



# EITI Newsletter

Early Intervention Training Institute

Summer 2013

Rose F. Kennedy Center, University Center for Excellence in Developmental Disabilities

## DSM 5 and the new Autism Spectrum Disorder Criteria: What's it all about?

By Lisa Shulman MD., Developmental Pediatrician, Director of the Infant and Toddler Team and the RELATE program

The community of families and professionals who work with children with autism spectrum disorders (ASD) is holding its collective breath. This May 2013, the American Psychiatric Association released its revised Diagnostic and Statistical Manual of Mental Disorders (referred to as the DSM 5), the first update in nearly twenty years, and it includes extensive changes to the criteria for autism. The DSM is the standard reference for mental disorders and the criteria it establishes for conditions can have widespread implications for diagnosis, treatment, research, insurance eligibility coverage and government entitlements. How will the new criteria affect current diagnostic practices?

The changes have generated quite a bit of controversy. The New York Times ran a headline in January 2012 stating that, "New Definition of Autism Will Exclude Many Now Diagnosed", based on statements and research from a renowned autism expert. The media reports implied that the change in criteria was being utilized to stem the autism epidemic. The media frenzy instilled fear in the parents of

children with autism who became concerned that under the new criteria, their children would lose the diagnosis (and therefore their services). Well-organized parent groups and their lobbyists even introduced bills before some state legislatures, (NY included), stating that insurance companies, educational systems or entitlements such as social security, should continue to utilize DSM IV criteria for these eligibility determinations.

### **ELIMINATION OF SUBTYPES AND USE OF SPECIFIERS**

So, why make changes in the ASD criteria? There are a number of compelling, evidence-based reasons. First, it seems that diagnosticians, while good at recognizing that a child has ASD, lack consistency in how they assign children to the particular subtype diagnoses under the umbrella of Pervasive Developmental Disorders, set forth in DSM IV. Research indicated that the specific ASD diagnosis (autism, PDD.NOS or Asperger's Syndrome), that a child in a study sample received, was more related to *where* the child underwent the evaluation, than the pattern or severity of the clinical symptoms. On the basis of these findings, it was decided that in the new DSM 5, all of the PDD subtypes would be collected into a single broad category called Autism Spectrum Disorder. Rather than using an unreliable diagnostic category to depict a

child's particular ASD profile, various clinical "**specifiers**" would be utilized in order to characterize that child's language function, cognitive function, emotional/behavioral co-morbidities, active medical issues, etiology, pattern of onset of symptoms and severity, defined as the degree of support required to function in mainstream settings.

### **REDUCTION FROM THREE TO TWO CORE DEFICITS**

Another major change in DSM 5 supported by research, is the move from three core deficits, namely *social, communication, and restricted/repetitive interests and behaviors* to two. Researchers have shown that the social and communication deficits of the ASDs travel together stemming from the same essential deficit. Separating them out was like "double dipping", giving them too much weight in the diagnostic process. Therefore, instead of twelve criteria with no minimum criteria for PDD.NOS in DSM IV, under DSM 5, there are seven criteria across the two domains of **social/communicative impairment and restrictive/repetitive patterns of behavior, interests or activities**. In addition, there is the requirement that five out of the seven criteria be met for a diagnosis of ASD, with all three social/communicative criteria required.

### **CONSIDERATION OF SENSORY SENSITIVITIES**

Other changes in the criteria are the inclusion of sensory sensitivities among the ASD criteria, for the first time. Sensory symptoms have long been a prominent clinical symptom of ASD described by families and individuals with ASD themselves, but they have not been included among the formal criteria until now.

### **SEPARATION OF BEHAVIORAL CRITERIA FROM MEDICAL DIAGNOSES**

The diagnosis will now also separate out the diagnosis of ASD from medical conditions. Between fifteen and twenty per cent of children with ASD, have an underlying cause for their behavioral symptoms of ASD which can be established based on medical evaluations. These may include syndromes or other problems such as: Fragile X syndrome, Williams Syndrome or Tuberos Sclerosis, brain abnormalities, infantile spasms or genetic microdeletions or duplications. The co-occurrence of medical conditions and ASD symptoms has had a tendency to confuse parents and systems: are their child's symptoms due to Fragile X Syndrome or due to autism? Are symptoms due to agenesis of the corpus callosum or autism? Now it is clearer; the diagnosis of ASD is based on the behavioral criteria, while the medical etiology is coded as the etiology "specifier" for the child's ASD.

Early studies looking at the potential impact of the new DSM 5 criteria on children already diagnosed (retrospective studies) have highlighted that individuals with higher intelligence (IQ), and milder social impairment (e.g. PDD.NOS or Asperger's Syndrome) were at risk of being excluded. These retrospective studies may have painted a bleaker picture for continued inclusion under the ASD umbrella, due to the probability that information needed to apply the diagnosis of ASD under the new criteria, may not have been available (e.g. sensory sensitivities). More valid assessments of the proposed criteria require prospective or field studies applying the new criteria to actual children, rather than charts, and

with access to current parent input. Such studies have been in process, generally looking at groups of school- age children, to clarify how easy the new criteria are to use, and their reliability when applied by different professionals. These studies have shown that the large majority of children retained the ASD diagnosis under the DSM 5 criteria. For those children who do not meet criteria for ASD, they may be diagnosed under a new category of Social Communication Disorder. This category, to be used only when ASD is ruled out, is based on evidence of difficulty in the social uses of verbal and nonverbal communication in natural contexts, without the presence of restricted and repetitive interests and behaviors.

The Committee on Neurodevelopmental Disorders, an interdisciplinary group of experts charged with revising the definition of autism, based their revisions upon more than 15 years of research, designed to provide better clarity on what constitutes autism and what does not. Their intent was not to seek to stem the autism epidemic through the creation of stricter criteria in order to exclude individuals with autism from receiving the diagnosis. Their aim was to make the diagnosis of autism spectrum disorder less subjective, more specific, correctly excluding those who do not have the diagnosis, while correctly

identifying and including those who do. This is especially important for promoting research seeking to find the causes of autism, effective treatments, and to address the interplay of genetic risk with environment factors.

The new criteria raise certain practical considerations. Their use requires that clinicians have more familiarity with the features and terminology of autism. Clinicians will need to undergo training in order to use the criteria as they were intended. While the changes in the criteria were evidence- based and crafted by extremely experienced clinicians, it will be important to monitor for unanticipated outcomes which may arise in their application on real populations, in real time. We will need to have a special eye toward their potential impact on diagnosis of children with milder social symptoms, higher cognition, older teens and adults, and the youngest of children being referred for initial diagnostic evaluation. For now, it seems, we will need to continue to hold our breath.

**Reference:**

[www.autismspeaks.org](http://www.autismspeaks.org)