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One Jump Forward, Two Jumps Back: A Qualitative Study of Parental Issues Raising Adolescents with Autism

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One Jump Forward, Two Jumps Back: A Qualitative Study
of Parental Issues Raising Adolescents with Autism

Molly Anne Rosenbaum

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Educational Specialist

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ABSTRACT

One Jump Forward, Two Jumps Back: A Qualitative Study of Parental Issues Raising Adolescents with Autism

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There have been numerous investigations seeking to quantify the experience of parents raising adolescents of autism, but remarkably few have looked at the total experience qualitatively, as reported by parents. The present study was conducted along with a larger study for adolescents with autism participating in the PEERS® social skills group intervention, which includes simultaneous parent sessions. This study analyzed comments made in the parent group, identifying the issues parents reported spontaneously through a qualitative analysis of 12 unstructured hour-long sessions including parents ($n = 16$) and graduate student clinicians. The purpose of this investigation was to explore the meaning and experiences of these parents to gain increased understanding about the needs of both parents and adolescents with autism. Themes resulting from the hermeneutic analysis of these videos focused on the adolescents and their “spark,” a term coined by the parents denoting the unique strengths of their children, the values they share with the family, the impact of autism on the family, lack of self-awareness, being included and finding “one good friend.” There was also a strong theme of the parents seeking support from one another. Finally, the parents spoke often of planning for/hoping for the future and what it may bring for their adolescent with autism. These themes can help describe the challenges/successes of parenting an adolescent with autism. This study provides some direction for further research to inform supports for parents whose children are approaching or are in the midst of adolescence with autism. Some other findings in our study were that parents are very concerned about acceptance of family values by their adolescent. Future studies can explore further what parents’ needs are and how clinicians can help them.

Keywords: autism, parents, adolescents with autism, parent child relationship, parent experiences, hermeneutics, successes/challenges

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *One Jump Forward, Two Jumps Back: A Qualitative Study of Parental Issues Raising Adolescents with Autism*, is written in a hybrid format. This hybrid format combines traditional thesis requirements and journal publication layouts. The thesis report is presented as a journal article and conforms to the length and style requirements for submitting research reports to psychology, education and nursing journals. The additional support for the findings, including a literature review, the Parent Background Survey and a list of study quotes appear in Appendices A, B and C respectively. Two reference sections are included. The first applies to the journal-ready article and the second contains references for the extended literature review.

Background

Few disabilities appear to be more taxing on parents than raising an adolescent with autism (Seltzer, Krauss, Orsmond, & Vestal, 2001). Several factors have been proposed to account for the more difficult experience of raising an individual with autism including the uncertainty surrounding an ASD diagnosis and the long-term prognosis of individuals with autism. The stressful nature of autism symptoms and associated behavior problems, as well as the lack of public understanding of and tolerance for these behaviors can lead to a poorer sense of psychological wellbeing in parents and elevated levels of depression when compared to parents of adolescents without disabilities (Ekas & Whitman, 2010; Smith, Greenberg, & Seltzer, 2012).

Through the taxing experience of raising an adolescent with autism, parents have many supports available to them. These support networks can be as small as one close friend in whom they confide, to as large as a social media group of individuals who know someone with autism. Studies found that having a greater number of support network members was associated with improvements in maternal well-being, as well as associated with declining levels of depressive symptoms (Smith et al., 2012). Further studies have found that anxiety for parents was higher when social support networks were smaller and when more stressful life events were experienced (Baker et al., 2011). The more support parents feel as they raise a child/adolescent with autism, the better. Having a positive support system with many members may have a positive impact on the psychological wellbeing of parents as they raise their adolescent with autism.

However, even with these support networks, raising an adolescent with autism comes with a unique set of demands. Parents need the proper support in order to be successful in the taxing experience of raising an adolescent with autism. One study found that the most common

unmet support needs of parents with adolescents with autism are the adolescent's social functioning (e.g., the ability to have friends, and ability to have social activities with people outside of family); family-wide impacts (e.g., time to spend alone with partner, counseling for self or partner, family vacations); and future planning (e.g., fears about adolescent's future) (Hartley & Schultz, 2015). Another unmet need that many parents may face if they are involved in religion, is concern for the religiosity of their adolescent (Poston & Turnbull, 2004). A brief summary of how each of these areas affect the parent will be discussed.

Adolescents' Social Functioning

An adolescent's level of social support has a notable impact on parents. In studies of parents of adolescents with autism, higher levels of social support have been associated with lower levels of negative impact, psychological distress, negative mood and depressive symptoms in parents (Bishop, Richler, Cain, & Lord, 2007). Most parents want to ensure that their adolescent's social needs are being met. This becomes a greater challenge when their adolescent has autism because of the deficits in social communication functioning. Social support has long been recognized as an important component in the stress process and a predictor of psychological well-being (Pearlin, 1989). This support can be found at school or in the community (e.g. local church groups, sports teams, neighborhood friends).

Family-Wide Impacts

Few disorders in adolescents pose a greater threat to the psychosocial well-being of other family members than autism (Seltzer et al., 2001). There is a significant time commitment with regards to raising an adolescent with disabilities that affects parents and all of their children. Family members of persons with autism may also face a dual challenge of the demands of caring for the individual with autism and, at the same time, dealing with an elevated risk of

neurological, cognitive, communicative, and psychiatric difficulties in themselves, their spouse and their other children (Seltzer et al., 2001).

Planning for the Future

Autism is a lifelong disability that affects the adolescent from infancy through the remainder of their lives. Planning ahead for the future can seem very daunting to a parent of an adolescent with autism. Research has shown that after a typically developing young adult has moved out of the family home, anxiety of parents was significantly lower (Baker et al., 2011). Raising a child with autism can be a little different, because their adolescent may not ever reach that point of independence in adulthood. Many parents are primary caregivers for their children well into adulthood and this prolonged caregiving period coincides with additional challenges associated with their own aging (Smith et al., 2012). Because some adults with autism never transition into independent living, anxiety for these parents may never decrease.

Religiosity

A less researched, but important aspect of a child's functioning is level of religiosity. In the back of their minds, some parents who place value on religion or spirituality may be concerned for their child in a spiritual sense, looking for evidence of spirituality in their church attendance, participation, discussions, or other inward or outward manifestations of spirituality. Many parents turn to their spirituality and faith as a source of support. They may possibly join religious communities as a way to share and develop their spirituality with others. Strength is gained from faith and these activities provide a resource that enables family members to meet the challenges they face in everyday life (Poston & Turnbull, 2004). Without appropriate supports, parents may be either reluctant to attend congregation meetings or are unable to benefit from attendance because they spend their time providing direct support to their children with

disabilities. Based on Poston and Turnbull's research (2004), families are looking for three things from their religious community: acceptance of their child, spiritual and emotional support for themselves, and supports for their child during services so that both their child and the family can have meaningful participation in organized religious activities.

Purpose of the Study

The purpose of this investigation was to gain an increased understanding about the issues faced by parents of adolescents with autism. There have been decades of research on parenting and autism. There has also been research measuring the effects of raising an adolescent with autism with quantitative data to describe the experience (Baker et al., 2011; Smith et al., 2012); however, there is a gap in the literature describing the parents' perspectives on the daily issues of raising teenagers with autism. Given the unique challenges of parenting an adolescent with autism, a greater understanding of their experiences in dealing with these challenges will prove valuable. This study employed a qualitative approach to explore the meaning of experiences reported by parents of adolescents with autism. We included a diverse sample of participants to show commonalities among parents of adolescents with autism as well as illustrating their differences. Understanding their daily experience is likely to help service providers offer appropriate support and assistance to help adolescents make a healthier transition into adulthood. Whereas many of the prior studies have been designed to gather data using questionnaires driven by researchers' questions (Hartley & Schultz, 2015) there are very few studies in which parents were allowed to simply report what their experiences have been, without a framework of specific questions. We believe the less structured approach may provide parents an opportunity to tell us about the more compelling issues in their lives with their adolescents. There was one main question driving the study: What are the experiences of parents raising adolescents with autism?

Method

The present study is part of a larger project investigating the total experience for adolescents with autism participating in the PEERS® manualized group intervention for social skills (Laugeson & Frankel, 2010). Parent group sessions were a simultaneous component of the adolescents' participation in the PEERS® social skills intervention group. Adolescents received direct instruction and behavioral rehearsal on age-appropriate social skills topics in one room, while their parents met separately to briefly review the week's lesson. The stated goal of the parent group was to allow parents to better support generalization of social skills learned by sharing common vocabulary and discussion topics with their adolescents during the week.

This study analyzed the parents' group as they commented about the weekly topics and turned the conversation each week to be more tailored to discussions about their own experiences raising their children. Our study used a hermeneutic analysis of recorded videos of the PEERS® parents' group, according to the process outlined by Kvale and Brinkmann (2009). Hermeneutics is defined as a branch of knowledge that deals with interpretation. Throughout this paper, we will refer to the *parents of adolescents with autism* as the participants for the purposes of this study.

Consent

All study procedures were approved by the university's institutional review board. All parents signed informed written consent prior to the beginning of the PEERS® social skills group intervention for themselves and their adolescents. Parents gave informed, written consent for data collection, including video and audio data collection as they were talking about their children in the parent group. Adolescent participants gave written assent for their participation in the related study of their own social skills.

Investigator Assumptions

A series of assumptions were made by the researchers in this study. First, the assumption was made that the adolescents of the participants in this study have actual disabilities (autism). We followed the requirement stated in the PEERS® curriculum that adolescents in the group have age-appropriate cognitive and language levels and enough behavioral control to participate in the group independently (Laugeson & Frankel, 2010). We assumed that due to disabilities of their adolescents, the parents may have unique experiences that include both suffering and benefiting. Second, we assumed that the potential for conflict exists between the therapists who alternated working directly with the adolescents or as facilitators in the parent group. A personal bias may have been introduced because the therapists have a working relationship with the adolescents in a given week and are listening to the parents talk about them a week later as they rotated to the parent group. Third, we assumed that comments made in group are likely to include ideas about the day's topics. Because of this, there will be more comments about the social challenges of the parents' teenagers that may or may not occur in a different setting. Finally, we assumed that a qualitative approach was the best method for describing these experiences of the parents when raising their adolescents with autism. The group is designed for direct instruction and discussion about the lesson topic, but the parents typically chose to use the time in the group session to seek support and information from each other. We assumed that the atmosphere of this session functioned as a support group, which enabled parents to give a rich description of what their experiences are raising adolescents with autism.

As the principal investigator, I recognize my own context and subjectivity relating to this study. I have worked with individuals with autism for several years. I've worked in clinic as well as in-home settings, in direct contact with parents every day. I have a positive attitude when

it comes to parenting and autism, because I recognize the sacrifice parents are making. Personally watching parents give so much for very small gains motivated me to research further into exactly what parents would report as the issues they are facing as their children grow through adolescence. As a religious individual myself, I also recognize my own affiliation and interest in autism may have an impact on the group discussions. Recognition of these assumptions and the use of the hermeneutic circle—as described below—were efforts to maintain validity and trustworthiness.

Participants

The study included 15 participants. Participants in this study were parents of 10 adolescents with autism. Nine of the adolescents came from two-parent homes and one came from a single parent home. Both mothers and fathers participated in the social skills group. All mothers ($n=10$) attended at least one session and 6 fathers attended at least one session. Basic demographic information about participants was collected via questionnaire that was sent to all participants who consented to participate in the study. The average age of our participants was 44.75 (mothers= 43.6 and fathers= 46.67). All participants had at least “some college,” and the majority had college degrees. All of our participants were the birth parents of the adolescents in our group. Four of our participants were born outside of the United States. With non-native English speakers in the group, we want to additionally note the potential lack of reliability in their verbal reporting for participants with heavily accented English or difficulties with word choice in a second language. We did not gather information about religious affiliation; however, because the setting was a faith-based institution, it is very likely to have had an effect on parents’ willingness to discuss religion as a topic in the group.

As part of their adolescents' participation in the larger social skills study, all parents completed several questionnaires about their adolescents' social abilities both pre- and post-intervention, which may have influenced their perceptions of their adolescent during group sessions. Participant characteristics are shown in Table 1, with adolescent characteristics in Table 2.

Table 1

Participant Characteristics

	Fathers	Mothers	Total
Gender, <i>n</i> (%)	6 (37.5)	10 (62.5)	16 (100)
Age, mean (SD), range	46.67 (7.38) 37-58	43.6 (5.85) 35-54	44.75 (6.13) 35-54
Highest Education Level, <i>n</i> (%)			
Some College	1 (16.7)	5 (50)	6 (37.5)
College Degree	5 (83.3)	5 (50)	10 (62.5)
Region of Origin, <i>n</i> (%)			
USA	5 (83.3)	7 (70)	12 (75)
Outside of USA	1 (16.7)	3 (30)	4 (25)

Table 2

Characteristics of Adolescents with Autism

Demographics	
<hr/>	
Gender, n (%)	
Male	8 (80%)
Female	2 (20%)
Age, mean (SD), range	13.3 (1), 12-15
Full Scale IQ, mean (SD), range	97.1 (17.5), 65-122
Co-morbid Diagnostic Histories	5
Attention-Deficit/Hyperactivity Disorder	3
Bipolar Disorder	2
Oppositional Defiant Disorder	2
Anxiety Disorders	2
Depression	1
Specific Learning Disability	1
Intellectual Disability	1
Educational Placement	
At or Above Grade Level	6
1-2 Years Behind	2
3-4 Years Behind	1

Setting

The study was conducted at a large private, faith-based university in the United States. Adolescents and parents came to the university's Child and Family Studies Lab on a weekly basis after school for 60-minute sessions and up to 30 minutes of additional time reuniting the adolescents and their parents following each session. The study time period included winter months, which affected attendance occasionally as some families were not able to drive to campus in heavy snow storms. Adolescents met in a large group room, and parents initially met in a classroom, while their room was under construction. After the first five weeks, the parent group transitioned to a smaller, more intimate group room (with chairs rather than desks). All rooms were furnished with video and audio recording equipment. This system was not functioning for one of the sessions (Lesson 6: Peer Entry I – Entering a Conversation), and the 14th session was a graduation party at completion of the program, so recording data were not collected on those two occasions.

Procedures

Participants were recruited from within a 50-mile radius of the campus from suburban areas. Recruiting participants was done through word of mouth from local autism clinicians, emails to local school districts, and announcements at local community autism workshops. Parents contacted the university with interest in the study, then were given instructions on how to enroll. To be enrolled, the adolescent needed to be between 12 and 17 years old, have an autism diagnosis or suspected of having autism and needed language and cognitive skills to be placed within two years of chronological age academically (by parent report). Cognitive and language skills were evaluated as part of the study using standardized cognitive measures (e.g., Wechsler Intelligence Scales for Children, Fifth Edition (Wechsler, 2014) or Stanford Binet, Fifth Edition

(Roid, 2003)). Autism symptoms were verified in the adolescents through administration of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) by a research-reliable clinician.

Twelve parent sessions were recorded in total, each lasting approximately one hour. These sessions were semi-structured (Kvale & Brinkmann, 2009), beginning with the prescribed parent session information in the PEERS® manualized curriculum. While discussions were led by student therapists, parents often chose their own discussion topics, which were accommodated by the therapists. These parent-driven discussion topics focused on the parents' experience of raising an adolescent with autism. During these sessions, parents reflected, commented, and asked questions to the group.

In analyzing these group sessions, qualitative approaches, as opposed to quantitative ones, allow for the hermeneutic circle to function. A general topic or lesson, related to building social skill competence in the adolescents was presented by the facilitator each week to help structure some of the discussion. The facilitators would then guide the conversation and provide advice or feedback. These topics/lessons were coordinated with the teen group topic for the week, in summary form for the parent group. The topics/lessons were provided according to the PEERS® curriculum. Topics are shown in Table 3. Parent conversation often stemmed from the day's lesson topic, but would quickly shift to topics outside of the PEERS® curriculum. The potential bias from the curriculum impacting the findings will be discussed.

Table 3

PEERS® Curriculum (Schedule of Discussion Topics)

Week	Lesson Title
1	Introduction and Conversational Skills I – Trading Information
2	Conversational Skills II – Two-Way Conversation
3	Conversational Skills III – Electronic Communication
4	Choosing Appropriate Friends
5	Appropriate Use of Humor
6	Peer Entry I – Entering a Conversation
7	Peer Entry II – Exiting a Conversation
8	Get Togethers
9	Good Sportsmanship
10	Rejection I – Teasing and Embarrassing Feedback
11	Rejection II – Bullying and Bad Reputations
12	Handling Disagreements
13	Rumors and Gossip
14	Graduation and Termination

Data Analysis

Each session was recorded and analyzed by the entire team, which consisted of three female graduate level school psychology students who were both facilitators in the parent group

and therapists in the adolescent group. Full transcripts of each session were not completed, but specific quotes were transcribed throughout the analysis as researchers deemed they were relevant to the research question. The videos were viewed in their entirety and data were recorded using the Collaborative Hermeneutic Interpretation (CHI) method (Kvale & Brinkmann, 2009). Hermeneutics is the process of obtaining knowledge from interpretation (Gadamer, 2004). Validity is an issue often raised when discussing qualitative research. Kvale and Brinkmann (2009) assert that qualitative research uses a continual process of validation throughout the designing, interviewing, transcribing, analysis, and reporting of a given theme by checking, questioning, and theorizing about the sessions with each successive watching. The analytic process was as follows:

1. Each member of the research team was involved in sessions as facilitators.
Facilitators rotated responsibility of the teen group and the parent group with other therapists who were not research team members. Thus, members of the research team directly participated in approximately 50% of the sessions.
2. All members of research team watched all videos to obtain a more general sense or overview of the sessions. Because the research team only initially participated in 50% of the sessions, the purpose of re-watching all of the videos is to get an overall idea of those sessions that were not witnessed live.
3. Each team member again watched the videos, this time with more purpose, to identify meaningful themes and quotes.
4. Team members met together to discuss common themes and quotes identified.
5. Members of the team watched the videos for a final time, this time paying attention to similar themes and discrepancies between themes and disconfirming statements.

6. Finally, team members met again to construct a final collaborative interpretation.
7. The final interpretation was sent to the parent participants in the group as a “member check.” One participant reported that they felt the themes were a fair representation of the comments made in the group. There was no disagreement from any participants.

Themes will be interpreted by prevalence, intensity and frequency. The purpose of multiple viewings and subsequent analysis is to provide a “thick description” of the experience of parents raising adolescents with autism. In an article for *The Qualitative Report*, Ponterotto (2006) provided the following working definition for thick description:

Thick description refers to the researcher’s task of both describing and interpreting observed social action (or behavior) within its particular context. The context can be within a smaller unit (such as a couple, a family, a work environment) or within a larger unit (such as one’s village, a community, or general culture). Thick description accurately describes observed social actions and assigns purpose and intentionality to these actions, by way of the researcher’s understanding and clear description of the context under which the social actions took place. Thick description captures the thoughts and feelings of participants as well as the often-complex web of relationships among them. Thick description leads to thick interpretation, which in turns leads to thick meaning of the research findings for the researchers and participants themselves, and for the report’s intended readership. Thick meaning of findings leads readers to a sense of verisimilitude, wherein they can cognitively and emotively “place” themselves within the research context. (p. 543)

It is our hope that the resulting thick description gained from these sessions with the parents will provide a better understanding of the issues parents raising adolescents with autism face.

Trustworthiness

The trustworthiness of the themes extracted from the interviews is addressed through the collaborative efforts and dialogue of the research team throughout the analysis process. The member check completed after analysis, further validates the analysis as parents have approved the extracted themes. The hermeneutic circle and analysis is rooted in a relational philosophical framework (Schwandt, 2000). This indicates that perspective and knowledge are built in the relationship between the researchers and the videos of these parents. Watching of these videos independently by each member of the research team may help avoid group think and result in more authentic understanding of the experiences of parents with adolescents with autism.

Findings and Themes

Analysis of session videos produced several themes surrounding the parent-adolescent relationship. Four of these included direct concern and appreciation for their adolescent. These included: “the spark” (a term coined by a parent in the group, meaning adolescents finding a passion or drive in a certain area of interest), family values, family impacts, and moving toward the future. One theme, however, did not include the adolescent, but parents as they themselves seek support from other parents. Other themes that emerged included parents’ overall concern for their adolescent’s self-awareness, being included and making at least one good friend. These themes are interconnected, as will be evidenced in the participant quotes that support them. Many of these themes included humor to help cope with their challenges. Understanding these themes may help explain the challenges and successes that parents with adolescents with autism may experience. A list of the common themes and their quotes (included some not listed

here) will appear in Appendix C. All pronouns have been changed to male to protect the confidentiality of the female students in the group.

Seeking Support

Many parents reached out to become part of this social skills group for the support. “I’m looking for that group of people for support,” was a common phrase heard at the beginning of our group. These parents are all experiencing challenges when it comes to raising their adolescent with autism and yearn for support. “I want to know I’m not alone in my struggles.” As humans, we’re all constantly seeking that validation and support. That need to feel comforted and sustained through life is a common theme in our group of parents raising adolescents with autism. These parents may already have support systems in place but are really looking for those individuals who can understand and have complete empathy. “I live in a remote area, and I know there are parents of children with autism, but they must be hiding. I talk to my friends, but they just don’t get it,” They seem hopeful that other parents raising adolescents with autism with “get it.”

Use of humor. One example of how individuals seek support and connection with others is through the use of humor. There were many instances where parents laughed with one another about the oddities seen in their adolescents. They seem to be using this humor as a coping mechanism to help relate through the unique experience of raising an adolescent with autism. For example, we see this behavior manifested as parents are laughing with one another about how their adolescent can’t keep a normal distance during conversation and using humor to cope with the embarrassment that may come with dressing/grooming challenges. Within each session, there was always laughter at these simple things. A parent made a comment in response to another parent talking about how their adolescent told a lie:

“Isn’t that so funny? We get so excited when our adolescents do something age-appropriate. Look! My adolescent just told a lie to get out of something they don’t want to do. That’s so great and I’m so proud of them. But wait, is it great that I’m so excited about lying, stealing, etc.?”

There was a roar of laughter around the room after this comment was made. Parents seem to be using this laughter as a defense mechanism. They don’t want to face the reality that their adolescent is atypical and so they cope by making jokes about it. In doing this, they are seeking validation through the laughter of others.

These jokes were always centered around autism; the symptoms, the battles, the successes, etc. There is a unique jargon surrounding the world of autism. Most of this jargon is made up of commonly used acronyms (such as IEP, ABA, etc.). As parents of autism come together, the ‘autism lingo’ is used often with the correct assumption that the acronyms don’t need to be explained. If an individual with no experience of autism were to come in the room, they may feel lost as to why people are laughing at the parent’s concern that their adolescent has been required to play dodgeball saying, “can we get a little more sensory overload?” This jargon unites the parents as a group sharing one common interest. Their laughter over this common interest brings them closer together. They can all speak to, and agree through laughter to a comment one parent made, “I can’t stand another autistic person in my life... I collect them!” This type of interaction between the parents shows comfort and trust. The ability to laugh with others come from being in a group sharing a core element that all members can connect to. The parents’ ability to joke may show the safety they feel in this group.

This “seeking support” theme was also apparent throughout sessions in how parents spoke in plurality. Speaking about the challenges for “our” teenagers is an attempt to unite

themselves together sharing the same experience. In one instance, a parent was talking about how they are looking for that “one friend” who will invite and include their adolescent. In introducing this topic, another parent commented, “I think everyone wants that.” To this response, many heads nodded and there was a palpable feeling of longing in the air. Parents raising adolescents with autism are seeking that “one friend” and they are united in this pursuit. In speaking of seeking out support, one parent said:

A counselor we met with a while ago suggested that WE (parents) get a confidant friend. That friend would understand the things WE'RE going through and can help give US support. WE have found that friend and it's been a huge blessing. Sometimes we'll send [our child] over to her house, or she'll babysit so WE can have a break. She even took him on a road trip once to give US a mini-vacation. This has been one of the biggest suggestions that has helped our family the most.

By coming to this group and interacting with other individuals in similar situations, these parents are seeking that confidant friend, or group of friends for themselves.

A spectrum within a spectrum. While parents in the group agreed on this one similarity, their experiences are still different. As autism is a spectrum disorder, the experience of a parent raising an adolescent also occurs across a spectrum. One simple example illustrates this when one parent said, “[my child] has the ultimate “OCD” with the lights. They're always making sure the lights are all turned off.” To which another parent commented, “You're lucky. That definitely doesn't happen in our house.” Throughout the sessions, the differences between the children became more apparent. Some adolescents with autism strive to be the joke teller, while others don't understand what a joke is. There are some adolescents with high sensitivity to loud noises, while others can't turn their headphones up loud enough. Each adolescent on the

spectrum is different and this makes each experience of parenting different. These parents come together with this sense of unity, but with their experiences being so diverse, their ability to connect with each other is limited. On several occasions, a parent would bring up a frustration to which another would respond how that frustration may be a triumph in their family.

Just as adolescents are constantly comparing themselves to one another, sometimes adults do too. As researchers, we noticed this occurrence within the group. When one parent shared an experience they had, another one would seem to “one-up” their experience with a new story that sometimes was the opposite of what the other parent said. For example, one parent commented, “my [child] loves watching the anime television shows,” to which another parent added, “my [child] watches movies in other languages! He’ll watch them so fast that sometimes I think he is trying to teach himself Japanese!” Several parents in the group have additional children who also have autism. Many of these are an older child on the spectrum. These parents commented that even between their own children there are differences. To many, these individuals became the “expert parents” within the group, because they had a sense of wisdom having already parented one adolescent with autism into adulthood. These parents sought comfort in similarities in the group and yet isolated themselves by explaining how their situations are different. It was interesting to note that the parents placed themselves on a spectrum that may have prevented them from getting too close. The natural results of their differences prevented them from getting too close. They may have purposefully set themselves apart as different to protect themselves.

“The Spark”

This theme centers on the overall joy and acceptance parents feel toward their adolescent. Each parent spoke to the positive qualities/characteristics and individuality that is their teen. That is, what makes them, them and what guides their life and gives them meaning. Several of

the parents labeled this as “the spark.” One parent commented in an early session that parents should, “feed the fire that is [their child]. Let them be them and embrace themselves.” This spark was described across a range of examples from a fixation with finances to their knowledge about computers and technology. In some ways, having this spark is exciting and gives parents hope: “He can do crazy equations and loves anything brainy. I know one day those skills will serve him well.”

However, there is a deeper theme here. Many parents are annoyed or frustrated with their adolescent’s chosen spark. Their child’s fixation feels like something they get stuck on that will last a lifetime. One parent commented, “the bad news is, they can’t break out.” Parents understand the success that can come from having a spark, and yet wish they could choose their adolescent’s given strength. They would change this spark if they knew how. It is notable to mention that the majority of parents reported that they agree that video games should not be the spark that their child is obsessed with. One parent stated, talking about a specific video game, “[my child] can go so fast that I get cyber sick. The more they get into this [game], the faster their brains can function. It’s amazing, but the bad news is they can’t break out.” Another parent commented, “if my child can just shift this spark to programming, I think he will have a very successful career as a computer programmer. There are no careers in video games.” These quotes illustrate the frustrations the many of these may feel when it comes to what spark their child is fixated on. This theme will re-appear as the theme of moving toward the future is discussed.

Family Values

Another theme centered around family values and the heartache that can come when adolescents don’t share their parents’ values. The two most common values brought up centered

around religion and pornography. Because of the geographic setting of the study, many of our participants were religious individuals sharing a common religious affiliation. Having this commonality may have generated more sharing on this topic than would be observed in a different setting. Having the freedom to talk through these personal beliefs was probably comforting for the participants as demonstrated by how frequently the topic of religiosity was brought up.

Parents often commented about the attendance, or lack thereof, of their adolescent at religious events. They also brought up the reluctance of their adolescent to even practice their religion, “The other day [my child] said to me that he wishes he wasn’t affiliated with religion at all,” or having their child say, “sometimes I wish I wasn’t [part of this religion].” Having this discrepancy between their beliefs as parents and their adolescent’s beliefs may be hard for many. An unspoken concern is that the parents may be afraid for their adolescent’s spirituality and are expressing that concern through means of complaining about church attendance. Thus, they spoke more about religious actions, but their fundamental fear is that their adolescent may not be experiencing spirituality the same way as others. The parents in our study reported that adolescents with autism have a hard time internalizing values. And whatever values a family has, it is difficult for a parent to see their adolescent’s values not matching their own. One parent expressed his deep concern and frustration about religion over his adolescent playing video games, “One of the video-gamers [my child] plays with said he was God. I was shocked that [my child] actually believed him. We had a long talk about religion after that.”

With the parents’ values being disrespected, parents often have to be the “bad guys” in hopes of getting their adolescent to try to raise their expectations. Often in teenagers with

autism, they simply have a hard time internalizing these values. One parent speaks of the difficulties that arise with these values:

“[My adolescent] is really struggling right now. He is not doing well in several aspects of his life. We are talking to his teachers right now and he has also had his technology privileges taken away. This has been hard on him, but it’s ten times harder on me. His life is in turmoil right now. But it is what it is. You take the successes and roll with the setbacks. I’m definitely the enemy right now, but that’s typical for teenagers anyway.”

Sometimes the disrespect for these values can be sensitive to the family. Especially in a religious culture, there are some topics that are almost taboo to approach. For many of the parents in our group, viewing pornography is seen as disrespecting the family values and family religious beliefs. This was one topic that was brought up on several occasions without explicitly stating the problem.

For example, parents talked about the use of phones and when privileges should be given to their adolescents. One parent commented that getting a flip-phone “eliminates a lot of the problems [that come] with the smart phone.” Another parent added her thoughts to this, “they don’t really use phones for communication, but they are always on [media sites] and you just don’t know what it is that they are looking at.” Yet another parent commented, “we blocked those apps to prevent [our child] from seeing things boys just don’t need to see.”

One parent finally used the word, “pornography,” and there was a palpable heaviness in the air that confirmed this theme/concern of these parents. One parent added that with pornography, “these kids don’t have boundaries. It’s hard for them to know how far they can go. That’s why it’s easier to just make the decisions for them.” Implications of this theme not being explicitly stated on several occasions will be brought up in the discussion section. Taking a look

into family values is a great segue into the impact raising an adolescent with autism has on the whole family.

Impact on Families

Frequently, the parents are accounting for the burden that comes upon the entire family. One parent commented, with regards to those family values, “He’s had some technology privileges taken away, which has been really hard on him. But it’s been harder on me, and dad, and the rest of the family.” It appears that the whole family will sometimes suffer due to the effects of autism. The family has to “walk on eggshells,” so to speak, in order to prevent an aggressive outburst. “[My child] thinks everyone is teasing and he thinks the family is bullying him. You just don’t know what is going to set him off. If you bring it up he’ll just go on with how horrible we are with teasing him.” Another parent shares in this struggle, “My husband loves to tease [my child], and it upsets him frequently.” Families often learn to adapt and create an environment in an attempt to avoid more behaviors, “When he has Scouts, we don’t bring it up until right before to keep him from exploding.”

There is also a challenge that arises from raising children to have equitable opportunities and setting equal boundaries within the home. “[My child] has so many rules and the other kids have zero rules. Complete freedom. I think this is a big challenge.” Whether the child with autism is the oldest, youngest, or somewhere in the middle, these challenges were acknowledged within our group. “[My child] is like, well why can’t I do that (what other kids are doing), and I tell him, you know why.” One of the common subthemes here was the question of when to get your child a cell phone. Many parents nodded in agreement at this parent’s concern, “We couldn’t give one of our children a cell phone without also giv[ing] one to [child with autism].” This, along with other challenges, appears to have an impact on the family as a whole.

Lack of Self-Awareness

One of the common symptoms of autism is a difficulty interpreting social cues: body language, facial expressions and tone of voice. This symptom increases the difficulty of empathizing and understanding other's perspectives (Seltzer et al., 2001). Many parents shared their surprise that this extended into a lack of self-awareness and inability to form emotional relationships. "[My child] doesn't recognize emotions in others and this surprises me. It's surprising to see that [my child] was not sensitive to others, he may not experience empathy at all." Raising an adolescent with autism can be a huge learning experience as parents come to understand this lack of self-awareness as one parent comments, "whenever I'm asking emotional questions, he always says 'I don't know.' And I think he really doesn't understand these questions." One parent shares with the group a hard realization they had come to:

"[My child] told me he doesn't even care to make friends. He told me he doesn't care. I'm still trying to process this. He said he doesn't think he feels any feelings at all. He says he doesn't know if he's sad or happy for someone. For me, this was shocking! He's really struggling right now. Kind of depressed."

Many parents echoed similar concerns of their adolescents not feeling emotions stating, "he is completely void of emotional attachment," and "it's hard to teach kids that [referring to emotions]." This deficit in social awareness can have many negative impacts on the whole family, thus these themes are interconnected. One quote that ties these two themes together would be, "[My child] will often complain about how annoying our family is when he doesn't even realize that he is the worst one."

Learning to accept that your child has autism comes in different stages for different parents. This realization may come as parents learn to cope and also help their adolescents cope

with these barriers they have in life. One parent relates her adolescent's experience to the "glass box syndrome" by stating:

"There is this idea of the glass box syndrome. You may see everything going on around you, but you can't touch it or connect with it. I've taught [my children with autism] to try and have a good time while in this box. Don't tell them they can't do something they want to do."

Trying to balance the challenges surrounding social limitations that arise from raising an adolescent with autism with acceptance for them may be difficult. The integration of these experiences, combined with attempts at inclusion to be discussed in the next section, gives a small insight into what these parents day-to-day experiences include.

Being Included

Another common theme for parents raising adolescents with autism centered around the attempts at inclusion of their adolescent and the frustration and concern that comes with it. Many parents spoke to the difficulties that arise when dealing with professionals, friends and the general public who don't understand what it's like to live a day in the parent's shoes.

"Sometimes I feel like [my child] is making progress and other times I get so frustrated and I wish the teacher would intervene more," was just one of many comments stating the frustration that comes from trusting others with their child. Another parent shared an experience when speaking about a boy's camp her [child] went to with a neighborhood group:

"I got called to go down there three times during the evening and night. He had to sleep alone because nobody wanted to share a tent with him. He would get really scared and act out. It turns out the leaders of the group weren't giving him his medications. No wonder he was struggling so bad!"

To this comment, one parent spoke up and said, “I haven’t even let my [child] go to [Boy] Scout camp yet,” and another saying, “I asked if I could go with, because I was so nervous with how he would be treated and if he could do the things he needed to do.” It can be hard to put trust in teachers, leaders and other professionals when these trusted adults fail to adequately support their adolescent. And yet, they find themselves required to exercise that trust, because they can’t face this challenging experience of raising an adolescent alone.

Many parents pre-emptively plan for the lack of understanding within the public sector. Several parents in our group spoke about emailing teachers at the beginning of each school year or contacting new principals. These parents have learned throughout their child’s life about the lack of public understanding and are just trying to protect their adolescents. One parent spoke of the “cover story” he uses when meeting new people:

“When we meet people, we tell them: you’ve probably already noticed, but [our adolescent] is a little different. We tell them he has high anxiety. This is just our cover story. We don’t spill our life story to everyone we meet, but just some heads up about [our adolescent]. We tell adults they can call us if they need help, or they can have him take a break. We try to share the burden of our child.”

By doing this, many parents ease the guilt they may feel for the challenge their adolescents can be. Teaching others about their child can help increase understanding about challenging behavior they may see. One parent shared, “most people are nice about it. They treat [my adolescent] very nicely.”

This can also be true for peers the adolescent may interact with. Having an adolescent with autism seems to bring a lot of skepticism surrounding the intentions of others. Several

parents mentioned this fear at one point during our sessions: Are kids being nice to my child, or being friends with my child just to be nice? One parent vocalized this concern:

“If [my adolescent] were to have a friend that accepted him the way he was, that would be amazing. But when I sit down and think about what this friend would look like, I realize it’s going to be that weird friend in school. If someone accepted [my adolescent] as a friend, he would be just like him! Then we would have two [adolescent]s!”

It was mentioned earlier that many parents have a goal of having that “one friend,” for their child, however, with the skepticism many feel, these parents are imagining the “wrong” type of friend.

This skepticism may stem from how individuals with disabilities can often be taken advantage of. One parent shares this experience about their adolescent:

“[My adolescent] is sixteen and is a little more severe. One day at the mall, there was a kiosk to sign up for a credit card and new cell phone. I turned my back for one minute, and when I turned around he had successfully signed up for these gadgets. I felt that salesman took advantage of him. He was still a minor at the time, so I told the salesman the contract was void. This is when I realized that my [child] is “prey” for these people. And this is a huge concern.”

Many parents echoed this by sharing experiences they found their adolescent in. These experiences included the adolescent’s friends asking for money, classroom peers placing blame on the adolescent for things they didn’t do, or even as simple as one parent said, “[my adolescent] wanted his friends to like him so much that he let them tease him and bully him.” This theme of mistrust of other’s intentions seemed to come up time and time again through the parent session.

“One Good Friend”

As was mentioned in the “seeking support” theme earlier, many parents would be “happy to have just one good friend.” At some point in the group, every parent voiced a similar thought to one parent that said, “I would get so much joy to see [my child] flourish with friends.” For many, this has been an obstacle they’ve been enduring since they were younger. One parent speaks to how her desires have evolved over time:

“When he was younger we hadn’t accepted it, we were just like “why can’t he make friends?” but now that we have accepted it, we are just hoping for that one friend. And it might be a weird friendship, like they just text or something.”

Another parent voiced a similar concern, “I want [my child] to recognize that he can have friends. He had kind of decided that he will never have friends, so he is only going to watch anime because he can’t make friends.” This theme seemed to resurface time and time again throughout the sessions.

Combining this theme with that of lacking self-awareness, parents may be projecting their own desire for their adolescent to have friends stating, “I just want him to have a connection.” Some parents believe their adolescent desire for friends matching their own, “I don’t think he wants to be alone. But he got used to it and accepted it.” While others know their adolescent’s values don’t line up, but they’re trying to convince them otherwise, “He just doesn’t see the point of friends. We tell him if you want to be successful in life, you have to have friends.” This illustrates the “spectrum” of experiences parents may encounter when dealing with this spectrum disorder.

In our group, it was found that more often their adolescents were making steps toward friendships, they just don’t understand the correct steps to take. For example, one parent shares

an experience that happened while on the playground during recess with her 6th grader with autism:

“There was a situation where 2nd graders were bullying older kids. [My child] went over and talked to them and they pushed [my child]. He didn’t retaliate, which surprised me. The principal was really proud of how [my child] handled it. When [my child] gets a friend, he’ll tunnel vision them and try to monopolize all their time.”

This parent continued, by saying how this “obsession for the friend” has made it hard for her [child] to keep up with the friendship. The friend doesn’t like to engage with her [child] anymore because he was “too intense” of a friend.

Another parent shared a story that illustrates how her [child] also sought out friends in a different way:

“I got a call from the vice principal. [My child] has been saying to the other kids, “this guy is my boyfriend.” He was doing this as a joke because he got a reaction. The boy asked [my child] to stop, but he wouldn’t. [My child] is just trying to make friends. I can tell he’s lonely.”

These parents want their children to be happy and successful. There is a very common theme involving the “one good friend.” Parents in the group share their concern for finding friends, but there also an underlying theme surrounding that one “special” friend and relationships. This theme will be brought up more extensively in “moving toward the future.” One parent summed up what many parents were potentially thinking by saying, “Right now we just want one good friend and then we’ll tackle the relationships.”

Moving Toward the Future

Because autism is a lifelong condition, parents were thinking about what this means for their adolescent's future. On the whole, parents have hope for what is in store for their adolescent. As mentioned before, some of our "expert parents" have already raised adolescents into adulthood and told of the success they have found in going to college, finding jobs, etc. The other parents in the group listen intently when these "expert parents" are speaking. It appears that they love to hear these stories and share their own stories (from popular literature, etc.) about people on the spectrum finding success in adult life.

The parents in our group all daydream about their adolescent's future. One parent told a story about two adults with autism falling in love and says, "This is what I want for [my adolescent] so badly." Another parent stated, "[my adolescent] thinks he'll be working at Walmart. But I know he has so much more potential than that. I think he'll be an engineer." Other parents echoed this as they envision successful careers for their adolescents. They have hope that one day they will be independent by pushing them. As one parent says, "Life isn't always going to be easy. We need to prepare him to do things he doesn't want to do."

With a bright hope for the future, there is a hidden sense of anxiety along with it. One parent spoke to a 'bunny-hop' analogy for her experience, "I feel like we'll take one jump forward, and then for several weeks we'll be taking two jumps back." Another parent replied by saying, "Yours only lasts for two weeks?" To this, the room filled with laughter as the parents used humor to cope with this fear of regression. One parent blatantly asked the group what the future for their adolescent looks like. Several parents dodged the question by talking about irrelevant experiences. This demonstrated the deep concern and anxiety many of these parents feel with regards to the future.

Another reality that parents raising adolescents with autism must face are issues with custody and guardianship. One parent approached the subject by asking,

“What do you guys think we should do about custody? Should we take guardianship because he needs the support? We know he can’t do it by himself, but he does have the skills to talk to people. I want to hope for independence.”

Although these parents have high hopes for the future, they still have fears that leave their adolescents dependent on them. One parent commented, “It’s my instinct if things go awry to immediately help him.” Another parent chimed in, “That has been one of the hardest things –to let him figure these social things out on his own. Sometimes I have to leave the room because I can get so upset by watching him fail.” Parents seem to constantly be at battle between letting their adolescent learn and grow and having hope for the future while still compelled to parent their adolescent.

Along those lines, one parent made a humorous comment about how one day they envision their adolescent “making millions,” because they finally found the “spark” for something worthwhile. He continued his comment by saying, “and because [my adolescent] will still be living at home, I will be the gatekeeper for all this money!” This quote really illustrates how these parents have hope for the future, but that hope is accompanied by fears. Their overarching fear is that their adolescent will never become fully independent.

Results Summary

There were many themes that arose during the weekly sessions. These themes revolved around the parent seeking support, and yet feeling isolated by the scope of the autism spectrum. There were also many themes focused directly on the child with their “spark,” the values they share with the family and the attention and intentions from others around them. Finally, the

parents were often planning for and/or hoping for the future and what it may bring for their adolescent with autism.

Discussion

The purpose of this investigation was to gain an increased understanding of the issues that parents with adolescents with autism face. There have been decades of research on the effects of parenting and autism as conceptualized by researchers; however, there is a gap within the literature that has not previously included opportunities for parents to describe the challenges and joys of raising an adolescent with autism. Given the unique experience of parents of adolescents with autism, a greater understanding of their lives in dealing with these challenges, as well as their concerns, will prove immensely valuable to clinicians and families through this period of development.

Authentically describing an experience using quantitative statistics can be challenging and may not have been informative. Therefore, this study employed a qualitative approach to explore the meaning and experiences of parents of adolescents with autism. Whereas many of the prior studies have been designed to gather data using questionnaires driven by researchers' questions, there are very few studies in which the parent was allowed to simply report what their experiences have been, without a framework of specific questions. This less structured approach provided parents with the opportunity to tell us what they think of as the more compelling issues in their lives with their adolescents.

Parents discussed their experiences throughout the sessions. Prominent themes that arose included: seeking support, "the spark," intentions of others, family values, social skills and future planning. The following sections will discuss the findings in light of the current body of

literature, review the limitations of the study, highlight implications of the results, and provide suggestions for future research.

Reflection on Themes and Current Literature

In the existing literature, the most common unmet support needs of parents with adolescents with autism are the child's social functioning, family-wide impacts, relationships with professionals and future planning (Hartley & Shultz, 2015). One could argue that these unmet support needs are the concerns and topics a parent would bring to group. Thus, the common themes we saw should map onto these unmet needs.

Unmet needs of parents that are most common, according to research, were also seen as common themes in our sessions. Concern for the adolescent's social functioning came out multiple times throughout the session. Parents often commented about having that "one good friend" for their adolescent. The purpose of this social skills group was to learn how to make and keep friends. This could lead to a biased result, as all of our parents voluntarily signed their teens up for this group knowing the purpose was to increase social skills. There is definite concern for the adolescent's ability to have friends, and this concern was continually manifest throughout the sessions.

The second most common unmet need for parents centers around family-wide impacts (Hartley & Shultz, 2015). Having an individual with autism in the family poses one of the greatest threats to the psychosocial well-being of each family member (Seltzer et al., 2001). This impact was heavily voiced throughout each session. Comments about having to "walk on eggshells," symptoms of autism getting in the way of everyday functioning, as well as how to deal with trying to have some level of sibling equality when one of them has autism were frequent themes during sessions. Many parents voiced concerns over the significant time

commitment that comes along with dealing with difficult behaviors and deficits in communications. The themes from our study coincide with this recognized support need from the literature.

The next topic in the literature that parents raising adolescents with autism find challenging revolves around relationships with professionals and the general public understanding and acceptance or toleration of autism symptoms. The results section discusses one of the more common themes found in our study about the intentions of others. Parents were often found complaining about the lack of support from teachers and other administrators. Parents also spoke to the loneliness they feel daily and how they sought out this support group to help them feel a sense of approval. Current research states that this lack of understanding from the public is what may isolate families from the general public (Baker et al., 2011). Parents in our group, as well as those in other research groups, report that they have less positive interactions with others than parents raising adolescents without disabilities (Hartley, DaWalt, & Shultz, 2017).

The last unmet support need mentioned by Hartley and Shultz (2015) is about planning for the future. Autism is a lifelong disability that impacts both adolescent and parent throughout the entire course of their lives together. Our findings strengthen the validity of Hartley and Shultz's (2015) study in stating that parents of adolescents with autism have many concerns about their child's future. Parents in our study often voiced concerns over their adolescent succeeding in careers, finding marriage, and issues with guardianship. In our sessions, parents often had these conflicting feelings of having hope for the future as well as feeling anxious about the future. At one point during the sessions, one of the therapists asked the parents what they saw in their adolescent's future. This was a heavy question for these parents, as many refused to

even answer or answered in a way that avoided the question. Most parents wanted to hold their hope strong, only occasionally letting their fears slip through. Research shows that many parents will be the primary caregiver over their child with autism well into adulthood and, in many cases, their entire life (Smith et al., 2012). Parents in our study seem to understand this fact, and yet have that ounce of hope that their adolescent will be one of the few who perhaps will reach full independence, get a career and/or get married.

Limitations

There are limitations of the current study. First of all, while videos can be expected to give opportunities for repeated watching for analysis, one session was missed due to technical difficulties. At times, the camera didn't capture the speaker's face, making it more difficult to match a voice to a participant. While this will not significantly affect the results of the study, it is important to note some reliability challenges to complete data collection that can come through use of technology.

Another limitation was the setting of the study. Because this study took place at a faith-based university, participants may have more inclination to discuss religion than participants in a different setting. The physical location of this social skills group may have evoked a possible bias for more comments related to spirituality. Although religious membership was never disclosed, many of the participants may have assumed the others shared in the same religious values, which may have created a climate in which these topics were comfortably discussed and were more likely to come up. None of the parents expressed discomfort with discussion of religion; however, perhaps lack of participation in religious discussion on the part of a couple of participants could be interpreted as discomfort. Specific tenets of the parents' religions were not discussed directly, although family values regarding pornography may have been influenced by

the religious beliefs of the parents. Researchers broadened the theme into respecting family values, regardless of religion or affiliation, in hopes of generalizing to a wider population of all parents who raise adolescents with autism.

Another limitation came through using the PEERS® curriculum in sessions. Because a general topic for conversation was presented to the parent group each week, conversations may have been slightly more likely to revolve around social skills and making friends. This was a topic that was on the minds of many parents and may have caused the theme of inclusion and making friends to be more obvious than it would be in a less structured session. Although, even with the presentation of a theme each week, parents tended to drive the conversation elsewhere. Thus, the daily topic would get parents talking and their own concerns and experiences would move the conversation.

Implications for Practice

Understanding the daily experiences of parents raising adolescents with autism can help service providers offer better support. The assistance provided by services can be more direct and focused on those unique needs parents with adolescents with autism are facing. As service providers help parents, they are ultimately helping the adolescents to make a healthier transition into adulthood. By highlighting some of the themes captured in sessions, we can learn what things are important issues for parents and start brainstorming how to help accommodate these concerns. For example, many parents seem to be struggling with their adolescent's lack of acceptance of family values (e.g. pornography). Offering more counseling services to address this issue may help parents learn to cope better.

We may find that it is most important to not just listen to what parents are saying, but also to what they are not saying. Those concerns that parents do not seem to be explicitly saying

are concerns that need to be addressed more (Kvale & Brinkmann, 2009). Knowing the scope of those topics that parents are too anxious to even mention can help service providers target ways to help address those concerns. One of the hidden concerns that our study found was that deep anxiety about the future. Parents often focus on the present and hide behind trivial concerns they encounter each day. Tackling the deep challenges and helping the parents plan for the future may help to eliminate some of that anxiety. This difficult experience of raising adolescents with autism can be attributed to many factors, including uncertainty about the long-term prognosis of individuals with autism. It makes sense, then, that strong themes arose about future planning and how the spectrum may isolate their adolescents from their peers.

An individual entering the world of parenting autism, either as a parent themselves, or as a professional seeking to work with these individuals, can learn from this study. There is a unique lingo that is spoken within autism culture. This lingo combined with the humor parents find and use to support one another is a great means to connect with parents raising adolescents with autism. Understanding their world, the language they use day-to-day, and those things that humorous as well as challenging, can help create a bond and be a bridge into the autism world. However, one of the paradoxes that was noted within the study found that while these parents have ways of connecting, they also like to maintain their distance.

As noted in the “spectrum within a spectrum” section, many of the parents in the study were constantly trying to highlight the differences between their children and the differences in their experiences. With parenting a child with disabilities, there is a special status or a sense of “pride” that these parents hold. These parents may not want to be the “same” as everyone else in the group, because it takes away the “special” and unique nature of parenting a child or adolescent with autism. Understanding this bit of information can help mental health

professionals understand how to interact with these parents and how to help them maintain their uniqueness.

During adolescence, we see an increase in hormones and depression (Smith et al., 2012). This increase in depression can also be seen through social isolation and social barriers adolescents with autism experience. Studies have shown that when challenging behaviors manifest at a higher rate in teens, depressive symptoms and anxiety in parents are also higher (Baker et al., 2011). There is a direct emotional impact on parents as they raise an adolescent with autism. Knowing the common themes that a parent raising an adolescent with autism experience can help clinicians (including therapists and medical providers) know how to better help them, especially with the deeper issues that were commonly unstated or understated in our observations.

Raising an adolescent with autism comes with a unique set of needs. Parents need the proper support in order to be successful. The most common unmet support needs of parents with adolescents with autism are the child's social functioning (e.g., the child's ability to have friends, child's ability to have social activities with people out of family); family-wide impacts (e.g., time to spend alone with partner, counseling for self or partner, family vacations); relationship with professionals (e.g., encouragement to ask for help); and future planning (e.g., fears about child's future; Hartley & Schultz, 2015). The unmet needs from this study seem to map onto those that were found in our group. As well, parents frequently mentioning the impact on their family and their constant desire to have their adolescent be included.

Recommendations for Future Research

This study confirmed findings of existing research that there are many challenges of raising an adolescent with autism. This study also lends direction for further research into what

the issues are for a parent raising an adolescent with autism. Many of the themes produced were ones that are already present in research. In looking at our participants; however, we see there is possibly more parental concern placed on family values and what a future will look like than other studies have demonstrated. Future studies can further explore what exactly these parent's needs are and how clinicians can help them.

Utilizing a qualitative approach allowed parents to freely talk about the issues they face while raising an adolescent with autism. However, having therapists ask more directed questions may help gain even more understanding into adolescent parenting issues and what can be done to help.

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APPENDIX A: Review of Literature

Parents are responsible for the care and nurture of their children. In addition, parents are also responsible for raising their children to be happy, healthy and successful adults, which includes raising them through adolescence. Caring for an adolescent rather than a child introduces new challenges for the parent as their once young child is growing and moving towards adulthood. Adolescents experience changes in hormones, hygiene and social relationships (including romantic relationships) to name a few. With all these changes, the experience of raising an adolescent is usually emotionally draining for parents. The experience becomes more draining when that adolescent has a disability. Raising an adolescent with a developmental disability places additional challenges on parents (Baker et al., 2011).

One developmental disability increasing in prevalence in recent years is autism spectrum disorder (ASD). The Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network (ADDMM) estimates the current prevalence rates for ASD in the United States to be approximately 1 in 59 children (Baio, 2018). This rate is almost double the rate 12 years ago, when in 2006 the prevalence rate was 1 in 110 children (Christensen et al., 2016). Autism is characterized by lifelong impairments in both social communication and restricted interests or repetitive behaviors (American Psychiatric Association [APA], 2013). There is strong evidence to suggest that these social impairments and behaviors persist throughout life (APA, 2013; Howlin, Mawhood, & Rutster, 2000). Although raising an adolescent with any disability is challenging, autism is not simply another disability many parents have to learn to cope with. There is some evidence that show few disabilities appear to be more taxing on parents than raising an adolescent with autism (Seltzer, Krauss, Orsmond, & Vestal, 2001).

Parenting a Child with Autism

Several factors have been proposed to account for the more difficult experience of raising an individual with autism including the uncertainty surrounding an ASD diagnosis and the long-term prognosis of individuals with autism. The stressful nature of autism symptoms and associated behavior problems, as well as the lack of public understanding of and tolerance for these behaviors can lead to a poorer sense of wellbeing in parents. With all the responsibilities that come from parenting an adolescent with autism (e.g., teaching skills, treatment care, behavior management), mothers often have elevated levels of depression (Smith, Greenberg, & Seltzer, 2012). Parents of adolescents with autism are responsible for managing possible symptoms and co-occurring behavior problems, assisting their child with everyday living skills, and coping with family-wide effects. In addition to these responsibilities, parents raising children/adolescents with autism are constantly concerned about intervention and treatment. This concern starts when the child is young with early intervention services and continues throughout adolescence and into adulthood. The necessity for these interventions and treatments in adolescence skyrockets, perhaps because of the influx of hormones in an adolescent's system (Aman, Lam, & Collier-Crespin, 2003).

The need for medication in adolescents also increases, because impulsivity and other maladaptive behaviors are intensified and growth in stature and weight require changes in dosage and medication management (Handen & Lubetsky, 2005). With the increase in hormones in adolescence, depression symptoms in adolescents also increase (Smith et al., 2012). The social isolation that an individual with autism experiences is a major factor that may lead to an increase in depression rate. Difficulty connecting with others leads to individuals with autism feeling lonely and socially isolated (Ahlers, Gabrielsen, Lewis, Brady, & Litchford, 2017). Being

depressed can create more barriers to social success (i.e., more socially isolating behaviors) for these teens as they move toward adulthood. Studies have shown that when these challenging behaviors are more prevalent in teens, depressive symptoms and anxiety in parents are also higher (Baker et al., 2011). There is a positive correlation between challenging behaviors in adolescents and depressive symptoms in parents. This correlation shows a direct emotional impact on parents as they raise an adolescent with autism (Baker et al., 2011).

Intervention/Treatment Options

Although sufficient academic and basic behavioral supports are available for individuals with autism, supports for complex social emotional issues are more difficult to access (Ahlers et al., 2017). While there may be more early intervention centers and other treatment options available for young children with autism, services become very limited once the individual reaches adolescence. Studies have found a significant reduction in number of formal services available to families of individuals with autism in high school and following the transition out of high school and into early adulthood (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Unfortunately, an ASD diagnosis includes lifelong symptoms that do not stop when an individual reaches adolescence. Parents rely heavily on continued support through community groups, school resources and often medication and diet for maintenance and treatment of symptoms and behaviors for their adolescent/adult with autism.

One way adolescents with autism can receive support is through social support/social skills groups. The key building blocks for social relationships (i.e., communication, social understanding, and emotional responsiveness) are impaired in individuals with autism (Orsmond, Seltzer, Greenberg, & Krauss, 2006). Therefore, intervention for autism often involves teaching social skills as well as coping skills. Of the packaged social skills programs that are readily

available, one of the social skills programs with some consistent evidence is PEERS® (Program for the Education and Enrichment of Relational Skills; Laugeson, 2017). PEERS® is a 14-week evidence-based intervention to help adolescents with ASD learn how to make and keep friends. This program has been shown to be effective long-term for those teens (i.e. those with age appropriate cognitive and language functioning), specifically with autism, who have participated in at least one PEERS® social skills group (Mandelberg et al., 2014). An integral feature of the PEERS® program is parent involvement in parallel weekly sessions and homework assignments. Parents play a key role in the PEERS® model as they provide the opportunity to generalize skills learned in the group to the real world outside of the group. Parents learn a common vocabulary during sessions to help their teen with the goals for that week.

In addition to social impairments, individuals with autism may also display a range of behavioral concerns including anxiety, aggression, agitation, over-activity, self-injury and stereotypic behavior (APA, 2013). Adolescents with autism have the same basic health care needs as adolescents who do not have autism, however they tend to experience higher levels of stress, decreased physical activity, unsafe sexual activity, and depression and suicide (Strunk, Pickler, McCain, Ameringer, & Myers, 2014). Recent estimates indicate that over 45% of individuals with autism are prescribed psychotropic medications for management of associated behavioral disorders (Aman et al., 2003). Because no current medications have empirical evidence showing effects on the core features of autism, psychotropic medications are used to treat specific behavioral and/or psychiatric symptoms. Individuals with autism seem to have a relatively high rate of comorbid psychological conditions (Gillberg, & Billstedt, 2001; Handen & Lubetsky, 2005). Adolescents with autism suffer from those same symptoms that typically increase in adolescence (depression, anxiety, suicide, etc.), but with more frequency and severity

(Gillberg & Billstedt, 2001; Handen & Lubetsky, 2005). Studies suggest that individuals with autism may respond to many psychotropic medications in ways similar to the typically developing population; however, response rates tend to be poorer and more variable, and the occurrence of side effects tends to be greater (Handen & Lubetsky, 2005). The use of medication is one of the few treatment options available for some mental health concerns, and yet it is not a completely reliable option.

Impacts on Parents

Raising a child with autism can have a direct negative impact on parents. Parents are in charge of managing the child's symptoms and co-occurring behavior problems, providing assistance with activities of everyday life and navigating services. With all of these responsibilities, it is no surprise that parents of adolescents with autism are at risk for poor psychological well-being as compared to parents of adolescents without disabilities (Ekas & Whitman, 2010). Even with the additional stress of rearing an adolescent with autism, parents feel compelled in their efforts to try their best for their child. One study showed that there was a moderate association between positive parenting attributes and child outcomes even within the developmental disability population (Dyches, Smith, Korth, Roper, & Mandelco, 2010). Parents must be mindful of their actions and how they approach parenting their child, because it may directly impact the development of their adolescents. It is critical that effective parenting skills are recommended when providing services for adolescents with disabilities to ensure these adolescents with substantial disadvantages have the greatest opportunity for success (Dyches et al., 2010).

As parents deal with the many struggles of raising an adolescent with autism, they are also likely experiencing a direct impact on their own well-being. Adolescent behavior problems

were found to contribute to greater symptoms of depression and lower feelings of parenting efficacy as well as increases in depressive symptoms over time in parents (Woodman & Hauser-Cram, 2013). Specifically, daily mood for mothers has been found to be more negative when they care for a child with autism as opposed to a child without disabilities (Smith et al., 2012). Parenting an adolescent with autism can be very tiresome and emotionally draining on the parent.

Raising an adolescent with autism comes with a unique set of demands. Parents need the proper support in order to be successful. Mothers have more unmet support needs than fathers (Hartley & Schultz, 2015). The most common unmet support needs of parents with adolescents with autism are the adolescent's social functioning (e.g., the ability to have friends, and ability to have social activities with people out of family); family-wide impacts (e.g., time to spend alone with partner, counseling for self or partner, family vacations); relationship with professionals (e.g., encouragement to ask for help); and future planning (e.g., fears about adolescent's future) (Hartley & Schultz, 2015).

Adolescent's social functioning. An adolescent's level of social support has a notable impact on parents. In studies of parents of adolescents with autism, higher levels of social support have been associated with lower levels of negative impact, psychological distress, negative mood and depressive symptoms in parents (Bishop, Richler, Cain, & Lord, 2007). Every parent wants to ensure their adolescent's social needs are being met. Parents want their offspring to have friends and social activities to attend. This becomes a greater challenge when their adolescent has autism because of the deficits in social communication functioning. Social support has long been recognized as an important component in the stress process and a predictor of psychological well-being (Pearlin, 1989). This support can be found at school or in the

community (i.e. local church groups, sports teams, neighborhood friends). The key here is that the support is found, and friends are made with individuals outside of the family. Informal support appears to be a more effective stress-buffer than formal support (Boyd, 2002). This means that adolescents have more success with casual friendship relationships rather than those coming from mandatory or formal groups.

Family-wide impacts. Few disorders in adolescents pose a greater threat to the psychosocial well-being of other family members than autism (Seltzer et al., 2001). There is a significant time commitment with regards to raising an adolescent with disabilities that affects parents and siblings. Families of teenagers with autism have a lot to cope with, for example; dealing with difficult behaviors and a long-term diagnosis, dealing with deficits in communication with family, and restricted, repetitive interests or obsessions. Family members of persons with autism may also face a dual challenge of the demands of caring for the individual with autism and, at the same time, dealing with an elevated risk of neurological, cognitive, communicative, and psychiatric difficulties in themselves, their spouse and their other children (Seltzer et al., 2001).

Families are also impacted by the adolescent's personal hygiene. Due to increased hormones and also the fact that individuals with autism have routines they get "stuck" in, the need for appropriate hygiene increases significantly, but adolescents with autism have difficulty adjusting to new hygiene demands. Parents can no longer bathe their adolescent as they did when the child was younger, and thus they may be constantly trying to remind their adolescent of the need for cleanliness. Showering introduces a sensory issue that may make some adolescents with autism hesitant to engage in the activity. The sensation of water running on the body may elevate the adolescent's activity state in which their maladaptive behaviors (e.g., whining,

tantrums) may increase (O'Donnell, Deitz, Kartin, Nalty, & Dawson, 2012). The lack of hygiene and increase in these behaviors can potentially affect the whole family as well as increase social isolation.

The public's understanding of and tolerance for the behaviors surrounding autism is low (Baker et al., 2011) and may result in families being socially isolated from participating in public events. Since this often leads to a feeling of personal isolation, it is important that all family members rely on one another for support. One study found that spouses were rated as the most helpful emotional support, while professional helpers were only rated as 'somewhat helpful' (Searing, Graham, & Grainger, 2015). While the spouse is rated as the most helpful support, time spent with one's spouse decreases when parenting an adolescent with autism. Parents of adolescences with autism reported less time with their partner, lower partner closeness and fewer positive couple interactions than the comparison group (Hartley, DaWalt, & Schultz, 2017).

Relationship with professionals. Because of the significant amount of time required for interventions, especially for more significantly affected individuals, parents may be constantly working with professionals in the world of autism. Parents interact with a plethora of professionals including pediatricians, speech-language pathologists, physical and occupational therapists, behaviors therapists, and special education teachers. There is a broad consensus within the field of developmental disabilities that these supports should be provided in the context of family-centered care (Dunst, Trivette, & Hamby, 2007). Family-centered care emphasizes the importance of establishing relationships with parents based on mutual respect and open communication, matching the changing needs and priorities of the family, and providing parents with choices and control over treatment decisions.

In one study, it was found that one of the top ten support needs of mothers is the quality of professionals for the adolescent; however, this wasn't on fathers' top ten list (Hartley & Schultz, 2015). There are many different types of professionals, and it is important that parents select one with whom they see the most successful path for their adolescent. As far as informal supports go, families want to maximize the quantity of help; however, when it comes to formal support, parents may want to ensure quality of the professional and will likely get the best quality they can afford. Having a well-trained, helpful, supportive professional can make all the difference for a family raising an adolescent with autism. Mothers reported importance of quality of professionals (experience working with children with same disorder and show respect toward families) as their top 10 support needs (Hartley & Schultz, 2015).

Planning for the future. Since autism is a lifelong disability that affects the adolescent from infancy through the remainder of their lives, planning ahead for the future can seem very daunting to a parent of an adolescent with autism. For parents of a typically developing child, the job is to pave the way for success as an adult through teaching daily living skills, furthering education, as well as teaching the critical skills of independence. Once a child is grown, they are ready to transition out of the home and into their newfound independence. This can be a bitter-sweet time for any parent, but research has shown that after the typically developing young adult has moved out of the family home, anxiety of parents was significantly lower (Baker et al., 2011). Raising a child with autism can be a little different, because their adolescent may not ever reach that point of independence in adulthood. Many parents are primary caregivers for their children well into adulthood and this prolonged caregiving period coincides with additional challenges associated with their own aging (Smith et al., 2012). Because some adults with autism never transition into independent living, anxiety for these parents may never decrease.

Supports for parents. Parents of children or adolescents with autism have many supports available to them. These support networks can be as small as one close friend with whom they confide, to as large as a social media group of individuals who know someone with autism. Studies found that having a greater number of support network members was associated with improvements in maternal well-being, as well as associated with declining levels of depressive symptoms (Smith et al., 2012). Further studies have found that anxiety for parents was higher when social support networks were smaller and when more stressful life events were experienced (Baker et al., 2011). The more support parents feel as they raise a child/adolescent with autism, the better. Having a positive support system that has many members can have a positive impact on the psychological wellbeing of parents as they raise their adolescent with autism.

Summary of impact of autism on parents. Parents with adolescents who have autism may have support needs that are unmet in terms of the adolescent's social functioning, family-wide impacts, relationship with professionals and future planning (Hartley & Schultz, 2015). Specifically, fathers may benefit from increased opportunities for self-care and relaxation, whereas mothers may benefit from assistance with accessing child treatments and therapies, education about autism, help with housework, and involvement in family support groups, as these needs are currently not being met (Hartley & Schultz, 2015). Mothers reported frequently using strategies of denial (refusal to believe what is happening) and planning (coming up with strategies about what to do) but rarely using strategies of mental and behavioral disengagement to cope with recent stressful situations (Woodman & Hauser-Cram, 2013). In summary, raising an adolescent with autism comes a plethora of obstacles that parents and families must learn to juggle.

Family Characteristics/Dynamics

Every family is unique. Variety in families involve family size, race, culture, economic status, and marital status. Any combination of these unique characteristics can change the family's dynamic and their need for support and interventions when it comes to raising an adolescent with autism. For example, it was found that fathers with a lower household income reported a lower number of important support needs than fathers with a higher household income (Hartley & Schultz, 2015). Experiences that all families deal with (e.g., sleep disruption) as well as those affecting only some (e.g., divorce) and those affecting most (e.g., death) may have more pronounced effects when there are children with autism in the family. Parents try to be conscious of the needs of all their children, although they can't necessarily meet all their needs equally. At times, parents routinely use strategies that prioritize the needs of the adolescent with disabilities first (Koch & Mayes, 2012). This can have many implications on the family and the varying levels of support that all children in the family feel.

Sleep. Sleep problems are common in families raising children with autism. Families often struggle with difficulties ranging from bedtime resistance to delay of sleep for several hours, to frequent night awakenings. Parents of children with autism report more sleep problems in themselves and their children than parents of typically developing children (Bourke-Taylor, Pallant, Law, & Howie, 2013). Sleep difficulties in adolescents with autism are common and can affect the individual's behavior as well as family functioning (Reynolds & Maslow, 2011). When problematic behaviors increase in the adolescent with autism, the whole family may have to adapt and work around the individual in order to function. With a strong preference for routines being one of the common characteristics of autism, it can be difficult to alter an imbalanced sleeping routine for the entire family. Less sleep for any single member of a family

may affect the family as a whole. An imbalanced sleeping schedule in the family is a seemingly simple yet possibly hardest problem to change when there is an adolescent with autism.

Divorce. Parenting a child or adolescent with autism can take an extreme toll on marriages. One study found that parents of children with autism had a higher rate of divorce than the comparison group of parents of typically developing children (23.5% vs. 13.8%; Hartley et al., 2010). The rate of divorce remained high throughout the son's or daughter's childhood, adolescence and early adulthood for parents of children with autism, whereas it decreased following the son's or daughter's childhood (after about age 8 years) in the comparison group of parents of typically developing children. This may mean that raising a child with autism does not get easier as they grow into adolescence and adulthood. Younger maternal age when the child with autism was born and having the child born later in the birth order were positively predictive of divorce for parents of children with autism (Hartley et al., 2010).

Death/grief/loss. Every individual will experience the death of a loved one at some point in their lives. It is not uncommon for an adolescent to experience the death of a beloved adult, and this includes adolescents with autism. Characteristics of autism typically include a desire to maintain routines and a feeling of sameness, so the grief process can lead to feelings of great distress when it causes interruptions in an adolescent's life (Hume, Regan, Megronigle, & Rhinehalt, 2016). The experience of grief can sometimes cause individuals to react in ways that are unexpected. When a person has an "opposite" stress reaction, they display feelings that do not truly represent the actual emotions they are experiencing. Because adolescents with autism often have difficulty empathizing with others and recognizing emotions, they sometimes react in ways that are not typical (Hume et al., 2016). These deficits within their social skills and

communication can limit the adolescent's ability to express and display their own emotion, which could lead to their missing out on support during these traumatic times in their lives.

Religiosity. A less researched, but important aspect of every child's functioning is religiosity. In the back of their minds, some parents may be concerned for their child in a spiritual sense by their church attendance, participation, etc. or lack thereof. Many parents turn to their spirituality and faith as a source of support. They may possibly join religious communities as a way to share and develop their spirituality with others. Strength is gained from faith and these activities provide a resource that enables family members to meet the challenges they face in everyday life (Poston & Turnbull, 2004). Without the appropriate supports, however, parents are either reluctant to attend or are unable to benefit from attendance because they spend their time providing direct support to their children with disabilities. Based on Poston and Turnbull's research (2004), families are looking for three things from their religious community: acceptance of their child, spiritual and emotional support for themselves, and supports for their child during services so that both their child and the family can have meaningful participation in religious activities.

Conclusion

Raising an adolescent with autism presents many unique challenges to parents and families. These challenges include the uncertainty surrounding an ASD diagnosis and the long-term prognosis of individuals with autism. Parents must confront the stressful nature of autism symptoms and associated behavior problems as well as the lack of public understanding and tolerance. Dealing with all of these problems, it is no wonder that these parents of adolescents with autism have unmet support needs as well as elevated levels of depression (Hartley & Schultz, 2015; Smith et al., 2012). Parents of adolescents with autism have high concern for

their child's social functioning, family-wide impacts, relationship with professionals as well as future planning for their growing adolescent. Many parents/families also face challenges surrounding sleep, divorce and death on top of everything else. Given all of these challenges, parents raising an adolescent with autism do not have the same experience as parents raising a typically-developing adolescent.

Purpose of the Study

The purpose of this investigation was to gain an increased understanding about the issues parents of adolescents with autism face. There have been decades of research on parenting and autism. There has also been research measuring the effects on a parent of raising an adolescent with autism measured quantitatively; however, there is a gap in the literature describing what daily life for parents raising teenagers with autism is like from a more qualitative perspective. Given the unique challenges of parents, a greater understanding of their experiences in dealing with these challenges will prove valuable. Therefore, this study employed a qualitative approach to explore the meaning and experiences of parents of adolescents with autism. We included a diverse sample of participants to show commonalities among parents of adolescents with autism as well as illustrating their differences. Understanding their daily experience will help service providers offer better support and assistance to help adolescents make a healthier transition into adulthood. Whereas many of the prior studies have been designed to gather data using questionnaires driven by researchers' questions, there are very few studies in which the parent was allowed to simply report what their experiences have been, without a framework of specific questions. We believe a less structured approach may provide parents with the opportunity to tell us what they think of as the more compelling issues in their lives with their adolescents.

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APPENDIX B: Background Survey

Thank you for taking the time to complete this questionnaire. The information that you share will help us match you or your family to appropriate research studies. This information will be entered in a research database. Please answer all questions to the best of your ability, using any documentation you have to help you remember information when needed. Information provided to us is confidential and no personal information will be shared with any participating researchers without your prior consent. Thank you!

Form completed by:

Mother Father Other Legal Guardian

Section I: Participant

Race and Ethnicity (check all that apply):

White/Caucasian American Indian
 Black/African American Hispanic
 Asian Other (specify):

Primary Language spoke in the home:

English Spanish Other (specify):

Is the participant:

a single birth triplet- fraternal
 twin- fraternal triplet- identical
 twin- identical Other (specify):

Does the participant have siblings?

No
 Yes- Name of Siblings: _____

Section II: Parent/Guardian**MOM****You are the (check all that apply):**

- Legal Guardian
 Birth Parent
 Adoptive Parent
 Foster Parent

DAD**You are the (check all that apply):**

- Legal Guardian
 Birth Parent
 Adoptive Parent
 Foster Parent

Parent/Guardian Age (in years): _____**Parent/Guardian Age (in years): _____****MOM****Parent/Guardian Education:**

- some high-school
 completed high school
 some college
 2 years 3 years
 graduate (specify): _____

DAD**Parent/Guardian Education:**

- some high-school
 completed high school
 some college
 2 years 3 years
 graduate (specify): _____

 Single Parent Home**Is Mother of Participant Currently Pregnant?**

- Yes No

Is Mother of Participant anticipating having other children?

- Yes No

Section III: Other Information regarding the Participant

Has any medical doctor or other professional (for example, educator, psychologist, speech therapist, behavioral health practitioner, or occupational therapist) ever thought that the participant has any of the following Pervasive Developmental Disorders?

	Yes	No	Type of Professional Suggesting Diagnosis
Autism	<input type="checkbox"/>	<input type="checkbox"/>	
Asperger Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	
PDD-NOS	<input type="checkbox"/>	<input type="checkbox"/>	
Autism Spectrum Disorder	<input type="checkbox"/>	<input type="checkbox"/>	
Rett's Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	
Childhood Disintegrative Disorder	<input type="checkbox"/>	<input type="checkbox"/>	

Please check any of the following chromosomal or genetic syndromes the participant has:

- Fragile X Syndrome Down Syndrome
 Prader-Willi Syndrome Tuberous Sclerosis
 Duplication of Chromosome 15 Don't know
 None of the above

Has the participant ever experienced:

- Head Injury Loss of consciousness
 Brain tumor Neurofibromatosis
 Febrile seizures Hydrocephalus
 Stroke Other brain bleeding
 Seizures (specific frequency): _____
 Other (specify): _____
 Don't know None of the above

Please check any other conditions that the participant has ever been diagnosed with:

- Bipolar Disorder Schizophrenia
 Conduct Disorder Oppositional Defiant Disorder
 Anxiety Depression
 Learning Disorder Obsessive Compulsive Disorder
 Attention Deficit Disorder (with or without hyperactivity)
 None of the above

Has the participant ever been diagnosed with Developmental Delay?

No Yes (specify level: _____)

Has the participant ever been diagnosed with Intellectual Disability or Mental Retardation?

No Yes (specify level: _____)

Please indicate the participant's overall language level:

Does not speak Uses single words Speak in sentences

Has the participant ever had a speech/language disorder or delay?

Yes No

Does the participant have any first degree blood relatives (for example, full siblings, biological parent, offspring) or second degree blood relatives (half-sibling, grandparent, aunt/uncle, niece/nephew) who have an Autism Spectrum Disorder?

No Yes (please specify relationship to participant):

Please answer the following questions about the birth history of the participant, to the best of your memory:

At how many weeks was the participant born?

About how much did the participant weigh at birth (pounds & ounces)?

What were the participant's APGAR scores? (1st score)

What were the participant's APGAR scores? (2nd score) -

Did the participant require any of the following immediately after birth?

Oxygen

Hospitalization or intensive care (if yes, for how many days?): _____

If the participant was adopted, was he/she adopted at or before 3 months of age?

Yes

No

Does not apply (participant not adopted)

School or Educational Placement: Compared to his or her typically developing same-aged peers, in most subjects, the participant is academically:

At or above grade level

1-2 years or grades behind

3 or more years or grades behind

Does not apply (has not yet started or has completed school)

Does the participant currently have a visual disorder that cannot be corrected by glasses?

No

Yes (specify): _____

Does the participant currently have a hearing disorder that cannot be correct by hearing aids?

No Yes (specify): _____

Does your child currently receive special education services?

No Yes

If yes, which of the following categories for educational classification is listed on your child's IEP?

- Autism
- Deaf/Blindness
- Developmental Delay
- Emotional Disturbance

- Hearing Impairment/Deafness
- Intellectual Disability

- Multiple Disabilities
- Orthopedic Impairment

- Other Health Impairment
- Specific Learning Disability

- Speech/Language Impairment
- Traumatic Brain Injury

- Visual Impairment

Does your child receive free or reduced lunch at school?

No Yes

APPENDIX C: Quotes to Illustrate Themes

Seeking Support

- “I want to know I’m not alone in my struggles”
- “I’m looking for that group of people for support”
- “I live in a remote area, and I know there are parents of children with autism, but they must be hiding. I talk to my friends, but they just don’t get it.”
- “We’ve been there.” (in response to someone’s story)
- “I think everyone wants that.”
- “A counselor we met with a while ago suggested that WE (parents) get a confidant friend. That friend would understand the things WE’RE going through and can help give US support. WE have found that friend and it’s been a huge blessing. Sometimes we’ll send [our child] over to her house, or she’ll babysit so WE can have a break. She even took him on a road trip once to give US a mini-vacation. This has been one of the biggest suggestions that has helped our family the most.”

A Spectrum within a Spectrum

- “[my child] has the ultimate “OCD” with the lights. They’re always making sure the lights are all turned off.”
- “You’re lucky. That definitely doesn’t happen in our house.”
- One parent says to accept that their kid doesn’t want to go to dances (acceptance of child) while other parent says that their kid wants to, they just don’t know how to (skill deficit)
- “My [child] loves watching the anime television shows,” to which another parent added, “my [child] watches movies in other languages! He’ll is watch them so fast that sometimes I think he is trying to teach himself Japanese!”
- The parents say that it is good that [one specific child] is so smart, but the mom thinks [the child] is hiding behind everything. All of the parents are jealous and then they discount the mom’s concerns by saying that at least [the child] has friends.
- Parents talk about how their kids are not competitive or interested in sports. Some kids go “it’s my turn, it’s my turn” when playing soccer. Another parent talked about how [their child] flies around with his arms up in the air like an airplane during sports.”
- “My [child] is so obedient he does whatever” Another parent: “That would be so awesome.”
- One parent is upset scouts made him sleep alone-another mom says my [child] would only go if he COULD sleep alone.
- “I’m amazed that your [child] even cares about money! Money burns a hole right through [my child]’s pockets.”

Use of Humor

- “My child had a disjointed ‘favorites’ conversation” – people laughed
- “Keep a normal distance during conversation” –laughter
- “Can we get a little more sensory overload?” (referring to at scouts when they play dodge ball)
- “Isn’t that so funny? We get so excited when our adolescents do something age-appropriate. Look! My adolescent just told a lie to get out of something they don’t want to do. That’s so great and I’m so proud of them. But wait, is it great that I’m so excited about lying, stealing, etc.?”
- “I can’t stand another autistic person in my life... I collect them!”
- “He’s going to be a millionaire. He’ll be living at home and I am his guardian: ‘Ten dollars for you; a million dollars for me’”
- “I think he’s learning Japanese!” - From watching anime with subtitles; he is serious but thinks it is funny
- “it’s like super PMS!”

“The Spark”

- “Feed the fire that is [their child]. Let them be them and embrace themselves”
- “Divorce yourself from the expectations you have of your child”
- “Once they start getting bigger, you just can’t fight them anymore. If you want to fight him, you have to fight him yourself.”
- “He can do crazy equations and loves anything brainy. I know one day those skills will serve him well.”
- “I’m completely fine with whatever he does. Let it go and see what happens.”
- “He can go so fast that I get cyber sick. The more they get into this (referring to Minecraft), the faster their brains can function. It’s amazing, but the bad news is they can’t break out.”
- “if my child can just shift this spark to programming, I think he will have a very successful career as a computer programmer. There are no careers in video games.”

Family Values

Religion

- “You mentioned scouting and having a hard time getting him to go. Is anyone else

having a hard time with this?”

- “[My child] has scout issues too. The leaders gave up on him and the kids are not nice.”
- “Kids are really nice but most of them have stopped, because they don’t get feedback. [My child] figures not to say anything because they ignore him.”
- “[Our child] will go and the kids know he is different and not very social. The kids will make their own group and forget about [our child].”
- “People in our ward were intuitive enough to tap into [my child]’s skills to be a family history consultant.”
- “The other day [my child] said to me that he wishes he wasn’t affiliated with religion at all.”
- “He actually accepted a church calling which was HUGE. That’s a lot of progress for us...a LOT OF PROGRESS in a short amount of time.”
- “[My adolescent] is really struggling right now. He is not doing well in several aspects of his life. We are talking to his teachers right now and he has also had his technology privileges taken away. This has been hard on him, but it’s ten times harder on me. His life is in turmoil right now. But it is what it is. You take the successes and roll with the setbacks. I’m definitely the enemy right now, but that’s typical for teenagers anyway.”
- “[My child] will say things like “I wish I wasn’t [religious affiliation].” And he won’t turn off the sacrilegious games that we get upset by.”
- “One of the video-gamers [my child] plays with said he was God. I was shocked that [my child] actually believed him. We had a long talk about religion after that.”
- “The [religion] culture is all about “advancement, advancement” but [my child] will go and do the things, but he doesn’t care.”
- “[My child] said the other day, gosh sometimes I wish I wasn’t [religious affiliation].” We told him it wasn’t Christlike to go around shooting people.”
- “[My child] asked that if he earned his eagle scout if he could earn his technology back. He’s never been interested in this before now.”

Pornography

- “We just got him a flip phone because it eliminates a lot of the problems with the smart phone”
- “They don’t really use phone for communication, but they are always on YouTube, etc. and you just don’t know what it is that they are looking at.”
- “We blocked those apps to prevent [our child] from seeing things boys just don’t need to see.”
- “I have seen things I never want to see” (referring to pornography)
- “I think with these things they just don’t know where to stop” (referring to pornography-

multiple parents made similar comments.)

- “these kids don’t have boundaries. It’s hard for them to know how far they can go. That’s why it’s easier to just make the decisions for them.”

Family Impacts

- “My husband loves to tease [my child], and it upsets him frequently”
- “[My child} thinks everyone is teasing and he thinks the family is bullying him. You just don’t know what is going to set him off. If you bring it up he’ll just go on with how horrible we are with teasing him.”
- “We couldn’t give one of our children a cell phone without also giving one to [child with autism].”
- “When he has scouts, we don’t bring it up until right before to keep him from exploding.”
- “[My adolescent] is really struggling right now. He is not doing well in several aspects of his life. We are talking to his teachers right now and he has also had his technology privileges taken away. This has been hard on him, but it’s ten times harder on me. His life is in turmoil right now. But it is what it is. You take the successes and roll with the setbacks. I’m definitely the enemy right now, but that’s typical for teenagers anyway.”
- “it’s hard when your oldest has autism because of the family wide impact. It takes years to unravel”
- “he’s had some technology privileges taken away, which has been really hard on him. But it’s been harder on me, and dad, and the rest of the family.”
- “We keep saying my 8-year-old is going to babysit before [my child with autism] babysits.”
- “[my child] got a cell phone because his little sister needed one (she was in cheer and so many other things) we didn’t want to give it to her without giving it to him first.”
- “[My child] is like well why can’t I do that (what the other kids are doing) and I tell him, you know why.”
- “I plan on having a lot of rules, he is the oldest.”
- “[My child] has so many rules and the other kids have zero rules. Complete freedom. I think this is a big challenge.”

Lack of Self-Awareness

- “Whenever I’m asking emotional questions, he always says “I don’t know”. And I think he really doesn’t understand these questions.”
- “It’s hard to teach kids that.” (referring to emotions)
- “[My child] will say “hi” in a text message over and over again without a Cover Story and he gets no responses. He doesn’t understand to stop.”

- “Sometimes I want to jump in [while my child is on the phone] and tell them what to say- “Ask him what he likes to eat,” or “What do I like to eat?””
- “[My child] will often complain about how annoying our family is when he doesn’t even realize that he is the worst one”
- “My child is rude...this is something I need him to be aware of is that he can be outspoken.”
- “[My child] doesn't recognize emotions in others and this surprises me. It’s surprising to see that [my child] was not sensitive to others, he may not experience empathy at all.”
- “He is completely void of emotional attachment.”
- “[My child] told me he doesn’t even care to make friends. He told me he doesn’t care. I’m still trying to process this. He said he doesn’t think he feels any feelings at all. He says he doesn’t know if he’s sad or happy for someone. For me, this was shocking! he’s really struggling right now. Kind of depressed.”
- “There is this idea of the glass box syndrome. You may see everything going on around you, but you can’t touch it or connect with it. I’ve taught them to try and have a good time while in this box. But don’t tell them they can’t do something they want to do.”

Being Included

- “We frequently email teachers and get on top of things at the beginning of every school year. If you don’t know what an IEP is- you should know that.”
- “At the beginning of the year, I send out an info sheet to teachers, church leaders, etc. with his strengths and weaknesses. “
- “We almost micromanage him.”
- “[my adolescent] wanted his friends to like him so much that he let them tease him and bully him.”
- “The Principal knows us very well.”
- “I've noticed that usually when he hung out with this kid in the past it was pretty quick he was like, “oh well got to go, bye,” But this time it was longer, so I am hoping he wasn’t having a horrible time.”
- “When we meet people, we tell them: you’ve probably already noticed, but [our adolescent] is a little different. We tell them he has high anxiety. This is just our cover story. We don’t spill our life story to everyone we meet, but just some heads up about [our adolescent]. We tell adults they can call us if they need help, or they can have him take a break. We try to share the burden of our child.”
- “most people are nice about it. They treat [my adolescent] very nicely.”
- “Those in charge just don’t see it!” (people agreed).
- “Even when I was there, and the teacher was there, it didn’t stop these kids from bullying [my child], and I just didn’t know what to do, so we moved.”

- “He wanted these kids to like him so much that he would just say “oh it’s okay mom,” even though they were teasing him.”
- “[My adolescent] is sixteen and is a little more severe. One day at the mall, there was a kiosk to sign up for a credit card and new cell phone. I turned my back for one minute, and when I turned around he had successfully signed up for these gadgets. I felt that salesman took advantage of him. He was still a minor at the time, so I told the salesman the contract was void. This is when I realized that my [child] is “prey” for these people. And this is a huge concern. “
- “Most of it they weren’t bad kids, they just needed education. Once I talked to the leaders they put their foot down and it stopped.” (church setting)
- “A big thing is education- the atmosphere needs to be that these kids are special, and it is a privilege to help them. Not these are kids who are obnoxious or difficult.”
- “More prevalent than active bullying is kids just ignore them, but the teacher’s job is supposed to help with that!”
- “[My child] gave a kid who asks for money 5 bucks.”
- “Oh yeah, my kid would do that too.”
- “[my child] would give his whole wallet!”
- “If [my adolescent] were to have a friend that accepted him the way he was, that would be amazing. But when I sit down and think about what this friend would look like, I realize it’s going to be that weird friend in school. If someone accepted [my adolescent] as a friend, he would be just like him! Then we would have two [adolescent]s!”
- “Sometimes I feel like [my child] is making progress and other times I get so frustrated and I wish the teacher would intervene more,”
- “I got called to go down there three times during the evening and night. He had to sleep alone because nobody wanted to share a tent with him. He would get really scared and act out. It turns out the leaders of the group weren’t giving him his medications. No wonder he was struggling so bad!”
- “I haven’t even let my [child] go to [boy] scout camp yet,”
- “I asked if I could go with, because I was so nervous with how he would be treated and if he could do the things he needed to do.”

“One Good Friend”

- “When he was younger we hadn’t accepted it, we were just like “why can’t he make friends?” but now that we have accepted it, we are just hoping for that one friend. And it might be a weird friendship, like they just text or something.”
- “Learn the importance of making friends”
- “I want [My child] to be able to make and KEEP friends.”
- “We’d be happy to have just one good friend”

- “I think that’s all of our goals.”
- “I agree. Better one good friend than a whole group. With one friend you can control the situation better, if they are a good friend they will be a good example on your child.”
- “If [my adolescent] were to have a friend that accepted him the way he was, that would be amazing. But when I sit down and think about what this friend would look like, I realize it’s going to be that weird friend in school. If someone accepted [my adolescent] as a friend, he would be just like him! Then we would have two [adolescent]s!”
- “I would get so much joy to see [my child] flourish with friends.”
- “I got a call from the VP- [my child] has been saying to the other kids “this guy is my boyfriend.” He was doing this as a joke because he got a reaction. The boy asked [my child] to stop, but he wouldn’t. [My child] is just trying to make friends. I can tell he’s lonely.”
- “I don’t think he wants to be alone. But he got used to it and accepted it.”
- “He’s on the outskirts. He wants to be in the group, but doesn’t understand how”
- “I want [my child] to recognize that he can have friends...he had kind of decided that he will never have friends, so he is only going to watch anime because he can’t make friends. This is my world””
- “[My child] has a hard time talking on the phone unless he uses the speaker.”
- “Texting is preferred over phone because they can take time to think it out. The processing and language makes it harder.”
- “I just want him to have a connection.”
- “When he was younger, my [child] tried so many new things to try and make friends, but now he has given up. I think he wants friends, he just doesn’t do much because he’s given up”
- “[my adolescent] wanted his friends to like him so much that he let them tease him and bully him.”
- “He just doesn’t see the point of friends. We tell him if you want to be successful in life you have to have friends.”
- “struggled with self-worth. He found a computer game club. This has given him a sense of belonging which is very new for him.”
- “you guys are talking to each other more. Yeah mom, we know each other more.”
- “There was a situation where 2nd graders were bullying older kids. He went over and talked to them and they pushed [my child]. He didn’t retaliate, which surprised me (in a good way). The principal was really proud of how [my child] had handled it. When [my child] gets a friend, he’ll tunnel vision them and try to monopolize all their time.”
- “Right now we just want one good friend and then we’ll tackle the relationships.”

Moving Toward the Future

- “We just think things are looking up and we are making progress and then something happens”
- “. . . and because [my adolescent] will still be living at home, I will be the gatekeeper for all this money!”
- “I feel like we’ll take one jump forward, and then for several weeks we’ll be taking two jumps back.”
- Another parent responded, “yours only lasts for two weeks?”
- When one parent asked about future hopes
- “That makes me cry”
- “Yeah that’s a sensitive subject for me.”
- “There’s a lot of anxiety involved in that question”
- “I worry so much.”
- “Life isn’t always going to be easy. We need to prepare him to do things he doesn’t want to do.”
- “I just know we are going to burn through like 20 jobs. He’ll be fired every other day and “Oh well,” you just go get another one”
- “Once they start getting bigger, you just can’t fight them anymore. If you want to fight him, you have to fight him yourself.”
- “I want to know the potential of a child with Autism. . .”
- “[my adolescent] thinks he’ll be working at Walmart. But I know he has so much more potential than that. I think he’ll be an engineer.” But he is scared. He has so much anxiety, that he won’t let himself progress.”
- “even when he was 5 years old he was asking about his future. Wrote out a plan for him that he kept for years under his bed.”
- “It’s my instinct if things go awry to immediately help him.”
- “That has been one of the hardest things- to let him figure these social things out on his own. Sometimes I have to leave the room because I can get so upset by watching him fail.”
- “What do you guys think we should do about custody? Should we take guardianship because he needs the support? We know he can’t do it by himself, but he does have the skills to talk to people. I want to hope for independence.”
- “I want him to learn how to talk to someone he likes”
- “I want him to understand how to act around someone he likes. For example, how to ask someone to dance without being too personal”
- “I want him to have a relationship with someone he loves”

- “He’s completely void of emotional attachment”
- “[My child] wants to play by himself, he doesn’t want to play with girls.”
- “I want him to learn how to make friends and eventually a romantic relationship.”
- “They need good friends before marriage.”
- “This last month he decided that girls are pretty and started getting excited to talk to them. He was complaining that there isn’t [sic] more girls here [in this group].”
- Lots of laughter in response
- “I hope someday [my child] and [another child] and all of these kids can find each other. And they can practice and try all of this stuff with each other. Social stuff they weren’t able to try with other kids.”
- “The teacher said [my child] said something inappropriate to a little girl...but he just said he wanted to marry her. I was relieved.”
- “Well it’s a little much, but not inappropriate.
- Everyone laughed
- “I heard a story about two adults with autism who had fallen in love with each other. This is what I want for [my child] so badly. Then he can practice doing that social stuff.”
- One parent requested that we have their [child] call one of the few girls in the group.