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The Challenge of Divergent Diagnosis in Relation to Diagnosing High Functioning Autism

by

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MSW Clinical Research Paper

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School of Social Work

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In Partial fulfillment of the Requirements for the Degree of

Master of Social Work

Committee Members

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Autism diagnosis is on the rise, yet there continues to be no specific characteristics or symptoms connected to high functioning autism in how it presents or varies in presentation in primary school aged children. A qualitative exploratory study was conducted using in depth interviews to examine characteristics and symptoms presented by primary school aged children, components of an accurate assessment, training of professionals diagnosing and assessing, and looking at why there continues to be divergent diagnosis among professionals and across settings. Themes that emerged from the data were assessment process, barriers to the assessment process, presentation of HFA, professional judgment versus data, and DSM-5. Social workers in practice can utilize findings towards a better understanding of how to serve high functioning autism individuals and families.

Keywords: high functioning autism, autism, Asperger's, divergent diagnosis, ASD

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Autism diagnosis is on the rise as well as the need for a clear understanding of autism spectrum disorder, how it presents, and how to make an accurate assessment. The Center for Disease Control and prevention (CDC) estimated, “1 in 68 children (or 14.7 per 1,000 eight-year-olds) in multiple communities in the United States has been identified with autism spectrum disorder (ASD)” (2014). However, a new government survey suggests it has risen to 1 in 45 children with the ages ranging from three to seventeen (autismspeaks.org, 2016). These numbers indicate that many individuals, their family, friends, and loved ones are affected by an autism diagnosis. It is particularly prevalent when we take into account high Functioning Autism Spectrum Disorder (HFA) or what was commonly known as Asperger’s syndrome. Goldstein, Naglieri, Rzepa, and Williams (2012) describe HFA as:

“Best conceptualized as a biologically determined set of behaviors that occurs with varying causes. Autism is a disorder in which individuals can evidence problems ranging from total impairment to near typical performance. Children with autism experience a wide variety of developmental difficulties involving communication, socialization, thinking, cognitive skills, interests, activities, and motor skills” (p. 1001).

Richard Auger states that “Autism spectrum disorder is an umbrella label that describes a set of developmental disabilities marked by significant impairments in social interaction and verbal and nonverbal communication and some level of restricted interests and/or repetitive behaviors”, what distinguishes High functioning autism spectrum disorder (HFA) from classic autism is less severe symptoms and the absence of language delays (2013, p1). . Children with HFA frequently have good language and cognitive skills. (Autism Society, 2015).

Due to the continuous physical, mental, and emotional changes that occur in children as they grow, they are often known as more difficult to diagnose. While the diagnosis of autism

may be clearer, the diagnosis of HFA is often less clear because it is part of the broader spectrum and can present as typically developing, especially in the early years and elementary aged children. Yates and Couteur (2008) state, “Studies have shown that diagnosis of autism at 2 years of age is possible and stable overtime, although it is less reliable for the broader spectrum” (p.57). Goldstein, Naglieri, Rzepa, and Williams (2012) state, “It has been suggested that autism is the most complex developmental disorder with the best empirically based, cross-national diagnostic criteria”(p.1002).

Experts agree diagnosing HFA is complex; it is even more complex diagnosing across professional systems. A variety of professionals can diagnose HFA and the diagnosis can take place in a variety of settings, adding to the difficulties with diagnosing HFA. K. Karim, L. Cook, and M. O’Reilly (2012) state, “considerable variation was seen in the practice between and within different professional groups” (p.120). There can be little correspondence among children diagnosed by each system as having ASD” (Paul T.Shattuck and Scott D. Grosse, 2007). Autistic symptoms have yet to be broadly studied across the general population, the current diagnostic symptoms have been historically attained by consensus, not through research (Goldstein et. al., 2012).

With autism spectrum disorders becoming more and more prevalent it is inevitable that social workers will encounter clients that are diagnosed on the autism spectrum or in need of a diagnosis in their practice. Thus, social workers play a critical role in the diagnosis of children with HFA. It is important for social workers to have a clear understanding of autism spectrum disorder and how high functioning autism presents. It is also important to understand the importance of collaborating with multidisciplinary teams of professionals in the assessment process to better diagnose and serve clients and their families. An accurate diagnosis is critical and especially

important for early identification, intervention, and support. Estes, Munson, Rogers, Greenon, Winter, and Dawson (2015) state: “Intellectual ability, communication and language functioning, adaptive behavior, and educational placement and support have all been demonstrated to improve with early intervention” (p 580).

With the prevalence of autism diagnosis on the rise and an all too often divergent diagnosis among professionals the importance of an accurate assessment is even more critical at this time. This author sought to better understand the nature of the experience of high functioning autism and how it presents in elementary age children through better understanding the components of an accurate, careful, and responsible diagnosis from the perspective of multiple providers with expertise in autism spectrum disorder diagnosis. This author did this through a two part research question. The first question is: What does high functioning autism look like as it presents in elementary school aged children? The second research question is: What does an accurate assessment involve?

Literature Review

Many will know or work with someone in their lifetime or clinical practice who is affected with autism spectrum disorder. The Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network (2015) states, “About 1 in 68 children has been identified with autism spectrum disorder (ASD)”. Literature on the topic of autism spectrum disorders appears abundant; however literature on high functioning autism is limited. The literature researched for this study focuses on five specific themes found in relation to high functioning autism (hereafter abbreviated as HFA): Defining HFA, DSM-5 Changes: Autism versus Asperger’s, how HFA presents, instruments and tools used to assess HFA, and divergent diagnosis among professionals.

Defining HFA

There are many definitions for autism spectrum disorder (ASD) within the literature and many of these definitions are similar in that they focus on three main impairments: social interaction, communication, and restricted or repetitive behaviors. Within the literature there are no exact definitions of HFA: it consists mostly of descriptions or comparing and contrasting of the differences between ASD and HFA. The DSM-5 describes the criteria for meeting an ASD diagnosis. Within the criteria and diagnostic features section the DSM-5 provides information on these differences as well. The new Diagnostic And Statistical Manual Of Mental Disorders, Fifth Edition (DSM-5), from the American Psychiatric Association (2013) has criteria for Autism Spectrum Disorder (F84.0) under Neurodevelopmental Disorders.

The diagnostic criteria for autism spectrum disorders include two sets of behavioral descriptions. Criterion A focuses on “essential features of reciprocal social communication and social interaction” (DSM-5, p.53); criterion B focuses on “restricted, repetitive patterns of behavior, interests, or activities”; the time in which these impairments become noticeable may vary depending upon the “characteristics of the individual and his or her environment”; for criterion C and D “These symptoms are present from early childhood and limit or impair everyday functioning”; the diagnostic features in the DSM-5 (2013) go on to say that, “Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence the term *spectrum*” (p.53).

Lauritsen (2013) states, “The distinction between the different ASD’s is suggested to be dependent on the severity of the disorder, the language level, and presence of learning

disability/mental retardation” (p.S38). Authors and researchers Li, Zhu, Liu, and Li (2014) describe the difference between ASD and HFA as follows:

“Autism can occur at any point on the intelligence quotient (IQ) continuum, and IQ is an important index of clinical diagnosis for ASD. Although language delay is not necessary for clinical diagnosis for ASD, level and language function by age six is also important for reference. Children with autism are classified as high functioning or low functioning depending on the absence or presence of mental retardation, which is reflected in an IQ lower or higher than 70. High functioning autism (HFA) refers to the condition of an ASD individual whose developmental age is near his or her chronological age or whose IQ is above or equal to 70” (p.1658).

Volker et al., (2009) describe high functioning autism spectrum disorder (HFA) as:

“In contrast to students with more significant impairments associated with autism, students with HFASDs demonstrate relative strengths in cognitive ability and language levels, though pragmatic language deficits are frequently observed” (p.188). Losh and Capps (2006) similarly describe HFA:

“Unlike severely delayed autistic groups, however, high functioning individuals who do not suffer mental retardation often express deep desire to engage in social-emotional interactions with others and display knowledge and expression of emotions that they were once thought not to possess. In contrast with early views that autism involves an absence of emotional expression and indifference to others, rigorous investigations of the strengths and weaknesses in autism have demonstrated surprising capabilities. Particularly among high functioning groups, evidence suggest

that autistic individuals are able to recognize and express basic (i.e., simple) emotions such as happiness, sadness, and anger and are no less emotionally expressive, overall, than are comparison children” (p.809).

The literature clearly indicates a limitation on having an exact definition of high functioning autism as well as displaying a difference in opinions on what strengths and capabilities individuals with high functioning autism possess and present. There is an ongoing debate among professionals, families, and individuals regarding the changes that have occurred with ASD in the new DSM-5. Many still believe that there is a difference between high functioning autism on the autism spectrum disorder and Asperger’s disorder, not believing that the two should have been merged on a spectrum (Lauritsen, 2013).

DSM-5 Changes: Autism vs Asperger’s

There have been some relatively significant changes in the DSM-5 in contrast to the DSM-IV, particularly in relation to autism spectrum disorder. Previously in the DSM-IV there were many individual disorders that are now part of the autism spectrum in the DSM-5. As of May 2013 when the DSM-5 was published there would have been fourteen years that had passed since the previous edition. It is custom to redefine the criteria in the DSM to adapt to practice, diagnosing, and changes in society (Lauritsen, 2013). The DSM-5 (2013) acknowledges this change, “Autism spectrum disorder encompasses disorders previously referred to as early infantile autism, childhood autism, Kanner’s autism, high functioning autism, atypical autism, pervasive developmental disorders not otherwise specified, childhood disintegrative disorder, and Asperger’s disorder” (p.53). The changes in the new DSM-5 were greatly anticipated by professionals and confusion surrounding the changes is still present today. Lauritsen (2013) describes the changes:

“Several changes have been made compared to the previous diagnostic criteria. They include no emphasis on language delay and age of onset except that ASD is defined as a neurodevelopmental disorder with symptoms in early childhood although the disorder may first be diagnosed later in life. The three areas of impairments in ASD are reduced to two areas, namely a social-communication domain including fixated interests and repetitive behaviors. In addition, the clinical presentation of ASD in the individual is described in more detail in terms of clinical specifiers” (p.S37).

Lauritsen (2013) goes on to say that one of the goals with creating ASD was the validity of the criteria and that it should essentially be the same in that there should not be more or fewer diagnoses because of the change. She also mentions limitations of the new ASD diagnosis, such as being only “sparsely validated and especially the reliability of different diagnoses across countries and cultural backgrounds and between clinicians is not fully investigated” (p.S38). One of the most disputed and controversial changes in the DSM-5 is the removal of Asperger’s Syndrome. The literature is conflicting in this controversy as some researchers found differences and other researchers did not find differences between the two groups. Lauritsen (2013) states, “There have been numerous studies that have shown there is no clear difference that could be found with different measures of outcomes with Asperger’s Syndrome and autistic disorder” (p. S39).

Macintosh and Dissanayake (2006) explain the reasoning behind merging the two disorders into a single spectrum, “According to the current classification systems (DSM-IV), Asperger’s Disorder can only be diagnosed in the absence of an intellectual disability. Thus, in order for Asperger’s Disorder to be considered a unique diagnostic category, it must be distinguishable from high functioning autism (that is, autism without an associated intellectual

disability)” (p.1067). On the contrary, Macintosh and Dissanayake conducted a review of the literature and found that there are “firm conclusions about the diagnostic validity of Asperger’s Disorder as separate from autism have not been possible due to variations in methodology, inconsistent findings between studies, flaws in research design, and the paucity of research on some key areas that require examination in order to resolve the diagnostic controversy” (p.1067). The debate between the disorders being separate and limitations on valid research still continue today. No matter which way one leans, the new DSM-5 is now widely used. Additionally, High Functioning Autism, though not a DSM-5 diagnosis itself, is a term that is becoming more common to describe those who once were classified under Asperger’s disorder.

How HFA Presents

Social Skills and Problem Behaviors

The literature is limited in describing the specific characteristics and traits presented in HFA. Lauritsen (2013) explained, “detecting the specific early signs of ASD has been found to be hard and no specific signs have yet been identified” (p S38). Although there are no specific signs of HFA and research is greatly limited, there are many characteristics or traits that have been arrived at through professional consensus. The literature points out that many thoughts and ideas we once had about the characteristics and abilities of individuals with HFA are mistaken. HFA individuals can present with a complex display of characteristics, traits, and abilities; what we once thought was black and white is now seen as very grey. Molina, Jr. (2014) supports this well; “There is still enough confusion among researchers that has not allowed for clear differentiation in symptoms, behaviors and diagnosis” (p 29).

Additionally, Losh and Capps (2006) state, “In laboratory settings, high functioning individuals with autism also seem able to discuss experiences with simple emotions but have trouble with more complex or self-conscious emotions such as pride and embarrassment” (p 809). Mitchell, Mrug, Patterson, Bailey, and Hodgens (2015) conducted research on the effects of a six-week summer behavioral treatment program for children with high functioning autism to treat chronic functional behavior. Their research included twenty, six to eleven-year-old boys diagnosed with HFA. Mitchell et al. (2015) identify HFA symptoms they have observed:

“Impairment in social functioning represents a primary defining feature of HFASD, with deficits in social behavior contributing to problems in peer relationships. For instance, children with HFASD initiate peer interactions and respond to peers overtures about half as often as age and IQ-matched children and adolescents with typical development. Other social deficits commonly observed in children with HFASD include a failure to establish a shared reference point when conversing with others, overreliance on scripts for conversation, difficulties understanding the nature of friendship, misinterpretation of nonverbal aspects of communication, and a lack of respect for personal space of others. In addition to social behavior deficits, many children with HFASD exhibit ridged behavioral routines and rituals that interfere with their ability to function effectively in a peer group. Finally, symptoms of inattention and hyperactivity are very common in children with ASD” (p 2298).

Macintosh and Dissanayake (2006) conducted research on social skills and problem behaviors of primary school age children with HFA and Asperger’s Disorder through reports from the children’s parents and teachers using the Social Skills Rating System (SSRS). Participants were twenty males diagnosed with HFA, nineteen males diagnosed

Asperger's, and seventeen typically developing male children. The children were between the ages of four years, four months to ten years, ten months old. The SSRS rates social skills and problem behaviors through a standardized questionnaire. The social skills the SSRS rates are "co-operation, assertiveness, responsibility, and self-control" (p 1066). The problem behaviors rated are, "externalizing and internalizing symptoms and hyperactivity" (p 1066).

Macintosh and Dissanayake (2006) discussed the results of their study:

"The teachers' and parents' reports indicated that primary-school aged children with high functioning autism and Asperger's Disorder showed deficits in the social skills of co-operation, assertion and self-control across a variety of real-life settings relative to their typically developing peers. The teachers' and parents' reports were also concordant in describing the children with autism and Asperger's Disorder as having substantially more problems with both hyperactivity and internalizing symptoms compared to the typically developing children" (p 1073).

The scores of the SSRS indicated and confirmed that primary school aged males diagnosed with HFA or Asperger's Disorder experience greater severity of problem behaviors such as severe internalizing and hyperactivity symptoms. A correlation was found between child having fewer social skills and a greater number of problem behaviors that child will present with (Macintosh and Dissanayake, 2006).

Friendships

With social skills comes friendship skills and at this time there is not a definition of friendship on which researchers and professionals agree. However, Bauminger and Shulman

(2003) define how friendship is perceived, “as a close, intimate affective tie between children that is based on reciprocal and stable (6 months and above) social interactions with a peer” (p81). It was once believed that children with HFA or Asperger’s Disorder did not seek out or have a desire for friendship with peers. Calder, Hill, and Pellicano (2012) acknowledge this and state, “some authors suggest that social motivation is a driving force guiding human behavior and that ‘autism can be construed as an extreme case of diminished social motivation’ “ (p311).

Calder, Hill, and Pellicano (2012) conducted research on the degree and nature of HFA children’s friendships. They gathered the information from the children diagnosed HFA themselves seeking their perspectives on friendship, classroom peers, parents, and teachers through semi-structured interviews and observations. Participants in the study were twelve families that had a child diagnosed with autism from nine mainstream primary schools in London, eight males and one pair of male monozygotic (single egg) twins, age five to six years old. The study found “remarkable consistency across reports from the wide variety of sources” (p309). Calder et al. (2012) explain their results; “Although we did not explicitly compare autistic children’s degree of social motivation with that of their non-autistic peers, many children in our sample nevertheless expressed a real desire for social relationships during the qualitative interviews” (p 311). They concluded their research stating,

“This study demonstrates that primary school-aged children *can* and *do* form friendships and are part of classroom social networks within mainstream schools. The findings suggest that children with autism have a different understanding of what constitutes ‘friendship’, which might be based more on sharing company than sharing emotions, and that generally they were satisfied with their current friendships” (p312).

How friendship skills present in HFA can also depend upon the frequency of play dates the child encounters and experiences within the home setting. Frankel, Gorospe, Chang, and Sugar (2011) conducted research to assess the relationship between the frequency of play dates and peer conflict on the school playground. Participants included twenty-seven boys and four girls diagnosed with HFA, with twenty nine of the children mainstreamed and two of the children receiving special education services for half of the school day. Frankel et al. (2011) discussed the results, “First order correlations indicated that children with ASD who had more play dates in their home tended to engage for greater time in mutual behaviors such as offering of objects, conversing and other turn taking activities with peers (joint engagement). They also received more positive responses to their overtures from peers” (p576).

Theory of Mind

Historically it is believed that children diagnosed with ASD have deficits in theory of mind, which is also known as the theory of mind theory. Scheeren, Rosnay, Koot, and Begeer (2013) define theory of mind (TOM) as classically referring to “the ability to ascribe mental states to people and to explain and predict their behavior in terms of underlying mental states” (p2). There have been almost three decades of studies on TOM that have dominated research on individuals diagnosed with ASD however, there is limited research on the abilities in TOM of individuals with HFA (Scheeren et al., 2013). Scheeren et al., (2013) conducted research to examine advanced TOM understanding in school-aged children with HFA compared to their typically developing peers.

The participants consisted of 194 children diagnosed with HFA with 165 of the children boys and 29 of the children girls and 60 typically developing peers with 52 boys and 8 girls. The

children were split into two descriptions, children aged 6-11 and adolescents 12-20 years old. Scheeren et al. (2013) explain their findings,

“Counter to our expectations, no group differences were found on any of the stories. We did not find an advanced TOM impairment in children with HFASD (6-12 years). Both children and adolescents with ASD appear to be equally capable of inferring mental states of story protagonists. Although this finding is incompatible with the TOM theory of ASD, children and adolescents with HFASD may none the less show limited ability to infer mental states during social interactions occurring in everyday life” (p10).

The researchers point out and mention that the discrepancy could be caused by the difference between the stories in the TOM instruments and real life situations of “everyday social interactions” (Scheeren et. al., 2013).

Gender Differences

High functioning autism is diagnosed later and less in girls than in boys, in fact ASD is diagnosed four times more in boys than in girls, high functioning autism ratios for boys to girls is ten to one (Hiller, Young, and Weber, 2014). Currently, little is known as to why there is such a large gender gap for HFA children, and research on the sex differences in core symptoms has been inconsistent (Hiller et. al., 2014). Hiller et. al., (2014) conducted research to investigate the sex differences of how it presents in children and adolescents diagnosed with ASD. To gather their information they “examined the diagnostic assessment and reports of children and adolescents who had all been diagnosed with high functioning ASD” (p1382). The researchers also gathered information in the home and school setting to be able to compare and contrast

manifestations and presentations. Hiller et. al., (2014) discuss their findings from the research noting, “There was evidence of sex differences in many readily observable impairments, including nonverbal behaviors and conversation skills. Moreover, girls presented with different types of obsessive interest that may be more difficult to diagnose” (p1391).

The behavioral differences the researchers found in the presentations between boys and girls are explained as, “boys and girls reportedly suffered equally from a lack of social understanding (e.g., the ability to interpret nonverbal cues), however the overt behavior impairments which may influence a decision to explore a potential ASD diagnosis manifested quite differently between the sexes. Examples included girls being better able to use nonverbal gestures and engage in reciprocal conversations” (p1391). Girls were more likely to fall in the “somewhat” category when looking at the DSM criteria, almost as though girls almost fit the criteria but it did not present as intense or as impairing as it does in boys. The other finding was that girls do not have as restricted interests and are less likely to have lined up or sorted toys, girls had much different fixations than those of the boys such as, random objects, animals, rocks, shells, and books (Hiller et. al., 2014).

There continues to be a great demand for more research and knowledge in the sex differences with ASD, especially in primary aged children, which the literature has described as limitations. With more research and understanding of how HFA presents the more opportunities there will be to examine and create tools and instruments that can help in the assessment of ASD and HFA in both sexes.

Instruments/Tools

There are many instruments and tools professionals can use in assessing for autism however, lack of research, consistency, and validity with tools specifically for HFA are very limited. Falkmer, Anderson, Falkmer, and Horlin (2013) describe the use of assessment tools; “At present, ‘gold standard’ diagnosis of autism spectrum disorders (ASD) is lengthy and time consuming process that requires suitably qualified multi-disciplinary team (MDT) personnel to assess behavioral, historical, and parent report information to determine a diagnosis. A number of different tools have been developed to assist determination” (p329). The researchers conducted a systematic review to address the “accuracy, reliability, validity and utility of reported diagnostic tools and assessments” (p329).

For their information gathering sixty-three articles were examined and seventeen tools were assessed, unfortunately many of them did not have “high quality-independent studies” (p329). From the research the two primary tools that had the highest level of evidence based sensitivity and specificity were the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R). The results indicated that the best outcomes come from using these two tools together to create the most accuracy (Falkmer et al., 2013). On the contrary, Li et. al., (2014) state they did not use the ADOS and ADI-R in their study, noting “Standardized clinical instruments, such as ADI-R or ADOS, were not adapted in this study because their clinical sensitivity is low for the diagnostic identification of individuals with higher-functioning autism and they have small power to distinguish between children with milder forms of ASD” (p1660). They used the Autism Spectrum Quotient-Children’s Version in their research of behaviors among primary aged HFA children in their study. It is not as clear when assessing and using tools for HFA, “accuracy and evidenced base best supported the use of the Gilliam Autism Diagnosis Scale

(GADS). However, most Asperger disorder-specific tools lack a large evidence base to support their use” (p337).

Though these tools or instruments are important in the assessment process, Foegan and Resan (2009) point out that the instruments themselves are not reliable or valid alone. They are to be used alongside other evaluation means such as criterion-referenced assessments, achievement assessments, observation, and work samples. A common theme throughout the articles reviewed was how important it is to use multiple means of assessments and evaluations in the process of assessing and diagnosing ASD. Many of the instruments used have been developed for gathering information on the history of the child and observing play (Baird, Cass, & Slonims, 2003). Karim et. al., (2012) states, “there is no fool proof way of diagnosing ASD”, their article explains that even though there has been the development of many helpful tools the diagnosis is still open to some subjectivity. Another common theme throughout the articles reviewed was the limitation of consistency, and how lack of funding and reimbursement for specific assessment tools has lead to inconsistencies in the assessment process.

Divergent Diagnoses among Professionals

There are many different professionals that can diagnose ASDs and each of these professionals can be located in a variety of settings. Such professionals can be psychologists, psychiatrists, physicians, therapists, neurologists, and a social workers. Each setting and profession has their own purpose, tools, and diagnostic criteria they use contributing to the potentially divergent diagnosis of ASD. As part of the assessment process, professionals take a full history as well as developmental history, family history, presenting problems, and educational needs. Autism diagnosis can be provided by many different professionals in a variety

of settings, through different service systems, for different purposes, and with varied criteria (Shattuck & Grosse, 2007).

Additionally, Shattuck and Grosse (2007) explain the difficulties in having many systems, professionals, and settings:

“A major impediment to coordinated and economical identification and diagnosis is that autism diagnosis can be provided by different professionals (e.g., physicians, psychologists, educators) through different service systems (e.g., health plans, schools) and for different purposes (e.g., eligibility determination, treatment planning). Diagnostic criteria vary across professions, systems, and purposes.

Resulting diagnoses are not always recognized by other systems or professions. For instance, a school diagnosis of ASD may not be recognized by a child’s health plan and vice versa” (p131).

Zahn (2013) also explains inconsistencies among professionals and diagnosis:

“Autism is a neurological disorder that is diagnosed by observations of behavior in the absence of a specific physiological marker, and so it is not surprising that some inconsistencies among clinicians exist. When considering the heterogeneous presentation of ASD’s, changes in diagnostic criteria and classifications, the use of a broad and undefined spectrum, and variations in diagnostic methodologies, the inconsistencies are perhaps even less surprising” (p.17).

Zahn (2013) conducted quantitative research to examine the divergent diagnosis among clinicians diagnosing autism with the DSM-IV, using vignettes that had the same set of symptoms in different contexts. She also analyzed attitudes and preferences in relation to the

classification and methodology to examine the decision making process of the clinicians. Her participants for the study included many different divisions of psychology: Developmental, Society of Clinical School, School, Society of Counseling, Intellectual and Developmental Disabilities, Society for Child and Family Policy and Practice, Clinical Neuropsychology, Society of Clinical Child and Adolescent, and Society of Pediatric Psychology. These professionals were located in a variety of setting such as school, clinical, early intervention, and other.

There were many findings in her research. The first finding she identified is that of the many different ideas and concepts for what ASDs looks like or how it presents. This lack of agreement among clinicians as to how ASDs present creates one of the factors contributing to divergent diagnosis (Zahn, 2013). Zahn (2013) explains another finding found in her research, “Differences among clinicians do appear to vary widely in regards to the process utilized to diagnose ASDs and the variation in methodologies can result in measurable differences in diagnostic outcomes” (p30). Zahn’s research states, “The analysis of this group (other) in comparison to others appears to support the potential existence of influences on diagnostic choices associated with the professional setting in which a diagnostician practices” (p66).

Some of the literature also compared and contrasted the differences of assessment versus diagnosis across systems such as schools. Karim, Cook, and O’Reilly (2012) and Shattuck & Grosse (2007) provide information on the differences and barriers of educational, clinical, and medical assessments and diagnosis. Foegen and Resan (2009) included clear statements throughout the article of the differences between assessment and diagnosis. Foegen and Resan (2009) state, “Individualized Education Plan (IEP) teams make educational eligibility determinations, not medical diagnosis”. Clinical professionals take a full history as well as

developmental history, family history, presenting problems, and educational needs. Autism diagnosis can be provided by many different professionals in a variety of settings, through different service systems, for different purposes, and with varied criteria (Shattuck & Grosse, 2007).

Shattuck & Grosse (2007) discuss limitations in regards to the service systems to provide the assessment in a “timely, coordinated, accurate, economical, and equitable manner”. The article also discusses the limitations of the growing demands for services and the challenges this brings for service providers and policy makers, improving diagnostic and treatment services, and the need for funding ASD services. Karim & Resan (2012) focused on the benefits of multi-professional and multi-agency assessments and diagnosis. This article explains that this approach is designed to minimize variations and enhance services. They concluded that it is not about the different models, but it is about working together to give the best outcome for client services. Mao, Narasimhan, & Treadwell-Deering (2007) explored how it is ideal to have a multidisciplinary team and that in fact many professionals prefer this approach to diagnosing ASD. A common theme was the need for more professionals in communities specialized in ASD and the need for more funding for these services (Shattuck & Grosse, 2007).

The literature offers information on comparing and contrasting HFA versus ASD which includes low functioning autism. It speaks to how the absence or presence of an intellectual disability distinguishes low functioning versus high functioning ASD. We know children with HFA do not have an intellectual disability, which means their IQ is at or above 70 and that their developmental age is at or above their chronological age (Li et. al., 2014). However, literature and research is very limited and sometimes contradictory as to how HFA presents in characteristics and behavior. The literature has presented a clear understanding of the changes in

the DSM-5; however, research is extremely limited in providing a clearer understanding of the differences between Asperger's and HFA and if Asperger's should perhaps have stayed in the DSM-5 as its own diagnosis. Literature reveals there are many instruments and tools a professional can use to help assist in the assessment process. However, research is extremely limited on the validity of these instruments and tools, especially with regard to HFA. All of these limitations contribute to the continuous divergent diagnosis across systems and professionals clearly indicating a critical strong need for further research in high function autism spectrum disorder.

Conceptual Framework

This study utilized the book, *The Complete Guide to Asperger's Syndrome* by Tony Attwood. This framework offers a guide and lens in explaining what high functioning autism also known as Asperger's syndrome, looks like or presents from his perspective as well as a framework for diagnosing HFA. The characteristics, traits, or symptoms of HFA are laid out in nine headings of teasing and bullying, theory of mind, the understanding and expression of emotion, special interests, language, cognitive abilities, movement and coordination, and sensory sensitivity. The information in each of these headings is important in my research as the characteristics described within each of them serve to help guide my research by way of offering sensitizing concepts to listen for.

Attwood's book is also a good choice as research in high functioning autism is limited, especially in relation to its specific characteristics. Attwood (2013) incorporates historical data with current data as well as professional experience with personal experiences of individuals diagnosed with HFA throughout his book to give a solid foundational understanding of HFA. Attwood's work is also strength-based when defining and discussing individuals with HFA,

which better aligns with my perspective of HFA and the social work profession. His book was created to help parents, professionals, and individuals with HFA better understand the symptoms and diagnosis (Attwood, 2013).

Jessica Kingsley Publishers in London, UK and Philadelphia, PA first published the *Complete Guide to Asperger's Syndrome* by Attwood in 2006. The new and revised edition was published in 2015 to include the new DSM-5 autism spectrum and criteria as well as updated research and information with HFA. In the preface to the first edition, the author explains that the book is based on his “personal perception of children, teenagers and adults with Asperger Syndrome based on my extensive clinical experience and reviewing and contributing to research studies and publications”(Attwood, 2013, p21). This work is thus also a good choice in terms of being informed by both research and practice.

Attwood explains that he chose to continue to use the term Asperger's Syndrome despite the new DSM-5 Autism Spectrum Disorder Level 1, without accompanying intellectual or language impairment because he feels it is easier for people to grasp, research, and understand as the term has been around since the early 1980's. Dr. Attwood is an adjunct Associate Professor at Griffith University in Queensland and a practicing clinician. He has a degree in Psychology, a master's degree in Clinical Psychology, and a PhD. Attwood has written publications on Asperger's Syndrome and this book has been translated into many languages (TonyAttwood.com, 2013).

Attwood identifies and acknowledges the historical significance of the work of Hans Asperger's, when he writes, “The more I explore the world as perceived by people with Asperger's Syndrome, the more I acknowledge the accuracy of his detailed descriptions of four children, Fritz, Harro, Ernst, and Hellmuth, over 60 years ago. I never met Hans Asperger but I

have great respect for his understanding and admiration of a distinct group of children who are also my heroes” (Tony Attwood, 2013, p21).

Methodology

This researchers two part research question is: 1. What does high functioning autism look like as it presents in primary or elementary age children? 2. What does and/or should accurate assessment involve? Question number one has two sub questions; A. How does it tend to present? B. To what degree does it vary in its presentation? Question number two has four sub questions; A. Where do assessments happen and what do they involve, look for, and consider? B. How are people trained? C. What accounts for the frequent divergence in opinions and how to be more systematic? D. What are some components of an accurate, thorough, well done assessment as an emerging “best practice?”

Research Design

The purpose of this study was to better determine what high functioning autism looks like as it presents and varies in presentation in primary age children, what an accurate assessment involves and where assessments take place, components of an accurate assessment, how professionals are trained, and with the goal of having a better understanding of the divergent diagnosis among systems and professionals in diagnosing high functioning autism. The literature offers explanations of the differences of high functioning autism versus low functioning autism. However, it lacked specific characteristics and presentations of high functioning autism in primary aged children. Therefore, further research is needed to identify specific characteristics and presentations of high functioning autism. The research design for my research question was a qualitative, exploratory study interviewing a range of professionals in a variety of settings

about how they recognize high functioning autism (HFA), assess for it, strengths and gaps in assessment strategies, training in HFA, the role of professional judgment or specialized trainings, and resources to be aware.

Population and Sample

The study sample consisted of five professionals, a Ph. D clinical developmental/neuropsychologist, a Ph. D psychologist/ASD and research specialist, a Ph. D psychiatrist /ASD specialist, a masters in communication disorders/ASD certificate, and lastly, a masters in special education /bachelors in social work and ASD license that were located throughout Minnesota. The professionals are employed through a variety of agencies and organizations of centers, hospitals, clinics, and advocacy groups. These professionals previously and currently work with as well as diagnose autism spectrum disorders. Participants were selected through purposive sampling. Padgett (2008) defines purposive sampling as, “a deliberate process of selecting respondents based on their ability to provide the needed information” (p53). All participants were selected on the basis of being trained or certified in ASD, being able to diagnose ASD, and working with children diagnosed with ASD.

Protection of Human Participants

To ensure protection of human participants an informed consent form (see appendix A for consent form) was created and developed from a template approved by the University of St. Thomas Institutional Review Board (IRB). The elements of the informed consent form include, a brief description of the study and procedures, this researcher’s contact information, any risks and benefits in participating in the research, and to assure the participant of confidentiality and that participation is voluntary so they may withdraw at any time without repercussion (Padgett,

2008). This informed consent form was approved by the research committee that is comprised of Claribel Santiago-Severson, Tyra Taylor, David Roseborough, and by the Institutional Review Board prior to administering to participants. Before the research was conducted participants reviewed the form and had the opportunity to explore and ask any questions they may have. Participants were given a copy of the informed consent form to keep for their records. This researcher used a professional transcriptionist to transcribe the interview audio recordings. The researcher also used a confidentiality form for the transcriptionist and the researcher reviewed and signed. (see Appendix B for confidentiality form).

Data Collection

A qualitative research design was used in gathering data from participants through interviews. The interviews were conducted in a semi-structured format with a set of questions that were pre approved by the research committee and Institutional Review Board (see appendix C for interview questions). Questions were designed to better understand high functioning autism (HFA) as it presents in primary aged children, the assessment process as well as tools and instruments utilized and what experience and training professionals who work with HFA children have. The questions were open ended, with the goal of being non-biased, and used objective wording in hopes of gaining honest and open feedback from the participants.

The questions were created through limitations within the existing literature. The interviews began by getting to know the interviewee as well as their experience and interest with high functioning autism. Questions were asked about the prevalence of high functioning autism in their practice, their approach to the assessment process and tools used in the assessment process, changes they have seen from the new DSM-5, presentations and characteristics they have observed, and information on trainings they are offered or attend.

Data Analysis

Data analysis for this research is based on descriptive phenomenology, which is a research method where the researcher describes the themes (in this case common experiences) that emerge from the data. A researcher first collects data and then takes this raw data and analyzes it. Once the researcher has analyzed the data the phenomenon begins to be formed and described as a way of organizing commonalities from that data (Monette, Sullivan, Dejong, & Hilton, 2014). This research method is used to ensure the data analysis is as close to the respondent's meanings as possible. The interviews were audio recorded, transcribed, reviewed, and coded. The researcher had someone transcribe the interviews and also had the person transcribing sign a confidentiality form. Open coding was used to find recurring themes from the data by labeling the themes along the margins of the text in the transcription. Recurring themes were then grouped into main themes and then reviewed again to ensure accuracy of the themes identified.

To ensure reliability of the codes identified, the researcher conducted a secondary review or selective coding of the transcriptions and themes. After completing the secondary review the researcher compared the codes identified between the initial and secondary review to be sure themes were not missed. The researcher then redefined the themes based on the codes identified in both reviews.

Results

The sample for this study included five participants, all of whom were female. The ages of the participants ranged from 29 to 50 years old. Four of the participants had 11 or more years of experience and one of the participants was in their first year within the field of working with autism spectrum disorders. This researchers sample includes five professionals; a Ph. D clinical

developmental/neuropsychologist in a urban/ rural community, a Ph. D psychologist/ASD and research specialist in an urban community, a Ph. D psychiatrist /ASD specialist in an urban community, a masters in communication disorders/ASD certificate, lastly, a masters in special education /bachelors in social work and ASD license that were located throughout Minnesota. Each interview ranged from 50 minutes to one hour and 15 minutes.

The method selected to recruit participants was selective and purposive sampling that Padgett (2008) defines as, “a deliberate process of selecting respondents based on their ability to provide the needed information” (p. 53). The researcher sent out emails and made phone calls to professionals that assess and diagnose autism spectrum disorders. The five participants responded to emails and phone calls and agreed to take part in a one on one audio-recorded interview.

The professionals who agreed to participate were asked about how they recognize HFA, assess for it, strengths and gaps in assessment strategies, their training in HFA, their role of professional judgment or specialized trainings, and resources to be aware. All five of the interviews were audio-recorded and transcribed. The interviews took place in person at a location chosen by the participant.

When explored inductively, themes emerged within five main areas: assessment process, barriers of the assessment process, presentation of HFA, professional judgment vs. data, and DSM-5. Within the area of assessment process, five subthemes emerged: tools and instruments, family history, components of a good assessment, multidisciplinary, and training. Within the theme of presentation of HFA four subthemes emerged: social skills/friendship, behaviors/symptoms, gender, and theory of mind. Within the theme of barriers to the assessment process four subthemes emerged: stereotypes/bias on how HFA presents, access to services, and

training, education and experience in relation to divergent diagnosis. Within the theme of DSM-5 respondents noted they thought the changes were better, and others spoke to what needs improvement. Within the theme of professional judgment vs. data respondents spoke to how both were equally important.

Themes of Divergent Diagnosis with diagnosing HFA

Theme # 1: Assessment Process

Participants were asked to reflect on what their process looks like when diagnosing or assessing for autism spectrum disorder within six main areas of assessment: tools or instruments used, gathering family history, components of a good assessment, multi professional approach, barriers, and training. The participants were asked about these specific areas of focus in this order during the interview process. All five participants identified and explained their process of diagnosing covering six areas of focus. These six areas of focus during the interview process were condensed to five subthemes within this theme: tools/instruments, family history, components, multidisciplinary, and training. Barriers became it's own theme with subthemes. All participants also reported that they see more higher functioning children on the autism spectrum at this time, than they do the children who display more classic symptoms of autism.

Subtheme # 1: Tools / Instruments

Participants were asked about the tools and or instruments that they utilize during the assessment process. Two of the five participants stated they utilized the Autism Diagnostic Observation Scale (ADOS), one participant stated they used the Autism Diagnostic Interview Revised (ADIR), and two participants stated they used the Child Autism Rating Scale (CARS),

the second revision. Two Participants stated they utilized the ADOS, Both of these participants were from a rural community school setting. One participant stated, “Right now, the primary golden standard that we’re using is what we call the ADOS.” They reported that it is a test where they can sit down with the student and do the testing one on one however, with some of the higher functioning children they excel in that setting so sometimes they chose not to use it. Another participant stated, “Our gold standard is kind of the ADOS”. They reported that it is a very interactive tool that can be used for both younger and older children. Two respondents both stated they used the CARS. Another participant stated, “I often use the CARS here which is the Child Autism Rating Scale”. She reported that the second revision was divided into a questionnaire for higher functioning children. She also reported that she previously used the Asperger’s Diagnostic Scale prior to the DSM-5. Another participant stated, “I choose to use the CARS”. She reported that she knows a lot of schools and programs use the ADOS but that she knows that the standardization and reliability for it is not strong and so she decided not to use the ADOS.

All participants stated that they mailed out and or gave parents and teachers questionnaires about the child’s functioning at home and in the classroom. One participant stated, “Particularly I use the BASC and BRIEF, those are my kind of two standard instruments, which both have parent and teacher versions”. Another respondent stated, “Sometimes we give a screening questionnaire called the Social Communication Questionnaire or we use the Social Responsiveness Scale”. However, another participant reported that they did not think screeners worked very well because they did not help with triaging patients and identifying needs over time. Three of the five participants stated they use both face-to-face interviews and packets that are sent home to gather family history about the child. All three of these participants felt strongly

that having both was a critical part of the assessment process. Two of the five participants stated they only sometimes conduct face-to-face interviews with the parents to gather family history, with both of these participants assessing in a school setting for services. All participants stated that they utilize observations within the assessment process; only the two participants who work in a school setting were able to observe the children in the school setting. One of the participants did acknowledge this difference and stated, “ It would be nice if I could go observe them at school, but practically speaking its not feasible”. All participants did gather information from schools and or conducted their own testing for IQ and academic testing.

Overall, all participants reported benefits of utilizing tools and instruments throughout the assessment process to gather critical history and information to help in deciding if the child met criteria for ASD services or diagnosis.

Subtheme # 2: Family History

The second subtheme that emerged throughout coding and this researchers questions were family history. Participants were asked regarding their approach when gathering family history in the assessment process. All participants reported the importance of gathering family history in the assessment process, in order to get a clear picture of early childhood and functioning. Three out of five participants reported doing both face-to-face interviews with the parents, as well as providing packets of information and questionnaires for the parents to complete in gathering the family’s history. Two of the five participants that assess for services in school reported that they only conduct face-to-face interviews if they feel they need more information from the parents than their questionnaires had allowed or if they felt they needed more information. One respondent reported she utilizes a history form that is sent home prior to their first visit, that clients are required to fill out. She states,

“That way we can see if there’s any medical conditions, what medical records we might need, what psychiatric records we might need, um what school records, any other treatments or counseling or anything like that and you know for some of these kids we get birth records, if they had birth complications”.

She went on to say that assessors could build upon the information they receive from the history they receive. One participant also reported that she conducts interviews with the family as well. The first visit is the parent interview without the child present to gather more family history. She reported that these interviews go from one hour to an hour and a half.

Another respondent reported that they send home a packet for gathering family history prior to the first visit. She reported that the second visit is the parent interview to gather more family history. She states,

“So the two pieces of a diagnostic evaluation that are critical are the parent interview and the structured observation”.

Another participant reported that a major part of the assessment is the developmental history. She stated that she loves the way the new DSM-5 criteria was written because it no longer makes a child have to have symptoms present before age 3, it’s just once the social demands outweigh the abilities. When one of the participants was asked if any of the family history that was gathered was face to face she stated:

“It can be both ways. It depends on you know as consultants we get to know our teachers fairly well and so if we know the teacher is top notch, we know that, that the history is going to be good. If we’ve got a really challenging kid, and we don’t know, sometimes it’s nice to have that face to face just because you can ask for more information”.

Another participant reported that they use a developmental history interview that they send home to families to complete and return back to the school. She stated,

“It goes through everything you know cancer and everything like that. Any other kids in the home who have ASD, sensory issues, hearing or visual issues, texture you know, are they super picky eaters, social interaction like when they were small, concerns, eye contact, its actually really comprehensive”

Another respondent reported that they send home a family history packet that the families must complete and return before being able to schedule an appointment for their first meeting. She also stated that the first meeting includes the family interview where they gather more information and expand on information from the parents. She stated,

“One of my favorite parts of the assessment process is meeting with the family for the first time, I can gather so much critical information through those meetings. I love hearing the stories from the families and seeing where they are at in the process and where they have been, so many of the families I have worked with have a lot to say and have had a long struggling road to get where they are sitting with me”.

All of the participants reported the importance and significance in meeting face to face with the families of the children they are assessing in order to gather family history and how that is critical to the assessment process.

Subtheme # 3: Components of a good assessment

The third common subtheme that emerged through the coding process and questions was components of a good assessment. Participants were asked about what they believed were components of a good assessment specific to children with high functioning autism. Three of the

five participants reported that all of the components are a critical part of the assessment process so they can pull it all together to make an educated diagnosis.

One participant reported that having clear and solid family history, observations, and data are critical components of the assessment process so they can look over all the information and use their professional judgment with the data to make their diagnosis. Another Participant reported that the parent interview and structured observation are the two most critical parts of the assessment process she stated,

“The two pieces of a diagnostic evaluation that are critical are the parent interview and then the structured observation and then having some indication of what language level and adaptive skill helps you put those social behaviors in context and also think about intervention needs or differential diagnosis”.

Another respondent reported that the biggest component she believed in the assessment process was the observations. A different participant reported that the main component of an assessment is what she calls connectedness, and observing this connectedness. She states,

“I think one of the main things is what I call connectedness, you know we have to observe that child’s connectedness with those around them. Whether we are talking about a three year old or a sixteen year old, you know what do these kids look like in their natural environments? I am a very visual person and so that’s where I get most of my information”.

Subtheme # 4: Multidisciplinary

The fourth subtheme identified was multi-disciplinary approach. The participants were asked what their thoughts were on the multidisciplinary approach within the assessment process.

Two of the five participants stated they utilized the multidisciplinary approach and felt it was the best approach when assessing for services for clients within the school setting. Two of the five participants reported they did not feel it was as necessary or important as people said it was. One of the five participants reported that they understand why people think it is important and they did utilize this approach at her place of employment which is called a team evaluation however, she felt it can be redundant and not as important as people say it is. A different participant described this by stating,

“We have a developmental behavioral pediatrician who sees some of the children and then for those cases it would be what we call a team evaluations, a team of two, and he does some testing or questioning around medical history. He does a physical exam. He asks a lot of diagnostic questions though that I am already covering in greater detail. And in a more standardized way, so in that sense he’s sort of duplicating my work, but in a worse way and my feeling about multi-disciplinary evaluations is that I don’t think they are as important as people say they are”.

One participant reported that in the past she has worked in multidisciplinary teams, which she viewed as having an advantage and a disadvantage. She described finding that each person would have a part in the process so there were a lot of little parts within the team however, someone was still responsible for putting all of those little parts together, which was her role. She stated, “I just find that you need somebody to put the pieces together and that’s what I’m best at”. One respondent described their multidisciplinary approach as very comprehensive and that it was a team of many professionals working together,

“We have the school psychologists doing an observation and cognitive testing, special education teacher doing academic testing, I do very specific autism testing, and then

speech and language do their testing, physical therapy and occupational therapy if needed, and all of this comes together on a plan”.

One respondent reported that since they are assessing for services in school they do a thorough and comprehensive assessment using the multidisciplinary approach with many professionals. She stated that, “As a matter of fact kids who are tested educationally will often take our evaluations to a medical facility and that helps with their diagnosis there, because you know ours are so thorough”. A different participant reported that she felt the information gathered by a multidisciplinary team could be helpful depending upon what each professional was assessing for. She stated,

“If you are using a multidisciplinary team for different testing throughout the assessment process, that could work however, if you are using a team of professionals to come together all to discuss the diagnosis, I think it would be a waste of time and money. If you have well educated professionals they are all going to see or not see the diagnosis, so why have a team of them diagnosing when you can have one doing the same?”

Subtheme # 5: Training

The fifth and last subtheme for the theme assessment process is training. Participants were asked what training they had and continue to receive in the assessment process. Many participants reported that they did not receive any official training when they started conducting assessments. Many respondents reported that they had hands on training with a supervisor observing and learning from their supervisor and peers. One responded stated,

“I had really good supervisors and I would go sit in on assessments, including the interviews, the feedbacks, the interactions, and so you know I think you always get some really good ideas about how you want to do things from those initial training phases”.

A few of the respondents also stated that their education combined with their hands on training is what they received on conducting the assessment process. One participant discussed the difference between master’s level education and a Ph. D talking about how different levels of training provide them with a different starting point and experience when entering the field.

The two respondents working within the school setting discussed getting their autism certificate and how the state was now changing the requirements to needing an ASD license. They discussed how they believed the certificate was being phased out. They also discussed how professionals are only able to get an ASD license if they have a special education degree: the license is an add on to the degree. The two respondents also spoke to getting most of their knowledge and training with hands on training when they entered the field through observations of their peers and supervisors. One of the respondents illustrates this by stating, “Yep, they’ve moved from a certificate into a full blown license”. One respondent shared her thoughts that there are not enough people trained to work with this population. This same respondent reported that she did not have any formal training, she illustrated this by this statement, “I had one developmental psychology class I think that covered autism. So most of my training was on the job”. Overall, the participants felt their official training was provided on the job and not during their education process.

It is clear through what the participants have shared that the assessment process whether in a school setting or a medical setting, is a very extensive detailed process that involves many components such as: tools and instruments that can be utilized, gathering clear and solid family

history through both questionnaires and face to face interviews, utilizing multidisciplinary teams if and when necessary, and being provided good training through both an education for that foundational information and on the job training for learning the specifics of the process.

Theme # 2: Barriers to the Assessment Process

The second main theme found during the data analysis and interview questions was the barriers to and within the assessment process. All of the participants spoke to the stereotypes and bias that is present in how HFA presents, the present concern of divergent diagnosis among professionals, and training and education. Only one spoke to the limited access to services and poverty as being a barrier. One of the respondents reported experience as being a barrier within the assessment process and a cause of divergent diagnosis among professionals.

Subtheme # 1: stereotypes and biases on how HFA presents

One of the respondents reported that there is a lot of discrepant diagnoses among the medical community at this time and she spoke about medical doctors not knowing enough information about autism yet some telling parents that it is for sure not autism when in fact it might be. She also touched on some medical doctors not believing current research as well. This same respondent also discussed how some practitioners and professionals just have weird ideas about what autism is. She displays this well in this statement,

“What they used to call classic autism, sitting in the corner or on the other hand some people get really caught up on things that are not core symptoms, so this happens a lot with the higher functioning kids”.

Another respondent stated that she felt they run across stereotypes and bias by center, stating that, “For a while I know the physicians that I worked with would say, “well if you send them to

her center, they're going to get autism diagnosis". Another participant responded that she believes there are many professionals out there who still view higher functioning children as the child sitting in the corner not having any interest in interacting with others or the world. She states,

"This perception is very outdated and incorrect, current research displays that this population of children have many abilities and want to interact with peers as well as the world, and they will and do learn and adapt. We must keep educating professionals on what this truly looks like or we will always see divergent diagnosis among professionals in the field".

One the other hand another respondent stated she feels that the bias and stereotypes are getting better within the last five or six years, stating, "where you know, autism isn't Rain Man anymore. You know its not somebody being able to drop toothpicks on the floor and going 'oh there's twenty seven thousand two hundred forty two' the perspective seems to be changing quite a bit". One of the respondents also responded that they felt these stereotypes and biases had an effect on the parents being guarded and defensive in getting or receiving an autism diagnosis that they feel labels their child. She stated, "I've had school psychologists who have, you know, then done an assessment for school and tried to prove me wrong and all these little arguments in their reports."

Subtheme # 2: Access to Services

Access to services was one of the subthemes that was identified under the main theme, barriers. A few of the respondents spoke to access of services as being one of the barriers in the assessment process. One of the respondents spoke to the individuals and families themselves

whereas other respondents spoke to socioeconomic status or what population one may be in. Other participants discussed long wait lists as being a barrier to accessing services.

One of the respondents discussed how children can be resistant to come to therapy because it is out of their comfort zone and when you do work on it (i.e. related to autism) you can have children have huge meltdowns and so parents are resistant to bring them to therapy to try and avoid the meltdown. She discussed how individuals and families are becoming avoidant to services;

“Parents are going, “we don’t know what to do” but they don’t want to come to therapy and talk about it and work on it either and you see this especially in kids with more in the teenage years, but even ten, eleven, twelve, you’re starting to see that avoidance”.

One of the respondents spoke to income as a barrier to access for services. She reported that she had seen many cases where a wealthy family will get a referred for services yet if it is a low income family or an immigrant family they wont be referred until they are much older or be referred for other services. She spoke to the fact that professionals have biases against these populations and that these professionals will refer low income and immigrant children to head start instead of the autism clinic even when they have huge red flags. She stated;

“I didn’t say to them, you should go sue, and I didn’t want to make them feel bad that they didn’t like work harder to get around these pediatricians, but, yeah, those kinds of things happen more than they should”.

Some of the participants spoke to the long wait lists for centers and autism specialists. They discussed how families have to wait at least six months to get in and a lot of times it can be up to a year before a specialist can see you. They talked about how there are limited

professionals specializing in ASD and increasing knowledge of ASD so more kids are being referred causing the wait lists to climb. One respondent stated, “I know other big autism clinics around the country just have terrible wait lists, longer than they do here”.

Subtheme # 3: Training, Education, Experience in Relation to Divergent Diagnosis

All of the participants spoke to the training, education and experience that correlated with barriers and was associated with the divergent diagnosis when diagnosing high functioning autism. One of the respondents discussed how she felt that people are not well educated about ASD. She stated, “I think another barrier is that a lot of people aren’t well educated, including professionals, about ASD”. A few of the participants stated that the level of training they receive, the type of training, and setting affects one’s perception and understanding of high functioning autism. One of the participants stated, “ A couple of the respondents discussed the difference in a person who has been trained with a high level of familiarity with the population being autism spectrum disorders versus someone who has been trained where a very small part of the clientele or population being served includes those with autism spectrum disorders. One of the participants stated, “There’s a lot of difference between somebody that’s been trained in a setting where that’s a high percentage of the population that comes in versus a low percentage”.

One respondent discussed how she believes the divergent diagnosis is caused by the interpretation of the criteria. She reported that the educational criteria is very set and yet in the DSM criteria there is a lot of room for misinterpretation. She stated, “I think it’s the interpretation of you know, our criteria, educationally our criteria is very set”. Many of the respondents also spoke to the experience and lens that the professional has with autism spectrum disorders can be both a barrier and a benefit in the assessment process. They discussed that it could be a barrier if they as providers only ever see ASD and all of a sudden everyone had an

ASD diagnosis. They also discussed how that same lens can be of a benefit to help the assessment process. One of the participants stated,

“I think the professionals history with ASD and you know, we’ve got some psychologists who’ve been doing it for twenty years and their eyes are just there, you know they can see it. If you’re just maybe a year or two out of college and you’re experience has been through case studies, well”.

A few of the respondents also spoke to receiving outside trainings and going to yearly trainings offered by their employer for trainings specific to autism. One respondent also spoke to receiving training on the ADOS and ADI and how to administer those specific tools and instruments. All of the participants spoke to training, education and experience and how it can either help or impair the professional’s ability to make an accurate diagnosis from the assessment process.

Theme # 3: Presentation of HFA

The third theme that emerged from participant’s responses and through the questions was how primary aged children with high functioning autism presented in five main areas. The subthemes for this theme were these five main areas of; social skills and friendship, behaviors and or symptoms, gender, and theory of mind. All participants were able to share and discuss their thoughts within each of these areas.

Subtheme # 1: Social skills and friendship

Throughout the interview process each participant spoke to how they believed high functioning autism presents in primary aged children through social skills and what friendship looks and feels like for these children. All of the participants discussed what social skills can look like for children with high functioning autism. One of the respondents stated, “Their nuts

and bolts of language is all fine with them, their vocabularies are awesome, their word finding is great, they can talk a mile a minute”. One participant spoke to how this population can look precocious especially early on. She stated,

“I think what we see with the higher functioning group is that early on they look quite precocious and they don’t really make a lot of friends and maybe you know in those preschool years, because they are kind of precocious and they have these selective interests and that’s what they want to talk about and people think they’re so cute and they encourage that and you know yet they can’t really relate to other kids unless they have similar interests”.

All of the participants spoke to the higher functioning children struggling with reciprocal conversations, one participant stated,

“They don’t have good reciprocal conversations, they don’t know anything about turn taking both in and out of conversations. They want to direct the play and if it’s not the way they want it they’ll walk away”.

Another respondent added that they are interested in talking to people if it is something interesting to them stating, “They might be interested in talking to people, but only if its on their interest they may not be responsive unless it involves something their interested in”. She added, “It’s a feeling of more indifference rather than or like the lack of interest in social interaction”.

One of the respondents talked about social situations making high functioning children anxious because they don’t know what to do and how social skills are like a foreign language to them. All of the participants discussed how different ages come with different emotional and social demands. They talked about when children are in elementary school they often have one

primary teacher and then in middle school it changes to multiple teachers. One participant stated, “Once in elementary school you get one teacher for a whole classroom and then suddenly you get split up into different groups and pods”. They also discussed how the social demands increase with age, that in elementary school socially they relate over playing together where as in middle school they start to relate socially. All participants also spoke to the lack of picking up social cues such as facial expressions and body language.

One of the respondents talked about how she felt that some of the social skills they lack also act as a protection for them as well, she stated, “I kind of think there is a little bit of protection built in for them just because they don’t get some of those social keys”. All of the participants spoke to that the high functioning children may not be doing things like greeting other people or making small talk. All the participants also discussed how they try to control the social interaction and play.

All of the participants also spoke to friendship and what that looks like for children with high functioning autism. All of the participants stated that they believed children with high functioning autism do have the desire and want to have friends. One of the respondent’s stated, “Some kids really want friends but struggle to understand the dynamics or the definition”. Another respondent stated, “A lot of primary age with friendships will just think everyone in their class is their friend or they’ll have friends but they don’t know their names, so you wonder if they really are friends”. One participant talked about how children with high functioning autism do really well with other friends that are also on the spectrum. She stated,

“If they have a friend that is similar, I’ve often found that they kind of bond around their similar interests and if they are both on the spectrum for example, they don’t care if one of the other just walks away”.

One of the respondents stated that they think it is a common misconception that children on the spectrum do not want friends she stated, “People often think if they are on the spectrum that they don’t care if they have friends or not, I think they do care”.

Subtheme # 2: Behaviors and or Symptoms

The second subtheme that emerged through data analysis and the research questions was problem behaviors and or symptoms that the respondents observed among primary school aged children diagnosed with high functioning autism. Participants all spoke to and discussed behaviors and/or symptoms that they observed in children diagnosed with high functioning autism. All of the participants spoke to one of the symptoms presented and possibly the most challenging problem behavior as meltdowns or tantrums. One of the participants stated,

“Probably the most common problem behavior I see is the meltdowns, just its not going the way I want it to, the way I think it should, the way you said it would and I cannot tolerate it”.

Another respondent stated, “Difficulties with change, little minor changes really make them very, very upset and can lead to challenging behaviors”. Quite a few of the participants discussed how it could vary greatly on the degree to which children display tantrums or meltdowns some can be more aggressive and others become more withdrawn. One participant stated;

“Again, it can range you know I’ve had some very high functioning children who in eighth grade will throw themselves on the floor and tantrum all the way to complete withdrawal “I’m not going to do that” you know they become almost defiant, “that’s just stupid” and “that’s the dumbest thing I ever heard” you know it kind of depends a lot on their natural tendencies to begin with”.

Another respondent spoke to the more aggressive children possibly needing more or deeper sensory needs, she stated,

“I wonder if there’s a sensory component in that, that kids who are striking out in a more violent way need some sort of deeper sensory input that they’re trying to get, its just a speculation”.

One of the respondents spoke to how children grow out of behaviors such as hand flapping, lining objects up, sniffing toys, and peering closely at objects, and that by middle elementary to middle level school high functioning children are not displaying these behaviors any longer. Lastly, Another participant discussed comorbid diagnoses when talking about problem behaviors and talked about how common they are among children with high functioning autism, only adding to the behaviors and complexity of managing the behaviors.

Subtheme # 3: Gender Differences

The third subtheme found was how high functioning autism presents differently across gender. Participants were asked about their perspective of high functioning autism and how it presents in primary school aged children among genders. All but one participant described differences they observed among boys and girls and the differences in how they present. Most of the participants described differences such as girls not looking as socially unskilled, better able to blend in, taking longer to receive a diagnosis, getting a miss diagnosis, and having friends. One participant described observing girls on the spectrum as:

“I’ve seen girls that have kind of a I guess I would say less typical presentation, so these can be some of the girls who do have significant behavior issues and meltdowns and you

know all kinds of acting out kind of aggressive behaviors and people say “oh it’s a mood disorder”.

One participant talked about how girls are just not recognized as being on the spectrum:

“I think people don’t tend to think of girls so much as being on the spectrum and so a lot of stuff gets missed and even girls that may be struggling socially while they’re not a behavior problem, so its no big deal”.

One of the participants shared that boys tend to act out more externally as where girls tend to act out internally:

“Boys tend to act outwardly, you know they play with their toys oddly or they’re always sharing all their knowledge about vacuums with you as where girls seem to be more inward. You know girls on the spectrum look shy, they look quiet, they look depressed even sometimes”.

One of the participants discussed how girls seem to have friends;

“Girls with autism will often have a good friend, it might not necessarily be a healthy relationship, but they seem to understand that people are suppose to have friends and I think girls seem to do a little bit better job of faking it”.

On the other hand one participant shared how she felt there was no difference between boys and girls in how they present. She discussed how there has been research on the ADOS and the ADI and that those tests do not present any gender differences. She also discussed how she believes that people think there is a difference due to girls being protected a little more by saying that girls are more socially attuned. She stated:

“The girls I used to have a social skills group for girls with ASD and they had the same types of issues as the boys had or just being kind of socially oblivious, sort of irritable, these were all for verbally and cognitively intact kids”.

This same participant shared a situation where she had two of the girls from that same skills group who were transgender. One participant discussed how they as professionals are looking for things such as: do girls use gestures differently? She stated,

“So some people have said they use more facial expressions, but they have trouble reading other people’s facial expressions, that’s the girls presentation. Whereas the boys just don’t use and don’t understand facial expressions”.

All of the participants shared how there is a lot more research that needs to be done in regards to gender difference in ASD so professionals are not making inaccurate assumptions about what girls impairments are going to be.

Subtheme # 4: Theory of Mind

This final subtheme for how high functioning autism presents is theory of mind. Autismspeaks.org (2016) defines theory of mind as, “One’s ability to perceive how others think and feel, and how that relates to oneself”. Participants all responded to how they observe primary school aged children with high functioning autism presenting in regard to theory of mind. All but one participant spoke to children with HFA having great abilities with theory of mind, contrary to what some still believe. One of the participants discussed how the children do well on theory of mind tasks one on one but can struggle utilizing those same tasks in an actual social situation. She stated,

“I would say a lot of the kids that I see are able to do reasonably well on the formal theory of mind tasks, but you ask them to do it in a real social situation and they’re going to completely fail at it”.

She went on to explain how during testing, children are given time to observe and think about the answer;

“I think that’s even true with the emotional recognition piece that we do, because part of the task is you know we’ll show him or her a picture that has maybe six faces with different emotions and then there’s an example face up here and we say, okay, pick the two faces down here that are showing the same feeling. So you have the example and you have the pictures, well these are nice still pictures and you get as much time as you need to look at them, that’s totally not like a real social situation”.

Similarly, another woman discussed her observations and prospective,

“That (theory of mind) was a big trend when I first started getting into autism, it was including, it was actually focused on kids with Asperger’s and theory of mind. You know, the woman I worked for, she never really was a believer in theory of mind and said “you know most of that is like receptive language skills”, and it really is”.

She went on to say that theory of mind is really a social deficit stating, “It’s part of the difficulties reading social situations”.

Interestingly, both of the participants who work in a school setting both responded that they believed theory of mind deficits were present within how high functioning autism children presented. One of the participants stated,

“It’s usually in their ability to empathize or sympathize with another person or you know in primary age, some of the standards are, what was the author thinking when he did this? Or how is that character feeling when this happened? And if you’re asking factual kids about the information in the text they can give you that all day long, but for them to pull pieces from that or come to a conclusion is often really, really difficult”.

Similarly, the other participant who works in the school setting stated, “It’s that higher level of cognitive thinking that gets in the way for them”. Additionally, she mentioned a theory of mind test that they use within the assessment process called the Sally Ann Test. She discussed how she uses this test with all of the children she assesses no matter if they are higher functioning or more classic presenting autism. She stated,

“Sally puts her ball in the basket and then she leaves, Ann moves the ball. So when Sally comes back in where is she going to look? Okay, so the answer is she’s going to look in the basket, because that’s where she left it. And invariably, I mean whether I’ve got a kid with a sixty five IQ or if I’ve got a kid with one hundred and twenty five IQ is going to look in the box”.

Overall, participants either believed theory of mind was something that children displayed as a deficit or something that participants believed was an ability they displayed. These two separate views were separated by the setting that the participants worked in. The participants who worked within a school setting assessing for services viewed theory of mind as a deficit these children displayed. The participants that worked in a setting where they were diagnosing viewed theory of mind as an ability the children had.

Theme # 4: Professional Judgment Vs. Data

Participants were asked what they seen as the role of professional judgment versus data when assessing clients. All the participants responded that both professional judgment and data are equally as important when assessing children for ASD. However, the two participants who worked within a school setting really focused in on the multi disciplinary team as the role they see as a context for professional judgment. Another participant focused more on the tests and instruments for the data. One of the participants stated,

“There’s research on this, the best most reliable diagnosis, meaning one that’s stable over time and that other people agree with is done by people who are, who have a lot of experience in autism and standardized measures so their using ADI to go through their questions. They’re using the ADOS to look at the symptoms, so you’re trying to standardize social opportunities. I think that’s really important, it’s structured, its data based, it’s supported by research”.

Additionally, she added:

“I think having those standardized tools cant be overstated, but then there are times when I need to use my clinical judgment”. She went on to say that there are times when a test can be thrown off by the child’s participation level and that is e when you really need to use professional judgment. She also discussed how its important to gather the data in a consistent standardized way so you can put it all together like a puzzle.”

Another respondent also described using professional judgment versus data like a puzzle, she stated,

“I think to have a good assessment and diagnosis you really need to make sure that you have all the pieces. You need a good history, you need rapport from parents and

sometimes that's really hard to get. You need teacher input and sometimes over the summer for example that's not easy to get. I think if you can take all of those different pieces into consideration and the data fits you're doing well".

One of the participants who works within a school setting discussed how they really rely on their teacher and school psychologist feedback because they are unable to truly see and observe the child as much as the teacher and school psychologist are able to so they really rely on their feedback for the test and instruments and how to measure those questions. She stated,

"That's when you really depend on you know your teachers, "okay was he just having a bad afternoon? Or was that a really awesome afternoon?" you know having another set of trained eyes like our school psychologists, speech paths, you know so even if I do get a really bad afternoon you still got four, five, six other eyes to see and say "no, it just wasn't you, it was everybody".

Another participant who works within the school setting similarly stated,

"By training we had it drilled into us that it's all about the data. Its about the number of trials given, success, what's your percentage, where are you, where were you yesterday, where are you going tomorrow, its all very measurable. That's why we rely so much on our school psych and teachers, they help us with that professional judgment piece".

Overall, all of the participants felt that it took more than just data or professional judgment; it took putting everything together to really have a good and solid assessment.

Theme # 5: DSM-5

The fifth and finale theme that emerged from participants responses and questions asked within the interview process were their thoughts on the new DSM-5 changes with Autism Spectrum Disorders. Participants were asked what differences or changes they have seen in regards to the new DSM-5 Autism Spectrum Disorder and how they felt about the removal of Asperger's Disorder. The respondents who worked within a school setting talked about how the educational criteria have not been affected by the changes of the DSM-5 and how they were not affected by the removal of Asperger's because educationally its always just been autism. One of the respondents sated,

“Our criteria educationally has not changed as a result of the new DSM-5 but some of the things that we are using are starting to change like the developmental history. I don't know if our educational criteria will change at all”.

Additionally she spoke to the removal of Asperger's Disorder,

“My understanding of this was going from way back you know the difference between high functioning and Asperger's is that they had typically developing language and a child who has high functioning autism had disordered or delayed, well now we don't have those guys anymore”.

Similarly, the other respondent who works within the school setting spoke to the removal of Asperger's Disorder stating,

“I have a lot of parents ask, “well would you say he's more Asperger's?” and again, medically I cant, well we don't get to say that, but I'm glad its just autism instead of parents feeling its better if its Asperger's”.

All of the other participants that are in a diagnosing position with autism spectrum disorders spoke to the new DSM-5 as being much better than the DSM-4. One respondent stated, “It’s a lot cleaner, the symptoms are much better qualified and quantified so that they are mutually exclusive”. Another participant stated,

“I just happen to work on a CDC study where we’re reading through records and applying DSM-IV criteria and DSM-5 criteria separately and its much, much easier to go through a report and say, ok, this symptom is met on DSM-5 than on DSM-IV because they’re so murky”.

Similarly, another respondent stated, “Trying to say you have to meet so many symptoms and all these areas and people just are not consistent, they were not consistent on the DSM-IV”. One of the participants did speak to needing that good developmental history when using the DSM-5 and she also talked about how she believed the DSM-5 is made by psychiatrists who do not necessarily do the assessments, they prescribe the medication.

Discussion

The purpose of this study was to explore with professionals assessing and diagnosing high functioning autism how they assess, perceive, and diagnose high functioning autism in primary school aged children. Since there is a limited amount of research done in the area of high functioning autism the results are compelling in many ways. The data revealed information that is consistent with research that has already been done in the area of HFA as well as new valuable information to consider for primary school aged children when assessing and diagnosing. Overall, the participants were very open and honest with sharing their professional opinions and

experiences in how they, assess, diagnosis and perceive HFA to present in primary school aged children.

Each participant was able to identify components of an accurate and well done assessment, what they implicitly or explicitly do within their assessment process, and identify what challenges or barriers they see within the assessment process that could contribute to the divergent diagnosis of HFA. Each participant was also able to identify how they observed children presenting in characteristics or symptoms of HFA what role they felt professional judgment versus data played in the assessment process, what differences they have seen with the new DSM-5, and thoughts about the removal of Asperger's Disorder.

Assessment process

One of the most outstanding findings in this study was the assessment process professionals used with assessing and diagnosing HFA. Professionals spoke often of how each component of the assessment process is important and plays a role however, the professional's main role was to gather all of the available data and to analyze it with their experience and professional judgment to have the most accurate diagnosis. All of the professionals spoke about how it was their job to put all of the pieces together like pieces of a puzzle.

Another important finding within the assessment process was that many professionals who participated were not specifically utilizing a multidisciplinary team of people; however, they were utilizing information gathered from multiple disciplines. All of the professionals either obtained documentation from the schools or other professionals that had conducted assessments on the child or completed their own assessments utilizing the same tools and instruments that would be used by those same professionals in other settings. Ultimately, they were utilizing the

data from multi professional teams and incorporating it into their overall data to analyze it as part of their assessment and diagnosis.

All participants discussed that all of the data within the assessment process is important. However; they suggested it comes down to professional judgment with someone being able to put all those components together. All participants also suggested that family history and observations were two of the biggest components of the data within the assessment process.

All of the professionals spoke to how diagnosing HFA is much more complex than diagnosing classic autism due to all of the subtleties and differences in presentation. Similarly, Yates and Couteur (2008) found that diagnosing autism for the broader spectrum is less stable and less reliable overtime. One of the biggest factors to the complex nature of diagnosing HFA is that research suggests there are not clear and specific characteristics or symptoms of HFA. This research strongly suggested that assessing and diagnosing HFA is much more complex than classic autism.

Presentation of HFA

Professionals in this study shared their experiences and observations about how HFA presents in primary school aged children within the areas of social skills, friendships, problem behaviors, gender differences, and theory of mind. All of the participants spoke to the challenge of providing a direct and specific characteristic within each area due to the spectrum of how it presents within each of the areas I was focusing on. Molina (2014) supported this idea by discussing how there is confusion among researchers that has prevented a clear differentiation in symptoms and behaviors. This research strongly suggested that primary school aged children do

present some common characteristics and symptoms. However; the characteristics and symptoms are on a spectrum themselves ranging from mild to more severe.

The professionals spoke to the abilities of HFA children describing that this population does not have language or cognitive impairments. The respondents discussed common misconceptions of high functioning individuals and how high functioning autism does not look like we once believed it to look. Losh and Capps (2006) discussed how in their research high functioning individuals were able to understand basic emotions but struggled with more complex or self-conscious emotions. The participants also talked about how HFA children are very precocious and have great language and vocabulary skills early on. They discussed how children with HFA have select interests and have a lot of parallel play. Though they play through parallel play it was discussed by all the participants that children with HFA do want to have friendships but may struggle with understanding the dynamics of a friendship. These results correlated with the literature. Calder et. al. (2012) found through their study of twelve families with a child diagnosed with HFA that many children in their sample expressed a real desire for social relationships and that primary school aged children can and do form friendships.

Professionals discussed common problem behaviors that can be present in primary school aged children. All participants spoke to the most common behaviors displayed including “meltdowns” rigidity, and very black and white thinking. These behaviors correlate with Macintosh and Dissanayake (2006) reported symptoms of showing deficits in co-operation, assertion, and self-control through their study of parent and teacher reports. This research strongly supported the idea that primary school aged children display and struggle with problem behaviors within the school, home and community settings.

Conceptual Framework

This study utilized the framework of Tony Attwood and his book *The Complete Guide to Asperger's Syndrome* 2007, revised edition 2015. This research strongly correlates with Attwood's perspective on how high functioning autism (Asperger's Syndrome) presents in characteristics and or symptoms in those diagnosed with high functioning autism. The characteristics that Attwood describes individuals with Asperger's Syndrome as presenting are struggling to understanding and express emotions, having special interests of clinical significance, cognitive abilities, struggling with movement and coordination, and sensory sensitivity. The professionals that participated in this research study spoke to observing and experiencing the characteristics similarly as Attwood describes in his research. Attwood emphasizes children with this diagnosis struggling with emotional maturity and problems expressing and controlling anger. He also discusses about the presentation of special interests and how children often can display a pre occupation with their area or topic of interest as early as two years of age, collection of facts and figures about a specific topic, and knowledge on the interest is often self-directed and self-taught.

Attwood also explains his perspective of cognitive abilities as; often starting school with academic abilities above grade level, distinctive learning styles, talent in understanding the logical and physical world, being easily distracted, appearing to have a one track mind and fear of failure, and struggles organizationally. However, the one area where the data from this research did not fit with Attwood's perspective was that of theory of mind. The majority of respondents in this study suggested they did not feel children with high functioning autism had deficits in theory of mind. Attwood suggested that children with HFA or Asperger's Syndrome do have deficits in the area of theory of mind. Overall, Attwood's book became a natural fit for this study as his perspectives correlated with the themes that emerged from the data.

Strengths and Limitations

This current study has both strengths and limitations due to the qualitative research design, how the data were analyzed, and the participants chosen. The qualitative nature of the study limited the sample size to five participants who spoke about their professional observations and experiences. This is a limitation because it only gathered data from a few professionals among a large population of professionals that work within the field of assessing and diagnosing high functioning autism, which can make the findings difficult to generalize for the perspectives of many different professionals working with the HFA population.

This study was only able to recruit five participants, which limits the amount of data and feedback this study was able to obtain and analyze. On the other hand, this study was able to have a diverse group of professionals to interview with different educational backgrounds, communities, and settings in which they worked in giving this study richness in diversity and experiences. This study also offered participants to speak openly about their professional experiences and ideas on what HFA looks like as it presents in primary school aged children and what barriers they see within the assessment process. Another limitation of this study is that all of the participants in this research study were females and that the majority of professionals in this field are female.

Research Implications

High functioning autism continues to be an area of research that is understudied in the areas of how it presents with specific characteristics of social skills, friendships, problem behaviors, gender differences, and theory of mind. Without further research on how high functioning autism presents it will continue to be an area within the spectrum that will face

divergent diagnosis among professionals and across settings. Research done with a larger sample size of professionals across settings and focused on specific areas on how HFA presents would likely produce more generalizable results. Also, research in the area of how the multi-disciplinary approach is utilized would also be beneficial; this would allow us to better understand if utilizing the same tools and instruments multi-disciplinary teams use would create the same outcome as having the professionals present within the assessment process.

Lastly, There continues to be a need for more research to better understand gender difference within the high functioning autism population in if they present differently and if so how do they present differently. Also, looking at what different abilities genders have when presenting their symptoms across settings.

Implications for Social Work Practice

The Center for Disease Control and prevention (CDC) previously estimated, “1 in 68 children (or 14.7 per 1,000 eight-year-olds) in multiple communities in the United States had been identified with autism spectrum disorder (ASD)” (2014). However, a new government survey suggests it has risen to 1 in 45 children with the ages ranging from three to seventeen (autismspeaks.org, 2016). With these numbers it is inevitable that social workers will work with children and adults diagnosed with autism spectrum disorder as well as families and loved ones caring for these children and individuals. Social workers working with these children and families need to be knowledgeable in how high functioning autism presents and varies in presentation so they are better able to serve this population. It is the social worker’s ethical responsibility to have commitment to the client and promote the well-being of clients. With knowing that autism rates are increasing we know that social workers will have both children and adults diagnosed or needing to be appropriately diagnosed on the autism spectrum on their

caseload. If social workers are not appropriately and adequately trained to better understand autism are they able to truly promote the well being of those clients if they are unable to recognize it to diagnose it or refer them to a specialists that can?

Research has displayed that early identification and intervention significantly increases a child's opportunities to benefit from early intervention and services. Research also revealed that many children are not being diagnosed with high functioning autism until middle school or later when the social demands increase causing the child to present with more symptoms. With this said, providing autism education specifically to school social workers would be of great benefit in the early identification of high functioning autism.

Training and education

It is critical for professionals working within a school setting to clearly identify the differences between assessing and diagnosing to families. There needs to be a clear understanding for families that the schools are not diagnosing children; they are assessing them to see if they meet the criteria for services under special education, not to see if they meet the criteria for a diagnosis under the DSM-5. Resources should be available to these families within the school so they can, if they choose, pursue a diagnosis. Research suggests parents are not informed of this information or the professionals within the school setting are failing to inform parents of this critical difference. This creates a huge barrier for children with high functioning autism because it delays the child and families of receiving critical early intervention services.

Therefore, there should be more in depth and extensive training on autism spectrum disorders and the new DSM-5 to professionals working within the school setting. It is best practice to be as educated and knowledgeable as possible with the populations we serve. If we

train our professionals working with children diagnosed on the autism spectrum in all areas and aspects of the disorder they will be better prepared to fulfill their professional roles.

Lastly, research from this study suggested that there is a lack of trained professionals working or interested in working with individuals and families affected by autism spectrum disorders. This lack of and need for trained professionals working within the area of ASD has caused long waiting lists for clients which is another barrier for our clients in receiving critical services. It would be of great benefit for graduate school programs to offer elective courses as part of their curriculum options so more students were exposed to and had the opportunity to learn about autism spectrum disorders. This could potentially lead to more professionals working within the field as well as within rural communities, where there is a great need for services for the ASD population.

Conclusion

It is known that autism spectrum disorders are increasingly prevalent and the need for professionals, services, and research is at an all-time high. In spite of this knowledge, there continues to be a critical need for more research to better understand how high functioning autism presents and varies in presentation in primary school aged children to help increase early identification.

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Appendix A Request for Establishing MSW Clinical Research Committee

STUDENT NAME: _____ Student UST ID# _____

I have discussed my research with and request that the following comprise my research committee

CHAIR: _____
Faculty Chair Signature Date

COMMITTEE MEMBERS:

By signing below, committee members acknowledge their responsibility to, at minimum, meet as a committee once each semester, to read and comment on student's written work, to offer support and guidance throughout the research process and to attend the public presentation of the paper in May.

1. COMMITTEE MEMBER:

Name (PLEASE PRINT) Signature

Date

Institution/Agency

Email address to send Final Program and other communication – PLEASE PRINT clearly

2. COMMITTEE MEMBER:

Name (PLEASE PRINT) Signature

Date

Institution/Agency

Email address to send Final Program and other communication – PLEASE PRINT clearly



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Appendix B Consent Form

The Challenge of Divergent Diagnosis in Relation to Diagnosing High Functioning Autism

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You are invited to participate in a research study about better understanding high functioning autism as it presents in primary school age children, the assessment process, and the ways professionals approach the process of diagnosis. I invite you to participate in this research. You were selected as a possible participant because you are knowledgeable in autism spectrum disorders. You are eligible to participate in this study because you have or currently are working with children diagnosed on the autism spectrum. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Mallori Sheik (Avery) and will be advised by David Roseborough, through St. Thomas University School of Social Work. The Institutional Review Board at St. Thomas University approved this study.

Background Information

The purpose of this study is to determine what high functioning autism looks like as it presents and varies in presentation in primary school age children, what an accurate assessment involves and where assessments take place, components of an accurate assessment, how professionals are trained, and to gain a better understanding of how diagnosis is approached across a number of systems and professionals diagnosing high functioning autism.

Procedures

If you agree to participate in this study, I will ask you to do the following things: participate in a 45 minute to one hour interview that will be audio recorded and later transcribed. The location of the study will take place where it is most convenient and comfortable for you. There will be an estimated number of eight participants that will participate in the study.

Risks and Benefits of Being in the Study

This study has minimal risks. I will be asking about your professional opinions in relation to a professional topic. I will be asking for your opinion, but will not ask you to speak on behalf of or to represent your workplace or discipline. If you decide to participate, I would audio record the interview and either myself or a transcriber will transcribe the interview. If a professional transcriptionist is utilized, he or she will sign a confidentiality agreement. The digital audio recording will be deleted by September 1, 2016.

There are no direct benefits you will receive for participating in this study.

Compensation

There is no compensations for participation in this study.

Privacy

Your privacy will be protected while you participate in this study. This researcher will protect your privacy through making sure your name is not attached to any documents and the researcher will not have any highly identifiable information transcribed (such as your name or the names of specific locations or other people you might mention). The researcher will delete the audiotapes and shred the transcriptions by September 1st 2016. As the interviewee, you can choose the location and time of the interview as well as the amount of information you are comfortable sharing. You can skip or decline to answer any specific questions, you would be able to see the interview questions in advance if you would like to.

Confidentiality

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you. The types of records I will create include digital audio recordings and transcriptions of the interview, master lists of information, and computer records. The recordings will be digitally recorded and will be stored on a password-protected desktop at the researcher's home. The transcriptions will be transcribed by a professional transcriptionist and will sign a confidentiality form created by St. Thomas University Institutional Review Board. The researcher will give the transcriptionist a password protected flash drive to store the transcriptions on and when the transcriptions are complete the researcher will store the transcriptions on a password-protected desktop at the researchers home. The master lists of information and computer records will also be stored on a password-protected desktop at the researcher's home. The interview recordings will be destroyed by September 1st 2016. All information gathered will be available to my research professor, Dr. David Roseborough. All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

Voluntary Nature of the Study

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Thomas University or St. Catherine University, with the School of Social Work, or with your employer. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. Should you decide to withdraw, data collected about you will not be used. You can withdraw up to two weeks after the interview. If you choose to do so, please contact me at the phone number or email below to express your request that your data not be included in the study. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Mallori Sheik (Avery). You may ask any questions you have now and any time during or after the interview. If you have questions later, you may contact me at 218-820-1023 or aver0013@stthomas.edu. You may also contact the advisor David Roseborough at DJROSEBOROUG@stthomas.edu or 651-962-5804. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

Statement of Consent

I have had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give my permission to be audio recorded during this study.

You will be given a copy of this form to keep for your records.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix C Interview Questions

1. Please tell me a little about yourself including: length of experience working with autism spectrum disorders/with children, educational background in ASD, role in your position, and interest in ASD.
2. What does your approach to the assessment process look like for diagnosing Autism Spectrum Disorder?
 - a. Tools or Instruments Used
 - b. Gathering family history
 - c. Components of a good assessment
 - d. Multi professional approach
 - e. Barriers
 - f. Training
3. Is there anything you implicitly or explicitly do in the assessment process when assessing for HFA? That is, how is your assessment process similar and/or different?
 - a. Are there any additional or unique strategies you use here?
4. Research suggests there are not necessarily clear characteristics or symptoms of high functioning autism in how it looks and or presents. From your perspective, what does high functioning autism look like or present in primary age children?
 - a. Social skills and friendship
 - b. Problem behaviors
 - c. Gender differences
 - d. Theory of mind

5. . What challenges do you see, if any, when diagnosing high functioning autism vs low functioning autism?
 - a. Does the assessment process change for HFA
 - b. Do the instruments or tools vary when assessing for HFA
6. Do you see more children diagnosed with high functioning autism or low functioning autism?
7. . Do you ever see among providers the phenomena of, myths, confirmation bias, and prejudice, or any other variables that affect the accurate assessment of HFA?
8. What is the role of professional judgment vs “data” or literature when assessing and diagnosing HFA?
9. . Research suggests that divergent diagnosis among professionals and across settings is very prevalent at this time, what do you think might account for it?
10. What differences or changes have you seen in regards to the new DSM-5 Autism Spectrum Disorder?
 - a. Assessment process
 - b. Diagnosis
11. Research suggests there continues to be controversy over the removal of Asperger’s Disorder in the DSM-5, How do you feel about the removal of Asperger’s disorder?
12. Any thoughts or feelings that you would like to share/feel are important in regards to high functioning autism?

