

Bookmarks: Autism and Asperger syndrome

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I was recently asked to present to a group of autism and Asperger syndrome clinicians. This was an area that I had little knowledge of – apart from the controversy on MMR, I had never worked with the subject. As we were planning to appraise some research in autism, I thought that it might be a good idea to look at some websites on the topic. What I found was interesting – lots and lots of associations (I counted 12) and many websites (far too many to list here), all of varying quality, but usually covering much the same content.

According to the BBC page,¹ approximately 580,000 people, mostly male, have autistic spectrum disorders. Autism and Asperger syndrome are part of a range of conditions (the autistic spectrum) that cause communication and emotional problems. As with many of the BBC sites, the design and coverage was excellent and answers all the major questions in a concise and readable way.

In terms of associations, the first site that I looked at was the National Autistic Society (NAS).² The Society exists to champion the rights of all people with autism and the website was well presented and very colourful. I particularly liked the newspage, which was very up-to-date and well written. There was also a regional portal – if, for example, you live in Scotland, you can click on that portal and it will give you details of events and support in your area. The only negative was that there

was no external links page, meaning that the NAS made no reference to any other autistic organisation, an issue that I noticed with a lot of the autism sites that I reviewed.

Another interesting resource was Autism Independent UK.³ On the day I accessed it, there was a blank area in the centre of the home page and you had to scroll down to the bottom to reach any information about the site. It describes itself as a 'non-medical advice and information centre'. Despite the poor design and presentation, the website

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did have some redeemable qualities. For instance, the 'Autism Factfile' answered a number of questions such as where the term autism comes from (apparently it means 'absorption in fantasy as escape from reality' – something I think could be used to describe a number of other activities).

The Autism Collaboration⁴ was another site which could have been designed better – to see the whole of the webpage, you had to scroll to the right (one of my pet hates). Even the black and white photograph of an autistic child on the homepage was depressing and downbeat. It was unclear what the site is there for, or who it was aiming to reach, as it merely listed the various organisations who are part of the collaboration. The site does have a search engine – the

bizarrely named 'A+ Recovery Search engine' – which was useful, but I got exactly the same results from a Google search.

In terms of patient information, the Royal College of Psychiatrists have an excellent fact sheet⁵ on their site which was well explained and simply presented. It looked at the main issues around socialising, unusual behaviour, causes and, most importantly, sources of help. I thought that this was a really useful resource, well written and informative.

The National Institute of Neurological Disorders and Stroke (NINDS) website⁶ is aimed at clinicians and has a very useful question and answer approach to the topic explaining the main issues, treatments, prognosis and the current research being undertaken worldwide. However, as with many of the autistic websites, they only listed their own research and appeared to have no interest in the activities of other autism organisations.

MedlinePlus⁷ is a useful resource and the page on autism was one of the best resources available that I found. It detailed all of the signs and symptoms and explained the issues well. I was also fascinated to find that despite most of the websites using autism and Asperger syndrome as synonyms, this was the only site that explained the differences between the two (Asperger syndrome is similar to autism, but patients have normal language development).

In closing, I found it very interesting researching autism and Asperger syndrome, but the unusual aspect of this topic was the sheer quantity of associations and websites available out there and the fact that so many of them appeared to be operating independently of each other.

Websites

1. <www.bbc.co.uk/health/conditions/autism1.shtml>.
2. <www.nas.org.uk>.
3. <www.autismuk.com>.
4. <www.autism.org>.
5. <www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthandgrowingup/12.autismandaspergers.aspx>.
6. <www.ninds.nih.gov/disorders/autism/autism.htm>.
7. <www.nlm.nih.gov/medlineplus/ency/article/001526.htm>.