

Autism Data: a database of resources in the field of autism

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Experiences of setting up Autism Data as a free, searchable database available on the Web

Autism (including Asperger syndrome) is a life-long developmental disability that affects the way a person communicates and relates to people around them. It is estimated that there are 535,000 people with autism in the UK.

The National Autistic Society (NAS) exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs. Founded by a group of parents in 1962, the NAS has grown to become the UK's leading autism charity. Today, it has 15,000 members, 65 branches, 600 volunteers and over 2500 employees providing a range of services for people with autism, their families and professionals across the UK.

We wanted to be able to make this information freely accessible online as a sophisticated but easy-to-use tool with professional expertise and support available as required.

The NAS Information Centre exists to support the information needs of colleagues within the organisation and provides a free information service to professionals and students working in the field of autism. We have a key role to play in meeting the NAS objectives of raising awareness and understanding of autism, providing information services and practical support to a range of stakeholders, and sharing best practice across the organisation. We respond to 9000 enquiries a year from colleagues, professionals and students working in a range of disciplines.

Our services

The NAS Information Centre provides a range of information

services including a free enquiry service, information sheets and packs on a range of topics targeted at a range of professions, a library open by appointment (housing, to our knowledge, the largest collection on autism in Europe), a photocopy service (subject to copyright), a range of current awareness and subscription services, and a range of databases freely available on the Internet.

With a range of internal and external customers with varying levels of information skills and based across the UK and indeed around the world, the importance of electronically accessible information with the back up of professional expertise cannot be stressed enough.

Our annual surveys of both internal and external customers show that most external customers find us through the Internet, and that internal customers expressed a need for better access to information, particularly electronically.

Our databases

Our databases comprise key electronic resources in the field of autism. These include: PARIS (the Public Autism Resource & Information Service) available at <www.info.autism.org.uk>, a searchable directory of services catering for people with autism, their families, and professionals; Research in Progress available at <www.autism.org.uk/

<researchinprogress>, the Information Centre's database of current research in the field of autism; and our key resource, Autism Data available at <www.autism.org.uk/autismdata>, our database of over 17,500 books, journal articles and multimedia in the field of autism.

Autism Data: background

Autism Data is a key resource which the NAS Information Centre and Autism Helpline have used to respond to the 45,000 enquiries a year we receive from people with autism, their families and professionals. Until recently, this information was stored on a library management system (LMS) accessible in-house only to key members of staff. We wanted to be able to make this information freely accessible online as a sophisticated but easy-to-use tool with professional expertise and support available as required.

Making the case

Making Autism Data freely available on the Internet fitted perfectly with the NAS strategic objectives of raising awareness and understanding of autism, providing information services and practical support to a range of stakeholders, and sharing best practice across the organisation. The Information Manager (IM), Mary Draffin, benefited from the support of the then NAS Director of Communications and Public Affairs, and also enjoyed good working relationships with the then Information Systems Business Support Analyst, and the Web Editor, a fellow qualified library and information professional.

He@lth Information on the Internet

Achieving our vision

We decided to maintain our link with Soutron, provider of our previous LMS, and upgraded to the Inmagic® CS/ TextWorks® and CS/Text® WebPublisher PRO content server and Web publishing applications. We planned for Autism Data to be part of the existing NAS Web site hosted by Wrenhill. Our vision was of an online database that was easily identifiable with the NAS, and facilitated easy, seamless navigation between the database and

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our existing NAS Web resources, in particular the NAS Web site available at <www.autism.org.uk>. It was also important for the facility to comply with Web accessibility guidelines and recommendations. The standard 'off the shelf' design of the Web publishing application did not meet these needs in its 'raw state' but did offer the flexibility to achieve our vision for Autism Data. However, this required a great deal of practical technical work on the part of the IM and other colleagues within the NAS, in particular html writing for pages, screens and commands. This work also required a great deal of co-ordination by the IM between our in-

...to contribute positively to our goal of raising awareness and understanding of autism, and providing quality information services.

house Web and technical teams, our content server and Web publishing applications provider, and our Web site host. Clarity of plans and clarity of communication of these plans was also very important and we learnt that our plans and requirements were more complicated than initially thought. Our deadlines were moved and missed as we struggled to achieve our specifications. This meant that it was very difficult to plan a marketing campaign effectively for the launch of Autism Data. Eventually, we decided to delay marketing until well after the database was completed and we were

quite sure that our vision had been achieved.

Autism Data: going live!

After an intensive period of work during summer 2005, Autism Data finally went live on the NAS Web site in September 2005 in time for the NAS International Conference. The IM and I enjoyed the opportunity of sharing Autism Data at the conference with a range of professionals in the field of autism. This was an invaluable oppor-

tunity to gain feedback both positive and constructive after all our hard work. In particular, we were grateful to one delegate for 'planting the seed' for an idea for a simple search screen in the vein of popular search engines.

Autism Data: features

Autism Data offers both simple and advanced search screens. It is possible to search by author, title, source, keywords, abstract, and year published. The simple search screen allows the user to search across all these fields (with the exception of source) using free text. There is also a free text field on the advanced search for searching across the title,

keywords and abstract fields. Autism Data caters for a range of search techniques including Boolean operators, parentheses, phrase searching, and truncation.

Search results are displayed in a reverse chronological list of 5 per page offering brief details for each reference. Users can opt to view full details providing essential information for tracing the publication. Where items are available to purchase through NAS Publications, a link is provided through to our online shop. A URL is also given for items that are available in full text online. Print and

request functions allow users to build up print and photocopy request lists. Users can use the process request list facility to generate a copyright declaration form complete with their photocopy request details ready for them to read, print off, and return to us with contact details, signature and payment to make use of our photocopy request service.

Subscription services

We have also been able to make our current awareness services *Autism Update* and *Titles in Autism* available online. *Autism Update* is a bi-monthly bulletin of recent additions to Autism Data, and has a practical focus listing additions by subject. *Titles in Autism* consists of a list of all articles from peer-reviewed academic journals added to Autism Data in the previous two months. Subscribers can access these services on our Web site via a login. We used 'canned searches' and programmed the screens using html commands through the CS/Text® WebPublisher PRO application, and a user manager module through our content management system (CMS) polopoly to make this possible.

Marketing

The IM liaised with our membership department and we were able to offer *Autism Update* as a free membership benefit. Our marketing campaign of potential information service users began in October 2005, targeting students with an email to relevant university departments. In January 2006, we began a 3-month mail out targeting a range of professionals working in nurseries, schools, adult services, assessment and diagnosis services, and providers of interventions and therapies, training, and support groups. During this period, the NAS saw a rise in corporate membership. We were delighted to have played a part in this.

We also submitted contributions to a number of e-newsletters, and discussion lists during spring 2006 and have this summer liaised with our PR and Media Department to arrange for press releases to a range of relevant journals and magazines.

Positives

Being involved with the planning and launch of Autism Data online has been a useful learning experience for members of the Information Centre team, none of whom had previous experience in this area. Though a steep learning curve at times, we picked up some valuable lessons, in particular the need for clarity of planning and communication to achieve specifications. The experience also reinforced the importance of co-ordination between partners, good working relationships across the organisation, and the ability to make a business case for achieving strategic objectives.

Speaking personally as a librarian, the key reason I joined the profession was the desire to empower people through access to information. Our project of making Autism Data, our key resource of publications in the field of autism, freely available on the Internet, has made us very proud to contribute positively to our goal of raising awareness and understanding of autism, and providing quality information services. It is a joy to be able to refer enquirers to Autism Data. Librarians do have a role of acting as intermediaries to electronic information, in particular to those who do not have Internet access or do not possess the necessary information skills. Autism Data has both empowered those users with the requisite skills and those users new to online searching who we have been able to share our database with and talk through basic searches. We are, of course, delighted to continue to offer a free literature search service. The easy-to-use accessible format of the database, and professional information service offered by the librarians is also complemented by a brief guide to searching Autism Data, empowering users to develop search techniques and make full use of this facility. With almost 8000 visits from October 2005 to August 2006, Autism Data has proved a valuable addition to our existing NAS Web resources.

The last word, appropriately I think, is left to one of our users who emailed me to say: 'Autism Data is by far the most useful place I have used on the Internet'.

View from the front line – Medical images online

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Acquiring images online

A picture is a worth a thousand words – we have all heard that before but it is a reasonable assumption. (If you are curious as to where this expression came from, check out http://en.wikipedia.org/wiki/A_picture_is_worth_a_thousand_words.) However, that expression holds true today, just as it did 85 years ago. Of course trends change and I notice we tend not to call a picture 'a picture' any more, it is an 'image'. Other words used are 'media' and 'digital assets'. Another sign of the times is that the image is possibly digital and stored on a computer, hard drive or optical media and can be printed out and altered again via computer or IT equipment. With digital cameras (or camera-enabled mobile phones), we can easily and relatively simply create images, manipulate them and rapidly print them out or email them to anywhere in the world. Also, images may not necessarily be stored as a photograph or illustration, they can be videos. The use of online videos is exploding and no doubt that will be soon be a significant medical online activity, especially since broadband is becoming a mainstream infrastructure.

Of course, you can find an image on a Web site; in fact, Web sites are meant to be a multimedia experience. Text, pictures and videos can all sit together easily on a Web site, making a trip to a well-designed Web site all the more comfortable and informative.

Medical education is very much a visual experience, and learning by pictures (sorry images!) or illustrated textbooks has always been an integral part of gaining knowledge. Acquiring an image for such use can often mean a trip to cyberspace. It is also a part of everyday clinical work, recording images and analysing them and sometimes we need to access images.

Before rushing to acquire that image from an online source, think about copyright. Although the images are available to the general public online, that does not necessarily mean that they are yours to use. Some providers will want attribution for free use, other copyright holders will want payment. Be fair to the provider and respect their wishes before acquiring their image for your use and be absolutely clear in your own mind what the owner of the image wants from you.

Okay, so where you do start? Well looking for a medical image can be like looking for a needle in a haystack. There is so much available online, it is difficult to know where to start. Well, good starting points are collections of medical sites that hold images and that may be a more specific and targeted search, rather than using a general search engine. One possible starting point is the superb

www.mic.ki.se/MEDIMAGES.html.

This is an excellent resource produced by the Swedish Karolinska Institute. At the top of the home page comes a copyright warning which points out that many of its target sites may have copyright restrictions and specific permission may be required from the owner. Collections are divided by specialty and it is easy to scroll down and pick out something that may interest you and which merits further exploration. Another 'supersite' that contains collections of links to image databases is the Hardin MD collection at www.lib.uiowa.edu/hardin/md/pictures.html.

Remember that an image may not be a clinical image as such, for example it could be an electrocardiograph (ECG). Learning to interpret an ECG is without doubt an important clinical skill and the more ECGs you see and understand then the more you learn. So some folk