Editorial: DSM-5 and autism spectrum disorders – two decades of perspectives from the JCPP

The newest revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the DSM-5, will be published in less than a year and anticipation is high. The changes to the Pervasive Developmental Disorders (PDD) criteria are likely to be among the most extensive of the revisions to the manual, as well as among the most contested. Worries about loss of diagnosis and service eligibility are common, especially among parents. Some have felt that the proposed changes are confusing, even capricious, or poorly justified (e.g., Ghaziuddin, 2011). The rationale for combining the individual PDD diagnoses into a single category of Autism Spectrum Disorder (ASD), when we hear so much about the heterogeneity of autism, has been questioned. Rather than referring to “autism” as a unitary condition, many researchers now refer to “autisms” in the plural (Boucher, 2011) so the DSM-5 proposal to lump rather than split can seem perplexing.

But in fact the proposed changes have a clear empirical basis, resulting from extensive literature reviews and secondary data analyses undertaken by the DSM working groups. JCPP, with its 50-plus year history of tracking changes in child and adolescent psychiatry and psychology (Berger & Hersov, 2009; Rutter, 1999), has published a number of papers of direct relevance to the DSM revisions. A comprehensive search of the Wiley-Blackwell database turned up 535 papers on PDD/ASD from the period between the first edition of JCPP in 1961 to today. Of these, 158 papers were specifically on diagnostic or classification issues. It is likely that the work of contributors to JCPP was in the minds of the Neurodevelopmental Disorders working group as the DSM-5 criteria were developed. In this Virtual Issue, I have selected a dozen papers from the Journal that trace the changing conceptualizations of the PDDs over the last two decades, highlighting the evolution of the Asperger Syndrome classification, and raising several of the diagnostic issues that were ultimately addressed by the proposed DSM-5 criteria. As I hope this editorial will make clear, the changes are anything but capricious or arbitrary. It was not difficult to find a dozen papers from JCPP alone that were supportive of the new DSM criteria. Quite the reverse, it was challenging to find those that supported a “DSM-as-usual” approach.

To ground this within the appropriate context, I begin with a list (not exhaustive) of the proposed changes to the criteria:

- **Change in name from Pervasive Developmental Disorder to Autism Spectrum Disorder**
- **Creation of a single diagnosis, Autism Spectrum Disorder, rather than a category containing five individual diagnoses**
  - Autistic Disorder, Asperger Disorder, Childhood Disintegrative Disorder, and PDD Not Otherwise Specified are subsumed under one label: Autism Spectrum Disorder
  - Rett Disorder is eliminated now that its molecular basis is known (the DSM focuses on disorders without a molecular or biological test, that must instead be defined behaviorally)
- **Three symptom domains (social, communication, and repetitive behavior) become two (social-communication and repetitive behaviors)**
- **Number of symptoms streamlined from 12 to 7 by merging criteria that were overlapping or described similar behaviors (e.g., limited social-emotional reciprocity, limited sharing of interests, and reduced back-and-forth conversation are combined into one reciprocity symptom) and eliminating symptoms that are not specific to ASD (e.g., delayed development of language)**
- **Provision of “severity” criteria to better capture the spectrum nature of the disorder and the inter-individual variations that differ less in quality than in quantity (e.g., intensity and duration of symptoms, degree of impairment, and distress they cause)**
- **Development of a new Social Communication Disorder category (outside the autism spectrum) to provide diagnostic coverage to children who present with only social-communication problems and do not display the repetitive and stereotyped behaviors of ASD**

Now let us turn to the individual papers featured in this Virtual Issue. Each represents a point of view in our evolving understanding of the classification of ASDs and each has contributed significantly to the conceptual development of the proposed DSM-5 criteria.

As described in Cantwell’s (1996) incisive review of classification issues, each DSM revision strives to be more accurate than its predecessors, with a strong emphasis on increasing reliability across clinicians, investigators, institutions, and even nations. The DSM had hoped to “carve nature at its joints” by defining a finite set of non-overlapping
categories. Over time, however, it has become clear that the boundaries between DSM categories are not nearly as tidy as envisioned and hoped; this was evident even 15 years ago, as clearly described by Cantwell (1996). There is now extensive evidence that DSM diagnoses co-occur at very high rates in psychiatric patients, a phenomenon that was presciently described in another paper included in this Virtual Issue, a seminal contribution by Caron and Rutter (1991) on comorbidity in child psychopathology. This widely cited paper, which pre-dated DSM-IV by several years, explains how comorbidity may arise in a number of ways that are artifactual, such as artificial subdivision of syndromes, overlapping criteria between disorders, and one disorder being an early manifestation of another disorder. The clear conclusion of this paper is that published rates of comorbidity between “supposedly separate” DSM disorders are inflated and misleading. These two papers are well worth re-reading to remind us of some of the reasons, identified decades ago, that the DSM revisions were undertaken in the first place.

The Virtual Issue also includes three short papers from a former section of the Journal, called Debate and Argument, devoted to public scientific deliberation on topical issues. This particular series focused on the question, “Is Autism a Pervasive Developmental Disorder?” The three papers provide both a justification for the PDD label (Volkmar & Cohen, 1991) and a vivid debate of the term’s utility (Gillberg, 1991). Happe and Frith (1991), weighing in on the dissenting side of the debate, contended that the label is both misleading, in obscuring the nature of the specificity of the deficits, and unhelpful, in obscuring the relationship with autism. They (again very presciently) suggested that the terminology “autism spectrum disorders” be used instead. While these words of wisdom were ahead of their time and were not applied to DSM-IV, the term rapidly came into wide usage by professionals and the public alike. The term will now be explicitly adopted by DSM-5, over twenty years later.

DSM-IV was published in 1994, including, for the first time, the diagnosis of Asperger Disorder. Articles on this topic quickly began to appear in the JCPP and several of them are included in the Virtual Issue, illustrating different points along a chronological timeline of our evolving insight into this clinical presentation. An influential paper by Klin and colleagues (1995) ushered in this new era, laying out a model for how to study whether two purported subtypes were distinguishable. Klin et al.’s results suggested that Asperger Syndrome and autism had different neuropsychological profiles, an exciting finding at the time that stimulated a great deal of later work by other research teams. Shortly thereafter, however, questions were raised about the validity of the DSM-IV Asperger criteria by Miller and Ozonoff (1997), who applied DSM-IV criteria to the four cases described in Asperger’s original paper (Asperger, 1944). They found that all four individuals met DSM-IV criteria for Autistic Disorder (and none met Asperger criteria), largely due to the so-called “precedence rule” in which Asperger Disorder is ruled out if criteria for Autistic Disorder are met. Over the next several years, studies of independent samples demonstrated that most children with an Asperger-like presentation or a non-DSM Asperger classification actually met DSM-IV criteria for Autistic Disorder. One of these papers is included in the Virtual Issue. Gilchrist and colleagues (2001) found that 80% of their Asperger group (defined on the basis of lack of delay of speech development) met DSM-IV Autistic Disorder criteria. They also demonstrated that their high-functioning autism and Asperger Syndrome groups performed very similarly on most measures, although they were easily distinguishable from a contrast group of children with Conduct Disorder. Reviewing a decade of empirical work and dozens of papers on the discriminant validity of Asperger syndrome and autism, two further papers in this issue (Frith, 2004; Macintosh & Dissanayake, 2004) conclude that there is insufficient evidence to consider the two subtypes as distinct conditions. Thus, although the subsuming of Asperger Disorder within an Autism Spectrum Disorder diagnosis has been controversial, these papers collectively illustrate the empirical basis upon which the decision was made and hopefully serve to dispel some of the mystery surrounding the rationale. Important questions remain regarding how the proposed criteria will affect rates of diagnosis at the higher functioning end of the spectrum that must await answers from publication of the highly anticipated field trials later this year. While it might seem paradoxical at first glance, the “lumping” approach taken by the new criteria may address inequities that exist in much of the United States and many parts of the world, where individuals with Asperger Disorder (and often PDDNOS) are ineligible for government-based services. From my perspective as a practicing clinician, if these conditions cannot be validly distinguished empirically, then it is logically questionable (as well as patently unfair) to deny services to some while providing a full range of interventions to others.

Coming at the question from a different angle is a paper by Prior and colleagues (1998) that used a cluster analysis approach to look for subtypes within the autism spectrum. While three clusters were identified, the nature of the differences among them was driven more by quantitative than qualitative variation. That is, the three identified clusters differed in their level of impairment, severity of symptoms, and level of cognitive function, not in the nature of their symptoms. These results are directly supportive of the DSM-5 move toward one autism spectrum diagnosis that provides dimensional ratings to capture disease severity and index the level of support needed for optimal functioning.
A new diagnosis, called Social Communication Disorder, is also being proposed by the DSM-5 Neurodevelopmental Disorders Working Group. It is intended to provide a label for children with significant social and communication difficulties who do not exhibit the repetitive behaviors of ASD. This may provide a new diagnostic “home” for those children classified with DSM-IV PDDNOS who do not display significant stereotyped behaviors and thus would not meet DSM-5 ASD criteria. It will also help identify a group of children not recognized in the DSM-IV, those with significant pragmatic language disorders, who often show co-occurring social delays. An important paper by Bishop and Norbury (2002) concludes the Virtual Issue. It explores the relationship between ASD and pragmatic language impairment (PLI), finding both overlap and distinctions. While about a quarter of the PLI sample met criteria for ASD, most did not. One clear differentiator of the non-ASD PLI group and the ASD group was the presence of stereotyped or repetitive behaviors. The study did not support the assumption made by some that “all children with PLI are misdiagnosed cases of autistic disorder” (p. 926). Thus, having an additional classification to identify this group and inform their treatment needs may be helpful. Several critical questions have been raised, however, about the validity of the new Social Communication Disorder diagnosis (Skuse, 2012; Tanguay, 2011): essentially, what is the evidence that this condition is any different (e.g., etiology, symptom profile, management) from ASD? I would second these concerns, which are highly reminiscent of those posed about Asperger Disorder when it was first included in DSM-IV. It seems logically and internally inconsistent for the DSM-5, which explicitly takes a dimensional approach, to introduce a separate category that is so qualitatively similar to another condition. Let’s not take two steps forward and one step back.

It was a challenge to limit the selection of papers in this Virtual Issue to only 12 and a number of relevant contributions could not be included. I chose to concentrate on papers published more than 5 years ago (and many a decade or two ago) that may, at this point in time, be out of sight and out of mind, but are well worth revisiting as we move into the new era of DSM-5. As a collection, these papers provide a window into the empirical and conceptual forces that molded the revision, what lessons were learned, and what issues remain yet to be resolved. On balance, contributions from the JCPP over the last two decades suggest that we are indeed moving forward.

Sally Ozonoff
Joint Editor, JCPP

References

[“The 12 articles marked with an asterisk are available for immediate access at http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1469-7610/homepage/autism.htm]


