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### Publication Date

2019

Peer reviewed|Thesis/dissertation

Parent Involvement in the Treatment of Autism Spectrum Disorder: Validation of a Parent  
Involvement Survey

by

Michael Tiura

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Doctor of Philosophy

in

Education

in the

Graduate Division

of the

University of California, Berkeley

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Summer 2019



## Abstract

## Parent Involvement in the Treatment of Autism Spectrum Disorder: Validation of a Parent Involvement Survey

by

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Doctor of Philosophy in Education

University of California, Berkeley

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Researchers have acknowledged that parents play a pivotal role in their children's autism spectrum disorder (ASD) treatment (Burrell & Borrego, 2012). Unfortunately, many measures of parent involvement for this population use fewer than 10 items and focus only on parents' reinforcement of therapy skills at home, planning with clinicians, and/or knowledge about treatments (Burrell & Borrego, 2012; Solish & Perry, 2008). A measure of parent involvement that includes all the theorized ways parents support their children's ASD treatment is necessary for researchers to investigate how parent involvement is related to ASD treatment outcomes. In this study, the validity and reliability of the scores of a new measure for parents' involvement in their children's ASD treatment, the Parent Involvement Survey for Autism Treatment-Version 2 (PISAT-2), were investigated using item response theory. Results indicated that PISAT-2 scores had good internal consistency and differentiated well among four of the five proposed levels of parent involvement. Scores from the PISAT-2 were found to be positively correlated with parent self-efficacy ( $r = 0.38$ ), but not correlated with parent stress. Scores from the PISAT-2 were negatively related to parent education level and annual income, but not related to gender, ethnicity, number of caregivers in the home, reported SES, or work hours per week. The difficulty levels of the PISAT-2 items were similar for participants irrespective of gender, ethnicity, SES, annual income, or work hours per week. However, one item was found to be more difficult for participants with some high school as their highest level of education completed. Participant feedback indicated that the PISAT-2 covered the majority of the ways in which parents are involved in their children's treatment with some suggestions for improvement.

## **Parent Involvement in the Treatment of Autism Spectrum Disorder: Validation of a Parent Involvement Survey**

There has been an increase in new cases of autism spectrum disorder (ASD) in the last few decades. With this rise, both the psychological and educational communities have had to serve ever increasing numbers of children with ASD. Many treatments exist for children with ASD, and the majority of these are based on applied behavior analysis (Odom, Boyd, Hal, & Hume, 2010). Research indicates that children's cognitive functioning (Anderson et al., 2007; Ben-Itzhak & Zachor, 2007; Gabriels, Hill, Pierce, Rogers, & Wehner, 2001; Harris & Handleman, 2000, Trembath & Vivanti, 2014), age of entry into treatment (Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009; Harris & Handleman, 2000; Stahmer, Schreibman, & Cunningham, 2011), treatment hours per week (Granpeesheh et al., 2009), diagnosis severity (Ben-Itzhak & Zachor, 2007), and language skills (Szatmari, Bryson, Boyle, Streiner, & Duku, 2003) can affect the course of treatment.

In addition, researchers have claimed that parent involvement in treatment, such as rehearsing therapy skills at home and knowledge about ASD treatments, is linked to better outcomes (Benson, Karlof, & Siperstein, 2008; Burrell & Borrego, 2012; Solish & Perry, 2008). However, a validated measure of parent involvement in autism treatment that includes all the theorized domains of parent involvement does not exist in the literature (Burrell & Borrego, 2012). To investigate how parent involvement is related to treatment outcomes, there needs to be a reliable method of measuring parent involvement for this unique population that then allows us to draw valid conclusions.

In this paper, I first provide an overview of ASD and its current conception. Next, I briefly describe the most prominent treatments for ASD and the research on how client characteristics are related to treatment. Then, I present some of the research around parent involvement and parent involvement in ASD treatment. Afterward, I describe the development of a tool to measure parents' involvement in their children's ASD treatment, including the results of a pilot study. Last, I detail the development and validation of a revised version of a parent involvement survey for ASD treatment.

### **Autism Spectrum Disorder**

The first description of autism was posited by Leo Kanner in 1943 (Eisenberg & Kanner, 1956). He originally borrowed the term, autism, from descriptions of schizophrenia, which stated that patients lived in their own world cut off from normal social interaction. Kanner considered autism to be genetically determined, but he also posited that autism could be influenced by parenting. His ideas about the effects of parenting arose as a result of his observations of the parents of his patients with autism, who often led busy lives as successful academics and professionals.

Shortly after Kanner's (Eisenberg & Kanner, 1956) original description of autism, Hans Asperger proposed the existence of another form of autism. In 1944, Asperger described what he called autistic psychopathy (Asperger, 1991). Children with this condition exhibited highly intelligent behavior, but they seemed uninterested in and unable to interact with others socially. His description of this form of autism was later added to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as Asperger's Syndrome (American Psychiatric Association, 1994). Decades later, parenting practices were dismissed as a cause of ASD, and genetic influences were deemed the root cause of the disorder (DeMyer, Hingtgen, & Jackson, 1981). Asperger's Syndrome and autism were most recently combined in the fifth

edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as ASD (American Psychiatric Association, 2013).

Currently, ASD is conceptualized as a biologically determined set of behaviors that occurs with varying presentations and severity. Children with ASD present with a variety of developmental delays in the areas of communication, socialization, cognitive skills, interests, and motor skills (Goldstein & Naglieri, 2013). Significantly more boys receive an ASD diagnosis than girls (Smalley, Asarnow, & Spence, 1988), and ASD presents equally across socio-economic backgrounds (Gillberg & Schaumann 1982). Also, it is estimated that one quarter of children with ASD have a concurrent diagnosis of epilepsy and up to 75% experience intellectual delays (Goldstein & Naglieri, 2013). Average or above average intellectual functioning has been found to be the best predictor of a good prognosis (Gillberg & Steffenburg, 1987; Howlin, Goode, Hutton, & Rutter, 2004; Venter, Lord, & Schopler, 1992).

Social functioning skills, such as interpersonal skills, capacity to engage in interactive play, coping strategies, and communication skills, are consistently the most pervasive impairment for children with ASD. Also, researchers have found that social impairments are the strongest predictor of receiving an ASD diagnosis (Siegel, Vukicevic, Elliott, & Kraemer, 1989). As expected, these impairments have been shown to lead to difficulties in social relations and interpersonal abilities (Baron-Cohen, 1989; MacDonald et al., 1989). Overall, children with ASD exhibit much lower social skills than expected relative to their cognitive abilities (Goldstein & Naglieri, 2013; Volkmar et al., 1987).

The DSM-5 (American Psychiatric Association, 2013) has two main criteria for classifying children with ASD. The first criterion is persistent deficits in social communication and interaction across multiple contexts. These social-communication and interaction deficits include deficits in social-emotional reciprocity; nonverbal communicative behaviors; and the development, maintaining, and understanding of relationships among people. The second criterion is restricted, repetitive patterns of behavior, interests, or activities. These behaviors include stereotyped or repetitive motor movements, use of objects, or speech; insistence on sameness, inflexible adherence to routines, or ritualized patterns of behavior; highly restricted, fixated interests that are abnormal in intensity or focus; and hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment. Lastly, ASD must occur in early childhood and significantly impair functioning; impairments must not be better explained by intellectual disability or global developmental delay.

### **Treatment of ASD**

In a 2010 meta-analysis, Odom et al. identified 30 treatments for children with ASD. The researchers found that the majority of the treatments they identified were based on behavioral theory and, more specifically, applied behavior analysis (ABA). ABA therapy has been utilized for the treatment of ASD since the early 1960s (Goldstein & Naglieri, 2013). Lovaas (1987) gave a detailed account of the ABA therapy model and conducted one of the first experimental studies of ABA therapy. Lovaas first demonstrated that ABA therapy can result in large cognitive gains and placement into general education settings for children with ASD.

In Lovaas' (1987) study, children with ASD received 40 hours of one-on-one ABA therapy. Children with ASD were taught target skills by clinicians who broke a task into its component parts and taught each component in isolation using reward systems. Gradually, clinicians added the component behaviors together to build more complex behavior. Treatment was based on operant conditioning procedures, which included both rewards for desired behaviors, such as snacks and praise, and punishments for undesirable behaviors, such as

ignoring and time-outs. The target behaviors for each child depended on their presentation of ASD. Target behaviors in ABA therapy often included reducing aggressive or repetitive behaviors and teaching skills such as functional communication and self-care tasks.

A second treatment model often used in educational settings is the TEACCH model. The primary strategy used in TEACCH is structured teaching, which involves the teaching of new skills as well as the use of visual and organizational supports in the environment. TEACCH has two major goals: (a) to create an organized and predictable environment for children with ASD, meeting their need for sameness and routine; and (b) to teach skills that are functional and promote independence (Bourgondien & Coonrod, 2013). Longitudinal and meta-analytic studies have found that TEACCH programs significantly improve cognition and perception, decrease negative behaviors, foster independence, and increase motor function for children with ASD (Bourgondien & Coonrod, 2013; Odom et al., 2010).

Despite the effectiveness of both ABA therapy and TEACHH, some concerns have been noted by scholars in the literature. Scholars have noted that ABA therapy and TEACCHH often lack opportunities for the spontaneous use of skills and that behavior instruction is typically divorced from communication (Goldstein & Naglieri, 2013). In an attempt to address these concerns, some researchers have begun to add social-emotional elements to treatment plans. Social-emotional techniques include instruction through modeling (Bellini & Akullian, 2007), naturalistic teaching strategies (McGee & Daly, 2007), peer groups (Carter, Meckes, Pritchard, Swensen, Wittman, & Velde, 2004), pivotal response training (Koegel, Koegel & Carter, 1999), and social narratives (Goldstein & Naglieri, 2013). White, Koenig, and Scahill (2007) found that interventions focused on self-awareness and teaching social scripts had better outcomes for children with ASD than strict behavioral interventions.

The Early Start Denver Model (ESDM) is an example of a comprehensive treatment for children with ASD that incorporates both behavioral theory and social-emotional learning. The ESDM incorporates elements from ABA therapy with social-communication development, imitation skills, social motivation, and naturalistic teaching (Rogers & Dawson, 2010). The ESDM includes play activities, positive reciprocal interactions, and joint activities; it also utilizes transition periods. Researchers have found that the ESDM can be more effective than strict ABA therapy (Odom et al., 2010). Also, in one study, children who participated in an ESDM program demonstrated long-term gains in overall intellectual ability, adaptive behavior, symptom severity, and challenging behavior up to two years after treatment (Estes et al., 2015).

### **Predictors of ASD Treatment Outcomes**

After reviewing the literature on predictors of treatment outcomes for children with ASD, Trembath and Vivanti (2014) argued for a new approach in investigating treatment outcomes. These researchers suggested that behavioral features of individual children with ASD should be investigated in relation to treatment response. To support this claim, they focused on Vivanti, Dissanayake, Zierhut, Rogers, and Team's (2012) investigation of predictors of treatment outcomes for children with ASD treated using the ESDM. Vivanti et al.'s findings indicated that behavioral tendencies not used in diagnosis, such as children's functional object use and their ability to infer goal directed behavior, predicted which children benefited most from treatment. Trembath and Vivanti (2014) proposed that researchers should investigate individual characteristics of children with ASD that are not related to diagnosis to discover which children would benefit the most from each treatment type.

Tiura, Kim, Detmers, and Baldi (2017) investigated client characteristics in an effort to demonstrate how each predicted children's growth over the course of ABA therapy. In the

study, 35 participants with a mean entry age of 3 years received ABA therapy. Children were assessed at intake and every 6 months thereafter using the Developmental Profile-3 (Alpern, 2009) to measure their communication, social-emotional, adaptive behavior, and physical development. The researchers used longitudinal growth curve analysis to investigate if the age at entry, diagnosis severity, cognitive functioning, treatment hours per week, gender, parent education level, and primary language spoken at home significantly predicted the growth trajectories of ABA treatment outcomes.

The findings indicated that higher cognitive functioning predicted significantly faster growth across all four developmental domains, but no other client characteristic predicted growth rates across all four domains. Diagnosis severity was related to slower growth rates in physical development, and speaking English as a primary language predicted faster growth in social-emotional and physical development. Male participants tended to improve more quickly in adaptive behavior and physical development. Last, age at entry, treatment hours per week, and parent education level did not predict growth trajectories of ABA treatment. Tiura et al. (2017) noted that although they did not find age of entry to be related to growth, many other studies have found that entering treatment at a younger age is associated with better prognosis (e.g., Ben-Itzhak & Zachor, 2007; Eikeseth, Smith, Jahr, & Eldevik 2002; Gabriels et al., 2001; Granpeesheh et al., 2009; Harris & Handleman, 2000).

In addition to children's individual characteristics, researchers have acknowledged that parents play a pivotal role in their children's ASD treatment. Researchers have found that parents reinforce treatment at home and that parental competency in ABA techniques can improve children's outcomes (Benson et al., 2008; Burrell & Borrego, 2012; Solish & Perry, 2008). Unfortunately, a validated measure of parent involvement in autism treatment, which includes all the ways parents are theorized to be involved, does not exist in the literature. Many measures use fewer than 10 items and focus only on the parents' reinforcement of therapy skills at home and their collaboration with therapists (Benson et al., 2008; Burrell & Borrego, 2012; Solish & Perry, 2008). A measure of parent involvement that includes the many theorized domains of parent involvement is necessary for researchers to get a broader understanding of how the domains of involvement relate to ASD treatment outcomes.

### **Parent Involvement**

Parent involvement has been studied for decades in education. Studies indicate that parents are involved in home-based and school-based support (Epstein, 2010; Hoover-Dempsey & Sandler, 1997; Pomerantz, Moorman, & Litwack, 2007). Examples of home-based support include helping with homework assignments, providing academic enrichment activities, and contacting the child's teachers (Hoover-Dempsey & Sandler, 1997). Also, parents often provide enriching activities for their children in the community, such as visiting libraries and museums. School-based support comprises volunteering at the school site, attending parent-teacher conferences, and being involved in parent-teacher associations (Epstein, 2010). Distinguishing between home-based and school-based involvement has been found to have the advantages of being concrete and easily interpretable by parents, educators, researchers, and policy makers across disciplines (Pomerantz et al., 2007).

Epstein's (2010) model of parent involvement divides parent involvement even further into six categories that represent both school-based and home-based involvement. The six categories of parent involvement in Epstein's model are parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community. Practices in the category of parenting help families establish a home environment that supports learning, such as



parent trainings and establishing age appropriate conditions for learning. Communicating encompasses practices that establish effective lines of communication between home and school including regular conferences, systematic progress reports, and invitations for communication. Volunteering involves recruiting and organizing parent help at the school site, such as parents in the classroom or after school for homework help. Learning at home includes activities parents do at home to support learning (e.g., help with homework and outside enrichments activities). Decision making involves including parents in school decisions and developing parent leaders and representation, as in parent-teacher associations and district-level councils. Collaborating with the community includes identifying and integrating resources from the community to strengthen school and parent practices, such as connecting with community health, recreational, and advocacy organizations. These six domains come together to form a complete picture of all the ways parents are involved in their children's education in Epstein's model of parent involvement.

**Parent involvement and culture.** In the United States, parent involvement correlates with decreased parent stress, increased parent self-efficacy, higher socio-economic status (SES), and higher levels of parent education (Epstein, 2010; McWayne, 2015; Pomerantz et al., 2007). Research also indicates that parents with differing cultural backgrounds in the United States and across cultures engage in differing types of parent involvement practices. Recent studies have demonstrated that Black and Latinx parents engage in home-based parent involvement practices, but very few school-based practices (Calzada et al., 2015; Jeynes, 2016, 2017). Consistent with other studies of parent involvement, Jeynes found a positive correlation between parent involvement and higher SES, as well as a positive correlation between parent involvement and student academic achievement for both Black and Latinx families.

Cross-cultural studies have revealed both similarities and differences in parent involvement in the United States, China, and Japan. Wang, Deng, and Yang (2016) found that parent involvement was related to higher SES and higher parent education in a Chinese sample of 12,724 parents, which is consistent with parent involvement studies in the United States (Epstein, 2010; McWayne, 2015; Pomerantz et al., 2007). Studies conducted in Japan have found that higher SES was related to scheduling more enrichment activities outside of school, but related to a decrease in school-based involvement (Holloway et al., 2016; Holloway, Yamamoto, Suzuki, & Mindnich, 2008; Yamamoto, Holloway, & Suzuki, 2006, 2016). Research conducted in Japan also found that parent self-efficacy was related to increased parent involvement, consistent with the findings of studies on parents in the United States (Holloway et al., 2016; Yamamoto et al., 2006, 2016).

**Parent involvement and ASD.** Consistent with the results of studies involving typically developing children, the parents of children with ASD are involved in their children's education both at home and at the school site (Benson et al., 2008). Benson et al. found that the involvement of parents of children with ASD depended on how many opportunities for involvement were offered and how often families were contacted by school sites. Additionally, Benson et al. found that diagnosis severity, parent self-efficacy, parent stress, and SES were associated with parent involvement. Diagnosis severity was found to be negatively related to school-based involvement and parent stress was found to be negatively connected to parent involvement, generally; parent self-efficacy and SES were found to be positively correlated to parent involvement.

There is limited research on the relationship between parent involvement and ASD treatment. Burrell and Borrego (2012) conducted a review of literature studying parent

involvement in their children's ASD treatment. Their review indicated that parent involvement has been studied using survey items asking about involvement at the clinic site and home support. These questions have covered collaboration at a clinic site, reinforcement at home, education through research and advocacy groups, and coordination between service providers. However, these studies do not consider all six categories of parent involvement that Epstein (2010) described in her model. Instead, many of the studies used survey items related to two or three of these categories. For example, Solish and Perry (2008) measured parent involvement in ASD treatment using six items, three assessing parent collaboration at the clinic site and three assessing parent reinforcement at home. Burrell and Borrego (2012) indicated that no study measured parent involvement using all the domains that have been identified in literature.

### **Development of a Pilot Parent Involvement Measure for ASD Treatment**

In 2017, I developed a pilot measure based on Epstein's (2010) model of parent involvement using the four building blocks model (Wilson, 2005). The four building blocks model includes developing a construct map, item responses, an outcome space, and then selecting a measurement model to test how well the items and respondents fit the construct map. The partial credit model of measurement from item response theory was used to test the fit of the pilot measure.

**Development of the construct map.** The construct map was workshopped with colleagues, parents, and clinicians. Clinicians and parents indicated that some parents may be involved in indirect ways or in differing combinations of types of parent involvement (e.g., at the clinic site, home support, outside enrichment, and research and advocacy), and the age-group of children asked about in the survey needed to be specified. This last point is important because children at different developmental levels, such as in childhood versus adolescence, may be supported by parents in different ways. With these suggestions, the target population for the measure was defined to be parents with elementary-aged children in treatment for ASD, and the levels in the construct map were modified to be a summation of parent involvement across the domains. Each level represented varying amounts of parent involvement based on the frequency of that involvement across domains, as well as how much they agreed or disagreed on a Likert scale about the amount of their engagement in certain activities across all the domains (Table 1). The categories of parent involvement mirrored Epstein's (2010) model, except for the category of volunteering, which was not included because feedback from clinicians indicated that treatment is only conducted by trained staff and never by parent volunteers at clinic sites.

Table 1  
*Parent Involvement Construct Map*

Levels	Frequency Items	Likert Items
Level 5 Superiorly Involved	Parents participate two or more times per week in the five domains of parent involvement.	Parents who select strongly agree to questions about the five domains of parent involvement.
Level 4 Highly Involved	Parents participate weekly in the five domains of parent involvement.	Parents who select agree for questions about the five domains of parent involvement.
Level 3 Moderately Involved	Parents participate monthly in the five domains of parent involvement.	Parents who select neither agree nor disagree for questions about the five domains of parent involvement.
Level 2 Minimally Involved	Parents participate rarely in the five domains of parent involvement.	Parents who select disagree for questions about the five domains of parent involvement.
Level 1 Uninvolved	Parents never participate in the five domains of parent involvement.	Parents who select strongly disagree for questions about the five domains of parent involvement.

**Item development.** Item formats and content were modeled after existing scales of parent involvement in education, including the Family Involvement Questionnaire (FIQ; Grover, 2015) and the Parent Teacher Involvement Survey (PTIS; McWayne, 2015). The original set of items totaled 20, with four items covering each of the five domains of parent involvement. Two of the four items asked about the frequency with which parents engaged in activities (*rarely*, *sometimes*, or *often*), and the remaining two were Likert-style items where parents had to choose among *strongly disagree*, *disagree*, *neither agree nor disagree*, *agree*, or *strongly agree*. After development, the items were paneled to solicit feedback from colleagues on how they could be improved, leading to several changes.

First, items needed to be specific about the frequency each was probing for (e.g., *two or more times per week*, *weekly*, *monthly*, etc., instead of *rarely*, *sometimes*, or *often*). Next, some of the items needed to be more specific, and some items were asking two questions instead of one (e.g., “I maintain clear rules at home that my child can follow”). The items that were seen as asking two questions were then broken apart and made more specific to the target population (e.g., “I maintain explicit rules at home” and “my child can follow the rules we have at home”). Last, there were concerns about only including one question on reading about autism. Thus, items were added about specific sources of information such as research studies and news articles. The revised pilot measure consisted of 30 items spanning the five domains of parent involvement described earlier (i.e., clinic site, home support, outside enrichment, coordinating services, and advocacy and research). Each of the five domains had six questions each, with three frequency items and three Likert scale items (see Appendix 1).

**Pilot study participants.** The measure was emailed to the parents of children who are receiving treatment for ASD at two autism treatment clinics in California by clinic directors using the Google Forms online platform. Twenty-six parents participated and the average age of their children with ASD was 5.5 years old. Thirteen of respondents were male and 13 were

female. Ten of the respondents identified as White, 10 identified as a minority (six Hispanic, three Black, and one Filipino), and six did not indicate their ethnicity. Eight respondents had a high school diploma, six had earned an associate's degree, seven had earned a bachelor's degree, three had earned a master's degree, and two had a specialist or doctoral degree. Also, four respondents identified as working class, seven as lower-middle class, seven as middle class, seven as upper-middle class, and one as upper class.

**Additional measures.** Parents completed additional questions on demographic variables, parent stress, and self-efficacy, and they were asked to give feedback about the measure. Parent stress and parent self-efficacy were included as external validity measures (McWayne, 2015; Pomerantz et al., 2007). Parent stress was assessed with three Likert scale questions ( $\alpha = 0.72$ ) adapted from the Parental Stress Scale ( $\alpha = 0.83$ ; Berry & Jones, 1995). Parent self-efficacy was assessed with three Likert scale questions ( $\alpha = 0.69$ ) adapted from the General Self-Efficacy Scale ( $\alpha = 0.86$  to  $0.94$ ; Luszczynska, Scholz, & Schwarzer, 2005) and the Parenting Sense of Competence Scale ( $\alpha = 0.75$  to  $0.88$ ; Gilmore & Cuskelly, 2008). Demographic items included questions on gender, ethnicity, highest level of education, SES, and the age of their child with ASD. The final set of questions solicited feedback on the scale from respondents. These questions included asking for suggestions to improve the measure and for clarification on why respondents may have skipped an item.

### **Results of the Pilot Study**

**Reliability evidence.** Cronbach's alpha was found to be 0.83 for parent involvement scores, and person separation reliability was found to be 0.85, indicating that the scores on the 30-item measure had good internal consistency. Split-half reliability was calculated by splitting the measure into the odd numbered and the even numbered items and correlating the scores. The division resulted in both sets having the same number of frequency and Likert scale items. Split-half reliability was found to be 0.94. Cronbach's alpha for scores from the parent stress Likert scale items was found to be 0.72 and Cronbach's alpha for the parent self-efficacy Likert scale scores was found to be 0.69.

**Response process validity.** Twenty-four of the respondents (92%) indicated that the measure did cover all the ways that they are involved in supporting their children's treatment. Respondents' comments to improve the measure included suggestions to add a frequency option of every other week to the frequency items, add questions about home support that covered using sensory tools and toys, and add questions that address other treatment types that children with ASD often receive, such as speech and language therapy. A think-aloud session was also conducted with one parent who was asked to fill out the measure while thinking about how she supported her 7-year-old child. This parent indicated that the questions were easy to understand. She also agreed that questions about additional services, such as speech therapy and social skills groups, should be added and that it would be helpful to re-word the frequency categories differently.

**Internal structure validity.** A Wright map was used to investigate the internal structure of the measure (Figure 1). The Wright map showed a general upward trend at each threshold between the five levels of parent involvement. Similar to this trend, the average mean threshold location between each level increased as expected (-1.25, -0.85, -0.03, 0.96).

Investigations of item responses revealed that respondents only selected on or two levels for Items 4, 18, 19, and 20. Additionally, respondents only chose the highest level on Item 5 ("I play with my child") and thus Item 5 was excluded from analyses. An investigation of infit mean squares by item revealed that the majority of items' infit mean squares were within the

expected range (between 0.75 and 1.33), thus indicating that they matched the construct map. Three items fell outside the acceptable range (Items 13, 14, and 17). Many of the respondents (16 of 26) had good infit (between 0.75 and 1.33), indicating that their pattern of responding was consistent with the construct map. However, five respondents (1003, 1004, 1007, 1008, and 1017) fell above 1.33 and five respondents (1012, 1020, 1021, 1022, and 1024) fell below 0.75. The respondents who fell above 1.33 did not fit the expected pattern of responding and those below 0.75 fit the pattern of responding better than would be expected given random error.

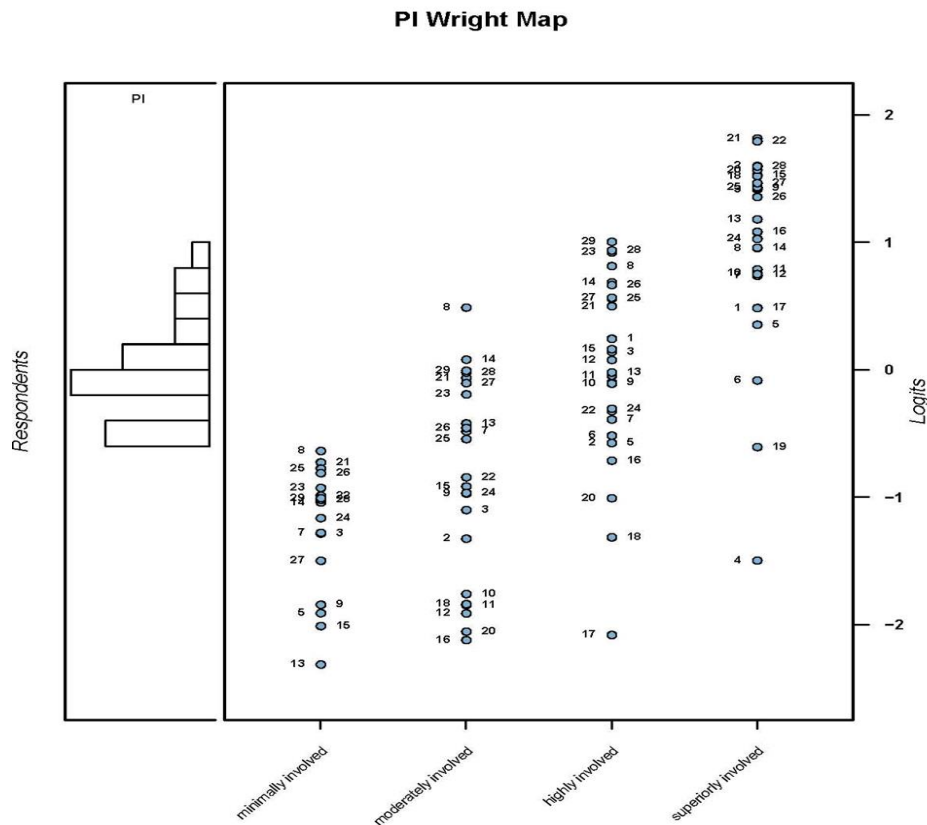


Figure 1. Pilot study Wright map by construct level.

DIF and correlational analyses required equal groups of at least 10 participants in each group, which was achieved in this sample. The DIF analysis by gender revealed that Item 7 was more difficult for male participants than for female participants. Items 4, 6, and 13 were questionable as to if and how much they functioned differently based on gender. The DIF analysis by ethnicity was conducted with the 20 respondents who indicated their ethnicity when responding to the measure. These data were collapsed into two categories, White and Minority, in order to have large enough group sizes to conduct the analyses (at least 10 participants in each category). The results of the DIF analysis by ethnicity indicated that two items (3 and 4) were more difficult for Minority respondents than for White respondents. Age of the child with ASD ( $r = 0.025$ ,  $p = 0.91$ ), parents' education level ( $r = -0.015$ ,  $p = 0.94$ ), and SES ( $r = -0.037$ ,  $p = 0.86$ ) were not meaningfully correlated with parent involvement.

**External validity.** As found in the extant literature, parent involvement was positively and meaningfully correlated with parent self-efficacy ( $r = 0.39, p = 0.049$ ). The correlation with parent stress was negative as expected ( $r = -0.20, p = 0.34$ ), but the effect size was modest.

### **Discussion of Pilot Study**

The purpose of the pilot study was to create a method for measuring parent involvement in a new population, the parents of children in treatment for ASD. Although several of the items did not function in the way they were expected, scores on the measure yielded evidence of internal consistency, validity, and split-half reliability. DIF analyses revealed that many of the items were functioning similarly by ethnicity and gender, and parent involvement was not related to the age of the child with ASD, parent education, or SES. A positive correlation was found between parent involvement and self-efficacy scores. However, the pilot study was based on a small sample of 26 parents. These results may not be consistent with other findings in the literature because the pilot study did not have the statistical power to detect small effects (Burrell & Borrego, 2012; Calzada et al., 2015; Holloway et al., 2008, 2016; Jeynes, 2016, 2017; Wang et al., 2016; Yamamoto et al., 2006, 2016).

### **The Present Study**

Currently, no validated measure exists that includes all the theorized domains of parents' involvement in their children's ASD treatment. This study applied Epstein's (2010) parent involvement framework from education, professional clinician feedback, and parent feedback to create a measure of parent involvement for ASD treatment. Parents support their children through their participation at the clinic site by checking in with clinicians, planning treatment goals, coordinating services between sites (clinic, schools, day-care, etc.), and planning for the future (Burrell & Borrego, 2012; Goldstein & Naglieri, 2013; Rogers & Dawson 2010; Solish & Perry, 2008). Parents are involved at home by using behavioral techniques to reinforce treatment, implementing routines, and using environmental supports such as visual aids at home (Burrell & Borrego, 2012; Goldstein & Naglieri, 2013; Solish & Perry, 2008). Parents provide their children outside experiences, such as enrolling them in clubs and scheduling outings (Burrell & Borrego, 2012; Goldstein & Naglieri, 2013). Additionally, parents are involved through advocacy and research by joining parent support groups, reading about ASD, and engaging with ASD advocacy groups (Bourgondien & Coonrod, 2013; Burrell & Borrego, 2012; Goldstein & Naglieri, 2013). Utilizing a consistent measure of parent involvement that includes all the theorized domains of parent involvement will allow researchers to compare results across studies, as well as investigate how each domain of parent involvement may function differently for parents of children with ASD.

The goal of this study was to validate scores on a new measure of parents' involvement in their children's ASD treatment, the Parent Involvement Survey for Autism Treatment-Version 2 (PISAT-2), developed by revising the instrument used in the pilot study. Several research questions were addressed. The first question was about the internal consistency and structural validity of PISAT-2 scores. I hypothesized that the items of the PISAT-2 would reliably differentiate varying levels of parent involvement (*uninvolved, minimally involved, moderately involved, highly involved, and superiorly involved*). Fitting an item response theory model would yield a Wright map with a clear separation of the five levels of parent involvement as outlined in the construct map (Table 1), with mean threshold locations between each level increasing accordingly. Scores on the PISAT-2 would have reliability equal to or above 0.70 for both Cronbach's alpha and person separation reliability. The Likert scale items from the pilot version of the survey, which make up the majority of the items on the PISAT-2, differentiated between

all five levels and had excellent internal consistency and split-half reliability in the pilot study, although the pilot sample was small. Additionally, the survey was based on Epstein's (2010) model of parent involvement, and other scales that use this framework in education have been shown to have acceptable reliability (Grover, 2015; McWayne, 2015).

The second question was about the association between parents' scores on the PISAT-2 and parent stress and parent self-efficacy. I hypothesized that the scores from the PISAT-2 would be related to parent stress and parent self-efficacy as predicted in the parent involvement literature. Previous research has shown that parents who are more involved will report higher levels of self-efficacy and less stress (McWayne, 2015; Pomerantz et al., 2007), and results from the pilot study yielded similar findings.

The third question was about the relationship between parents' scores on the PISAT-2 and parents' demographic variables (gender, ethnicity, education level, and SES). I hypothesized that the construct of parent involvement being measured by the PISAT-2 would be similar across groups. The PISAT-2 was based on Epstein's (2010) model of parent involvement and other scales that use this framework in education that have shown to work similarly across groups (Grover, 2015; McWayne, 2015). Also, the results from the pilot study found that parent involvement was not related to parent education or SES.

The fourth question was about the fairness of the items on the PISAT-2 across groups (gender, ethnicity, education level, and SES). I hypothesized that the items of the PISAT-2 would not function differently for different populations of respondents (gender, ethnicity, education level, and SES). DIF analyses by gender, ethnicity, education level, and SES would show that items are functioning similarly for all respondents regardless of these factors. I believed this to be the case because the items on the survey were modeled after other parent involvement surveys that have been shown to contain un-biased language, such as the FIQ (Grover, 2015) and the PTIS (McWayne, 2015). Also, the items that were functioning differently across groups in the pilot version of the survey were removed or modified in the PISAT-2.

The fifth and final question was about response process validity of the PISAT-2 through parent feedback. I hypothesized that parent feedback would support the existence of a parent involvement construct for ASD treatment that includes parent involvement at the clinic site, at home, outside enrichment, coordinating services, and advocacy and research. Research in parent involvement in ASD treatment indicates that parents are involved in treatment at the clinic site, at home, outside enrichment, coordinating services, and advocacy and research (Burrell & Borrego, 2012). Additionally, parent feedback from the pilot study indicated that the majority of parents agreed that the survey included all the ways they are involved in their children's treatment.

## **Method**

### **Participants**

Participants were recruited from autism treatment clinics and autism parent networks in the United States. The goal was a sample size of 250, which was based on a power analysis that indicated a sample size of at least 200 was required for correlational analyses to detect an  $r$  value of 0.20 using a  $p$  value of 0.05 for statistical significance when investigating the association of scores on the PISAT-2 with parent stress and parent self-efficacy. Participants were the parents or guardians of school-age children (ages 4–10) with ASD currently receiving treatment. In total, 340 parents participated in this study. Of those 340 participants, 268 (79%) identified as female and 72 (21%) identified as male. Participants' reported number of caregivers in the home

ranged from one and six, with the average number of caregivers in each home being two. Table 2 displays the full details of participants' characteristics.

Table 2  
*Participant Characteristics*

Characteristic	<i>n</i> , (missing)	%
Gender	340, (0)	100
Female	268	79
Male	72	21
Ethnicity	335, (5)	98
White	228	67
Black	48	14
Hispanic	44	13
Asian	13	4
Middle-Eastern	1	< 1
Native American	1	< 1
Education	337, (3)	99
Some High School	14	4
High School Diploma	101	30
Associate's Degree	86	25
Bachelor's Degree	92	27
Master's Degree	40	12
Specialist or Doctoral	4	1
SES	340, (0)	100
Working Class	91	27
Lower-Middle Class	92	27
Middle Class	122	36
Upper-Middle Class	33	10
Upper Class	2	< 1
Annual Income	335, (5)	98
< \$15,000	46	14
\$15,000 – \$34,999	74	21
\$35,000 – \$49,999	71	21
\$50,000 – \$74,999	81	24
≥ \$75,000	63	19
Work Hours per Week	338, (2)	99
< 10	131	39
10 – 20	23	7
21 – 30	27	8
31 – 40	80	23
> 40	77	22

## Procedure

Data were collected through an online survey platform using Google Forms. Clinic supervisors and parent network leaders emailed the survey to participants individually. Posts advertising the study were also included on social media websites and the webpages of autism advocacy groups. Participants' names were not collected to keep participant identities anonymous. Participants were informed that the purpose of this survey was to determine the ways parents support their children's treatment and development, to gather feedback on ways to



improve the survey, to see if parent involvement is related to stress and self-efficacy, and to attain demographic data to see if items are fair across demographics. Directions at the beginning of the survey directed parents to indicate whether they *strongly disagree*, *disagree*, *neither agree nor disagree*, *agree*, or *strongly agree* with each statement in the survey. Participants were allowed to complete the survey at their leisure using their personal computers. The survey began with the items from the parent involvement construct presented to participants in a randomized order. Those items were then followed by items about parent stress, parent self-efficacy, demographics, and feedback.

### Measures

**Parent Involvement Survey-Version 2 (PISAT-2).** The second version of the Parent Involvement Survey for Autism Treatment was used in this study to measure parents' involvement in their children's ASD treatment. This version of the survey has 15 Likert scale items and included items about coordinating with a variety of service providers in accordance with parent feedback from the pilot study. Possible responses ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Survey items spanned the same five domains of activities as the first pilot measure with three items in each category.

An analysis of the reading level of the survey estimated that the items on the PISAT-2 were at the fourth-grade reading level based on Fry (1969) readability and the seventh-grade level based on the Flesch-Kincaid scale (Kincaid, Braby, & Mears, 1988). A full list of the items of the PISAT-2 can be found in Appendix 2.

**Parent stress.** Three of the 18 Likert scale items from the Parent Stress Scale (Berry & Jones, 1995) were used to assess parent stress levels. These three items from the Parent Stress Scale were selected because they asked explicitly about stress. Possible responses ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Scores from the Parent Stress Scale have been found to have good internal reliability ( $\alpha = 0.83$ ) and test-retest reliability ( $r = 0.83$ ; Berry & Jones). Additionally, scores from the Parent Stress Scale have been found to be positively correlated with scores from the Perceived Stress Scale ( $r = 0.41, p < 0.01$ ; Berry & Jones). Cronbach's alpha for the parent stress Likert scale items was found to be 0.65 in this study.

**Parent self-efficacy.** Three Likert scale items were used to measure parent self-efficacy. Possible responses ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). One of the three items was adapted from the General Self-Efficacy Scale because it was related to handling unexpected events, which was indicated as being related to parenting by clinicians and parents (Luszczynska et al., 2005). Luszczynska et al. (2005) found that the scores from the General Self-Efficacy Scale had good internal consistency reliability in a German sample ( $\alpha = 0.94$ ), Polish sample ( $\alpha = 0.90$ ), and South Korean sample ( $\alpha = 0.86$ ). The remaining two items were adapted from the Parenting Sense of Competence Scale because they explicitly asked about parents' confidence in solving parenting problems (Gilmore & Cuskelly, 2008). Validity evidence for the General Self-Efficacy Scale scores includes significant positive relationships with well-being ( $d = 0.50$ ), health promotion ( $d = 0.29$ ), and coping ( $d = 0.52$ ; Luszczynska et al., 2005). Gilmore and Cuskelly (2008) reported that the scores from the Parenting Sense of Competency Scale were found to have good internal consistency reliability ( $\alpha = 0.75$  to 0.88). Cronbach's alpha for scores on the three parent self-efficacy items was found to be 0.75 in this study.

**Demographic variables.** Participants were asked to indicate their own gender, ethnicity, highest level of education, SES, annual income, number of hours they work outside the home each week, as well as the number of and education levels of other caregivers in the home, when

applicable. These questions were included in order to examine if the survey overall and its items were functioning differently for different groups of participants.

**Parent feedback.** The survey included several questions soliciting feedback from participants. These questions asked for suggestions for improvements and for clarification on why participants may have skipped an item. The purpose of asking these questions was to receive feedback from parents, confirm that the survey included all the ways parents reported supporting their children's treatment, and ensure that parents understood the items.

### **Data Analysis**

ACER ConQuest version 2.0 was used to conduct data analyses. The ConQuest software was specifically designed to conduct analyses using statistical models from item response theory (Wu, Adams, Wilson, & Huldane, 2007). Also, ConQuest can produce internal consistency measures, conduct DIF analyses, fit latent regression models, and conduct correlational analyses. A Rasch partial credit model and a Rasch rating scale model were fit to the data in order to determine which model fit best for analyses because the Rasch partial credit model is less restricted, but the PISAT-2 was designed as a rating scale, indicating that a Rasch rating scale model may be more appropriate. The Rasch partial credit model uses total raw scores from the data to estimate item difficulties and mean threshold locations between levels. The distance between each level in a Rasch partial credit model can vary and are estimated individually. The Rasch rating scale model also uses the total raw scores from the data to estimate item difficulties and mean thresholds between levels, but assumes that the distance between each level is equal, which is often the case in rating scales.

In support of internal consistency, estimates based on Cronbach's alpha and Rasch person separation reliability were calculated. In order to examine structural validity, ConQuest software was used to produce a Wright map, mean threshold locations, and infit mean squares statistics. Correlational analyses were conducted to examine the relationship between scores on the PISAT-2 and variables related to parent involvement (parent stress and parent self-efficacy). Pearson's  $r$  was calculated to indicate the direction of relationships. Latent regression was then used to calculate the predictive power of each demographic variable for PISAT-2 scores.

DIF analyses by gender were conducted by making a gender dummy variable where 0 represented female and 1 represented male. DIF analyses by ethnicity were conducted for White, Black, Hispanic, and Asian participants by creating similar dummy variables with 1 representing the ethnicity examined and 0 representing participants identifying as another ethnicity. Unfortunately, analyses for Middle-Eastern and Native American groups were not run because these groups were too small to conduct statistical analyses (one participant each). Education, SES, income, and work hours per week were treated as polytomous variables for DIF analyses using ConQuest. Participant's responses to the feedback items were organized and coded based on content themes. These results were then summarized to give validity evidence of whether or not parents agree that the measure is about the construct of parent involvement and that parents understand items on the measure.

### **Results**

Preliminary analyses of the survey data gathered from participants involved finding an item response theory model that best fit the data. Both a Rasch partial credit model and a Rasch rating scale model were fit to the data. The AIC and BIC of both models were compared to investigate which model fit the data better. For the Rasch partial credit model, the AIC was 13311.656 and the BIC was 13545.225. For the Rasch rating scale model, the AIC was 13381.891 and the BIC was 13440.641. The AICs for both models were similar, but the BIC for

the Rasch rating scale model was more than 100 points lower than the partial credit model, indicating a better fit. Thus, the Rasch rating scale model was chosen for statistical analyses because it had a better fit based on BIC estimates.

### **Internal Consistency and Structural Validity**

Internal consistency estimates were run using a Rasch rating scale model. Cronbach's alpha was found to be 0.78 and Rasch mean person separation reliability was found to be 0.80 for scores from the PISAT-2, indicating good internal consistency. Structural validity was investigated through creating a Wright map, calculating the mean threshold location between each level of parent involvement from the PISAT-2, and calculating infit mean squares statistics for each item of the PISAT-2. Figure 2 shows the Wright map of participants' scores on the PISAT-2. A visual examination of the Wright map revealed that the PISAT-2 differentiated Levels 1, 2, 4, and 5 well. However, Level 3 did not appear to be different from Level 2. Mean threshold locations between each level were calculated to be -0.977, -0.140, -0.129, and 1.246. The mean threshold locations increased from one level to the next, indicating that each level measured ever increasing amounts of parent involvement. However, the second and third mean threshold locations (-0.140, and -0.129) were not significantly different, which is further evidence that scores from the PISAT-2 were not able to consistently differentiate Level 3.

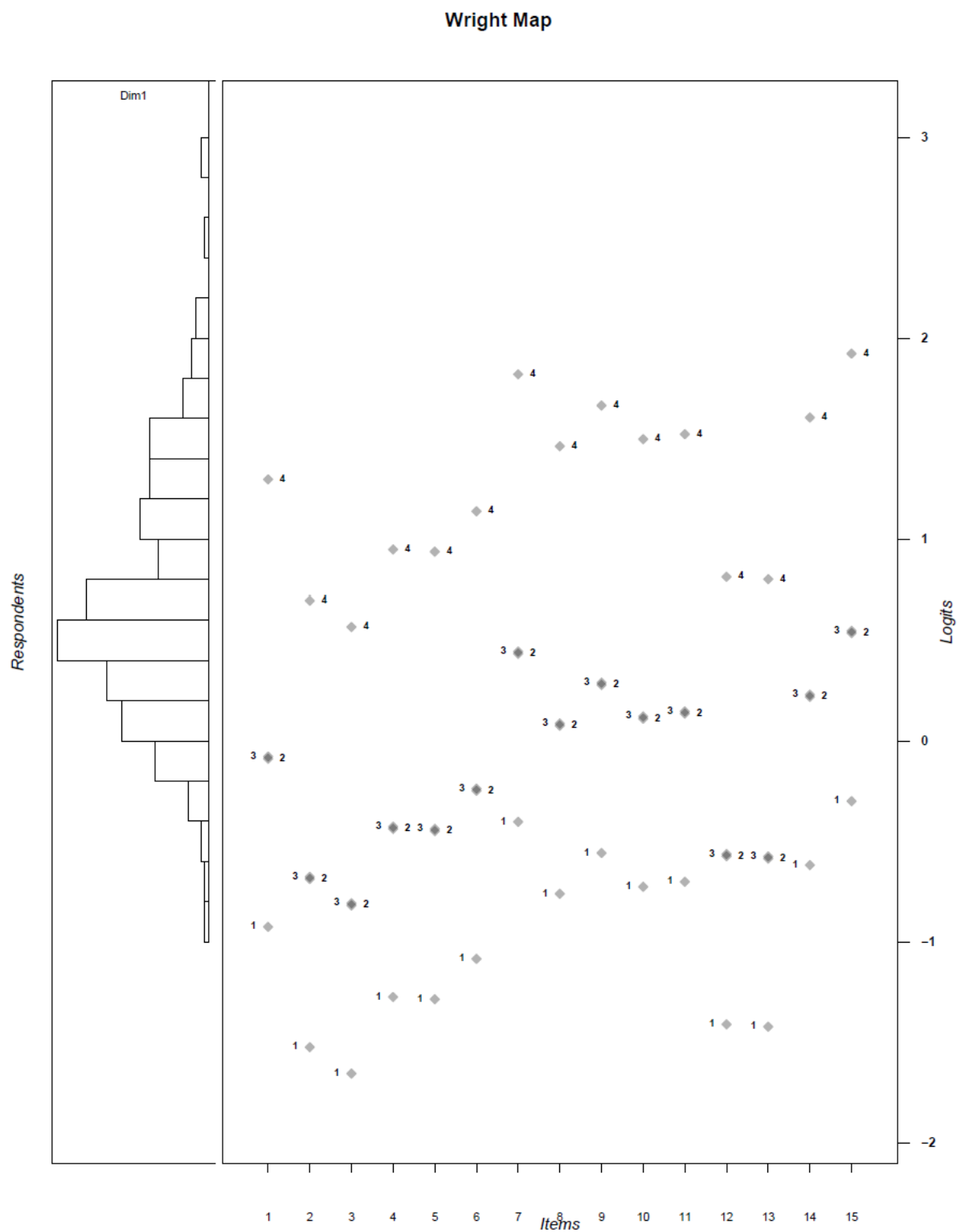


Figure 2. PISAT-2 Wright map by item and level.

The results of calculating infit mean squares statistics for each item in the PISAT-2 are shown in Figure 3. All of the items on the PISAT-2 with the exception of Item 4 were found to have infit mean squares between 0.75 and 1.33, indicating that the items fit the expected pattern as outlined in the construct map in Table 1 given random error. Item 4 had an infit mean squares statistic of 0.74, which indicated that it fit the expected pattern of responding better than would be expected given random error.

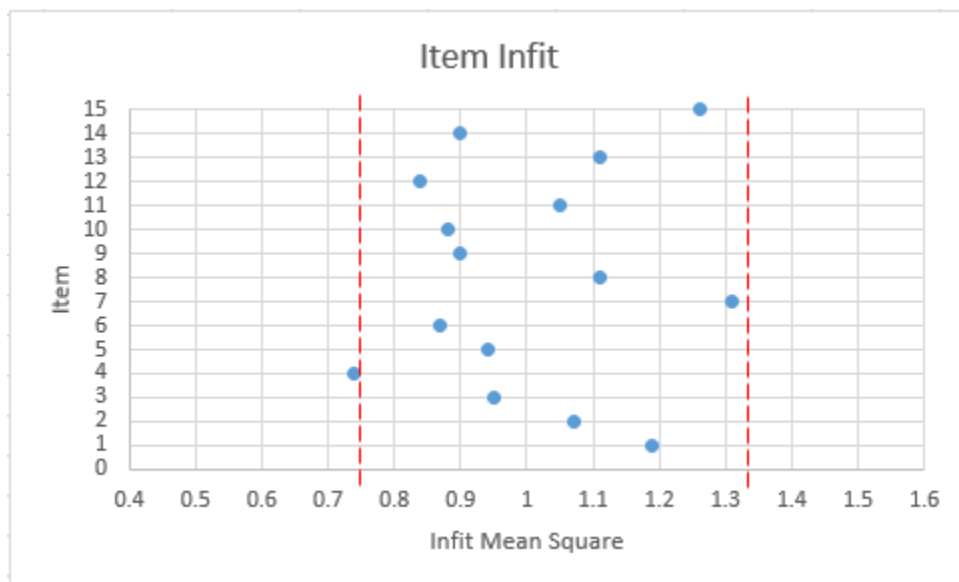


Figure 3. PISAT-2 infit mean squares by item.

### Correlational and Latent Regression Analyses

Correlational analyses were run between scores on the PISAT-2, parent stress, and parent self-efficacy. Scores on the PISAT-2 were not found to be statistically significantly correlated with participants' self-ratings of stress ( $r = 0.04$ ,  $p = 0.51$ ). Scores on the PISAT-2 were found to be statistically significantly positively correlated with participants' self-ratings of self-efficacy ( $r = 0.38$ ,  $p < 0.01$ ).

A latent regression analysis was conducted between scores on the PISAT-2 and demographic variables. The results of the latent regression analysis are summarized in Table 3. Participants' highest level of education and annual income were found to have a statistically significant negative relationships with scores on the PISAT-2. No relationships were found between participants' scores on the PISAT-2 and their gender, their ethnicity, the number of caregivers in the home, their household's overall education level, their SES, or their number of work hours per week.

Table 3  
*PISAT-2 Latent Regression Results*

Variable	$\beta$	Standard Error	$p$
Constant	-0.040	0.591	0.946
Gender	-0.061	0.084	0.468
White	0.697	0.564	0.217
Black	0.928	0.569	0.104
Hispanic	0.830	0.569	0.146
Asian	0.539	0.586	0.358
Number of Caregivers	0.022	0.054	0.684
Education	-0.091**	0.040	0.024**
Household Mean Education	0.057	0.034	0.095
SES	0.057	0.039	0.145
Annual Income	-0.075**	0.032	0.020**
Work Hours per Week	0.058	0.030	0.054

\*\*Statistically significant at the  $p < 0.05$  level

### Differential Item Functioning Analyses

DIF analyses were conducted for dichotomous variables to determine if items on the PISAT-2 were functioning differently by gender or ethnicity. Middle-Eastern and Native American DIF analyses were not possible due to the small number of participants who identified as those ethnicities (one for each). None of the items on the PISAT-2 were found to not be functioning differently for participants based on gender or ethnicity.

DIF analyses were then conducted for polytomous demographic variables to investigate if the items on the PISAT-2 were functionally differently for participants with different levels of education, SES, annual income, and work hours per week. The DIF analyses by SES, annual income, and work hours per week revealed that the items on the PISAT-2 were not functioning differently for these groups of participants. The DIF analysis by education level found that the items of the PISAT-2 were functioning similarly across all participants' levels of education with the exception of Item 9. Item 9 was significantly harder ( $p < 0.05$ ) for participants with some high school education to answer at the highest level (i.e., *strongly agree*) than for participants with other educational backgrounds.

### Parent Feedback

Parent feedback was gathered using four open-ended questions at the end of the survey given to participants. The first question asked participants if they had questions about any of the items on the survey. A vast majority of participants (325 or 95%) indicated that they did not have any questions about items on the survey. Six participants asked why the survey asked for demographic information (e.g., gender, ethnicity, income, etc.); three participants asked how the information would be used for research; three participants asked why the items about collaborating between services providers did not include more examples (e.g., occupational therapy, speech services, special education teacher, pediatrician, etc.); and three participants asked why the items on the stress and self-efficacy scales were so broad.

The second open-ended feedback question asked participants if there were any items that they skipped and why they skipped those items. Three hundred thirty eight participants (99%) indicated that they did not skip any items. The remaining two participants indicated that they

had skipped the ethnicity and annual income items because they did not feel comfortable reporting their ethnicity or annual income.

The third open-ended feedback question asked participants if the survey covered all the ways they support their children's treatment and if not, what other topics needed to be added. Three hundred twenty-three participants (95%) indicated that the survey included all the ways that they support their children's treatment. Eight participants indicated that the survey needed to include items about parents' involvement in planning special education services at school. Three participants commented that the survey items should include questions about more types of therapy and medication. Three other participants commented that the survey should include items about the amount of time spent transporting their children to appointments with service providers and scheduling appointments with service providers. Another three participants commented that the survey should include items about parenting styles and behavioral strategies used at home.

The fourth open-ended feedback question asked participants for any other comments they had about how to improve the survey. Three hundred thirty participants (97%) did not have any comments about how to improve the survey. Four participants commented that the stress associated with finding community resources for their children and that topic should be included in the parental stress items. Two participants commented that the survey should ask if parents believe that treatment has been effective for their children or not. Two other participants commented that the survey should include a question about how many other family members have a diagnosis of ASD. One participant commented that adding "now or in the past" to each item would help with clarity. Another participant commented that the survey should ask about comorbid disorders, such as epilepsy.

### **Discussion**

The goal of this study was to validate scores from the PISAT-2. The PISAT-2 was based on Epstein's (2010) parent involvement framework from education, parent involvement research in other populations, professional clinician feedback, and parent feedback. Research and expert feedback indicated that parents support their children through their participation at the clinic site, reinforcement at home, providing outside experiences, coordinating services, and advocacy and research efforts (Bourgondien & Coonrod, 2013; Burrell & Borrego, 2012; Goldstein & Naglieri, 2013; Rogers & Dawson 2010; Solish & Perry, 2008).

This study had five hypotheses about the reliability, validity, and fairness of the items and scores from the PISAT-2. First, I hypothesized that scores from the PISAT-2 would have good internal consistency and the items of the PISAT-2 would reliably differentiate varying levels of parent involvement. Results indicated that PISAT-2 scores had good internal consistency and items differentiated well among four of the five proposed levels of parent involvement. Second, I hypothesized that the scores from the PISAT-2 would be negatively related to parent stress and positively related to parent self-efficacy as predicted in the parent involvement literature (Holloway et al., 2016; Yamamoto et al., 2006, 2016; McWayne, 2015; Pomerantz et al., 2007). Scores from the PISAT-2 were found to be positively correlated with parent self-efficacy, but not correlated with parent stress.

Third, I hypothesized that the construct of parent involvement being measure by the PISAT-2 would be similar across groups. Scores from the PISAT-2 were negatively related to parent education level and annual income, but not related to gender, ethnicity, number of caregivers in the home, reported SES, or work hours per week. Fourth, I hypothesized that the items of the PISAT-2 would not function differently for different populations of respondents.

The difficulty levels of the PISAT-2 items were found to be similar for participants irrespective of gender, ethnicity, SES, annual income, or work hours per week. However, one item was found to be more difficult for participants with some high school as their highest level of education completed. Fifth, I hypothesized that parent feedback would support the existence of a parent involvement construct for ASD treatment that included parent involvement at the clinic site, at home, outside enrichment, coordinating services, and advocacy and research. Participant feedback indicated that the PISAT-2 covered the majority of the ways in which parents are involved in their children's treatment with some suggestions for improvement.

### **Internal Consistency and Structural Validity**

Scores from the PISAT-2 had good reliability and internal structural validity. The implication of this finding is that the items of the PSAT-2 were measuring the construct defined in the construct map, parent involvement, reliably. Unfortunately, the items of the PISAT-2 did not consistently differentiate one of the five levels of parent involvement, Level 3. One possible reason for this could be that item response that corresponded to Level 3 (*neither agree nor disagree*) was not perceived by participants as distinctly different than the response corresponding to Level 2 (*disagree*). Another reason could be that participants choose *neither agree nor disagree* to indicate an item was not applicable, because a *not applicable* option was not available. To address this possibility in future versions, the concept map could be revised to combine Level 2 and Level 3 because participant data indicate that they are similar. Alternatively, item responses could be altered to more clearly distinguish between Level 2 and Level 3, as well as adding in a *not applicable* response option.

### **Parent Stress and Self-Efficacy**

Scores from the PISAT-2 were found to be positively related to parent self-efficacy. This result can be used as validity evidence for scores from the PISAT-2 because parent involvement has been found to be positive related to parent self-efficacy in previous studies (Holloway et al., 2016; Yamamoto et al., 2006, 2016; McWayne, 2015; Pomerantz et al., 2007). However, there was no significant relationship between scores from the PISAT-2 and parent stress, which has been shown to be negatively related to parent involvement (Holloway et al., 2016; Yamamoto et al., 2006, 2016; McWayne, 2015; Pomerantz et al., 2007).

There are at least two reasons why no relationship was found between PISAT-2 and parent stress scores. First, the parent stress scale items were found to have low internal consistency ( $\alpha = 0.65$ ). Second, parent feedback indicated that items about the specific stressor of finding resources and support in the community was missing from the parent stress scale. Future studies should include items about the stress caused by trying to find community resources when measuring parent stress in this population, which could increase the reliability and validity of parent stress scores.

### **Parent Involvement Scores by Demographic Groups**

A latent regression analysis revealed that scores on the PISAT-2 did not differ among participant groups based on gender, ethnicity, the number of caregivers in the home, reported SES, or number of work hours per week. This finding is consistent with research on similar scales used in other populations of parents based on Epstein's (2010) model of parent involvement (Grover, 2015; McWayne, 2015). However, parent education level and annual income had small, negative relationships with parent involvement.

The negative relationships between parent involvement and parent education and annual income were unexpected because previous research has found that more highly educated and wealthier parents participate in more parent involvement (Epstein, 2010; McWayne, 2015;



Pomerantz et al., 2007). However, parents with more education and those with higher annual incomes appeared to have participated in fewer parent involvement activities in this population. One possible reason for this is that parents with more education or higher incomes focus more on other types of involvement, such as outside enrichment, and participate less at the clinic site. Research has found that highly educated and high-income Japanese parents are involved less at the school site and more with outside enrichment activities when supporting their children's schooling (Holloway et al., 2008; Holloway et al., 2016; Yamamoto, Holloway, & Suzuki, 2006, 2016). A similar trend may be taking place here for the parents of children in ASD treatment.

### **Item Fairness**

DIF analyses by gender, ethnicity, SES, annual income, and work hours per week revealed that the vast majority of the items were functioning similarly across these populations of participants. The implication of this finding is that each item was understood equally well and was not more difficult for any one group that was investigated. It was hypothesized that this would happen because the items on the PISAT-2 were based on a sound theoretical model and expert feedback, and the pilot study did not reveal any evidence of bias. However, Item 9 was found to be more difficult for participants with some high school as their highest level of education completed.

It is not clear why Item 9 was more difficult for parents with some high school as their highest level of education. Previous research on parent involvement has found parents' education level to be related to parent involvement, where parents with less education tend to be less involved (Epstein, 2010; McWayne, 2015; Pomerantz et al., 2007; Wang, Deng, & Yang, 2016). Also, these same participants did not find a similar item, Item 8 (I schedule playdates for my child with children who were not on the autism spectrum), more difficult to answer, which suggests they likely understood Item 9. Taking these points into consideration, one possible explanation is that parents with some high school as their highest level of education find it more difficult to schedule playdates for their child with children on the autism spectrum.

### **Parent Feedback**

An overwhelming majority of the participants agreed that the items on the PISAT-2 were easy to understand and the PISAT-2 covered the majority of the ways they support their children's treatment. However, some participants did indicate areas of improvement for future revisions of the PISAT-2. These improvements included utilizing more specific examples of other services providers; including items about transportation time and costs; including items about collaborating with school-based special education services; including items about parenting styles and behavioral strategies at home; including items about parents' belief that treatments are effective; and including items about co-morbid disorders. The PISAT-2 should be revised to reflect these suggestions. Including additional items about transportation time, school-based special education collaboration, and home behavioral supports could enhance the validity of the survey because these topics fit into the framework of parent involvement outlined in previous research (Burrell & Borrego, 2012; Epstein, 2010; Goldstein & Naglieri, 2013; Rogers & Dawson 2010; Solish & Perry, 2008). Additionally, using more specific examples on items in the survey could increase the clarity of items.

### **Strengths and Limitations of Online Surveys**

This study used an online survey to collect data. There are both advantages and disadvantages to conducting survey research online. Online surveys lower costs by eliminating printing costs, the need to pay multiple raters, and the cost of delivering surveys to participants (Duffy, Smith, Terhanian, & Bremer, 2005; Wright, 2017). Online survey platforms also save

time by enabling researchers to collect data into an analyzable format instantly (Duffy et al., 2005; Wright, 2017). The design of online surveys can be more flexible than paper surveys, with the potential to use video and interactive visuals on the internet (Duffy et al., 2005). Convenience is another advantage of online surveys because participants are able to complete online surveys on their own time rather than at a designated time and place with an interviewer in person or over the phone (Duffy et al., 2005). The use of online surveys also has the advantage of not needing interviewers, which has been shown to decrease the interviewer effect of participants feeling pressured to answer in socially desirable ways (Comley, 2003). Additionally, conducting research online can give researchers access to unique communities of participants through interest group webpages, social media, and advocacy group websites (Wright, 2017). It has also been found that online surveys have higher participation rates than paper, in-person, or phone surveys (Duffy et al., 2005; Heim et al., 2016).

Online surveys also have some major disadvantages. Some researchers have found that participants choose the *neither agree nor disagree* and *not applicable* options more often in online surveys with odd numbers of options, which can make the data less informative (Duffy et al., 2005). Also, internet access is not universal and thus participants without a home computer or access to the internet cannot participate. Sampling errors can also occur more often in online surveys because of the difficulty of verifying participants' identity and the accuracy of information over the internet (Wright, 2017). A final important disadvantage is that a sample of participants cannot be random if it is generated from an online community or email list because participants self-selected into those communities and lists.

### **Conclusion**

The results from this study provided evidence that the PISAT-2 does measure parent involvement in the population of parents of children with ASD. Scores from the PISAT-2 were found to have good reliability and internal structural validity. The items from the PISAT-2 did not function differently for different groups of participants. Scores from the PISAT-2 were found to be positive related to parent self-efficacy as predicted by previous literature on parent involvement (Holloway et al., 2016; Yamamoto et al., 2006, 2016; McWayne, 2015; Pomerantz et al., 2007). Participant feedback indicated that the PISAT-2 covered the majority of the ways in which parents are involved in their children's treatment with some minor suggestions for improvement.

Despite some proposed changes, the PISAT-2 is a psychometrically sound tool for measuring parents' involvement in their children's ASD treatment. The development of the PISAT-2 is a critical first step in allowing clinicians to measure and utilize parent involvement to improve ASD treatment. The PISAT-2 should be utilized in clinical settings to help clinicians guide parents in supporting their children's ASD treatment and in future research investigating how parent involvement is related to ASD treatment outcomes.

### References

- Alpern, G. D. (2009). *Developmental Profile* (3rd ed.). Los Angeles, CA: Western Psychological Services.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Anderson, D. K., Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A.,...Pickles, A. (2007). Patterns of growth in verbal abilities among children with autism spectrum disorder. *Journal of Consulting and Clinical Psychology, 75*, 594–604. doi:10.1037/0022-006X.75.4.594
- Asperger, H. (1991). “Autistic psychopathy” in childhood. In U. Frith (Ed.), *Autism and Asperger syndrome* (pp. 37–92). Cambridge, MA: Cambridge University Press.
- Baron-Cohen, S. (1989). Do autistic children have obsessions and compulsions? *British Journal of Clinical Psychology, 28*, 193–200. doi:10.1111/j.2044-8260.1989.tb01369.x
- Bellini, S., & Akullian, J. (2007). A meta-analysis of video modeling and video self-modeling interventions for children and adolescents with autism spectrum disorders. *Exceptional Children, 73*, 264–287. doi:10.1177/001440290707300301
- Ben-Itzhak, E., & Zachor, D. A. (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism. *Research in Developmental Disabilities, 28*, 287–303. doi:10.1016/j.ridd.2006.03.002
- Benson, P., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism, 12*, 47–63. doi:10.1177/1362361307085269
- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*, 463–472. doi:10.1177/0265407595123009
- Bourgondien, M. E. V., & Coonrod, E. (2013). TEACCH: An intervention approach for children and adults with autism spectrum disorders and their families. In S. Goldstein & J. A. Naglieri (Eds.), *Interventions for autism spectrum disorders* (pp. 75–105). New York, NY: Springer.
- Burrell, T. L., & Borrego. (2012). Parents’ involvement in ASD treatment: What is their role? *Cognitive and Behavioral Practice, 19*, 423–432. doi:10.1016/j.cbpra.2011.04.003
- Calzada, E. J., Huang, K.-Y., Hernandez, M., Soriano, E., Acra, C. F., Dawson-McClure, S.,...Brotman, L. (2015). Family and teacher characteristics as predictors of parent involvement in education during early childhood among Afro-Caribbean and Latinx immigrant families. *Urban Education, 50*, 870–896. doi:10.1177/0042085914534862
- Carter, C., Meckes, L., Pritchard, L., Swensen, S., Wittman, P. P., & Velde, B. (2004). The friendship club: An after-school program for children with Asperger syndrome. *Family & Community Health, 27*, 143–150.
- Comley, P. (2003, July). *Innovation in online research – Who needs online panels?* Paper presented at the MRS Research Conference, San Francisco, CA.
- DeMyer, M. K., Hingtgen, J. N., & Jackson, R. K. (1981). Infantile autism reviewed: A decade of research. *Schizophrenia Bulletin, 7*, 388–451. doi:10.1093/schbul/7.3.388
- Duffy, B., Smith, K., Terhanian, G., & Bremmer, J. (2005). Comparing data from online and face-to-face surveys. *International Journal of Market Research, 47*, 615–639.

- Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism: A 1-year comparison controlled study. *Behavior Modification, 26*, 49–68. doi:10.1177/0145445502026001004
- Eisenberg, L., & Kanner, L. (1956). Childhood schizophrenia: Symposium, 1955: 6. Early infantile autism, 1943–55. *American Journal of Orthopsychiatry, 26*, 556–566. doi:10.1111/j.1939-0025.1956.tb06202.x
- Epstein, J. L. (2010). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan, 92*, 81–96. doi:10.1177/003172171009200326
- Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., & Dawson, G. (2015). Long-term outcomes of early intervention in 6-year-old children with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 54*, 580–587. doi:10.1016/j.jaac.2015.04.005
- Fry, E. B. (1969). The readability graph validated at primary levels. *The Reading Teacher, 22*, 534–538.
- Gabriels, R. L., Hill, D. E., Pierce, R. A., Rogers, S. J., & Wehner, B. (2001). Predictors of treatment outcome in young children with autism: A retrospective study. *Autism, 5*, 407–429. doi:10.1177/1362361301005004006
- Gillberg, C., & Steffenburg, S. (1987). Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders, 17*, 273–287. doi:10.1007/BF01495061
- Gillberg, D. C., & Schaumann, H. (1982). Social class and infantile autism. *Journal of Autism and Developmental Disorders, 12*, 223–228. doi:10.1007/BF01531368
- Gilmore, L., & Cuskelly, M. (2008). Factor structure of the parenting sense of competence scale using a normative sample. *Child Care, Health & Development, 38*, 48–55.
- Goldstein, S., & Naglieri, J. A. (Eds.). (2013). *Interventions for autism spectrum disorders: Translating science into practice*. New York, NY: Springer.
- Granpeesheh, D., Dixon, D. R., Tarbox, J., Kaplan, A. M., & Wilke, A. E. (2009). The effects of age and treatment intensity on behavioral intervention outcomes for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*, 1014–1022. doi:10.1016/j.rasd.2009.06.007
- Grover, K. A. (2015). *A validation of the Family Involvement Questionnaire-High School Version* (Unpublished doctoral dissertation). Minnesota State University, Mankato.
- Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four- to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*, 137–142. doi:10.1023/A:1005459606120
- Heim, R., Konowalczyk, S., Grgic, M., Seyda, M., Burrmann, U., & Rauschenbach, T. (2016). Online surveys in youth research: A methodological study. *Zeitschrift Für Erziehungswissenschaft [Journal of Educational Science], 19*, 783–805. doi:10.1007/s11618-016-0685-3
- Hoover-Dempsey, K. V., & Sandler, H. M. (1997). Why do parents become involved in their children's education? *Review of Educational Research, 67*, 3–42. doi:10.2307/1170618
- Holloway, S. D., Campbell, E. J., Nagase, A., Kim, S., Suzuki, S., Wang, Q.,...Baak, S. Y. (2016). Parenting self-efficacy and parental involvement: Mediators or moderators between socioeconomic status and children's academic competence in Japan and Korea? *Research in Human Development, 13*, 258–272. doi:10.1080/15427609.2016.1194710

- Holloway, S. D., Yamamoto, Y., Suzuki, S., & Mindnich, J. D. (2008). Determinants of parental involvement in early schooling: Evidence from Japan. *Early Childhood Research & Practice, 10*, 1–10.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*, 212–229. doi:10.1111/j.1469-7610.2004.00215.x
- Jeynes, W. H. (2016). A meta-analysis: The relationship between parental involvement and African American school outcomes. *Journal of Black Studies, 47*, 195–216. doi:10.1177/0021934715623522
- Jeynes, W. H. (2017). A meta-analysis: The relationship between parental involvement and Latinx school outcomes. *Education and Urban Society, 49*, 4–28. doi:10.1177/0013124516630596
- Kincaid, J. P., Braby, R., & Mears, J. E. (1988). Electronic authoring and delivery of technical information. *Journal of Instructional Development, 11*(2), 8–13. doi:10.1007/BF02904998
- Koegel, R. L., Koegel, L. K., & Carter, C. M. (1999). Pivotal teaching interactions for children with autism. *School Psychology Review, 28*, 576–594.
- Lovaas, I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*, 3–9. doi:10.1037/0022-006X.55.1.3
- Luszczynska, A., Scholz, U., & Schwarzer, R. (2005). The General Self-efficacy Scale: Multicultural validation studies. *The Journal of Psychology, 139*, 439–457. doi:10.3200/JRLP.139.5.439-457
- MacDonald, H., Rutter, M., Howlin, P., Rios, P., Conteur, A. L., Evered, C., & Folstein, S. (1989). Recognition and expression of emotional cues by autistic and normal adults. *Journal of Child Psychology and Psychiatry, 30*, 865–877. doi:10.1111/j.1469-7610.1989.tb00288.x
- McGee, G. G., & Daly, T. (2007). Incidental teaching of age-appropriate social phrases to children with autism. *Research and Practice for Persons with Severe Disabilities, 32*, 112–123. doi:10.2511/rpsd.32.2.112
- McWayne, C. M. (2015). Family–school partnerships in a context of urgent engagement: Rethinking models, measurement, and meaningfulness. In S. M. Sheridan & E. Moorman Kim (Eds.), *Foundational aspects of family-school partnership research* (pp. 105–124). Cham, NJ: Springer International Publishing.
- Odom, S. L., Boyd, B. A., Hall, L. J., & Hume, K. (2009). Evaluation of comprehensive treatment models for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40*, 425–436. doi:10.1007/s10803-009-0825-1
- Pomerantz, E. M., Moorman, E. A., & Litwack, S. D. (2007). The how, whom, and why of parents' involvement in children's academic lives: More is not always better. *Review of Educational Research, 77*, 373–410. doi:10.3102/003465430305567
- Rogers, S. J., & Dawson, G. (Eds.). (2010). *Early start Denver model for young children with autism: Promoting language, learning, and engagement*. New York, NY: Guilford Press.
- Siegel, B., Vukicevic, J., Elliott, G., & Kraemer, H. (1989). The use of signal detection theory to assess DSM-III-R criteria for autistic disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 28*, 542–548. doi:10.1097/00004583-198907000-00013

- Smalley SL, Asarnow RF, & Spence M. (1988). Autism and genetics: A decade of research. *Archives of General Psychiatry*, *45*, 953–961. doi:10.1001/archpsyc.1988.01800340081013
- Solish, A., & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders*, *2*, 728–738. doi:10.1016/j.rasd.2008.03.001
- Stahmer, A. C., Schreibman, L., & Cunningham, A. B. (2011). Toward a technology of treatment individualization for young children with autism spectrum disorders. *Brain Research*, *1380*, 229–239. doi:10.1016/j.brainres.2010.09.043
- Szatmari, P., Bryson, S. e., Boyle, M. h., Streiner, D. l., & Duku, E. (2003). Predictors of outcome among high functioning children with autism and Asperger syndrome. *Journal of Child Psychology and Psychiatry*, *44*, 520–528. doi:10.1111/1469-7610.00141
- Tiura, M., Kim, J., Detmers, D., & Baldi, H. (2017). Predictors of longitudinal ABA treatment outcomes for children with autism: A growth curve analysis. *Research in Developmental Disabilities*, *70*, 185–197. doi:10.1016/j.ridd.2017.09.008
- Trembath, D., & Vivanti, G. (2014). Problematic but predictive: Individual differences in children with autism spectrum disorders. *International Journal of Speech-Language Pathology*, *16*, 57–60. doi:10.3109/17549507.2013.859300
- Venter, A., Lord, C., & Schopler, E. (1992). A follow-up study of high-functioning autistic children. *Journal of Child Psychology and Psychiatry*, *33*, 489–597. doi:10.1111/j.1469-7610.1992.tb00887.x
- Vivanti, G., Dissanayake, C., Zierhut, C., Rogers, S. J., & Team, V. A. (2012). Predictors of outcomes in the early start Denver model delivered in a group setting. *Journal of Autism and Developmental Disorders*, *43*, 1717–1724. doi:10.1007/s10803-012-1705-7
- Volkmar, F., Sparrow, S., Goudreau, D., Cicchetti, D., Paul, R., & Cohen, D. (1987). Social deficits in autism: An operational approach using the vineland adaptive behavior scales. *Journal of the American Academy of Child & Adolescent Psychiatry*, *26*, 156–161. doi:10.1097/00004583-198703000-00005
- Wang, Y., Deng, C., & Yang, X. (2016). Family economic status and parental involvement: Influences of parental expectation and perceived barriers. *School Psychology International*, *37*, 536–553. doi:10.1177/0143034316667646
- White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of Autism and Developmental Disorders*, *37*, 1858–1868. doi:10.1007/s10803-006-0320-x
- Wilson, M. (2005). *Constructing measures: an item response modeling approach*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Wright, K. (2017). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, *10*, 1 – 22. doi:10.1111/j.1083-6101.2005.tb00259.x
- Wu, M. L., Adams, R., Wilson, M., & Haldane, S. (2007). *ACER ConQuest version 2.0: generalized item response modelling software*. Camberwell, Australia: ACER Press.
- Yamamoto, Y., Holloway, S. D., & Suzuki, S. (2006). Maternal involvement in preschool children's education in Japan: Relation to parenting beliefs and socioeconomic status. *Early Childhood Research Quarterly*, *21*, 332–346. doi:10.1016/j.ecresq.2006.07.008

Yamamoto, Y., Holloway, S. D., & Suzuki, S. (2016). Parental engagement in children's education: Motivating factors in Japan and the U.S. *School Community Journal*, 26, 45–66.

## Appendix 1 Pilot Parent Involvement Measure

### Frequency Items by Domain

#### Clinic Site

1. I attend meetings with my child's tutor/behavior tech to talk about my child's progress
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
2. I contact (call, email or text) my child's tutor/behavior tech to get information
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
3. I suggest treatment goals or things I would like to see worked on to my child's tutor/behavior tech
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*

#### Home Support

4. I practice the skills my child has learned in sessions with him/her at home
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
5. I play with my child
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
6. I ask my child about their experience in therapy
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*

#### Outside Enrichment

7. I take my child with me when I run errands in the community
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
8. I take my child places in the community to teach them about new things (e.g., museum, church)
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
9. My child attends clubs about his/her interests
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*

#### Coordinating Services

10. If my child attends a school, I update my child's teacher about his/her progress in therapy sessions
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
11. I update my child's tutor/behavior tech about his/her performance at school
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
12. I talk with my child's teacher and tutor/behavior tech about how he/she gets along with peers
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*

#### Advocacy and Research

13. I read research articles about Autism Spectrum Disorder
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
14. I check the news for stories about Autism Spectrum Disorder
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*
15. I talk with other parents of children with ASD about treatment strategies, home supports, activities, clubs, etc.
  - a. *Never, Rarely, Monthly, Weekly, or Two or more times per week*



## Likert Items by Domain

### Clinic Site

16. I sit in during my child's therapy sessions
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
17. I praise my child in front of his/her tutor/behavior tech
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
18. I contact (call, email or text) my child's tutor/behavior tech if I am concerned about something
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

### Home Support

19. I keep a regular daily schedule or routine for my child
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
20. I praise or reward my child when he/she successfully performs new skills he/she has learned
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
21. I maintain explicit and concrete behavior rules at home
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

### Outside Enrichment

22. My child participates in sports or performing arts (music, art, acting, etc.)
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
23. I schedule playdates for my child with other children who are not on the Autism Spectrum
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
24. I schedule playdates for my child with other children who are on the Autism Spectrum
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

### Coordinating Services

25. My child's teacher and tutor/behavior tech are in contact with each other
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
26. I talk with my child's teacher and tutor/behavior tech about how to support my child's transition to middle school
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
27. I talk with my child's teacher and tutor/behavior tech about how to support my child's transition to high school
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Advocacy and Research**

28. I attend workshops or conferences about Autism Spectrum Disorder  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
29. I participate in activities run by Autism advocacy groups (e.g., Autism Speaks)  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
30. I attend a support group for parents of children with ASD  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Other Measures****Parent Stress**

31. Overall, I feel stressed most of the time  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
32. A major source of stress in my life is my child(ren) diagnosed with ASD  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
33. The behavior of my child(ren) is often embarrassing or stressful to me  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Parent Self-Efficacy**

34. I feel that I am an effective parent  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
35. I can solve difficult parenting problems  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
36. I am confident that I can deal with unexpected events  
 a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Demographics**

37. What is the age of your child with ASD?
38. Your Gender  
 a. *Male, Female, Other \_\_\_\_\_*
39. Your highest level of Education completed  
 a. *Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
40. Your socio-economic status  
 a. *Working Class, Lower-Middle Class, Middle Class, Upper-Middle Class, Upper Class*
41. Your Ethnicity

**Feedback on Survey**

42. What questions do you have about items on the survey?
43. Were there any items that you skipped? If yes, why did you skip them?

44. Did the questions in this survey cover all the ways in which you support your child's treatment? If not, what other topics need to be covered?
45. What other feedback or comments do you have about how this survey could be improved?

**Appendix 2**  
**Parent Involvement Survey for Autism Treatment-Version 2**

**Clinic Site**

1. I sit in during my child's therapy sessions
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
2. I suggest treatment goals or things I would like to see worked on to my child's tutor/behavior tech
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
3. I contact (call, email or text) my child's tutor/behavior tech if I am concerned about something
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Home Support**

4. I keep a regular daily schedule or routine for my child
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
5. I reward my child every time he/she successfully performs new skills he/she has learned in therapy
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
6. I maintain explicit and concrete behavior rules at home
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Outside Enrichment**

7. My child participates in sports or performing arts (music, art, acting, etc.)
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
8. I schedule playdates for my child with other children who are NOT on the Autism Spectrum
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
9. I schedule playdates for my child with other children who are on the Autism Spectrum
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

**Coordinating Services**

10. My child's tutor/behavior tech is in regular contact with my child's other health service providers (pediatrician, speech and language pathologist, etc.)
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*
11. All of my child's health service providers collaboratively plan ahead for my child's future (transitions to elementary, middle school, high school, and beyond)
  - a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

12. I regularly update my child's health service providers and teachers about how he/she gets along with peers

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

### **Advocacy and Research**

13. I read scientific research to learn more about ASD

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

14. I participate in activities run by Autism advocacy groups (e.g. Autism Speaks)

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

15. I attend a support group for parents of children with ASD

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

### **Other Measures**

#### **Parent Stress**

16. Overall, I feel stressed most of the time

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

17. A major source of stress in my life is my child(ren) diagnosed with ASD

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

18. The behavior of my child(ren) is often embarrassing or stressful to me

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

#### **Parent Self-Efficacy**

19. I feel that I am an effective parent

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

20. I can solve difficult parenting problems

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

21. I am confident that I can deal with unexpected events

- a. *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree*

#### **Demographics**

22. Your Gender

- a. *Male, Female, Other \_\_\_\_\_*

23. Your highest level of education completed

- a. *Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*

24. Your socio-economic status

- a. *Working Class, Lower-Middle Class, Middle Class, Upper-Middle Class, Upper Class*

25. Total hours per week that you work outside the home

- a. *Less than 10 hours, 10 - 20 hours, 21 – 30 hours, 31 – 40 hours, More than 40 hours*
- 26. Your Ethnicity
  - a. *White, Black or African American, Hispanic or Latinx/a, Asian, Middle-Eastern*
- 27. The total number of other adult caregivers in the home, excluding yourself
  - a. *1 - 5*
- 28. Caregiver 1's highest level of education completed
  - a. *Not Applicable, Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
- 29. Caregiver 2's highest level of education completed
  - a. *Not Applicable, Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
- 30. Caregiver 3's highest level of education completed
  - a. *Not Applicable, Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
- 31. Caregiver 4's highest level of education completed
  - a. *Not Applicable, Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
- 32. Caregiver 5's highest level of education completed
  - a. *Not Applicable, Some High School, High School Diploma, Associate's Degree, Bachelor's Degree, Master's Degree, Specialist or Doctoral Degree*
- 33. Household total yearly income (including all members of the home)
  - a. *Less than \$15,000; \$15,000 - \$34,999; \$35,000 - \$49,999; \$50,000 - \$74,999; \$75,000 or more*

**Feedback on Survey**

- 34. What questions do you have about items on the survey?
- 35. Were there any items that you skipped? If yes, why did you skip them?
- 36. Did the questions in this survey cover all the ways in which you support your child's treatment? If not, what other topics need to be covered?
- 37. What other feedback or comments do you have about how this survey could be improved?