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## Diagnostic Statistical Manual 5 Changes to the Autism Diagnostic Criteria: A Critical Moment for Occupational Therapists

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## Diagnostic Statistical Manual 5 Changes to the Autism Diagnostic Criteria: A Critical Moment for Occupational Therapists

### Abstract

Changes in the soon to be released Diagnostic Statistical Manual (DSM) – 5 (American Psychiatric Association, 2012) bring new opportunities for occupational therapy, but the profession must prepare for the impact these changes forecast. While well positioned to capitalize on newly defined specifications of Autism Spectrum Disorders (ASD) and the elevation of sensory processing difficulties to a core feature of the disorder, the profession must be alert to the potential downside of the pending changes. The more stringent diagnostic rubric will likely exclude a significant number of individuals currently eligible for therapeutic and academic services. Autism will be defined as a neurodevelopmental disorder that must be identifiable before early childhood (age 5), even if it is not detected until later as a result of environmental factors (minimal social demands, support from caretakers, etc.). The new diagnostic criteria will add the explicit recognition of sensory behaviors within a subdomain of stereotyped motor, verbal, and sensory-based behaviors and researchers suggest only 60% of those who currently meet the threshold for an autism spectrum diagnosis will continue to meet criteria under the new categorization. The proposed changes will likely encourage researchers to use greater specificity when recruiting sample populations and, as a result, help to determine interventions that are most advantageous for specific subtypes. Addressing sensory processing in the diagnostic criteria may authorize interventions aimed specifically towards reduction of sensory-related disabilities through remediation, environmental support, or parent education while simultaneously calling upon us to deliver evidence for Ayres' sensory integration<sup>®</sup> (ASI) approaches. The change also presents an urgent call to our profession to promote the unique scientific contributions occupational therapy makes for individuals with ASD, their families, and their educational contexts both including and in addition to the use of ASI approaches. These changes to the manual used by the psychological community for diagnosis offer occupational therapists an opportunity to emerge as the recognized leaders in the diagnosis and intervention of sensory processing disorders/dyspraxia. The issue is, then, how can the profession of occupational therapy clearly articulate our role and our knowledge to stakeholders and team members so occupational therapists are recognized as scientists and clinical experts, both key players in the diagnosis of sensory processing difficulties and the treatment of ASD?

### Keywords

Sensory Processing; Autism; Diagnostic Statistical Manual 5

### Cover Page Footnote

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### Credentials Display

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The new definition of Autism Spectrum Disorders (ASD) is expected to appear in May 2013 in the finalized Diagnostic Statistical Manual (DSM) -5 (American Psychiatric Association, 2012). The current DSM-IV criteria uses Pervasive Developmental Disorder (PDD) as the umbrella term for autism, a classification that many professionals believe has been outdated for several years. ASD will be the new name for the category that includes “autistic disorder (autism), Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified” (APA, 2012). It will also serve to better differentiate autism spectrum disorder from typical development as well as from similar but otherwise "nonspectrum" disorders. The hope is to reduce variability in diagnosis and subject recruitment across sites, especially those criteria associated with severity, language level, or intelligence. The purpose of the new definition is to (a) view autism through a wider lens, (b) support better diagnosis, more clarity in patient-centered outcomes research, and targeted interventions, and (c) provide a classification system more responsive to evolving clinical and scholarly discoveries by moving to an online, more easily edited format.

As proposed by the diagnostic criteria in the DSM-5, to be diagnosed with autism, an individual must meet all four diagnostic features (APA, 2012). Unusual sensory behaviors are explicitly included within a subdomain of stereotyped motor and verbal behaviors, expanding the specification of different behaviors that can be coded within this domain, with examples particularly relevant for younger children. The severity of ASD will be ascertained on three levels, with level 3 “requiring very substantial support,” level 2 “requiring substantial support,” and level 1 “requiring support” with regard to social communication deficits and restricted interests/repetitive behaviors (APA, 2012).

In addition to the positive expected outcomes of the DSM-5 changes, there are concerns. Specifically, the potential reduction in access to services for individuals who currently meet the criteria for ASD diagnosis but who may not with the new criteria raises concerns in the autism community (Dawson, 2012). Scholars have identified that the new diagnostic criteria may likely exclude 40% of individuals currently diagnosed with ASD, especially those individuals who are more cognitively able and those with ASD who fail to meet thresholds for Autism Disorder (McPartland, Reichow, & Volkmar, 2012). Families who receive benefit from services that bridge the gap between performance and potential for their child with ASD, such as those provided by occupational therapy, may have less access to those services under the new criteria (McPartland et al., 2012).

### **Occupational Therapy's Role in ASD**

Occupational therapists (OTs) have a role in ASD intervention, and parents of children with ASD have sought our services as beneficial and helpful. For example, in a large study conducted by the Interactive Autism Network (IAN), parents described occupational therapy intervention as the 3<sup>rd</sup> and 5<sup>th</sup> most commonly used intervention for individuals with ASD (IAN, 2010). Our visionary work in sensory integration can, at times, overwhelm the more global contribution OTs make to children with ASD and their families, but occupational therapy teaches skills that help individuals with ASD to live as independently as possible and to participate fully in meaningful and purposeful activities and occupations (Case-Smith & Arbesman, 2008). For example, playing with peers at recess and successfully participating in religious services and family meal times. With the potential exclusion of individuals who have been benefiting from our intervention services, OTs will need to expand the role of activist, advocating for both current and future clients. Table 1 provides an overview of the role of occupational therapy in

relation to the four proposed diagnostic criteria of ASD in the DSM-5.

Table 1

*The Role of Occupational Therapy in Relation to the Proposed Diagnostic Criteria in the DSM-5*

Proposed operationalization of diagnostic features (APA, 2012)	OT's Role
A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:	
1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.	The primary childhood occupation of play—we are able to find what is meaningful and important to the child and family, and use it to engage the child in meaningful social interaction.
2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.	Using our knowledge in sensory processing, we are able to reduce environmental stimulation, provide calming activities, and help the child attain a state of arousal as a mechanism for more complex social behavior (e.g., joint attention, empathy).  Helping the child make the connection between the movement of the body and words related to spatial concepts and/or actions through child-directed activity (crawling through tunnels, climbing over tires) is a common feature of high fidelity sensory integrative methods.
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.	Interest in others is related to co-participation in occupational pursuits. Using our skill in activity analysis and child development to craft developmentally appropriate play activities encourages development of play and imitation in naturalized settings and normalized play schemes.
B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:	
1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple	Our knowledge of praxis and using Ayres' sensory integration <sup>®</sup> (ASI) to increase ideation

<p>motor stereotypies [<i>sic</i>], echolalia, repetitive use of objects, or idiosyncratic phrases).</p>	<p>is firmly based in over 60 years of clinical expertise and pragmatic inquiry. Our profession uniquely qualifies to support reduction of non-purposeful sensory motor behaviors. Our use of activity analysis provides the just right challenge to motor skill with object use.</p>
<p>2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).</p>	<p>Our ability to analyze the inter-relationships between PEO to help families manage the child's needs with the family's needs in terms of routines, patterns, and life changes.</p>
<p>3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).</p>	<p>Using activity analysis, ASI, and developmentally appropriate play to expand interests contributes to interdisciplinary clinical treatment and informal patient-centered outcome research initiatives.</p>
<p>4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).</p>	<p>ASI and sensory strategies, modification of environments and tasks in relation to their sensory-motor properties, provides parent and teacher education regarding sensory processing and behavioral reactions, helping to problem solve, identify antecedents related to internalized reinforcements. OTs guide children to participate in selected sensory-based activities, thereby supporting better regulation of their behavioral responses to sensations and situations that they find upsetting.</p>

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities). Our curriculum focuses heavily on adaptation across the lifespan, translating theory to practice within all student programs.

D. Symptoms together limit and impair everyday functioning [enhancing occupational performance in ADLs, school, etc.]. The OT education uniquely prepares practitioners to maximize function and promote adaptive occupational performance.

The proposed DSM-5 adds severity qualifiers, from the most severe to the least severe: Level 3, “requiring very substantial support,” level 2, “requiring substantial support,” and level 1, “requiring support” (APA, 2012). The OT’s role may vary based on the severity level of the child with ASD. For example, for the least severe (level 1), rituals and repetitive behaviors (RRB’s) “cause significant interference with functioning in one or more contexts.” Individuals with ASD “resist attempts by others to interrupt RRB’s or to be redirected from fixated interest” (APA, 2012). OTs can improve function across contexts, such as by reducing sensory seeking or avoiding behaviors, by creating enabling habits, restorative rituals, and productive routines, as outlined in the Occupational Therapy Practice Framework (AOTA, 2008). At level 2, “RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB’s are interrupted.” At the most severe, level 3, OTs might address “preoccupations, fixated rituals and/or repetitive behaviors [that] markedly interfere with functioning in all spheres; marked distress when rituals or routines are interrupted; and [a client who is] difficult to redirect from fixated interest or returns to it quickly,” (APA, 2012) the last of which is one of the primary barriers to family quality of life (Freedman & Whitney, 2011; Lee, Harrington, Louie, & Newschaffer, 2008).

### **Implications for Occupational Therapy Practice**

Increasingly, scholars and families propose that interventionists and researchers focus on helping families and individuals thrive with the autism diagnosis, measuring outcomes related to quality of life (Lee et al., 2008). While many consider “cure” to be the absence of pathology within the person, occupational therapy has always employed curative occupations to focus on restoration of usefulness and productiveness, both capabilities believed to reside within the



person. Our profession was founded to measure observed and pragmatically measured outcomes when clients participate in ecological systems (Bing, 1997), not exclusively in an overly controlled environment. OTs believe engaging in co-created occupations heal, and that through occupational engagement, the human spirit emerges and adaptation occurs.

Internally, our profession must orchestrate leadership roles on diagnostic teams, working to better distinguish the role sensory-based mechanisms have in internalizing and externalizing behaviors. We must provide diagnostic tools with specificity for autism, administered and interpreted by our profession (such as the Sensory Experiences Questionnaire, Baranek, David, Poe, Stone, & Watson, 2006). This will provide an essential, and to date missing, component to improving cross-disciplinary measurement of ASI<sup>®</sup> intervention effectiveness (Parham et al., 2011). By using ASI as a frame of reference, the child's internal motivation is valued and, in turn, the family and the child have time to focus on more than just compliance with adult-derived behavior plans. More, OTs can assist in the development of comprehensive and functionally-based evaluation and treatment for non-engaging behavior, complementing social-cognitive or behavioral frames of reference. Occupational therapy researchers must further document the effectiveness of occupational therapy using ASI that will provide support for families who report that occupational therapy is one of the top three most sought-out interventions for their child with ASD (IAN, 2010).

Higher levels of rigor in research designs are less vulnerable to bias and error, more effectively generalized, more likely to have outcomes attributed to the intervention being studied, and have a greater replicability. The field of autism research has struggled to agree upon classification of evidence-based criteria, in part, due to discipline-specific methods with distinct purposes, orientations, theories, and relevant but diverse research methods (Reichow, Volkmar,

& Cicchetti, 2008). The authors of this study recommend two categories of evidence-based practice (EBP): Established EBP (practices effective across multiple methodologies demonstrating enough evidence for confidence in the treatment's efficacy) and Promising EBP (effective treatments across multiple studies but with weaker methodological rigor, fewer replications, or an inadequate number of independent researchers demonstrating significant effects). Our occupational science has contributed to the body of knowledge supporting the value of ASI with more than 70 published articles examining its efficacy (Parham et al., 2011). However, there is more work to be done: the National Autism Standards Project sought to determine which results of reviewed studies were believable enough to expect similar results in other studies that used equal or better research methodologies, specifically those related to ASD. They identified ASI as "unestablished," distinct from "ineffective" (Reichow et al., 2008), encouraging strong methodological rigor.

Part of our scholarly efforts clearly must include educating others to understand what levels of evidence really mean to the public, facilitating best practices using promising treatments, and defending against biased scientific reports that self-servingly mislead the public by suggesting that "unestablished" is equal to "ineffective" (Lang et al., 2012). While there are limited studies using randomized controlled trials and the most rigorous methods (Miller, 2003; Miller, Coll, & Schoen, 2007), and many studies to date have not implemented the intervention with fidelity (Parham et al., 2011), accusations of "no evidence" are ill-informed and suggest that the review of existing literature is insufficient (Miller, Schreck, Mulick, & Butter, 2011; Pfeiffer, Koenig, Kinnealey, Sheppard, & Henderson, 2011; Schaaf, 2011). Omitting from a literature review the body of work that contradicts a researcher's agenda is bad science. The occupational therapy profession must demand rigor in all evidentiary work (Lang et al., 2012). OTs can

contribute by publishing more studies outside our own professional journals, holding our own profession accountable to practice with fidelity, and demanding greater fidelity from those outside of the profession of occupational therapy who are interested in exploring sensory motor concepts (Parham et al., 2011).

Given all the work done by Ayres and other occupational therapists on developmental dyspraxia (Parham & Mailloux, 2010), it is concerning that no citation to Ayres or other publications from the occupational therapy field was provided in the otherwise well-regarded article on developmental dyspraxia in children with ASD (Mostofsky et al., 2006). Additionally, in this paper, the authors identify the lack of a tool designed for praxis assessment in children as a limitation, thus necessitating the re-purpose and use of one from the adult population.

Although the authors report that a measure of praxis standardized for children has not yet been developed (Mostofsky et al., 2006), a standardized praxis evaluation, the Sensory Integration and Praxis Test, is tailored for children and can be extended to everyday clinical use. While it is encouraging to have an increase in empirical inquiry about sensory integrative approaches from other professions, future practice in research would hopefully see greater collaboration to assure outcomes are pragmatically relevant. Other recent papers published in the autism literature have addressed sensory processing issues and have cited some occupational therapy literature, but clearly have not understood, or correctly applied, the theory of sensory integration as proposed by Ayres (Devlin, Leader, & Healy, 2009; Wodka, 2011). Still others discuss sensory processing/integration with no clear link to occupational therapy (Miller et al., 2011; Simpson, 2005) or without exploring the prior similar work done in our field (Harrison & Hare, 2004; Klintwall et al., 2010). Others misrepresent the science and practice of ASI altogether, even

presenting misleading and biased interpretation, cherry-picking evidence and interpreting findings through a myopic lens (Lang et al., 2012).

OTs must take it upon ourselves to respond when we see bad science, the faulty interpretations of outcome data due to a lack of awareness of the literature, or poor fidelity and validity such as recent response to the Devlin article by Schaaf & Blanche (2011). More, in keeping with the ethos of our profession as collaborators, a priority and opportunity is before us: To seek out continued cross-disciplinary publishing opportunities (Baranek, Parham, & Bodfish, 2005; Schaaf & Miller, 2005) and to capitalize on the newly structured DSM-5 criteria. Exemplary models for this expression of partnership can be seen in Clark's response to the recent American Medical Association position paper (2012), the newly-merged Sensory and Motor Special Interest Group at the 2012 International Meeting for Autism Researchers (IMFAR), and even in the language in the DSM-5 explicitly identifying sensory features of ASD.

## **Conclusion**

The proposed re-definition of ASD in the DSM-5 will require the profession of occupational therapy to powerfully translate how what we do matches the characteristics of ASD, and how our treatments contribute to evidence-based outcomes for individuals with ASD and their families. Enabling curative occupations through sensory integration theory, sensory-motor development, and mental health and wellbeing are unique and proprietary domains of the occupational therapy profession. Sensory integrative approaches have the same level of evidence as many other clinical interventions, and each discipline must be mindful not to undervalue highly-regarded treatments that have yet to complete sufficient empirical studies. Occupations have curative value but are not a cure. Our profession would be wise to review and adhere to the criteria proposed by leading autism researchers (Reichow et al., 2008) to ensure our

research is strategically aligned within the evidentiary continuum. The profession must also directly confront other disciplines that misrepresent or ignore the body of evidence accrued within our profession's scholarly work, thereby ensuring that best practices and best science is available to scholars and families. We must also anticipate the significant and predicted public health ramifications related to eligibility for occupational therapy and other related services, the consequential impact on the occupational therapy practice patterns, and prepare advocacy materials to enable families access to needed interventions. The change is new, but what occupational therapy offers is not—as the clarification of the new criteria unfolds, so will the clarification of occupational therapy's role to contribute to ASD intervention. OTs, ultimately, endeavor to serve individuals with ASD and their families; we must embrace our authoritative voice in the diagnosis and treatment of the occupational deficits related to ASD.

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