DSM-5 – Concerns and Questions From the Autism Community

Follow Up with Dr. Susan Swedo - February 7, 2012

Following up to our two group calls and outreach to Dr. Swedo, Katie Weisman, Eric Uram, Sallie Bernard and Lyn Redwood had a phone conference with Dr. Swedo, the chair of the DSM-5 neurodevelopmental disorders work group, today. This is a summary of her preliminary answers to the questions we posed. She told us that the committee is dedicated to ensuring that all individuals with autism will be diagnosed under the new criteria and that they are open to discussions with the community about our concerns. The following were the questions from the group call on Monday, the 6th that we used as a basis for the agenda.

1) Do you have the full data from the Volkmar study - or do you know when it will be published? Which criteria was it based on? The study is due to be published in about 2 weeks. The NDD committee will be providing a formal commentary on it. The committee does not believe the study is accurate as it contrasts sharply with all the other data they have. Clinical diagnosis in 1993 was very different from clinical diagnosis today (2012). The criteria on the website are the current proposed criteria.

2) Is there consensus within the committee about how to deal with the concerns? The committee is open to discussing all issues with the community. They have spoken to Autism Speaks, ASAN and are willing to do public webinars to answer questions. The committee has been working on the revisions for over 6 years, but there is still time to address problems. The final criteria are due by the end of December 2012.

3) How are they planning to use the severity levels? Parents are concerned about insurance abuse and more restrictive placements. The severity levels are to be used for each domain (ie. each child will have a score for social/communication and a score for RRBs/sensory symptoms). The severity levels are to help with research stratification and service models. They specifically avoided using the words mild, moderate and severe. Severity levels are not to be used to prohibit services. There will be an explanatory text along with the chart to spell out explicitly that meeting the criteria for autism spectrum disorder, regardless of severity, entitles an individual to services appropriate to their needs. They will specify that ASD is a lifelong disorder. Ultimately, the goal is to diagnose as accurately as possible to ensure that services are individualized. In the past, the names autism, PDD-NOS and Asperger's were used as severity levels which was not the intention of DSM-IV. For some individuals, it was actually harder to meet the Asperger's diagnostic criteria than the criteria for PDD-NOS which led to poor categorization. Specifically, the Asperger's criteria included very specific social deficits that some individuals did not meet. In actual practice, different clinicians were throwing vastly different individuals into the PDD-NOS pot which made it too heterogeneous to be useful.

4) What other research is in the pipeline? Is it APA or AS? They have the preliminary results of the two large autism trials that are currently being prepared for publication. The results are reassuring regarding capturing all individuals on the spectrum. These studies were based on 5-

20 year-olds. They have videotaped all of the interviews and experts independent of the centers that did the studies will review the borderline cases to make sure that they were appropriately categorized. Dr. Swedo also mentioned that they will be providing case vignettes as part of the guidance for the criteria to give examples of how different individuals might present. She saw the Autism Speaks statement indicating that they will do more research, but doesn't have the details of what they are planning.

5) What are the reasons that changes from DSM-IV are necessary (committee's opinion)? When the committee looked at the evidence on the DSM-IV, they would have been very happy to say "Oh, it's doing a great job – let's not change it". Unfortunately, it has not done a good job. The research indicates that females, older adolescents and adults, minorities and very young children were being under-diagnosed using the DSM-IV criteria. Because autism was not allowed to be a co-morbid diagnosis under DSM-IV, some borderline kids with ADHD or bipolar were being shunted into those categories and not receiving services for their social needs. In the DSM-5, an individual will be allowed to be given dual diagnosis if they fit criteria for multiple disorders. The reverse was also true – some kids with ADHD and bipolar were ending up on the spectrum. One study showed the DSM-IV criteria had 75% sensitivity but only 50% specificity. The new criteria are testing out in the 90th %iles on both measures. Whenever there has been a debate about sensitivity vs. specificity in terms of symptoms, the committee has always chosen to err on the side of sensitivity (ie. including borderline cases being preferable to excluding cases).

When they looked at existing datasets (Simons, etc.) 53% of individuals were diagnosed PDD-NOS – that was supposed to have been a very small subset of the spectrum (single digits) which means that the old criteria weren't accurately describing core features autism. The goal of the new criteria is to allow for a full spectrum of individual characteristics.

6) How do they envision the new criteria improving diagnosis and treatment? Soundbites have been vague... Along with the new criteria, there will be approximately 10 specifiers which doctors will be asked to evaluate as part of the diagnosis. These are still being hammered out by the committee, but they will include age of onset, history of regression, any known genetic risk factors present (Fragile X, Rett's, etc), language functioning level (or Landau Kleffner), co-morbid diagnoses, medical problems (gastrointestinal, seizures, immune, etc) and adaptive functioning. Dr. Swedo said that they will try to get these up on the website shortly so that the public can see how they have set this up. These are not included in the diagnostic criteria because they do not apply to the entire spectrum and because the ASD symptoms are behavioral, but the committee hopes that these will be of great use to researchers in picking subsets of individuals and finally gaining traction on designing treatment studies. The DSM-5 will encourage dual diagnosis. For example, a child can be diagnosed with ADHD and ASD or a child can have a primary ASD diagnosis and a secondary diagnosis of Down Syndrome. The committee intends that there will be an infinite number of ways to be diagnosed if you are on the spectrum.

I asked about the lack of specific age of onset in the new criteria. Dr. Swedo said that they literally spent two full days on just that discussion and came to the conclusion that they had to just say "symptoms present in early childhood" because ASD is a neurodevelopmental diagnosis but that age 3 was too restrictive. For those rare cases of regression into autism at older ages due to encephalitis, etc. the plan is to diagnose them as major neurocognitive disorder with

secondary diagnosis of symptoms of autism spectrum disorder. The example that she gave is individuals who have a stroke in the basal ganglia who often present very similarly to individuals with ASD.

7) How are they going to ensure comparability for ongoing research? We discussed the problem of not being able to track numbers going forward. Dr. Swedo said that the CDC is already starting to look at how the old criteria will map onto the new criteria but that this is complicated by the fact that they pull from both school and medical records. She agreed that more work needs to be done in this area. They expect that there will be some shifting at the fringes (borderline individuals) but that it will likely go both ways (increase and decrease). They think it is likely that we will see some more adults being diagnosed. I suggested, and she agreed, that the committee should put together the existing data comparing the two sets of diagnostic criteria and put it up on the website along with an explanation of what they think the potential impacts of the new criteria will be.

8) Can regression be captured for both services and research? Addressed in number 6.

9) Several sources have talked about misdiagnosis (over-diagnosis)- we don't see this in our support groups - what evidence is this based on? Dr. Swedo said that the committee sees evidence of over-diagnosis in private practice and some clinics to get more school services. They are concerned that some children more properly diagnosed as LD are being diagnosed as ASD. I shared with her that the community does not agree with that perception and that we have evidence that school districts are guilty of categorizing kids as speech/language or other health impaired rather than ASD to avoid paying for intensive services. I also mentioned that it is typical for school districts to pay for the "independent evaluations" to test preschool children and that this creates a conflict of interest and potential for under-diagnosis. Because we didn't have our data to hand, we agreed to disagree for the moment, but it is likely worth continuing this discussion after putting together some concrete information.

10) How will the new criteria allow for kids who improve dramatically as they get older? They are strongly emphasizing in the explanatory text that an individual who has improved through maturity and/or treatment will not lose their diagnosis. Presence of ASD symptoms at any time in the developmental history is sufficient to make the diagnosis. The exact phrase is "if it has ever been true". So a person who is a functional adult can still be diagnosed on the spectrum if they have had more severe symptoms in the past that they do not currently exhibit. In the committee's opinion, many of the RRBs improve over time through training and improved stress management.

11) Is there a precedent in the DSM before for a disorder this controversial getting a major overhaul? Dr. Swedo was researching OCD when they made a huge change in the diagnostic criteria between DSM-III and DSM-IV and she saw firsthand how much it messed up the research and all the problems that it created. She is committed to making sure that those kind of problems are absolutely minimized with this change.

12) Could APA just train diagnosticians better rather than changing the criteria? What prevents the same kind of subjectivity problems with the new criteria compared to the old criteria? Unfortunately, not everyone who uses the DSM has research quality training in diagnosis. One of

the reasons that the committee felt strongly about overhauling the criteria is to make it as simple and non-subjective as possible. Dr. Swedo shared a note they found in one case file where the doctor had written, "This boy does not fit the criteria for autism, but I am diagnosing it anyway because I know he has it". They hope to eliminate situations where doctors feel the need to do this. Because DSM-5 will be used internationally by many different specialties, there is a limit to what they can do beyond making the criteria as sensitive and specific as possible and providing as much guidance as possible.

13) What can be done to help make a smooth transition for tracking incidence and prevalence? See number 7.

14) What can be done to ensure that the new severity codes don't just come to represent the old names? See number 3.

15) What about ICD-10 codes? There is coordination in the works. Two members of the ASD workgroup are also on the committee that is preparing a document for primary care physicians and insurance companies (for the entire DSM-5) that will spell out any changes in the billing codes and help with the transition. Dr. Swedo also shared that the ADOS and the ADI-R will be modified to match the new criteria and that these instruments will be available publically for the first time (i.e. free of charge) shortly after the publication of the DSM-5.

16) What is the rationale behind Social Communication Disorder? Some parents are afraid that individuals will be shunted into it. The committee felt that there was a need to create a diagnosis for individuals who have only social/communication symptoms but no RRB's to qualify for an ASD diagnosis. It isn't on the website yet, but ASD would have to be ruled out to get this diagnosis and there will be explicit instructions that borderline individuals should be given an ASD diagnosis (in other words, ASD will trump social communication disorder). ASHA has been involved in this discussion. I asked how you would tell the difference between a child with social communication disorder and co-morbid OCD from a child with ASD and Dr. Swedo said that would take a very talented diagnostician which is why ASD trumps social communication disorder.

Notes: We didn't discuss specifics of John's insurance documents because I hadn't had time to read all of them yet and Dr. Swedo hadn't either.

Respectfully submitted,

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SafeMinds Board Secretary

On behalf of the community coalition