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Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV?

Lorna Wing^a, Judith Gould^a, Christopher Gillberg^{b,*}

^a The NAS Lorna Wing Centre for Autism, Elliot House, 113 Masons Hill, Bromley, Kent BR2 9HT, UK

^b University of Gothenburg, The Gillberg Neuropsychiatry Centre, Kungsgatan 12, 411 19 Gothenburg, Sweden

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ABSTRACT

The DSM-V-committee has recently published proposed diagnostic criteria for autism spectrum disorders. We examine these criteria in some detail. We believe that the DSM-committee has overlooked a number of important issues, including social imagination, diagnosis in infancy and adulthood, and the possibility that girls and women with autism may continue to go unrecognised or misdiagnosed under the new manual. We conclude that a number of changes need to be made in order that the DSM-V-criteria might be used reliably and validly in clinical practice and research.

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1. Introduction

The DSM-V committee has published proposed diagnostic criteria for autism (at DSM-V.org) and invited comments that will (hopefully) be taken into account before the definitive manual is published (scheduled for 2013). Our comments here, which point out problems in the DSM-IV and the draft DSM-V, are confined to the section on Pervasive Developmental Disorders (Autism Spectrum Disorders).

2. The 'triad of impairments'

The DSM-IV refers to the basic triad problems underlying autism as impaired social interaction, impaired social communication and restricted behaviour pattern. The draft of the DSM-V reduces this to two – impaired social interaction and communication (now regarded as one conjoined problem) and restricted behaviour.

However, two of us (Gould, 1982; Wing, 1981a; Wing & Gould, 1979) were the first to suggest a 'triad' of three basic impairments in autism, and these are:

i. Impairment of social interaction

This refers to the marked reduction of non-verbal signs of interest in and pleasure from being with another person – making eye contact, initiating and responding to smiling, initiating and responding to affectionate physical contact such as hugging, kissing, greeting and waving good-bye. The beginning of social interaction can be seen in sociable children from birth, long before language develops, and can be seen in sociable, severely disabled children and adults who have no language, even in those who are non-mobile.

ii. Impairment of social communication

* Corresponding author. Tel.: +46 31 342 59 70; fax: +46 31 342 59 79.

E-mail address: christopher.gillberg@pediat.gu.se (C. Gillberg).

This refers to the decreased ability to “converse” non-verbally and verbally with another person, sharing ideas and interests or to negotiate in a positive friendly way. The earliest manifestation of social communication in typically developing children is joint referencing to share an interest, seen in the last part of the first year. People in the autism spectrum also often have problems understanding what is said to them, tending to interpret things literally.

iii. Impairment of social imagination

This is the decreased capacity to think about and predict the consequences of one's own actions for oneself and for other people. In typical development it does not develop until after 3 years of age. Impairment of this ability is perhaps the most important and disabling of all the consequences of having an autism spectrum condition of any kind. We believe that it should not have been ignored by the designers of the DSM-IV or the DSM-V (and ICD-10). The DSM instead introduced repetitive behaviour patterns, not the impaired social imagination, as the last leg of the triad.

Although the various aspects of the Wing and Gould Triad can be described separately, they are closely related. We now consider that the fundamental problems underlying all autistic conditions and the Triad of Impairments, is absence or impairment of the social instinct present from birth in the great majority of cases. However, [Happé and Ronald \(2009\)](#) consider that the Triad is ‘fractionable’ because different genes are responsible for the different elements. These researchers, unlike us, considered the repetitive behaviours to be one of the core elements of the triad. We hope that research work into the behavioural neurology of the social instinct will be carried out in the near future. Results from recent research in this area suggest that a combination of specific cognitive skills underlies the social instinct ([Ecker et al., 2010](#); [Yoshida et al., 2010](#)).

The problems of social interaction seen in the autism spectrum are specific to these conditions and must be present for a diagnosis to be made, but the underlying nature of the social instinct has yet to be investigated. The absence or impairment of the social instinct must be differentiated from the abnormalities of social behaviour found in anti-social psychopathy. As pointed out by one of us ([Gillberg, 1992](#)) the anti-social psychopath usually has a full understanding of what goes on in his/her own and other people's minds. However, he/she uses this knowledge to manipulate other people to achieve his/her own ends. He/she has empathy but no sympathy. A person with an autism spectrum condition lacks empathy but may have sympathy in situations where they can perceive another's distress. When they do understand, they respond. Some of those of higher ability are very sad to read of the hardships of children in, for example, Africa, but are unable to understand the signs of emotional upset in their parents or siblings – which may be in response to the behaviour of the person with an autism spectrum condition. However, [Rogers, Viding, Blair, Frith, and Happé \(2006\)](#) found a small number of boys with ASD, also had psychopathic tendencies. The authors considered that this was a ‘double hit’ – the psychopathic behaviour was an additional problem, and was not due to the autism spectrum disorder. Boys and girls with pathological demand avoidance ([Newson, Le Marechal, & David, 2003](#)) may also have such a ‘double hit’.

3. Responses to sensory input

Abnormalities in this area – reduced and enhanced sensitivity – are very common in those with autism spectrum conditions and some people in the field have argued that they should be included as a diagnostic criterion. The problem is that odd responses to sensory input are not confined to autistic conditions and are probably not seen in absolutely all people with these conditions.

However, [Billstedt, Gillberg, and Gillberg \(2007\)](#) in their follow-up study, found that the problems of reactions to sensory input was the most consistently impairing symptom present from early childhood, and more than 95% still had such problems around age 30 years of age. This was slightly more than the proportion (exactly 95%), who still had social interaction impairment at around 30 years of age. This had been present in 100% in childhood. [Leekam, Nieto, Libby, Wing, and Gould \(2007\)](#) also found that 90% of the children with autism spectrum disorders that they studied had sensory problems, often in two or three sensory domains, regardless of age and IQ. Also, we have found unusual reactions to auditory stimulation to be the single most typical feature of very young children with autism, distinguishing them from other children with developmental delay ([Dahlgren & Gillberg, 1989](#); [Gillberg et al., 1990](#)).

The draft of the DSM-V does not include problems of responses to sensory inputs as an essential feature of autism. It suggests the inclusion of ‘stereotyped unusual sensory behaviour’ as one type of ‘restricted repetitive patterns of behaviour’ (for example, fascination with flickering lights). This does not solve the problem of whether sensory abnormalities should be included as an essential feature.

The difficulty that arises from extending the essential criteria for autism spectrum conditions is that the more essential criteria are required for a diagnosis, the more individuals will be excluded. One possible solution is to include a note in the DSM-V to say that if sensory impairments of the relevant kind are present, careful attention must be given to the possibility that these are part of an autism spectrum condition.

4. Definitions of clinical criteria

The DSM and ICD systems are intended to be helpful for clinicians. DSM-IV and DSM-IV-TR listed different sub-groups and laid down criteria for each. The problem was that the main criteria and the sub-criteria were expressed in general terms. Some did have added qualifications that were of some help but others had none. (One example of the latter is Criterion A(i)(d) – Lack of social or emotional reciprocity.)

For each diagnostic criterion we have listed items of behaviour from the Diagnostic Interview for Social and Communication Disorders (DISCO – see below) (Leekam, Libby, Wing, Gould, & Taylor, 2002; Nygren et al., 2009; Wing, Leekam, Libby, Gould, & Larcombe, 2002) describing specific behaviours, which if present, are considered evidence for the ICD-10 and the DSM-IV diagnostic criterion concerned. The number of items for the criteria varied from 2 to 16. For example, the criterion ‘Lack of social and emotional reciprocity’, which had no qualifications in DSM-IV and DSM-IV-TR, was related to 16 DISCO items.

The draft DSM-V lists three main criteria. The first two each have three sub-criteria. For Criterion 1 (social and communication problems) all three sub-criteria must be present. For Criterion 2 (repetitive behaviour) two of the three sub-criteria must be present. In the draft, the sub-criteria are not defined in terms of objective observable behaviour. Perhaps this will be corrected in later versions but, as it stands, the criteria are even less defined than they were in DSM-IV. Only professionals with very considerable experience in the field of autism could use the criteria appropriately.

As mentioned above, the DSM-V criteria (like DSM-IV) do not mention the lack of imagination leading to the inability to foresee the consequences of one’s actions for oneself or for others. This is perhaps the problem that leads to the most severe social difficulties for the person with autism spectrum conditions and those involved with him/her. This should certainly be included in DSM-V.

The third criterion in the DSM-V draft is ‘Symptoms present in early childhood (but may not become fully manifest until social demands exceed limited capacities)’.

The problems of social interaction are present from birth in individuals with any autism spectrum disorder (unless a condition such as encephalitis or a brain injury at some time after birth leads to autistic behaviour). However it needs an experienced observer (or a very observant parent) to recognise the earliest signs in infants. (These signs are not described in DSM-IV or draft DSM-V, though they should be – see below.) The problem in clinical work is that individuals presenting for the first time in later childhood, adolescence or adult life may not have anyone who knew them in early childhood to give an accurate history, or, in other cases, the informant is unable, for various reasons, to give a clear and accurate picture of the early years. If the DSM-V is accepted in its present form, individuals in this situation may be denied appropriate help.

The only way out of this dilemma is for professionals in the field to recognise the symptoms and signs of autism spectrum conditions as they present in adult life, to recommend ways of helping that would be appropriate for an autism spectrum condition of the type shown by the individual, and to carefully observe the results.

We conclude that the third criterion should be removed, or discussed in appropriate detail, so that adults without informants can be diagnosed. It could be reformulated as “Problems of social interaction are present from infancy but may not become fully manifest or obvious to lay people until social demands clearly exceed limited capacities (which may not happen until adolescence or later.)” see Kopp (2010) for more information about girls whose autism diagnoses are often delayed into adolescence or missed completely for just these reasons.

4.1. *Diagnosis in infancy*

There is now general agreement that early diagnosis of autism (including in infancy in severe cases) is required for early intervention and better outcome (Myers & Johnson, 2007). Thus, it is essential that diagnostic criteria are tailored to meet the needs of diagnosis of autism in under-three-year-olds. Looking at the proposed DSM-V-criteria, it is easy to see that many children, even some with classic Kanner autism, might be missed if the algorithm is strictly applied. First of all, there is a requirement that both nonverbal and verbal communication be impaired. The verbal bit may be impossible to evaluate in a very young child. Second, “peer relationships” in a two-year-old may be very difficult to assess unless the child is already in daycare or has access to peer interaction on a regular basis. Finally, routines and rituals, and, particularly, restricted, fixated interests may not be obvious in a very young child (whose autistic behaviours may well be “obscured”, for instance, by commonly associated hyperactivity at the time of assessment). All of these caveats need to be highlighted in some way in the final DSM-V-text on autism spectrum disorder, either in the introduction, or, better still, in direct relationship to the presentation of each specific subcriterion.

Signs suggesting an autism spectrum disorder occur in the first year of life (Barbaro & Dissamayake, 2009; Yirmiya & Charman, 2010) and include those listed below. These signs occur at different stages in the first year. Even if the child does have an autism spectrum condition, he or she will usually not show them all, but is likely to show several. In order for early diagnosis of an autism spectrum condition to be made correctly as often as possible, the relevant criteria should be included in DSM-V (Barbaro & Dissamayake, 2009). The following is a summary of the problems. The DSM-V should include them in appropriate detail.

- (a) Odd patterns of behaviour – for example, excessive crying and screaming, or unusually good, quiet and passive.
- (b) Lack or dislike of social interaction – for example, does not look into other people’s eyes, does not lift arms to be picked up, does not point to things to share the interest.
- (c) Problems of development of pre-speech communication – for example, lack of response when spoken to, lack of response to own name, lack of babbling.

(d) Interests are limited and specific – for example, fascinated by lights and certain sounds, over- or underreactivity to visual or auditory stimuli.

5. Problems of diagnosing autism spectrum conditions in girls and women

With increasing experience of autism over the years it has become evident to those in the field that many girls and women with autism spectrum conditions have a clinical picture that differs in some ways from those in boys and men (Kopp & Gillberg, 1992; Kopp, Kelly, & Gillberg, 2010), making diagnosis more difficult in certain cases. This should be discussed in the DSM-V.

6. Removal of subgroups

This is an important and controversial aspect of the draft DSM-V (Ghaziuddin, 2010).

We, in our many years of clinical diagnostic work, have observed how extremely difficult, even impossible, it is to define boundaries of different sub-groups among children and adults with autism spectrum conditions (that is those who have an absence or impairment of the social instinct). While there is a very great difference in the clinical picture of one child with classic Kanner syndrome and learning disability compared with another with very high ability in their area of special interest who fits the criteria for Asperger's syndrome, there are large numbers of individuals who have a mixture of features of both conditions. Furthermore, changes occur over the years and a child who was appropriately diagnosed with Kanner's autism can grow into an adolescent who fits Asperger's descriptions. Other sub-groups have been suggested in addition to those in the DSM-IV (and ICD-10). The same problem of defining the boundaries exists for all of these. Likewise there is difficulty in defining the boundaries between autism and the enormous range of "typical" development especially in individuals who have very high skills in specific areas.

It was observing these clinical facts that made us suggest that the concept of a spectrum of autism fitted the facts better than any of the suggested sub-groups (Gillberg, 1990; Wing, 1998; Wing & Gould, 1979). In fact, the evidence now indicates that we are dealing with several different "autism spectra", and the most appropriate term for the whole group of disorders discussed here might be "the autisms" (Coleman & Gillberg, in press).

Our view on this has not changed, but we do recognise the problems that arise if the sub-group labels are no longer used. Many people with the diagnosis of Asperger's syndrome object very strongly to the possible loss of their label, which they much prefer to that of autism spectrum disorder or just "autism". They also worry that their current diagnosis of Asperger syndrome will make them ineligible for medical or social services if DSM-V comes into use in the future.

The sensible solution would be to retain in the DSM-V a list of sub-group names that have been used, any of which will place the recipient within the autism spectrum. No specific diagnostic criteria need be attached, though it would be helpful to have a brief description attached to Asperger's disorder, and childhood disintegrative disorder. For example:

Asperger's disorder refers to individuals who have impairment of social interaction, social communication and social imagination but who have an average or high IQ, a wide vocabulary and good grammar but who use speech in non-social ways, e.g. to talk only about their special interests. In some individuals, the picture in the early years was like that of autistic disorder, but changes occurred with increasing age. The diagnosis of Asperger's syndrome must be made on the current picture and not on the past, because it is the current picture that determines the individual's needs.

Childhood disintegrative disorder refers to individuals whose development was typical (normal) up to 2 years or more, but who then became impaired in social interaction, social communication and social imagination. When making this diagnosis it is essential to obtain full details of behaviour in the years before the impairments became obvious. Some infants have these impairments from birth but in a rather subtle form and their parents are unaware of their significance. The relevant behaviour then becomes more marked after 2 years of age and, if a detailed history is not taken by an experienced professional, it is assumed that the problems have only just started. A diagnosis of childhood disintegrative disorder is not appropriate in such cases.

7. Assessment of individual needs

The argument whether or not to retain sub-groups leads on to the subject of how to assess the needs of individuals. The introductions to both DSM-IV and DSM-IV-TR point out that, to quote, "the diagnostic categories, criteria and textual description are meant to be employed by individuals with appropriate clinical training and experience in diagnosis. It is important that DSM-IV not be applied mechanically by untrained individuals. The specific diagnostic criteria provided in DSM-IV are meant to serve as guidelines to be informed by clinical judgement and are not meant to be used in a cookbook fashion".

The draft DSM-V suggests a dimensional approach but this appears to be confined to the domains of social interaction, communication and repetitive behaviour. However, in the introduction to DSM-IV-TR, under the heading Use of DSM-IV in Treatment Planning it is emphasised that "to formulate an adequate treatment plan, the clinician will invariably require considerable additional information about the person being evaluated beyond that required to make a DSM-IV diagnosis".

In the DISCO (Nygren et al., 2009; Wing et al., 2002) we include the domains of receptive and expressive language, visuo-spatial skills, gross and fine motor skills, reactions to sensory input as well as social skills, repetitive activities and pattern of behaviour. For each individual, the developmental history and the current level of attainment in these areas are recorded and a detailed profile obtained. This information is much more helpful for defining the needs of each individual than is giving them a sub-group label.

DSM-V could include a list of the domains that are relevant to the needs of individuals along with the basic criteria for autism. It would be helpful to add a comment about the fact that there is so often a mismatch between verbal and non-verbal skills, which can be hidden if only the overall cognitive level is reported.

8. Association of autism spectrum conditions with other disorders

DSM-IV and DSM-IV TR both state that pervasive developmental disorders (autism spectrum conditions) cannot be diagnosed together with some other conditions, including ADHD, stereotyped movement disorder and psychiatric conditions such as schizophrenia and anxiety states. Clinical work demonstrates that autism can be present with any other developmental, psychological or psychiatric condition. As mentioned above, the clinical picture in an individual can change over the years, for example from classic Kanner's syndrome to Asperger's syndrome.

It is important for understanding the needs of each individual to name the conditions he/she has currently, including any developmental, psychological or psychiatric conditions in addition to any autism spectrum condition (Wing, 1998; Wing, 2005). It is to be hoped that DSM-V will follow this pattern.

9. Final comments

One criticism of DSM-IV that has been expressed is that it is responsible for widening of the criteria for autism spectrum conditions, thus leading to the recent marked increase in published prevalence rates. Some critics fear that DSM-V will accentuate this trend.

In actual fact widening of the criteria for autistic conditions has followed from increase in knowledge of the work of Hans Asperger and the belief that his syndrome is part of the autism spectrum. The DSM-IV and DSM-V draft have followed, not started, (Wing, 1981b) this clinical trend.

The introductions to DSM-IV and DSM-IV-TR contain some eminently sensible comments on the limitations of such a system of classification. They emphasise the necessity for those using the DSM system to have wide clinical experience so they can understand the limitations as well as the usefulness of such a widely used system.

The comments in the introductions on the use of DSM-IV and DSM-IV-TR in the forensic field and on ethnic and cultural considerations are interesting and highly relevant.

It is to be hoped that the introduction to DSM-V will cover these and other relevant areas in the same interesting and useful way. It would be helpful if some way could be found to emphasise the importance of reading and following the ideas in the introduction. The sad truth is that, with DSM-IV and DSM-IV-TR, many professionals use the systems without having studied (or have forgotten) the introductions.

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