower levels of education endorsed



significantly lower levels of perceived negative impact than African American mothers with higher levels of education, and Caucasian mothers of all education levels (Carr & Lord, 2013). It is possible that more education increases parental awareness of challenges and issues associated with raising a child with ASD. These differing results regarding parental stress may also be related to the age of their child during the assessment as well as the interplay of education and culture in the perceived impact of having a child with a developmental disability. This information taken together suggests the importance of exploring how parent-specific factors relate to challenges in finding services following diagnosis.

#### *1.4 Role of Parental Self-Efficacy in Parenting Behaviors*

In order to prepare parents whose children were recently diagnosed with ASD, it seems necessary to mitigate their feelings of grief and increase their feelings of competence in their abilities to adequately care for their child. The construct of parental self-efficacy has frequently been researched as an important construct related to child and parent adjustment and psychological functioning (Jones & Prinz, 2005). According to Teti and colleagues (1996), parental self-efficacy is defined as a parent's judgment of their functioning and ability to handle challenges related to a caregiving role.

Parental self-efficacy has been investigated as a mechanism for changing parenting behaviors (Jones & Prinz, 2005). For example, Miller-Heyl and colleagues (1988) designed an EI program for children between the ages of two and five to prevent later substance abuse. A core tenet of their program focuses on building parental self-efficacy, which was shown to influence greater use of effective child-rearing practices (Miller-Heyl, MacPhee, & Fritz 1988). They hypothesized that parents with higher self-efficacy may be more likely to persevere despite isolated failures and maintain hope for eventual success. Similarly, Spoth and colleagues (1995)

found that maternal self-efficacy predicted parenting skills gains in a family training program to reduce risk for early substance abuse. Research has also indicated that building parental self-efficacy may be more influential in changing parenting practices, as opposed to solely providing social support (Izzo, Weiss, Shanahan & Rodriguez-Brown, 2000). Parental self-efficacy has also been explored across racial groups. Economic pressures and family hardships have been shown to decrease feelings of parental self-efficacy in both African American and Caucasian parents (Elder, Eccles, Ardel, & Lord, 1995).

Greater parent empowerment has been related to fewer parent mental health problems (Weiss, Cappadocia, MacMullin, Viecili & Lunsy, 2012). Parent empowerment was defined as a parent's sense of self-efficacy in relation to their child's disability, knowledge of their child's disability and their ability to act to obtain goals (Weiss et al., 2012). Parents of children with ASD who felt they were active participants in their child's development had higher levels of parental self-efficacy, whereas parents who felt guilty regarding their child's disorder tended to endorse lower levels of parental efficacy (Kuhn & Carter, 2006). Hastings and Brown (2002) identified parental self-efficacy as a mediator in the relationship between childhood behavior problems and maternal depression and anxiety. Mothers of children with ASD with higher levels of parental self-efficacy had better mental health outcomes despite the severity of disruptive child behaviors. Due to the positive influence of parental empowerment and self-efficacy it is important to create interventions that promote these qualities in parents.

### *1.5 Current Intervention Literature: Supporting Parents Following ASD Diagnosis*

Given the high levels of parental stress within the context of raising a child with ASD (Davis & Carter, 2008; Estes et al., 2009) several interventions have begun to target parenting stress and parenting self-efficacy as a treatment outcome. Research has highlighted the benefit

and feasibility of parents implementing autism-specific training programs in their homes. Hastings and Smynes (2002) explored parental self-efficacy as an outcome measure in a sample of mothers serving as one of their child's therapists on applied behavior analysis (ABA) program teams. Due to the high financial costs and limited insurance coverage, many families with children on the spectrum are unable to afford ABA therapy; parents acting as therapists may make the intervention more accessible by reducing the cost. When using parental self-efficacy as an outcome, Hastings and Smynes found that greater rates of parental self-efficacy as a parent therapist were related to greater support from an ABA therapy team, lower levels of maternal stress, and children with less severe symptoms of autism. These findings suggest the interplay of program and therapy factors that influence a parent's sense of efficacy. Additionally, this research emphasizes the important role of qualified professionals as a support system for parent-led interventions.

Given that parental stress may negatively influence a parent's ability to actively participate in EI services (Osborne, McHugh, Saunders & Reed, 2008), research has begun to target parental stress after receiving an ASD diagnosis. Feinberg and colleagues (2014) investigated problem-solving education in a randomized clinical control trial to target maternal stress and depression following a child's diagnosis of ASD prior to the age of six. Problem-solving education is a manualized cognitive behavioral treatment that is designed to treat depression. During each session, parents worked with a trained interventionist to identify a single problem and engage in brainstorming possible solutions and action planning. The objective of this six-session intervention was to address parental mental health to better prepare parents to navigate autism EI services. Receiving problem-solving education resulted in a reduction of clinically significant depressive symptoms and parenting stress (Feinberg et al., 2014). Other

therapy modalities such as Acceptance Commitment Therapy (ACT) have shown promising results for the reduction psychological distress of parents of children with ASD (Blackledge & Hayes, 2006). Additionally, parent-training programs have been shown to reduce levels of stress in raising a child with ASD (McConachie & Diggle, 2005; Smith, Buch, & Gamby, 2000). Dababnah and Parish (2015) adapted an empirically based program, *The Incredible Years*, as a psycho-educational group training for parents with preschool aged children with ASD. Their small pilot feasibility study identified the program as a potential way to increase parental support surrounding raising a child with ASD (Dababnah & Parish, 2015). These findings taken together emphasize the importance of targeting parental stress following a diagnosis of ASD to improve a parent's ability to participate in their child's treatment.

Certain U.S. states have developed programs that attempt to address access issues by using parent-to-parent support groups (Santelli, Turnbull, Marquis, & Lerner, 1997). The Pediatric Practice Enhancement Project (PPEP; Silow-Carroll, 2009), based in Rhode Island, serves the families of several pediatric primary and specialty care practices. This program utilized parent consultants who have already experienced having a young child with developmental disabilities. A parent consultant was placed at each practice in order to assist physicians and their staff in identifying resources and support services for families in need. These parent consultants also provided follow-through support by checking with families to confirm they have made appointments with local providers. Families served by the PPEP program endorsed greater satisfaction with their healthcare providers, greater sense of empowerment, and greater knowledge of local supports (Burke et al., 2007). Although a program similar to PPEP may not be feasible in other states, the positive results of providing families with adequate support following a diagnosis cannot be ignored. It may be advantageous for providers

to encourage families who have recently received a diagnosis to first contact local organizations that have parents who already have experience navigating the EI system (e.g., Parent to Parent of Georgia).

Estes and colleagues (2014), explored the implementation of a parent-delivered Early Start Denver Model (P-ESDM), an evidenced-based treatment approach for children aged 12-24 months with ASD. P-ESDM includes 12, one-hour weekly intervention sessions. In comparison to a community sample, parents who participated in P-ESDM reported lower parenting stress. Parental sense of competence was also explored as an outcome upon the completion of treatment. No significant differences were observed in parental sense of competence following the implementation of the intervention. This suggests the potential for implementing a parent training intervention immediately following diagnosis as a means to reduce parental stress (Estes et al., 2014).

### *1.6 Using Technology as a Modality for Intervention Post-Diagnosis*

To date, no studies have investigated what immediate resources parents seek following a diagnosis. Furthermore, research has not identified brief cost-effective interventions that facilitate the transition to EI services following an initial diagnosis. Therefore, it is important to explore ways to improve access to EI for children with ASD who have been identified at an early age. As a result of the continued integration of technology within the mental health and medical fields, research has explored video and telehealth as a treatment modality. More recent studies have explored the use of telehealth (live streaming and self-guided website) to deliver parent-led interventions (Vismara, McCormick, Young, Nadhan & Monlux, 2013; Wainer & Ingersoll, 2014). Pickard, Wainer, Bailey and Ingersol (2016) explored the implementation of ImPACT Online, an internet based adaptation of an evidenced based parent training intervention for ASD.

Parents were assigned to participate in a self-directed online program or a therapist assisted online program. Parents in both groups perceived the intervention as acceptable, feasible and beneficial to parents. However, several parents underscored the utility of having support from a therapist in learning the intervention (Pickard et al., 2016). This suggests the importance of exploring feasibility when adapting the dissemination of evidenced based interventions for ASD.

Other studies have used video to implement interventions and provide psycho-education in other clinical populations (Krouse, 2001; Resnick, Acierno, Armstadter & Self-Brown, 2007). Sanders and colleagues (2000) provided parents with a 12-episode television series on disruptive childhood behaviors in children ages two to eight. Each episode lasted approximately 30 minutes and focused on a variety of family issues (e.g., school involvement, parenting strategies, teaching children self-help skills). When compared with a waitlist control group, parents who received the video intervention reported significantly higher levels of parental competence (based on the Parental Sense of Competence Scale; PSOC) and decreased parent ratings of childhood disruptive behaviors. Parents also endorsed that they enjoyed the program and that they were willing to use the program (Sanders, Montgomery, & Brechman-Toussaint, 2000). Consistent with these findings, psycho-educational videos are successful in delivering information and reducing parental stress. Rheingold, Danielson, Davidson, Self-Brown and Resnick (2013) developed a 20-minute video designed to inform parents and their children about the comprehensive medical exam to gather evidence about child sexual abuse. When comparing the video condition to the standard of care, parents found the intervention helpful and endorsed lower anxiety ratings following the medical exam (Rheingold et al., 2013). These results suggest the positive potential of using media as a way to improve parental perspectives of their child's behaviors, their sense of self-efficacy and decrease parental stress.

Conversely, other investigations have shown that video delivery of information may not be equivalent to brief face-to-face intervention. Keen, Couzens, Muspratt and Rodger (2010) compared a two-day parent workshop with ten (one hour, twice weekly) home-based consultations with a facilitator to an interactive instructional DVD with similar content and activity sheets as means to promote social communication, increase parenting competence and reduce parenting stress six months after receiving a diagnosis of ASD. Their findings suggested that the professionally led face-to-face intervention reduced child-related parenting stress and improved parenting self-efficacy in comparison to the DVD intervention. It is important to note that this investigation was a direct comparison between face-to-face intervention and interactive DVD; no control group was included within this design. Additionally, engagement or compliance with using the DVD was lower when compared with the professional led intervention. Therefore, prior to exploring the effectiveness of interactive multimedia interventions, it is important to assess the feasibility of using these materials following diagnosis and explore additional outcomes outside of improving child skill acquisition.

Research also highlights the importance of receiving information regarding the diagnosis at the time of assessment feedback being related to higher ratings of parent satisfaction (Hasnat & Graves, 2000). Since video has been helpful in improving parental sense of competence in other clinical populations, it could be a useful strategy to disseminate psycho-education regarding diagnosis and accessing services for ASD. Video recommendations could minimize the stress parents feel after receiving a diagnosis and serve as a supportive bridge to access EI services. These video recommendations may help families from underrepresented populations to advocate for their child's development following diagnosis, who may not understand the necessary steps to access EI services. Finally, since the interim period between diagnosis and

treatment onset has not been fully explored, it will be important to gather information regarding specifically what parents find helpful after their child is diagnosed with a developmental delay.

In order to promote the implementation and use of novel treatments, dissemination research has highlighted the necessity to involve stakeholders (Flaspohler, Meehan, Maras & Keller, 2012). There are numerous stakeholders to consider when understanding the dynamics of the EI system. This includes and is not limited to, families, providers who focus on assessing ASD, and providers who focus on treatment. When determining the feasibility and sustainability of an intervention, it is important to avoid placing too much responsibility on one stakeholder to increase the probability for sustainability. Therefore, research should be dedicated to identifying small, sustainable ways for providers to support families in initiating contact with EI services. In order to determine whether or not an intervention is appropriate for further investigation, researchers often design feasibility studies to assess sustainability (Bowen et al., 2009). Feasibility research also highlights what methodology may require modification such as research and recruitment strategies (Bowen et al., 2009). Given that there are no previously published studies exploring recommendation modalities following early diagnosis, addressing questions of feasibility will be necessary prior to determining intervention efficacy or effectiveness.

### *1.7 The Current Study*

The current study aimed to improve access to EI for children with ASD and other developmental delays (specifically Global Developmental Delay [GDD] and Language Disorders) by focusing on provider-led techniques that may help parents navigate the EI system. This was accomplished by supplementing treatment as usual with a DVD/YouTube link describing the meaning of different diagnoses and what steps to pursue next (e.g., local resources to contact). The goal of using video recommendations was to minimize feelings of stress and



potentially increase hope and resilience within families by validating their experience and highlighting resources. The study addresses the feasibility of improving access to EI for children with ASD, or other developmental delays who are diagnosed around their second birthday.

According to Bowen and colleagues (2009) feasibility studies can address eight general areas of focus. Depending on the specific investigation, these may include data that targets some of the following areas of focus: acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy testing. Given that there is a paucity of research surrounding the time frame following diagnosis, it is imperative to first explore factors that can lay the foundation for a successful intervention. The present feasibility study will first characterize the current sample by exploring the influence of demographic variables and individual characteristics that relate to study recruitment and retention. This study also plans to address how individual recipients react to the video recommendation and the provider list (acceptability) and the use of the intervention (demand; Bowen et al, 2009). Additionally, this study will examine the preliminary efficacy of the intervention using outcome measures of parental stress, parental sense of competence and access to EI services. The specific aims and main hypotheses are:

Specific Aim 1: This study is intended to be a pilot study to explore the feasibility of using video recommendations to supplement current standard of care (i.e., written recommendations, including provider list) during the period of time between diagnosis and EI. This aim will be addressed by examining recruitment, retention and demand.

Hypothesis 1: Factors associated with acceptability of participating in the current research will be explored. Previous studies examining interventions following a child's diagnosis have indicated that lower SES and higher negative affectivity (Nguyen, Fairclough and Noll, 2015; Reno & McGrath 2006) predicted higher maternal dropout rates in intervention studies. Given that maternal education is often used as a marker for SES (Desai & Alva, 1998), it is predicted that parents with lower levels of maternal education will be less likely to complete the 8-week study. Additionally, exploratory analysis regarding other factors (i.e., treatment group, therapy hours prior to the evaluation, diagnosis, and child specific characteristics) will be explored to determine individual factors that may contribute to study retention. Given the preliminary nature of this research there are no specific assumptions regarding total percentage of study completion.

Hypothesis 2: It is predicted that there is a demand for receiving a brief video intervention and a provider list immediately following diagnosis. The percentage of parents that use the video recommendations and provider list and satisfaction rates will be calculated to determine the demand for the intervention. It is expected that most parents (75%) within the treatment plus video group will use the video recommendations and endorse high ratings of satisfaction (average rating 4 or higher). In order to better understand the demand for video recommendations and provider list, maternal education, parental race, child's diagnosis, whether or not a child was involved in therapy prior to receiving a diagnosis, and child specific characteristics will be explored as factors that may predict whether or not parents use the materials.

Specific Aim 2: Preliminary outcome data will be used to explore the potential efficacy of the intervention. Given that the use of inferential statistics in pilot studies is significantly limited by sample size (Leon, Davis, & Kraemer, 2011), all results will be interpreted with caution and effect sizes will also be calculated.

Hypothesis 3: It is predicted video recommendations will demonstrate preliminary efficacy as an intervention. Differences in outcome data (i.e., parental sense of competence, parental stress, and engagement in intervention) will be explored based on recommendation type (treatment as usual vs. video recommendations). Preliminary efficacy of the provider list will also be explored. Maternal education will be explored as a potential covariate given the strong correlation between maternal education and SES (Desai & Alva, 1998).

## 2 METHODS

### 2.1 *Participants*

The current research project builds on a larger on-going screening study using the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F), a measure that evaluates toddlers at risk for ASD during well-child care visits. The majority of at-risk toddlers in the on-going screening study attend a diagnostic evaluation and typically receive a diagnosis of ASD, GDD or a language disorder. Research has frequently cited the challenges of pre-determining sample size for feasibility and pilot studies (Leon, Davis & Kraemer, 2011; Rounsaville et al., 2001). Leon, Davis and Kraemer (2011) recommend that pilot sample size is

based on the pragmatics of recruitment and the necessity for examining feasibility as opposed to relying on power analysis. Other researchers have cited using 2-3 participants at each site prior to engaging in a multi-site efficacy trial to explore challenges related to implementation (Dawson & Odom, 2006). Rounsaville, Carroll and Onken (2001) emphasize that although no fixed number can be recommended for early pilot studies, they suggest using a rough guide of 15-30 participants per cell. A total of 53 children received a diagnosis of ASD ( $N= 21$ ), GDD ( $N= 22$ ), or Language Disorder ( $N=10$ ). See Table 2.1 on the next page for additional demographic information. Their parents were subsequently invited to participate in the study.

Table 2.1. *Demographics*

Characteristic	Treatment as Usual <i>N</i> = 23	Treatment Plus Video <i>N</i> = 26	Total Sample <i>N</i> = 49
Child Age in months			
<i>M (SD)</i>	23.96 (4.33)	22.23 (2.89)	23.04 (3.70)
Sex of Child <i>n (%)</i>			
Male	17 (73.91)	21 (80.77)	38 (77.55)
Female	6 (26.08)	5 (19.23)	11 (22.45)
Child Diagnosis <i>n (%)</i>			
ASD	9 (39.13)	10 (38.5)	19 (38.8)
GDD	10 (43.47)	10 (38.5)	20 (40.8)
Language Disorder	4 (17.39)	6 (23.1)	10 (20.4)
Parent race <i>n (%)</i>			
Caucasian	9 (39.13)	9 (34.61)	18 (36.73)
African American	14 (60.87)	15 (57.69)	29 (59.18)
Latino	0 (0)	2 (7.69)	2 (4.08)
Maternal Education			
<i>M (SD)</i>	14.57 (2.43)	14.81 (2.58)	14.69 (2.49)
Marital Status <i>n (%)</i>			
Married/Partnered	15 (65.22)	16 (61.54)	31 (63.27)
Single	7 (30.43)	10 (38.46)	17 (34.69)
Divorced	1 (4.34)	0 (0)	1 (2.04)
MSEL Early Learning Composite			
<i>M (SD)</i>	67.32 (16.99)	61.28 (8.19)	64.11 (13.27)
VABS-II Adaptive Learning Composite			
<i>M (SD)</i>	83.87 (10.99)	84.15 (10.91)	84.02 (10.83)
ADOS-2 Total Score			
<i>M (SD)</i>	13.09 (7.40)	14.00 (8.48)	13.57 (7.92)
CARS Total Score			
<i>M (SD)</i>	28.19 (8.52)	28.70 (8.60)	28.47 (8.47)
In therapy prior to evaluation <i>n (%)</i>			
Yes	9 (39.13)	12 (46.15)	21 (42.85)
No	14 (60.87)	14 (53.85)	28 (57.14)

No significant treatment group differences were observed in child age, child sex, child's diagnosis, child specific measures, maternal education, parent race, or total time between the diagnosis and follow-up interview.

Of the 53 eligible participants, 49 parents consented to participate in the current investigation and were assigned randomly using a stratified approach to balance demographic variables to either the treatment as usual group or treatment plus video group. Only one parent per family completed the measures for the study. One father completed the measures for the current study, and all other participants were mothers. Of the four parents who declined to participate in the study, two parents reported feeling overwhelmed by the diagnosis and lacking resources. One parent was not invited to the study due to lack of time during assessment feedback, and the other parent declined due to concern that the research study would not help them directly. Of the 49 parents who consented to participate, 29 parents (59%) fully completed the follow-up measures at Time 2 (ESI over the phone plus PSOC and PSI-4-SF either by mail or on the phone). Seven parents (16%) partially completed the follow-up (completed only the ESI), 12 parents (24%) were unreachable (did not respond to calls or letters), and one parent (1%) declined to participate at the 8-week follow-up. Please see Figure 2.1 on the next page for a graphic depiction of study participation.

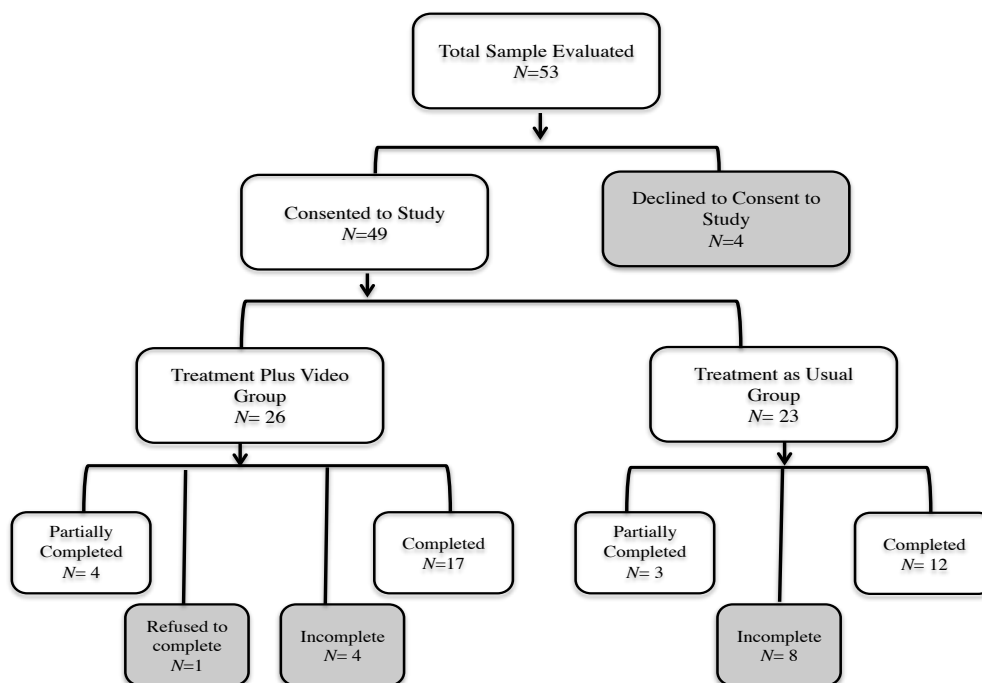


Figure 2.1. *Study Participation*

*Note.* Completed means that at Time 2, both Evaluation Satisfaction Interview (ESI) and PSOC/PSI were complete; partially completed means that at Time 2, only the ESI was completed. Incomplete means neither the ESI or the PSOC/PSI were completed.

## 2.2 Measures

**Parental Stress.** Parental stress was assessed using the Parent Stress Index, Fourth Edition, Short Form (PSI-4-SF) that has been validated in diverse families to detect the magnitude of stress in the parent-child system (Abidin, 2012; Reitman, Currier, Stickle, 2002). Parents were asked to rate 36 statements on a 5-point scale (strongly agree, agree, not sure, disagree or strongly disagree) as related to the evaluated child. The measure consisted of three domains: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. The three domains combine to form a Total Stress scale. The PSI-4-SF took approximately 10 minutes for parents to complete. The PSI-4 has shown a high degree of internal consistency (.96 or higher) and has been used in studies focusing on several different clinical populations. Test-retest reliability is

also satisfactory for each domain (Total stress = .84, Parental Distress = .85, Parent-Child Dysfunctional = .68, Difficult Child = .78). The PSI-SF has also been normed for different clinical populations and diverse demographic groups that match the demographic composition of the 2007 census. Total scores for each domain are converted to percentiles. Percentiles ranging between 16-84 fall in the “Normal range,” 85-89 fall in the “High Range” and percentiles above 90 fall in the “Clinically Significant Range.” For the purpose of this investigation, the Total Stress scale will be used as a continuous outcome variable.

*Parenting Self-Efficacy.* The Parenting Sense of Competence (PSOC) scale, originally developed by Gibaud-Wallston and Wandersmann (1978), was used to assess parent’s motivation, frustration and sense of efficacy (Gilmore & Cuskelly, 2009; Johnston & Mash, 1989). The PSOC is a 16-item questionnaire consisting of two subscales, Satisfaction and Efficacy. The Satisfaction sub-scale is derived from items regarding parenting frustration, anxiety and motivation; the Efficacy sub-scale score reflects parenting competence, problem-solving ability, and capability in parenting role. A Total score is also computed for the entire scale. Each item is answered on a 6-point scale ranging from strongly agree (1) to strongly disagree (6). The PSOC has shown evidence of stable factor structure and validity (Ohan, Leung, & Johnston, 2000). Additionally, the Satisfaction ( $\alpha = .75$ , mothers  $\alpha = .80$ , fathers  $\alpha = .80$ ), Efficacy ( $\alpha = .76$ , mothers  $\alpha = .80$ , fathers  $\alpha = .77$ ) and Total Scores ( $\alpha = .79$ ) have demonstrated acceptable levels of internal consistency (Johnston & Mash, 1989). The PSOC has also demonstrated satisfactory test-retest reliability results ranging .46 to .82 (Gibaud-Wallston & Wandersmann, 1978). When investigating the normative properties of the PSOC, Johnston and Mash (1989) did not note any significant differences in responses based on demographic (SES, sex of child) characteristics. The PSOC has been frequently used in other studies to assess



the construct of parenting-self efficacy (Jones & Prinz, 2005; Sanders et al., 2000). The current evaluation focused on the Total Efficacy Score as a continuous outcome variable measuring parental self-efficacy. A score of 70-96 is indicative of high parental sense of competence, 51-69 indicates moderate sense of competence and 16-50 is suggestive of low parental sense of competence.

***Parental Satisfaction.*** An Evaluation Satisfaction Interview (ESI) was created to assess parental satisfaction with video recommendations. Questions were formulated drawing on studies that used surveys to gather information about parental experiences when receiving a diagnosis (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Kerrell, 2001; Mansell & Morris, 2004; Siklos & Kerns, 2007). The interview included a set of questions with a 5-point Likert scale (1= strongly disagree, 5 = strongly agree) assessing parents' ability to understand information provided at feedback, their ability to understand the suggested recommendations, their experience with the assessment team, and how supported they felt following the diagnosis. Graduate student clinicians conducted the interview, which was typically completed within 30 minutes.

***Access to EI.*** The ESI was also used to ask parents open-ended questions about their behaviors related to accessing EI services (e.g., whether or not they have contacted any providers, if an intake appointment has been scheduled, hours of service child is receiving following diagnosis). This measure also included open-ended questions to gather qualitative and person-centered data about the evaluation experience. Parent responses were scored according to a continuous variable coding scheme. Parents responses were coded based on the following scale: 0 = "I have not contacted EI services", 1 = "I have contacted *one* EI service, or I am on a waitlist/set up initial intake appointment for *one* EI service", 2 = "I have contacted *several* EI

services/providers.” “I am on the waitlist/set up initial intake appointment for *several* EI service providers” 3 = “My child is currently receiving therapy.” Child is receiving *less* than 10 hours of services per week. “My child was receiving therapy before evaluation and they are receiving the same amount after the evaluation.” 4 = “My child is currently receiving therapy.” Child is receiving *more* than 10 hours of services per week. “My child was receiving therapy before evaluation and there has been *an increase* in services following evaluation.” The quotes provided were examples of anticipated responses from parents; this current list is not exhaustive, and raters used the anchors as coding examples. Two separate coders rated parent responses based on the above coding scheme and there was almost perfect agreement between coders Kappa = .89  $p < .001$ . The ESI is included in the appendix of this document.

### ***Child Diagnostic Measures***

The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardized test of cognitive abilities used with children from birth to 5 years and 8 months. The Mullen has an internal consistency ranging from  $\alpha = .75-.83$  within each scale, test-retest reliability from .75-.96, and inter-rater reliability from .91-.99 (Mullen, 1995). The Mullen includes the following scales: visual reception, receptive language, expressive language, fine motor, and gross motor. The visual reception, receptive language, expressive language and fine motor scales combine to create the Early Learning Composite, which is a general measure of intelligence (Mullen, 1995).

The Vineland Adaptive Behavior Scales, Second Edition (VABS-II; Sparrow, Cicchetti, Balla, 2005) is a standardized parent-report interview designed to address adaptive skills including Communication, Daily Living, Socialization, and Motor domains. The scales combine to create an Adaptive Learning Composite Score. The Vineland’s overall reliability and validity have been well-established (Sparrow, Cicchetti, Balla, 2005). Split-half reliability for the four

domains ranges from .83-.97. Correlations between each subdomain for the Vineland-II are moderate ( $r \geq .75$  for 75% of domain comparison), but are higher for young children. Split-half reliability within each domain ranges from .91-.95. The average test-retest reliability was .85 and average inter-rater reliability was .75 (Sparrow, Cicchetti, Balla, 2005).

The Autism Diagnostic Observation Schedule, Second Edition Toddler Module (ADOS-2; Lord, Luyster, Gotham & Guthrie, 2012) is a semi-structured standardized observational assessment of ASD. The ADOS-2 directly examines, communication, social interaction, play, and repetitive behaviors. The toddler module demonstrates moderate to high internal consistency among scales ( $\alpha = .50-.90$ ). Test-retest reliability was determined to be between .64 and .88. Inter-rater reliability was assessed at .60. For the purpose of the current evaluation, the ADOS-2 Toddler Module Total Score was used as a measure of autism severity.

The Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler, Van Bourgondien, Wellman, & Love 2010; Schopler, Reichler, DeVellis, & Daly 1980) is a behavior rating scale designed to determine ASD symptom severity through direct observation. The CARS-2 assess a child based on 15 functional areas including: relating to people, imitation, emotional response, body use, object use, adaptation to change, visual response, listening response, sensory response, fear or nervousness, verbal communication, nonverbal communication, activity level, level of consistency of intellectual response, general impressions. The original CARS demonstrated good inter-rater reliability of .84 and internal consistency ( $\alpha = .93$ ); test-retest reliability was .82 (Schopler et al, 1980). Correlations between item ratings on the CARS-2 ranged from moderate to high .42 to .77 (Schopler, Van Bourgondien, Wellman, & Love 2010; Vaughan, 2011).

### 2.3 *Design and Procedure*

An experimental design was used to evaluate the study hypotheses. Participants were recruited from the M-CHAT-R study after their child received a diagnosis. As part of the larger M-CHAT-R study, parents were scheduled for an evaluation at Georgia State University based on ASD risk. Before attending the evaluation, parents completed a history form that includes information regarding basic demographic information (income, maternal education, racial identification). The evaluation takes approximately two to three hours. During this time the child's cognitive (Mullen Scales of Early Learning, MSEL) and social abilities (Autism Diagnostic Observation Schedule Second Edition, ADOS-2) were assessed. Parents also complete interviews and questionnaires to assess their observations of their child's social and adaptive functioning (i.e., Vineland Adaptive Behavior Scales Second Edition Survey Interview, VABS-II). Upon completing the assessment, the assessment team (graduate student clinician and licensed clinical psychologist) met to discuss the scores and complete a diagnostic checklist, as well as the Childhood Autism Rating Scale (CARS-2, Second Edition). After the assessment team agreed upon a diagnosis, assessment feedback was completed, typically on the same day as the evaluation. For parents with scheduling conflicts, the assessment feedback was completed at a later date. Typically oral feedback lasted approximately 30 to 45 minutes. Parents were provided with information regarding their child's performance, diagnosis, and information regarding EI services and other community resources.

If a child was diagnosed with ASD, Global Developmental Delay (GDD), or Language Disorder, a researcher invited the parent to participate in the proposed study and review the IRB-approved informed consent. Parents of children who were typically developing and those who received no diagnosis were not invited to participate in the study. If a parent had two children

eligible for the study, follow-up data were only used for the first child recruited for the study. Parents were assured that if they declined to participate in the study, their participation in the larger screening study would not be influenced. Only one parent (typically the mother) per family completed the measures for the study. One father completed the measures for the current study. For families who had already received a diagnosis ( $n = 1$ ; 2%) prior to the evaluation or if they were already receiving intervention services ( $n = 21$ ; 43%), this was noted in the ESI, and accounted for when coding access to EI.

Parents who agreed to participate were randomly assigned to a treatment as usual (treatment as usual) group or a treatment plus video recommendations group (treatment plus video). Group status served as a dichotomous predictor for all analyses. In order to ensure a balance of participants in each group based on child's race and child diagnosis, stratified randomization was used. A separate randomization was completed within each subset of participants. Assignment to groups was placed in envelopes marked with groups (race and diagnosis). Clinicians opened envelopes to learn which participants were assigned to treatment as usual or treatment plus video group, prior to oral feedback with parents. All parents were encouraged to provide a variety of contact options to aid in collection of follow-up data (phone, email, address).

*Treatment as Usual.* Parents were provided with oral feedback regarding their child's diagnosis at the evaluation, and given a written list of therapy providers in Metropolitan Atlanta area. The objective of the provider list was to provide parents with a list of services and their contact information, as well as helpful books and websites. The provider list is a 24-page document that provides a sentence description about the type of service each organization provides. The list includes contact information for EI programs such as Babies Can't Wait,

Parent to Parent of Georgia, advocacy services, speech therapy, ABA therapy, etc. The list also includes information regarding preschool contacts, books, and websites with additional information. The provider list offers helpful contacts for families regardless of diagnosis. Clinicians answered questions from parents and directed parents to the most relevant recommendations on the provider list based on their child's strengths and weaknesses.

*Treatment plus video.* In addition to a provider list, a stratified sample of parents also received a DVD (and YouTube Playlist link) of video recommendations with information regarding diagnosis and EI information. The objective of the video recommendations was to provide information about diagnosis, prognosis and services in the Metropolitan Atlanta area. The importance EI and self-care was also emphasized throughout the video as a means to motivate parents to access EI, increase parental sense of competence, and decrease parental stress. The YouTube video was "unlisted" online, and only parents in the treatment plus video group were able to view the video. The video-enhanced recommendations included a general introduction (1 minute) and separate videos for ASD (approximately 11 minutes), GDD (approximately 8 minutes) and Language Disorders (approximately 7 minutes). Each video included brief descriptions about the disorder and the importance of EI in improving developmental outcomes. Each video concluded with which agencies to contact first (e.g., Babies Can't Wait, Parent to Parent). Each video recommendation was a different chapter (or different video for the YouTube Playlist), which allowed providers to highlight specific sections that may be helpful based on a child's specific disorder. Parents were reminded of the YouTube link ([https://www.youtube.com/playlist?list=PLm4naRdw\\_vryOrqQKLhJJkaotsEXJp2c](https://www.youtube.com/playlist?list=PLm4naRdw_vryOrqQKLhJJkaotsEXJp2c)) when they received a written copy of their report. See Table 2.1 for demographic data based on treatment group.

All parents received a brief score summary of the results of the evaluation after approximately two weeks ( $M = 13.16$  days,  $Median = 11.50$  days,  $SD = 9.12$ ) following the evaluation. This summary included results from the measures used in the evaluation, along with the diagnostic impressions. Parents were mailed a written psychological report approximately eight weeks ( $M = 51$  days,  $Median = 51$  days,  $SD = 16.20$ ) following the evaluation, along with an additional copy of the provider list. A student clinician began to contact parents by phone to complete the ESI after eight weeks had passed since the evaluation and the final report had been sent (i.e., if the report was delayed, the clinician waited before inviting parent to complete the ESI). A graduate student interviewer attempted to contact the parent by phone five times at varying times of day to maximize the likelihood of reaching each parent. They were also mailed copies of the PSOC and PSI-4-SF along with a return envelope to complete. If they were unable to return the PSOC and PSI-4-SF forms via mail, they were contacted to attempt to complete questionnaires by phone. Ten parents completed the measures by mail, and 19 parents completed the measures by phone. No significant differences were observed in follow-up measures by modality. The entire follow-up procedure was completed within 13 weeks post-evaluation; the ESI was completed approximately 12 weeks after the evaluation ( $M = 87.28$  days,  $Median = 78.50$  days,  $SD = 27.56$ ) and the PSOC and PSI-4-SF were completed approximately 13 weeks after the evaluation ( $M = 91.38$  days,  $Median = 77.00$ ,  $SD = 39.78$ ). Parents in the treatment as usual group were given a copy of the YouTube link upon their completion in the study. See Table 2.2 for a depiction of the general procedures.

Table 2.2. General Procedures

Treatment Group	At Evaluation	2 Week Post-Evaluation	8 Weeks Post-Evaluation	13 Weeks Post-Evaluation
Treatment as usual	Provider list	Score summary	Complete psychological report	ESI, PSOC and PSI-4-SF
Treatment plus video	Provider list <u>and</u> video recommendations	Score summary	Complete psychological report	ESI, PSOC and PSI-4-SF

### 3 RESULTS

All data were analyzed using the Statistical Package for Social Sciences (SPSS 18). Given that this is a feasibility study, literature regarding sample size was used to guide sample size recruitment (Dawson & Odom, 2006; Leon, Davis & Kraemer, 2011; Rounsaville et al., 2001). Effect sizes were also calculated for all analyses to ensure that non-significant results were not due to insufficient power. Significant non-normal distributions were observed in Time 2 PSI-4-SF Total Stress  $D(28) = 0.17, p = .03$ , and EI access  $D(28) = 0.37, p < .001$ . No major violations of other assumptions (i.e., linearity, homoscedasticity, independence of errors, multicollinearity) were found. Data transformation was not used given that primary analyses consisted of ANOVA and regression (fairly robust to violations to normality assumption).

In order to better understand and characterize the current sample, descriptive analysis based on treatment measures according to assigned treatment group were conducted. Please see Table 3.1 for descriptive statistics of measures for treatment group. There were no significant treatment group differences based on outcome measures. Parents on average across both groups reported parental stress within normal limits. Parents in the treatment as usual group reported high parental sense of competence and parents in the treatment plus video group reported moderate parental sense of competence. Parents across both groups had contacted several EI



providers, were on a waitlist, or had set up initial intake appointments. Of the mothers enrolled in the current study, 21 (42.9%) reported that their children were involved in therapy prior to the evaluation. Within the treatment as usual group, nine (39%) of parents reported that their child was receiving therapy. Twelve (46%) parents in the treatment plus video group reported that their child was receiving therapy prior to the evaluation.

*Table 3.1. Average Scores on Measures Based on Assigned Treatment Group*

Outcome Measure	<u>Treatment as Usual Group<sup>a</sup></u>		<u>Treatment Plus Video Group<sup>b</sup></u>	
	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>
PSI Total Stress	12	69.17 (21.02)	17	58.47 (22.63)
PSOC Total	12	71.17 (14.15)	17	67.35 (10.52)
Access to EI	15	2.26 (1.33)	21	2.42 (1.08)
Total intervention hours	15	3.70 (10.15)	21	2.54 (8.60)

<sup>a</sup> *n* = 23. <sup>b</sup> *n* = 26

Outcome measures were also explored as they relate to child's diagnosis and maternal education. Please see Table 3.2 for descriptive statistics based on diagnosis. Across all groups, parents reported an average level of parental stress. Parents of children with ASD reported high ratings of parental sense of competence, whereas parents of children with GDD or language disorder reported moderate levels of parental sense of competence. Parents of children with ASD and GDD had contacted several EI providers, were on a waitlist, or had set up initial intake appointments, while parents of children with a language disorder had contacted one EI service, or were on a waitlist/set up initial intake appointment for one EI service.

Table 3.2. Average Scores on Measures Based on Diagnosis

Outcome Measure	ASD <sup>a</sup>		GDD <sup>b</sup>		Language Disorder <sup>c</sup>	
	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>
PSI Total Stress	10	58.20 (23.99)	12	74.33 (17.84)	7	50.00 (19.25)
PSOC Total	10	71.60 (9.21)	12	68.25 (13.02)	7	66.29 (14.84)
Access to EI	13	2.69 (1.03)	14	2.50 (1.09)	9	1.67 (1.32)
Total intervention hours	13	4.31 (10.83)	14	3.50 (10.52)	9	0.44 (0.68)

<sup>a</sup> *n* = 19. <sup>b</sup> *n* = 20. <sup>c</sup> *n* = 10.

There were significant differences in maternal education by diagnostic group,  $F(2, 48) = 3.67, p = .03, \eta^2 = 0.86$ , large effect. Mothers of toddlers with GDD,  $M = 13.60, SD = 2.16$ , had significantly lower levels of maternal education than mothers of toddlers with ASD,  $M = 15.53, SD = 1.74$ . There was also a significant difference in maternal education between Caucasian,  $M = 16.44, SD = 1.89$ , and minority mothers,  $M = 13.68, SD = 2.23, t(47) = 4.43, p < .001$ . Given that maternal education is significantly associated with income, maternal education was entered as a covariate throughout the analyses. Significant differences based on diagnosis were also observed in Time 2 parental stress,  $F(2, 28) = 3.52, p = .04, \eta^2 = 0.21$ . This statistically significant difference was not observed when controlling for maternal education,  $F(2, 48) = 2.79, p = .08, \text{partial } \eta^2 = 0.18$ , large effect.

In order to understand the relationship between outcome measures, correlations were used. See Table 3.3 for correlations between outcome measures. Access to EI was positively associated with hours of therapy,  $r(36) = .39, p = .02$ . There was a lack of an observed correlation between access to EI and parental stress and parental sense of competence. The number of hours of therapy was negatively associated with parental stress at follow-up,  $r(28) = -.39, p = .04$ . Additionally, when controlling for maternal education, total number of therapy

hours at follow-up marginally predicted lower scores of parental stress at follow-up  $R^2 = .20$ ,  $F(2, 28) = 3.20$   $p = .057$ ;  $\beta = -.39$ ,  $p = .03$ .

Table 3.3. *Correlations of Outcome Measures*

Outcome Measure	1	2	3	4
1. PSI Total Stress <sup>a</sup>	_____			
2. PSOC Total <sup>a</sup>	-.44*	_____		
3. Access to EI <sup>b</sup>	-.09	.11	_____	
4. Total intervention hours <sup>b</sup>	-.39*	.33	.39*	_____

\* $p < .05$ . \*\* $p < .01$ .

<sup>a</sup>  $n = 29$  <sup>b</sup>  $n = 36$

### 3.1 Hypothesis 1: Acceptability of Participating in Research and Factors Associated with Study Retention

In order to assess whether maternal education, treatment group, involvement in therapy prior to diagnosis, and diagnosis influenced study retention, binary logistic regression was used. Given that this investigation is designed to evaluate what differentiates individuals who completed and failed to complete the follow-up, partial completers and full completers were combined into one group. Parents who partially completed the study only completed the ESI, whereas parents who fully completed the study completed the ESI, PSOC and PSI-4-SF, at Time 2. Maternal Education, treatment group, whether or not parents were receiving therapy prior to the evaluation, and diagnosis (ASD vs. Non-ASD-DD [Developmental Delay]) were entered in the first step. See Table 3.4 for results of binary logistic regression.

Table 3.4. *Predictors of Study Completion*

	<i>B (SE)</i>	Odds Ratio	95% CI
Maternal education	-0.07 (0.15)	0.93	[0.70, 1.25]
Treatment group	0.93 (0.69)	2.55	[0.65, 9.93]
Therapy prior to evaluation	-1.08 (0.70)	0.34	[0.09, 1.34]
Child's diagnosis (ASD vs. Non-ASD-DD)	0.28 (0.71)	1.32	[0.33, 5.31]

*Note.* CI = confidence interval.

The binary logistic regression model was not statistically significant  $\chi^2(4, N = 49) = 4.93$   $p = .29$ . Nagelkerke's  $R^2$  of .14 indicated a weak relationship between the predictive model and the outcome. No individual variables in the equation were significantly associated with study completion. Of note, parents in the treatment plus video group were 2.55 times more likely to complete the study than parents in the treatment as usual group.

In an exploratory analysis, child specific factors, such as cognitive functioning (MSEL Early Learning Composite Score), adaptive functioning (VABS-II Adaptive Learning Composite), ADOS-2 Total Score, and CARS-2 Total Score, were examined as possible factors that predict study completion. See Table 3.5 for results of binary logistic regression.

Table 3.5. *Child Specific Predictors of Study Completion*

	<i>B (SE)</i>	Odds Ratio	95% CI
MSEL	-0.08 (.04)	0.92*	[0.85, 0.99]
VABS-II	0.10 (.04)	1.10*	[1.01, 1.20]
ADOS-2	-0.05 (.11)	0.95	[0.77, 1.17]
CARS-2	0.02 (.10)	1.02	[0.85, 1.23]

*Note.* CI = confidence interval.

The binary logistic regression model was not statistically significant  $\chi^2(4, N = 43) = 8.56$   $p = .07$ . Nagelkerke's  $R^2$  of .26 indicated a weak relationship between the predictive model and

the outcome. Although the omnibus model was not significant, two predictors significantly predicted study completion. VABS-II Adaptive Learning Composite, *Wald's criterion* = 4.77  $p = .03$ , and MSEL Early Learning Composite Score, *Wald's criterion* = 3.97  $p = .05$ , added significantly to the ability predict whether or not parents completed the study. Parents of children with higher adaptive behavior scores were 1.10, 95% *CI* [1.01, 1.20] times more likely to complete the study. Parents of children with higher MSEL scores were 0.91, 95% *CI* [0.85, .99] times less likely to complete the study. It is important to note that VABS-II,  $r = .20$ ,  $p = .16$ , and MSEL score,  $r = -.15$ ,  $p = .31$ , were not significantly correlated with study completion. Therefore, their significance within the context of the logistic regression model may not be meaningful.

### 3.2 Hypothesis 2: Acceptability and Demand for Video Recommendations

In order to explore if the video recommendations were an acceptable intervention, the percentage of parents that reported use of the video recommendations was calculated. Thirty-six (73%) parents completed the ESI by phone approximately eight weeks after their child's evaluation and therefore provided data on whether or not they used provider list or the video recommendations. Of the 36 parents who completed the ESI, 21 parents were in the treatment plus video group. Of those 21 parents, only 6 (29%) parents reported that they had watched the video recommendations. For the 15 parents who did not view the video recommendations, they were asked an open-ended interview question to explore barriers to watching the video. The majority of parents ( $n = 11$ , 52%) cited "no time," and other parents ( $n = 4$ , 19%) stated they "forgot" to watch the video.

Satisfaction rates were examined in order to assess the demand for the current video intervention. Of the six mothers (maternal education  $M = 15.67$ ,  $SD = 2.66$ ; three mothers were

Caucasian, three mothers were racial minorities) who watched the video recommendations, the average satisfaction rating (1=strongly disagree, 5=strongly agree) for the videos was 4.50,  $SD = 0.55$ . The majority of mothers who watched the video reported that they found the videos “helpful” and that they “liked” the videos,  $n = 5$ , 83%, and most mothers,  $n = 5$ , 83% did not identify ways to improve the video recommendations. One mother suggested that the video recommendations include “More information about subcategories of ASD and how to figure out what exactly needs to be addressed within the spectrum he is in.” When looking at the diagnostic breakdown of the children of the mothers who watched the video recommendations, four mothers had children with ASD and two mothers had children with a language disorder. See Figure 3.1 for a graph of mothers who used the video recommendations based on their child’s diagnosis.

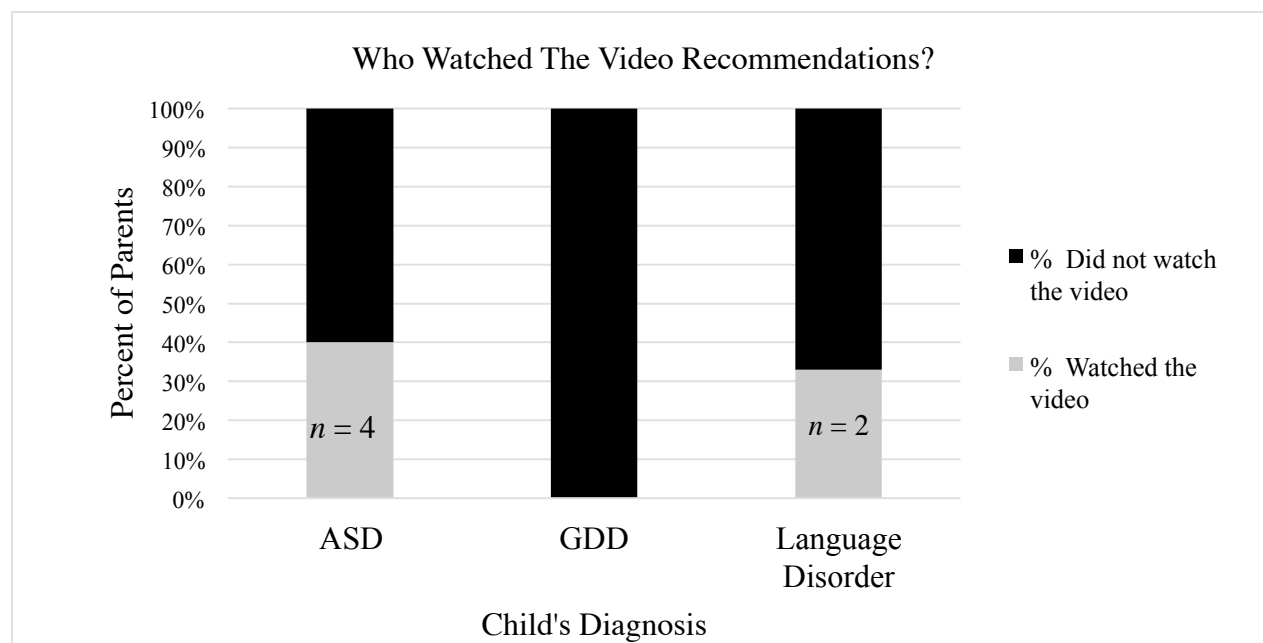


Figure 3.1. *Percent of Mothers Who Watched the Video Recommendations*

Binary logistic regression was used to explore if maternal education, parental race, and child’s diagnosis (ASD vs. Non-ASD-DD) were associated with using the video

recommendations. Please see Table 3.6 for results of binary logistic regression. The logistic regression model was not statistically significant  $\chi^2(4, N = 21) = 3.61, p = .31$ . Nagelkerke's  $R^2$  of .23 indicated a weak relationship between the predictive model and the outcome. No individual variables in the equation were significantly associated with watching the video recommendations.

Table 3.6. *Predictors of Whether or Not Parents Used Video Recommendations*

	<i>B (SE)</i>	Odds Ratio	95% CI
Maternal education	0.09 (.25)	1.09	[0.67, 1.77]
Parent race	-0.62 (1.23)	0.54	[0.05, 5.93]
Child's diagnosis (ASD vs. Non-ASD-DD)	-1.74 (1.08)	0.18	[0.02, 1.47]

*Note.* CI = confidence interval.

Whether or not a child received therapy prior to the evaluation was not included within the logistic regression model due to inadequate sample size. Please see table 3.7 for frequencies of parents who used the video recommendations based on whether or not a child was already involved in therapy prior to their evaluation. Sixty-six percent of parents ( $n = 14$ ) in the treatment plus video group also reported that they consulted with other types of information online (e.g., Google).

Table 3.7. *Involvement in Therapy Prior to Evaluation and Parent's Use of Video Recommendations*

In Therapy Prior to Evaluation	Did Not Watch n (%)	Watched n (%)	Total n (%)
No therapy	7 (46.67)	5 (83.33)	12 (57.14)
Therapy	8 (53.33)	1 (16.67)	9 (42.85)
Total	15 (71.43)	6 (28.57)	21 (100)

In an exploratory analysis, child specific factors such as cognitive functioning (MSEL Early Learning Composite Score), adaptive functioning (VABS-II Adaptive Learning Composite), ADOS-2 Total Score, and CARS-2 Total Score were examined as possible factors that predict use of video recommendations. The logistic regression model was not statistically significant  $\chi^2(4, N = 20) = 9.15 p = .06$ . Please see Table 3.8 for results of the binary logistic regression. *Nagelkerke's R<sup>2</sup>* of .52 indicated a moderate relationship between the predictive model and the outcome.

Table 3.8. *Child Specific Predictors of Use of Video recommendations*

	<i>B (SE)</i>	Odds Ratio	95% CI
MSEL	0.20 (.17)	1.22	[0.87, 1.72]
VABS-II	0.18 (.12)	1.20	[0.96, 1.51]
ADOS-2	-0.20 (.22)	0.82	[0.54, 1.26]
CARS-2	0.63 (.41)	1.87	[0.83, 4.20]

*Note.* CI = confidence interval.

No individual variables in the equation were significantly associated with using the video recommendation.

### 3.3 Hypothesis 2: Acceptability and Demand for Provider List

The acceptability of the provider list was also explored. All 36 parents (across both treatment groups) who completed the ESI had the option of using the provider list; 27 (75%) parents reported that they used the provider list. See Table 3.9 to see the percentage of parents who used the provider list within each treatment group. Within the context of the treatment as usual condition, 15 parents completed the ESI and reported data regarding whether or not they used the provider list. Eleven (73%) parents reported using the provider list, four (27%) did not.



Within the context of the treatment plus video condition, 16 (76%) of parents reported that they used the provider list.

Table 3.9. *Number of Parents Who Use of Video Recommendations and Provider List*

	Treatment As Usual (N=15)	Treatment Plus Video (N=21)	Total Parents Who Reported Use (N=36)
Provider list	11 (73%)	16 (76%)	27 (75%)
Video recommendations	--	6 (29%)	6 (16%)

*Note.* Sample size based on the number of parents who reported whether or not they used the materials.

The demand for the provider list was also explored. The average satisfaction rate for the provider list was 4.41,  $SD = .90$ . Binary logistic regression was used to explore if maternal education, parental race, child's diagnosis, and involvement in therapy prior to evaluation were associated with using the provider list. See Table 3.10 for binary logistic regression results. The logistic regression model was not statistically significant  $\chi^2(4, N = 36) = 6.92$   $p = .14$ . *Nagelkerke's R<sup>2</sup>* of .26 indicated a weak relationship between the predictive model and the outcome. No individual predictors were significantly associated with whether or not parents used the provider list. Of note, minority parents were 3.68 times more likely to use the provider list than Caucasian mothers.

Table 3.10. *Predictors of Use of Provider List*

	<i>B (SE)</i>	Odds Ratio	95% CI
Maternal education	0.06 (.22)	1.06	[0.69, 1.62]
Parent race	1.30 (1.16)	3.68	[0.38, 35.75]
Child's diagnosis (ASD vs. Non-ASD-DD)	-2.40 (1.27)	0.09	[0.01, 1.11]
Therapy prior to evaluation	-0.90 (.95)	0.41	[0.06, 2.65]

*Note.* CI = confidence interval.

It is helpful to explore characteristics of the nine parents who did not use the provider list. Please see table 3.11 for frequencies of parents who used the provider list based on whether or not a child was already involved in therapy prior to their evaluation.

Table 3.11. *Involvement in Therapy Prior to Evaluation and Parent's Use of Provider List*

In Therapy Prior to Evaluation	Did not use n (%)	Used n (%)	Total n (%)
No therapy	5 (55.55)	13 (61.90)	18 (60.00)
Therapy	4 (44.44)	8 (38.10)	12 (40.00)
Total	9 (30.00)	21 (70.00)	30 (100)

Additionally, there were four parents of children with GDD, four parents of children with a language disorder who did not use the provider list. Only one parent of a child with ASD did not use the provider list. Regarding race, of the parents who did not use the provider list, five were Caucasian and four were racial minorities.

Child specific factors such as cognitive functioning (MSEL Early Learning Composite Score), adaptive functioning (VABS-II Adaptive Learning Composite), ADOS-2 Total Score, and CARS-2 Total Score were examined as possible factors that predict use of the provider list as an exploratory analysis. See Table 3.12 for results of logistic regression. The logistic

regression model was not statistically significant  $\chi^2 (4, N = 32) = 4.02 p = .40$ . Nagelkerke's  $R^2$  of .18 indicated a weak relationship between the predictive model and the outcome. No individual predictors were significantly associated with whether or not parents used the provider list.

Table 3.12. *Child Specific Predictors of Use of Provider List*

	<i>B (SE)</i>	Odds Ratio	95% CI
MSEL	0.06 (.07)	1.22	[0.93, 1.20]
VABS-II	-0.003 (.05)	1.20	[0.91, 1.10]
ADOS-2	-0.03 (.12)	0.82	[0.76, 1.23]
CARS-2	0.17 (.16)	1.87	[0.87, 1.62]

*Note.* CI = confidence interval.

### 3.4 Hypothesis 3 Limited Efficacy Testing: Exploring Parental Sense of Competence, Parental Stress, and EI Access as Outcomes

Given that only six parents reported using the video recommendations, differences in outcome data were not analyzed by comparing the assigned treatment groups (i.e., treatment as usual vs. treatment plus video). Within the context of the treatment plus video condition, differences in outcome data (i.e., parental sense of competence, parental stress, and engagement in intervention) were explored based on whether or not the parent watched the video recommendations using ANCOVA. MANCOVA was not used due to limited study power. When controlling for maternal education, parents who used the video recommendations did not endorse significantly higher ratings of parental sense of competence,  $M = 69.75$  moderate parental sense of competence  $SD = 14.86$ , compared to parents who did not use the video recommendations,  $M = 66.62$  moderate parental sense of competence  $SD = 9.48$ , at Time 2,  $F (1,16) = .67, p = .43$ , *partial*  $\eta^2 = .05$ , small effect. Parents who used the video recommendations did not endorse

significantly lower ratings of parental stress,  $M = 47.00$  normal range of stress,  $SD = 32.35$ , compared to parents who did not use the video recommendations,  $M = 62.00$  normal range of stress  $SD = 19.08$ , at Time 2,  $F(1,16) = .93$ ,  $p = .35$ ,  $partial \eta^2 = .06$ , medium effect. Finally, parents who used the video recommendations did not report significant differences in how far along they were in the EI process at Time 2,  $M = 2.50$ ,  $SD = 1.38$ , compared to parents who did not use the video recommendations,  $M = 2.40$ ,  $SD = .99$ ,  $F(1, 20) = .02$ ,  $p = .89$ ,  $partial \eta^2 = .001$ , small effect.

Differences in outcome data were also explored comparing parents who used the provider list as opposed to parents who did not use the provider list. The entire sample was used in order to increase the power to detect effects of the provider list. Parents who used both the provider list and video recommendations were excluded from this analysis, to focus on the independent effects of the provider list. When controlling for maternal education, parents who used the provider list,  $M = 68.00$  moderate parental sense of competence  $SD = 12.82$ , did not endorse significant differences in their levels of parental sense of competence, in comparison to parents who did not use the provider list,  $M = 71.33$  high parental sense of competence  $SD = 8.94$ ,  $F(1, 22) = 0.27$ ,  $p = .61$ ,  $partial \eta^2 = 0.01$ , small effect. Parents who used the provider list,  $M = 67.16$  normal range of parental stress,  $SD = 21.05$ , did not report significantly different levels of stress when compared to parents who did not use the provider list,  $M = 60.00$  normal range of parental stress,  $SD = 16.34$  at Time 2,  $F(1, 22) = 0.84$ ,  $p = .37$ ,  $partial \eta^2 = .04$ , small effect. Finally, parents who used the provider list,  $M = 2.33$ ,  $SD = 1.11$ , were no further along in the EI process than parents who did not use the provider list,  $M = 2.33$ ,  $SD = 1.32$  at Time 2,  $F(1, 27) = 0.002$ ,  $p = .97$ ,  $partial \eta^2 < 0.01$ , small effect. Parents who used and did not use the

provider list reported that they had on average contacted several EI providers or set up several intake appointments.

### 3.5 *Exploratory Analyses: Additional Factors Associated with Outcome Measures*

Exploratory analyses also considered the influence of diagnosis on outcome measures. Results of ANCOVA (controlling for maternal education) analysis revealed medium to large effect size in Time 2 parental stress based on diagnosis,  $F(2, 25) = 2.79, p = .08, \text{partial } \eta^2 = 0.18$ , large effect, Time 2 parental sense of competence,  $F(2, 25) = 0.93, p = .41, \text{partial } \eta^2 = 0.07$ , medium effect, or EI access,  $F(2, 32) = 2.35, p = .11, \text{partial } \eta^2 = 0.13$ , medium effect. Parents of children with ASD,  $M = 71.60, SD = 9.21$ , expressed higher ratings of sense of competence at follow-up than parents of children with GDD,  $M = 68.25, SD = 13.02$ , and parents of children with a language disorder,  $M = 66.29, SD = 14.84$ . In regards to stress, parents of children with GDD,  $M = 74.33, SD = 17.84$ , expressed higher ratings of stress at follow-up than parents of children with ASD,  $M = 58.20, SD = 23.99$ , and parents of children with a language disorder,  $M = 50.00, SD = 19.25$ . When concerning EI access, parents of children with ASD,  $M = 2.69, SD = 1.03$ , were further along in the EI process than parents of children with GDD,  $M = 2.50, SD = 1.09$ , and parents of children with a language disorder,  $M = 1.67, SD = 1.32$ . Only five parents reported that they had not contacted EI. See figure 3.2 on the next page for a graphic depiction of EI access by diagnostic category.

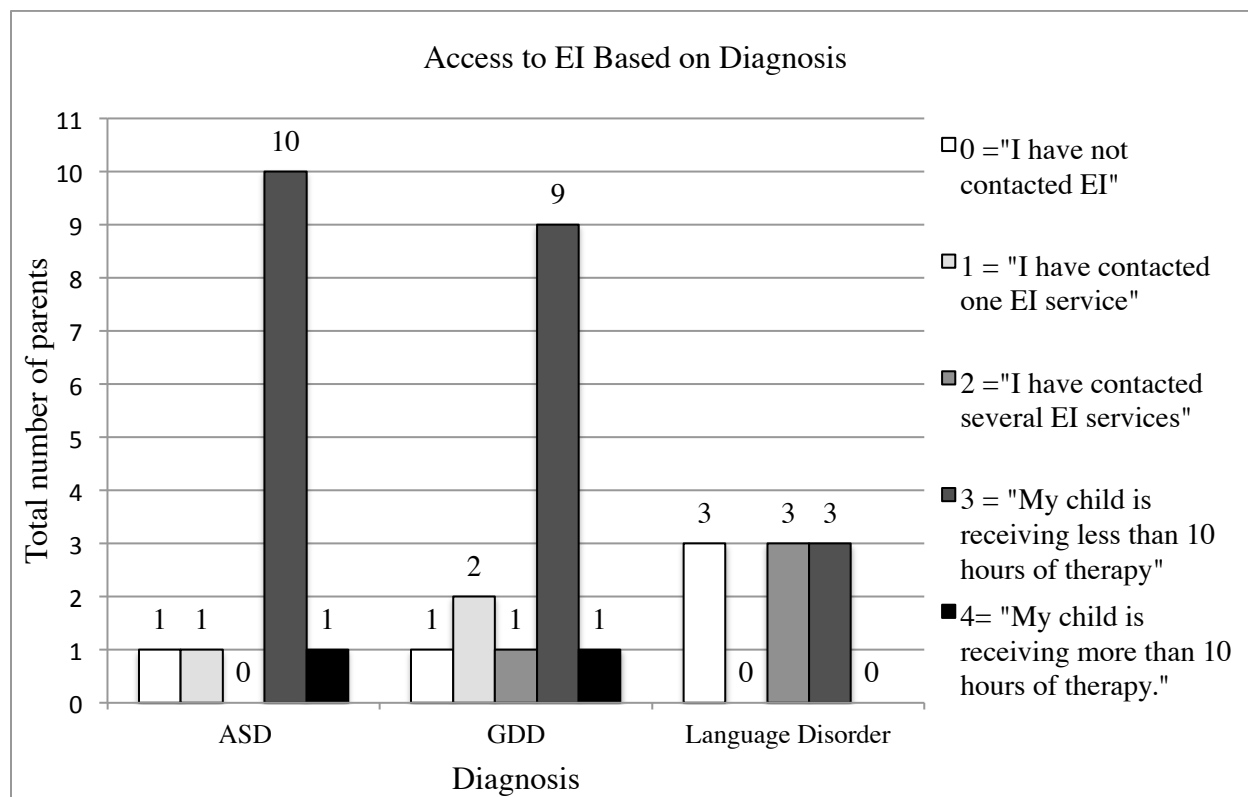


Figure 3.2. Average EI Access by Diagnostic Category

Correlational and regression analyses were used to explore potential relationships between child and parental characteristics and outcome variables. There were no significant associations between child specific factors such as cognitive functioning (MSEL Early Learning Composite Score), adaptive functioning (VABS-II Adaptive Learning Composite), ADOS-2 Total Score, and CARS-2 Total Score and Time 2 parental stress or Time 2 parental sense of competence. More contact with EI providers was positively associated with child's ADOS total score  $r(34) = .35, p = .04$ . When controlling for maternal education, child's ADOS total score,  $\beta = .33, p = .07$ , did not significantly predict changes in EI access  $R^2 = .12, F(2, 33) = 2.24, p = .12$ .

Significant associations were also observed between race and EI access. Caucasian mothers were more likely than minority mothers to be further along in the EI process  $r(35) = -$

.39,  $p = .02$ . Race,  $\beta = -0.46$ ,  $p = .02$ , predicted access to EI above and beyond maternal education,  $R^2 = .16$ ,  $F(2, 35) = 3.21$ ,  $p = .05$ . When accounting for maternal education, Caucasian mothers were more likely to be further along in the EI process (i.e., their child is actively receiving therapy) than minority mothers (i.e., they are on a waitlist or contacted several EI providers). This finding was not observed when using total number of therapy hours as an outcome. There were no significant differences in total hours of therapy between Caucasian,  $M = 1.42$ ,  $SD = .38$ , and minority mothers,  $M = 4.07$ ,  $SD = 11.64$ ,  $t(34) = -.85$ ,  $p = .40$ ,  $d = .32$ , small effect.

Parents were also asked forced-choice questions (5-point Likert scale, 1=strongly disagree, 5=strongly agree) regarding the evaluation process. Maternal education was negatively associated with strongly endorsing the statement “I felt relieved after hearing the diagnosis,”  $r(36) = -.44$ ,  $p = .008$ . This suggests that parents with higher education were less likely to feel relieved following the diagnosis. Parents of children diagnosed with ASD,  $M = 3.15$ ,  $SD = 1.41$ , were more likely to endorse feeling upset regarding the results of the diagnosis than parents of children with GDD,  $M = 1.86$ ,  $SD = .66$ , or language disorder,  $M = 2.11$ ,  $SD = 1.27$ ;  $F(1, 33) = 4.78$ ,  $p = .02$ ,  $\eta^2 < 0.22$ , large effect.

On average, parents strongly agreed with the statement “Having my provider follow up with me after the evaluation is helpful.” ( $M = 4.50$ ,  $SD = .56$ ). Parents were also asked the question “How could the process of finding services for child be improved? Do you have any recommendations for providers?” Four (11%) parents requested changes in the insurance process (e.g., “So many doctors do not take insurance.”). Several parents ( $n = 9$ , 25%) reported that additional options for services and extended hours would be helpful (e.g., “Having hours outside of regular business hours could be helpful.” “More services in area.”). Other parents ( $n = 8$ ,

22%) highlighted the importance of collaboration between mothers who also have children with delays and other providers to better facilitate access to services (e.g., “Having all providers in one place or having a provider network with direct referrals would be nice.” “Talking to a parent... getting trusted referral is always better.”). 11% ( $n = 4$ ) of parents provided specific suggestions regarding the provider list (e.g., “Mailing the information was helpful, email afterwards would have been great. And this call to check in has been helpful.” “Provider list packet was very overwhelming especially for being emotionally overwhelmed. Maybe make different smaller packets with less information? Divide information based on location of services?”). The remaining 11 (31%) of parents did not have any suggestions for changes in the process.

#### 4 DISCUSSION

The purpose of this study was to address the feasibility of using video recommendations to supplement a paper provider list as a means to bridge the gap between early diagnosis and access to EI. Given the importance of EI in promoting skill acquisition in children with ASD and other developmental delays, it is necessary to explore possible ways to facilitate EI access. The primary aim of this study was to explore the demographic factors associated with satisfaction and demand for the video recommendations and provider list. The secondary aim of this study was to explore if using the video recommendations or the provider list was associated with a reduction in parental stress, improvement of parental sense of competence, and access to EI for toddlers recently diagnosed with ASD, GDD or a language disorder.



#### *4.1 Hypothesis 1: Acceptability of Participating in Research and Factors Associated with Study Retention*

The first hypothesis explored factors associated with study retention. Previous research has highlighted the impact of SES and negative mood symptoms (Nguyen, Fairclough and Noll, 2015; Reno & McGrath 2006) on study retention. The current study did not find that maternal education or any other factors were significantly related to study completion. Based on the results of the current study, it appears that parents are fairly receptive to a phone follow-up post diagnosis. A majority of parents (73% total) partially completed (14%) or fully completed (59%) the current study. Of those who partially completed the study, they successfully completed the follow-up phone interview but did not complete the final questionnaires by mail or phone. Parents also reported high satisfaction rates for having a provider follow-up with them by phone after they received a diagnosis. This suggests that time frame between diagnosis and onset of intervention may be an acceptable time frame to conduct research.

#### *4.2 Hypothesis 2: Acceptability and Demand for Video Recommendations and Provider List*

In order to address the second hypothesis, it was predicted that there would be a demand for a brief video intervention immediately following diagnosis. There appear to be several challenges related to the acceptability and demand for the current brief video intervention. Only 29% of parents who were randomized to the video condition reported that they viewed the video recommendations; most of the other parents in the video group reported they did not watch the video due to time constraints or that they forgot to watch it. In comparison, 75% of parents across both groups (73% within the treatment as usual condition; 76% in the treatment plus video condition) used the provider list indicating a higher acceptability and demand compared to the video. No factors (i.e., maternal education, parental race, child's diagnosis, prior involvement in

therapy, or child specific characteristics) were associated with use of the video recommendations or provider list.

When comparing the video recommendations to the provider list it is helpful to take into consideration the differences between the materials. It is possible that parents found it easier to review the provider list, given the relative efficiency of reading and the immediacy of access. For example, in order to access the YouTube Link or watch the DVD, the parent would need to go through additional steps to receive the information (e.g., access a computer or DVD player, find time to watch the material, remember to watch the video). It is also practical to consult a written document for phone numbers and addresses. It is also possible that the video recommendations and the provider list may serve different needs for parents. The video recommendations were intended to reduce parental stress and empower parents to access EI, whereas the provider list solely provided information regarding the practical aspects of EI access (i.e., telephone numbers and websites). Additionally, due to the methodological design of the current study, parents were not shown any portion of the video recommendations during feedback. Parents were primed to read the provider list, as it was often referred to multiple times during feedback. Therefore, future researchers may wish to take into consideration how materials or resources are emphasized within the context of oral feedback. It is possible that if the video were presented during the oral feedback session, parents may be more likely to refer back to it again after the session.

Given advancements in technology and increased availability of information online, it is also likely that other information online (e.g., Google) may provide parents with similar benefits as the video recommendations. Consistent with this hypothesis, the majority of parents in the treatment plus video group (66%) reported that they used the internet to gather other types of

information. This further suggests that some parents may have a bias towards turning to preferred methods of information gathering (i.e., google).

Although several parents did not use the video recommendations, those who did were highly satisfied with the material. Similarly, parents also reported high satisfaction rates with the provider list. This appears to be consistent with previous survey research suggesting providing information regarding the diagnosis and therapeutic options is associated with higher satisfaction rates (Gaspar de Alba & Bodfish, 2011; Hasnat & Graves, 2000). However, qualitative responses highlighted that too much information is perceived as overwhelming, at least to some parents. Thus there may be additional factors such as the coping style of the parent to take into consideration when understanding the process parents embark on between diagnosis and access to intervention. Dabrowska and Pisula (2010) explored the relationship between parental coping style and parental stress in raising a child with ASD and Down syndrome. Their findings suggest that parents who used an emotion-oriented (e.g., responding to stressor based on minimizing the emotion) coping style demonstrated a higher level of stress (Dabrowska & Pisula, 2010) than parents who used a problem-solving coping style. Therefore, it is possible that the manner in which materials are presented by the clinician and the content of the material provided at feedback may need to match the parent's coping style. Parents with a more task-oriented, or problem-solving coping style, may be more likely to prefer a larger volume of information at the time of the diagnosis, whereas parents with an emotion-oriented or avoidance-oriented coping style may need time to process their emotions with a supportive provider prior to receiving the information in order for them to use the information constructively.

### *4.3 Hypothesis 3: Limited Efficacy Testing: Exploring Parental Stress, Parental Sense of Competence and EI Access as Outcomes*

The findings from the current study did not support or disprove the third and final hypothesis. Although changes in parental sense of competence, parental stress, and EI access were not observed, results from the current study did not determine the effectiveness of the video recommendations due to limited use. There are a number of factors that may have contributed to the lack of significant findings. This is potentially related to the lack of demand for the video recommendations. Given that only six parents watched the video recommendations, there is limited statistical power to adequately explore the impact of the intervention on the outcome measures. It is also possible that the lack of significant findings may be related to the limited effectiveness for the current intervention. Although the parents who watched the video were satisfied with the material, there is no evidence that watching the video increased their sense of competence, decreased their sense of stress, or increased access to EI. It is also important to take into consideration that the current sample reported parental stress levels within the normal range and parental sense of competence between the moderate to high range. This is partially inconsistent with previous research, which suggests higher levels of parenting stress immediately following diagnosis (Feinberg et al., 2014). Moderate to high scores on parental sense of competence following diagnosis have been noted in previous studies (Estes et al., 2014). Since parents in the current sample are within the average to high average ranges on the outcome measures, it may be difficult to fully interpret clinically meaningful change based on the use of recommendation materials. Future research may benefit from exploring how to best assess change in stress and sense of competence after a parent receives a diagnosis.

The lack of significant findings may also be attributed to the limitations of using a brief intervention and a fairly short follow-up time frame (eight weeks). Estes and colleagues (2014) did not find significant differences in parental sense of competence in the three-month period following the diagnosis of ASD in toddlers. They suggested the potential changes in parental sense of competence may be a cumulative and longer-term process (Estes et al., 2014). It is also possible that a more intensive intervention is necessary in order to see a clinically significant decrease in parent stress following diagnosis. Future research should focus on creating supportive interventions for parents that facilitate access to EI, as well as interventions that are designed to treat impairments associated with developmental delay. When assessing the effectiveness of supportive parent interventions, researchers may wish to take into consideration not only the intensity of the intervention, but timing of follow-up procedures. For example, it is possible that a face-to-face follow-up meeting two weeks following diagnosis may be more impactful than a telephone call eight weeks following a diagnosis. When considering when to follow-up with parents, it is necessary to balance challenges related to retention as well as the need to influence change.

#### *4.4 Exploratory Analyses: Additional Factors Associated with Outcome Measures*

When exploring additional demographic factors associated with the study outcome measures, parental race significantly predicted access to EI, even after accounting for maternal education. Minority mothers (predominantly African American) were less likely to be as far along in the EI process as Caucasian mothers at follow-up. On average, minority mothers had contacted several EI providers but were not currently receiving therapy, whereas Caucasian mothers were already receiving therapy at follow-up. However, it is important to take in

consideration that the number of therapy hours did not significantly differ between Caucasian and minority toddlers.

These findings are commensurate with previous research regarding the associations between parental race, lower SES and difficulty accessing to EI (Bailey et al., 2004; Carr et al., 2015; Zwaigenbaum, 2015). Therefore, minority and low-resources families may benefit from additional support in accessing services and information regarding specific treatment resources within their community. Research suggests that low-resourced families often demonstrate higher rates of treatment attendance when intervention services are delivered in a flexible and accessible manner. For example, Carr and colleagues (2015) found that providing treatment within the context of a home or neighborhood and offering flexible schedules increased treatment attendance in low-resource, minority families. Increased efforts are required to understand how to best improve research and clinical practices in order to improve access to EI in underserved populations.

When exploring the influence of diagnosis on outcomes, parents of children with GDD endorsed higher scores of parental stress at follow-up in comparison to parents of children with ASD or language disorders. When controlling for maternal education, there was a large effect of diagnosis on parental stress at follow-up. Results of the current study are inconsistent with previous studies that suggest parents of children with ASD have higher levels of stress in comparison to parents of children with other developmental delays (Estes et al., 2009; Pisula, 2007). It is important to note that although parents of GDD reported higher levels of stress, parents on average (across diagnoses) reported stress within the normal range. Therefore, this result may not be clinically meaningful.

The current investigation did not find a significant correlation between EI access and parental sense of competence or parental stress. Although this could be attributed to the small sample size of the study, the relationship between EI access and parental stress has been noted within the literature (Mackintosh, Myers & Goin-Kochel, 2005). It is possible that the process of accessing EI may be stressful for some parents given the amount of effort involved in finding services. Conversely, some parents may endorse lower stress levels due to the fact that they are being proactive about finding therapeutic options. Future research may benefit from exploring parental outcomes such as parental stress and parental self-efficacy when determining the feasibility and effectiveness of an intervention.

#### *4.5 Clinical Implications of Current Research*

When considering how to improve clinical practices to address parents' needs, findings from the current investigation suggest that better coordination between diagnostic services and EI will be critical to addressing the unmet therapeutic needs of children with developmental delays. Within the context of the study, parents were highly satisfied with having a provider follow-up by phone after the evaluation. This suggests that parents may benefit from a phone-call after completing an evaluation to further ask questions or receive additional support. This finding is consistent with research suggesting that when parents perceived greater collaboration with their provider, they demonstrated higher levels of parent satisfaction and lower levels of stress (Moh & Magiati, 2012). This emphasizes the importance of forming alliances between diagnostic and interventions services as a means to better serve parents of children with developmental delays. Several parents within the current investigation also underscored the importance of communicating with other mothers who also have a child with ASD. This is consistent with previous research that parents often describe other parents of children with ASD

as helpful sources of information, more often than other groups of professions (Mackintosh, Myers & Goin-Kochel, 2005). Research has begun to emphasize the importance of family-centered care as a way to promote provider and parent collaboration as well as parent self-efficacy (Tomasello, Manning & Dulmus, 2010). Tomasello and colleagues (2010) also recommend that the families of children with disabilities have unique needs due to caregiving related stress and depression. One potential approach to address these needs is through parent mentorship programs (Dykens, Fisher, Taylor, Lambert & Miodrag, 2014; Magaña, 2014). For example, programs like PPEP that integrate the use of parent consultants within their pediatric practice have been effective at improving parent satisfaction, empowering parents, and increasing their knowledge of local supports (Burke et al., 2007). Given that mothers of children with ASD and other developmental delays have a shared experience of the EI system, they may be well equipped to support and empower one another.

Parents also recommended that improvements in the availability of therapeutic options (e.g., more services, flexible hours) would be helpful to increase therapeutic options and facilitate quicker access to EI services. This is commensurate with previous findings that parents often report they are unaware of the services available for their child (Raspa et al., 2010). Research has begun to show the effectiveness of economical interventions that incorporates parent training and parent implementation of skills (i.e., P-ESDM; Vismara, Colombi, Rogers, 2009). Parent mediated interventions may be particularly helpful for very young children, given that intervention programs for toddlers often require intensive parental involvement (Zwaigenbaum et al., 2015). Parent mediated interventions can also be provided within the home, which may increase availability and access to therapeutic options (Zwaigenbaum et al., 2015). Although parental implementation of intervention may be necessary and economical for



younger children with developmental delays, it is important to take into consideration that intensive parental involvement may be challenging for parents who are also working full-time.

#### *4.6 Limitations and Future Directions*

When understanding the results of the current study, it is important to take into consideration the study's limitations. Due to the fact that this is a feasibility study, sample size is a limiting factor. Reduced power from the small sample size influences the ability to generalize study findings to other populations. Additionally, few people watched the video recommendations and therefore there is limited feedback on how the content of the video can be improved, or if the content could influence outcome measures. It is also possible that being a part of the study or being involved in a larger research study may have influenced study completion, parental stress, or parental sense of competence. It is important to note that the following study did not use intent-to-treat analysis (Gupta, 2011); due to the fact that so few parents actually watched the video recommendations, intent-to-treat analysis would give limited information regarding the efficacy of the treatment.

Although the current brief intervention did not appear to be a feasible or acceptable intervention following diagnosis, it is imperative that future research utilizes mixed methods designs to explore how to collaboratively address the challenges to accessing EI (Pickard et al., 2016; Wandersman, Duffy, Flaspohler, Noonan et al., 2008). Given the complexity of the EI system, it is necessary to continue to involve multiple stakeholders (e.g., providers, parents, insurance companies) in conversations surrounding how to reduce stress and improve access. Additionally, future endeavors should continue to explore alternative modalities to implement skill development. For example, parent-led (Estes et al., 2014) and home-based (Carr et al., 2015) EI has begun to demonstrate promising results supporting their feasibility and

effectiveness. These alternative treatment modalities may provide families with additional opportunities to access evidence based EI services.

The time between early diagnosis and access to EI continues to be an interesting time frame for research and intervention. Although there were several challenges to delivering the brief video intervention, parents continue to express a desire for an integrated care system to better bridge the transition between diagnosis and access to EI. With the help of continued research, providers can continue to empower parents and reduce stress in the interim period between diagnosis and intervention and apply the principles of family-centered care.

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## APPENDICES

### Appendix A: Evaluation Satisfaction Interview

Did you receive a diagnosis before the evaluation at Georgia State University (GSU)?

**YES      NO**

Was your child receiving therapy before the evaluation at GSU?    **YES      NO**

*If yes, gather specific details about who is the therapy provider (Babies can't wait, private provide, etc.), type of therapy (ABA, speech, physical, occupational etc.), and intensity of therapy (hours per day or week).*

#### **Questions about your evaluation:**

1. Have you consulted with anyone since your evaluation? *If yes, specify who.*

3. Which aspect of the evaluation did you find the most helpful?

4. Which aspect did you find least helpful?

5. What did you want to learn more about during the evaluation?

**\*TREATMENT AS USUAL GROUP\***

#### **Since we last saw you:**

1. Did you consult the provider list offered to you following the diagnosis?    **YES      NO**

2. Did you consult another type of information (e.g., Parent to Parent, information online).

**Other** \_\_\_\_\_

Rate your level of satisfaction for each. On a scale from 1 to 5 how satisfied were you with (provider list, video recs, other) with 1 being Very Dissatisfied, 2 Dissatisfied, 3 Neutral, 4 Satisfied, 5 Very Satisfied:

**Provider List**                    1    2    3    4    5

**Other** (if applicable)            1    2    3    4    5

**\*TREATMENT PLUS VIDEO GROUP\***

**Since we last saw you:**

1. Did you consult the provider list offered to you following the diagnosis?    **YES**            **NO**

2. Did you consult the video recommendations provided to you following the diagnosis?

**YES**                    **NO**

3. Did you consult another type of information (e.g., Parent to Parent, information online).

**Other** \_\_\_\_\_

Rate your level of satisfaction for each. On a scale from 1 to 5 how satisfied were you with (provider list, video recs, other) with 1 being Very Dissatisfied, 2 Dissatisfied, 3 Neutral, 4 Satisfied, 5 Very Satisfied:

**Provider List**                    1    2    3    4    5

**Video Recommendations**    1    2    3    4    5

**Other** (if applicable)            1    2    3    4    5

4. If you watched the video recommendations, how could they be improved? Did you learn anything helpful from the video recommendations?

5. If you did not use the video-recommendations, what prevented you from using the video (e.g., time, unable to watch the video)? Did any other caregivers watch the video?

**\*FOR ALL PARENTS\***

**Access to EI**

6. Regarding your child's development, what challenges have you faced following the diagnosis?

7. Who have you discussed the diagnosis with (e.g., family members, people in the community)?

8. Did you seek services following your child's diagnosis      **YES**      **NO**

Has your child begun therapy or any other types of treatment? If you are receiving therapy please indicate when you started therapy (before or after the diagnosis). *Write parent's response below. Gather specific details about who is the therapy provider (Babies can't wait, private provide, etc.), type of therapy (ABA, speech, physical, occupational etc.), and intensity of therapy (hours per day or week).*

Code	Response Category (For coding post interview)
0	"I have not contacted early intervention service."
1	"I have contacted (called, inquired, emailed) <i>one</i> EI service/ therapy provider." "I am on a waitlist/scheduled intake appointment for one EI service."
2	"I have contacted <i>several</i> EI services/providers." "I am on the waitlist/scheduled intake appointment for <i>several</i> EI service providers"
3	"My child is currently receiving therapy." Child is receiving <i>less</i> than 10 hours of services per week.
4	"My child is currently receiving therapy." Child is receiving 10 <i>or more</i> hours of services per week. "My child was receiving therapy before evaluation and their has been <i>an increase</i> in services following evaluation."

9. Have you experienced difficulty finding services for your child? If you have not begun therapy what obstacles (e.g., unable to afford services, confusion finding services) have you experienced?

10. If you have contacted services, which have been the most helpful?

11. If your child is receiving therapy, approximately how many hours a week of therapy is your child receiving?

12. Have you been in contact with any other healthcare professionals (e.g., pediatrician, speech therapist, physical therapist etc.)?

13. How could the process of finding services for your child be improved? Do you have any recommendations for providers?

14. How have your opinions about your child's diagnosis changed over time?

Please rate the following statements using the following scale:

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

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1. I left the evaluation feeling confused.                               | 1 | 2 | 3 | 4 | 5 |
| 2. I had time to ask questions during the evaluation.                    | 1 | 2 | 3 | 4 | 5 |
| 3. The evaluation was carried out in a professional manner.              | 1 | 2 | 3 | 4 | 5 |
| 4. I was upset regarding results of the evaluation.                      | 1 | 2 | 3 | 4 | 5 |
| 5. I felt relieved after hearing diagnosis.                              | 1 | 2 | 3 | 4 | 5 |
| 6. I wish I had more help in caring for my child.                        | 1 | 2 | 3 | 4 | 5 |
| 7. The information I received was individualized to my child.            | 1 | 2 | 3 | 4 | 5 |
| 8. Having my provider follow up with me after the evaluation is helpful. | 1 | 2 | 3 | 4 | 5 |

Are you a single parent?    **Yes**    **No**

How do you identify racially? \_\_\_\_\_.

How far did you go in school? \_\_\_\_\_.

**Appendix B: Video Recommendations YouTube Link**

[https://www.youtube.com/playlist?list=PLm4naRdw\\_vryOrqQKLhJJkaotsEXJp2c](https://www.youtube.com/playlist?list=PLm4naRdw_vryOrqQKLhJJkaotsEXJp2c)