THESIS

AN ANALYSIS ON THE EXPERIENCE OF PARENTING FOR ADULTS WITH AUTISM

SPECTRUM DISORDER

Submitted by

Jonathan Lee

Department of Human Development and Family Studies

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Master's Committee:

      Advisor: Susan Hepburn

      Samantha Brown
      Lisa Daunhauer

ABSTRACT

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SPECTRUM DISORDER

A paucity of research has been conducted into the unique experience of parents with autism spectrum disorder (ASD). This lack of scientific understanding about a parent's lived experience is an obstacle to developing effective psychotherapeutic approaches to parents who have identified awareness of characteristic features of ASD. In this study, we present a qualitative case study of two adults with ASD who are parents. Both parents participated in an extensive interview focused on several domains: impacts resulting from characteristics of ASD, life changes resulting from a diagnosis or recognition of characteristics, impacts on executive functioning related processes, experience as a parent prior to recognition of characteristics or a diagnosis, belief in parenting ability, and insight into recommendations for support. Findings highlighted three main themes: 1) a conscious choice in accepting change, 2) saturation of self, and 3) the necessity for clinicians to adopt a learner's mindset.

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An Analysis on the Experience of Parenting for Adults with Autism Spectrum Disorder

When considering the role parents play in the healthy development of their children, the importance of identifying unique parenting experiences and the impacts these experiences have on style, approach, and self-identity becomes apparent. While a great deal is known about the experience of parenting for neurotypical individuals, there is a gap in the literature involving the experience of parents who have autism spectrum disorder (ASD). As autism impacts social adaptability, reciprocity, and interaction (McPartland & Volkmar, 2013), parents with ASD may be more likely to have trouble with relational characteristics of parenting, wherein a child's need-based behaviors are unnoticed. Additionally, parents with ASD may encounter higher rates of marital stress, due to autism related difficulties with adaptability (Pastor-Cerezuela et al., 2020). Developing an awareness for the experience of parents with ASD is a crucial first step in identifying interactional patterns between parents with ASD and their children, and in learning ways in which this population can be supported to increase the potential for positive child development, as well as parental mental/physical health.

Autism Spectrum Disorder is defined by The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM–5; American Psychiatric Association, 2013), as a neurodevelopmental disorder characterized by struggles with both social interaction and communication, and patterns of behavior, activities, or interests that may be restrictive and/or repetitive in nature. These symptoms can lead to some parents with ASD having trouble in reciprocation of attachment-based behaviors with children (Backer van Ommeren et al., 2017). This begs the question; how are attachment-based parenting behaviors impacted in adults who have either grown up with a diagnosis of ASD, or have been diagnosed as adults? Furthermore,

how are parent-child relationships impacted when a parent has a diagnosis of ASD, but a child does not? Based on the present paucity of research into this area, it is critical to understand the extant research into and adult diagnosis of autism, attachment, executive functioning, and parent-child relationships.

Adult Diagnosis of Autism

Huang et al. (2020) discuss that historically, there has been significant underdiagnosis of ASD in adults, which they relate to a lack of awareness regarding phenotypical characteristics of ASD presented in adults. Attwood (2021) attributes this to adaptations in behavior, thus making it harder to identify in cognitively functioning adults. Shifting mental health practices, new efforts to increase awareness and variance of the expression of symptoms and shifts in diagnostic criteria have all led to a relatively recent improvement in identification of ASD in adults (Huang et al., 2020). However, underdiagnosis has been damaging to many individuals who are in middle adulthood at the time for this writing due to delayed detection of this complex condition.

Diagnosis of ASD in Adult Females

To begin developing greater insight into the experience of parents with ASD, the experience of adult women on the spectrum must be addressed. It is well documented that autism is identified four times more often in males than in females (APA, 2013). Huang et al., (2020) reported that within studies involving reported autism diagnoses, most of these studies consisted of male-majority sampling, or male-only sampling. However, there has been a recent surge in research addressing this disparity, leading to an increase in available literature that has involved increased female sample sizes. As such, there is growing information regarding the experience of autism for women. Baldwin and Costley (2016), provide insight into the limited long-term research into the experiences of women with ASD, indicating that over half (58%) of the participants in a female-based study had not received a diagnosis of ASD until they were 18 years of age or older. Therefore, while both males and females with ASD are at risk of

underdiagnosis, which is likely to impact parent-child interactions, women face a potentially greater impact resulting from increased frequency of underdiagnosis.

Hull et al. (2017) discuss a coping strategy observed in individuals with ASD known as "camouflaging", typified by masking traits associated with ASD to appear competent in social settings, and avoiding situations wherein others may observe their social difficulties. According to Hull et al. (2017), camouflaging of autistic traits may be related to the underdiagnoses, or late diagnoses in women. Dean et al. (2016), observed 96 elementary age children, half of whom had a diagnosis of ASD (n = 24 females, 24 males) and half typically developing children (n = 24 females, 24 males). Children in this sample all exhibited a similar average IQ ($\geq$ 70) and were all in similar educational settings. Results from this study indicated support for what they call the "camouflage hypothesis" and how assessing the social landscapes in elementary age girls and boys with ASD provides insight into the lower frequency at which girls are diagnosed with ASD. As social situations provide easily observable insight, this study showed that girls are more likely to stick close to friends and avoid unfamiliar social exchanges and experiences; results showed an opposite trend in boys (Dean et al., 2016).Based on the above literature, women with ASD who become mothers may be at a higher risk of not receiving support and access to relevant services on the basis of decreased visibility of symptoms.

Meng-Chuan et al. (2011), found that while young girls and boys did not vary in autism severity and behavioral symptomology, women with ASD were less likely to experience socio-communication difficulties across the lifespan, and more likely to experience sensory issues across the lifespan than men with ASD. Matthews et al. (2015), observed individuals with autism aged 16-58 years (n = 75), identifying that the participants exhibited significantly higher cognitive adaptation skills when compared to behavioral adaptation skills. However, the

adolescent age group exhibited consistently higher average scores on adaptability scales, whereas average adaptive scale scores decreased in each following age group.

Implications of the above studies indicate that, as adaptive functioning is impacted in greater ways as an individual ages, an individual's ability to camouflage behaviors characteristic of ASD may be impacted as well. As women with ASD are more likely to use camouflaging behaviors, and the likelihood that visibility of symptoms will decrease into adulthood along with potential for behavioral adaptation, women are at significantly greater risk of delayed diagnosis resulting in a growing difficulty in symptom management. Lastly, living with undiagnosed or late diagnosed ASD may have parallels to the experience of complex trauma, defined as long-term, significant interpersonal traumatic experiences that may be recurrent or episodic in nature (Cobbett, 2021), and should be explored as a potential impact of living with undiagnosed or late diagnosed ASD.

Attachment

To begin analyzing the experience of parents on the autism spectrum, connections based in available research on the general experience of autism must be made. As discussed in previous sections of this review, a primary modality through which a parent and child build a connection is through mutual exchange of relational behaviors, based on reciprocity. As shown previously, one of the main characteristics of autism is a difficulty in reciprocity of attachment-based behaviors, and reflective response; therefore, it may be assumed that even in adulthood, the ability for parents on the spectrum to respond to their children's emotional behaviors could be limited.

Attachment may be described as the development of effective physical and emotional regulatory skills based on timely, consistent, and meaningful caregiver response to attachment behaviors (Menon et al., 2020). As noted by Mikulincer and Shaver (2016), attachment bonds are some of the strongest connections that can exist between individuals and take an extensive amount of time to form. Examples of attachment-based behaviors may be described as contact-seeking and maintenance, as shown in the Strange Situation experiment when children would share new experiences with caregivers and turn to caregivers in the event of an unknown factor entering their environment (Ainsworth & Wittig, 1969).

Attachment behaviors are described by Posada et al. (2018) as strategic and contextually based, with the goal of obtaining physical and emotional contact. As discussed by Oppenheim et al. (2012), parental sensitivity (particularly maternal sensitivity) is significantly correlated to the development of secure attachment in children. While individuals with ASD may struggle with reciprocity and reflective response in the themes described above, a strengths-based approach

would indicate that parents with ASD have the ability to create adaptable means of developing attachment security with their children. Each theme lends credence to the important tenets of attachment theory, theme one is based in mutual trust and providing learning and opportunity for growth, theme two is based in connection and shared experience, theme three is based in a parent joining with their child to instill coping skills and information about being born different, and theme four is based in sensitivity and timeliness of support. As such, it may be entirely possible for parents and children on the spectrum to develop secure attachment styles with one another.

Parental Attunement and Secure Attachment

While the level of symptom severity plays a large role in the formation of attachment styles in children with ASD, there is a great deal of literature to suggest that the level of parental sensitivity, responsiveness, and ability to self-reflect is an additional important factor in the formation of secure attachment. Oppenheim et al. (2012), showed that maternal sensitivity was linked to secure attachment in children with ASD. Coppola et al. (2016), found in a longitudinal study evaluating children at 14 and 24 months (n = 38), that children with secure attachment to their mothers expressed more confidence in exploring a novel experience, whereas children with less secure attachment to their mothers expressed more fear towards a novel experience, avoiding a new stimulus and seeking out comfort from their caregiver. This provides a basis for the importance of attachment security in a child's ability to effectively navigate unknown or potentially threatening experiences. As attachment behaviors are more observable in fear-based situations (Mikulincer & Shaver, 2016), it follows that a mother's capacity to recognize and resolve the needs of her child is directly related to the formation of secure attachment, while also highlighting the importance of this secure base to provide children with the confidence to explore novel experiences. Additionally, Siller et al., (2014) discuss how increased parental responsivity

increases the frequency by which children with ASD express behaviors indicative of secure attachment.

Siller et al., (2018), discuss how focusing on increasing parental capability for self-reflection could increase overall attunement to their children through instructing parents to reflect on the reasons and feelings behind their child's behavior, in order to develop a greater understanding of the internal needs of their child and how those internal feelings interacted with their child's outward behavior (Siller et al., 2018). Siller et al. (2018) concluded that mothers of children with ASD may be more sensitive to the needs of their children than mothers of children with insecure attachment styles. When considering research showing that symptoms of ASD are often misinterpreted as insecure attachment and vice versa (McKenzie & Dallos, 2017), the following question arises: does simply knowing that a child has ASD increase sensitive and responsive behaviors in parent caregivers?

To develop a prevention approach that focuses on the importance of parental attunement in the development of secure attachment in children with autism, it is important to address parental perceptions of their child's attachment style and create a transformation in this thought process. A focus on developing parental attunement could serve to increase the capability of parents to effectively respond to the needs of their child, thereby increasing the likelihood that the child will develop a secure attachment style. This method of prevention would include education regarding the difficulties that children with ASD face regarding reciprocity, thereby decreasing the role that parental perception plays in the formation of their child's attachment style.

Formation of Secure Attachment in Typically Developing Children

Mikulincer and Shaver (2016) offer a step-by-step process by which attachment bonds are formed, describing the initial phase as the pre-attachment phase, in which social interaction is sought out from any accessible source. Securely attached, typically developing children seek out connection with caregivers, respond to consistent acts of sensitivity and responsiveness with behaviors indicative of closeness and affection, and seek out new experiences while maintaining close social contact with caregivers (Mikulincer & Shaver, 2016). Meera (2020) notes that securely attached typically developing children have a higher capability to accurately assess and resolve negative emotion presented in a story-narrative format as opposed to insecurely attached children who were more likely to avoid negative emotion in these narratives. As such, it follows that a central component of secure attachment is accurate assessment of caregiver affect. A parent-child duo wherein parents are *responsive* to these attachment-seeking behaviors in a meaningful and timely fashion has a greater probability to develop secure attachment between caregiver and child.

Formation of Attachment Styles in Children with ASD

McKenzie and Dallos (2017), state that children with ASD and their parents are at high risk for developing insecure attachment styles, as opposed to typically developing children. Kahane and El-Tahir (2015) discuss that while there is potential for secure attachment styles to develop in children with ASD, this is not nearly as prevalent as in typically developing children. Teague et al. (2016), concluded that, while previously being seen as incapable of developing an identifiable attachment style with their parents, children with ASD could indeed form secure attachment styles with caregivers. Children with ASD, while struggling with lower social intelligence and poorly regulated interactions, formulate attachment in very similar ways to children without ASD. When considering that a typical experience of autism is avoidance of (or

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lowered capability for) social interaction and understanding, how then is attachment initially formulated between a child with ASD and a caregiver? Filippello et al., (2015) note that children with ASD still seek out and need physical and emotional comfort, and can develop secure attachment styles with their caregivers, while exhibiting less reciprocity in behaviors indicative of closeness or affection. This lack of reciprocity can be attributed to the lower capability for reflective functioning in children with ASD. Teague et al., (2016) discuss the concept of reflective functioning as the capacity to accurately assess emotions and psychological states in oneself and others and is a developmental milestone that typically takes place during infancy. Finally, Vandesande et al. (2019) provide insight into differences in attachment-based behaviors in children with intellectual disabilities, noting that children in the presented study displayed more intense expressions of attachment based needs in regard to contact seeking and maintenance, and were often more oppositional to their caregivers breaking contact.

Reflective Functioning

Reflective functioning involves the capability that an infant has to understand and react to their own and other's emotions and cognitive processes. Backer van Ommeren et al. (2017) concludes that typically developing children have a much higher capacity for reciprocal behaviors when compared to children with ASD. This lowered capability for reciprocity can lead to parents developing negative perceptions of their own capability to develop closeness with their child, regardless of whether secure attachment is being developed (Goodman & Glenwick, 2012). Rozga et al. (2018) found a significant interaction between autism severity and attachment quality, showing that children who were more securely attached to their caregivers also exhibited higher language capability than their peers with insecure or disorganized attachment styles. Finally, a study conducted by Grzadzinski et al., (2014) used the Pre-linguistic

Autism Diagnostic Observation Schedule (PL-ADOS) and the Autism Diagnostic Observation Schedule (ADOS) to discover the connection between autism severity and frequency of pro-social responses, identifying that there is a significant interaction between higher severity of autism symptoms and lower frequency of pro-social responses.

Implications resulting from the studies identified above indicate that while children with ASD experience a deficit in their ability to reciprocate relational behaviors and prosocial responses, parental perception plays a greater role in the development of secure attachment with their children. Therefore, assessing a parent's *belief* in their ability to respond to attachment-based needs in their children while receiving less frequent positive feedback from their children is necessary to identify the potential for developing secure attachment between a parent and child.

Executive Functioning

In addition to the more widely discussed difficulties in sensory and relational processing, it is important to discuss the effect of ASD on Executive Functioning (EF) processes to more fully evaluate the impact that ASD may have on individuals across the life span. Executive functioning is p. An individual's capacity for EF influences various aspects of physical and mental health, as well as relational, academic, and occupational performance (Snyder et al., 2015).

Executive Functioning Characteristics in Parents

Crandall et al., (2018) indicated that maternal executive function capacity was strongly related to the level of parental control, showing that executive functioning was inversely related to high-control behaviors. This suggests that parents with decreased EF capacity exhibited more high-control behaviors. Furthermore, Crandall et al., (2018) showed that maternal emotional control and EF capacity were significantly related to report on severity of child behaviors. As such, parents with decreased capacity for EF and emotional regulation were shown as more likely to report conduct issues with their children (Crandall et al., 2018). This indicates an importance to evaluate EF potential of parents with ASD, to gain insight into controlling parenting styles, and insight into reports on child behavioral issues.

Executive Function in Children and Adults with ASD

Fernandez-Prieto et al. (2021) examined executive functioning as a link between sensory processing functioning, and behavior in children with ASD. Results from this study indicated that, in children who took part in the study, emotional control and regulation were significantly associated with all identified behavioral outcomes. These findings highlighted that executive

functioning would be associated with prior reported negative behaviors (Fernandez-Prieto et al.,
2021). Secondly, results of this study indicate that obsessive, repetitive, and aggressive behaviors
were associated with limits in working memory (Fernandez-Prieto et al., 2021). This study posits
that chronic issues in executive functioning might be responsible for persistent and significant
impairment in social interaction/communication, adaptive functioning, and attention in children
with ASD (Fernandez-Prieto et al., 2021). Results showing the association between repetitive,
aggressive, and obsessive behavior and working memory may indicate that deficits in adaptive
information processing, (i.e., prioritizing goals, information, and behaviors to accomplish tasks)
are made apparent in repetitive patterns of behavior, and irritation (Fernandez et al., 2021).
Menon et al. (2020), found that attachment insecurity was associated with decreased EF
capability. To conclude, the results reported through these studies indicate that higher level
cognitive processes strongly influence characteristic phenotypic expression in individuals with
ASD. As such, it may be beneficial for future interventions with individuals across the lifespan
with ASD to include assessment of EF, and support in increasing EF capability.

Parent-Child Relationships

Crane et al. (2021) conducted a study on the experiences of parents with ASD and their children with ASD, parents reported that they felt well suited to guide their children using their own life experience and understanding. This study highlighted four primary themes seen in parents and their interactions with their children. First, parents emphasized the importance of being open and honest about how being autistic is a part of their lived experience in day-to-day life. Within this theme, parents impressed the importance of being "transparent" with their children about their diagnosis to decrease the probability that their children will have prior associations made with an ASD diagnosis. Theme two highlighted the importance of reporting on and creating a shared experience, wherein parents chose to connect with their child through identifying with their child's experience. The third theme involved supporting children in the reality of thinking of themselves as different in a positive manner. Finally, parents with ASD with children with ASD, discussed the importance of focused, age-appropriate, and tailored conversations regarding autism specific teaching based on their children's needs.

While this study provides necessary insight into the experience of some parents with ASD and their experiences with their children with ASD, the limitations of this study must be considered. As noted by Crane et al. (2021), the vast majority (94%) of the participants in this study identified as coming from a white-ethnic background, and most participants identified as mothers (88%). Therefore, results from this study may not be easily generalizable to a greater population based on gender and racial-ethnic populations but may be more generalizable to a spectrum of SES on the basis that the majority of children enrolled in the study attended mainstream schools. While this study explores the ways in which parents with ASD approach

parenting, there is no exploration into their own experience of parenting with autism. The current

study will seek to explore the experiential portion of the parenting process for parents with

autism.

The Current Study

Research Questions

The present study will serve as exploratory research into the experiences and perspectives of parents who identify as having ASD. Because of the dearth of knowledge in this area, this study will be conducted via qualitative methods of inquiry; specifically, thematic exploration using a descriptive case study design through narrative analysis. Bryman (2008), states that a case study design involves an extensive and in-depth analysis of a single case and should result in a deep and full description of the experience of the subject engaged in the case study. Descriptive case study designs implement a series of questions selected for the particular case involved; in the case of this study, a question set will be selected based on the diagnostic status of the participant (Maxwell, 2013). Additionally, a descriptive case study design involves purposeful selection, wherein participants are selected based on the goals of the study rather than generalizability (Maxwell, 2013). This is represented in the current study through recruitment of individuals with pre-existing diagnoses of ASD, or awareness of features of ASD present in their lives. A personal narrative approach can be described as an analysis of how human beings perceive and engage in the world, and as such are storytellers for their own experience (Connelly & Clandinin, 1990), therefore, this study engaged participants in such a way as to provide them a platform upon which they can build and share their own stories.

The primary research question is: How have parents personal experiences growing up with features of ASD influenced their parenting experiences? Specifically, how have parents' personal experiences with ASD impacted their attunement/attachment to their children? How have parents' perceptions of their own executive function skills impacted the experiences of

parenting? What supports and resources do parents with ASD features identify as beneficial for

parents with ASD?

Methods

Participants

      Recruitment. Participants were recruited through an existing database maintained by the Neurodiversity Research Lab within Colorado State University's Department of Human Development and Family Studies. These parents have either participated in research studies at CSU themselves or have had children who have participated in research studies and have provided the lead investigator with permission to be contacted about future research opportunities. These parents are located primarily in Larimer County and surrounding areas.

      Inclusion criteria for the present study are: (1) participants describe themselves as having characteristics of ASD in the initial intake interview for the Neurodiversity Lab or (2) participants report receiving a formal diagnosis of ASD after the age of 18 years, and (3) participants have at least partial custody of one child or more children, and (4) participants have access to online services through which they could take part in a 1:1 interview focused on their parenting experiences. Additionally, both fathers and mothers will be welcome to participate in the proposed study. Marital status of parents will not influence participation in the proposed study.

      Exclusion criteria for participation in this study include: (1) individual does not hold at least partial custody of at least one child, (2) individual is not a parent, (3) individual does not identify as having a diagnosis of ASD and is not aware of any characteristics of ASD present in their lives or, (4) individual is under the age of 18 years.

At the time of this study, the Neurodiversity Lab database included 6 local parents with ASD features who provided consent to be contacted for future studies and met all inclusion and exclusion criteria. [1]Of these, 2 consented to participate in this qualitative study.

Demographic Characteristics. Participants in the Neurodiversity Lab represent the demographic characteristics for Larimer County and surrounding areas (82% white, 10.61% Hispanic, 2.37% Multiracial identifying, 1.98% Asian, .5% Native American, and .9% African American) (Census Bureau, 2021). Median household income in Larimer County and Surrounding areas recorded in 2020 was $76,366/year (Census Bureau, 2021). Based on the statistics discussed above, it is expected that a typical participant in the proposed study will identify as a white, middle-class individual. Based on this, results from this study may not be entirely generalizable to a greater population in this initial study, however, we hope that these pilot interviews (See Appendix A and B) will be a foundation for future research examining the needs of parents who have ASD.

Table 1.

Participant Demographic Characteristics

Demographic Feature	Participant 1	Participant 2
ASD Status	Formally Diagnosed	Suspected/Assessment in progress
Gender	Male	Female
Age	Not disclosed	49
Race/Ethnicity	White/Caucasian	White/Caucasian

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[1] We considered recruiting more broadly through professional networks and connections; however, we decided to pursue more in-depth data collection on the local participants instead. This decision was informed by practicalities associated with the need to complete this masters' thesis in a relatively short time frame, as well as the benefits of conducting a deeper inquiry with a few people, given the lack of information on this topic.

Occupation	Advocate/Artist	Travel Agent
Marital Status	Divorced	Married
Family Composition	One adult child	Married, 2 Children
Sex/Age of Children	Female (Age not disclosed)	Female (12), Male (12)
Children ASD Status	No ASD Diagnosis	Both Formally Diagnosed

Note: Detailed information regarding both participants is presented in Table 1

Procedures

Following IRB approval, the Principal Investigator of the Neurodiversity Lab invited participants who are eligible for this study to participate via email. Interested participants emailed the Principal Investigator, who contacted the study's Lead Researcher. Follow-up emails were used to share informed consent materials, which detailed the purpose of the study, participant rights, and measures taken to protect the participant's identity. The Lead Researcher then met virtually with interested participants to review the consent form and informed the participant that the interviews were entirely voluntary and that the expected time for completion of the interview would be around one to one-and-a-half hours. Participants were informed that they could choose whether to answer any questions and would be allowed to discontinue the interview at any time.

Following the participant's agreement to participate in the proposed study, the researcher obtained information to complete the demographic form, and arranged for a time to conduct the interview via Microsoft Teams, a platform chosen due to its security and confidentiality measures. Special care was taken to provide guidelines for creating comfort for a participant and developing rapport before beginning interview questions. Additionally, a general script was created (See Appendix**) to emphasize the expectation that the participant be treated as the

expert in the room, and the researcher to take on a learner's perspective. Data was gathered in a similar way to how information would be obtained in an intake interview for a counseling session, wherein participant care and comfort is of primary concern.

Measures

Demographic Form

A demographic questionnaire was implemented with all participants. This form consisted of a brief survey of participant/family characteristics.

Parenting Interview

Participants underwent one of two interviews created specifically for the proposed study. Parenting Interview – Version 1 (Appendix A) was constructed for participants who have received a formal diagnosis of ASD in adulthood. Questions were formatted to fit this expectation. Parenting Interview – Version 2 (Appendix B) was constructed for participants who have not received a formal diagnosis of ASD, but have reported noticing characteristics of ASD present in their lives. Both interviews include questions designed to address: (1) experience as a parent with ASD or characteristics of ASD, and (2) impact of ASD or characteristics of ASD on attunement/attachment with their child(ren), and executive functioning processes. These interviews are based largely on research conducted by Crane et al. (2021), which indicated that parents with ASD reported four similar parenting characteristics: transparent communication, creating a shared experience, modeling positive self-talk and self-image, and developmentally specific conversation with their children about ASD.

Data Synthesis and Expected Results

Due to the more experiential, informational nature of this proposed study, data collection and synthesis consisted of recording participant responses, transcription, synthesis of responses into predetermined thematic categories (e.g., attunement/attachment as it interacts with EF challenges of parenting; reflective experiences; suggestions for resources and support). Responses were analyzed for themes that emerged from the interviews themselves but were not identified a priori. A narrative analysis approach breaks up transcript's responses into thematic blocks and allows for future analysis to compare findings to these themes (Kekeya, 2021). Interview recordings were broken up into excerpts, and individual excerpts were grouped together into themes. These themes will allow for future research to continue theoretical sampling of the population. Results have been expressed in a narrative format; wherein participant responses are outlined according to thematic category. Attachment and attunement focused questions and responses were discussed within executive functioning related conversation, as attachment behaviors and parental attunement are both heavily influenced by executive functioning capacity.

Results

Two adults completed in-depth interviews with the Lead Researcher (Jonathan Lee). In this section, we begin with a brief overview of the background of each participant; followed by summaries of responses that are organized into six themes: impact of ASD features, life changes as a result of recognition of characteristics, executive functioning related responses, experience as a parent before recognition of characteristics, belief in parenting ability, followed by participant insight regarding support/recommendations.

Participant one is currently a professional advocate for individuals with new ASD diagnoses and identifies as an artist. Participant one is has had his parental rights revoked to his daughter and discusses how his then undiagnosed ASD impacted his parenting experience in painful ways. Participant two is a travel agent for a large corporation, and a mother of two children with ASD. She has expressed that she suspects characteristics of ASD present in her own life and is currently looking into exploring this more deeply. For demographic information refer to Table 1 above.

Impacts of Features of ASD

Participant 1

Participant one reported that he has a formal diagnosis of Autism. Participant one identified that the two main impacts that the characteristics of autism had on his life were experiential in nature and based more on impacts resulting from disclosure or realization of his diagnosis. First, participant one has struggled until more recently to hold a job, which Participant two related to historical attempts to control others impression of who they are. Participant one made the observation that he has since made the intentional decision to avoid trying to control

others perception, by bringing up their diagnosis, and frontloading how these various characteristics are expressed, making sure that autism conversations are had early on in all work-related interactions. Participant one also reported that when he was a child, prior to awareness of his diagnosis, he asked their mom to send anyone who ever had any questions, or anything to say about him, directly to him so that he had a better chance of guiding or influencing their perceptions of him. To better describe this shift in his life, he reported that he had made the choice "to become comfortable with the extremely uncomfortable".

The second main impact that this participant reported was the process through which he lost custody of his child, which was the catalyst for him identifying his diagnosis and eventually seeking support and knowledge related to autism. It is important to note that while participant one has lost custody of his child, he was deemed eligible for the present study based on the amount of time he was present as a parent in her life before losing custody of his child.

Participant 2

Participant two reported that she does not have a formal diagnosis of autism, but rather through her son's diagnosis of ASD, she has begun to question characteristics that she has been aware of in her own life since childhood. Participant two reported that the most consistent impact that she has been aware of as it relates to these characteristics has been struggling with processing sensory-heavy experiences. Participant two reported that since she was young, she always had an aversion to noise, large groups of people, and would find herself becoming overwhelmed very easily and very quickly. Participant two additionally reported that she has always struggled to initiate friendships and cannot recall a time wherein this happened.

Life Changes as a Result of Recognition of Characteristics

Participant 1

Participant one emphasized the importance of the context in which he received an official diagnosis of ASD, which occurred parallel to his involvement with the court system during the series of hearing that resulted in his loss of parental rights to his daughter. Participant one reported that he was introduced to a variety of parenting classes and books, noting that his initial reaction was excitement as he was being offered an avenue to learn about himself and become a better parent. However, from the perspective of participant one, the court system used his new-found enthusiasm as evidence of his lack of capability as a parent and required family therapy for him and his daughter, wherein he began to become aware of the possibility that he may have characteristics of autism. Regardless, participant one reported that coming into the understanding that he was on the spectrum was elucidating, as he was able to assign a reason to the variance he saw between his behaviors and the behaviors of those around him. Following recognition of these characteristics, participant one reported that he began realizing that disclosure of any kind had the potential to impact his life in unforeseen ways, and that for him, becoming his own narrator was important. Participant one reported that the positive side of this was that embracing these characteristics allowed him to fully step into the role of artist and advocate, two central themes present throughout participant one's report. Participant one made the observation however, that while the features of autism more clearly recognizable in his life allow him to be an advocate and an artist, which allowed him to grow into the fullest version of himself, these characteristics also negatively impacted his family and his ability to maintain a regular job up until more recently.

Participant 2

Participant two reported that growing up, she often found herself mirroring the emotions and behaviors of people around her, in a way that she described without recognizing when it was

over the top. Additionally, she reported that she has historically forced herself to engage in activities or environments that were overstimulating. As she learned more about herself and her sensitivities to various experiences, participant two reported that she has become more comfortable in her own body and has been able to place boundaries for herself and others that limit her involvement with over stimulating environments, which she described during the interview as her development of the ability to understand what affects her, and knowing what she can avoid. Finally, participant two reported that a major long-term shift has been her growth in emotional regulation. Participant two discussed that she has previously been what she would describe an overly emotional person, who would cry very easily when she was happy, sad, angry, etc. Since then, participant two has noted that she has developed significantly greater emotional regulation skills.

Executive Functioning Related Responses, and its Impact on Attachment/Attunement

Participant 1

When asked to describe how he encounters and has encountered daily routines, mostly relating to parenting his daughter, participant one replied that "It is my emotional memory that routines were very difficult". When asked to clarify this response, Participant one reported that between him and his partner, routines with their daughter were always difficult, and a source of a great deal of distress between him and his partner. Participant one described how he would always have excuses as to why his daughter was not at school on time, or why he would forget various appointments or responsibilities. Additionally participant one described his parental involvement as his wife taking on maybe 75% of all parenting related tasks, and him taking on maybe 25%, which influenced his choices to try and do transport to school for his daughter in the mornings sometimes, and pickup at the end of the day as well as engaging in volunteering in the

classroom, leading reading groups with his daughter and other students. When asked to discuss his motivation behind these activities, participant one reported that "There are a lot of unwanted kids in this world, I did not want my kid to be one of them.". This quote highlighted a recurring theme for participant one that was apparent specifically in relation to how he would talk about his daughter, that may be described as softness and relational intentionality. Participant one reported that while he had never considered the reality of becoming a father, when he found out that his wife was pregnant, his reaction was "Okay, I wasn't expecting this, but I'm going to be a dad. I'm going to do the things that a father should do for their child. I'm going to show up and intentionally show this kid that they are wanted". Unrelated to tasks and routines, participant one also reported that sleep routines have also been a very difficult part of his experiences, describing his sleep routines as "autistic" in nature.

When discussing the process by which Participant one made the active choice to shift his attention on his child, participant one described that the two experiences that immediately came to mind were traumatic for both him and his daughter. The first experience involved him picking up his daughter from school, he was on his bike, and he explained how daily life at this point in time was causing a great deal of chronic, physical pain in his back just behind his rib cage. He reported that during this experience he brought his attention to the fact that in this moment, he did not have to deal with his ex-wife, he did not have to deal with work at this point in time, and he made the active decision to focus on his external environment, pointing out random interesting things to his daughter as they walked side by side. Participant one pointed out a squirrel climbing up a tree, involved his daughter into imaginary play wherein they pointed out flying ponies dashing through the sky above them, all while feeling that he was in a battle between two seemingly contradicting experiences; focusing on time with his daughter, and

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managing all the stressful life responsibilities that he was encountering at this time. During this experience, participant one reported that he felt himself making the choice to let all of the life stressors go in this moment and focus solely on his daughter. The second experience that participant one described as an example of focused attention involved his interactions with the court systems, wherein he was provided with a significant number of readings and resources. This client reported the following:

> ". . . now had lawyers and magistrates and therapists and everybody watching, shifting was so hard for me. It was so hard for me. And you know because the stakes couldn't be any higher. This is about whether I get to be my daughters dad or not. And so, I was trying to absorb every word, and read every document, and that's not possible for any human being. And I was spent, even after I was refreshed and just getting started, I was already spent.".

Participant 2

Participant two described routines as "hellish", noting that she believes her working memory is relatively poor, which is why she keeps so many lists. Her life was described as constant effort to multitask, as she discussed that her job operates on central time which means that she is up and working by 6:30 every day. Additionally, in her words she is consistently "trying to multitask times one thousand, with the kids getting them breakfast before school because they don't have the adaptive skills to get breakfast themselves". To assist her in this constant state of multi-tasking she has 4-5 alarms on her phone just for morning tasks with her children; one alarms for breakfast, one for medication, one reminding her to comb their hair, and one to get them out the door and in the car.

To navigate this myriad of tasks that she has every morning, participant two reports that to "keep her cool" she must disconnect sometimes and pull herself back from whatever situation is escalating her, which sometimes looks like leaving the room. When discussing emotional regulation skills that she employs when she becomes escalated, participant two reported that she likes to take space, focus on deep breathing, and naming the colors of the rainbow.

When asked about how she focuses her attention on her children or partner, participant two reported that she gets overwhelmed very quickly if everyone is talking or trying to be heard at the same time, and in order to be intentional about focusing her attention on each person involved, she has developed the habit of placing her hand up, indicating to everyone involved that they need to quiet down, and take turns speaking. When asked how she knows when to focus her attention on her children Participant two stated that based on eye contact, intensity of the attempt to gain her attention, urgency behind the request for attention, and injury are all the primary ways in which she receives external indications that she should focus her attention on her children, which all contribute to her experience of "overwhelm". Participant two stated that "I just sense it" as an additional response to the above question. Finally, within this line of questioning, participant two reported that while her husband is really supportive, he works two jobs so she does not get to see him often. When he is home and able to connect, she places a great deal of importance on focusing her attention on him and connecting with him on those moments

When discussing participant two's process of orienting to tasks, she reported that her primary way of approaching tasks is temporal, which she described as her always being in the process of trying to get organized, which leads to her feeling as though she is never really on top of her vast number of tasks. Influencing this, is participant two's frequent experience of

unforeseen tasks, such as her children telling her that they have something they need for a class five minutes before they leave the house. Additionally, Participant two reported that she will organize her approach to tasks on a tier list, wherein immediate concerns such as getting her kids up, fed, and ready for school are of primary importance, followed by tasks that are of less immediate importance such as fixing something, deep cleaning something, or paying a bill. This portion of the interview highlighted a recurring theme throughout the interview with Participant two: Inadequacy. Participant two reported throughout this interview that they consistently find themselves struggling with feelings of inadequacy, encapsulated in this section through Participant two's report that,

> "I'm always in the process of trying to get organized, and you know? I often feel bad that I don't, I never seem to have my act together. At least not enough to meet my own expectations.".

During this section, the interviewer asked participant two the Miracle Question, a therapeutic intervention that involves asking "If I were to hand you a magic wand, and one night you were to wave right before you fell asleep, and you woke up to a life where all of your problems have been solved, life is exactly the way you want it to be, what would be different, what would have changed?". Participant two responded that,

> "I would have twice as much time with my family, I would have a housekeeper, I would have all my bills paid, I would have my act together and feel organized and structured and in control, and I would have happy kids.".

As indicated above, participant two operates from a place wherein all of her needs come relatively secondary to the needs of her family, and her sense of inadequacy influences her

perception of a world wherein because she would be on top of things and not failing, her children would then experience happiness.

Experience as a Parent Prior to Recognition or Diagnosis

Participant 1

Participant one reported very little information pertaining to his experience as a parent prior to his recognition of characteristics of autism present in his life, and the majority the information regarding this theme can be found in the above section. Regarding recurring themes in the report of participant one, Participant one's experience as a parent before recognition may be described as based on positive, relational intentions with a great difficulty in focusing these intentions into meaningful parenting-based actions. Participant one discussed a concept known as The Intense World Theory, wherein hyper-functional neural processes result in hyper-reactive and hyper-malleable neural pathways, which contribute to an increase in cognitive/neuronal load primarily on the neocortex and the amygdala, which leads to hyper-emotionality, hyper-perception, hyper-attention and hyper-memory (Markram & Markram, 2010). Participant one described his experience as a hyper-involved one, wherein his emotional involvement was so intense at all times, that he was in a constant state of overwhelm, unable to shut off his emotional experience which resulted in a constant experience of depletion. Based on this, participant one reported that he struggled to be present, and struggled to assist his partner in parenting-based interactions. He reported that his ex-wife would likely describe him as rather persistently angry, tired, and avoidant of helping her parent. Based on previously gathered data from Participant one's involvement in the Neurodiverse Experiences Lab at Colorado State University, participant one appeared to identify with his diagnosis as an explanation of the majority of the "negative" expressions of his internal experience. Following his gaining of awareness of his diagnosis,

participant one expressed that he experienced an increased feeling of freedom, and that he had a reason behind the difficulties that he experienced.

Participant 2

Prior to gaining a curiosity of characteristics similar to autism in her life, participant two reported that "I feel a lot of faults". This elucidates a recurring theme for participant two, wherein she repeatedly reported feelings of inadequacy in her ability as a parent. As her children developed, and developmental concerns were becoming more evident, participant two reported that she originally tried to mold her children to fit the expectation of a typically developing child. However, as her children's difficulties in adaptive functioning became more apparent, she reported making a conscious decision to parent the children that she had, rather than the children that she envisioned. This allowed her an experience of confidence, as she now had a direction, and had made the choice to embrace change and the unknown. This choice brought her to a place where she realized she would do anything for her children, building her into a remarkably strong advocate for their quality of care. Participant two reported that in the course of fighting to have her children met with a correct diagnosis, and the research that accompanied this journey, she and her husband began identifying with various characteristics that they saw both in their children, and in research relating to autism characteristics. While participant two currently still struggles deeply with feelings of inadequacy, this experience of advocacy and learning allowed her to grow in her confidence as a parent.

Belief in Parenting Ability

Participant 1

Participant one described his belief in his parenting ability by describing what being a parent meant to him before his diagnosis involved the common parenting objectives of bathing,

feeding, and schooling. Following his diagnosis, he can only really remember a handful of times being a parent following receiving his diagnosis, which was difficult for him to report on because of the vast array of dynamics present in his life during this time. One of the main actions that began shifting his belief in himself as a parent was what Participant one described as self-talk, which he outlined below:

> "Instead of saying things like 'I'm such a shit' or some other version of that like, 'I can't sleep, I can't hold a job, I can't hold a marriage together', I could begin to say, 'I live these autism spectrum dynamics, I am doing my best and my best just looks different'.".

This encapsulated another recurring theme for participant one that may be described as a development of kindness towards self, wherein participant one's diagnosis allowed him the space to make decisions with his mental health, comfortability, and functionality in mind. Participant one began making allowances for things that he cognitively knew may be strange by standards of social acceptability, such as having sunglasses in his pocket in the court room that he could take out and use in the event that the lights became to overstimulating, or randomly doing a cartwheel while walking with his daughter because that was what he could "do right now". However, to the sadness and frustration of participant one, his diagnosis came too late for those with the power to make decisions regarding his parenting capability. Impacts as a result of this will be discussed in the support and recommendations section.

Participant 2

As described in the previous section, prior to becoming aware of characteristics similar to autism in her life, participant two tried to mold her children to fit her expectation of what a child should be. Participant two's belief in her parenting ability was amplified as she began stepping into an advocacy role with and for her children, which increased her confidence as a parent.

Participant two further reported that recognition of the characteristics that she believes she has have served to allow her to connect with her children where they are, see them for who they are. Participant two described her belief in her parenting ability as bolstered by the lack of consistent or reliable support in parenting her children, as her extended family does not understand the unique experience that she or her children have, because they have never encountered anything like this before. Furthermore, growing belief in herself as a parent has included a recognition that she will do absolutely anything for her children, that she will "walk across coals" for them to receive the services and support that they need, not only for their developmental trajectories, but for them to become the best versions of themselves that they can be as well. When asked how this advocacy role shows up in her life, she described this role as not taking no for an answer, noting that "since they were a year and a half old, I knew something was wrong, something wasn't the way that it should be, and that I just had to keep asking, keep pushing.". Participant two reported that she felt as though she was often seen as someone who was trying to make something out of nothing by the majority of the clinicians that she encountered. Finally, Participant two reported that she receives validation in her ability as a parent in the fact that she believes her children feel very safe with her, that they feel supported by her, and that they feel as though they can talk to her about anything.

Support and Recommendations

Participant 1

When asked to discuss recommendations for support for parents with characteristic of autism, participant one expressed the importance of a learner's approach for clinicians, noting that while there are characteristics patternable enough to appear in the DSM and the ICD-10,

"Talk to anybody that's an 'autism expert' and they'll tell you 'I'm just learning.' People that have been doing it for 40 years will be like 'Each time I'm learning' and that's the kind of person that I want to talk to. . . when you say you're an autism expert you don't have a lot of credibility in my mind. But when other people call you an autism expert, but when I talk to you and you say, 'yeah I'm just learning' okay now I'm listening to you.".

Participant one went on to say that he believes what parents with autism need as far as emotional support is the same as what anybody would need as far as emotional support, and sometimes this may look like help with reparenting their own inner child. Additionally, if parents are struggling with poverty, legal issues, etc., support in navigating those particular systems would be beneficial. Participant one described that support in this area may look like helping an individual or family access a "professional navigator" that could assist them in encountering these various systems. The major theme in participant one's response may be described as, parents with autism need what anyone else would need, and those needs are going to be varied.

Additionally, participant one placed a great deal of importance on aiding the natural supports of parents or children with autism: siblings, foster parents, extended family, therapist, and other systems. While this identification and support of systems present in these individual's lives, may appear to be an overwhelming task, reframing this as an opportunity for creative and individualized care offers a radical, unprecedented alternative to traditional support plans.

Participant 2

This portion of the interview began with asking Participant two what about being a parent left her feeling unsupported or overwhelmed, which she responded with saying "Trying to do it all I think and having to fight for certain things with doctors. I don't think medical professionals, or the pediatricians are able to spot mental health issues as well as they should, and so those

things are easily overlooked and that has caused a lot of problems in my life.". The following

quote from the interview encapsulates Participant two's experience navigating a system that she

believed was insufficient in their efforts to support her children.

> "In my own perspective, so when my son was diagnosed in second grade, I wanted my
> daughter, I thought my daughter had ADHD too, but at the time testing required both a
> parent analysis and a teacher analysis, and she was a very shy, quiet kid and the second
> grade teacher felt like he didn't know her, and couldn't complete the form so he gave it to
> her first grade teacher to do, this was midway through the year. She's just a quiet kid
> whose squeaky wheel always gets the grease and that was not her. Her teacher didn't
> know her enough after six months to be able to complete the diagnosis. And I went back
> repeatedly, because you know, kids in class, if they are the quiet ones, people don't pay
> as much attention to them. I remember going to my primary care doctor at the time
> saying I think I might have ADHD and her question was 'have you been changing jobs
> frequently', and no, I've been working with the same company for 27 years, and so she's
> like no, you don't have ADHD. And then she prescribed me with anxiety medication."

Following this excerpt, Participant two reported that it was not until her daughter's involvement

in an autism assessment through Colorado State Universities Neurodiverse Experiences Lab that

she not only received a diagnosis of ASD, but ADHD as well. Following this, Participant two

reported that she had known for five years at this point that her daughter likely had ADHD, and

that she had gone unsupported for five years, which instilled guilt in Participant two, as she

believed there was more that she should have or could have done to support and advocate for her

daughter.

When asked for her insight into support and recommendations for parents with characteristics of autism, or children with characteristic of autism, Participant two reported that first, reading and research were incredibly impactful for her in developing a confidence in being an effective parent with her children. Secondly, Participant two reported that while finding the right support networks and support groups took her a very long time, it has been one of the most impactful influences on her feeling as though she is not alone in her experience. Participant two made the observation that for an individual on the spectrum, seeking out these communities is already very difficult, so support in connecting individuals on the spectrum to these communities would be very beneficial.

When asked what recommendations she would have for clinicians, Participant two reported that in addition to what she had already described, every pediatrician, general practitioner, and general counselor never saw the signs in her children, and that just getting in to see a psychiatrist takes a minimum of six months, so this is a whole area that needs a great deal of extra support. In the course of this interview, Participant two brought attention to the fact that she believes clinicians are sometimes maybe too preoccupied with specific diagnostic criteria, and maybe a little too avoidant or dismissive of personal experience and how this personal experience translates into a unique experience of these diagnostic characteristics.

Discussion

To orient the following discussion, it feels necessary to bring understanding to the fact that this project was developed, run, and reported from the theoretical perspective of a Marriage and Family Therapist, wherein a systemic approach to individual experience is the basis for clinical training and practice. In essence, it is the perspective of Marriage and Family Therapy that in order to build an effective, deep understanding of individual experience, we must view an individual in the context of not only their internal experience, but the interactions between these individual's and their systems, be this the interactions these individuals have with their family and friends, their interactions with their educational systems, legal systems or social program, or their interactions with dominant socio-cultural narratives to develop a well-rounded understanding of the countless influences on these individual's experience. As such, it must be understood that this perspective in no way minimizes or invalidates that powerful impact that clinical psychology, behavioral psychology, medically oriented perspectives, and more have on the experiences of parents and children on the spectrum, but rather offers an opportunity for greater collaboration in the support of this population.

In this section, an outline of important themes will be explored, as well as potential strategies for addressing these themes. As this study explored in-depth case studies with two parents, each exemplary of characteristics typical to parenting with aspects related to ASD, these themes may not be entirely generalizable to a greater population and are therefore meant to be interpreted as general opportunities to create connection, probe support needs, and enhance shared understanding.

Implications for Clinical and Therapeutic Intervention

To create an effective understanding of the parallels between a diagnosis of autism and the experience of complex trauma, this section will provide a definition for complex trauma, as well as parallels between the experience of living with ASD, and factors that create a trauma impact. As stated previously in this work, complex trauma is defined as long-term, significant interpersonal traumatic experiences that may be recurrent or episodic in nature (Cobbett, 2021). Within this definition, complex trauma is perpetuated by attachment-based impacts, and involve both biological and systemic aspects. Kliethemes et al. (2014) conducted a review on growing awareness of complex trauma indicating that one of the major causes of complex trauma is the existence of emotional issues resulting in a greater frequency of externalizing behaviors such as aggression, dysfunction in interpersonal interaction, and greater risk of victimization. As discussed by Hepburn (2021), factors that moderate the experience of trauma as it relates to a diagnosis of ASD involve developmental functioning characteristics, severity of mental/physical health conditions, social/interpersonal experience, co-morbid conditions, temperament, age, sex/gender, and access to treatment. As Hepburn (2021) described, trauma increases the likelihood of social isolation and withdrawal, disengagement from emotional experience, and masking trauma impacts. As these characteristics of trauma are closely related to characteristic features of autism, wherein individuals with autism have trouble in social/emotional adaptability, withdrawal from overstimulating environments, and masking of various characteristic expressions of this adaptive deficit, it may be stated that individuals with autism are pre-disposed to experiencing complex trauma over the course of their lifespan.

To generate greater clarity for the interplay between autism and trauma, the following research was explored. Jones et al. (2012) conducted a meta-analysis of 17 studies from a pool of 10,663 references to determine whether children with disabilities are at greater risk of

experiencing physical, sexual, and emotional abuse. Results from this study indicated that children with developmental disabilities were significantly more likely to experience abuse than typically developing peers (Jones et al., 2012). McDonnell et al. (2019), conducted a meta-analysis with children born between 1992 and 1998 with ASD only ($n = 316$), ASD and intellectual disability (ASD + ID) ($n = 291$), ID only ($n = 1,280$), and children without either ASD or ID ($n = 3,101$). Results indicated that children with ASD, ASD + ID, ID groups were at significantly greater risk of experiencing maltreatment (McDonnell et al., 2019). McDonnell et al. (2019), concluded that, based on these results, assessment and intervention methods aimed at treating complex trauma are extremely lacking and extremely needed. Unfortunately, as with research identifying the experiences of parents with autism or characteristics of autism, there is a lack of research aimed at identifying meaningful therapeutic, assessment, and intervention methods to be used for parents who have likely experienced complex trauma as a result of these characteristics. Major themes identified from this study, as well as potential interactional strategies and therapeutic interventions have been outlined below.

Major Themes

Theme 1: Choice in Change

As shown in the results of the two case studies, a primary theme that was pulled from the interviews involved reporting a conscious choice towards accepting change. This was identified in participant one's description of the concept that he could either live through the resentment and dissatisfaction with the expression of his diagnosis, and the impacts that it had in his life, as well as his encounters with various systems in his life that he believed had failed him, or he could choose to make different choices based on his awareness of his diagnosis.

This theme was identified with participant two based on the recurring description of the importance she placed on realizing that she had been trying to mold her children to fit her own expectations, resulting in her actively choosing to take on a learner's perspective wherein she parented the children she had. With Participant two, choice in change may also be presented as evidence towards adaptive potential, as Participant two noted that over the course of her life she had attempted to deal with overwhelming and overstimulating environments as a means of masking what she described as social difficulties, which she later decided to stop placing herself in these overwhelming environments where possible and seek out support and accommodation where not.

Theme 2: Saturation of Self

Saturation of self has been identified as the second theme and takes on a very different appearance between these individuals. For participant one, this saturation of self is depicted in this individual's drive to control the narrative surrounding others perception of who he is, as evidenced in his report that as a child he frequently reminded his mother that if anyone came to her with questions or statements about him, that she should send them directly to him so that he could control the narrative. In adulthood, this is depicted in participant one's intense presence in frontloading characteristics of his diagnosis in work and social environments as the premier topic of discussion. These examples illustrate the depth of importance that participant one places in how he is perceived in any arena, with a notable difficulty in expressing how others share a role in his story. Additionally, saturation of self was depicted in the vast amount of import that participant one placed on his role as an artist, and an advocate, wherein his voice in these two arenas allowed him a sense of power in his expression of self.

Participant two expressed this theme in a very different way, wherein her saturation of self was so closely tied to an almost debilitating sense of inadequacy. For Participant two, the health, happiness, and positive developmental trajectory of her children is entirely based on her ability to stay organized, involved, attuned, and present at all times, with little regard to her own needs, and very little kindness towards herself in her acceptance of the things that she is doing incredibly well. As Participant two grew in her level of confidence as a parent, her entire self as a parent was focused on advocating for her children and fighting for their needs to be met in meaningful ways. As Participant two experiences such self-neglecting and self-avoidant characteristics, her saturation of self may be best depicted as an over identification of inadequacy in who she is as a parent.

Theme 3: Learners Approach

Both participants reported very similar recommendations for support and change regarding what they believed parents and children with autism or characteristics of autism would benefit from. For clinicians, adoption of a learner's approach to working with parents and children on the spectrum was of primary importance for both individuals, exemplified in a clinician's ability to view a client as the experts on themselves and their families. Participant one described that to build rapport with a clinician, he needed to see that they were willing to learn, that they would not come into an interaction as the experts themselves, but as willing to see the individual as the expert. Finally, participant two made the observation that parents with autism or features of autism would benefit from the same types of support as parents without these features. Participant two impressed the need for clinicians and other supporting services to allow families concerns, insights, and experience to influence medication, treatment, and referrals.

Potential Interactional Strategies

Based on the previously described themes, this section will provide a few potential avenues that were exceptionally beneficial in building rapport and building shared understanding of individual experience, as well as insight into potential interventions that may be beneficial based on the expression of these themes in parents with autism or features of autism. First, I would like to discuss what I would call learning the language that an individual feels heard in.

Participant 1

For participant one, his self-description as an artist and an advocate gave initial insight into this language, which developed into what he described as a "jukebox" way of accepting, and interpreting information. This client will be reminded of a song based on the content of a conversation and will present the song as a vehicle to increase shared understanding. Therefore, as the interview developed, there were opportunities presented to speak in this individual's language, wherein content in parts of the conversation would bring a song to my mind, which I would then get to express to participant one as a way of creating shared understanding. As this continued, participant one expressed feeling more and more heard, and understood in his reflections of his own experience. As Participant one reported consistently throughout the interview, his ability to control other people's perception of him was incredibly important from the time he was a child, shown in him asking his mother to direct anyone with questions or opinions about him directly to him, and shown through his current experience through his intentional front-loading of how characteristics of autism show up in his life. As such, a particularly impactful therapeutic modality that was implemented in a very basic way was a narrative therapy approach. Narrative therapy, developed by Michael White and David Epston, is a collaborative approach to therapy wherein a therapist works with a client to identify problems present in their lives, separate the problem from the person, identify dominant narratives that

influence the problems that they experience in their lives, and co-author preferred narratives wherein a client identifies ways in which they can take an empowered stance against the problems present in their lives (Gerhart, 2018).

With participant one, his experience of the problems he faced in his life prior to gaining a realization of the features of his diagnosis influenced his need to direct the narratives that he believed himself subject to. Currently, participant one continues to fight against the dominant narratives that are being told about him as a man with autism, by frontloading his own preferred narrative in his initial interaction with peers. In my interactions with participant one, it became clear that he held this belief that he was being single-storied, that because he had autism, it was going to be expressed in ways that fit with current diagnostic criteria. Collaborating with participant one in identifying his preferred story about himself and working with him to identify how this story could include others in equally important roles in his life was tremendously beneficial in the creation of deep rapport.

Participant 2

For participant two, the impact of Participant two's negative self-talk and self-belief greatly influenced her experience as a parent, and her own confidence in her capability as a parent. As the saturation of self for participant two involved a deep and pervasive sensitivity to her faults, it was important to not only validate her perspective, but it was also important to offer a reframe of her experiences as well. An example of how I chose to engage in this type of interaction can be described here:

> "I am hearing you tell me that all you can see are your faults, and the feelings that you're sharing with me that are coming from this belief that you can never do enough make so much sense and sound so overwhelming, and I'd like to offer another perspective. While

you feel as though you are never on top of things as much as you feel like you should be, here are some of the things you have described to me that offer me evidence that you are managing so many moving pieces in such an amazing way. You tell me that you feel as though you are not able to provide your children with what they want and that they must be unhappy, and when you tell me that they can tell you anything, that they trust you, and they seek you out when they need something, that is evidence to how absolutely in tune you are with your children, and how in tune they are with you.".

Engaging with a parent who feels inadequate and ineffective provides a beautiful opportunity to build evidence to the fact that there are strengths present in who they are as parents. As such, developing a strengths-based approach when interacting with parents with autism is absolutely essential in not only developing rapport, but highlighting evidence to the fact that they do, in fact, have tools and qualities that indicate that they are effective parents. A strength-based approach allows a clinician to collaboratively identify evidence to the fact that sometimes, all you can do is enough. Creating belief in one's own capabilities is crucial in developing those abilities further.

Finally, a powerful intervention tool that was used in the interview with participant two was challenging negative self-talk and offering curiosity regarding what might happen if participant two would allow themselves more kindness towards themselves and their efforts as a parent.

Limitations and Future Directions

As previously identified, based on the in-depth case-study design of this study, themes that have been identified through these two interviews may not be generalizable to a greater population. Additionally, demographic generalizability is also impacted as both participants

identified as white, middle-class individuals, with a greater opportunity for access that would not be represented in a larger population. Future research should seek to further develop the interviews used to address a larger population and evaluate how the identified themes may be represented in a larger pool of participants. Additionally, as noted by Kekeya (2021), trustworthiness of the data and themes developed from the data increases as application of the data gathering techniques increases. Therefore, replication of this study using the interviews developed for evaluation of this population will offer additional insight into how the identified themes are exhibited across larger populations, increasing trustworthiness.

Based on the results gathered from this study, one contribution that this study hopes generate in clinicians specifically, is a greater confidence in interacting with and supporting individuals with autism. As identified in these case studies, and in the reporting of prior research, individuals with autism have emotional, community, and support needs that are similar to those of typically developing individuals. As such, it follows that in order to support these individuals and families, we as clinicians do not necessarily need to identify as "specialists" in ASD, we just need to be able to create space to listen, to learn, and to allow these individuals to share their self-expertise with us in a way in which they will feel heard and understood. As such, while future research should develop these themes, and replicate this study with much larger participants, future directions may include development of clinical counseling programs focused on providing this space, providing individualized support based on participant feedback and input, for parents of children with ASD, or who have ASD themselves. Additionally, future research should seek to develop a greater understanding of the experience of parents with autism, and the development of specific therapeutic approaches for work with parents with autism,

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Parent Interview Version 1

Parenting interview version 1 was created for implementation with parents who have

received a formal diagnosis of ASD. Therefore, questions were formatted towards diagnositic

criteria related to ASD.

Questions for focus group/one on one interview: Set 1 (Formal Diagnosis)
- Created for Master's Thesis Project by Jonathan Lee

Steps to set up the interview:
1.) Build rapport, create comfort
2.) Thank the individual for taking part in the interview
3.) "This is a study focused on learning more about adults who have characteristics or features of autism, we want to learn more about what it is like for you to be in the role of a parent! To begin, I'd like to hear about when you first recognized that you had features of autism, and what that experience was like for you.
   a. Additional Prompts:
       i. Were you formally diagnosed? How did you find out? When did you first notice any characteristics show up for you?"
4.) **If the individual has not been previously diagnosed, refer to Interview set 2**
5.) Follow up on responses to questions
6.) **A diagnosis should not be a source of shame or blame; bolster questions with kindness, understanding, and patience. More sensitive questions may need additional lead up, front loading questions with support. See questions E, and F**

1.) **Interview questions**
   a. **Autism can impact people in so many different ways, socially, relationally, sensory aspects, emotional regulation, and attention. . . where do you see autism impacting your life in the biggest ways?**
       i. **Follow up:**
           1. **You know, a lot of people perceived the characteristics of Autism to be debilitating, however, we can see that a lot of these characteristics can be strengths! Are there any aspects of your experience with Autism that have helped you experience a more satisfying life?**
           2. **what characteristics of Autism do you see as a strength or of some benefit to you?**
   b. **Have certain things in your life shifted since you learned about your characteristics of Autism?**

  c. **(Executive Functioning based questions)**
   i. **Can you describe how daily routines like getting your child ready for school or to leave the house goes for you?**
   ii. **Tell me about a time that you focused your attention on your child. How did you know that you should bring your attention to your child in this moment?**
   iii. **Being a parent is complicated, and involves so many different moving parts. Can you talk to me about how you decide what you should do first when you have a lot of different things to do?**
   iv. **Again, being a parent often involves keeping track of so many things all at once, can you tell me about how you feel about your ability to remember things like your own and your child's appointments, schedules, etc.?**
   v. **Unfortunately, we cannot always plan for everything that could happen in our lives, or the lives of our kids. Could you describe how you manage unfamiliar or unexpected circumstances?**
   vi. **If you had a magic wand that you could wave and immediately have everything be exactly the way you wanted it to be, what would be different?**
  d. **Prior to your diagnosis, I'd like to hear about your experience as a parent.**
   i. **What are areas in which you believe you did well?**
   ii. **What are areas you believe you struggled in?**
   iii. **what beliefs about yourself did you have prior to this diagnosis?**
   iv. **Now that you have knowledge of this diagnosis, have some of these beliefs changed?**
  e. **How has your diagnosis influenced your belief in your ability to parent your children?**
   i. <u>**Potential follow up questions:**</u>
    1. **What about being a parent do you feel really confident about**
    2. **What about being a parent makes you feel overwhelmed or under supported?**
    3. **What makes you feel supported and capable?**
    4. **What strategies or supports have you developed or implemented that have increased your confidence in your parenting ability?**
  f. **How has your diagnosis influenced your confidence as a parent?**
  g. **Would you mind describing how you identify and respond when your child needs something from you?**
2.) **Supports and recommendations**
  a. **What would you recommend to a parent that learns that they have Autism, characteristics of Autism, to be as effective of a parent as possible?**

Appendix B

Parenting Interview Version 2

Parenting interview version two was created for implementation with parents who have not received a formal diagnosis of ASD. Therefore, questions asked have been formatted towards characteristic features of ASD, rather than posing questions as related to diagnostic criteria.

<u>**Questions for focus group/one on one interview Set 2 (No formal Diagnosis)**</u>
- Created for a Master's Thesis project by Jonathan Lee

<u>**Steps to set up the interview:**</u>
    1.) Build rapport, create comfort
    2.) Thank the individual for taking part in the interview
    3.) <u>"This is a study focused on learning more about adults who have characteristics or features of autism, we want to learn more about what it is like for you to be in the role of a parent! To begin, I'd like to hear about when you first recognized that you had features of autism, and what that experience was like for you.</u>
        a. <u>Additional Prompts:</u>
            i. <u>Were you formally diagnosed? How did you find out? When did you first notice any characteristics show up for you?"</u>
    4.) **If the individual has not been previously diagnosed, refer to Interview 2**
    5.) Follow up on responses to questions
    6.) **A diagnosis should not be a source of shame or blame; bolster questions with kindness, understanding, and patience. More sensitive questions may need additional lead up, front loading questions with support.**

    3.) Interview questions
        a. **These characteristics can impact people in so many different ways, socially, relationally, sensory aspects, emotional regulation, and attention. where do you see any of these factors impacting your life in the biggest ways?**
            i. **Follow up:**
                1. **You know, a lot of people perceived these characteristics to be debilitating, however, we can see that a lot of these characteristics can be strengths! Are there any aspects of your experience with these characteristics that have helped you experience a more satisfying life?**
                2. **what characteristics do you see as a strength or of some benefit to you?**

b. **Have certain things in your life shifted as a result of experiencing these features in adulthood?**
c. **(Executive Functioning based questions)**
   i. **Can you describe how daily routines like getting your child ready for school or to leave the house goes for you?**
   ii. **Tell me about a time that you focused your attention on your child. How did you know that you should bring your attention to your child in this moment?**
   iii. **Being a parent is complicated, and involves so many different moving parts. Can you talk to me about how you decide what you should do first when you have a lot of different things to do?**
   iv. **Again, being a parent often involves keeping track of so many things all at once, can you tell me about how you feel about your ability to remember things like your own and your child's appointments, schedules, etc.?**
   v. **Unfortunately, we cannot always plan for everything that could happen in our lives, or the lives of our kids. Could you describe how you manage unfamiliar or unexpected circumstances?**
   vi. **If you had a magic wand that you could wave and immediately have everything be exactly the way you wanted it to be, what would be different?**
d. **How have these features influenced your belief in your ability to parent your children?**
   i. <u>**Potential follow up questions:**</u>
      1. **What about being a parent do you feel really confident about?**
         a. **It is important to provide validation and encouragement when hearing what makes someone feel confident.**
      2. **What about being a parent makes you feel overwhelmed or under supported?**
         a. **Again, providing validation regarding the difficulties that these parents may be experiencing is important.**
      3. **What makes you feel supported and capable?**
      4. **What strategies or supports have you developed or implemented that have increased your confidence in your parenting ability?**
e. **How have these features influenced your confidence as a parent?**
f. **Prior to developing an awareness of these features, tell me about your experience as a parent.**
   i. **What are areas in which you believe you did well?**
   ii. **What are areas you believe you struggled in?**
   iii. **what beliefs about yourself as a parent did you have prior to developing an awareness of these features?**

      iv.   Now that you have knowledge of these features, have some of these beliefs changed?

g. Would you mind describing how you identify and respond when your child needs something from you?

h. What would you recommend to a parent that learns that they have features of autism, to be as effective of a parent as possible?