Early Findings of the University of Illinois at Chicago National Research and Training Center's Web-Based Survey on Consumer Self-Determination and Technology

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Introduction

The purpose of the project described in this paper was to conduct an Internet survey of a large number of mental health consumers about issues related to self-determination and technology. Participants were asked to describe their personal feelings and experiences of self-determination, opinions about the mental health service delivery system, and use of information technology. The survey was created by the University of Illinois at Chicago (UIC) National Research and Training Center's (NRTC) Self-Determination and Technology Workgroup. This participatory action workgroup is comprised of consumers, advocates, and researchers interested in the application of information technology to mental health issues.

Self-determination refers to the right of individuals to have full power over their own lives, encompassing concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction (Cook & Jonikas, 2002). In the United States today, individuals with serious mental health problems experience minimal self-determination given society's failure to provide them with adequate, recovery-oriented services or choices in how to use available services

(Ahern & Fisher, 1999; Lamb, 1994; Manderscheid, Henderson, et al., 1998). For those who do seek help, services often fall far short of those considered even minimally adequate for clinical care, rehabilitation, and recovery (Lehman, Steinwachs et al., 1998). This has created a need for consumers to be able to access information about desired services and supports, as well as the latest scientific breakthroughs in the causes and treatments of mental illness.

In society in general, and in the field of rehabilitation in particular, new information is being distributed at an unprecedented rate (Barrett, 1994), which is increasing exponentially due to advances in information technology (IT), particularly use of the Internet. This has led to concerns about maximizing access to IT by a wide variety of stakeholders, especially consumers of rehabilitation services (Fullmer & Mujumder, 1991). Similarly, there is growing recognition in disability disciplines that the gap between the development of knowledge and knowledge application can impede both consumers' personal progress as well as innovation in service settings and systems (Zeren et al., 1999).

Many individuals and organizations, particularly those attuned to mental health consumer and family issues, cannot afford even minimal funds to bring in experts to conduct training or pay for technical assistance and consultation. This suggests that the use of technology, such as personal computers and electronic networking, may serve as a cost effective way to distribute information to vast underserved audiences. However, many people lack access to these new technologies, leading to the much-discussed "digital divide." According to the U.S. Department of Commerce, households with incomes above $75,000 are 20 times more likely to have access to the Internet than lower-income households (Foxhall, 2000). Differences in literacy rates, inadequate computer education, lack of high-speed equipment, and scarcity of culturally relevant information on the World Wide Web also impede the appeal and utility of technology for many communities.

Because of these issues, the NRTC survey focused on the level of consumers' access to and use of information technology, specifically the Internet, as well as how this was related to self-determination. The audience for the survey results was conceptualized as including consumers/survivors, policy makers, families, advocates, researchers, service providers, and system administrators.

Methodology

A convenience sample was obtained through an announcement posted to a number of mental health listservs and Websites, sent to members of the NRTC mailing list, and advertised in newsletters targeted to consumers and other mental health stakeholders. This announcement explained the purpose of the survey, described eligible respondents, and directed interested participants to a secure Web address where they could complete the survey online with complete anonymity. Contact information for UIC NRTC project staff was provided for the use of respondents with questions or those having difficulty completing the survey.

The survey Website could be visited by anyone having access to the Internet. At the Website, participants were presented with a series of survey question that took approximately ten to twenty minutes to complete, depending on the "skip pattern" created by replies to certain questions. As surveys were completed and submitted, each respondent's information was automatically entered into a secure and protected database, accessible only to the UIC research staff. The survey Web page and database were hosted with WebSurveyor Corporation, a private, for-profit research firm. All transmitted data were encoded using Secure Sockets Layer encryption. No Internet Protocol (IP) addresses linked to specific hardware used to complete the survey, nor any other identifying information about the respondents were collected.

Individuals eligible to complete the survey were those who self-identified as having experienced mental health difficulties, those reporting a diagnosis of mental illness or use of psychotropic medication, and/or those who said they had been hospitalized for mental health reasons. Exclusion criteria included individuals who could not read English, those without access to the Internet, individuals who did not self-identify as mental health consumers, and minors (given human subjects requirements of parental consent, all information from individuals indicating that they were less than 18 years of age was excluded). The preliminary posting period occurred from July through September of 2003.

The survey was comprised of three basic sections. The first section elicited respondents' feelings about the degree of self-determination in their lives by asking consumers: 1) an open-ended question about what fostered and impeded their own self-determination; 2) closed-ended questions about different aspects of self determination such as control over finances, residential status, and treatment; 3) for a rating of the degree of self-determination in their lives on a scale from 0 to 10; and 4) about their level of self-determination as it related to receiving mental health services. Those not receiving services responded to a separate set of questions asking why this was so. The second section of the survey asked about respondents' access, use, and barriers to use of information technology. The third section asked about respondents' demographics (including gender, age, education, and racial/ethnic background), as well as features of their clinical history (such as diagnosis, prior psychiatric hospitalizations, and whether they were receiving mental health services).

Results

Characteristics of the respondents. A total of 619 individual respondents completed the survey. The large majority of survey respondents either reported a specific diagnosis (97%), said they were currently taking psychotropic medication(s) (97%), and/or had experienced a mental health hospitalization (88%). Most respondents (88%) were Caucasian, with smaller proportions of African Americans (3%), those with mixed ethnicity (3%), and 2% Hispanic/Latinos (2%). Close to three-quarters (72%) were female, and their average age was 45 years (with a range from 18-71 years). Most were single, with only 38% reporting being married or cohabiting. The large majority (90%) had completed high school or a GED. Half (51%) were employed (35% full-time and 16% part-time). A third (33%) had household incomes less than $15,000/year, while only 15% reported household incomes greater than $70,000/year. Close to two tenths (38%) lived in urban areas or suburbs (38%), and a quarter (24%) resided in rural communities. In addition to their status as individuals with mental health problems, 46% reported that they were advocates, 44% were relatives of someone else with MH problems, 16% were program directors, 15% were service providers, 13% were students, 11% were researchers, 10% were teachers, and 15% did consulting.

Degree of personal self-determination. As defined for respondents in the survey instructions, the concept of self-determination referred to the freedom to be in charge of one's own life including one's residence, friends, and activities. It also meant having the resources to create a good life, make responsible decisions, and choose where and how one received support and assistance for mental health problems. When asked to rate their degree of personal self-determination, 47% said they did not have enough money to live reasonably well, and 41% said they did not feel part of their community. Around a third (34%) did not feel that other people in their lives respected their beliefs and needs, 34% felt they did not have the freedom to live the way they wanted to, and 32% did not feel that their basic civil and human rights were respected. On the other hand, 82% reported having control over how their money was spent, 83% felt they had a decent and affordable place to live, 74% indicated having a choice about whether they wanted to live alone or with someone else, and 84% reported that they had the transportation they needed.

Regarding the degree of self-determination in their mental health treatment, 47% of the respondents felt they did not have a choice about the amount of mental health treatment they received, 38% said they lacked choice about the type of treatment, and 42% reported that their health care coverage did not allow them to get the treatment they felt they needed. On the other hand, 82% reported that they knew ways to manage their own emotional problems, 80% felt they had the skills to advocate for themselves, 78% reported having access to self-help or support groups, and 78% said that recovery was the focus of their mental health treatment.

<u>Experiences with mental health service providers</u>. A large majority of respondents (85%) reported having mental health care insurance coverage, and 83% reported currently receiving services “from a doctor, counselor, therapist, or nurse.”

Respondents receiving services were asked their opinions about the provider with whom they had the most contact. Regarding these providers, 37% felt their providers were not helping them to build a meaningful community life, 22% felt their providers failed to focus on life areas other than mental illness, 18% felt their providers failed to accept consumers' desired treatment goals and plans, and 15% felt their providers did not work in partnership with them. On the other hand, 89% of respondents felt their providers respected their life choices, 88% felt providers honored their need for autonomy, 87% felt their providers avoided use of coercion or intimidation, and 87% felt their providers honored their service choices.

Only 17% of respondents reported that they were not currently receiving services. When asked why they were not receiving services, 46% said they did not need services, 43% did not like the services they had received in the past, 37% said they did not trust service providers, 30% felt that they had recovered, and 29% said they did not have the ability to pay for services (respondents could check more than one answer to this question). Of those who were not receiving services but felt they needed them (i.e., the 54% who did not indicate that they no longer needed services), 48% said they did not trust providers or disliked past services, 31% said there were no good providers in their local areas, and 24% said they wanted to avoid past coercive, restrictive or traumatic experiences they'd had with providers.

Relationship between provider experiences and self-determination. In order to determine whether respondents' experiences with their service providers were related to their self-assessed level of self-determination, we examined zero-order relationships between these two domains. Results revealed that consumers who rated themselves highest on self-determination were significantly more likely (p<.001) to feel that their providers were helping them build a meaningful community life, to work with providers who respected their choices about mental health services, to work with providers who were willing to revise treatment plans and goals whenever requested, and to have access to self-help and peer support services.

Reported use of information technology. As expected, given the nature of the study as an Internet survey, the large majority of respondents (97%) said they used a computer, and 87% said they did so at home. When asked to estimate their frequency of use, most said they used the Internet 3 to 5 times a week. Of the 97% who reported that they used the Internet, the most common uses were: sending or receiving email (98%); searching for health or medical information online (97%); obtaining information about mental health issues (92%); visiting government Web sites (92%); and getting news online (92%). People who used the Internet more frequently were significantly more likely (p<.05) to be younger, male, married, employed, a college graduate, and from higher income brackets.

Relationship between use of information technology and self-determination. Finally, we wanted to explore potential relationships between respondents' Internet use and the degree of self-determination in their lives. Respondents reporting higher levels of self-determination were significantly more likely (p<.001) to report that they had access to a computer, and that they used the Internet more frequently. Those with higher levels of self-determination also were more likely to say they knew how to access the Internet in their local communities (for free or for a fee), and more likely to report using the Internet to do work, look for local/state/federal government information, to purchase a product online, or do word processing ($p < .001$).

Summary and Conclusions

The results of this study revealed that survey respondents were a highly educated, primarily Caucasian, mostly female group of consumers. Their average age was in the mid-forties, most were college graduates, and most were computer owners and frequent Internet users.

The large majority of respondents were users of the formal mental health service delivery system, and many reported having access to self-help and peer support. Most were fairly satisfied with the degree of choice and respect they encountered in the mental health service system, but a notable minority reported dissatisfaction with their service providers and/or services they received.

Many consumers felt that their providers honored their life and treatment choices and that they were able to determine their own treatment goals. Fewer felt their providers were helping them create a meaningful life in the community, and that their providers focused on issues other than mental illness. Some avoided treatment because of lack of good providers in their local area or prior bad experiences with mental health treatment. There was a statistical relationship between reporting positive experiences with service providers and respondents’ self-assessed degree of personal empowerment.

Many consumer Internet users reported that they sought information about mental health services, medications, and diagnoses on the Web. Many also searched for service providers on the Internet, and visited government Websites for information.

There was a statistical relationship between frequency of Internet use and self-assessed degree of personal empowerment. Frequent Internet users reported higher levels of self-determination in their lives, which may or may not have been due to use of the Internet.

Our first look at these data raises some concerns, but also offers several inspiring messages. While many respondents felt that they had control over their money, housing situation, and transportation, many also reported not having enough money to live reasonably well, and a lack of choice and control over mental health treatment choices. Many respondents did not feel a part of their communities, nor respected by others, and did not feel they had the freedom to live as they wanted to. But most reported having the skills to advocate for themselves and manage their own emotional problems, along with the belief that the major goal of their mental health treatment is recovery.

Since close to half of this group identified themselves as “advocates” in this survey, it is noteworthy that many appear to be using tools, such as the Internet, that enable individuals to advocate for themselves, as well as to organize others in groups that can advocate for each other. Compared to the “average” Internet user in the U.S., as described in the Pew Internet and American Life Tracking Surveys (March 2000 - June 2003), larger proportions of these mental health consumers used the Internet to access health and mental health information, visit a government Web site, get news, and send or receive email. This suggests cautious optimism about the ability of some consumers (admittedly those already online) to access and use the Internet to better their lives and enhance their freedom of choice. Hopefully, others will explore these issues in subsequent surveys, so that the benefits of those and other forms of information technology can be made available to increasingly larger groups of mental health stakeholders.

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