



Information from the AMI Board of Directors On Significant Changes to the Diagnosis of Autism Spectrum Disorders

On December 1, 2012 the DSM 5 Committee voted to move forward with proposed changes to the DSM 5 (Diagnostic and Statistical Manual 5th Revision). These changes will take effect early in 2013. For the Autism community, this move is considered significant, and controversial.

What is the DSM?

The DSM is the manual for clinicians (psychologists, psychiatrists, and pediatricians or family doctors) who are diagnosing 'mental disorders'. Autism has been in the manual for decades, originally thought to be a childhood type of schizophrenia in DSM 1 and 2. Autism is now understood to be a neurodevelopmental disorder, and is categorized as such in more recent versions of the DSM. Most diagnosticians in North America use the criteria from the DSM to assess and diagnose people with an Autism Spectrum Disorder. Asperger Syndrome was only identified as a separate diagnosis about 20 years ago in the DSM 4.

The DSM is only revised and updated every few years, so revisions can carry significant implications for people affected by these diagnoses.

What has changed?

The most significant change for people with Asperger's Syndrome is that the diagnosis of "Asperger's Syndrome" has been eliminated in the new DSM 5. Instead of being a separate diagnosis, it has been rolled into a broader definition of the Autism Spectrum, along with PDD-NOS and Childhood Disintegrative Disorder. The differences between people on this very broad spectrum will now be delineated by numerical severity levels (ie. levels 1-3) and other specifiers.

In addition, the criteria for diagnosing Autism has been rewritten and reorganized. This is largely a structural change to the way the criteria are laid out in the manual, rather than a wholesale change in the criteria themselves. However, there are some changes to the way the criteria are assessed. In addition, a new disorder called Social Communication Disorder has been proposed, and has been placed inside the DSM but outside of the Autism Spectrum Disorder diagnosis. This disorder is diagnosed when repetitive and restricted interests/behaviours are not present in an individual.

How do these changes affect people with Asperger's Syndrome?

The short answer is, no one knows for certain. It will take time – potentially several years – before any real analysis on the effect of these changes can be done. We do know that the DSM 5 Committee has indicated that those who currently have an AS diagnosis will not 'lose' that diagnosis, and that they expect the vast majority of those who met the old criteria to meet the new criteria as well. They have stated that the new criteria will help





clinicians more accurately and consistently diagnose ASDs, and that they expect this will lead to more effective targeting of services.

AMI is hopeful that this assessment of the changes will prove true, and that services and supports will become available to a broader range of people than those who currently receive them.

Specific concerns expressed by people with AS, families of children with AS, and professionals include:

- Fears that some clinicians may misdiagnose Asperger's as Social Communication Disorder, which (as of the last draft of the DSM 5 that was available to the public) is not part of the Autism Spectrum and will likely not qualify for the same level of supports and services.
- A belief that people with AS benefit from a separation from the Autism Spectrum in terms of specific supports and a more accurate understanding of the way their challenges may differ from others on the Spectrum. Some experts, including Dr. Tony Attwood who spoke at AMI's Conference last year, have indicated their displeasure with the change on a number of levels. Dr. Attwood indicated that many clinicians who disagree with the DSM 5 changes, may choose to continue using the Asperger's diagnostic criteria long after it is removed from the manual.
- A sense of confusion about why and how the changes are being made, and why there seems to be disagreement within the mental health community about the changes. The head of the previous DSM 4 Committee has publicly expressed significant disagreement with the way the DSM 5 Committee has changed the diagnostic criteria, going so far as to call it a "disaster". Some studies have shown the new criteria will result in a significant decrease in ASD diagnoses. However, other studies have shown there will be no significant change. Adding fuel to this fire were comments made by the current head of the DSM 5 Committee that indicated the present level of autism diagnosis was a "cost issue", leading many to infer that the diagnostic changes were politically motivated. The DSM 5 Committee later attempted to clarify the statement and indicated this was not their intended message.
- People with AS are somewhat divided over the change. Some feel the change is positive because it eliminates artificial divisions between people who share the same overall set of needs – they feel it will help to unite the Autistic community. Others are concerned about losing their sense of identity and community. They also worry about whether they would still qualify for a diagnosis under the new criteria, and whether the change will affect services and supports for those deemed to have a lower severity level.
- Families of children with AS have expressed fears that the numerical level of severity assigned by the new DSM 5 could be used as a justification for reducing the level of support provided by governments (for example, the child's severity level is assessed under the new DSM 5 as level 1, but the level of support needed in school is really a level 3).

What is AMI doing in response to these changes?

Like most observers, AMI is unsure of how the new DSM 5 revisions will affect people on the Autism Spectrum. What we know for certain is this: the needs of the autistic community – whether they are labeled with names like Asperger's Syndrome or rated on a numerical scale, have not changed. Autistic people across the spectrum continue to require diligent efforts to promote awareness and acceptance of Autistic differences, and advocacy





for their civil rights in terms of education, employment, and housing. People with Asperger's Syndrome, regardless of how they are labeled, continue to need a sense of community and empowerment. These are the areas that AMI will continue to focus on as we move through this time of diagnostic change.

At the same time as the elimination of the term 'Asperger's Syndrome' from the DSM 5, the needs of the Asperger community in Manitoba are growing. Given these challenges, AMI's Board of Directors has decided now is the time to develop a strong vision and a strategic plan so our organization can keep pace, stay relevant, and increase our effectiveness. As such, we are in the process of hiring a professional strategic planner to assist our organization in identifying the steps we must take to meet the challenges ahead. AMI has received grant funding to assist specifically with strategic planning for the organization. We will be consulting with members, and the community at large during this two-year process. We look forward to hearing your thoughts and ideas. In the meantime, please check the AMI website for updates.

