

**EXPERIENCES OF CAREGIVERS OF MIDDLE SCHOOL CHILDREN WITH
AUTISM SPECTRUM DISORDER IN MIDDLE SCHOOL**

A DISSERTATION

SUBMITTED TO THE GRADUATE SCHOOL

IN PARTIAL FULFILMENT OF THE REQUIREMENTS

FOR THE DEGREE

DOCTOR OF PHILOSOPHY

BY

GRACE YODER

DISSERTATION ADVISOR: DR. MOLLY TSCHOPP

BALL STATE UNIVERSITY

MUNCIE, INDIANA

JULY 2021

Table of Contents

Dedication and Acknowledgments	5
Literature Review.....	8
Autism Spectrum Disorder and its Effect on Families.....	8
Caregivers of Children with ASD	9
Caregiver Stress.....	9
Dealing with High Levels of Chronic Stress	11
Caregiver Stress and Facets of Life.....	12
Middle School Children with Autism Spectrum Disorder	13
Developmental Considerations.....	14
The Role of the Individualized Education Plan.....	17
Parents Interaction with the IEP	19
The Present Study	20
Methods.....	21
Philosophical Assumptions	21
Research Design.....	22
Researcher-as-Instrument.....	23
Phenomenological Reflection.....	24
Participants	28
Procedures	28
Interview Procedures	29
Member Checking	31
Data Analysis	31
Results.....	34
Individual Textual-Structural Descriptions.....	34
Participant One	34
Participant Two.....	36
Participant Three.....	39
Participant Four	40
Participant Five.....	42
Participant Six.....	44
Participant Seven	46
Participant Eight	49
Participant Nine	50
Participant Ten.....	52

Participant 11 54

Participant 12..... 55

Participant 13..... 57

Invariant Constitutes 59

 Accommodations need to be present and tailored specifically to the child..... 59

 Caregivers are generous in providing advice and offering help to the next cohort of parents with special needs..... 60

 Change will not happen unless the caregiver takes a position of advocating for the child.. 62

 The best way to help your child through this process is teaching them to advocate for themselves. 63

 Child behaviors that do not relate to academics affect the way the child is treated at the school..... 64

 The processes of communicating with the school and going to IEP meetings is a very difficult and emotional one..... 65

 Succeeding in the processes of communicating with the school and going to IEP meetings requires sacrifice..... 66

 School personnel have a huge impact on how the process of communication goes. 67

Discussion..... 68

 Themes 68

 Accommodations 68

 Advice..... 69

 Advocacy 69

 Emotions..... 70

 Sacrifice 70

 School personnel..... 71

 Implications..... 71

 Implications for Counseling Practice 72

 Implications for Schools 74

 Implications for Caregivers 76

 Implications for Research..... 78

 Strengths and Limitations..... 80

 Credibility 80

 Transferability 81

 Dependability..... 82

 Confirmability 82

 Intersubjective Validity 83

School Communication	4
Conclusion	83
References.....	86
APPENDICIES	93
Appendix A – Extended Literature Review.....	94
Autism Spectrum Disorder and its Effect on Families.....	94
Stress, Anxiety, & Depression in Parents of Children with Autism Spectrum Disorder	94
Middle School Children with Autism Spectrum Disorder	96
Individualized Education Plan.....	97
IEP Process	97
Dealing with High Levels of Chronic Stress.....	97
Needs of Parents of children with ASD	100
Empowerment.....	101
Social Support.....	102
Resilience.....	103
Phases of Life	104
Receiving the Diagnosis of the Child	105
Problem Behavior	106
Finding and Affording Services.	107
Child Starting Kindergarten.....	108
Stress Related to Creating the First IEP	109
Child Becoming an Adult.....	111
Parents Planning for their own Death.....	111
Conclusion.....	112
References.....	113
Appendix B – Demographic Data.....	120
Appendix C – Recruitment Materials	121
Appendix D - Informed Consent.....	124
Appendix E – Demographic Questionnaire	126
Appendix F - Interview Questions.....	128

Dedication and Acknowledgments

I'd like to dedicate this project to my little brother Toby. He taught me all about Autism and how it impacts families. But more than that he taught me about love, honesty, and enjoying life in ways that I never imagined possible. Toby and his autism are the reason I got into psychology. I am so proud of how far Toby has come since our family started our journey with him in 2004. Even though things like school and dissertation don't matter so much to Toby, he's happy that I'm happy and I love him for that.

I would like to take this opportunity to thank the wonderful people who played a role in supporting this project. First, I'd like to thank my family. My Omi recently called to tell me how proud she is of me and all I have accomplished. She said Opa would be proud of how motivated I am and how passionate I am about helping others. To show how proud they were, she offered to pay off all my student loans so as I finish this process and go into the working world, I can start on top of things instead of drowning in debt. This gives more relief than one could imagine. My parents have provided so much support, financial and emotional, that I don't know what I would do without them. I could not have done this without my wonderful boyfriend Drew Kimmerling. He put up with all the emotional turmoil that comes from the dissertation and PhD process.

Second, I would like to thank Charles Hunt and Cassie Hudak. They spent numerous hours with me pouring through the data and making sense of it. They were willing to challenge me and argue with me when I needed it. No amount of thanks (even if it comes in the form of Puerta Vallarta) is enough for the Friday evenings they gave up so that I could move forward with my career.

I'd also like to thank my dissertation advisor and committee chair, Dr. Molly Tschopp. Her feedback has been invaluable. She encourages me to reach for my dreams and helps me to

keep my feet on the ground to get it done. Finally, I would like to thank my doctoral committee: Drs. Theresa Kruczek, Ashley Hutchison, and Jungnam Kim. All of them have met with me, offered suggestions, and been extremely supportive through this process.

ABSTRACT**DISSERTATION:** Experiences of Caregivers of Middle School Children with Autism

Spectrum Disorder in Middle School

STUDENT: Grace Yoder**DEGREE:** Doctor of Philosophy**COLLEGE:** College of Health**DATE:** July 2021**Pages:** 128

This study takes a deep look into the experiences of guardians of middle school children with Autism Spectrum Disorder (ASD) communicating with the school. Caregivers of children with ASD have high levels of stress. Caregivers report needing accommodations that are tailored specifically to their child. They are generous in providing advice and help to caregivers in the same situation. Caregivers tend to take a position of advocating for their child or teaching the child to advocate themselves. Child behaviors that do not relate to academics affect the way the child is treated at school. Caregivers describe the process of communicating with the school and going to IEP meetings as very difficult, emotional, and requiring sacrifice. In addition, school personnel have a huge impact on whether the process of communication goes well or not.

Understanding this experience is important for practitioners, schools, caregivers, and researchers.

Experiences of Caregivers of Middle School Children with Autism Spectrum Disorder in
Communicating with their Child's School

Literature Review

Autism Spectrum Disorder and its Effect on Families

Autism Spectrum Disorder (ASD) is a developmental disorder categorized by persistent deficits in social communication and restricted, repetitive patterns of behavior (American Psychological Association [APA], 2013). Caregivers of children with ASD have a unique parenting experience and are greatly affected by their role as caregiver. Numerous studies suggest that parents of children with ASD face higher levels of stress than parents of neurotypical children (e.g. Al-Farsi et al., 2016; Bitsika & Sharpley, 2004; Dabrowska & Pisula, 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007). When parents of children with ASD were asked how their child with ASD affected their lives, the most frequent theme throughout the qualitative accounts was stress (Myers, Mackintosh, & Goin-Kochel, 2009). Parents responded similarly when asked how the child with ASD affected the lives of other members of the family. Many studies have been done examining the general stress of parents of children with ASD (e.g. Dabrowska & Pisula, 2010). The source of stress changes depending on the child's phase of life (Papageorgio & Kalyva, 2010).

While studies have been done on caregiver stress during some specific aspects of life with a child with ASD, such as when the child is first diagnosed with ASD (Barnett et al., 2003; DeGrace, 2004; Fleishmann, 2004) and the influence of problem behaviors (Floyd & Phillippe, 1993; Myers, 2009), there is a dearth of research on considerations during other phases of life. Several broad qualitative studies of general stress faced by caregivers of children with ASD include a brief discussion of experiences such as communicating with the middle school, the

Individualized Education Plan (IEP) process, and parents planning for their own death (e.g. Cadman et al., 2012; Ooi, 2016) but do not examine these phase of life considerations in depth. The purpose of the current study is to fill in part of that gap by providing a detailed description of the caregivers' experience of communicating with the school and the IEP process while their child is in middle school. This exploration was done to introduce a deeper look into the overall experience of parents of children with ASD when they are working with their child's school. By looking deeply into this specific phase of life I hope to illuminate helpful information for counselors and psychologists working with caregivers of children with ASD, particularly those caregivers who may be facing high levels of stress.

Caregivers of Children with ASD

Caregiver Stress

Evidence of caregiver stress, previously measured only by self-report, has been corroborated using biological markers of chronic stress, showing that this stress contributes over time to negative health effects and increases levels of depression and anxiety (Bitsika et al., 2017). While noting that raising a child with a developmental disorder raises the level of parenting stress, many other indirect effects are overlooked. There are several other psychological outcomes related to raising a child with ASD. Overall, maternal well-being is lower in mothers of children with autism than mothers of children with any other developmental disabilities, even when controlling for maternal education, child behavior problems, and the child's cognitive level (Eisenhower, Baker, & Blacher, 2005). Mothers of children with ASD perceived that their children were more likely to have a negative impact on the family and less likely than other children to have a positive impact on the family (Eisenhower et al., 2005). Caregiver burden in parents of children with ASD is positively related to unmet needs in social

relationships, mental health problems, safety of self, and communication (Cadman et al., 2012). Parents often report being stretched beyond their limits and feel unable to cope with the demands that come with raising a child with ASD (Bitsika, Sharpley, & Bell, 2013).

Parents of children with ASD also have negative experiences directly related to the problem behaviors of their children (Blacher & McIntyre, 2006). Children with ASD tend to have higher levels of problem behaviors than children with other developmental disorders, which increases the level of depression and decreases morale in mothers of children with ASD (Blacher & McIntyre, 2006). Comparing parents of children with different types of intellectual disabilities, Eisenhower et al. (2005) found that mothers of children with ASD had the highest levels of maternal depression. Even though locus of control has been shown to mediate the relationship between parenting stress and both depression and anxiety in parents of children with no developmental disorder, it fails to mediate the same relationship in parents of children with ASD (Hamlyn-Wright et al., 2007). Concluding from the research above, it is likely the stress is not mediated by locus of control because the type of stress faced by parents of children with ASD is chronic stress caused by a situation that the parents cannot have control over (the diagnosis of their child).

There are also financial outcomes related to caring for a child with ASD that contribute to caregiver stress. Mental health disorders, including ASD, have been identified as the costliest set of childhood disorders (Thomas et al., 2016). Children covered by combined private and wrap-around Medicaid had the highest total expenditures (\$11,596, $P < .05$) and the highest expenditures paid by their insurance (\$10,638, $P < .05$). Having Medicaid alone doubled the chances that parents would report inadequate coverage. Difficulties understanding insurance and benefits adds to this financial burden (Thomas et al., 2016).

Dealing with High Levels of Chronic Stress

Parents of children with ASD face stress caused by a life-role that is typically unalterable; this is known as chronic stress (Bitska et al., 2013). A problem with chronic stress is that the stimuli for the negative feeling is unalterable, so individuals must find a way to reduce the negative feelings without changing the situation. For example, mothers of children with developmental disabilities have rated denial as the most common way they cope with the stress of parenting (Woodman & Hauser-Cram, 2013). Social support (Cohen & Wills, 1985), higher empowerment in the parent (Fleischmann, 2004), or higher levels of resilience (Luthar & Cicchetti, 2000) have been found to relieve caregiver stress. However, it is rare for parents of children with mental health needs, such as ASD, to seek out mental health services for themselves and rarely receive resources to help address their needs as caregivers (Gerkenmeyer et al., 2008). Parents of children with ASD are less likely to use social and spiritual support, likely because parents of children with developmental disorders report that there is less community support available (Nachshen & Minnes, 2005). Compared to other parents a main difference in coping for parents of children with ASD is less frequent use of social diversion (Dabrowska & Pisula, 2010).

Dispositional coping describes the typical way individuals respond to different types of stress. It can be divided into problem-focused or emotion-focused types of coping (Brown, Westbrook, & Challagalla, 2005). Typically, parents of children with an ASD will use combinations of the forms of problem-focused and emotion-focused coping skills that are available to them (Cappe et al., 2011). The combination of different types of coping skills and different responses to different types of stressors (i.e. situational coping) makes coping a complex process. Parents of children with an ASD who use more emotion-focused coping

strategies are more likely to experience distress at work (Cappe et al., 2011). Many parents of children with ASD use avoidance styles of coping (an emotion focused way to cope), which has a strong relationship to negative affect (Ben-Zur, 2009). Many parents report needing both instrumental and emotional support (Woodman & Hauser-Cram, 2013). Instrumental support refers to getting advice or active help from another person. Emotional support refers to getting comfort or understanding from another person. Understanding caregivers' changing needs and stressors as they and their children with ASD move through life phases may be key to identifying the most relevant and effective coping strategies and sources of support (Woodman & Hauser-Cram, 2013).

Caregiver Stress and Facets of Life

While there is substantial evidence of higher levels of stress for caregivers of children with ASD than for those of neurotypical children, there is a gap in the literature to explain how that stress changes over the lifespan of the child (Ooi, 2016). Papageorgio and Kalyva (2010) reported that caregivers of children with ASD have different needs and face different challenges based on the phase of life their child is facing. They found that mothers and fathers identified similar problems for their child with ASD, but these problems differed as a function of the child's age. Parents of older children tended to be more concerned about problems with self-help skills, self-occupation, and behavioral problems, while parents of younger children were more concerned about communication problems (Papageorgio & Kalyva, 2010). One facet that has been studied in depth is the point in time when caregivers receive the diagnosis of ASD for their child. This can happen at any time during the child's life but typically happens when the child is young, often as they are starting pre-school. Learning of the diagnosis causes a strong emotional reaction: often uncertainty, guilt, confusion (Barnett et al., 2003), anger (Ooi, 2016), or feeling

robbed of their child's "normality" (DeGrace, 2004). Another facet common in the life of a child with ASD is hearing from the school problem behaviors. Negative themes that emerge when parents talk about their child's problem behavior are difficulty dealing with child's behavior problems, time demands for care and therapies, sleep problems and exhaustion, and struggles with schools and services (Myers et al., 2009). Many caregivers of children with ASD are stressed by the transition into kindergarten as they see it as a central event in the education of their child (Forest et al., 2004). For more information on the facets of life that have been studied, see the extended literature review in Appendix A. The transition into middle school, though it has many changes and likewise a central event in the child's education has not been studied for children with ASD. The experience of children with ASD in middle school overall is a gap in published research. In the current study, I seek to explore how caregivers experience the phase of life of their child being in middle school, specifically the caregiver's experience communicating with the school.

Middle School Children with Autism Spectrum Disorder

Most individuals diagnosed with ASD as children remain dependent on their family or other services in adulthood and receive lower levels of education (Elmose et al., 2013). Despite expectations however, the developmental course of ASD tends to be one of improvement (Elmose et al., 2013). There is great variability in outcomes for children with ASD. Much of this variability stems from the resources that parents are able to obtain for their children throughout their schooling experience (Elmose et al., 2013). There is a growing research base for early diagnosis and intervention but there is a definite lack in knowledge on how to serve these children once they are school aged (Dykstra Steinbrenner & Watson, 2015). There is also a lack of knowledge about how adolescents with ASD learn academic skills both in special education

and general education settings (Kurth & Mastergeorge, 2012). With this deficit of knowledge in mind, there is a need to consider the developmental aspects of pre-adolescence and adolescents and how they interact with the demands of the middle school environment. This is necessary to come to an understanding of the experience of middle school years for children with ASD.

Developmental Considerations

During pre-adolescence (approximately ages 11-14), children are experiencing large shifts socially. Relationships become much more complex and children must start dealing with peer pressure. Tight-knit social groups begin forming and children become focused on who is in what group and where they are (or are not) accepted. These social circles can go through sudden large shifts, which are very confusing and important to the child. In addition, children will want to spend more and more time with their friends, meaning less time with their parents and families (ParentFurther, 2018). Dealing with unclear and changing social rules can be very difficult for a child with autism, as they often are unable to pick up on non-verbal social cues that their neurotypical peers use. A lack of understanding of emotion may damage the child's social relationships as their peers are expressing emotions more intensely and more frequently (Ben-Itzhak et al., 2016).

Because of their impaired social skills and lower motor skills, pre-adolescents with ASD are at a high risk of social exclusion (Lopez et al., 2017). A program that includes both social skills training and learning the rules of a well-known game (i.e. football) has been shown to facilitate social development (Lopez et al., 2017). This improves their quality of life, social relationships, and creates healthy sporting habits (Lopez et al., 2017). While pre-adolescents typically pick up information from their peers and naturally join in, pre-adolescents with ASD would benefit from more specific direction on rules and facts about the trending subjects.

During this time, most children will enjoy the social aspects of learning (e.g. working in small groups) but become more interested in their socialization than doing their schoolwork (ParentFurther, 2018). It is important for caregivers to encourage the social development of their child while also helping them to maintain their functioning at school. It is important to use the things pre-adolescents are interested in (whether it is socialization or another hobby) to foster learning. Children with ASD are less likely to pick up on the social learning as they will be distracted by the myriad difficulties of navigating the social situation (ParentFurther, 2018).

Children will have more exposure and more chances to engage in risky behaviors during this time of their life. Some children are biologically prepossessed to have a higher chance of engaging in these behaviors. Fortunately for caregivers, those children who are at high risk are more likely to cooperate with monitoring their behavior if the caregivers engage in positive parenting. Optimal parenting leads to a negative attitude toward substance use, giving the children high in risk a more adaptive outcome than their low-risk peers (Kochanska et al., 2015).

Children are experiencing puberty during this time which can have a strong impact on their emotions. They may become more emotionally sensitive, engage in more risk behaviors, or experience higher lability of emotion. As the emotions children are experiencing in this time feel stronger or more intense, it is important for parents to help them learn to express those emotions appropriately (ParentFurther, 2018). Caregivers must respond to this difficulty differently depending on the way their child's ASD affects them. Parents can do this through engaging in direct conversation with their child about emotions and modeling appropriate responses to emotions. If the child's emotions seem particularly intense, it may be helpful to seek out individual or group counseling to help the child with emotion regulation skills. The understanding of one's own emotions in pre-adolescents with ASD has typically been measured

by the ability to recognize different facial expressions and label them appropriately. While it is unclear how much the emotional understanding of pre-adolescents with ASD is impaired, there are significant differences in how they process emotions. Neurotypical pre-adolescents remember events high in emotionality better than non-emotional events, but this difference is not there for children with ASD (Ben-Itzhak et al., 2016). For children with ASD, recall was facilitated more by coherence of content. Pre-adolescents with autism are equal to their neurotypical peers in their ability to describe previous experiences involving simple emotions (e.g. sad, happy) but have significantly more trouble describing experiences involving complex emotions (e.g. embarrassment, guilt). When allowed to respond freely, pre-adolescents with ASD include less emotional expression in their accounts of past events (Ben-Itzhak et al., 2016). Caregivers can help their children during this time by giving them chances to express emotions and talking frankly with them about these emotions in an effort to understand them. As their peers are becoming more emotional and more sensitive, it may be difficult for a pre-adolescent with ASD to understand what is happening and how to relate to their friends. Helping the child to practice responding appropriately to others' emotions will not only allow them to understand better what their friends are going through, but to connect better in order to maintain relationships.

In an observation of middle school children with ASD, students were jointly engaged approximately 25% of the time, which the authors admit may be an over-estimate, meaning they are engaged only about 7.5 hours out of a 30-hour school week (Dykstra Steinbrenner & Watson, 2015). Students who know that one of their peers is diagnosed with ASD tend to have more negative attitudes towards that peer (Tonnsen & Hahn, 2015). This can make socialization, which tends to be difficult for children with ASD, even more difficult. Since children with ASD

are at an increased risk for bullying (Zablotsky et al., 2014) parents tend to worry even more about their child's social skills as they progress through grade school.

The Role of the Individualized Education Plan

Many caregivers of children with ASD collaborate with their school by creating an Individualized Education Plan (IEP). The Individuals with Disabilities Education Act (IDEA, 2004) requires that public schools create and follow an IEP for any child at their school who is receiving special education. The document is required by law and the school is legally bound to follow the stipulations put forth in the document. The IDEA requires an IEP to include a statement of the child's current level of performance at school, the child's education goals, services that the school will provide, modifications and accommodations for the child in class and in standardized tests, and a plan to measure the child's progress towards goals (Stanberry, 2018).

The process of creating an IEP can be very stressful for parents, especially if they do not know their child's legal rights (Stanberry, 2018). The IEP is created by an IEP team. This team includes the student's caregivers, at least one of the child's general education teachers, at least one of the child's special education teachers, a school psychologist, a school district representative, and the child (if they are over 16). Middle school is the time when the student is more likely to become involved in this process. Legally all these members of the team must contribute to the IEP. In addition, the parent has the right to invite others to the IEP meeting. Most often this includes an advocate, a health care professional, or a translator (Stanberry, 2018). In addition to this first meeting, the IDEA requires the IEP team to review the IEP at least once a year. These meetings are to update the parents on the child's present level of performance

(PLOP), update the school personnel on the parent's concerns for their child, and to make sure that the IEP is working for the child (Stanberry, 2018).

Given the school's legal responsibility for individualized education (IDEA, 2004) it might be expected that the school provides support for parents of children with disabilities to navigate this complex procedure. However, this is often not the case (Banach et al., 2010). Parents often feel like outsiders during this process (MacLeod et al., 2017). Parents report the school is not transparent during the meetings and they are not made aware of their rights by the school (Loschen, 2015). In an interview with 12 parents of children with autism, all parents stated they could not find a place they considered adequate for their child's education, the teachers were not effective in producing any behavioral change, and the time spent for education was too short. One father stated, "my child is getting older, there is no school where I can take him, I don't know what to do, these children need education just like other children" (Aylaz, Yilmaz, & Polat, 2012, p. 401). Another parent reported, "public school has been a nightmare. We have had to fight for everything we've gotten for him.... I was called nearly every day by the school because of behavior issues" (Myers et al., 2009, p. 676).

There is a significant lack of research on what is helpful for parents during this stressful time which the researcher hopes to address with the present study. Parent support groups that add information about approaching the IEP to the curriculum have been shown to be helpful to parents. These groups tend to be more helpful than groups without the information. After attending a group including this information, empowerment in the family, service system, and community/political levels increased in the parents (Banach et al., 2010). The authors did not compare groups without this information, so it is unclear if the gains are related directly to the inclusion of the information about approaching the IEP. Beyond this there is a lack of

suggestions on what the parents perceive their own needs to be when approaching the IEP or what is helpful from professionals.

Parents Interaction with the IEP

There is an extremely limited amount of research on how parent of children with ASD interact with the middle school and experience the IEP process. Parents of children in preschool and elementary school whose children had diagnosed disabilities and written IEPs report that they feel involved and that they play an important role on the IEP team (Bennett, 1997). Very few felt the need to advocate or push to get the services they felt were best for their child (Bennett, 1997). However, a study that only included parents of children with ASD showed a different pattern. Parents raising children aged four to eight who were diagnosed with ASD were surveyed on their satisfaction with the IEP process. Four areas of satisfaction were measured on a five-point Likert-type scale: satisfaction with IEP content, satisfaction with actual services, agreement between content and actual services, and IEP team effectiveness (Slade et al., 2018). Only slightly over half of parents were satisfied in each category. Of these parents, 61% were dissatisfied with at least one area of the IEP process and felt they needed to push or advocate to make it better (Slade et al., 2018). Even among parents of children with an IEP where a mostly positive attitude was presented, amount of advocacy was negatively correlated with relationships to team members (Bennett, 1997). Seeing the high number of parents who are dissatisfied with the services their children are receiving, Slade et al. (2018) call for improvement in special education services. Since their research only looked at elementary children, they speculate that parent dissatisfaction may grow as children get older.

Evidence demonstrates that the experience with the school is different for parents of older children. In one phenomenological study, parents of children in high school were asked to

describe their experience with the IEP process (Sparks, 2007). Most parents felt the education program their child was included in was effective but needed improvement. Parents overall seemed to be satisfied with the IEP and talked about how important communication is (Sparks, 2007). However, they seemed to have a low understanding of the IEP assessment and progress reports (Sparks, 2007). This study included any caregiver whose child had an IEP. Only three out of 38 of the children described in this study had a diagnosis of ASD (Sparks, 2007).

Only a few studies have examined how this process is specifically for parents of children with ASD. One similarity to studies that generalizes despite the type of disability is the feeling of being put in an adversarial position if the parent works to advocate for their child (Tucker & Schwartz, 2013). In this study, parents of children ages 3-25 were surveyed. Parents reported school staff does not have disability specific knowledge of ASD. In addition, they reported conflict between members of the IEP team. Common barriers to collaboration between parents and the school included opportunities to provide input, communication difficulties with school teams, and negative perception of school professionals. A large number of parents reported feeling excluded from the IEP process (Tucker & Schwartz, 2013). Another study that surveyed parents of children with ASD of all ages found authors described parents' experience with the school as a roller coaster, with great highs and great lows. Satisfaction fluctuated corresponding with location, which school personnel they interacted with, and year to year changes (Kurth, Love, & Pirtle, 2020). With so many variables an in-depth study is necessary to determine the experience at different, specific points in time. There is a severe gap in the literature surrounding parents of children in middle school.

The Present Study

Caregivers of children with ASD do not have sufficient support to face the high levels of stress that come with their parenting role (Troy et al., 2007). For professionals to be able to provide this support it is essential that they understand the different phases of life children with ASD face and how each one impacts the caregivers. Some aspects of life, such as the time of initial diagnosis (Barnett et al., 2003; DeGrace, 2004; Fleishmann, 2004) have been studied in depth, including rich qualitative descriptions of the caregivers' experience. Other phases of life, such as the middle school years, have not been examined deeply on their own. There is a need for greater understanding of experiences across the lifespan. This author seeks to contribute to this understanding with the present study exploring caregivers' experiences of their child in middle school and the middle school aspects of the IEP process. Knowing this, the present study seeks to answer two questions:

1. What is the experience of caregivers of middle school children with ASD in communicating with the school and creating IEPs?
2. What could be helpful to caregivers during this experience, by their own report?

Methods

Philosophical Assumptions

Coming from a social constructionist perspective, this study investigates how parents themselves view, process, and make meaning of their experiences (Savin-Baden & Major, 2013). A social constructionist perspective places meaning in the hands of the participants (Savin-Baden & Major, 2013). The purpose of social constructionist research is to determine the meaning participants place on the phenomenon under study (Savin-Baden & Major, 2013). It is an underlying belief of the researcher that to understand the experience of caregivers of children

with ASD in communicating with the middle school, researchers need to know what meaning they make of this experience in order to make useful change. The researcher's interpretation of the experience is less important than the participant's interpretation of the experience because the research is intended to serve the population under study.

Research Design

The present study is a phenomenological study to develop rich answers to these two questions as the caregivers understand their own experience. Phenomenological research focuses on gathering thick, detailed descriptions of participants' experiences (Moustakas, 1994). Participants are involved in leading and determining the direction of the interview, and as such, they are considered co-researchers (Moustakas, 1994). For ease of understanding, participants/co-researchers will be referred to as participants throughout this study. Having the participants describe their experiences in as much detail as possible allows the population under study to determine what is considered important about the topic, removing some of the researcher's bias (Moustakas, 1994).

Phenomenological research describes the meaning of a common lived experience for several individuals (Creswell & Poth, 2018). Transcendental phenomenology is grounded in the concept of setting aside as much of the researcher's preconceived notions as possible (i.e. transcending from the everyday view of things), allowing the research to present the phenomenon in the way that the participants see it (Moustakas, 1994). In order to achieve this, the first step in transcendental phenomenology is Epoche. This means to refrain from judgment and stay away from the everyday, ordinary way of perceiving things to try to see the phenomenon from a fresh naïve vantage point (Moustakas, 1994). In addition to helping the researcher be aware of their biases and try to remove themselves from it, including these

statements in the paper allows readers to understand biases that may have leaked in and colored the interpretation of the participants' experience.

Researcher-as-Instrument

The research team for this study included three doctoral students in the Counseling Psychology program. The two additional researchers were trained in phenomenological research methods by the primary researcher. Both researchers had some prior experience in qualitative research and qualitative data analysis prior to this study. Information on phenomenology was sent to the research team to read and study. A handout describing the purpose and process of phenomenological research created by Dr. Linda Finlay, PhD which can be found at <http://lindafinlay.co.uk/phenomenology/>, was used. The team was encouraged to talk about and ask questions regarding the process. After discussing the basics of phenomenology, the researchers were presented the proposal of the specific project. Both researchers had a history in working with individuals with ASD and an interest in learning more about it.

The primary researcher then described the concept of Epoche and the process of phenomenological reflection. The primary researcher modeled by writing out her own phenomenological reflection and giving it to the team to read. She then talked about it with the researcher team, explaining how different experiences influence her motivation for doing the research and interpretation of potential results. The primary researcher encouraged the team to be open, noting that anything they felt uncomfortable sharing publicly could be sufficiently de-identified in the final report. Both members of the research team reported they felt confident talking about their personal and emotional reactions surrounding the topics of school, parenting, communication, and ASD. Research team members wrote their own phenomenological reflections (see below) and discussed them with the team. All members of the team reported

feeling comfortable having others ask about their disclosures and challenge them if they thought prior experiences and emotions were affecting the researcher's work. At the beginning of each step in the process, research members reviewed the phenomenological reflection of the research team member whose work they were responsible for checking. The research team was in frequent communication virtually and in person about how personal biases may interact with interpretation of the data. The research team was encouraged to "play devil's advocate" and think of alternate explanations or arguments to challenge each other.

Phenomenological Reflection

Principal investigator. Phenomenological research asks the researcher to identify their personal experiences with the phenomenon under study as to be transparent about any biases and to attempt to set them aside (Creswell & Poth, 2018). I became interested in studying autism because my younger brother has a diagnosis of autism. He moved in with my family as a foster child when he was three years old. Being significantly older than him, I was often a part-time caregiver for him. My mother (his primary caregiver) experienced significant frustration with the schools in trying to create an IEP that met his needs and make sure it was implemented in the school. She obtained the help of a paid advocate and had to move my brother to several different schools to get the help he needed. While some people in the schools were extremely helpful and genuinely seemed to care about my brother, many others were focused on the business aspects of school and saw my brother as a bad investment. I experienced a lot of stress and frustration at this time. I often felt angry at the school professionals and could not understand why they were not caring for the children in the best way possible. Taking time to figure out what was possible for my brother and fight the school to get it took time away from both my and my mother's other obligations.

In addition, I worked in the autism field for several years (both in applied behavioral analysis and respite care) and often heard stories of similar frustrations from families I worked closely with. One family eventually removed their daughter from school, finding it more effective for one caregiver to give up work and homeschool her. Though they did this willingly and lovingly for the sake of their daughter, it did hinder the mother's professional development and increase levels of stress. Many parents I spoke with felt that the schools were not willing to dedicate the time and resources to their child that they needed to succeed. One special education teacher I talked with told me that her administrators had forbid her from suggesting to the parents what would be helpful for the child. She stated that if the parents asked for specific accommodations the school would have to pay for them so the school did not want her to make recommendations they would have to pay for. Stories like this are infuriating and unjust. Laws have been put in place to protect parents and their children from things like this but if the families do not know their rights or how to navigate the system, there will still be extra barriers for children with developmental disabilities to succeed. It made me very sad to watch the kids I work with go through this. Seeing children treated as if they are not as important as neurotypical children was heartbreaking for me and made me angry. As I prepare for this study, I note that I have extremely negative views of schools when it comes to their interactions with children with autism. Throughout the study I will have to make sure I am not guiding caregivers into primarily negative descriptions of their experience, instead allowing them to inform me of how it is for them personally.

Team Member One. Within my own personal life and history, I have limited experience with the systems in place to assist those with special needs in terms of education. I have been involved within a public-school system, to an outsider, that appeared to be achieving the goals

and needs of its students, but I am unsure how this experience was felt by those needing the assistance and fight for these services. My personal experiences have been more aligned with that of an ally or advocate for those with Autism, specifically those who have Asperger's Disorder. I have a few close friends who I met as adults who were diagnosed and struggled with getting their educational and social needs met while in school, particularly middle and high school ages. From their experiences I was able to glean the following understanding of the various people and roles within the lives of those who have special education needs.

Particularly, from my understanding, we have a divide in the classrooms at the ground level in terms of needing to assist those in need and viewing these adjustments as detracting from the overall educational system. Specifically, being mentioned or spoken of here are the Teachers and Teacher's Aids. I have seen and heard the different reactions, one side being that these adjustments taxes already thinly stretched teachers in classrooms that are already lacking support. Others believe it is a necessary precaution to ensure that everyone has equal access to opportunities of learning. The next level up I've learned about is that of the guidance counselors and assistants who again have been torn on engaging with the needs and advocating wholeheartedly and those who believe it is an unnecessary burden. Lastly, I have heard from administrators at various levels within school systems be more negative toward educational plans due to the costs in monetary value it places on the school and their lack of resources. Though this is a valid concern it is required and necessary to provide these resources to students to try and ensure as level of a playing field as possible. I tend to believe that many of the educational plans and interactions will be reactionary in nature as opposed to pre-emptive in assisting individuals and believe this to be mainly due to Top-Down pressure (administrators and finances as opposed to teachers and parents).

It is my belief that many of the levels involved within the implementation and creation of IEP will be more negative particularly with themes of meeting the actual needs of the child, the differences on expectations and reality of the adjustments/assistance given, and the reactions of support and guidance being given to them from superintendents and professionals involved.

Team Member Two. As a researcher, I have had many personal experiences that may make me prone to many biases. I began working with special needs children and adults while volunteering at a therapeutic riding center in high school. After five years of working with neurodivergent individuals and their parents (or caregivers) through hippotherapy, I developed a deep interest for working with this population. As an undergraduate at Purdue University, I worked closely with the Autism Awareness Club and Pete's Pals, an organization dedicated to encouraging physical activity among neurodivergent children. Working in these environments, parents and caregivers often spoke negatively about lack of or quality of services available to their children. More recently, I worked for Meridian Health Services as a Behavioral Clinician and Family Navigator in a local elementary school. Multiple students on my caseload had IEPs and/or were on the autism spectrum. Seeing firsthand the parents' frustrations with the school and my own frustration with the lack of support for these children may have created biased viewpoints of the IEP process. In some cases, I was the only support listed on the children's IEP, while parents were unable to elicit other school accommodations. On the rare opportunities I was permitted in special education classrooms, the extra "support" my clients received was provided by overworked teachers in chaotic classrooms, where existing IEPs were not being followed. It was a disheartening experience to be both, part of the potential solution but also part of the problem. As I was forbidden to attend IEP meetings, my clients' parents felt unsupported,

unheard, and defeated by school administrators. This experience has left a negative impression regarding IEPs and how they are carried out, at least within the local school district.

Participants

This study's sample included 13 primary caregivers of middle school children with ASD. This included anyone who defined themselves as a primary caregiver. Caregivers who were not parents were not excluded since the data and past research did not indicate that their experience is drastically different. To be included, their children must have completed sixth grade and not yet attended any high school (ninth grade). This way only caregivers who have had at least one year of experience with the middle school were sharing their experience. Children who were homeschooled were excluded.

Participants were primarily female (12; 92%). All participants identified as non-Latinx White/Caucasian. Most caregivers were the biological mother of their child (11; 85%); there was one biological father (8%) and one grandmother (8%). Participant age ranged between 36 and 58 ($M=44.8$; median=47). The children were all enrolled in or had just completed sixth (6; 46%), seventh (5; 38%), or eighth (2; 15%) grade, depending on the timing of the interview. Children's ages ranged between 12 and 15, with most participants (7; 54%) aged 12-years-old ($M=12.77$; median=12). See Appendix B for demographic details.

Procedures

Caregivers were recruited through collaboration with the director of Ball State University's music program for children with ASD: Prism Project. Prism Project is an annual show put on by children with ASD ages 6-14. They practice music and dancing weekly with an assigned "buddy" and perform for family and friends at the end of the program. Participants were also gathered through snowball sampling (i.e. caregivers were encouraged to pass on the

researcher's information to other eligible caregivers willing to be interviewed). Additionally, Interlock, a local group supporting people with ASD and their families, allowed the researcher to set up a table at their annual event, an Autism Walk. There, the researcher spoke to many caregivers and passed out flyers. Further, most of the sample was recruited through various Facebook pages that serve as support groups for caregivers of children with ASD. Recruitment materials included a brief explanation of the study, indication of IRB approval, researcher contact information, and the informed consent. See Appendix C for recruitment materials. The recruitment invitation was posted in open groups and in closed groups permission was gained from the owner of the group.

Interview Procedures

Prior to the interview participants were given the informed consent document (See Appendix D) and given a chance to ask any questions to the researcher. Participants were then given the demographic questionnaire (See Appendix E). Those who did not fill out the questionnaire ahead of time were asked the questions during the interview. Information such as age and race/ethnicity of the caregiver and age, gender, and grade of the child was gathered. Additionally, the questionnaire included open-ended questions related to family composition, services for the child from the school, and services for the child outside of the school. The purpose of this form was to gain a thick description of the family and provide context for their experience interacting with the middle school. The answers to these questions are summarized in the first paragraph of the individual textual structural summary for each participant.

Each participant was interviewed individually by the principal investigator. The interviews were held in a place that was comfortable for the participant and maintained their privacy: either a location connected to the recruitment site or the Ball State University

Counseling Practicum Clinic. For participants where distance precluded meeting in person, interviews were conducted via Facebook Video Chat or Skype. The interview time was mutually determined by the researcher and participant. Interviews were audio recorded. The interview that took place in the Practicum Clinic was video recorded, but the video was not used for research purposes. The video was deleted by the clinic administrator during the summer of 2019. It was planned that if participants became distressed talking about their experience, they were referred for services to the Ball State Counseling Practicum Clinic or another appropriate mental health service. No participants evidenced distress in talking about their experience. In contrast, most seemed to appreciate the chance to talk about it.

Interviews were non-structured beginning with four general questions:

1. Tell me about the positives and negatives (negatives and positives) in communicating with the middle school about your child.
2. What influenced your experiences of communicating with the school about your child?
3. Tell me about the positives and negatives (negatives and positives) in the IEP process.
4. What influenced the IEP process?

The interview was highly non-directive (Moustakas, 1994). Phenomenological interviewing is an informal, interactive process. The investigator used open ended questions, comments, clarifications, and reflections to demonstrate understanding. The interview began with the investigator giving the participant a few moments to reflect on the experience. The investigator then gave the participant a chance to explain the phenomenon in their own words, showing interest and asking for clarification (Moustakas, 1994). The interviews were scheduled for one hour and lasted as long as it took for the caregivers to feel their experience had been understood. Interviews ranged from 15 minutes to one hour. All interviews were transcribed by the primary researcher. Transcription software (Descript) was used and the primary researcher

cleaned up the transcripts and checked them for accuracy. Each transcript was then checked again by one of the researchers before the individual summary was written. Participants were given the option of a \$10 Amazon gift card or a \$10 donation to the Autism charity of their choice as an incentive to participate.

Member Checking

Participants are also considered co-researchers (Moustakas, 1994). This means they have input on how the data is analyzed. They were sent individual summarized descriptions of what they stated in the interview. These are known as textural- structural descriptions. A Textural Description includes the content of the interview (i.e. the story that the participant is telling). A Structural Description includes the meaning that participants have made of the content. These two parts of the interview are synthesized together to give a more complete essence of the experience (Moustakas, 1994). The descriptions were written by one of the analysis team members and checked by a second. All descriptions were sent back to the participant to check for accuracy. The textural-structural descriptions were sent via e-mail to get comments and perspective from the participants on the interpretation of the information they provided in the interview. Only one participant had edits, which were incorporated in the description presented below.

Data Analysis

The interviews were analyzed using transcendental phenomenology methods. The first step in analysis was to write the Individual Textural-Structural Descriptions. The researchers were encouraged to “dwell in the data.” They were to listen to the interview once fully before starting work to get the full story the participant was telling. To follow up on training, the primary researcher wrote the first description and checked it with the participant as an example

for the other descriptions. Each team member was assigned interviews and wrote the description. That description was then reviewed another team member and then sent to the participant for member checking.

Second, the team engaged in horizontalization (Moustakas, 1994). The primary researcher and the researchers were each assigned interviews. Each interview was given to member of the research team who had not yet worked with that specific transcript (i.e. had not written the individual textual description or done the review of the description). They were to listen to the interview and check the transcript for accuracy. Researchers were encouraged to again “dwell in the data.” They were to listen to the interview once fully before starting work to get the full story the participant was telling. Researchers then divided the transcript into chunks (sentences or paragraphs) that expressed one idea. These are known as expressions. Filler words (e.g. umm, really, ya know) were removed and statements that did not relate to the research question were removed (e.g. calling out to pets to be quiet in the background, telling children to leave the room). Each researcher listed every expression included in the transcript.

The research team met and brainstormed possible themes. Research members listed any concepts or themes they noticed as they had been immersed in the data. By this point, all research team members had listened to each interview or read each transcript twice. All potential themes and categories were listed without discrimination. Following this process, each expression was read aloud, discussed, and listed under one or more potential category. If it did not fit with a category that had been brainstormed one was added. Research team members were encouraged to consider each expression from different vantage points (such as opposite meanings and various roles). For example, the expression “If I feel like there's an issue, I may get emotional about it, but I'll communicate what I feel needs to be done or what I feel is wrong”

was read. Initially one team member suggested it be listed under the emotion theme. Another team member thought it would fit better under the communication theme. After discussion, the three team members decided it fit under both. As the expression was being discussed, a member of the research team pointed out that the primary researcher was assuming this was negative emotion, which is not explicitly stated in the expression. This process was purely imaginative, not empirical, and allowed the research team to come up with multiple hypotheses of the meaning of the participants' words (Moustakas, 1994). By imagining opposite meanings (e.g. what if the participant meant she was excited when she said emotional) and placing that meaning in the context of the interview, the team eventually concluded that the emotion was perceived by the participant to be negative and an emotion that she did not want the school administration to see.

Finally, each theme was tested to determine if it is an invariant constituent (a necessary component of the experience). Each theme was checked with two criteria developed by Moustakas (1994) to determine if the statement is an important theme for the research: 1) does the statement show a component of the experience that is a necessary and sufficient constituent for understanding it? and 2) can the statement be abstracted and labeled? If the expression met both criteria, it was considered an invariant constituent and is detailed below. An invariant constituent is a part of the experience that is present for every individual and helps the outsider to understand it. It describes a fundamental component of the experience. Third, the invariant constituents were checked for accuracy by the research team. Each theme was checked against the transcripts of the research participants for the following criteria: 1) is the theme expressed explicitly in the complete transcript? 2) is the theme compatible if it is not expressed explicitly? If the theme did not meet one of those criteria it was removed (Moustakas, 1994). Both social

pressures (mentioned by two participants) and need for change in the community (mentioned by three participants) were considered as themes but removed. Using these perspectives, the primary investigator summarized the themes presented (see below).

Results

Individual Textual-Structural Descriptions

The caregiver's answers to the demographic questionnaire are summarized in the first paragraph of the individual textual structural summary for each participant.

Participant One

Participant one was a 37-year-old, non-Latinx White, female. She and her husband lived with her mother and two children (10 & 12). Her son (12) was diagnosed with autism by a geneticist when he was 2 years old. He was generally laid back and happy. He liked horses, his iPhone, and making YouTube videos. He tended to mess with objects that can be unsafe or get him in trouble (e.g. water heater or furnace). He was entering the seventh-grade next year. Even though he is intelligent enough for the mainstream classes, he was in special education because it was hard for him to handle the commotion or high level of distraction. He did well in school and didn't get in trouble often. However, sometimes when he would get upset, he would have a melt down, sometimes including self-injurious behaviors, hitting people, or breaking things.

Participant one described a positive relationship with the middle school. One main factor making this such a positive experience is the teacher, who was her first point of contact. She talked with the teacher frequently through text message. The teacher messaged her with information and different articles for support, education, and additional resources. She spoke highly of her son's teacher and the ways in which she is supportive, understanding, and accommodates her son. She said: "I appreciate her understanding, her knowledge, her trying to

work with me.” Participant one reported it can be hard to find support when going through this stress, as a lot of people, even family, don’t understand the experience; “they’re real sympathetic and listen and they don’t fully get it because they don’t live it, but they’re really nice about it and try to understand and stuff like that.”

The difference between communication with the middle school and elementary school has been like “night and day.” Specifically, she was able to work more readily with the teacher in terms of being able to modify her son’s IEP (late starts) and about communication. The lack of clear and consistent communication in elementary school resulted in CPS being called due to attendance concerns which would have been addressed through the IEP with proper consultation and communication regarding the subject’s son’s needs (behaviors causing delays or missed days at school).

IEP meetings in middle school were “more laid back,” easier, and have less people attending than the IEP meetings for her son in elementary school. The meetings were on time, and she felt like they covered the problems her son was likely to face. She appreciated that they took time at the meetings to plan for the transition from elementary to middle school. The people at the meeting were supportive and wanted to help, but she stated it can be emotionally trying when they all have something negative to say about her student and their own idea of what is right and what she should do as a parent. “So, you try to keep the anger and the tears and stuff back. But sometimes it’s hard to do that.” The teacher was particularly helpful in these meetings as a support for both her and her son.

Her advice to other parents is to make sure they do their research ahead of time and know what their rights are. INSource is a good resource in Indiana. There are free online classes available about the laws and rights regarding the IEP. She stated some parents have issues with

the meetings because “the school doesn't want to budge, or they don't want to make accommodations or things like that. Even though they're [the student] entitled to it.” She advised that parents put in effort to educate themselves on what their child is legally entitled to in their state. Building a relationship with the school before there were any problems helps increase the responsiveness and receptiveness of the administration and teachers.

Participant Two

Participant two was a 50-year-old, non-Latinx White, married, female, having three children in total (28, 24, and 14 years old). The family composition at the time of the interview was Mom, Dad, and son who is currently 14-years old, and recently finished the eighth grade. She had two older children (28 & 24) who had moved out of the house. Caregiving time was split between mom and dad, with Mom taking priority over school related needs and caregiving in general within their household. Their son enjoyed drawing, video games, and swimming. He was described as honest, funny, and a “great kid”. He had food obsessions; he was a picky eater but also overindulges in the foods he is willing to consume. This was a concern the family was working to address. He was diagnosed with Autism at eight-years old by a Social Mental Health professional. He remained in the same middle school for the entirety of his junior high education and was in mainstream classes for art and science. He was taking math and ELA at the time of the interview and was doing well. He was reported as wanting to drive when he turns 18-years old, which was currently causing mom high levels of anxiety. She predicted her son would go to college after high school but will need to overcome difficulties such as threatening bullies while at school to defend himself. She reported it was hard to find support for in caring for her son, but her daughter (28) and her husband helped. Sometimes it was “easier to take care of everyone else” than talking about her own experiences. Her son received therapy as well as medication via

care from a psychiatrist. Specifically, he was being treated for ADHD with anxiety, and anger issues, specifically related to bullying and bullying-related instances.

Her experience with the middle school was negative, specifically experiences with the principle and nurse threatening to report her to court due to her son's attendance. This was during a period in which her son was acting out more than normal and the family was seeking extra services and therapy to address the concerns being raised at that time. Her son's stress levels were extremely high during his sixth-grade year and he was not in the collaborative, an alternative to mainstream classes, though it was reported as being available. Even after meeting with school officials with her son's therapists (ABA and another) they did not get the assistance needed until after getting an advocate. She saw her son as a victim in the circumstances, forced to wait until proper services were offered and given, specifically due to the costs associated with them. Seeing him having to suffer due to the lack of assistance he was receiving was very difficult. It was painful to her to witness his emotional pain and hear him say he was "not wanting to be here" due to bullying experiences and stress from school. Her son was the one who convinced the school to change his IEP by going to the social collaborative teaching room instead of his normal classroom. The school could have been more helpful by taking her reports of her sons desire to commit suicide more seriously than they did when it was reported. She reported feeling dismissed and as though the public-school system did not truly care about her child's education and his IEP but their own "bottom line" and thus enacted services that were not fully appropriate or in the best interest of her child.

She reported her son's sixth grade science teacher was a great help and communicated well with her. Because of his care, her son was able to be in a mainstream science class. The math teacher clashed with her son over learning styles and understanding. Specifically, her son

had learned a different way to approach problems and asserted this with his teacher who responded to negatively from that point on. Shortly after this her son entered the social collaborative, an alternative learning environment within the school, for all classes except art class, which remained mainstream. In seventh grade, one teacher was more communicative than others and helped ensure communication occurred. The eighth-grade science teacher was communicative as well. Her son does not like to ask for help when he is struggling because it disrupts his image of himself as smart. She reported being able to speak directly to this teacher and explain this which dramatically increased the communication and her son's comfort in the mainstream class.

The IEP meetings were particularly rough particularly. Participant two reported she was disliked because she “stood up to [the administration] and wasn't just bowing down.” Her son's own attendance and self-advocacy was a critical component for these meetings and being able to ensure he as getting what he needed to succeed in school. The participant stated her son was nervous at first when attending these meetings but gained self-confidence and understanding of how to gather his thoughts and express them within these meetings. She even reported her son was doing research on Autism to be able to use this information at the meeting to help advocate for himself. Her son's speech therapist, the District Placement personnel, her son, herself, their advocate, the director of the mini school, as well as other administrative staff (superintendent/assistant superintendent) attend the IEP meetings for her son. The IEP team wanted her son to enter traditional learning environment in high school. She felt as though he was smart enough for the challenge academically, which made her very uneasy. She was less anxious once she was able to meet privately with the director of the mini-school and learned

about the supports her son would have (i.e., access to his IEP team members, particularly members who have been well received by her son and helpful in the IEP process).

Her advice to other parents was to connect with the Department of Developmental Services (DDS) or a related agency to gain assistance for advocating within the school system for your child. If their child qualifies, DDS will pay for advocates or direct them towards other state level services. State-ran hospitals can help assist with services in general, though maybe not directly linked to the IEP. She wants parents to know even if they have an advocate that they will have to “fight tooth and nail for it” but the services for your child to succeed are well worth the efforts.

Participant Three

Participant three was a 58-year-old, non-Latinx White, male. He lives with his wife and two children (9 & 12). He was the main caretaker for his 12-year-old son with autism. His son was nonverbal until age five and occasionally engages in headbanging. A pediatrician diagnosed him with PDD-NOS at age two. His son enjoyed participating in Cub Scouts, Special Olympics, and creating children’s games on YouTube. He also enjoyed math, science, and writing classes. His son was entering the seventh grade and had a 3.4 GPA. The participant’s son attended mainstream classes, though he functioned better in smaller classes. His son was intelligent and skilled at “outsmarting people.”

Participant three described a negative relationship with the middle school. He stated his son had a 42-page long IEP that he has had to challenge the school to create for his son. He reported that an IEP was better the longer it was. The middle school provided a smaller class size for the participant’s son in addition to “some therapy.” To supplement this, his son attended therapy at a local autism center, but the results were disappointing. The lack of consistent

communication from the school was a main source of conflict. He received accessible emails (accommodating his visual disability) or prints from his son's teacher regarding grades and upcoming assignments. However, he reported that more communication from the school with updates would be helpful. The lack of communication contributed to his son's behavior at school (purchasing "junk food" and consuming it at school without his father's knowledge). His son was suspended seven times over the last school year for various activities including crawling under a bathroom stall door and pocketing his vitamins, causing the school to assume he may be selling drugs.

He reported attending regular IEP meetings at the school. He found it helpful that he knew many of the people at the meetings and other school officials such as the superintendent, the principal, and the vice principals. In addition, recognition of his achievements within the community and with his son, helped him to feel more in control at the IEP meetings. However, recognition and familiarity alone were not been sufficient to create the environment his son needed to excel at school. He stated, "You have to go up the ladder...if you want something done...Most people don't want to challenge the system." Overall, he found IEP meetings to be a supportive environment for his son and sought social support for himself in a group therapy for middle school parents.

His advice for other parents, particularly those preparing to enroll their children with ASD in middle school is be involved in the school and find ways to volunteer, voice their and their child's needs, and self-education.

Participant Four

Participant four was a 52-year-old non-Latinx White woman. She was a caregiver of her 12-year-old grandson. Her grandson was diagnosed with autism by a psychologist when he was

seven-years-old, but the family suspected he may be autistic earlier when he had not begun speaking at age three. Her grandson lived with her daughter, age 32, and her other grandson, age eight, who was diagnosed with DMDD and an anxiety disorder. Her grandson enjoyed anything mechanical, especially computer games and coding. He joined a club at school for games which has helped him gain friends. Her grandson finished sixth grade this spring, attending mainstream classes at a local middle school.

She and her grandson faced multiple stressors at the middle school including difficulty implementing an IEP plan and bullying. Despite informing the middle school and her grandson's teacher about his IEP, autism diagnosis, and psychological evaluations, she had to submit a certified letter to the school to get the initial IEP meeting after the first three months of school passed without one. Over the course of the school year, six IEP meetings were held in which she requested additional help for her grandson including a one-on-one aid and extra time for assignments and testing. The school responded by reporting they did not have a teacher or a class to meet these needs for the IEP and did not provide services. The school did not provide status updates on how he was improving and areas in which he was lacking during the IEP meetings. His teacher said, "Oh, there's nothing wrong with him; he doesn't need all this stuff." In addition, the teacher was upset by additional testing the family requested. Her grandson's grades fell from Bs and Cs to failing grades when he began to be bullied. He struggled in school, pulled out his hair, and picked at his arms and legs which required psychopharmaceuticals and increased therapy sessions to prevent him from hurting himself.

She got mixed support from the school. She communicated with the school's principal, the exceptional children's director, her grandson's teacher, and the superintendent in person and through email. She tried to start at the roots but when there was no change, she stated they left

her no choice but to file a lawsuit against the school with the Office of Civil Rights. Following the suit, the principal had everyone in the school read a book about a child with Asperger's and requested a referral for an advocate from the Autism Society to come speak at the school. She identified getting the school to listen and understand was challenging. For her daughter, obtaining disability for her sons was a stressor. She suspected the school did not have enough support for the teachers and children. They had one teacher for so many children on different levels with different needs. She also believed that a lack of training for teachers about special needs children in mainstream classrooms was adding to the stress experienced in the schools.

She provided this advice for parents: know the IEP and what it means. She encourages parents to ask questions to clarify the IEP. She also recommends taking a supportive friend or advocate to IEP meetings. She found support through the Autism Society. It is important to know the process and your child's rights. Caregivers should document when they do not agree with the IEP and begin inquiring about the next steps to improve the IEP. She had suggestions for the school as well. She asked schools make IEPs understandable for all parents of all education levels and provide information about the IEP process upfront.

Participant Five

Participant five was a non-Latinx White, 50-year old married female. She and her husband were the primary care givers for their 12-year-old son and have been since he was diagnosed with Autism at age 3.5 years old. Prior to this last year, she was the leader of a parental support group for Autism, and was heavily involved with researching treatment, providers, and services, for herself and others. Her husband was going to a support group. Previously, they enrolled their son in therapeutic services such as speech therapy, occupational therapy, social skills training, and general behavioral emotional counseling. During the time of

the interview, their son was not attending these services and was working independently at home with his parents on independent living skills, such as chores. She felt that “we haven’t figured out what’s the other thing he might need” but reported her son is doing extremely well. She believed her son will be able to drive a car but wishes to delay this until he is 18. Additionally, she hoped he would attend a community college prior to a University to transition into the additional levels of stress involved, not due to the academics, but structure, social skills, and other factors. At the time of the interview, their son was preparing to enter seventh grade after summer. During sixth grade he achieved all A’s and was enrolled in all mainstream classes, with advanced placement in Math. Prior to the past year, their son utilized his resource teacher, and outside of the classroom teacher to help alleviate anxiety as needed and was incorporated into his educational plan. Since enrolling in the sixth grade, he has not had to use this, and has been able to rely on his in-classroom teachers for social support as needed.

Participant five was more anxious about the upcoming transitions within her sons’ life, specifically puberty and the transition into high school, than about his middle school experience. At the time of the interview, due to the efforts made earlier in their son’s life and his currently level of functioning and ability, she was not too concerned about his struggling with behaviors or academic achievement within middle school. She reported working with professionals in the community heavily, and specifically utilizing her developmental pediatrician who was extremely helpful and supportive in understanding her son and Autism. She reported that prior to this past year and a half she felt she was “figuring it out” before getting “comfortable” with his progress and abilities.

Participant five developed a personal relationship with the principals at the elementary and middle schools while navigating the educational needs for her child. Because of this, the

experience in middle school was very positive. She was also a member of the PTA of her son's school since he began public education. She was a practicing attorney and utilized her abilities and skills to present her son's case and advocate for the needs for her son since the beginning of his diagnosis. She also attributed the positive experience to her ability to clearly communicate with the school regarding her sons' education, saying "I'm not aggressive but I am just really super prepared and I'm super involved and I'm super visible." The principal, school resource teacher, occupational therapist, the LEA from the district, regular teacher, and herself attended the IEP meetings and typically agree on a course of action for the upcoming year. One accommodation that came out of these meetings was the understanding that his artistic ability would not be graded or affect his grades, since he struggles with fine motor skills. She communicated with her son's teachers regularly through e-mail and text message and also made sure to connect home behaviors to school related activities and vice versa, taking the teachers steps and initiatives home with them to help with consistency for their son.

Her advice to other parents beginning this process is: present their needs, desires, and wants for their child from a collaborative and helpful manner, specifically working with the teachers and staff members to accommodate the needs of your child. Advocate for themselves and their needs but do it in a manner that is aiding in the ability to have the meetings or get the needs met for your child. A specific example of this was having a draft of the IEP prior to the meeting and asking to change the meeting to have a draft available prior to the meeting to ensure efficiency as opposed to canceling due to a lack of preparedness/cooperation of the school. Have the school know they are on their team to meet the goals and needs of their child, not making demands, but assisting in establishing proper support and response to their child's needs.

Participant Six

Participant six was a non-Latinx White, 38-year-old female, who was currently living with her two children, ages 16 and 13. Her 13-year-old daughter was diagnosed with Autism by her primary care provider when she was about ten years old. She was also diagnosed with a learning disorder. At the time of the interview, her daughter was preparing to enter eighth grade. She was in special education classes and receiving all A's. Her daughter had great manners and as a people pleaser. She disliked chores and liked electronics.

After her daughter was diagnosed with ASD, Participant six advocated for her daughter to be in an Autism support group which would give her more access to resources for her education. Since the school focused on the learning disorder as the primary diagnosis, her daughter was actively denied these services. It was not until getting an advocate that they were able to successfully place her in the special education classes she needed. Her daughter began to grow immensely in her abilities soon after being placed within the specialized program and education which helped the participant cope with the process of obtaining these services.

Her daughter's IEP meetings were more adversarial than collaborative, particularly at first when advocating for services for her daughter. The director of special education, the principal, advocate, occupational therapist, and speech therapists were typically present at the yearly meeting. The head of the special education department, who held the most control in the IEP meetings, was commonly heard saying "we are providing what the state requires" and urged the participant to seek outside services, such as speech therapy and specialized reading instruction. Because of this she had to pay for these additional services out of pocket. Additionally, she recalled moments of degradation with the interview, stating school officials asked her "what kind of mother would do this?" when she was advocating for her daughter to be in special education. The more she advocated for her child, the harder and worse the IEP

meetings were, due to asking for more from the staff for her daughter. She stated many parents give up too easily, take the criticisms too personally, and do not know the law well enough to advocate for their child effectively.

She had regular communication with her daughter's teachers and felt they were extremely supportive, communicative, and responsive to her needs and the needs of her daughter. She felt an increase in support and understanding from her daughter's teachers since going into the special education classes that specialize in ASD. She felt that communication with the teachers and the principal outside of the IEP meetings was more positive in nature and collaborative but the IEP meetings were ran based upon law and policy with little room for negotiations. Though the meetings were extremely daunting she maintained positive relationships with her daughter's teachers during her education. She reported having a similar more positive and collaborative relationship with the principal but communication outside of the IEP is more limited than that of the teachers. Lastly, she had limited contact with the director of the special education department except during IEP meetings.

Her advice to other parents and caregivers is to get attached to support groups, find an advocate, and get to know the laws in your state. In Pennsylvania the laws have been broken down into more manageable chunks for the general population to be able to understand and utilize to get access to services. Additionally, parents should research the available services and needs as thoroughly as possible and be aware that many school districts will try to avoid providing them due to the costs of services. Seeking additional support and understanding of the services and applicable laws helps them advocate more effectively.

Participant Seven

Participant seven was a 36-year old, non-Latinx White woman with three children (9,11, and 13). Her oldest was diagnosed with Autism at two-years-old from a University Clinic. It took several months to get an appointment to get him diagnosed. He was smart, funny, trusting, and has special interests in trains, working on his bike, cars, and Legos. Additionally, he always “treated things he loves like they have human feelings.” He was deeply attached to these items and mourns when the family loses or changes vehicles. At the time of the interview, he was preparing to enter the eighth grade and was enrolled in both mainstream classes (core coursework) and in specialized art and PE classes. Her son was intelligent and got B’s in most of his classes. He struggled the most in mathematics. She hoped he will be able to drive at 16 and will be able to live independently in the future, but she described these as her biggest concerns going forward. She worried most about people taking advantage of her son and who would help care for him if something happens to her as his primary guardian. To cope, she attended a support group, prayed, talked to other parents and family, and maintained a “focus on today.”

Communication with the middle school was good overall. It was primarily with his teachers through e-mail, Facebook messenger, or texting. They also communicated randomly in the community when the teachers came to her place of employment. She felt like the school wanted to help; she often needed to provide direction on how. Her son did well at “holding it together: throughout the school day, and only she saw the meltdowns when he got home. She tried to stay calm, but often was frustrated to receive the blowback from him holding it in all day. She often went into the school to address or voice the issue to the principle for investigation and further remediation, and the school was receptive of this.

Her experiences with IEP’s in middle school were fairly good. It was a scary process when she began with him in the second grade, but by educating herself, being available, voicing

her concerns, and trying to be open, it went well in middle school. The meetings occurred twice yearly with re-evaluation every three years. Her son's teacher, the principle, and special education director were present for the IEP meetings which have been fairly smooth so far. Her son's sixth grade year was his most difficult due to having his hardest classes at the end of the day, causing anxiety. In seventh grade his classes were reorganized so that his harder core classes were in the morning and he was able to deescalate throughout the afternoon. Since this change, he had less homework due to his special education teacher and class time being utilized to complete homework. He was allowed to take sensory breaks as necessary. He utilized these three times per day for ten-minute intervals and used them around his hardest class (math) to cope with the increased anxiety prior to and after the class. Her son experienced a high degree of bullying that increased as he got older, and this contributed to his dislike of school. Participant seven was concerned her son would continue to be bullied or used since he did not understand social cues but desired friendships and connections. This also contributed to her concerns about him living on his own after turning 18 and going off to college at a university. His sisters were a source of emotional and social support and take pride in "knowing him better" than anyone else. Though he does not have behaviors very often, some breakdowns disrupted family events and caused alterations in family plans or outings.

Her advice for other parents going through this process is to make sure to get connected to the support groups and various resources that exist in your area to help them navigate these services. She also warned that many people will face resistance from school, but to maintain a positive attitude and keep advocating for their child and their needs. If the parent hasn't heard back from the school, stay on top of it. If they communicate what is going on with their child to the teachers, they tend to be responsive.

Participant Eight

Participant eight was a 47-year-old, non-Latinx White woman, with a background in early childhood education. She was the mother of seven children, four who lived at home with her and her husband (12, 11, 8, and 5). She was the main caregiver of everyone in her household. At the time of the interview, her 12-year-old son was preparing to enter the seventh grade. She suspected her son was autistic from an early age and had him tested by a neuropsychologist last year. He was diagnosed with autism at age 11 after multiple misdiagnoses. Her son was an “avoider,” “seeker for sensory issues,” always moving, highly intelligent, and quiet. Her son also enjoyed people, but from a distance. He preferred to be reading or doing something electronic in his room.

Her son did not have any behavioral concerns and did not display many of his autistic symptoms in school or public. After school, he flapped or bounced at home because he held it in at school all day. He attended mainstream classes for all seven classes. He achieved high grades, mostly As and some Bs. He had a 504 plan through the school but did not qualify for an IEP. He attended speech and occupational therapy outside of the school because he did not qualify for these in-school services. She sought out activities and care for her children outside of school, including a summer camp hosted by a local university’s speech pathology department, therapies, and new activities such as wrestling. She believed her son would learn to drive but was concerned about his reaction time. She reported her son had discussed college but was concerned about him being on his own. She imagined he will never get married (unless he changes his mind and wants to) or move out but that he will definitely have a job. She reported that her son will always need someone to support him.

She felt his 504 plan as appropriate for his age and current level of functioning. In the past, she wanted an IEP for her son, but he did not qualify. In her school district, children with behavioral concerns that inhibit learning receive IEPs but because he did not display these, he did not qualify. She reported being frustrated for a while but was happy with it at the time of the interview since the 504 can follow him to high school and college. She was concerned that her son is not excelling as much as he could with the extra support. At school, he had few accommodations. He had reduced classes (three to four instead of seven a day), a bouncy ball and bungee cord to help with “sensory issues,” and accommodations in gym class. He could benefit from more but since he was not failing or having behavior problems, they would not provide more. She worried that her son will not advocate for himself enough at school and about the lack of services available to her son locally. She felt better supported in the middle school than she did in the past but reported the need to strongly advocate for her child’s needs or “nothing happens.”

Her advice for other parents about to begin this process includes advocating for their children, being diligent, going to parent-teacher conferences, and communicating with the teacher. She reported that making a list of what works and does not work for her child and providing it to the teacher has helped in the past. Additionally, parents need to educate themselves and ask the schools about their behavior plans and assessments.

Participant Nine

Participant nine was a 49-year-old, non-Latinx White woman, who lived with her husband, two kids (11 and 12), and her mother (86, with severe congestive heart failure). Her 12-year-old son was diagnosed with autism at 2 ½ by a neurologist. During the time of the interview he was preparing to enter seventh grade. He was in mainstream classes and achieved grades of

As, Bs, and Cs. He had some trouble at school with social interactions and bullying. Her son struggled with anxiety but strived to have a good relationship with his family. He liked chess, softball, riding his bike, swimming, making comics and video games of his comics, and playing games on his Nintendo DS. One big stressor for the family was her son's difficulty in interactions with his sister.

The communication with the school was pretty good. However, they had had to determine what their priorities were and make compromises. "We haven't had to fight tooth and nail for everything that he's needed. That being said, there's limited resources and I felt like he needed more help this year with managing the workload and you can ask for more time, but it doesn't make this special ed teacher, the speech therapist, suddenly, magically have more time in their schedule to make it work." She found that the teachers appreciated being kept informed about what was going on in her son's life. She said on some level, you have to trust the process. Instead of dictating what she thinks is best, she asked them open ended questions. She brought resources from outside the school and got ideas from the school personnel. It was a very collaborative but stressful process. The IEP meetings went well but she had better results if she brought someone along to help ask questions and take notes. She obtained some information before IEP meetings (notes, drafts of testing) so if she had an emotional reaction, she could process it on her own instead during the meeting. Her son attended the beginnings of some of the meetings. Participant nine hoped to include him more in the IEP process as he gets older to teach him to self-advocate.

She found e-mail to be the most effective form of communication. The regular tools the school had for communicating with parents weren't quite enough for her to know what his modified requirements were. Her son had access to a sensory room and used it each morning to

get his mind and body ready to learn. He had occupational services on a consultative basis. A speech therapist assisted him a couple of times per week in language arts while a special education teacher assisted him a couple of times per week in math. In addition, he had accommodations for homework and testing. Some assignments were modified to fit his needs.

Her advice to parents who are about to begin this same process was to ask for documents (goals, draft notes, testing results) before the IEP meeting. Keep track of the questions they have so you can get them all answered during the meeting. If parents can send them information they want included before the meeting, that makes it easier for them as well. Having respectful communication and following proper channels helps any parent have good communication with the school. Another piece of advice was to not always assume that your child will need one-on-one all the time. There are natural supports that can develop if the child is not always with an adult, and those supports can be more valuable than what is structured in the IEP.

Participant Ten

Participant ten was a 38-year-old, non-Latinx White woman who lives with her daughter (15). Her daughter was diagnosed with autism when she was eight years old. At the time of the interview, her daughter was preparing to enter the ninth grade. Her daughter was in mainstream classes and got primarily D's. Her daughter was stubborn and artistic; she liked Harry Potter, dolls, and playing on her phone and disliked chores and homework. The main stress as a caregiver during the time of the interview was navigating the transition to high school and what life will look like when she turns 18.

There was not a lot of communication between participant ten and the school until her daughter was failing. She tried to communicate with them early on and tell them what problems she foresaw but they did not respond. "They weren't proactive at all. There were very reactive."

Once her daughter was failing two of her classes in eighth grade, they finally intervened and changed her IEP. In sixth and seventh grade there was very little communication. She would e-mail every few weeks to check in and the teachers were good about responding. She was very stressed during this time, and things would have been a lot better if the supports came before her student was in crisis. It was frustrating for her, because her daughter was very smart and could succeed in General Education, but behaviorally and socially she would probably do better in an enclosed classroom.

The IEP process went fairly well once it got started. She was impressed with all the school personnel who attended the IEP meeting. Usually the assistant principal, sometimes the principal, her guidance counselor, all her teachers that were available, the parent mentor, and usually her SSA worker would attend the meetings. The parent mentor was employed by the school to help parents navigate the IEP process in special education services. The parent mentor helped find outside resources, provided sensory items for the school year, and offered support in the meetings. The meetings were collaborative. The main problem was that they did not start soon enough. Since her daughter had a behavior plan, they met every six weeks. This was the main form of communication. These meetings were positive because they were willing to listen and take her advice. She still reported that at times she felt the IEP meetings were more reactive in nature and was concerned for how these would change going into high school when they were just now establishing a good plan for her daughter.

Her advice to parents who are beginning the process was to “be the squeaky wheel. Be annoying if you have to.” She suggested that parents keep pushing and not give up. Parents should really research what is available and what is possible. The school didn’t tell her what was possible, she needed to know what to ask for.

Participant 11

Participant 11 was a 47-year-old, non-Latinx White woman. She lived with her husband and 12-year-old son. Her son was diagnosed with autism at age 3.5 at an Autism Clinic. Both parents share the caregiving responsibility equally. At the time of the interview her son was preparing to enter seventh grade. He loved horror movies. Her son attended behavior therapy once a week at home. He previously participated in occupational, speech, and other therapies. She believed her son can learn to drive a car and attend a local college in the future. Her son expressed interest in joining the military. She worried about her son when she and her husband would no longer be around to support him.

There was a lot of confusion in communication with the school. At one point, her son was told he could do a craft to calm down. Because of his interest in horror movies, he crafted a Jason mask and knife. This was a red flag to the school who said he needed a psychological evaluation. The evaluation concluded he was not a danger to the school, and he was allowed to return without a suspension. It is very frustrating to the participant when the school compared her son to neurotypical children; she stated some leeway should be provided for neurodivergent children. She sat down with the principal and the vice principal to convey her son's needs. She communicated regularly with her son's teachers who called her if he is having a bad day. In school, he tended to rush his assignments and have meltdowns when he got something wrong. He enjoyed having good grades and typically achieved As, Bs, and Cs. When his grades were lower, she encouraged her son to work on his grades and communicated with his teachers to help him at school. Independence and teaching her son independence, were important to her and her husband. They taught their son to advocate for himself at school and care for himself at home.

The IEP process went pretty smoothly and the school was pretty accommodating. Her son attends mainstream classes and social therapy at school. His homeroom teacher was a special education teacher. If he began to struggle in the mainstream classroom, he had an aid that could assist him, or he could go to the special education room to calm down. For long classes, he had built in breaks. Participant 11 was proactive in securing the accommodations her son needed. She called “mini-meetings” in between IEP meetings to adjust the IEP as needed. IEP meetings were easier in middle school than elementary school because her son had matured more, and she did not have to fight for as many services. However, if needed, she was willing to push to secure those services. Her son did not attend IEP meetings regularly, but he sometimes attended part of them to answer questions about his needs. Outside of meetings, she contacted the special education teacher, or the principal if necessary, who addressed her concerns.

She provided the following advice to parents: keep open communication with the counselor, the special education teacher, or any other point of contact at the school on a regular basis. Also, communication with their kids is important, and their input when changing the IEP can be beneficial. She encouraged parents to not be afraid to make a phone call or go to whoever is necessary when something is wrong.

Participant 12

Participant 12 was a 40-year-old, non-Latinx White woman who currently lives with her husband and son (14). Her son was diagnosed with autism at 18 months by his pediatrician and completed further testing to confirm. During the time of the interview he was preparing to enter the eighth grade. He was primarily in mainstream classes and did well in school, but he struggled with the social aspects. He was very empathic, liked to help people, and liked to make people smile, but struggled interacting with peers of his own age. He was mostly happy (with his

“teenage moments”) and loved to learn about the middle ages, play hot wheels and Legos, ride his scooter, hike, camp, and be a part of Boy Scouts. Some of the stressors that were present for participant 12 as a caregiver during the time of the interview were: money for services, military deployments of her husband, and co-morbid anxiety in her son which increases her own anxiety.

Her experience with the middle school was good overall. She felt very lucky that they got a good team at school to help with her son’s progress. It was better than elementary school because the IEP was actually being followed and the administration was more involved. She particularly appreciated the principal, who got to know the kids, volunteered to help at lunch so the special education teachers can get a break, and even volunteered to help in classrooms. The teachers communicated with her well, both formally and informally. She could even chat with them over the summer to see if they had suggestions for problems the family was facing. Some teachers knew her son well enough that they could tell if he is feeling a little off, and they called and tell her what is going on. Part of what made this communication so positive is that she didn’t approach the school in an angry way. “I’ve always gone in with a let’s work together attitude versus this is going to be a battle and I have to win. I’m not supposed to win at the IEP meeting. My son is.” She always tried to see the reason anytime the school was not doing what she wanted; sometimes it was budget constraints, sometimes the administration blocking the teachers, sometimes aids who shouldn’t be in that position. It never helped to get angry at the wrong person.

Communication with the school was almost entirely through the special needs teachers, who communicated with the mainstream teachers. Per the IEP, she got daily communication via a tracking sheet. Some problems arose with this when they found out the bus driver was reading it aloud so other kids could hear on the bus. The bus driver has since left the school and the

teachers accommodated her son's understandable anxiety about the sheet by communicating about more sensitive issues over the phone. The special education teachers did well at accommodating material for him to learn; for example, they found documentaries and YouTube videos to teach him history. This fit his particular learning style. One thing that helped the IEP meetings to go smoothly was that the main teacher had a form her son filled out before the meeting, so they had input from him. The meetings also went well because the mainstream teachers showed up and cared about her son.

Her advice to parents was to ask questions from the teachers instead of making demands. She also suggested that caregivers talk with their kids about everything having to do with puberty. This includes what to expect and how to do things safely. She suggested they talk to them about emotional triggers for them and make sure their teachers know so that they don't accidentally say something about it and set them off. The teachers who work in the middle school level – “they are Saints because they chose to teach the puberty level They probably know what they're talking about.” Teachers are supportive when they know how they can help.

Participant 13

Participant 13 was a 40-year old, non-Latinx White woman. She lived with her husband and two sons (9.5 and 13). Her 13-year-old son was diagnosed with autism when he was three years old, but she turned it down waiting until he could be tested for giftedness. Once he was labeled as gifted, she allowed the testing for autism. He was advanced in all his subjects and got all As. At the time of the interview, he was preparing to enter the eighth grade. He planned to attend college for electrical engineering. He loved to run (did track, cross country, and soccer) and loved geography and maps.

They had a very positive experience with the middle school. Since her son was so well-behaved and intelligent, the school wanted to nurture that. Unfortunately, their willingness to help may have been because they knew he would do well on state testing. There were a lot of great people on his team who bent over backwards for him. His gifted teacher used her personal time to give him a personal tour of the middle school to help him transition in. Participant 13 saw the school personnel as caring about her son, stepping up, and doing what needed to be done so that her son could be successful in school and achieve independence. She had “a great team that comes in and they seem to know my child. They seem to have talked with him. They have information about him. They always have feedback from his teacher.”

Her communication with the school was primarily through e-mail unless there was a need to talk in person. Typically, she found that the teachers respond back quickly. She found that it is best to approach the teacher first. Going higher up turned the teacher off, as they may feel attacked or tattled on. She communicated with the teachers the first week as an introduction. She let them know she was a concerned parent who will put in the effort to help her son and his school progress. The IEP/504 meetings went very well. They meet once a year for both the IEP and the 504 plan. A mainstream teacher, his gifted teacher, the School Psychologist, the Autism Support Coordinator, and an administrator attended. She could tell that the school personnel involved knew her son and were invested in him. Her son attended the meetings and advocated for himself and made choices. He even brought up a problem he was having in track (the gun being too loud) and they were willing to make accommodations for him there.

Participant 13 had a unique viewpoint as both a teacher and a parent of a middle school child on the spectrum. Her advice to parents was to let the teacher know in advance what works for the child and what doesn't. By the time a student gets to middle school, parents know a lot of

what might help and what they don't respond well to. Even though teachers may have new ideas, it helps them to know what has already been tried and how the child has responded to it. In addition, she recommended that parents talk to the teachers early. This way, "instead of fighting fire, you're just keeping things under control. And it works great."

Invariant Constitutes

Accommodations need to be present and tailored specifically to the child.

All caregivers described either some sort of accommodation that was provided for their child or an accommodation they wish their child could have had. This contrasts with previous literature in which parents knew that the program needed to be improved but did not have specific suggestions on how (Sparks, 2007). Caregivers in the current study had very specific ideas of what would help their child and were confident in their understanding of their child.

The preference for type of accommodation varied greatly between parents. Participant Three expressed the importance of these specified accommodations, saying, "I just think that it's an important thing to always be recognizing that the reason why our children are doing so well is because they get support." Nine of the caregivers talked about placement (mainstreaming or special education classroom) as an important issue. Each of these nine caregivers had a strong opinion about where their child should be placed. Those who felt the placement was correct talked about the strong impact it had on their child. Participant Six stated, "But after she was in the correct placement, she really grew as a person and she really was academically doing better." Some parents preferred their child to be in special education classes, while others preferred mainstreaming. Participant Seven prefers her child to be in the special education to start the year, moving more towards mainstreaming as he adjusts. Participant ten was frustrated that neither

option seemed to work for her daughter, “she’d need a lot of support for Gen Ed, but she’s too high functioning for an enclosed classroom.”

An unfortunate theme in four of the interviews was the lack of accommodations. These parents detailed how they asked for accommodations and were ignored or refused. Similar to past literature (Tucker & Schwartz, 2013), caregivers felt excluded from the IEP process. They talked about specific accommodations they felt would be easy to implement that were not provided by the school. Participant Four stated:

... his stress level was just so high. And they refuse to do anything about it. He could have been in the collaborative [a special education program] all the time, doing what he needed to do, but they refuse to see it.

Caregivers are generous in providing advice and offering help to the next cohort of parents with special needs.

All 13 of the participants had advice for caregivers who were about to begin the same process. Previous literature has not addressed caregivers interacting with each other or their specific suggestions to improve the process. The two most mentioned pieces of advice were to keep open communication (mentioned by ten caregivers) and to educate themselves about resources and the IEP process (mentioned by eight caregivers). Participants wanted future caregivers going through the same experience to be sure to keep communication open with the teachers, their student, and other parents. Participant One stated, “some parents just overlook it, communication is a big key.” It is vital to make sure everyone on the child’s team is on the same page and understanding each other, as Participant Seven stated:

My advice to them would be to just keep all the communication open. Make sure that they're communicating with their counselor, special ed, whoever their point of contact is, on a regular basis. Communicate with their kids, see what's going on.

Caregivers gave advice on forms of communication that worked best for them (e-mail, Facebook, texting, phone calls, in person meetings, and school systems set up to communicate about grades). Despite the differences in forms of communication, most caregivers stressed the need to remain calm and assert themselves when communicating with the school. Education and research were mentioned emphatically by several participants. Participants encouraged caregivers to know the IEP process, their legal rights, what is written in their child's IEP, what supports are available (e.g. Advocates), and what specific accommodations to ask for. Participants provided information specific to their school, state, or region on how parents could educate themselves. Participant Six lamented, "a lot of the parents, I feel like, when a school district says no, or they can't, they just give up and they just don't go further. They don't understand the IEP. They don't know the law." Participant Eight explained that the IEP process is "going to be a battle, and I have to win," and that the way to do that was by knowing the laws surrounding it.

Secondary pieces of advice were to bring someone with you (a friend or Advocate) to the IEP meeting (mentioned by five caregivers) and to ask questions (mentioned by three caregivers). Several participants mentioned that they were often nervous before the meeting and that IEP meetings could be intimidating. Participant Two, who works as an attorney, reported:

At this point I don't find it intimidating. I find it stressful still, but I don't find it intimidating and obviously that's privilege. I do feel like an equal in the room. And it

saddens me to think about parents who don't feel that, who do feel very intimidated, who feel like it's going over their head...

Participant Three suggested caregivers take someone with them, "that way it's not one against five or one against six – because they [the school personnel] will speed it along. You need to get someone in there who's not afraid to say, 'woah, woah, wait a minute. Explain to me what that is.'" Unfortunately, two out of the five participants who talked about Advocates mentioned that they can be cost prohibitive and difficult to obtain. Being nervous or intimidated during meetings also seemed to prevent caregivers from asking questions. Those who were able to get past that advised future caregivers to ask every question they had. Participant 12 suggested writing down questions before the meeting so that they were not forgotten in the heat of the moment.

Change will not happen unless the caregiver takes a position of advocating for the child.

Eight participants talked about the importance of advocating for their child. Of those, six saw advocacy as a collaborative process that includes communication, being involved, and increasing understanding in all parties. Participant 13 explained how "just the administration listening to the teachers and myself and taking into account what we thought..." made a huge impact. Participant Three echoed this saying, "for me as a caregiver helping her, [the main stressor is] just trying to get the school to listen and trying to get the school to understand." Caregivers talked about how being involved in the school in other ways (e.g. joining the PTA) made it easier for them to advocate for what their child needed.

Two participants talked about advocacy as being in a place of power and distrust. This is similar to how parents in the past have seen advocacy as often resulting in conflict (Bennett, 1997; Slade et al., 2018). Participant Five stated, "they know I have a platform; I know lots of people including the new board of trustee." He explained how he often had to go above teacher's

heads to the administration, or above the administration to the school board. Participant Four reported that she had to go up the chain of school personnel several times as she did not trust people to tell the truth unless their superiors were there.

The best way to help your child through this process is teaching them to advocate for themselves.

Seven participants talked about the ways in which their child advocated for themselves and how they encouraged this as caregivers. Advocating from the student as opposed to the caregiver did not seem as conflictual as advocacy has been described in the past literature (Bennett, 1997; Slade et al., 2018). One way that caregivers encouraged this was by having the child attend their IEP meetings. For the children who are verbal and aware of their diagnosis, Participant Seven explained that it makes sense, “because the IEP is about him [the student].” All caregivers who talked about their child coming to the meeting and stating their needs to the team said that it was powerful for the school personnel to hear the child’s needs in their own words. Participant Four stated:

He’s been telling them what he thinks, what he wants, and what he knows. Basically, being his own advocate! The first time he was a little scared, so he finally got it that he could take a few minutes to get the thoughts together and then say what he wanted to say.

Participant 12 talked about the learning process to have her son at the IEP meeting. She gives him the choice of whether to attend. She finds it very valuable for him to learn to speak his needs and know that there is a team of people at the school who are there for him and support him. Some participants were clear that their child did not go to the IEP meetings and felt they did not have the capabilities to advocate for themselves. For some this was a cognitive or communication issue and for others the child simply did not want to attend. Participant 11 talked

about a situation in gym class where she was able to coach her son to talk to the teacher and resolve an issue. He needed help finding the language and courage to talk to the teacher, and Participant 11 helped by talking to the teacher as well. She felt this was a valuable experience for her son and was encouraged about his future seeing he was beginning to advocate for himself.

Child behaviors that do not relate to academics affect the way the child is treated at the school.

Ten caregivers talked about how their child's behavior and emotional reactions to stress affected their standing at school. In contrast to past literature (Sparks, 2007) it was clear that caregivers were confident in their knowledge of their child and accommodations needed for the behavioral and emotional issues. Participant Nine attributed their good experience to this "I think that part of it is that my child is well behaved and he's intelligent. So, I think they want to nurture that." However, the other nine participants who spoke about their child's behavior mentioned how it interfered with learning. Participant Five told how his son had been suspended seven times this year, interfering with his attending school and learning. Behaviors and maturity sometimes prevent the student from being involved even if they are intellectually capable.

Participant Eight, whose son loves science, stated:

Although he's still really only at about a fourth-grade comprehension level [in terms of emotional maturity], and that impacted his ability to take science classes. He can't take a mainstream science class because he doesn't have the comprehension for the safety things for some of the experiments they do...

Five participants talked about the stress and anxiety that their child faced. For Participant Two, the school was understanding:

When we see issues coming up at home, we're always (I think this is a critical piece for us that has been really successful)... when we see something at home, we've always been

able to figure out a way to explain it to the school for them to understand how it's impacting his education.

Other participants described how the school would not address the anxiety because it was not impacting the child's academics. Participant Eight described an unfortunate bullying incident instigated by the bus driver that caused her son to begin hiding his anxiety from school personnel. Three other caregivers described how bullying affected their child.

The processes of communicating with the school and going to IEP meetings is a very difficult and emotional one.

Twelve participants talked about their emotional reactions to these processes. Four participants talked about both positive and negative emotions, seven talked about only negative emotions, and only one talked only about positive emotions. Most participants talked about the stress and anxiety, which we have seen in caregivers in many other situations and facets of life (e.g. Al-Farsi et al., 2016; Bitsika & Sharpley, 2004; Dabrowska & Pisula, 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007). Participant Six stated:

I mean, it was a positive in the end, but honestly, I probably stressed myself out and worried myself and got myself sick like half that season. And anyway, lost weight just because of emotional eating and emotional stress.

Some talked about anger, anticipation, frustration, confusion, disappointment and the feeling of being overwhelmed. Many of these feelings are similar to what a caregiver experiences when they first learn of their child's diagnosis of ASD (Fleischmann, 2004). Participant Ten talked about how intense these emotions were during the IEP meeting: "I would dread meetings; I would go into meetings shaking." Those who talked about positive feelings expressed that they knew their experience wasn't like others they had heard. Participant Nine said, "We've had a

very positive experience, but I can't say that it's the same for all School Districts. This school district has been phenomenal." Participants also indicated that even when the process goes well, it is still emotional and stressful. Participant 12 explained:

I think it's such a personal and worrisome topic and you're so concerned about all of it and that you can get very intense about things or angry when something doesn't go the way it should have gone... My husband and I both try to go [to IEP meetings] when we can and it's collaborative and it's great and it's still incredibly stressful.

Participants suggested that you recognize the emotion, seek out support, and don't schedule anything else important for big meeting days. In addition, a few participants recommended keeping those emotions to yourself and not sharing them with the school personnel. Participant Seven expressed how she was unable to do this and she "just let the vice principal have it, and he hasn't spoken to me or looked at me since." Participant 12 plans ahead now if she knows she will be getting sensitive information. She asks for it ahead of time, so that if she is going to have an emotional response, she can have it at home without everyone seeing.

Succeeding in the processes of communicating with the school and going to IEP meetings requires sacrifice.

Eight participants mentioned sacrifices they made as a caregiver to make sure that their child succeeded in middle school. Several parents talked about financial concerns and effects on their careers. Mental disorders, such as ASD, have been identified as the costliest set of childhood disorders (Thomas et al., 2016). Participant Eight reported that her husband had several tempting job offers they had to turn down because moving schools was not feasible. Participant One stated, "Its hard because I've had to put a lot of stuff in my life on hold. I want to finish my degree." The amount of time she had to commit to communicating with the school and

advocating for her child interfered with her finishing her career and changing jobs. A different job may not provide the flexibility needed if she had to pick her son up unexpectedly. She stated, “I know I need to get a better job and make more, but this for the situation right now works out good.” Participant 11 described her time commitment as follows:

As a parent, what is challenging is like just helping him manage all the things. And then every day it would be like, okay, I’m going to check Google Classroom. I’m going to check the homework page and then I’m also going to check Infinite Campus. And it just ends up being kind of a lot.

Another sacrifice is physical and mental health. Past research has also looked at caregiver burden stress affecting the health of the caregiver (Cadman et al., 2012). Participant Six described how stress lead to sickness and weight loss. The amount of time caregivers spend managing communication with the school interferes with activities that reduce stress and self-care activities. Even parent support groups are limited in the amount of help they provide. Participant 11 described one group that did not offer childcare, “and so it’s like a room filled with parents with kids with autism and nobody’s interacting because we’re focused on our children.”

School personnel have a huge impact on how the process of communication goes.

Twelve participants talked about school personnel and how they impact the process. Past research has commented on how variant experiences are, citing school personnel as one reason for that (Kurth, Love, & Pirtle, 2020). Teachers have a particularly strong impact, as mentioned by nine of the participants. Participant One explained, “depending on your school district and what kind of teacher you have, everyone has vastly different experiences. And not all of them are good.” Several participants mentioned special education teachers who went above and beyond

and used their own time to help the process. Participant Nine talked about how the school “bent over backwards” to help her son transition into middle school. She said:

The gifted teacher was the one that took him on the tour. She took from her personal time and took him on a littler personal tour with just he and I so that he can get his bearings inside of that building.

Caregivers seemed to have more difficulty communicating with mainstream teachers. Participant Three was frustrated by the lack of understanding, saying:

And I think the teachers themselves don’t have the training for a lot of the special needs children, even though they’re in a regular classroom. They don’t have the training to work with children who are on the Spectrum. That’s a big disadvantage, I think, for the teachers.

Participant Six expanded on this, talking about how they interacted with mainstream teachers during the IEP meeting. She said, “a lot of times you can tell they feel awkward during it.” She was frustrated by the lack of input from them; “they’re just there to read off her goals and new goals.”

Discussion

Themes

Accommodations

Caregivers had very strong opinions about what was needed for their child to succeed in middle school. Caregivers appreciated the impact of a correct placement or accommodation. The right accommodation for their child is the key to their child’s changes in behavior and academic performance. Although many parents felt that their child was not getting the correct accommodation, there was consistency between parents in that they knew what was best for their

child. Though teachers generally realize the importance of parent involvement (Bennett, 1997), there is often pushback when a parent tries to express what they think is best for their child. Parents know their child intimately and have valuable knowledge to share. The combination of school personnel's professional knowledge and the caregiver's family knowledge is a recipe for success; however, communication problems often prevent this collaboration. Parents expressed the sentiment, consistent with past literature that if they had to advocate, they were put in an adversarial position (Tucker & Schwarz, 2013).

Advice

Caregivers had advice for future parents who would go through the same process. As there was a great deal of information they "wished they knew" when they were going through the process, it is evident that the means to pass this advice along are not sufficient. Much of this advice centered around helpful ways to communicate with the school or information that parents should know. One participant mentioned that Pennsylvania has the state laws about education specifically written for the lay person to understand (The Rights Done Right: The Procedural Safeguards in Plain Language; PEAL Center). Resources such as this for each state would be useful for parents. In addition, parents must be able to find these resources. Many resources that are available seem to be accessed only by parents with higher levels of education and more financial resources (Gerkenmeyer et al., 2008). Many parents give or ask for advice via social media or support groups. These resources need to be developed and made more accessible to the population.

Advocacy

Most caregivers felt the need to advocate for their child. Many wanted to teach their child to advocate for themselves. Some saw advocating as a collaborative and communicative process

while others likened it more to fighting a battle. Past research suggests that parents often are put in a combative role if they try to advocate for their child (Tucker & Schwartz, 2013). It is natural for caregivers to try and avoid conflict with school personnel who are responsible for the care and education of their child. This could be due to a power dynamic where parents feel that administrators have more control over the situation than them. One participant stated that she knew she experienced privilege in this situation because she felt like in an equal in the room during IEP meetings due to her law degree. Many caregivers do not have this advantage and need supports that help them to feel like an equal.

Emotions

Caregivers were very emotional about the process but hid emotions from the school. One participant reported she would try to prepare herself before an IEP meeting if she thought she might be getting information that would make her feel emotional (e.g. a reassessment of her child). She wanted access to the information early so that she could have the emotional reaction privately, specifically not in front of the school personnel. Caregivers need a safe space to be able to share those emotions somewhere. This could be accomplished through supports such as a support group or individual/family counseling. Very little previous research has looked specifically into the emotional reactions of parents during IEP meetings and other communications with the school. This is an important area that could be further developed in future research.

Sacrifice

Caregiver burden and stress can have a negative impact on the individual (Myers, Mackintosh, & Goin-Kochel, 2009). Parents described making sacrifice in their personal lives, relationships, schooling, and careers to ensure that their child was taken care of. The sacrifices

were deemed necessary to the success of their child in school, but parents were not thanked or appreciated for the sacrifices. In fact, several seemed to feel that school personnel did not understand or respect these sacrifices. Consider Participant six who spent time and money advocating to get her child into special education. She was chastised by the school for these efforts. There is a clear need for compassion and care for caregivers who are making sacrifices not only from the school personnel but counseling professionals as well.

School personnel

Most caregivers described ways in which different school personnel affect their experience with the school. Similar to past literature (Kurth, Love, & Pirtle, 2020) experiences could be drastically different year to year based on the personality and approachability of the teacher. Other school personnel (principals, administrators, special education teachers or directors) were more stable throughout the child's time in middle school and often set the tone for how the child was treated by the teacher. Understanding in detail what type of school personnel and factors about the individuals make the experience better could have a significant impact on teacher or administrative training. Many parents in the current study and past literature (Tucker & Schwartz, 2013) felt that school personnel did not have sufficient training in ASD specifically. Adding training on ASD that includes what works in communicating with parents and students could be extremely beneficial to changing the climate of the educational system for these caregivers.

Implications

To ensure the results present a clear path of action, the implications are explained in terms of a multicultural competence framework. Ratts and colleagues (2015) revised the original model (Sue et al., 1982) to offer a framework that helps implement social justice competencies

into counseling theories, practice, and research. Aspirational competencies organize the findings and implications into a path that can be followed. These aspirational competencies include attitudes and beliefs, knowledge, skills, and action (AKSA).

Implications for Counseling Practice

Attitudes and beliefs. Counselors and Psychologists should see caregivers as collaborators and allies. Results from the current study about communication suggest that parents respond best when their opinions are respected and valued. Support provided by practitioners must be sensitive to the caregiver's time needs and childcare needs. Caregivers report a large time commitment for effective communication with the school and IEP support. In addition, seeking support is often hindered by lack of childcare. Parents of children with developmental disorders report that there is less community support available (Nachshen & Minnes, 2005). Practitioners who are organizing group support for caregivers of children with ASD need to be mindful of the caregiver's responsibilities in order to make them comfortable enough to learn and express their emotions.

Knowledge. The purpose of this research was to understand the experiences of caregivers of children with ASD when communicating with middle schools and going through the middle school IEP process. Parents described that the process is lengthy, time consuming, and often stressful. In addition, parents sometimes feel disempowered or helpless. Practitioners should be aware of the resources in the community that can aid families. This varies from state to state and sometimes even school to school. In Indiana, INSource is an extremely helpful resource that provides information about special education laws, emotional support via connections with other parents, and advocates who can help with the process.

Counselors should also develop knowledge of the process of the IEP and the current culture in educational settings. The basis for most IEP law is found in the Individuals with Disabilities Education Act (IDEA, 2004). Practitioners should be knowledgeable about this act. In addition, some states have more specific laws that must also be followed. IDEA guarantees four basic rights to children with disabilities that practitioners should understand: free appropriate education, education within the least restrictive environment, provision of supplementary aids and services, and requirement of an assessment to determine the child's needs.

Skills. Psychology practitioners can help in two main ways: providing information and providing emotional support (Woodman & Hauser-Cram, 2013). This means that practitioners must educate themselves on the legal rights of children in schools so that they can help pass this information on or translate it so the caregiver can understand. It is not within a practitioner's scope to provide legal advice for a client but suggesting when to seek it out may be. Practitioners must build their communication skills to talk to caregivers in a respectful and knowledgeable manner that shows an understanding of the situation.

Several of the participants in the current study mentioned that it was a positive experience for them to have someone to talk to about their experience who cared and wanted to understand. Practitioners are well suited to fill this need with skills they use in everyday practice. Empathy and sensitive listening are valuable to caregivers who often must hide their emotional reactions from their children and the schools. In addition, practitioners must understand the caregiver's experience of fighting for and advocating for what is best for their child from a position of less power.

Action. If a practitioner is looking to help an individual client with this process, they can use their social power and influence through letters or presence at IEP meetings. Practitioners can be helpful by helping the caregiver to locate and understand the information available.

To help at a local level, practitioners can help to disseminate information to both caregivers and school personnel. There is also a strong need for an accessible data base so that caregivers can find all the information they need in one trustworthy place. Parents can become easily overwhelmed trying to find the information they need. Often the information is written by lawyers or doctors and is not written at an accessible and understandable reading level.

Practitioners from across the country need to work together to identify and share resources and supports that are available per state and city. To disseminate knowledge to school personnel, practitioners can offer trainings on communication, working with children on ASD, and the experience of caregivers of children with ASD.

To help at a national level, practitioners can help to advocate for change in the current system. This could be done through legal advocacy (to update special education laws) or simply promoting awareness of the issues faced by caregivers of children with ASD. Getting involved with programs such as Autism Speaks or other advocacy/research programs about ASD can help to further the cause.

Implications for Schools

Attitudes and beliefs. Public schools have a legal responsibility to provide free and appropriate education for all students regardless of disability status (Individuals with Disabilities Education Act (IDEA), 2004). Often the “appropriateness” of the education is determined by accommodations made through an IEP or 504 Plan. However, it is clear that schools can meet these legal requirements without doing all that is best for the child and their family. Many

caregivers describe the school as doing “what is required by law” or “the bare minimum.” The attitude and culture in the education system needs to be changed to providing the highest standard of care as opposed to the minimum required.

The present study’s results make it clear that there needs to be a change in how schools talk with parents. Caregivers describe feeling “talked down to” or not included in the IEP. In both the current study and past research, many caregivers reported feeling excluded from the IEP process (Tucker & Schwartz, 2013). The past research suggests that parents were made to feel unknowledgeable about their child’s education (Sparks, 2007) and the current research suggests they feel ignored if they do have suggestions for their child’s education. As an institution, school personnel have an inherent power over caregivers. This is exacerbated if a parent does not have the education or communication skills to stand up for themselves. Parents expressed in the current study and in past literature (Tucker & Schwartz, 2013) that advocating for themselves becomes a negative confrontation.

Knowledge. School personnel need more in depth knowledge of working with children with ASD specifically. Teachers should receive more education and support for including children with ASD in their mainstream classes. Many parents heard from their child’s teacher that they felt they did not have the time, resources, or training necessary to do what was needed for the student. Caregivers in the current study and past literature (Tucker & Schwartz, 2013) report that their students’ teachers don’t have enough of an understanding of ASD and how to deal with it in the school.

Skills. School personnel need trainings on how to effectively and respectfully communicate with caregivers of children with ASD so their ideas are heard and valued. Caregivers in the current study report wanting to advocate and have a collaborative process with

the school personnel. In the past literature, parents report feeling excluded from the IEP process for their child (Tucker & Schwartz, 2013). A boost in the communication skills for school personnel could help

Action. To remedy this inequality, schools should provide education for parents on their legal rights and the process of creating an IEP or 504 Plan. In the current study and past literature, parents report the school is not transparent during the meetings and they are not made aware of their rights by the school (Loschen, 2015). Groups could be implemented that provide this information and talk about the process itself. One participant talked about an employee of the school (a parent mentor) whose job was to help her through the process. This person was very valuable in the IEP meetings and the caregiver felt they were able to help them act in the best interest of the student.

Implications for Caregivers

Attitudes and beliefs. Several participants mentioned that their attitude toward school personnel made a difference on how the process went. Caregivers who approach the IEP team as a collaboration, not a fight, tend to succeed more. Caregivers gave advice that they should be aware of their emotions surrounding their child and not blame the school or school personnel. For instance, some parents may still feel angry after receiving the diagnosis for their child (Ooi, 2016). If this anger is expressed in the caregiver's attitude toward the school, meetings will not go as well. In addition, it is important to understand the reason certain things aren't happening. One parent reported that she was angry with the school until she realized they wanted to help but were too understaffed and underfunded. Though she was still frustrated, she was able to redirect her energy in a way to create effective change.

Knowledge. Caregivers are confident in their knowledge about their child and what their child needs to succeed. However, they are often not able to express these because of their lack of knowledge of the IEP process and their child's legal rights. Caregivers should be familiar with the Individuals with Disabilities Education Act (IDEA, 2004) and the four basic rights it guarantees for children with disabilities: free and appropriate education, education within the least restrictive environment, provision of supplementary aids and services, and continuing assessment to determine the child's needs and progress. They should also know the laws specific to their state and any resources that are available in their state. In Indiana, INSource helps caregivers to understand the law and connects them with needed services.

Skills. Caregivers could benefit from assertiveness training and training in communication. They need to be able to communicate effectively with the school personnel about their child's strengths, deficits, and needs for aids and services. Many caregivers could benefit from being taught how to communicate these in a professional way that the school personnel will understand and respect. Caregivers in this study reported that they wanted to advocate for their child. It may be that if they do not have the training in how to effectively advocate and come off to school personnel as aggressive and dismissive of the considerations of the school. Training in these skills could help the caregivers share the knowledge they already have about their child and the ideas they have to help them succeed in school.

Action. Many of the participants suggested that parents should bond together and share knowledge, resources, and support. As the practitioner's responsibility is to make these resources available and to provide ways for them to share with each other, the caregivers' responsibility is to seek out these resources and use them. The process of getting an appropriate education for your child can be very stressful, time consuming, and require sacrifice from the guardian. The

most repeated advice for caregivers was to know what your legal rights and options are and to keep the lines of communication open. Parents can form groups (in person or virtually) to share resources. In addition, many parents feel they have “go out of their comfort zone” to advocate for their child and push for the accommodations that will help their child best succeed. Support groups can give the parents the courage and emotional support to continue doing this even when they begin to feel disheartened (Douma, Dekker, & Koot, 2006).

Implications for Research

Attitudes and Beliefs. Considering participants as co-researchers is an important attitude to continue this work. Many research studies see participants as a source of data or something separate from the research itself. If research is approached with an attitude of creating change and bettering situations, instead of simply collecting knowledge, we can get more in depth information about experiences and what the co-researchers need in the situation under study.

Knowledge. Researchers should approach their population of study with some prior knowledge about the population. For instance, working with caregivers of children with ASD, researchers should be aware of the high levels of stress in the population, the difficulties in obtaining childcare, and the flood of research requests received by this population, not only to gather information about them but about their children as well.

Skills. Researchers should build their skill in creating studies that eliminate bias of the researcher. Many quantitative studies have very specific research questions that do not allow the participants to fully participate in the study. Counseling skills such as reflecting, summarization, and open-ended questions are very valuable in a qualitative interviewing process. This helps the interview to be non-leading and give participants control over the direction of the study and the direction of the change that follows it.

Action. The current study looked in depth at one identified facet of life that families who have a diagnosis of ASD face. There are still many facets of life that have not been studied in individuals with ASD. In order to help the individuals and their caregivers, practitioners need a higher level of understanding of each of these facts. By reading the summaries of their experience and agreeing, participants expressed that they felt heard and understood after these interviews. They were able to provide clear direction of what they needed: instrumental and emotional support. However, these needs will change depending on the situation faced by the caregiver and individual with ASD. Research similar to this study focusing on other facets of the individual's life with ASD are needed to understand the challenging experiences for these families. Facets that could be studied include receiving the diagnosis of the child, problem behaviors, finding and affording services, the child starting kindergarten, stress related to creating the first IEP, the child growing into adulthood, the child learning to drive, romantic relationships of the child, and parents planning for their own death. Phenomenological research on more phases of life that caregivers of children with ASD face will benefit caregivers in multiple ways. By giving them the opportunity to explain their experience and talk about it we learn more about them and an underserved population has the chance to tell their story and feel valued.

We need research on the emotional experience of caregivers during IEP meetings. The results of the current study show that caregivers often feel the need to hide their emotional reactions from school personnel but does not tell us what would happens when these emotional reactions occurred during meetings or how the emotions get processed elsewhere. Emotions that are hidden or unexpressed could be adding to the caregiver burden or stress of the caregivers (Myers, Mackintosh, & Goin-Kochel, 2009).

In addition, research needs to be done on how the experience of communicating with the school varies between caregivers. From the limited sample in this study, researchers can surmise that there may be differences based on gender, age, socioeconomic status, and education level of the caregiver. Beyond that, research should be done to see if the supports designed help caregivers when they have access to them. Parents have identified needs (specifically better access to resources and information and emotional support; Douma, Dekker, & Koot, 2006), and research needs to be done to see what changes when parents are provided with these resources. In this way the research can affect real change in how caregivers communicate with the school.

Strengths and Limitations

The criteria for quality in qualitative research differ from the standard validity and reliability criteria used in quantitative research. Lincoln and Guba (1985) developed a gold standard for quality of the research and writing that has been accepted and used by many qualitative researchers. These criteria include credibility, transferability, dependability, and confirmability. In phenomenology, discerning researchers also look for intersubjective validity as a criterion for the value and quality of the research (Moustakas, 1994).

Credibility

In phenomenological terminology, credibility is also referred to as truth (Moustakas, 1994). A study that is credible represents some sense of reality (Savin-Baden & Major, 2013). In phenomenology, a study is true if it represents the truth of the participants (Moustakas, 1994). Within the study, this is accomplished by conducting a non-leading interview (Savin-Baden & Major, 2013). In this study, the researcher relied heavily on training in counseling psychology to ensure she was not leading participants. The questions to begin the interview were open and

encouraged the participants to share their experience in a broad sense without including the biases of the researcher. Follow up questions were asked based on what the participant was saying. The interviewer was conscious about not asking about themes she had noted with other participants unless the participant brought it up themselves. This was done by taking time to reflect before each interview. The researcher focused on being mindful and thinking about the participant as an individual with a separate story, not related to past participants. This practice is known as reflexivity (Savin-Baden & Major, 2013). The qualitative researcher is aware that their position and perspective shapes everything they do. To preserve the truth of the data, the researcher recognizes their perspective and shares it with their audience (Savin-Baden & Major, 2013). The current study aims to be transparent through the researcher-as-instrument section.

Another way to make sure that the data reflected the truth of the participants was through member checking (Savin-Baden & Major, 2013). Each Textual-Structural summary was sent to the participant to check for accuracy. Every participant responded to approve the summary. This is a significant strength of the research as many times in qualitative research there is difficulty in getting all participants to re-engage. Credibility could have been improved more if participants had read all invariant constituents and provided feedback on those. However, considering the high levels of stress and sacrifice the parents make for their children, this was determined to be too much of a burden on the population this study intends to help.

Transferability

Transferability refers to how much the results apply to situations elsewhere. This is similar to the concept of external validity in quantitative research (Savin-Baden & Major, 2013). The themes presented in the results are very clear about how many participants expressed each theme independent of each other. The interview was careful not to prompt themes as they began

to emerge, which means if a concept was brought up, it was independent of other participants. The themes that were brought up by more participants are more transferable than those that were brought up by fewer participants. For instance, every participant talked about their strong opinion about the accommodations that were appropriate for their child. This concept is highly transferable. The sample was primarily female and entirely non-Latinx white. The transferability of concepts to caregivers who do not identify as female or non-Latinx white is low. This is not necessarily a weakness to the study but does suggest a direction for future research.

Dependability

Dependability suggests that the research findings will endure over time (Savin-Baden & Major, 2013). The current study is dependent within the current legal context. The findings are within the context of a legal and educational system that follows the Individuals with Disabilities Act (IDEA, 2004). This requires schools to provide free and appropriate education to all students (IDEA, 2004). The current results suggest that following the law is not enough to reduce the stress of parents and ensure success for the students. If the laws surrounding special education change or the advocacy of professionals on behalf of parents of children with ASD causes a change in the system, these results will no longer fit in the current educational context.

Considering the severe distress and sacrifice caregivers face when they are working with their child in Middle School, we would hope that the context changes making these results no longer applicable. However, within the context that currently exists in the educational system, these results will persist over time.

Confirmability

Confirmability indicates the researcher has remained neutral during data analysis and interpretation (Savin-Baden & Major, 2013). This was done in the current study by including a

research team in the analysis process. The entire research team was comprised of students, so there were no perceived power differentials that would discourage the research team from disagreeing with the primary researcher's interpretation. The research team included two females and one male; however, all had been trained in counseling psychology through the same training program and live in the same region of the United States. This could skew the balance of the team as many of the critical thinking skills and opinions are culturally bound within the training and geographic location.

Intersubjective Validity

Intersubjective knowledge is needed to understand a phenomenon while staying committed to community as a way to verify knowledge and experience (Savin-Baden & Major, 2013). Phenomenologists recognize that an individual's experience is unique and intersubjective communication is needed to get as clear an understanding as possible of the other's experience (Moustakas, 1994). Intersubjective communication is the process of testing one's understanding of the other's experience (Moustakas, 1994). In the current study this was done through member checking. The participant shared their experience through the interview. During the interview, the primary researcher frequently checked their understanding of the participant's experience by asking follow up questions or summarizing what the participant had said. This is a common practice in counseling psychology to make sure that the therapist understands the experience the client is communicating. The primary researcher used these skills to enhance the understanding of the participant's experience. The process was reinforced when the Individual Textual-Structural summaries were sent to participants for verification.

Conclusion

Parents and caregivers of children with ASD face a great amount of stress that is qualitatively different than the stress of other parents and caregivers. The present study sought to understand and find ways to cope with one facet of life that causes stress for these caregivers. Caregivers of middle school children with ASD were interviewed and asked about their experience communicating with the school and with the IEP process. All caregivers described either some sort of accommodation that was provided for their child or an accommodation they wish their child could have had. These accommodations need to be based on the child's needs and tailored specifically to the child. In addition, all of the participants had advice for other caregivers with children in middle school. Caregivers value the advice they had been given and are anxious to help others. Most caregivers gave advice to keep open communication with the school and to educate themselves about resources and the IEP process.

Another important theme is advocating for their child. Most caregivers see this as their duty and a process of collaborating with other team members for the benefit of their child. Advocating was described as necessary for change and many caregivers hope their child will eventually be able to learn to advocate for themselves. Communication with the school and the way the child is treated at school are affected by both academic performance and child behaviors. In addition, the personality and communication style of the school personnel make a big difference in how communication and IEP meetings are handled.

Communicating with the school and going to IEP meetings is a very difficult and emotional process. There are both positive and negative aspects of it, however the most striking and dramatic emotion is the stress and anxiety. Caregivers explained that succeeding in the processes of communicating with the school and going to IEP meetings requires sacrifice and advocacy on their part.

Overall, the current study shows that caregivers of middle school children with ASD want advice from each other and need support and information from professionals who have the power to make change in these situations. Professionals who work with these families have an obligation to use the privilege they have to understand the inequalities and stress faced by caregivers and do something to change it. The current study suggests this can be done by making information more available to caregivers and helping them to advocate for their child specifically and change in the process generally. More research needs to be done on different facets of life that cause stress, the differences between caregivers when facing this stress, and how effective the interventions to reduce this stress are.

References

- Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbaty, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: A case-control study. *Neuropsychiatric Disease and Treatment, 12*, 1943-1951.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Aylaz, R., Yilmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: a qualitative study. *Sexuality and Disability, 30*, 395-406.
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post Autism diagnosis support group for parents. *Social Work with Groups, 33*, 69-83.
- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaption to their child with special needs. *Infants and Young Children, 16*, 184-200.
- Ben-Itzhak, E., Abutbul, S., Bela, H., Shai, T., & Zachor, D. A. (2016). Understanding one's own emotions in cognitively-able preadolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(7), 2363-2371.
- Bennett, T., Deluca, D., & Bruns, D. (1997). Putting inclusion into practice: Perspectives of teachers and parents. *Exceptional Children, 64* (1). 115 – 17.
- Ben-Zur, H. (2009). Coping styles and affect. *International Journal of Stress Management, 16*, 87-101.
- Bitsika V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Australian Journal of Guidance & Counseling, 14*, 151-161.

- Bitsika, V., Sharpley, C. F., Andronicos, N. M., & Agnew, L. L. (2017). What worries parents of a child with Autism? Evidence from a biomarker for chronic stress. *Research in Developmental Disabilities, 62*, 209-217.
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities, 25*, 533-543.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*, 184-198.
- Brown, S. P., Westbrook, R. A., & Challagalla, G. (2005). Good cope, bad cope: Adaptive and maladaptive coping strategies following a critical negative work event. *Journal of Applied Psychology, 90*, 792-798.
- Cadman, T., Eklund, H. Howley, D., Hayward, H., Clarke, H., Findon, J., ... Glaser, K. (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition to adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*, 879-888.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research, 20*, 1279-1294.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). Thousand Oaks, CA: Sage.

- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and down syndrome. *Journal of Intellectual Disability Research, 54*, 266-280.
- DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy, 58*, 543-550.
- Dykstra Steinbrenner, J. R., & Watson, L. R. (2015). Student engagement in the classroom: The impact of classroom, teacher, and student factors. *Journal of Autism and Developmental Disorders, 45*, 2392-2410.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657-671.
- Elmose, M., Trillingsgaard, A., Jorgensen, M., Nielsen, A. Bruhn, S. S., & Sorensoen, E. U. (2013). Follow-up at mid-school age (9-13 years) of children assessed for autism spectrum disorder before the age of four. *Nordic Journal of Psychiatry, 68*. 362-368.
- Fleishmann, A. (2004). Narratives published on the internet by parents of children with autism: What do they reveal and why is it important?. *Focus on Autism and Other Developmental Disabilities, 19*, 35-43.
- Floyd F. J., & Phillippe, K. A. (1993). Parental interaction with children with and without mental retardation: Behavior management, coerciveness, and positive exchange. *American Journal on Mental Retardation, 97*, 673-684.
- Forest, E. J., Horner, R. H., Lewis-Palmer, T., & Todd, A. W. (2004). Transitions for young children with autism from preschool to kindergarten. *Journal of Positive Behavior Interventions, 6*, 103-112.

- Gerkenmeyer, J. E., Perkins, S. M., Scott, E. L., & Wu, J. (2008). Depressive symptoms among primary caregivers of children with mental health needs: Mediating and Moderating Variables. *Archives of Psychiatric Nursing*, 22, 135-146.
- Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *SAGE Publications and The National Autistic Society*, 11, 489-501.
- Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400 (2004).
- Kochanska, G., Boldt, L. J., Kim, S., Yoon, J. E., & Philibert, R. A. (2015). Developmental interplay between children's biobehavioral risk and the parenting environment from toddler to early school age: Prediction of socialization outcomes in preadolescence. *Development and Psychopathology*, 27(3), 775-790.
- Kurth, J. A., Love, H., & Pirtle, J. (2020). Parent perspectives of their involvement in IEP development for children with Autism. *Focus on Autism & Other Developmental Disabilities*, 35(1), 36–46
- Kurth, J., & Mastergeorge, A. M. (2012). Impact of setting and instructional context for adolescents with autism. *Journal of Special Education*, 46. 36-48.
- López, J. M., Moreno-Rodríguez, R., Alcover, C., Garrote, I., & Sánchez, S. (2017). Effects of a Program of Sport Schools on Development of Social and Psychomotor Skills of People with Autistic Spectrum Disorders: A Pilot Project. *Journal of Education and Training Studies*, 5(8), 167-177.
- Loschen, R. S. (2015). Parents of children with autism: Empowerment issues related to school services. Unpublished Dissertation.

- Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: implications for interventions and social policies. *Development and Psychopathology*, 22, 3-16.
- MacLeod, K., Causton, J. N., Radel, M., & Radel, P. (2017). Rethinking the Individualized Education Plan process: Voices from the other side of the table. *Disability and Society*, 32, 381-400.
- Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670-684.
- Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research*, 49, 889-904.
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745-762.
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13, 695-705.
- Papageorgiou, V., & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, 4, 653-660.

- ParentFurther. (2018). Developmental overview: Ages 10-14. Minneapolis, MN: Search Institute. Retrieved from <<https://www.parentfurther.com/content/ages-10-14-developmental-overview>>
- Ratts, M. J., Singh, A. A., Nassar-McMillan, S., Butler, S. K., & McCullough, J. R. (2015). Multicultural and social justice counseling competencies. *American Counseling Association Governing Counsel*.
- Savin-Baden, M., & Major, C. H. (2013). *Qualitative Research: The essential guide to theory and practice*. New York, NY: Routledge.
- Slade, N., Eisenhower, A., Carter, A. S., & Blacher, J. (2018). Satisfaction with Individualized Education Programs among parents of young children with ASD. *Exceptional Children*, 84(3), 242–260.
- Sparks, K. R. (2007). Parent perspectives on the feasibility and effectiveness of the individualized education plan. *Dissertation*.
- Stanberry, K. (2018). Understanding Individualized Education Programs. Retrieved from: <https://www.understood.org/en/school-learning/special-services/ieps/understanding-individualized-education-programs>
- Thomas, K. C., Williams, C. S., deJong, N., & Morrissey, J. P. (2016). Examination of parent insurance ratings, child expenditures, and financial burden among children with autism: A mismatch suggests new hypotheses to test. *Pediatrics*, 137(Suppl 2), S186–S195.
- Tonnsen, B. L., & Hahn, E. R. (2015). Middle school students' attitudes toward a peer with Autism Spectrum Disorder: Effects of social acceptance and physical inclusion. *Focus on Autism and Other Developmental Disabilities*, 34. 262-274.

- Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health: A Multidisciplinary Research and Practice Journal*, 5(1), 3–14.
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19, 251-260.
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 57, 513-530.
- Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2014). Risk factors for bullying among children with autism spectrum disorders. *Autism: The International Journal of Research & Practice*, 18, 419-427.

APPENDICIES

Appendix A – Extended Literature Review

Appendix B – Demographic Data

Appendix C – Recruitment Materials

Appendix D – Informed Consent

Appendix E – Demographic Questionnaire

Appendix F – Interview Questions

Appendix A – Extended Literature Review

Autism Spectrum Disorder and its Effect on Families

Parents of children with autism spectrum disorder (ASD) face higher levels of stress than parents of children with other developmental disorders and parents of neurotypical children (Bitsika & Sharpley, 2004; Dabrowska & Pisula, 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; for cross-cultural collaboration see Al-Farsi et al., 2016). They often face this stress in ways that are not helpful to them (Gerkenmeyer et al., 2008). The stress can generally be relieved by social support (Cohen & Wills, 1985), higher empowerment in the parent (Fleischmann, 2004), or higher levels of resilience (Luthar & Cicchetti, 2000). This current review examines what is known about the parent's stress in different phases of life of the child's life (i.e. time of diagnosis, start of problem behaviors, finding and affording services for the child, the child starting kindergarten, creation of the first IEP, the child becoming an adult, and the parent planning for their own death) to introduce a deeper look into the stress experienced by parents of children with ASD when they are working with their child's school to create the first IEP. Only by looking deeply into each phase of life separately will service providers be able to provide individualized care for these parents who are facing such high levels of stress.

Stress, Anxiety, & Depression in Parents of Children with Autism Spectrum Disorder

Parents of children with ASD show higher levels of stress, anxiety, and depression than parents of children with other developmental disorders and parents of neurotypical children (Bitsika & Sharpley, 2004, Dabrowska & Pisula, 2010, Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; for cross-cultural collaboration see Al-Farsi et al., 2016). When parents of children with ASD were asked how their child with autism affected their and their family's lives, the most frequent theme throughout the accounts was stress (Myers, Mackintosh, & Goin-Kochel, 2009).

Evidence of this stress, previously measured only by self-report, has been corroborated using biological markers of chronic stress, showing that this stress contributes over time to negative health effects and increases in levels of depression and anxiety (Bitsika et al., 2017). While noting that raising a child with a developmental disorder raises the level of parenting stress, many other indirect effects are overlooked.

There are several psychological outcomes related to raising a child with ASD. Overall, maternal well-being is lower in mothers of children with autism than mothers of children with any other developmental disability, even when controlling for maternal education, child behavior problems, and the child cognitive level (Eisenhower, Baker, & Blacher, 2005). Mothers of children with autism perceived that their children were more likely to have a negative impact on the family and less likely than other children to have a positive impact on the family (Eisenhower et al., 2005). Caregiver burden in parents of children with ASD is positively related to unmet needs in social relationships, mental health problems, safety of self, and communication (Cadman et al., 2012). Parents often report being stretched beyond their limits and feel unable to cope with the demands that come with raising a child with ASD (Bitsika, Sharpley, & Bell, 2013). Parents of children with ASD also have negative experiences directly related to the problem behaviors of their children.

Children with ASD tend to have higher levels of problem behaviors than children with other developmental disorders, which increases the level of depression and decreases moral in mothers of children with ASD (Blacher & McIntyre, 2006). Comparing parents of children with different types of intellectual disabilities, Eisenhower et al. (2005) found that mothers of children with autism had the highest levels of maternal depression. Even though locus of control has been shown to mediate the relationship between parenting stress and both depression and anxiety in

parents of children with no developmental disorder, it fails to mediate the same relationship in parents of children with ASD (Hamlyn-Wright et al., 2007). This is likely because the type of stress faced by parents of children with ASD is chronic stress caused by a situation that the parents cannot have control over (the diagnosis of their child).

Middle School Children with Autism Spectrum Disorder

The experience of children with ASD in middle school is largely a mystery in the body of research. Most children diagnosed with ASD remain dependent on their family or other services and receive lower levels of education. Despite expectations however, the developmental course of ASD tends to be one of improvement. There is a lot of variability in outcomes for these children (Elmose et al., 2013). Much of this variability stems from the resources parents are able to obtain for their children throughout their schooling experience. There is a growing research base for early diagnosis and intervention but there is a definite lack in knowledge on how to serve these children once they are school aged (Dykstra Steinbrenner, & Watson, 2015). There is also a lack of knowledge about how adolescents with ASD learn academic skills both in special education and general education settings (Kurth & Mastergeorge, 2012).

In an observation of middle school children with ASD, students were jointly engaged approximately 25% of the time (which the authors admit may be an over-estimate), meaning they are engaged only about 7.5 hours out of a 30-hour school week (Dykstra Steinbrenner, & Watson, 2015). Students who know that one of their peers is diagnosed with ASD tend to have more negative attitudes towards that peer (Tonnsen & Hahn, 2015). This can make socialization (which tends to be difficult for children with ASD) even more difficult. Since children with ASD are at an increased risk for bullying (Zablotsky et al., 2014) parents tend to worry even more about their child's social skills as they progress through grade school.

Individualized Education Plan

Many parents of children with ASD collaborate with their school by creating an Individualized Education Plan (IEP). The Individuals with Disabilities Education Act (IDEA, 2004) requires that public schools create and follow an IEP for any child at their school who is receiving special education. The document is required by law and the school is legally bound to follow the stipulations put forth in the document. The IDEA requires an IEP to include a statement of the child's current level of performance at school, the child's education goals, services that the school will provide, modifications and accommodations for the child in class and in standardized tests, and a plan to measure the child's progress towards goals (Stanberry, 2018).

IEP Process

The process of creating an IEP can be very stressful for parents, especially if they do not know their child's legal rights. The IEP is created by an IEP team. This team includes the student's parents, at least one of the child's general education teacher, at least one of the child's special education teachers, a school psychologist, a school district representative, and the child (if they are over 16). Legally all these members of the team must contribute to the IEP. In addition, the parent has the right to invite others to the IEP meeting. Most often this includes an advocate, a health care professional, or a translator (Stanberry, 2018).

In addition to this first meeting, the IDEA requires the IEP team to review the IEP at least once a year. These meetings are to update the parents on the child's present level of performance (PLOP), update the school personnel on the parent's concerns for their child, and to make sure that the IEP is working for the child (Stanberry, 2018).

Dealing with High Levels of Chronic Stress

Parents of children with ASD face stress caused by a life-role that is typically unalterable; this is known as chronic stress. Stress is a construct that is difficult to define consistently due to the plethora of definitions from individuals and researchers alike. One definition is that it is “an aversive state in which reduction of the negative feelings or sensations is a potent motivator” (Baum, 1990, p. 661). Though these negative feelings typically come from negative events they can also be triggered by positive events. Though chronic stress is clearly different from acute stress, it is not clear what all the differences are. A defining difference between acute and chronic stress is that the event that causes the negative feelings is not a one-time event: it either occurs repeatedly or is a long-term situation that is not expected to change. Baum (1990) suggests that each time the experience is relived, either a new stress experience begins, or the same stress experience occurs again. No form of coping will make the stressor end or disappear. This suggests that some helpful ways of responding to acute stressors (e.g. problem solving) may not be adequate for responding to chronic stress since the stressor is not amenable to change.

There are effective ways to respond to chronic stress that mitigate the negative consequences of it. Couples raising a child with ASD who use positive dyadic coping (a process by which the couple works together to cope with the chronic stressor that one or both partners face) tend to show less biological markers of chronic low-grade systemic inflammation, which indicates stress and leads to increased health risks (Gouin et al., 2016). Parents who use problem-focused coping strategies (as opposed to emotion focused strategies) are happier day to day (Ben-Zur, 2009). One helpful type of coping for parents of children with ASD is reframing. Parents who consider their experience with their child as a threat or a loss have a lower quality of life and experience less self-fulfillment than those who view their experience as a challenge.

Engaging in social and family activities also strongly correlates to a higher quality of life (Cappe et al., 2011). Although there are some effective ways to respond to chronic stress, many people facing chronic stress cope in maladaptive ways.

Parents of children with autism often face their stress in ways that are not helpful to them. It is rare for parents of children with mental health needs to receive mental health services and resources to help address their needs as caregivers (Gerkenmeyer et al., 2008). Parents of children with ASD are less likely to use social and spiritual support, likely because parents of children with developmental disorders report that there is less community support available (Nachshen & Minnes, 2005). Mothers of children with developmental disabilities have rated denial as the most common way they cope with the stress of parenting (Woodman & Hauser-Cram, 2013). Compared to parents of children with Down Syndrome and parents of neurotypical children, the only difference in coping is less frequent use of social diversion in parents of children with ASD (Dabrowska & Pisula, 2010). Dispositional coping can be divided into problem-focused or emotion-focused types of coping (Brown, Westbrook, & Challagalla, 2005). Typically, parents of children with an ASD will use combinations of the forms of problem-focused and emotion-focused coping skills that are available to them. The combination of different types of coping skills and different responses to different types of stressors makes coping a complex process. Parents of children with an ASD who use more emotion-focused coping strategies are more likely to experience distress at work (Cappe et al., 2011). Many parents of children with ASD use avoidance styles of coping (an emotion focused way to cope), which has a strong relationship to negative affect (Ben-Zur, 2009). These conclusions lead researchers to ask what needs parents of children with ASD have and what can be done to meet these needs.

Needs of Parents of children with ASD

Parents of children with ASD need several different kinds of support. Most parents (67.4%) of children with intellectual disabilities report that they need at least three types of support and almost all (88.2%) report that they need at least of type of support. Types of support include: a friendly ear, information, activities for the child, respite care, practical or material help, child mental health care, and parental counseling, with the mostly frequently indicated need being a friendly ear. Many of these needs remain unmet, mainly because parents want to solve the problems themselves or don't know where to seek out help (Douma, Dekker, & Koot, 2006). Of these different types of support, parents of children with ASD tend to endorse some as more preferred than others.

Not every aspect of parenting a child with ASD is negative, and sometimes parents need a place where they can talk about and be accepted for the positive aspects of their child. In most narratives posted online by parents of children with ASD, positive aspects of coping with autism or of their child are presented. Parents tend to not be ashamed of their child and like to talk about their positive relationship with their children. One parent described her son as follows: "P is a very special and sweet little spirit. When he was just 2 ½ P was diagnosed with Autism. Despite his disability, P is a very integral part of our family and we wouldn't want him any other way. We feel so blessed and privileged to have P as part of our family" (Fleishman, 2004, p. 37). Parents find that autism creates odd situations where a smile tends to disarm one's sense of alarm. Parents also note that the experience of raising a child with ASD changes them (Fleischmann, 2004). This puts parents in a situation where they feel that their humor towards their situation or their understanding of the world is not understood by people who are not in the

same situation. One way parents can express themselves and feel heard is in a support group focused on emotional support and developing a sense of belonging.

Empowerment

Parents of children with ASD can face these stressors better if they are empowered (Fleischmann, 2004). The stress of raising a child with ASD results from an unchangeable situation (the child's diagnosis; a situation out of the parent's control). When faced with this chronic stress, the anxiety and depression resulting from it is not mediated by the parents' locus of control. Because the stress is unchanging, parents have the same levels of anxiety and stress whether they think of stress as internal or external to themselves. (Hamlyn-Wright et al., 2007). Instead, parents must work to increase their sense of empowerment. An increase in parental empowerment helps parents to view autism as a challenge that they can and will surmount (Fleishman, 2004). Parents who view the diagnosis as a challenge are more fulfilled and report a higher quality of life than parents who view the diagnosis as a loss (Cappe et al., 2011). Approximately one-half of narratives posted on the internet about children with autism relate to the parents increasing levels of empowerment (Fleishman, 2004). The increase in empowerment helps not only the parent but the child as well.

Parental empowerment has been studied in many different ways due to lack of consensus in a definition. It is defined as both a process and a state and as both an individual and group phenomenon. Empowerment is the reduction of powerlessness, gaining or developing power, the ability to influence other people and organizations, and attaining control over one's life. Empowerment can occur at three levels: service system, community political, and family (Koren, DeChillo, & Friesen, 1992). The service system level of empowerment pertains to how the parent obtains their own and their child's right to benefits, how services are used, and the level of

understanding with service providers. The community/political level of empowerment measures the perception of the structure of services in the community, the relationships or contacts with politicians, lobbying, assisting other families in gaining services, and an awareness of rights (Itzhaky & Schwartz, 2010). The family level pertains to the immediate situation at home (Koren et al., 1992).

Parental empowerment is positively related to a child's outcome in treatment (Taub, Tighe, & Burchard, 2001), parent's confidence in dealing with the mental health system (Bickman et al., 1998), child functioning (Resendez, Quist, & Matshazi, 2000), problem behaviors in the child, psychological well-being, positive parenting experience (Graves & Shelton, 2007), and adjustment problems (Taub et al., 2001) and negatively related to mental health issues in the parent. Knowing all these positive aspects of empowerment encourages practitioners to find ways to help parents increase their levels of empowerment. Empowerment can occur in different ways.

Social Support

The stress buffering model (SBM) states that in the presence of support, stressors (such as the chronic stress of raising a child with ASD) have less impact on parents' psychological wellbeing. This is a well-validated model (Vaux, 1988) that gives suggestions on how to help buffer the stress that parents of children with ASD are experiencing. A meta-analysis of studies using the SBM makes it clear that embeddedness in a social support network and access to social resources have beneficial effects on well-being (Cohen & Wills, 1985). Despite this, parents of children with ASD are less likely to use social support to cope than the adults in the general population (Tway et al., 2007). Parents of children with ASD report significantly less community

support and report feeling less understood by parents of children with other developmental disorders (Nachshen & Minnes, 2006).

One way for professionals to provide this social support is by facilitating parent support groups (PSG). Overall, parents who use PSG report being satisfied with them (Clifford & Minnes, 2013b). However, results are mixed in what way the groups are helpful. Many studies measure satisfaction but not changes in levels of stress, empowerment, or other outcome variables. Researchers conducting different studies have mixed results, sometimes reporting that participants of PSG do not show changes in well-being (parenting stress, anxiety, or positive perceptions) over time (Clifford & Minnes, 2013b) while other times reporting increases in self-concept and decreases in distress (Clifford & Minnes, 2013a). These studies have parents give their opinion whatever type of PSG they have attended at any time in the past, so the results are a conglomerate of all types of PSG from across the country. In one type of group, mothers of children with ASD were shown to have lower rates of depression after participating in a stress management program (Sevim, 2007). Most parents report that groups are helpful in that they meet other parents (89%), get to share their feelings (79%), receive information about their resources (68%), and receive information about their child's illness/disability (63%). Some parents (32%) report that groups are helpful because they get time away from home (Smith et al., 1994).

Resilience

Parents of children with ASD Resilience is positive adaptation despite adversity. Resilience refers to an individual's capacity to cope with stressors and to resist the harmful effects of future negative events. It is not an attribute or trait, but a dynamic process that involves exposure to adversity or stress and the manifestation of positive adjustment outcomes. This

means a person can increase or decrease their level of resilience with the proper supports.

Typically, internal locus of control and social support are protective factors that relate to higher levels of resilience. These protective factors can derive from three levels: community, family, or the individual (Luthar & Cicchetti, 2000).

In a study of parents of children with ASD attending parent support groups, resilience was shown to buffer against anxiety and depression, suggesting that despite the stress parents with higher levels of psychological resilience could combat the negative effects of it. This suggests that increasing resilience in parents will benefit them (Bitsika et al, 2013). Since resilience is associated with the availability of social supports (Bonanno et al., 2007), increasing social support through parent support groups may be one way to provide this. However, only surveying parents who were currently attending support groups limits the generalizability of these conclusions.

Phases of Life

While there is substantial evidence of higher levels of stress for parents of children with ASD than for parents of neurotypical children and parents of children with other disabilities, there is a gap in the literature to explain how that stress changes over the lifespan of the child (Ooi, 2016). Parents of children with ASD have different needs and face different challenges based on the phase of life their child is facing. Mothers and fathers do not differ in the problems they identify for their child with ASD, but these problems differ as a function of the child's age. Parents of older children tend to be more concerned about problems with self-help skills, self-occupation, and behavioral problems, while parents of younger children are more concerned about communication problems (Papageorgio & Kalyva, 2010). This review looks at the

information already gathered about different phases of life and seeks to deepen the description of parent's stress related to developing their child's first IEP.

Receiving the Diagnosis of the Child

Receiving the diagnosis of ASD for their child is a very emotional and stressful time for parents. When talking about their experience with their child online, almost every parent mentions the time they received the diagnosis (Fleischmann, 2004). When their child is first diagnosed with autism parents may experience distress, uncertainty, avoidance, and isolation. They may be preoccupied with guilt, anger, or unanswerable questions about who is to blame for the diagnosis. They will feel uncertain about what will happen to their child in the next stages of life. Often members of the medical community may appear insensitive and the parents may withdraw from family and friends if they feel they do not understand (Barnett et al., 2003). Anger is a common sentiment, due to resentment towards people who treat their situation as hopeless and health care professionals who do not present the diagnosis in a sensitive manner (Ooi, 2016). In one qualitative study, several parents of a child with autism expressed that they felt "robbed" when receiving the diagnosis (DeGrace, 2004). One parent said: "it kinda robs you of, any chance of having, you know, a real personal level of content inner satisfaction. It's kinda like a burden that's always, always hanging over you" (DeGrace, 2004, p. 546).

Although the results are mixed (see Clifford & Minnes, 2013a; Clifford & Minnes, 2013b) some parents who participate in support groups after receiving their child's diagnosis of ASD report increases in knowledge and levels of parental empowerment (Banach et al., 2010). Parents can decrease their stress and anxiety in this stage by reframing how they view the diagnosis. Cappe et al. (2011) and found that parents of children with an ASD who consider their experience with their child as a threat or a loss had a lower quality of life than those who

perceive it as a challenge. In addition, those parents who viewed their experience with their child as a challenge instead of those who perceive it as a loss experienced greater self-fulfillment. This stage is very emotional for parents and has received a lot of attention in research and treatment of parents. Often parents seek out this diagnosis because they notice certain negative behaviors in their child, which are also a source of stress.

Problem Behavior

Shortly after coming to terms with the ASD diagnosis (and sometimes before the diagnosis) parents and children begin dealing with any problem behaviors that come along with the disorder. Parents of children with ASD report that their child's development is not what they expected, with one of the main problems identified being behavioral problems (Midence & O'Neill, 1999). Parents of children with intellectual disabilities tend to spend more time than parents of children without disabilities issuing commands and working to gain compliance from their children. More of their time is spent in what are considered coercive parent-child interactions and in struggles to manage the child's behavior (Floyd & Phillippe, 1993). Negative themes that emerge when parents talk about their child's problem behavior are difficulty dealing with child's behavior problems, time demands for care and therapies, sleep problems and exhaustion, and struggles with schools and services (Myers, 2009). A child with ASD who has problematic behavior can increase the demands on the parent or caregiver, thereby increasing stress. Some behaviors common with children with ASD can be attributed to intolerance to changes in the environment and highly routinized behavior. Aggressive behaviors or uncontrollable and unpredictable tantrums are commonly experienced in response to changes in the environment or routine of the child. Aggressive behaviors may be directed toward the parents, siblings, or property. These difficulties are especially strong for inexperienced parents,

or parents whose first child is diagnosed with autism or who have just recently began experiencing the symptoms of ASD with their child (Ooi, 2016). Children with ASD tend to have higher levels of problem behaviors than children with other developmental disorders. This in turn is positively correlated with the level of depression in mothers and is negatively correlated to morale in mothers of children with ASD (Blacher & McIntyre, 2006).

In order to cope with these behaviors, parents adopt new coping strategies. Many strive to improve their knowledge through reading books, conversing with other parents, and using the Internet. Coping with these behaviors improves over time. Some strategies parents use to cope with their child's problem behaviors include hypervigilance of the environment and the child's responses, anticipation of difficulties, preplanning of responses and preparation of the child to prevent challenging behaviors from occurring when switching between environments. In addition, adopting a fixed routine, role playing the transition, and providing warnings were found to be effective to cope with behaviors triggered by changes in the environment or plan. Another significant way to cope with the behaviors is to find treatment services for their child (Ooi, 2016).

Finding and Affording Services.

Because there are so many different treatment options available for ASD (e.g. applied behavior analysis, talk therapy, animal assisted therapy, medications, etc.) it can be very confusing for parents to find the right ones for their child and get access to them. Banach et al. (2010) suggest that PSG could be strengthened by discussing specific intervention approaches for working with children with ASD. Seeing behavioral improvement in their child as a result of participating in services provides hope for the parents which in turn helps them to cope (Ooi, 2016). Services are often restricted by insurance coverage or what is available in the nearby

community. Some parents report moving to a new city or state for the purpose of getting access to desired services for their child. Some parents reported going into debt to pay for the many types of therapies and medications needed for their child (Myers, 2009).

Child Starting Kindergarten

Parents of children with ASD face more concerns than parents of children with other developmental disabilities when preparing their child for kindergarten. Preschool teachers also report higher concerns and overall involvement when transitioning a child with ASD to kindergarten as opposed to children with other developmental disabilities. This stage is important because it is the beginning of more academically oriented time, as opposed to the more play-based early childhood education (Quintero & McIntyre, 2010). The transition is perceived by parents as a central event in the education of their child (Forest et al., 2004). The transition can be difficult as Rimm-Kaufman & Pianta (1999) demonstrated in a longitudinal and cross-sectional study. The rates and characteristics of communication between parents and teachers changes from pre-school to kindergarten. Often the communication between parents and teachers prior to kindergarten is more positive, while in kindergarten there is less contact overall, but more negative parent-teacher contact (Rimm-Kaufman & Pianta, 1999).

Forest et al. (2004) outlined a suggestion for parents on how to make the transition easier. It outlines each of the tasks that parents and children face during the transition into kindergarten. Parents of children with ASD express many different concerns related to this transition. One year before the transition parents attempt to identify one individual at the new school as a transition contact person, create a timeline for the transition, identify related services for their child, and start to build a team. In the next six months parents try to arrange classroom visits at multiple sites, select a kindergarten program, and develop specific educational goals to make sure the

child has the skills required for the next year. In the six months prior to the transition parents try to arrange a time where the current preschool can visit the kindergarten classroom and the future kindergarten teacher can visit the current preschool classroom. This requires more effort and time on the part of both teachers and can be difficult to arrange. During this time the parent also has the child visit the kindergarten classroom, identifies the curriculum for kindergarten, creates a daily schedule, and coordinates all the related services. Even after the transition, most parents feel it is highly important to evaluate the transition process for a time (Forest et al., 2004).

Stress Related to Creating the First IEP

Every child in the United States with a disability has the right to an appropriate public education at no cost to their families (Individuals with Disabilities Education Act [IDEA], 2004). To meet these needs, the school and parents work together to develop an Individualized Education Plan (IEP). The IEP includes accommodations needed for the child to succeed in school and can also include related services (e.g. outside therapy) that the child needs to be able to learn. The school is then responsible for providing these services. The IDEA also states that children with disabilities must be educated in the least restrictive environment (LRE), meaning whenever possible they should attend the same classes they would if they did not have a disability and be in classes with their non-disabled peers. The school is legally obligated to keep the parents informed and give parents meaningful opportunities to be involved in their child's education process.

Typically, this involvement consists of attending and advocating for their child at the annual IEP meeting. Each meeting should cover the child's current level of performance, annual goals for the child, and the individualized supports and services that can help the child reach the goals. The team that meets to develop and update the IEP consists of the parents, at least one

general education teacher, at least one special education teacher, a school district representative, a school psychologist, and the child the plan is being developed for (when appropriate). By law, parents are equal partners on their child's IEP team. The IDEA states that the IEP team cannot change the child's placement (where and how the child will be taught) without giving the parent a chance to challenge that change. However, parents often feel like outsiders during this process (Macleod et al., 2017).

Given the school's legal responsibility for individualized education (IDEA, 2004) it might be expected that the school provides support for parents of children with disabilities to navigate this complex procedure. However, this is often not the case (Banach et al., 2010). Parents report the school is not transparent during the meetings and they are not made aware of their rights by the school (Loschen, 2015). In an interview with 12 parents of children with autism, all parents stated they could not find a suitable place for their child's education, the teachers were not effective in producing any behavioral change, and the time spent for education was too short. One father stated, "my child is getting older, there is no school where I can take him, I don't know what to do, these children need education just like other children" (Aylaz, Yilmaz, & Polat, 2012, p. 401). Another parent reported, "public school has been a nightmare. We have had to fight for everything we've gotten for him.... I was called nearly every day by the school because of behavior issues" (Myers et al., 2009, p. 676).

There is a significant lack of research on what is helpful for parents during this stressful time which the researcher hopes to address with the present study. Adding information about approaching the IEP to the curriculum of PSG has been shown to be helpful to parents. After a group including this information, empowerment in the family, service system, and community/political levels increased (Banach et al., 2010). This study did not compare groups

without this information, so it is unclear if the gains are related directly to the inclusion of the information about approaching the IEP. Beyond this there is a lack of suggestions on what the parents perceive their own needs to be currently or what is helpful from professionals.

Child Becoming an Adult

Caregivers of children with ASD have very high levels of burden during the transition through adolescence and adulthood. These levels are comparable to or higher than caring for individuals with serious medical disorders. The parent's perception of their level of unmet needs significantly predicts the amount of burden the parent experiences, even when controlling for the symptoms and severity of the ASD. Some of these unmet needs include social contact, appropriate daytime activities, safety of self, and communication (Cadman et al., 2012). Parents report wanting their child to have an independent life, most reporting their hopes as positive and realistic (Midence & O'Neill, 1999). One parent described their mixed feelings on their child's future, "Now I think about his future, his education. I would like him to live independently but we have to be practical. I don't think parents want to know about the future, you have too much on your plate" (Midence & O'Neill, 1999, p. 282). Parents may fail to provide their child with needed information about sexual behavior (using birth control, social aspects of dating, etc.) because they cannot imagine a future where their child has a partner (Ballan, 2012). Cadman et al. (2012) suggest that providing autism-specific services that target ASD and comorbid conditions are lacking and may be useful in reducing this burden.

Parents Planning for their own Death

The high dependency of children with ASD on their parents tends to raise concerns of the time they are no longer able to care for their child (Ooi, 2016). Parents tend to report their biggest worry is what would happen to their child and who would look after them. In an

interview, one mother stated, “Who will look after this child when I die? I don’t have any sister, mother or father around, they are now, but they won’t be. I’m afraid that he will wonder around and be abused” (Aylaz et al., 2012, p. 400). Parents also express the sentiment that they do not expect a good or exemplary life for their child, they simply hold a hope that they can survive.

Another mother said, “We don’t expect our child to become a doctor or a teacher, it is enough for us if he could do his own work and buy a loaf of bread” (Aylaz et al., 2012, p. 401).

Conclusion

Parents of children with ASD do not have sufficient support to face the high levels of stress that come with this role (Twyo et al., 2007). For professionals to be able to provide this support it is essential that they understand the different phases of life children with ASD face and how each one impacts the parents. Some phases of life (such as the diagnosis of the child and the problem behaviors) have been studied in depth while others (such as the development of the IEP and parents planning for their own death) are mentioned in qualitative studies of general stress faced by parents of children with ASD but not examined deeply on their own. There is a need for researchers to focus in on each of the stages that is not understood, and this author seeks to do so with the current study for the development of the IEP. This examination of the stage of developing the IEP seeks to provide guidance for behavioral health professionals treating parents in this stage and provide a model for studying other stages.

References

- Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbaty, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: A case-control study. *Neuropsychiatric Disease and Treatment, 12*, 1943-1951.
- Aylaz, R., Yilmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: a qualitative study. *Sexuality and Disability, 30*, 395-406.
- Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*, 676-684.
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post Autism diagnosis support group for parents. *Social Work with Groups, 33*, 69-83.
- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaption to their child with special needs. *Infants and Young Children, 16*, 184-200.
- Baum, A. (1990). Stress, intrusive imagery, and chronic distress. *Health Psychology, 9*, 653-675.
- Ben-Zur, H. (2009). Coping styles and affect. *International Journal of Stress Management, 16*, 87-101.
- Bickman, L., Helflinger, C. A., Northrup, D., Sonnichsen, S., & Schilling, S. (1998). Long term outcomes to family caregiver empowerment. *Journal of Child and Family Studies, 7*, 269-282.
- Bitsika V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Australian Journal of Guidance & Counseling, 14*, 151-161.

- Bitsika, V., Sharpley, C. F., Andronicos, N. M., & Agnew, L. L. (2017). What worries parents of a child with Autism? Evidence from a biomarker for chronic stress. *Research in Developmental Disabilities, 62*, 209-217.
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities, 25*, 533-543.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*, 184-198.
- Bonanno, G. A., Galea, S, Bucciarelli, A., & Vlahoz, D. (2007). What predicts psychological resilience after disaster? The role of demographics, resources, and life stress. *Journal of Consulting and Clinical Psychology, 75*, 671-682.
- Brown, S. P., Westbrook, R. A., & Challagalla, G. (2005). Good cope, bad cope: Adaptive and maladaptive coping strategies following a critical negative work event. *Journal of Applied Psychology, 90*, 792-798.
- Cadman, T., Eklund, H. Howley, D., Hayward, H., Clarke, H., Findon, J., ... Glaser, K. (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition to adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*, 879-888.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum

- disorders and in the development of relevant support and assistance programmes. *Quality of Life Research*, 20, 1279-1294.
- Clifford, T., & Minnes, P. (2013a). Who participates in support groups for parents of children with Autism Spectrum Disorders? The role of beliefs and coping style. *Journal of Autism and Other Developmental Disorders*, 43, 179-187.
- Clifford, T., & Minnes, P. (2013b). Logging on: Evaluating an online support group for parents of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43, 1662-1675.
- Cohen, S., & Wills, T. A. (1995). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and down syndrome. *Journal of Intellectual Disability Research*, 54, 266-280.
- DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy*, 58, 543-550.
- Douma, J. C. H., Dekker, M. C., & Koot, H. M. (2006). Supporting parents of youths with intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research*, 50, 570-581.
- Dykstra Steinbrenner, J. R., & Watson, L. R. (2015). Student engagement in the classroom: The impact of classroom, teacher, and student factors. *Journal of Autism and Developmental Disorders*, 45, 2392-2410.

- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657-671.
- Elmose, M., Trillingsgaard, A., Jorgensen, M., Nielsen, A. Bruhn, S. S., & Sorensen, E. U. (2013). Follow-up at mid-school age (9-13 years) of children assessed for autism spectrum disorder before the age of four. *Nordic Journal of Psychiatry, 68*. 362-368.
- Fleishmann, A. (2004). Narratives published on the internet by parents of children with autism: What do they reveal and why is it important?. *Focus on Autism and Other Developmental Disabilities, 19*, 35-43.
- Floyd F. J., & Phillippe, K. A. (1993). Parental interaction with children with and without mental retardation: Behavior management, coerciveness, and positive exchange. *American Journal on Mental Retardation, 97*, 673-684.
- Forest, E. J., Horner, R. H., Lewis-Palmer, T., & Todd, A. W. (2004). Transitions for young children with autism from preschool to kindergarten. *Journal of Positive Behavior Interventions, 6*, 103-112.
- Gerkenmeyer, J. E., Perkins, S. M., Scott, E. L., & Wu, J. (2008). Depressive symptoms among primary caregivers of children with mental health needs: Mediating and Moderating Variables. *Archives of Psychiatric Nursing, 22*, 135-146.
- Gouin, J. P., Scarcello, S., da Estrela, C., Paquin, C., & Barker, E. T. (2016). Dyadic coping and inflammation in the context of chronic stress. *Health Psychology, 35*, 1081-1084.
- Graves, K. N., & Shelton, T. L. (2007). Family empowerment as a mediator between family-centered systems of care and changes in child functioning: Identifying an important mechanism of change. *Journal of Child & Family Studies, 16*, 556-566.

- Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *SAGE Publications and The National Autistic Society, 11*, 489-501.
- Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400 (2004).
- Itzhaky, H., & Schwarz, C. (2010). Empowerment of parents of children with disabilities: The effect of community and personal variables. *Journal of Family Social Work, 5*, 21-36.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321.
- Kurth, J., & Mastergeorge, A. M. (2012). Impact of setting and instructional context for adolescents with autism. *Journal of Special Education, 46*. 36-48.
- Loschen, R. S. (2015). Parents of children with autism: Empowerment issues related to school services. Unpublished Dissertation.
- Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: implications for interventions and social policies. *Development and Psychopathology, 22*, 3-16.
- MacLeod, K., Causton, J. N., Radcl, M., & Radcl, P. (2017). Rethinking the Individualized Education Plan process: Voices from the other side of the table. *Disability and Society, 32*, 381-400.
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *SAGE Publications and the National Autistic Society, 3*, 273-285.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has

- affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670-684.
- Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research*, 49, 889-904.
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745-762.
- Papageorgiou, V., & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, 4, 653-660.
- Quintero, N., & McIntyre, L. L. (2010). Kindergarten transition preparation: A comparison of teacher and parent practices for children with Autism and other developmental disabilities. *Early Childhood Education Journal*, 38, 411-420.
- Resendez, M. G., Quist, R. M., & Matshazi, G. M. (2000). A longitudinal analysis of family empowerment and client outcomes. *Journal of Child and Family Studies*, 9, 449-460.
- Rimm-Kaufman, S. E., & Pianta, R. C. (1999). Patterns of family-school contact in preschool and kindergarten. *School Psychology Review*, 28, 426-438.
- Sevim, B. (2007). The effects of stress management program for mothers of children with Autism (unpublished master's thesis).
- Smith, K., Gabard, D., Dale, D., & Drucker, A. (1994). Parent opinions about attending parent support groups. *Children's Health Care*, 23, 127-136.

- Stanberry, K. (2018). Understanding Individualized Education Programs. Retrieved from:
<https://www.understood.org/en/school-learning/special-services/ieps/understanding-individualized-education-programs>
- Taub, J., Tighe, T. A., & Burchard, J. (2001). The effects of parent empowerment on adjustment for children receiving comprehensive mental health services. *Children's Services: Social Policy, Research, and Practice, 4*, 103-122.
- Tonnsen, B. L., & Hahn, E. R. (2015). Middle school students' attitudes toward a peer with Autism Spectrum Disorder: Effects of social acceptance and physical inclusion. *Focus on Autism and Other Developmental Disabilities, 34*, 262-274.
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners, 19*, 251-260.
- Vaux, A. (1988). Social support: Theory, research, and intervention. New York, New York: Praeger Publishers.
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research, 57*, 513-530.
- Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2014). Risk factors for bullying among children with autism spectrum disorders. *Autism: The International Journal of Research & Practice, 18*, 419-427.

Appendix B – Demographic Data

	1	2	3	4	5	6	7	8	9	10	11	12	13	Mean	Median	Mode
Age	37	50	58	52	50	38	36	47	49	38	47	40	40	44.77	47	50
Race	non-Latin x White			non-Latin x White												
Gender	Female	Female	Male	Female			Female									
Child Age	12	14	12	12	12	13	13	12	12	15	12	14	13	12.77	12	12
Child Gender	Male	Male	Male	Male	Male	Female	Male	Male	Male	Female	Male	Male	Male			Male
Child Grade	6	8	7	6	6	7	7	6	6	8	6	7	7	6.69	7	6
Participant's Relationship to Child	Mother	Mother	Father	Grandmother	Mother			Mother								

Appendix C – Recruitment Materials

Flyer:



Research Study

Experiences of Caregivers of Middle School Children with
Autism Spectrum Disorder in Communicating with their Child's School
IRB Approval Number: 1413033

Hello! Do you have a 7th or 8th grader with Autism? I would love to interview you on your experiences communicating with the school and navigating the IEP (Individual Education Plan) process. Hopefully the finished product will help professionals help parents like you who are experiencing the same thing.

If you choose to participate, you'd fill out a short survey (10-15 minutes) and then talk with me about your experiences (20 min- 1hr) either in person or over Skype. You'll get to choose between a \$10 gift certificate or having \$10 donated to an Autism charity of your choice.

If you wish to participate or have any questions, please contact me (Grace Yoder) by email at gmyoder@bsu.edu or call me at 765-749-9006.
Can't wait to talk with you!

Facebook Post:

Hello! Do you have a 7th or 8th grader with Autism? I would love to interview you on your experiences communicating with the school and navigating the IEP (Individual Education Plan) process. Hopefully the finished product will help professionals help parents like you who are experiencing the same thing.

If you choose to participate, you'd fill out a short survey (10-15 minutes) and then talk with me about your experiences (20 min- 1hr) either in person or over Skype. You'll get to choose between a \$10 gift certificate or having \$10 donated to an Autism charity of your choice.

Please e-mail me (gmyoder@bsu.edu) or call me (765-749-9006) if you have any questions or are interested in being interviewed!

Can't wait to talk with you!

Project Title: Experiences of Caregivers of Middle School Children with Autism Spectrum Disorder in Communicating with their Child's School
Ball State IRB Approval Number: 1413033

E-mail through Ball State Communication Center:

Hello! Do you have a 7th or 8th grader with Autism? I would love to interview you on your experiences communicating with the school and navigating the IEP (Individual Education Plan) process. Hopefully the finished product will help professionals help parents like you who are experiencing the same thing.

If you choose to participate, you'd fill out a short survey (10-15 minutes) and then talk with me about your experiences (20 min- 1hr) either in person or over Skype. You'll get to choose between a \$10 gift certificate or having \$10 donated to an Autism charity of your choice. 😊

Please e-mail me (gmyoder@bsu.edu) or call me (765-749-9006) if you have any questions or are interested in being interviewed!

Can't wait to talk with you!

Project Title: Experiences of Caregivers of Middle School Children with Autism Spectrum Disorder in Communicating with their Child's School
IRB Approval Number: 1413033

Researcher Contact Information

Principal Investigator:
Grace Yoder, Graduate Student
Counseling Psychology- Ball State University
Muncie, IN 47306
Email: gmyoder@bsu.edu

Faculty Supervisor:
Dr. Molly Tschopp, PhD, HSPP
Counseling Psychology Ball State University
Muncie, IN 47306
Email: mtschopp@bsu.edu

E-mail through Ball State Programs:

Hello!

My name is Grace Yoder. (REPRESENTATIVE) has agreed to send out this e-mail so I could get in touch with you. I'm a student at Ball State, working to get my doctorate in Counseling Psychology. I'm doing some research on parents of children in middle school with Autism, and I would like to interview you on your own experiences communicating with the school and navigating the IEP (Individual Education Plan) process. Hopefully the finished product will help professionals help parents like you who are experiencing getting their child through middle school.

This has nothing to do with your/your child's involvement in (PROGRAM) and it is completely up to you if you want to participate. If you choose to participate, you'd fill out a short survey (10-15 minutes) and then talk with me about your experiences (20 min- 1hr). We would meet on Ball State Campus in the Practicum Counseling Center.

Please e-mail me (gmyoder@bsu.edu) or call me (765-749-9006) if you have any questions or are interested in being interviewed!

Thank you so much!!!

Grace

Appendix D - Informed Consent

Study Title Experiences of Caregivers of Middle School Children with Autism Spectrum Disorders
Study # 1413033

Study Purpose and Rationale

I am doing this study so that counselors and other professionals can understand what it is like for you to communicate with the school while your child with Autism Spectrum Disorder (ASD) is in middle school. I'm hoping this will lead to more research that will provide resources to other parents going through this experience.

Inclusion/Exclusion Criteria

To participate in this research, you must be 18 years or older and be the primary caregiver of a child with a confirmed diagnosis of Autism Spectrum Disorder (ASD) who is enrolled in grade 7 or 8 or will be during the next school term. Your child must be currently living with you and attending public school.

Participation Procedures and Duration

To participate in this study, you will first read this document and ask any questions you have to the researcher. If you would like to participate, you will review this form and be given a survey to fill out about your family especially your child with Autism. The researcher will then ask you to describe your experience with your child's school. It will take around 10-15 minutes to fill this out the survey and the talk will last between 20 minutes to an hour and will be video recorded. This can either be done in person at the Ball State Practicum Counselling Center or online via Skype. You will also be asked to provide a way to contact you at a later date. Within the next 6 months, the researcher will contact you with a summary of the information you provided. You will be asked to meet with the researcher, read or listen to this summary, and provide any feedback to make the summary more accurate to your experience. The second meeting will last about 30 minutes, making your total participation time between 1-2 hours. For your participation, you can choose between a \$10 gift card or having \$10 donated to the Autism charity of your choice.

Audio Tapes

The interview process will be audio recorded. These recordings will be kept until my date of graduation (August 2021) then deleted. The recordings will be stored on a password protected computer and only my advisor and I will have access to them.

Data Anonymity

All data will be maintained as confidential and no identifying information such as names will appear in any publication or presentation of the data.

Storage of Data and Data Retention Period

The data will be stored on a password protected online storage system. Only my advisor and I will have access to it. The videos of your interview will be transcribed, have any information that identifies you taken out, and deleted by August 2021. The transcriptions and questionnaires

without your personal information will be kept indefinitely in case people have questions about the research or I want to learn more about your experiences as a parent.

Risks or Discomforts

There are no perceived risks for participating in this study.

Benefits

There are no direct benefits to you for participating in this study. You will have the chance to talk about your experience with your child's school. If you found this type of conversation helpful feel free to contact the Ball State Practicum Counseling Center (765-285-8047) for low cost counseling (at your own expense) to explore this issue further. You are also more than welcome to contact other counseling centers or ask the researcher for recommendations. A counselor will be able to help you process this experience and deal with any repercussions from it more than we can in this short conversation.

Voluntary Participation

Your participation in this study is completely voluntary and you are free to withdraw your permission at any time for any reason without penalty or prejudice from the investigator. This study is in no way connected with your child's school or treatment so your choice to participate or not will not affect your child's standing at the school or treatment facility. Please feel free to ask any questions of the investigator before signing this form and at any time during the study.

IRB Contact Information

For one's rights as a research subject, you may contact the following: For questions about your rights as a research subject, please contact the Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5052 or at orihelp@bsu.edu.

Study Title Experiences of Caregivers of Middle School Children with Autism Spectrum Disorders
Study # 1413033

Researcher Contact Information

Principal Investigator:
Grace Yoder, Graduate Student
Counseling Psychology- Ball State University
University
Muncie, IN 47306
Email: gmyoder@bsu.edu

Faculty Supervisor:
Dr. Molly Tschopp, PhD, HSPP
Counseling Psychology- Ball State
University
Muncie, IN 47306
Email: mtschoop@bsu.edu

YES NO

11. What classes are they taking?

12. What are typical grades for your child?

13. Do you think your child will be able to drive when they turn 16? Later in life?

14. What do you see your child doing after high school?

15. Does your child get in trouble at school? If so, what for?

16. What services does your child receive at the school?

17. What services (therapies) does your child receive outside of school?

18. Are you involved in a parent support group?

YES NO

19. What types of supports have you found to be helpful to your role as caregiver?

20. What are some of the main stressors for you right now as a caregiver?

Appendix F - Interview Questions

For these questions, please think about your child with ASD in middle school.

1. Tell me about the positives and negatives (negatives and positives) in communicating with middle school about your child.
2. What influences your experiences of communicating with the school about your child?
3. Tell me about the positives and negatives (negatives and positives) in the IEP process.
4. What influenced the IEP process?