Medicalization of autism spectrum disorders: implications for services

Medicine exists in social and cultural contexts and diagnosis has wide implications. Autism was introduced as a medical category in 1943 by Kanner and for four decades the main thrust of scientific research around diagnosis was to establish the distinctness of this category, developing internally consistent criteria for diagnosis and differentiating it from other categories such as intellectual retardation and childhood schizophrenia. In spite of growing evidence of the biological aetiology of the disorder, no distinct biological markers were established and autism is still diagnosed on the basis of patterns of development with behavioural 'signposts'.

Medicalization

The acceptance of autism as a medical category had undoubted benefits. It enabled scientific research on its nature and prevalence and established its biological base, thus removing the stigma for parents of being blamed for its development. It enabled the development of specialized teaching techniques and schools, and eventually the recognition of the special and unique educational needs of these individuals, based on an understanding of the condition (Jordan, 2005).

In the 1980s, however, the tight category of 'autism' broadened. Wing (1996) had not only established that autism could exist alongside cognitive impairment but also introduced the English-speaking world to the group of children studied by Asperger (1944), who were more able intellectually and did not suffer from structural language difficulties.

Thus, 'autism' was widened to an 'autism continuum' and then an 'autism spectrum' (autism spectrum disorders), characterized by impairments in three areas of development: social and emotional understanding, communication, and flexibility in thinking and behaviour. Diagnostic systems introduced the categories of 'Asperger's syndrome' and 'atypical autism' but the behavioural manifestations of the underlying developmental impairments became more varied and more difficult to categorize.

Category or dimension?

The diagnostic tools that had been developed for autism were harder to establish for the broader category, so that 'diagnosis' of an autism spectrum disorder became more dependent on unaided (and thus more subjective) clinical judgment and in time more influenced by considerations of policy and practice. The separation of categories within the spectrum became harder to justify, either in terms of science (most studies being unable to distinguish reliably between Asperger's syndrome and 'autism without intellectual or current language impairment') or in terms of the educational or social implications. Allocation of services on the basis of diagnostic category became an increasingly arbitrary affair.

As Volkmar (1998) recognized, a categorical medical model was valuable for research and to provide apparent order in a complex field, but it did not match the reality of individuals nor was it a good basis for planning services. Services needed to be individually based, deriving need from a dimensional rather than a categorical model of the disorder.

The broadening of the categories also meant that more able and articulate individuals were receiving diagnoses within the autism spectrum. Severity of autism varies independently from intellectual or language ability, so many of these did have severe needs, but their understanding of themselves and their needs did not necessarily fall within a medical model.

Pathology or human diversity?

Many saw their difficulties as arising not from a 'disease' but from the way mainstream society conceptualized and treated difference. In other words, they saw autism spectrum disorders as largely iatrogenic. Their problems, they argued, came from the narrow view that any deviations from the typical (i.e. any differences in development) were seen as 'abnormal' and 'unhealthy', assuming that the typical way of developing and understanding and processing the world is the only way to be valued and accepted. Comparing people with autism spectrum disorders with 'neurotypicals' will reveal differences, but these are not necessarily symptoms. If alternative ways of developing were accepted as equally valid (and equally human) then the differences could simply be seen as part of human diversity and adaptability. They only become a problem when they are not recognized as valid nor allowed for in the management of services, such as education.

That view provides a useful corrective in a society that overvalues conformity and making everyone a 'team player'; even universities have lost many of the opportunities for people to study their obsessional interest without needing to socialize or work in a group. Yet it ignores some real dilemmas. There needs to be some way of recognizing this autistic style so the person can understand him-/herself, can find others to relate to, and can be understood by parents and professionals.

There also remain individuals whose needs are so severe that they are present in all situations, no matter how autism-friendly. It is a denial of the very severe needs of this group to say that they just have a difference. Such people cannot enjoy their difference and partake in social interaction on-line, as others may do, but are prisoners of their uncertainty and confusion, and the fear and anxiety that follow.

The treatments may still be educational or social (since there are as yet no medical treatments for autism spectrum disorders) but the medical category provides a rationale for the service provision and support that they need. All societies need a way of channeling resources to the most needy and a diagnosis (while not perfect for the role of gatekeeper) is one, relatively fair, way of doing this. This has become a problem for services since the category is now so broad that it no longer functions well as the gatekeeper for access.

The middle way?

Clearly then, there are pros and cons to medical classification of autism spectrum disorders, but is there a middle way? Scientific research lends some support to the position of different but not deficient, in that strengths as well as weaknesses are being associated with autism spectrum disorders.

Attempts to find a single (or even a single set) of biological or even psychological deficits underlying autism spectrum disorders have so far not borne fruit. In spite of evidence of a strong genetic link, some research suggests that it is the cognitive style rather than any deficits that constitute the inherited element of autism spectrum disorders, so it seems possible to have differences that are not necessarily dysfunctional. However, even the most able are vulnerable to mental health problems and failures in coping if they are not supported and their particular learning style understood and accommodated. They are vulnerable, in other words, to having a disorder.

The autistic mind

It would seem reasonable to confine a medical category to those who genuinely have a 'disorder', i.e. whose differences are interfering with development and capacity to function. Additional mental health problems should also be diagnosed but there would need to be some way of recognizing that the individual had an autistic mind, which would affect treatment. In the same way this autistic mind needs to be recognized in education and by parents so that the style can be understood and accommodated, to try to prevent a disorder developing. It may even be that those with a medical disorder could receive such effective education and treatment that they move out of the disordered category, while retaining their basic autistic mind.

It would be a pity to have to reproduce the medical system within psychology, for example, to enable this 'dual classification' to operate. Perhaps more multidisciplinary ways of working will make it possible to have a single system but a dual outcome: a medical disorder of autism spectrum disorders or a recognition of an autistic mind but no medical condition. It would then depend on services, such as education, to be genuinely inclusive and to differentiate teaching to accommodate differences in development and information processing style; only those who needed more support than this, and access to particular resources, therapy and specialist teaching would have those needs underpinned by a medical diagnosis. BJHM

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KEY POINTS

- The recognition of Kanner's autism as a medical condition was an important step in enabling scientific research, establishing autism as a biological disorder, and facilitating the development of specialized teaching approaches.
- The broader medical category of an autism spectrum is no longer internally coherent or uniquely distinct from 'eccentric normality' and is not well suited to a gatekeeper role in the provision of services and support.
- A non-medical category of an autistic mind would enable understanding and accommodation to different processing styles but would only constitute a medical condition (autism spectrum disorder) if the differences seriously interfered with development and functioning or if they led to mental health disorders.