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Qualitative Development of Items for a Young Adult Autism Spectrum Disorder Screener

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QUALITATIVE DEVELOPMENT OF ITEMS FOR A YOUNG ADULT AUTISM
SPECTRUM DISORDER SCREENER

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By
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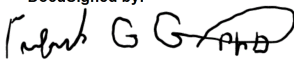
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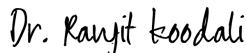
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ABSTRACT

QUALITATIVE DEVELOPMENT OF ITEMS FOR A YOUNG ADULT AUTISM
SPECTRUM DISORDER SCREENER

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by deficits across multiple domains such as deficits in social communication and restricted, repetitive patterns of behavior. The prevalence of ASD has increased over time, and while there are ample screeners and assessments for children, there is a distinct lack of screeners for young adults between the ages of 18 and 25 years. The present study focused on exploring the gap in screeners for ASD in young adults and assessing the insight of experts in the field toward the development of a screener for ASD in young adults. Participants ($N = 6$) were individuals who have earned a doctorate, have expertise diagnosing or working with individuals diagnosed with ASD, and have been working with this population for at least two years. Thematic analysis was utilized to reveal themes of the presentation of ASD in young adults between the ages of 18 to 25 years through the lens of each of the diagnostic criteria for ASD found in the DSM-5-TR. This study helps to shed light on the gap in psychological screeners for ASD, and it provides potential information for the development of a psychological screener for ASD in young adults.

Keywords: autism, screener, assessment, young adult

I dedicate this master's thesis to my Papaw, Gary McMillin, who has always believed in me to

achieve unbridled greatness in all things. Your commitment and investment in me has

encouraged me every day to work hard for the right reasons.

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Chapter 1 Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects an individual's social communication and social interactions (American Psychiatric Association [APA], 2022). The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is utilized by trained professionals to classify mental disorders, including ASD, with associated criteria for the facilitation of more reliable and valid diagnoses (APA, 2022). In the DSM-IV, ASD originally consisted of three different disorders: Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (APA, 1994). However, in 2013, the APA published the DSM-5, which combined the three different autism-related diagnoses into one broad diagnosis of Autism Spectrum Disorder (APA, 2013).

In 2022, the APA released the DSM-5-TR, which updated the diagnostic criteria of ASD to improve clarity and maintain a high diagnostic threshold (APA, 2022). New phrasing of ASD criteria aims to prevent misunderstanding and misreading of essential components that make up the diagnostic threshold. Specifically, the new phrasing utilized in the DSM-5-TR explains an individual would have to experience persistent differences in *all* the following areas: social-emotional reciprocity; nonverbal communication behaviors used in social interactions; and developing, maintaining, and understanding relationships (APA, 2022). Additionally, at least two of four types of restricted or repetitive behaviors must be present to meet DSM-5-TR criteria, which include patterns of movement or speech, sameness of routines or rituals, special and highly focused interests, and strong responses to sensations in the environment (APA, 2022). Finally, the DSM-5 originally asked professionals to specify whether a person also had "another neurodevelopmental, mental, or behavioral disorder," (APA, 2013, p. 51), but the DSM-5-TR asks professionals to specify whether a person is associated with "another neurodevelopmental,

mental, or behavioral problem," (APA, 2022, p. 57). See Table 1 for specific diagnostic criteria for ASD from the DSM-5-TR.

Table 1

Diagnostic Criteria for Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or pervasive interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Table 1, continued

C. Symptoms must be present in the early developmental period (but may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual developmental disorder (intellectual disability) or global developmental delay. Intellectual developmental disorder and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual developmental disorder, social communication should be below that expected for general developmental level.

Diagnostic and statistical manual of mental disorders (APA, 2022, pp. 56-57)

Clinicians rely on utilizing psychological assessments and screeners that are grounded in DSM-5-TR criteria to diagnose ASD. While assessing people for ASD requires advanced diagnostic skills, the current body of assessments for ASD are directed towards children, who can be diagnosed possibly as early as 12 months of age (Autism Speaks, 2018; Hedley et al., 2015; Joshi et al., 2011; Lazenby et al., 2016; Pasco et al., 2021). Developmental screening tools are frequently utilized to assess for developmental delays and potential disabilities for children, and research suggests identifying signs of ASD at earlier ages for intervention yields more positive outcomes for individuals rather than being diagnosed later in life (Autism Speaks, 2018). However, Category C of the DSM-5-TR states symptoms "…may not become fully manifest until social demands exceed limited capacity," (APA, 2022, p. 57). Thus, characteristics of ASD may not be recognized in individuals until they are older and placed in social situations that exceed their social abilities, such as school (Jordan, 2013). While individuals are in school, social and developmental gaps become more apparent between typically developing children and individuals who may meet criteria for ASD. In addition, while there are an increasing number of

individuals who are not diagnosed with ASD until later in life, there is still a lack of screening measures for ASD developed for use with individuals between the ages of 18 and 25 years (Girolamo et al., 2020; Mandy et al., 2017; Morrier et al., 2017; Volkmar et al., 2014). For the purposes of the present study, the term "young adults" refers to individuals between the age of 18 to 25 years.

With the release of the DSM-5, diagnostic criteria moved from three subcategories of autism-related disorders to a single ASD diagnosis with a multi-dimensional assessment of severity, which has been continued in the release of the DSM-5-TR (APA 2013; APA, 2022). Severity levels for ASD can be found in Table 2. The different levels of severity allowed for retaining a strong reliability for overall ASD diagnoses (Mazurek et al., 2019). However, research suggests assessments and screeners for individuals with ASD may have difficulty detecting signs of ASD for individuals with lower levels of severity than individuals with greater levels of severity (Mazurek et al., 2019; Mazurek et al., 2017; Mehling & Tassé, 2016).

Table 2

Severity Levels for Autism Spectrum Disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behaviors, extreme difficulty coping with change, or other restricted / repetitive behaviors markedly interfere with functioning in all spheres. Great/distress / difficulty changing focus or action.

Table 2, continued

Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted / repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and / or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full senses and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Diagnostic and statistical manual of mental disorders (APA, 2022, p. 58)

Purpose of the Present Study

ASD is conceptualized as a lifelong neurodevelopmental disorder, and research surrounding ASD has generally been focused on child participants (APA, 2022; Farley et al., 2018). Receiving a diagnosis of ASD later in life has been associated with transitioning from being self-critical to self-compassionate, increased agency, greater acceptance, and greater

understanding of the self, but in order to diagnose, there needs to be the necessary tools to screen for the diagnosis (Leedham et al., 2020; Legg & Tickle, 2019). Due to the field focusing on assessing children while they are young, there are ample screeners and assessments for evaluating ASD among children below the age of 12 years, but there is a gap in the availability of specific screeners for ASD for young adults (Mandy et al., 2017; Mason et al., 2021; Volkmar et al., 2014). Therefore, the purpose of the present study was to collect qualitative and assess the insight of experts in the field for the development of items to be used in a new screener for ASD in young adults. The following research question was of primary interest:

1. What items would be on a screener for ASD for individuals aged 18-25 years?

Chapter Two: Literature Review

Prevalence of Autism Spectrum Disorder

In 1943, Kanner published the first systematic description of infantile autism, and when Kanner first described the disorder, it was seen as an exceedingly rare condition that was prevalent in 2 to 4 children out of every 10,000 children (Kanner, 1943). However, the prevalence of ASD diagnoses has increased over the past few decades (Kulage et al., 2020; Maenner et al., 2020). In 1996, the Center for Disease Control (CDC) began monitoring the prevalence of ASD in metropolitan Atlanta, Georgia (Yeargin-Allsopp et al., 2003). Since the year 2000, the CDC has released biennial reports of the prevalence of ASD in various communities after the Children's Health Act of 2000 passed to establish the Autism and Developmental Disabilities Monitoring Network (Maenner et al., 2020). In 2000, the CDC estimated that 1 out of every 150 children has a diagnosis of ASD, or they have behaviors that are consistent with ASD (Christensen et al., 2016). In 2018, the CDC estimated that 1 out of every 44 children has a diagnosis of ASD, or they have behaviors that are consistent with ASD (Maenner et al., 2020).

ASD has been reported to be four times more common among males than among females, and ASD has been reported to be prevalent among all racial, ethnic, and socioeconomic groups (Maenner et al., 2020). However, the Autism and Developmental Disabilities Monitoring Network reported African American children with ASD were more likely to have an accompanying intellectual disability than Caucasian children with ASD (Maenner et al., 2020). Additionally, Caucasian children are more likely to be evaluated for ASD at younger ages than African American children (Maenner et al., 2020). Recent findings report that only 44% of children with an ASD diagnosis received their diagnosis by the age of three (Maenner et al.,

2020). While less than 1% of adults with a mild intellectual disability or no intellectual disability had an ASD diagnosis, 2 in 5 adults with moderate to severe intellectual disability have an ASD diagnosis (Brugha et al., 2016).

Social Communication and Social Interaction

Category A of an ASD diagnosis addresses deficits in social communication and social interaction. Social-communication skills are generally defined as "the ability to develop, maintain, and understand relationships," (Carter et al., 2014, p. 3) and social-communication skills allow individuals to form connections and make friendships. Category A is comprised of three criteria: difficulties with social-emotional reciprocity, deficits in nonverbal communication used for social interaction, and deficits in development, maintenance, and understanding of relationships (APA, 2022). The first criterion within Category A of an autism diagnosis addresses difficulties with social-emotional reciprocity, which is engagement in typical back-and-forth interactions (APA, 2022; Sanrattana et al., 2014). This behavior can be demonstrated through atypical social approach (e.g., difficulties greeting others or sharing information appropriate to the context), failure to initiate or respond to interactions, or a lack of shared interests, emotions, or affect (Schreiber, 2011).

There are a variety of reciprocal social-emotional behaviors that individuals with autism may exhibit (Koegel, 2007). Some examples include participating in conversations, maintaining eye contact, difficulty understanding emotions and non-verbal cues, and dwelling on certain topics (Carter et al., 2014; White et al., 2007). In typical social interactions, individuals utilize their information-processing skills to deduct social and linguistic rules for the purpose of conveying future information (Bandura, 1989). However, people with an ASD diagnosis struggle with semantic and pragmatic thinking and communication (VanBergeijk et al., 2008).

The second criterion within Category A of an ASD diagnosis is deficits in nonverbal communication used for social interactions. This can present as abnormal eye contact or body language, difficulty making inferences, a lack of understanding and use of gestures, and/or a complete lack of facial expressions (Barnhill et al., 2002). Individuals with autism not only struggle to read others' emotions, but they also struggle to regulate their own emotions, such as anxiety, depression, an increase in aggression, and self-injurious behaviors (Barnhill et al., 2002; Carter et al., 2014). Among children with ASD, 40% are primarily non-verbal or significantly delayed in verbal communication until much later into their childhood (Howlin et al., 2014). Additionally, 25% to 30% of children with an ASD diagnosis go through a pattern called regressive onset, which is when a child can speak some words at 12 to 18 months of age and then loses the ability to say these words, or the children speak with great frequency in odd or atypical ways (Barnhill et al., 2002; Howlin et al., 2004; Howlin et al., 2014; Sanrattana et al., 2014).

The third criterion within Category A of an ASD diagnosis addresses deficits in the development, maintenance, and understanding of relationships (APA, 2022). For example, the deficits in relationship-relevant behaviors range from "… difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers," (APA, 2022, p. 56). Children with ASD generally desire social interactions and friendships (Bauminger & Kasari, 2000). However, deficits in understanding relationships have been shown to hinder a person's ability to engage and form friendships (Carter et al., 2014; Howlin et al., 2004).

Compared to individuals without an ASD diagnosis, people with an ASD diagnosis were lonelier, reported having fewer quality relationships, and had a poorer understanding of how to overcome their loneliness (Bauminger & Kasari, 2000). Previous interventions for promoting

social competence and relational connections for people with an ASD diagnosis encourage an integration of student, peer, educator, occupational, and family-focused interventions (Carter et al., 2014; Koegel, 2007; Wehman et al., 2013). Howlin and colleagues (2014) defined social competence and social behavior among individuals with ASD as "… the specific ability to develop, maintain, and understand relationships (p.7)." They concluded reinforcement and reciprocity are critical components of social competence, and they stated individuals with ASD struggle with these exact components of social competence, which results in difficulties with relationship development and maintenance (Howlin et al., 2014).

Repetitive, perseverative, and stereotyped behavior

Category B of ASD includes the presence of restricted, repetitive patterns of behavior, interests, or activities (APA, 2022; VanBergeijk et al., 2008). Examples of restrictive, repetitive patterns of behavior, interests, and activities include repetitive motor movements, repetitive use of objects, echolalia, insistence on sameness, fixated interests with a high degree of intensity, and hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (APA, 2022; Howlin et al., 2004; Wehman et al., 2013). Research suggests many transition-age youth and adults without an intellectual disability or language disability learn to suppress repetitive behavior, and individuals with intense interest in specific or peculiar subjects have found motivation, education, and employment in areas concerning their special interests (APA, 2022; Farley et al., 2018; Mason et al., 2021). Therefore, developing screeners for ASD for transition-age youth and adults is more difficult due to the nature of ASD in older populations (Leedham et al., 2020; Ratto et al., 2010)

Individuals may meet the diagnostic criteria of ASD when restricted, repetitive behaviors were clearly present during childhood or at some time in the past, even if symptoms are no

longer present (APA, 2022). However, they still face difficulties with their social, sensory,

motor, and cognitive processing and functioning (Henninger & Taylor, 2013; Larsen &

Mouridsen, 1997). Research suggests people who receive an ASD diagnosis during adolescence

recognized their difficulties creating and maintaining friendships due to several factors

(Leedham et al., 2020; Mandy et al., 2017). These factors include having awkward interactions

with peers, exhibiting inappropriate social and emotional behaviors, and having limited gesture

use and facial expressions, which are due, in part, to their repetitive and stereotyped behaviors

(APA, 2013; Mason et al., 2021).

      For some with ASD, there is a preference for sameness in routines and a strict reliance on

a structured schedule, and any deviation of the routine could result in emotional outbursts,

defiance, or negative behaviors, which has been reported in newer and older research concerning

ASD (Mason et al., 2021; Rutter et al., 1967). Preservation of sameness is often exhibited by

those with ASD causing them to become anxious and perseverative about maintaining the same

routines and activities (Mason et al., 2021). Additionally, hyperreactivity and hyporeactivity to

sensory aspects of the environment can also occur (APA, 2022; Steinhausen et al., 2016).

Individuals with ASD might have atypical sensory experiences and responses; therefore, they

might have a reduced ability to respond as expected on some tasks that are thought of as routine

for most children (Howlin et al., 2013; Wilkinson et al., 2022)

      Stereotyped and repetitive behaviors can cause severe impairment in daily functioning,

and stereotyped and repetitive behaviors are one of the primary reasons for pharmacological

interventions for individuals with ASD (Staal et al., 2012). Due to this increased interest in

pharmacological interventions for individuals with ASD, research addressing the gap in studying

the neurobiological foundations of ASD has become more popularized (Jiujias et al., 2017; Staal

et al., 2012). While there is research addressing underlying neurobiological differences in individuals with ASD, externalized symptoms of ASD may be initially subtle for individuals and arise later in life (APA, 2022; Jiujias et al., 2017).

Transition into early adulthood for individuals with ASD

The third category of an autism diagnosis addresses the presence of symptoms within an individual's developmental period (APA, 2022). However, telltale symptoms of ASD may not become obvious until social demands exceed the individual's limited capacities, or the individual may mask limited social competencies through learned strategies in later life (APA, 2022; Mason et al., 2021). Earlier studies addressing long-term outcomes of individuals with ASD concluded 50% to 60% of individuals with ASD would be categorized within "poor" or "very poor" outcomes, regarding leading independent lives (Gillberg & Stefenburg, 1987; Rutter et al., 1967). While these categorizations are no longer utilized within current research among individuals with ASD, the previously mentioned research findings provide an enlightening historical context on the perceived outcomes of individuals with ASD. Additionally, while much of the existing research on ASD has focused on infants and children, more recent studies have begun to focus on the presentation and diagnosis of ASD among transition-age youth and young adults (Farley et al., 2018; Lounds Taylor, 2017; Mason et al., 2021).

Studies measuring outcomes among individuals with ASD have sought to conceptualize outcomes for these individuals through alternative frameworks (Howlin et al., 2004; Mason et al., 2021). For example, Howlin et al. (2004) measured outcomes across three distinct domains: independent living, employment, and friendships/romantic relationships. Currently, existing data seeks to identify individual characteristics that may predict outcomes, and general outcomes for adult individuals with ASD are generally identified as poor in terms of independence,

employment, and relationships (Mason et al., 2021). Over fifty percent of individuals with an ASD diagnosis do not achieve an independent living status, employment, or close relationships outside the home, which agrees with previous meta-analyses with similar samples (Mason et al., 2021; Rutter et al., 1967; Steinhausen et al., 2016). Predictive variables of outcomes for individuals with ASD are the individual's intelligence quotient (I.Q.), symptom severity, and degree of language functioning (Farley et al., 2009; Howlin et al., 2013; Mason et al., 2021). However, some studies have argued the concept of an individual's 'outcome' to be reductive in nature since it only assumes individual factors affect outcome rather than broader familial and contextual status (Farley et al., 2018; Larsen & Mouridsen, 1997; Mason et al., 2021).

An individual's quality of life is generally conceptualized as a person's perception of satisfaction with their daily life, which can be an individual's perception of well-being, life-satisfaction, functioning, and health (Quilty et al., 2003). While an individual's quality of life stretches across many domains, research suggests employment, communication level, autonomy, and social involvement are significant predictors of predicting higher quality of life (Mason et al., 2021). However, individuals with ASD struggle across all domains of adult life such as independent living, employment, post-secondary education, community engagement, and social integration (Newman et al., 2011). Additionally, while I.Q. has been identified as the strongest protector against poor outcome profiles, it does not guarantee good outcomes for individuals with ASD (Pickles et al., 2020). Transitioning from childhood to early adulthood is often difficult for all people, and challenges associated with adolescents on the spectrum transitioning from school to adulthood has only recently started attracting attention from researchers (Wehman, 2013).

Assessing

Assessing individuals for ASD requires good, valid, and reliable assessments and screeners, especially if they are adolescents, young adults, minorities, or have been exposed to maltreatment (Girolamo et al., 2020; Wilkinson et al., 2022). Research suggests individuals with an ASD diagnosis have similarities with individuals exposed to maltreatment during childhood including difficulties understanding and maintaining relationships, social interactions, emotional expression and reciprocity, sensitivity to schedules and routine, and hyper- or hyporeactivity to sensory inputs, which all may affect assessment and diagnosis (Wilkinson et al., 2022). Additionally, the creation of diagnostic assessments and participant samples in ASD research have frequently utilized upper middle class, Caucasian children from Western countries to develop normative samples (Durkin et al., 2015). While assessing for ASD requires special attention and expertise, research suggests adults receiving a diagnosis of ASD later in life experienced greater acceptance and understanding of the self, decreased self-criticism, increased self-compassion, and an increased sense of agency (Leedham et al., 2020).

Undiagnosed adults have a high risk of experiencing functional and emotional difficulties due to their undiagnosed ASD (Volkmar et al., 2014). However, deficits in social functioning are universal across the spectrum and generally persist through the lifespan, and the primary challenge of transition-age youth and adults with undiagnosed ASD is social difficulties (Ratto et al., 2010; Volkmar et al., 2014). Social-communication skills are critical in adolescence and young adulthood, but individuals with ASD struggle with social interactions, negatively influencing achieving independence in adulthood (Ratto et al., 2010). Due to difficulties understanding social rules and expectations, conversing in a reciprocal manner, and social avoidance, there is a general lack of professional knowledge about adults with ASD and a lack of

access to quality services (Volkmar, 2013). This lack of knowledge and access to services leads to many adults with ASD being diagnosed later in life (Volkmar, 2013). Additionally, individuals who were not diagnosed with ASD until later in life experienced poor support, being misunderstood, and negative consequences for their functioning and wellbeing prior to diagnosis (Bargiela et al., 2016).

In developing assessments and screeners for ASD, researchers have mentioned difficulty in discriminating ASD from non-ASD (Joshi et al., 2011; Mandy et al., 2017; Morrier et al., 2017). This is due, in part, because research suggests individuals who are administered an ASD assessment may attempt to camouflage symptoms of ASD when they would otherwise meet criteria for ASD (Belcher et al., 2021). Additionally, individuals who do not meet criteria for ASD may attempt to malinger or feign symptoms to receive an ASD diagnosis (Belcher et al., 2021; Mason et al., 2021). Therefore, screeners for ASD for adolescents and young adults must account for the suppression of repetitive behaviors and subtlety of externalized symptoms of ASD in some individuals (Ashwood et al., 2016; Volkmar et al., 2014).

Current Screeners

While the prevalence of ASD diagnoses is increasing, there is a lack of representative and reliable screeners for young adults (Maenner et al., 2020). For example, the Autism-Spectrum Quotient (AQ) has been developed as a self-report measure of ASD for individuals 16 years and above (Allison et al., 2012). Since its inception, the AQ has been cited by clinicians and researchers in the singular systematic review of the AQ as an effective tool for screening ASD (Ruzich et al., 2015). However, more recent research has called into question the reliability and validity of the AQ, suggesting the screener may not be as clinically useful as previously established (Jia et al., 2019). While there may be a lack of valid and reliable ASD screeners for

individuals between 18 and 25 years, there are many other current ASD screeners available for clinicians to utilize in their practice also screen for other psychopathology.

The Behavior Assessment System for Children, Third Edition (BASC-3; Reynolds & Kamphaus, 2015) has long been utilized by clinicians as a multidimensional, multimethod system of assessing an individual's emotional and behavioral functioning, while also screening for psychopathology (Reynolds & Kamphaus, 2015). While this screener has items that load onto symptomology of ASD, the scales are not directly constructed for screening ASD (Reynolds & Kamphaus, 2015). For example, when the Developmental Social Disorders content scaled score of the BASC-3 is elevated while the Conduct Problems and Aggression scaled scores of the BASC-3 are not elevated, it could be indicative of ASD (Reynolds & Kamphaus, 2015). Additionally, when the Withdrawal, Atypicality, and Attention Problems scaled scores of the BASC-3 are elevated, it could be indicative of ASD, but since the BASC-3 does not directly screen for ASD, clinicians run the risk of improperly guiding the assessment, diagnosis, and treatment for clients (Reynolds & Kamphaus, 2015).

To say there is an overall lack of screeners for ASD would be incorrect. The field is replete with screeners for ASD, but these screeners are directed towards early childhood. In 2022, the CDC released a web page to provide health care providers with a list of screeners and diagnostic instruments for ASD (CDC, 2022). On this web page, there are no recommended ASD screeners for individuals over the age of 36 months (CDC, 2022). Similarly, the Autism Research Institute (ARI) released a web page that listed ASD screening and assessment tools for clinicians to use, and none of the listed screening tools were for individuals over the age of 36 months (ARI, n.d.).

The Autism Spectrum Rating Scales (ASRS; Goldstein & Naglieri, 2009) is a screening instrument utilized by many clinicians to help guide diagnostic decisions concerning ASD for individuals aged 2 through 18 years. Goldstein (2021) argued due to the recognition and prevalence of ASD rising, the need for valid and reliable screening tools is critical. The literature could not agree more (Maenner et al., 2020; Mason et al., 2021). However, since the ASRS has an age range of 2 through 18 years, there is a need for a new, valid, and reliable ASD screener for young adults (Goldstein & Naglieri, 2009). Therefore, the development of a screener for ASD in young adults may be necessary.

Chapter Three: Methodology

Justification for a Qualitative Approach

Qualitative research enables the researcher to collect diverse, critical data; elicit

comprehensive and complete patterned responses that address the research question; and analyze

the meaning within the data set (Braun & Clarke, 2006). The data collected was non-numerical

in nature, and the data comprised of experts' individual opinions, beliefs, and suggestions. With

the goals of the present investigation, qualitatively analyzing the data most effectively elicited

meaningful, useful, and practical results. Therefore, conducting a qualitative research study was

the best methodology to achieve this goal.

Participants

Purposeful sampling was utilized to recruit experts in the field of ASD who have a strong

understanding of ASD assessment and the psychometric properties associated with ASD

screeners. The sample size of a basic qualitative study generally ranges from 6 to 10 participants

(Creswell & Clark, 2007; Haase, 1987). Therefore, the target goal for recruitment of participants

involved a total of six professionals who have earned a doctoral degree and have expertise

working with individuals diagnosed with ASD. The participants must work or have worked

closely with individuals with an ASD diagnosis. Participants were recruited from agencies that

offer ASD assessments and college universities.

A total of eight professionals participated in the present study, but due to not completing

the entire survey and not meeting inclusion criteria, two of the participants were excluded from

the study, which resulted in a sample of six participants. For the respondents that did not meet

inclusion criteria, one individual had less than three years of experience with autism, and one

individual did not complete the entire survey. The mean age of the experts was 36.33 years (*SD*

= 4.93). All professionals who participated earned a doctorate, and they all reported having

expertise diagnosing or working with individuals diagnosed with ASD. Professionals reported an

average of 7.3 (SD = 2.79) years of experience working with and/or studying individuals with

ASD.

When examining demographics, the sample revealed little diversity amongst

professionals with respect to race/ethnicity. All participants were Caucasian (n = 6, 100%). There

were two (33%) male participants, four (66%) female participants, and no participants who

identified as other possible genders. No participants identified as Hispanic or Latinx.

In terms of services rendered to individuals diagnosed with ASD, each participant

reported engagement in more than one domain of services rendered to individuals diagnosed

with ASD. Five participants (83%) reported administering diagnostic assessments and

diagnosing individuals with ASD. Four participants (66%) reported administering psychotherapy

to individuals diagnosed with ASD, and two participants (33%) indicated engaging in

supervision of diagnostic assessment. One participant (16%) reported supervising treatment for

individuals diagnosed with ASD, and one participant (16%) reported conducting research

concerning ASD. Finally, one participant (16%) reported running a clinic that specializes in

treatment for ASD. See Table 3 for additional information.

Measures

There were two measures utilized for the present research study: a demographic survey

and an open-ended survey. The demographic survey comprised of a set of questions to assess

gender, age, ethnicity, professional qualifications, years of experience, and involvement level of

services rendered to the target population (e.g., duties, areas of specialty). The demographic

questionnaire is in Appendix A.

Table 3

Experience with Autism

Respondent	Years of experience	Involvement with autism
1	9-11	Run a clinic that specializes in providing treatment for individuals with autism; conduct individual and group therapy to children and adults with autism; also provide autism assessments.
2	6-8	Supervise and assess a number of neurodevelopment disabilities including ASD. I provide group and individual intervention for individuals on the spectrum.
3	3-5	ASD assessment and diagnosis + supervision of diagnosis & treatment.
4	6-8	I evaluate and diagnose Autism, and I have been most frequently seeing adolescents and young adults.
5	6-8	I implement behavioral interventions for people with autism. I provide diagnostic assessment for autism.
6	12+	Research, teaching, and providing interventions for youth and adults with autism.

The second instrument was an open-ended survey to collect the insight of experts in the field for the development of items for a new ASD screener directed towards young adults. An open-ended survey allows for the collection of rich data to identify, analyze, and report patterns within data to serve as a foundation for the development of an ASD screener. The open-ended survey questions can be found in Appendix B.

Research Design

Thematic analysis (Braun & Clarke, 2006) was used to identify, analyze, and interpret patterns in the data. Thematic analysis has been established as a useful and enriching method of conducting qualitative research, which captures essential data in relation to the research question,

elicits patterned responses, and analyzes meaning within the data set (Braun & Clark, 2006). Data were collected via survey, and each response was read through three times before coding. Coding was conducted by the thesis author and a graduate student within the Department of Psychology at Western Kentucky University. Codes were grouped into analytical and descriptive themes. Inter-rater agreement must be .80 or higher to consider a code valid, and inter-rater agreement was .94 for the coding of all responses in the present study, which is considered adequate (Gisev et al., 2013).

Procedure

Approval from the Institutional Review Board (IRB) of Western Kentucky University was received before the collection of data for the present study. Participants accessed the study via the Western Kentucky University Department of Psychology Qualtrics website. The study was completed online and in one sitting. Participants first had to consent to participate in the study by digitally agreeing to an informed consent document. Participants then filled out demographic information regarding gender, age, ethnicity, professional qualifications, years of experience, and involvement level of services rendered to the target population (e.g., duties, areas of specialty). Participants then completed the open-ended survey regarding the development of items for a new ASD screener directed towards young adults. There was not a word limit for these questions to allow for the collection of rich, thorough data. The study was projected to take approximately between 15 to 20 minutes to complete.

Data Analysis

Thematic analysis allows researchers the ability to systematically link qualitative data to a series of broad concepts, or themes (Braun & Clarke, 2006). As such, a qualitative thematic analysis, following the six-phase guidelines set forth by Braun and Clarke (2006), was conducted

by the research team to analyze the open-ended responses gathered from participants. These survey items included in the present study can be found in Appendix A and Appendix B. Each response was independently coded by the thesis author and a graduate student within the Department of Psychology at Western Kentucky University, and the independent codes were then compared for interrater agreement. If codes differed, data were either recoded or placed into a new code, which is considered the correct course of action (Braun & Clarke, 2006).

Phase one of conducting a thematic analysis is *familiarization*, where the researchers observe and acquaint themselves with the data (Braun & Clarke, 2006). Phase two of conducting a thematic analysis is *coding*, where the researchers highlight sections and phrases of the data and develop shorthand labels for the content (Braun & Clarke, 2006). Phase three of conducting a thematic analysis is *generating themes*, where researchers may combine several shorthand labels into one overarching theme of the data (Braun & Clarke, 2006). Phase four of conducting a thematic analysis is *reviewing themes*, where researchers return to their original data and juxtapose them with the elicited themes (Braun & Clarke, 2006). Phase five of conducting a thematic analysis is *defining and naming themes*, where themes are operationalized to conceptualize how they assist in understanding the data (Braun & Clarke, 2006). Phase six of conducting a thematic analysis is *writing up*, where the analysis of the data is comprehensively explained to describe the process of how the thematic analysis itself was conducted (Braun & Clarke, 2006).

Chapter 4: Results

The research question for this thesis sought to determine what items would be on a screener for ASD for individuals aged 18-25 years. To fully answer this question, experts in ASD completed a survey concerning the presentation of ASD in individuals between the ages of 18 to 25 years, which assessed this presentation of ASD through the lens of each of the ASD criteria in the DSM-5-TR (APA, 2022). A total of 66 items were extracted from the 11 open-ended response questions, and the data from respondents ($n = 6$) were analyzed, with some contributions fitting more than one theme per item. These contributions were counted more than once, dependent on the number of themes they met. See Table 4 for the results of the thematic analysis.

Through the lens of the ASD criteria in the DSM-5-TR, the implications of understanding the presentation of ASD in this age group allows for a greater understanding of recurring themes and the overarching display of ASD in this age group (APA, 2022). Through understanding the recurring themes, individual questions and items that are drawn from the recurring, dominant themes can be developed for an ASD screener. Themes were assessed concerning each of the domains necessary for an ASD diagnosis, and results of emergent themes for each survey question are discussed.

Deficits in Social-Emotional Reciprocity

For the first question, "*What are signs/symptoms of clients in the age range of 18-25 for deficits in social-emotional reciprocity*," six (100%) participants responded. All responses were categorized into four major, broad themes, including (a) deficits in reciprocal conversations, (b) deficits in empathy, (c) deficits in matching emotions, and (d) literal conversations.

Table 4

Thematic Analysis Results

Theme	N (%)
1. What are signs/symptoms of clients in the age range of 18-25 for deficits in social-emotional reciprocity	
deficits in reciprocal conversations	5 (83.3%)
deficits in matching emotions	4 (66.7%)
deficits in empathy	3 (50.0%)
literal conversations	1 (16.7%)
2. What are signs/symptoms of clients in the age range of 18-25 for deficits in nonverbal communicative behaviors used for social interaction	
deficits in understanding nonverbal behaviors	5 (83.3%)
limited affect	3 (50.0%)
deficits in social matching	2 (33.3%)
3. What are signs/symptoms of clients in the age range of 18-25 for deficits in developing, maintaining, and understanding relationships	
deficits in social skills	4 (66.7%)
difficulties understanding relationship components	4 (66.7%)
lack of relationships	2 (33.3%)
behavioral rigidity	2 (33.3%)
4. What are signs/symptoms of clients in the age range of 18-25 for stereotyped or repetitive motor movements, use of objects, or speech	
atypical motor movements	6 (100.0%)
repetitive speech	2 (33.3%)
use of objects	3 (50.0%)
5. What are signs/symptoms of clients in the age range of 18-25 for insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior	
inflexibility of rules/routines	5 (83.3%)
intense distress at disruption of routine/rules	4 (66.7%)
verbal repetition	2 (33.3%)
6. What are signs/symptoms of clients in the age range of 18-25 for highly restricted, fixated interests that are abnormal intensity or focus	
negative social impact of fixated interest	5 (83.3%)
special interest	4 (66.7%)
impacts functioning	4 (66.7%)

Table 4, continued

7. What are signs/symptoms of clients in the age range of 18-25 for hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment	
impairment in functioning	5 (83.3%)
seeking sensations	4 (66.7%)
avoiding sensations	4 (66.7%)
8. Behaviors or characteristics that would make you consider ruling out ASD	
developmental delay	4 (66.7%)
communication deficits	2 (33.3%)
compulsory behaviors	2 (33.3%)
rigidity of daily schedule	2 (33.3%)
9. Open-ended questions	
social-emotional reciprocity	3 (50.0%)
abstract reasoning	3 (50.0%)
insistence on sameness/routines	2 (33.3%)
history	2 (33.3%)
10. How would you prefer the questions to be formatted	
yes/no	0 (0.0%)
ranges	5 (83.3%)
other	1 (16.7%)
11. This screener should be filled out by the…	
clinician	1 (16.7%)
client	1 (16.7%)
other	4 (66.7%)

Participants reported deficits in reciprocal conversations ($n = 5$ responses) as the primary theme of deficits in social-emotional reciprocity. Several respondents reported, "lack of a back-and-forth in conversation," and "difficulty engaging in and continuing conversations about topics that are not interesting to them," as strong indicators of deficits in social-emotional reciprocity. One participant reported how individuals with ASD may attempt to redirect the conversation back to one of their own interests, regardless of whether the other person is interested in the topic or not. Other professionals reported a "lack of modulating levels of formality contingent on the

person they are speaking to," and a "lack of eye contact" as indicators of deficits in social-emotional reciprocity.

Respondents also reported deficits in matching emotions ($n = 4$ responses) as an indicator of deficits in social-emotional reciprocity. For example, respondents stated, "flat mood/affect in communication," and the "inability to match the emotions of another person with whom they are engaged in conversation," would mark a deficit in social-emotional reciprocity. Additionally, the theme of deficits in empathy ($n = 3$ responses) arose from responses such as, "difficulties understanding/empathizing with other people," and "difficulty taking others' perspectives." Finally, one respondent ($n = 1$) stated, "difficulties grasping abstract questions/abstract reasoning – takes conversations literally." While taking conversations literally was not represented in enough responses to create a theme, it does elicit an important facet of this criterion.

Deficits in Nonverbal Communicative Behaviors Used for Social Interaction

For the second question, "*What are signs/symptoms of clients in the age range of 18-25 for deficits in nonverbal communicative behaviors used for social interaction*," six (100%) participants responded. All responses were categorized into three major, broad themes, including (a) deficits in understanding nonverbal behaviors, (b) limited affect, (c) deficits in social matching.

Deficits in understanding nonverbal behaviors ($n = 5$ responses) was the most frequently answered theme for this question. Participants responded with answers such as, "inability to accurately identify social cues," and, "Difficulties understanding the nonverbal behaviors of other people." Additionally, one responded provided specific examples for this answer by answering, "No eye contact, no social cue readability."

A second theme that emerged from the thematic analysis was limited affect ($n = 3$ responses), with participants providing responses such as, "limited range of affect," and, "Expressing a limited range of facial expressions." The final theme that emerged from this question was the theme of social matching ($n = 2$ responses). Respondents provided answers such as, "Difficulty matching expressions and gestures to content," and, "body language that are matched to what I'm talking about or what they are talking about."

Deficits in Developing, Maintaining, and Understanding Relationships

For the third question, "*What are signs/symptoms of clients in the age range of 18-25 for deficits in developing, maintaining, and understanding relationships*," six (100%) participants responded. All responses were categorized into four major, broad themes, including (a) deficits in social skills, (b) difficulties understanding relationship components, (c) lack of relationships, and (d) behavioral rigidity.

The theme of deficits in social skills ($n = 4$) emerged with participants' responses including items such as, "Difficulty taking others' perspectives … Difficulty with reciprocation," and "inability to provide proper care and attention to significant others in romantic relationships." Another similar theme that arose from this question was difficulties in understanding relationship components ($n = 4$). For example, respondents reported a "lack of understanding how to create friendships or the importance of relationships, sees familial relationships as the only important relationships to keep," and "inability to describe friendships, inability to describe other intimate relationships like romantic relationships," as important aspects of conceptualizing the presentation of deficits in developing, maintaining, and understanding relationships.

Lack of relationships ($n = 2$) was a theme of this question, with one respondent stating, "Few or no meaningful relationships … lack of involvement in hobbies that involve others." Another respondent wrote, "Lack of social group/interactions." Finally, the theme of behavioral rigidity ($n = 2$) arose with two participants writing "Behavioral rigidity," and "Behavioral rigidity with relationships."

Stereotyped or Repetitive Motor Movements, Use of Objects, or Speech

For the fourth question, "*What are signs/symptoms of clients in the age range of 18-25 for stereotyped or repetitive motor movements, use of objects, or speech*," six (100%) participants responded. All responses were categorized into three major, broad themes, including (a) atypical motor movements, (b) repetitive speech, and (c) use of objects.

The most prevalent theme that arose from this question was atypical motor movements ($n = 6$ responses). Respondents mentioned "rocking," "flapping," and "atypical finger movements" as key components to atypical motor movements. Another respondent stated "stimming" was an important descriptor of stereotyped or repetitive motor movements. However, one respondent supplied the answer "Rocking during concentration/testing/enjoyment of tasks," which provides an intriguing contingency on the presentation of stereotyped, atypical motor movements.

A second theme that arose from the analysis was repetitive speech ($n = 2$ responses). Respondents provided answers such as, "repetition of specific words or phrases," or "repeating the same words or phrases over and over," which were coded as falling under the repetitive speech theme. The final theme that emerged from this question was the use of objects ($n = 3$ respondents). One participant stated, "Ordered objects in room, maybe ordering personal materials or supplies like car parts in the garage," as an example of the use of objects.

Insistence on sameness, Inflexible Adherence to Routines, or Ritualized Patterns of Verbal or Nonverbal Behavior

For the fifth question, "*What are signs/symptoms of clients in the age range of 18-25 for insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior*," six (100%) participants responded. All responses were categorized into three major, broad themes, including (a) inflexibility of rules/routines, (b) intense distress at disruption of routine/rules, and (c) verbal repetition.

For this question, participants consistently responded with the theme of inflexibility of rules/routines ($n = 5$ responses). For example, one respondent stated, "Keeps a mental or physical schedule of planned events that is inflexible and rigidly kept," and another respondent similarly stated "Has routines that must be abided by and followed." A second theme that emerged from the answers from this question was intense distress at disruption of routine/rules ($n = 4$ responses). Respondents mentioned similar descriptions of "intense feelings of distress," "anxiety," and "strong reactions" when a disruption occurs in their schedule. The final theme that emerged from this question was verbal repetition ($n = 2$ response), with one respondent stating, "saying the same phrase or sentence repeatedly."

Highly Restricted, Fixated Interests That Are Abnormal in Intensity or Focus

For the sixth question, "*What are signs/symptoms of clients in the age range of 18-25 for highly restricted, fixated interests that are abnormal in intensity or focus*," six (100%) participants responded. All responses were categorized into three major themes, including (a) negative social impact of fixated interest, (b) special interest, and (c) impacts functioning.

The theme of negative social impact of fixated interest ($n = 5$) arose as a strong theme for this question. Participants responded with answers such as, "Discuss fixated interest even if other

person is uninterested, excitable and keeps individuals socially hostage while in conversation about their fixated interest," and "Tendency to want to discuss that topic and direct conversation to that topic regardless of the other person's interest." This first theme paired well with the second theme that arose from this question, which was the theme of special interest ($n = 4$). Participants answered this question with responses such as, "Intense interests in highly specific topics," and "they have highly restricted, fixated interests." Finally, the third theme of impacts functioning ($n = 4$) arose, which was conceptualized from answers such as, "They may spend excess time acquiring, reading about, and engaging in this interest and it may have adverse effects on other areas of their life," "consuming and isolating," and "engaging in activities to a degree that negatively impacts other areas of functioning."

Hyper- or Hyporeactivity to Sensory Input or Unusual Interest in Sensory Aspects of the Environment

For the seventh question, "*What are signs/symptoms of clients in the age range of 18-25 for hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment,*" six (100%) participants responded. All responses were categorized into three major themes, including (a) impairment in functioning, (b) seeking sensations, and (c) avoiding sensations.

Most participant responses held a consistent theme of impairment in functioning ($n = 5$ responses). Responses included content such as, "Inability to complete tasks due to certain sensory input," and "apparent indifference to painful stimuli, not noticing a peer in class or at work has started talking and talking over them." This theme also included content related to restricted eating, including answers such as, "Restricted eating to several specific foods/meals," and "Extreme picky eating."

A second theme that arose from the thematic analysis of this question included seeking sensations (*n* = 5). Responses included content such as, "Seek out … more noise… Excessively engage in specific tactile sensations, displays unusual interest in specific sensations," and "Seeks out sensory input (compression, lights, sounds, etc.)." Finally, the third theme of avoiding sensations (*n* = 3) was present. Participants suggested individuals with ASD between the ages of 18 to 25 display hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment through avoiding sensations, with responses such as, "Avoidant of social engagements in large crowds… avoiding sensory input. Avoidant/forgetful of hygiene," and "Seek out less… noise, avoid… specific tactile sensations."

Ruling out ASD

For the eighth question, "*Suppose a person in the age range of 18 to 25 was referred to you to consider the possibility of ASD. Some indicators of ASD are present. Other than the obvious indicators that a person does not have ASD (e.g., Has appropriate social-communication and social interaction skills that clearly do not meet DSM-5 criteria), what are some examples of behaviors or characteristics that would make you consider ruling out ASD,*" six (100%) participants responded. All responses were categorized into four themes, including (a) developmental delay, (b) communication deficits, (c) compulsatory behaviors, and (d) rigidity of daily schedule.

Participants noted developmental delay (*n* = 4 responses) as a key domain to ask about when considering ruling out ASD. Participants answered this question with responses such as, "No developmental delays," and, "lack of caregiver input into ASD symptoms in early development." A secondary theme that arose from this question was the concept of communication deficits (*n* = 2 responses). Respondents included answers stating, "Difficulty

understanding others' perspectives Difficulty modulating communication formality between different groups of people (peers, professors, bosses, parents, etc.)," and "eye contact."

The third theme that arose from this question was the concept of compulsatory behaviors ($n = 2$ responses), which included responses such as, "Testing for OCD symptoms," and "Difficulty with reciprocity perseverative behaviors." Finally, the concept of rigidity of daily schedule ($n = 2$ response) emerged as a theme for this question. One respondent highlighted ruling out ASD through providing questions such as, "tell me about your daily schedule. What would happen if you did not follow your schedule?"

Open-Ended Questions

For the ninth question, "*If a screener for those 18-25 were developed, what are some open-ended questions that would be helpful to ask the person being evaluated that might provide information on the presence or absence of ASD,*" six (100%) participants responded. All responses were categorized into four themes, including (a) abstract reasoning, (b) social-emotional reciprocity, (c) insistence on sameness/routines, and (d) history.

Participant feedback elicited the first theme of abstract reasoning ($n = 3$ responses) through answers such as, "What happens if your plans for a particular day change," and "Abstract reasoning questions." The second theme to arise from this question includes social-emotional reciprocity ($n = 3$ responses). Participants provided answers such as, "Assessing lack of social-emotional understanding, etc. (e.g., what would happen if you broke your schedule? Describe how to make a friend)," and "How do you get along with others? How do you know how someone else is feeling? How do you solve conflicts?"

The third theme to arise from this question includes insistence on sameness/routines ($n = 2$ response), which one respondent answered this question stating, "Describe your typical day."

Finally, the topic of history (n = 2 response) includes an answer of, "Trauma history, transition from high school to whatever was next in their life."

Formatting

For the tenth question, "*How would you prefer the questions to be formatted*," six (100%) participants responded. All responses were categorized into two options, specifically (a) ranges and (b) other.

Participants predominantly answered this question with the choice of ranges (n = 5 responses). Participants answered with a variety of different ranges, including answers such as, "Ranges, SD-SA," "Ranges – Strongly disagree / never – strongly agree / always," and "Ranges 1-5." Additionally, one researcher chose to answer this question with the other (n = 1 response) option, and they stated they believed "open" would be the best option for completing this survey.

Who Fills Out the Screener?

For the eleventh question, "*This screener should be filled out by the…*," six (100%) participants responded. All responses were categorized into three options, including (a) client, (b) clinician, and (c) other. Participants responded heavily with the "other" (n = 4 responses) option, with 2 responses including, "Both client & clinician," one response including, "Client & caregiver," and one response stating, "Clinician orally administering." One participant selected the "Clinician" option (n = 1 response), and one participant selected the "Client" option (n = 1 response).

Chapter 5: Discussion

Review of the Results

The purpose of the present study was to qualitatively assess the insight of experts in ASD for the development of items to be used in an ASD screener for individuals 18 to 25 years of age. Therefore, the research question utilized in the present study was, "What items would be on a screener for ASD for individuals aged 18-25 years?" To fully answer this research question, individuals with a doctoral degree and expertise working with persons diagnosed with ASD completed a survey designed to elicit insight in the presentation of ASD for people between the ages of 18 and 25 years.

The survey addressed each criterion of ASD from the DSM-5-TR as it would appear for individuals between the ages of 18 and 25 years (APA, 2022). Additionally, research suggest there has been difficulty in discriminating ASD from non-ASD during the development of assessments and screeners for ASD (Joshi et al., 2011; Mandy et al., 2017; Morrier et al., 2017). Therefore, the survey included one open-ended question asking participants to list behaviors or characteristics that would make them consider ruling out ASD. The participants were then asked to provide open-ended questions that would be helpful to ask the person being evaluated to provide information supplemental information on the presence or absence of ASD. Finally, the participants were asked two questions concerning the formatting of the screener and who should complete the screener. The thesis author and a graduate student within the Department of Psychology at Western Kentucky University thematically analyzed and coded the responses to produce the following results.

With respect to deficits in social-emotional reciprocity, experts noted individuals within this age group display themes of deficits in reciprocal conversations, deficits in matching emotions, deficits in empathy, and taking conversations literally. Research suggests there are a

variety of reciprocal social-emotional behaviors that individuals with autism may exhibit (Koegel, 2007). However, this theme is consistent with the literature, which suggests individuals with ASD struggle with sematic and pragmatic thinking and communication (VanBergeijk et al., 2008). Additionally, young adults with autism struggle with reading others' emotions; regulating their own emotions, such as anxiety, depression, aggression; and engaging in self-injurious behaviors (Barnhill et al., 2002; Carter et al., 2014). Therefore, prospective sample items for this section include "I have difficulties talking to people for extended periods of time," "My mood generally remains neutral while other people are expressive," and "I have difficulties feeling what other people are feeling."

For deficits in nonverbal communicative behaviors used for social interaction, themes of deficits in understanding nonverbal behaviors, limited affect, and social matching emerged as consistent themes for this question. In the literature, young adults with ASD can present with abnormal eye contact or body language, difficulty making inferences, a lack of understanding and use of gestures, and/or a complete lack of facial expressions (Barnhill et al., 2002). Additionally, supplemental research confirms this theme due to individuals with ASD struggling with maintaining eye contact and difficulty understanding emotions and non-verbal cues (Carter et al., 2014; White et al., 2007). Prospective sample items for this section include "I have a hard time picking up what people are trying to say nonverbally," and "My affect is neutral more often than not."

Concerning deficits in developing, maintaining, and understanding relationships, emerging themes were conceptualized as deficits in social skills, difficulties understanding relationship components, lack of relationships, and behavioral rigidity. These themes are consistent with the research because research suggests individuals with ASD generally desire

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social interactions and friendships (Bauminger & Kasari, 2000). However, deficits in understanding relationships have been shown to hinder a person's ability to engage in and form friendships (Carter et al., 2014; Howlin et al., 2004). Additionally, compared to individuals without an ASD diagnosis, people with an ASD diagnosis were lonelier, reported having fewer quality relationships, and had a poorer understanding of how to overcome their loneliness, which is consistent with the present findings (Bauminger & Kasari, 2000). Prospective sample items for this section include "I have a hard time making new friends," and "I understand how to make people comfortable and engaged while I talk to them."

For the domain of stereotyped or repetitive motor movements, use of objects, or speech, there were the prevalent themes of atypical motor responses, repetitive speech, and use of objects. The current research suggests many transition-age youth and adults without an intellectual disability or language disability learn to suppress repetitive behavior, and individuals with intense interest in specific or peculiar subjects have found motivation, education, and employment in areas concerning their special interests (APA, 2022; Farley et al., 2018; Mason et al., 2021). Some of the responses mentioned from the experts included stereotyped or repetitive motor movements based on contingent circumstances, such as when an individual is enjoying a task that requires their concentration. Therefore, as the research and results suggest, while some individuals have learned to suppress their repetitive behaviors, there are still contingencies in which the repetitive behaviors can arise. Additionally, individuals may meet the diagnostic criteria of ASD when restricted, repetitive behaviors were clearly present during childhood or at some time in the past, even if symptoms are no longer present (APA, 2013). Prospective sample items for this section include "When I'm having fun, uncomfortable, or concentrating, I tend to

rock in my seat, flap my hands, or do something other people may consider atypical," and "I sometimes say the same word or phrase over and over again."

Concerning insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior, the themes of inflexibility of rules/routines, intense distress at disruption of routine/rules, and verbal repetition were elicited. The current body of research with ASD aligns with these emergent themes. For example, for young adults with ASD, there is a strong likelihood of a preference for sameness in routines and a strict reliance on a structured schedule (Mason et al., 2021; Rutter et al., 1967). Preservation of sameness is often exhibited by those with ASD causing them to become anxious and perseverative about maintaining the same routines and activities (Mason et al., 2021; Rutter et al., 1967). Prospective sample items for this section include "I have a daily routine I follow very closely," and "If my routine is disrupted, I become anxious."

The domain of highly restricted, fixated interests that are abnormal intensity or focus elicited themes such as negative social impact of fixated interest, special interests, and negatively impacts functioning. These themes are consistent with ASD research suggesting young adults with ASD with intense interest in specific or peculiar subjects have found motivation, education, and employment in areas concerning their special interests (APA, 2022; Farley et al., 2018; Mason et al., 2021). However, the intense interest in specific or peculiar subjects can cause functional impairments in daily living for young adults (Mason et al., 2021). Prospective sample items for this section include "I have an intense interest in a niche subject matter not many other people understand," and "The things I'm interested in seem to make other people disinterested or uncomfortable."

For hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment, the themes of impairment in functioning, seeking sensations, and avoiding sensations arose from the thematic analysis. Research surrounding hyper- or hyporeactivity to sensory input suggests individuals with ASD might have atypical sensory experiences and responses (Howlin et al., 2013). Therefore, they might have a reduced ability to respond as expected on some tasks that are thought of as routine for most individuals (Howlin et al., 2013; Wilkinson et al., 2022). Additionally, individuals with ASD may experience hyperreactivity and hyporeactivity to sensory aspects of the environment, but some individuals with ASD learn to suppress their negative reactions to sensory inputs (Steinhausen et al., 2016; Wilkinson et al., 2022). Prospective sample items for this section include "I avoid certain sensations or noises," "I seek out certain sensations or noises," and "My seeking/avoiding certain sensations or noises has negatively influenced me in several ways."

Prospective sample items for the section of Ruling out ASD include "I achieved all developmental milestones at the expected time and rate," "I have difficulties communicating with others," "I engage in behaviors or mental acts that are repetitive because I feel compelled to do them," and "I have a rigid daily schedule." Additionally, noting trauma history is an interesting contribution, due to research suggesting individuals with an ASD diagnosis have similarities with individuals exposed to maltreatment during childhood (Wilkinson et al., 2022). The article cites examples of ASD looking like maltreatment history by including difficulties understanding and maintaining relationships, social interactions, emotional expression and reciprocity, sensitivity to schedules and routine, and hyper- or hyporeactivity to sensory inputs, which all may affect assessment and diagnosis (Wilkinson et al., 2022). Prospective sample items for this section include "I have difficulties finding the underlying meaning of people's

intentions," "I have to complete my daily routines as planned every day," and "I have difficulties reciprocating emotions with other people."

Limitations

The present study was limited in several ways. One limitation of the present study is the small sample size, which reduces the generalizability of the results. Additionally, the open-ended survey was the only survey included to collect the insight of experts in the field concerning the presentation of ASD in individuals between the ages of 18 to 25 years, which has not been established as a valid or reliable survey to gather data. The quality of the respondents is heavily dependent on the observations, skills, and beliefs of the individual respondents, which is heavily influenced by personal biases and idiosyncrasies. Thematic analysis itself has limitations in its precision, consistency, and encapsulation of the data, which affects the traceability and verification of the analysis conducted (Nowell et al., 2017). Furthermore, due to the thematic analysis being conducted by individuals who are not seasoned in conducting thematic analyses, there is greater margin for error in conducting this analysis, and it is therefore difficult to assert absolute confidence in the results.

Recommendations for Future Research

The present study provides a foundation for the development of a screener for ASD in young adults between the ages of 18 to 25 years. The development and validation of this screener could prove incredibly useful for entities who provide diagnostic assessments to screen for ASD among individuals between the ages of 18 to 25 years. For example, individuals working at universities, community mental health agencies, and private practices would be able to utilize this screener to assist individuals within this age range to rule in or rule out the need for a full ASD assessment. Future studies should seek to create specific, individual questions for the

screener, which can be used to assess the reliability and validity of said questions. Administration and validation of this screener would need to be done with a diverse sample from different regions of the nation so that the validity and generalizability of the screener can be determined.

Conclusion

To say there are not effective screeners or assessments for ASD would be incorrect. However, there is a critical gap within the availability of screeners for ASD directed towards individuals between the ages of 18 to 25, which is when many individuals transition to new chapters of their life such as college, full-time employment, and independent living. Criterion C of ASD in the DSM-5-TR indicates symptoms of ASD must be present in the early developmental period of an individual's life, but these symptoms of ASD may not become fully manifested until the social demands of their present experience exceed their limited capacities (APA, 2022). Many demanding, transitional events occur during this 18- to 25-year-old period in a person's life, and the lack of screeners for ASD for this population marks a critical and appalling gap in screening for psychopathology.

To address this critical gap, the present study sought to obtain the collective insight of experts in ASD for the development of items for an ASD screener for individuals between the ages of 18 to 25. The present findings attempt to establish a foundation for the development of an ASD screener for this target population. Specifically, the present findings utilize the expertise of professionals in the field concerning the presentation of ASD in individuals between the ages of 18 to 25 in various domains. These domains include the presentation of deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction, deficits in relationship formulation and comprehension, stereotyped or repetitive motor

movements in various domains, insistence on sameness, inflexible adherence to routines, ritualized patterns of verbal or nonverbal behavior, highly restricted and fixated interests with abnormal intensity or focus, and hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. The results also include questions to be used to rule out ASD and additional open-ended questions to gather supplemental information that may be pertinent to the diagnostic picture. Finally, the findings address formatting of the screener and who should complete the screener.

The present findings have the potential to be incredibly helpful for the development of a screener to clinically screen young adults for ASD. Adults with undiagnosed ASD present a high risk of experiencing functional and emotional difficulties due to their lack of an ASD diagnosis (Volkmar et al., 2014). Therefore, the development, validation, and distribution of this screener would provide direction and insight into the lives of many individuals seeking answers for why they are the way that they are. With the rising recognition and prevalence rates of ASD, there is an express need for valid and reliable screening tools (Goldstein, 2021). Although many individuals diagnosed with ASD are diagnosed during early childhood, this does not mean all people with ASD are diagnosed during early childhood (Girolamo et al., 2020; Wilkinson et al., 2022). By responding to this express need through developing this screener with the data from the present study, many individuals between the ages of 18 and 25 will finally be given direction in answering the question, "Do I have autism?"

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Appendix A

Demographics Questionnaire

Directions: For the following items, please check boxes related to the best fitting answer and/or write in a short response where asked.

1. **Please indicate how you identify your gender. Check the box next to the most applicable response**:

   ☐ 1. Female   ☐ 2. Male   ☐ 3. Other, please specify: _____

2. **With what race do you most closely identify?**
   ☐ 1. American Indian or Alaskan Native
   ☐ 2. Asian or Pacific Islander
   ☐ 3. Black or African American
   ☐ 4. Native Hawaiian and/or Other Pacific Islander
   ☐ 5. White and/or Caucasian
   ☐ 6. Two or More races
   ☐ 7. Other, please specify: _____

2a. **Hispanic or Latinx**
   ☐ 1. No   ☐ 2. Yes

3. **Please write in your age (in years):** _____ years.

4. **Please identify your professional qualifications:** _____.

5. **How long have you been working with and/or studying individuals with autism spectrum disorder (ASD)?**
   ☐ 0-2 years
   ☐ 3-5 years
   ☐ 6-8 years
   ☐ 9-11 years
   ☐ 12+ years

6. **Describe your involvement level of services rendered to individuals with ASD (e.g., duties, areas of specialty, etc.).**

   _____

Appendix B

Open-Ended Survey

1) What are signs/symptoms of clients in the age range of 18-25 for:

   a) Deficits in social-emotional reciprocity: _____

   b) Deficits in nonverbal communicative behaviors used for social interaction: _____

   c) Deficits in developing, maintaining, and understanding relationships: _____

   d) Stereotyped or repetitive motor movements, use of objects, or speech: _____

   e) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior: _____

   f) Highly restricted, fixated interests that are abnormal in intensity or focus: _____

   g) Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment: _____

2) Suppose a person in the age range of 18 to 25 was referred to you to consider the possibility of ASD. Some indicators of ASD are present. Other than the obvious indicators that a person does not have ASD (e.g., Has appropriate social-communication and social interaction skills that clearly do not meet DSM-5 criteria), what are some examples of behaviors or characteristics that would make you consider ruling out ASD? _____

   _____

3) If a screener for those 18-25 were developed, what are some open-ended questions that would be helpful to ask the person being evaluated that might provide information on the presence or absence of ASD?

   _____.

4) How would you prefer the questions to be formatted?

   a) ☐ Yes/No

   b) ☐ Ranges

      i) If ranges, what range would you prefer (e.g., 0-5, 1-10, Strongly Disagree – Strongly Agree)? _____.

   c) ☐ Other: _____.

5) This screener should be filled out by the…

   a) ☐ Client

   b) ☐ Clinician

   c) ☐ Other: _____.

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