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# Exploring Experiences, Expectations and Perceptions of Parents of Children with ASD in Receiving Parent Education from Speech-Language Pathologists

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EXPLORING EXPERIENCES, EXPECTATIONS AND PERCEPTIONS OF  
PARENTS OF CHILDREN WITH ASD IN RECEIVING PARENT EDUCATION  
FROM SPEECH-LANGUAGE PATHOLOGISTS

by

Vinaya Kulkarni

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

Master of Science  
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at

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December 2014

## ABSTRACT

### EXPLORING EXPERIENCES, EXPECTATIONS AND PERCEPTIONS OF PARENTS OF CHILDREN WITH ASD IN RECEIVING PARENT EDUCATION FROM SPEECH-LANGUAGE PATHOLOGISTS

by

Vinaya Kulkarni

The University of Wisconsin-Milwaukee, 2014  
Under the Supervision of Professor Paula Rhyner, Ph.D.

As the prevalence of autism spectrum disorder (ASD) rises, an increasing number of parents are faced with questions related to diagnosis and intervention for their child with ASD. The purpose of the present study was to examine parental experiences, expectations, and level of satisfaction regarding parent education received on ASD from practicing speech-language pathologists (SLPs). A 36-question online survey: *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perception* was created to collect data regarding parental experiences, expectations, and level of satisfaction pertaining to information provided by SLPs in the following areas: (a) the nature of ASD, (b) specific treatment approach(es) used with their child with ASD by the practicing SLP; and (c) evidence based practice in ASD. Participants were parents of children with ASD who responded to a recruitment flyer and the informed consent posted on the Facebook pages of the parent support organizations Autism Speaks Milwaukee and the Autism Society of Southeastern Wisconsin. A total of 23 respondents met the inclusion criteria and completed the online survey via the Survey Monkey website. For each question, the percentage of responses for each response choice for

each question was calculated. Data analyses revealed a high percentage (84.2%) of the respondents reported receiving information about specific treatment approaches used with their child. Information about common facts about ASD (e.g., causes, symptoms, and prognosis) was not received by 47.4% of the respondents and information about evidence-based practice related to ASD was not received by 63.2% of the respondents. The majority of respondents (62.5%) indicated the information received was partially understood and 68.5% of the respondents indicated that the information provided only partially met parental expectations. Respondents expressed the need for weekly communication from their child's SLP about their child's progress in therapy. Overall, the findings suggest that to further improve education for parents of children with ASD, education regarding common facts about ASD and about evidence-based practice needs to be emphasized. The findings also illustrate the need for additional research on the effectiveness of parent education for children with ASD.

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To

My son Mihir, whose diagnosis of autism  
introduced me to the wonderful world of speech-language pathology

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## LIST OF ABBREVIATIONS

ABA	APPLIED BEHAVIORAL ANALYSIS
ADDM	AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING NETWORK
ASA	AUTISM SOCIETY OF AMERICA
ASD	AUTISM SPECTRUM DISORDER
CDC	CENTER FOR DISEASE CONTROL
CDD	CHILDHOOD DISINTEGRATIVE DISORDER
DSM-IV TR	DIAGNOSTIC & STATISTICAL MANUAL OF MENTAL DISORDERS -4 <sup>TH</sup> EDITION
EBP	EVIDENCE-BASED PRACTICE
EI	EARLY INTERVENTION
EIFS	EARLY INTERVENTION FAMILIARITY SCALE
IDEA	INDIVIDUALS WITH DISABILITIES EDUCATION ACT
IRB	INSTITUTIONAL REVIEW BOARD
NAC	NATIONAL AUTISM CENTER
NASET	NATIONAL ASSOCIATION OF SPECIAL EDUCATION TEACHERS
NIMH	NATIONAL INSTITUTE OF MENTAL HEALTH
NRC	NATIONAL RESEARCH COUNCIL
OT	OCCUPATIONAL THERAPY
PDD-NOS	PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED
PDDs	PERVASIVE DEVELOPMENTAL DISORDERS
PT	PHYSICAL THERAPY

SLP(s)      SPEECH-LANGAUGE PATHOLOGIST (s)  
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WI         WISCONSIN

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## Exploring Experiences, Expectations and Perceptions of Parents of Children with ASD in Receiving Parent Education from Speech-Language Pathologists

### Introduction

According to the National Institute of Mental Health (NIMH, 2012), autism spectrum disorder (ASD) consists of a group of developmental neurological disorders and the term “spectrum” indicates a range of symptoms, skills, and severity levels that children with ASD can display. The Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition (DSM V) published a revised definition and classification of ASD in the spring of 2013 (Dawson, 2012). The new definition and classification introduces two main changes: (a) autistic disorder and Asperger syndrome are included under one diagnosis of autism spectrum disorder instead of two distinct autism subtypes; and (b) social communication and repetitive /restrictive behaviors are now the only two symptom domains for diagnosis instead of the previous three domains (social impairment, communication deficits and repetitive/restricted behaviors) (Dawson, 2012). In the past, the diagnostic guidelines in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR) (American Psychiatric Association [APA], 2000) listed the following five disorders, referred to as pervasive developmental disorders (PDDs), that fall under the umbrella term of ASD: (1) Autistic Disorder (referred to as the classic ‘autism’), (2) Asperger’s Disorder (Asperger Syndrome), (3) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), (4) Rett’s Disorder (Rett Syndrome) and (5) Childhood Disintegrative Disorder (CDD)

As per the National Association of Special Education Teachers (NASET, 2007), the federal special education law, the Individuals with Disabilities Education Act 2004

(IDEA, 2004), classifies the subtypes of ASD under the single term- “Autism”. Thus, identifying autism as one of the 15 eligibility categories for special education, the federal legislation, Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400 (2004) defines autism as:

...a disability significantly affecting the child’s verbal and nonverbal communication and social interaction, generally evident before age 3 years that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. Autism does not apply if a child’s educational performance is adversely affected primarily because the child has an emotional disturbance. A child who manifests the characteristics of autism after age 3 years could be identified as having autism if he or she has characteristic symptoms. (Part 300/A/300.8/c/1)

In 2000, the Centers for Disease Control (CDC) established the Autism and Developmental Disabilities Monitoring (ADDM) Network (CDC, 2014). The ADDM Network is an active surveillance system that estimated the prevalence of ASDs and describes other characteristics among children that are 8 years of age and whose parents or guardians resided within the 11 ADDM sites (states) in the United States for the surveillance year 2010 (CDC, 2014). According to the findings of the 2010 surveillance summary, reported in March 2014, a total of 5,338 children (8 years of age) out of

363,749 children from 11 states in the United States of America had a confirmed diagnosis of ASD (CDC, 2014). Thus, it was estimated that 1 in 68 children had a diagnosis of ASD. The survey also reported that out of the 5338 children with a confirmed diagnosis of ASD, 3822 (72%) had a specific diagnosis of a subtype of ASD (autistic disorder or PDD-NOS or Asperger's syndrome) (CDC, 2014). The remaining 1516 children (28%) had a diagnosis of ASD without specific identification of a subtype. Of the 3822 children, 1656 (43%) had autistic disorder, 1749 (46%) had PDD-NOS and 417 (11%) had Asperger's disorder (CDC, 2014). According to NIMH (2012), Rett syndrome and childhood disintegrative disorder (CDD) are two very rare forms of ASD that are characterized by a regression in development. Only 1 of every 10,000 to 22,000 girls has Rett syndrome (NIMH, 2012). Even rarer, only 1 or 2 out of 100,000 children with ASD have CDD (NIMH, 2012).

According to the CDC (2014), 1 in 108 children (i.e., 9.3 per 1,000 8-year-old children) was identified with ASD. Among the 11 states where the CDC estimated the prevalence of ASD, Wisconsin was one of the states that indicated a lower prevalence of ASD than the national average (1 in 68 children) (CDC, 2014).

Over the last several years, there has been a significant increase in prevalence of autism. According to ADDM Network surveillance reports, the prevalence of autism was 1 in 150 children in the year 2000, 1 in 125 in 2004, 1 in 110 in 2006, 1 in 88 children in 2008 (CDC, 2012) and 1 in 68 in 2010 (CDC, 2014). The data reflect a 23% increase in the prevalence of autism from 2006 to 2008 (CDC, 2012) and a 29% increase of autism from 2008 to 2010 (CDC, 2014).



In addition to the increase in the overall prevalence of autism, as observed by the CDC, data from the US Department of Education has shown an increase in the number of children receiving special education and related services through the schools due to a diagnosis of autism. In 2002, approximately 120,000 children diagnosed with autism were being served under the federal legislation of IDEA (U.S Government Accountability Office, 2005). The number of children diagnosed with autism served under the IDEA has increased by more than 500% in the last decade (U. S. Government Accountability Office, 2005). Additionally, data from the U.S Department of Education and National Center for Education in 2010 revealed that students with ASD made up one of the largest populations of students receiving special education and related services. (Zablotsky, Boswell & Smith, 2012).

As an increasing number of children are diagnosed with ASD, an increasing number of parents find themselves faced with a myriad of questions related to the diagnosis and intervention for children with autism. A review of studies regarding parental experiences during the diagnostic process of autism indicates that parents of children with ASD often seek information related to (a) understanding the nature of ASD, (b) selecting appropriate interventions programs based on evidence-based practice (EBP), and (c) learning how to be active participants in their child's intervention (e.g., Osborne & Reed, 2008; F. J. Sansosti, Lavik, & Sansosti, 2012; Auert, Trembath, Arciuli, & Thomas, 2012). The present study will focus on examining parental experiences, expectations and levels of satisfaction in working with speech-language Pathologists (SLPs), with regards to receiving adequate information about ASD and selecting evidence based interventions related to ASD.

### **Review of Parental Inquires Following Diagnosis of ASD**

In an effort to explore parental perceptions of the diagnostic process for autism, Osborne and Reed (2008) conducted 15 focus group interviews with 70 parents of children in three age groups (preschool, primary and secondary-aged children) in five regions in southeast England. Parents of children that had received diagnosis of autism not less than 6 months and not more than 7 years prior to the study participated in focus group interviews. The focus group interviews were conducted by a trained moderator using a scripted format of questions to ensure consistency in the procedure. The questions were: (1) Who made the diagnosis? (2) Which factors led them to make the diagnosis? (3) What support, advice, and information were you given? (4) What did you find helpful about the process? (5) What could have been improved? (6) What help have you been offered? and (7) When should information have been given to you? (Osborne & Reed, 2008). Results indicated that at the time of initial diagnosis, most participants felt the need for basic information about autism to combat negative information obtained from other sources such as internet websites (Osborne & Reed, 2008). Additionally, some parents also valued general information that had been provided in the form of leaflets/pamphlets. While parents of young children with autism valued getting an overall picture with general information at the time of diagnosis, parents of older children with autism expressed an interest in receiving more follow-up information relevant to transitioning to and graduating from high school (Osborne & Reed, 2008).

In most cases, parents or primary caregivers are the people that ultimately make intervention choices for children with ASD, therefore it is important that parents or

primary caregivers of children with ASD receive the information and guidance they seek regarding understanding the nature of their child's disorder and selecting treatment approaches for their child. Additionally, parent education and involvement in assessment and treatment of children with ASD has been consistently documented in literature to be a valuable factor for positive intervention outcomes.

### **Importance of Parent Education and Parent Involvement**

Parent education and involvement has been historically valued as an important element in intervention and has over time evolved to be referred to via different terms and definitions such as “parent empowerment,” the “enabling model,” “parent-professional partnerships,” and “collaborative partnerships.” In a review of the literature on effective intervention models, Brookman-Frazee (2004) noted that discussion of such terms and their definitions in the literature led to development of the concept of parent education. As Brookman-Frazee (2004) noted, “...an *empowered parent* is the one who demonstrates confidence and effectiveness in teaching his or her child, managing daily routines, interacting with service providers, and obtaining services for the child (Koren, DeChillo, & Friesen, 1992)” (p. 196). The literature review by Brookman-Frazee (2004) also revealed that intervention models that focused on parent education resulted in families that exhibited improved confidence in problem solving and attaining family needs and goals (McDowell & Klepper, 2000). As a result, family-focused or family-driven models, in which the service providers focused on educating the families, were referred to as “enabling models” (Rappaport 1981; Brookman-Frazee, 2004). Additionally, the terms “parent-professional partnerships” and “collaborative

partnerships” were well established in the literature as essential tools to promote active parent participation through shared knowledge and common goals (Dunst & Paget 1991; Brookman-Fraee 2004).

Given the well-documented importance of parent education, Brookman-Fraee (2004) conducted a study comparing outcomes of the same type of intervention (Pivotal Response Training) for children with autism delivered using two different models. The models included the Partnership Model (parent-clinician partnership) and the Clinician-Directed Model. In the Partnership Model, parents received education about the principles of the intervention used, were trained to participate in the treatment, and were asked to provide input about goals for their child. In contrast, minimal parent participation was encouraged in the Clinician-Directed Model. Outcome measures for the intervention included: (1) observed parental stress, (2) observed parent confidence, (3) observed child affect, and (4) child responding and engaging. The findings revealed lower parental stress, higher levels of confidence and more positive parent-child interactions when parents were engaged as partners or collaborators with clinicians. The findings were attributed to the fact that under the Partnership Model, parents received education and training about the intervention approach used (Pivotal Response Training) and actively participated in intervention by helping to develop goals and treatment plans for their child (Brookman-Fraee, 2004).

The significance of parent education and involvement is well documented in literature (e.g., Brookman-Fraee, 2004; McDowell & Klepper, 2000; Rappaport 1981). Organizations and governing bodies such as the National Research Council (NRC) and the American Speech-Language-Hearing Association (ASHA) also acknowledge the

value of parent education and family involvement in assessment and treatment of individuals with ASD. Hence, when establishing guidelines and principles for clinical practice involving individuals with ASD, both the NRC and ASHA incorporate the importance of parent education and involvement.

To assist parents, administrators, advocates, researchers and policy makers, the National Research Council (2001) published *Educating Children with Autism*, which outlines intervention recommendations based on a comprehensive evaluation of the scientific evidence related to educational practices, programs, and strategies for children with autism. Based on the recommendations suggested by the NRC and other empirical evidence, ASHA delineated roles and responsibilities, guidelines, and principles for speech-language pathologists (SLPs) when serving individuals with ASD and their families (American Speech-Language-Hearing Association [ASHA], 2006a, 2006b, 2006c.)

Under the American Speech-Language-Hearing Association (2006a) guidelines for SLPs, listed as one of the “Active Ingredients of Effective Programs” for individuals with ASD is:

*Inclusion of a family component, including parent training:* Concerns, priorities and perspectives of the family need to actively shape educational planning. All of the comprehensive intervention programs with the best treatment outcomes included a strong family component. Family members should be supported to be effective members of the educational team and provided with the opportunity to learn strategies for teaching their child

new skills and reducing problem behaviors (NRC, 2001). (American Speech-Language-Hearing Association, 2006a, p. 31)

Building upon the value of parent empowerment, recent trends in promoting parent education with regards to assessment and treatment of communication disorders including ASD, particularly focus on making parents informed consumers and guiding them in making appropriate intervention decisions based on evidence-based practice.

Evidence-based practice refers to the:

...conscientious, explicit and judicious integration of the (1) best available external evidence from systematic research, (2) best available evidence internal to clinical practice, and (3) best available evidence considering the preference of a fully informed patient...(Dollaghan, 2007, p.2)

When it comes to making decisions about intervention for children with ASD, the parent or primary caregiver plays an important role. Thus, in order to implement the principles of evidence-based practice it is important to fully inform parents and primary caregivers about the empirical evidence of the various treatment options.

In summary, parents of children with ASD seek (a) information regarding the nature of ASD, and (b) guidance in selecting appropriate services for their children with ASD. It is important that parents of children with ASD receive adequate general information about ASD and specific guidance about evidence-based practice in ASD because, as per research findings, intervention models that promote parent education and involvement yield greater treatment outcomes with regards to parental confidence and parent-child relationships (Brookman-Frazer, 2004, ). Additionally, organizations and governing bodies such as NRC and ASHA endorse the value of parent education and

involvement when stipulating guidelines for best clinical practices for working with individuals with ASD. Finally, one of the principles of evidence-based practice suggests incorporating evidence gathered from preferences of fully informed patients (Dollaghan, 2007), which establishes the value of fully informed parents in case of children with ASD.

Despite the comprehensive endorsement of parent education and involvement in intervention of children with ASD, through research findings and clinical practice guidelines recommended by organizations such as NRC and ASHA, there is an unclear understanding as to who is responsible for providing parents with the desired information. Parents of children with ASD often interact with multiple professionals in multiple settings such as special education teachers in educational settings, pediatricians in medical settings, therapists in private clinics. By definition, ASD is characterized by deficits in verbal and non-verbal communication resulting in impairment in social interaction skills (ASHA, 2006c). Thus, parents of children with ASD are likely to have interactions with SLPs, making the SLP a valuable information resource for parents of children with ASD. In order to understand the responsibilities of the SLP in providing parent education regarding ASD, the role of the SLP can be examined specifically in: (a) diagnostic process of individuals with ASD; (b) intervention for individuals with ASD; (b) working with families of children with ASD; and (c) providing guidance about evidence-based practice in ASD related intervention.

### **Role of SLPs in the Diagnostic Process of ASD**

Diagnosis of ASD requires careful evaluation of a range of developmental skills including communication and social interaction skills. As professionals who specialize in the area of communication disorders, SLPs are considered to be one of the important team members of an ASD intervention team (American Speech-Language-Hearing Association, 2006b). Accordingly, one of the principles for SLPs working with individuals with ASD states:

Speech-language pathologists who acquire and maintain the necessary knowledge and skills can diagnose ASD, as part of a diagnostic team in schools or in other multidisciplinary collaborations, and should make appropriate referrals to rule out other conditions and facilitate access to comprehensive services. (American Speech-Language-Hearing Association, 2006b, p. 29).

Furthermore the principle also specifies that speech-language pathologists with adequate training in the use of diagnostic and assessment tools for ASD and the application of the clinical criteria for ASD may be qualified to diagnose these disorders as an independent professional. (American Speech-Language-Hearing Association, 2006b).

Roles and responsibilities of an SLP extend well beyond the diagnostic phase and into the treatment of ASD. Several studies have examined the types of interventions that are most often used by parents of children with ASD. Given the nature of the communication deficits associated with ASD, it was found that speech and language



therapy is the intervention provided most frequently for individuals with ASD (Green, Pituch, Itchon, Choi, O'Reilly, Sigafoos, 2004; Hume, Bellini and Pratt, 2005).

### **Role of SLPs in Intervention for ASD**

In order to understand the decision making process of parents in selecting intervention approach for their child with ASD, Green, Pituch, Itchon, Choi, O'Reilly and Sigafoos (2004), documented the number and types of treatments used by parents for their children with ASD. The online survey listed 111 treatments from 7 different categories (e.g., medications, educational/therapy approaches). Speech and language therapy was found to be the most commonly used treatment, with 70% of the respondents stating that they were currently using speech and language therapy and 23% of the parents stating that they had used speech and language therapy in the past (Green et al, 2004).

Similarly, Hume, Bellini and Pratt (2005) attempted to examine the use and perceived outcomes of early intervention and early childhood programs for young children with ASD. A total of 195 parents of children with autism between 2 and 8 years of age, representing 50 of the 92 counties (distributed across rural, suburban, and urban counties) in Indiana completed a mail-in survey. The survey asked the parents about: their demographic information, the types and amounts of interventions used with their child, the strategies used and curricular areas addressed, and the settings in which intervention was provided. Parents were also asked to evaluate interventions, service delivery and outcomes of interventions using a four-point Likert scale for each of the evaluations. Results indicated that 89.2% of the respondents were using or had used

speech therapy. Moreover, when asked to rate the statement, “This service was effective and contributed to my child’s growth,” the top two choices for a rating of *strongly agree* were ‘parent training’ (78.2%) and ‘speech therapy’ (76%).

The results of the available research indicate that speech-language services were one of the most utilized services, and speech-language therapy was considered one of the most effective treatments for children with ASD by parents of children with ASD. In the process of serving individuals with ASD, the SLP typically also serves the families of individuals with ASD. When stipulating principles of best clinical practice for SLPs working with individuals with ASD, American Speech-Language-Hearing Association (2006b, 2006a) clearly defines roles and responsibilities of SLPs with regards to parent education and involvement.

### **Role of SLPs in Working with Families of Children with ASD**

The American Speech-Language-Hearing Association (2006b) position statement on serving individuals with ASD notes that a critical role and responsibility of the SLP is to form partnerships with families of individuals with ASD in assessment and intervention because effective programs have active family involvement. Furthermore, the SLP is expected to provide counseling, education and training, coordination of services, and advocacy for families (American Speech-Language-Hearing Association, 2006a).

Marcus, Kunce, & Schoper (2005) outlined certain services and support activities that could be implemented by SLPs when working with families of individuals with ASD. The services and support activities consisted of:

(a) education, in which the SLP provides information from the professional literature on topics such as ASD, child development, learning principles and intervention approaches to family members; (b) co-therapy, in which the professionals and family members play complementary roles in developing intervention goals and providing direct intervention to the individual with ASD; (c) behavioral approaches, in which family members learn and apply specific behavior-shaping strategies in intervention with the individual with ASD; (d) relationship enhancement, in which family members learn to attend to the interests of the child with ASD and to incorporate child-directed intervention strategies into their interactions; (e) cognitive approaches, in which family members develop skills such as problem solving, cognitive restructuring, and setting realistic expectations; (f) emotional support, in which the SLP provides empathetic listening and problem-solving strategies for family-identified concerns; (g) instrumental support, in which professionals assist family members in case coordination and access to resources and services; and (h) advocacy training and support, in which professionals assist families in learning to advocate for services and system changes that the individual with ASD requires to meet his or her needs across the lifespan. (American Speech-Language-Hearing Association, 2006 a, p. 10).

Another area in which parents of children with ASD require additional support is selecting appropriating intervention approaches for their children with ASD. In addition to providing education about nature of ASD, co-therapy training, advocacy training

(Marcus et al. 2005), SLPs are expected to play an important role in guiding parents of children with ASD in selecting appropriate intervention approaches based on empirical evidence.

### **Role of SLPs in Providing Parent Education Regarding Evidence-based Practice**

A wide range of approaches is available for assessment and intervention of ASD. However, because of the diverse symptoms and unique characteristics associated with ASD, currently there is insufficient empirical evidence on the effectiveness of specific approaches in the treatment of individuals with ASD. As a result, the American Speech-Language-Hearing Association (2006b) reports a high emergence of unproven treatments for ASD, which are advertised using exaggerated claims for effectiveness but lack empirical evidence. Parents of individuals with ASD face unique challenges such as accepting their child's lifelong disability or accepting poor prognosis despite normal physical appearance of their children (American Speech-Language-Hearing Association, 2006b). As a result of such unique emotional challenges, parents of children with ASD may be especially vulnerable to pursuing a range of treatments, which may or may not have empirical evidence (American Speech-Language-Hearing Association, 2006b). Considering the potential parental vulnerability in the decision making process of selecting evidence based treatment for their children with ASD, American Speech-Language-Hearing Association (2006b) states that, "Professionals have an important role in assisting families in evaluating the evidence available on intervention options for a family member with ASD..." (p. 32). Additionally, one of the principles by American

Speech-Language-Hearing Association (2006 b) for SLPs serving individuals with ASD, stipulates that:

Speech-language pathologists can also help assist families in differentiating treatments that lack evidence base from those that are contraindicated based on available research (p. 32).

In summary, SLPs bear a valuable share of responsibility in educating parents of children with ASD regarding the nature of the disorder and evidence-based practice because: (a) Given the nature of communication deficits associated with ASD, SLPs are one of the important professionals for diagnosis, treatment and providing support for families with ASD (American Speech-Language-Hearing Association, 2006 a), (b) Based on parent reports, speech and language therapy is the most used service for children with ASD (Green et al, 2004; Hume et al, 2005) so that SLPs are in a position to influence parents' decision regarding ASD related treatments, and (c) Educating parents of children with ASD regarding evidence-based practice is one of the professional expectations stipulated by American Speech-Language-Hearing Association (2006b).

There is a vast body of literature that establishes the importance of parent education for parents of children with ASD. Additionally, the role of SLPs in providing parent education (regarding nature of ASD and selecting evidence based intervention approaches for ASD) for parents of children with ASD is also well established through guidelines and principles stipulated by the governing body of American Speech-Language-Hearing Association. However, little is known about the status of parent education provided by SLPs to parents of children with ASD. There is an unclear understanding of whether parents of children with ASD are receiving adequate

information and guidance to help them understand the nature of ASD and to help them make appropriate intervention selections based on evidence-based practice. Moreover, there is limited data available to verify whether SLPs are being instrumental and proactive in providing parents of children with ASD the required education and professional guidance. Review of studies which looked at parental perceptions and experiences during assessment and intervention for their children with ASD can be helpful in providing insight into the status of parent education provided to parents of children with ASD.

### **Research on Status of Parent Education Related to ASD and Evidence-based practice in ASD**

Focusing on parental experiences during the diagnostic process of ASD, a handful of studies in the recent years have addressed the current status of parent education for parents of children with ASD by investigating the following factors: (a) the percentage of parents receiving information regarding nature of ASD, resources related to ASD and evidence-based practice in ASD; (b) the sources from which parents obtained the required information; (c) parental satisfaction with the information provided; (d) the strategies that parents used in making decisions about services for their children; and (e) the extent to which parents select evidence-based services. Although most of the available studies focused on parental experiences with professionals in the healthcare settings (e.g., physicians, pediatricians, psychologists), the results can be relevant in establishing the need for parent education for parents of children with ASD.

To determine if professionals and service providers working with individuals with ASD are instrumental in educating parents of children with ASD regarding EBP, it is first necessary to examine how service providers implement EBP when working with individuals with ASD. To determine the types of intervention techniques (those with and without an evidence base) used by Early Intervention (EI) service providers in community settings, Stahmer, Collings and Palinkas (2005), conducted a qualitative study. Stahmer et al. (2005) investigated practices of EI service providers working with children with autism under the age of 5 years in two southern California counties. Four focus group interviews were conducted with 22 EI service providers. The focus group interviews consisted of some introductory questions such as, “What brought you to special education and specifically to working with children who have autism?” (Stahmer et al., 2005, p. 78), as well as questions based on vignettes created by the authors describing hypothetical case history of a child with ASD. The questions based on the vignettes required specific information such as, “What type of program would you set up for this child if he came to your program today?” (Stahmer et al., 2005, p. 78).

The results indicated that EI service providers reportedly used intervention techniques with and without empirical evidence. Additionally, the study noted that many service providers combined and modified both types of techniques (techniques with and without empirical evidence), which negated the standardized procedures of the evidence-based interventions (Stahmer et al. 2005). In response to the findings of the study by Stahmer et al. (2005), authors F.J. Sansosti, Lavik & Sansosti (2012) argued that if professionals working with children with ASD do not completely adhere to and advocate for standards of evidence-based practice, then parents of children with ASD might be less

likely to be aware of situations when approaches without empirical evidence are implemented with their child. Thereby, Sansosti et al. (2012) performed a study to investigate common family experiences during the ASD diagnostic process and the child and family variables that might be related to different diagnostic outcomes. A secondary aim of the study by Sansosti et al. (2012) was to evaluate the participating families' knowledge of the available empirical evidence for various interventions.

A total of 16 participants were recruited from a local chapter of the Autism Society of America (ASA) of Northeast Ohio. Participants were primarily caregivers of children between the ages of birth and 7 years with a diagnosis of autistic disorder (56.3%), Asperger syndrome (37.5%), or PDD-NOS (6.3%). Information on family experiences related to the diagnostic process for ASD was obtained using a semi-structured interview that consisted of open-ended and closed questions. Examples of open-ended questions were, "After the doctor(s) provided you with the diagnosis, what did they tell you or recommend to you for intervention/services for your child?" and "Tell me about the barriers to receiving an earlier diagnosis" (Sansosti et al. 2012, p. 84). Participant responses were recorded verbatim. To assess parental awareness regarding research based intervention approaches, a list of early intervention practices was created. The list consisted of the early intervention practices ranging from those with demonstrated empirical research (e.g., Applied Behavior Analysis [ABA], discrete trial training) to those with promising empirical research (e.g., social stories, video modeling), as well as those with no research support (e.g., gluten free, casein free diet, weighted vests). The norms for degree of available research support were based on National Standards Project (National Autism Center [NAC], 2009), which provides national



reports about effectiveness of interventions for ASD. Sansosti (2012) designed the *Early Intervention Familiarity Scale* (EIFS) to assess parent/caregiver familiarity with available evidence for common early intervention practices listed in the questionnaire. Participants rated each approach as having “strong,” “promising,” and “no” empirical evidence. They also had the option to rate an approach as “familiar, but don’t know research” or “unfamiliar.” Percentage agreement was determined by calculating the percentage of parents whose ratings of awareness of empirical evidence of intervention approaches agreed with the National Standards Report rating of research support.

During open-ended questions parents reported that they often received no specific recommendations after receiving the diagnosis of ASD for their children. The study also reported that parents perceived medical and educational professionals as a ‘barrier’ to receiving services for their child with ASD due to lack of communication between the educational and medical agencies. For example, one parent reported “getting the runaround from professionals and schools...no recommendations...no road maps” (Sansosti et al. 2012, p. 88). As a result, parents reported conducting their own investigative research to learn facts about ASD and appropriate services for their child with ASD. The results of the parents’ self-reported familiarity with evidence regarding interventions of ASD indicated that a majority of participants demonstrated an adequate understanding of evidence-based practices for children with ASD. For example, 50% of parents rated ABA as having “strong” empirical evidence, which matched with the National Standards Report (NAC, 2009) rating for empirical evidence for ABA. Similarly the intervention approach called, “visual supports” had an 88% agreement between parental rating for sound empirical evidence and the rating by the National Standards

Report (NAC, 2009). The results suggested that parents of children with ASD had a relatively accurate understanding of the empirical evidence for ASD related interventions by the means of their own research. On the other hand, parents were equally aware of interventions which have not been viewed by the research community as having empirical support, thereby, indicating that parents of children with ASD were continually bombarded with mixed messages regarding appropriate interventions for ASD.

The study by Sansosti et al. (2012) concluded that the participating parents acquired an adequate understanding of evidence-based interventions/treatments for children with ASD primarily through self-education, and were equally aware of treatments without sufficient empirical evidence. In order to understand gaps in parent education, it is important to look at studies, which examined treatment choices, made by parents of children with ASD.

Green et al. (2004), discovered a lack of data documenting the number and types of ASD related interventions, programs, and therapies that parents chose for their children with autism. The authors suggested that such data could provide insight into the process that parents of children with ASD use to make decisions about interventions for their children. Thus, Green et al. (2004) developed an internet survey to identify the number and types of interventions, programs, and therapies used by parents of children with autism. A secondary aim was to determine whether certain parent or child characteristics influenced the number and types of treatments used.

Internet survey was distributed via colleagues and chapters of the Autism Society of America and Autism Organizations Worldwide. A total of 552 usable surveys were completed by parents of children with autism. Respondents were from United States

(N=434), Canada (N=37), Australia (N=25), New Zealand (N=13), and Philippines (N=8). Each of the remaining 23 respondents was from one of the following: Afghanistan, Albania, Algeria, Denmark, Egypt, Iceland, India, Israel, Malaysia, South Africa, and the United Kingdom. The survey listed 111 treatments, grouped under the following categories: (a) medications, (b) vitamin supplements, (c) special diets, (d) medical procedures, (e) educational/therapy approaches, (f) alternative therapy/medicine, (g) combined programs. For each treatment category, parents were asked to indicate whether they: (a) were currently using the treatment, (b) had used the treatment in the past, but were not currently using it, or (c) had never used the treatment. Space was provided for parents to list additional treatments and provide comments.

Green et al. (2004) found that the mean number of current therapies being used by parents was 7 and the highest number of different treatments used by any one parent was 47 (currently) and 39 (in the past). Parents of children with severe autism reported using the greatest number of treatments (an average of 8.7), while parents of children with Asperger's syndrome reported using the fewest number of treatments (an average of 4.5). Speech therapy was the most commonly used treatment (70% of parents reported using speech therapy currently; 23% reported using speech therapy in the past). Among the 111 treatments listed in the survey, both the most commonly used treatments as reported by parents and the least commonly used treatments as reported by parents included treatments with and without empirical support. Thus, the results suggested that the presence or absence of empirical evidence did not influence the parents' choices.

The study by Green et al. (2004) revealed that parents of children with autism used a wide range of treatment options over a period of time and the severity of

symptoms influenced the number and types of treatments. The most alarming finding, however, was that both the most commonly and least commonly used treatments included those with empirical and without empirical evidence. Thus, parents' treatment choices were likely influenced by a range of factors, including the availability of empirical evidence. Such a finding suggests that education for parents of children with autism should include information on factors to consider in the selection of treatment for their child. To date, there is limited available research on the nature of the parent education that is provided to parents on ASD in general and treatment selection for ASD in particular.

In order to better understand factors that might influence the decision making process of parents of children with ASD in selecting appropriate interventions, identifying the sources that parents use to obtain information and guidance about selecting appropriate interventions for their children with ASD can be helpful. Identifying sources of information used by parents can provide an insight into the type of information received by parents.

With a purpose of establishing the importance of physicians' knowledge of ASD, Rhoades, Scarpa & Salley (2007) conducted a study that tested the hypotheses that: (1) Children with ASD would be diagnosed between ages 3-4 years, (2) Caregivers would receive little information beyond the diagnosis from their medical providers, and (3) Caregivers would turn to other sources, outside of their local health care professionals to learn more about ASD. A survey was provided on relevant websites in Virginia such as the Commonwealth Autism Service, Blue Ridge Autism Center, and the Autism Society of America—Greater Roanoke Valley Chapter. Inclusion criteria consisted of parents or

caregivers currently residing in Virginia. A total of 146 ASD caregivers responded to the online survey.

The first section of the survey consisted of demographic information. The second section was designed to collect information that was specific to the child's ASD as well as information about the providers and included questions such as: *What is your child's current diagnosis?* (3=autistic disorder, 2=Asperger's, 1=PDD NOS); *How old was your child when he or she got the initial diagnosis?*; *What type of professional diagnosed your child with ASD?* (4=developmental pediatrician, 3=psychologist, 2=neurologist, 1=other/psychiatrist/primary care physician); *What information was provided by the diagnosing professional?* (no additional information, gave information about resources, gave literature about autism, spent time talking about autism, referred to an autism specialist, referred to a support group, advised on educational programs, advised on medical programs); *Who/what helped parents learn about ASD upon receiving the initial diagnosis?* (i.e., healthcare professionals, education professionals, parent resource centers, parents of children with autism, family members, friends, support groups, advocacy groups, internet, books, magazines and video tapes, conferences and workshops, did not seek further information, and other); and *Are you a member of a support group or advocacy group for parents?* (Roades et al. 2007).

The final section surveyed parents' opinions regarding the status (availability, perceived need, and quality) of autism-related outpatient services in their local area. Parents also were asked to identify which services they had used and currently used and then evaluate the services using a scale of 1 to 5 with 5 being highest. A range of intervention approaches was included in the survey such as, biomedical (e.g.,

medications, dietary restrictions), behavioral (e.g., applied behavioral analysis, pivotal response training) and educational services (e.g., early intervention, speech therapy).

Parents were asked to rate the services based on the availability and ease of locating the services in the area and the parent's satisfaction with and perceived need for such a service in the area (Rhoades et al. 2007).

The results of the study showed that the average age at which children received a diagnosis of autism was 58 months indicating that as hypothesized, the majority of the children received a diagnosis of autism between the ages of 3 and 4 years. Contrary to the hypothesis that caregivers would receive little or no information beyond the diagnosis from their medical providers, the results indicated that majority of medical professionals (82%) gave some type of additional information at the time of diagnosis (e.g., 40% of the professionals provided general information about ASD, 15-34% offered advice on educational or medical programs, and 6% professionals made referrals to autism specialists). Based on parent report, only 18% of the professionals did not provide any additional information beyond the diagnosis of autism. Consistent with the hypotheses that in absence of professional guidance, caregivers would turn to other sources such as the books, videos, magazines, to obtain information about ASD, it was observed that most parents turned to multiple sources of information about ASD outside of their healthcare or service providers. For example, 71-73% of the parents used internet/books and videos, while 42% of the parents relied on other parents, and only 15-20% of the parents received information from local healthcare, educational and early intervention professionals. Results from the final section of the survey indicated that the top 5 services rated by the parents as highly needed but scarcely available included approaches with and

without empirical evidence. For example, behavioral treatment and social skills training both have significant empirical evidence (NRC, 2001), while sensory integration and auditory integration approaches have limited empirical evidence (NRC, 2001), however the both treatments were rated by parents as highly needed but scarcely available. It was concluded that although the majority of physicians provided parents information about ASD, more efforts were needed to be taken in providing additional information about nature of ASD, resources for ASD , and selecting appropriate ASD intervention approaches based on empirical evidence.

Rhoades et al. (2008) noted that, as a trusted source of information, physicians are in a perfect role to guide families toward information with empirical support. Similarly, as an important member of diagnostic and intervention teams for ASD (ASHA, 2006a), SLPs can appropriately bear responsibility for educating parents regarding empirical evidence for different treatment options for ASD. However, very little is known about the status of parent education provided to parents of children with ASD, specifically by SLPs.

To date, only one study has examined parents' experiences and the level of parent education related to evidenced-based SLP services in the area of ASD. Auert, Trembath, Arciuli and Thomas (2012) conducted a focus group study in Sydney, Australia to explore the expectations, awareness, and experiences of parents in their efforts to access evidence-based SLP services for their children with ASD. Participants included parents (17 women and 3 men) of children with ASD ranging in age from 3 to 6 years, all of whom were recruited through early intervention and parent support programs for children with ASD across two locations in Sydney, Australia. Among the total participants, 85%

of them had accessed SLP services in private practice in addition to the early intervention program. Four focus groups (with 4 to 7 parents in each group) were conducted using a semi-structured question guide. A range of issues were discussed including:

(a) participants' experiences of working with SLPs, (b) the extent to which EBP was evident in their children's therapy programs, (c) their level of confidence when interacting with their SLPs, (d) their role in the therapy process, and (e) their expectations of the services provided (Auert et al. 2012).

Two central themes emerged during analyses of the focus group discussions, which could sum up parental expectations, awareness and experiences of accessing evidence-based speech-language services. Under the first theme, "Speech-language pathology: More than just a business" (Auert et al. 2012, p. 112), parents described the nature of their interactions with the SLPs and the challenges they faced while accessing appropriate and effective services for their child with ASD. Pertaining to the interaction between parents and SLPs, many parents indicated that they had little information about their child's intervention including the rationale for selecting particular approach. For example, when asked if they received information about intervention being provided one of participants responded, "...Still don't know how she got her idea [for therapy] or if she has got experience...[my son] goes there 2 years and he's doing better, but I still have no idea [about the evidence]" (Auert et al. 2012, p. 112). Some parents argued that by giving parents information and a practical role to play in the therapy process, SLPs could help instill in parents a sense of ownership and control over their children's therapy. For example, one of the participants stated, "Teaching the parent why they're doing the seemingly irrelevant, useless, and superfluous thing that we have no ownership of [is



important] because we don't know that it's gonna help us...teaching us would be really valuable so we can take ownership of what we're teaching them [our kids] knowing that it will help us down the track." (Auert et al. 2012, page 112). A small number of parents stated that communication between themselves and their children's SLP was effective and they felt informed about their children's program. For example, two of the participants provided the following individual statements, (a) "I get the knowledge from my speech therapist...My speech therapist is explaining to me whenever she wants to do something.", (b) "Our therapist is always giving us information and things from conferences" (Auert et al. 2012, p.112). Results also indicated that, few of the parents simply declined the idea of interaction with the SLPs, by saying "No" when asked if the SLP shared information about what they are working on. In summary, the participants reported receiving different amounts of information from their SLPs, which influenced the extent to which they felt informed and involved. Under the second theme called, "Parents and Power" (Auert et al. 2012, p.112), parents expressed their views regarding use of evidence-based practice during intervention for their child with ASD and parental perception of the role parents played in treatment of their child with ASD. When asked about EBP, parents had mixed opinions. For example, one of the parents expressed his opinion that, he valued a well-informed SLP who had up-to-date knowledge and understands the empirical evidence for the treatment the SLP provides. (Auert et al. 2012). On the other hand, one of participants stated, "I don't care so much about the research...[I care more that] they're telling you what they're doing and that I'm seeing progress in my child...I think that's more important to me than a study." (Auert et al.2012, p. 113).

According to the principles of EBP, clinical practice should be based on best available systematic research evidence, clinical practice evidence, and best available evidence related to preferences of fully informed patient (Dollaghan, 2007). The results indicate that SLPs were inconsistent with regards to following the EBP principle of fully informing the parents regarding the implemented intervention approach. Overall, parents reported a range of expectations regarding the services provided by SLPs, such as, an SLP should: (a) provide parents with information and research literature, (b) involve them in the decision making process, and (c) teach them how to deliver therapy at home (Auert et al. 2012).

The study by Auert et al. (2012), provides a foundational insight into parental expectations and experiences of parents of children with ASD with the help of insightful comments made by parents. However, the study fails to provide objective data regarding the number of parents and the level of parental satisfaction in receiving parent education about EBP from SLPs. Additionally, Auer et al. (2012) did not provide specific information such as the frequency with which the parents received ASD related education (e.g., at the time of diagnosis, during therapy, during parent meetings, or never). To enhance the quality of the education that SLPs provide to parents of children with ASD, it is important to identify specific gaps or deficits in the delivery of parent education.

Review of various studies mentioned above, revealed that there is an inconsistency in parental reports of receiving adequate information regarding ASD and EBP for ASD through professionals including SLPs (Auert et al. 2012; Sansosti et al. 2012, Rhoades et al. 2007). Additionally, due to lack of information provided by professionals working with children ASD, parents seek information through external

sources such as the Internet and other parents (Rhoades, 2007). Lastly, the review of studies also revealed that, parents' knowledge about selecting evidence-based practice is inconsistent as reflected from parent's choices in selecting interventions for their children with ASD (Green et al. 2004; Sansosti et al. 2012). Review of studies thus indicates that in order to implement better clinical practices in providing parent education it is essential to examine parental experiences, expectations and level of satisfaction in receiving information about ASD and EBP related to ASD from practicing SLPs.

### **Rationale**

Parents often face array of questions when they receive a diagnosis of ASD for their child. Research findings support the value of parent education in the light of empowering parents and eliciting better treatment outcomes. Recent trends in parent education focus on the idea of educating parents regarding evidence-based practice. Given the wide range of available treatments with and without empirical evidence, studies have shown that parents might rely on other sources such as the media or other parents to make intervention decisions. In an effort to promote use of evidence-based practice various organizations such as ASHA and NRC have stipulated policies and guidelines for professionals such as SLPs to educate parents regarding evidence-based practice. Given the nature of ASD, SLPs are considered important team members for diagnosis and intervention of ASD.

There is limited availability of data regarding experiences, expectations and level of satisfaction of parents of children with ASD for receiving ASD related education from practicing SLPs. Such information can aid in understanding the gaps in parent education

provided to parents of children with ASD by practicing SLPs. Exploring parental expectations regarding parent education can help professionals to provide services that effectively meet parental expectations. Additionally, evaluating the extent to which SLPs provide parent education can enhance the quality of clinical practices in terms of meeting parental expectations for parent education.

### **Purpose**

The purpose of this study was to examine parental experiences, expectations, and level of satisfaction regarding parent education received on ASD from practicing SLPs. Specific data was collected to determine parental experiences, expectations, and level of satisfaction for each of the following areas of information provided by SLPs: (a) nature of ASD, (b) specific treatment approach used with their child by the practicing SLP; and (c) evidence-based practice in ASD.

The research questions that were addressed in the proposed study were:

- (1) What are the parental experiences in receiving information about the nature of ASD, specific treatment approach(es) used by their child's SLP and about EBP in ASD?
- (2) What are the parental expectations for parent education on ASD from practicing SLPs?
- (3) What is the level of parental satisfaction related to the information that the SLP provided on the nature of ASD, intervention approaches used with their child with ASD and about EBP in ASD?

Data collected to address each research question were used to provide insight on the extent to which SLPs provide sufficient and relevant education to parents of children with ASD as described by ASHA (2006a; 2006b). The current study can have important implications for SLPs with regard to: (a) provision of effective education to parents of children with ASD; (b) assurance of high levels of parental satisfaction with parent education provided by SLPs; and (c) facilitating parents' intervention choices based on clinical evidence provided via parent education

## Method

### Participants

The participants for this study were parents of children with ASD who were recruited through Facebook pages of the following organizations: Autism Speaks Milwaukee and Autism Society of Southeastern Wisconsin. Potential participants were contacted via an online flyer and an informed consent posted on the Facebook pages of the Autism Speaks Milwaukee and Autism Society of Southeastern Wisconsin. Through the online flyer the respondents were invited to respond to an anonymous, web-based survey on Survey Monkey, a provider of web-based survey options for people of varying experiences ([www.surveymonkey.com](http://www.surveymonkey.com)). The study protocol was reviewed and approved by the University of Wisconsin Milwaukee (UWM) Institutional Review Board (IRB) prior to recruitment of participants. Appendix A includes the copy of the IRB approval letter for the current study.

To recruit participating parents, the investigator sent an email describing the nature of the study and requesting member participation to the respective authorities of the two organizations: Autism Speaks Milwaukee and the Autism Society of Southeastern Wisconsin. Both the organizations also received a copy of the UWM IRB approval letter for the conducting the study. Upon reviewing the approval letter, authorities of both organizations (Autism Speaks Milwaukee and Autism Society of Southeastern Wisconsin) posted the Survey Monkey link to the survey, along with the recruitment flyer and the informed consent to the respective Facebook page of each organization.

The inclusion criteria for respondents for the study were that: (a) the respondent was a parent of a child with a diagnosis of ASD who was between three and twelve years of age, (b) the respondent and their child with ASD resided in the state of Wisconsin, (c) the respondent's child received the diagnosis of ASD more than six months and less than 3 years before the date of completing the survey, (d) the respondent's child with ASD either was currently receiving or had received services from an SLP for at least six months in the state of Wisconsin, (e) the respondent had only one child with ASD in the family, and (f) only one parent or primary caregiver per family completed the survey. Upon reconsideration, one of the inclusion criteria was modified to include parents of children with ASD that received the diagnosis of ASD more than six months and less than 4 years before the date of completing the survey. The change was reviewed and accepted by the IRB. The survey was designed in a way such that the respondents that did not meet the inclusion criteria were unable to complete the survey.

A total of 50 respondents attempted the survey. Of the 50, 23 respondents (46%) were qualified and 27 respondents (54%) were disqualified for at least one of the eligibility criteria. The demographic information pertaining to the 23 respondents who qualified and participated in the present study is presented in Table 1. For each choice within each category (relationship to the child, age, gender, race/ethnicity, highest level of completed education, average household income, number of years lived in the state of WI, names of counties lived in past, county living in currently and zip code of current residence), the data were reported as response count (the number of respondents that selected the choice) and percentage of the total respondents. The design of the survey allowed respondents to skip questions as desired thus, all of the 23 respondents did not

answer all 36 questions in the survey. The number of respondents for each question is specified as  $N$  for each category in Table 1 (e.g., out of 23 respondents, 22 respondents specified their gender while one respondent skipped the question, thus, the  $N$  is specified as 22 [ $N=22$ ] for that category). The response count ( $n$ ) represents the frequency of response for each choice.

Table 1

*Demographic Information about the Parent/ Primary Caregiver of Child with ASD*

Response	Response count ( $n$ ) <sup>a</sup>	Percentage (%) <sup>b</sup>
<b>Relationship (<math>N=23</math>)</b>		
Mother	23	100.0
Father	0	0
Step mother	0	0
Step Father	0	0
Adoptive Mother	0	0
Adoptive Father	0	0
Legal Guardian	0	0
Other	0	0
<b>Age (<math>N=23</math>)</b>		
Under 20	0	0
21-30	6	26.1
31-40	11	47.8
41-50	6	26.1
50-above	0	0
<b>Gender (<math>N=22</math>)</b>		
Male	0	0
Female	22	100.0
<b>Race/ Ethnicity (<math>N=23</math>)</b>		
African American	0	0
Asian/Pacific Islander	0	0
Native Hawaiian	0	0
Caucasian/European American	20	87.0
Native American	0	0
Latino, Hispanic, or Chicano	3	13.0
Other (please specify)	0	0
<b>Highest Level of Education (<math>N=22</math>)</b>		



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Some High School	0	0
High school graduate	3	13.6
Some college	5	22.7
College degree	9	40.9
Some graduate studies	2	9.1
Graduate degree	3	13.6
Household Income ( <i>N</i> =22)		
Under \$20,000	3	13.6
\$20,000-\$39,999	2	9.1
\$40,000-\$59,999	3	13.6
\$60,000-\$79,999	7	31.8
\$80,000-\$99,999	1	4.5
\$100,000 and above	6	27.3
Years lived in state of WI ( <i>N</i> =23)		
0-10	3	13
11-20	4	17.4
21-30	5	21.7
31-40	7	30.4
40-Above	4	17.3
Counties resided in the past ( <i>N</i> =23)		
Brown	3	9.1
Calumet	1	3.0
Dane	1	3.0
La Crosse	1	3.0
Milwaukee	11	33.3
Oneida	1	3.0
Outagamie	2	6.1
Ozaukee	1	3.0
Polk	1	3.0
Racine	2	6.1
Waukesha	7	21.2
Winnebago	2	6.1
Currently residing county ( <i>N</i> =23)		
Milwaukee	9	39.1
Oneida	1	4.3
Outagamie	1	4.3
Racine	2	8.7
Waukesha	7	30.4
Winnebago	3	13.0
Zip code of current residence ( <i>N</i> =23)		
53045	1	5.3
53051	2	10.6
53072	2	10.6
53110	1	5.3
53118	1	5.3
53129	2	10.6

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53172	1	5.3
53186	1	5.3
53209	1	5.3
53214	2	10.6
53217	1	5.3
53222	1	5.3
53405	1	5.3
53406	1	5.3
54568	1	5.3
54902	1	5.3
54913	1	5.3
54952	1	5.3
54956	1	5.3

*Note.* <sup>a</sup> For the category: *Counties resided in the past*, respondents could list multiple counties. Thus, the response count can exceed total number of responses and <sup>b</sup> the total percentage could exceed 100% for the specific category.

All respondents (100%) were mothers of a child with ASD. Most of the respondents (11 of 23, 47.8%) were in the age range of 31 to 40 years. None of the respondents were younger than 20 or older than 50 years old. Majority of the respondents (20 of 23, 87.0%) were Caucasian/European American and 3 respondents (13%) were Latino, Hispanic or Chicano. Three of 22 respondents (13.6%) indicated the highest level of education they completed was high school graduation. Only 5 of 22 respondents (22.7%) reported having had some college education, while 2 respondents (9.1%) had some graduate level education and 3 (13.6%) indicated they had completed a graduate degree. Most of the respondents (7 of 22, 31.8%) had an average household income in the range of \$60,000-\$79,000. Most respondents listed Milwaukee county as one of the *counties resided in the past* (33.3%) and as *currently residing county* (33.3%). A range of

other counties (e.g., Brown, Calumet, Dane) were listed under counties lived in past and currently residing county. The respondents were from a wide range of area zip codes.

Respondents were also asked to provide demographic information about their child with ASD. Demographic information about the children with ASD (age, gender, level of education completed, current diagnosis, and age at the time of diagnosis) is included in Table 2.

Table 2

*Demographic Information about the Respondents' Child with ASD*

Response	Response count (n)	Percentage (%)
<i>Age (N=22)</i>		
6 -36 months	1	4.5
37-72 months	7	31.8
73-108 months	9	40.9
109-144 months	4	18.2
145 and above	1	4.5
<i>Gender (N=22)</i>		
Male	18	81.8
Female	4	18.2
<i>Level of education completed (N=21)</i>		
None	4	19.0
Pre-school	5	23.8
Kindergarten	8	38.1
Elementary School	4	19.0
Middle School	0	0.0
<i>Current Diagnosis (N=22)</i>		
Autism Disorder	15	68.2
Asperger's Disorder	1	4.5
Childhood Disintegration Disorder	0	0.0
Rett's Syndrome	0	0.0
Pervasive Development Disorder-Not Otherwise specified	6	27.3
Not known	0	0.0
Other	0	0.0
<i>Age at the time of diagnosis (N=22)</i>		

0-24 months	3	13.6
25-48 months	14	63.6
49-72 months	2	9.1
73-96 months	3	13.6
97 and above	0	0.0

The data show that most of respondents reported that their child with ASD was: (a) within the age range of 73-108 months (40.9%), (b) male (81.8%), and (c) had completed kindergarten (38.1%). Fifteen of the 22 respondents (68.2%) reported that their child had a diagnosis of autism disorder. Most respondents (14 of 22, 63.6%) reported their child received the diagnosis of ASD in the age range of 25 to 48 months (2 to 4 years).

Additional information collected from the respondents included information about the services received by their child with ASD. Information about other services and specific speech and language services received by the child is included in Table 3 and 4 respectively.

Respondents were asked to list the types of professionals that provided the diagnosis of ASD for their child and the professionals that currently worked with their child with ASD. The data for the information that the respondents provided about the services that their children with ASD received are included in Table 3.

Table 3

*General Information about the Services Received by the Child with ASD*

Response	Response count (n) <sup>a</sup>	Percentage(%) <sup>b</sup>
Professionals that diagnosed ASD ( <i>N</i> =19)		
Professionals		
Medical Doctors	3	15.8
Psychologists	10	52.6
SLP	1	5.3
Teachers	1	5.3
Organizations		
Autism Intervention Milwaukee (AIM)	1	5.3
Catalpa Health	1	5.3
Racine Unified School District	1	5.3
Weisman Center, Madison	1	5.3
Wisconsin Early Autism Project (WEAP)	4	21.1
Professionals currently working with the child ( <i>N</i> =16)		
Professionals		
Applied Behavior Analysis ( <i>ABA</i> ) Specialists	4	25.0
Behaviorist	1	6.3
Developmental Individual Relationship ( <i>DIR</i> ) consultant	1	6.3
Line Therapists	2	12.5
Medical Doctors	3	18.8
Occupational Therapists ( <i>OTs</i> )	7	43.8
Psychologist	5	31.3
Relationship Development Intervention ( <i>RDI</i> ) Consultant	1	6.3
Special Education Teachers	2	12.5
Speech-Language Pathologists	7	43.8
Organizations		
Children's Behavior Health Network	1	6.3
Fox Valley Treatment Program	1	6.3
Public School (Special Education)	2	12.5
Sonenberg Consultants	1	6.3
Washington Early Learning Center	1	6.3
WEAP	1	6.3

*Note.* <sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

Although most of the respondents listed the type of professional that provided the ASD diagnosis for their child (e.g., doctor, psychologist), some of the respondents listed name of the specific professional(s) (e.g., Dr. XYZ) or name of specific organization (e.g., Catalpa Health) through which the diagnosis was provided. In instances where the respondent had specified the name of the professional, an internet search using the *Google* search engine was conducted to obtain information on the individual's professional area counted towards the category of that profession (e.g., doctor, psychologist). Most respondents listed psychologist (52.6%) and the Wisconsin Early Autism Project (WEAP) (21.1%), when asked to list the professional that provided the diagnosis for their child with ASD. Similarly, when asked to list the professionals that currently work with the child, most parents listed the psychologist (31.3%) and the special education division in the public school (12.5%).

Table 4

*General Information about Speech and Language Services Received by the Child with ASD*

Response	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Currently receiving SLP services		
Yes	17	89.5
No	2	10.5
Duration of receiving SLP services		
0-24 months	3	15.8
25-48 months	11	57.9
49-72 months	0	0.0
73-96 months	4	21.1
97-120 months	1	5.3
Places of receiving SLP services		
Public School	17	89.5

Hospital	1	5.3
Private School	0	0.0
Private Clinic	2	10.5
Home Program	7	36.8
Other	1	5.3

Note. N=19

<sup>a</sup> For the category *Places of receiving SLP services*, respondent could listed multiple places where the child received SLP services. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100% for the specific category.

Respondents were asked: (a) if their child currently received SLP services, (b) the duration for which their child had received or was currently receiving SLP services, and (c) the places where the child received or was receiving SLP services. Of the 19, 17 respondents (89.5%) indicated that their child currently received SLP services at the time of completing the survey. Most of the respondents (11 of 19, 57.9%) indicated their child had received SLP services for 25 to 48 months (2 to 4 years). The majority of the respondents (17 of 19, 89.5%) reported that their child with ASD received SLP services through the public school system. Respondents provided further information about their experiences, expectations and levels of satisfaction by responding to questions beyond the demographic information questions listed on the online survey.

## Materials

The survey, *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions* was an online survey that consisted of 36 questions (See Appendix B). The format of the question responses were in Likert-type scales, yes/no, multiple choice, and “select all that apply”. The sections of the survey pertaining to

demographic and general information about the participants, their children with ASD and related speech-language pathology services included questions from available surveys from prior studies (Rhoades et al. 2007; Hume et al. 2005). Questions related to parental experiences, expectations, and levels of satisfaction were developed by the investigator based on the review of available studies and published literature on experiences with parent education for parents of children with ASD (Osborne & Reed, 2008; Auert et al. 2012). Questions probing for information about commonly used sources of information by parents of children with ASD were based on questions used in the study by Green et al. (2004), which examined the treatment selection process of parents of children with ASD.

The survey questions for the proposed study were organized into 7 general topics, which included:

- a. Eligibility Information (e.g., questions related to inclusion criteria such as currently residing in the state of Wisconsin);
- b. Demographic information about the parent of children with ASD (e.g., household income, level of education, age, gender);
- c. Demographic information about the child with ASD (e.g., age, gender, level of education, type of diagnosis);
- d. General information about other services and SLP services received by the child with ASD (e.g., setting in which SLP services were received, duration of SLP services received)
- e. Parental experiences regarding receiving parent education about ASD (e.g., received information about symptoms, causes, treatment options, clinical



research; received parent education at the time of diagnosis, during therapy, at parent conferences or never)

- f. Parental expectations regarding parent education about ASD (e.g., comments about suggestions for SLPs regarding type, amount and format of information the parents would like to receive)
- g. Parental level of satisfaction and perception regarding the parent education about ASD (e.g., parents rating the received ASD related information as adequate or inadequate, parents reporting level of confidence in making treatment choices based on information provided)

The first six questions in the *Qualifying Information* section of the survey established the respondent's eligibility by confirming that the respondent currently resided in WI, that the respondent's child was between the ages of three years to twelve years, that the respondent's child had received a diagnosis of ASD between January 2010- February 2014, that the child received services from a certified SLP in WI for at least 6 months, that the respondent had only one child with ASD in the immediate family, and that no one else in the family had taken previously taken the survey. To understand the characteristics of the eligible respondents, the survey questions allowed for the gathering of demographic information in terms of general information about the parent (primary caregiver), the child, and about the speech-language pathology services received. General information about parent or primary caregiver included: The respondent's relationship to the child (e.g., mother, father, step mother, step father, adopted mother, adopted father, legal guardian, and other relationship), age, race/ethnicity (e.g., African American, Asian/pacific islander, native Hawaiian, Caucasian/

European American, native American, Latino/Hispanic, other), highest level of education completed (e.g., college degree, high school, graduate degree), annual household income (e.g., under \$20,000, \$20,000-\$39,999, \$40,000-\$59,999, \$60,000-\$79,999, \$80,000-\$99,999, \$100,000- Above), number of years as a Wisconsin resident (years and months), and Wisconsin counties in which they have resided in the past, and the area zip code and the county in which they currently resided. The general information about the child with ASD included: age (years, months), gender (male, female), level of education (none, preschool, kindergarten, elementary school, middle school), the child's current diagnosis (Autism disorder, Asperger's disorder, childhood disintegration disorder, Rett's syndrome, Pervasive development disorder- Not otherwise specified [PDD-NOS], Not known, Other), age at which the child was diagnosed (years and months), and the professionals who diagnosed the child. General information about the speech-language pathology services was obtained via questions such as: "Which professional(s) provided the diagnosis of ASD for your child", "Please list the team of professionals that currently work with your child", "Does your child currently received SLP services" and "Where does/did the child receive SLP services? (e.g., public school, hospital, private school, private clinic, home program, other).

To evaluate the frequency and type of information received, parents were asked to specify the times at which they received a specific type of ASD related information (e.g., During my interaction with my child's SLP, I received general information about ASD – Choose all that apply: a. *at the time of diagnosis*, b. *during therapy*, c. *at parent meetings*, d. *never*). To examine parental expectations, parents were asked to provide overall suggestions about the type, amount and format of parent education that they would have

liked to receive from practicing SLPs. Information on the level of parental satisfaction was obtained by asking the parents to rate the ASD related information as adequate or inadequate.

The order of presentation of the survey questions was the same for each participant because the questions followed a sequence regarding the parents' experiences, expectations, satisfaction level, and perceptions. Appendix B includes a listing of the questions in the order in which they were presented in the *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions* online survey.

## **Procedures**

The Midwest Regional Director for Autism Speaks Milwaukee and the program manager at the Autism Society of Southeastern Wisconsin were sent the following documents: (a) the UWM IRB approval letter for the present study, (b) the recruitment flyer inviting parents to participate in the survey (presented in the Portable Document Format [PDF] format for posting on Facebook page of the respective organization), and (c) the informed consent (presented in PDF format for posting on Facebook page of the respective organization). The recruitment flyer and the consent letter consisted of information summarizing purpose of the study, informing potential participants that the participation is voluntary and could be terminated at any point during the survey, and explaining potential participants that completion of the survey implied that the participant gave informed consent (See Appendix C). The Survey Monkey link to the survey was also sent to the authorities of the respective organizations. Both authorities at the respective organizations reviewed the IRB approval letter, the recruitment flyer and the

informed consent, and posted the survey on the respective organization Facebook pages on August 8<sup>th</sup> 2014. Each week the recruitment flyer with informed consent and the link to the survey were reposted on the Facebook pages of each organization. The survey was available online until September 12, 2014.

### **Data Analysis**

The demographic variables for the study for parents included: (gender, age, annual income, highest level of education, length of time as Wisconsin residents). The demographic variables for the respondents' children with ASD included: (gender, age, current level of education, specific diagnosis, age at which the child received the diagnosis of ASD). Additional information about the services received by the respondent's child with ASD included: (type of professionals that provided diagnosis and currently working with the child, the duration for which the child has received SLP services and the settings in which the services were provided). The current study was conducted to obtain specific information to describe parents' expectations for parent education related to ASD. The study was also designed to obtain information on the experiences of parents of children with ASD with parent education about ASD and how the experiences might have influenced parental level of satisfaction with parent education in ASD.

Descriptive statistics was used to analyze the data in the current study. The data collected from the respondents' responses to items on the *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions* were analyzed using the Excel program (Microsoft Office 2011). The raw data were entered into the Excel

program, and used to calculate frequencies of response choices for multiple choice, yes/no and “select all that apply” questions. Each frequency was converted to a percentage by dividing the number of responses recorded for each choice by the total number of responses for the question and multiplying by 100. For questions in which respondents selected one or more response, percentage was calculated for each response.

## Results

Results of the present study were derived using descriptive statistics. A percentage of parent responses was calculated for parental experiences, and parental level of satisfaction and perceptions regarding ASD related information received from the SLP. Tables 5-20 include data for parental experiences, levels of satisfactions and perceptions related to the parent education the parents received. Free-text responses to open-ended question regarding parental expectations about ASD related information received from their child's SLP were reviewed for similarities and differences. Appendix C includes the respondents' verbatim responses. The results of the data analyses are presented for each of the research questions that were addressed in the present study.

### Research Question #1

*What are the parental experiences in receiving information about the nature of ASD, specific treatment approach(es) used by their child's SLP and about EBP in ASD?*

Parental experiences in receiving information about the nature of ASD, specific treatment approaches used by their child's SLP and about EBP in ASD were targeted by Question #26 on the *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions* survey (see Appendix B). Question# 26 consisted of 7 statements that followed the prompt, "During my interaction with my child's SLP, I received information about ..." Each statement that followed the prompt pertained to parental experiences of: (1) receiving information about common facts regarding ASD [e.g., causes, symptoms, prognosis], (2) receiving information about child's specific speech and language difficulties related to ASD, (3) receiving

information about specific treatment approaches that the SLP used with the child, (4) engaging in discussion about available clinical research regarding the specific treatment the SLP used with the child, (5) parental involvement in providing input in selecting specific treatment approach for the child, (6) receiving information about the meaning of “Evidence-Based Practice” and (7) receiving information about importance of looking for clinical evidence when selecting treatments for their child with ASD. Parents were asked to choose one of the following responses for each statement: (a) *at the time of diagnosis*, (b) *during therapy*, (c) *at parent meeting*, and (d) *never*. The total number of respondents for each statement was specified as *N* and frequency of response for each choice was represented as response count (n). For each statement, response count (n) for *Never* was subtracted from the total responses (N) to obtain the response count indicating that the information was received at some point during parent and SLP interaction. Tables 5-11 present data on the frequency and percentage for each response choice for the identified statement about the parent’s experiences in receiving information about ASD.

Table 5

*Responses to the Survey Question #26, Statement 1: For the following statements choose all that apply: “During my interaction with my child’s SLP, I received information about common facts regarding ASD (e.g., causes, symptoms, prognosis)”*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Received <sup>*</sup> ( <i>R= 10</i> )		
At the time of diagnosis	8	80.0
During therapy	5	50.0
At parent meetings	4	40.0
Never	9	47.4

*Note. N=19*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

\**R*= Total number of respondents indicating that the information was received at least once or multiple times during their interaction with their child's SLP. The value of *R* was obtained by subtracting the response count (*n*) for *Never* from total number of respondents (*N*). Percentage for *Received* was obtained based on *R*.

Table 5 includes the data for Statement 1 of Questions # 26. A total of 19 out of 23 (82.6%) respondents answered Statement 1 of Question # 26. Of the 19 respondents, 9 (47.4%) indicated that they never received information about common facts of ASD. Thus, 10 of 19 respondents (52.6%) indicated that they received the information about common facts regarding ASD at least once or multiple times during their interaction with their child's SLP. Thereby, 8 of 10 respondents (80.0%) indicated they received information about common facts of ASD at the time of diagnosis, 5 of 10 respondents (50.0%) indicated they received the information during the time in which their child received therapy, and 4 of 10 respondents (40.0%) indicated they received the information at parent meetings.



Table 6

*Responses to the Survey Question #26, Statement 2: For the following statements choose all that apply: “During my interaction with my child’s SLP, I received information about my child’s specific speech and language difficulties related to ASD”.*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Received Information <sup>*</sup> (R=13)		
At the time of diagnosis	8	61.5
During therapy	5	38.5
At parent meeting	9	69.2
Never	6	31.6

*Note. N=19*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

<sup>\*</sup>R= Total number of respondents indicating that the information was received at least once or multiple times during their interaction with their child’s SLP. The value of R was obtained by subtracting the response count (n) for *Never* from total number of respondents (N). Percentage for *Received Information* was obtained based on R.

Table 6 includes data for Statement 2 of Question # 26. A total of 19 of the 23 respondents (82.6%) answered Statement 2 of Question #26. Of the 19, 6 respondents (31.6%) indicated they never received information about their child’s specific speech and language difficulties related to ASD. Thus, 13 of the 19 (68.4%) respondents indicated they received information about their child’s specific speech and language difficulties related to ASD at least once or multiple times during their interaction with their child’s SLP. Thereby, 8 of the 13 respondents (61.5%) indicated they received information about their child’s specific speech and language difficulties related to ASD at the time of

diagnosis, 5 of the 13 respondents (38.5%) indicated they received this information during therapy and 9 of the 13 respondents (69.2%) indicated they received the information at parent meetings.

Table 7

*Responses to the Survey Question #26, Statement 3: For the following statements choose all that apply: “During my interaction with my child’s SLP, I received information about specific treatment approaches he/she used with my child”.*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Received Information <sup>*</sup> (R=16)		
At the time of diagnosis	5	31.3
During therapy	7	43.8
At parent meeting	11	68.8
Never	3	15.8

*Note. N=19*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

<sup>\*</sup>R= Total number of respondents indicating that the information was received at least once or multiple times during their interaction with their child’s SLP. The value of R was obtained by subtracting the response count (n) for *Never* from total number of respondents (N). Percentage for *Received Information* was obtained based on R.

Table 7 includes data for Statement 3 of Question # 26. A total of 19 of the 23 respondents (82.6%) answered Statement 3 of Question # 26 about the information they received about specific treatments used by their child’s SLP. Of the 19, 3 respondents (15.8%) indicated that they never received this information. Thus, 16 of the 19

respondents (84.2%) indicated they received information about the specific treatment approach(es) the SLP used with their child, at least once or multiple times during interaction with their child's SLP. Thereby, 5 of the 16 respondents (31.3%) indicated they received information about the specific treatment approach(es) used with their child at the time of diagnosis, 7 of the 16 respondents (43.8%) indicated they received this information during therapy and 11 of the 16 respondents (68.8%) indicated they received the information at the parent meetings.

Table 8

*Responses to Survey Question #26, Statement 4: For the following statements choose all that apply: "During my interaction with my child's SLP, I was engaged in discussion about available clinical research regarding the specific treatment the SLP used with my child".*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Engaged in Discussion(s) *(R=6)		
At the time of diagnosis	4	66.7
During therapy	4	66.7
At parent meeting	3	50.0
Never	12	66.7

*Note. N=18*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

\*R= Total number of respondents indicating that they were engaged in discussion(s) at least once or multiple times during their interaction with their child's SLP. The value of

R was obtained by subtracting the response count (n) for *Never* from total number of respondents (N). Percentage for *Engaged in Discussion(s)* was obtained based on R.

Table 8 includes data for Statement 4 of Question #26. A total of 18 of the 23 respondents (78.3%) responded to Statement 4 of Question #26. Majority of the respondents (12 of 18, 66.7%) indicated that discussion(s) about available clinical research regarding the specific treatment the SLP used with their child never occurred during their interaction with their child's SLP. Thus 6 of the 18 respondents (33.3%) indicated they were engaged in the discussion(s) about clinical research at least once or multiple times during their interaction with their child's SLP. Thereby, 4 of the 6 respondents (66.7%) indicated they were engaged in discussion(s) at the time of diagnosis, 4 of the 6 respondents (66.7%) were engaged in discussion(s) during therapy and 3 of the 6 respondents (50.0%) indicated they were engaged in discussion(s) about available clinical research, at parent meetings.

Table 9

*Responses to the Survey Question #26, Statement 5: For the following statements choose all that apply: "During my interaction with my child's SLP, I was asked to provide input in selecting specific treatment approach for my child".*

Response Choices	Response count (n) <sup>b</sup>	Percentage (%) <sup>a</sup>
Asked to Provide Input *(R= 13)		
At the time of diagnosis	3	23.1
During therapy	7	53.8
At parent meeting	10	76.9
Never	5	27.8

*Note. N=18*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the total percentage can exceed 100% and the <sup>b</sup> response count can exceed the total number of respondents.

\**R*= Total number of respondents indicating that they were asked to provide input at least once or multiple times during their interaction with their child's SLP. The value of *R* was obtained by subtracting the response count (*n*) for *Never* from total number of respondents (*N*). Percentage for *Asked to Provide Input* was obtained based on *R*.

Table 9 includes data for Statement 5 of Question #26. A total of 18 of the 23 respondents responded to Statement 5 of Questions #26. Of the 18, 5 respondents (27.8%) indicated they were never asked to provide input in selecting the specific treatment approach(es) for their child during their interaction with their child's SLP. Thus 13 of the 18 respondents (72.2%) indicated they were asked to provide input at least once or multiple times during their interaction with their child's SLP. Of the 13, 3 respondents (23.1%) indicated they were asked to provide input in selecting specific treatment approach for their child at the time of diagnosis, 7 of the 13 respondents (53.8%) were asked to provide input during therapy. Ten of the 13 respondents (76.9%) were asked to provide input during parent meetings.

Table 10

*Responses to the Survey Question #26, Statement 6: For the following statements choose all that apply: "During my interaction with my child's SLP, I received information about the meaning of Evidence-based practice related to ASD"*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Received Information <sup>*</sup> (R=7)		
At the time of diagnosis	3	42.9
During therapy	4	57.1
At parent meetings	5	71.4
Never	11	61.1

*Note.* N=18

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

<sup>\*</sup>R= Total number of respondents indicating that the information was received at least once or multiple times during their interaction with their child's SLP. The value of R was obtained by subtracting the response count (n) for *Never* from total number of respondents (N). Percentage for *Received Information* was obtained based on R.

Table 10 includes data for Statement 6 of Question #26. A total 18 of the 23 respondents responded to Statement 6 of Question #26 pertaining to parental experiences of receiving information about the meaning of “evidence-based practice.” Of the 18 respondents, the majority (11; 61.1%) indicated that information about the meaning of “evidence-based practice” was never shared during their interactions with their child's SLP. Thus, 7 of the 18 respondents (38.9%) indicated that they received this information at least once or multiple times during their interaction with their child's SLP. Thereby, fewer respondents indicated they received information about meaning of “evidence-based practice”: 3 of the 7 respondents (42.9%) at the time of diagnosis, 4 of the 7 respondents (57.1%) during therapy and 5 of the 7 respondents (71.4%) at parent meetings.

Table 11

*Responses to the Survey Question #26, Statement 7: For the following statements choose all that apply: “During my interaction with my child’s SLP, I was engaged in discussion(s) about the importance of looking for clinical evidence when selecting treatments for my child”.*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Engaged in discussion(s) *(R=7)	5	71.4
At the time of diagnosis		
During therapy	3	42.9
At parent meetings	4	57.1
Never	12	63.2

*Note. N=19*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

\*R= Total number of respondents indicating that they were engaged in discussion(s) least once or multiple times during their interaction with their child’s SLP. The value of R was obtained by subtracting the response count (n) for *Never* from total number of respondents (N). Percentage for *Received Information* was obtained based on R.

Table 11 includes data for Statement 7 of Question #26. A total of 19 of the 23 respondents responded to Statement 7 of Question #26. The majority of the respondents (12 of 19, 63.2%) indicated that discussion(s) about the importance of looking for clinical evidence when selecting treatments for their child never occurred during interactions with their child’s SLP. Thus, 7 of the 19 respondents (36.8%) indicated they were engaged in this discussion(s) at least once or multiple times during their interaction with their child’s

SLP. Thereby, 5 of the 7 respondents (71.4%) indicated they were engaged in discussion(s) at the time of diagnosis, 3 of the 7 respondents (42.9%) were engaged in discussion(s) during therapy, and 4 of the 7 respondents (57.1%) were engaged in discussion(s) during parent meetings.

Research question # 2 of the current study inquired about parental expectation regarding receiving parent education from their child's SLP. Parents were asked about their expectation in the form of free-text response to survey question #27. The verbatim responses were reviewed for similarities and differences. Results of research question # 2 include a review of verbatim responses provided by the respondents.

### **Research Question #2**

*What are the parental expectations for parent education on ASD from practicing SLPs?*

In order to get an insight into parental expectations regarding the information that they received from their child's SLP, parents were asked to respond to a free-text response question: *Based on your experience of working with your child's SLP, what suggestions would you give to practicing SLPs regarding the parent education component of their job? Please specify the type, amount and format of the information that you expect an SLP should provide.* Ten of the 23 respondents (43%) provided text responses to this question. Appendix D includes the participants' verbatim responses. The expectation reported by 3 of the 10 respondents (30%) was for weekly communication from their child's SLP. The expectation of responding parents regarding the weekly communication was primarily for two reasons: (1) to get information about what the SLP



was focused on currently in therapy with the child, and (2) to get information about the progress the child had made. Similarly, 3 of the 10 responding parents (30%) indicated that they expected information about what they as parents could do at home with their child to carry over the techniques that the SLP used in therapy to their home or to learn about how to teach their child. Two of the 10 responding parents (20%) indicated that they expected the SLP to have an updated knowledge about current research and they expected more information about evidence-based practice. One of the 10 responding parents (10%) expressed that, "...I also would suggest understanding culturally the family needs. We were advice (granted, I know she meant well) that doing therapy in a bilingual sessions could give us delayed results due to the length it may take my child to learn and process both. Granted, at the time of the diagnosis, we had spoken to our child only in Spanish. At that moment we switched to English only and waited to see if our son could pick up language easily. We have now started teaching him Spanish and he is picking it up well. We love to see him become bilingual. It was very difficult for us to drop Spanish all together...". Another responding parent stated an expectation of, "More parent input."

### **Research Question #3**

*What is the level of parental satisfaction related to the information that the SLP provided on the nature of ASD, intervention approaches used with their child with ASD and about EBP in ASD?*

Information about parental levels of satisfaction with and perceptions of the ASD related information that was provided to them by their child's SLPs was targeted through

Question #28 through #36 on the *Parent Education in Autism: Experiences, Expectations and Perceptions* survey (See Appendix A). Questions such as, *How would you rate the general information provided to you by your child's SLP about ASD?* were included to obtain information about levels of satisfaction. To obtain information about parental perceptions parents were asked questions such as, *Which factors influenced your decision the most in deciding which treatments to use for your child?* Responses to Questions #28-#36 pertaining to parental level of satisfaction and perception regarding ASD related information provided to by their child's SLP are presented in Tables 12 through 20.

Through Questions #28 and #29, the respondents were asked to rate their level of satisfaction with information received about: (a) common facts about ASD, and (b) specific treatments used with their child. Respondents were asked to use following ratings: *Information was adequate, Information was somewhat adequate, Information was inadequate or No information was provided.* Data for responses to Questions #28 and #29 are presented in Table 12 and Table 13, respectively.

Table 12

*Responses to the Survey Question #28: How would you rate general information provided to you by your child's SLP about autism spectrum disorder?*

Response Choices	Response count (n)	Percentage (%)
Information was adequate	5	31.2
Information was somewhat adequate	4	25.0
Information was inadequate	3	18.8
No information was provided	4	25.0

*Note. N=16*

Table 12 includes data for Question #28 on the survey. A total of 16 of the 23 respondents answered Question #28 on the survey. When asked to rate the adequacy of the general information about ASD that was provided by their child's SLP, 5 of the 16 respondents (31.2%) indicated that the information was adequate while 3 of the 16 respondents (18.8%) indicated that the information was inadequate. An equal percentage of respondents (25%) indicated that either there was inadequate or no general information about ASD was provided.

Table 13

*Responses to the Survey Question #29: How would you rate the information provided by SLP about the specific treatment approach he/she used with your child?*

Response Choices	Response count (n)	Percentage (%)
Information was adequate	6	37.5
Information was somewhat adequate	7	43.7
Information was inadequate	1	6.3
No information was provided	2	12.5

*Note. N=16*

Table 13 includes data for Question #29 on the survey. A total of 16 of the 23 respondents provided a rating for the information provided by SLP regarding the specific treatment approach(es) used with their child. Of the 16, 7 respondents (43.7%) indicated that information about the specific treatment approach(es) used with their child was somewhat adequate. Two of the 16 respondents (12.5%) indicated that no information was provided regarding the specific treatment approach used with their child.

Question #30 asked parents to rate the information about evidence-based practice provided by their child's SLP based on the following ratings: *Gave me clear understanding, Gave me some understanding, Gave me no understanding, and No information was provided.* Table 14 includes data for Question #30 on the survey.

Table 14

*Responses to the Survey Question #30: How would you rate the information provided to you by your child's SLP regarding the concept of evidence-based practice?*

Response Choices	Response count (n)	Percentage (%)
Gave me a clear understanding	4	25.0
Gave me some understanding	5	31.3
Gave me no understanding	2	12.4
No information was provided	5	31.3

*Note. N=16*

A total of 16 of the 23 respondents answered Question #30 on the survey. When asked to rate the information that was provided to parents by their child's SLP, most respondents (5 of 16, 31.3%) indicated the information gave the parents some understanding regarding the concept of evidence-based practice. However, an equal percentage of respondents (31.3%) indicated no information was provided regarding the concept of evidence-based practice.

Question # 31 asked parents about the level of confidence in advocating for their child based on the knowledge of clinical evidence, through following response choices: *Very confident, Somewhat confident or Not confident.* Table 15 includes data for Question #31 on the survey.

Table 15

*Responses to the Survey Question #31: How confident do you feel in advocating for your child's services based on your knowledge about clinical evidence?*

Response Choices	Response count (n)	Percentage (%)
Very confident	7	41.2
Somewhat confident	5	29.4
Not confident	5	29.4

*Note. N=17*

A total 17 of the 23 respondents answered the questions about how confident they felt in advocating for their child's services based on the knowledge about clinical evidence. Of the 23, 7 respondents (41.2%) reported that they felt very confident. An equal number of respondents (5 of 23, 29.4%) either felt somewhat confident or not confident in advocating for their child's services based on clinical evidence.

Question # 32 inquired about how well parents understood the ASD related information that they received from their child's SLP based on the following choices: *Completely understood the information, Partially understood the information or Did not understand the information at all.* Table 16 includes data for Question #32 on the survey.

Table 16

*Responses to the Survey Question #32: How well did you understand the information that was provided to you by your child's SLP?*

Response Choices	Response count (n)	Percentage (%)
Completely understood the information	4	25.0
Partially understood the information	11	68.8
Did not understand the information at all	1	6.2

*Note. N=16*

Of the total 23 respondents, 16 answered the questions about how well parents understood the information that was provided by their child's SLP. Of the 16, 4 respondents (25%) indicated that the information was completely understood while 11 of the 16 respondents (68.8%) indicated that the information was partially understood. Only one respondent (6.2%) indicated that the information was not understood at all.

Question # 33 inquired whether the information provided by the SLP met parents' expectations based on the ratings: *Exceeded expectation*, *Fully met expectation*, *Partially met expectation*, and *Did not meet expectation*. Table 17 includes data for Question #33 on the survey.

Table 17

*Responses to the Survey Question #33: To what extent did the information you received from SLP meet your expectation?*

Response Choices	Response count (n)	Percentage (%)
Exceeded expectation	1	6.2
Fully met expectation	3	18.8
Partially met expectation	10	62.5
Did not meet expectation	2	12.5

*Note. N=16*

A total 16 of the 23 respondents provided a rating about the extent to which the information received from the SLP met their expectations. One respondent (6.2%) indicated that the information received exceeded expectations while the majority 10 of

the 16 respondents (62.5%) indicated that the ASD related information received from their child's SLP only partially met parental expectations.

Questions #34 through #36 inquired about parental perceptions regarding SLPs as source of ASD related information by inquiring about: (a) other therapies used for the child with ASD besides speech and language therapy, (b) factors that influenced parental decisions about selecting appropriate treatment approach for their child with ASD, and (c) sources of information parents commonly used when selecting the appropriate treatment approach(es) for their child with ASD. Data for Questions#34, #35 and #36 is included in Tables 18, 19 and 20 respectively.

Table 18

*Responses to the Survey Question #34: Besides speech and language therapy, are you using any other treatments for your child? Please list.*

Response	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Applied Behavior Analysis (ABA)	7	53.8
Art Therapy	1	7.7
Massage Therapy	1	7.7
Music Therapy	1	7.7
Occupational Therapy(OT)	7	53.8
Physical Therapy (PT)	1	7.7

*Note. N=13*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

Question #34 asked parents to list other therapies used with their child with ASD besides speech and language therapy. A total of 13 respondents answered question 34. Besides speech and language therapy, most parents reported using Applied Behavior

Analysis (ABA) therapy (53.8%) for their child with ASD. An equal percentage of respondents reported using Occupational Therapy (OT) for their child with ASD. Other therapies reported by parents included: massage therapy, music therapy, art therapy and physical therapy.

Question #35 asked parents to identify the factors which influenced their decisions in selecting treatment approaches for their child with ASD. Parents were asked to choose as many factors as applicable from the following list that potentially influenced their decisions of selecting treatment approaches for their child: *Opinions of other parents, Guidance from the SLP, Guidance from other educational professionals, Guidance from medical professionals, Personal experiences, Information about clinical research for the treatment, and Other (please specify)*. Data for Question #35 is presented in Table 19.

Table 19

*Responses to the Survey Question #35: Which factors influenced your decision the most in deciding which treatments to use for your child? Please choose all that apply.*

Response Choices	Response count (n) <sup>a</sup>	Percentage(%) <sup>b</sup>
Opinions of other parents	5	31.3
Guidance from SLP	5	31.3
Guidance from other educational professionals	10	62.5
Guidance from medical professionals	9	56.3
Personal experiences	8	50.0
Information about clinical research for the treatment	9	56.3

*Note. N=16*



<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

When asked about the factors that are most influential when selecting a treatment approaches for their child with ASD a total 16 of 23 respondents answered the question. Of the 16, 10 respondents (62.5%) indicated that they relied on the guidance of an education professional. Five of the 16 respondents (31.3%) indicated that they relied on the guidance of an SLP.

Question # 36 on the survey asked parents to identify the sources of information the parents commonly used when selecting treatment approaches for their child with ASD. Table 20 includes data for Question #36.

Table 20

*Responses to the Survey Question #36: Which sources of information do you most commonly use when selecting treatment approaches for your child? Please choose all that apply.*

Response Choices	Response count (n) <sup>a</sup>	Percentage (%) <sup>b</sup>
Online search	10	66.7
Speech-language pathologists	7	46.7
Medical professionals	8	53.3
Educational professionals	12	80.0
Other parents	11	73.3
Journal articles	4	26.7
Advocacy groups	8	53.3
Other (please specify: "OT" Occupational Therapist)	1	6.7

*Note. N=15*

<sup>a</sup> Respondents could choose multiple responses that applied. Thus, the response count can exceed the total number of respondents and <sup>b</sup> the total percentage can exceed 100%.

A total 15 of 23 respondents answered the questions pertaining to sources of information parents commonly used when selecting treatment approaches for their child. A majority of the respondents (12 of 15; 80%) indicated that they sought advice from educational professionals; 11 of 15 respondents (73.3%) choose other parents as the source of information. Seven of the 15 respondents (46.7%) sought information from an SLP when selecting treatment approaches for their child. Only one respondent (6.7%) indicated Occupational Therapist (OT) as one of the commonly used sources of information when selecting appropriate treatment approaches for their child with ASD.

## Discussion

The present study examined parental experiences, expectations, and level of satisfaction regarding ASD related parent education provided with SLPs specifically with regard to: (a) the nature of ASD, (b) the specific treatment approach(es) used with their child by the practicing SLP; and (c) evidence-based practice in ASD. Overall, the data revealed that the responding parents (i.e., mothers) reported receiving information about the specific speech and language difficulties for their child with ASD and the about specific treatment approaches used with their child from their child's SLP. Additionally, the majority of the respondents reported being asked to provide input about their child's treatment by their SLPs. Despite such engagement of the parents in decisions regarding their child's speech and language treatment approach, the majority of the respondents reported that they never received information about common facts about ASD or about evidence-based practice related to ASD. When the SLP provided information, the parents felt that they either completely or partially understood the information; however, the frequency of communication was insufficient as per parental expectations reported in the current study. Most of the respondents expressed a need for weekly communication about their child. Further, the majority of the respondents reported that the information provided only partially met their expectations. Possible causes, implications and direction for future research to improve parental experiences, expectations and levels of satisfaction regarding parent education they received are further discussed.

### **Research Question #1**

*What are the parental experiences in receiving information about the nature of ASD, specific treatment approach(es) used by their child's SLP and about EBP in ASD?*

The findings in the current study indicate that majority of the respondents reportedly received information about their child's specific speech and language difficulties (68.4%), and about specific treatment approach used with their child (84.2%), at least once or multiple times during their interaction with their child's SLP . The findings of the current study also revealed that majority of the respondents (72.2%) were reportedly asked to provide input in selecting treatment approach(es) for their child. According to Brookman-Frazer (2004), under the *Partnership Model*, parents that received education and training about the intervention approach used with their child, and parents that actively participated in intervention by helping to develop goals and treatment plans for their child, exhibited lower parental stress, higher levels of confidence and more positive parent-child interactions. Thus, it can be speculated that parents that participated in the current study could have experienced low parental stress and higher levels of confidence and more positive parent-child interactions, however further research is warranted to examine specific impact of parent education.

The data of the current study revealed that majority of respondents indicated two important areas in which no information was provided to them: (a) common facts regarding ASD (e.g., causes, symptoms, and prognosis), and (b) evidence-based practice. Ten of the 19 respondents indicated that information about common facts about ASD was provided to them at least once or multiple times during their interaction with their child's SLP. However, 9 of the 19 respondents indicated information about common facts about

ASD was never provided to them during their interaction with their child's SLP. It is concerning that almost half of the respondents indicated that important basic information such as causes, symptoms and prognosis was reportedly never provided to parents even at the time of diagnosis, or during therapy or at parent meetings. Osbourne and Reed (2008) explored parental perceptions of the diagnostic process for autism and found that parents of young children with autism valued getting an overall picture with general information about ASD at the time of diagnosis of their child. Given the fact that most of the children in the current study were diagnosed with ASD during the age range of 25-48 months, the results of the present study are consistent with those of Osbourne and Reed (2008), indicating that it is important to provide parents of young children with information pertaining to common facts about ASD during the initial stages of diagnosis. Along with the lack of provision of information about common facts of ASD, parents also reported lack of provision of information about evidence-based practice related to ASD.

Majority of the respondents (63.2%) in the current study reported never being engaged in discussion(s) about available clinical research about the specific treatment approach(es) used with their child. High percentage of respondents also indicated that information about the meaning of evidence-based practice related to ASD was not provided and that discussion(s) about importance of looking for clinical evidence when selecting treatments for their child with ASD never occurred during their interaction with their child's SLP. According to Dollaghan (2007) principles of evidence-based practice are based on integration of the: (a) best available evidence from systematic research, (b) best available evidence from clinical practice, and (c) best available evidence considering

preferences of a fully informed patient. In order to implement the principles of evidence-based practice, the SLP must inform and engage parents/primary caregivers of children with ASD in discussions about available scientific evidence for any specific treatment approach used with their child. Moreover, one of the principles set forth by American Speech-Language-Hearing Association (2006b) for SLPs serving individuals with ASD is that SLPs can help assist families of children with ASD in differentiating treatments based on lack of or availability of appropriate scientific evidence. The data from the current study suggest that additional efforts might be necessary to ensure that parents are provided with information about evidence-based practice related to ASD. Clearly, further research is needed to explore parental understanding of evidence-based practice.

### **Research Question # 2**

*What are the parental expectations for parent education on ASD from practicing SLPs?*

Through the free-text responses the respondents of the current study expressed a need for weekly communication with their child's SLP, mainly for two reasons: (1) to get information about what the SLP was focused on currently in therapy with the child, and (2) to get information about the progress the child had made. Given the nature of ASD, each child might have a different rate and pattern for progress and the SLP might feel the need to report progress intermittently rather than weekly. However, the SLP could regularly provide parents with information about the current focus in therapy with the child and about treatment strategies that the SLP is using. The National Research Council (NRC, 2001) reports that an intense family involvement is often noted as a prominent

feature of all of the comprehensive treatment programs for ASD that have best outcomes. Thus, the NRC (2001) recommends including family members of children with ASD to become members of the educational team by teaching them strategies for working with the child. By further informing parents about the specific strategies that the SLP is using with the child, parents get an opportunity to use the same strategies at home, thus promoting generalization. Besides weekly updates, parents also expressed a need for the SLP to be knowledgeable about evidence-based practice.

Two respondents expressed that they expected the SLPs to have an updated knowledge about current research and expected more information about evidence-based practice. The verbatim responses expressed by the respondents can be associated with the findings for research question #1 (What are the parental experiences in receiving information about the nature of ASD, specific treatment approach(es) used by their child's SLP and about EBP in ASD?) which indicate that information about evidence-based practice was reportedly never provided to number of parents during their interaction with their child's SLP. Thus, further efforts in educating parents about ASD related evidence-based practice can be made by sharing information from conferences, referring parents to credible resources and articles and sharing news about recent developments in treatment approaches.

Only one of the 10 respondents expressed that the SLPs need to be culturally sensitive by talking about the dilemma her family faced when they were told not to use Spanish when communicating with their child. In order to avoid cultural dilemmas and to promote parent education for bilingual families, information about empirical research in the treatment of bilingual children with ASD should be provided to these parents.

### Research Question # 3

*What is the level of parental satisfaction related to the information that the SLP provided on the nature of ASD, intervention approaches used with their child with ASD and about EBP in ASD?*

The findings for the current study pertaining to research question # 1, indicated that the specific deficiencies in providing parent education related to ASD are providing information about (a) common facts about ASD and (b) evidence-based practice. Despite the specific gaps in the provision of parent education, parental satisfaction levels related to information provided by SLPs indicate overall positive reviews.

The majority of the respondents rated the information provided about ASD and about specific treatment approach used with their child as *adequate* or *somewhat adequate*. Majority of the respondents also indicated that the information about evidence-based practice was *clearly* or *somewhat clearly* understood and based on the information that was provided, majority of the respondents indicated feeling *very* to *somewhat confident* in advocating for their child's services. Based on the findings of the current study it might be concluded the parent education that the SLPs provided to the respondents of the current study was generally provided in a manner that helped parents understand the information and helped parents feel confident about advocating for their child's services related to ASD. It is important to note that while few respondents indicated that the information provided fully met their expectations, majority of respondents indicated that the information provided only partially met their expectations. Research on the methods (e.g., brochures, workshops, discussions) by



which parent education is provided is warranted to gain insight into effective strategies for parent education. It is important to note that the education levels of the respondents in the current study might have influenced their rating of understanding the provided information, illustrating the need for the SLP to consider education and health literacy levels of parents when presenting information.

In addition to parental satisfaction levels, the research question # 3 also examined parental perceptions regarding ASD related information provided by SLPs. It is important to note that when asked to choose all of the factors that influenced parental decisions in choosing appropriate treatment approach(es) for their child with ASD, the majority of the respondents (62.5%) reported relying on guidance from educational professionals followed by guidance from medical professionals (56.3%) and information about clinical research for the treatment (56.3%). Only 31.3% of the respondents indicated they are influenced by guidance from their child's SLP. It is possible that parents do not perceive the SLP as a strong source of information when consulting about selecting appropriate treatment approach(es) for their child. Engaging in discussion(s) about evidence-based practice and about selecting treatments with empirical evidence can change parental perceptions in considering SLPs as useful resource for information.

In order to evaluate parental perceptions regarding information provided by the SLPs, respondents were also asked to identify source(s) they most commonly used when selecting treatment approaches for their child with ASD. Majority of respondents selected *Online Search* as a commonly used source of information to aid in their selection of treatment approaches for their child. The American Speech-Language-

Hearing Association (2006b) cautions that due to the emergence of numerous treatments that lack empirical evidence, parents of children with ASD are especially vulnerable to making inappropriate treatment choices for their child. Additionally, the study by Green et al., (2004) examined the number and types of intervention approaches used by parents of children with autism, which revealed that both the categories of treatments: the most commonly used and the least commonly used treatments, included those with empirical and without empirical evidence. Thus, further research is warranted to investigate which online resources are most commonly used by parents when making treatment choices for their child. Only 46.7% of the respondents indicated they most commonly consult their child's SLP when making treatment choices. Further efforts are indicated to improve parental perception of SLPs as commonly used source of information.

### **Limitations**

The most critical limitation of the current study is that it has low external validity, which limits the extent to which the results can be generalized to other parents of children with ASD. Numerous factors contributed to the low external validity of this study, including the: (a) small number of survey respondents (b) lack of diverse populations represented by the respondents, and (c) topic of interest bias and internet accessibility and or literacy. With regard to the small number of respondents, it is important to note that in the present study, fifty respondents attempted to complete the survey, however only 23 qualified. Additionally, the survey was designed in such a way that allowed respondents to skip any number of questions thus, the response rate for each questions varied. For

example, only 10 respondents answered Question # 27 on the survey, thus even though 23 respondents took the survey, is it important to note that results for Question # 27 are based on opinions expressed by only 10 respondents. Factors such as restrictive inclusion criteria, limited number of weeks that the survey was open on the web (5 weeks) and overall length of the survey (36 questions) may have resulted in overall small number of respondents completing the survey.

Another factor that contributed to low external validity of the current study was the lack of diversity represented by the respondents' demographic profiles. All of the respondents of the present study were female and most of the respondents (87.0%) were Caucasian/European Americans that were predominantly from middle class to upper middle socioeconomic background. Thus, the experiences, expectations and perceptions expressed by the survey respondents cannot be generalized to a diverse population of parents of children with ASD. Additionally, the survey included only respondents from WI, again making it difficult to generalize the results to parents of children with ASD who reside in other states.

As with most surveys, it is important to take into account that respondents that chose to complete the survey may have an interest in the topic and so the results might not include a sufficiently broad range of experiences, expectations, and perceptions of parents of children with ASD. Moreover, the survey in the present study was a web-based survey and participants were recruited via Facebook pages of the parent support organizations, Autism Speaks Milwaukee and the Autism Society of Southeastern Wisconsin. Thus, parents who did not have an internet access or literacy or who did not

follow the Facebook pages of the parent support organizations, were automatically excluded from the survey.

### **Implications for Future Research**

The findings of current study have important implications for future research on parent education in ASD. One important finding of the current study related to parental experiences was that important basic information about common facts related to ASD was reportedly not provided to a number of parents at the time of diagnosis, or during any of their interactions with their child's SLP. Future research could investigate the diagnostic process of ASD to further determine if and when parents are likely to receive information about the common facts of ASD. Further research is also warranted to examine the role of other professionals (e.g., OTs, psychologists, pediatricians), which work with children with ASD, in providing parent education.

Another important finding of the current study was that information about evidence-based practice was reportedly not provided to a number of parents during their interactions with their child's SLP, including information about meaning of evidence-based practice and about empirical evidence when selecting appropriate treatment approach(es) for their child. A Study by Green et al., (2004) suggested that in order to provide parents with education regarding evidence-based practice it is important to investigate the decision-making process of parents of children with ASD, when selecting treatment approaches for their child. Given the findings of current study, future research could be focused on exploring parental decision-making process when selecting appropriate treatment approaches for their child with ASD.

One of the relatively positive findings of the current study related to parental satisfaction level was that majority of the respondents indicated that the overall information provided by the SLPs was completely or partially understood. The findings suggests that even though information related ASD was not fully or always conveyed to parents, whenever it was provided, it was conveyed in a manner that helped parents to understand the information. Future research could investigate: methods currently used by SLPs to provide parent education, and parent preferences for methods of receiving information in order to further improve the quality of parent education.

Another finding of the current study related to parental satisfaction was that the majority of the respondents (62.2%) indicated that the information provided by the SLPs partially met their expectations. Based on the findings of the current study it could be speculated that parental expectations were only partially met due to (a) lack of information provided about common facts and evidence-based practice related to ASD, and or (b) lack of weekly communication as expected by parents. Clearly, future research is indicated to examine specific parental expectations regarding parent education.

Finally, based on the findings of the current study it can be stipulated that most parents in the current study did not perceive SLPs as important source of information or guidance when selecting appropriate treatment approach(es) for their child. As an important team member of the diagnostic and intervention teams for individuals with ASD, SLPs the bear responsibility to provide parent education related to empirical evidence. Future research can explore ways in which SLPs can improve their role in providing parent education related to evidence-based practice related to ASD in order to

improve parental perception and to promote use of treatment approach(es) with empirical evidence.

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APPENDIX A  
IRB APPROVAL LETTER



**New Study - Notice of IRB Exempt Status**

**Melissa Spadanuda**  
*IRB Manager*  
*Institutional Review Board*  
Engelmann 270  
P. O. Box 413  
Milwaukee, WI 53201-0413  
(414) 229-3173 *phone*  
(414) 229-6729 *fax*

<http://www.irb.uwm.edu>  
[spadanud@uwm.edu](mailto:spadanud@uwm.edu)

**Date:** July 28, 2014

**To:** Paula Rhyner, PhD  
**Dept:** Communication Sciences and Disorders

**Cc:** Vinaya Kulkarni

**IRB#:** 15.013

**Title:** Exploring Experiences, Expectations and Perceptions of Parents of Children with ASD in Receiving Parent Education from Speech-Language Pathologists

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been granted Exempt Status under **Category 2** as governed by 45 CFR 46.101(b).

This protocol has been approved as exempt for three years and IRB approval will expire on **July 27, 2017**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, please respond to the IRB's status request that will be sent by email approximately two weeks before the expiration date. If the study is closed or completed before the IRB expiration date, you may notify the IRB by sending an email to [irbinfo@uwm.edu](mailto:irbinfo@uwm.edu) with the study number and the status, so we can keep our study records accurate.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., [FERPA](#), [Radiation Safety](#), [UWM Data Security](#), [UW System policy on Prizes, Awards and Gifts](#), state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,  
*Melissa C. Spadanuda*  
Melissa C. Spadanuda  
IRB Manager

## APPENDIX B

## SURVEY AS APPEARED ONLINE

The information below is the *Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions* survey as it was presented on the Survey Monkey Website. Each heading within the survey (e.g., Qualifying information) indicates a new page as it was presented to the participants.

Parent Education in Autism Spectrum Disorder: Experiences, Expectations, and Perceptions

**Qualifying Information:**

1. Do you currently reside in the state of Wisconsin?
  - a. Yes
  - b. No
2. Is your child between 3 years to 12 years of age?
  - a. Yes
  - b. No
3. Did your child receive a diagnosis of Autism Spectrum Disorder between the periods of January 2010- February 2014?
  - a. Yes
  - b. No
4. Has your child received speech-language pathology services within the state of Wisconsin for at least six months?
  - a. Yes
  - b. No
5. Do you have only one child with ASD in your immediate family?
  - a. Yes
  - b. No
6. Has anybody else in your family previously completed this survey?
  - a. Yes
  - b. No

**General Information About the Parent**

7. What is your relationship to the child?
  - a. Mother
  - b. Father
  - c. Step Mother

- d. Step Father
  - e. Adoptive Mother
  - f. Adoptive Father
  - g. Legal Guardian
  - h. Other Relative (please specify \_\_\_\_\_)
8. How old are you? \_\_\_\_\_
9. What is your gender?
- a. Male
  - b. Female
10. What is your race/ethnicity? (optional)
- a. African American
  - b. Asian/Pacific Islander
  - c. Native Hawaiian
  - d. Caucasian/European American
  - e. Native American
  - f. Latino, Hispanic, or Chicano
  - g. Other (please specify \_\_\_\_\_)
11. What is your highest level of completed education? (optional)
- a. Some High School
  - b. High School graduate
  - c. Some college
  - d. College degree
  - e. Some graduate studies
  - f. Graduate degree
12. Which of the following is closest to your annual household income? (optional)
- a. Under \$20,000
  - b. \$20,000 - \$39,999
  - c. \$40,000 - \$59,999
  - d. \$60,000 - \$79,999
  - e. \$80,000 - \$99,999
  - f. \$100,000 and above
13. How long have you lived in Wisconsin?
- a. Years \_\_\_\_\_.
  - b. Months \_\_\_\_\_.
- Please list all the counties where you have resided in Wisconsin:
- \_\_\_\_\_
14. In what county do you currently reside? \_\_\_\_\_
15. Please specify the zip code of your residence in WI \_\_\_\_\_

### General Information About the Child

16. How old is your child?
- Years \_\_\_\_\_.
  - Months \_\_\_\_\_.
17. What is your child's gender?
- Male
  - Female
18. What level of education has your child completed?
- None
  - Preschool
  - Kindergarten
  - Elementary School (specify highest grade completed \_\_\_\_\_)
  - Middle School (specify highest grade completed \_\_\_\_\_)
19. What is your child's current diagnosis?
- Autism Disorder
  - Asperger's Disorder
  - Childhood Disintegrative Disorder
  - Rett's Syndrome
  - Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
  - Not known
  - Other (please specify \_\_\_\_\_)
20. How old was your child when he/she got the diagnosis?
- Years \_\_\_\_\_.
  - Months \_\_\_\_\_.

### General Information About the services received by the child

21. Which professional(s) provided the diagnosis of ASD for your child?

\_\_\_\_\_

22. Please list the team of professionals that currently work with your child:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

23. Does your child currently receive services from a speech-language pathologist?
- Yes

b. No

24. How long has your child received speech-language pathology services?

a. Years \_\_\_\_\_.

b. Months \_\_\_\_\_.

25. Where did/does your child receive speech-language pathology services? Please choose all that apply.

a. Public School

b. Hospital

c. Private School

d. Private Clinic

e. Home Program

f. Other, please specify \_\_\_\_\_.

**Information About Parents' Experiences:**

26. For the following statement, circle appropriate option(s). Choose all that apply:

**“During my experiences of interacting with my child’s SLP(s)...”**

**4. At the time of diagnosis    3. During therapy    2. At parent meetings    1. Never**

a. I received information about common facts regarding ASD (e.g., causes, symptoms, prognosis)	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
b. I received information about my child’s specific speech and language difficulties related to ASD.	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
c. I received information about specific treatment approach the SLP used with my child	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
d. I was engaged in discussion about available clinical research regarding the specific treatment the SLP used with my child	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
e. I was asked to provide input in selecting specific treatment approach for my child	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
f. I was engaged in discussion(s) about importance of looking for clinical evidence when selecting	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>

treatments for my child				
g. The concept of 'Evidence-Based Practice' was explained to me	4	3	2	1

### Open Response Question

27. Based on your experience of working with your child's SLP(s), what suggestions would you give to practicing SLPs regarding the parent education component of their job? Please specify the type, amount and format of information that you expect an SLP should provide?

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### Information About Parents' Perceptions

28. How would you rate the general information provided to you by your child's SLP about autism spectrum disorder?
- Information was adequate
  - Information was somewhat adequate
  - Information was inadequate
  - No information was provided
29. How would you rate the information provided by the SLP about the specific treatment approach he/she used with your child:
- Information was adequate
  - Information was somewhat adequate
  - Information was inadequate
  - No information was provided
30. How would you rate the information provided to you by your child's SLP regarding the concept of evidence-based practice?
- Gave me a clear understanding
  - Gave me some understanding
  - Gave me no understanding
  - No information was provided
31. How confident do you feel in advocating for your child's services based on your knowledge about clinical evidence?
- Very confident
  - Somewhat confident
  - Very confused
32. How well did you understand the information that was provided to you by your child's SLP ?

- a. Completely understood the information
  - b. Partially understood the information
  - c. Did not understand the information at all
- 33.** To what extent did the information you received from the SLP meet your expectation?
- a. Did not meet expectation
  - b. Partially met expectation
  - c. Fully met expectation
  - d. Exceeded expectation
- 34.** Besides speech and language therapy, are you using any other treatments for your child? Please list:
- 
- 
- 
- 35.** Which factors influenced your decision the most in deciding which treatments to use for your child? Please choose all that apply
- a. Opinions of other parents
  - b. Guidance from the SLP
  - c. Guidance from other educational professionals
  - d. Guidance from medical professionals
  - e. Personal experiences
  - f. Information about clinical research for the treatment
  - g. Other (please specify) \_\_\_\_\_
- 36.** Which sources of information do you most commonly use when selecting treatment approaches for your child? Please choose all that apply:
- a. Online search
  - b. Consulting SLP
  - c. Consulting Medical professionals
  - d. Consulting educational professionals
  - e. Other parents
  - f. Journal articles
  - g. Advocacy groups
  - h. Other (please specify) \_\_\_\_\_.



## APPENDIX C

### INFORMED CONSENT INFORMATION

The following informed consent information was included with the Facebook recruitment flyer along with the link to the survey for participants to read prior to completing the survey

#### **University of Wisconsin – Milwaukee**

#### **Consent to Participate in Online Survey Research**

**Study Title:** Exploring Experiences, Expectations and Perceptions of Parents of Children with ASD in Receiving Parent Education from Speech-Language Pathologists

**Person Responsible for Research:** Vinaya Kulkarni, graduate student, under the supervision of Dr. Paula Rhyner.

**Study Description:** The purpose of this study is to examine parents' experiences, expectations, and level of satisfaction regarding the parent education they received about autism spectrum disorder from practicing SLPs. Approximately 200 parents will participate in this study. If you agree to participate, you will be asked to complete an online survey that will take approximately 15-20 minutes to complete. The questions will ask demographic information about yourself and your child (e.g. gender, education level), general information about speech language pathology (SLP) services (e.g. type of setting where SLP services were received). Questions will also include information about what type of parent education you were provided by your child's SLP and how helpful the information was to you, as well as your suggestions for the future about parent education provided by SLP.

**Risks / Benefits:** Risks to participate are considered minimal. Your responses are anonymous, meaning your name does not appear on this survey and is not associated with any responses. The data are sent to the researcher via secured email from the secured Survey Monkey (i.e. online survey) website. Collection of data and survey responses using the internet involves the same risks that a person would encounter in everyday use of the internet, such as breach of confidentiality. While the researchers have taken every reasonable step to protect your confidentiality, there is always the possibility of interception or hacking of the data by third parties that is not under the control of the research team. After completion of the survey the researchers will retain data for five years. Data may be used for purposes of publishing articles in scholarly journals. Data will be copied on a flash drive and the flash drive will be stored in a locked file in Dr. Rhyner's lab.

There will be no costs for participating, nor will you benefit from participating other than to aid in obtaining useful research findings. Your participation is completely voluntary.

**Limits to Confidentiality:**

Identifying information such as your name, email address, and the Internet Protocol (IP) address of this computer will not be asked or available to the researchers. Data will be retained on the (Survey Monkey) website server for two weeks and will be deleted by the research staff after this time. However, data may exist on backups or server logs beyond the timeframe of this research project. Data transferred from the survey site will be saved on a password protected computer for three months (Until December 2014). Only Vinaya Kulkarni and Dr. Paula Rhyner will have access to the data collected by this study. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

**Voluntary Participation:** Your participation in this study is voluntary. You may choose to not answer any of the questions or withdraw from this study at any time without penalty. Your decision will not change any present or future relationship with the University of Wisconsin Milwaukee.

**Who do I contact for questions about the study:** For more information about the study or study procedures, contact Vinaya Kulkarni at [vhk@uwm.edu](mailto:vhk@uwm.edu)

**Who do I contact for questions about my rights or complaints towards my treatment as a research subject?** Contact the UWM IRB at 414-229-3173 or [irbinfo@uwm.edu](mailto:irbinfo@uwm.edu)

**Research Subject's Consent to Participate in Research:**

By entering this survey, you are indicating that you have read the consent form, you are age 18 or older and that you voluntarily agree to participate in this research study.

**To begin the survey, please click the below link:**

<https://www.surveymonkey.com/s/autismsurveyparenteducation>

**Thank you.**

## APPENDIX D

## OPTIONAL FREE-TEXT RESPONSE QUESTION # 27: RESPONSES

The following information was the verbatim responses of the 10 participants who chose to answer the question: Based on your experience of working with your child's SLP(s), what suggestions would you give to practicing SLPs regarding the parent education component of their job? Please specify the type, amount and format of information that you expect an SLP should provide.

1. Details on what they are working on, what I can do at home, and what good methods are.
2. More parent input
3. Providing specific things they are working on each week so we can work on them too at home. I would like more information sent home as to his progress, challenges etc. more often than quarterly.
4. SLP have a duty to inform parents if they have a professional opinion and concern regarding possible ASD diagnosis. We were blessed to work with a SLP through Birth to 3 whom within two weeks of working with our son, she dropped the ASD bomb on us. I had already suspected it, but my husband was in denial. He needed to hear it from someone else other than me. As long as it is done professionally and SLP can share specifics leading to the concerns (lack of eye contact, engaging, etc.) this can help a parent understand it from the point of view of the SLP. I also would suggest understanding culturally the family needs. We were advice (granted, I know she meant well) that doing therapy in a bilingual sessions could give us delayed results due to the length it may take my child to learn and process both. Granted, at the time of the diagnosis, we had spoken to our child only in Spanish. At that moment we switched to English only and waited to see if our son could pick up language easily. We have now started teaching him Spanish and he is picking it up well. We love to see him become bilingual. It was very difficult for us to drop Spanish all together. SLP need to stay on top of all recent evidence practices and ideas out there. I have always been told by ABA providers that I need to stop when my son scripts and echoes. Well, I have come to realize that those things usually seen as deficits are actually what are helping my son develop his own language. His current private SLP is going to a conference all about using scripting into her practice and I plan to share that information with his school SLP. My son can turn all this borrowed language into his own. That's a gift and he just needs us to help him make it more of his own.
5. I would have liked more interactive dialogue between myself and the SLP or my senior and the SLP on a weekly basis to ensure that certain concepts are being targeted simultaneously, and presented similarly to achieve the best results. We

had a "communication book" so we knew what [CHILD] was working on in school with the SLP, but never any parent contact unless in IEP meeting

6. I think it's just important to talk a lot and make sure that all questions are answered, also ask a lot of questions to make sure info are being understood as sometimes it can be overwhelming. I personally like to talk to someone in person and be able to also text them or email them with questions.
7. I appreciate the continuing dialogue concerning my son's treatment. I have had a minimum of weekly contact with his SLP. I would appreciate more information concerning available resources for children with autism and other special needs. It would be great if an SLP made the knowledge of such resources a priority, and possibly guided the parent to a centralized source of information if one should exist.
8. Using a pec system earlier with completely nonverbal kids it made my daughter have an easier time learning to use the prologue2go app on her iPad
9. More regular communication of progress
10. Information on treatment options and evidence-based practices would be very welcome.