

AUTISM: A DIFFERENCE OR DISORDER? IMPLICATIONS FOR ACCESS TO SERVICES



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The APPG on Scientific Research in Learning and Education was re-launched in October to continue exploring issues at the interface between scientific research and education. The most recent meeting, chaired by Baronesses Warnock and Greenfield, focused on whether Autism is best described as a disorder or a difference. Autism is characterised by social and communication problems along with restrictive or repetitive behaviour and interests. It affects about 1% of the population and can be divided into high- and low-functioning Autism, which are marked by impaired language development and differentiated by IQ; and Asperger's Syndrome in which language development and IQ may be normal but social and communications problems persist.

The meeting heard from Professor Simon Baron-Cohen (Cambridge University) and Professor Patricia Howlin (Institute of Psychiatry, London). Howlin opened by stating that to call Autism a difference or disorder is more than a debate over semantics and is, in fact, critical in enabling access support services. Although acknowledging that the debate is not black and white and that, in reality, Autism may be both these things, Howlin presented persuasive arguments for seeing Autism as a disorder including that such an approach is likely to lead to improvements in therapy. She stated that even children with High Functioning Autism, can find adulthood very hard thus warranting the disorder label, for what appear the more mild cases. She stated that, as adults, less than 10% of such individuals live independently, less than 1% has a high quality of life and around 25% develop psychiatric problems. She also suggested that there are dangers of labeling Autism as a difference, including the risk of teasing, rejection and bullying. Howlin acknowledged that in an ideal world we should be more tolerant of difference, but the reality of the situation, especially in the current economic climate where services are stretched, is that a difference will not be treated with empathy. Given that an individual with Autism may appear healthy and highly educated, society and those in frontline health services will lack

sympathy for them. Howlin concluded by stating that whilst the term disorder may be unpalatable to some, it is likely to be of help to many in order to provide them with appropriate, and much needed, support.

Baron-Cohen began by stating that Autism and Asperger's Syndrome are unambiguously medical conditions and that 'condition' or 'disability' may be more appropriate terms than 'disorder'. He reasoned that disorder implied something was broken and had a known cause, whilst both 'condition' and 'disability' give access to support if needed, without implying something requiring fixing. Nevertheless, he noted that low-functioning Autism may co-exist with disabling characteristics, in addition to social and communication problems, such as epilepsy, gastrointestinal problems and anxiety. He went on to argue that those with high-functioning Autism and Asperger's Syndrome, whilst suffering from disabling social and communication problems, will show key differences to the general population, which may be advantageous. These include excellent attention to detail and ability to gain a deep understanding of a particular topic, such that they could be seen as specialists rather than generalists. Baron-Cohen went on to suggest that the current focus on weaknesses associated with Autism rather than strengths, together with the idea

that there is a single, normal route to adulthood may be counter-productive. Perhaps more provocatively he suggested that everyone falls on a continuum for autistic traits, with those with a diagnosis typically, but not always, having a higher autistic spectrum quotient. He even proposed that it is not the score that determines diagnosis but rather the environment, with some people finding themselves in a more supportive environment not needing help or diagnosis, whilst others greatly need the diagnosis to access support services. Baron-Cohen closed by suggesting that both a disability and difference approach remain useful.

In conclusion, both speakers agreed that the situation was not clear-cut and that Autism does produce differences in functioning; that this label alone, however, could preclude access to services. Both speakers also supported more research with girls and adults with Autism, which have received less funding to date. They also suggested that, given the prevalence of autism, schools should expect to have children with autism in each year group and must show flexibility in supporting the heterogeneous group with both disabilities and differences. In sum, the debate raised many valuable questions and addressed key considerations in how nomenclature can impact on societal views and access to support services.