PARENTAL GOALS AND STRATEGIES FOR CHILDREN WITH AUTISM:
CONSIDERATIONS FOR DIVERSE FAMILIES

Katharine H. Robinson

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Approved by:

Harriet Able

Elizabeth Crais

Lynne Vernon-Feagans

ABSTRACT

KATHARINE H. ROBINSON: Parental Goals and Strategies for Children with Autism:
Considerations for Diverse Families
(Under the direction of Harriet Able)

Autism spectrum disorder (ASD) is increasingly prevalent among children in the U.S.

For school children with ASD, parents and educators strive to identify goals to enhance

development. Unfortunately, parental goals for their children are not always understood by

educators, especially among parents of diverse backgrounds. The purpose of this study is to

increase understanding of parental goals for children with ASD and explore how goals affect

services and supports parents seek. Five parents from diverse backgrounds participated in

qualitative, in depth interviews during which they described their goals and interventions for

their children. Through microanalysis of data, differences in short and long term goals were

identified based on culture, ethnicity, socioeconomic status, and family background.

Informal and formal supports were discussed as they related to goals. By cultivating

increased understanding of parent perspectives, this study promotes effective early

intervention strategies by aligning parental goals to the education children receive.

Dedicated to parents who love their children unconditionally. To my own, who have supported me throughout my educational pursuits and instilled in me a love of learning. To my husband and partner in parenting, whose unfailing belief in me encouraged me to never give up. And to the parents I interviewed for this study – it is an honor to share in the bond of parenthood with you. You have inspired me more than you know.

And finally, to my son Everett. I love you right up to the moon – and back.

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Chapter 1: Introduction

According to the Centers for Disease Control and Prevention (2012), approximately 1 in 88 children living in the United States is diagnosed with Autism Spectrum Disorders (ASD). These children are members of diverse families, all of which are characterized by unique socio-cultural, familial, or personal circumstances. Thus, the personal and educational goals of parents of children with ASD may vary based on family priorities and background, leading them to pursue different strategies for raising their children. The goal of this study is to increase the understanding of individual parental goals for children with ASD with a particular focus on parents from diverse backgrounds. By cultivating an improved understanding of parent perspectives, there may be a better match between parental goals and priorities for children and the early intervention and education they receive.

This qualitative study expands on research by Zhang, Landmark, Grenwelge, and Montoya (2010), which demonstrated that parents living in the United States exhibit differences in the educational and personal goals they have for their children dependent on their cultural group. Although the authors focused on the effect of culture on familial goals and expectations among parents of children with and without developmental disabilities, they recognized that the presence of disabilities among some children may have been a confounding variable in their findings. For this reason, they recommended further research be conducted to focus on the effect of culture on the goals for individuals with disabilities. This study expands upon the research of Zhang et al. (2010) by focusing on parents who have young children between the ages of three and six with ASD. For the purposes of continuity

in identifying children with similar levels of functioning, the author of this study spoke with parents whose children were diagnosed with ASD before age three. The assumption was that by focusing on children with one disability, the families involved would have considered the special circumstances of their child with ASD when formulating priorities and goals.

This study also expanded upon the research of Epley, Summers, and Turnbull (2011), who looked at family outcomes of early intervention. Their findings suggested that, in general, families were satisfied with early intervention services. They determined that "further consideration of families as primary decision makers in determining needs and services is also warranted" (p. 216). Their findings regarding parental satisfaction were promising, but the authors believed families deserved greater involvement. Furthermore, the above study was based on a sample including predominantly middle-income white families. The authors suggested expanding upon their study by focusing on a larger socioeconomic demographic. This study worked purposefully with parents of different cultures and income levels.

Increased understanding of parental priorities for children with ASD may lead to a higher success rate for the education of these children, especially when they come from diverse families. Research by Cheatham and Santos (2005) showed that, in order for children with disabilities to have a beneficial school experience, teachers, parents, and students need to work together toward achieving the same educational goals. If the child involved is living in the United States but does not come from a nuclear Anglo-American family, this important collaboration can be challenging. Barrera and Corso (2002) argue that the key to "addressing the challenges posed by cultural diversity" is "understanding the dynamics of culture" (p. 103). Rather than expecting educators to become familiar with all cultures of the families

with whom they work, the authors suggest adopting a strategy of respect, reciprocity, and responsiveness as a means to achieving competency for working with all types of diverse families. By using such strategies, educators may better understand the priorities of diverse families and more fairly and effectively work with them towards educating their children with disabilities. Thus, practitioners and care providers can competently negotiate between parental goals and their own expectations in order to help children with disabilities achieve success.

The educational and personal goals parents have for children with ASD are not always understood by outsiders, including educational practitioners and the general population. As Santarelli, Koegel, Casas & Koegel (2001) found, there is a need for educators and practitioners to gain a better understanding about cultural background and the unique circumstances of each family with whom they work. After all, the priorities of one family may not match those of another or the expectations of the educators themselves. Important factors such as cultural background, socioeconomic status, and family structure are not always taken into account when educators consider the goals parents have for children with ASD. Rather than make assumptions regarding family priorities and appropriate intervention strategies, educators must seek to develop respectful and reciprocal working relationships with diverse families. As Barrera and Corso (2002) noted, "there is a clear and growing need for early childhood special education practitioners to develop effective strategies for serving children and families whose cultural and linguistic backgrounds are different from their own" (p. 103). This implies a reciprocal relationship between educators and families in which educators can learn from families, as well as provide parents with information. As Turnbull, Blue-Banning, Turbiville & Park (1999) argued, parents have

expertise about their children that renders them capable of providing education to professionals. To that end, Jackson Brewin, Renwick, and Schormans (2008) included a parental perspective in their study about quality of life among children with disabilities. Their rationale for working with parents was not only because of their expertise concerning the well-being of their children, but also because they had valuable information to contribute regarding their children. By looking specifically at the parental perspective, this study may provide educators with increased understanding of various goals for children with ASD, and consequently result in increased success for these children.

This study seeks to expand on the research above because of a continued need to understand how family circumstances and values affect parental priorities and goals for their children with ASD. As Brantlinger, Jiminez, Klingner, Pugach & Richardson (2005) noted, qualitative research in special education has the potential to influence policy by providing examples and evidence for necessary changes. Pugach (2001) argued further that real-life stories about individuals with disabilities have the power to influence societal perceptions of people with disabilities. Through qualitative research that tells disciplined stories, researchers may enable individuals with disabilities and their families to have their voices heard and may foster a better quality of life for individuals with ASD and their families.

Statement of Purpose

The purpose of this study is to better understand the personal and educational priorities and goals parents from diverse backgrounds have for their children with ASD, as well as determine how their priorities and goals affect the services and support parents seek. The study will look at five specific families to investigate the individual nature of parental goal setting for children with autism. By investigating the stories of a few diverse families,

the researcher gained insight on these parents' goals for their children with ASD, what factors influenced goals, and what intervention strategies, services, and supports are pursued to meet these goals.

Participant words and examples provide insight into the many factors that influence parents in formulating goals and strategies for children with ASD. Parents were found to formulate long-term goals based on their personal background and level of family support. Short-term goals also took into account current abilities of the child. Intervention strategies, services, and support were pursued by parents both in and outside of school with the hope that such supports would help parents achieve their goals. Findings of this nature may help to address the current problem of familial goals being misunderstood by practitioners and the general population. Furthermore, increased understanding may help foster intervention and supports that assist diverse families and individuals with ASD, resulting in their ability to pursue priorities and goals through strategies aligned with their cultural and familial values.

Chapter 2: Literature Review

Previous literature approaches the subject of parental goals for children with autism form a variety of angles. Literature has explored the emphasis in education to recognize the diversity of families and their priorities concerning their children. Often this diversity is expressed through cultural differences, which can result in varying views of disability. Previous research has found that educators working with diverse families can face challenges, often due to cultural misunderstandings in education. For that reason, collaboration between parents and educators in the education of children with disabilities is especially important. Though previous literature is rich in information, deficiency in the literature suggests that further research is needed on the ways in which diverse families set goals and pursue interventions for their children with autism.

Family Diversity and Priorities Concerning their Children

It is extremely important for educators to understand the different views held by families and how they affect the goals parents have for their children, whether or not these goals involve skills typically taught in school (Rogers-Adkinson, Ochoa & Delgado, 2003). In their study on adulthood goals as they are perceived by parents and youth with disabilities, Powers, Geenen, and Powers (2009) reported that parents were focused on the ability of youth to learn how to care for themselves, protect their safety, and communicate their needs. When considering children with ASD, parents ranked life skills as most important, along with the future goal of residential living (Grigal & Neubert, 2004). Powers et al. (2009)

found that the least important goals in the first five years of an adolescent's adulthood were for youth to have families of their own and to live on their own or with friends.

Though Powers et al. (2009) discussed commonalities among some goals expressed by parents in their study, not all parents of children with disabilities prioritize the same things. For that reason, it is important to become familiar with the cultural values and unique circumstances of each family prior to planning intervention strategies (Santarelli et al., 2001). Zhang et al. (2010) noted that, although parents of all cultural backgrounds encouraged their children to practice household chores, European American parents were the most proactive in preparing their children for independence. Adulthood goals such as this were discussed by all parents, but Latino and African American parents focused more on employment goals than on independent living. One family had this to say: "We are Hispanic and I don't think he has to leave the house when he turns 18. He is going to stay at home with his family" (p. 181). This finding is one specific example that emphasizes the importance of understanding cultural variables when considering the goals of diverse families.

Socioeconomic status has also been shown to affect the ways in which parents set goals for typically developing children. Although many European American parents prioritize independence, self-sufficiency, and self-confidence, parental goals vary as a function of socioeconomic status (LeVine, 1980). Kohn (1963) found that families from low socioeconomic backgrounds value conformity to societal norms rather than independent thinking. Furthermore, parents of low socioeconomic status are less likely to believe in their own self-efficacy, or the notion that their actions influence their children's adulthood (Elder, Eccles, Ardelt, & Lord, 1995). As these studies indicate, socioeconomic status can impact parents' goal setting and pursuit of goals in similar ways as cultural diversity.

As Powers et al. (2009) argued, further research is needed to specifically investigate the interaction between racial and ethnic factors and the goals most highly valued for children with disabilities. Research by Landmark, Zhang & Montoya (2007) indicated that culturally diverse parents of students with disabilities often lacked knowledge about the school transition process or were not adequately involved. While culturally diverse parents were shown to have goals for their children, they did not always pursue those goals or know which steps schools pursued on behalf of their child. In an investigation into this issue and the relationship between parents and educators by Zhang et al. (2010), the authors found that when educators strive to understand families from various cultures, their efforts empower parents to work towards their goals for their children.

Cultural Views of Disability

Engaging diverse families in education and intervention planning for their children with disabilities can be difficult. Prior research indicates parental involvement in education intervention plans is insufficient, especially among culturally and linguistically diverse families (Cameto, Levine & Wagner, 2004). This may be due to the fact that individuals from different cultures interpret disability in a variety of ways, either as something positive, negative, or a mixture of both (Rogers-Adkinson et al., 2003). In mainstream U.S. culture, disability is often medicalized in a way suggesting that individuals with disabilities require treatment. Conversely, other cultures may view disability as something to be accepted, or occasionally as a spiritual blessing or gift (Kalyanpur, 1999). For instance, immigrant Muslim families with children with ASD reported feeling blessed by Allah to raise a "special child" (Jegatheesan, Miller & Fowler, 2010, p. 102). Families sought to immerse their children in every aspect of life, based on their interpretation of the Qur'an. Accordingly,

parents believed their children with ASD should be included in ordinary school and religious activities in the home, their mosque, and the community. As one parent said, "We think our son can be married and have a family like a normal person. We believe he can live a normal life, have children, be a father and a husband" (p. 103).

Cultural views about the meaning of a disability influence the ways in which families seek to raise a child with a disability, as was shown in Santarelli et al.'s (2001) study of Latino families living in the U.S. The authors found that the families with whom they worked often had large familial networks and, for that reason, did not feel the need for external intervention services. Families also had less knowledge about how to access services that might be helpful to them. In Zhang et al.'s (2010) study among Asian, African American, European American, and Latino families, the only parents who mentioned seeking outside sources of help for their children were European American parents. Similarly, Irvin, McBee, Boyd, Hume & Odom (2011) found that the children with ASD of families identifying as Hispanic or Asian received a smaller dose of school-based occupational and speech therapy in comparison to white children, all of whom were of high socioeconomic status. The authors hypothesized these findings may reflect the ability of families with higher socioeconomic to advocate for their child to receive higher dosages of services. Alternatively, lower participation in services among culturally diverse students may relate to a shortage of culturally or linguistically competent educators (Stapleford & Todd, 1998). These findings speak to the fact that culture and the diverse needs of families can influence the ways in which parents seek services for their children with disabilities. Unfortunately, a lack of involvement in services by members of certain cultures may result in negative judgments by members of other cultures. In mainstream U.S. culture, it can be seen as

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negative behavior for parents to accept a low level of functioning by their children, rather than seek services to treat them (Rogers-Adkinson et al., 2003). Ideally, various levels of involvement in intervention strategies should be understood and respected by practitioners.

Working with Diverse Families

Previous research has shown varying relationships between diverse families and school personnel. Landmark et al. (2007) found European American parents place a high value on communicating with the school about their children with disabilities, while Asian and African American parents more highly valued working with their child at home. This shows that, while some non-white parents may not be communicating with the school as much as white parents, it is likely that they are highly involved in working towards goals at home. This was the case in a study by Rogers-Adkinson et al. (2003), who observed a child with a disability who was having difficulty achieving toilet training. School educators assumed the child's parents did not share that goal, but in reality the child lived with many people in a small house without adequate access to a bathroom. This insight revealed that there may be subtle issues at play when it comes to working with real families in the midst of their everyday lives. It also revealed that issues of family structure, such as how many people are living in one household, ad living conditions can influence the ways in which parents raise their children with disabilities. Exploring and understanding each family's culture, circumstance, and individualized needs is a necessary step to developing successful working relationships (Rogers-Adkinson et al., 2003). Powers et al. (2009) argued that strength-based problem solving is an excellent technique for working with students with disabilities and their families, especially when families have different understandings of disability. In order to employ this method, interventionists must view individual challenges

not as deficits but rather as gaps between what is desired and what is presently achievable (Powers et al., 2009). Practitioners must develop relationships and seek to understand the specific goals parents have for their children.

Cultural Misunderstandings in Education

As Kalyanpur and Harry (1999) argued, the special education field in the U.S. is dominated by a mainstream, medicalized understanding of disability. Furthermore, educator knowledge is shaped by the belief that disability necessitates treatment. This belief can cause controversy in cross-cultural communication when families do not share a medicalized perspective. The authors argued that mainstream ideology needs to be made explicit if educators hope to understand their own biases and eventually become effective collaborators with individuals from other cultures. An example of cultural disconnect was shown in Cheatham and Santos' (2005) work with a first generation American boy named Sebi who was reported to be disruptive in class. The researchers visited him at home and found Sebi's immigrant parents encouraged him to actively participate in storytelling, which may have influenced him to speak out during reading time at school. This perceived interruption in school was a direct result of Sebi's parents' goal of encouraging him to make his voice heard. The authors discussed the role that cultural norms play in encouraging some children to participate in collaborative conversation by answering questions in tandem with help from a teacher or peer. Different cultures' learning styles are not always understood or accepted by educators, despite the fact that they may reflect the goals of the family. According to Cheatham and Santos, teachers should not assume children will understand their classroom expectations and should strive to accept alternative learning styles. This is especially true

when parents have not experienced the U.S. school system themselves, as they may not be familiar with the expectations for educational goals for their children.

Thus it seems important to understand cultural and socioeconomic variables within a family when designing intervention strategies (Santarelli et al., 2001). Many diverse families, including recent immigrants, may not have the same cultural values as the majority culture in the U.S. (Rogers-Adkinson et al., 2003). Often families have a difficult time balancing their native culture and the dominant culture, and discord may occur when American practice conflicts with cultural traditions. In a study of Puerto Rican parents with children with disabilities, Harry et al. (1992) found families to be more concerned with family identity, language, and educational practices than with a labeled disability. This focus conflicted with that of the education system, causing cultural misunderstandings between parents and educators. The authors argued that educators could have aligned themselves with parents by focusing on skills a child had, rather than stringently labeling deficits. Findings suggested that, while the Latino parents in this study had a broader view of normalcy than educators, they were realistic in their expectations of their children's abilities. In order to properly and successfully provide intervention strategies for children with disabilities, it is important for practitioners, parents, and children to find common ground where they can work together. This is especially important if the families involved have cultural backgrounds or belief systems different from those of the educators or practitioners who work with their children (Cheatham & Santos, 2005).

Collaboration in the Education of Children with Disabilities

It is widely-accepted that collaborative planning between youth, parents, and schools is critical in setting goals because of the strong level of family support required for

individuals with disabilities (Powers et al., 2009). Parental involvement is routinely pursued

in early intervention in an attempt to consider family values, priorities, and unique

characteristics in goal-setting. Research has shown that encouraging parents to participate in

the planning process has resulted in parents having a better understanding of the need to set

goals (Zhang et al., 2010). Furthermore, research by Dunst, Boyd, Trivette & Hamby (2002)

suggests parents appreciate intervention techniques with family-oriented paradigms. They

found that "program models either implicitly or explicitly adopted by helpgiving

organizations and agencies mattered a great deal in terms of how professionals were judged

by people they were attempting to help" (p. 227). For instance, in comparative studies of

family-centered verses practitioner-centered help-giving practices, parents reported educators

working within family-centered, participatory frameworks to be more collaborative and

helpful.

Involving parents in educational intervention has benefits for educators as well as

families. As Turnbull et al. (1999) argued, parents are significant resources to educators, as

they can share expertise about their children. Expertise can come in the form of knowledge

about the child's relationships to family and community members, the child's overall quality

of life, or what priorities are important to the child and his or her family. A study by Hunt,

Soto, Maier, Liboiron, and Bae (2004) about Unified Plans for Support showed that when

parent collaboration occurred, educators found parental involvement to be appreciated and

useful in planning intervention. Blair, Lee, Cho, and Blair's (2010) study on the impact of

individual support plans implemented through family–school collaboration indicated that the

children's target behaviors improved with family-centered intervention. This evidence

suggests that education strategies are more effective when family recommendations are taken

into account. This finding is parallel to that of Santarelli et al. (2001), who found that interventionists with a better understanding of family needs and specific goals had an increased likelihood that their family-centered intervention strategies were implemented and maintained on an on-going basis. Further findings suggested that a group effort between youth, their family, and service providers can create a clear and achievable road map of goals for children with disabilities (Powers et al., 2009).

Despite the numerous benefits of family collaboration, practitioners have reported that working with parents of children with severe disabilities is a challenge, especially when parents come from diverse backgrounds (Rogers-Adkinson et al., 2003). As Able-Boone (1996) noted in her study on ethics and early intervention, families and educators often have value conflicts when it comes to education and early intervention. To overcome these difficulties, the author proposed a critical communication model centered on trust and equity. Ultimately, educators should strive to promote respectful and understanding relationships that lead to agreed-upon decisions between themselves and families. Bruder (2000) succinctly reminds educators that "the children we work with belong to their families" (p. 110). Collaborating with diverse families may be difficult, but the potential benefits are such that educators must re-commit themselves to doing so.

As the literature suggests, understanding the specific family structure and culture of diverse families is crucial to helping children with disabilities succeed in school and beyond. This literature review provides a basis for understanding how various types of diverse families comprehend disability and are involved in goal-setting for their children, both through educational institutions and at home. It also provides specific examples of previous

findings related to the various goals and strategies exhibited by families of different

backgrounds.

Deficiency in the Literature

Different cultural groups have unique reactions to the realization that a child is not

developing typically, and these attitudes have been studied in educational literature focusing

on the relationship between multiculturalism and ASD. Despite this research, there is

insufficient literature about how diverse families seek support through educational and social

services and interventions (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004).

Additional open-ended research is necessary to explore the role that culture and family

structure play in the establishment and pursuit of parental goals. This study looked closely at

diverse families and will explore how their views about having a child with ASD directly

affected their attitudes toward goals as well as intervention strategies.

Although the intersection between ASD and culture has been studied from many

angles, there is insufficient research on the ways in which family structure (i.e. the number of

children and adults in a family) affects how parents pursue goals for children with ASD. In

addition to looking at how culture influences parental goals and strategies for children with

ASD, this study explores differences in goals and strategies among diverse families such as

parents with one child, families with multiple children, and parents with varying levels of

extended family support. The ultimate goal of this qualitative study is to consider the needs

and goals of five specific diverse families in order to provide insight into the many factors

that may influence any given family when making decisions about their children with

disabilities.

Chapter 3: Method

Participants were recruited to participate in a qualitative research study regarding the short and long term goals and strategies that parents employed for their young children with autism. Research was conducted primarily though in depth interviews, and data was analyzed as it addressed the research questions outlined for in the study. High priority was placed on ethics and reciprocity in order to preserve participant autonomy and do no harm to those involved in this study.

Research Questions

The purpose of this study is to understand how the educational and personal priorities and goals parents have for children with ASD are affected by personal and family circumstances, such as family structure, culture, religion, socioeconomic status, etc. The specific research questions are: What short and long-term goals do families have for their children with ASD? What factors have gone into formulating these goals? How do goals affect the intervention strategies sought by families? These questions were formed in adherence to Marshall and Rossman's (2011) advice that "research questions should be general enough to permit exploration but focused enough to delimit the study" (p. 73). The method described below explored participants' perspectives regarding their goals for their children with ASD and intervention strategies sought to reach these goals.

Qualitative research is driven by and for participants, rather than focused on meeting a defined theoretical agenda. According to Spradley (1979), "instead of beginning with theoretical problems, the ethnographer can begin with informant-expressed needs, then create

a research agenda to relate these topics to the enduring concerns within social science" (p. 14). This research study was designed as such by being exploratory in nature. The main goal was to understand how family circumstances affect the goals parents have for their children with ASD by revealing specific hopes, dreams, fears, and strategies parents use to facilitate their children's development.

The study's purpose is to develop an understanding of the goals parents set for their children with ASD. Thus, practitioners may be able to recognize how complex family circumstances affect the priorities and goals parents have for their children. If family goals are better understood by practitioners, it is more likely that intervention strategies supporting these goals will be used. Furthermore, it is argued that children are more likely to reach goals when parents are involved in educational goal setting and family-centered interventions because families have increased investment in the education of their children.

Participant Recruitment

Families were recruited through one local church and three community support networks providing services and assistance to families with children with disabilities. A copy of the recruitment form is shown in Appendix A. Within two weeks of the recruitment announcement dissemination, nine parents contacted the researcher to express interest in the study. Of these nine parents, seven fit the criteria for participation. The participation criteria included having a child between the ages of three and six who had been diagnosed with ASD before age three. Only one parent per child was eligible to participate. The researcher explained the study by phone or email and provided a consent form (Appendix B) to each of the seven parents. Of those seven parents, five consented to participate.

Rather than a random sample designed to be representative of entire groups or populations, a small sample of diverse parents was sought to specifically address the research questions. The intention was not to gather data that suggested trends across different cultural or economic groups, but rather to explore the relationships between a variety of goals and circumstances within specific families. Rather than providing evidence for broad assumptions, participant diversity allowed for different perspectives that shaped how these parents understood ASD and developed goals for their children.

The intention was to gather a diverse sample consisting of four to seven parents. By limiting the focus to this number of families, the researcher would be able to gain in depth information about each parent's goals and priorities for their children with ASD. In order to ensure a diverse sample, the researcher provided each parent with a demographic information form (Appendix C) to complete. This form contained questions related to income, race, ethnicity, and place of birth created based on questions adapted from the U.S. Census (United States Census Bureau, 2010). The answers were used to inform the sample demographics. The demographics of the initial five families who were willing and eligible to participate provided a sample that was sufficiently diverse, so the recruitment effort was not continued beyond that point.

Ethics and Reciprocity

Because this study was conducted with families and involved discussions about their children, it was necessary to put ethical considerations at the forefront of the research. The concern in this regard echoed Piotrkowski's (1979) research with families, where he said "since my relationship with them was not long-term, I had to be responsible for the effects the interview process had on those involved" (p. 300). The first step to addressing ethical

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concerns was to have participants provide informed consent before beginning data collection. One aspect of this process involved making the research outcomes and agenda of this study explicit to families. As McGraw, Zvonkovic & Walker (2000) noted, researchers must ensure that families do not have personal, political, or professional expectations that are not in line with the aims of the researcher. In this case, this meant informing families that the researcher was not a service provider and would not be talking to school professionals or policy-makers on behalf of their children. Rather, the research conducted would result in a written thesis with the goal of increasing readers' understanding and perhaps ultimately adding to professional literature that may influence educational practices or policies. All participants, their children, and the names of any other identifying information have been changed to maintain their privacy.

In addition to maintaining privacy, Marshall and Rossman (2011) advocated respect for participants, saying "respect for persons captures the notion that we do not use the people who participate in our studies as a means to an end" (p. 47). In order to work towards this goal, not only did this researcher seek to truly learn from the participants but also took deliberate steps to provide reciprocal help to families in gratitude for their participation. To that end, one $20 gift card was provided to each family from either Food Lion, Harris Teeter, Weaver Street Market, or Whole Foods. Stores donated one to two gift cards to this study, with several store representatives saying they knew someone with a child with ASD and were pleased to help support the families involved in the study. This reciprocity was important so that this study directly benefitted the participants in a small way.

Another ethical consideration concerned the close, personal discussions between parents and the researcher. In circumstances such as these, the researcher took extra

precautions to ensure that the benefit of the work outweighed potential harm to family members. These types of "ethically important moments" were discussed by Guillemin and Gillam (2004). The authors suggested handling such moments thoughtfully by engaging in constant reflexivity on the methodology and ethics of research. Throughout the interview process, there were a few moments when parents became upset or a topic discussed caused visible discomfort. One parent shed some tears, and the researcher paused until the parent was ready to resume the interview. During another interview conducted in the presence of the child being discussed, the parent's answers reflected his presence. When the parent discussed goals for her son's adulthood, she glanced at him regularly and used vague language, obviously sensitive to his feelings. In those times, the researcher chose to avoid further probing questions that may have made the participant uncomfortable. This decision was made so as to not add further emotional distress to parents. While this may have resulted in less discussion about the topic, the goal was to minimize emotional harm to participants.

The overall goal of this research was to maintain participant autonomy. Throughout data collection and analysis, the researcher strove to meet this goal by accurately representing participants and not letting personal biases, misunderstanding, or past experiences misrepresent them. After an interview was transcribed, each participant was given a copy of their entire interview transcript, as well as a summarized version, which was one to two pages in length. Through this method, participants were invited to read and comment on either version, depending on their time and desired level of involvement. As Brantlinger et al. (2005) noted, engaging in member-checking can increase the credibility and reliability of qualitative data. Through the practice of member-checking, participants were given the opportunity to correct mistakes made in transcription or amend anything they may have said

that did not accurately reflect their beliefs. Two out of the five parents wrote back with changes, most of them being minor diction changes. Some of the summary edits were changes that altered meaning slightly (i.e. "his responsibility as a parent" vs. "the responsible thing to do as a parent"). One parent corrected the age at which their child had been diagnosed with ASD. The opportunity for parents to review the interview and summary helped ensure that the transcribed data accurately represented participant views. Ultimately the goal was to honor and respect the words and autonomy of the participants while fulfilling the research purpose.

Instrumentation

An interview protocol listing a series of open-ended interview questions was designed to help guide conversations. Pilot research was conducted with a mother of a young child regarding the specifics, subtleties, and wording of interview protocol questions. The researcher asked each question and probe during the pilot interview, and the parent provided answers. The researcher and the parent discussed questions and the answers they elicited. The parent gave advice regarding awkward wording or unclear questions. This preliminary research assisted the researcher in amending the questions before interviews with study participants were conducted. After the pilot interview, the researcher omitted some questions, combined others, and changed question wording to better investigate the research questions. This pilot research assisted in the development on the final version of the interview protocol used in this study (Appendix D).

The protocol included a variety of questions to build rapport and get to know the family, as well as specific probing questions with the goal of informing the research questions. Table 1 below shows each interview question and how it informed research

questions. Because this study was qualitative, the interview questions were not rigid, but served as guidelines for the interviews. The goal was to foster parent-driven explorations of goals for their children and the underlying factors affecting formulation of goals.

Table 1

Interview Questions

Research question	Interview question
Getting to know you questions (rapport building).	Tell me about your family.
	When did you learn that your child has autism?
	What are some of your child's strengths and challenges?
What short and long-term goals do families have for their children with autism?	What are your biggest concerns for your child right now?
	What about hopes for the future?
	What do you envision your child's life to be like as an adult?
What factors have gone into formulating these goals?	Which priorities do you view as being most important?
	How are your priorities influenced by your values and beliefs?
	How are your priorities affected by the specifics of your family structure?
	Have your actions been impacted by your financial situation?

Research question	Interview question
How do goals affect the intervention strategies sought by families?	What do you do to help your child achieve your goals? What does your child's school do to help you with these priorities? Has your child been involved in intervention services outside the school?

Procedure

The primary data collection method was an in-depth interview with each parent. The rationale for choosing in-depth interviews as the primary data collection method was the likelihood of informing the research topic through participant perspectives and an iterative research process. Participant interview is a primary data collection method with strengths in uncovering participant points of view, providing flexibility in formulating working hypotheses, and encouraging cooperation and collaboration (Marshall & Rossman, 2011). These attributes were all important components to this data collection. Interviews also attempted to meet Piotrkowski's (1979) goal of not only having "the researcher's interpretations of what happens in the lives of families studied, but…also [having] interpretations made by participants about their own lives" (p. 316).

Interviews were supplemented by the researcher giving parents an optional journal entry asking the questions: "What is your biggest hope or dream for your child? Why is this important to you?" (Appendix E). The rationale for providing this option was for participants to have the opportunity to express their views using either spoken or written

word. Two of the parents said they appreciated having that option because they found it easier to express things in writing. At the time this thesis was completed, one of the two parents who had expressed initial interest had elected to turn in a journal entry.

Parents were contacted to arrange an interview in their home or another location of their choice. This was done in order to provide settings that were comfortable and familiar to participants. In his work with families, Piotrkowski (1979) found that conducting interviews in homes allowed for his participants to manage their stress and anxiety in more natural ways. Seeking to give the parents in this study similar benefits, the researcher offered to conduct interviews in a location of their choice.

Three parents elected to hold interviews in their home, one at their work setting, and another in a public location near their work setting. Participants selected sites based on a variety of factors related to their preferences and convenience. For example, some parents did not want the interview to infringe on childcare responsibilities; hence they asked me to meet them during the workday at or near their work setting. Others told me they could not meet where they worked and asked me to come to their home. The intention was for the sites to be comfortable for participants and foster natural conversations.

An allotted time of one and a half hours was scheduled to complete the interview, and all of the interviews were completed in that timeframe. All participants agreed to let interviews be audio-recorded for future transcription. The researcher took hand written field notes during the interviews and after meetings to record impressions and reflections regarding the setting, tone, and emotional impact of the interview. Notes taken during interviews provided details not captured by the audiotape (i.e. body language). Notes after interviews helped the researcher organize reactions to each interview. Field notes were used

as part of ongoing process of reflection about each interview and self-reflection about potential biases of the researcher. A sample from the field notes is provided in Appendix F.

Data Analysis

After each interview, the recording was transcribed verbatim by a research assistant. The primary investigator reviewed 20% of the transcriptions to verify accuracy and found very few errors in most of the transcriptions. One parent had an accent, which was, at times, difficult to transcribe. The primary researcher reviewed 90% of that interview transcript in order to verify accuracy. Because entire interviews were transcribed, all the data was considered in the initial analysis. Findings were not limited by pre-determined categories, but rather participants' perspectives generated thematic categories related to the research questions.

The researcher analyzed the data through microscopic examination of the data, or microanalysis (Strauss & Corbin, 1998). This line-by-line coding process consisted of closely reviewing the transcribed interviews and identifying thematic categories. Sections of text were coded using open coding based on emerging categories and themes based on the research questions. Pre-formulated coding themes included family priorities, goals for adulthood, extended family involvement, school satisfaction, intervention strategies, culture, and religion. Categories including personal background, circumstances, challenges, and ideas for school improvement emerged from the data. As each interview was analyzed, themes and codes changed and evolved as more emerged. Axial coding was used to relate emerging categories and subcategories to one another (Strauss & Corbin, 1998). This iterative process allowed the researcher to microanalyze data in an on-going manner as interviews were transcribed.

The researcher's initial coding process was completed once the data was saturated with thematic codes. Each interview was then given to one of two secondary coders who were trained by the student researcher. Training included describing the nature of line-by-line thematic coding and discussing the thematic codes assigned to the text. The secondary coders and the researcher discussed the codes so that the researcher's intended meaning of each code was understood by the secondary coder. The secondary coders were given the primary researcher's codes in advance as guidelines but could propose additional codes as needed.

After the interviews were coded by the secondary coders, the data was reviewed by the secondary coders and the researcher to reach shared conclusions regarding inconsistencies. The reliability coders and the researcher managed to reach shared agreement on all of the data. At times a portion of text shifted from one code to another. More often, a coded portion of text was found to fall under more than one category. The coding categories were not mutually exclusive, so much of the data fit in more than one code. For example, one parent said it was not one of her goals for her child to go to college because she believed it would be anxiety-producing for him as it had been for her. This statement fit under the categories of goals for child's adulthood and parent's personal background. Many statements similar to this were coded under multiple categories. The reliability coding process helped ensure the thematic codes, assumptions, and conclusions were not due to researcher subjectivity, but rather were also shared by both coders.

Following reliability coding, the student researcher compared, contrasted, and analyzed the codes to identify overarching themes addressing the research questions. Some of the original codes were found to represent larger, overarching themes (i.e. family

involvement), and some codes represented categories within a larger theme (i.e. school contribution). Specific findings from each family were analyzed based on their codes, and key quotes were identified to highlight points noted in each category. The coded themes and categories were used to frame the results to highlight the factors influencing parental goal-setting for their child with ASD. Table 2 includes a comprehensive list of themes, categories, examples, and how they related to the research questions.

Table 2

Thematic Codes

Research q.	Themes	Categories	Examples
What factors have gone into formulating goals?	Personal background	Individual parent's circumstances (i.e. past experiences, culture, religion, profession)	"I, above all, hope that he is able to come to know God in an intimate way because our Heavenly Father will be there for him in ways none of us can" – Val "I wanna make a good, better impression with him than I did with my other kids. So that's why I'm hoping for those things for him. I wanted those things with them, but I wasn't a part of their lives." – Lisa
	Family involvement	Immediate family Extended family	"Mike and I have just done everything we can to make sure people understand what his needs are, and that these needs will be lifelong." – Erin "I chose not to tell my family back in India because I know they don't know what this really means…and they really can't support me one way or the other, so why am I telling them?" – Vishal

Research q.	Themes	Categories	Examples
What short and long-term goals do families have for their children with ASD?	Current goals/ priorities	Goals for child Challenges	"I wish some of these traits would go away, and some of 'em I can live with. I can live with the toe walking; I can't live with that noise (bucket shaking). I can't live without him talking. I can't live without him talking." – Lisa "My biggest concern right now is the fact that he really needs interaction with neurotypical peers. But because of [his] anxiety and the emotional struggles he is in the self-contained classroom, and it's really hard to facilitate that." – Amy
	Goals for child's adulthood	Higher education Employment Independent living	"I shy towards going to work after high school rather that college, because college to me was anxiety-producing." – Erin "Every child will find their own friend somehow. Maybe one friend, two friends, but my concern is him having an employment and getting an earning so he can be independently living." – Vishal

Research q.	Themes	Categories	Examples
What short and long-term goals do families have for their children with ASD? (cont.)	Goals for child's adulthood (cont.)	Companionship Community support Big picture goals	"I always say the only thing I want for him is for him to have a friend… I'm not concerned about him finishing high school or going to college or having a job - I believe those things will happen, if that's what he wants - but I feel like success in life for him would be to have that love reciprocated." – Amy "I do believe that it would be good for him to have support, and probably necessary to have support in the community, in order to go to college or to have a job" – Amy "We just want him to be happy; we don't want him to live in a world where he's anxious all the time." – Erin
How do goals affect intervention	Intervention strategies, services, and support	External services	"Mike and I take advantage of every single pre-social group thing out there, because we think it's really important." – Erin

Research q.	Themes	Categories	Examples
strategies sought by families?	Intervention strategies, services, and support (cont.)	School contribution	"I love it. The class size is very small, his teachers are great, they always keep me informed on things, they do have a support group – that I have only been able to make it to once because of the time. I mean, I think they're doing wonderful. I don't have any complaints." – Val
			"The whole public school system, I don't feel any of them are advocating for us. They are just doing a job because they have a job, and they have to do that because the law says so." – Vishal

The in depth interviews, journal entry, and field notes involved in this data collection garnered evidence to provide a deep understanding of the research questions. Participant autonomy was maintained through emphasis on ethical considerations, member checking, and participant autonomy. These methods produced interesting findings regarding parental goals and intervention strategies for children with ASD, which are discussed in the following results section.

Chapter 4: Results

Five parents from diverse backgrounds were interviewed as participants in this research study. The goal was to understand the personal and educational priorities and goals they had for their children with ASD, as well as how their priorities and goals affected the services and support they sought. During recorded interviews, each parent discussed their lives, their relationships with their partners and their children, and what they hoped for their children's near and distant futures. Analysis of the interview transcripts identified five major themes related to the research questions: personal background; family involvement; current goals/priorities; goals for children's adulthood; and intervention, services, and support. Many of the specific examples made by parents fell under more than one theme, which illustrated the interconnectedness of themes. The themes of personal background and family involvement are discussed in the section related to factors influencing goals. This information is presented first in order to introduce each family and provide the reader with a framework of the individual characteristics of these families as it related to their goal setting and service seeking. Subsequently, the themes of current goals/priorities and goals for children's adulthood are discussed relative to parental goals for their children. Finally, the interventions, services, and supports are provided.

Participants

The participant sample included five parents of children with ASD. Four mothers and one father were interviewed. One parent was African American, one parent was Asian, and three parents were Caucasian. One parent was born in India and four were born in the United

States. The socioeconomic status of the parents ranged from a combined family income of

below $20,000 per year to above $100,000 per year. Three parents were part of mixed race

families, with each parent coming from a different race or linguistic-ethnic origin. The

number of children each parent had ranged from one to four. See Table 3 outlining key

parent demographics and characteristics.

Table 3

Parent Demographics and Characteristics

Name	Age	Race	Place of birth	Annual income	Child with ASD	Number of children
Lisa	42	Caucasian	U.S.	Below $20,000	Ethan	4
Val	36	African American	U.S.	$41,000-60,000	Jayden	3
Erin	44	Caucasian	U.S.	$80,000-100,000	Cameron	1
Vishal	45	Asian (Indian)	India	Above $100,000	Sid	1
Amy	34	Caucasian	U.S.	$41,000-60,000	Daniel	1

The children with ASD were boys between the ages of three and six who were

diagnosed with ASD by a trained professional before age three. Two of the children were

non-verbal, one had some labeling and repetitive language, and two were verbal. Though

some of the parents used the words "high-functioning" to describe their children, all of the

children had a school placement of a self-contained classroom for at least part of the school

day. See Table 4 outlining key child demographics and characteristics.

Table 4

Child Demographics and Characteristics

Name	Age	Age at diagnosis	Verbal functioning	School placement	Classroom placement
Ethan	3	2.5	Non-verbal	Public school	Separate classroom
Jayden	4	2	Non-verbal	Public school	Separate classroom
Cameron	5	3	Verbal	Public school	Separate classroom (50%) Mainstream classroom (50%)
Sid	3.5	2.5	Some words and short phrases	Public school (2 days a week) Private school (3 days a week)	Separate classroom (public) Mainstream classroom (private)
Daniel	6.5	2	Verbal	Public	Separate classroom with occasional mainstreaming

Factors Influencing Goals

The two factors influencing goals found to be most important were parents' personal backgrounds and the level of involvement by their immediate and extended family. Personal background included religion, culture, life experiences, philosophy, and other factors that were identified by participants as being relevant to their self-identity or current circumstances. Family involvement included the number of children in the home, proximity and support of extended family, and the nature of interpersonal relationships between family members and the child with ASD. Generally, personal background and family involvement were important factors in parental goal setting. The results below consider these factors as they influenced goals, providing a framework for understanding goal setting and services sought.

Personal background. During the interviews, parents expressed the beliefs, backgrounds, philosophies, and life experiences influencing their individual circumstances and approaches to parenting. Often, personal background influenced the goals parents had for their children with ASD and the services and supports they sought. In order to understand each parent's perspective and construct a framework by which to understand and interpret priorities, goals, and strategies for support, a portion of each parent and child's personal background is discussed below.

Lisa and Ethan. *"I want him to learn to live a normal life, regardless of his disability."* Lisa was a working class mother of four who lived with the father of her youngest child in a rural mobile home community. She had a high school diploma and worked as a medical technician for a nursing center. Lisa's youngest child, Ethan, was

diagnosed with ASD at age two and a half. At the time of the interview Ethan was three years old and non-verbal.

When Lisa's son Ethan was first diagnosed with ASD, Lisa blamed herself. She had used drugs during the first two months of pregnancy before realizing she was pregnant. Upon learning she was pregnant, she refrained from drug use for three months before relapsing. "It was like one day. I promise you, it was one day." She explained with emotion and regret about her relapse. "And then, after that, I quit again. And then I quit the whole pregnancy; the whole pregnancy!"

Lisa indicated she was not highly involved in her older children's lives due to her continued substance abuse. She hoped sobriety would allow her to be a more active and attentive parent to Ethan. As a result of her relapse during pregnancy, she underwent treatment at an inpatient rehabilitation center after Ethan was born. Subsequently, her social worker secured a job for her as a medical technician. She became determined to be a better role model for Ethan than she had been for her other children. After achieving sobriety and securing a job, Lisa felt she had achieved her goal of being a more responsible and supportive mother to Ethan. Her next goal was for him to lead a successful and productive life. Explaining this sentiment, she said, "I wanna make a good, better impression on him than I did with my other kids. So that's why I'm hoping for those things for him. I wanted those things with them, but I wasn't a part of their lives." Social normalcy was particularly important to Lisa, as she emphasized, "I just want him to see that we're normal. He's normal. We're all normal." Lisa's primary goal was to be a good mother who enabled her child to become a successful adult.

Val and Jayden. *"I, above all, hope that he is able to come to know God in an intimate way because our Heavenly Father will be there for him in ways none of us can."* Val was an African American mother of three who was married and had three children. She had an Associate's degree and was very involved in her family, church, and small rural community. Her son Jayden was diagnosed with ASD when he was two years old. At the time of the interview he was four years old and non-verbal.

It was clear throughout the interview that religion and faith were important aspects of Val's life and have played significant roles in her parenting. Val's family changed from one congregation to another because their former church did not have resources to support individuals with disabilities. This negatively affected Val's family because Jayden could not sit through an entire service or attend a regular church nursery. "It's not enough to just have a nursery," she explained. "You have to have a special needs ministry, and, unfortunately, there's only 4% of the churches in the country that have a special needs ministry." One of Val's primary goals for Jayden was for him to develop his own understanding of their faith, which was dependent on his ability to attend worship services at their church. For her three children, this experience "helps them to come to know about God, know that they can depend on God, and know they can see beyond mom and dad as their protector and their caregiver." Val relied on their shared faith to be a source of comfort, support, and protection for Jayden and the rest of her family.

One of Val's other priorities was to educate the community about ASD. This priority related to her goal of cultivating a world that is more accepting for Jayden. To this end, she said:

> Anything that I come across, I share with anybody I know…families who have children with autism – and families or people who *don't* have children with

autism – because I feel like education is the key; I feel like the more I share with the world, the better it will be for him and for other kids like him.

The priority she placed on community education was derived from her experience as an active member of a religious congregation and as an African American. She expressed that both her church community and the Africa American community lacked awareness about ASD. After educating members of her communities, people began to communicate with her and approach Jayden in more understanding ways:

> With my culture in particular, I think educating people has made the difference, because their approach is so much different now. Whereas before they just didn't know; they just based it off of what grandma and them used to do, or what grandma and them used to say…now some people in my family will talk to me about it or they will ask questions like, 'Well, how do I help him?' or 'If we wanted to watch him for you, what do we do?'

Church and family were high priorities for Val, and many of her goals for Jayden were framed within a sense of community belonging. She was highly engaged in her community, especially her church and extended family. Thus, she wanted these communities to be supportive of Jayden. By sharing information and knowledge with community members, she hoped to ultimately create communities of tolerance and acceptance for Jayden and others with ASD.

Erin and Cameron. *"We just want him to be happy; we don't want him to live in a world where he's anxious all the time."* Erin worked as a lawyer in a mid-sized city. She was married with one child named Cameron, who was diagnosed with ASD at age three. At the time of the interview Cameron was five years old and had a verbal ability similar to that of typically developing peers without known disabilities. He had difficulty with emotional regulation and maintaining relationships with peers.

Erin grew up in a family for whom "higher education was seen as the ultimate goal." She and her siblings all attended the same prestigious university, where one of their parents was also an alumnus. Although Erin was proud of her educational achievements, she felt the college experience was anxiety-provoking. "Not that it's not a great place, and I learned so much," she said of her experience. "It was wonderful, but to me college sounds really overwhelming." For this reason, Erin did not prioritize Cameron attending college as an adult. She said, "I know the stress that it places to have to be self-motivating to get oneself through that level of education and that life path." Because Cameron struggled with social anxiety, Erin was not eager to encourage him to pursue undergraduate education, a goal that she had found "overwhelming" to achieve.

Erin believed her decision not to encourage her son to attend college was a notable deviation from her family's traditional focus on education. "I think in some way [attending college] would have been what one would expect would be my vision for my child, even with a diagnosis, and it just is not." Erin's firsthand experience with the stress of completing an undergraduate degree at a competitive university caused her to attempt to minimize stress and anxiety for Cameron as much as possible. Erin explained, "Autism is still so misunderstood. I do think there's that notion of, well Steve Jobs probably had Asperger's…I think there's that notion that there's this real brilliance that happens with high-functioning autism." This misconception was troubling to Erin, who felt that prioritizing Cameron's happiness and minimizing anxiety were more important goals than demonstrating genius.

Vishal and Sid. *"If he can do a task – a job – there will be somebody who will pay him. If there is a payment coming, then he can fulfill his needs."* Vishal and his family lived in a nice neighborhood in a mid-sized city. Vishal had a doctoral degree, and his family had

a combined family income of over $100,000. Vishal's son Sid was diagnosed with ASD at age two and a half. At the time of the interview Sid was three and a half years old and had some language ability, including word repetition and short phrases.

Vishal was a scientist who had previously worked at a pharmaceutical company. He lost his job a few months before the interview and was at home full time caring for Sid. Vishal's scientific training influenced how he perceived the efficacy of his son's therapies. "Therapies: are they truly effective or not? I don't know; I'm not convinced. As I told you, I'm a scientist…I haven't seen the stronger evidence," he said.

Vishal was a member of a multicultural and multilingual family. Vishal was born and brought up in India, and his wife's family was Haitian. They spoke Hindi, Japanese, and Telugu in their home. Although Vishal was raised in India, he said, "I grew up being an atypical Indian – *not* a typical Indian – in a sense that I did not follow any cultural norms." Vishal's mother had an undiagnosed medical condition that resulted in her being ill much of the time. Because he was the oldest child, he carried the responsibility of household work and caring for his younger siblings. This burden affected his beliefs. He said:

> I see these other people talking about religion and books saying God's children
> are equal – it never made sense to me. If God creates, God makes them all
> equal, then why the hell do kids all have different abilities, different
> opportunities?

Vishal was faced with limited opportunities as a child because of his family circumstances, which influenced the person and parent he would become. His lack of religion and identity as an "atypical Indian" cultivated his belief that individuals should be free to violate the norms of the society in which they live. "I learned that society and cultural norms are temporal and spatial variables in the sense that they vary by time; they vary by region; they are not constant."   This personal belief influenced Vishal as a parent. He was not concerned

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with Sid meeting societal expectations dictating he should act a certain way, follow social norms, or be expected to have a spouse or start a family of his own. Rather, he emphasized raising Sid to be independent so he could meet his own personal and financial needs.

Amy and Daniel. *"It would be a complete loss for him to end up in a place that he wasn't celebrated."* Amy and her husband Juan lived in a townhouse in close proximity to a large university. They both had post-secondary degrees and stable jobs. Amy was Caucasian and Juan was Hispanic. They had one child named Daniel, who was diagnosed with ASD at age two. At the time of the interview Daniel was six and a half years old and conversationally verbal. He struggled with social interactions and anxiety, especially when interacting with peers.

Amy worked full time for a non-profit organization serving individuals with developmental disabilities. In exchange for providing goods and services to those with disabilities, the organization asks parents and families to contribute to their mission in some manner that employs parents' individual skill sets. When Amy learned of this policy, she thought, "Well that's just a brilliant idea…I told them how impressed I was with the fact that they ask people what they have to give back." The notion that everybody has talents and gifts to share became a philosophical belief for Amy. It seemed to influence her priorities and goals for Daniel. In discussing her desire for Daniel to form friendships, Amy expressed the sentiment that Daniel's peers had as much to gain from a friendship as Daniel did. "It goes back to everybody has something to give; everybody has a strength; everybody has a gift…he's got lots of them." Amy did not expect typically developing peers to interact with Daniel out of pity or kindness. Instead, she believed his peers would enjoy his friendship as much as he enjoyed theirs.

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Amy's goal for her son to participate in reciprocal friendships with individuals without developmental disabilities was derived from her belief that everyone has specific talents, strengths, and weaknesses. "We all have things we struggle with, and we all have to make up for them in different ways," she said. "So we just talk about the commonality of that." It was important for Daniel to understand it is acceptable to become frustrated or upset by feelings or events in his life, but that he should not act out physically by biting himself or striking another person. To convey this point, Amy related the difficulties Daniel experienced to her own. "I tell him – he takes Zoloft; I take Zoloft. So I'm like, Mommy takes the same medicine that you take because Mommy has a hard time with anxiety. I mean, I don't sit there and make him my therapist, but I just explain to him that it's not all that weird." Amy felt it was important for Daniel to recognize his own strengths and weaknesses and encouraged Daniel to talk about his feelings and actions. "We just talk a lot," she said. "I think that's been one of the biggest things – to just normalize it."

Overall, each parent's personal background influenced the nature of the goals they set for their children with ASD. Lisa was proud because being employed and maintaining sobriety allowed her to be a positive role model for Ethan. She felt her struggles with substance abuse and past failures as a mother had been barriers to the success of her older children, which in turn affected her goals for Ethan's life as an adult. Val was a religious person who had been a part of communities lacking in education about ASD, causing her to educate others about Jayden's ASD and pursue the goal of helping him cultivate his faith. Erin struggled with generalized anxiety related to her own educational pursuits, which affected her goals for Cameron, who she hopes will be able to live with minimal anxiety in his life. As a scientist who doubts the efficacy of intervention services, Vishal was skeptical

about whether or not his son's treatment goals were being met. Coupled with an identity as an "atypical Indian," Vishal set goals based on what he believed will enable Sid to provide for himself as an adult. Amy's life experience and personal philosophy instilled in her a belief that every person has inherent strengths and weaknesses. She applied this philosophy to her son Daniel, and it influenced her goals for him to cultivate self-worth and pursue his talents. In addition to being influenced by their personal background, the parents' goals often related to family involvement in the lives of their children with ASD.

Family involvement. The support of immediate and extended family often played an important role in parents' goal setting and influenced the services and support they sought for their children. The factors considered included the siblings of the child with ASD, extended family involvement and support, and the potential role of family in the child's futures.

Immediate family. All of the parents interviewed had partners who participated in the parenting and support of their children with ASD. While many goals were shared between partners, others were not. Regarding disagreement regarding Sid's adulthood between him and his wife, Vishal said, "I don't care if he has a partner, no children, no marriage. That's not in my vision; however, my wife would like all of this." More often than not, parents expressed gratitude for their partner's involvement in parenting duties and engagement with their children with ASD. This notion was expressed succinctly by Erin, who said, "I'm thankful that I have a spouse. I mean, I really am. I think doing this on my own would be inconceivable."

Of the five parents interviewed, Val and Lisa were the only two who had more than one child. Each of them spoke about the relationship between their child with ASD and their siblings. Both of their immediate families were involved in caring for their children with

ASD to some degree. Val's family consisted of her husband of seventeen years, their 14-year-old son Doug, their two year old daughter Zoe, and their four year old son Jayden, who had ASD. These five family members made up what Val called their "core," and she described how acceptance of Jayden's ASD characterized their family dynamics: "If he's having a hard time or a tantrum, for us, that's normal. You know, if you walked in our house you would be like, 'Somebody do something!' But it's just what we know." Each member of Val's family had a unique and special relationship with Jayden, especially two-year-old Zoe. For example, she made accommodations for Jayden by patting his head when he was upset because she knew he did not like to be hugged. Val felt Jayden's relationships with his siblings helped him to feel included in the family unit. Belonging to their "core" was a critical aspect of Jayden's life as Val envisioned it.

Erin, Amy, and Vishal each had only one child. For Amy and Vishal, the decision to have only one child was influenced by having a child with ASD and feeling unsure about providing the necessary resources to support another child. For Erin and her husband, Mike, the fact that Cameron had ASD did not affect their decision to have only one child. "Mike and I made a decision that we were only going to have one child before we had Cameron," Erin said. "So it had nothing to do with his diagnosis." When Cameron was diagnosed with ASD, some of Erin's acquaintances asked her if she wished she had another child who could provide future care for Cameron, which was shocking to Erin. "What, so I would have a child merely to create a typically developing caretaker for Cameron? No."

Erin believed her pursuit of interventions and services was positively affected by the fact that Cameron was an only child. "Financially and emotionally, we put everything into Cameron," she explained:

> We don't have to make choices about what we are doing for our family. All of it is Cameron; all of it is always in Cameron's best interest, never to the detriment of someone else, or another child. We're never like 'Oh, we really need to do OT, and speech, and social playgroup, so I'm sorry you're not going to be able to do your typically developing basketball league.' We don't have to make those choices.

Because Erin had only one child, she felt she could pursue goals for Cameron in ways that were most beneficial to him. She did not have to balance his needs with that of another child.

Extended family. In some cases extended family played a large role in goal setting and services sought by parents. For example, Erin significantly involved her extended family in Cameron's life, saying "My parents, brother, and sister - who have typically developing children – all understand that they have a responsibility to Cameron, and that their children do." It was important for Erin to involve extended family in her plans for Cameron's future, as she envisioned them playing a critical role in helping him achieve long term success. "Mike and I have just done everything we can to make sure people understand what his needs are, and that these needs will be lifelong." She believed Cameron's needs would be provided for by his extended family. "I do have faith that they will care for him," she said.

Similarly, Amy had assistance in achieving her goals because of the support of her husband's parents, who lived nearby and maintained a close relationship with her son Daniel. "Everything they do is for this child, and it's really, really amazing," she said. "That bond he has with them is very special." Daniel benefitted from both emotional and financial support from his grandparents. "They've helped us financially a lot. They pay for all of his therapy out-of-pocket. And they don't have it – I mean, he's a retired veteran – but they do. The clothes that he's wearing – they bought." Furthermore, the care they provided Daniel enabled Amy to have a job outside the home. "They're the only reason I can work," she said.

Her ability to earn extra income, in conjunction with financial support, helped Amy and her husband afford extra intervention services for Daniel.

Not all the parents in this study benefitted from the support of extended family. Vishal's extended family lived all over the world and provided minimal support. When asked about his family's reaction to Sid's diagnosis, he said, "We haven't told anybody…I chose not to tell my family back in India because I know they don't know what this really means." Vishal believed his family did not have an understanding of ASD or what it meant for Sid to have been diagnosed with the disorder. Furthermore, they were unable to provide support because they lived abroad. "They really can't support me one way or the other, so why would I tell them?" Vishal asked. "I got no purpose. If they're around here, then maybe they would have a different support that they can provide…but they're not here." Thus, Vishal and his wife set goals and pursued services without the support or involvement of extended family.

While many individual factors affected each parent's goals for their child with ASD, personal background and the level of family support were most significant. Personal background was determined by experience, religion, culture, parenting philosophy, etc. The level of immediate and extended family involvement in the care of each child with ASD influenced parental goal setting because it often affected the amount of social, medical, and financial support each child received. The specific goals parents had for their children with ASD are explored in the section below.

Parental Goals for Child

The parents interviewed described multiple goals for their children with ASD, both in the short and long term. Current goals included personal health maintenance,

communication, self-satisfaction, and involvement with typically developing children. Goals

for adulthood focused on higher education, companionship, independent living, employment,

and community. Parents also discussed more general goals for their children's lives and

challenges in their goal setting.

Current goals/priorities. Parents expressed a range of short term goals for their

children with ASD. These goals included personal health maintenance, communication, self-

satisfaction, and friendship-building. Factors involved in formulating goals were the child's

current abilities, parents' personal backgrounds, and the skills parents hoped children would

acquire to prepare them for adulthood.

Personal health maintenance. Vishal and Erin both expressed concerns about their

children's personal health maintenance; Vishal prioritized Sid's self-care, while Erin focused

on Cameron's emotional regulation. Vishal said:

> I want him to get to the self-care level. Self-care in the sense of taking care of
> his bodily needs, taking a bath, or going to the potty; telling us what he needs or
> what he's feeling; if he's hurt or if it's painful.

At age three, Sid was still developing many skills related to self-care, which Vishal

considered critical for future success and self-sufficiency. At five years old Cameron had

already achieved proficiency in toileting and dressing himself, which allowed Erin to focus

more on his emotional health. It was important for her that Cameron practiced emotional

regulation during times of anxiety or frustration. "[I'm] not saying that he never gets

frustrated," she said, "but I do think those are important skills, and I think this is the time for

them – in the next year or two." Erin believed that self-regulation of his emotional state was

a valuable skill for Cameron to be socially successful in the future.

Communication. The parents of Sid, Jayden, and Ethan, who had not yet achieved

conversational language, prioritized the development of their children's communication skills

in the short term. The impetus for focusing on communication was parents' concerns about

their children's abilities to express their needs. For example, Lisa lamented, "Sometimes I

don't understand what he wants; what he needs…If he's hurt or something's hurting him, it's

hard for him to tell me, ya know? That's what I don't like – he's not able to speak." Among

those children who had not yet achieved spoken language, this goal was a top priority.

Self-satisfaction. In addition to prioritizing their children's communication and ability

to manage physical and emotional health, some parents expressed a desire for their children

to experience self-satisfaction and success in their endeavors. For example, Erin wanted

Cameron to be "successful in the way that he wants to be." In this case, 'success' may have

been defined as having a positive interaction with another child, enjoyment derived from

participating in an activity, or engaging in a new pursuit or hobby. "I really hope that he

finds an activity that he really likes," Erin said, "'cause I think that would just give him self-

satisfaction; you know, sort of this pride in himself."

Friendship-building. Erin and Amy expressed concerns about their children's abilities

to build friendships with peers, noting that they did not want their children to become

socially isolated. Amy worked towards this goal by pursuing interactions with typically

developing peers. She said:

> My biggest concern right now is the fact that he really needs interaction with
> typically developing peers. In the self-contained classroom it's really hard to
> facilitate that, so I feel like it's hard to grow in that area right now, because we
> don't have the opportunity.

Because Daniel did not get significant interaction with typically developing peers at school,

Amy proactively tried to facilitate these opportunities through interactions and activities

outside of school. Amy said, "I've been emailing parents from the general education class, like 'Hi, would you like to play with Daniel?'" Amy believed these interactions were important, as she did not want Daniel to be held back socially. This priority also resulted in Amy and her husband disassociating from the word "autism." She explained: "I think some people get really, really stuck, where they just cannot move past it, and everything is just about their child's ASD. And I think some people set the bar extremely low for their child." Amy pursued interactions for Daniel with typically developing children whenever possible in order to meet her goal for him to build friendships.

Regarding Cameron's difficulty in building and maintaining friendships, Erin said, "I think that's his challenge – to really figure out how to interact with someone, how to maintain a friendship, and what it means to have a friendship." Although Erin and other parents tried to help their children engage in friendship-building through interactions with peers, they were often met with frustration. Vishal lamented:

> We do try to make play dates, but they always stop after the first play date. I can never dig in what's the reason; they sensed something [and] feel that their kid is going to be affected by how our kid behaves.

Not only did Sid have personal challenges with social interactions, but Vishal believed he faced further challenges due to the unwillingness of parents to allow their typically developing children to pursue friendships with him.

Goals for child's adulthood. The participants all discussed goals for their children's adulthood. While some expectations were clear, others were more ambiguous. Because the children were still young, most goals were open-ended or involved some level of flexibility. The topics discussed included higher education, employment, living situation, companionship, community, and "the big picture" or general goals for the future.

Higher education. Post-secondary education was not a high priority for most of the parents interviewed. The parent who placed the most value in this goal was Lisa, who did not pursue higher education herself. In discussing this goal she said, "I've heard about some autistic kids going to a regular school or going to college. That's what I'd like for him – to be able to go to a regular school." Recalling the words of the practitioners who assessed Ethan, she said, "I know they're saying that he's develop [sic] delayed, and he's not speaking, but I'm hoping that'll change, and I'm hoping he'll be able to go to a regular school…maybe college, where he'll send mama some money!" Beyond earning a high school degree, Lisa hoped Ethan would achieve post-secondary education in part because she equated a college education with increased financial success. When asked why Ethan's education was important to her, she said, "It strengthens the mind. And I'm hoping his is strengthened." Although Lisa had a high school diploma, her goal was for Ethan to surpass her educational achievement and attend college.

Employment. Lisa, Vishal, Erin, and Amy all discussed the goal of employment for their children. This goal was especially important for both Lisa and Vishal, who placed high value on their children's abilities to support themselves financially. As Vishal put it, "For me, the biggest [goal], if it's possible, I want him to earn his own living." His rationale for this goal was to guarantee that Sid could provide for himself and survive independently. "If he can do a task – a job – there will be somebody who will pay him. If there is a payment coming, then he can fulfill his needs." Vishal was aware of the fact that he and his wife would not be able to care for Sid indefinitely, and with no extended family support in the U.S., his priority was for Sid to become independent.

Lisa focused on Ethan's employment as a meaningful goal for Ethan in part because she was proud that she had secured a steady job. "I just want him to see me working," she said, "because I've never worked before, really." She mused about him thinking, "Where my mama at? Okay, mama's at work." Upon arriving home, it was important for her that Ethan knew where she had been. "When I get here, he knows, 'cause I got a uniform on, he knows I've been at work. So he knows that. And then when daddy leaves in the evenings, he knows daddy's going to work." Lisa hoped Ethan would one day follow in these footsteps, unlike her other grown children from a previous relationship:

> I got a 22 year old – she's not working; she stays with her dad. She's getting back and forth staying with her boyfriend, or staying with her dad, or staying with whoever. And then you got my 17 year old – he stays with his dad; no, he stays with his uncle now; he's not working. Then I got a 9 year old – she stays with my grandma. So I have none of them with me. And, ya know, I'm trying to do the best I can with him.

Lisa felt she had failed to be a positive a role model for her eldest three children, which negatively affected their social development. Therefore, it was important for her to serve as a role model for Ethan. Maintaining employment was an important aspect of doing so because she hoped Ethan would work one day as she did.

Erin and Amy also discussed the goal of employment for their children, focusing on their children having jobs that made them happy. Amy said, "I really want him to be happy. So what does that mean? That's up to him, you know? He says he wants to make video games when he grows up, so I believe he could totally do that." On this subject, Erin said:

> I would be psyched if he has a trade that he loved…if he were to be an electrician, a plumber, something like that, where I feel like it's a skill base that he could acquire, it doesn't necessarily involve this endless human interaction. What, he's going to be a lawyer? No. That is not to his benefit.

Although their motivations and rationales were different, Vishal, Lisa, Amy, and Erin all emphasized employment for their children. The extent to which they valued this goal was dependent on their personal background and priorities. Vishal valued employment because of the financial security he believed it would provide Sid. Lisa valued employment because of her own struggle maintaining a job as a parent. Amy and Erin valued employment because they wanted their children to be involved in rewarding activities as adults.

Independent living. Living situation was another topic discussed by parents, although many parents were uncertain what would be possible for their children. Still, Vishal, Erin, and Amy were all hopeful that their children could live independently one day. Amy spoke about the satisfaction she would feel if Daniel was successful in living independently. "It would be nice for me to know that he could live independently – like I said, with some support – but I think that would be comforting." Erin also hoped for Cameron to achieve this goal, which she thought was realistic. She said:

> In some way I actually can see that he could live independently…he learned how to dress himself late, but not crazy late, you know? I mean, he's five. And, well, toilet training happened at three and a half…so there hasn't been an independent living skill that one would expect a five year old to have that he does not have. So in some way I can't really figure out what would be the difficulty for him. I mean, he'll need support.

Both Erin and Amy believed their children could achieve independent living if they had necessary supports; however, they also emphasized that their overall priority was their children's health and happiness. As Erin said, "I want him to live independently if he can, but that's really if he can, and if he wants to…if he has to live with us, we'll figure it out." Erin hoped Cameron would live independently one day, but she only prioritized this goal if it did not detract from her son's safety and happiness.

Val approached the notion of Jayden's living situation differently, as she already had a tentative plan including semi-independent living with parent support. She said:

> I've talked to several other parents who have adult children, and what a lot of them have done is they have a basement, where they have that set up as their own individual, like an apartment, I guess. So they can have their independence but still be close to them. So, that's kinda, sort of the set up I would like to have.

Val had considered several options for Jayden's living situation, including an apartment attached to their home, living with one of his siblings, or living in a group home. Jayden's exact living situation was not particularly significant to Val, rather her "biggest hope for the future is for Jayden to have the best opportunity to live a wholesome life while fulfilling his life purpose." In Val's case, whatever living situation provided him with purpose and personal satisfaction would be a viable option for the future.

Companionship. Personal companionship was discussed by all parents, although there were significant differences in their points of view on this topic. Vishal did not prioritize Sid having a companion, although that was something his wife hoped for. Erin had trouble conceptualizing the idea of a companion for Cameron, saying "The companion stuff is really foggy. I couldn't even – he's five." Amy prioritized companionship for Daniel, but she defined companionship as more of a loving friend than a romantic partner. She said:

> I always say the only thing I want for him is for him to have a friend. I'm not concerned about him finishing high school or going to college or having a job – I believe those things will happen, if that's what he wants – but I feel like success in life for him would be to have that love reciprocated, in whatever way it is.

It was important to Amy that Daniel received love and support from another individual, whether from a spouse, partner, or close friend.

Romantic companionship was not prioritized by Vishal, Erin, or Amy; however, Lisa

and Val both hoped their children would get married and have families of their own. Each of

them was unsure about the feasibility of marriage, but still they valued this goal for their

children. Regarding Jayden's adulthood, Val said:

> I hope for him to get married. I hope for him to have a family. I don't know if
> he will. I don't know how he's gonna progress. I mean, he may be talking and,
> you know, teaching a lecture somewhere as far as I know.

Although Val was not sure whether or not Jayden would be able to start his own family, she

hoped he would have the ability to pursue this goal as an adult.

Community. Throughout conversations focused on goals for the adult lives of their

children, some parents mentioned the fact that their children would require continued support

past adolescence. This support could come from family, a companion, or from the

community. Building community support was mentioned by Erin, Amy, and Val. Val

actively tried to educate family and community members about ASD and helped them to

understand Jayden's needs. The goal of creating a community of support was important for

Val, as she said:

> I just try to imagine if I'm not around…everybody else don't know him like I
> know him. So for him to be able to function in a world that doesn't know him
> and be safe and protected and flourish…

Val found that, after learning more about ASD and spending time with Jayden, many people

in his family and community developed strategies for comforting, communicating, or playing

with Jayden that were responsive to his needs. Val believed building a supportive

community helped ensure that Jayden had support and care beyond his immediate family.

It was also important for Erin to provide a community of support for Cameron. Erin

had been a member of the Catholic Church during childhood, but she no longer practiced as

an adult. After Cameron was diagnosed with ASD, she joined a Unitarian Universalist

fellowship, which she felt would be an inclusive community for Cameron. "Cameron got

diagnosed, and I thought 'Oh my gosh, I have got to have a larger community for him. He

needs – he will need, our family will need – to have a larger community.'" Both Erin and

Val believed the community involvement was beneficial to their children. "This is our

second year of it," said Erin, "and it's important. I truly believe that it's important for him to

be part of this community."

Rather than join a community organization, such as a religious congregation, Amy

found existing supports within the community that benefitted her child. She felt community

involvement would facilitate Daniel's independence. She said, "I do believe that it would be

good for him to have support, and probably necessary to have support in the community, in

order to go to college or to have a job." Amy formulated this goal because of experiences

she has had as the mother of a child with ASD and the types of challenges she believed

Daniel may face as an adult:

> We have periods where everything falls apart, and I don't know what that looks
> like when you're twenty. I mean, that's scary to me. What if you fall apart at
> Chick-fil-A and you're twenty, and nobody knows why? And he's arrested or
> something – you know? So that's why I feel, on this trajectory, that he would
> need some support.

These concerns reflected the uncertainty Amy faced when considering her child's future.

Because of this uncertainty, the details of her goals may change over time. Regardless of the

specific priorities and abilities of their children, parents hoped that building communities of

support would increase the likelihood of them having safe, healthy, and happy lives.

The big picture. Although specific goals and priorities were often dependent on

individual circumstances, parents expressed general hopes for their children's futures that

were not based on specific details. Rather, these goals focused on more abstract desires, such as their children's happiness or place in the world. Although most 'big picture' goals were important to parents, they were also relatively ambiguous, since parents believed the future to be uncertain.

The overarching goal for Jayden was for him "to be the best that he can be." This big picture goal showed Val's focus on his abilities rather than his limitations. By setting a broad goal that was informed by Jayden's abilities, Val increased the probability that Jayden would meet this goal in the long term. Erin's overall goal for Cameron was for him to find happiness and purpose in life. "We want Cameron to be happy…we don't want him to live in a world where he's anxious all the time," she said. She believed this goal was realistic because she, family members, and community partners worked diligently to provide for Cameron's needs. "I have a lot of faith in Cameron's skill and my ability, Mike's ability, [the] public schools' ability, and all the services that we seek to find a placement for Cameron in the world." It was not immediately apparent what Cameron's 'place in the world' would be, but Erin expressed confidence that goal would be met.

Amy's overall goal was for Daniel to be valued by people in his life, whether they were family members, friends, co-workers, or community members. She said:

> I just want him to be happy and to feel valued. Really, that's it. I think I try to
> live as a mother – I try to be the kind of mother that he knows that I live in
> amazement of him. And that he's enough and I feel so very lucky. And I don't
> ever want to make him feel like he has a deficit in any way.

Amy hoped for Daniel to feel happy and valued, regardless of his ability to gain employment, live independently, or have a significant other. Amy placed higher priority on this big picture goal than on other details of Daniel's adult life.

Some parents' big picture goals were rooted in frustration and a desire for normalcy. One parent who was vocal about this challenge was Lisa, who maintained hope for Ethan to live what she viewed as a normal life:

> I don't know, I just want, I mean, I just want him to be normal. I say that a whole lot. Even when I get frustrated with him, I'm like, 'I wish you were normal, I wish you were normal.' You know, normal kids go to normal schools…I want that for my child.

Whether Ethan will ultimately achieve what Lisa perceived to be a normal life was not yet clear to her; however, the frustration she felt regarding some of his challenges was obvious. "I wish some of these traits would go away, and some of 'em I can live with," Lisa said, referring to the behaviors she associates with her son's ASD. "I can live with the toe walking. I can't live with that noise [referring to noise of plastic bucket shaking]. I can't live without him talking." Lisa's goals for Ethan's adulthood were not always in sync with his development. This misalignment of expectations and reality challenged and frustrated Lisa as she pursued her goals for her son.

As described above, parents' goals for their children with ASD were classified as either current goals/priorities or goals for adulthood. Current goals/priorities focused on personal health, communication, self-satisfaction, and friendships. Goals for adulthood focused on the topics of higher education, employment, living situation, companionship, community, and big picture goals. Parents also spoke about challenges they faced when pursuing goals. In many instances, the goals discussed affected the intervention strategies, services, and supports parent sought for their children. Additional strategies will be explored in the section below.

Intervention Strategies, Services, and Supports.

Parents expressed many goals for their children with ASD, many of which were pursued through informal supports such as family involvement, play dates with peers, or church services. Parents also took advantage of more formal or structured supports to achieve their goals, such as interventions and external services outside of school and internal services provided by the children's schools.

External services. Parents generally pursued intervention strategies, services, and support based on the goals they had for their children with ASD. The types of services most often sought were developmental therapies, such as speech, occupational, and behavioral therapies; social supports; and physical activities. Parents also discussed the role of practitioners as allies in the care of their children and the burdens relieved by support specialists who shared goals with parents. Finally, parents noted challenges in the implementation of services.

Developmental therapy. All of the children participated in speech, behavioral, or occupational therapy at school, home, or both. Lisa was the only parent who was not engaged in formal intervention services outside of school. Val, Erin, and Amy credited external therapies for some of their children's progress. Val described how specialists had helped her learn more about Jayden's abilities:

> We didn't know until his speech therapist said, 'Do you know he knows his colors?' And we were like, 'What?' And she said, 'Watch this.' And she would say, 'Okay Jayden, pick red.' And he would pick it. She would say 'Pick blue.' And he would pick it.

Val valued the service providers for helping Jayden achieve specific goals and for sharing the burdens associated with treating Jayden's ASD. Vishal's son Sid was also engaged in

therapies outside school, although Vishal was unsure about the extent to which they

benefitted his son. Still, he continued to pursue therapy several days a week, saying:

> Just because I don't see evidence, it doesn't mean I have the conviction to say I
> should not try. There is no proven harm. So I personally believe, same as my
> wife, we need to do as best as we can to help him…I don't want to think back
> five years from now that I didn't do what I could afford to do.

As shown above, parents pursued interventions aggressively and viewed these services as

helpful to their children.

Social supports. In addition to speech, behavioral, and occupational therapy, social

support services were another primary support that parents discussed. Vishal, Erin, and Amy

all discussed the priority of facilitating interactions with typically developing peers either in

school, through one-on-one interactions, or through group social services. "Mike and I take

advantage of every single pre-social group thing out there because we think it's really

important," Erin noted regarding the social support focus. To further pursue this goal, Erin

considered enrolling Cameron in partner behavioral therapy with a peer. "At this point we

need to do more of Cameron with another child, rather than just the behavioral therapist

working with Cameron," she explained. "I think that's where we are developmentally for

Cameron. I think last year he still needed the one-on-one to really build up the social

communication, but maybe we're ready for that." In Erin's mind, behavioral therapy alone

was insufficient if her goals were to be achieved. Rather, she wanted Cameron to practice

behavioral skills in conjunction with a peer to better prepare him for using those skills in

daily peer interactions.

Physical activity. The final service parents discussed was physical activity. Erin,

Amy, and Vishal all mentioned the importance of physical fitness. Amy pursued this goal by

enrolling Daniel in a Karate class serving children with and without disabilities. Vishal

brought Sid to a gym program to expend energy and interact with other children. Erin's son Cameron was enrolled in buddy basketball, a program pairing children with disabilities with volunteers on the basketball court. "I think it's good to have the exercise piece," Erin said, regarding this service. These types of services were sought because of the physical benefits, the interactions they facilitated, and the enjoyment they provided.

Practitioners as allies. Some parents discussed the value of practitioners, therapists, and other educators because they served as advocates for their children. When Cameron was first diagnosed with ASD, Erin contacted service agencies and accessed as many services and supports as possible. "The way I have always handled stress or anxiety is to become extraordinarily proactive," she said. This skill provided immediate benefit, as Erin built a network of support for herself and her child. "I really took advantage of all the [local] agencies," she said. "I thought they were allies." Val shared in the opinion that area service providers were essential in helping to treat her child. On that topic, she said:

> You can't do it on your own. I mean, you can, but chances are you are
> overwhelmed with the guilt; you are overwhelmed with a task that's too big for
> you. And I don't care how much you love your child. You can't give them
> enough. It's like a bottomless pit – it's just never gonna be enough.

Those parents who found support in intervention strategies and services felt they had gained valuable partners in pursuit of their goals.

Challenges. Although external services and service providers provided many benefits to parents, identification and implementation of strategies was not without challenges. Such challenges were described by Val, who had difficulty identifying new resources and information to meet Jayden's needs. To that end, she said:

> If there was just a little bit more transparency with getting support for children with
> disabilities, I think that would make a world of difference for families. 'Cause right

now it's hard enough being the caregiver all the time and trying to stay on top of their needs, but then when you're trying to navigate that system, it's like a nightmare.

Not only was navigating the system difficult for Val, but at times she struggled with implementing Jayden's intervention strategies while juggling her other family responsibilities. She said, "Where I struggle is having the time to implement or, if I have the time, then I'm dealing with the meltdown, or I'm dealing with the two-year-old meltdown, or I'm dealing with the fourteen-year-old meltdown." Although Val highly valued Jayden's interventions, she was only able to devote a certain amount of time to his services due to her other parental responsibilities. Thus, the help she was able to receive from outside service providers was essential.

School contribution. The participants' children all attended school five days a week. All children were enrolled in a separate classroom for children with disabilities for at least part of their time in school, and most children were in a separate classroom for the majority of their school day. Parents spoke about the large role school played in the lives of their children. Most were very happy with their child's school, but parents occasionally expressed dissatisfaction with the actions or attitudes of school personnel. Generally, parents felt that school was a vital component in providing services to help their children achieve their goals.

School satisfaction. School was seen by most parents as an essential partner in the pursuit of goals for their children with ASD. Parents were satisfied with educators' skills and abilities, the school's flexibility/adaptability to meet goals, and communication. As Erin said, the "public schools always had my son's best interest at heart." This comment reflected the sentiment most parents' felt about school.

Educator ability. Most parents believed their children benefitted from high quality education and services. For example, Val's four year old son Jayden was enrolled in a rural

public school system in separate pre-kindergarten classes for children with developmental disabilities. Val reported that Jayden loved going to school, and Val appreciated the efforts of his teachers. "I think they're doing wonderful," she said about the school. "I don't have any complaints." Similarly, Erin was satisfied with the quality of the teachers in Cameron's school, which was part of a large public school system in a diverse, mid-sized city. Cameron had a school placement in a self-contained classroom with some mainstreaming during the day. Erin felt comfortable pursuing this educational path because she "[felt] confidence in our teachers." This general belief in educators and practitioners caused parents to view the school as a partner in the education of their children.

School flexibility/adaptability. Another key component to school satisfaction was the schools' willingness to tailor the educational plans of each child to meet the parents' goals. For Erin, the ability to have Cameron spend time in both a separate and a mainstream classroom was important. "He is mainstreamed for about 50% of his time in a mainstream pre-K classroom," she said. "I think the balance now is great." At first the decision to have Cameron split time between classrooms was difficult, but the support of the school throughout the decision making process was immensely helpful. "Pulling Cameron out of [the] mainstream [classroom]," she remembered, "it was not easy to do. But I am not medicating my child for anxiety without first trying to minimize the stressors for him." Erin made the decision not to push Cameron into the mainstream class before she believed he was ready, and the school provided flexibility to facilitate this plan. Eventually Erin wanted to see Cameron thrive in a classroom with typically developing peers, and she hoped he was making progress towards that goal. "I really feel strongly that the separate environment is critical to give him the building blocks so that he actually can be more successful in a

mainstream classroom." Erin believed the school was helping her achieve both her immediate and long term goals for Cameron.

Some of Erin's school-based goals were similar to those of Amy, the mother of the oldest child discussed in this study. Amy's six year old son Daniel was enrolled in a small public school system in a college town. His school placement was in a self-contained classroom for children with disabilities, but, as Amy said, "He also spends some time in the general education class too. We're working on that." Academically, Daniel was above grade level, so it was important to Amy that Daniel's teachers continued to challenge and engage him. Still, Amy appreciated that Daniel's teachers were receptive to his needs and able to identify when he needed the support of the separate learning environment.

> They are really, really good about being flexible in the way that they work with him, which means that if there is a day that is just not a good day, they reduce the expectations, scale it back. You know, 'Well, we were going to go to art with the first grade class today, but we're not going to do that because it's too much.' So that is huge.

Amy was satisfied with Daniel's teachers' willingness to push him academically while reducing the emotional and intellectual demands of the classroom when necessary.

Communication. Communication between school personnel and parents was very important for participants. Amy was pleased because Daniel's teacher emailed her several times a week to discuss ideas, introduce new initiatives, or simply to exchange information about what happened with Daniel throughout the school day. When Lisa discussed her three year old son Ethan, who was enrolled in a separate pre-K classroom in a rural public school, Lisa said, "It is wonderful." The only intervention Ethan received was the occupational and speech therapy he got at school, so Lisa was grateful for these services and to the school for informing her about his progress. "I get feedback; they write it down for me," she said. "I

just haven't had a chance to go to the school – 'cause of my hours – to really talk to them, 'cause I never really know what days they're there." Although Lisa had not had time to attend school meetings because of her work schedule, the school's services and ongoing information were greatly appreciated.

Overall, several parents believed the schools focused on the child's best interest. Erin provided an example of this when recounting an IEP meeting in which she and school personnel discussed Cameron's classroom placement:

> I just remember one of them saying, 'Remember, this is not about you. You need to get over yourself in terms of feeling like, oh I want my child in mainstream, and realize that that is not necessarily the most supportive environment for Cameron.'

This perspective from a special education teacher encouraged Erin to place Cameron in a separate classroom, and it also resulted in a realization that the school had the best intentions for her son.

Concerns regarding school. Although parents were generally satisfied with their children's schools, a few expressed distinct disappointments as well. Some dissatisfaction arose when parents felt educators inadequately advocated for their children or failed to help them to understand school policy or state laws. To that end, Vishal said "there is no advocate, nobody on the parent side, so now it is becoming a burden on the parent, so what is the law is really doing?" Other difficulties derived from educational placement in separate classrooms and appropriateness of fit for their children.

Lack of educator alignment. A significant amount of frustration was expressed by Vishal, whose son Sid spent two days a week in a separate public school classroom and three days a week at a private school with typically developing classmates. Vishal did not feel that the educators in the public school system related to him as a parent. Rather than providing

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him with helpful information or resources, educators provided minimal assistance. To that end, he said:

> They just give the answers per the law or the talking points. They only answer from the question that you ask, not any other things that may be available, or other things that are possible, or other things to think about.

Vishal did not feel aligned with the school in the pursuit of goals for Sid and was frustrated with the lack of assistance from school personnel. He lamented:

> I need to become the expert myself. In the whole educational law, my rights, the resources, not only the law and my rights, but also how the whole school system works. If I need to learn all of it, then how am I going to do my own job to earn a living?

This dissatisfaction limited Vishal's ability to pursue both his career and resources and services for his son. "The whole public school systems, I don't feel any of them are advocating for us," he said. "They are just doing a job because they have a job, and they have to do that because the law says so." Vishal felt school personnel were only making minimal effort to educate his son and doing so only because they were required by law. Rather than feeling able to partner with the school to accomplish his goals for Sid, he felt isolated by the school's lack of communication and the minimal assistance they provided.

Child's classroom placement. A second concern shared by parents was the classroom placement for their children. Vishal, Erin, and Amy all hoped their child would one day have a mainstreamed classroom placement. Although Vishal was frustrated by the numerous laws surrounding education for children with disabilities, he realized these laws were designed to benefit the child. "Before the law they could just put them in a separate class," he said. "So maybe that's the good thing about it." Vishal appreciated the law in this regard because he believed children with disabilities benefit from educational environments where typically developing children can act as role models.

Although Erin valued the supports the separate classroom provided Cameron, she had concerns about Cameron's abilities relative to his peers in the separate class. She said, "I think he was the highest functioning there, and that was tough." The fact that Cameron was a high functioning student in a separate classroom was difficult for Erin, especially when he began mimicking the non-verbal cues of some of his classmates. "I found that hard because, even though he himself was verbal, he was picking up a lot of non-verbal ways of communicating," she said. While, Erin appreciated some aspects of the separate classroom, she was unsure about which placement was most appropriate for Cameron in the short and long term.

Similarly, Amy said her "one disappointment with school" was the fact that Daniel did not easily fit into a category of either a separate or a mainstreamed class. "[In the separate class] he is the highest functioning child; he is by far the most verbal and social child," she said. "However, he can't go to a classroom with twenty-five kids, where he needs more one-on-one support." This underlying theme of a lack of fit was frustrating for Amy, who hoped Daniel's academic strengths would continue to be supported. "At some point if you're in self-contained, you're not on the standard course of study anymore. And that's not fair, you know? This child can get a diploma – and should – and should have the same opportunities." Although Amy believed the school was not at fault for Daniel's lack of fit into one of the two tracks offered, she would be disappointed in the school if he was unable to earn a diploma.

Suggestions for improvement. Those parents who were disappointed with their children's schools had suggestions for ways in which schools could do more to help children achieve their goals. Suggestions focused on a centralized model of services, facilitating interactions with typically developing children, and a new type of classroom featuring

"reverse inclusion." All suggestions were designed to help parents achieve their goals for their children.

Some of Vishal's frustration stemmed from the disjointed nature of the services provided to Sid by his school. "Right now, it's like everything is so contained and so partitioned, and the team doesn't work as a team. Everybody does their little piece. Whether it's really working or not, it doesn't seem to matter." He felt that when Sid transitioned from place to place or from service provider to teacher, he lost focus, energy, and momentum. Because the services provided by school were insufficient or disorganized, Vishal considered independently pursuing them himself. "Maybe one day I will create a business model or a system where…you have every service that one needs under one umbrella – meaning physical location – and the kids can fully explore and learn about themselves." This holistic view of education and intervention was important to Vishal, and in his mind the school was failing to provide Sid with this type of care.

One of Erin's biggest concerns for Cameron was for him to interact with typically developing peers while at school. "I'd like to know that they're really trying to facilitate his interactions with other children when he's in his mainstream classroom," she said. Erin believed it was important for Cameron to have meaningful interactions with typically developing peers, not only for his benefit, but also for benefits and learning opportunities the interactions could provide his mainstreamed classmates. "Are they trying to teach children kindness to others?" she wondered. Her goals in this area transcended those she had for Cameron and encompassed her hopes for society as a whole. She said,

> My goals are that somehow Cameron grows up in a world that is more tolerant
> for kids who are different, or adults who are different…you just want to know
> that we are creating a community that is more tolerant than we have been.

Similarly, Amy wanted Daniel to be given the opportunity to interact with typically developing peers while at school. She asked school personnel if it would be possible to do "reverse inclusion," where typically developing kids would spend time in the separate classroom. The benefit for Daniel would be: "he can build a rapport with them, work on those friendships, relationships, and then maybe feel more comfortable going with them to PE, art, or math." She believed the mainstreamed students would benefit from the friendships with students like Daniel because of the opportunity to learn character building and compassion in the separate classroom. The school so far had balked at her idea, which was frustrating to Amy. She valued Daniel's academic abilities and wanted him to get the support he needed from the school, if not in a general education classroom, then in an innovative new kind of classroom. She saw this as "a smaller classroom that [is made up of] some typically developing children, some kids with different abilities…some kind of hybrid." In order for Daniel's school to help him achieve these goals, they need to be willing to consider new ideas to meet the needs of students like Daniel.

In summary, the five parents interviewed were all focused on achieving the best outcome possible for their children with ASD. The ways in which they defined their specific goals varied based on their individual circumstances. Long term goal setting was influenced by factors such as personal background and the level of family support. Current goals and priorities were often also influenced by the child's development. Goal setting ultimately affected the intervention strategies, services, and supports parents pursued for their children, both in and out of school. The use of parents' own words throughout this text provides unique accounts of their goals, the factors influencing these goals, and the ways in which these goals were pursued.

Chapter 5: Discussion

The purpose of this study was to explore the personal and educational priorities and goals parents from diverse backgrounds had for their children with ASD. A secondary research question was to determine how priorities and goals affected the services and support parents sought. Data were gathered through qualitative, in depth participant interviews between the primary student researcher and a parent of a child with ASD. Data analysis revealed several topics of interest within three key themes. Within the theme of parental goals for children are the topics of high hopes, independent living, employment, and desire for normalcy. Within the theme of formulation of goals are current abilities of children, cultural views of disability, and individual experience. Within the final theme of services and supports are parents' alignment with school and informal and formal supports. These themes, as well as limitations, directions for future research, and implications for practice are discussed in the sections below.

Parental Goals for Children

Parents expressed both immediate priorities and adulthood goals for their children with ASD. Specific goals were reviewed in the results section. Key findings related to the topics of high hopes, independent living, employment, and a desire for normalcy are discussed below.

High hopes. A common theme across the interviews was the high hopes parents had for their children with ASD. Some parents hoped their children would go to college or get married. Others hoped their children would live independently, sustain themselves

financially, and/or have fulfilling careers. Some parents held high hopes without planning

for the alternative. For example, Lisa had not formulated specific goals related to Ethan's

living situation or career. Vishal fervently hoped Sid would achieve independence because

he was daunted by the prospect of his son being unable to care for himself. Even Val, who

had formulated a plan that involved Jayden living in an apartment attached to her home,

maintained hope that Jayden would eventually start a family or attend college. Most parents

did not have a specific plan, saying only that they would "figure it out" in regards to living

situation, finances, or caring for their children as adults.

Parents were unwilling to accept a low level of functioning for their children's futures.

One reason behind parents' high hopes could be the young age of their children. With many

years before their children reach adulthood, parents did not have a clear picture of how their

children would develop. Some parents noted their children had changed so much in the last

year, they could never know what they would be capable of in another year, let alone in

adulthood. Research by Powers et al. (2009) among adolescents with disabilities found that

parents' top priorities were for their children to finish high school, have health insurance, and

have a good doctor. These goals are more specific and pragmatic than the general high hopes

expressed in this study among parents of younger children. It may be that parent

expectations change over time based on their children's level of functioning. It is also

possible that parents approach goals one day at a time based on the age and needs of their

children. Rather than focusing significantly on goals for adulthood, the parents in this study

may have been more focused on current goals for their children.

Another possible explanation for parents' high hopes might be that some parents

continue to maintain high hopes for their children regardless of circumstances. It is possible

that some parents of older children or adolescents would hope for their children to continue to progress developmentally and achieve skills they had not yet acquired. This notion has been supported somewhat by previous research among parents of diverse cultures. Specifically, among cultures who view disability as something to be accepted rather than treated, parents may expect their children to live typical lives (Kalyanpur, 1999). In this study, parents' high hopes framed many of their goals, regardless of the specific priorities or reasons goals were formulated.

Independent living. One topic of concern for parents was their children's future living situations. Previous research has shown European American parents to be the most proactive in preparing their children for independence, while Latino and African American parents focused more on employment goals than on independent living (Zhang et al., 2010). Previous research was supported somewhat by Amy and Erin in this study, who were both focused on preparing their children to live independently. Their children also had the highest functioning at the time of the study, which may have influenced their belief in the feasibility of this goal. Vishal also placed high value on preparing Sid for independent living. Previous research is unclear as to whether this goal is shared by other members of the Asian or Indian cultural group. Val's goals also aligned with the previous research of Zhang et al. (2010) in that she was not overly concerned with preparing Jayden to live independently. However, rather than focusing on employment, she prioritized his religion and sense of belonging in the community.

Interestingly, Lisa did not highly value independent living for Ethan, as previous research by Zhang et al. (2010) would suggest is typical of European American parents. Rather, she said she would "miss him too much" if Ethan lived somewhere other than with

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her. Previous research has indicated that European American parents of different socioeconomic status have varying goals for their children (Kohn, 1963). In this case, her low socioeconomic or other individual factors status may have caused her goals to deviate from those of other European American parents.

Employment. Employment was another topic of interest, with parents prioritizing this goal for a variety of reasons. Amy and Erin both hoped their children would eventually find employment, mostly due to socio-emotional goals. Erin said she would be "psyched" if Cameron had a trade that he loved. Amy supported Daniel's goal of designing video games. This priority may be related to notions of self-satisfaction and self-confidence, which previous research has shown European American parents to prioritize (LeVine, 1980). Not only did Amy and Erin want their children to have careers that provided an income, but they also wanted their children to feel fulfilled and satisfied.

Vishal and Lisa placed extremely high emphasis on their children achieving employment as adults. Interestingly, Vishal and Lisa represented the highest and lowest earners in this study, and their motivations for prioritizing this goal were different. Vishal seemed to take a pragmatic stance towards this goal, wanting Sid to earn a living so he could function independently and provide for his needs. Lisa's goal seemed to relate to Ethan seeing her as a role model. She overcame personal struggles in order to secure a job, and she hoped Ethan would follow in her footsteps as an adult. Because Lisa lived below the poverty line, her goal may also have been related to financial struggles and firsthand knowledge of the importance of earning a living.

Normalcy. A final topic of interest for parents was a desire for normalcy. Lisa was the most vocal about her desire for normalcy, prioritizing this goal for both Ethan and

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herself. Lisa hoped to be a role model for Ethan by going to work and being an involved

mother. She wanted Ethan to explicitly recognize that she was engaging in what she

perceived to be a normal lifestyle by going to work each day and abstaining from drug use.

She wanted the same for him in the future, not wanting his ASD to stand in the way of her

personal goals as a mother. Because she was not able to be a role model for her other

children, the goal of normalcy was of particular importance to her with Ethan.

Val also discussed the concept of normalcy, redefining what normal meant for her

family. Val used the phrase "our normal" many times to describe the ways in which her

family was different from other families but typical for her. For example, she believed her

household was noisier and more chaotic than those of other families, but those dynamics

were still typical for her. This normalization of the effect of ASD on the family dynamic was

a critical component of some of Val's goals, such as the ability of her family to go to church.

The process of attending church as a family unit was a challenge for Val, but she was

determined for her family to attend church together. She searched until she found the support

Jayden needed in order to maintain this important, typical practice for her family.

Formulation of Goals

Parents formulated short and long-term goals for their children in a variety of ways,

some of which were made explicit by parents and some of which were derived from

interpretation by the researcher. Key factors influencing goals were the current abilities of

children, cultural views of disability, and the individual experience of the parent. The

sections below discuss how these topics affected goal setting in order to provide increased

understanding regarding formulation of goals.

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Current abilities of children. Children's current abilities greatly influenced parents' short-term goal setting but did not play a significant role in long-term goal setting. Lisa and Val, whose children were not verbal, prioritized the immediate goal of attaining communication skills. Vishal, whose son possessed some verbal ability, prioritized both communication and self-care. Amy and Erin, whose children were fully verbal and had attained many self-care skills, prioritized social interactions and relationship building. In these ways parents' short-term goals were in line with their children's cognitive and socio-emotional development. The fact that parents have realistic expectations of their children's abilities is supported in the literature by Harry et al. (1992), who showed that culturally diverse parents who had varying views on disability and normalcy also exhibited realistic notions of their children's strengths and weaknesses.

Current abilities of the child did not appear to influence long-term parental goal setting in the same manner as short-term goal setting. Some parents said they set goals based on their children's current abilities. Erin and Amy believed their children could achieve independent living and employment based on some of their demonstrated current abilities. They mentioned intelligence, self-care, and other skills that might make independence possible for their children. Interestingly, Val and Lisa also believed their children could possibly achieve independence. For example, although their children did not have verbal abilities like those of typically developing peers, they did not believe their children would remain non-verbal. Val hoped Jayden might be able to teach a lecture in the future, and Lisa hoped Ethan would go to college. These hopes were not due to their children's current abilities, but were based on the premise that anything could happen in the future. They stated that they did not know how their children would develop or what the future would bring.

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While current abilities played an important role in the formulation of short-term goals for children with ASD, long-term goals seemed to be affected more by the culture and individual experiences of parents.

   Cultural views of disability. Out of the five parents interviewed, two were part of the U.S. majority culture, whose beliefs are espoused by most schools and service providers (Kalyanpur & Harry, 1999). As Caucasian parents with middle class earnings, Erin and Amy were part of the U.S. majority culture. While Erin and Amy shared a majority culture view of disability, they did not have similar personalities, nor did they share all the same specific goals for their children. For example, Erin did not want Cameron to endlessly play video games as an adult, while Amy encouraged Daniel to follow his dreams of becoming a video game designer. Erin felt strongly about not medicating her child for anxiety; Amy was open about the fact that she and Daniel both took Zoloft. Still, some of Erin and Amy's overall belief systems and broad goals were similar. Both were open about their children's diagnosis and connected to other parents with children with ASD. Both were concerned with providing opportunities for their children to interact with peers and the larger community. Both actively sought formal supports and were highly engaged with their children's schools. Although they had different personalities and experiences, in many ways they prioritized and pursued goals similarly to other members of their majority culture group (Landmark et al., 2007; Rogers-Adkinson et al., 2003; LeVine, 1980). While their personal backgrounds affected their specific goals and current priorities, their culture affected their big picture goals and pursuit of formal supports. This finding may relate to the medicalized view of disability in the U.S. majority culture (Kalyanpur & Harry, 1999). As members of the U.S. majority culture, Erin and Amy may be more likely to believe in the importance and efficacy of

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formal supports, regardless of the specifics of their goals. The understanding of ASD as something requiring treatment may have deeply affected their goal-setting and strategies for their children with ASD.

Three of the parents interviewed were not part of the majority culture. Val, who was African American; Vishal, who was Asian (Indian); and Lisa, whose earnings were below the poverty line (United States Census Bureau, 2013), were all members of minority cultures. Although Lisa was Caucasian, previous research suggests that living in poverty influences priorities in parenting, resulting in goals for children that are not aligned with those of the majority culture (Kohn, 1963). For example, parents with lower socioeconomic status tend to place higher emphasis on television and pragmatic discussions and less emphasis on play (Rowe & Casillas, 2011). Given this previous research and Lisa's priorities for Ethan, she seems to align more with a minority cultural view of disability.

Some goals of the parents from minority cultures were less aligned with that of the majority culture. Just as Amy and Erin were vocal and open about their child's ASD, some parents in minority culture were more private. This desire for privacy may relate to findings by Harry et al. (1992), who found that some members of minority cultures prefer not to overtly label or discuss deficits about their children. Vishal and his wife had not told their extended family about Sid's diagnosis. Vishal also was not a member of the larger community of parents with ASD. Rather, he had connected with others with children with ASD in more discrete ways. For example, Vishal conversed with a colleague about their children with ASD after he happened to mention a service provider with which Vishal was familiar. Similarly, Lisa did not have acquaintances with children with ASD, nor was she involved in the ASD community.

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As a vocal parent who was highly focused on educating others about ASD, Val represented a different picture of a parent from a minority culture. Still, she believed the African American community in general lacked awareness about ASD. Only after she took the time to educate her family and community members about ASD did people begin to open up to her about Jayden's diagnosis. It is possible that Val never held the same views as other members of her culture. It is also likely that her perceptions of disability and ASD evolved since having a child with ASD. Her cultural background did not seem to greatly impact her notions of disability or the ways in which she communicated Jayden's needs to the community.

Individual experience. Although parents' goals seemed to be affected somewhat by their cultural backgrounds, they also were greatly influenced by their individual experience. For example, Val identified as an African American, but also as a member of her church. Her identity as a religious person greatly affected her goals for Jayden. When asked to name her top priority for his future, she expressed the desire for Jayden to develop an intimate relationship with God. Val's focus was similar to that of other religious parents of children with disabilities, who also felt it important to include their children in religious and community activities (Jegatheesan et al., 2010). In this way, Val's experience as a person of strong faith was the most important factor related to her goal setting for Jayden.

Lisa was similarly affected by her individual experience. As the only parent interviewed who did not pursue education past high school, Lisa was the parent who was most vocal about hoping her child would go to a "regular school" and possibly college. Lisa may have prioritized this goal because she regretted being unable to support her other children's education. Another possible explanation is that she hoped Ethan would surpass

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her in education level, income, or quality of life. This focus on upward mobility might have influenced her goals for Ethan. Lisa's goal for Ethan to attend college was different from that of Erin, for example, who did not prioritize higher education for Cameron. Because Erin had the individual experience of higher education, attending college was not an abstract dream. Rather, it was a stressful personal experience she did not want for Cameron. Erin's individual experience attending college influenced her goal setting just as the fact that Lisa had not attended college influenced her.

Services and Supports

Parents set goals for their children based on a variety of factors, such as their child's current abilities, their cultural background, or their individual experience. Goals ranged from high hopes in the realms of independent living and employment to an overall desire for normalcy. The ways in which parents set goals, as well as the personal background of each parent, affected the services and supports they sought for their children with ASD. Services and supports are explored in terms of parents' alignment with school and involvement in informal and formal supports.

Alignment with school. Most of the parents interviewed greatly valued the work of the school, with some parents experiencing close relationships with school personnel. Erin, Amy, and Val were most vocal in their views about seeing school personnel as allies. Erin and Amy seemed to have the highest levels of communication with the school. While Val greatly appreciated the work of the school, she was less vocal about communicating with school personnel than about her efforts outside school. These findings support previous research by Landmark et al. (2007), who found that European American parents place high value on communicating with the school about their children with disabilities, while Asian

and African American parents more highly valued working with their child at home. Lisa also valued the work of the school and the feedback they provided her, but she mentioned never having attended a meeting at school due to her work schedule and other factors. This lack of communication with school may relate to her low socioeconomic status and work demands. As is shown is previous research, parents of lower socioeconomic status are less likely to believe in their own self-efficacy, or the notion that their actions influence their children's adulthood (Elder et al., 1995). Although Lisa valued the work of the school, she may not have viewed herself as integral to Ethan's intervention.

Vishal was the parent who expressed the most dissatisfaction with the school, in large part because he did not feel he had an advocate in the school system. In many ways his dissatisfaction was a result of negative experiences with practitioners. Some negative experiences may have been exacerbated by the fact that Vishal moved to the U.S. as an adult, so he did not experience the U.S. school system himself. Previous research indicates that immigrant parents who attended school outside the U.S. are often misunderstood by their children's U.S. educators (Cheatham & Santos, 2005). Because Vishal did not experience the U.S. educational system, he was at a disadvantage when navigating the U.S. school system and engaging school personnel. This lack of alignment with school personnel is especially troubling given previous research indicating parental involvement in education is insufficient, especially among culturally and linguistically diverse families (Cameto et al., 2004). Vishal's disadvantage as an immigrant parent may have negatively affected his relationship with school personnel and ultimately his feeling of misalignment with Sid's school. It is also possible that Vishal's personal background as a scientist has resulted in

diminished feelings of confident in the efficacy of school-based interventions or school personnel.

Informal and formal supports. All parents interviewed participated in informal supports for their children with ASD. These supports included extended family, religious congregations, and community activities. Lisa's involvement in informal supports may have diminished Ethan's participation in formalized services or therapies, as Ethan was not involved in intervention services outside of school. Rather, Ethan spent a significant amount of time with his extended family. Previous research by Santarelli et al. (2001) found that Latino families with large familial networks did not feel the need to participate in external intervention services. Like the Latino families studied by Santarelli et al. (2001), Lisa's large family size may have reduced Ethan's participation in formal intervention services.

Lisa's low socioeconomic status seemed to play an important role in her pursuit of informal and formal supports for Ethan. Although previous research by Irvin et al. (2011) suggested that Caucasian children had higher participation in intervention therapies than children of color, these investigations only evaluated families of high socioeconomic status. It is possible that Lisa's low socioeconomic status biased her involvement toward informal support. Interestingly, Ethan's limited involvement in formal supports did not seem to be a direct result of cost. Although Lisa had limited financial resources, she said she would not pursue intervention strategies differently if she had more money. This belief may be due to Lisa's satisfaction with her involvement in informal supports. It also may be related to the previously discussed feelings of a lack of self-efficacy. A final possibility is that Lisa had limited knowledge regarding formal supports such as private therapies. Whatever the reason,

Lisa reported being satisfied with the ways in which she pursued intervention strategies, services, and supports for Ethan.

Findings based on interviews with Val and Vishal suggest that previous research is inadequate in understanding how socioeconomic status, culture, race, and family structure affect participation in formal intervention services. In a study among Asian, African American, European American, and Latino families, Zhang et al. (2010) found the only parents who mentioned seeking outside sources of help for their children were European American parents. Although they did not come from European American backgrounds, Val and Vishal were both highly involved in outside services for their children with ASD. Furthermore, these formal supports did not seem to be affected by their participation in informal supports. Val was heavily involved in the informal supports of extended family and church, while Vishal was not significantly involved in informal supports. Still, both parents sought formal supports for their children. Among the parents in this study, race, cultural background, and family structure did not seem to greatly impact participation in formal or informal supports. Rather, socioeconomic status seemed to be the biggest distinguishing factor behind parents' involvement in informal supports.

Directions for Future Research

There are many interesting directions for future research about diverse parents' goals for their children with ASD. Because the children involved were so young, goals related to adulthood ranged from specific plans to vague hopes. Some parents were unable to formulate goals because their children's adulthood seemed too distant. Other parents had strong goals but were unsure about their children's ability to achieve such goals. One possible direction for future research would be to explore the goals of parents of older

children with ASD. These parents would have a better idea of how their children were developing, and their goals for their adulthood may be clearer. Another direction for future research would be a longitudinal study about how parent goals change over time. This type of study could examine how goals change and shift as children continue to develop towards adulthood.

Another interesting topic expressed by parents was the notion of normalcy. Some parents had a desire for their children to lead what they perceived to be normal lives. Other parents redefined their sense of the word normal and what it meant for them and their families. Some parents did not use the word normal but still prioritized their children engaging in activities one could describe as normal (i.e. higher education, marriage, or children). A study on the desire for normalcy and how parents of children with disabilities define normal would be an interesting perspective for future research.

There is significant previous research on the intersection of culture and disability as it relates to certain cultural groups. However, the literature is insufficient in terms of parents from South Asian backgrounds, specifically India, and the ways in which they set goals for their children with disabilities. Given the unique perspective expressed by Vishal in this study, and the high number of South Asian immigrant families involved in the U.S. K-12 system, it seems important for increased research in this area. Similarly, there is insufficient research on goal-setting for children with disabilities among parents of different socioeconomic status. Given the interesting perspective expressed by Lisa, further research focused solely on the effects of socioeconomic status across cultural backgrounds should be conducted. Future research could serve to provide interesting insights on these minority cultural groups.

The final area of interest for potential future research is parental involvement in formal and informal interventions, services, and supports. The findings in this study regarding this topic are the most dissimilar from previous research, suggesting that subsequent research is warranted to increase understanding. It is possible that, as is the case with this study, most of the research on this topic has been conducted with limited sample sizes, resulting in findings that may not be representative of entire cultural or socioeconomic groups. In addition, there is always individual variability among any one family, which may make their views distinct from other members of their cultural or socioeconomic group. Further research with larger sample sizes would be interesting to provide further insight on this topic.

Limitations

Although this study elicited interesting results, it was not without limitations. First, the participants represented a small sample size, so findings are not transferrable to entire cultural or socioeconomic groups. Rather, findings may serve to support or question previous literature and provide directions for future research. Additionally, rich detail on a few individuals provides insight into the many goals and intervention strategies that individuals have for their children with ASD and the factors that may influence parental goal setting across families, cultures, and socioeconomic groups.

The individual personalities, backgrounds, and circumstances of the parents influenced the makeup of the sample group itself. Because parents self-selected to participate in this study, parents who participated may have had a specific reason for doing so. Some parents may have participated because they were involved in the autism or research community. Others may have participated because of the $20 gift card. The reasons for participation are

unclear, but it is likely that the parents interviewed in this study provided different information than parents who may have been unwilling to be interviewed.

Similarly, the specific characteristics of the parents' children certainly influenced parents' priorities and goals. Because ASD is a spectrum, the children discussed in this study represented a continuum of development and functioning. Although the effects of current abilities on parental goal setting were discussed to some extent, it is still possible that the varying abilities of children could have limited this study. Parents were formulating goals and pursuing strategies for their specific child, and their actions or priorities may have changed if their child had a different level of functioning.

Additionally, the data was collected from one interview with parents, plus one submitted journal entry. Questions were developed and presented by the researcher, who guided discussions based on an interview protocol. In the time spent during interviews, parents were only able to discuss goals and strategies to a certain extent, and it is likely that topics were omitted from conversations. These omissions may have affected the results, as some conclusions by the researcher were based on topics that may not have been discussed by parents.

Finally, it is possible that the researcher was influenced by personal biases, such as the cultural and socioeconomic background of the researcher in relation to these families. The researcher is a member of the U.S. majority culture and inherently has biases that are in line with this majority cultural group. Although efforts were made to minimize biases, it is possible that data collection and analysis were affected. Interestingly, the two longest interviews were those of Erin and Amy, the two parents also in the majority culture. It is possible that these parents felt the most comfortable and open in sharing their perspectives

with a member of their own cultural background. Future research might pair parent
participants with interviewers of similar socio-cultural backgrounds.

Implications for Practice

By examining the goals and strategies diverse parents have for their children with
ASD, several implications for practice can be drawn regarding how educators can more
effectively work with parents of children with ASD. Implications relate specifically to
increased understanding of parent perspectives and the help needed by parents of children
with ASD.

Understanding parent perspectives. It is critical for educators to understand
parents' goals for their children with ASD. It is also important for educators to acknowledge
that parents may not have the same goals as educators. As was discussed in this study, parent
goals vary based on numerous factors, and goals are not always shared by parents. According
to Barrera and Corso (2002), striving to understand parental perspectives is the first step to
building respectful and reciprocal relationships with parents resulting in positive
relationships and outcomes for students.

It is especially important to seek to understand and respect parental goals when parents
come from diverse cultural or socioeconomic backgrounds, as minority cultural views may
be different than those typically espoused is schools. For example, if educators discuss
children using labels or deficits, they may inadvertently disrespect parents and their views of
disability (Kalyanpur & Harry, 1999). Rather, educators should seek first to listen to the
needs and perspectives of parents. Subsequent discussions should be based on child abilities,
goals, and strategies rather than deficits or labels.

Finally, educators should not assume a parent does not value a specific goal simply because they are unable (or unwilling) to implement strategies supporting this goal at home. As this study shows, parents have many competing demands on their time. Thus, they may be unable to implement strategies to work toward certain goals. Val exhibited signs of this with the difficulty she faced balancing parenting responsibilities for Jayden and her other children. Previous research by Rogers-Adkinson et al. (2003) supported this finding, showing that external factors in the lives of families may inhibit parents from working towards goals at home. In these circumstances, educators may believe that parents do not value goals. In reality, parents may highly value a goal but be unable or unwilling to devote sufficient time to working towards it during their daily routines with their children. In this scenario, the work of educators becomes even more important to support parental goals and children's development.

Working with parents of children with ASD can be challenging, but it is important for educators to support the previously-discussed high hopes of parents who have young children with ASD. Research suggests parents appreciate educators and practitioners who focus on working with families (Dunst et al., 2002). This effort on the part of educators is not only important for child development in the school setting, but research shows it may help empower parents to work towards their goals for their children as well (Zhang et al., 2010). Efforts to understand and support parents who come from diverse background are especially important, as previous research suggests culturally and linguistically diverse parental involvement in education intervention plans is insufficient (Cameto et al., 2004). Educators must make extra efforts to understand the goals of diverse parents and help them work toward these goals for their children with ASD.

Help needed. Although most of the feedback parents expressed regarding schools was positive, there were areas in which help was still needed by parents of children with ASD. Vishal expressed the need for a centralized place in which Sid could access the interventions and services he needed, rather than constantly transitioning between different physical locations. Vishal and Val both felt they would benefit from accessing information regarding policies and resources all in one place. A natural place to provide such services would be at school. Easily accessible information and resources could result in parents feeling empowered to access the supports they require for their children. With this help parents could spend less time seeking supports and researching policy and more time working towards their goals and being loving parents.

This study explored significant findings and implications for practice regarding the goals and intervention strategies of five diverse parents of children with ASD. Specific short and long-term goals were identified, as well as the personal background and family structure that affected the formulation of goals. Intervention strategies, services, and supports were reviewed as they related to parents' pursuit of goals. The discussion sought to explore goals and strategies further within the scope of the previous literature. Limitations to this study were explored and directions for future research were proposed. This topic is of high importance to educators working with children with disabilities, as well as school leaders and decision makers grappling with the role of education in the lives of individuals with disabilities and their families. Furthermore, the quick response of families to this recruitment effort showed the social validity of this study and importance of this topic to parents. Parents are eager to have their voices heard. It is critical for educators to understand parental goals for their children, and how these goals affect their work as educators of children with ASD.

Invitation to Participate in a Research Study
University of North Carolina-Chapel Hill

Dear Parents,

You are being invited to participate in an interview-based research study though UNC at Chapel Hill titled *Parental Goals and Strategies for Children with Autism: Considerations for Diverse Families.* Please read the information below if you are interested in participating. I hope you will join us and share your insight.

All the Best,

Katharine Robinson, Master of Arts in Education Candidate
UNC at Chapel Hill School of Education
krobinson@unc.edu, 919-843-7793

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What is the purpose of this study?
This study has been designed to better understand the personal and educational priorities and goals that parents from diverse backgrounds have for children with autism, as well as explore how their priorities and goals affect the services and support parents may seek.

The researcher hopes to explore parents' unique personal and educational goals for their children with autism. The goal of this study is to promote a better understanding of the priorities of diverse families, which may result in more family-centered education policy and children with autism being educated in a way that is more aligned with their family values.

What is involved?
This research uses interviews to better understand the personal and educational priorities and goals parents from diverse backgrounds have for children with autism, as well as how priorities and goals affect the services and support parents seek. The interview will take up to 90 minutes, depending on how much you would like to say. With people's agreement, the interview will be recorded electronically. Later the interview will be transcribed and analyzed alongside the interviews of the other participants. You will be invited to review your interview transcription and amend or correct anything you may have misstated or we may have misheard. You will also be asked to respond to one journal entry question about your biggest hope for your child's future as well as complete a demographic survey to tell us more about yourself and your family.

If you decide to participate, you will be interviewed once, at a time and place convenient to you. You will be given a $20 gift card for participating in this interview study.

Joining the study, leaving the study.
We are inviting parents (one parent per child) to participate in this interview study. The parent's child with autism should be between the ages of three and six (3-6) and have been diagnosed before age three (3). Because there are eligibility criteria concerning children's age and age of diagnosis, only those meeting the criteria can participate. Furthermore, this study is designed to focus on diverse families, so parents will be purposefully selected who display a variety of ethnic, racial, religious, and socioeconomic backgrounds.

You are free to quit the study at any point you choose. Even if you are half way through an interview, you can stop if you wish to do so. If you choose to leave the study you do not have to provide any explanation or justification of this choice.

If you would like to participate, or if you have any questions, please contact the principal investigator and study contact, Katharine Robinson, at krobinson@unc.edu or 919-843-7793. Thank you.

University of North Carolina-Chapel Hill
Consent to Participate in a Research Study

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IRB Reference ID   122504
Consent Form Version Date: 11/16/2012

Title of Study: Parental Goals and Strategies for Children with Autism: Considerations for Diverse Families

Principal Investigator: Katharine Robinson, krobinson@unc.edu, 919-843-7793

UNC-Chapel Hill Department: School Of Education

Advisor: Harriet Able, hable@unc.edu, 919-962-9371

Study Contact: Katharine Robinson, krobinson@unc.edu, 919-843-7793

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What are some general things you should know about research studies?
You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researcher named above any questions you have about this study at any time.

What is the purpose of this study?
The purpose of this study is to better understand the personal and educational priorities and goals parents from diverse backgrounds have for children with autism, as well as determine how their priorities and goals affect the services and support parents seek.

Why are you being asked to participate in this study?
You are being asked to take part in this research because you have been identified as possibly meeting the requirements to enroll in this study. In order to meet these requirements, you must be either a mother or a father of a child between the ages of three and six who was diagnosed with autism before age three.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 4-7 people in this research study, which is being conducted in North Carolina among mothers and fathers of young children with autism.

How long will your part in this study last?

Your participation in the interview will last approximately 1.5 hours. In addition to the in-person interview you will be asked to write one journal entry that may take between 10 minutes and 1 hour to complete. After the interview audio recordings have been transcribed, we will invite you to review the transcription and make any edits you would like to help the researchers better understand the content of what you said during the interview. Any personally identifiable information will be deleted from the transcript prior to your reviewing the transcript. If you choose to review the transcript, this should take an additional 30 minutes of your time. You will also be asked to complete a demographic survey to describe yourself and your family, which may take between 15 -30 minutes to complete.

What will happen if you take part in the study?

Parents will be contacted to arrange an interview in a location of their choice. We will audiotape the interview to ensure our accuracy in capturing your views and perspectives. If you become uncomfortable with the audio recording, you may ask for the recording device to be turned off at any time. At the interview, parents will be asked to complete a demographic information form containing questions related to income, race, ethnicity, place of birth, and place of child's birth. Interviews will be supplemented by the researcher asking families to write or type a single journal entry answering the questions, "What is your biggest hope or dream for your child? Why is this important to you?" The answer can be as long or as short as the participant would like and is an optional, supplemental component to the interview.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. The researcher hopes that, by exploring parents' unique personal and educational goals for their children with autism, this study will promote a better understanding of the priorities of diverse families. Increased understanding on this topic has the possibility of ultimately affecting changes in educational practices or policies, which may result in children with autism being educated in a more parent-focused and effective way.

What are the possible risks or discomforts involved from being in this study?

The only risk we anticipate to you from being in this study is any emotional discomfort that may occur due to the private and personal nature the conversation. All comments made during the interview will be kept confidential, and the findings discussed will be reported under a pseudonym. The researcher will make every effort to remove identifying features about you and your family from the final product, but it is possible that readers may guess at specific identifying features. Therefore, we encourage you to be as honest and open as you can but remain aware of limits in protecting confidentiality.

How will your privacy be protected?

Every effort will be taken to protect your identity as a participant in this study. You will not be identified in any report or publication of this study or its results. Your name will not appear on any transcripts; instead, you will be given a pseudonym. After the interview has been transcribed, the recording will be destroyed, as will any record of your contact information that may have been retained by the researcher.

Will you receive anything for being in this study?

You will be given a $20 gift card for participating in this interview study. These cards will be available after the interview.

Will it cost you anything to be in this study?

There will be no costs for being in the study.

What if you are a UNC employee?

Taking part in this research is not a part of your University duties, and refusing to participate will not affect your job. You will not receive any special job-related consideration if you take part in this research.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions or concerns, you should contact the researcher listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

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Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

_____   _____
Signature of Research Participant   Date

_____
Printed Name of Research Participant

_____   _____
Signature of Researcher Obtaining Consent   Date

_____
Printed Name of Researcher Obtaining Consent

APPENDIX C: DEMOGRAPHIC SURVEY

1. Please print your name. (Note: all names will be omitted from final report and responses will be kept confidential) First _____ Middle _____ Last _____

2. What is your sex? □ Male   □ Female

3. What is your marital status? □ Married   □ Widowed   □ Separated
                                    □ Divorced □ Never married

4. What is your age? _____

5. Where were you born? (City and Country) _____

6. If you were born outside the U.S., in what year did you come to live in the U.S.? _____

7. What is your race? (Check one or more boxes) □ American Indian   □ Asian   □ Black □ Spanish/Latino/Hispanic   □ White (non-Latino)   □ other race _____

8. What is your ancestry or ethnic origin? (For example: African Am., Dominican, French Canadian, Korean, Lebanese, Polish, Nigerian, Mexican, Ukrainian, and so on) _____

9. Do you speak a language other than English at home? __ If so, what language? _____

10. What is the highest level of school you have completed? □ None □ Nursery to 4th grade □ 5th to 11th grade □ High school □ Associate degree □ Bachelor's □ Master's □ Doctorate

11. What was your total family income in 2012? (before taxes; including job wages, unemployment, pensions, child support, etc.) □ $20,000 and below □ $21,000 - $40,000 □ $41,000 - $60,000   □ $61,000 - $80,000 □ $80,000 - $100,000 □ $100,000 and above

12. How many children do you have? _____

13. Where was your child with autism born? (City and Country) _____

14. In what year was this child born? _____ **How old is this child?** _____

15. At what age was this child diagnosed with autism? _____

16. What is this child's language ability? _____

17. What is this child's school classroom placement (if applicable)? _____

Questions adapted from: United States Census 2000. United States Census Bureau. (2010, June 14). United States Census 2000. Retrieved from http://www.census.gov/dmd/www/content.htm.

APPENDIX D: INTERVIEW PROTOCOL

Tell me about your family.

      Probe: How many children do you have?

                Do you have a spouse or partner who is involved in your child's life?

                Does anyone else lives in your home?

When did you learn that your child has autism?

      Probe: How old was (s)he?

                How did you feel?

What are some of your child's strengths and challenges?

      Probe: What's (s)he good at?

                What is hard for him/her?

What would you say are your biggest concerns for your child right now?

      Probe: What do you worry about most and why?

What do you hope they will achieve in the near future (next 1-2 years)?

      Probe: What do you want your child to be able to do?

When considering lifelong goals, what are your priorities?

      Probe: What one or two things do you want most for your child's future?

                Why are these most important to you specifically?

How are your priorities influenced by your values or beliefs?

      Probe: Are your priorities influenced by cultural values?

                What about religion?

                Do you think other parents share your priorities for their autistic child's future?

                If you see different views, what do you think about the beliefs of others?

Are your priorities affected by the other people in your family (spouse, siblings)?

Probe: What are the roles of your other children in your child with autism's future?

Would things be different if you had more or less other children?

A more or less involved partner?

What do you envision your child's life to be like as an adult?

Probe: Where do you think (s)he will live?

Do you think (s)he will be married and/or have children?

What do you think (s)he will do for work?

What role do you have in helping your child achieve your goals?

Probe: Have you ever felt frustrated?

Have your family's actions helped your child?

Do you wish you had more time or resources?

Do you wish you had more help from others?

Is your child is enrolled in a school or child care center? What do they do to help you with your priorities?

Probe: Are you happy with the work of the school?

Have the school's actions helped your child?

Do you wish the school would do anything differently?

Has your child been involved in intervention services or programs outside the school?

Probe: For how long?

Have you been satisfied with these services?

If not: Are there reasons why your child has not been involved?

Has your involvement in outside services been impacted by cost or other factors?

Is there anything else you want to share about your priorities for your child with autism?

"What is your biggest hope for the future of your child? Why is this important to you?"
This answer can be written or typed and can be as long or as short as you wish. Please focus your answer however you'd like, but you may wish to comment on your child's abilities, living situation, relationships, etc.

APPENDIX F: SAMPLE FIELD NOTE

Val's son Jayden is four. His family is excellent at picking up his cues. They define their normal/typical. Her oldest son was adopted at age four. Jayden was their first baby experience, which is why she did not realize he had autism. First she said they were just a typical family, and then as she described them she noted "I guess were not a typical family."

Val receives support from CDSA in her county. She uses speech therapy, occupational therapy. It's important with her to find caring supports for him. They are clearly very bonded, and she worries others won't care for him/understand him like she does. Educating the world is important for this reason. She started with her community/culture, her church, and her extended family.

Jayden is smart and physically active. He has difficulty with communication and language, and he melts down when he gets frustrated. Val wants him to achieve some kind of communication – speech or otherwise – to alleviate his frustrations. She also prioritizes potty training. She has specific plans for Jayden's adulthood – attached apartment. Understands he may not live alone. Prepared emotionally, practically, and mentally. Still, maintains hope that he will get married, have children, have a job.

Church/God is important. Used a phrase "un-churched" to describe the difficulty of leaving her church because they did not have a special needs ministry. She was clued into the issues, statistics, and terminology regarding church, disability, etc. She badly wants Jayden to have a relationship with God; needs for him to go to church with their family. Not just for him, or for her, but for family.

Val seems torn between feeling burdened by parenting a child with autism, and wanting to do everything Jayden needs. It's a burden she is happy to have. She also is grateful for help from her family and service providers. She thinks you cannot do it alone. Would recommend to any parent to find support. Even though she is plugged into resources, she still has difficulty finding support. She wants to find even more services; she wishes she could have respite so she and her husband could have time for themselves. When I told her about The Arc care providers, she seemed intrigued.

Val is obviously very involved in Jayden's care and active in the autism community. She and her husband both work in addition to their parenting duties. Her hopes for the future are realistic, but she is open to possibilities. Her goals seemed different than previous literature about African American parents. Regarding need for centralized services – could this be role of schools?

Katharine: So what about life long goals? What are something you hope Isaac will have or be able to do, you know, as an adult?

Parent: Well I've seen, well I've heard about some autistic kids going to a regular school or going to college. That's what I'd like for him. To be able to go to a regular school, and uh, I know they're saying that he's develop, develop delayed and he's not speaking, but I'm hoping that'll change and I'm hoping he'll be able to go to a regular school. Maybe college, where he'll send mama some money. (laughs)

Katharine: (laughs) I was gonna say, why, why is, why is school your focus? What, why do you think that is important?

Parent: It strengthens, it strengthens the mind. Yeah and I'm hoping his is strengthened. Cause like I said I know he's smart, it's just, you know

Katharine: So how do you think, these things that are important to you, school, speech, how do you think those might be impacted by who you are as a person? Or maybe who your background, or your family, either your values, beliefs, anything like that, whatever you want to speak to.

Parent: I don't know, I just want, I mean, I just want him to be normal. I say that a whole lot. Even when I get frustrated with him. I'm like, I wish you were normal, I wish you were normal. You know, normal kids go to normal schools. They like might act up, I want that for my child. Is he gon act up, is he gon act out when he's a teenager. Is he gonna go to a regular school? Don't know. Ya know. Is he gonna go to work? I don't know. Ya know. I just have to wait.

Katharine: Yeah

Parent: Ya know. It's, it's different with your other kids. Ya know. I got a 22 year old, she's not working. She stays with her dad. She's getting back and forth staying with her boyfriend, or staying with her dad, or staying with him, who, whoever. And then you got my 17 year old, he stays with a dad, no, he stays with his uncle now. He's not working. Then I got a 9 year old. She stays with my grandma. So I have none of them with me. And uh ya know, I'm trying to do the best I can with him.

Katharine: Of course.

Parent: And my 9 year old, she comes over every other weekend. And now, once upon a time, I haven't seen her since she was two. Cause I was out, no, yeah. But I wanna make a good, better impression with him, than I did with my other kids. So that's why I'm hoping for those things for him. I wanted those things with them, but I wasn't a part of their lives. So.

Katharine: Of course. So basically, what any parent would want.

Parent: Yeah.

Katharine: You want a normal life.

Parent: Ha, yeah I wanted that.

Katharine: You want

Parent: Yeah

Katharine: You want him to be in school, regular school.

Parent: Yeah. I just want him to play with, ya know, I know he, he plays good with other kids. So his, ya know, his cousin,

Katharine: That's good.

Parent: His uncle, his nephew, anyway. He's five. He plays with him. Real good.

Katharine: Do you know any other parents with children with autism?

Parent: Nope

Codes used in the sample coded interview above:
Child's adulthood
Parent frustration
Child's Strengths
School
Current priorities/goals
Community/Friends
Family

Other codes (not used in the sample coded interview above):
Parent's job
Deficits/difficulty
Medical issues/diagnosis
Interventions/services
Personal background/circumstance
Culture
Religion/God

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