

THE ROLE OF INFORMATION & COMMUNICATION TECHNOLOGY IN PROMOTING MENTAL HEALTH CONSUMERS' SELF-DETERMINATION

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Introduction

Recently I have been training a group of practitioners in a welfare-to-work program on the topic of mentoring. We talk about all the issues the program's customers raise in the course of their incredibly challenging transition from being welfare recipients to being employed and self-sufficient providers. During a recent session a number of participants shared the concern that their customers often report some degree of depression, and they did not know how to respond, how to determine the severity of the problem, or how to advise the customers.

One young staff person, who had lived in Nigeria, offered the perception that this trend was part of a tendency in our U.S. culture to convert experience – such as a headache, for example – immediately into a diagnosis, and then to address it right away with a medication. In Nigeria, she said, rather than responding to a headache with a pill, the typical response would be to take a cup of tea or a nap.

She asked my opinion as to whether Americans are disposed to depend on and believe in drugs as the answer to everything. I replied that I think that our culture reveres technology, and that pharmaceuticals are just an instance of technology. In fact, I ultimately did address the staff's need for guidance on responding to customers' reports of depression by turning to technology for help, but that is another story for later in this paper. This story is meant to imply the caveat that, while technology can be a tool and a powerful asset, with the perspective of a certain distance one can see that over-identification with the technology can make it a substitute for experience-based responses that honor our ability and responsibility to determine our own life choices and who we are as individuals. Like the tourist who subordinates her vision to the camera's lens, a person may become less than a fully realized person if he invests so much in technology that it comes between himself and his immediate inner and outer experience.

Acknowledging this caveat, we address in this paper the ways that information and communication technology can and do promote self-determination among mental health consumers. The primary aims will be: to show within the frame of a proposed conceptual model concrete ways that technology use *can* support self-determination; to review evidence suggesting that technology use does promote self-determination; to uncover real and perceived challenges, barriers, and pitfalls that confront individual mental health consumers who use or might wish to use technology; and to offer practical information, resources, and strategies for surmounting those difficulties.

An Operational Model: Awareness → Choice → Efficacy

In this examination, we will construe self-determination to be the operational result of a set of conditions applying to an individual: first, awareness – the state of being informed about the range of alternatives relevant to a problem to be solved or objective to be achieved; second, the perception and reality in the life of an individual that s/he has a free choice among the identified alternatives; and, finally, a sense of efficacy, i.e., the power and means to implement a choice once it is made, and thereby to have an effect on one's own life. By this model, factors that facilitate awareness, choice, and, most critically, the sense of efficacy promote self-determination.

It has been recognized that the sense of efficacy is so often undeveloped in people with mental illness and with disabilities in general. Sands and Wehmeyer make this connection, describing it as "...an all-too-frequent consequence of the absence of choice and control: Individuals with disabilities fail to develop a sense of self-direction and self-efficacy" (1996, p.312).

The exercise of self-determination by individuals is a pattern of action, action freely taken with the intention and the expectation of producing an outcome. To the extent that use of technology provides a context in which this pattern can be experienced and assimilated, then it becomes not only an arena for the exercise of self-determination, but a context to foster the development of the personal self-attribution of efficacy, a prerequisite to a natural expression of self-determination.

Survey data from several sources validate this connection between technology use, efficacy, and self-determination. A recent research report from the multi-year Pew Internet & American Life Project based on interviews of over 3,500 people (with and without disabilities) concluded that “a person’s sense of efficacy can make a difference in her decision to go online or not.” (Lenhart, 2003, p.28) Interestingly, while this formulation suggests that the sense of efficacy precedes the act of going online, Lenhart finally concludes:

While it is not possible to assert causality definitively, it seems reasonable that those who have convenient access to a great deal of information and those who have multiple ways to communicate with others would feel more in control of their lives. (p.28)

The UIC NRTC Self-Determination Project Web Survey, currently in progress, has produced preliminary data that reveal a parallel correlation. Respondents reporting more self-determination in their lives report using the Internet more often compared to those who describe themselves as having less self-determination in their lives. Consistent with our proposed model of self-determination and technology use, the inference that those respondents are actually *exercising* self-determination via their technology use is borne out by the preliminary data showing that those reporting more self-determination were more likely to do work, look for local/state/federal government information, to purchase a product, or do word processing. In other words, they are conducting

activities that have meaningful consequences and integrate them as active agents in the life of the community.

Resources for Enhancing Awareness, Choice, and Efficacy

Generic Resources

The Internet has become a household fixture for most Americans, with penetration hovering at about 60% for the last few years (Lenhart, 2003).

Every day people seek information, communicate, and conduct business across the spectrum of life management areas. We use the technology for employment, health, legal and financial matters, housing, transportation, travel and recreation, news and community affairs, and more. Advancing our aim of encouraging broader use of the technology as a tool to enhance self-determination, we explore here selected technology resources – both generic and those more germane to the needs and aspirations of mental health consumers.

General Internet guidebooks support both novice and advanced users in getting started and applying the tools for specific purposes. These guidebooks conform with our operational self-determination model in that they provide information about the range of resources and services available (awareness), they help consumers evaluate the choices available both in terms of quality and reliability as well as in measuring the degree to which any particular site fits the individual user's needs and purposes (facilitating a competent choice), and finally they lead

to mastery and efficacy through instruction in the “how-to’s” of exercising the decision to go ahead and access/use one’s chosen Internet resources.

A recent trip to a bookstore yielded several recommendable publications – although surprisingly not as many for the new user as expected. This is one area in which it may be worthwhile to invest in a book of one’s own, in part because the pace of technology and Internet development is so great that one must seek out the freshest, most up-to-date materials to get the best advice, and for newcomers it may be reassuring to have a reliable reference at hand that does not depend on computer competence for access.

A well-sequenced and highly functional basic handbook is *Using the Internet*, by Matt Lake, (Barnes & Noble Basics™, 2003). A paperback, it retails for about ten dollars. The key to this resource is that it observes the old “KISS” principle, keeping it simple for the person getting into the water for the first time. This might be a useful text for an introductory workshop for consumers at a clubhouse, inasmuch as it guides without going into technical depth or complexity. Therefore, it is not intimidating, overwhelming, or confusing with more nuances than novices can assimilate. For example, the section on search engines is but two pages. As such, on the other hand, it lends itself to a situation in which peer or staff support is available when desired.

In this connection, it is relevant momentarily to jump forward in our agenda to note that one of the key barriers to Internet use reported by mental health consumers and by people with disabilities generally is the perception that computers and the Internet are too confusing and too hard to learn to use. The UIC Web Survey earlier described asked non-users why they were not online, and nearly a third of them responded that this perception of difficulty was their primary reason – by far the most frequently cited reason among the eight closed code options and “other.” The above-cited Pew research found that 21% of non-users with self-reported disabilities had the perception that the Internet is confusing and hard to use (Lenhart, 2003, p. 31). Only nine percent of “non-disabled people” in the Pew study cited perceived difficulty as a barrier to using the Internet.

These survey findings strongly suggest that these perceptions, along with factors such as convenience, affordability, and privacy of access, likely underlie the well-documented digital divide. The same Pew study found a significant divide between people with disabilities, 38% of whom use the Internet, and all Americans, 58% of whom use the Internet (p.30). Given such findings, we would expect that the availability of supports that incorporate resources such as guidebooks are potentially effective strategies for those consumers who do have an interest in using technology but are not currently doing so.

Now, for users who have already mastered basic cyber-mechanics enough to have made the connection, other references offer guidance in taking the best advantage of it while avoiding its pitfalls. Thousands of sites are listed in directory format, cross indexed, and annotated in paperback guides such as Joe Kraynak's *Best of the Internet* (QUE, 2003). In most categories, one "Best" site is recommended, and sites that offer products or services for purchase are so marked. Categories run the full gamut from social services and health/mental health resources to sites for planning one's next trip to Chicago or for finding a romantic partner. Publishers of such guides say they check the listed sites to insure they are active and have the content described. However, new sites are born, old sites become defunct regularly, so current references are imperative.

Resources of special interest to mental health consumers

We look with a finer focus now in surveying selected technology resources that are contributing to greater efficacy in various spheres of life management for people with mental health difficulties. This survey primarily samples resources specific to mental health and employment – two areas of great interest to mental health consumers, if we rely on the previously cited early UIC NRTC Web Survey data. In that survey, consumer respondents who use the Internet say they are likely to do work and look for local/state/federal government information. Also, six out of seven non-user respondents who said they are interested in becoming users cited employment-related purposes, and seven out of ten said they would search for information on mental health diagnoses, treatments, and medications.

A substantial number of Americans are accessing mental health information on the Internet. A recent Harris poll concluded that 60,000,000 Americans searched for health information on the Internet in 2002, and of that number 40 percent were seeking information on mental health (APA PsychNET[®], 2003). We can not know how many were in fact mental health consumers, but we can certainly see that seeking such information on the Internet has become a mainstream activity.

Recall the scenario that opened this paper – the staff training session that turned to an energetic discussion of depression. Participants wanted information on how to respond, how to determine the existence and severity of clinically significant depression, and how to advise their customers. I shared with them my own personal experiences with depression to convey the serious emotional and functional impact it can have, and as an example of the symptom profile that often is the signature of depression. Frankly, it was evident that some attached a stigma to psychiatric problems, so I also wanted to demonstrate that a person they saw as competent and functional – i.e., me – could experience serious and challenging psychoemotional problems at times in his life. It is noteworthy that my sharing led several participants to offer their own experiences for discussion.

However instructive the example of one person's experience, the class needed comprehensive and systematic reference points for helping customers to assess the problems they were reporting as well as to provide a set of local mental health resources to recommend to customers who want to pursue evaluation and

treatment services. To that end, I conducted a Google search on the phrase “symptoms of depression” and found that about 61,000 web sites turned up with that phrase in their site contents. What was the first site listed in my search results on “symptoms of depression?” It was SymptomsofDepression.com!

The SymptomsofDepression.com site yielded a succinct page and-a-half on identifying symptoms of depression, along with numerous links to other resources. Given that almost all the customers served by the staff I train are women, I also downloaded an in-depth 11-page document from the National Institute of Mental Health, “Depression: What Every Woman Should Know” (NIMH, 2000). Finally, I consulted the web site of the Mental Health Association of Southeastern Pennsylvania, www.mhasp.org, and was able to download an up-to-date listing of community mental health centers, referral centers for private licensed practitioners, and a listing of privately available services offered for a fee based on income, such as university-affiliated clinics.

Finding and gathering all this information into packets for my class took an hour or two of my time. My methods were basic and required no great sophistication as a user of the technology.

Selected Mental Health-Related Resources

As noted, there are many more mental health-related resources on the Internet than one person could ever take advantage of. Listed in this section are selected examples of sites that have reliable and useful information as of October, 2003.

National Institute of Mental Health / www.nimh.nih.gov

This is a major gateway as a link to many research and information sources as well as a offering a wealth of resources published by NIH.

National Alliance for the Mentally Ill / www.nami.org

NAMI is a support and advocacy organization of consumers, families and friends of people with severe mental illness, with 1,200+ state and local affiliates.

National Mental Health Association / www.nmha.org

An association that works with 340 affiliates to promote mental health through advocacy, education, research, and services.

Resource Center to Address Discrimination and Stigma Associated with Mental Illness / www.adscenter.org

The Resource Center to Address Discrimination and Stigma Associated with Mental Illness (ADS Center) was born out of a need to assist individuals, the public, state and local governments, and private and non-profit organizations in the design, implementation and operation of programs to reduce discrimination

and stigma associated with mental illnesses. The goal of the ADS Center, which is a project of the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA), is to enhance mental health consumer independence and community participation by ensuring that people have the information they need to counter discrimination and stigma.

For individuals, one of the ADS Center's most valuable forms of direct assistance is its annotated listing of Internet web sites for information and contacts related to ten defined spheres in which discrimination and stigma are active factors. The ten categories of web site resources are:

- Employment
- Housing
- Health Care and Insurance
- Culture and Gender
- Children
- Older Adults
- Media and Entertainment Industry
- Language and Terminology
- Policy and Legislation
- Effects of Stigma and Discrimination.

On the topic of Health Care and Insurance, as an example, 21 sites are broken out across three types of resources available at the respective sites: Brochures and Fact Sheets; Books, Articles and Research; and Resource Organizations. Each of the listed sites has been visited and reviewed by Center staff and each listing includes a narrative description of key contents of special value to users.

National Mental Health Consumers' Self-Help Clearinghouse

www.mhselfhelp.org

Especially informative site for identifying and networking with groups and individuals active in promoting advocacy and recovery efforts, and for researching and identifying quality mental health services, with particular emphasis on peer-run services. The Clearinghouse offers a valuable Technical Assistance Guide, ***Advocacy and Recovery Using the Internet.***

UIC National Research and Training Center / www.psych.uic.edu/uicnrtc

The National Research and Training Center on Psychiatric Disability conducts research, training, technical assistance and dissemination activities designed to promote self-determination among people with psychiatric disabilities. The overarching premise of the Center's activities is that persons with psychiatric disabilities have the right to maximal independence, which grows out of making choices regarding the decisions that affect their lives. The Self-Determination Workshop Series is a UIC NRTC program. One of these workshops, a webcast devoted to using the Internet for advocacy and for job search, is available for download as an archive on the site. The NRTC offers a "starting-from-scratch" guidebook for gaining access to the Internet and finding resources,

NAVIGATING THE INFORMATION SUPERHIGHWAY: INCREASING INTERNET KNOWLEDGE AND USE AMONG MENTAL HEALTH STAKEHOLDERS.

International Society for Mental Health Online / www.ismho.org

As stated on the site, “The International Society for Mental Health Online (ISMHO) was formed in 1997 to promote the understanding, use, and development of online communication, information and technology for the international mental health community. ISMHO is a nonprofit corporation.”

The site highlights emerging literature via direct links to articles, and a special focus of its resources is the online provision of services.

American Psychological Association / www.apa.org

In addition to featuring activities and publications of the APA as a professional organization, several consumer-oriented components of the site make it particularly valuable for the promotion of self-determination. The site’s “Help Center” is a user-friendly resource that is organized by questions that lay people with mental health-related concerns would ask.

Another apa.org component, at helping.apa.org, offers downloads of consumer-oriented brochures and information. Highly recommended here is *dotCOMSENSE: Common Sense Ways to Protect Your Privacy and Assess Online Mental Health Information*. This resource guides online users with detailed, practical measures and links to specialized sites for such further resources as “cookie management software.” Its pages cover core topics for users’ self-protection: Privacy, What are Cookies and How Do I Block Them?, Watch for Commercial Influences, Exercise Caution, and Resources, including

links to government and private organizations that help consumers protect their privacy and uncover untrustworthy dealings. *The Road to Resilience* is another printable publication that addresses psychoemotional resilience as a key factor in mental health and features grounded, practical approaches to building and maintaining resilience.

Selected Employment-Related Resources

The Internet is rife with employment-related resources, both general and those targeted to serve people with disabilities. The range of these resources is sampled and evaluated in the above-referenced UIC NRTC Self-Determination Workshop Series Live Webcast, October 22, 2002, available as an archive for viewing. There are 40+ pages of downloadable print exhibits and resource listings associated with the employment-oriented segment of that webcast, titled “The Electronic Career Stairway: Steps to Finding the Right Work via the Internet” (Dansky, 2002). In this section selected employment resources of special interest to consumers are reviewed.

Ability Forum / www.abilityforum.com

A diverse gateway to many Internet resources and services. Main menu offers “**Job Center**,” “**Resource Center**,” and “**Town Square**.” The job listing database numbers over 10,000 job postings. Other features of the site include pages on Ticket To Work, Assistive Devices, Educational Programs, and a social meeting place, called Meeting Place.

Job Access / www.jobaccess.org

Assists job seekers looking for work with businesses, government, or nonprofits.

Job Accommodation Network (JAN) / www.janweb.icdi.wvu.edu

JAN is a free service of the U.S. Dept. of Labor Office of Disability Employment Policy. JAN provides information and consultation on job accommodations, the ADA, and the employability of people with disabilities. JAN consultants respond to online user questions concerning employment accommodations for individuals.

The **Small Business and Self-Employment Service (SBSES)** is a program of the Job Accommodation Network which provides comprehensive information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. The SBSES Web site provides an extensive database of resources addressing both disability-related and self-employment issues. Those who regularly use SBSES services include:

- Individuals with disabilities who are interested in exploring self-employment and small business development options.
- Service providers working with consumers who are interested in exploring self-employment.
- Friends and family members of someone who is interested in becoming self-employed.

SBSES consultants assist consumers in exploring self-employment options by providing consultation and resources related to business planning, marketing research, potential funding sources, Social Security work incentives, credit repair strategies, microenterprise development, and many other issues.

National Center on Workforce and Disability/Adult (NCWD/A) /

www.onestops.info

Rich source of, and gateway to, information and resources on best practices, guidelines on needs and rights of consumer/survivors seeking work, disability-related policies and laws, ADA, Ticket To Work, etc. The NCDW/A is based at the Institute for Community Inclusion at the University of Massachusetts Boston.

State Vocational Rehabilitation Agencies / www.parac.org/svrp.html

This Pennsylvania Rehabilitation Council web site links to all state VR agencies.

Ticket to Work Web site from SSA / www.ssa.gov/work/Ticket/ticket_info.html

This site provides information of interest to beneficiaries who want to learn about the ins and outs of the Ticket To Work program for supporting return to work.

Challenges, Barriers and Pitfalls

Several of the challenges, barriers and pitfalls encountered in consumers' use or prospective use of information and communication technology have been cited in the course of this review. One is the digital divide between the disabled and non-disabled population and its causes. Other references have alluded to two major

concerns that have particular salience for mental health consumers, namely privacy issues and the trustworthiness of online information and online interactions, whether of a business, professional, or social nature. These legitimate concerns need to be brought to light, and it should be recognized that there are strategies for minimizing their causes and the perceived and real risks.

A key phenomenon widely addressed in the literature is the digital divide. In the discussion of resources above, several surveys suggested that consumers who would like to use the Internet avoid doing so because they perceive it as too confusing and hard to use. The inference drawn by Lenhart from the Pew Internet & American Life research is that many non-users become new users when they attend unintimidating classes that provide personal attention and are tailored to their needs, and when they had more affordable access to computers and the Internet.

In the case of the community experience of mental health consumers, all of these conditions might most easily be met in the context of an accommodating psychosocial rehabilitation program. However, a survey conducted at a national psychosocial rehabilitation conference in 2000 revealed that consumer participants in three-quarters of the programs represented in the survey did not typically have access to computers at the program site (Dansky, Granger, Bradley and Jonikas, 2001). While libraries and other public venues may afford free access, they also may discourage consumers because they are public

venues. As the one place outside the home that honors and supports consumers and their aspirations for full community participation, these programs need to be encouraged and guided in engaging consumers with online resources.

Privacy is a major concern for people who may have experienced intrusions on their privacy as well as legitimate concerns about stigmatization. However, one has a choice of turning a concern into an impenetrable barrier or of approaching with due caution and armed with prudent and effective strategies for self-protection. For those who would make the latter choice, the APA publication dotCOMSENSE referenced earlier guides the user in assessing the privacy protections of web sites and in actually regulating the exchange of information (in the form of cookies) so as to avoid leaving identifying information with the site.

There are various strategies for hiding one's identity online. A review of strategies for keeping one's identity to oneself while online appears in *PC Magazine* (Canter, 2003). These strategies range from easy-to-implement no-cost ways of hiding one's identity – e.g., obtain a Web e-mail address from Yahoo! for sending e-mails – to anonymous remailers that involve more sophisticated knowledge but are more difficult to penetrate, to much more technically demanding encrypted remailers that are most secure from penetration.

Finally, the Identity Theft Resource Center at www.idtheftcenter.org is a nonprofit organization online “dedicated to developing and implementing a comprehensive

program against identity theft. Users will find updated information about schemes and scams and advice on the best protections and practices for avoiding – and/or responding to – identity theft.

The issue of trustworthiness of online information and interactions rightly looms large. Again, dotCOMSENSE at the APA web site had a set of guidelines for evaluating credibility and quality of a site's information. There are hoaxes and scams, and there are ways of recognizing them. Brad Berens' "Can You Believe a Web Site?" (<http://www.earthlink.net/elink/issue29/focus.html>) and the unattributed "The Truth About Email Hoaxes" (http://www.earthlink.net/elink/cmp/focus/focus_100702.html) advise users on the signs of illegitimate sites and communications. In this connection, one often-referenced and highly regarded web site that merits special mention is snopes.com, at www.snopes.com, also known as the Urban Legends Reference Pages. It is an online credibility report maintained by the husband and wife team of Barbara and David Mikkelson.

Conclusion

Our aim has been to make the case that technology is a valuable and powerful tool for promoting individuals' self-determination. Our model was drawn through general and specific instances to show operationally how, at least in theory, certain types of Internet use can become the scaffolding by which consumers might experience and assimilate a pattern of awareness, choice and efficacy.

We asserted that there is too much value to be gained from consumers' use of technology to be deterred by the challenges, barriers and pitfalls associated with that use. Most of this review has been devoted to demonstrating that value, in the belief that consumers must first see and be drawn to that value before they make the adaptation to become technology users. There are solutions to issues of access and adoption. There are effective ways of protecting privacy and testing trustworthiness, ways of recognizing and avoiding pitfalls on the Internet.

In asserting the role of the Internet in promoting consumers' self-determination and proposing a model to show operationally how that comes about, we know that we still lack empirical validation. The survey research now being undertaken is the first phase of looking at patterns and consequences of the relationship between consumers and this technology. Model--testing research lies in the future.

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