Content Analysis of Online Autism Specific Sites

Jeeshan Chowdhury, Jane Drummond, Darcy Fleming, and Susan Neufeld

Abstract

The Internet has become the source for a wide range of information for families with children with special needs. Although parents use the Internet as a library, it lacks some important safeguards of libraries. Scientific review, guidelines for acquisition, and accreditation criteria are part of a library system and facilitate the collection of valid and reliable resources. These processes are absent from the Internet, and in combination with the obvious commercial goal of the Internet, leave families of children with special needs conducting online research at risk of acquiring misguided, biased, and invalid information. The purpose of this study was to qualitatively evaluate the content of the Internet as an information source for families of children with autistic characteristics. A sample of 145 online sites were reviewed. The results indicate the need for a system of peer review to insure the quality and validity of information for families of children with autistic characteristics.

Background

Parents of children of special needs are front line advocates (McMahon, 1993) who work outside of service delivery systems and intervene in those service delivery systems on behalf of their child to obtain services and resources necessary for the promotion of their child's health and well-being. The collection of thorough and accurate information is critical in this advocacy role. The Internet is a resource that is readily available to many parents who find it a rapid and easy way of accessing information about their child's medical diagnosis or condition.

Supporters of the Internet suggest that it is a revolutionary form of digital communication that has the potential to transcend geographical and cultural borders. It is purported to have the potential to establish a new "online paradigm of decentralized power" (Wayne, 1996, p. 8) or function as the library of the future (Theodore, 1996). However, there is rising concern about the ability of the Internet to meet its potential as the library of the future due to difficulty in accessing reliable, valid, and unbiased information from it.

Despite the fact that the Internet is maintained by private companies and composed primarily of commercial content, the ‘everyday’ user thinks of it as an information resource not unlike a library. Nevertheless, the Internet is propagated by commerce while the library institution functions to screen and store valid information. The library is guided and governed by critical safeguards and intellectual structures that have developed across the centuries to discriminate between honest thought and rampant speculation (Theodore, 1996). The Internet, true to its roots in free speech and free enterprise, has become an interconnected web of ‘for profit’ and ‘not for profit’ sites that become intermixed into a confusing conglomeration for the everyday user. For example, if one wished to find information on heart disease and typed it into a search engine, which is the card catalogue of the Internet, non profit foundations, health care delivery agencies, pharmaceutical manufacturers, and interested individuals would all be identified. Most of these Internet sites would not have been subjected to common screens for validity, such as scientific peer review. For this reason, the naïve reader may accept suspect research findings and incorrectly interpret outcomes as true. This may lead to expenditure of personal and family resources on implementing strategies that have limited or no likelihood of success. In the present study, Internet resources that might be accessed by parents of children with autistic characteristics were organized and the quality of these resources were evaluated. Autism proved to be an excellent choice for a study on Internet resources. Primarily, the rate of generation of information in the field of autism is accelerating. The literature and expertise related to autism that has developed off line is limited and hard to access. Most of the recent information about autism has developed contemporarily with the Internet. However, the small pool of sound information ‘off line’, combined with the explosion of information about autism ‘on line’, places families at risk of drawing suspect conclusions regarding treatment options.

Purpose/Objective

The ultimate goal of this study was to build a resource of quality online sites for parents of children identified with autism spectrum or pervasive developmental disorders. In order to accurately gauge the validity and accuracy of information about autism on the Internet, an analysis of a sampling of sites pertaining to autism was conducted. A framework to determine the utility of the online information was also established. The content analysis was meant to meet the needs of lay consumers. The objectives of the project were to:

- Develop sampling strategy for accessing online sites with significant focus on information for families of children with autistic characteristics.
- Formulate summary criteria to evaluate the information on the online sites sampled.
- Carry out a content analysis of the sample.

- Formulate critical guidelines and intellectual structures like those that currently exist in institutions like a library but which could be adapted for use with the Internet.

Method

Sampling

From July 1999 to August 1999, the information on the Internet relating to autism was studied. On July 8, 1999 a search of the Internet was carried out using the keyword "autism". "Dogpile" (www.dogpile.com), a meta-search engine that includes queries from 24 separate search engines, accumulated 304,181 "hits" or matching documents. This initial sample consisted mainly of pages containing the word "autism" at least once and not of sites specifically related to autism. The sample was also limited to those sites that had been submitted into the search engines' databases. In the initial search a significant number of sites related to autism were not accessed but were found through hyperlinks and references. "Paid result" sites with no relevance to autism also contaminated this sample. These sites were commercial health web sites that had paid the search engine to be included in any health related search regardless of the query. As such the sample produced by the initial search was considered unusable due to its sheer size and misrepresentation of online resources.

An appropriate sample was created by limiting the number of sites recalled by each search engine to 10. Since search engines index the sites in order of matching content, only sites with more than an 85% match to autism were included in the sample. The search then produced a sample of 68 sites that had a matching relevancy to autism of at least 85%. However as stated above, the search engines only recalled sites that had been registered into their databases. Thus, investigating the initial search results showed hyperlink and reference resources to other related sites that were primarily relevant to autism. These additional resources were arbitrarily included into the sample since they were evaluated to have a matching relevancy of over 85% as judged by the researcher. The final sample included 145 sites. The sampling period was ended when separate searches and hyperlink resources produced similar results.

Summary forms

Summary forms for the 145 sites were created. They were developed in order to identify the content of the sites and to make some evaluation of it. Each site was first described using name, location (i.e. URL) and the sponsoring organization or author. Then the content features were summarized. Early exploration of autism sites revealed common content features that were consistent with information relevant to other developmental disabilities. They include: diagnostic information, intervention strategies, perspective/target audience, and communication approaches supported by each site. Finally, overall judgements of the content features were made concerning focus, content, and format of each site. These judgements are consistent with the OMNI Guidelines for Resource Evaluation (http://omni.ac.uk/agec/archive-evalguid.html; Oct, 2000). A sample of the summary form is presented in Figure 1. The review of the 145 sites was completed in 14 days and a database of the annotated reviews of the sites was complied for analysis.

Figure 1. Criteria and Rationale for Their Use with Autism Related Sites

Criteria	*Rationale*
Site Background	
· Site Name	To describe the vital statistics of the site
· URL	To assess the purpose for the site
· Sponsoring Organization/Author	To evaluate the perspective of the site
· Purpose of the site	
· Information transfer	
· Commercial sales	
· Discussion stimulation	
· Perspective	
· Individuals' experience	
· Researchers' findings	
· Clinicians' approaches	
· Business for profit	
Content	
· Diagnosis, Epidemiology, Pathophysiology, and Etiology	To provide a summary of the information on the site
· Treatment	
· Medical/pharmocological	
· Social/behavioural	
· Occupational therapy	
· Speech/language therapy	
Level of Knowledge	
· Professional	To assess the level of knowledge required of the intended audience
· Family/layperson	
Overall Impression	
· Parent/family resource	To make a judgment on overall suitability of the site as a resource for families of children with autistic characteristics
· Up-to-date information	
· Quality/depth of information	
· Design and aesthetics (layout, frames, organization, presentation)	

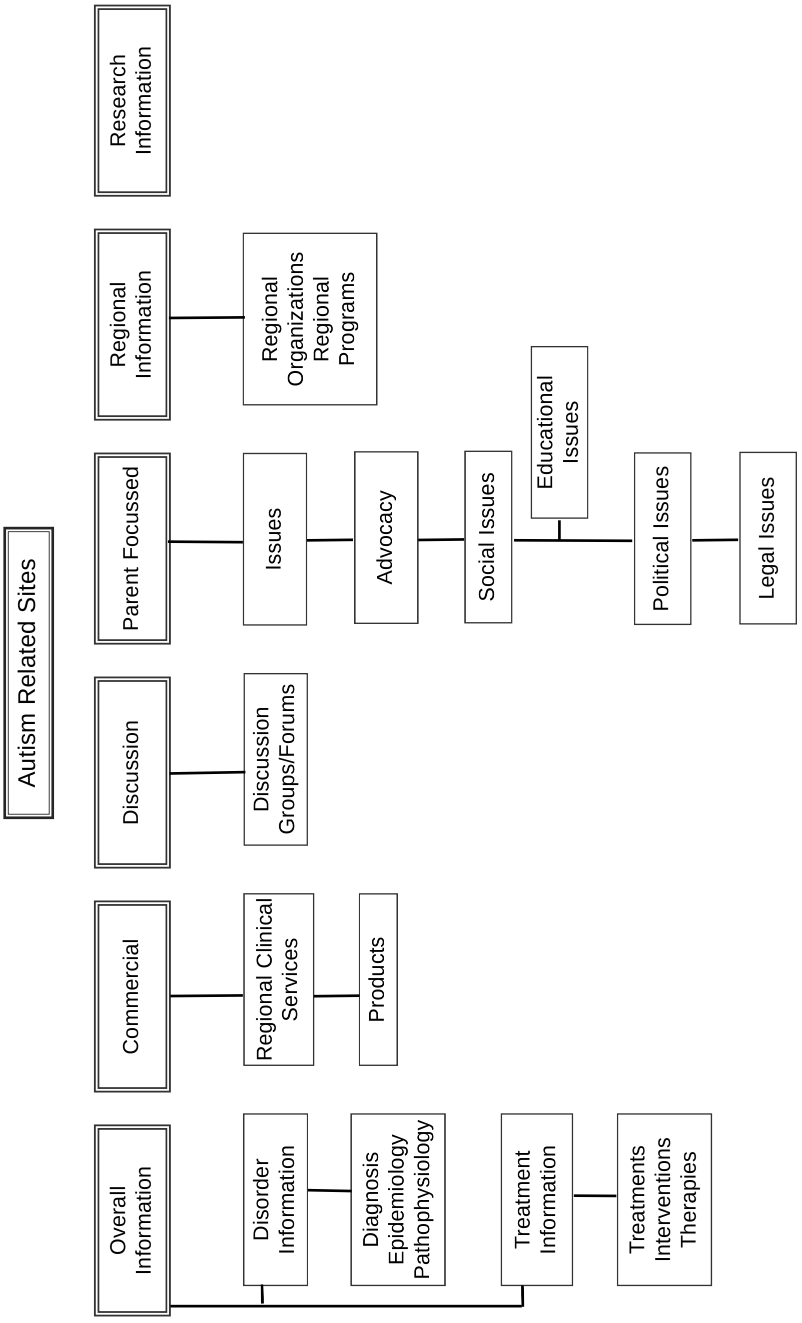


Figure 2. Categorization of Summary Forms on Autism Specific Sites

Content analysis

Thematic analysis of the summary forms revealed a number of themes, which guided the formation of a categorization system pictured in Figure 2. Most categories were self-evident. Others required discussion and a triangulation of agreement between three members of the research team. The number of categories was not set a priori. Categories were created in order to accommodate new themes as they emerged in the analysis of the summary forms. The six categories developed were sufficient to enable each site summary to be placed into one primary category. Subcategories were developed to provide further description.

Results

Frequencies were calculated and graphed for the following aspects of the site summaries and the content analysis: focus, perspective/target audience, sponsoring organization, and categories.

Focus

The majority of the sites (80%) were formed to provide information to web users on some aspect of autism. Commercial sales were the second most frequent purpose (12%) for an autism specific site. The remaining eight percent included bulletin boards, chat forums, mailing lists, and portal sites used to network users.

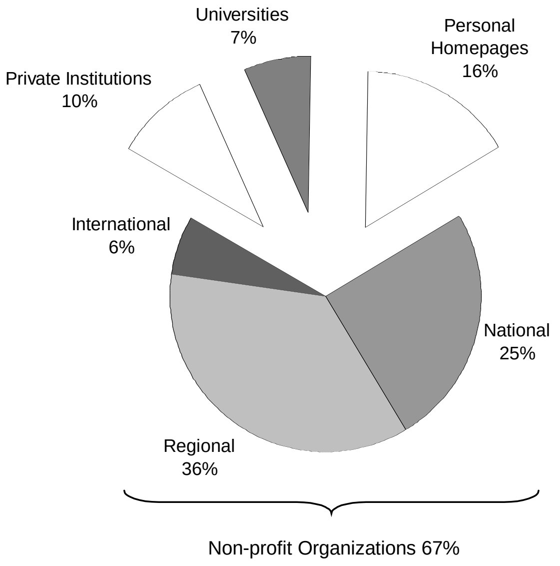
Perspective/target audience

Half (49%) of the autism specific sites were platforms for the perspectives of individuals or private citizens not affiliated with any academic institution or any business. The information in these sites varied in quality. Sites that utilized or reported on original research were the next most common (28%). The remaining sites were evenly divided between sites where professionals promoted clinical approaches and/or program perspectives (11%) and commercial groups or companies (12%).

Sponsoring organization

The sponsoring organization of each site was established. Most of the sites (67%) were produced by non-profit organizations that were regional, national or international in origin. See Figure 3 for a breakdown of these non-profit sponsors. Personal homepages not associated with any other organization or business sponsored the second largest group of autism specific sites (16%). Private institutions such as businesses and companies provided 10% of the sites. Universities were the smallest group (7%) sponsoring autism specific sites.

Figure 3. Sponsoring Organization of Autism Related Sites (n=145)



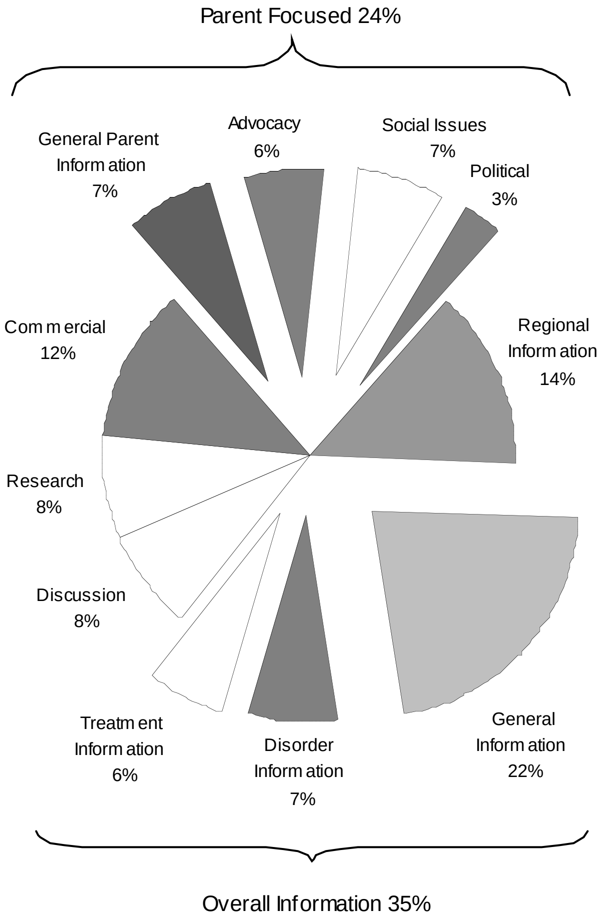
Categories from content analysis

The quantity of sites in each category was calculated. The largest category involved general information (35%) followed by information specific to parents (24%). The number of sites within sub classifications is presented in Figure 4. For instance within the classification of General Information, Disorder Information (diagnosis, epidemiology and pathophysiology) constituted seven percent and Treatment Information constituted six percent of all sites. Commercial (12%) and Regional Information (14%) together constituted another quarter of the sites. Sites dedicated to Research and Discussion were the least plentiful (8% each).

Implications

Consideration of the results in combination with knowledge of the difficulties experienced in carrying out the project lead to the determination of three key implications. First, the sites reviewed were both varied and difficult to assess with respect to purpose and perspective of sponsor. Second, there was an overall dearth of research used in the sites. Third, the former two implications imply the need for an online filtering service for parents wishing to access information from autism specific sites. The team members were naïve as to the effort required to launch such a site as directed by the fourth objective of this project.

Figure 4. Breakdown of Content in Autism Related Sites



There is diversity in the online information on autism specific sites. Although the sites were developed in the majority to impart information, half of the sites gave information from a personal perspective that was sponsored by nonprofit organizations or the individual themselves. There was considerable challenge experienced when trying to determine the perspective of the site sponsor. Commercial sites would be masked as having clinical or research perspectives and individual or nonprofit organizations frequently did not present their experiences as quantifiable data. Strategies used to make accurate determinations of perspectives included: backtracking from the page designated by the search engine to the parent home page, use of links on the page designated by the search engine, e-mailing the author of the site, and examining contact information on the page designated by the search engine.

The scientific validity of information on most sites was suspect. Only 28% of the sites had a research perspective. Twenty percent used information that could be traced to research published in the traditional manner. The remaining eight percent of sites functioned to publish original research findings outside of the scientific review process. Overall then, 80% of online autism-specific sites have information that cannot be verified.

The volume of sites coupled with lack of clarity in the perspective of the sites and the minimal use made of verifiable research contributes to the immediate need for an online resource to evaluate autism specific sites for the public. On the basis of the findings from the present study, the development of such a site was planned. The major challenge to its success was lack of funding. Manpower capacity to operate, and to maintain such a site, is a lesser challenge.

Summary

In summary, a number of quality sites are available to families.[1] The content analysis carried out in this project has demonstrated that an impartial review of sites is possible. The challenge to parent consumers is the identification and accessing of valid sites. The sampling methods, evaluation criteria, and classification of content developed here could function as the foundation for a new online filtering resource.

Endnote

[1] For example, see References in the Preface and other articles in this voume (Editors' note).

References

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OADD
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