

A brief history of autism

Details

Created on Monday, 17 December 2012 16:04

***Maggie Wilson** considers the big ideas that have shaped our ever-changing understanding of autism*

Throughout the history of autism, those at the forefront of change have been parents; they have challenged prevailing professional attitudes and opinions and pushed the boundaries of intervention. Some of the professionals in the field have also been parents of children with autism – perhaps most notably Bernard Rimland and Lorna Wing – and parents continue to play a large part in the evolution of knowledge about the condition. More recently, people with autism themselves have found a voice through which to share their experiences and shape the political, social and research agenda in relation to autism.

Over the past seventy years, the concept of autism has undergone several changes in line with the concurrent professional and scientific milieu. This article will examine these changes along with some thoughts about future directions in our framing of the experiences, similarities and differences in the population of people labelled “autistic”.

Autism in historical accounts

Several interesting accounts of children who were markedly unusual in their abilities and interactions have been noted through the centuries. Perhaps the most famous of these is Victor, a youngster who was discovered in 1797 near St-Sernin-sur-Rance, France, having spent several years living in isolation (Lane, 1977). Jean Itard, a physician, worked tirelessly over many years with Victor, focusing on socialising him. Although Victor’s expressive language did not develop, his understanding of the world and of other people improved considerably.

Several reports of “feral” children of varying reliability (Newton, 2002) are included in the literature on autism, although, as with Victor, it is difficult to differentiate the effects of early deprivation from a biological condition. This has been the difficulty with identifying cases from historical accounts of possible autism – the unknown influence of the environment. However, more recent examples where a lack of stimulation in early childhood has led to autism-like conditions have been seen in the effects on development of children unfortunate enough to have been “cared for” in Romanian orphanages at the beginning of this century.

A medical condition

Children whose abilities and behaviour accord with our current understanding of autism have also been described by some early psychiatrists. John Haslem (1809) and Henry Maudsley (1879) had patients who spoke of themselves in the third person, were solitary, had a very narrow range of deep interests and did not form attachments to caregivers (Wolff, 2004). These difficulties were conceptualised within the dominant paradigm of the time – that of insanity. Psychiatry was at a very early stage at the turn of the twentieth century and the idea of cognitive disabilities and differences took several decades to emerge and to influence clinical practice.

A psychogenic disorder

In the 1940s, two clinicians working independently outlined the conditions we know as autism and Asperger's syndrome. Leo Kanner (1943), working in America, differentiated a group of children with distinctive patterns of strengths and needs from other children with difficulties. He outlined the diagnostic criteria which are, largely, still followed and called these children "autistic" (Rutter, 2005).

Hans Asperger (1944) also outlined the condition, although his work was not recognised widely until Lorna Wing addressed the broader autism question in the 19'80s. Although Asperger's syndrome is soon to be no longer an independent part of the DSM 5 schedule, I retain it here for clarity.

In the mid-twentieth century, the reasons for autism were sought in family relationships. Whilst both Kanner and Asperger recognised the constitutional basis of autism, it came to be known popularly as "juvenile schizophrenia". Coupled with the cultural and professional dominance of psycho-analytic approaches to emotional, cognitive and mental health challenges at the time, this led to a particular conceptualisation of and approach to the condition. Reasons for the child's condition were sought within the relationships in the family and parenting styles were scrutinised. The concept of parents who were emotionally unavailable – the "refrigerator mother" of Bettelheim's view – must have added to families' distress. Approaches such as removing the child from the "pathogenic" family (Rutter 2005), holding therapy, where the child was held until the adult could "break through", and lengthy psychoanalysis of the whole family stemmed from the conceptualisation which marked this era.

A neurological condition

In the 1960s, an American psychologist and parent of a child with autism, Bernard Rimland, wrote a landmark text suggesting that autism was a neurological disorder – based in biology, not faulty relationships. At the same time, professional thinking around the formation of, and interventions for, mental, cognitive and emotional disorders was changing and behaviourism moved the focus from early relationships to learned behaviours. If individuals had learned inappropriate or unhelpful behaviours, they could be helped to learn more adaptive behaviours. Through the '70s and '80s, behavioural study continued and the work of Ivar Lovaas, whilst controversial then and since, was influential in demonstrating that children with autism could learn more normative behaviours (Anderson, 2007).

Autism was thus seen as a neurological condition, which was treatable by psychological intervention. Many of the earlier observations were forgotten: Kanner had remarked on the increased head size of children with autism; Asperger had noted similar personality traits in the parents of children with Asperger's syndrome (Wolff, 2004). Whilst some of the strategies used over this period are now anathema to professionals, this phase in the evolution of our understanding of autism recognised that children are able to learn and to develop.

A developmental disorder

As technology gave researchers greater ability to collect and collate data about populations and individuals, so the conceptualisation of autism advanced. Lorna Wing and Judith Gould's seminal work in the '70s and '80s led to a re-evaluation of the condition, giving estimates of prevalence and also broadening the diagnostic gate. The concept of the "autism spectrum"

was fundamental in shifting the professional and popular mindset from autism as a discrete disorder to that of a continuum of strengths and needs. The emergence of Asperger's syndrome (again Wing's work) as part of the spectrum strengthened this concept.

Work through the '80s and '90s framed autism as a developmental disorder: affected children did not reach developmental milestones in the areas of language, socialisation and imagination/flexibility of thought and behaviour. Toward the end of the '90s, it became increasingly recognised that people on the spectrum also had high rates of anxiety and marked sensory-perceptual differences, resulting in a number of important texts dealing with these aspects of the condition (see Seroussi, 2002).

This understanding of the developmental nature of the condition led to an emphasis on the importance of early intervention – the need to teach the young child not only the skills which s/he did not acquire in the way that neurotypical children did, but also to teach the child how to learn. Approaches to helping those with autism offered educational options based on particular understandings of autism. So, whilst autism was seen as a neurological issue, intervention was largely educational.

During this period, the Human Genome Project captured both the professional and popular imagination. As is often the case, when seeking simple answers to complex questions, many were quick to use the latest ideas to produce all-encompassing theories; “faulty genes” were sought for a whole range of human difficulties, from autism to diabetes. The discovery that some gene sites appear to be implicated in the development of autism seemed to offer some answers. The downside of this approach is, of course, the accompanying mistaken notion that one's genes are one's destiny: that genetic make-up dictates biological futures.

The future: a multi-system condition

As research methods have become yet more sophisticated, so our picture of autism has become less plausible, particularly in terms of our conception of autism as:

- (a) a disorder comprising the discrete variants: autism, Asperger's syndrome, childhood disintegrative disorder and PDDNOS
- (b) present from birth and
- (c) fixed.

Diagnosis

The suggestion for DSM 5 (due to be published in 2013) is that the diagnostic differentiations are dropped, and a single diagnosis of “autism” is available to the clinician. This emphasises the unique presentation of the condition in individuals. “Autism” indicates the presence of difficulties in the anticipated fields of social communication and restricted patterns of behaviour, but the general feeling is that the new criteria will lead to a decrease in diagnosis rates as many people with difficulties will not meet the new criteria.

An autism constellation?

Further, the range of conditions which are associated with autism – such as ADD/ADHD, OCD and dyspraxia – point to a much more complex aetiology and presentation (Seroussi, 2002). Given our advancing understanding of these relationships, in the future, we may well see an “autism constellation” where these associated conditions also become part of the individual's primary diagnosis. Thus, whilst we may have one, broad diagnosis (autism) the

elements of the individual's condition can be more thoroughly described and defined within it.

“Late onset” autism

For many decades, parents have been reporting that children, who at two to three years old are clearly autistic, had become so following a period of typical development and regression. The advent of cheap and reliable audio and video recording has made it possible for clinicians to view the individual child's development closely from home movies and, indeed, the proportion of children who are later diagnosed with autism, who regress after a period of typical development, does appear to be increasing.

Gastro-intestinal challenges

Perhaps the most exciting field of change is that of the awareness of other body systems involved in an individual's autism. Again, for decades parents have been reporting the gastro-intestinal problems their children have: diarrhoea, food intolerances, stomach cramps and extreme food preferences (the beige diet). Whilst previously these have been ignored, parental pressure has recently focussed much more attention on these difficulties, which are, in some cases, extreme. The gluten-free, casein-free diet, seen as outlandish ten years ago, is now part of the mainstream approach to autism. One would hope that in another ten years time, thorough gastro-intestinal investigation would be part of the diagnostic and therapeutic approach to autism in individuals.

Immune system challenges

More recently, it has been suggested that the food issues discussed above are part of a broader picture of immune system dysfunction in individuals with autism. It is broadly thought that the immune system over-reacts to some substances and under-reacts to others (see Zimmerman, 2008). The relationship here – whether cause or effect – is unclear, but many parents report the onset of autistic regression following a biological insult, such as an infection or seizure.

Metabolic differences

A new area of research is that of metabolic functioning in individuals with autism. Research in this field is pretty disparate; however, work on oxidative stress apparently indicates significant differences in functioning between the neurotypical and autistic individual at a cellular level (James, in Zimmerman, 2008).

Taken together, this work suggests a much more complex and intricate picture of autism than previously imagined. Should the research on immune and metabolic differences in autism come to fruition, we may see a protocol for early intervention which includes not just work on language, social understanding and sensory sensitivities, but on dietary supplementation and attention to individuals' metabolic profiles. All of this marks another paradigm shift – away from fixed, developmental unfolding of the condition (albeit ameliorated by educational intervention) toward the concept of a multi-faceted condition, amenable to physical as well as educational intervention.

Conclusions

Autism has received an increasing amount of research and media attention over the past two decades. The questions around causes of the condition and the apparent anomalies of human functioning (savant syndrome, Tourette's syndrome) make it appealing to the media. As the

brief commentary above has noted, our conceptualisation of autism is a cultural product, not an objective categorisation. It depends on the direction of scientific advances, societal attitudes and values, and (certainly in research terms) competing voices. However, the prevalence of the condition – now estimated at 1 in 100 – would warrant a continuing high level of interest. As a result of this, we can anticipate further changes in our understanding of what autism is.

References and Bibliography

- Anderson, M., *Tales from the Table: Lovaas/ABA Intervention with Children on the Autistic Spectrum* (2008) London: Jessica Kingsley Publisher.
- Bettelheim, B., *The empty fortress: Infantile autism and the birth of the self* (1967) New York: Free Press.
- Happe, F., *Autism: An introduction to psychological theory* (1994) London: UCL Press.
- Herbert, M. and Weintraub, K., *The autism revolution: Whole-body strategies for making life all it can be* (2012) New York: Random House Books.
- Hermelin, B., *Bright splinters of the mind: A personal story of research with autistic savants* (2011) London: Jessica Kingsley Publisher.
- Houston, R. and Frith, U., *Autism in history: The case of Hugh Blair of Borgue* (2000) Oxford: Blackwell Publishers Ltd.
- Huws, J. and Jones, R., Missing Voices: Representations of autism in British newspapers, 1999-2008. *British Journal of Learning Disabilities*. (2010) 39, 98-104.
- Lane, H., *The Wild Boy of Aveyron* (1977) London: Allen and Unwin.
- Newton, M., *Savage girls and wild boys: a history of feral children* (2002) London: Faber and Faber.
- Rimland, M., *Infantile autism: The syndrome and its implications for a neural theory of behaviour* (1965) London: Methuen.
- Rutter, M., Autism research: Lessons from the past and prospects for the future. *Journal of Autism and Developmental Disorders* (2005) 35(2) 241-256.
- Sanders, J., Qualitative or quantitative differences between Asperger's disorder and autism - Historical considerations. *Journal of Autism and Developmental Disorders* (2009) 39 1560-1567.
- Seroussi, K., *Unravelling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research & Recovery* (2002) New York: Broadways Books.
- Silverman, C., *Understanding Autism: Parents, doctors and the history of a disorder* (2011) New Jersey: Princetown University Press.
- Wolff, S., The history of autism. *European Child and Adolescent Psychiatry* (2004) 13, 201-208.
- Zimmerman, A. (Ed.), *Autism: Current Theories and Evidence* (2008) New Jersey: Humana Press.

Further information

Dr Maggie Wilson runs Autism: Learning and Development Ltd, a company which provides early educational intervention for pre-school children on the autistic spectrum. She also works with schools to support children and staff groups to address the aspects of autism spectrum conditions in individuals which may prove challenging in the classroom.

www.autismdevelopment.co.uk