Self-Determination and Technology
for People with Psychiatric Disabilities:
An Annotated Bibliography of Resources

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Azar, B. (2000). *A web of research. They're fun, they're fast, and they save money, but do web experiments yield quality results?* <u>Monitor on Psychology</u>, April 2000, 42-44.

This article discusses some of the benefits and limitations of conducting psychological research on the Internet. The author interviews several researchers who either are conducting their own research on the Internet, or evaluating the Internet-based research of others. Most of these researchers believe that quality results can be obtained from Internet-based research, especially when sampling population and technical limitations are taken into consideration.

Azar, B. (2000). *Online experiments: Ethically fail or foul? Researchers are facing new ethical challenges as they conduct experiments on the World Wide Web.* <u>Monitor on Psychology</u>, April 2000, 50-52.

This article discusses some of the ethical challenges and considerations that researchers encounter when conducting research on the Internet. Although these ethical considerations aren't new, the Internet is a new medium for conducting research, and poses a unique set of challenges. An example of one such challenge is obtaining informed consent. Another question about conducting research on the Internet that is discussed in this article is whether open discussion forums on the Internet are in the public domain, and therefore exempt from these identified ethical considerations. Since these issues are relatively new, much of the information discussed in this article is in some way concerned with the development, rather than enforcement, of standards.

Barak, A. (1999). *Psychological applications on the Internet: A discipline on the threshold of a new millennium.* <u>Applied and Preventive Psychology, 8</u>, 231-246.

This paper categorizes and reviews ten different Internet-based psychological applications. These include: information resources on psychological concepts and issues; self-help guides; psychological testing and assessment; the decision to undergo therapy; information about specific psychological services; single-session psychological advice through e-mail or e-bulletin boards; ongoing personal counseling through e-mail; real-time counseling through chat; web telephony and videoconferencing; synchronous and asynchronous support groups, discussion groups, and group counseling; and psychological and social research. For each application, the author provides a description of the service, examples (i.e., URLs) of specific web sites, and a critical analysis of the implementation of these services. Research into the efficacy of delivering these services via the Internet is cited whenever possible, and there is an extensive set of references that reflect this thoroughness. A separate section discusses the ethical concerns with providing professional psychological services and conducting research via the Internet. In his conclusion, the author comments that the Internet is relatively new, and that there will inevitably be both costs and benefits associated with such a rapidly developing set of technologies.

Clay, R.A. (2000). *Linking up online. Is the Internet enhancing interpersonal connections or leading to greater social isolation?* <u>Monitor on Psychology</u>, April 2000, 20-23.

This article reviews the preliminary findings of several studies that examined individual as well as societal Internet use, well being, and social involvement. One study, conducted by Robert Kraut and colleagues at Carnegie Mellon University, included 169 individuals from 93 families in Pittsburgh. The Internet usage of these persons, who had not owned computers or had Internet access prior to the study, was tracked and rated over one or two years on several psychological

scales. Another study, conducted at Stanford Institute for the Quantitative Study of Society,

collected data from a nationally representative sample of 2,689 households. The findings from

the Carnegie Mellon and Stanford studies indicate that some people who spent more time online

also spent less time interacting in other social situations, and were more likely to report being

depressed. Reactions and criticisms of these pioneering studies are included. A third study,

conducted by Katelyn Y.A. McKenna and John A. Bargh at New York University, found that

socially anxious or lonely people were using the Internet to form and maintain relationships.

This article also looks at online sexuality and discusses whether this activity is pathological or

has socially adaptive or enhancing properties.

**Couper, M.P., Blair, J., & Triplett, T. (1999). *A comparison of mail and E-mail for a survey
of employees in a federal statistics agency.* <u>Journal of Official Statistics, 15</u>, 38-56.**

This paper reports on a study that was conducted to compare two different modes of delivering

an organizational survey, via E-mail or via conventional mail. The study was embedded into an

organizational survey that was administered to employees at several federal government

agencies. The primary finding is that employees who received the E-mail version of the survey

were less likely to respond (42.6%) than those who received the survey by mail (70.7%). In

reviewing this discrepancy, the researchers concluded that the potential cost-saving benefits of

using E-mail to deliver surveys may not be realized due to the technical difficulties that often are

encountered.

Davis, R. N. (1999). *Web-based administration of a personality questionnaire: Comparison to traditional methods.* <u>Behavior Research Methods, Instruments, & Computers: A Journal of the Psychonomic Society, Inc., 31,</u> 572.

This study compared the results of a personality questionnaire, the Ruminative Responses Scale

(RRS), delivered using two different modes: paper-based and web-based questionnaires. This

scale measures rumination, which is the tendency to focus one's attention on one's depressed

mood and events that support it, rather than taking action to alleviate the depressed feelings.

Results of the research indicated that the rumination construct was reliably measured, whether

the questionnaire was delivered via paper and pencil or via web form. There were significant

mean group and gender differences on the RRS that conformed to the original hypotheses. The

author concluded that using the web is just as viable of a method for conducting personality

research as paper and pencil questioning.

Epstein, J. (1988). *Information systems and the consumer.* In Glastonbury, B., LaMendola, W., Tools, S. (Eds.), <u>Information Technology and the Human Services</u> (pp. 13-25). New York, John Wiley and Sons, Ltd.

This paper looks at information systems and applications from the end user's perspective. The

author includes a comprehensive list of criteria for evaluating applications from the user (i.e.,

consumer) perspective, and then presents a study that looks at the introduction of an information

technology system in a U.K. social service agency. The authors of the study report that users

found the computer application an effective way to receive benefits information. Staff at the

agency, however, actively avoided the computer system, and in some cases held views that might

discourage their clients from using the system. The author concludes that social service agencies

should devote more resources to investigating whether information technology applications

might be a more effective way of delivering their services, but should also always try to analyze the potential effects on the people they are serving.

Foxhall, K. (2000). *A renaissance for everyone? The technology revolution could widen old gaps in opportunity*. <u>Monitor on Psychology</u>, **April 2000, 32-34.**

This article discusses the variations in access to information technology among different groups in the U.S. Differences in income, education, and race are compared as variants in accessing emerging information and telecommunications technologies. Findings from the U.S. Department of Commerce indicate that households with incomes above $75,000 are 20 times more likely to have access to the Internet than low-income households. The author also cites findings that minorities and women are less likely to specialize in science and technology fields, which may limit their participation in creating and directing these technologies. This is particularly timely since access to and mastery of these technologies are becoming a prerequisite to participating in an emerging information economy and education system. The role of psychologists in addressing these problems also is outlined. National and community programs have been formed to address some of these inequalities, and psychologists can take a role in informing and implementing these programs.

French, S. (1993). *What's so great about independence?* **In Swain, J. Finkelstein, V., French, S., Oliver, M. (Eds.),** <u>Disabling Barriers – Enabling Environments</u> **(pp. 44-48). London: Sage Publications Ltd.**

This author posits that attempts to help persons with disabilities gain independence can have a disempowering effect. She states that independence gained at the most basic levels of functioning often comes at the cost of enormous amounts of time, and may stand in the way of

enabling persons with disabilities to engage in more rewarding activities. The presence of

technological aids may lead individuals who are in a position to help those with a disability to

assume incorrectly that their assistance is no longer needed. The individual and societal factors

that contribute to the concepts of independence and enabling are discussed.

HIV-Related Knowledge and Stigma – United States, 2000. **Morbidity and Mortality Weekly Report (December, 2000), Vol. 49, 1062-1064.**

This is a brief statistical report about the results of an HIV-Related Knowledge and Stigma

module included in a national health and aging survey. After selecting 7,493 participants from a

nationally representative sample, the researchers gave the participants a standard television and

set-top device connected to the Internet to complete the survey. This strategy of providing the

device was used to isolate the benefits of conducting research over the Internet while addressing

the potential bias caused by lack of universal access. The study found that most people do not

hold stigmatizing beliefs about people with HIV. Only 18.7% of the 5,641 persons who

responded agreed with the statement that was used to indicate stigma about HIV: "People who

got AIDS … through sex or drug use have gotten what they deserve."

Kaye, H.S. (2000). *Disability and the digital divide*. **Disability Statistics Abstract, number 22.**

This abstract reports on data collected in a national representative sample of U.S. households in

December of 1998. The abstract focuses on the computer ownership and Internet access of

persons, and households of persons with a disability. For purposes of these analyses, persons

with a disability were defined as those respondents who reported having a health problem or

disability that prevents or limits their ability to work. The findings indicate that persons with a

disability are significantly less likely to own a computer (23.9%) than those without disabilities (51.7%). Persons with a disability also are far less likely to have Internet access (9.9%) than those who are not disabled (38.1%). Lower computer ownership and Internet use were seen in individuals with disabilities even when the results were analyzed according to educational attainment, family income, and race/ethnicity.

Kraut, R., Patterson, M., Lundmark, V., Kiesler, S., Mukopadhyay, T., & Scherlis, W. (1998). *Internet paradox: A Social technology that reduces social involvement and psychological well-being*. <u>American Psychologist, 53</u>, 1017-1031

This is a longitudinal study that examined the effects of Internet use over the course of one to two years. The researchers began providing Internet service to 169 people in 73 households in 1995 and 1996. The families had not previously owned a computer or had access to the Internet in their household. Researchers logged the Internet usage of persons in those households, and conducted regular assessments of social functioning, including measurements of family communication, social circles and support, loneliness, stress, and depression. The results of the study suggest that greater use of the Internet resulted in declines in communication with other family members in the household and smaller social circles, and increases in depression and loneliness. The researchers conclude that there are limitations to the generalizability of the findings, but that the evidence is strong enough to cause concern and should be investigated.

Jerome, L.W., DeLeon, P.H., James, L.C., Folen, R., Earles, J., & Gedney, J.J., (2000). *The coming of age of telecommunications in psychology research and practice*. <u>American Psychologist, 55</u>(4), 407-421

Much of this article describes and analyzes the current state of telehealth, defined as the "practice of providing health care services by using technology and communications." In particular,

psychological training, distance learning, research, and electronic publishing are examined. In

their summary, the authors discuss the evolutionary nature of information and communication

technologies in our society, and the need for psychologists to be involved in the process of

explaining and guiding these processes.

Martlett, N. (1988). *Empowerment through computer telecommunication.* **In Glastonbury, B., LaMendola, W., Tools, S. (Eds.),** <u>Information Technology and the Human Services</u> **(pp. 13-25). New York, John Wiley and Sons, Ltd.**

This author describes the development of the Disability Information Services of Canada

information network, or **DISC.** This network, which predates the Internet, was developed "to

facilitate the exchange of information among disabled persons and those who work to improve

their status." The author, who is employed by **DISC,** describes the goals of the system and the

technical, social, and political issues involved in its development. The author then shifts to a

discussion of how the network serves to empower persons with disabilities. The author

concludes by stating that the system has been successful, and discusses goals and direction for

the next phase of its development.

Pitkow, J.E. & Recker, M.M. (accessed 6/21/2001). *Using the as a survey tool: Results from the second WWW survey*. http://www.cc.gatech.edu/gvu/user_surveys/papers/survey_2_paper.pdf

This paper presents the results of a World Wide Web population survey conducted in 1994, in

which there were 18,503 respondents. Details about the methodology and construction of the

questionnaire also are included. There is a section dedicated to explaining how the researchers

were able to conduct adaptive questioning on the web. The survey included questions about

demographics, web use, and HTML web page authoring. Results suggested that the typical user

at the time of the study was a thirty year-old, educated male employed in the computer field.

Schmidt, W.C. (1997). *World-Wide Web survey research: Benefits, potential problems, and*
solutions. Behavior Research Methods, Instruments & Computers, 29(2), 274-279

This author describes the use of the World-Wide Web as a survey research tool. The benefits of

conducting research on the web include lower costs, time savings, and interactivity. The author

also outlines strategies for addressing issues of concern, such as informed consent, sampling

bias, validity, potential for abuse on the web, and the difficulties of promoting a survey. Finally,

the paper contains a discussion of the Common Gateway Interface, or CGI method of form and

data handling, which is one of several software and server platforms available for processing

web-based surveys.