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Reconceptualizing Autism Spectrum within Diagnostic and Statistical Manual, Fifth Edition: Clinicians' Perspectives

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Reconceptualizing Autism Spectrum within Diagnostic and Statistical
Manual, Fifth Edition: Clinicians' Perspectives

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
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St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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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

This qualitative study examined the clinicians' perspectives on the reconceptualization of Autism Spectrum Disorder within the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013), also referred to as DSM-5. Data were collected through six semi-structured interviews (n = 6) with clinical professionals who work directly with children and adolescents with Autism Spectrum Disorder (ASD), otherwise known as Pervasive Developmental Disorders (PDD). Clinical professionals included licensed independent clinical social workers, licensed clinical social workers, and licensed psychologists. Grounded theory method was used with open coding to analyze various themes and subthemes within transcribed interviews. This study examined participants' perceptions on overall changes to ASD criterion in DSM-5, participants' views on strengths and challenges with new ASD criterion in DSM-5, and participants' perspectives on implications of DSM-5. The findings from this study were consistent with similar literature and research on the changes of ASD from DSM-IV to DSM-5 and provided additional information. Professionals both support and criticize changes to the ASD diagnostic criteria in DSM-5.

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Introduction

An understanding of Autism Spectrum Disorder (ASD) has evolved over time since the condition was first introduced as infantile autism in the 1940s by Leo Kanner. Kanner observed 11 children he worked with who presented with similar deficits in social interests, communication, and behavior that he described as rigidity to change and transitions (Volkmar & Reichow, 2013; Woodbury-Smith & Volkmar, 2009). Around the same time Hans Asperger, an Austrian pediatrician, described social deficits in relating to peers within a group of boys between the age of six and 11 (Woodbury-Smith & Volkmar, 2009). During this time, neither Kanner nor Asperger were aware of one another's work.

Similar to Autism Spectrum Disorder's evolution over time, prevalence rates of ASD diagnoses have continued to increase since the publication of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) in 1994. According to statistics from Centers for Disease Control and Prevention, in 2013 one in 50 children aged six to 17 had received an Autism Spectrum Disorder (ASD) diagnosis, as reported by their parents; boys are more than four times as likely as school-aged girls to be so identified (CDC, 2013). Historically a diagnosis of ASD is much more common in boys than girls. The CDC's latest figures are significantly higher than their estimate from 2007, which reported that one child in 86 had been diagnosed with ASD. The increase in ASD rates from 2007 to 2013 led to public speculation about causes, but may be attributed to the fact that more children were diagnosed after the year 2008 (Blumberg et al., 2013). The increasingly common

diagnosis of ASD coincides with the transition from DSM-IV-TR to DSM-5 as diagnostic tools. Although the exact nature of the shift in ASD prevalence remains unclear (DSM-5, 2013), these changes may be attributed to increased awareness and recognition of ASD by the community, educational settings, and professionals (Blumberg et al., 2013; McPartland, Richow, & Volkmar, 2012). Yet many questions remain about DSM-5's diagnostic criteria for ASD. This research paper seeks to explore some of these concerns among a sample of professionals working in the field.

Autism Spectrum Disorder, also known as Pervasive Developmental Disorders, include five categories: Autistic Disorder, Asperger's Disorder, Child Disintegrative Disorder, Rett's, and Pervasive Developmental Disorder, Not Otherwise Specified (NOS) (Phetrasuwan, Shandor, Miles, & Mesibov, 2009). *Autistic Disorder* can be described as deficits in social and communication skills, rigid and repetitious actions or behavior, strong abnormal focus with certain topics or objects, inflexibility with schedule and routine, as well as repetitive use of language. *Asperger's Disorder* is similar to autism with deficits in social interactions, and repetitive and rigid behavior; however, overall there is less impairment, no deficit in early language skills, and higher intelligence quotient (IQs). *Child Disintegrative Disorder* can be described as a regression in development, social skills, and communication, as well as repetitive behaviors, occurring after a child has developed normally through two years of age. *Rett's Disorder* can be described as a decline, at an age between seven and 18 months, in behavior, cognition, and motor skills which is seen mainly in girls and is a degenerative disorder. This disorder now fits under a different section in the DSM-5. *Pervasive Developmental*

Disorder, NOS can be described with similar deficits as autism but not enough symptoms to meet the minimum threshold for diagnosis of autism (Phetrasuwan et al., 2009).

During the last decade, since the publication of DSM-IV-TR in 2000, much work and research have resulted in the reorganization of the fifth edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-5). One of the most important changes is the reorganization of the ASD diagnosis criteria (APA, 2013). The changes have eliminated Asperger's Disorder, Child Disintegrative Disorder, and Pervasive Developmental Disorder, NOS diagnoses, consolidating them into one umbrella diagnosis: Autism Spectrum Disorder (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013; Tsai, 2012).

Elimination of Asperger's and Pervasive Developmental Disorder labels raise questions among clinicians and professionals whether changes will be beneficial or disadvantageous for clients. Professionals both support and criticize changes to the ASD diagnostic criteria in DSM-5. Those supporting the changes believe the revisions will provide more clear and reliable standards for ASD (Lai et al., 2013; Singer, 2012; Swedo, 2013; Tsai, 2012). However other professionals fear that a significant number of higher functioning autism and Pervasive Developmental Disorder, NOS patients diagnosed under DSM-IV-RV may not meet criteria under DSM-5 (Lai et al., 2013; Matson et al., 2012; Singer et al., 2012; Tsai et al., 2012). Failure to meet criteria could result in possible implications for services, increased stigma among those formerly diagnosed with Asperger's (generally viewed more positively than autism), and increased diagnostic labels among those with Asperger's (who may have previously been underdiagnosed) (Kite, Gullifer, & Tyson, 2013; Wing, Gould, & Gillberg, 2011).

The implications of changes to the ASD criteria in the DSM-5 may not be completely evident for some time for clinical social workers who provide services to clients with ASD. Impacts may become evident only after practice and additional research are conducted. Some of the following implications will be considered:

- How will treatment look for clients who no longer meet the Autism Spectrum Disorder under the new criteria DSM-5, who had previously met a diagnosis under the Pervasive Developmental Disorders diagnosis in DSM-IV-TR (and who may still meet a diagnosis such as Social Communication Disorder)?
- How will diagnostic tools change for clinicians with revisions to DSM-5?
- How will special services change for those who do meet the DSM-5 Autism Spectrum Diagnosis criteria?
- How diagnosis prevalence shifts will change for clinicians with the new criteria? (Blumberg, et al., 2012).

This study will explore clinicians' perspective on changes to the DSM-5 criteria for Autism Spectrum Disorder. The study interviewed a variety of clinicians and clinical social workers who work with and diagnose children with ASD. The questions for the interview were semi-structured relating to reorganization of the DSM-5 Autism Spectrum Disorder diagnosis. The information gathered during this study may expand clinicians' knowledge on other clinicians' experiences with the new DSM-5. This may be helpful for clinicians as they interpret and further implement the DSM-5.

Literature Review

The literature reviewed for this study reveals changes to the diagnostic criteria from the DSM-IV-TR (2000) to the DSM-5 (2013), Autism Spectrum Disorder criterion, history of the DSM, as well as clinicians' and professionals' perceptions of these changes. The literature suggests both positive and negative perceptions of the reorganization of the DSM-5 Autism Spectrum Disorder. This review will analyze, in detail, the specific changes in the DSM from DSM-IV-TR to DSM-5. The resources used include the DSM-IV-TR, DSM-5, journal articles, internet reports, research studies, videos, and books. The following themes will be discussed within this examination of the literature:

- definition of Autism Spectrum Disorder in the DSM-5;
- definitions of Pervasive Developmental Disorders and Autism Spectrum Disorder in the DSM-IV-TR;
- characteristics of Autism Spectrum Disorder;
- diagnosis tools for Autism Spectrum Disorder;
- prevalence shifts of Autism Spectrum Disorder diagnosis;
- clinicians' perceptions of changes resulting from DSM-5;
- impact of these changes to educational institutions;
- and, impact of these changes on clinical social workers.

This review includes a comparison of four research articles that presented significant information to this topic, and which will be considered as clinicians' perspectives.

This research will focus on children from birth to 17 years old with Autism Spectrum Disorder, otherwise known as Pervasive Developmental Disorder. Autism Spectrum Disorder will be used interchangeably with Pervasive Developmental Disorder. Autism has evolved from an initial diagnosis of infantile autism in the 1940s, to childhood schizophrenia through the '60s and '70s, autism under Pervasive Developmental Disorders, and now finally Autism Spectrum Disorder as defined by DSM-5.

Prevalence of ASD

The reasons for dramatic and increased prevalence of Autism Spectrum Disorder over the past decade remain ambiguous. These shifts may be associated with expanded criteria, increased awareness, diversified and increased interested in ASD-related research, or increased accuracy in diagnosis of Autism Spectrum Disorder (DSM-5, 2013). According to Blumberg and colleagues (2013), increased recognition of autism has had an important impact in prevalence, as seen in improvements in screenings by healthcare professionals, changes in autism awareness in parents and healthcare professionals, increased access to diagnostic services, and increased special education in the community.

There is a significant increase in prevalence over the past decade. The “Autism and Developmental Disabilities Monitoring (ADDM) Network revealed a 78% increase in ASD prevalence between 2002 and 2008 (6)” (Blumberg et al., 2013, p. 24). According to the CDC, the increase between 2007 and 2012 is related to more recent diagnoses in 2008 or after. The most common increase in prevalence was for children from six to 13 years of age. The highest increase, 50%, was in children ages six through

nine, second highest increase, 20.8 %, was in children aged 10 to 13, and third highest, 13.5%, in children aged 14 to 17. Children six to 17 years of age, diagnosed in 2008 or after, were more likely to have a mild diagnosis of autism and less likely to have a severe diagnosis, and were less than one-half as likely as children diagnosed in or before 2007 to have severe ASD (6.9% compared to 16.9%). According to the CDC, increase in prevalence rates is largely accounted for by new diagnosis accuracy rather than survey reliability. Nearly one-third of the school-aged children whose parents reported as having Autism Spectrum Disorder in 2011-2012 were diagnosed on or after 2008. These findings strongly suggest that the evolution of ASD prevalence may be connected with changes in the diagnosis criteria and definitions.

Conceptualization of ASD

The prevalence of autism diagnoses has expanded greatly over the last 30 years since autism's introduction as a category of disorder via DSM-III in 1980. The shift toward Autism Spectrum Disorder and the rise in its higher prevalence are likely influenced by multiple factors. The concept of Autism Spectrum Disorder emerged when Lord (as cited in Benaron, 2006) studied the consistency of the condition using diagnoses in children ages two, five and nine. Lord found that those who had received an autism diagnosis at age two were 89% more likely to receive the same diagnosis at ages five and nine. Diagnoses of PDD, NOS were not as reliable predictors, as only 50% of subjects received the same diagnosis at ages two, five, and nine. This finding reinforced the suggestion that PDD and autism should be considered as locations on the same spectrum, and that range called the Autism Spectrum Disorder. At the time of Lord's study, autism diagnoses were subjective and the concept of best-fit was not used consistently among

clinicians (Benaron, 2006, p. 39). According to the DSM-5 (2013), the term *spectrum* considers that the disorder can vary greatly in severity, and may affect the child developmentally as she/he progresses in chronological age (p. 53).

The spectrum of autism can be described in words such as severity, difference in symptoms, features, traits, subgroups, differences and similarities, and range of symptom severity (Lai et al., 2013; Swedo, 2013). The severity of each person's symptoms is assessed on a progressive scale within specific parameters. The term *spectrum* is not only used in autism but in other illnesses and disorders as well. Over the past decade the trend is to consider umbrella-type diagnoses instead of separate, discrete conditions. "There is currently a shift in diagnoses towards the recognition of spectrum disorders in a variety of conditions, including obsessive-compulsive spectrum disorder, bipolar spectrum disorder, and even schizophrenia spectrum disorder" (Benaron, 2006, p. 38).

Definitions and Evolution of Autism Spectrum Disorder

The definition and criteria for autism has evolved over time from its early label of childhood schizophrenia in the '60s, to Pervasive Developmental Disorder emerging in the '80s, and in most recent years Autism Spectrum Disorder (Benaron, 2006). The characteristics of Autism Spectrum Disorder provide a general idea of autism. The characteristics have remained closely similar since the condition was first codified in the 1940s.

Characteristics of Autism Spectrum Disorder. Living with Autism Spectrum Disorder is a unique experience for each individual. Generally, impaired social communication and social interaction among those with ASD are most evident (e.g., language and social skills deficits), followed secondly by unusually restricted or

repetitive behaviors, interests, or activities (American Psychiatric Association, 2013; Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). It is common for those diagnosed with ASD to have sensory processing impairments; however, these symptoms do not occur exclusively within the context of Autism Spectrum Disorder, and are not often cited in research literature (Wing, Gould & Gillberg, 2011). The concept of ASD has remained similar since Asperger and Kanner first assigned a label to these characteristics. Refer to Table 1 for a reference to the DSMs' defining characteristics that have evolved over the past 33 years.

Table 1

Diagnostic and Statistical Manual of Mental Disorders, Third Through Fifth Editions

| Diagnostic category | Specific changes in manual | Diagnostic Manual |
|--|---|--|
| Pervasive Developmental Disorders (PDD): 1. Autism Disorder 2. A typical PDD | Deficit in social skills including deficits in language and communication, rigid with keeping things the same and routine, specific physical movements, and other odd actions. | DSM-III (1980) |
| Pervasive Developmental Disorders (PDD): 1. Autism Disorder 2. Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS) | Categories were changed with this DSM to include three categories: social, communication, and resistance to change. (These changes significantly broadened criteria to over-diagnose autism.) | DSM-III-R (1987) |
| Pervasive Developmental Disorders: 1. Autism Disorder 2. Asperger's Disorder 3. Child Disintegrative Disorder 4. Rett's 5. PDD, NOS | This version added Asperger's Disorder, Child Disintegrative Disorder, and Rett's. Changes to sensitivity in diagnosis criteria in IQ and age. Broadened criteria. | DSM-IV (1994) (Introduced three additional disorders) |
| Pervasive Developmental Disorders: 1. Autism Disorder 2. Asperger's Disorder 3. Child Disintegrative Disorder 4. Rett's 5. PDD, NOS | Revisions were made to narrow the subcategory criteria. | DSM-IV-TR (2000) |
| Autism Spectrum Disorder: 1. Level 1 — Mild 2. Level 2 — Moderate 3. Level 3 — Severe | Elimination of subtypes; Asperger's, Child Disintegrative Disorder, PDD, NOS. Rett's was moved into another category. Criteria was changed from three categories to two, sensory processing was added as a criteria | DSM-5 (2013) |

Note. The PDD characteristics are from Volkmar & Reichow (2013). DSM III is Diagnostic and Statistical Manual of Mental Disorders, Third Edition (1980). DSM-III-R is Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (1987). DSM-IV is Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (1994). DSM-IV-TR is Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, (2000). DSM-5 is Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013).

Evolution of the Diagnostic and Statistical Manual of Mental Disorders

The Diagnostic and Statistical Manual of Mental Disorders (DSM) was first introduced in 1958, however autism was not included until 1980. The first introduction of autism to the DSM was included in the DSM-III after years of children being misdiagnosed with childhood schizophrenia under similar criteria (Benaron, 2006).

History of ASD and an introduction to DSM. In the 1940s autism first emerged as a category through Leo Kanner's work in identifying 11 children with deficits in social, behavioral, and communication skills. Around the same time Hans Asperger, a pediatrician, identified atypical behavior in several boys with odd patterns of functioning when interacting with their peers. The descriptions by Asperger and Kanner identified similar findings, without awareness of the other's findings.

Kanner's term "autism" was derived from a Swiss psychiatrist, Ernst Bleuler, in 1909. Bleuler introduced the term "autos" meaning "self" which, at that time, was used to describe a symptom of schizophrenia. This term was then used by Kanner to describe children with symptoms such as ignoring others, shutting down, or failing to respond. Even though Kanner and Asperger identified and labeled these special characteristics, it was not included in the DSM until 1980. The first presentation, closest to describing what is now known as autism, was identified in *Diagnostic and Statistical Manual of Mental Disorders, Second Edition* (DSM-II, 1968), as schizophrenia, childhood type. The APA first became committed to including autism in DSM-III when autism was included in the 1979 ICD-9 by the World Health Organization (Benaron, 2006).

DSM-III. In 1980, autism was first described in the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition* (DSM-III) as a new class of conditions called

Pervasive Developmental Disorders, which are a group of disorders relating to deficits in social and communication development. Autism was then included as a subcategory under Pervasive Developmental Disorders.

DSM-III evolved from an approach that described the behavior to a working approach that defined criteria in order to allow clinicians to make a diagnosis (Tsai, 2012). The classification and criteria were then revised to add Pervasive Developmental Disorders, Not Otherwise Specified under the Pervasive Developmental Disorder in the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised* (DSM-III-R, 1987).

DSM-III-R. DSM-III-R was similar to the DSM-III; however it expanded the criteria to include one disorder, and thus the threshold was broadened, which led to over-diagnosis of autism (Volkmar & Reichow, 2013). The revision included a change in atypical PDD to Pervasive Developmental Disorder, NOS. The criterion was revised to include problems with social interaction, communication, and rigidity in change (Volkmar & Reichow, 2013; Benaron, 2006).

DSM-IV. DSM-IV made significant changes by adding Asperger's Disorder, Childhood Disintegrative Disorder, and Rett's Disorder under Pervasive Developmental Disorders, adding to Autism Disorder and Pervasive Developmental Disorder, NOS. Sensitivity and specificity were revised with the intention to improve reliability (Volkmar & Reichow, 2013). Major changes made in the DSM-IV broadened the criteria which, after research, resulted in yet another change to the DSM-IV-TR (APA, 2013).

DSM-IV-TR. The DSM-IV-TR, published in 2000, categorized Pervasive Developmental Disorders into five different diagnoses: Autistic Disorder, Asperger's

Disorder, Rett's Disorder, and Childhood Disintegrative Disorder, or the Pervasive Development Disorder, Not Otherwise Specified. Here the definition for autism was defined in three categories: First, a number of deficits in social interaction; second, a number of deficits in communication skills, including verbal and/or nonverbal; and third, rigid repetitive and stereotyped patterns of behavior, interests, and activities. Six criterion had to be met from the three categories. The other disorders under Pervasive Developmental Disorder were required to be considered before diagnosis of Autism Disorder.

Key Changes to DSM-5. The removal of Asperger's Disorder and Pervasive Developmental Disorder, NOS as labels is one of the most significant changes to the DSM-5 in relation to the Autism Spectrum Disorder, previously called Pervasive Developmental Disorders. The prevalence rates and removal of diagnosis are the most discussed topics in the literature in relation to the changes to Autism Spectrum Disorder (American Psychiatric Association, 2013; Swedo, 2013; McPartland, et al., 2012).

The DSM-V diagnosis criteria for Autism Spectrum Disorder are now assessed in two categories: severity of social communication and social interaction impairments, and restricted repetitive patterns of behavior (autismspeaks.org, 2013; Lai et al., 2013; Kurita, 2011). The categories include a severity scale which can explain the reason for the label "spectrum" within the name of the diagnosis (Lai, et al., 2013).

The changes to the DSM-5 reorganized Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and the Pervasive Development Disorder, Not Otherwise Specified into one umbrella disorder called Autism Spectrum Disorder. The American Psychiatric Association believes this will allow clinicians to consider variation

and severity of symptoms on an individual level and provide more consistency in diagnosis (American Psychiatric Association, 2013). The DSM-5 provides criteria that allow for description and clinical presentation of the client and levels of severity which may provide more guidance for clinicians (Borden, 2011; Rutter, 2013).

Dr. Susan Swedo, DSM-5 Neurodevelopmental Disorders work group chair, reports in a video on the American Psychiatric Association website that in her perception, the criteria are basically the same as DSM-IV-TR. She believes there is little change other than that criteria “have been modified to be much more descriptive of individual patients and to more accurately reflect the range of symptom severity” (Swedo, 2013).

The changes to DSM-V had an impact on research. Swedo reports over 95% of the publications over the past five years now refer to Autism Spectrum diagnosis rather than individual diagnoses of autism, Asperger’s Disorder, or PDD, NOS (Swedo, 2013). Swedo is a supporter of these changes and a key player in the work and research conducted. That she is the chair of the DSM-5 work group that was responsible for the changes to the DSM-5, and thus not entirely unbiased, should be considered.

The DSM-5 has been recognized in the literature as being clearer in describing symptoms and therefore may be more reliable with elimination of ASD subtypes (Lai et al., 2013). A primary goal for the DSM-5 work group was to address diagnosis of toddlers, preschool-age children, adolescents, and young adults, as well as girls and women. In addition the changes address cultural considerations which they felt needed improvement from the DSM-IV-TR (Swedo, Baird, et al., 2012). “It remains to be seen in real-life settings how diagnostic practice, service delivery, and prevalence estimates will

be affected by applying DSM-5 Autism Spectrum Disorder criteria” (Lai et al., 2013, p. 2).

DSM-5. Autism Spectrum Disorder (ASD) in DSM-5 includes two categories for diagnosis: social communication and interactions, and restrictive, repetitive patterns of behavior whether current or historical. The following is a breakdown of the diagnostic criteria for DSM-5, which can be found on the Autism Speaks website (Autism Speaks Organization, 2013). Also see table 2 for a brief breakdown of changes within Autism Spectrum Disorder in the DSM-5.

Criterion A includes three sub-categories: deficits in social-emotional interactions with others; deficits in non-verbal communication; and lack of building normal relationships. An example of deficits in social-emotional interactions with others is a school-age child who is spoken to but does not respond appropriately or does not respond at all. An example of non-verbal communication may be a child who is not making eye contact when having a conversation, or the child is unable to understand non-verbal messages. An example of lack of relationship development with others is a child who shows no interest in playing with other children at school and prefers to play alone, or perhaps a child’s brother is playing imaginatively and he does not follow nor understand his brother’s imagination. The child may become upset with his brother and correct his play.

Criterion B is described as narrow and repetitious patterns of behavior, interests, or activities as evidenced by at least two of the following criteria, either presently or in the client’s history. These include: stereotyped or repetitious body movements, speech, or handling of items; insistence on keeping things the same and rigidity with routine; rigid,

set interest with extreme intensity or targets; and high or low sensitivity to sensory processing, meaning abnormal interest in sensory options.

For example, stereotyped or repetitious body movements, speech, or handling of items may look like a school-age child who excessively lines up his toys. Insistence on keeping things the same and rigidity with routine may look like a school-age child who always goes the same route, and if school is canceled the child may become very upset that the routine was disturbed. Rigid, set interest with extreme intensity or targets may look like a middle-age child who is abnormally obsessed with air planes and often talks to others about this regardless if it is off topic. High or low sensitivity to sensory processing, meaning an abnormal interest in sensory options, may look like a child who has low tolerance to pain or temperature, or one who covers his ears to certain sounds, or gags on mashed potatoes because of the texture. If criteria are met for a diagnosis, the condition is assessed on a severity scale. Levels of the scale range from one, least severe to three, most severe.

Once a child receives the diagnosis of ASD under DSM-5, three levels of functioning are assessed to determine whether the child meets the category of mild, moderate, or severe levels of ASD. Level one is the least restrictive and least severe, and may include mild deficits in social communication and challenges in starting social interactions with others. Back and forth communication can be impaired and friendships may not be successful. Level two includes moderate deficits, wherein a child may lack interaction with others. Deficits in language and limited interests may be noted with abnormal body language. Level three is the most severe, with impairments in social communication, both nonverbal and verbal, which causes significant handicaps in the

daily activities of living; here the child has very little social interactions, and has little response to others, which may be observed as social inaction.

The symptoms need to be apparent in early childhood development in order to qualify as ASD, however indicators may not manifest until social situations are presented to children that exceed their lower capacity or challenge their coping strategies. Learned coping skills may help manage symptoms. The symptoms cause deficits in social interactions and important functional areas to the point where they are clinically significant. A diagnosis of ASD is called for if the deficits are not better met through other disorders such as intellectual disability. If children have impairments in their social communication and do not meet other criteria of Autism Spectrum Disorder, they should be deferred to Social Communication Disorder, which is a new category in the DSM-5.

The new criteria will be used along with a number of standard tools that have been developed over the years to assist in accurately diagnosing and treating ASD.

Table 2

Key DSM-5 Autism Spectrum Disorder Changes

| Levels of severity (addition) | Elimination of subtypes | Criteria changes |
|---|---|---|
| 1. Level 1 — Mild 2. Level 2 — Moderate 3. Level 3 — Severe | Asperger’s Disorder Child disintegrative disorder PDD, NOS Rett’s was moved into another category. | Criteria was changed from three categories to two: 1. Social communication and interactions 2. Restrictive, repetitive patterns of behavior Sensory processing was added as a criterion under one of the two categories. |

Note. PDD, NOS is Pervasive Developmental Disorder, Not Otherwise Specified. From Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013) and Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (2000).

Screening and Diagnosis Tools

There are many tools used to screen for ASD in educational, medical, and mental health settings to help identify those who may have traits of ASD. In primary care pediatrician (PCP) settings children are often screened for ASD if a parent identifies concerns for their child, or if the PCP sees that the child is not where they need to be. The two most common screening tools in a PCP setting are the Modified Checklist for Autism in Toddlers (M-CHAT) and the Social Communication Questionnaire (SCQ) (Benaron, 2006).

Screening Tools. According to Benaron (2006), the M-CHAT is a 23–question, yes/no questionnaire designed to be filled out for parents of toddlers under 30 months of age which identify red flags to ASD. The SCQ is used for children 40 months and older, and was developed from the Autism Diagnostic Interview (ADI). This questionnaire asks

40 questions, also yes or no, to assess whether a child has red flags for ASD. There are two versions of the SCQ; the current version, which assesses current behavior, and the lifetime version which looks at overall development and focuses on the history of the child up to four to five years of age (Benaron, 2006). If a child is screened and determined to have traits of autism they are referred to a mental health professional for further testing. An official diagnosis needs to come from a clinical professional.

Diagnostic Tools. Standard tools used for the diagnosis of Autism Spectrum Disorder include the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnosis Interview-Revised (ADI-R), along with clinical judgment (Gastgeb et al., 2013; Mesibov, Phetrasuwa, Shandor Miles, 2009; Woodbury-Smith, 2009). These tools will continue to be used with the implementation of the DSM-5.

ADI was first created in the late 1980s as a standard interview tool which asks questions about a child's history and the child's current developmental functions. The ADOS was then created to compliment the ADI. This tool was used to create a standard for face-to-face observations of children's social skills, communication, and behavior. The tools were initially intended to be used with children five to 12 years of age; however, as treatment and diagnosis evolved by the early 1990s, younger children were being diagnosed, hence the need for revisions to the ADOS and the ADI. The ADOS was then revised to Autism Diagnostic Observation Schedule-Generic (ADOS-G) to expand the age range and broaden the developmental categories to include very young children and adults (Lord, Risi et al., 2000).

The literature reviewed analyzes how these tools have been considered with the publishing of DSM-5. The Autism Diagnostic Observation Schedule (ADOS) and the

Autism Diagnosis Interview-Revised (ADI-R) are gold standard tools used to diagnose Autism Spectrum Disorder (Hanson et al., 2013; Mazefsky, McPartland, Gastgeb, & Minshew, 2013; Phetrasuwan, Shandor Miles, Mesibov, 2009). A study conducted using criteria for DSM-5 indicated that “ADOS alone had a low proportion of individuals meeting criteria (33%) with ADI-R meeting criteria at 83%, [and] a combination of ADOS and ADI-R at 93%, which results indicate discrepancy between the ADOS and ADI-R capturing DSM-5 ASD criteria” (Phetrasuwan et al., 2009, p. 1240). Those who participated in the survey of this study were previously diagnosed with ASD. This indicates there is some reliability in using the tools along with the DSM-5. However, using the ADOS alone would only capture 33% of those previously diagnosed with ASD. The severity of the diagnosis needs to be considered. The Calibrated Severity Score (CSS) is a tool used with the ADOS to help determine the severity of symptoms. This study is relevant as it suggests compatibility of ADOS and ADI-R with the DSM-5. The most recent version of ADOS is ADOS-2 (Center for Autism and the Developing Brain, 2013.) The tools described are standard tools; however, there are many tools used with the diagnosis and treatment of autism.

The tools described above provide a general overview of common screening and diagnostic tools used in clinical mental health professional and PCP settings. This is not inclusive of the educational screening, which follow their own guidelines.

Implications for Educational Systems

The tools used for screening children with ASD vary within each setting. The assessment results for special education services need not have the DSM diagnosis in order for a child to qualify for services. However, a diagnosis under DSM-5 could lead to

special education services as documents from the DSM are reviewed during the screening for educational services. It's unclear whether the DSM-5 will impact the educational system. The school system screens based on disability or other presenting problems, such as if a parent or teacher identifies problems academically, functionally, or developmentally (Minnesota Department of Education, 2012). Children may have disabilities or present problems within the classroom or social settings, which may inhibit their learning. A child may then be screened by a special education evaluation to see if they meet criteria for Autism under an educational diagnosis. The Individual Education Plan (IEP), "documents the student's present level of performance, identifies a need for services, and delineates what, how, and by who the services will be provided to the student, including the location, duration, and frequency of the services" (Lacey, 2009, p. 459). Under the Individuals with Disabilities Education Act (IDEA), a federal regulation providing standards for the development and revision of an IEP was developed by the U.S. Department of Education (2006). Children with autism, that meet educational criteria, will have an Individual Education Plan that provides a record of the child's educational progress to ensure that schools are meeting their expected educational needs. The IEP is re-evaluated every three years to determine if the child continues to meet criteria. IEPs are a beneficial tool for students with special needs or gifted children to help monitor the educational progress for the child (Lacey, 2009).

Implications for Clinical Social Workers

The impact of DSM-5 changes to ASD on clinical social workers will encompass multiple areas. First, clinicians will consider the change in diagnosis criteria of autism with the possibility of revised tools and assessments. Second, the International

Classification of Diseases, 9th Ed. (ICD)-9 codes, the codes assigned to diagnosis for billing, will be revised to International Classification of Diseases, 10th Ed. (ICD)-10 will align with DSM-5; this change is expected to be completely implemented by October 2014 (Center for Medicare & Medicaid Services, 2013).

The full impact of the DSM-5 has yet to be determined. Its effects will be seen once professionals fully implement DSM-5 into practice, and begin to use it for diagnosis. The American Psychiatric Association gave clinicians permission to start integrating the DSM-5 into practice; however, the full implementation from DSM-IV to DSM-5 is not required until October, 2014 (APA, 2013; dsm5.org, 2013). It may be hard to anticipate clinicians' perception of the DSM changes until they have fully integrated the DSM-5 into practice. The perceptions reviewed in the literature are based on research studies, commentaries, and responses from professionals who have been actively involved in the transition from DSM-IV to DSM-5.

Clinicians' Perceptions of DSM Changes

The DSM-5 revisions to Autism Spectrum Disorder have led to a great deal of response from many professionals within the field. The review of literature in this area identifies a mixed response that considers both strengths and challenges of the new protocol (Buxbaum & Baron-Cohen, 2013).

A study conducted by Huerta, Bishop, Duncan, Hus, and Lord (2012) concluded that most children with a diagnosis of PDD will remain eligible for the ASD diagnosis in DSM-5. This study was based on information gathered from previous clinical diagnoses, using DSM-IV, in three samples of children from different locations. The items collected to match criteria were taken from the ADI-R and the ADOS from each child's clinical

assessment. This was then mapped with both DSM-IV and DSM-5 to pull items that would meet criteria for a diagnosis under each. This study supports the reconceptualization of ASD within DSM-5, suggesting it to be a more specific and reliable diagnostic tool.

In contrast a qualitative study done by McPartland, Reichow, and Volkmar (2012) deduced the possibility there may be some who lose their autism, Asperger's, or PDD, NOS diagnosis because they will no longer meet criteria and may fall into another category. McPartland and colleagues estimated that 60.6% of those who previously met criteria under the DSM-IV-TR will continue to meet criteria under the DSM-5, but 39.4% would not—a significant number. (The breakdown for the first set includes 75.8% of child clients with a clinical diagnosis of Autistic Disorder, 25% with a previous diagnosis of Asperger's Disorder, and 28.3% of cases with PDD-NOS.) These authors suggested that those who formerly met criteria for a PDD diagnosis in DSM-IV-TR, but do not under DSM-5, will likely meet criteria for Social Communication Disorder (SCD), new to DSM-5. However they suggested that the population of those diagnosed may change along with changes to description of symptoms and a requirement to assess the quantity of symptoms under both categories. Because the SCD diagnosis is new, it is yet to be determined what type of services, if any, a child will qualify for. McPartland and colleagues questioned whether a diagnosis of SCD may be too loosely defined.

In counterpoint, an article by the DSM-5 work group for ASD by Swedo, Baird, and colleagues (2012) responded to McPartland's study by suggesting that it had too many limitations. The DSM-5 work group did not support the data McPartland used, noting that the information had been gathered almost 20 years ago, from field trial studies

in the '90s, and so could not support McPartland's dramatic findings. The work group also felt that McPartland's study could not assess the sensitivity of DSM-5 when McPartland's original data compared the DSM-III-R and the DSM-IV. Swedo went on to observe that her neurodevelopmental disorders work group started in 2007 to address issues with earlier criteria for autism and PDD, working to make improvements in diagnosing toddlers, preschool age children, adolescents, young adults, girls, and women, and better represent varied cultural and racial aspects, as well as make improvements to the overall diagnosis criteria.

The primary author of the DSM-IV Pervasive Developmental Disorders section, Dr. Fred Volkmar, who contributed to McPartland's study and was quoted in a 2013 article by Buxbaum & Baron-Cohen, identified concerns that some higher functioning children with autism will not meet criteria and will no longer be eligible for services. Volkmar suggested that the removal of Asperger's is a dramatic move and questioned the impact this would have on those who identify with Asperger's. He was concerned that comorbidities, such as depression, are common with this group and should be watched carefully by professionals for a possibility of increased depression with the loss of diagnosis. The changes cannot be predicted in a real scenario until research is completed and the DSM-5 fully implemented (Buxbaum & Baron-Cohen, 2013).

According to the same Buxbaum and Baron-Cohen article, Dr. Cathy Lord's group had a positive perspective on the DSM-5 changes and was active in the APA neurodevelopmental disorders work group. Lord and colleagues support the change and suggested that it will provide higher reliability. They specified that the reduction of three

categories to two reorganized the previous overlap of social and communication skills and supported the severity levels addition.

Another large study challenged that stance. Dickerson Mayes, Black, and Tierney (2013) provided a meta-analysis reviewing seven studies related to the Autism Spectrum Disorder DSM-5 changes. Their findings show a decrease in incidence and prevalence in ASD diagnosis under the DSM-5 criteria as compared to the DSM-IV-TR. This same group then conducted a study with 100 participants ranging in age from one to 16 years old. They reported that 25% of those who had met the criteria for DSM-IV-TR no longer met criteria under DSM-5. The study reported similar findings with six other studies compared. This combined study supported the idea that PDD, NOS diagnoses are not well represented within the Autism Spectrum Diagnosis as suggested by the American Psychiatric Association. Dickerson Mayes and colleagues then assessed the Social Communication Disorder criteria and concluded that only five of the 18 subjects who did not meet criteria for ASD in DSM-5 subsequently met Social Communication Disorder criteria. They indicated that some authors within their mega-analysis recommend future research to discern how many of those who do not meet new criteria for ASD will meet criteria for Social Communication Disorder.

Similar concerns were raised by Worley and Matson in their 2012 study. Their findings revealed a decrease in ASD diagnoses by 32.3% with the use of the DSM-5 instead of the DSM-IV-TR, suggesting a trend of decreased incident and prevalence once the DSM-5 is fully implemented. Their research suggests that those who will meet criteria for DSM-5 will have more impairments than those who formerly met criteria in DSM-IV-TR. Their concern is that those who still had significant autism symptoms may

no longer be covered for services. Some children who had previously met criteria now do not. These children are no longer eligible for assistance but continue to have many symptoms of ASD, as compared to a child who is developing normally. Worley and Matson are also concerned for those children who may no longer meet criteria as they age. These young clients may be refused early intervention services. The question remains where these children will access the additional help they need to stay in step with a normally developing child. Worley and Matson suggest that “service delivery will remain important for the treatment of symptoms” (2012, p. 969), emphasizing that clients, regardless of diagnosis, will still need treatment for symptom management.

Conceptual Framework

With the review of this research on the DSM-5 reconceptualization of the Autism Spectrum Disorder emerged an ecological model that focuses on a systems perspective, or ecological framework, developed by Urie Bronfenbrenner in the late 1970s. “A child’s ability to learn to read in the primary grades may depend no less on how he is taught than on the existence and nature of ties between the school and home” (Bronfenbrenner, 1979, p. 3). Bronfenbrenner believed that what happens within a child’s environment, whether at school, home, community, had equal importance and that all areas are interconnected. For example, if a child has little support at home from caregivers it will affect how that child learns in school.

The *ecological model* is a systems theory focusing on the mind, body, and environment (Siporin, 1980). This perspective is a classical model used in social work focusing on person and environment. This model may apply to any system, for example, individuals, family, organizations, clients, programs, businesses, or events such as life changes. Bronfenbrenner referred to life changes as ecological transitions. Some which may apply to this research are, for example a child starting daycare, going to preschool, parents getting a divorce, remarrying, or a parent’s new job. The ecological model focuses on the idea that in order to have a well-balanced system and subsystems, they need to be integrative and flow well within each other. If there is dysfunction in any of these systems, such as mental illness, drug problems, financial problems, or family problems, then the system will also be dysfunctional (Siporin, 1980). What dysfunction might look like specifically for children with ASD may be interruptions for a child who is

getting services through the school and/or mental health agency, and whose parents are supposed to follow through with practices taught during therapies. If those systems are not connecting and providing consistency, it may cause harm to a child with ASD, who because of the nature of their condition, relies on that consistency. Inconsistencies are likely to cause confusion for the autistic child.

An example of ecological model applications to this research is the very function of clinical social work. If a clinical social worker expects to do their job well, then the social worker needs appropriate resources and services that can be integrated in the client's plan of care. If the client's therapeutic systems flow well the client's therapy will most likely function well. If client's therapeutic systems do not flow well, this system may be disrupted and lead to dysfunction.

I would like to focus on the *microsystem* within this framework, which includes the closest parts of the system to the individual, and is considered a subsystem. The microsystem may include family, school, friends, spiritual connections, child care services, and health services (Bronfenbrenner, 1979). This would apply closely to a child with ASD and highlights the importance of connections within this subsystem. A child with ASD relies heavily on consistency. Thus if the parents, mental health professional, or teacher are not connecting and providing consistency for a child with ASD, Bronfenbrenner's model predicts this will have an effect on that child.

Professional Lens

My professional lens on this research topic comes from my work with children who had a diagnosis of autism and Asperger's Disorder. I found it fascinating working with these children because of their persistence with certain topics and rules. This

experience led to my interest in learning more about children with autism and Asperger's. I now currently work as a medical social worker but plan to eventually transition to therapeutic services with children. I hope to eventually specialize in working with children with ASD; that, however, will depend on the training and time involved.

I have a desire to learn more about ASD and have been fascinated through this research process by the complexity of this disorder. I look forward to seeing how the changes with the DSM-5 will affect diagnosing Autism Spectrum Disorder. I initially had mixed feelings towards the proposed changes, particularly with the elimination of Asperger's; however, after the research my feelings are neutral. I believe this research is teaching me to be more objective and to consider all perspectives. In order to manage my biases I continue to review the information in an objective way by looking at the facts in the information. I look forward to learning more about this topic and continued research as changes to the DSM-5 are fully integrated.

Personal Lens

I have two sons, one of whom is diagnosed with a sensory processing disorder. Although he does not have an autism diagnosis, he requires special education assistance and currently has an IEP. My son does very well with these services in place at his school because the one-to-one assistance provided for him improve his ability to learn. I am not sure how well he would be doing if his condition had not been identified and if service was not available. I suspect it could affect his learning abilities, but it is hard to say. My life experience informs my personal point of view regarding the treatment of autism in mental health and education settings. The experiences help me relate positively to

challenges that other parents face with their children and in their attempts to work with providers on behalf of their children within these settings.

Methodology

The current study sought to answer this question: What are clinicians' perspectives on the reorganization of Autism Spectrum Disorder in DSM-5? Clinicians provide a variety of professional services through their diagnosis and treatment of Autism Spectrum Disorder, and will be deeply affected by the revisions. This qualitative research project gave voice to clinicians' experience and perceptions of the changes to ASD in DSM-5. To accomplish this objective, this study relied on qualitative research techniques, specifically open-ended interview questions.

Research Design

Designing the investigation. The design of this research was built around semi-structured interviews with open-ended questions. The researcher developed 11 open-ended questions with the advice of her committee members and chair. The nature and framing of the questions were informed by the literature as reviewed by this researcher, which concerned published clinicians' perspectives of DSM-5's reorganization of Autism Spectrum Disorder. The interview questions for this study were devised to clarify the questions raised by the literature. The questions were carefully considered in order to be low-risk to the respondents. Topics that these interview questions addressed were:

- perceptions of overall changes to the ASD criteria;
- perceptions of the elimination of Asperger's and Pervasive Developmental Disorder, NOS from the previous criteria;
- implications for clinical services currently provided;
- and, perceptions on the new diagnosis of Social Communication Disorder.

The researcher's committee members reviewed these questions, as well as the full research proposal, and provided feedback to the researcher. The researcher made appropriate revisions, under the direction of the chair. A full list of interview question can be read in Appendix B.

Privacy protections and anonymity for respondents. The interview process was designed to respect and protect the subjects' privacy. As planned, the interviews took place in private settings, using conference phone calls, arranged between the researcher and each respondent. In addition to the phone interviews, the researcher used a survey to ensure anonymity. The research results were kept confidential and secure by keeping the information in a locked safe in the researcher's home. The data collected during the research will be disposed on or before July 31, 2014, after the completion of this study.

The IRB process and protection of human subjects. Once the design was complete, the researcher's chair approved this project for submission. The researcher submitted the proposal to the University of St. Thomas' Institutional Review Board (IRB). One of the IRB's primary concerns is assessing the risk of the research to those being studied.

The researcher asserted that the risk to human subjects was low because the participants were all highly trained, experienced clinicians working in the field. This research did not involve children with Autism Spectrum Disorder nor parents of ASD children. Because the population under study, clinical service providers, had low vulnerability, and because the study questions were deemed to be low risk, the IRB expedited the review process. The IRB gave its approval prior to any recruitment of participants.

Consent forms. The respondents were provided with a consent form (Appendix C) prior to the interview. The consent form:

- explained the purpose of this study;
- contained a statement of confidentiality;
- explained that the respondent can opt out at any time;
- advised that the respondent has the right to skip a question;
- and, explained that the respondent has the right to totally withdraw from the interview and ask that their information not be considered in the study.

The risks and benefits of this study were explained with the expectation that this study will be low risk and of little personal benefit to the respondent. The researcher emailed a copy of the consent form prior to the start of the interview, explained the consent verbally, and asked that the respondent scan and email back the signed consent form or fax the consent form to a confidential fax number.

Interview preparation. Once the consent form was received, the interviews were scheduled. Each participant was sent the list of questions prior to the start of their interview. The respondents were invited to ask any questions regarding this research project.

Recruitment. The researcher recruited six licensed professionals, both clinical social workers and clinical psychologists, who had experience working with children with Autism Spectrum Disorder. Potential participants were found through public sources such as telephone directories and internet listings. Snowball sampling was also used. A telephone script (Appendix D) was used to approach possible participants. If the

participants were interested in taking part in this study, an informational letter was then sent via email (Appendix E).

Description of Respondents

The sample for this study was six respondents. Each participant met the criteria: a licensed clinician: one who identifies as clinical social worker, psychologist, or mental health professional who is licensed to practice, diagnose, and/or treat children, from birth to 17 years old, with Autism Spectrum Disorder. The exclusion criteria for this sample ruled out professionals who did not have a comparable certification as the licensed clinical social workers.

Respondents lived and worked in a variety of locations within the U.S., including Minnesota, Louisiana, Washington state, and California. The researcher sought participants from several national locations in order to increase the likeliness of meeting the desired sample size.

The respondents, whether local or national, were all clinical professionals with licenses, including: Licensed Clinical Social Worker (LCSW), Licensed Independent Clinical Social Worker (LICSW), and Licensed Psychologist (LP). Table 3 identifies the characteristics of the participants.

Table 3

Characteristics of Participants in the Study Who Work with Children Diagnosed with ASD

| | <i>n (%)</i> |
|------------------------|--------------|
| Gender | |
| Male | 3 (50%) |
| Female | 3 (50%) |
| Profession | |
| Clinical social worker | 4 (60%) |
| Licensed psychologist | 2 (40%) |

Note. This table reflects participants' professional licensure.

Data Collection and Data Analysis

Data collection: The interviews. The interviews were all conducted in a private setting mutually agreed upon by the researcher and respondent over the phone. A semi-structured questionnaire was used during the interviews as the primary instrument to obtain information.

The estimated length of the interviews was between 15 to 35 minutes, with expected length of time explained prior to the start of the interview. The researcher audio recorded the interviews in a private location by conference phone, after permission was received from the respondent.

Post-interview resources. At the end of the interview, participants were offered a list of resources that could provide emotional support for the respondent in case they suffered any emotional response. For those who accepted the resources, the researcher explained that any contact with those resources would be not be compensated by this researcher nor the University of St. Thomas.

After the interviews were complete participants were sent a ten-dollar Target gift card as a nominal token of appreciation for their time and cooperation in the research. The researcher mailed the gift card via a drop box with no identifying information on the envelope and no return address. There were no other material benefits to the subjects.

Data Analysis Plan. Data analysis was based on the grounded theory model. “Grounded theory begins with open coding of interview transcripts. The process of coding may use sensitizing concepts drawn from the literature, extant theories, and previous research, but its primary goal is inductive” (Padgett, 2009, p.33). Ground theory allows the subjects agency to influence the direction of the results, an apt choice since much of clinical treatment is interpretation.

Completed interviews were transcribed by the researcher. These transcriptions were kept in a password-protected computer for confidentiality. In order to protect identities each participant was assigned a number and code name in the document.

Next the researcher carefully reviewed the transcriptions and searched for codes and themes within the documents. This researcher then re-read codes and data for any missed themes. The researcher considered the research topic while reviewing the transcripts, looking for perceptions and objective data that might be relevant and included in the paper. For each theme this researcher searched for multiple quotes from different respondents, to ensure accuracy of the data reported.

Once the data were processed and analyzed, the research committee reviewed the material and provided feedback. The researcher and the chair of this project discussed this feedback to determine appropriate revisions.

As the interviews yielded themes and insights, the researcher worked to integrate the findings into useful data.

Findings

The interviews resulted in the development of three main themes. The themes all derived from the interview questions, which included: 1. Participants' perceptions on overall changes to ASD criteria in DSM-5; 2. Participants' views on the strengths and challenges of ASD criteria in DSM-5; and, 3. Participants' perspectives on the implications and consequences of implementing DSM-5 in their practices.

Within the theme of overall changes to ASD criteria in DSM-5, there were two subthemes, including views on the addition of levels of severity and perceptions of the elimination of Asperger's and PDD, NOS. Within the theme of strengths and challenges the two subthemes were simply: strengths and challenges. Within the theme of implications of DSM-5 there were two subthemes, including addition of Social Communication Disorder, insurance, and services for clients. The participants all touched on most of the themes listed but had differing views. Table 4 demonstrates common themes and subthemes from the participant interviews.

Table 4

Themes, Subthemes, and Sample Responses of Participants

| Category | Thematic category | Sample response |
|---|------------------------------------|---|
| <i>Theme 1. Participants' perceptions on overall changes of ASD in DSM-5.</i> | | |
| O1 | Addition of levels of severity | <i>"they tell you more about your child"</i> |
| O2 | Elimination of diagnosis | <i>"it's such a specific disorder"</i> |
| <i>Theme 2. Participants' views on strengths and challenges with ASD criteria in DSM-5.</i> | | |
| SC1 | Strengths | <i>"I think it's much clearer"</i> |
| SC2 | Challenges | <i>"I think...you are getting too generalized"</i> |
| <i>Theme 3. Participants' perspectives on implications of DSM-5.</i> | | |
| I1 | Social Communication Disorder | <i>"it feels less severe"</i> |
| I2 | Insurance and services for clients | <i>"potential impact for...insurance reimbursement"</i> |

Note. O = overall changes, two subthemes; SC = strengths and challenges, two subthemes; I = implications, two subthemes.

Participants' Perceptions on Overall Changes to ASD Criteria in DSM-5

Views on level of severity addition. The addition of levels of severity to ASD in DSM-5 was a common theme among participants. Three of the six participants made comments about additions to level of severity. Those who touched on this topic shared benefits of the addition. Sharon stated, *"I think they are positive... The specifiers help because they tell you more about your child... It paints a clearer picture of your child."*

John described his thoughts on the severity level in relation to autism as just one disorder instead of separate disorders: *"I think in this case it is sharpening a little bit, but is it truly one disorder?... At the moment it is certainly what it looks like with different levels of severity."*

There were differing views between participants on this topic. Not all participants held the same views about the addition. Nancy shared her feelings on the change:

I'm very upset...now because they have different cognitive patterns, different achievement patterns, different social and emotional patterns... It's not just one data point between autism and Asperger's and PDD, it's a whole evaluative process that's different.

In comparing the statements above, they all differ in perception of addition of levels of severity, two of which were similar.

Perceptions of elimination of Asperger's and PDD, NOS. All six participants shared their perceptions of the elimination of Asperger's and PDD, NOS. Most of the participants in the study had similar views on the elimination of Asperger's, with similar comments. Thomas described his thoughts on the elimination of Asperger's Disorder:

"Given all the literature... writings, books, articles, publications on Asperger's Syndrome, I don't quite know the rationale for omitting the name Asperger's... There is no real clarity as to why."

Two participants discussed their perception on differences with Asperger's compared to higher functioning autism. Amy stated, *"I am not particularly thrilled about the changes.... It's hard to wrap my head around it because I have kids at school that I think are high functioning autism that are definitely not Asperger's."* Nancy referenced her personal experience with clients at work when comparing higher functioning autism to Asperger's, stating: *"I personally have seen in my work that [someone with] high functioning autism looks significantly different than someone with Asperger's."*

Two of the six participants discussed their view on Asperger's as a specific disorder. Nancy stated, *"I don't know how they eliminate Asperger's disorder, because to me, it's such a specific disorder."*

The second participant who described Asperger's as a specific disorder also shared his feeling on the loss of this disorder, stating: "*Asperger's... is the one that comes mostly to mind In my experience, Asperger's really does seem like a distinct kind of category... It feels to me like there is something lost there.*"

Two participants shared their views of how they perceive that their clients see Asperger's Disorder. Thomas indicated two clients in particular whom he works with who really identify with Asperger's:

I have a few clients who have a current Asperger's diagnosis and one of them [is an] adolescent who has strongly identified with that diagnosis, and one is a 7-year old child whose parents strongly identified with his diagnosis.

John shared his perception of how some of his clients might view the changes. He indicated there is a culture of people who identify with Asperger's, stating:

I can tell you I have had young adults in here who... don't want to be cheated of their Asperger's designation... There is a whole culture that, as a whole population, really identifies with the Asperger's and they are quite upset about it.

Sharon indicated that she viewed the changes as positive, and noted how communication to clients and parents was especially important when the parents are used to hearing a different name for their child's diagnosis. She stated:

It can be confusing for parents who are used to hearing autism, or Asperger's, PDD, NOS and that doesn't exist anymore.... [H]ow you communicate those changes to parents... I think is the bigger challenge.

Participants' Views on Strengths and Challenges of ASD Criteria in DSM-5

Another important finding was participants' varying views on strengths and challenges. The majority of participants identified both strengths and challenges within the changes to ASD in DSM-5.

Strengths. The strengths of the changes to ASD within DSM-5 were a consistent theme as it was derived directly from one of the questions in the semi-structured interview. Out of all participants four of six clearly made comments that could be interpreted as approval of the strengths. Amy indicated she did not believe services in the school would change for her clients. John stated: *"From a logical standpoint, it probably makes some sense. At this point at our level of knowledge, it would appear that they are more on a spectrum than they are separate disorders."*

Sharon shared a personal experience with her daughter's diagnosis of autism 15 years ago. Sharon indicated that there was not a lot of clarity during the time her daughter received her diagnosis, but she relied on what she knew from her professional work as a clinical professional. Sharon stated:

I think the strengths are, I think it's much clearer for providers and for parents. I think it gives more detailed, in-depth information about a child and I think it can also, because of that, better inform treatment.

An additional comment that could be interpreted as strength was, *"One of the ways I think about the diagnosis is: Will it lead to more effective treatment and better ways of understanding your child?"*

One participant did not speak about strengths; Nancy indicated she tried to see the justification in the changes: *"I tried to see their side and tried to understand.... I don't*

think it streamlines anything.” This leads to the topic of challenges with adopting the DSM-5.

Challenges. As the literature review and participant comments indicated, challenges were a common theme with the reconceptualization of ASD in the DSM-5. The views of participants on challenges to the ASD criteria were similar to the literature reviewed. Amy indicated she had challenges with the subtypes, stating: *“I think the challenges are that you are getting too generalized. I think they look different, higher functioning autism looks different than Asperger’s.”*

Sharon indicated that she was concerned that no matter what kind of change, clients and providers tend to get nervous about it. She stated:

I think the down side is that, this is like with any change, people get nervous about change and they get worried that somehow it’s going to disqualify them from getting services.... It’s always a matter of time before people realize perhaps it hasn’t had the negative effect that they might have anticipated.

Three of the six participants referenced their professional expertise and understanding of the differences between autism, Asperger’s and PDD, NOS. Nancy stated:

I think people that don’t specialize in it, they don’t think there is any difference between the three [autism, PDD, NOS, and Asperger’s].... [Those of us that do nothing else but this for a living, we know the differences.]

Participants’ Perspectives on Implications of DSM-5

Addition of Social Communication Disorder. The last common theme derived from the semi-structured interview questions was the implications of the addition of Social Communication Disorder. Their views differed on this matter. Five of the six

participants made comments about Social Communication Disorder. Amy described the new designation as a positive: *“I can definitely see, in a general setting, the benefits for parents to say, oh, he has a Social Communication Disorder. It feels less severe.”*

Two of the six participants shared their perceptions of the addition of Social Communication Disorder as a possible replacement to the PDD, NOS diagnosis. Sharon shared her view:

I think providers would say that they often saw kids that they may have ended up giving a PDD diagnosis to, who [now] would fit under Social Communication Disorder, because they didn't meet all the [autism] criteria but there was something there.

John discussed his thoughts on the addition of Social Communication Disorder. He indicated the addition was something similar to a milder version of autism, stating:

So the differential diagnosis with autism, is that [SCD] just a milder version of what we are talking about?...[H]ave we possibly separated something that just represents a little less severity,... the people with Social Communication Disorder?

Another common theme that was sometimes combined with discussion about Social Communication Disorder was possible changes to insurance and service coverage.

Insurance and services for clients. The last common theme that came out of the interviews was participants' perspectives on implications of the DSM-5 changes for insurance and services for clients. Observations and concerns about insurance and services often went hand in hand. All six of the participants touched on insurance and/or services for clients.

John expressed worry over insurance coverage in regards to severity level one, which is categorized as mild, stating:

One thing I worry about is, I have heard a rumor that using the DSM-5 diagnosis and giving someone a severity level of one... that insurance companies might not pay for that... [B]ecause someone with a one will still have some fairly significant social problems, and that is the main issues that keeps them from working and functioning in society.

Sharon confided that the autism center where she works served many clients per day; she did not share concerns over insurance coverage, stating:

I would say here in Washington... the kids who didn't qualify before don't qualify, but they didn't qualify before because...PDD, NOS or Asperger's were excluded.... The system... is such that our mental health centers don't serve kids with autism.

Thomas indicated he felt like his professional group was currently in limbo and voiced his concern that he was unsure if insurance companies were using the DSM-IV-TR or DSM-5. Thomas stated:

In terms of practice... what has the most bearing is the potential impact for families who turn to insurance reimbursement.... Right now I have a hard time knowing if insurance companies are still using the DSM-IV or DSM-5.... I just talked to an insurance company the other day and... their behavioral health department didn't really know.

Two participants shared similar perceptions on services and insurance coverage for those who may fall into the Social Communication Disorder category. John shared his

concern in regards to levels of severity. John indicated that he had heard from others “worry that insurance companies won’t pay for the first level of severity or the Social Communication Disorder.” Peter shared his perception that Social Communication Disorder would most likely fall into an Axis II diagnosis: “There are a lot of insurance companies that typically do not reimburse for Axis II-only disorders, they want the Axis I disorders.”

Two of the six participants touched on services in the school setting. Thomas shared his thoughts on the uncertainty of the new diagnoses and referred to bureaucratic matters in his state, California, as “in limbo.” Thomas shared his perception on how DSM-5 may affect the school system, stating:

It seems equally, if not more, important how that relates to IDEA or Individuals with Disabilities Education Act, and how they will take those categories into consideration or not and what services are available through the school district or not.

Amy indicated that the clients she worked with are all on the severe end of the autism diagnosis: “It’s hard for me to see this impacting my clients one way or the other because they are so severe and so low functioning.”

As shown above, the comments on implications of services and insurance coverage for clients were varied. The comments ranged from concern about coverage for services, insurance coverage for Social Communication Disorder, disability qualifications, service in the schools, Axis I versus -II coverage, concern that those who didn’t meet criteria before will not meet criteria now, and no concern.

Only one of the six participants had implemented the DSM-5, the others had not begun use of the manual in their diagnostic practices at this point. This factor could provide for different findings in a year from now, for example, when everyone will be required to implement the DSM-5 under insurance requirements, and clinicians will have more experience in its use.

Summary

Clinicians interviewed in this study shared their perspectives on overall changes to the DSM-5 in these areas: addition of ASD severity levels and elimination of Asperger's and PDD, NOS; strengths of the new designations and challenges to implementation; and insurance and services for clients. The range of their concerns mirror previous research. The participants of this study shared their perceptions and views of the changes through their own personal and professional experience.

Discussion

This research project examined six clinicians' views on ASD changes in the DSM-5 through an ecosystems lens. The participants in this study both supported and deviated from the current literature on ASD changes within the DSM-5. The participants all identified primarily working with children with autism or Asperger's Disorder. This section will examine the variations between the literature reviewed and the current findings and themes from this study, as well as differences that emerged through this research.

This research was conducted using the perspective of the ecological model, which is a systems theory relating to the interconnections between everything within one's life. The ecological model was supported through participants who indicated how services and support may be affected by what diagnosis their clients might receive.

Participants' Perceptions on Overall Changes to ASD Criteria in DSM-5

Participants' views on overall changes were broken down into two subthemes: the addition of the severity levels and perception of elimination of Asperger's and PDD, NOS. Similar to this study, Buxbaum and Baron-Cohen (2013) found a positive perspective on the addition of the severity levels, indicating that Dr. Cathy Lord's group, which was active in development of the neurodevelopmental disorders work group, provided support for this addition. This was consistent with two of the six participants in the present study who shared their perspective on the addition of severity levels. One of the participants indicated that she believed a new scale of severity provided a clearer picture of the child client. In the literature, those supporting the DSM-5 changes suggest

revisions that will provide clearer and more reliable criteria for ASD (Lai et al., 2013; Singer, 2012; Swedo, 2013; Tsai, 2012).

In contrast to this published research, one participant in this study questioned how a parent might perceive the level of severity as applied to their child. One of the participants questioned how it may make a parent feel. The participant shared how some parents already expect a diagnosis, whereas others may be devastated. So, receiving a diagnosis labeled mild, moderate, or severe may make a difference to those parents, the children's primary caregivers. Previous research did not show measureable negative findings concerning the addition of levels of severity in the ASD diagnosis.

Like previous literature reviewed, there appeared to be mixed perceptions and views on the elimination of Asperger's and PDD, NOS. Child Disintegrative Disorder was not included in this theme because only one participant mentioned ASD-5's elimination of this. That participant indicated that because of the severity level of those with Child Disintegrative Disorder, those with that diagnosis would not be affected by the changes.

Five of the six participants shared feelings of concern over the loss of the Asperger's diagnosis, four of the six participants specifically declared that Asperger's was separate from a high functioning autism diagnosis. Two other participants mentioned how clients and/or parents identify with the Asperger's diagnosis, and were concerned for clients who identify with this disorder. This was consistent with Dr. Fred Volkmar's view (as quoted in Buxbaum & Baron-Cohen, 2013) that the elimination of Asperger's was a "dramatic move." McPartland, Reichow, and Volkmar (2012) voiced concern over those who currently meet Asperger's criteria may lose that designation

altogether, and suggested that these clients may meet criteria under the Social Communication Disorder. The current research supports previous research in this area and moves this discussion forward by demonstrating how the changes may impact clients.

Participants' Views on Strengths and Challenges

The findings from this study both support and deviate from previous literature. Much of the previously literature posited the DSM-5 changes to be clearer and more detailed on a spectrum. In this study three of the six participants commented on the positive strengths of the changes. Some of those comments included validation that diagnoses in a clinical setting appeared to be more accurate on a spectrum than by division into a subtype such as Asperger's or PDD, NOS. Another strength noted by a participant perceived that the changes provide more detailed and in-depth information about the individual child. As supported by previous literature (Lai et al., 2013; Singer, 2012; Swedo, 2013; Tsai, 2012), this study finds that the changes appear to provide a clearer, more descriptive, and consistent diagnostic criteria.

In other findings, this study continued to support some of the previous literature and also provide counter examples. Some of the previous literature suggested that the DSM-5 criteria are too loosely defined. This is supported by one participant who commented that the changes were too "generalized." The previous literature included studies that found some clients with previous autism and Asperger's diagnoses may no longer meet criteria with the changes (McPartland, et al., 2012; Worley & Matson, 2012), while others countered that those who had a previous diagnosis will still meet criteria for ASD with the DSM-5 (Huerta, Bishop, Duncan, Hus, & Lord, 2012). This study found

that those who had concern about individuals meeting criteria indicated that those individuals would likely be diagnosed with Social Communication Disorder. It was more common for these respondents to mention coverage of services if discussing whether a client may fall into a different category or if clients met level one in the scale of severity.

This study helps move autism research forward by demonstrating other professionals' perceptions of strengths in the DSM-5 as well as challenges. It's important to consider that during the time frame of this study, many professionals are in a transitional period from the DSM-IV-TR to the DSM-5. Only one participant out of six indicated that she was using the DSM-5 now, the other participants were still in transition. It's important to mention this in order to understand participants' views on the changes. Thus an assessment of strengths and challenges for professionals moving forward in implementing the DSM-5 is especially timely.

Participants' Perspectives on Implications of DSM-5

Participants' perspectives on implications of DSM-5 support previous studies and also differed from other studies. The previous research provided very little information on Social Communication Disorder. A study by McPartland, Reichow, and Volkmar (2012) suggested that individuals who meet previous criteria for PDD, NOS, and do not meet criteria for autism in the DSM-5, are likely to meet criteria for Social Communication Disorder. This was similar to perceptions by two of the participants. Participants who commented on this had differing views, including thoughts that SCD may be more amenable to some clients because it sounds less severe a diagnosis than autism, and also concern that SCD may be similar to a milder version of Autism

Spectrum Disorder. Participants in this study often voiced perspectives of Social Communication Disorder along with concerns about insurance and services.

Similar to previous research, this study indicated concerns for insurance and coverage for clients, especially for those whose diagnoses will change to meet different criteria, such as the Social Communication Disorder in place of PDD, NOS or Asperger's. Previous research identified a fear that a significant number of children with higher functioning autism and Pervasive Developmental Disorder, NOS diagnosed under DSM-IV-TR may not meet criteria under DSM-5 (Lai et al., 2013; Matson et al., 2012; Singer et al., 2012; Tsai et al., 2012). Previous research suggested implications for services for clients indicating the possibility of a child losing services they may have been previously eligible for (Kite, Gullifer, & Tyson, 2013; Wing, Gould, & Gillberg, 2011).

A fresh topic in this study, not yet addressed in previous research, was a participants' concern over coverage for severity level one with the ASD diagnosis.

This study adds to knowledge in the field by considering the possibility that those who do not meet criteria for ASD may meet criteria for Social Communication Disorder. It will be important for professionals to consider how this will impact clients, such as services that may or may not be available. Many of the responses on Social Communication Disorder also touched on insurance and/or services for clients, such as whether and how insurance may cover a diagnosis such as SCD. One participant expressed apprehension that Social Communication Disorder alone may not meet criteria for insurance coverage unless there is a co-morbid diagnosis along with it that meets Axis I criteria, such as depression or anxiety.

Strengths and Limitations

This qualitative research examined clinicians' perspectives on the reconceptualization of ASD within DSM-5 in comparison to DSM-IV-TR. There were strengths within this study along with limitations.

Some strengths of this project may be an increase in clinicians' understanding of other clinician's interpretations of the DSM-5. Second, this research may contribute to clinicians' knowledge base of the new Social Communication Disorder and understanding of how others are interpreting this change. Last, the information may help expand other social workers' knowledge of the changes to the DSM-5 as well as educational professionals. One of the strengths of the study is that information was gathered from clinical professionals who work directly with clients. The clinicians may be those who best know how this research directly affects the clients they serve. An additional strength is the qualitative method used, because the professionals could answer opened-ended questions and provide more personal stories. The findings were directly taken from the participants' comments, sharing their direct voices, which provides strong support for acknowledgement of this study. An additional strength was that the participants varied in their professions, with the majority being clinical social workers (60%) and the second most represented being licensed psychologists (40%). The varied geographical locations of the participants— with respondents from four different states— improved the study through regional diversity. This heterogeneity added to knowledge by noting that states differ in their mental health services for Autism Spectrum Disorder, with Washington having stricter rules on coverage than California, Louisiana, or Minnesota.

The limitations of this study may include the small sample size of six participants. Another limitation may be the research sample in relation to the practice of social work. There may be a variety of clinician credentials whose practitioners could offer differing perspectives based on their philosophy of practice. Some contributing factors to responses may include how much training the participants had and how much they familiarized themselves with the changes, whether they had already started to implement the DSM-5, and what their views were on Asperger's Disorder and Pervasive Developmental Disorder, NOS, as a separate diagnosis.

Recommendations for Future Research

The reconceptualization of Autism Spectrum Disorder in the DSM-5 will continue to be a topic for research because many professionals are still in transition from the DSM-IV-TR to DSM-5. Autism Spectrum Disorder is a complex disorder and much research has already been completed previous to the implementation of the DSM-5. It would be helpful to focus on implications of the DSM-5 once they are better known, with providers required to use the updated manual and integrate it into practice. Once the changes have been experienced, it will be important for professionals to share how this is impacting clients and their families.

Another area that emerged from this study is implications of the addition of Social Communication Disorder. Practical questions include where Social Communication Disorder will fit with services already offered to clients, and how insurance coverage for this diagnosis may be affected.

Implications for Future Social Work Practice

This study has implications for social work practice as the DSM-5 is integrated into diagnostic procedures. Most participants in this study indicated that they had not yet integrated the DSM-5 into their current practice. It can be noted that the review of current literature, as well as this study, have returned mixed reviews of the DSM-5 changes to Autism Spectrum Diagnosis. In order to assess the implications of the ASD changes, clinicians may need additional time to transition from the DSM-IV to DSM-5.

It is important that social workers understand the differences between the previous diagnostic criteria and the current one as they serve clients who may be affected by this. Professionals should continually assess their clients who may be affected by the changes, such as a child who had a diagnosis of Asperger's and who will no longer be in that diagnostic category. Social workers should learn how to best serve clients who may struggle with the changes or who may be affected by fewer services in the community.

Implications for Future Policy

The social work profession, as a whole, is expected to voice concerns and advocate for the clients they serve. In the context of changes with Autism Spectrum Disorder, social workers can advocate for services if clients are affected, regardless of the clients' diagnoses. A common concern of participants in this study was how changes would affect the clients, whether it is just because change is difficult for some, especially if a client strongly identifies with Asperger's or Pervasive Developmental Disorder, NOS, or if a parent struggles with a diagnosis of Autism Spectrum Disorder on a severe severity level. It is the social worker's obligation to advocate for and support clients.

Social workers will need to continue to offer supportive services regardless if the client meets or no longer meets criteria.

Conclusion

The current research adds new information to the literature by exploring clinicians' perspectives to Autism Spectrum Disorder changes within the DSM-5. This research supported previous research in areas such as mixed perceptions of the elimination of Asperger's Disorder and PDD, NOS, the addition of levels of severity, and the restructuring of Autism Spectrum Disorder itself as one umbrella term. The DSM-5 changes have been controversial since their introduction, with clinicians who support the majority of changes and those who do not. Professionals are currently in a transition period, as indicated by participants, so the full impact for both professionals and clients is not yet evident.

The participants in this study all shared the commonality of being clinical professionals working with clients with Autism Spectrum Disorder. Their professional experience ranged from four years in the field to over 30 years. Every clinician expressed differing perceptions and experiences with the overall changes to ASD within the DSM-5. Participants in the study articulated a variety of views on multiple areas of the changes, some in favor and some not. Their perspectives ranged from very mild concern as to how individuals and families will be best educated on the DSM-5 changes, to concern that some clients may no longer meet Autism Spectrum criteria. Differences in responses may be factors of their professional setting, respondents' personal and professional experiences, and individual knowledge of the DSM-5 changes.

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Appendix A

Recruitment Flyer

Professionals working with treating and diagnosing children with Autism Spectrum Disorder

Would you like to participate in research relating to professional perspectives on DSM-5 and the changes related to Autism Spectrum Disorder otherwise known as Pervasive Developmental Disorder?

Do you treat or diagnose children with Autism Spectrum Disorder and have a current license to practice?

If yes, please contact me!

My name is Lori Dobson and I am a student in the School of Social Work at the University of St. Thomas and St. Catherine University of St. Paul, MN. I am currently working on completing my Masters' Degree in Clinical Social Work and I am interested in interviewing people who have been using the DSM-IV-try and/or will be using the DSM-5.

The interview would last approximately 45-60 minutes, and will be held in a private location. Interviews will also be audio-taped for transcription purposes. Your participation in this study is completely voluntary and anonymous.

I will be providing a \$10 Target gift certificate to participants as a gesture of appreciation for your time.

I would love to share more information about this project with you. Please call me at xxx-xxx-xxxx or email me at dobs5950@stthomas.edu for additional information.

If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739.

Appendix B

Interview Questions

1. Can you tell me a little about the work you do?
2. Can you tell me a bit about your experience working with children, birth to 17 who have ASD?

Prompts:

How long have you worked with them?

What diagnosis do you predominantly work with?

What initial training did you receive?

Have you seen any shifts that have occurred in the field since you began?

3. What type of training have you received on DSM-5 related to Autism Spectrum Disorder?
4. When will you and/or your agency fully implement the DSM-5 criteria for Autism Spectrum Disorder?
5. What are your perceptions of overall changes to the ASD criteria in the DSM-5?
6. What are your perceptions on the elimination of:
 - a. Asperger's diagnosis?
 - b. Pervasive Developmental Disorder NOS?
 - c. Child Disintegrative Disorder?
 - d. What benefits can you identify with the new criteria Autism Spectrum Disorder?
7. How do you believe the changes will affect your clients?

8. What is your perspective on implications of children that did meet criteria in DSM-IV-TR and no longer meet ASD criteria under DSM-IV-TR? Do you believe some will fall into a different category?
9. What is your perspective on the addition to the Social Communication Disorder?
10. What implications do you believe DSM-5 will have on services for children?
11. What negative or positive feedback have you heard from clients relating to the changes to the Autism Spectrum Disorder diagnosis in DSM-5?

Appendix C

CONSENT FORM

UNIVERSITY OF ST. THOMAS

GRSW 682 RESEARCH PROJECT

Clinicians' Perspectives: DSM-5 Reorganization of Autism Spectrum Disorder

IRB Tracking #: 554903-1

I am conducting a study about clinicians' perspectives on the reorganization of Autism Spectrum Disorder in the Diagnostic and Statistical Manual of mental disorders, Fifth edition (DSM-5, 2013). I invite you to participate in this research. I have selected you as a possible participant because you are a licensed clinical professional with a license equivalent to Licensed Clinical Social Worker. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Lori Dobson, a graduate student at the St. Catherine University/University of St. Thomas School of Social Work.

Background Information:

The purpose of this study is: In this study I will interview a variety of clinicians and clinical social workers who treat and/or diagnose children with Autism Spectrum Disorder. I will ask semi-structured, open-ended questions relating to the clinicians' perspectives on the reorganization of the DSM-5 Autism Spectrum Disorder diagnosis. The information gathered during this study may help expand clinicians' knowledge on other clinicians' experiences and perceptions with the new DSM-5. This information may be helpful for clinicians' in interpreting and further implementing the DSM-5.

Procedures:

If you agree to participate in this study, I will ask you to do the following things: answer semi-structured, open-ended questions relating to your perceptions on the reorganization of the DSM-5 Autism Spectrum Disorder diagnosis. The estimated length of the interview will be between 45-60 minutes with time frame explained prior to the start of the interview. I plan to audio record the interviews in a private location such as private office, conference room and/or via Skype or by phone after your permission. After the interview is complete you will be provided with a ten dollar Target gift card.

Risks and Benefits of Being in the Study:

The overall level of risk for you is low. The use of providers decreases vulnerability vs. if I had used ASD children or parents which would be higher vulnerability. While there are no direct benefits of participation in this study, expressing your perspectives and feelings of your clients may be valuable for you as well as other professionals as a whole.

Confidentiality:

The records for this study will be kept confidential. In any report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include transcriptions, field notes and audio recorded media (until transcribed). The protection of human subjects is low risk because the participants will all be clinicians working in the field. The research information will be kept confidential and safe by keeping the information in a locked safe in the researcher's home. The data collected during the research will be disposed on or before July 31, 2014.

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 the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until April 1, 2014. Should you decide to withdraw, data collected from you will be discarded. During the interview you are free to skip any questions I may ask without question from me or need for explanation. If you choose to skip a question, I will directly proceed to the next question.

Contacts and Questions

My name, researcher, is Lori Dobson. If you have any questions, please feel free to ask them now. If you have questions following this interview, you may contact me at (xxx) xxx-xxxx. My Advisor's name for this project is Kari Fletcher and may be contacted at (651) 962-5807. If you have additional questions, you may contact the University of St. Thomas Institutional Review Board at 651-962-5341 for further information or concerns.

Statement of Consent:

I have read the above information and understand I have the right to ask any questions I may have prior to beginning of this interview. My questions, if any, have been answered to my satisfaction. I consent to participate in this study and am at least 18 years of age. I consent to the use of audio recording and, if applicable and agreed upon, Skype during the interview.

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 D

Recruitment Telephone Script

P=Potential Participant R=Researcher

R= Hello, my name is Lori Dobson, I am looking to speak with (P).

P=I am (P)

R= My name is Lori Dobson and I am a Masters student in the School of Social Work at the University of St. Thomas and St. Catherine University of St. Paul, Minnesota. I am currently conducting research under the supervision of my professor Kari Fletcher, on Clinicians' perspectives to the reorganization of Autism Spectrum Disorder in the DSM-5. As part of my research, I am conducting interviews with clinical social workers and other licensed mental health professionals with an equivalent license to clinical social workers.

I received your name from (public directory, internet, or snowball sample). I understand you are a licensed clinician with experience working with children with Autism Spectrum Disorder. I am looking for interview participants on their perceptions of the changes to the Autism Spectrum Disorder in the DSM-5. Is this a convenient time for you to ask you a few questions and provide you with further information about the study and interview process?

P=No, could you call back later (ask what time would be more convenient to call this P back).

Or

P=Yes

R= I would like to verify that you meet the expectations for this particular study. Would you consider yourself a licensed clinician with experience working with children with ASD. Are you aware of the DSM-5 changes to Autism Spectrum Disorder? Would you consider yourself to be a good candidate for this study? Why or Why not?

P=Response

R=I will be conducted interviews starting in January of 2014. The interviews will last about 45 minutes to one hour and will be audio recorded to capture all information, and later transcribed verbatim for analysis by myself or a hired staff at the University of St. Thomas. Involvement in this interview is entirely voluntary and confidentiality is ensured. The questions will focus on the changes to the Autism Spectrum Disorder changes in the DSM-5 as well as the Social Communication Disorder addition. With your permission, I would like to email/mail/fax you an informational letter which has all of these details along with contact names and numbers on it to help assist you in making a decision about your participation in this study.

P=No Thank you, OR

Sure. (Get contact information from potential participant i.e., mailing address/fax number/email.)

R=Thank you very much for your time. May I call you in 2 or 3 days to see if you are interested in being interviewed? Once again, if you have any questions or concerns please do not hesitate to contact me on my confidential cell phone at xxx-xxx-xxxx.

P=Good bye.

R=Thank you, I will talk to you soon, good bye.

Appendix E

Recruitment E-mail

Dear Potential Participant,

My name is Lori Dobson and I am a Masters student in the School of Social Work at the University of St. Thomas and St. Catherine University in St. Paul, Minnesota. I am currently conducting research under the supervision of my professor, Kari Fletcher, PhD, LICSW. As you may know, in the past year ASD has been re-organized in the newly published DSM-5 (2013). As part of my study, I am conducting interviews with mental health professionals to discover their perspectives on the reorganization of the DSM-5 in relation to Autism Spectrum Disorder (ASD).

I received your name and credentials from (public directory, internet, or snowball sample). I understand that you are a licensed clinician with experience working with children with ASD. I would like to interview clinicians on their perspective on the DSM-5 changes to ASD.

The following is some background information on the interview:

The interview would last 45 minutes to one hour, and would be arranged for a time convenient for your schedule.

Involvement in this interview is entirely voluntary and there are no known or anticipated risks or benefits to your participation in this study.

I will be providing a \$10 Target gift card to participants as a gesture of appreciation for your time.

You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview anytime.

With your permission, the interview will be audio-recorded to capture all information, and later transcribed verbatim for analysis by myself or a hired staff at the University of St. Thomas.

All information you provide will be considered confidential.

The data collected will be kept in a secure location and disposed of on July 31st, 2014.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact myself at xxx-xxx-xxxx or my supervisor Kari Fletcher at 651-962-5807.

I would like to assure you that this study has been reviewed and received ethics clearance through the Internal Review Board (IRB) at the University of St. Thomas and St. Catherine University in St. Paul, Minnesota. However, the final decision about participation is yours.

After all of the data has been analyzed, the findings will be published as well as publically presented at St. Catherine University of St. Paul, MN.

With your permission, I would like to call you in 2-3 days to see if you are interested in being interviewed. Once again, if you have any questions or concerns please do not hesitate to contact me on my confidential cell phone at xxx-xxx-xxxx.

Thank you for your consideration,

Lori Dobson, LSW
Graduate Student at the School of Social Work
University of St. Thomas and St. Catherine University

If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739.

Appendix F

Resources

American Psychological Association, <https://www.apa.org>

Autism Speaks, www.autismspeaks.org

National Institutes of Health, www.nimh.nih.gov

National Association of Social Workers, www.socialworkers.org