## DSM-5 – Concerns and Questions From the Autism Community – January 25th, 2012

Background – The Neurodevelopmental Disorder Work Group of the APA's DSM-5 task force has spent almost a decade developing new criteria to diagnose autism spectrum disorders. Prime among the goals has been to improve the specificity of the diagnosis and to ensure that the criteria are evidence-based and clinically useful.

A coalition in the autism community had already been preparing public comment for the spring 2012 comment period based on concerns about the proposed criteria. On Friday, January 20th, 2012, an article in the New York Times dramatically upped the stakes. The article discussed a study whose lead author, Dr. Fred Volkmar of the Yale Child Study Center, was the chair of the DSM-IV committee that created the current autism spectrum diagnostic criteria. The study, based on 372 high-functioning people with autism from the dataset of a DSM-IV study done in 1993, found that only 45% of the subjects would meet the new criteria for an autism spectrum disorder.

The autism community has been stunned by this finding since previous estimates of diagnostic tightening had indicated no more than a 12% reduction in cases (Frazier et. al, 2012). The APA's press release in response to the NYT article includes the following quote, "Field testing of the proposed criteria for autism spectrum disorder does not indicate that there will be any change in the number of patients receiving care for autism spectrum disorders in treatment centers--just more accurate diagnoses that can lead to more focused treatment." Given this huge disparity parents and individuals with autism need much more information about the impacts of the new criteria and an opportunity to voice their concerns. This document is an attempt to briefly consolidate concerns and questions from the members of the coalition.

### Concerns:

### 1) Impact on Medicaid and disability services

Current criteria for Medicaid Waiver (for children with disabilities) and disability income for impaired adults typically includes both an IQ cut off (below 70) and/or significantly impaired scores (greater than two standard deviations below normal) in adaptive behavior. The concern is that, for higher functioning individuals who may not qualify for an autism spectrum diagnosis under the new criteria, the lack of a formal diagnosis may be an impediment to receiving necessary services – particularly if their adaptive function is borderline.

### 2) Impact on insurance coverage

A) Twenty-nine states have passed laws providing various levels of insurance coverage for autism. All states will need to investigate whether their insurance bills for autism will still provide coverage for

people who no longer qualify for an autism diagnosis based on the new criteria (the higher end of the spectrum). Is the APA assuming that people who do not meet the new criteria will be too high-functioning to require ABA? What about social skills groups provided by a licensed psychologist or social worker?

B) Also, the new DSM-5 criteria for autism include the phrase, "not accounted for by general developmental delays". Many young children with autism do not show perseverative behaviors until they are toddlers. In a young child, how would you distinguish a child with autism who is non-verbal and has additional motor delays from a child with non-autism speech delay and motor delays? How might this impact their insurance coverage for ABA?

**3) Impact on school services/early intervention**

A) Some states have regulations that relate specifically to children with an educational classification of autism. Will school districts use the stricter criteria for autism to exclude children from the intensive support they need? For example, New York state has a regulation that:

*The class size for such students shall be determined in accordance with section 200.6(f) and (h) of this Part, provided that the class size of special classrooms composed entirely of students with autism shall be in accordance with section 200.6(h)(4)(ii)(a) of this Part.*

*(ii) (a) The maximum class size for special classes containing students whose management needs are determined to be highly intensive, and requiring a high degree of individualized attention and intervention, shall not exceed six students, with one or more supplementary school personnel assigned to each class during periods of instruction.*

B) IDEA requires that school districts annually report the number of children with autism that they serve in various categories of disability. Parents have documented cases of school districts intentionally classifying children with autism in different categories to avoid providing the extensive services that the research supports. Typically, such children are classified under the "speech/language" or "other health impaired" categories. One parent reports that some school districts use a category called SMI (Severely Multiply Impaired) when a child has autism and a developmental cognitive delay. This category has more than doubled in the last 5 years in her state. The school districts get more money to serve the children but then deny services based on the contention that the deficits are unlikely to respond to treatment. This is an additional reason that parents are concerned about the phrase "not accounted for by general developmental delays" because they have seen what can happen when service providers manipulate the system. We would recommend elimination of this phrase since a child would still have to meet the criteria for autism spectrum disorder to receive a diagnosis.

C) Will the new more stringent criteria incline professionals to under-diagnose autism? Early intervention evaluations are typically paid for by counties and school districts that also have to pay for the services to the child. While children with other diagnoses typically receive services, intensive ABA is usually reserved for those with a formal autism diagnosis.

**4) Impact on epidemiology**

A) Autism prevalence in the United States (and around the world) has been rising dramatically in the past three decades. The reason for the increase is arguably the single most pressing question in children's health today. In the early 1980's, autism rates were in the range of 1-4 individuals per 10,000. Today, in the United States, autism spectrum disorders are diagnosed in 91 individuals per 10,000 – at least a 23-fold increase. The Centers for Disease Control documented a 57% increase in the prevalence of autism spectrum disorders in 8 year-olds from the 1994 to 1998 birth cohorts.

The CDC has said they can adjust their surveillance studies to maintain trend comparisons despite any change in diagnostic criteria. Advocates do not want to be in same position as 1991-93 when DSM IV came out and many ascribed the epidemic to the DSM changes. How will the CDC do this and will they guarantee this? If Dr. Volkmar's study is accurate, is it even possible to statistically compare the new and old diagnostic criteria? What about the other longitudinal studies going on? If rates of autism go down dramatically, what impact will that have on future research funding? Can the APA address this before implementing the new criteria?

B) Currently, there are two guides to diagnosing autism spectrum diagnosis, 1) The Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) is published by the American Psychiatric Association (APA) and the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10)published by the World Health Organization. The ICD-10 will not be adopted by the United States until October, 2013. Diagnosis with either of these guides is often used to screen candidates for research studies.

The following table shows relationships between clinical terms and their sources.

**Pervasive Developmental Disorders**

| DSM-IV | ICD-10 |
|---|---|
| 299.00 Autistic Disorder | F84.0 Childhood Autism |
| 299.80 Rett's Disorder | F84.2 Rett's Syndrome |
| 299.10 Childhood Disintegrative Disorder | F84.3 Childhood Disintegrative Disorder |
| 299.80 Asperger's Disorder | F84.5 Asperger's Syndrome |

**Pervasive Developmental Disorders**

| DSM-IV | ICD-10 |
|---|---|
| 299.80 Pervasive Developmental Disorder not otherwise specified (PDD-NOS) (including Atypical Autism) | F84.1 Atypical Autism |
| | F84.8 Other pervasive developmental disorders |
| | F84.9 Pervasive developmental disorders, unspecified |
| | F84.4 Overactive disorder associated with mental retardation and stereotyped movements |

PDD-NOS in the DSM-IV includes F84.1, F84.8 and F84.9 from the ICD-10

The conditions labelled F84.2, F84.3 and F84.4 are considered rare.

Will the ICD-10 codes be aligned with the new DSM-5 criteria? Currently, they more closely reflect the DSM-IV criteria? Will this happen before the US implementation of the ICD-10 codes in October, 2013? How would a disparity in the two sets of diagnostic criteria affect international epidemiology?

C) With the paradigm shift to environmental causation in the autism research, the shift in diagnostic criteria will impair the ability to investigate environmental factors over time and between different geographic regions. What can be done to provide clarity so that future international and regional autism rates can be tracked and compared to past rates?

D) Can APA provide written interpretation or guidance to clinicians on their intentions regarding the new autism criteria in order to minimize the clinical variations in how the criteria are applied? Can the APA prepare this in advance of formally releasing the new criteria so that clinicians can be fully prepared to make the transition? Also, can the committee prepare a summary document of the research so far on specificity and sensitivity in the field trials to be shared with the community?

## 5) Impact on biomedical research

A) One very significant change to the new autism criteria is the exclusion of a distinction in language development between autism and (what used to be called) Asperger's Syndrome. Many parents believe that the etiology is different in these two groups despite the fact that they may present similarly as adults. In addition, many children with autism develop language and then lose language skills. The committee has merged the spectrum diagnoses based on clinical utility for treatment, prognosis and assessment, but appears not to have considered causation and prevention. How does the committee anticipate that researchers will subgroup individuals when environmental investigations are done?

B) Rett's Disorder, and Childhood Disintegrative Disorder have both been subsumed into the autism category, yet the new criteria for autism make no mention of regression which is clinically important in both those disorders and many cases of autism. How can the committee

include this critical piece of information that may suggest differential environmental exposures in the diagnostic criteria? Could the criteria explicitly deal with the issue of regression (children with documented normal development who lose previously-acquired skills)?

## 6) General Concerns

A) Children may be diagnosed with other disorders that are close to autism (perhaps the child misses an autism diagnosis by a single criterion and ends up not receiving early treatment as a result even though they later meet autism criteria). Currently, intensive behavioral therapy is reserved for autism spectrum disorders so the name is important. Two examples of other diagnoses where this might happen are:

### *Intellectual or Global Developmental Delay*

*This diagnosis can be used in situations where there is clear evidence of significant intellectual or general developmental delay or disability, but criteria for another specific disorder are not fully met. This could be because additional clarifying data are required before once can make a diagnosis of Intellectual Disability, or because the individual is too young to fully manifest specific symptoms or unable to complete requisite assessments.*

*Or:*

### *Social Communication Disorder*

*Updated December 9, 2010*

*A. Social Communication Disorder (SCD) is an impairment of pragmatics and is diagnosed based on difficulty in the social uses of verbal and nonverbal communication in naturalistic contexts, which affects the development of social relationships and discourse comprehension and cannot be explained by low abilities in the domains of word structure and grammar or general cognitive ability.*

*B. The low social communication abilities result in functional limitations in effective communication, social participation, academic achievement, or occupational performance, alone or in any combination.*

*C. Rule out **Autism Spectrum Disorder (ASD)**. Autism Spectrum Disorder by definition encompasses pragmatic communication problems, but also includes restricted, repetitive patterns of behavior, interests or activities as part of the autism spectrum. Therefore, ASD needs to be ruled out for SCD to be diagnosed.*

*D. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).*

Also, please note the following comment from the American-Speech-Language-Hearing Association (ASHA) in June of 2011.
"We find the rationale for separating **social communication impairment** under-developed because language impairment includes pragmatics. Language impairment can affect the domains of vocabulary; grammar; narrative, expository and conversational discourse; and other pragmatic language abilities individually or in any combination. The need for a separate category is not clear. The utility of the diagnosis seems to rest in identifying children with pragmatic language impairments who either do not have the diagnosis of ASD or do not meet the criteria for diagnosis of ASD because this category excludes those diagnosed with ASD. If a child has this label owing to a problem with locating an appropriate professional to appropriately assess ASD, which would seem to prolong a misdiagnosis.
The Language impairment diagnosis specifically states impairment can occur in any realm; the fact that some have found individuals with intact abilities in other realms than pragmatics does not mean those children are not language impaired, which a separate diagnostic category clearly implies. This category appears to be based on a discrepancy between total language ability and social communication ability. This clinical profile is not sufficiently marked to warrant separating it from the primary diagnosis of language impairment."

B) The APA and the committee have stated that there is no intention of diagnosing fewer individuals with autism and have expressly stated that they intend for the new criteria to improve targeted

interventions. What evidence is there that this will happen and what does the APA plan to do if the new criteria show evidence of reducing services?

C) The criteria are vague on age of onset. Can age of onset be added as an aid to research stratification?

D) Can the APA address the question of the **need** for new criteria? Can they briefly explain the evidence that the new criteria will be more valid?

E) What happens if in the second round of field trials, we see many children being de-diagnosed? What is the plan for these children to get the help they need? For those de-diagnosed, would their intervention plans be any different than for someone who maintains their diagnosis?

F) Which diagnoses are intended to be allowed to be co-morbid with autism in the new criteria and which will be mutually exclusive?

G) How will the new severity scale be implemented? Is an individual given a single score, or are there separate domain scores given for speech/social vs. perseverative/sensory problems?

H) How is the committee defining early childhood? Will limited parent recall of early behaviors prevent the diagnosis of autism in older high-functioning individuals?

I) The DSM-5 website indicates that the field trials are done. Will there be any further field trials of the autism criteria given the concerns raised by Dr. Volkmar's study?

J) Does the new criteria allow for the continuation of services for an individual that has clearly met the diagnostic criteria in the past, but no longer does due to treatment? Many individuals have residual behaviors that require support even after they no longer meet the criteria for an autism diagnosis.

## Community-Perceived Improvements Over DSM-IVR

The following are things that make sense about the new criteria:

1. Taking into account that Asperger Syndrome and High-Functioning Autism have similar clinical presentations.

2. Moving autism spectrum disorders from Axis Two to Axis One. The disorders on Axis I are clearly more closely related to autism in the research literature and most, such as depression, ADHD and schizophrenia have been linked to environmental toxins and infections which is consistent with the autism research. It is unfortunate that co-morbid conditions in autism like gastrointestinal disorders, seizures and immune dysfunction are beyond the scope of the DSM-5.

3. Inclusion of sensory abnormalities and unusual sensory behaviors in the diagnosis of spectrum disorders since they are present in the vast majority of individuals on the spectrum.

The autism community requests that the APA's NDD Work Group meet with representatives from various groups to discuss our concerns and questions about the new diagnostic criteria for autism.

Respectfully submitted,

Katie Weisman

SafeMinds Board Secretary on behalf of the community coalition