Perspectives

Making Links, Making Connections: Internet Resources for Self-Advocates and People With Developmental Disabilities

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Self-advocates–people with intellectual or developmental disabilities–are now using the Internet to further their civil rights movement (the self-advocacy movement). The Internet is a tool that they can use to connect with other members, groups, and supporters of their movement.

Why would self-advocates be interested in accessing the Internet? My initial response would be, "Why would *anyone* be interested in accessing the Internet?" The Internet has many benefits; benefits that do not depend on whether a person has a disability. Self-advocates can and do experience the benefits of the Internet.

Here, I share information on how efforts of self-advocates and other people with developmental disabilities to use the Internet began, how computers and the appropriate tools were found, and why Internet access is so important to the work of self-advocates.

When the Efforts Began

In 1996, Central England People First, a leading self-advocacy group in the United Kingdom, began the first Internet discussion lists for self-advocates by mailing lists for self-advocates. Members of these lists began to discuss attending the April 1998 International People First conference in Anchorage, Alaska (*People First* is an alternate name used to describe the self-advocacy movement). Many self-advocates realized that they would not be able to attend this conference due to distance and expense. So, with their support persons, I being one of them, they began to look for an alternate way to participate that was easy to use, accessible to many people over great distances, and inexpensive. The organizing then began in earnest. Efforts to connect self-advocates on the Internet commenced. A core group of people began to work out the details of the Internet connections for the international conference. This group discovered several Internet chat tools that were accessible and inexpensive and could be used with very little outside support.

Finding Access to Computers

For many people with disabilities, owning a computer is a luxury (Doe, 1998). One of the first issues to tackle was to find either inexpensive computers to purchase or alternate means to access the Internet. There are now many corporations that will donate computers to schools or nonprofit organizations, but not many donated computers are available to people with limited income. Some individuals are also fortunate to belong to self-advocacy groups that have their own computers or have access to computers.

Although the costs of multimedia computers have plummeted in recent years, making ownership for many more people a reality, people with disabilities are less likely to own a computer than are other people and even less likely to access the Internet (Enders, 2006; Goddard, 2004; Kaye, 2000; Stanley, 2002).

Finding Tools That Work for People With Different Abilities

There are numerous types of assistive devices and software available, but many are very expensive. The challenge had been to find chat tools and other useful Internet programs that provide accessibility in various ways for different users and to find software that was free or inexpensive. Many such programs once available have changed or are no longer used.

The chat program/tool used the most in all of the Internet planning and organizing that Central England People First was involved with was "ICQ" (I Seek You). This program was selected for a va-

riety of reasons. First, it could be used on older computers. Second, there are many programs that could be easily used with ICQ. These are mostly programs that ICQ could automatically initiate and use online without having to enter and exit different programs, and at the most require microphones; video cameras; and, in some cases, sound cards.

Programs like ICQ were preferred due to privacy issues. For example, ICQ is structured in such a way that the users have the ability to choose the people to be added to their contact list and can select or invite particular individuals on their list to participate in a chat. Yes, there are many public chat rooms, but, unfortunately, many of these rooms are filled with distracting advertisements and the topics are often inappropriate. The ICQ also has a function that enables users to select their online status (away, free for chat, invisible, do not disturb).

Most program developers attempt to find Internet access for a variety of people with differing abilities. Although some people can type, others may want to talk online instead of typing or have their messages read to them for ease of use, simplicity, or any number of reasons. Some people have even worked to adapt standard computer technology to be used by people with disabilities (MacDonald, 1999).

Perhaps one of the most important considerations in choosing these programs is the level of support required to operate them. The basic supports for people with disabilities and self-advocates are setting up connections, installing software, and hooking up microphones and cameras. There may be instances where more support is needed, but this was mostly just help in typing, spelling and grammar, and holding onto microphones. A distinction between what is considered support and communication and what is considered interference is important. People with disabilities should be allowed ample opportunity to express their own thoughts and ideas without having a support person manipulating their words and concepts. Because the tools I have discussed above are easy to use and operate, they serve to liberate self-advocates and people with disabilities.

Benefits of the Internet

For people with disabilities, using the Internet can have several benefits, many of which are interconnected:

Gain visibility and invisibility at the same time. When using the Internet, people have no way of knowing how the information was entered—with a mouse, a voice syntheses program, a blow stick, or keyboard (D'Aoust, 1997); therefore, people with disabilities can appear to be like "any other surfers" (Blasiotti, Westbrook, & Kobayashi, 2001). Typical reactions and attitudes to the sight of a person using a wheelchair or a white cane or body movements and appearances that can be distracting are not apparent online (Amtmann & Johnson, 1998; Bierly, 2004; Carpenter, Endler, & Peischl, 1997; Coombs, 1995; Deatherage, 1996; Doe, 1998; Oestreich, 2000). As Doe wrote: "People are able to interact online without having to deal with the way people react to disabilities." Scott Stevens, a college professor with muscular dystrophy who teaches exclusively online, explains that most of his students do not even realize that he has a disability. "Online, no one knows I'm disabled. . . . It doesn't really matter. In this environment, we don't recognize people by race or disability or how they look. None of these things get in the way of communication" (Convene International, 1999, pp. 26–27).

For some, connections online with other people who have the same problems can create important social bonds and self-esteem. People with disabilities can also connect to places on the Internet where they do not have to feel embarrassed to have a disability and want to connect with people who have had similar experiences (D'Aoust, 1997). If people wish, they can connect exclusively with other persons who have disabilities in order to build a sense of collective identity, disability pride, and shared experiences.

Empowerment. Many people with disabilities feel powerless to control and contribute to the various aspects of their own lives (Lord, 1991). The use of the Internet gives people power to express themselves, have a voice, and give themselves power in ways we all may take for granted: (a) buying things online, (b) taking a course online through distance education, (c) joining and participating in an Internet mailing list, and (d) telecommuting to work.

These experiences can be crucial to an individual who has difficulty finding accessible transportation or has any sort of physical limitations (Doe, 1998). Participation in Internet activities has the potential for improving self-confidence. The more self-confident, the more people can use the resources around them, seek other opportunities for interactions, and assert a sense of control over their own

lives (Lord, 1991). Amtmann and Johnson (1998) cited an example of an individual with a disability who created a web page showcasing his skill at creating web sites, thus enabling him to advertise his abilities and availability to use these skills; through this, he gained part-time employment maintaining web sites for several organizations.

Access. Connecting to the Internet has become much easier for people with disabilities, especially with programs and tools that are not difficult to set up and use. The application and use of microphones, video cameras, and free and low-cost software has enabled many people to communicate. The rapid pace that newer technology develops makes it easier for most people to connect; however, people with disabilities are less likely to have access to computers and the Internet (Enders, 2006; Goddard, 2004; Kaye, 2000; Stanley, 2002).

Liberation. The use of computers and the Internet has a great potential to remove barriers and allow all people equal access. "Today, more and more of the disadvantaged are asking for empowerment so they can help themselves. They want the freedom to compete with the rest of society on a more nearly even playing field" (Coombs, 1991). The Internet can give everyone freedom to (a) help themselves, (b) make discoveries, (c) meet new people, (d) become connected with the world, and (e) open doorways of opportunity. One of best things that can happen to people when they get online and connect to the Internet is that their lives can really be changed. "E-mail and other Internet information technologies can serve as a unique tool for people with disabilities and others to engage directly in advocacy and social change activities" (Blasiotti et al., p. 338). With the use of assistive technology and access to the Internet, many individuals have a broad range of people they correspond with by email, and some have newspapers and magazines read out loud to them (McGuinness, 1998).

Traveling without moving. The wide range of new multimedia technologies provides a connection for rural or remote areas to the rest of the world. Whether for financial or other reasons, traveling is often very difficult for many people with disabilities. Virtual tours of historic landmarks and museums are now available for people to access via the Internet. Web cams can also offer glimpses of distant locations and people.

Resources. There are many resources to supplement the usual places people find information, especially newspapers, magazines, books, and TV. There are almost certainly online versions of almost any newspaper or magazine published today, and even more *e-zines* (i.e., magazines published entirely online). Many books are also available on the Internet; chapters and selected portions of text can be downloaded and read out loud with simple computer tools. News and radio broadcasts are archived and can be replayed at the discretion of the user.

Connections. The Internet can help people stay in touch with friends, colleagues, and other self-advocates, especially when meeting face-to-face is not possible.

Fun. No matter what people like to do for fun, there are many resources to access and use on the Internet. People can listen to radio broadcasts and music, watch video clips from movies and television, play games online with people all over the world, shop for a wide range of different things from groceries to toys, and create personal web pages to stay in touch with family and friends and make connections.

Conclusion

The rapid increase in the use of technology has also greatly increased the visibility of people with disabilities in our society (Lathrop, 1995/1966), and as our society continually perceives people with disabilities differently, "the expectations for electronic information systems to inform, provide services, and foster personal and targeted social interactions will continue to increase" (Blasiotti et al., p. 344). The use of the Internet by self-advocates and people with disabilities can offer many benefits that are not dependent on whether or not a person has a disability. The Internet can offer "new avenues for personal fulfillment and political action" (Seymour & Lupton, 2004, p. 303).

Work is being done to teach self-advocates and people with intellectual and developmental disabilities, as well as people with other disabilities, the basics of computer use (Conklin, 2001), and, increasingly, there is more research being conducted about how people with disabilities use the Internet (Amtmann & Johnson, 1998; Bowker & Tuffin, 2004; Davies, Stock, & Wehmeyer, 2001; Goggin & Newell, 2002, 2003, 2006; Grimaldi & Goette, 1999; Harrysson, Svensk, & Johansson, 2004; Hayes, 1998; Lewis, 2006; Seymour & Lupton, 2004; Sohlberg, Fickas, Ehlhardt, & Todis, 2005).

We need to continue to work on technological

access and literacy for self-advocates and all people with disabilities, but we also need to teach people how this technology can be used to change their lives (Agre, 1998; Children's partnership, 2002; DiMaggio, Hargittai, Neuman, & Robinson, 2001; From digital disconnect, 2001; Kirschenbaum & Kunamneni, 2001; Morino Institute, 2001; U.S. Department of Commerce, 2000). Because self-advocates and people with disabilities are less likely to access technology and the Internet, it is especially important that those of us who do have access continue to observe how this technology can help the self-advocacy movement and share what we find.

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Appendix

Resources on Self-Advocacy and the Internet

- http://www.aina-ri.org/
  This is the web site of Rhode Island's statewide self-advocacy organization Advocates in Action.
- http://www.selfadvocacy.com/
  "Advocating Change Together (ACT) is a nonprofit disability rights organization run by and for people with developmental and other disabilities. We are committed to freedom, equality, and justice for all people with disabilities."
- http://www.fvkasa.org/
  "Kids As Self Advocates (KASA) is a national, grassroots network of youth with special needs and our friends, speaking on behalf of ourselves. We are leaders in our communities, and we help spread helpful, positive information among our peers to increase knowledge around various issues. We are an organization created by youth with disabilities for youth to educate society about issues concerning youth with a wide spectrum of disabilities and special healthcare needs. KASA believes in supporting self-determination, creating support networks and proactive advocacy for all youth with disabilities in our society."
- Learning the Web (http://www.libertynet.org/speaking/web.html)
  This page was developed by Speaking for Ourselves to help users learn the web.
- http://www.hsri.org/leaders/
  The Self-Advocate Leadership Network is a team of self-advocates and professionals who will travel anywhere to train others on self-determination, community integration, participant-driven supports, and systems change. The purpose of the Leadership Network is to prepare self-advocates to play a leadership role in guiding developmental disabilities systems change in ways that promote self-determination, community integration, and participant-driven supports.
- http://www.SelfAdvocateNet.com/
  "This is the home page of the SelfAdvocateNet. We are based in the lovely Fraser Valley of Beautiful British Columbia, Canada. Recently we have begun networking across our region. The region is quite large, about 50 kilometers from one end to the other. We have worked hard to develop this web site as a way of staying in touch not only across our region, but across the province and the world beyond."
- http://www.sabeusa.org/
  "OUR MISSION: To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes."

- http://indie.ca/roeher
  A Straightforward Guide to the Internet: This guide provides a basic introduction to the Internet. It is written in plain language, with lots of images. Produced in an easy-to-read, larger than usual format, *A Straightforward Guide to the Internet* is divided into short manageable chapters. It explains what the Internet is, how you get connected, what e-mail is, and how to "surf the net."
- http://www.ctserc.org/library/bibfiles/self–determine02–03.pdf
  This is a comprehensive bibliography on self-determination and self-advocacy. It contains two sections: (a) references to journal articles, books, instructional materials, and inservice educational material; and (b) a variety of web sites.

