Communicating with Health Care Providers: Perceptions of Parents of Children with Autism Spectrum Disorders

By

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To my husband David, who has been by my side in all of life’s adventures, and to our baby girl Malin, who waited until just the right time to make her arrival!

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CHAPTER 1

INTRODUCTION

1.1 Statement of the Problem

Pediatric health care, particularly related to young children, includes many communication interactions between parents and providers (Howells & Lopez, 2008). The perceived value of these interactions has been linked to ratings of quality of care and satisfaction, levels of parental understanding of medical information, and adherence to treatment recommendations (Clark et al., 2008; Clark et al., 1998; Hart, Drotar, Gori, & Lewin, 2006; Hart, Kelleher, Drotar, & Scholle, 2007; Wissow et al., 2011). Despite a large body of research identifying key elements for providers to include during health care communication with parents (e.g., Epstein et al., 2005; Fisher, Broome, Friesth, Magee, & Frankel, 2014; Glascoe & Trimm, 2014; Howells & Lopez, 2008), and studies evaluating interventions to improve parent-provider communication (e.g., Hayutin, Reed-Knight, Blount, Lewis, & McCormick, 2009; Mika, Wood, Weiss, & Trevino, 2007; Sices, Drotar, Keilman, Kirchner, Roberts, & Stancin, 2008; Triggs & Perrin, 1989), parents and providers continue to describe difficulties with their communication interactions. Our understanding of the causes of these difficulties is still unclear, particularly as it relates to the impact or role of the many personal characteristics that both parents and providers bring to these communication interactions. One critical clinical area with very limited knowledge about the nature of parent-provider communication is child development in pediatric primary care (Rydz et al., 2006; Shah, Kunnavakkam, & Msall, 2013; Sices, Egbert, & Mercer, 2009).

Communication about child development and suspected developmental delays occurs most frequently in the primary care setting (Sices et al., 2009). Most parent-provider discussions occur within the context of well-child visits during developmental screening (Sices et al., 2009). It is during these health care encounters that parents and providers have an opportunity to discuss a child's overall development, identify potential developmental delays, and plan the next steps for a child in need of related referrals (Myers, 2014). The importance of effective communication between parents and providers around child development in primary care is highlighted in recommendations from the American Academy of Pediatrics (Council on Children with Disabilities, 2006). The overall importance, coupled with the fact that about 13% of children in the United States (U.S.) actually have a developmental delay (Boulet, Schieve, & Boyle, 2009; Rosenberg, Zhang, & Robinson, 2008), underscores the need for a better understanding of the communication process between parents and providers around developmental delays.

Autism Spectrum Disorder (ASD) is a common childhood developmental delay with an estimated prevalence near 1.5% in the U.S. (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators & Centers for Disease Control and Prevention, 2014). ASD is a complex neurodevelopmental disorder characterized by impairments in social communication and interactions and the presence of repetitive, stereotyped behaviors (American Psychiatric Association, 2013). Several months or years may pass between the time when children are first identified with concerns for ASD and when they receive a diagnosis. This period represents a time when parents may have frequent interactions with health care providers (Rosenberg et al., 2008; Simpson, Colpe, & Greenspan, 2003), yet little is known about the communication processes that occur during this time.

Communication between a parent and a provider is an expectation of quality pediatric health care (Levetown and AAP Committee on Bioethics, 2008). Numerous professional, national, and international organizations underscore the importance of health communication in patient and family-centered care (Committee on Hospital Care and Institute for Patient- and Family-Centered Care [IPFCC], 2012; Institute of Medicine, 2001; Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002; Robert Wood Johnson Foundation, n.d.). Family-centered care has been defined by the American Academy of Pediatrics (AAP) as "an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life" (Committee on Hospital Care and IPFCC, 2012, p. 394). Family-centered care is critical to communication interactions between parents and providers, especially during the time when a child is being diagnosed with ASD, as it promotes listening to and honoring/respecting the child and family, sharing information, collaborating with families on care, and recognizing and building on the child's and family's strengths (Committee on Hospital Care and IPFCC, 2012). Recent studies report that parents want to receive the following family-centered care elements during the diagnostic process for ASD: feeling they are listened to and asked about their questions (Abbott, Bernard, & Forge, 2013; Brogan & Knussen, 2003), sharing and receiving information (Crane, Chester, Goddard, Henry, & Hill, 2016; Osborne & Reed, 2008; Siklos & Kerns, 2007), and collaborating with professionals (Moh & Magiati, 2012).

Although previous studies outline specific elements and characteristics of desired communication processes during the diagnostic process for ASD, these studies have some significant limitations. Very often, the focus is only on the limited time period when an actual diagnosis is given (Abbott et al., 2013; Brogan & Knussen, 2003), they have been conducted with samples of parents outside the U.S., which due to health care differences between countries, may represent a different experience for obtaining an ASD diagnosis (e.g., parents from the United Kingdom [U.K.] in Abbott et al., 2013 and Crane et al., 2016; Scotland in Brogan & Knussen, 2003; Sweden in Carlsson, Miniscalco, Kadesjo, & Laakso, 2016; Singapore in Moh & Magiati, 2011; England in Osborne & Reed, 2008; and Canada in Siklos & Crane, 2007); and/or they have included samples where the majority of parents are reporting on experiences many years after their children received a diagnosis of ASD (Crane et al., 2016; Moh & Magiati, 2012; Osborne & Reed, 2008; Siklos & Kerns, 2007), thereby failing to explore the recent experiences of parents in the process of obtaining a diagnosis of ASD for their children.

Parental reports indicate overall dissatisfaction with the diagnostic process for a child with ASD (Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012; Siklos & Kerns, 2007). These reports specifically highlight issues regarding communication with health care providers. Most often, parents report not receiving needed information related to the diagnostic and referral resources (Crane et al., 2016; Moh & Magiati, 2012; Siklos & Kerns, 2007), resulting in significant stress noted by the parents (Brogan & Knussen, 2003). Parents were more likely to report satisfaction with the overall diagnostic process if they were given what they perceived to be quality verbal and written information about ASD (Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012; Siklos & Kerns, 2007); were asked about their questions and concerns (Abbott et al., 2013; Brogan & Knussen, 2003); and had their initial concerns about their child's development validated during the process (Brogan & Knussen, 2003). Most of these studies used survey methodology (Brogan & Knussen, 2003; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012; Siklos & Kerns, 2007) in samples ranging from 56 parents (Siklos & Kerns, 2007) to over 1000 parents (Crane et al., 2016) of children diagnosed with ASD. As a result, this evidence provides only broad insight into which elements of communication are important to parents when their child is in the process of being diagnosed with ASD. It is limited in articulating specific parental perceptions of barriers to and/or facilitators of the overall communication process that occurs between parents and providers, especially during a closer period of time when a child is diagnosed with ASD, and specifically during the time before a diagnosis of ASD is obtained.

1.2 Statement of the Problem

The purpose of this study was to identify key elements, barriers to, and facilitators of the communication process between parents and health care providers during the diagnostic process for ASD in a sample of parents in the U.S. whose children had been diagnosed during the prior 12 months. Findings from this study can be used to undergird new communication strategies between parents and health care providers that could lead to improved parental understanding of the child's condition, and timelier referral, access, and follow-through to community resources for treatment and intervention (e.g., Early Intervention Services).

1.3 Significance of the Issue

1.3.1 Significance to Health Care and Society

Communication is a critical element of health care nationally and internationally. High quality communication in health care overall, and communication around child development specifically, are part of our nation's health goals (Healthy People 2020 Health Communication and Health Information Technology Objectives, 2014; Healthy People 2020 Early and Middle

Childhood Objectives, 2014). Numerous professional organizations underscore the importance of health communication in patient/family-centered care (IPFCC, 2012; Institute of Medicine, 2001; Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002; Robert Wood Johnson Foundation, n.d.). Professional organizations and accrediting bodies require health care professionals to demonstrate competence in patient and parent/family communication, underscoring the importance of this element in patient care (Accreditation Council of Graduate Medical Education, 2013; American Association of Colleges of Nursing, 2008; Benson, 2014; Fisher et al., 2014; National Organization of Nurse Practitioner Faculties, 2012).

A diagnosis of ASD has a significant effect on society as the cost of lifetime care for an individual with ASD ranges from $1.4-2.4 million (based on the presence of intellectual disability) and is primarily due to expenses for special education, health care, and lost parental productivity in the workforce (Buescher, Cidav, Knapp, & Mandell, 2014; Gurney, McPheeters, & Davis, 2006). The ability to communicate effectively with parents of children in the process of being diagnosed with ASD has the potential to impact immediate and long-range care and health outcomes, potentially resulting in significant cost-savings to society. An example of possible cost-savings is effective communication with parents that results in more timely access to early childhood programs such as Early Intervention, a program with potential to ameliorate the lifetime effects of developmental delays (Council on Children with Disabilities, 2006). In a seminal study published by the staff of the Federal Reserve Bank of Minneapolis (Rolnick & Gruenwald, 2003), the researchers found that for every $1 invested in early childhood programs, an $8 return to society was realized. Shortly after, the High/Scope Educational Foundation published findings from the Perry Preschool longitudinal study showing a $17 return on every $1 invested in early childhood programs (Schweinhart et al., 2005), notably due to returns to society in the following areas: 1) economics/workforce; 2) education; and 3) reduction in crime.

1.3.2 Significance to Nursing

Nurses, as key members of the health care team, are in constant communication with patients and families and have an ethical responsibility to ensure adequate and effective communication in the health care setting (American Nurses Association, 2015). Improvements in communication within the discipline of nursing have the potential to significantly influence our health care system and society. Effective communication by nurses and other health care providers, when a child is being diagnosed with a developmental delay such as ASD, could result in a shared understanding of the child's condition and treatment, discussion and detection of psychosocial risks, and the ability to provide anticipatory guidance for timely next steps in the diagnostic process (Antal et al., 2015). Given nurses represent the largest group of health care providers in the U.S. (Health Resources and Services Administration, 2010), nurses who are able to understand and effectively respond to parents during the time when their children are being diagnosed with ASD has the potential to impact positively a significant number of families.

1.4 Research Question

The main research question for this study was the following:

What do parents identify as the key elements of their communication with health care providers when their child was in the process of being diagnosed with ASD?

The sub-questions for this study were the following:

1. Does parental report of key elements vary based on their own sociodemographic, personal, and/or mental health characteristics?
2. What do parents report as barriers to and facilitators of the communication process with health care providers in understanding the concerns about their child's development?

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL MODEL

2.1 Critical Analysis of Relevant Literature and Definition of Terms

Although numerous models and frameworks related to patient and provider communication and interpersonal relationships exist (e.g., REDE Model of Health Care Communication in Windover, Boissy, Rice, Gilligan, Velez, & Merlino, 2014; SEGUE Framework in Makoul, 2001; The Four Habits Model in Frankel & Stein, 1999; and Peplau's Theory of Interpersonal Relationships in Peplau, 1997), theory-driven research related to communication in health care is generally lacking (Beck, Daughtridge, & Sloane, 2002; Hannawa, Garcia-Jimenez, Candrian, Rossmann, & Schulz, 2015; Hart et al., 2006; Street, 2013). The aforementioned models and frameworks have generally been used to guide clinical practice and education (Frankel & Stein, 1993; Makoul, 2001; Peplau, 1997; Windover et al., 2014), rather than guide research around the key elements of the communication process in the health care setting. Recently developed models and frameworks, such as the Andersen's Behavioral Model of Health Care Use (Andersen & Davidson, 2001), the Conceptual Framework for Patient-Professional Communication (Feldman-Stewart, Brundage, Tishelman, & Team, 2005), and the Direct and Indirect Pathways of Communication (Street, Makoul, Arora, & Epstein, 2009) have attempted to depict the communication process between patients and providers, but due to their complexities, are very limited in guiding research efforts. There are, however, recurring factors that emerge from these models and frameworks: parent/patient and provider sociodemographic and personal characteristics; parent/patient mental health; a time period of focus (i.e., time from identification of problem to diagnosis); and communication functions. These correlates of communication will provide the basis for presenting the existing state of science related to communication processes between parents and providers around child developmental issues mainly in the primary care setting.

2.1.1 Parent Sociodemographic and Personal Characteristics.

2.1.1.1 Race/Ethnicity.

Race/ethnicity is how one identifies oneself. The U.S. government categorizes race as 1) American Indian or Alaska Native, 2) Asian, 3) Black or African American, 4) Native Hawaiian or other Pacific Islander, and 5) White; and ethnicity as 1) Hispanic or Latino or 2) Not Hispanic or Latino (National Center for Education Statistics, n.d.). The impact of a parent's race or ethnicity on the communication process with their child's pediatric provider remains unclear (Carlin, Yee, Fagnano, & Halterman, 2014; Clemans-Cope & Kenney, 2007; Magana, Parish, & Son, 2015; Montes & Halterman, 2011; Parish, Magana, Rose, Timberlake, & Swaine, 2012; Sobotka, Francis, & Vander Ploeg Booth, 2016; Yu, Nyman, Kogan, Huang, & Schwalberg, 2004). Studies suggest that in regards to race/ethnicity, minority parents of children with a known clinical issue with potential for poor outcomes may report more communication with health care providers (e.g., asthma in Carlin et al., 2014), while other larger, nationwide studies examining the influence of race/ethnicity (i.e., Black, Latino, and Hispanic) on elements of family-centered care and communication, lean more to perceived difficulties with the communication process (Clemans-Cope & Kenney, 2007)

In a sample of 166 Hispanic and non-Hispanic parents with children with asthma (Carlin et al., 2014), Hispanic parents reported more positive communication with providers regarding management of their child's chronic health issues related to asthma compared with non-Hispanic parents. The researchers hypothesized that the children in the study had poorly controlled asthma, so providers may have focused more on communication, resulting in improved scores for perceptions of communication. In contrast, Clemans-Cope and Kenney (2007), in a national survey with over 25,000 families examining the effects of income and language spoken at home on ratings of provider communication, found that foreign-born, Spanish speaking parents were two times more likely to report poor communication compared with English-speaking parents of U.S.-born children. Magana and colleagues (2012) also used national survey data to examine racial and ethnic disparities in the quality of care received by families of children with ASD and found that for over 4400 Black and Latino families, significantly more Black and Latino parents reported not receiving adequate communication with providers compared with White parents. These findings were similar to those in a study by Montes and Halterman (2011) that used national survey data with over 1800 families to explore the association between race/ethnicity and ratings of family-centered care, including communication, and found disparities in elements of communication for Black families when compared with White families.

It may be that race/ethnicity directly impacts perceptions of communication, though this may be mediated when the communication occurs around a particular clinical issue (e.g., asthma as in Carlin et al.). Continued research examining diverse groups of parents of children with ASD is needed to explore the influence of race/ethnicity on communication between providers and parents, especially research on perceptions of the barriers to and facilitators of the communication process as seen from the parents' perspectives.

2.1.1.2 Gender

Most often, gender is defined as either how one identifies oneself (U.S. Census Bureau, 2012) or whether one is male or female (Merriam-Webster, n.d.). Mothers (female caregivers) remain the primary caregivers most often seen in the pediatric primary care setting (Stevens, Mistry, Zuckerman, & Halfon, 2005). Consequently, most studies conducted in the field of communication between parents and providers are done with mothers as the primary parent respondent (e.g., Fagnano, Berkman, Wiesenthal, Butz, & Halterman, 2012; Fry-Bowers, Maliski, Lewis, Macabasco-O'Connell, & DiMatteo, 2014; Howell-Koren & Tinsley, 1990; Sices et al., 2009). However, there is a growing body of qualitative research that includes a notable sample of fathers (e.g., Jones, Woodhouse, & Rowe, 2007; Krahn, Hallum, & Kime, 1993; Watson, Kieckhefer, & Olshansky, 2006).

Findings have been mixed whether the gender of the parent impacts perceptions of their communication with providers. For example, Jones and colleagues (2007) used semi-structured interviews to examine differences in perceptions of communication strategies used by nurses in a sample of 20 mothers and 13 fathers with an infant in a neonatal intensive care unit. Findings suggest some distinct differences may exist between perceptions of mothers and fathers. Mothers talked more than fathers about elements of effective conversations, including the use of positive facial expressions, demonstrations of interpersonal control (i.e., people assuming their appropriate roles of provider or parent during the conversation), feelings of being well treated, and receipt of positive feedback. Fathers reported more ineffective communication than mothers and noted that poor interpretability (i.e., how people adapt their communication to others) affected communication. Fathers also reported distress when they received conflicting information from providers. Findings from other studies using qualitative interviews with parents of children diagnosed with developmental disabilities (Krahn et al., 1993; Watson et al., 2006) suggest there are not differences in parents' perceptions of the communication process based on parent gender.

The evidence regarding the influence of parent gender on the communication process is inconclusive. More studies are needed to examine the perceptions of both mothers and fathers to explore the influence of parent gender on the communication process. With further research, we may gain insight into potential differences that exist in how parents prefer to receive information based on their gender, which could help guide the development of targeted interventions or communication strategies based on gender.

2.1.1.3 Income, Social Class, and Education.

Income or determination of social class is a factor commonly included in behavioral research. Level of education is often used as a proxy to reflect income or social class (Braveman, 2010). Health disparities are often associated with poverty (Wolfe, 2015). Poverty generally refers to an individual's or a family's income at or below 200% of the Federal Poverty Level (FPL; Healthcare.gov, n.d.). The FPL is updated annually by the U.S. Department of Health and Human Services to assess eligibility of individuals and families for public programs based on family size and income (Healthcare.gov, n.d.). For a family of four in 2017, income at the 200% poverty level is $49,200 (FamiliesUSA, 2017).

Some studies have examined the relationship between poverty and parent ratings of satisfaction with care. Kenney, Denboba, Strickland, and Newacheck (2011) used a national survey with over 40,000 families to look at parent ratings of family-provider partnerships and satisfaction with care. They found lower ratings of partnership and satisfaction in families living in poverty (defined as a family income less than 200% of the FPL). Smalley, Kenney, Denboba, and Strickland (2014) and Montes and Halterman (2011) also had similar findings in studies using national survey data with 40,000 and 2000 families, respectively. They found that parent ratings of key elements of communication with providers were lower for families with incomes at less than the 200% poverty level compared with those above that level.

There is some evidence that providers speak differently to individuals in various social classes. For example, a systematic review of 12 studies by Willems and colleagues (2005) found that providers may use a style that is more directive with individuals from a lower socioeconomic bracket which results in giving less information and directions, along with less partnership building and support offered. Clemans-Cope and Kenney (2007) examined low income parents' report of communication issues with providers using data from a national survey and found that almost a quarter of parent respondents who were low-income reported that the child's provider "never" or only "sometimes" listened carefully or explained things in an understandable way.

Several studies were identified that examined differences in communication perceptions by educational level (Kenney et al., 2011; Korsch, Gozzi, & Francis, 1968; Magana et al., 2015; Montes & Halterman, 2011; Smalley et al., 2014). A classic study by Korsch et al. (1968) looked at communication interactions between 800 sets of doctors and parents and found differences in satisfaction with communication by parent educational level. Parents with some high school and college education had higher ratings of satisfaction with communication with providers compared with those who had full high school, but no college education. Similar findings were reported from a national survey of over 1800 parents of children with ASD (Montes & Halterman, 2011). The study found that parents with more than a high school education were significantly less likely to report poor communication with health care providers, including elements such as the provider not giving the family needed information or listening carefully to their concerns (Montes & Halterman, 2011).

Overall, evidence suggests that parents living in poverty, those from a lower social class, or those with lower levels of education, report decreased levels of satisfaction with the communication process with health care providers. A better understanding of the impact of varying levels of parental income, social class, and education on the communication process is needed to help potentially develop targeted interventions or strategies for parents that address their unique preferences for communication based on these variables.

2.1.1.4 Parent Mental Health

Parent mental health issues may influence perceptions of the communication process. From mental health nursing, we know that mental health issues can affect patient communication and that effective communication by health care providers such as nurses is one of the key therapeutic interventions used with patients experiencing mental health issues (Morrissey & Callaghan, 2011). Studies (Graugaard, Eide, & Finset, 2003; Kai & Crosland, 2001) and reviews (DiMatteo, Lepper, & Croghan, 2000; Stewart, 1995) with adult patients have explored the effects of mental health issues such as depression and anxiety on communication interactions and health behaviors (e.g., adherence to treatment recommendations in DiMatteo et al., 2000). Significant differences in interactions with providers and subsequent health behaviors have been found for patients with mental health issues compared to those without (DiMatteo et al., 2000; Graugaard et al., 2003; Kai & Crosland, 2001; Stewart, 1995). For example, those with depression were found to be more likely than those without depression to adhere to treatment recommendations given by providers (DiMatteo et al., 2000). Research also found that providers gave more information to patients with lower levels of anxiety and that those patients rated their satisfaction with visits higher than those with anxiety (Graugaard et al., 2003). A qualitative study with 34 patients with a variety of mental health issues detailed how these patients value good relationships with their providers who allow them opportunities to express their concerns, have discussions about their treatment options, and feel empowered (Kai & Crosland, 2001). These studies demonstrate that mental health issues may affect communication processes and that patients with mental health issues value good communication with providers. Similar studies pointing to the effect of mental health issues on communication processes with parents and providers are beginning to emerge in the pediatric literature.

A child with a parent who is depressed may have delayed child development (Deave, Heron, Evans, & Emond, 2008; Letourneau, Tramonte, & Willms, 2013), decreased access to primary care (Sills, Shetterly, Xu, Magid, & Kempe, 2007), and increased sick and emergency room visits (Sills et al., 2007). When examining the effects of parental depression on the communication process with a sample of 195 caregivers of young children with asthma, Fagnano et al. (2012) found that parents with a diagnosis of depression were less likely to report key elements of communication, such as the provider being reassuring and encouraging, asking the family about how they manage the asthma, and giving information. Parents who were depressed were significantly more likely to report a decreased level of satisfaction with the visit overall and also reported more needs being unmet in the visit than those parents without a diagnosis of depression. In conclusion, there is evidence supporting the effect of depression on child development and a recent study (Fagnano et al., 2012) suggesting parental depression may affect ratings of communication between parents and providers.

Stress may influence how parents either communicate or receive information. Stress is defined as a process that requires adjustment in one's coping in order to prevent adverse outcomes (both psychosocial and physiological) that affect the ability to cope with day-to-day demands (Deater-Deckard, 2004). Parents of children with ASD experience significant stress during the diagnostic process (Brogan & Knussen, 2003; Costa, Steffgen, & Ferring, 2017; Crane et al., 2016; Siklos & Kerns, 2007). For example, Siklos and Kern (2007) explored the diagnostic process for ASD with 56 parents and found that over 80% of parents reported the diagnostic process to be stressful. These results are similar to those in a recent study (Crane et al., 2016) with over 1000 parents where 84% indicated significant stress during the diagnostic process, and this high stress was found to be the strongest predictor of dissatisfaction during the diagnostic process.

Elevated stress may also decrease the effectiveness of a communication process such as patient health teaching (Osborne, McHugh, Saunders, & Reed, 2008). Osborne et al. (2008) performed a series of teaching interventions for parents of 65 children with ASD and found that the interventions were less effective for parents reporting high levels of stress compared with those reporting lower levels of stress. Stress may interfere with the ability to receive and process information about the child and the child's diagnosis. Evidence supports the presence of stress in parents of children undergoing a diagnosis of ASD (Crane et al., 2016; Siklos & Kerns, 2007) and as a result, that stress may interfere with aspects of parents' communication functions (Osborne et al., 2008).

Parental anxiety may be an important mental health issue to consider when identifying key elements of the communication process during the diagnostic period for ASD. Anxiety is defined as feelings of tension, worried thoughts, and associated physical changes (American Psychological Association, 2016). In a qualitative study of nine parents of older children regarding their experience of receiving news of a diagnosis of ASD, Abbott et al. (2013) found that parents appreciated when providers were supportive, were aware of the parent's anxiety, and tried to help them feel at ease. These parents also valued being provided an opportunity to ask questions and to be listened to. No further studies have been identified exploring the influence of anxiety on communication functions in a sample of parents; so evidence is new to emerge in this area with further studies needed.

Although research exploring the influence of parent mental health issues on the communication process is relatively new, evidence suggests parental depression, stress, and anxiety may impact the communication process that occurs with the child's health care provider. Recognition of the impact of maternal mental health, specifically depressive symptoms or depression, on the development of the child has resulted in professional and clinical recommendations to screen mothers in the postpartum period for depression when they attend well child visits in the pediatric primary care setting (Earls and the Committee on Psychosocial Aspects of Child and Family Health, 2010). There have been calls for even broader psychosocial screening for families in pediatric primary care beyond the postpartum period (Garg & Dworkin, 2011). With the potential increase in screening for mental health issues in pediatric primary care, more research is needed to explore the effects of these issues on specific elements of the communication process, especially for families of children who may be experiencing developmental delays or specific diagnoses such as ASD.

2.1.1.5 Time from When Parent First Identified Concerns to When Child Diagnosed with ASD

Parental concerns, that is expressions of concern by a parent related to his or her child (Glascoe, 1996), are important indicators of a child's potential risk for developmental, behavioral or social delays (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2014). Evidence suggests only about half of parents surveyed report that their concerns about their child's development are elicited by providers (Coker, Shaikh, & Chung, 2012; Glascoe, 1996; Guerrero, Rodriguez, & Flores, 2011; Zuckerman, Boudreau, Lipstein, Kuhlthau, & Perrin, 2009). When parent concerns are elicited by providers, parental reports of family-centered care, including elements of communication, are rated more positively than when parent concerns about the child are not elicited (Guerrero, Garro, Chang, & Kuo, 2010; Guerrero et al., 2011; Halfon et al., 2004).

Identifying parental concern is a particularly important factor for parents of children with ASD. Findings from a recent, nationally representative survey of U.S. parents of over 1400 children with ASD suggest from the time when parents first noticed concerns about their child's development to when their child received a diagnosis of ASD can be quite prolonged (Zuckerman, Lindly, & Sinche, 2015). Parents reported they first noticed concerns related to their child's development on average at 2.1 (95% CI= 1.9-2.3) years of age and on average, expressed these concerns to health care providers when the child was 2.3 (95% CI=2.2-2.5) years of age (Zuckerman et al., 2015). These same parents report first being told by a provider their child had ASD at an average of 5.2 (95% CI=4.9-5.5) years of age, representing an average lag time of 2.7 years (95% CI=2.5-3.0) between the parents' first discussions of concerns with a provider and when they were told their child had ASD (Zuckerman et al., 2015). As noted earlier, parents report significant stress during the prolonged diagnostic process for ASD (Brogan & Knussen, 2003; Costa et al., 2017; Crane et al., 2016; Siklos & Kerns, 2007). Intuitively, this lag time from when parents first express concerns to when they receive a diagnosis for their child may influence parents' perceptions of the communication process, but this factor has yet to be explored in research in this area to date.

2.1.2 Health Care Provider Sociodemographic and Personal Characteristics

2.1.2.1 Race/Ethnicity

Although it seems intuitive that health care provider race/ethnicity may impact the communication process with parents, limited empiric evidence could be found. A study using national data from nearly 2000 parents examined parent ratings of family-centered care based on provider race/ethnicity and concordance with reported parent race/ethnicity (Stevens et al., 2005). No significant differences in parental ratings of family-centered care by concordance of race/ethnicity between parent and provider emerged. This is similar to the findings of Arauz Boudreau and colleagues (2010) who examined 462 Latino parents' perceptions of communication with providers who spoke the same or different languages and found no difference in ratings of elements of communication based on whether or not the parent and provider spoke the same language.

There is some evidence in the broader literature (i.e., adult) that patients rate visits with providers of the same race/ethnicity with high levels of satisfaction and describe the visits as lasting longer and being more participatory (e.g., Cooper et al., 2003; Cooper-Patrick et al., 1999). A recently published study (Sweeney, Zinner, Rust, & Fryer, 2016), using national survey data from an extremely large number of adult patients receiving primary care from a usual source of care, found no difference in ratings of communication by concordance of race/ethnicity between the patient and provider. A comprehensive literature review conducted by Meghani and colleagues (2009) found inconclusive evidence from 27 studies on the effect of concordance of race/ethnicity on patient outcomes, including patient-provider communication. With such conflicting information in this area for adults, and limited knowledge in the pediatric population, it is important to consider the potential influence provider race/ethnicity may have on the communication process.

2.1.2.2 Gender

Limited empiric evidence exists that focuses on the impact of provider gender on communication interactions with parents. Bernzweig and colleagues (1997) examined provider gender and its relationship to the communication process between parents of 212 children and 64 providers during pediatric primary care visits. The study found female physicians were more active participants in communication interactions with parents. Parents reported that visits with female physicians were longer and involved more exchange of information, encouragement, and communication (Bernzweig et al., 1997). A systematic review of 33 studies (Jefferson, Bloor, Birks, Hewitt, & Bland, 2013) explored physician gender and its effect on communication categories such as information giving, partnership building, and length of visit. The study found female physicians engaged in longer visits and used more partnership or rapport building techniques in their interactions with patients (Jefferson et al., 2013). The reviewed studies indicate female physicians may spend longer time with patients and may engage in more active and participatory communication; therefore, it is important to consider the potential influence provider gender may have on the communication process.

2.1.2.3 Type of Provider

For the purposes of this study, type of provider included physician, physician assistant, nurse, nurse practitioner, psychologist, or therapist (including speech, occupational, behavioral, or physical therapist). An emerging body of research indicates potential differences in parents' ratings of communication experiences by type of provider in the primary care setting (Horrocks, Anderson, & Salisbury, 2002; Venning, Durie, Roland, Roberts, & Leese, 2000; Wasserman, Inui, Barriatua, Carter, & Lippincott, 1983). A systematic review of 23 randomized controlled trials and prospective observational studies comparing primary care provided by nurse practitioners (NPs) to physicians yielded the following major findings: NPs provide care that is of similar or higher quality compared with physicians; NPs spent more time with patients compared with physicians; patients were generally more satisfied with NPs; and patients rated receiving higher levels of communication from NPs, such as information giving and offering advice (Horrocks et al., 2002). Similar findings related to provider type and its relationship to communication and quality of care were found in two studies within pediatric primary settings (Venning et al., 2000; Wasserman et al., 1983). Wasserman and colleagues (1983) found parents seeing NPs rather than physicians had more interactions, more conversations initiated, and more information offered. Venning and colleagues (2000) found NPs spent more time on consultations compared with general practitioners and received higher ratings of satisfaction from parents. These studies report NPs provided many elements of family-centered care, namely the NP spent time with the parent and the parent reported getting needed information (Venning et al., 2000; Wasserman et al., 1983).

It is important to note many NPs are females, so it is possible that some of the differences experienced in quality of care based on provider type are more related to provider gender rather than actual provider type. Since provider gender was not collected in the aforementioned studies, more research may be needed to examine provider type while controlling for the effect of provider gender. Based on findings highlighting potential differences that may exist in elements of communication based on provider type, asking parents to report provider type may help ascertain potential differences in elements of communication by provider. This information may offer insight into the variable training that may occur for providers on health care communication, especially as it relates to child development. These findings could result in the development of more effective interventions and strategies that can be used with certain types of providers to enhance their communication with parents.

2.1.2.4 Level of Provider Experience

Level of provider experience refers to the number of years a provider has been in practice, from the end of graduate education moving forward (adapted from the American Medical Association, n.d.). To date, this characteristic has been represented as a provider being generally either very experienced or inexperienced in a limited body of literature examining parents' (Clark et al., 2008; Cramm & Dowd, 2008; van Dulmen & Holl, 2000) and simulated parents' (Nikendei et al., 2011) perceptions of communication with health care providers in pediatric health care settings. Overall, the studies find providers with more experience tend to receive better ratings from parents regarding elements of communication such as listening to and eliciting concerns and spending enough time with the family (Clark et al., 2008; van Dulmen & Holl, 2000). Providers with less experience may encounter more issues in communicating with families (Cramm & Dowd, 2008).

Training interventions focused on enhancing communication skills, even for experienced providers, result in improved parent ratings of communication (Nikendei et al., 2011). Clark et al. (2008) used a descriptive study to examine parents' perceptions of quality of care for children with asthma in a sample of 452 families seeing 48 pediatricians and they found that among a relatively experienced group of providers (average experience was 20 years), parents overwhelmingly had positive perceptions of providers' listening and conversation skills both at baseline and 12 months later, with no interventions performed. Cramm and Dowd (2008) explored the level of agreement in parent-provider communication in a pediatric emergency department setting based on what the parents were waiting for related to their child's care. The researchers only examined pediatric residents and found that parents seeing residents (who are relatively inexperienced) were more likely to report disagreement on what they were waiting for.

Of the remaining studies that focused on either very experienced (van Dulmen & Holl, 2000) or inexperienced providers (Lewis, Pantell, & Sharp, 1991; Nikendei et al., 2011), all studies were interventional and involved some type of communication skills training. All three studies found elements of communication were rated higher for providers in the intervention group compared with the control group. Examples include parents remembering more information given to them (Lewis et al., 1991), providers using more relationship building skills (Nikendei et al., 2011), providers asking more psychosocial questions, and providers making good eye contact (van Dulmen & Holl, 2000). These findings highlight the differences that may exist in communication based on the provider level of training. Therefore, level of training may be a beneficial variable to collect about providers and to further examine in relationship to parents' perceptions of the key elements of communication.

2.1.3 Communication Functions

2.1.3.1 Parent and Provider Exchange of Information

Exchange of information between a parent and provider refers to a process of transmitting ideas and beliefs based on the parent's goals for the communication process through conveying messages and interpreting the receipt of information from others (adapted from Feldman-Stewart et al., 2005). Exploration of the exchange of information between parents and providers when a child receives a diagnosis of a developmental delay (Abrams & Goodman, 1998; Sices et al., 2009) and/or an ASD diagnosis (Abbott et al., 2013; Braiden, Bothwell, & Duffy, 2010; Brogan & Knussen, 2003; Carlsson et al., 2016; Chao, Chang, Chin, Li, & Chen, 2017; Gaspar de Alba & Bodfish, 2011; Kennan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Moh & Magiati, 2012; Siklos & Kerns, 2007; Tait, Fung, Hu, Sweller, & Wang, 2016; Wong, Yu, Keyes, & McGrew, 2017) has been the focus of several studies. Many specific elements have been examined in these studies: the communication style and manner of the diagnosing professional (Abbott et al., 2013; Abrams & Goodman, 1998; Gaspar de Alba & Bodfish, 2011; Sices et al., 2009); parents' perceptions of the diagnostic experience (Abbott et al., 2013; Braiden et al., 2010; Brogan & Knussen, 2003; Carlsson et al., 2016; Chao et al., 2017; Kennan et al., 2010; Moh & Magiati, 2012; Sices et al., 2009; Siklos & Kerns, 2007; Tait et al., 2016; Wong et al., 2017); and the structure and content of the conversation (Abbott et al., 2013; Abrams & Goodman, 1998; Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012). Major themes emerging from these studies will be further described below, but in general, suggest there are differences in how parents prefer to receive information (Abbott et al., 2013; Abrams & Goodman, 1998; Sices et al., 2009); the communication style of the provider is important (Abbott et al., 2013; Sices et al., 2009); many parents still experience dissatisfaction with the diagnostic process (Brogan & Knussen, 2003; Moh & Magiati, 2012; Siklos & Kerns, 2007; Wong et al., 2017); and specific information about ASD is desired at the time of diagnosis (Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012).

Parents may have different ways they prefer to receive information from health care providers, especially based on whether their child has a confirmed developmental diagnosis (Abbott et al., 2013; Abrams & Goodman, 1998; Sices et al., 2009). Sices and colleagues (2009) conducted focus groups with 46 participants to explore parents' experiences of discussing child development in the primary care setting with mothers of children with typical development, mothers of children who received Early Intervention, and Early Intervention specialists. Mothers of children who received Early Intervention reported they wanted more direct information about their child's development from providers in contrast to parents of children with typical development who preferred a more indirect style of receiving information so as to not create alarm (Sices et al., 2009). Studies also found parents want sensitive communication at the time of diagnosis of a developmental disorder for their child (Abbott et al., 2013; Sices et al., 2009). Mothers of children who received Early Intervention in the study by Sices et al. (2009) reported the value of having a calm and compassionate provider who helped prepare them for the eventual diagnosis. Additionally, this same group of mothers reported that having their concerns heard and acknowledged about their child's development was important in feeling supported. Mothers who did not experience having their concerns heard and acknowledged reported feelings of self-doubt (Sices et al., 2009).

Some parents express dissatisfaction with the disclosure of an ASD diagnosis for the child (Brogan & Knussen, 2003; Moh & Magiati, 2012; Siklos & Kerns, 2007; Wong et al., 2017). Brogan and Knussen (2003) used a researcher-developed, parent-completed questionnaire to explore satisfaction with provider disclosure of an ASD diagnosis in a sample of 126 Scottish parents identified through hospital records and a volunteer organization. Only 55% of parents in the sample indicated they were either "satisfied" or "very satisfied" with the disclosure of an ASD diagnosis (Brogan & Knussen, 2003, p.36). Satisfaction with the disclosure of the diagnosis of ASD was significantly higher for parents who 1) reported disclosure that was done in a thoughtful and caring manner by the provider; 2) were provided with information, especially written, at the time of the disclosure; 3) had their early suspicions about their child's development accepted; and 4) had a provider who was open to answering their questions and listening to their concerns, as compared with parents who rated their satisfaction more negatively.

Parents have articulated needing specific types of information at the time of diagnosis of ASD for their child (Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012). Findings from studies with parents recruited from a variety of settings (e.g., schools, health care centers, patient registries) on information needs at the time of diagnosis of ASD, suggest parents appreciate receiving the following information: 1) description of the child's specific problems; 2) general details on ASD; 3) anticipatory guidance related to what to expect for the child; 4) parent support resources, including counseling and support groups; and 5) treatment or therapy resources such as Early Intervention programs, speech/language therapy, medical/psychological services, and special education (Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012). Two studies noted that approximately 30% of parents in their samples reported that no, or very little, help or information was offered when their child was diagnosed with ASD (Moh & Magiati, 2012; Osborne & Reed, 2008).

The aforementioned studies have examined exchange of information through how parents prefer to receive information (Abbott et al., 2013; Abrams & Goodman, 1998; Sices et al., 2009); what types of communication they want to receive at the time of diagnosis (Abbott et al., 2013; Sices et al., 2009); their level of satisfaction with the disclosure of an ASD diagnosis (Brogan & Knussen, 2003; Moh & Magiati, 2012; Siklos & Kerns, 2007; Wong et al., 2017); and the specific information needed (Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012; Siklos & Kerns, 2007). These studies find parents want specific types of information exchanged between them and providers related to their child. In addition, they have specific ways they prefer that information to be exchanged. Future research on this topic needs a greater understanding of potential barriers and facilitators regarding the exchange of information, especially from the perspective of parents who have a child in the process of being diagnosed with ASD.

2.1.3.2 Family-Centered Care

There are specific elements identified as essential if the intent is to provide family-centered care (Child and Adolescent Health Measurement Initiative [CAMHI], 2012, Health Resources and Services Administration, 2010). These elements include the following items: provider spends time with the parent; provider elicits concerns and listens carefully; provider sensitive to the family's values and customs; parent reports getting needed information; and parent feels like a partner in the care of their child. Many of the key communication functions in studies have emerged from or are related to these elements of family-centered care (e.g., Cheak-Zamora & Framer, 2015; Clemans-Cope & Kenney, 2007; Coker et al., 2012; Kuo, Bird, & Tilford, 2011; Magana et al., 2012; Montes & Halterman, 2011), and therefore, these elements may actually represent key elements of the communication process.

The implementation of family-centered care has been examined in surveys (e.g., National Survey of Children with Special Health Care Needs in Cheak-Zamora & Farmer, 2015; Kuo et al., 2011, Magana et al., 2012, and Montes & Halterman, 2011; National Survey of Children's Health in Coker et al., 2012; and National Survey of America's Families in Clemans-Cope & Kenney, 2007) with nationally representative samples ranging from around 3000 (Cheak-Zamora & Farmer, 2015) to nearly 40,000 parents (Kuo et al., 2011). Most families in these studies report high-quality, family-centered care, although disparities exist by following factors noted to have potential influences on parents' perceptions: income (Clemans-Cope & Kenney, 2007); language other than English spoken in the home (Clemans-Cope & Kenney, 2007; Kuo et al., 2011); Black race and/or Hispanic/Latino ethnicity (Clemans-Cope & Kenney, 2007; Magana et al., 2012; Montes & Halterman, 2011); and/or the presence of child health and development issues (Cheak-Zamora & Farmer, 2015; Coker et al., 2012; Montes & Halterman, 2011).

Clemans-Cope and Kenney (2007) examined data from a national survey with over 25,000 low-income parents and found that almost a quarter of parent respondents who were low-income reported the child's provider "never" or only "sometimes" listened carefully or explained things in an understandable way. They also found that over 36% of parents who had the interview for the survey conducted in Spanish reported the child's provider "never" or only "sometimes" listened carefully or explained things in an understandable way. Montes and Halterman (2011) explored disparities in elements of family-centered care based on parent race for slightly over 1800 families of children with ASD. In these families, they found Black parents were between two to five times more likely to report not receiving elements of family-centered care compared with White parents. Magana et al. (2012) found similar racial disparities in over 4400 families of children with autism and other neurodevelopmental disorders so that for families who were Black or Latino, there were more statements to indicate the provider does not spend enough time with families, lacks sensitivity to family's values/customs, and does not make the family feel like a partner. In a national survey which examined family-centered care in reports of over 22,000 families (Coker et al., 2012), parents of children at moderate or high risk for developmental delays (measured by scores on a developmental screener in the survey) were significantly less likely to report that their doctor usually or always spends enough time with them, listens carefully, provides them with needed information, shows sensitivity to family's values and customs, and helps the parent feel like a partner in care. These studies highlight some of the existing disparities in the provision of elements of family-centered care, namely by income level, race/ethnicity, and the child's developmental status.

Although family-centered care has been examined extensively from a broad perspective through national surveys, needs exist to understand qualitatively parents' perceptions of family-centered care and how the presence or absence of the elements of family-centered care, which could be viewed as key elements of communication, may affect how parents perceive the communication with a provider when their child is in the process of being diagnosed with ASD, including barriers to and facilitators of communication. Qualitative studies exploring these elements of family-centered care, especially with parents of children in the process of being diagnosed with ASD who have frequent communication with providers, could provide the underpinnings for future communication strategies with these families. Comparing these qualitative findings to standard measures of communication functions such as those used in previous studies (e.g., elements of family-centered care from the National Survey of Children's Health [2012] and National Survey of Children with Special Health Care Needs [2010]) may also provide insight into how effectively results on surveys and other measures of communication align with actual reports of parents' experiences.

2.2 Study Conceptual Model

Based on parental and provider factors and communication functions presented above, the *Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis* was developed (see Figure 1).

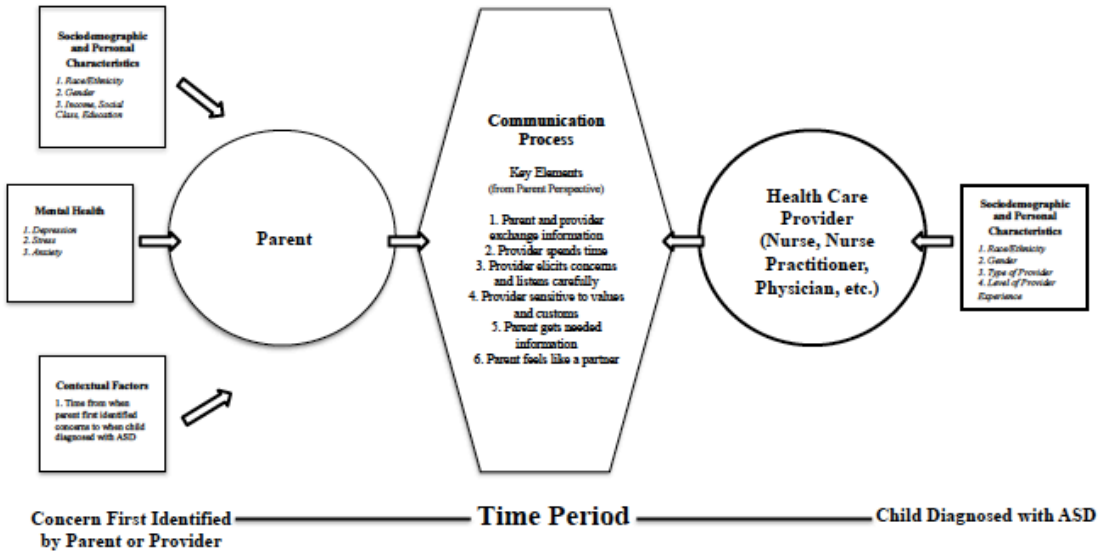

Figure 1: Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis

The model illustrates factors affecting both the parent and the provider in the communication process as represented by small circles on the right and left side of the model feeding into either the larger circle for the parent or the provider. In the small circles, items in italics are those suggested through research to have a potential influence on the communication process for either the parent or provider. For the parent, items that have some evidence to support their possible influence on the communication process are race/ethnicity, gender, income/social class/education, and mental health issues (i.e., depression and stress). For the provider, these items include race/ethnicity, gender, type of provider, and level of experience. Items in regular font are believed to influence the communication process, but have not yet been studied or demonstrated in pediatric research. These items include anxiety in the parent and the length of time from when a parent first identifies a concern to when their child is diagnosed with ASD. In the center of the model, the key elements of the communication process are listed. The

key elements of the communication process are the same elements as those used to define family-centered care (i.e., provider spends time with the parent; provider elicits concerns and listens carefully; provider sensitive to the family's values and customs; parent reports getting needed information; and parent feels like a partner in the care of their child), as well as an additional element related to the exchange of information between parents and providers.
The model is specific for the time frame from when a parent or provider first identifies concerns to when the child is diagnosed with ASD. This time frame is represented with a line extending from left to right at the bottom of the model.

This model was used to guide this dissertation study. As the full model is intended to represent an overall process, it was beyond the scope of the dissertation to examine all model elements. Therefore, for the purposes of the present study, the following key elements of the model were examined: parental sociodemographic and personal characteristics, parental mental health, contextual factors, and elements of the communication process from the parents' perspective, including parent and provider exchange of information and elements of family-centered care (i.e., provider spends time with the parent; provider elicits concerns and listens carefully; provider sensitive to the family's values and customs; parent reports getting needed information; and parent feels like a partner in the care of their child). The items explored in this study are highlighted in gray in the conceptual model in Figure 2 below. With the exception of provider type (which provides critical information about what types of health care providers parents report communicating with), items in the model related to the provider (i.e., race/ethnicity, gender, and level of experience) were not explored in this study. These provider elements are included in the model below as they may be areas for exploration in future studies based on the aforementioned conceptual literature describing their potential relationships with the communication process.

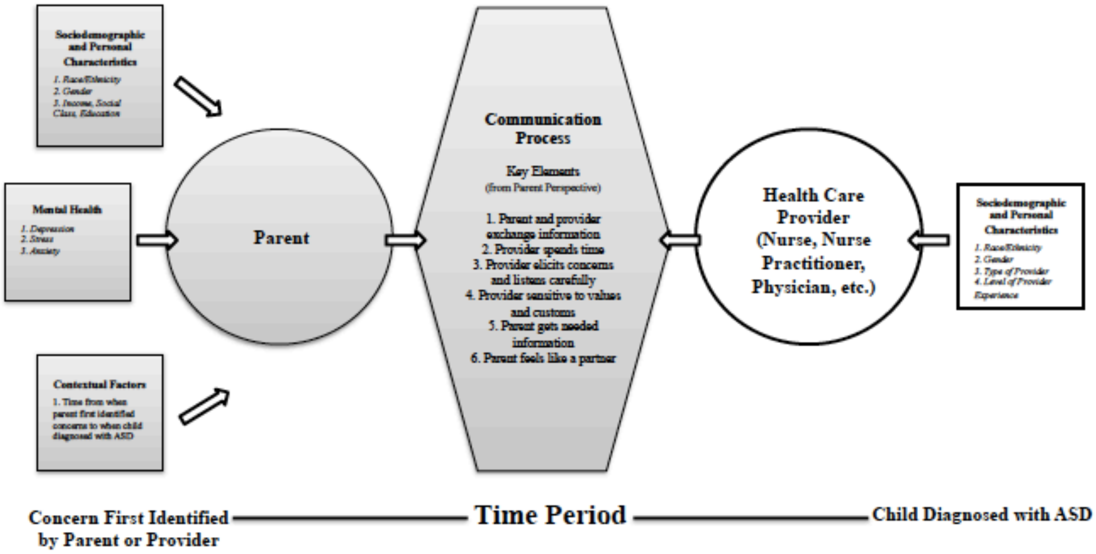

Figure 2: Elements Explored in Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis

CHAPTER 3

METHODOLOGY

3.1 Research Design and Assumptions

A mixed methods design that incorporated both qualitative and quantitative methods was used to conduct this study. Previous studies exploring parents' experiences with the diagnostic process for ASD have been primarily conducted using survey methodology (e.g., Brogan & Knussen, 2003; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Moh & Magiati, 2012; Siklos & Kerns, 2007) and only recently, have studies started to examine the process using either qualitative or mixed methods designs (e.g., Abbott et al., 2013; Wong et al., 2017). Therefore, this study was designed using mixed methods to not only describe, but also explore the communication process that occurs between parents and providers during the diagnosis of ASD. One-on-one interviews were conducted with parents using a primary investigator (PI)-developed interview guide. The interview guide was aligned with the study's main research question and sub-question related to facilitators and barriers of communication and guided by the study's conceptual framework. Additionally, a short parent survey was administered via phone following recruitment, as well as an online survey after the completion of the interview. The main questions in the interview guide mirrored those in the online survey and represent integration of methods through merging, a mixed methods strategy described by Fetters, Curry, and Creswell (2013).

Since previous studies around the diagnostic process for ASD have relied heavily on quantitative methods (e.g., Brogan & Knussen, 2003; Crane et al., 2016; Gaspar de Alba &

Bodfish, 2011; Moh & Magiati, 2012; Siklos & Kerns, 2007), the predominant method used in this study was qualitative in order to delve deeper into exploring the communication process from parents' perspectives. The primary assumptions guiding the use of a mixed methods design in this study are that the methods complement each other and draw their on respective strengths and together minimize weaknesses. As a result, the design can examine broad questions that cannot be adequately explored with just one method alone (Johnson & Onwuegbuzie, 2004).

3.2 Description of Research Setting

Participants for this study were recruited from a multitude of sources located primarily in Minnesota and Tennessee. Minnesota and Tennessee were selected because the PI had connections with settings in both states that helped enhance the recruitment process. The recruitment sources included ASD parent groups (i.e., Facebook parent groups and a clinic-based ASD support group), advocacy organizations (i.e., societies for ASD and individuals with disabilities), diagnostic resource centers, and a research listserv for a major university community. Another recruitment source for the study was ResearchMatch. ResearchMatch is "a national health volunteer registry that was created by several academic institutions and supported by the U.S. National Institutes of Health as part of the Clinical Translational Science Award (CTSA) program. ResearchMatch has a large population of volunteers who have consented to be contacted by researchers about health studies for which they may be eligible" (ResearchMatch, n.d.). Figure 3 illustrates the study recruitment and participants' eligibility to participate in the study by recruitment source.

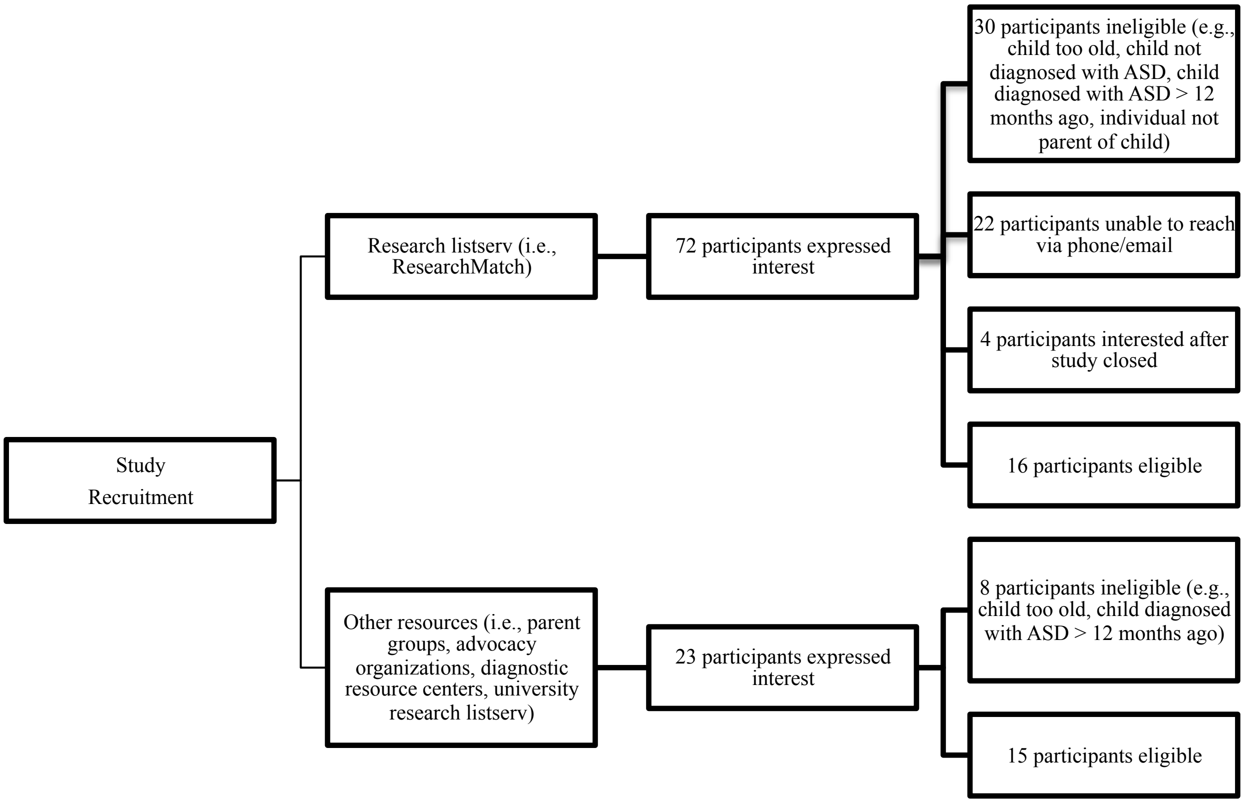

Figure 3. Study Recruitment Sources and Eligibility

3.3 Sample and Sampling Plan

3.3.1 Nature and Size of Sample

The target sample for the study was approximately 20-30 individual parents in the U.S. representing at least 20-30 children. Based on sample sizes in other qualitative studies exploring communication with parents (Howe, 2014; Howe, Cipher, LeFlore, & Lipman, 2015; Jimenez, Barg, Guevara, Gerdes, & Fiks, 2013; Shannon, 2004; Sices et al., 2009; Stille et al., 2010; Stille et al., 2013; Watson et al., 2006), this sample size was estimated to be likely to allow the PI to achieve saturation of themes. In total, 31 parents participated in the study. Saturation of themes was noted at a sample of 20 parents. An additional 11 parents were recruited after that point to ensure no new themes arose and to utilize remaining funding available for parent participation.

3.3.2 Criteria for Sample Selection

Inclusion and exclusion criteria for the study were developed to ensure the population included a sample that would allow the PI to address the research questions. The PI screened potential parent participants to determine their eligibility for the study based upon the criteria noted below.

Inclusion Criteria:

1. Individual parents of children 18 months to 6 years of age
2. Parents of children who have received a professional diagnosis of autism spectrum disorder by a health care provider (e.g., physician, nurse practitioner, physician's assistant, psychologist, psychiatrist, etc.) for their child in the last 12 months
3. Parents who speak English

4. Parents who are age 18 or older
5. Parents who are legal guardians of the child and primary caretakers
6. Parents with access to a phone or computer with a microphone and video camera connected to high-speed internet who are familiar with and able to use FaceTime, Google Hangouts, or Skype

Exclusion Criteria:

1. Caregivers of children in foster care
2. Parents with auditory, oral, or visual impairments that prevent use of phone or videoconferencing technology for interviews
3. Parental inability to provide informed consent (e.g., developmental delay, intellectual disability, neurological impairment, etc.)

3.3.3 Methods for Subject Recruitment

Parents were recruited via an informational flyer either posted on a website or sent out via email from the recruitment sources for the study. The flyer (or email) described the basic information related to the study (see Appendix A for a sample of the Recruitment Flyer). Parents interested in participating in the study were asked to contact the PI via phone or email to learn more about the study. Upon initial phone contact, the PI reviewed the eligibility criteria with the parents using an eligibility screening checklist (see Appendix B) to determine whether or not they met the inclusion criteria to be included in the study. Parents who met inclusion criteria were invited to participate in the study during that initial contact and assigned a participant code. After eligibility was determined, the PI also collected basic sociodemographic and personal information from the participants. This information was directly recorded into REDCap

(Research Electronic Data Capture). REDCap is a product “hosted at Vanderbilt University and is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources” (Harris et al., 2009). For those not meeting eligibility criteria, the PI collected basic information related to why the parent was not eligible. The primary reasons for ineligibility were that parents did not have a child in the correct age range for the study (e.g., the child was greater than six years of age) or the child was diagnosed with ASD more than 12 months ago.

3.3.4 Strategies to Ensure Human Subjects Protection

Study procedures began after approval of the research protocol by the Vanderbilt University Institutional Review Board (IRB). Consent for the study was collected from eligible parents prior to the start of the interview. Since the interviews were conducted via phone or videoconferencing technology, a waiver of documentation of informed consent for the study was approved by the IRB to eliminate the potential burden that may have been placed on parents to sign and return a paper copy of the consent in advance of participation in the interviews. Instead, verbal consent was obtained prior to the start of the interviews with parents according to the procedure approved by the IRB (see Appendix C for the consent script used at the start of Interview Guide).

Although the methods used in this study posed minimal risk to participants, the PI acknowledged parents might experience some discomfort providing information related to caregiving. As with any research study, all parents were informed in the consent process regarding the voluntary nature of the study and their right to refuse to answer any questions and/or terminate the study at any point. In addition, although the study did not directly involve children as participants, the informed consent process included the requirements of the PI to report to appropriate authorities any concerns that came up in the interview with the parent related to child abuse and/or neglect.

Additional strategies to ensure human subjects protection were undertaken in the study. One strategy was to ensure the amount of time asked of parents to participate in the interview and survey was reasonable and did not place an undue burden on them. The average time required to complete the interview for most parents was around 20-30 minutes. The PI provided parents with a small amount of compensation (i.e., $50 Amazon Electronic Gift Card) for their time spent participating in the study. The PI also received a waiver from the IRB for the collection of social security numbers for participant payment as this was an item that posed some difficulty to obtain in an interview that did not take place face-to-face, which may have otherwise prevented some parents from participating in the study due to privacy concerns related to providing this information online or over the phone.

3.4 Procedures

3.4.1 Pilot Testing of Study Materials

Since the study was primarily qualitative, the validity of the interview guide was critical to assess. The interview guide used in the study was designed to explore qualitatively key elements of the communication process as outlined in the study's conceptual model, and the guide was based on the study's main research question and subquestion related to facilitators and barriers of communication. The PI's dissertation committee, which included three nurse researchers with expertise in pediatrics, reviewed the interview guide. Two additional researchers with expertise in ASD also reviewed the interview guide. The interview guide was also pilot tested with four parents who met the inclusion criteria for the study and represent the study's first four participants. These parents were first asked to respond to each interview question and then provide feedback related to how easy it was to understand the question, what they thought the question meant, if they thought the question should be re-worded, and/or any questions they thought should be added. Only one parent made suggestions for some minor edits to enhance the clarity of a few questions and the prompts included in the final interview guide. The other three parents did not suggest any edits.

3.4.2 Full Study Data Collection Methods

3.4.2.1 Qualitative.

3.4.2.1.1 Procedures. During recruitment, parents were asked to schedule a time to meet via phone or FaceTime, Google Hangouts, or Skype (based on their preference and/or availability of method) with the PI to complete the qualitative interview. Most parents requested to complete the interview immediately after the recruitment process. If parents asked to schedule the interview at a later time, these parents received an email confirmation following the initial recruitment phone call with the interview details, time, date, and instructions for the method of technology that would be used for the interview approximately one day prior to the scheduled interview.

The PI conducted interviews with each of the participating parents using the final interview guide (Appendix C). The PI who conducted the interviews for this study was a female, advanced practice nurse with specialized training in pediatrics, public health, and research. The PI was unknown to the parent participants prior to the interview and only basic information related to her background (i.e., that she was an advanced practice nurse and PhD candidate) was provided to the parents prior to the interview. The PI had a copy of the interview guide available for each interview to record notes from the interview. Interviews between the PI and parent were audio-recorded using a computer-based application (QuickTime, Version 10.4, 2014). Interviews were transcribed verbatim via a secure, professional transcription service (i.e., Rev.com). The PI reviewed each of the transcripts for accuracy and minor corrections were made based on notes taken by the PI during the interview for items that were inaudible to the transcriptionist. Additionally, identifying information related to the participants was removed (i.e., references to names, facilities, states, cities, etc.) from the transcripts. Both a word processing program (Microsoft Word, Version 14.6.1, 2011) and a spreadsheet program (Excel, Version 14.7.2, 2011) were used to document and format, respectively, the data obtained from the interviews. All audio recordings and transcribed interviews were de-identified and kept in an encrypted, virtual storage system (i.e., Vanderbilt Box), with access granted only to the PI and the researchers assisting with data analysis.

3.4.2.2 Quantitative

3.4.2.2.1 Procedures. Upon completion of the qualitative interviews, parents were asked to complete an online survey via a link in an email that was sent directly to them (see Appendix B). The survey was administered electronically through REDCap. The online, structured survey was used to collect the following information from parents: contextual factors (i.e., age at which the child was identified with concerns for and diagnosed with ASD); parent mental health (depression, anxiety, and stress); and parents' perceptions of parent-provider communication (i.e., family-centered care questions from the National Survey of Children's Health [NSCH, 2012] and National Survey of Children with Special Health Care Needs [NS-CSHCN, 2010]). An additional question related to family structure (i.e., number of children and any health issues for those children) was also included. Upon completion of the online survey, parents were sent a link for an electronic Amazon gift card to compensate them for their participation in the study. Documentation of gift card receipt for each parent was completed according to the Vanderbilt University School of Nursing protocol.

3.5 Instruments

In addition to the aforementioned interview guide, a variety of instruments were used and questions were asked in the study to collect perceptions of parent-provider communication and parent and/or provider sociodemographic, personal, and contextual factors. Table 1 lists the instruments and questions used through the recruitment, interview, and online survey phases of the study. Additionally, a description of the instruments used and questions asked follows the table.

Table 1: Instruments Used and Factors Collected in the Study.

Recruitment	Interview	Online Survey (REDCap)
Parent and child age	Provider gender	When parents first noticed concerns about their child's development
Parent and child gender	Provider type	When parents first received a diagnosis of ASD for their child
Parent and child race/ethnicity	Estimated number of interactions with provider	Information about the number of other children in the home

	during diagnostic process	and any health issues for those children
Child health insurance type		Patient Health Questionnaire-4
Annual household income		Parent rating of stress
Parent marital status		Parent-provider communication (NSCH and NS-CSHCN questions)
Parent educational level		
Current state of residence		
Recruitment source		

3.5.1 Sociodemographic, Personal, and Contextual Factors

Information about the parent, provider(s), and the child who was the focus of the interview were based on elements included in the *Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis* that have been shown through previous studies to have associations with parent-provider communication processes. Information collected from the parents during the *recruitment* stage (after determining eligibility for participation in the study) included parent and child age, gender, and race/ethnicity, child health insurance type, annual household income, parent marital status, parent educational level, current state of residence, and recruitment source. Information collected from parents during the *interview* included provider gender, type, and estimated number of interactions with the provider during the diagnostic process. Information collected from the parents during the *online survey* following the interview included when parents first noticed concerns about their child's development, when parents first received a diagnosis of

ASD for their child, and information about the number of other children in the home and any health issues for those children.

3.5.2 Parent Mental Health Issues

Information related to parent mental health issues was collected in the *online survey* through both a standardized instrument exploring parent report of depression and anxiety, the Patient Health Questionnaire 4, and a Likert-scale question exploring the parent's level of stress during the time when their child was in the process of being diagnosed with ASD. Each measure is briefly described below.

<u>Patient Health Questionnaire (PHQ-4).</u> The PHQ-4 is a brief, valid, and reliable measure that is used to screen for depression and anxiety in adults (Kroenke, Spitzer, Williams, & Lowe, 2009). The measure was created by combining previous ultra-brief measures to assess depression (PHQ-2; Kroenke, Spitzer, & Williams, 2003) and anxiety (GAD-2; Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007).

The PHQ-4 consists of four questions that explore ratings (0=not at all, 1=several days, 2=more than half the days, 3=nearly every day) of how often in the past two weeks participants experienced problems related to depression and anxiety (Kroenke et al., 2009). Responses to all four items on the PHQ-4 are summed together to create a total score with the following interpretations: 0-2=normal; 3-5=mild symptoms of depression or anxiety; 6-8=moderate symptoms depression or anxiety; and 9-12=severe symptoms depression or anxiety. Since this study was asking parents to reflect on previous experiences, the instructions for the PHQ-4 were modified to ask parents to think back to the period when their children were being diagnosed with ASD. The original measure demonstrates good construct validity and was found through factor analysis to have two factors- depression and anxiety (Kroenke et al., 2009). The original measure has also been previously tested for reliability and demonstrates good internal consistency (α=.81; Khubchandani, Brey, Kotecki, Kleinfelder, & Anderson, 2016; Löwe et al., 2010) and adequate test-retest reliability (*K*=.69-.81; Löwe et al., 2010). The instrument is found on the public domain, so no permission for use was required. For statistical analysis in this study, the four items comprising the PHQ-4 were added together to provide a total scale score and a Cronbach's Alpha was calculated to determine the internal consistency of the scale, which was .893.

Rating of Stress. Parents were also asked to provide a rating of stress during the period when their children were being diagnosed with ASD. Stress was assessed using four-point Likert-scale question (1=not at all stressful to 4=very stressful) similar to the one recently used by Crane et al. (2016) in their study exploring parents' perceptions of the ASD diagnostic experience.

3.5.3 Parent–Provider Communication

Parent-provider communication was assessed in the *online survey* through the use of five standardized questions exploring elements of family-centered care from the NSCH (2012) and NS-CSHCN (2010) that represent parent-provider communication as outlined in the study's conceptual model. The NSCH and the NS-CSHCN are major national surveys funded by the Maternal Child Health Bureau out of the U.S. Department of Health and Human Services (CAMHI, n.d.; Centers for Disease Control and Prevention, 2015a,b). The survey questions focus on five key elements of communication: provider spends time with the parent; provider elicits concerns and listens carefully; provider sensitive to the family's values and customs; parent reports getting needed information; and parent feels like a partner in the care of their child

(NSCH 2012 & NS-CSHCN 2010; Centers for Disease Control and Prevention, 2015a,b). These questions have been used in several versions of the NSCH (2007, 2011-2012) and the NS-CSHCN (2001, 2005-2006, 2009-2010). Parents rate their level of experience for each element of communication on a six-point Likert scale (1=never, 2=sometimes, 3=usually, 4=always, 5=don't know, 6=refused). The questions demonstrate concurrent validity through previous research that found positive correlations between the five questions and measures related to having a medical home (Bethell, Read, Brockwood, & American Academy of Pediatrics, 2004). Additionally, the five questions together as a scale have been shown in research to demonstrate good internal consistency (Drummond, Looman, & Phillips, 2012).

The five questions have been used with hundreds of thousands of families in previous administrations of the NSCH and NS-CSHCN and were deemed to be understandable by parents responding to the surveys [S. Blumberg, personal communication, June 13, 2015], thus demonstrating face validity. These five questions were available on the public domain, so no permission was needed for their use. The questions were only slightly modified from their original form to remove the introductory clause in each question ("In the last 12 months") to better align with the flow of the survey. For statistical analysis in this study, a continuous variable to represent parent-provider communication was constructed indicating the number of key elements that a parent reported as "usually" or "always" receiving family-centered care. Values for the parent-provider communication variable ranged from "0" (no elements received) to "5" (all five key elements received). The Cronbach's Alpha for the scale in this study was calculated to be .803. Additionally, a dichotomous variable representing whether or not a parent reported receiving family-centered care was created using the same procedure outlined in

National Survey of Children's Health Codebook (2013) that defines receipt of family-centered care as responses of "usually" or "always" on all five questions from the NSCH.

3.6 Data Analysis

Data were analyzed in this mixed methods study using a concurrent or convergent design (Fetters, Curry, & Creswell, 2013). Initially, analysis of both the qualitative and quantitative data took place concurrently or independently. Subsequently, results from the qualitative analysis were merged with results from the quantitative analysis in such a way as to address the study's main questions. A table, which lists the thematic results obtained through the qualitative and quantitative methods side-by-side, was created as suggested by Creswell and Plano Clark (2011) for easy comparison of findings. Further details related to the procedures used for the qualitative and quantitative analysis individually are described below.

3.6.1 Qualitative Analysis

Directed content analysis was used to analyze the qualitative data. The analysis team included the PI (Coder 1) and an experienced, qualitative researcher with a master's in social psychology from the Vanderbilt University Qualitative Core as the second coder (Coder 2), with oversight from a senior researcher with a Ph.D. in Psychology directing the Qualitative Core. Each statement made by participants in the study was treated as a separate quote, and each quote was coded using a hierarchical coding system. The hierarchical coding system (Table 2) was developed using an iterative, inductive-deductive approach based on the study questions, interview guide and conceptual framework, as well as a preliminary assessment of the first several interviews. The coding system was organized into seven major categories: 1) initial concerns related to the child's development; 2) actions taken by the participant when concerns were identified; 3) provider interactions; 4) clinical services received; 5) evaluation of services; 6) facilitators and barriers to communication; and 7) personal reactions to the diagnostic process. Each of these categories were subdivided, and the subcategories were further expanded through up to the 13th interview to capture detail. The categories were represented with a numbering system (e.g., 5.1, 5.1.1, 5.1.2) for hierarchical organization (see Appendix D for full codebook with definitions). In total, 52 codes were developed and used to code 1429 quotes from parents.

Table 2. Hierarchical Organization of Coding System Used in Study.

Code	Category
1	**Initial concerns**
1.1	Delayed speech
1.2	Repetitive patterns
1.3	Sensory Issues
1.4	Comparison with other children
1.5	Developmental regression
1.6	Behavioral issues
2	**Actions taken by participant**
2.1	Internet searches
2.2	Seeking advice
2.3	Scheduling services
2.3.1	Medical provider
2.3.2	Early intervention services
2.4	Other
3	**Providers**
3.1	Explanation
3.2	Reaction to concern
3.2.1	Positive affirming supportive
3.2.2	Dismissive, without concern
3.2.3	Wait and see/monitor
3.3	Medical referrals
3.3.1	Referral to a diagnosing provider
3.3.2	Referral to Early Intervention
3.3.3	Referral to other therapist/therapy
4	**Clinical services**
4.1	Psychologist

4.2	Psychiatrist
4.3	Primary care pediatrician/nurse practitioner/family practice
4.4	Developmental pediatrician
4.5	Speech/occupational/physical therapy
4.6	Neurologist
4.7	Other
5	**Evaluation of services**
5.1	Satisfaction level
5.1.1	Satisfied
5.1.2	Dissatisfaction
5.2	Enough time
5.2.1	Yes
5.2.2	No
5.3	Listened
5.3.1	Yes
5.3.2	No
5.4	Answered concerns
5.4.1	Yes
5.4.2	No
5.5	Sensitivity to concerns
5.5.1	Yes
5.5.2	No
5.6	Communication quality
5.7	Understandability
5.8	Family partnership
5.8.1	Yes
5.8.2	No
5.9	Cultural/individual difference sensitivity
5.9.1	Yes
5.9.2	No
5.10	Information received
5.10.1	Yes
5.10.2	No
5.10.3	Additional information desired
5.11	Provider knowledge
6	**Facilitators/barriers**
6.1	Identified as facilitator
6.2	Identified as barrier
7	**Personal reflections**
7.1	Emotional
7.2	Family function
7.3	Financial
7.4	Job/career

The two coders independently reviewed all the quotes from the interviews, identified codes based on the coding system, and established inter-rater agreement. Quotes were assigned up to five different codes, based on the recommendation of the Core. The two coders met on a weekly basis to resolve all discrepancies in coding until all transcripts were coded. Each coder made notes to indicate codes or quotes that would be appropriate to discuss when meeting. Once coding was complete, an Excel spreadsheet was used to sort all codes and associated quotes. Separate columns were created within the spreadsheet to classify and organize the codes. The coded data were imported into SPSS, version 23, which was used to create a single record for each code, along with the quotation associated with the code. This method allowed for the extraction of significant issues and themes within the data. Table 3 demonstrates the method for coding organization from six quotes in a selected parent interview.

Table 3. Method for Coding Organization.

Interview	Quote Order	Line Code	Speaker	Quote	Code 1	Code 2	Code 3	Code 4	Code 5	Context 1	Context 2
22	24	22-24	Interviewer	The first question is thinking back to how accessible or how much time the health care provider spent with you during the process of the diagnosis did you think it was enough time, too much time or not enough time?							
22	25	22-25	Parent	I feel like it's been enough time. I don't know if I would have felt that way if I hadn't already known them before and our oldest hadn't been with them. I think that played a lot into it. Probably if I was like brand new to autism it might have been a little light but it's kind of hard to say because we knew each other, we were all the same page so I felt it was, for our situation, enough time.	4.1	4.5	5.2.1	1.4		22-24	

22	26	22-26	Interviewer	Was that primarily in reference to the neuropsychologist or including also your interactions with the speech and OT and PT?							
22	27	22-27	Parent	Probably everybody, yeah. The whole squad.							
22	28	22-28	Interviewer	Did you feel the health care providers were listening to you during the process of getting the diagnosis for [child]?							
22	29	22-29	Parent	The primary team, OT, speech, PT and the neuropsych really listened to me. Their pediatrician, I mean, we did have to check in with his pediatrician and that was just kind of a waste of time because he's just not very educated on autism. [child] is not textbook, stereotypical autistic and so he'd just be like, "He's just doing fine," and he would just blow us off.	5.11	4.5	4.3	4.1	5.3.1	22-28	

At the conclusion of the coding process, the P.I. (Coder 1) used an iterative process to read the quotes by categories and codes, summarize their main points, and compare the findings to theory to make revisions to the study's conceptual model. Next, both coders, along with the senior researcher from the Qualitative Core, met over several weeks to discuss the summary and major themes, along with revisions to the model, in order to ensure credibility and confirmability of the findings. After major themes were confirmed, illustrative quotes from the interviews were selected to support the themes. The senior researcher and second coder reviewed the final summary of the qualitative analysis with themes, associated quotes, and the final conceptual model to ensure accuracy and clarity.

3.6.2 Quantitative Analysis

Descriptive statistics were used to summarize the parents' responses to the items in the online survey. Frequencies and percentages were used to summarize nominal and ordinal categorical data. Means and standard deviations were generated to summarize normally distributed interval/ratio data; median and interquartile ranges were used for skewed interval/ratio data. Spearman correlations were calculated to assess the extent of the relationship of parental reports of the number of key elements of communication with parent mental health and contextual factors. Chi-Square Tests of Independence were used to assess possible differences in prevalence of key elements of communication between groups of parents defined by certain sociodemographic characteristics (race, gender, income, and education). No imputation of missing data was needed as parents completed all survey items in this study. SPSS, version 24, was used to conduct the quantitative analyses. An alpha of 0.05 was used for determining statistical significance.

CHAPTER 4

RESULTS

4.1 Sample Characteristics

A total of 95 individuals expressed an interest in this study. Of those individuals, 31 parents (representing 31 children) met the eligibility criteria. All 31 parents were interviewed and completed the study. Parents were recruited from 13 states broadly distributed throughout the U.S., with a larger sample of parents recruited from both Minnesota and Tennessee (n=8, 26% total sample each state). Basic demographic characteristics related to these parents and their children are summarized in Table 4. The average parental age was 34.5 years (SD=7.2) and average age of their children with a diagnosis of ASD was 3.9 years (SD=1.3) at the time of the interview. Most of the parents interviewed were white (74.2%) and female (90.3%). Most of the children were white (67.7%) and predominantly male (71.0%). The majority of parents reported being married or living with a significant other (80.6%).

Parents reported first having concerns about their child's development at a median child age of 1.3 years (IQR = 1.0, 1.8 years) and an average child age for ASD diagnosis of 3.3 years (SD=1.2). This represents a gap of 1.9 years (SD=1.3) from when parents first had concerns about their child's development to when their child received an ASD diagnosis.

Table 4. Descriptive Statistics of Participants and Their Children (n=31).

Characteristic	**N (%)**
Parent Gender	
Male	3 (9.7)

Female	28 (90.3)
Child Gender	
Male	22 (71.0)
Female	9 (29.0)
Parent Ethnicity	
Not Hispanic or Latino	30 (96.8)
Hispanic or Latino	1 (3.2)
Parent Race	
Asian	4 (12.9)
Asian and White	1 (3.2)
Black or African American	3 (9.7)
White	23 (74.2)
Child Ethnicity	
Not Hispanic or Latino	30 (96.8)
Hispanic or Latino	1 (3.2)
Child Race	
American Indian or Alaska Native	1 (3.2)
American Indian and White	1 (3.2)
Asian	4 (12.9)
Asian and White	1 (3.2)
Black or African American	2 (6.5)
Black or African American and White	1 (3.2)
White	21 (67.7)
Type of Insurance (Child)	
Private	16 (51.6)
Public	11 (35.5)
Military	1 (3.2)
Private and Public	1 (3.2)
Public and Military	2 (6.5)
Annual Household Income (USD)	
$0-10,000	1 (3.2)
$10,001-20,000	2 (6.5)
$20,001-30,000	4 (12.9)
$30,001-40,000	4 (12.9)
$40,001-50,000	4 (12.9)
$50,001-60,000	1 (3.2)
$60,001-70,000	1 (3.2)
$70,001 or more	14 (45.2)
Parent Marital Status	
Married or Living with Significant Other	25 (80.6)
Separated	1 (3.2)
Divorced	1 (3.2)
Single	4 (12.9)

Parent Highest Educational Level	
High School Education	2 (6.5)
Some College, No Degree	8 (25.8)
Associate's Degree	5 (16.1)
Bachelor's Degree	8 (25.8)
Master's Degree or Higher	8 (25.8)
	Mean (SD) and Minimum/Maximum
Parent Age (years)	34.5 (7.2), 19-48
Child Age (years)	3.9 (1.3), 2.0-6.0
Child Age when Diagnosed with ASD (years)	3.3 (1.2), 1.6-6.0
Time from First Concerns to Diagnosis (years)	1.9 (1.3), .25-5.0
	Median (IQR) and Minimum/Maximum
Child Age when Concerns First Identified (years)	1.3 (1.0, 1.8), 0.5-4.0

4.2 Qualitative Results

Key elements, as well as facilitators and barriers, to the communication process between health care providers and parents when their children were in the process of being diagnosed with ASD were explored through the qualitative portion of the study through the semi-structured questions noted in the interview guide (Appendix C). Four overarching themes emerged: 1) facilitators at the provider level; 2) facilitators at the system level; 3) barriers at the provider level; and 4) barriers at the system level. Within each of these broad themes, various subthemes emerged. Overarching themes and related subthemes are presented below along with illustrative quotes to support them. The interview also included introductory questions exploring types of providers parents saw, parents' initial concerns about their child's development and actions taken, and provider reaction to parent concerns. Parent responses to these questions are summarized below. Finally, outcomes of the communication process from the parents' perspective were identified through analysis of the interview content and are also presented below with illustrative quotes.

4.2.1 Facilitators

4.2.1.1 Facilitators at the Provider Level

Four subthemes emerged within the broad theme of facilitators at the provider level: 1) elicits concerns and listens; 2) sensitive to values and customs; 3) knowledgeable and gives information; and 4) treats parent as a parent. Each of these subthemes is presented below.

Elicits concerns and listens. This subtheme captures how parents' concerns were elicited or sought out and how parents felt listened to by providers. Many parents reported that providers asked about and were sensitive to their concerns about their child's development and answered their questions right away or got back to them later with responses if they did not immediately know the answers. Parents described how providers welcomed their concerns and that they were not left alone with their concerns, but put at ease. Parents detailed how providers not only asked questions, but also took the time to listen to the parent and clarify what was heard. Parents described ways in which they noticed providers were listening, including the provider making good eye contact, asking questions, taking notes, validating concerns, and not interrupting the parent. Many parents also brought up the value of feeling listened to and how that made the process of obtaining a diagnosis much easier or helped with determining how to proceed with next steps for their child's development. Providers eliciting concerns and listening is evidenced by the following quotes:

> *Okay. I would say for [diagnostic clinic] that yes, they listened to us and whatever questions that we had they made sure to answer them completely and they would ask a couple times, "Are you sure you don't have anything else?"… Participant 24*
>
> *She's very good at listening. She heard out what my concerns were and didn't blow them off. She also asked very good questions when she needed more clarification instead of jumping to conclusions that she understood. For instance, sensory seeking when I talk about head butting and spinning, she would ask thoughtful questions like when you say*

> *head butting can you give me an example of when that might be occurring...I really appreciated that listening component but then willing to ask me questions for clarification instead of just assuming that what I might've meant. Participant 1*

Sensitive to values and customs. This second subtheme depicts parental perceptions of how the provider demonstrated sensitivity to the family's values and customs. When asked about ways in which providers were sensitive to family's values and customs, many parents reported that providers were respectful. For example, a few parents addressed how providers respected their decisions to withhold vaccinations. There was also a subset of parents who had limited answers to this question because they did not feel that they had any particular values or customs that were necessary to consider in the care of their child. The following quotes contain evidence of providers demonstrating sensitivity to the family's values and customs:

> *...I mean she was really just very respectful. I mean she didn't push anything on me. Participant 9*

> *We didn't really do anything out of the norm, not until after the diagnosis. Everything was pretty much what they were accustomed to, I guess. Participant 2*

Knowledgeable and gives information. Providers who were knowledgeable and gave parents needed information was the third subtheme within the major theme of facilitators at the provider level. Parents described ways in which providers were knowledgeable about ASD. They referred to the variety of information and referrals to resources that they received from health care providers during the process of obtaining a diagnosis. A few parents discussed receiving written summaries from visits and how helpful this information was for the parent to review after the visits. Other parents talked about being given specific recommendations in terms of treatment, therapies, or referrals. The subtheme of providers being knowledgeable and giving information is evidenced by the following quotes:

> *She [psychologist] provided us with a five-page report, very detailed, of every assessment she used and those scores. Then the overall scores, as well as medical and developmental*

> *history, and the interview process for them. Then at the end she listed recommendations of what to continue with, and was able to supply me with resources in the area that I could get in touch with. Participant 3*

> *He [pediatrician] gave me a lot of handouts. He's a type of guy that likes to print out everything that can be going on at the moment that you're seeing him. And what to look for, and things like that. He also gave me the number for the special needs center...And then he gave me websites that I could go to and things of that nature... website print out, numbers I could call, and things like that. Participant 19*

Treats parent as a partner. The final subtheme within facilitators at the provider level depicts how providers treated parents like partners in the process of obtaining a diagnosis of ASD. Most parents felt that they were partners in the care of their child and provided examples of when they felt this partnership occurred. Parents talked about how providers gave them suggestions on what they could do with their child to enhance the child's development or asked the parent whether or not these suggestions would work for the family. Providers also checked in with the parent about what they thought regarding the next steps for their children in terms of treatment, therapies, or referrals. The following quotes offer evidence of providers treating parent as a partner:

> *They always make sure that I was okay with things and that it was okay for them to do certain things and they always kind of came back to you and made sure that you were okay with what the next thing that they were going to do. So they would explain it to the child, but at the same time, they're kind of asking permission. Participant 19*

> *Well, I mean they basically involved us in every step of the process. Especially with the therapists and everything…We kind of feel I guess as you say a partner in the whole thing…Participant 30*

4.2.1.2 Facilitators at the Systems Level

Two subthemes emerged within the broad theme of facilitators at the systems level: 1) enough time; and 2) direct communication. Each of these themes is presented below.

Enough time. A subtheme under facilitators at the systems level was providers having enough time to spend with parents in the health care environment. Parents specifically commented on providers who gave them the time to fully explain their concerns and who did not make them feel rushed. Many parents discussed how appreciative they were of the time the provider spent with them, especially in the context of a busy clinic setting. The following quotes give evidence of systems providing parents with enough time with providers:

> *Looking back, I can pretty much say that they took the time that was needed... Participant 30*
>
> *She was fine spending as much time with us as we needed to feel comfortable. She's always been very generous with her time despite the busyness of the practice. Participant 7*

Direct communication. A second subtheme for facilitators at the systems level was direct communication between providers and parents or among providers. Several parents specifically commented on having direct communication with providers through phone or email. Parents discussed their appreciation for being able to ask questions of their providers outside of the visit. Parents also commented on how helpful it was when providers communicated among themselves and this resulted in the parents feeling like their child was receiving comprehensive and coordinated care. The following quotes contain evidence of systems allowing parents direct communication with providers or direct communication among providers:

> *I have direct access to every one of their personal emails. If I have any questions throughout the week, I've been told more than once that I can shoot them an email, and they'll either call me back or just send a response email. Participant 23*
>
> *Well, something I really liked was very early on, right when she started seeing the behavioral therapist, I signed the sheet so that her pediatrician and behavioral therapist could communicate with each other…if I sent a message to the pediatrician, he would let me know he was going to forward it. And then I would get a message back from him and the behavioral therapist and I could see their notes to each other. It just definitely felt like, "Oh, good. Her pediatrician knows what's going on," which is a big deal for me because I really like the idea of the general practitioner being the central hub for the person. I want him to know what the specialists are saying. Participant 11*

4.2.2 Barriers

4.2.2.1 Barriers at the Provider Level

Three subthemes emerged within the broad theme of barriers at the provider level: 1) not trusting parent as expert in care of child/not treating parent as a partner; 2) not listening; and 3) lack of knowledge and information given. Each of these subthemes is presented below.

Not trusting parent as expert in care of child/not treating parent as a partner. A subtheme that emerged under barriers at the provider level was providers not trusting parents as the expert in the care or their child or not treating parents as partners in the diagnostic process. Some parents reported that they did not feel trusted or regarded as an expert in the care of their child, when indeed many parents felt like they had legitimate concerns about their child's development and wanted to be asked about those concerns or have those concerns acknowledged. Parents also discussed how they wished providers would take their concerns about their child's development seriously early on and make referrals for further exploration into those concerns, especially since parents spent the most time with their child and knew their child best.

Some parents reported not feeling like partners in the process of the diagnosis for their child. One parent commented how she had to rely solely on the decisions of the provider for next steps as their insurance did not cover referrals unless the primary care provider made them. A few parents mentioned specifically the challenge to find the right words to use with providers in order to speak at their level regarding ASD and the diagnostic process in order to feel that they were a partner in the care of their child. Providers not trusting parents as an expert in the care of their child or not treating the parent as a partner is evidenced by the following quotes:

> *I think that they should listen to the parent first, because that's the person that has the child all day long. They would know. I'm not saying that we're always right, but they*

> *should take into consideration our concerns and thoughts and what we see is not developing, as to what they see. Then putting all that together. My information, their information and then try to work out what we feel is the issue. Not you just telling me, "Oh, this is what it is." Nobody wants to be bulldozed into anything or feel that their opinion isn't valid. Participant 21*
>
> *It's a very helpless feeling because…you're very aware that they are the person with the degree and if they are not willing to sign a piece of paper saying you need more assistance or vouch for you that there's not really anywhere else to go in the system. You need a pediatrician to say this person needs something. So it's definitely a helpless feeling. Especially because we were on Medicaid in [state] and there's not- you don't have the freedom to say, "I'll just find a doctor who will tell me what I want to hear or something." Participant 11*

Not listening. Another barrier at the provider level that was identified as a subtheme was providers not listening to parents. Parents described ways in which they did not feel listened to, including feeling their concerns were not heard or were disregarded/doubted and feeling their providers were not taking the time to listen to the specific details related to their child. One parent specifically described an incident in which the provider talked over her and sought information from her husband instead. Some parents discussed how they felt their child might have received a diagnosis or services earlier in the process if the providers had listened more to the parents' concerns. Some parents reported that they did not initially feel listened to when they first brought forward their concerns, but as they moved further along in the diagnostic process, they were listened to. The following quotes offer evidence of providers not listening to parents:

> *With my pediatrician when we discussed things I felt like a lot of things that I mentioned to him he kind of chalked up as, "Well, kids do that," or "Kids will be that way," or "You're a first time parent so you're worried," and you know, those kinds of things that were dismissive. I did not feel like he was really listening to the specifics. I'm a mother, I have specifics. I got lots of them. I just did not feel like he was listening to what I was saying. I did not feel heard. Participant 27*
>
> *I wish they had listened more and had at least [said] that they really did feel like he wasn't autistic at five and just kind of hear me out ... And really just don't doubt me. I think a parent definitely knows more about their child ... They know when something is changing or something just seems off. I wish they had listened more... Participant 16*

Lack of knowledge and information given. Provider lack of knowledge and information given was an additional barrier at the provider level that emerged as a subtheme. Many parents expressed concern about provider knowledge regarding ASD, especially the lack of knowledge on how to diagnose ASD in younger children or in girls, and in understanding the various ways ASD may present, especially in high-functioning children. Parent concerns about provider knowledge were most often directed at the primary care provider. Parents felt primary care providers were unfamiliar with early detection of ASD as this was not their specialty versus some of the diagnosing providers or therapists who may have been far more experienced with diagnosing and/or working with children with ASD.

Many parents commented on additional information they wished they would have received from providers, which they only learned about later in the process. Parents provided examples of those types of information, which included referrals to other resources; services in the community such as social services or parent groups; suggestions on how to work with the child at home; and a checklist on the steps parents could take following a diagnosis to get the appropriate services set up for their child. Some parents discussed the complete lack of information they received related to their child's diagnosis or next steps, and the fact that they needed to find information entirely on their own. Parents specifically noted their concern about not being given information after some of the diagnostic testing and this was worrisome to parents as they were trying to understand what was going on with their child. A few parents discussed how they had children previously diagnosed with ASD, so they assumed some information was not given to them because they were thought to already have knowledge of the disorder. The following quotes offer evidence of providers lacking knowledge or not giving information to parents.

> *It would have really been great if the pediatrician was more autism literate and knew more of the signs aside from the one sheet, two-year-old questionnaire of is your kid speaking?...I mean, [child] completely fell through the cracks as far as the pediatrician side goes. I didn't let that happen and just went around him. I have to wonder how many other kids are out there that have fallen through the cracks and their parents don't know. They just don't know what they don't know. Participant 22*

> *...I feel like most of what I've learnt, I've looked up myself, I've read myself...I mean there's a lot of misinformation, even from I would say pediatricians. Participant 17*

4.2.2.2 Barriers at the Systems Level

Four subthemes emerged within the broad theme of barriers at the systems level: 1) not enough time; 2) long wait times/delay in diagnosis; and 3) financial and insurance issues; and 4) indirect communication. Each of these subthemes is presented below.

Not enough time. A subtheme for barriers at the system level was providers not having enough time to spend with parents in the health care setting. Parents discussed the lack of time available in a busy practice setting to discuss their concerns or questions with providers, or that the visit felt rushed. The following quotes present evidence of systems barriers resulting in parents not having enough time with providers.

> *It's always so extremely rushed like how fast can we get all the details we need and get you in and out of here… A major barrier was just the lack of time, always feeling rushed. Participant 25*

> *I would say probably not enough time, not through the fault of the pediatrician, but just by the nature of a general pediatrician I guess doesn't really have that much time to devote to each patient generally... It's like any doctor nowadays. You get a limited time with them, and it's not their fault, it's not that they don't care about the patients, it's just how it is with insurance and what not...Participant 6*

Long wait times/delay in diagnosis. Long wait times for appointments and delays in the child receiving a diagnosis of ASD were issues identified as another subtheme under barriers at the systems level. Parents discussed the long wait times to get in for diagnostic appointments and their concerns related to what the delay in diagnosis meant for their child. As a result, parents expressed ‘what if’ concerns of what could have been done earlier to give their child a better outcome. System barriers resulting in parents experiencing long wait times and delays in diagnosis are evidenced by the following quotes:

> *First of all, it's just hard to get an appointment, to be honest with you. It's not like you can pick up the phone and get an appointment next week. You have to wait, and it's not easy sometimes just to get the appointment…Participant 16*
>
> *Yeah. I really wish I would, I should have started it early like after he turned one or even earlier just with the you know I wish someone would have told me or even with the, after he was born with those visits when he was an infant someone would have told me you know just to get him checked or get him evaluated with the [Early Intervention] program. Participant 28*

Financial and insurance issues. Financial and insurance issues emerged as a subtheme for a barrier at the systems level. Parents discussed financial barriers, including not having enough money for gas to get to all the appointments. They described how expensive certain visits or diagnostic procedures were, and their challenges with insurance not covering certain providers and therapies. Financial and insurance issues are evidenced by the following quotes.

> *Another barrier for us was just lack of resources. It's hard to run to the doctor every day when I don't have the gas money to do so. Participant 25*
>
> *There's, you know, if your insurance is not that great and you've got outrageous deductibles then it's hard to get everything you need. I find that a barrier for most families unless they're on the military insurance, which we are not. Participant 8*

Indirect communication. A final subtheme that emerged was the notion that some communication with providers was indirect- either communication did not result in the parent being able to speak directly with the provider or providers were unable to speak to each other. Parents expressed frustration of not being able to speak directly with their providers and had to communicate through other staff at the clinics or centers before reaching the provider. They also talked about how communication was poor or non-existent between providers working in “silos,” which led to the parents being responsible for coordinating their child's care in a complicated system. Indirect communication is evidenced by the following quotes:

> *If you needed to call the office, you have to leave a message with a medical assistant or a secretary. And I'm one that I wanted to talk straight to the provider. I want to cut out the middle man...Participant 20*
>
> *Yeah, they're based in [Health System] but even within [Health System] she may not share the records with the pediatrician or the pediatrician may get a copy but not the allergist...With the physical medicine doctor, all those people are actually in the very same clinic. It's such a monster clinic that I think that they get very siloed…It's a huge burden for parents who are even if they're super educated, trying to keep up and understand medical records and keep them coordinated together and transporting them from place to place is very overwhelming. Participant 1*

4.2.3 Outcomes

Outcomes of the communication process emerged as an additional finding from the qualitative analysis of the interviews in this study and included both satisfaction and dissatisfaction with the communication process, along with positive and negative emotional reactions to the process.

4.2.3.1 Satisfaction

Many parents discussed their feelings of satisfaction with the communication process with providers, and specifically described the genuine support and help they received from providers. Many parents noted their communication interactions with primary care providers in particular to be positive, as these were the individuals they first connected with when they had concerns and most reported the providers were affirmative and supportive of the concerns. Even more parents commented on the positive experiences with the diagnosing psychologists and service providers for the child such as speech and occupational therapists, who were directly providing services to either diagnose or treat the child. The following quotes provide evidence of parent satisfaction:

> *Like I said before, [diagnostic clinic] has been absolutely great as a whole as an organization. They've provided us with more than enough documentation and sheets and just ideas of things to help [Son]. That's been really great, it is a little overwhelming to have so much things to read but that's been a great thing. Any time we've dealt with them…They have tended to go over and above I think like a normal doctor's office who would just call you and say, "You have an appointment tomorrow." They send out letters. If you have an issue with something like we have an issue with a bill, we were able to contact them and have somebody get that resolved for us. They've really been good throughout this process. Participant 24*

> *…When we went to the psychologist [psychologist's name], he was really thorough in what he did. It was really a positive experience because at the time it was so depressing what was going on and he kind of just put us at ease and he did take the time and probably a really good experience as a later process. Participant 30*

4.2.3.2 Dissatisfaction

A few parents described dissatisfaction with their interactions with providers, especially occurring during the initial interactions with their primary care providers. Parents described how they felt providers were not helpful, did not listen to them, were dismissive of their concerns, and/or did not spend enough time with the parent. Parents also expressed dissatisfaction when they felt they had waited too long for the diagnosis. Finally, several parents discussed how testing procedures used to diagnose the child with ASD were not always age-appropriate or sensitive to the child's daily schedule and this resulted in dissatisfaction for some parents. The following quotes provide evidence of parent dissatisfaction:

> *…the very first development pediatrician I saw, I was absolutely disgusted with that exam. I paid out of pocket because we hadn't met our deductible. It was a lot of money, a lot of inconvenience traveling, and he asked my son three questions. He asked him what his name was, he asked him to count, and can you say A,B,C or something. Those were the three questions. My son rapid-fire did all of those things. Basically, he said, based on that, he was fine developmentally, which I just thought was stupid. Participant 16*

> *I am still kind of bitter about the testing parts of it because I feel like if he went back today after this therapy that he wouldn't even be as severe as they are trying to say he is.. Participant 9*

4.2.3.3 Positive emotional outcomes

Several parents discussed positive emotions that were associated with learning about their child’s diagnosis. Some parents expressed relief and happiness that their concerns were heard and/or their child was diagnosed. One parent specifically addressed her appreciation for being given time to adjust to the diagnosis and coming to the realization that she was not a bad parent. Another parent discussed the shame in having a child with behavioral difficulties and how she no longer felt that when her child was diagnosed with ASD and they received support. One parent talked about how she appreciated being reassured by providers that she was doing a good job as a parent. Several parents discussed how they appreciated when providers were sensitive to the emotional impact of the diagnosis on the entire family and on the parents in particular. This sensitivity to the functioning of the family was also found in providers who understood the demands of the parents’ work schedule or caring for other children in the family, both those with typical development or those with special needs. Positive emotional outcomes are demonstrated in the quotes below:

> *Well, until really like we had a name, it was just kind of ... You know, like shameful. Like, oh yeah, she's not doing all she's supposed to at this age, it must be us. And we're trying to do everything we can possible, to get her to be normal or whatever you know, to just be like the other kids and it's just not working no matter what we're trying, you know. And so that was really, really hard, so ... we're finally like, finally we have a name and then we have support and now she's coming out of her shell and she's blooming, and blossoming and it's so ... amazing, the difference. Participant 4*

> *We have a very complex family right because we have three kids with disabilities. It's overwhelming and it's complex and it's very challenging. She [pediatrician] was phenomenal about asking about the other children and thinking about how everyone interacts with one another, what the support system is in place for me as well as for the siblings being impacted by [child’s] behaviors. I thought that she really understood our family. Participant 1*

4.2.3.4 Negative emotional outcomes

For some parents, feelings of worry, guilt, and frustration emerged when parents discussed their communication interactions with providers. Parents described the worry and guilt they felt that their child did not receive services earlier and frustration with long wait times that further delayed diagnosis or intervention. One parent discussed the guilt she felt in not being always being ready with questions for the providers. Parents also discussed feeling overwhelmed by the information they received and balancing that with the emotions of their child being just diagnosed with ASD. One parent, who had an older child previously diagnosed with ASD, discussed the sadness and frustration of meeting the same barriers again in the diagnosis of the second child. Negative emotional outcomes are demonstrated in the quotes below:

> *Just worried because I have seen the power of Early Intervention. I was seeing enough signs where I was just very, very anxious to get started with that intervention. I think that as parents we absolutely can over worry about a lot of different things. I know for sure I spent a lot of nights on Google when I should not be searching random weird spots and what not. I was pretty sure something was up with [child] so it was a bit of a nagging concern. Participant 1*

> *I mean, sad and then frustrated because it was the same ... my older son has autism already, so he [family practice physician] did the same thing with him, so we were hoping he would kind of believe it, I guess, more and be more helpful and maybe push us in the right direction instead of messing around and try to do it by ourselves. Participant 14*

4.2.4 Summary of Other Elements Explored in the Conceptual Model via Qualitative Methods

4.2.4.1 Sociodemographic characteristics- health care providers

Parents talked about seeing a variety of health care providers during the process of obtaining a diagnosis of ASD for their child. Most parents discussed interactions with their primary care providers, which included pediatricians, family practice doctors, and nurse practitioners. Additionally, parents talked about interacting with psychologists, neurologists, psychiatrists, and developmental pediatricians- mostly in the process of obtaining a diagnosis for their child, as well as speech, occupational, physical, or behavioral therapists or social workers who provided services or therapy. Many parents talked about interactions with community-based services like their local Early Intervention program or home health nurses.

4.2.4.2 Parent initial concerns and actions taken

The major concerns identified by parents related to their child's development were delayed speech, behavioral issues, sensory issues, developmental regression, and repetitive behaviors. Many parents also discussed how they noticed differences in their child compared with other children of similar ages or compared with their siblings. All parents noted they were the first to identify the concerns about their child's development and were able to easily identify what areas first alerted them to concerns about their child's development.

The primary action taken by parents when they identified concerns about their child's development was to seek out advice from a variety of professionals and sources, though most parents mentioned first connecting with their primary health care providers, generally during regularly scheduled well child visits. Some parents also noted seeking advice from family members, other parents, or other health care professionals, such as speech or occupational therapists. Many parents also sought out Early Intervention services after identifying concerns about their child's development. Other actions taken included conducting searches on the Internet to get more information, reading books about ASD, or consulting community resources, such as non-profit centers, for more information or guidance.

4.2.4.3 Provider reaction to parent concerns

When parents first brought concerns about their child's development to their health care providers, parents noted mixed reactions by the providers. Some parents noted their providers were dismissive of their concerns or took a "watch and wait" approach in which parents were asked to monitor the child's development until the next visit or for a specified period of time. Other parents reported positive and affirming responses from providers when they expressed their concerns about their child's development. Many of these parents were then referred on to a diagnosing provider such as a psychologist or developmental pediatrician, therapists in speech, occupational, physical, or behavioral therapy, and/or to Early Intervention services. Some parents reported receiving both affirmative and dismissive responses to their concerns with various providers. Descriptions of provider reactions are included in the following quotes:

> *It was a positive feeling that the doctor didn't want to beat around the bush or, "Oh, let's just give it another six months and see. Maybe she'll start to open up a little more."…We jumped on it right away. Participant 23*
>
> *With my pediatrician when we discussed things I felt like a lot of things that I mentioned to him he kind of chalked up as, "Well, kids do that," or "Kids will be that way," or "You're a first time parent so you're worried," and you know, those kinds of things that were dismissive...Participant 27*
>
> *We brought it up at his next appointment with his pediatrician, and she agreed it was something to follow up on and keep an eye on. But, she also said that he was younger and it was going to be really hard to identify whether it was a learned behavior from his older brother or whether it was a specific behavior towards him. So, at that point it was just a recommendation to just wait, to keep an eye on things, and then we would follow up. Participant 26*

4.3 Quantitative Results

Summaries of the parent perceptions of the key elements of communication are shown in Table 5. About half of parents reported receiving all five key elements of communication (54.8%, n=17), while 25.8% (n=8) reported receiving three or four, and 19.4% (n=6) reported receiving less than three. Although the majority of parents reported "usually" or "always" receiving each of these five key elements of communication from their health care providers, the highest percent of parents reporting "usually" or "always" was for the element regarding the provider being sensitive to the family's values and customs (96.8%, n=30). The lowest percent was for the element regarding the parent reporting getting information needed from the provider (67.7%, n=24).

Table 5. Parent Perceptions of Key Elements of Communication using the National Survey of Children's Health (n=31).

Key Element	**N (%)**
How often child's doctors and other health care providers spend enough time with him/her	
Never	3 (9.7)
Sometimes	5 (16.1)
Usually	14 (45.2)
Always	9 (29.0)
How often child's doctors and other health care providers listen carefully to parent	
Never	3 (9.7)
Sometimes	5 (16.1)
Usually	9 (29.0)
Always	14 (45.2)
How often were child's doctors and other health care providers sensitive to family's values and customs	
Sometimes	1 (3.2)
Usually	8 (25.8)
Always	22 (71.0)
How often did parents get specific information you needed from child's doctors and other health care providers	
Never	2 (6.5)
Sometimes	8 (25.8)
Usually	13 (41.9)
Always	8 (25.8)
How often did child's doctors or other health care providers help parent feel like a partner in child's care	
Never	2 (6.5)
Sometimes	6 (19.4)
Usually	9 (29.0)

Always	14 (45.2)
Number of key elements parents report "usually" or "always" receiving from health care providers	
0	1 (3.2)
1	3 (9.7)
2	2 (6.5)
3	4 (12.9)
4	4 (12.9)
5	17 (54.8)

Data related to parent mental health characteristics (stress and PHQ-4) are summarized in Table 6. Parents reported an average stress level during the diagnostic process of 3.06 (SD=.89) on a four-point Likert scale with score of 1 indicating the process was not at all stressful to 4 indicating the process was very stressful. When looking at percentages, most parents reported the time of diagnosis of ASD for their child as quite stressful or very stressful (71.0%, n=22). Parents reported a mean value on the PHQ-4 of 6 (25th and 75th Interquartile Range: 2, 8), a score that represents moderate symptoms of depression or anxiety. When looking at percentages of parent responses by categories representing symptoms of anxiety and depression, over half of parents reported experiencing moderate to severe symptoms of depression and anxiety during this same time (54.8%, n=17).

Table 6. Parent Mental Health Characteristics during the Time of Diagnosis (n=31).

Mental Health Characteristic	Mean (SD)
Parental Stress Overall Score	3.06 (.89)
	N (%)
Not At All Stressful	1 (3.2)
Not Very Stressful	8 (25.8)
Quite Stressful	10 (32.3)
Very Stressful	12 (38.7)
	Median (25th and 75th Interquartile Range)
PHQ-4 (Anxiety and Depression) Overall Score	6 (2, 8)
	N (%)
No Symptoms of Depression or Anxiety	8 (25.8)

Mild Symptoms of Depression or Anxiety	6 (19.4)
Moderate Symptoms of Depression or Anxiety	12 (38.7)
Severe Symptoms of Depression or Anxiety	5 (16.1)

Associations of parent reports of the child age when they first identified concerns in their child's development with when their child received a diagnosis of ASD, parental stress, parental anxiety/depression, and the number of key elements of communication parents reported receiving are shown in Table 7. A statistically significant inverse correlation was observed between parent reports of the number of key elements of communication and reported stress ($r_s = -.43$, $p=0.016$). That is, as the number of elements decreased, reported stress increased. There was also a statistically significant positive correlation between parental stress and symptoms of anxiety and depression as measured on the PHQ-4 ($r_s = .74$, $p < 0.001$). No other statistically significant correlations were identified ($p > 0.05$).

Table 7. Spearman Correlations between Elements of Communication and Parent Mental Health Characteristics (n=31).

Characteristic	**Number of Elements of Communication**	**Time From Concerns to Diagnosis**	**Parental Stress**
Time From Concerns to Diagnosis	.04 (0.838)	-	-
Parental Stress	-.43 (0.016)	-.01 (0.970)	-
PHQ-4	-.17 (0.364)	-.06 (0.740)	.74 (< 0.001)

Note: Values in the cells are r_s (p-value)

Summaries of the percentage of parents reporting receipt of all elements of communication using a dichotomous variable (i.e., reported receipt of elements of communication versus did not report receipt of elements of communication) by various sociodemographic characteristics are shown in Table 8. While none of the differences were statistically significant, all male parents (n=3) reported receipt of all elements of communication (100%) compared with only 50% of the female parents (n=12 of 23, $X^2_{(df=1)}$ = 2.74, p=.098).

Table 8. Percentage of Parents Reporting Receipt of Elements of Communication by Parent Sociodemographic Characteristics (n=31).

Characteristic	**Reported Receipt of Elements of Communication**	**Did Not Report Receipt of Elements of Communication**	**Pearson Chi-Square (p-value)**
	n (%)	n (%)	
Parent Race			.613
White (n=23)	12 (52.2)	11 (47.8)	
Other (n=8)	5 (62.5)	3 (37.5)	
Parent Gender			.098
Female (n=28)	14 (50.0)	14 (50.0)	
Male (n=3)	3 (100.0)	0 (0.0)	
Income			.200
<$50,001 (n=15)	10 (66.7)	5 (33.3)	
>50,0001 (n=16)	7 (43.8)	9 (56.3)	
Parent Education			.518
<Associate’s or Bachelor’s Degree (n=10)	6 (60.0)	4 (40.0)	
Associate’s or Bachelor’s Degree (n=13)	8 (61.5)	5 (38.5)	
Master’s Degree or Higher (n=8)	3 (37.5)	5 (62.5)	

Note: Used approximately 200% of Federal Poverty Level cut-off ($50,001) for a family of four to create dichotomous income variable.

4.4 Convergence of Qualitative and Quantitative Findings

In mixed methods research, it is important to integrate the findings from both methods in order to draw conclusions related to the significance of the findings (Johnson & Onwuegbuzie, 2004). Table 9 below presents the study results uncovered through qualitative and quantitative methods in order to help demonstrate the data obtained from both methods that were then integrated in order to discuss study results. Although qualitative interviews were the dominant method used in this study, the findings from these interviews were corroborated by results obtained through the administration of quantitative surveys to the parents.

The first section in Table 9 lists the facilitators and barriers to the communication process. These elements of the communication process were explored through the qualitative interview questions asked regarding the key elements of communication and specific facilitators and barriers that parents could identify in the diagnostic process, as well as through the administration of a quantitative survey exploring similar elements. The results of the quantitative survey show the percentage of parents reporting the receipt of particular elements (i.e., provider spends time with the parent; provider elicits concerns and listens carefully; provider is sensitive to the family's values and customs; parents report getting needed information; and parents feel like partners in the care of their children), while the qualitative interviews uncovered details related to specific facilitators and barriers related to each element to elucidate reasons why parents responded the way they did to the quantitative survey questions.

Looking at other elements in Table 9 below, the theme of direct and indirect communication was not explored in a quantitative survey question, but rather only uncovered through the qualitative interviews with parents. Meanwhile, the other themes of parents reporting long wait times, delays in diagnosis, and financial and insurance issues were explored through open-ended questions in the qualitative portion of the study, as well as more directly through survey questions asking about the time for the delay in diagnosis and household income. Outcomes of the communication process were initially identified from interview questions related to facilitators and barriers and include parent satisfaction or dissatisfaction with the communication process and emotional reactions (both positive and negative) to the process. The quantitative portion of the study uncovered the percentage of parents reporting receipt of the key elements of communication, as the questions comprising this outcome were asked through survey questions. This outcome was further explained in the qualitative arm through the answers parents provided to interview questions that specifically explored parents' perceptions related to how they experienced each of the key elements of communication.

Table 9. Results Related to Themes Based on Qualitative and Quantitative Methods.

Theme		
Communication Process	Qualitative Method	Quantitative Method
Elicits Concerns and Listens or Not Listening	Facilitators - Provider open and sensitive to concerns, answer questions, clarify what was heard -Not feeling alone -Feeling listened to -Provider making eye contact, asking questions, taking notes, validating concerns, not interrupting parent Barriers -Feeling like concerns were not heard or doubted -Provider talking over parent -Delay in diagnosing ASD due to provider not listening	-74.2% report "usually" or "always" provider listening
Sensitive to Values and Customs	Facilitators -Provider respectful	-96.8% report "usually" or "always" provider sensitive to values and customs
Knowledgeable and Gives Information or Lack of Knowledge and Information Given	Facilitators -Receiving variety of information from provider, including next steps in the care of their child, referrals, visit summaries Barriers -Lack of provider knowledge around ASD -Lack of information received at each step in the diagnostic	-67.7% report "usually" or "always" getting needed information from providers

	process	
Treats Parent as Partner or Not Trusting Parent as Expert in Care of Child-Not Treating Parent as Partner	Facilitators -Provider giving information on things to try with child -Provider checking in with parent Barriers -Parent not feeling trusted as expert or partner in process -Wishing provider would take concerns seriously -Relying solely on provider for next steps and no parental involvement in decisions -Parent feeling need to find right words to communicate with providers	-74.2% report "usually" or "always" provider helping parent feel like partner
Enough Time or Not Enough Time	Facilitators - Provider spends time with parent despite busy practice setting -Provider gives parent time to fully explain concerns and not rush parent Barriers -Not enough time in busy setting to spend with parent or discuss concerns -Visits feel rushed	-74.2% report "usually" or "always" provider spending enough time with parent
Direct Communication or Indirect Communication	Facilitators - Provider able to communicate directly with parent -Provider communicates with each other about care of child Barriers -Provider not able to speak directly with parent -Provider not able to speak directly with each other	-Not explored with method
Long Wait Times/Delay in Diagnosis	Barriers -Long wait times for diagnosis	-Time from concerns to diagnosis: mean=1.9 years (SD=1.3 years, range 0.3- 5 years) -No significant relationship between time from concerns

		to diagnosis and elements of communication
Financial and Insurance Issues	Barriers -Financial barriers to receiving care -Insurance issues with payment for diagnostics or treatment	-Roughly half of parents (48.3%) report household income less than $50,001 -Majority of children on private insurance (51.6%), followed by public insurance (35.5%)
Outcomes	Qualitative Method	Quantitative Method
Satisfaction/Dissatisfaction	Satisfaction -Genuine support and help from provider -Positive communication interactions -Affirmative and supportive of parent concerns Dissatisfaction -Provider not helpful, did not listen, dismissive of concerns, or did not spend enough time -Dissatisfaction with long wait times for diagnosis and testing procedures that were not age-appropriate	-Not explored with method
Emotional Reactions to Process of Obtaining Diagnosis	Positive -Relief and happiness -Appreciation of reassurance and sensitivity to emotional impact of diagnosis Negative -Worry and guilt -Overwhelmed -Sadness and frustration	-71% parents report process "quite stressful" or "very stressful" -54.8% report experiencing moderate to severe symptoms of depression and/or anxiety -Significant, inverse correlation between parent report of receipt of elements of communication and parental stress (r_s=-.43, p=.016)
Elements of Communication	*Explored through questions about whether or not provider spends time with the parent; provider elicits concerns and listens carefully; provider sensitive to the family's values and customs; parent reports getting needed information;*	-54.8% report "usually" or "always" receiving all five elements of communication -Significant, inverse association between parent reports of the number of elements of communication received and parental stress

	and parent feels like a partner in the care of their child which led to subthemes noted above related to facilitators and barriers	(p=.016) -No significant relationship between elements of communication and the following measures/variables: 1) parent race, 2) parent gender, 3) parent income, 4) parent education, 5) PHQ-4 (symptoms of depression and anxiety), and 6) time from concerns to diagnosis.

4.5 Revised Conceptual Model

Together, the results from the qualitative and quantitative arms led to revisions to the conceptual model initially developed for this study (see Figure 2, page 33, for initial model and Figure 4, page 82, for revised model). Since the qualitative arm of the study was the dominant method, the majority of the revisions in the model resulted from the qualitative arm of the study, while only a few revisions resulted from the quantitative arm.

The major themes resulting from the qualitative arm contributed most to the changes in the study's conceptual model, resulting in a revised model that now includes a communication process from the parents' perspective that is influenced by both facilitators and barriers related to provider or system factors. Outcomes were also added to the model and include parent satisfaction or dissatisfaction with the communication process and emotional reactions (both positive and negative) to the process from the qualitative results, along with parental report of receipt of key elements of communication from the quantitative results. Due to the fact that the quantitative arm of the study was based on a relatively small sample size, no parental sociodemographic, personal, or mental health factors, or contextual factors explored through the quantitative method were removed from the initial conceptual model for lack of significance in this study. Instead, the factor (i.e., stress) that was found to have significant associations with the key elements of communication was highlighted in bold in the model.

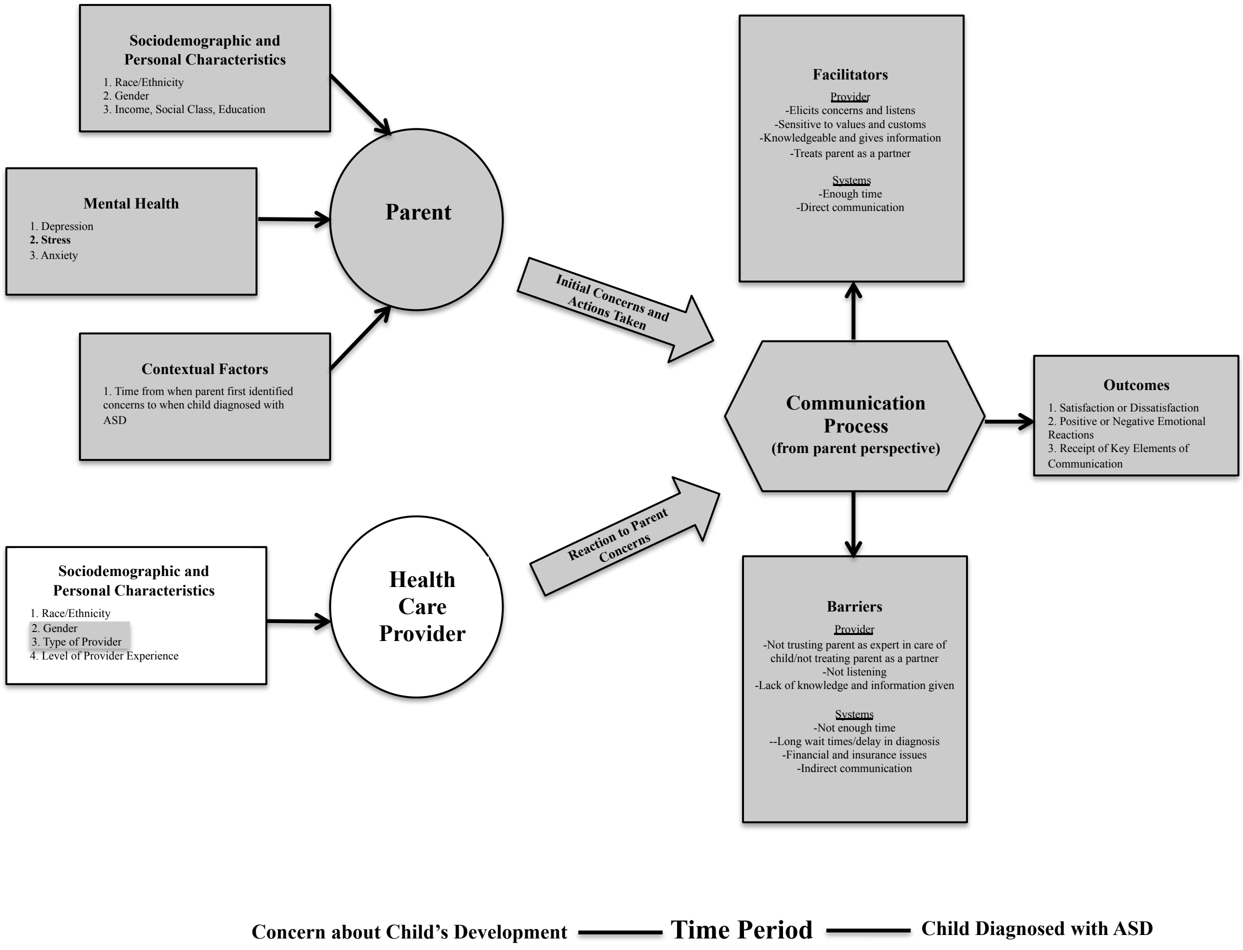

Figure 4. Revised Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis.

The organization of the model was also modified from its original design to better reflect the study's major findings. On the left side of the model, parents, providers, and the factors that have been noted through previous research and theory to influence the communication process are located (i.e., sociodemographic and personal characteristics for parent and provider, parent mental health characteristics, and contextual factors). Characteristics that are highlighted in gray represent those items explored in this study. The item “Stress” in bold under the parental mental health characteristics was shown through the quantitative arm of the study to be significantly related to the key elements of communication. The parent and health care provider still come together in the revised model at the communication process, but the addition of the arrows from the parent and provider pointed towards the communication process indicate that the parent brings forth initial concerns through some type of action and the provider reacts to those concerns.

In the communication process that is in the center of the model, the overarching themes of facilitators and barriers at the provider and systems level as identified through the qualitative arm of the study are presented with the subthemes derived from the study. The provider level indicates that it is an issue that pertains to the provider and provider’s behavior in the communication interaction, while the systems level refers to issues that occur within health care systems, such as clinics or treatment settings, that affect the communication process. Facilitators at the provider level include the following provider characteristics: 1) elicits concerns and listens; 2) sensitive to values and customs; 3) knowledgeable and gives information; and 4) treats parent as a partner. Barriers at the provider level include the following: 1) not trusting parent as expert in care of child/not treating parent as a partner; 2) not listening; and 3) lack of knowledge and information given. Facilitators at the systems level include the following: 1) enough time; and 2) direct communication. Barriers at the systems level include the following: 1) not enough time; 2) long wait times/delay in diagnosis; 3) financial and insurance issues; and 4) indirect communication.

The model concludes on the right side with the addition of outcomes related to parent satisfaction or dissatisfaction with the communication process and parents’ positive or negative emotional reactions to the process as identified through the qualitative arm of the study, and parents' reports of receipt of the key elements of communication as identified through the quantitative arm of the study. The time period that this model represents is noted at the bottom of the figure as extending from when initial concerns are identified about the child's development to the actual diagnosis of ASD for the child.

CHAPTER 5

DISCUSSION

5.1 Meaning and Significance of Findings

This study successfully identified key elements of communication with health care providers during the diagnostic process for ASD. This study is unique because it explored perceived communication between parents and providers from a mixed methods perspective in order to both describe and explore the communication process that occurs during the diagnostic period. This study differs from previous studies because it examined the perceptions of parents both closer to the time in which their child received a diagnosis of ASD (within the past 12 months) and in a sample of U.S. parents of children who were six years or less in age.

One of the study's subquestions specifically identified perceived facilitators and barriers to the communication process that occur at both the provider and systems levels. Some of the facilitators and barriers identified in this study are similar to past studies (e.g., Abbott et al., 2013: Osborne & Reed, 2008; Sansosti et al., 2012: Tait et al., 2016" Wong et al., 2017). For example, parents reported wishing they had received more information from providers, wanted more time with providers, and experienced frustration with long wait times and financial/insurance issues, but parents also reported being listened to by providers, had their concerns elicited, were able to engage in direct communication with providers, and felt respected.

On the other hand, some study findings are unique compared with previous studies. These unique findings include parents reporting specific ways in which they felt like a partner in the care of their child (i.e., being given suggestions on care for their child at home, checking in with the parent, and asking parents' opinions about next steps). No previous study was identified that specifically described how parents felt like partners in the care of their child. In contrast to other recent studies (e.g., Chao et al., 2017; Wong et al., 2017), parents also reported a shorter delay from when they first expressed concerns about their child to a diagnosis of ASD. This shorter delay was not related to parental reports of stress, either higher or lower, as was found in previous studies (Reed, Picton, Grainger, & Osborne, 2016; Wong et al., 2017). Findings in this study also uncovered high levels of stress, anxiety, and depression in parents of children with ASD. Although previous studies have described stress in parents of children diagnosed with ASD (Costa et al., 2017; Crane et al., 2016; Osborne et al., 2008; Siklos & Kerns, 2007), this study found a significant association between parents reporting higher levels of stress and receiving fewer key elements of the communication process. This study is also the first known to specifically identify elements of the communication process, including facilitators and barriers and the relationship between parental factors and the receipt of key elements of communication, and those elements are discussed in detail below.

5.1.1 Facilitators and Barriers to the Communication Process

Parents identified a variety of facilitators and barriers to the communication process. These facilitators and barriers were identified at the provider and/or systems level. The identified facilitators and barriers are discussed in detail below.

5.1.1.1 Elicits Concerns and Listens

In alignment with previous studies (Abbott et al., 2013; Braiden et al., 2010; Guerrero et al., 2010; Guerrero et al., 2011; Halfon et al., 2004), parents in the present study felt providers elicited their concerns about their child's development and listened to them. Only a few parents reported that providers were dismissive of their concerns. Conversely, some parents in the present study reported not feeling listened to during the diagnostic process. Hidalgo, McIntrye, & McWhirter (2015) also found parents reported challenges with health care providers (most frequently pediatricians) not listening to or validating parent concerns. The findings from the present study, coupled with others, support the importance of providers eliciting concerns and listening to the parent as a key element of communication during the diagnostic process for ASD. These simple actions by providers (i.e., eliciting concerns and listening) have the potential to greatly enhance the communication process during this time period.

5.1.1.2 Provider Sensitive to Values and Customs

Most parents reported feeling that providers were sensitive to their values and customs. Parents in the present study primarily described this sensitivity as the provider treating the parent with respect. Similarly, a survey conducted in the U.K. by Hackett, Shaikh, and Theodosiou (2009) regarding the ASD diagnostic experience found that all parents felt they were treated with respect. Providers demonstrating respect for the parent may be one of the ways in which parents feel provider sensitivity to their values and customs.

5.1.1.3 Knowledgeable and Gives Information

Although some parents in the present study specifically commented on how impressed they were with provider knowledge and the information they received from providers, some parents also reported concerns about the relative level of provider knowledge about ASD and listed specific information they wished they had received during the diagnostic process, similar to the findings of Sansosti et al. (2012). A survey by Golnik, Ireland, and Borowsky (2009) found pediatric and family practice doctors reported a low level of competency and a need for more education related to caring for children in primary care with ASD. Sansosti et al. (2012) found that parents were more satisfied with information received from providers who had special training in ASD. Therefore, interventions to target provider knowledge around diagnosis, early intervention, treatment, and support services for ASD may be warranted to increase provider knowledge and possibly also parent satisfaction.

Similar to other recent studies (e.g., Crane et al., 2016: Tait et al., 2016; Wong et al., 2017), parents in this study discussed the lack of information they received from professionals about ASD and next steps for their child. Parents reported they wanted information about such things as support groups, social services, and therapies, which is in alignment with findings in other studies (e.g., Osborne & Reed, 2008; Tait et al., 2016). On the other end of the continuum, a few parents discussed feeling overwhelmed at times with the information they received. This finding is similar to what Abbott et al. (2013) found in their qualitative interviews of parents of children diagnosed with ASD. It is important for providers to balance the amount and type of information provided to parents based upon parental readiness. One solution may be the use of things such as a checklist with essential steps to take following diagnosis, as recommended by one parent in the present study.

5.1.1.4 Treats Parent as a Partner

The majority of parents reported feeling like a partner in the care of their child, though some felt they were not valued as the expert on their child's development, similar to a previous study by Magana et al. (2015). Parents in the present study described the following specific ways in which they felt like a partner in the care of their child: 1) providers giving parents suggestions on what they could do at home to help the child, 2) providers checking in with parents about whether or not these suggestions were appropriate for the child and family, and 3) providers asking parents' opinion about next steps for the child in terms of treatment, therapies, or referrals. Conversely, a few parents also discussed their concerns about not being treated like experts in the care of their child or a partners in the diagnostic process, which is similar to the findings of a recent, large U.S. survey (Magana et al., 2015). Providers may be able to engage in simple steps described by parents in the present study, such as checking in with the parent and asking the parent's opinion, as a means of helping the parent feel like a partner and/or the expert on their child.

5.1.1.5 Enough Time

Parents had mixed feelings about the adequacy of the amount of time they had in the health care setting to interact with providers. Some felt they had adequate time, while others discussed feeling like they did not have enough time to talk with providers, especially primary care providers, which is similar to the findings in Sansosti et al. (2012). Several parents felt this lack of time was due to the busy nature of the health care system in the U.S. The importance of the parents feeling like they have the opportunity to spend enough time with providers represents a simple strategy that could aid the communication process and result in positive outcomes for parents and their children with ASD. Although it is difficult for an individual provider to change systems issues, support for policies that provide enhanced reimbursement for health care providers for time spent communicating with and counseling parents could be a step in the right direction in order to incentivize providers to spend more time with parents.

5.1.1.6 Direct Communication

Parents discussed how they appreciated opportunities to communicate directly with health care providers about their concerns, rather than communicate with them through a complicated series of phone calls or through other health care staff (e.g., nurse or administrative staff). Parents also discussed how beneficial it was for providers to be able to communicate among each other in order to coordinate the child's care, similar to the findings in Osborne and Reed (2008). Despite systems challenges preventing direct communication, providers can help advocate for policies that support time spent communicating with parents, as well as the role of care coordination and enhanced reimbursement for these services. Such advocacy may result in care that is more coordinated and in the parents feeling like providers are working together to support the development of the child.

5.1.1.7 Long Wait Times/Delay in Diagnosis

Parents described delays in the diagnosis of ASD for their child and long wait times for appointments, which presented as barriers to care. Findings in the present study indicate that there was an average delay of 1.9 years (SD=1.3 years, range 0.3-5.0 years) from the time parents first reported concerns about their child's development to when the child received a diagnosis of ASD. Recent studies have found longer delays. For example, Chao et al. (2017) found an average delay in diagnosis of 3.19 years (SD=2.75 years, with range of 1-9.5 years) and Wong et al. (2017) found an average of 28.72 months (SD= 27.12 months, range of 0-127 months). The lower average delay in this present study may represent better identification of ASD due to improved screening practices by health care providers that resulted in children being identified and referred earlier for diagnosis. There may also be better resources in the community for diagnosing and treating ASD that led to a shorter delay. It is also possible that children in the present study were more severely delayed than those in past studies, thereby potentially resulting in a faster diagnosis since providers may have seen more obvious signs of ASD.

No relationships were found in this study between the delay in diagnosis of ASD and other parental characteristics (i.e., demographics, stress, depression, or anxiety), nor receipt of the key elements of communication. In contrast, a recent study by Reed, Picton, Grainger, and Osborne (2016) found that mothers of children recently diagnosed with ASD reported more stress with shorter delays. Meanwhile, Wong et al. (2017) found that a longer delay was associated with lower parental reports of contextual social support (defined as “support from other families within the ASD community and professionals providing support to children with ASD”, p. 198), general social support (defined as “perceived social support”, p. 198), and parent physical health. Although the present study did not identify any significant relationships between the delay in diagnosis and parental characteristics or receipt of key elements of communication (potentially due to the shorter delay in diagnosis reported in this study or the small sample size), it is important to note that either a short or long delay in diagnosis may have an effect on parents’ mental and physical health and perceived support based on the results of previous studies. Providers may be able to demonstrate sensitivity to the effects of a delay in diagnosis on the parent by providing emotional support or referrals for further screening, diagnosis, and/or treatment for parental mental or physical health issues that may arise during this period. In addition, providers may want to refer parents to community resources, such as parent support groups, in order for parents to receive social support.

Through interviews, parents also expressed concern about the long wait times they encountered to receive a diagnosis of ASD for their child, which is in alignment with the long wait times reported by a high percentage (70%) of parents in Wong et al. (2017). Interestingly, studies conducted in other countries have found lower percentages of parents reporting long wait times for diagnosis (Kennan et al., 2010: Osborne & Reed, 2008). Although it is not clear why these differences in wait times across countries exist, it is possible that the multitude of insurance plans under which individuals are covered in the U.S. may result in some families experiencing longer wait times for diagnosis in contrast to single payer systems that exist in other countries.

Additionally, many parents in the present study expressed concerns whether the wait impacted their child's subsequent development potential. The results of the present study suggest it may be important for providers to recognize and act on parent concerns in a timely manner in order to help achieve the goal of prompt diagnosis and intervention for ASD. Timely diagnosis may help ensure children receive quick access to services such as Early Intervention, which may ameliorate the lifetime effects of developmental delays (Council on Children with Disabilities, 2006), and also to alleviate parent concerns about the potential effects of the delay on the child's subsequent development.

5.1.1.8 Financial and Insurance Issues

Parents reported financial and insurance coverage issues during the diagnostic process that presented barriers to care, similar to a recent study by Hidalgo et al. (2015) also exploring the ASD diagnostic process. In particular, parents in the present study noted frustration when the communication process with the provider was less than ideal due to the financial expense to see a certain provider. It is important for providers to be aware of the financial and insurance barriers parents experience. Although these barriers may not be something the provider can directly fix, providers could refer parents to alternative resources in the community for more affordable diagnosis or treatment when financial or insurance barriers are present for the parent and/or the child.

5.1.2 Parental Factors and Receipt of Key Elements of Communication

Quantitative findings from the study uncovered parental mental health issues, including stress, anxiety, and depression. The study also found a relationship between parental stress and the receipt of key elements of communication.

5.1.2.1 Parent Mental Health

Parents reported high levels of stress during the diagnostic process. A significant, inverse relationship was found between the level of parent stress during the diagnostic process and the number of reported elements of communication received, highlighting the potential impact parent stress may have on the communication process with providers. Previous studies have explored stress in parents of children undergoing diagnosis or having received a recent diagnosis of ASD and have similarly found high levels of stress (Costa et al., 2017; Crane et al., 2016; Osborne et al., 2008; Siklos & Kerns, 2007). Providers should be aware of the stress parents of children with ASD may experience, even before the child is formally diagnosed, in order to provide support to parents at the various stages of diagnostic process.

Parents in this study also reported moderate to severe symptoms of depression and anxiety during the diagnostic process. The relationship between parents' anxiety or depression and the child's diagnosis of ASD has only recently been explored in studies to date (Cohrs & Leslie, 2017; Lai, Goh, Oei, & Sung, 2015). For example, Lai, Goh, Oei, and Sung (2015) found that Asian parents of children with ASD reported more stress and depression compared with parents of children with typical development, but there was not any significant difference in parent report of symptoms of anxiety. Cohrs and Leslie (2017) discovered both mothers and fathers in a large U.S. sample had higher odds of depression when their child was diagnosed with

ASD compared with parents of children without ASD. Since the present study and others have found symptoms of anxiety and depression in parents of children diagnosed with ASD, it is important for providers to recognize and talk with parents about the potential effect an ASD diagnosis may have on a parent's mental health and to help parents get needed support and treatment during this time.

5.1.3 Other Findings

Although previous studies have explored parent satisfaction with the diagnostic process (e.g., Abbott et al., 2013; Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012; Siklos & Kerns, 2007, Wong et al., 2017), this study identified not only the level of satisfaction, but other communication process outcomes from the parents' perspectives (i.e., positive and negative emotional reactions and receipt of key elements of communication). Similar to previous research (Adelman & Kubiszyn, 2017; Sansosti et al., 2012: Wong et al., 2017), this study uncovered parents' initial concerns related to their children's development, actions taken by the parent, and providers' responses to parents' concerns. Discussion on outcomes of the communication process, as well as parents' initial concerns, actions taken, and providers' responses are detailed further in the sections below.

5.1.3.1 Satisfaction

Parents in the present study generally reported that they were satisfied with their communication with health care providers. Other studies have explored parent satisfaction with the diagnostic process for ASD with mixed results. For example, Abbott et al. (2013) specifically commented on the high satisfaction level of parents with a child diagnosed with ASD, while most studies to date have reported parent dissatisfaction with the diagnostic process

(Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012; Siklos & Kerns, 2007, Wong et al., 2017). Since most parents in the present study expressed satisfaction with the diagnostic process, it may be helpful to focus on what parents specifically described as actions by providers that resulted in reports of satisfaction. For example, parents reported they received genuine support and help from providers, they had positive communication interactions with providers, and that providers were affirmative and supportive of their concerns. As a result, it seems logical to encourage these actions by providers to enhance the communication process for parents of children undergoing diagnosis of ASD.

5.1.3.2 Positive and Negative Emotional Reactions

Parents in the present study discussed a mixture of positive and negative emotional reactions to the diagnostic process. Positive reactions ranged from being grateful and happy to feeling relief with having an official diagnosis, similar to the findings in Wong et al. (2017). One parent in the present study specifically described how having a label of ASD was a relief as it could help explain the behavior of the child. Previous studies have identified how the "label" of ASD may be beneficial for families (Mansell & Morris, 2004; Mitchell & Holdt, 2014), including providing parents with a better understanding of their child's condition and function, as well as a diagnosis to then receive resources and services. As ASD receives increased attention in the media and services become more available for children with ASD in communities, schools, and health care, it is possible that some of the stigma previously noted to accompany the label of ASD (Gray, 1993, 2002) may no longer be present. Indeed, Wong et al. (2017) commented on the potential impact increased media and public awareness around ASD may have on more recent parents' experiences related to the ASD diagnostic process and that parents may subsequently view an ASD diagnosis in a more favorable light than in years past.

Parents also described negative emotional reactions to the communication process such as guilt, sadness, and frustration, similar to findings in Abbott et al. (2013) where about a quarter of the families interviewed expressed anger about the length of time the diagnosis took. It is important for providers to explore the emotional reactions the parent may experience during the diagnostic process. The provider could use simple questions, such as asking the parents how they are doing, or how the family is functioning or holding together, to explore the parents' emotional reactions to the process and potentially intervene with recommendations or referrals for parent support.

5.1.3.3 Receipt of Key Elements of Communication

Parents reported as an outcome the receipt of key elements of communication, which were defined at the start of this study to include the receipt of the following five elements of family-centered care: provider spends time with the parent; provider elicits concerns and listens carefully; provider is sensitive to the family's values and customs; parents report getting needed information; and parents feel like partners in the care of their children. The survey on parent-provider communication found about half of parents reported "usually" or "always" receiving all five key elements of communication, which is similar to the percentage found in a study by Cheak-Zamora and Farmer (2015), who also used the same five elements to explore family-centered care in families of children with ASD. Additionally, the receipt of these elements was inversely related to parent reports of stress.

Since parents of children with ASD report less than ideal receipt of family-centered care and this is related to increased stress, providers may want to consider the potential effect a diagnosis of ASD for a child may have on the level of family-centered care parents perceive receiving. Providers can then use this knowledge to discuss with parents ways in which the provider can best spend time with the parent, elicit their concerns, listen, demonstrate sensitivity to the family’s values and customs, provide parents with needed information, and help them feel like a partner in the care of the child. Since the present study not only quantitatively explored the elements of family-centered care through standardized survey questions, but also qualitatively through interviews, the facilitators and barriers that parents identified in the study could be used to design interventions based on these elements to maximize the facilitators and minimize the barriers parents report receiving during the diagnostic process for ASD for their child.

5.1.3.4 Parents’ Initial Concerns and Actions Taken

All parents reported that they were the first to identify concerns about their child’s development that led them to take action. The concerns identified included the child having a speech delay, sensory or behavioral issues, or developmental regression, which are similar to those found in Wong et al. (2017). Parents in the present study reported taking a variety of actions when they identified concerns, namely accessing health care services, mostly through their primary care provider. Interestingly, a large number of parents also reported the use of Early Intervention services when they had concerns about their child’s development. National recommendations exist for the use of Early Intervention services for any child identified with concerns for a developmental delay (Council on Children with Disabilities, 2006), but previous research has shown only a small fraction of children with delays are receiving services (Rosenberg et al., 2008). The frequent use of Early Intervention services as noted by parents in the present study may point to a practice change with providers being more open to making referrals to Early Intervention, potentially due to expanded knowledge of the service. It is also possible that some of the public education campaigns around Early Intervention may have resulted in parents accessing this service for their child on their own when they identified concerns about their child's development.

5.1.3.5 Provider Reactions to Parent Concerns

Parents reported a variety of reactions from health care providers to their concerns. Most parents reported providers were positive and supportive of their concerns. A few parents discussed how some providers recommended a watch-and-wait approach, where the parent was to monitor the child's development for a period of time before a referral was made, similar to findings in a study conducted by Adelman and Kubiszyn (2017). Conversely, some parents discussed how providers were dismissive of their concerns, especially primary care providers who often were the first to hear the parents' concerns, similar to the findings in Sansosti et al. (2012). Brogan and Knussen (2003) found a positive, significant relationship between parents of children with ASD who reported professionals accepted their concerns about their child's development and their satisfaction with the diagnostic process. Therefore, the present study, along with others, point to the importance of providers acknowledging and supporting parent concerns and the potential for positive, supportive reactions to those concerns which could result in greater parent satisfaction with the diagnostic process.

5.1.4 Revisions to Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis

The results of the present study led to revisions in the Myers' Communication Process Model for Providers and Parents of Children with Autism Spectrum Disorders Undergoing Diagnosis (Figure 4, page 82). The revised model is strengthened in that it includes communication from the perspective of parents. The model also takes into account factors that precede the communication process that may influence the outcomes of the process. These factors include parental sociodemographic, personal, and mental health characteristics, contextual factors, parents' initial concerns, and actions taken by the parent. Another strength of the model is that it includes both facilitators and barriers to the communication process and how these influence the process to result in outcomes of parent satisfaction/dissatisfaction, emotional reactions, and parent report of the key elements of communication. Although the model includes factors related to the health care provider (i.e., race/ethnicity, gender, type of provider, level of experience), details related to these professionals and their perceptions were not fully explored in this present study with the exception of provider gender and type, which were collected during the interviews.

5.2 Strengths and Limitations of Study

This study included several strengths, namely the mixed methods design, the geographically diverse sample of parents from throughout the U.S., the recent time frame in which parents reported their child received a diagnosis of ASD (i.e., within the past 12 months), the young age of children who were the focus of the interviews (i.e., 18 months to six years of age), and the use of technology to recruit a geographically diverse sample of parents within the U.S. These strengths led to a study that not only described, but also provided some explanation for facilitators and barriers to the communication process between parents and providers. Limitations to the study included a small sample size, parents who, based on the recruitment sites used, were already connected to some type of resource, and less diversity in terms of parent race/ethnicity and gender. Instruments and study questions relied on parent-report only. Self-report may be associated with recall bias or influenced by social desirability. The study focus limited exploration of the communication process to the perspective of parents only. These limitations point to areas that could be explored in future replications of this study, such as conducting the study with a larger and more diverse sample, as well as collecting the perspective of providers.

5.3 Implications and Recommendations for Future Research

The results of the present study can be used to guide health care providers in the care they give to parents of young children undergoing diagnosis of ASD. In particular, the results highlight facilitators and barriers to the communication process during the diagnostic period and suggest potential ways in which providers may enhance the process from the parent's perspective.

The findings from the study were used to revise the study's initial conceptual model. This new model (Figure 4, page 82) has the potential to guide research and suggests possible areas for intervention around the diagnostic process for ASD in several ways. For example, findings from this study provide a list of facilitators and barriers to the communication process during the diagnostic process for ASD from parents' perspective. A future study could explore if these same facilitators and barriers exist from the perspective of a larger sample of parents with even more diverse sociodemographic backgrounds. Additionally, exploring the presence of these same facilitators and barriers from the perspective of providers would also be valuable.

The facilitators and barriers identified in this study could also be used to design educational interventions for parents and providers. For example, parents in the study commented on wanting more information about ASD from providers and that those providers often lacked knowledge about ASD. Interventions could be designed that educate providers on

ASD and local resources to refer families to and how to best communicate this information with families. The effectiveness of these interventions could be evaluated through some of the outcomes identified in this study, including parental satisfaction, emotional responses, and parent report related to receipt of key elements of communication. Additionally, studies could follow parents longitudinally to see if their perceptions of the communication process pre-, during, and post-diagnosis remain the same, worsen, or improve over time based on interventions like provider education around communication of an ASD diagnosis and referral.

Since this study focused on parents' characteristics and perceptions, future studies could be conducted to explore how demographic factors related to the health care provider, including provider race/ethnicity, type, gender, and level of experience, may influence the communication process. For example, parents could provide quantitative ratings of the communication process similar to what was done in this study and the results of these ratings could be correlated with provider demographic characteristics. The potential findings resulting from this study could then help identify providers based on demographic characteristics that may benefit from some type of intervention, namely an educational intervention, related to communication with parents about ASD. Another future study could also explore the perceptions of parents and providers simultaneously related to the how the communication process unfolds during a visit to provide insight into what is said between parents and providers and what each individual hears.

Since parents in this study reported experiencing symptoms of anxiety, depression, and stress during the diagnostic process and a significant relationship was found between parent stress and receipt of the key elements of communication, an intervention study targeting parenting stress or mental health broadly during the diagnostic process could be designed to further examine the potential effect of mental health issues on the communication process. For example, parents could be assigned to either a control group that receives standard care or a treatment group where they would undergo screening for mental health issues at the same time as their child is in the process of being diagnosed with ASD and referred for further treatment and care if needed. Both groups of parents could then be interviewed and surveyed similar to the methods used in this study regarding perceptions of communication at the end of the process to examine the potential effect of this screening and referral for mental health issues on parents' perceptions of communication.

In conclusion, further areas exist for exploration related to the communication process that occurs between parents and providers during the diagnostic process for ASD. This study's revised conceptual model provides a framework for those areas of exploration. With further research, the hope is that children with ASD receive timelier referral, diagnosis, and eventual treatment or intervention and that parents report outcomes such as satisfaction, positive emotional reactions, and receipt of the key elements of communication care as a result.

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APPENDIX A

Recruitment Flyer

Title: Study Exploring Communication with Parents and Health Care Providers

Has your child been diagnosed with autism spectrum disorder (ASD) in the last 12 months?

We are looking for parents whose child has been diagnosed with ASD in the last 12 months. We are conducting a study to learn more about parents' experiences communicating with health care providers during the time when their child was first identified with developmental concerns to when their child was diagnosed with ASD.

You may be eligible to participate if you:

1. are the parent of a child between the ages of 18 months-6 years who was diagnosed with autism spectrum disorder in the last 12 months.
2. are 18 years or older.
3. speak English.
4. are willing to be interviewed via phone or through videoconferencing. To interview via videoconferencing, you must have access to a computer with one of the following videoconferencing technologies: FaceTime, Google Hangouts, or Skype. The computer requires video and microphone capabilities and a high-speed Internet connection.

If you are interested and eligible to participate in this study, we will ask you to:

1. participate in one interview (via video-conferencing) that will last for about 30-60 minutes.
2. complete a short, online survey that will take about 10-15 minutes.

Participants who complete the interview and the survey will receive a $50 electronic Amazon gift card.

Please feel free to share this posting with other families you think might be interested in participating in the study.

If you are interested in participating or wish to receive more information, please contact:

Lynnea Myers, PhD(c), RN, CPNP at:
lynnea.h.myers@vanderbilt.edu or 952-451-7790

This study has been approved by the Institutional Review Board at Vanderbilt University, Nashville, TN - 615-322-2918 or toll free at 1-866-224-8273

APPENDIX B

REDCap Form (Eligibility Checklist and Online Survey)

Eligibility Screening

Study ID ________________________________

Eligibility Screening

For all parents contacted for research study, an eligibility screening form will be used. The PI will go through the questions in the form below to determine whether or not the parent meets the inclusion criteria for the study. The parent must answer yes to all the inclusion criteria questions and no to all of the exclusion criteria questions to be eligible to participate in the study.

Eligibility Screening and Follow Up Form

INCLUSION CRITERIA

	Yes	No
1. Are you the parent of child 18 months to 6 years of age?	○	○
2. Has your child received a professional diagnosis of autism spectrum disorder by a healthcare provider (e.g., physician, nurse practitioner, physician's assistant, psychologist, psychiatrist, etc.) in the last 12 months?	○	○
3. Do you speak and understand English?	○	○
4. Are you over the age of 18 years?	○	○
5. Are you the legal guardian of the child who is the focus of this discussion?	○	○
6. Do you have access to a computer with a microphone and video camera connected to high-speed internet and are familiar with and able to use FaceTime, Google Hangouts, or Skype?	○	○

EXCLUSION CRITERIA

	Yes	No
1. Is the child who is the focus of the discussion in foster care?	○	○
2. Do you have any auditory, oral, or visual impairments that would prevent the use of videoconferencing technology for the interview?	○	○
Question will be determined by PI during consent process: Is the parent unable to provide informed consent (due to developmental delay, intellectual disability, neurological impairment, etc.)	○	○

Inclusion/exclusion criteria status:

○ Eligible (meets criteria) ○ Ineligible (does not meet criteria)

For parents who do not meet inclusion criteria for the study, they will be asked the following:

Would you be willing to answer some basic questions related to you and your child that will be used to describe individuals who do not participate in the study?	○ Yes ○ No

COMPLETE DEMOGRAPHICS FORM

Demographics

Sociodemographic and Personal Characteristic Variables for Parent and Child:

1. What is your age (parent)? __________________________

2. What is the current age in months or years for the child who is the focus of the discussion: __________________________

Child's age given in months or years? ○ Months ○ Years

3. What is your gender (parent): ○ Male ○ Female

4. What is the child's gender: ○ Male ○ Female

5. What type of health insurance does the child have?

○ Private
○ Public
○ Military
○ Uninsured
○ Other
○ Prefer not to answer

Other insurance type: __________________________

6. Please indicate your annual household income:

○ $0-10,000
○ $10,001-20,000
○ $20,001-30,000
○ $30,001-40,000
○ $40,001-50,000
○ $50,001-60,000
○ $60,001-70,000
○ $70,001 or more
○ Prefer not to answer

7. Please indicate your marital status:

○ Married or Living with Significant Other
○ Separated
○ Divorced
○ Single
○ Prefer not to answer

8. Please select your ethnicity/race: ○ Hispanic or Latino ○ Not Hispanic or Latino

Ethnicity:

Race (select all that apply):

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Prefer not to answer

9. Please select your child's Ethnicity/Race: Ethnicity:	○ Hispanic or Latino ○ Not Hispanic or Latino
Race (select all that apply):	☐ American Indian or Alaska Native ☐ Asian ☐ Black or African American ☐ Native Hawaiian or Other Pacific Islander ☐ White ☐ Prefer not to answer

10. Please indicate your highest completed educational level:

○ Less than high school education
○ High school education
○ Some college, no degree
○ Associate's degree
○ Bachelor's degree
○ Master's degree or higher
○ Prefer not to answer

11. What state do you currently live in?

○ MN
○ TN
○ AL
○ AK
○ AZ
○ AR
○ CA
○ CO
○ CT
○ DE
○ DC
○ FL
○ GA
○ HI
○ ID
○ IL
○ IN
○ IA
○ KS
○ KY
○ LA
○ ME
○ MD
○ MA
○ MI
○ MS
○ MO
○ MT
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○ NV
○ NH
○ NJ
○ NM
○ NY
○ NC
○ ND
○ OH
○ OK
○ OR
○ PA
○ RI
○ SC
○ SD
○ TX
○ UT
○ VT
○ VA
○ WA
○ WV
○ WI
○ WY
○ American Samoa
○ Federated States of Micronesia
○ Guam
○ Marshall Islands
○ Commonwealth of the Northern Mariana Islands
○ Palau
○ Puerto Rico
○ U.S. Minor Outlying Islands
○ U.S. Virgin Islands
○ Baker Island
○ Howland Island
○ Jarvis Island
○ Johnston Atoll
○ Kingman Reef
○ Midway Islands
○ Navassa Island
○ Palmyra Atoll
○ Wake Island

12. Where did you hear about this study?

○ Autism Tennessee
○ Autism Society of Minnesota
○ Family Voices of Minnesota
○ Family Voices of Tennessee
○ Other

Other: ______________________________

Parent Perceptions of Communication with Health Care Providers

Please answer the following questions regarding your experiences with your child's health care provider during the time from when your child was first identified with concerns about his/her development to when your child was diagnosed with an Autism Spectrum Disorder (ASD).

1. How often did your child's doctors and other health care providers spend enough time with him/her?

○ Never ○ Sometimes ○ Usually ○ Always ○ Don't Know ○ Prefer Not to Answer

2. How often did your child's doctors and other health care providers listen carefully to you?

○ Never ○ Sometimes ○ Usually ○ Always ○ Don't Know ○ Prefer Not to Answer

3. When your child was seen by doctors and other health care providers, how often were they sensitive to your family's values and customs?

○ Never ○ Sometimes ○ Usually ○ Always ○ Don't Know ○ Prefer Not to Answer

4. Information about a child's health or health care can include things such as the causes of any health problems, how to care for a child now, and what to expect in the future. How often did you get the specific information you needed from your child's doctors and other health care providers?

○ Never ○ Sometimes ○ Usually ○ Always ○ Don't Know ○ Prefer Not to Answer

5. How often did your child's doctors or other health care providers help you feel like a partner in his/her care?

○ Never ○ Sometimes ○ Usually ○ Always ○ Don't Know ○ Prefer Not to Answer

Contextual Factors

Please complete the following questions for the child who was the focus of the discussion.

1. What age was your child when you first noticed concerns about his or her development?

○ List age (indicate in months or years) ○ I did not initially notice concerns

Age: ______________________________

Months or years: ○ Months ○ Years

If you did not initially notice concerns, please list who was the first to notice concerns (for example, another family member, day care provider, pediatrician, nurse, etc.)

○ another family member ○ day care provider ○ pediatrician ○ nurse ○ other

List other person: ______________________________

What age was your child at that time? Indicate in months or years ______________________________

Months or years: ○ Months ○ Years

2. What age was your child when you first learned he or she had a diagnosis of autism spectrum disorder? ______________________________

Months or years: ○ Months ○ Years

PHQ-4

Please complete the following items thinking back to the period when your child was in the process of being diagnosed with an Autism Spectrum Disorder (ASD)

PHQ-4

Thinking back to the period when your child was in the process of being diagnosed with ASD, how often were you bothered by the following problems:

1. Feeling nervous, anxious, or on edge?

○ Not at all ○ Several days ○ More than half the days ○ Nearly every day

2. Not being able to stop or control worrying?

○ Not at all ○ Several days ○ More than half the days ○ Nearly every day

3. Feeling down, depressed, or hopeless?

○ Not at all ○ Several days ○ More than half the days ○ Nearly every day

4. Little interest or pleasure in doing things?

○ Not at all ○ Several days ○ More than half the days ○ Nearly every day

Stress and Additional Demographics

Please complete the following items thinking back to the period when your child was in the process of being diagnosed with an Autism Spectrum Disorder (ASD).

Stress

1. How stressful did you find the period when your child was in the process of being diagnosed with ASD?

○ Not at all stressful ○ Not very stressful ○ Quite stressful ○ Very stressful

---

Additional Demographic Questions

Please complete the questions below for all your children, including the child who was the focus of the discussion. Leave blank any items you prefer not to answer.

How many children do you have?	______________________
Age in years (Child 1)	______________________
Gender (Child 1)	○ Male ○ Female
List any medical issues (Child 1)	
List any behavioral or psychological issues (Child 1)	
Age in years (Child 2)	______________________
Gender (Child 2)	○ Male ○ Female
List any medical issues (Child 2)	
List any behavioral or psychological issues (Child 2)	
Age in years (Child 3)	______________________
Gender (Child 3)	○ Male ○ Female
List any medical issues (Child 3)	

List any behavioral or psychological issues (Child 3)

Age in years (Child 4) ______________________________

Gender (Child 4) ○ Male ○ Female

List any medical issues (Child 4)

List any behavioral or psychological issues (Child 4)

Age in years (Child 5) ______________________________

Gender (Child 5) ○ Male ○ Female

List any medical issues (Child 5)

List any behavioral or psychological issues (Child 5)

Age in years (Child 6) ______________________________

Gender (Child 6) ○ Male ○ Female

List any medical issues (Child 6)

List any behavioral or psychological issues (Child 6)

Age in years (Child 7) ______________________________

Gender (Child 7) ○ Male ○ Female

List any medical issues (Child 7)

List any behavioral or psychological issues (Child 7)

Age in years (Child 8) ________________

Gender (Child 8) ○ Male ○ Female

List any medical issues (Child 8)

List any behavioral or psychological issues (Child 8)

Age in years (Child 9) ________________

Gender (Child 9) ○ Male ○ Female

List any medical issues (Child 9)

List any behavioral or psychological issues (Child 9)

Age in years (Child 10) ________________

Gender (Child 10) ○ Male ○ Female

List any medical issues (Child 10)

List any behavioral or psychological issues (Child 10)

Age in years (Additional Children) ________________

Gender (Additional Children) ○ Male ○ Female

List any medical issues (Additional Children)

APPENDIX C

Interview Guide

Introduction:

I am Lynnea Myers, a PhD candidate in nursing science from Vanderbilt University School of Nursing. Today's discussion will focus on your child who was diagnosed with ASD during the last 12 months. I want to learn more about your experiences during the time when (insert child's name) was first identified with concerns about his/her development to when you received a diagnosis of ASD. I am going to ask you a series of questions about your child's development and ways in which health care providers (defined as doctors, nurse practitioners, psychologists, therapists, and nurses) communicated with you about (insert child's name) development and next steps during the time it took to obtain a diagnosis of ASD. For the questions, please reflect on a primary health care provider you worked with during the process as well as other providers you may have encountered during this process. The information you provide will help me and other health care providers better understand the perspective of parents during the diagnostic process for ASD and identify better ways for providers to communicate with parents during this process. There are no anticipated risks for you to participate in this interview.

The interview will take about 30-60 minutes. Please answer the questions however you see appropriate. There are no right or wrong answers to the questions, rather, I am interested in gathering your experiences and opinions. You may choose to refuse to answer a question or to stop the interview at any time, without any penalty. Please ask me for clarification if a question is confusing. I have a few research details I am going to share with you now. All information you provide will be kept anonymous. A random numerical code has been assigned to you and will be linked to your responses. The only exception to maintaining confidentiality and privacy is if I am told something to indicate you may hurt yourself or someone else. In this case, I will need to share that information with appropriate individuals who can help. The interview will be audio-recorded for transcription purposes. If you would like to participate in this study, I ask you to provide consent verbally for your participation in the study with a 'yes, I would like to participate', indicating we may proceed.

Questions for Parent (in bold):

1) **Tell me a little bit about how the concern about (insert child's name) development was first identified?** Prompts: who, when, where, how, etc.
    a. If the parent indicates they first identified the concern: **What did you do once you identified the concern?** Prompts: Who did you talk to? How did you share these concerns with the health care provider? What happened after that?

2) **Thinking back to those first visits where you or your child's health care provider had initial concerns about your child's development,**
    a. **how did the provider explain the concerns about your child and his/her development (or if parent had concerns initially) or how did the provider react to your concerns?** Prompt: I heard you say…can you explain that more?

Probe: Did the provider directly describe his or her concerns or provide more vague information about his or her concerns?

b. **what were your thoughts as the provider talked to you about your child's development?** Prompt: I heard you say…can you explain that more?

The next set of questions will explore your interactions with your child's health care provider during the diagnostic process from when you first had concerns about your child's development up to the point when you received a diagnosis of ASD for your child. Often, parents work with one primary provider, but also interact with other providers during the course of obtaining a diagnosis. Was this the case for you? (Yes, No).

If yes, then

- Can you tell me what type of health care provider the main provider was (e.g., physician, physician's assistant, nurse practitioner, other nurse like public health nurse, clinic nurse, etc. or other [please describe])? Was the provider male or female? Can you give me an estimation of how many times you interacted with this provider?
- If you interacted with multiple providers, do you remember how many? What types of health care providers were they? Was the provider male or female?

If no, then

- Can you tell me what type of provider or providers you interacted? List out each – male/female and estimation of contact times for each.

For the questions below, focus on the main provider (parents can answer generally about other providers also)

3) **Thinking back to how accessible or how much time your child's health care provider(s) spent with you during the diagnostic process for ASD, was it was enough, too much or not enough time? What kinds of things made you feel that way?**
    a. Prompt: What amount of time did he or she spend per visit? What amount of time did he or she spend over the entire diagnostic process? Probe: If applicable, which health care provider(s) are your referring to?

4) **Did you feel your child's health care provider was listening to you during the diagnostic process for ASD? What kinds of experiences made you feel that way?** Probe: Did you feel your concerns were heard or acknowledged? If applicable, which health care provider(s) are your referring to?

5) **Was your child's health care provider sensitive to your family's values and customs during the diagnostic process for ASD? What kinds of experiences made you feel that way?** Probe: If applicable, which health care provider(s) are your referring to?

6) **What kinds of information did you get from your child's health care provider during the diagnostic process for ASD? How often did you get the information you needed?**
    a. Follow-up: If you did not get the information you needed, please describe why you felt that way and what additional information you would have liked to

receive. Did you feel like you got enough information or was it too little? Probe: If applicable, which health care provider(s) are your referring to?

7) **How did your child's health care provider help you feel like a partner in the care of your child during the diagnostic process for ASD? What kinds of experiences made you feel that way?**
    a. Follow-up: If the provider did not help you feel like a partner in the care of your child, please describe why you felt that way. Probe: If applicable, which health care provider(s) are your referring to?

8) **What did you see as barriers to communication with your child's health care provider during the diagnostic process for ASD?** Prompt: What, if anything, made it difficult to talk to your child's health care provider? Probe: If applicable, which health care provider(s) are your referring to?

9) **What did you see as facilitators or things that were positive to communication with your child's health care provider during the diagnostic process for ASD?** Prompt: What, if anything, made it easy or positive to talk with your child's health care provider? Probe: If applicable, which health care provider(s) are your referring to?

Is there anything else you would like to share about the communication you had with your child's health care provider during the diagnostic process for ASD or do you have recommendations for providers as they communicate with other families that have concerns about their child's development or a diagnosis of ASD? Probe: If applicable, which health care provider(s) are your referring to?

APPENDIX D

Full Codebook with Definitions

Code	Category	Description
1	**Initial concerns**	**Discussion centers on symptoms/problems presented by child**
1.1	Delayed speech	Symptom presented was delayed speech
1.2	Repetitive patterns	Symptom presented was repetitive patterns
1.3	Sensory Issues	Symptom presented was sensory seeking or other sensory issues
1.4	Comparison with other children	Noticed that the pattern of development of child was different than other children
1.5	Developmental regression	Child went from a more mature stage of development to less mature. For example, was speaking, then lost the ability to speak.
1.6	Behavioral issues	Discussion centers on behavioral issues displayed by the child
2	**Actions taken by participant**	**Discussion centers on actions taken by participant when s/he identified concern**
2.1	Internet searches	Researched the internet
2.2	Seeking advice	Sought advice (e.g., medical, friends, family)
2.3	Scheduling services	Scheduled a medical appointment
2.3.1	Medical provider	Actually scheduled appointment with medical provider
2.3.2	Early Intervention services	Sought Early Intervention services offered through schools or social services
2.4	Other	Actions taken that cannot be categorized above.
3	**Providers**	**Who you interacted with when identified concern**
3.1	Explanation	Provider approach in explaining condition
3.2	Reaction to concern	Provider's reaction to parent's concerns
3.2.1	Positive affirming supportive	Provider's reaction is positive, affirmed, and/or supportive
3.2.2	Dismissive, without concern	Provider's reaction is dismissive/without concern
3.2.3	Wait and see/monitor	Provider is not willing to commit to a judgment at this point and suggests monitoring and waiting, may be too early to detect
3.3	Medical referrals	Medical referrals
3.3.1	Referral to a diagnosing provider	Referred to diagnosing provider- e.g., psychiatrist, psychologist or developmental pediatrician
3.3.2	Referral to Early Intervention	Referred family to Early Intervention services
3.3.3	Referral to other therapist/therapy	Referred to other therapist/therapy- e.g., private speech therapist, occupational therapist, ABA therapy
4	**Clinical Services**	**Discussion centers on types of clinical services received**
4.1	Psychologist	Received services from psychologist
4.2	Psychiatrist	Received services from psychiatrist
4.3	Primary care pediatrician/nurse practitioner/family practice	Received services from primary care pediatrician/family practice doctor/nurse practitioner
4.4	Developmental pediatrician	Received services from developmental pediatrician
4.5	Speech/occupational/physical therapy	Received services from speech/occupational/physical therapist
4.6	Neurologist	Received services from neurologist
4.7	Other	Other services received that cannot be categorized above
5	**Evaluation of services**	**Discussion centers on adequacy of the services received**
5.1	Satisfaction level	Discusses level of satisfaction of services
5.1.1	Satisfied	Discusses satisfaction with services (e.g., positive statements by parent about interaction with provider)
5.1.2	Dissatisfaction	Discusses dissatisfaction with services
5.2	Enough time	Discussion centers on level of satisfaction regarding amount of time spent discussion condition with parent
5.2.1	Yes	Discusses that medical provider devoted a satisfactory amount of time discussing condition with parent
5.2.2	No	Discusses that medical provider did not devote a satisfactory amount of time discussing condition with parent
5.3	Listened	Discussion centers on whether or not the provider listened carefully to the parent
5.3.1	Yes	Discusses that medical provider listened carefully to the parent
5.3.2	No	Discusses that medical provider did not listen carefully to the parent
5.4	Answered concerns	Discussion centers on whether or not the provider answered the parent's concern
5.4.1	Yes	Discusses that medical provider answered her/his concerns
5.4.2	No	Discusses that medical provider did not answer her/his concerns
5.5	Sensitivity to concerns	Discussion centers on whether or not the provider displayed sensitivity to the parent's concerns
5.5.1	Yes	Discusses that medical provider was sensitive to her/his concerns
5.5.2	No	Discusses that medical provider was not sensitive to her/his concerns

5.6	Communication quality	Discusses communication dynamic
5.7	Understandability	Discusses information understandability
5.8	Family partnership	Response to the idea that the family and provider worked together
5.8.1	Yes	The family and provider did work together
5.8.2	No	The family and provider did not work together
5.9	Cultural/individual difference sensitivity	E.g., race, income, regional variation, ethnic background, occupation
5.9.1	Yes	Provider was sensitive to cultural/individual differences of the parent
5.9.2	No	Provider was not sensitive to cultural/individual differences of the parent
5.10	Information received	Explanation, education and information received about the child's condition, treatment, prognosis
5.10.1	Yes	Parents expressed that they did receive information
5.10.2	No	Parents expressed that they did not receive information
5.10.3	Additional information desired	Parent expressed additional information that s/he desired
5.11	Provider knowledge	Discusses whether there are limits to the providers' knowledge or limited understanding
6	**Facilitators/barriers**	**Discusses facilitators/barriers to communication of information**
6.1	Identified as facilitator	Participant identifies that some aspect of the communication or situation functioned as a facilitator- something that makes the process easier or improves the outcome
6.2	Identified as barrier	Participant identifies that some aspect of the communication or situation functioned as a barrier- something that makes the process more difficult or leads to negative outcomes
7	**Personal reflections**	**Reflect on their own reactions to the diagnostic process**
7.1	Emotional	Discusses emotional reactions to the diagnostic process
7.2	Family function	Discusses ways that diagnosis process impacted family relationships, interaction and well-being
7.3	Financial	Discusses ways that diagnosis process impacted financial situation
7.4	Job/career	Discusses ways that diagnosis process impacted job/career