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**Challenges in Defining Respondent Populations in a Web Survey of Individuals with  
Psychiatric Disabilities\***

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# **Challenges in Defining Respondent Populations in a Web Survey of Individuals with Psychiatric Disabilities**

## Introduction

Efforts over the past several decades to increase integration of individuals with disabilities into the political, economic, and social arenas of American society have raised concerns about self-determination. Self-determination refers to a person's ability to freely make important life choices such as where to live, with whom to associate, what kind of work to do, and whether to receive disability-related services. Given the difficulty of researching some populations whose disabilities are hidden or stigmatized, a Web-based survey approach may offer advantages in recruiting respondents and administering the research protocol. This study used Web-based survey technology to study self-determination among individuals with psychiatric disabilities. The study's methodological approach provided an opportunity to identify some of the advantages as well as the pitfalls of surveying people with psychiatric disabilities using Web recruitment and survey methodology.

## Review of the Literature

Self-determination involves having the resources to create a good life, make responsible decisions, and choose whether and how one receives services and support for mental health problems (Rothman et al., 1996). It encompasses concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction (Tower, 1994). In the United States today however, low levels of self-determination among people with psychiatric disabilities have been well documented (Cook & Jonikas, 2002). Many individuals with this disability live in conditions of poverty and cope with a host of unmet needs (Ware & Goldfinger, 1997). This significantly hinders their ability to have maximal

independence and to make meaningful decisions regarding their own lives (del Vecchio, Fricks et al., 2000). They experience higher than average levels of unemployment, incarceration, chronic medical illness, and social isolation (United States Department of Education, 2000). Perceptions persist that, compared to other groups, they are not as deserving of housing assistance and support (Center for Mental Health Services, 1998), so that sizable numbers are homeless or live in unstable housing (Rosenfield, 1991) while others are forced to reside with parents well into adulthood (Cook, Hoffschmidt et al., 1992).

Given the disadvantaged position of individuals with psychiatric disabilities in American society, recruiting them for research studies can be especially difficult. Because of the highly stigmatized nature of mental illness, individuals are often reluctant to self-identify as having a major mental disorder. Yet, since mental illness is a “hidden” disability, such self-identification is critical to researchers who are seeking to study this population. Another concern in research regarding this group is protection of confidentiality given the negative reactions of others to being publicly identified as having mental health problems. An additional barrier is that, even after agreeing to participate in research, subjects may feel constrained by positive response bias to report socially desirable attitudes and behaviors, further distorting study results.

Many of these problems can be addressed by employing Internet survey methodology in which potential respondents are recruited online and complete the survey instrument via Web technology. This methodological approach can be superior to others for several reasons. First, the Internet has been shown to be useful for studying specialized, difficult-to-reach populations (Kraut, Banaji, Bruckman et al., 2004) such as members of socially stigmatized communities who might hesitate to self-identify and permit face-to-face contact with researchers (Murray & Fisher, 2002; Subramanian et al., 1997). In one study, researchers soliciting a gay and lesbian

sample for a study of sexual behavior were successful in using a Web-based approach to collect one of the largest such samples to date (Epstein & Klinkenberg, 2002). Second, use of the Internet to collect data affords research participants a degree of anonymity and confidentiality that exceeds many other approaches such as face-to-face interviews or even mail surveys (Fawcett & Buhle, 1995). For example, in one Internet survey of oncology nursing experts (Im & Chee, 2002) the investigators reported that ensuring confidentiality was relatively simple as long as data collection consisted entirely of anonymous communication during completing and submission of survey responses. Third, research via the Internet is associated with less social pressure due to lack of interaction with and distance from the researcher (Kraut et al., 2004). In comparing responses of research participants to paper and pencil versus Web-based surveys, Joinson (1999) found that respondents reported lower social desirability and social anxiety when data were gathered via the Internet. These advantages, however, must be weighed against disadvantages of web-based surveys including problems of self-selection leading to sample and response biases (Gonzalez, 2002), inability to monitor drop-outs (Birnbaum, 2004), low response rates (Ranchhod & Zhou, 2001), lack of control over the data collection setting (Kraut et al., 2004), and difficulties in protection of human subjects (Im & Chee, 2004).

The primary purpose of the present analysis was to assess the utility of studying individuals with psychiatric disabilities using a Web-based approach. Three basic questions were addressed. First, would Web survey technology reach individuals with psychiatric disabilities and would they agree to participate? Second, how would individuals self-identify themselves in relation to their mental health problems? Third, would those with different self-identifications differ from each other demographically, clinically, and in their level of self-determination? The following section describes the procedures used to address these research questions.

## Methodology

Sampling Strategy. A convenience sample of individuals with psychiatric disabilities was obtained through announcements posted to a number of mental health listservs and websites, sent to members of the University of Illinois at Chicago National Research and Training Center on Psychiatric Disability (UIC NRTC) mailing list, and advertised in newsletters targeted to people with psychiatric disabilities 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 full anonymity. Potential respondents with questions or those having difficulty completing the survey were provided with contact information for UIC NRTC staff.

Web Survey Procedures. The survey website could be visited by anyone with access to the Internet. At the website, participants were presented with instructions and an explanation of the purpose of the study, followed by a series of survey questions 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 by the UIC NRTC project staff. The survey website and database were hosted with WebSurveyor Corporation, a private, for-profit research firm. All transmitted data were encoded using Secure Sockets Layer encryption. Neither Internet Protocol (IP) addresses linked to specific hardware used to complete the survey, nor any other identifying information about the respondents were collected. All research procedures were reviewed and approved by the University of Illinois at Chicago Institutional Review Board.

Inclusion and Exclusion Criteria. Individuals eligible to be included in the study were those who self-identified as having experienced mental health difficulties. The recruitment advertisement used for the study began as follows:

“We are conducting a survey of people who have used mental health services or have experienced emotional or mental health problems. We would like to know how much control they have over their lives and important life decisions, such as where they live, what kind of work they do, and how they spend their money...” (Web Survey Advertisement).

Again, when they logged onto the survey website, read the informed consent material, and consented to participate in the study, respondents were instructed on the first page of the survey as follows:

“[This] survey is about the experiences of adults (age 18 and older) who have used mental health services or have experienced emotional or mental health problems...By participating in this survey, you are helping to inform the mental health field about self-determination. Only adults who have used services or experienced mental health difficulties should complete this survey...” (Web Survey Instructions, p.1)

It was felt that these two ways of informing individuals about the study’s intended target population would be adequate but perhaps not sufficient to ensure participation of only the intended respondents. Thus, near the end of the survey, participants were asked a number of questions about their psychiatric histories, mental health-related groups with which they identified, and their current relationships with service providers. These questions were examined to determine whether survey participants were indeed members of the target population of the research, and serve as the source of data analyzed in the present study.

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 survey was posted for 9 months from July 2003 through April 2004.

Survey Instrument. The Web-based survey was programmed using a “dynamic” or interactive format (Tourangeau, 2004) and included automated skip patterns, immediate range and error checks, forced responses to all applicable items, and respondent-generated data submission. Some of the survey items were adapted from those used by the U.S. Bureau of the Census in its Technology Survey (Neuburger, 2001), as well as items from the Pew Internet & American Life Project survey protocols (Fallows, 2000). Other items were created by the UIC NRTC Web Survey Project Workgroup. The survey was comprised of three basic sections: 1) a section asking respondents about the degree of self-determination in their lives; 2) a section asking about their access, use, and barriers regarding information technology; and 3) questions about demographic characteristics and clinical history. A draft version of the survey was field-tested and revised according to psychometric results and field-test respondents’ feedback. The present analysis used data from the survey’s first and third sections.

Analysis. After inspection of frequency distributions and descriptive statistics, chi square and t-test analysis were used to explore demographic and clinical characteristics of those with different self-identifications. Following that, the mean self-determination scores of individuals with different self-identifications were examined and tested for differences.

## Results



Survey Completion and Response Rates. The first research question was whether Web survey technology would reach individuals with psychiatric disabilities and how they would respond to attempts to recruit them into a survey on self-determination. Given the use of convenience sampling, it was impossible to determine the number of eligible individuals who were contacted during the recruitment phase of the study, but decided not to complete the survey, the typical definition of a refusal rate. However, WebSurveyor technology did enable us to determine the number of times the survey was “requested,” that is, the number of times the survey was called up from the WebSurveyor server by a browser. Of the 1741 times the survey was requested, 1042 respondents completed the instrument and clicked on the “submit” button. This ratio suggests a response rate of 60%. However, it is possible that some respondents who did not submit the survey on the first try returned to request, complete, and submit it at a later date. Due to human subjects considerations, researchers did not capture the Internet Protocol (IP) address of respondents’ computers, which would have enabled us to answer this and other questions about whether the survey was requested or submitted from the same computer on multiple occasions. However, the Web survey approach does appear to have been successful in recruiting a large number of research participants whose disabilities are both hidden and accorded a great amount of social stigma.

Because the survey was intended for respondents age 18 or older, which was also mentioned in the survey advertisement, a screening question early in the protocol itself asked whether they were under this age. Respondents answering in the affirmative were immediately directed to a “Thank you” page, which expressed the researchers’ gratitude for their willingness to participate, but explained that they did not meet study eligibility criteria and ended the survey. However, in 11 instances, individuals’ responses to this and a later follow-up question about age

indicated that they were legal minors and their data was not included in the analysis, further reducing the study N from 1042 to 1031.

Respondents' Self-Identification. The next research question was how respondents identified themselves in relation to their mental health and emotional difficulties. First, they were asked whether they were a consumer, survivor, client or user of mental health services or a person with emotional difficulties, all of which are terms commonly used in the various mental health recovery communities. In what follows, these individuals are referred to as people with “mental health problems.” The large majority, 95% (n=981), checked this item, indicating that they were currently experiencing such problems or had in the past. Next, respondents were asked whether they “currently” had a “mental health service provider,” as a means of identifying all those who were receiving mental health services at time of survey completion. Once again, a sizeable majority, 83% (n=853), indicated the presence of a service provider in their lives. Finally, an item asked respondents whether their “mental health problems” currently kept them “from participating fully in work, school, housework, or other activities.” Those who reported functional limitations due to their mental health problems were considered to have a “psychiatric disability.” A lower proportion, 65% (n=675) responded “yes” to this item than to the first two, which was expected given that not all individuals experience role impairment as a result of their mental health difficulties. Other individuals reported their mental health difficulties by checking one of four items asking about hospitalizations for psychiatric reasons, receiving a diagnosis of mental disorder, taking psychiatric medications, or having had mental health problems as children.

In addition to the foregoing, however, there were seven respondents who did not indicate membership in any of the four groups and did not check any of the four items described above.

Thus, they did not identify as having current or past mental health problems, were not receiving mental health services, did not experience functional limitations, had never been given a diagnosis, had never been hospitalized, and had no childhood age of onset to report. Closer inspection of their responses to a checklist item asking about other types of mental health stakeholder roles revealed the following self-identifications: two said they were relatives of someone with mental illness; a third reported being a service provider, a fourth checked both family member of someone with mental illness and program director/manager/supervisor categories; a fifth checked both teacher and student; a sixth checked government official, program director, and service provider; and the seventh individual checked a number of categories (family member, program director, researcher, student, advocate, employer, and service provider). Because they did not meet study inclusion criteria, these seven cases were removed from the data, so that the final study N used in the remainder of the analysis was 1024.

Demographic Characteristics of the Respondents. The next research question was whether respondents' demographic features varied according to their self-identified mental health status. Table 1 presents the demographic characteristics of the 1024 remaining eligible respondents according to their membership in each of the three categories described above. Compared to the first two categories, smaller proportions of those with psychiatric disability were married or cohabiting (34% vs. 37-38%). Similarly, lower proportions those with disability were working (43% vs. 50-51%). The same was true for working full-time, reported by lower proportions of those with disability (25%) than those receiving services or having problems (33-35%). Compared to the other two groups, those with psychiatric disability also had the highest proportion of co-occurring disabilities (40%) and annual incomes under \$15,000 per year (38%). Finally, they were older on average (45 vs. 43 years of age).

However, the three groups were highly similar on other characteristics. Just over three-quarters of all three groups were women (76%), the majority were Caucasian (85-87%) and had high school degrees (98%), and over half were college graduates (58-61%). Around a third (35%) of all three groups resided in urban areas, two fifths (40-41%) in suburban, and a quarter (23-25%) in rural areas.

Table 1 also presents the results of chi-square and t-tests in which members and non-members of each of the three groups were compared. Those with mental health problems were more likely than those not in this group to be female, Caucasian, and to have incomes below \$10,000 and \$15,000 per year; they were also less likely to be male, Hispanic, African American, minority, married, employed full-time or working at all, and have annual income greater than \$50,000. Those currently receiving services were more likely than those who were not to be female, less likely to be African American or minority, less likely to be male or be married, to work or work full-time, and to have high annual income. Finally, those with psychiatric disability were less likely to be married, have a college degree, work or work full-time, and have high annual income; those with psychiatric disability were also more likely to be low-income and were older on average. Overall, membership in these three groups indicated more social and economic vulnerability due to lower income, education, employment, and lack of a spouse or intimate partner. Moreover, those with functional limitations stemming from their mental health problems appeared to be the worst off in these life areas.

Differences in Clinical Characteristics. Next, respondents' clinical characteristics were examined and tested to explore any differences. As shown in Table 2, the three groups were highly similar in their proportions ever hospitalized for mental health reasons, ever hospitalized for substance abuse, having a diagnosis, taking psychiatric medications, and average age at onset

of mental health problems. The only difference between the three groups was a higher proportion of co-occurring “other” disability among the group with psychiatric disability, compared to the other two groups.

Comparing members of each category with non-members, those with mental health problems were more likely than those without to have been hospitalized for mental health and substance abuse problems, to be diagnosed with a mental disorder, and to take psychiatric medications; they were also younger at the onset of psychiatric illness. Those currently receiving services were more likely than those not to have been hospitalized for mental health problems, to have been diagnosed, and to take psychiatric medications. Finally, those with disability were more likely to have been hospitalized for mental health or for substance abuse problems, to be diagnosed with a mental disorder, to have taken psychiatric medications, and to have a co-occurring disability; they were also younger at the time of their illness onset. Overall, membership in these three groups indicated more co-occurring problems (such as substance abuse and other disabilities), and more clinical involvement (younger age at problem onset and history of taking psychotropic medications). Clinically, those with disability due to their mental health problems appeared to be worse off in only one of these areas – the presence of a co-occurring disability.

Degree of Personal Self-Determination. The final research question was whether respondents’ self-assessed level of self-determination differed according to their membership in each of the three groups. As defined 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 finances, place of 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 services and support for mental

health problems. After reading this definition, respondents were asked to rate their current level of self-determination as low through high using a scale from 0 to 10.

Table 3 presents mean and median self-determination ratings for members versus non-members of each of the three groups. Compared to those without mental health problems, those with these problems had lower mean and median self-determination scores. However, the Kruskal-Wallis chi-square test revealed a significant difference in medians but the ANOVA F test did not reveal significant differences in the distributions of these ratings. Both the chi-square and ANOVA were significant for those currently receiving mental health services; here, those receiving services had significantly lower mean and median self-determination ratings than those not receiving services. Finally, those who reported functional impairment or disability related to their mental health problems had significantly lower mean as well as median self-determination ratings compared to those without disability. Thus, overall, membership in each of the three groups was associated with lower levels of self-assessed self-determination.

### Summary and Conclusions

The results of this study revealed that Web survey technology was successful in reaching and recruiting a large number of individuals with mental health problems to participate in a research study of self-determination. However, several important challenges in using this survey methodology to study this group were also identified. First, even though the target population was clearly identified in both survey advertisements and in the introduction to the instrument itself, some individuals who completed the survey did not meet eligibility criteria and had to be excluded. Thus, it is critical in such surveys to include items that verify whether or not respondents have the appropriate characteristics and experiences to qualify them as members of the target population. Second, even among those who did meet inclusion criteria, there was a

noteworthy degree of variability in self-identifications. Those with functional limitations, those receiving mental health services, and those with mental health problems were significantly different from their counterparts on demographic features, clinical characteristics, and level of self-determination. This highlights the diversity of this population and the related necessity of clarity on the researcher's part in defining and operationalizing the respondent pool.

Turning to the advantages and disadvantages of online recruitment and Web-based survey methodology in this study, several observations bear noting. First, this design yielded a very large sample of individuals from a specialized population that is highly stigmatized – people with significant mental health problems and impairments. Obtaining such a sample through traditional means would have been much more labor intensive and costly. Second, given the diverse self-identifications of this group, the interactive nature of the survey programming allowed administration of a protocol with complex skip patterns yet accompanied by very little respondent burden. For example, after reporting that they had a current service provider, service users were automatically directed to one set of questions about self-determination while nonusers were presented with another set. This and later skip patterns in the protocol would have been much more difficult for respondents to negotiate with a paper and pencil instrument.

On the other hand, there are concerns about the overrepresentation in this survey's respondent population of women, those with college educations, and Caucasians. While this was not surprising given that the last two characteristics mirror those of today's typical Internet user (Lenhart et al., 2003), it still calls for caution when interpreting the results. Still another concern was the fairly high level of self-determination reported by the study respondents in the face of a large volume of literature pointing to the low levels of self-determination among individuals with psychiatric disabilities. Perhaps self-determination is higher among Internet users, or among

some sub-groups of individuals with severe mental illnesses. This possibility is supported by research suggesting that individuals who use the Internet are more likely than nonusers to feel that they have control over their lives (Lenhart et al., 2003). Unfortunately, our study design does not permit us to address these and other intriguing questions about respondent self-selection and resulting lack of sample representativeness. Thus, the tradeoffs found in prior Web-based survey studies conducted with a wide variety of populations were true of this one as well.

Overall, the results of this study suggest that self-determination among people with psychiatric disabilities is an important concept that can be fruitfully investigated using Web-based survey technology. However, caution must be applied by researchers using this approach given that respondents with different self-identifications have different background characteristics and clinical experiences and, most importantly, different levels of self-determination. Hopefully future research can build on study findings to explore correlates of both self-determination and self-identification among this group, enhancing the possibility for self-determination to become more fully realized. In this way, larger numbers of people with psychiatric disabilities can move toward the achievement of maximal independence and full participation in community life.



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**TABLE 1**  
**Demographic Characteristics of Individuals with Different Mental Health Problem Identifications**

	Person with Mental Health Problems (N=981)	Current Mental Health Service Recipient (N=853)	Person with Psychiatric Disability (N=675)	Total (N=1024)
	%	%	%	%
Gender				
Female	76*	76**	76	75
Male	24*	24**	24	25
Race/Ethnicity				
Caucasian (not Hispanic)	87**	86	85	86
African-American (not Hispanic)	2*	2*	3	2
Hispanic	3**	3	4	4
Minority	6**	6*	7	7
Married/Living as married	38**	37**	34***	39
Education				
High school graduate	98**	98	98	98
College graduate	61	61	58**	62
Current Work Status				
Employed full-time	35***	33***	25***	37
Employed at all	51***	50***	43***	53
Annual Household Income				
Less than \$10,000	20*	20*	22***	19
Less than \$15,000	32**	32**	38***	30
Greater than or equal to \$50,000	25***	25*	21***	27
Geographic Area				
Urban	35	35	35	35
Suburban	42	42	40	42
Rural	24	23	25	23
Mean age in years	43	43	45***	43

\* = p<.05, \*\* = p<.01, \*\*\* = p<.001 in chi-square and t-tests comparing members and non-members of each group

**TABLE 2**  
**Clinical Characteristics of Individuals with Different Mental Health Problem**  
**Identifications**

	Person with Mental Health Problems (N=981)	Current Mental Health Service Recipient (N=853)	Person with Psychiatric Disability (N=675)	Total (N=1024)
	%	%	%	%
Ever hospitalized for mental health reasons	73***	70***	73***	68
Ever hospitalized for substance use reasons	13*	13	14*	12
Ever diagnosed with mental disorder(s)	100***	95***	96***	94
Ever taken psychiatric medications	100***	97***	98***	94
Other disability currently limits life activities	32	32	40***	32
Mean age experienced first mental health difficulties	18***	19	18***	19

\* = p<.05, \*\* = p<.01, \*\*\* = p<.001 in chi-square and t-tests comparing members and non-members of each group

**TABLE 3**  
**Self-Determination Ratings of Individuals with Different Mental Health Problem**  
**Identifications (N=1024)**

	Self-Determination Rating			
	With this Identification Mean (Median)	Without this Identification Mean (Median)	ANOVA F Test	Kruskal-Wallis H Test Chi-Square
Person with Mental Health Problems	6.7 (7.0)	7.1 (8.0)	3.54 <sup>ns</sup>	7.78 <sup>**</sup>
Current Mental Health Service Recipient	6.6 (7.0)	7.1 (8.0)	6.49 <sup>*</sup>	8.38 <sup>**</sup>
Person with Psychiatric Disability	6.0 (6.0)	8.0 (8.0)	193.68 <sup>***</sup>	187.11 <sup>***</sup>
Total	6.7 (7.0)			

ns = not significant, \* = p<.05, \*\* = p<.01, \*\*\* = p<.001