

Providing Web-based Support for Families of Infants and Young Children With Established Disabilities

Anat Zaidman-Zait, MA; Janet R. Jamieson, PhD

Infants and young children with established disabilities have significant problems across various domains of development. As a consequence, their parents may face various challenges and difficulties in parenting (M. J. Guralnick, 2004). During the years of infancy (or from the time of diagnosis) and throughout early childhood, parents often have continuing needs to obtain information, identify services for their child, and receive emotional support related to issues with which they are coping. Recently, the Web has become a major source for obtaining information and support, and it has been suggested that the Internet may be utilized to provide information and support to families as a valuable and convenient supplement to face-to-face service provision. This article discusses the advantages and disadvantages of Internet use for parents of children with disabilities, the implications of parents' Internet use for early intervention professionals, and recommendations for professionals interested in developing Web sites to provide information and support to parents.

Key words: *child disability, Internet, parents, professionals, support*

PARENTS whose infants and young children with established disabilities have significant problems in cognitive, social-emotional, motor, or sensory domains of development face various challenges and difficulties in parenting (Guralnick, 2004). These challenges in turn create a set of stressors related to parents' needs to obtain information, identify services for their child, cope with issues related to family support and interpersonal relationships, and instill a sense of confidence in their ability to parent their child (Guralnick, 2001). In particular, following diagnosis, parents have a high need for ob-

taining multifarious information with regard to the disability characteristics, treatment options, services, and resources available for their children (eg, McWilliam & Scott, 2001; Upshur, 1991). Traditionally, parents have turned to medical, rehabilitation, or educational professionals as reliable sources for informational support. Recently, the Web has become an additional major source for obtaining information, and, increasingly, individuals around the world are turning to the Web for health-related knowledge (eg, Baker, Wagner, Singer, & Bundorf, 2003; Dryburgh, 2001; Fox & Fallows, 2003; Fox & Rainie, 2002; Statistics Canada, 2004; U.S. Department of Commerce, 2000). Parents, for example, consult the Web regularly concerning their children's development and health (Ikemba et al., 2002; Zero to Three, 2000) and when their children have been diagnosed with disabilities (Blackburn & Read, 2005; Skinner & Schaffer, 2006; Zaidman-Zait & Jamieson, 2004a). In addition to providing informational support, the

From the University of British Columbia, Vancouver, British Columbia, Canada.

Corresponding author: Anat Zaidman-Zait, MA, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia, 2125 Main Mall, Vancouver, British Columbia, Canada C V6T 1Z4 (e-mail: zaidman@interchange.ubc.ca).

Web is a rich resource of emotional support in the form of various types of on-line discussion forums (eg, Jones & Lewis, 2001; Wright, 2002).

Proponents of helping theory (Dunst, Trivette, & Deal, 1994; Dunst, Trivette, & Hamby, 1996) and the support approach to early intervention (McWilliam & Scott, 2001) underscore the important role of professionals in supporting the various informational needs of parents in order to help them understand their child's disability, obtain information about available resources and intervention strategies, and make decisions accordingly, and also in facilitating the provision of emotional support. Given the increasing parent proclivity to consult the Web for these information and support purposes, professionals and parents alike need to keep in mind the inherent benefits and dangers of this type of information dissemination. On the one hand, for example, the Web provides easy access to thousands of pages of information on an as-needed basis, and it provides parents the opportunity to establish communication with professionals. In addition, by facilitating interaction with other parents who are going through similar experiences, the Web may also function as a source of emotional support. On the other hand, the Web also presents major problems, including little or no monitoring of the quality, reliability, and currency of the disseminated information (Martland, 2001), as well as information overload (McGrath & Hollingshead, 1994). The purposes of the present article are threefold: (1) to discuss the advantages and disadvantages of the Web as an informational and support resource for parents of children with disabilities, and to review empirical research on the effectiveness of the Web for information dissemination to parents and professionals; (2) to discuss the implications of Web-based information and support for parents; and (3) to provide recommendations for professionals interested in developing Web sites to provide information and support to parents.

INFORMATION RETRIEVAL BY PARENTS: ADVANTAGES AND DISADVANTAGES OF THE WEB

In comparison to traditional sources of information and support available to parents of infants and young children with disabilities, the Web provides an unforeseen ease of access to a great amount and a wide variety of information on an as-needed basis. Information retrieval is a technically straightforward process and usually begins with the use of search engines (Pallen, 1995), which help people locate information.

Among the variety of search engines available, Google is the most popular (Gwendolyn, 2002; Sherman, 2002) and the most likely to be used by parents. Merely by entering keywords, the user is directed within seconds to relevant Web sites. For families who already own computers and have Internet connections, the use of on-line health resources is virtually free. In 2004, most Canadian households contained computers in their homes with access to the Internet (Statistics Canada, 2004). Similarly, already by 2001, about 50% of American households had computers with access to the Internet (U.S. Department of Commerce, 2002). The cost of Internet use is also low or, in some cases, free for those who have access to municipal libraries that are connected to the Internet.

The Web permits parents to investigate current and emerging information about their child's condition in privacy and anonymity. It affords access to a wide variety of information and a variety of perspectives on the same topic (Fox & Rainie, 2000; Skinner, Biscope, & Poland, 2003). In addition, the Web provides access to information about rare or new conditions, such as the genetic condition of 22Q deletions, for which information is generally limited. The Web provides access to information about treatment and service options (eg, clinical trials) that doctors or other professionals might not have mentioned or of which they might not have been aware. Furthermore, the Web provides

access to information from other parents who can provide practical information that users might feel hesitant to discuss with their doctors (eg, Hardey, 1999) or information about which their doctors are less knowledgeable. For example, parents might learn about very specific behavioral modification strategies that are effective with children of a certain age with a particular disorder. In this connection, Skinner and Schaffer (2006) found that 83% of the parents of children with genetic diagnoses in their study turned to the Internet for some purpose related to their child's condition (eg, obtaining a diagnosis for their child's condition, searching for a second opinion, identifying appropriate services and treatment, and participating in on-line support and advocacy groups). In this process, the parents reported that they felt they had become increasingly knowledgeable consumers and had positively influenced the course of their children's treatment and intervention. Overall, on-line parent networks are sources of both informational and emotional support, as will be discussed later.

Parent education may be enhanced by diverse design features that enable creative and exceptionally clear presentation of complex information. For example, the Cochlear Corporation (www.cochlear.com) makes use of animation to educate parents about the physiology of hearing and the process of cochlear implant surgery for deaf children. Another example is the Strategies for Intervention in Everyday Settings (SPIES) Web site, which disseminates a research-based, modified curriculum that was developed by the Center for Persons with Disabilities in 1998. The aim of the curriculum is to teach parents strategies for interacting with young children who have disabilities (see Cook, Rule, & Mariger, 2003, for details). The goal of the SPIES Web site is to help parents relate an intervention to their daily routine, and to provide parent support through a self-paced tutorial that is available at any time. Parents reported that they found Web-based procedural guidance to be a useful support and a useful complement to the

provision of early intervention services (Cook et al.). Furthermore, there have been innovations in developing Web-based intervention programs using videoconferencing sessions with professionals and self-guided Web pages. For example, Wade, Wolfe, Brown, and Pestian (2005) described initial evidences of the feasibility and efficacy of an on-line family-centered intervention program for children with traumatic brain injury and their parents (The "Web-Based Family Problem Solving").

At the time of diagnosis of a child's disability, parents often experience intense emotional responses (eg, Koester & Meadow-Orlans, 1990) and are confronted with complex and unfamiliar medical and educational terminology, all of which can interfere with their ability to process detailed information concerning child characteristics or intervention options. However, subsequent to the overwhelming interactions with various professionals involved in the diagnostic process, parents can initiate an information-seeking process on the Web and attempt to sort through the complexities of the disability and available options at their own pace and in the convenience of their own homes.

The awareness of certain characteristics of material posted on the Web will help empower parents to use the information appropriately and to maximum benefit throughout the on-line information-seeking process. Particular aspects of which parents need to be vigilant include quality of information, clarity of accuracy markers, information overload, information coverage, and Web site design and maintenance.

Quality of information

Although the Web has indisputably become a valuable and convenient tool for parents, there are also many inherent risks involved in this relatively novel approach to information dissemination and support. First and perhaps most important, although the widespread ability to disseminate information on the Web is one of its democratic

advantages, this also contributes to one of the Web's major problems, namely, the issue of quality of information. There is no review or approval of the content of Web information for accuracy before it is available for parents, leading one researcher to describe the lack of quality control as "the Wild West of the Information Age" (Smith, 1999, p. 31). Furthermore, the heterogeneity of information disseminators (Jansen, Spink, & Saracevic, 2000; Wang, Hawk, & Tenopir, 2000; Zaidman-Zait & Jamieson, 2004b), such as government agencies, profit-based companies, and academic communities, that can be valuable in terms of giving a stage for differing agendas for presenting a wide range of views, can, at the same time, make it very challenging for parents to discern the reliability of a particular source.

There have been some attempts to evaluate Web sites by researchers, who have been alarmed by the lack of accountability on the new medium. For example, using different approaches for evaluating Web sites, researchers have evaluated the quality of information about various medical conditions, such as depression, childhood diarrhea, and management of children's cough (Lissman & Boehnlein, 2001; McClung, Murray, & Heitlinger, 1998; Pandolfini, Impicciatore, & Bonati, 2000; Wright, Williams, & Partridge, 1999). Web sites' information about the examined health-related condition was compared to the information available from reliable sources of information, such as current research or current guidelines from recognized medical organizations. Results from these studies indicated a low percentage of concurrence with reliable guidelines, suggesting that the quality of information produced by the Web search was quite low. The challenge for families who are seeking information about different disabilities on the Web is to separate the unreliable from the reliable sources available to them on the Web.

But what criteria do parents employ when evaluating the quality and authority of on-line health resources or the information they access on-line? Few studies have examined the

issue of quality of information from the perspective of parents' interaction with the information they access on the Web, the way parents evaluate health-related information, and their decision-making procedures regarding authority and quality. Of the few studies that exist, Fox and Rainie (2002) found that parents are less likely than nonparents to look for information regarding who disseminates information on Web sites, likely to spend more time on-line during a search, visit at least 4 sites for the desired information, and more likely to talk to their doctor about information they uncovered on-line. Hence, parents may be described as quite responsible searchers.

In another study, Bernhardt and Felter (2004) found that mothers of young children expressed serious concerns regarding the reliability of health information they access on the Web. Some of the strategies the mothers employed to determine their trust in the information retrieved included exploring the motives of the Web sites' owners, evaluating the source of information, and looking for information repetition and convergence. In addition, the mothers stated that they had a preference for on-line information that was presented by clinical professionals versus on-line advice from other parents. It seems reasonable to assume that parents will trust recommendations about Web sites from reliable sources, such as professionals in early intervention programs. In this connection, Taylor, Alman, and Manchester (2001) found that parents were likely to visit a Web site that was recommended by their doctor. Parents may be expected to incorporate information they glean and trust from the Web with other sources of information they already possess.

The increasing concern regarding quality of information on the Web has led to a number of initiatives to help consumers in the process of accessing and judging the information. Some Web sites have been developed by organizations that include references to only authorized Web sites that can be trusted as reliable, based on their dissemination source. For example, Healthfinder, a Federal Web site developed by the U.S. Department of Health

and Human Services together with other Federal agencies (www.healthfinder.gov), functions as a resource for finding the best government and nonprofit health and human services information on the Internet. By way of illustration, when the keyword "autism" was inserted into the Healthfinder Web site on November 5, 2004, 10 sites appeared. These sites included information disseminated by sources such as the Centers for Disease Control and Prevention (CDC), which is a federal government agency; a branch of the National Mental Health Information Center, which is part of the federal Department of Health and Human Services; and the National Dissemination Center for Children with Disabilities.

A similar example is the Health on the Net Foundation Code of Conduct (HONcode) for medical and health Web sites. This code helps standardize the reliability of medical and health information available on the Web. The HONcode (<http://www.hon.ch>) does not intend to rate the quality of the information provided by a Web site; rather, it only defines a set of rules, including holding Web site developers to basic ethical standards in the presentation of information and helping ensure that readers are aware of the source and purpose of the data they are reading. Another example of quality control is the "Web Guide" Web site (www.cfw.tufts.edu), which lists Web sites that disseminate information on child development, including information on specific disabilities such as autism and Down syndrome. The Web Guide site is unique in that it uses an objective, valid, and reliable evaluation tool that was developed by Martland (2001), who consulted experts in the field. Each Web site listed on the Web Guide is evaluated on the basis of 4 criteria: content (level of documentation provided for the information presented), authority (rated on the credentials of both the sponsoring organization and the individual authors of the information presented), stability of site (presence or absence of a creation/copyright date, evidence of maintenance), and ease of use (rated on the accessibility of material on the site, ease of navigation, consistent page lay-

out, working links, and acceptable loading time). Taken together, all of these quality-related Web sites are important in establishing the value of strictly monitored sites on the basis of evidence-based research, usability, and timely maintenance.

Unclear accuracy markers

To complicate matters further, the ease of publishing and editing on the Web may obscure traditional "markers" that enable naïve readers to discern between evidence-based research and popular but unproven views (Wyatt, 1997). This may prove especially problematic for parents, who are trying to educate themselves regarding their child's disability in order to inform their decision making. Nevertheless, there is a paucity of research aimed at identifying indicators of accuracy of information on the Web. One exception is a study conducted by Fallis and Frické (2002), who identified 3 indicators of accuracy that were correlated with the accuracy of the information. These indicators were the display of the HONcode logo, the organization domain, and copyright. However, in the absence of clear accuracy markers, parents have to make judgments of the wide range of quality and authority of Web information for themselves.

Information overload

Information overload may also pose a challenge to parents who are accessing information on the Web. When using a search engine to find information on a particular topic, it may be possible that thousands of matching Web sites will appear. This can contribute to information overload for parents, that is, having too many things to do at once on the Web site (McGrath & Hollingshead, 1994) or learning more than they want to know (Gutzman, 2001). Overload of information can be a problem in cases when a large number of ideas need to be organized and evaluated (Gallupe & Cooper, 1993). This may be the case when parents are seeking information with regard to their child's disability, because the massive amount of information initially confronted is

Table 1. Number of specific topic-related Web site matches identified by the search engine Google (November 2004)

Keywords	Matches (approx)
"Autism" and "children"	1,600,000
"Down Syndrome" and "children"	909,000
"Deafness" and "children"	365,000
"Cerebral Palsy" and "children"	581,000

not organized on the Web in a leading way to help them gradually absorb it. For example, as shown in Table 1, the keywords "Down Syndrome" and "Children" elicited about 909,000 Web sites on the Google search engine. Findings from a recent survey of Internet use by parents of disabled children (Blackburn & Read, 2005) indicated that high proportions of parents reported problems, such as the time and ability to find needed information. Parents need some strategies to reduce or sift through the large amount of information, and some of this assistance is available through Web sites. For example, Elliott (1999), using research-based criteria, classified sites on family life education on the Web and compiled an extensive list of sites that could be used as a reference for parents and family professionals. In addition, he conducted an analysis of the main content areas of family life education to determine what kind of valuable resources could be found and which areas had been neglected. On the basis of his findings, Elliott established a Web site that includes a list of Family Life Education sites classified into topic areas for the use of professionals. An example of a Web site that was designed to help parents handle the overload of information is the "Cochlear implants: Navigating a forest of information...one tree at a time" site developed by the Laurent Clerc Center of Gallaudet University (Nussbaum, 2003). This Web site organizes information on cochlear implants according to specific topics—trees (eg, what is a cochlear implant, candidacy, listening)—and under each topic provides information—

branches—as well as links to recommended Web sites that provide further information on that topic.

Information coverage

Information coverage is an additional concern. Does the information disseminated match parents' range of informational needs? In this connection, Zaidman-Zait and Jamieson (2004b) examined the coverage of information on the Web regarding cochlear implants. Their findings indicate that information related to education, key aspects of habilitation, and choice of communication approaches—all vitally important topics to parents of deaf children—were either barely addressed or neglected altogether. This information is particularly crucial because parents often make decisions concerning their child's educational placement and mode of communication concurrent with the decision for cochlear implantation. In fact, the issue of education has previously been reported as one of the greatest concerns to many parents of deaf children with cochlear implants (Christiansen & Leigh, 2002). It appears, then, that although Web sites may provide helpful knowledge, they may also be an imprecise match for parent information needs.

Another approach to investigating the coverage of information needs on Web sites is user-based assessments (Marton, 2000; U.S. Department of Health and Human Services, 2002). Marton examined whether the Women's Health Web site (WHW) met the health information needs of women by asking participant users to view the WHW in a computer laboratory and evaluate its design and content. The participating women had positive attitudes toward the delivery of health information on the Internet. They found the text-based content on the WHW interesting, easy to understand, and useful. However, they would have appreciated more communications channels, such as newsgroups, listservs and chat rooms, which are moderated by health care practitioners. Thus, user feedback

can be a useful tool for enhancing the content of Web site information and support.

Effects of user characteristics on information accessibility

Even though health information seeking appears to be appealing to individuals regardless of income status or race (Fox & Rainie, 2000), there are reported differences in the characteristics of consumers of on-line health information (see review in Cotten & Gupta, 2004). Cotten and Gupta examined how computer and Internet usage, health status, and sociodemographic characteristics affect health information seeking. Findings indicate that age, income, and education were related to whether individuals sought information on-line or off-line. Individuals with lower education and income levels were less likely to use the Internet for seeking health information. The authors concluded that “diminishing the inequalities may be a key to increasing on-line health information seeking and thus potentially empowering health care consumers” (Cotten & Gupta, p. 1804).

Another existing concern is whether everyone can benefit from the availability of on-line health-related information (Eng et al., 1998). There is discussion in the literature concerning the effects of factors such as low literacy levels, culture, gender, socioeconomic status, and disability on rates of general Internet use, rates of e-health use, and on users' capacity to navigate and interpret information found on-line (eg, Murray et al., 2003; Pandey, Hart, & Tiwary, 2003). In a recent empirical study, Birru and colleagues (2004) examined how 8 low-literacy adults, after a short intervention, accessed health information on the Web. Findings indicate that low-literacy adults face some challenges in accessing health information on the Web. For example, the participants did not use optimal search terms to answer their questions, they encountered reading difficulties as the health information was at a higher reading level than their current reading level, they found it difficult to interpret the information when presented, and they used only a limited number of the links

suggested by the retrieval page. The adverse findings regarding inequality in Internet ease of use raise concerns and highlight a need to improve Internet access for disadvantaged groups (Gustafson et al., 2001; Murray et al., 2003).

Web site design and maintenance

Another important feature for Web users, particularly naïve users, is a site's ease of use, which refers to the extent to which (1) a site can easily be navigated and information accessed, (2) the language can be easily understood, and (3) links to other sites are operational (Martland, 2001). Additional concern surrounds Web site user-friendliness. Broken links, complex frames, general disorganization, use of overly technical language, and relatively opaque search engines make many sites less than user-friendly, even for individuals with average or above-average literacy levels (Cline & Haynes, 2001; Jadad & Gagliardi, 1998). For example, the women in Marton's (2000) study of the Women's Health Web site experienced difficulty navigating the Web site, and they wanted to see the addition of more graphic organizers.

A further criterion of a Web site's quality is that it is current and regularly updated, as demonstrated by the copyright date or “last update” indication on the site. In this connection, parents need to be assured that the information they are obtaining is current, but in the medium of the Web, sites may still be on-line but not have been touched in years (Martland, 2001). In short, the Web is a highly dynamic environment that enables the retrieval of current information, but, in contrast, may also disseminate outdated information.

SUPPORT FOR PARENTS OF YOUNG CHILDREN WITH DISABILITIES

In addition to the function of the Web as a rich resource for vast amounts of information regarding special topics concerning children's disabilities, the Web also contains many electronic groups, chat rooms, and bulletin boards whose main purpose is

to enable communication between parents with similar interests. Virtual support communities have been defined as "a group of people with similar concerns who communicate via information technology" (du Pré, 2000). These communities typically consist of smaller discussion groups in which people can engage in communication about specific issues (Wright, 2002). The goals of on-line support groups include collaboration between participants, information sharing, social and emotional support, and personal empowerment (Bowers, 1997; Roberts & Fox, 1998; Sharf, 1997; Winzelberg, 1997). However, according to Jones and Lewis (2001), only a very few studies have examined the functioning of these groups and their efficacy.

Two main support functions can be provided in on-line groups. First, informational support is based on the knowledge and experience of the participants, who may also refer fellow users to other resources and Web sites containing information about the issue of interest (Wright, 2000). This function of the Internet to connect people to multiple sources of information appears to be one of the appealing features of on-line support groups (Rice, 2001; Weinberg, Schmale, Uken, & Wessel, 1995). Second, emotional support may also be a significant aspect of on-line groups. Finn (1999) and Braithwaite, Waldron, and Finn (1999) found that the majority of the discussion in on-line support for people with disabilities was providing social-emotional support.

As mentioned previously, parents of infants and young children with established disabilities are confronted with multiple challenges that may give rise to tremendous stress (Guralnick, 2004). One valuable source of parental support that has been frequently cited in the literature is parent-to-parent support (eg, Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001), which can, in turn, lead to a feeling of well-being (Dromi & Ingbar, 1999; Dunst & Trivette, 1990; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). The interaction with other parents whose children face similar challenges has been reported to pro-

vide support, reduce the parental sense of isolation, and suggest models and strategies for coping (Christiansen & Leigh, 2002; Cooper & Allred, 1992; Freeman, Carbin, & Boese, 1981). On-line communities for parents of children with diverse disabilities can be an important tool to help meet both the information and emotional needs of these parents.

In a recent study, Jones and Lewis (2001) explored the communication occurring on the Down Syndrome Discussion Group for a period of 6 months. The group exchanged information on issues such as medical matters, new treatments, services, policies, and personal life stressors. In addition, there was a sense of shared identity and support. The content analysis of the on-line interactions indicated that the discussion group served a number of positive functions for parents, including exchanging information, expressing personal opinions, sharing experiences and obtaining advice, and receiving mutual support.

Wright (2002) reviewed and summarized many of the advantages and disadvantages of on-line support groups in general. The advantages were numerous: participants can choose a group affiliation with other members with highly similar experiences; they can join the group according to their need and convenience; they are not confronted with traditional problems of arranging a time and place for meetings; and they can maintain their privacy and remain anonymous, and, thus, they might reveal more and be more open than they typically would in face-to-face interactions. Furthermore, the act of writing—still the main means of on-line communication—can be therapeutic by itself (Weinberg et al., 1995). From the perception of participants in an on-line support group for people with cancer and their families, the similarity between the on-line members and their experiences were seen to be the greatest advantages of the on-line community (Wright, 2002).

There are several groups of parents for whom online discussion groups might be an extremely beneficial source of support. First, parents living in rural areas, who do not have

close or regular contact with other parents of children with similar disabilities, may find on-line parent groups to be virtually the only regular means of parent-to-parent support. Second, parents whose children have a low-incidence condition, such as rare syndromes, may locate other parents of similar children only through the worldwide community accessing the Internet. The third group includes parents whose circumstances render leaving their homes a challenging endeavor, such as parents of children with behavioral disorders that make visits to professionals or libraries difficult, parents who work full-time and have little or no time to spend searching for resources outside of their homes, and parents who have disabilities or illnesses that make other forms of outreach difficult. The lack of face-to-face communication, seen as advantageous in many respects in on-line interactions, also gives rise to many disadvantages (Wright, 2000, 2002). For example, the inability of participants to make physical contact, lack of nonverbal cues, and slower feedback than typically occur in face-to-face conversation were all identified as potentially leading to misunderstandings or breakdowns in communication. Additional disadvantages include the possibility of hostile communication among on-line participants (Preece & Ghozati, 2001) and opportunities for misinformation due to uninformed participants (Braithwaite et al., 1999; Fox, 2000; Rice, 2001). Participants in Wright's (2002) study perceived the delayed feedback, the off-topic remarks, and inability to hear tone of voice as the significant disadvantages of the on-line support group.

INTERNET USE FOR PROFESSIONALS: IMPLICATIONS AND RECOMMENDATIONS

Professionals involved in early intervention with children with established disabilities and their families should be aware of the increased use of the Web by parents for obtaining information (Dryburgh, 2001; Horrigan & Rainie, 2002; Statistics Canada, 2004). Furthermore, professionals should reflect on their own atti-

tudes regarding parents' Internet use for information, and on the way they react to parents' communication regarding their information- and support-seeking through this medium. Potts and Wyatt (2002) examined the perception of Web-using doctors about the actual benefits and harms of Internet use to their patients. Problems identified by doctors included longer consultations than occurred during previous appointments; more unnecessary medical tests and investigations; more unnecessary treatments; and patients' desire for new, unavailable treatments. Doctors felt that there are cases in which patients can put too much faith in the Internet, and that, in turn, can undermine faith in the doctor, or can improve confidence, in cases where the information found matches the doctor's approach or knowledge base (see also Hardey, 1999). In another study, patients believed that health information on the Internet has more positive than negative effects on the physician-patient relationship (Murray et al., 2003).

The Internet represents a challenge to formerly hierarchical models of information giving, in which professionals had control over the content and flow of information provided to patients (Hardey, 1999). Traditionally, professionals have been the gatekeepers of specialized knowledge concerning children's exceptional needs and options for habilitation. Increasingly, however, the Internet is providing a means of equalizing the balance of knowledge-based power between parents and professionals: parents are now often arriving at the doors of early intervention programs with information derived from the Web (Fox & Rainie, 2002). Furthermore, parents are using the Internet to receive information and emotional support from on-line groups of parents facing similar challenges (Jones & Lewis, 2001). Keeping these changes in mind, professionals can utilize this new medium and its advantages in their collaborative work with parents, while keeping in mind its benefits and limitations in meeting parent needs.

Early intervention professionals may utilize the Web in their supportive interactions with

parents in at least 2 major ways. First, because the Web can serve as a valuable resource for parents, professionals can support and guide parents in their information-seeking activities, as the parents learn to discern which sites are useful and trustworthy. Second, professionals may even develop Web sites as part of their service delivery for parents. Each of these pathways, in turn, can enhance the parent-professional collaborative relationship.

Information-seeking guidance for parents

In terms of support and guidance, professionals can help parents organize the information they obtain on the Web into a useful form that can be applied in the decision-making process concerning their child. As previously mentioned, parents are exposed to a vast amount of information on the Web—some of it neither high-quality nor accurate—and parents who are new to this information may find it overwhelming to navigate their way through the Internet maze and judge the quality of the information. In this connection, professionals can educate parents about the advantages and disadvantages of the Web, particularly alerting parents to the notions of the authority of Web site creators and the stability of the sites. Professionals can also establish a list of recommended Web sites that have been reviewed by a panel of experts in the field or provide a list of trusted organizations or research-based sites that disseminate information on topics of interest (as done by Martland, 2001). Another option professionals might use is to direct parents to a central Web site (such as Healthfinder or Web-Guide) that directs users to authorized Web sites on particular subjects. Parents, like the academic participants in Wright's (2002) study, would probably appreciate receiving a list of trustworthy sites. This, in turn, could help parents cope with issues of information overload, authority, and quality.

It is important for professionals to be aware of the Web sites most likely to be accessed by the parents with whom they work, because the Web is not subject to peer review

(Pereira & Bruera, 1998), and parents may be accumulating both information and misinformation. One efficient means of accomplishing the type of search that parents undertake is to enter relevant keyword searches in Google and review the first 10 sites listed, which will usually be the only sites explored out of all the matches retrieved (Baeza-Yates & Ribeiro-Neto, 1999; Oard, 1997). Another, more direct approach is for professionals simply to ask parents about their own on-line searches and recommend that parents bring their findings to their appointments. (This would also reduce any parent concerns that professionals might regard parents' on-line searches as a challenge to their professional authority.) Professionals will then be in a position to discuss with parents the information the parents have accessed on the Web, fill in gaps of missing information, and correct any misinformation.

Professionals may also find the Web to be a valuable component of parent education. For example, outstanding Web sites, such as those containing clear and accurate videos and animation, may be used to help address parents' information needs. Professionals may also choose to use the Web to introduce parents to the range of available or possible treatment and habilitation options. The Web may also function as a source of emotional support to parents. As a supplement to the in-person emotional resources offered to parents, professionals may suggest that parents contact other parents on the Web for information and support, or read personal-experience stories of families facing similar challenges. These contacts and narratives may prove especially beneficial to parents living in rural areas, where specialized resources and parents in similar situations may be few in number.

The development of new Web sites

A second important manner in which early intervention professionals may choose to use the Web is to design and establish their own Web sites as a complement to existing "in-house" services. Rayport and Jaworski (2003) suggested a framework of 7 design elements

that are important in incorporating usability and accuracy for the consumer, and 4 of these, namely, context (ie, layout and design), community (ie, the interaction between users), connection (ie, the communication between the site and its users, as well as the linkages to other sites), and customization (ie, the extent to which a site is useful to different users), are important for professionals to keep in mind when establishing sites for parents. Wyatt (1997), Wyman (1997), and Martland (2001) all agreed that once Web sites are in operation they should be evaluated for a variety of factors, most notably accuracy, ease of use, and regular updating. Web sites individually designed by early intervention programs could be tailored to help meet parents' information and support needs, particularly if usability of the site was a central focus. In other words, the more a site uses lay language and is organized in pages with clear headings, the more parents can devote their attention to the site's content, rather than searching and scrolling (Cook et al., 2003). In addition, professionals can provide parents with references on Web sites for relevant research to help them make evidence-based decisions, and they can also establish links to other recommended sites. Finally, curriculum-based Web sites could be a supplement to the direct provision of early intervention services by providing parents with suggestions for interaction strategies and other teaching tips to use with their children, while incorporating videos, examples, and exercises.

Another feature that can be promoted by professionals is professional-to-parent communication. For example, an "Ask the Expert" feature on an organization's Web site would allow parents to contact experts with questions that might arise in the difficult days following diagnosis or as they consider various approaches to habilitation or treatment. By involving academic scientists among the panel of experts, this feature could also serve to ensure that parents have accurate and current information concerning research findings and advances (Bader & Braude, 1998). This could prove to be a tremendous resource

to parents living in rural areas, where specialized resources and professionals may not be readily available. Professionals who are not able to monitor and respond to e-mails on a daily basis might consider a "Frequently Asked Questions" section or offer some "On-line Office Hours" in the form of a moderated chatroom.

Web sites that are developed to help parents build an on-line community and to promote communication among parents, professionals, and researchers could provide an important parent support function. Different options could be made available to meet parents' logistical and support needs. For example, chat rooms provide real time communication and immediate feedback, whereas bulletin boards and e-mail listservs do not require parents to log on to the computer at the same time. These types of networks may help parents cope with different stressors, as described by the buffering model of social support (Schwarzer & Leppin, 1991), and also reduce stress, as suggested by the direct-effect model of social support (Cohen & Wills, 1985).

Early intervention programs that involved parents in building and evaluating Web sites would have a higher probability of addressing the needs of specific groups of parents for information and support, as opposed to those Web sites that were entirely established and driven by professionals. Furthermore, Web sites that are available in various languages—and that reflect cross-cultural understandings of disability and treatments—would help ensure their accessibility to parents representing a broad range of cultures and languages.

It is entirely appropriate that the new frontier of the Internet is being met with both enthusiasm and caution by parents of young children with established disabilities and the professionals with whom they interact. However, used with caution, imagination, and parent input, the Web has the potential to be a valuable means of enhancing parents' knowledge. This increased knowledge base may, in turn, promote parent empowerment, consistent with family-centered models of

early intervention (Turnbull & Turnbull, 1997; Turnbull, Turbiville, & Turnbull, 2000), and facilitate positive development and health

outcomes for their children, appropriate service delivery, and improved parent-professional collaborative partnerships.

REFERENCES

- Bader, S. A., & Braude, R. M. (1998). "Patient informatics": Creating new partnerships in medical decision making. *Academic Medicine*, 73, 408-411.
- Baeza-Yates, R., & Ribeiro-Neto, B. (1999). *Modern information retrieval*. Wokingham, UK: Addison-Wesley.
- Baker, L., Wagner, T. H., Singer, S., & Bundorf, M. K. (2003). Use of the Internet and e-mail for health care information: Results from a national survey. *JAMA*, 289, 2400-2406.
- Bernhardt, J. M., & Felter, E. M. (2004). Online pediatric information seeking among mothers of young children: Results from a qualitative study using focus groups [Electronic version]. *Journal of Medical Internet Research*, 6, e7.
- Birru, M. S., Monaco, V. M., Charles, L., Drew, H., Njie, V., Bierria, T., et al. (2004). Internet usage by low-literacy adults seeking health information: An observational analysis [Electronic version]. *Journal of Medical Internet Research*, 6, e25.
- Blackburn, C., & Read, J. (2005). Using the Internet? The experiences of parents of disabled children. *Child: Care, Health and Development*, 31, 507-515.
- Bowers, L. (1997). Constructing international professional identity: What psychiatric nurses talk about on the Internet. *International Journal of Nursing Studies*, 34, 208-212.
- Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication*, 11, 123-152.
- Christiansen, J. B., & Leigh, I. W. (2002). *Cochlear implants in children: Ethics and choices*. Washington, DC: Gallaudet University.
- Cline, R., & Haynes, K. (2001). Consumer health information seeking on the Internet: The state of the art. *Health Education Research*, 16, 671-692.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Cook, R. S., Rule, S., & Mariger, H. (2003). Parents' evaluation of the usability of a Web site on recommended practices. *Topics in Early Childhood Special Education*, 23, 19-27.
- Cooper, C. S., & Allred, K. W. (1992). A comparison of mothers' versus fathers' needs for support in caring for a young child with special needs. *Infant-Toddler Intervention*, 2, 205-221.
- Cotten, S. R., & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science & Medicine*, 59, 1795-1806.
- Dromi, E., & Ingbar, S. (1999). Israeli mothers' expectations from early intervention with their preschool deaf children. *Journal of Deaf Studies and Deaf Education*, 4, 50-68.
- Dryburgh, H. (2001). *Changing our ways: Why and how Canadians use the Internet*. Retrieved March 22, 2003, from Statistics Canada Web site: <http://www.statcan.ca/english/IPS/Data/56F0006XIE.htm>
- Dunst, C., & Trivette, C. M. (1990). Assessment of social support in early intervention programs. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 326-349). New York: Cambridge University Press.
- Dunst, C. J., Trivette, C. M., & Deal, A. (Eds.). (1994). *Supporting and strengthening families, Vol. 1: Methods, strategies, practices*. Cambridge, MA: Brookline Books.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (1996). Measuring the helping practices of human services program practitioners. *Human Relations*, 49, 815-835.
- du Pré, A. (2000). *Communication about health: Current issues and perspectives*. Mountain View, CA: Mayfield.
- Elliott, M. (1999). Classifying family life education on the World Wide Web. *Family Relations*, 48, 7-13.
- Eng, T. R., Maxfield, A., Patrick, K., Deering, M. J., Ratzan, S. C., & Gustafson, D. H. (1998). Access to health information and support: A public highway or a private road? *JAMA*, 280(15), 1371-1375.
- Fallis, D., & Frické, M. (2002). Indicators of accuracy of consumer health information on the Internet: A study of indicators relating to information for managing fever in children in the home. *Journal of the American Medical Informatics Association*, 9, 73-79.
- Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work*, 24, 220-231.
- Fox, S. A. (2000). The uses and abuses of computer-mediated communication for people with disabilities. In D. O. Braithwaite & T. L. Thompson (Eds.), *Handbook of communication and people with disabilities: Research and application* (pp. 319-336). Mahwah, NJ: Erlbaum.
- Fox, S., & Fallows, D. (2003). Internet health resources: Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access. Washington, DC: Pew Internet & American Life Project. Retrieved

- February 12, 2005, from http://www.pewinternet.org/pdfs/PIP_Health_Report_July_2003.pdf
- Fox, S., & Rainie, L. (2000). *The online health care revolution: How the Web helps Americans take better care of themselves*. Washington, DC: Pew Internet & American Life Project. Retrieved February 10, 2005, from <http://www.pewinternet.org>
- Fox, S., & Rainie, L. (2002). *Vital decisions: How Internet users decide what information to trust when they or their loved ones are sick*. Washington, DC: Pew Internet & American Life Project. Retrieved October 1, 2004, from <http://www.pewinternet.org>
- Freeman, R., Carbin, C., & Boese, R. (1981). *Can't your child hear?* Baltimore: University Park Press.
- Gallupe, R. B., & Cooper, W. H. (1993). Brainstorming electronically. *Sloan Management Review*, 35, 27-36.
- Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants & Young Children*, 14(2), 1-18.
- Guralnick, M. J. (2004). Family investments in response to the developmental challenges of young children with disabilities. In A. Kalil & T. Deleire (Eds.), *Family investments in children's potential: Resources and parenting behaviors that promote success* (pp. 119-137). Mahwah, NJ: Erlbaum.
- Gustafson, D., Hawkins, R., Pingree, S., McTavish, F., Arora, N., Salner, J., et al. (2001). Effect of computer support on younger women with breast cancer. *Journal of General Internal Medicine*, 16, 435-445.
- Gutzman, A. (2001, September). Top five marketing concerns for the next five years. *ECommerce-Guide.com, News & Trends*. Retrieved January 21, 2003, from <http://ecommerce.internet.com/news/insights/ebiz/article/0337110379.884831.00.html>
- Gwendolyn, M. (2002, April). Google protects its search results. News.com, The Net. Retrieved December, 12, 2002, from <http://news.com.com/2100-1023-883558.html>
- Hardey, M. (1999). Doctor in the house: The Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health & Illness*, 21, 820-835.
- Horrigan, J., & Rainie, L. (2002). *Counting on the Internet: Most expect to find key information online, most find the information they seek, many now turn to the Internet first*. Washington, DC: Pew Internet & American Life Project. Retrieved November 12, 2003, from <http://www.pewinternet.org/reports/index.asp>
- Ikemba, C. M., Kozinetz, C. A., Feltes, T. F., Fraser, C. D., McKenzie, E. D., Shah, N., et al. (2002). Internet use in families with children requiring cardiac surgery for congenital heart disease. *Pediatrics*, 109, 419-422.
- Jadad, A. R., & Gagliardi, A. (1998). Rating of health information on the Internet: Navigating to knowledge or to Babel? *JAMA*, 279, 611-614.
- Jansen, B. J., Spink, A., & Saracevic, T. (2000). Real life, real users, and real needs: A study and analysis of user queries on the Web. *Information Processes and Management*, 36, 207-227.
- Jones, R. S. P., & Lewis, H. (2001). Debunking and pathological model—The functions of an Internet discussion group. *Down Syndrome Research and Practice*, 6, 123-127.
- Koester, L., & Meadow-Orlans, K. (1990). Parenting a deaf child: Stress, strength, and support. In D. Moores & K. Meadow-Orlans (Eds.), *Educational and developmental aspects of deafness*. Washington, DC: Gallaudet University Press.
- Lissman, T. L., & Boehnlein, J. K. (2001). A critical review of Internet information about depression. *Psychiatric Services*, 52, 1046-1050.
- Martland, N. E. F. (2001). *Expert criteria for evaluating the quality of Web-based child development information*. Unpublished doctoral dissertation, Tufts University, Boston, MA.
- Marton, C. (2000). Evaluating the women's health matters Web site. *CyberPsychology & Behavior*, 3, 747-760.
- McClung, J. H., Murray, R. D., & Heitlinger, L. A. (1998). The Internet as a source for current patient information [Electronic version]. *Pediatrics*, 101, e2.
- McGrath, J. E., & Hollingshead, A. B. (1994). *Groups interacting with technology: Ideas, evidence, issues, and an agenda*. Thousand Oaks, CA: Sage.
- McWilliam, R. A., & Scott, S. (2001). A support approach to early intervention: A three-part framework. *Infants & Young Children*, 13, 55-66.
- Most, T., & Zaidman-Zait, A. (2003). The needs of parents of children with cochlear implants. *Volta Review*, 103, 99-113.
- Murray, E., Bernard, L., Pollack, L., Donelan, K., Catania, J., White, M., et al. (2003). The impact of health information on the Internet on the physician-patient relationship. *Archives in Internal Medicine*, 163, 1727-1734.
- Nunez, L. M., & Ceh, K. M. (2001, February). *Family needs of cochlear implant candidates and recipients from birth to 36 months*. Paper presented at the 8th Symposium on Cochlear Implants in Children, Los Angeles, CA.
- Nussbaum, D. (2003). *Cochlear implants: Navigating a forest of information...one tree at a time*. Retrieved November, 5, 2003, from Gallaudet University, Laurent Clerc National Deaf Education Center Web site: <http://clerccenter2.gallaudet.edu/KidsWorldDeafNet/e-docs/CI/index.html>
- Oard, D. W. (1997). The state of the art in text filtering. *User Modeling and User-Adapted Interaction*, 7, 141-178.
- Pallen, M. (1995). Guide to the Internet: The World Wide Web [Electronic version]. *British Medical Journal*, 311, 1552-1556.
- Pandey, S. K., Hart, J. J., & Tiwary, S. (2003). Women's health and the Internet: Understanding emerging trends and implications. *Social Science & Medicine*, 56, 179-191.

- Pandolfini, C., Impicciatore, P., & Bonati, M. (2000). Parents on the Web: Risks for quality management of cough in children [Electronic version]. *Pediatrics*, 105, e1.
- Pereira, J., & Bruera, E. (1998). The Internet as a resource for palliative care and hospice: A review and proposals. *Journal of Pain and Symptom Management*, 16, 59-68.
- Potts, H. W., & Wyatt J. C. (2002). Survey of doctors' experience of patients using the Internet [Electronic version]. *Journal of Medical Internet Research*, 4, e5.
- Preece, J. J., & Ghazati, K. (2001). Experiencing empathy on-line. In R. E. Rice & J. E. Katz (Eds.), *The Internet and health communication: Experiences and expectations* (pp. 237-260). Thousand Oaks, CA: Sage.
- Rayport, F. J., & Jaworski, J. B. (2003). *Introduction to E-Commerce*. New York: McGraw-Hill.
- Rice, R. E. (2001). The Internet and health communication: A framework of experience. In R. E. Rice & J. E. Katz (Eds.), *The Internet and health communication: Experiences and expectations* (pp. 5-46). Thousand Oaks, CA: Sage.
- Roberts, C., & Fox, N. (1998). General practitioners and the Internet: Modeling a "virtual community." *Family Practice*, 15, 211-215.
- Schwarzer, R., & Leppin, A. (1991). Social support and health: A theoretical and empirical overview. *Journal of Social and Personal Relationships*, 8, 99-127.
- Sharf, B. F. (1997). Communicating breast cancer on-line: Support and empowerment on the Internet. *Women and Health*, 26, 65-84.
- Sherman, C. (2002). Google tops in search hours ratings. *Search Day*. Retrieved September 22, 2002, from <http://www.searchenginewatch.com/searchday/article.php/2159961>
- Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1992). Development of infants with disabilities and their families. *Monographs of the Society for Research in Child Development*, 57(6, Serial No. 230).
- Skinner, D., & Schaffer, R. (2006). Families and genetic diagnoses in the genomic and Internet Age. *Infants & Young Children*, 19, 16-24.
- Skinner, H., Biscope, S., & Poland, B. (2003). Quality of Internet access: Barriers behind Internet use. *Social Science & Medicine*, 57, 875-880.
- Smith, C. A. (1999). Family life pathfinders on the new electronic frontier. *Family Relations*, 48, 31-34.
- Statistics Canada. (2004, July). Household Internet use survey. *The Daily*. Retrieved November 2, 2004, from <http://www.statcan.ca/english/dai-quo/>
- Taylor, M. R. G., Alman, A., & Manchester, D. K. (2001). Use of the Internet by patients and their families to obtain genetics-related information. *Mayo Clinic Proceedings*, 76, 772-776.
- Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early intervention*. New York: Cambridge University Press.
- Turnbull, A. P., & Turnbull, H. R. (1997). *Families, professionals, and exceptionality: A special partnership* (3rd ed.). Upper Saddle River, NJ: Merrill/Prentice-Hall.
- U.S. Department of Commerce (2000, October). *Falling through the net: toward digital inclusion*. Retrieved December 12, 2002, from <http://www.ntia.doc.gov/ntiahome/ftn00/falling.htm>
- U.S. Department of Commerce (2002, February). How Americans are expanding their use of the Internet. Retrieved February 12, 2005, from http://www.ntia.doc.gov/ntiahome/dn/nationonline_020502.htm
- U.S. Department of Health and Human Services (2002, November). *Understanding our users: How to better deliver health information online to American Indians and Alaska Natives*. Retrieved March 15, 2003, from <http://odphp.osophs.dhhs.gov/projects/aian/AIAN.pdf>
- Upsbur, C. C. (1991). Mothers' and fathers' ratings of the benefits of early intervention services. *Journal of Early Intervention*, 15, 345-357.
- Wade, S. L., Wolfe, C. R., Brown, T. M., & Pestian, J. P. (2005). Can a Web-based family problem-solving intervention work for children with traumatic brain injury? *Rehabilitation Psychology*, 50, 337-345.
- Wang, P., Hawk, W. B., & Tenopir, C. (2000). Users' interaction with World Wide Web resources: An explanatory study using a holistic approach. *Information Processing and Management*, 36, 229-251.
- Weinberg, N., Schmale, J. D., Uken, J., & Wessel, K. (1995). Computer-mediated support groups. *Social Work with Groups*, 17, 43-54.
- Winzelberg, A. (1997). An analysis of an electronic support group for individuals with eating disorders. *Computers in Human Behavior*, 13, 393-407.
- Wright, K. B. (2000). Perceptions of on-line support providers: An examination of perceived homophily, source credibility, communication and social support within on-line support groups. *Communication Quarterly*, 48, 44-59.
- Wright, K. B. (2002). Social support within an on-line cancer community: An assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. *Journal of Applied Communication Research*, 30, 195-209.
- Wright, B., Williams, C., & Partridge, I. (1999). Management advice for children with chronic fatigue syndrome: A systematic study of information from the Internet. *Irish Journal of Psychological Medicine*, 16, 67-71.
- Wyatt, J. C. (1997). Commentary: Measuring quality and impact of the World Wide Web [Electronic version]. *British Medical Journal*, 314, 1879-1881.
- Wyman, S. K. (1997). *User and system-based quality criteria for evaluating information resources and*

- services from federal Web sites: Final report.* Dublin, OH: OCLC Online Computer Library Center, Inc. (Eric Document Reproduction Services No. ED 409 020)
- Zaidman-Zait, A., & Jamieson, J. (2004a, April). *Cochlear implants in deaf children: Use of the critical incident technique to investigate parental experiences and implications for early intervention.* Poster session presented at the 18th biennial Conference on Human Development, Washington, DC.
- Zaidman-Zait, A., & Jamieson, J. R. (2004b). Searching for cochlear implant information on the Internet maze: Implications for parents and professionals. *Journal of Deaf Education and Deaf Studies, 9*, 413-426.
- Zero to Three (2000). *What grown-ups understand about child development: A national benchmark survey.* Retrieved November 5, 2002, from <http://www.Zerothree.org/Search/index2.cfm>

Current articles- http://depts.washington.edu/isei/iyc/iyc_comments.html

Back to lists of previous articles: http://depts.washington.edu/isei/iyc/iyc_previous.html