A ROSE BY ANY OTHER NAME…

The Appropriate Use of Diagnostic Terminology in Autism

Almost every family who has had a child on the autism spectrum has gone through the bewildering experience of trying to understand where their child fits in, according to the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition, commonly known as the DSM-IV. It is on the basis of interpretations of the DSM-IV that eligibility to services from the Provincial Ministries is often determined. Dr. Vikram Dua, a Child and Adolescent Psychiatrist based in Vancouver, argues the appropriateness of tying funding and service provision solely to a diagnosis through DSM-IV.

In the last two decades there has been an explosion of research on autism-like disorders. Mainstream medical nomenclature (best exemplified by the *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition; DSM-IV*) has introduced the umbrella term *Pervasive Developmental Disorders* (*PDD*) under which autism has been splintered into subtypes, including Autistic Disorder, Asperger's syndrome, and *PDD - Not Otherwise Specified* (*PDD-NOS*). Although these developments have arguably enhanced the sophistication and precision of research and treatment of autism, the proposed boundaries between the subtypes remains tentative and controversial. Many experts prefer a dimensional diagnostic label such as Autism Spectrum Disorder, arguing that the science does not yet reliably support subtle distinctions.

Given the lack of scientific consensus, it is not surprising that studies have found wide variability in how autism is diagnosed in the community. Predictably, these inconsistencies are disorienting for both families and administrators who determine eligibility for services. In contrast to the clinical recognition of a wider range of autism variants, third-party administrators often insist on a specific subtype diagnosis (such as Autistic Disorder), before granting intervention services. Precise labels, although uncertain and incidental, can have major ramifications on what treatment and support services patients receive.

I believe that part of this unfortunate situation has resulted from a misunderstanding of how diagnostic classification (or nosology) is conceived. Far too often there is a wholesale misappropriation of systems such as *DSM-IV* into settings where it has no legitimacy. My purpose in this piece is to shed some light on the basis of psychiatric nosology, and to clarify its limitations.

The word *autism* was introduced to psychiatry in 1930 by Eugene Bleuler in reference to the social withdrawal of individuals with schizophrenia. In 1943 Leo Kanner proposed the term *early infantile autism* for a discrete childhood disorder with profound social withdrawal and cognitive impairment. However, for many years the distinctions between autism and schizophrenia remained unresolved. The nature of atypical autistic-like conditions was equally elusive. Children with these latter disorders were labeled with a variety of diagnoses that were essentially backward extensions of diagnoses used in adult psychiatry.

In the early 1980's genetic research demonstrated the associations between autism variants. Fostered by the re-discovery of the work of Hans Asperger (a contemporary of Kanner), the clinical conception of autism and related disorders shifted. Asperger had described a group of children very similar to Kanner's patients, but who had stronger language and intellectual abilities. Asperger's writings validated what many researchers were already thinking - that autism is a heterogeneous disorder with varying degrees of

impairment. In response to the developments in the field of autism, *DSM-IV* (released in 1994) for the first time proposed subtypes of autism, each with its own "diagnostic criteria".

Since *DSM-I* (published in 1952), there have been four substantial revisions of the manual, with each edition attempting to keep abreast with evolving psychiatric knowledge. Categories of mental disorders are created by a *consensus* of experts charged with the task. Specific diagnostic criteria for a disorder are frequently not validated and often represent the best approximation of widely divergent points of view. As clinicians we accept this compromise in order to promote communication between professionals. However, we also recognize the flux in the field. As stated in the most recent practice parameters of the American Academy of Child and Adolescent Psychiatry, it is incumbent on the clinician to not only observe *DSM* criteria, but also be attentive to "the emerging literature on this topic."

There is a frequent and erroneous assumption that *DSM* subtypes are arranged in a hierarchical fashion. For example, it is often assumed that Asperger's syndrome and *PDD-NOS* represent milder or sub-threshold diagnoses of autism. Although this may be true in some cases, it is by no means a rule. DSM diagnoses are categorical – not dimensional – other aspects of the diagnostic schema (such as the severity specifiers and Global Assessment of Functioning) describe the degree of impairment. As well, the introductory section of the *DSM* instructs that although the *not otherwise specified* designation may be appropriate for a "sub-threshold" presentation, it is also appropriate when the presentation is atypical, mixed, uncertain, or when there is insufficient information available. The *NOS* category is provided for every major disorder because of the inherent recognition that categorical nomenclature cannot cover all possible presentations.

It is also critical to appreciate that the *DSM* is strictly a *clinical* manual, designed to "enable *clinicians* and *investigators* to diagnose, communicate about, study and treat" individuals affected with mental disorders [italics added]. The preface specifically cautions against use of the *DSM* "clinical and scientific" categories for "legal or other non-medical" purposes. It is specifically stated that *DSM* categories are not relevant for disability determination. It appears that administrators who establish the criteria to qualify for service provision have ignored this fundamental. *DSM* offers clinicians a useful guide to facilitate consistency and communication.

DSM or any other systems of clinical classification for autism are meaningless for social policy decisions. In the current environment of limited resources, eligibility criteria for services are to be expected. However, just as with other forms of illness, these criteria should be based on relevant factors. This includes the burden of illness, pain and suffering, likelihood of treatment response, expected degree of improvement with intervention, and so on. In addition, it is inappropriate to view subtypes as hierarchically reflecting severity of illness. As well, there is no medical evidence that society is better served by providing intensive treatment to only the most disabled. *There is no rational or scientific basis establishing the relevance of autism subtypes to the determination of service need.*

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