

WEB-SURVEY ON SELF-DETERMINATION & TECHNOLOGY

This interview protocol was developed for a project of the University of Illinois at Chicago National Research and Training Center (UIC NRTC) on Psychiatric Disability, directed by Judith A. Cook, Ph.D. The UIC NRTC is supported by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (Cooperative Agreement #H133B50004). The opinions expressed herein do not necessarily reflect the position, policy, or views of either agency and no official endorsement should be inferred.

Tell us about self-determination.

Self-determination means having the freedom to be in charge of your own life, choosing where you live, who you're with, and what you do. It means having the resources you need to create a good life and to make responsible decisions that are best for you and others around you. It also means choosing where, when, and how you will get support and assistance for mental health problems when needed.

1)	Many people identify indicate how much y				ermination possible for them. lowing statements.	Please
1a)	I have enough mone	y to live reas	onably w	ell.		
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree		
1b)	I have control over	how my mor	ney is spe	nt.		
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree		
1c)	My job pays me end	ough to live t	he kind o	f life I want.		
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree	Not Applicable	
1d)	I have mental health	care coverag	ge	[] YES	[] NO	
1e)	My mental health ca	re coverage	allows me	e to get the treatmen	nt I need.	
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree	Not Applicable	
1f)	I have a choice about	t where I live	e.			
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree		
1g)	I have a decent and a	affordable pl	ace to live	e.		
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree		
1h)	I have choice about	whether to li	ve alone o	or with someone els	se.	
	Strongly Disagree []	Disagree []	Agree []	Strongly Agree		

1i) I have the skills to ac	lvocate for n	nyself in c	order to get what I r	need.
Strongly Disagree []	_	Agree []	Strongly Agree	
1j) I can do whatever I s	et my mind	to.		
Strongly Disagree []		Agree []	Strongly Agree	
1k) Other people in my	life respect n	ny choices	s, beliefs, and need	s.
Strongly Disagree []	Disagree []	_	Strongly Agree	
11) I have transportation	to get to pla	ces I wan	t to go to.	
Strongly Disagree []		Agree []	Strongly Agree	
1m) I have choice about	the type of i	mental hea	alth treatment I reco	eive.
Strongly Disagree []		Agree []		Not Applicable
1n) I have choice about	the amount o	of mental	health treatment I r	eceive.
Strongly Disagree []	Disagree []	Agree []	Strongly Agree	Not Applicable
10) Recovery is the focu	s of my men	ntal health	treatment.	
Strongly Disagree []	Disagree []	Agree []	Strongly Agree	Not Applicable
1p) I know ways to man	age my own	emotiona	l problems.	
Strongly Disagree []	Disagree []	Agree []	Strongly Agree	
1q) I have access to self-	-help or supp	ort group	s. [] YI	ES []NO
1r) I have friends who he	elp me.			
Strongly Disagree []	Disagree []	Agree []	Strongly Agree	

1s`) I have	a spouse	or partner	who	helps	me.
IO.	, i mave	a spouse	or partifici	WIIO	ncips	mc.

Strongly Disagree Disagree Agree Strongly Agree

1t) I feel that I am a real part of my community.

Strongly Disagree Disagree Agree Strongly Agree

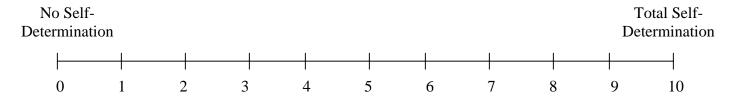
1u) My basic civil and human rights are respected.

Strongly Disagree Disagree Agree Strongly Agree

1v) I have the freedom to live the way I want to.

Strongly Disagree Disagree Agree Strongly Agree

2) On a scale from 0-10 how much self-determination do you have in your life right now?



3) What has made self-determination possible for you?

4) If there are certain areas of your life where you feel you don't have self-determination, what would you say are the reasons for this?

5)	Do you currently have a mental health service provider (doctor, counselor, therapist, nurse)? YES [SKIP TO #6] NO [CONTINUE WITH #5a]
	5a) Why aren't you currently receiving mental health services? (Check all that apply.)
	[] I don't need mental health treatment. [] I don't want mental health treatment. [] I don't have the ability to pay for treatment (either through health insurance or out-of-pocket) [] I have recovered from my emotional/mental health problems. [] There aren't any good mental health providers in my community or nearby. [] There aren't any mental health providers I trust. [] I am worried about what other people will think of me if I seek mental health treatment. [] I am worried that I will lose my job if I seek mental health treatment. [] I am worried that I will lose my children if I seek mental health treatment. [] I am avoiding things that happened to me in the past as part of my treatment (such as forced medications, physical restraint or seclusion, loss of rights and control, and so forth). [] I don't agree with the diagnosis/label I received. [] I din't like the services/treatment I was offered in the past. [] I wasn't given enough control over my own mental health treatment in the past. [] Other:
6)	Think about the mental health service provider with whom you <u>currently</u> have the <u>most</u> contact. How much do you agree or disagree that this person
	6a) - respects the choices you make about you own life?
	Strongly Disagree
	6b) - focuses on other aspects of your life besides mental illness?
	Strongly Disagree Disagree Agree Strongly Agree [] [] []
	6c) - helps you build a life in the community that is meaningful?
	Strongly Disagree Disagree Agree Strongly Agree [] [] []
	6d) - honors your right to choose your service providers?
	Strongly Disagree Disagree Agree Strongly Agree

6e) - accepts your de	sire to try th	ings for y	ourself?	
Strongly Disagree []		Agree []		
6f) - works in partner	rship with yo	ou in your	mental health treatment?	
Strongly Disagree []		Agree []		
6g) - respects the cho	oices you ma	ke about	your own mental health services?	
Strongly Disagree []	Disagree []			
6h) - allows you to cl	hange treatm	nent goals	or plans when you want to?	
Strongly Disagree []	Disagree []	_		
6i) - avoids the use o	f coercion or	r force in	your mental health treatment?	
Strongly Disagree []	Disagree []			
6j) -understands and respects your culture, gender, and other personal characteristics?				
Strongly Disagree []	Disagree []	Agree []	Strongly Agree	

[CONTINUE ON TO #7]

Many people feel that self-determination can be improved by having access to technology. The following questions ask about your use of computers and the Internet.

7)		than to complete this survey today, do you ever use a co top (IBM-compatible or Macintosh), laptop, PDA/handh	
		1 0	YES [GO TO #7A] NO [GO TO #7B]
	7a) D	o you have access to a computer you can use whenever	you want to?
		1	YES [SKIP TO #8]
		0	NO [SKIP TO #8]
	7b) D	o you have access to a computer you could use if you wa	anted to?
		1	YES [SKIP TO #11]
8) Do	VOU OV	vn your own computer?	NO [SKIP TO #12]
0) D C	you ov	vii your own computer.	
	[]YE	S []NO	
9)	Where	e do you use a computer? (CHECK ALL THAT APPLY)
	1	At home	
	2	At work	
	3	At school	
	4	At a public library	
	5	At a community center or neighborhood facility	the seas
	6	Someone else's privately owned computer (friend, fam	
	7 8	Commercial location (pay for use as you go Kinko's Mental health program, drop-in center, peer-support pr	
	9	Any place else/specify	
10) In gen	eral, how often do you use a computer?	
	1	Several times a day [SKIP TO #12]	
	2	About once a day [SKIP TO #12]	
	3	3-5 days a week [SKIP TO #12]	
	4	1-2 days a week [SKIP TO #12]	
	5	Every few weeks [CONTINUE ON TO #11]	
	6	Less often/specify	[CONTINUE ON TO #11]

(PLEASE CHOOSE ONE RESPONSE ON	NLY)
1 Cost, too expensive	
2 Not enough time to use it	
3 Not useful	
4 Confusing, hard to use5 Too inconvenient to get to a compute	ar .
6 No technical support	CI.
7 Concern about how children might b	e harmed by using it
8 Don't want it, not interested	, ,
9 Because others in my household are	<u> </u>
10 Concerned about my privacy and the	use of my personal information
10 Afraid to use it	
11 Other:	
This next set of questions has to do with the Interdifferent types of services: e-mail, electronic disc (WWW or "the Web"), telnet or remote login, F you use any of these services, you are using the In	cussion groups (listservs), the World Wide Web TP or File Transfer Protocol, and Gopher. If
12) As far as you know, is there a place you can go	• •
Internet is available to anyone who wants to use it for	or <u>free</u> ? 1 YES [GO TO 12a]
	0 NO [SKIP TO #13]
	0 1,0 [2222 1020]
12a) Where?	
Library	
College/university/school	14
Mental health program/community mental h	ealth center/peer-support program or drop-in center
Place of business/employment agency	
Some other place (please specify):	
T (1 7)	
13) As far as you know, is there a place you can go	in your neighborhood or community where the
Internet is available to anyone who wants to use it a	
	1 YES [GO TO 13a]
12a) Whama?	0 NO [SKIP TO #14]
13a) Where? Internet café	
Coffee Shop	
Business services center (e.g., Kinko	's, Staples)
Some other place (please specify): _	
[CONTINUE ON TO 14]	

11) What is the main reason you do not use a computer more often or at all?

	1 0	YES [CONTINUE ON TO #15] NO [SKIP TO #18]
15) Where	e do you use the Internet? (CHECK <u>ALL</u> THAT	APPLY)
1	At home	
2	At work	
3	At school	
4	At a public library	
5	At a community center or facility	
6	Someone else's privately owned computer (frie	
7	Commercial location (pay for use as you go	
8	Mental health program, drop-in center, peer-su	pport program
	By using a cell phone or other wireless device	
	Any place else/specify	
[CON	NTINUE ON TO #16]	
Within A year Two o	d you first start going online? In the last six months [SKIP TO #17] In ago [SKIP TO #17] In three years ago [SKIP TO #17] It than three years ago [CONTINUE ON TO #16] If "more than 3 yrs"	a]
	16a) About how many year have you had In [CONTINUE ON TO #17]	aternet access?
17) In ger	neral, how often do you use the Internet/go onlin	e?
1	Several times a day [SKIP TO #19]	
2	About once a day [SKIP TO #19]	
3	3-5 days a week [SKIP TO #19]	
4	1-2 days a week [SKIP TO #19]	
5	Every few weeks [CONTINUE ON TO #18]	
6	Less often/specify	[CONTINUE ON TO #18]

14) Other than to complete this survey today, do you use the Internet?

18) Wha	t is the main reason you do not use the Internet more often or at all?
(ON	E RESPONSE ONLY)
1	
1	, 1
2	E
3	
4	<i>C</i> ,
5	
6	1
7	
8	,
9	
	0 Concerned about my privacy and the use of my personal information
	1 Afraid to use it
	2 Other/specify
[CONTINUE ON TO #19]
10) D-	f1 dd d1 h1d
	you feel that your mental health problems make it harder for you to use the Internet?
_] YES
_] NO
_	Does not apply
[CONT]	INUE ON TO #20]
20) Here are	some things people sometimes say about the Internet. Just based on what you have heard
	ed, do you agree or disagree that
•	
20a)	The Internet is confusing and hard to use.
,	strongly agree / somewhat agree / somewhat disagree / strongly disagree
20b)	Internet access is too expensive.
,	strongly agree / somewhat agree / somewhat disagree / strongly disagree
20c)	The Internet is a dangerous thing.
,	strongly agree / somewhat agree / somewhat disagree / strongly disagree
	strongly agree / some what agree / some what disagree / strongly disagree
IIF ANSWI	ERED 'YES' TO #7 AND/OR #14, CONTINUE ON TO #21. OTHERWISE, SKIP
TO #22.]	
]	

21) Do you ever do any of the following when you use a computer or go online?

Complete school assignments.	1	YES	0	NO
Work/do your job.	1	YES	0	NO
Manage household records or finances.	1	YES	0	NO
Play games.	1	YES	0	NO
Search for information about products or services.	1	YES	0	NO
Look for health or medical information.	1	YES	0	NO
Look for information from a local, state, or federal government website.	1	YES	0	NO
Look for information about a job.	1	YES	0	NO
Look for information about a place to live.	1	YES	0	NO
Do word processing/typing or desktop publishing.	1	YES	0	NO
Use a calendar or do scheduling.	1	YES	0	NO
Send or read e-mail.	1	YES	0	NO
Participate in chat rooms or listservs.	1	YES	0	NO
Take an educational course online.	1	YES	0	NO
Buy a product on line (such as books, music, toys, or clothing).	1	YES	0	NO
Get news online.	1	YES	0	NO
Check weather reports or forecasts online.	1	YES	0	NO
View TV or movies or listen to the radio over the Internet.	1	YES	0	NO
Look for information about movies, music, books, or other leisure activities.	1	YES	0	NO
Make telephone calls over the Internet.	1	YES	0	NO
Do online banking.	1	YES	0	NO
Create artwork.	1	YES	0	NO
Search for information on the Internet about someone you know or might meet.	1	YES	0	NO

Search for information on mental health diagnoses/treatments/medications.	1	YES	0	NO
Search for information on job accommodations/supports.	1	YES	0	NO
Search for information on the Americans with Disabilities Act (ADA), Social Security Work Incentives, etc.	1	YES	0	NO
Search for information on service providers.	1	YES	0	NO
Any other purpose. Specify:	1	YES	0	NO

[SKIP TO #24]

22) Do you think you would like to use a computer if you had access to one?

1 YES 0 NO

[IF "YES," CONTINUE ON TO #23. IF "NO," GO TO #24.]

23) Which of the following things would you be interested in doing on the computer or the Internet?

Complete school assignments.	1	YES	0	NO
Work/do your job.	1	YES	0	NO
Manage household records or finances.	1	YES	0	NO
Play games.	1	YES	0	NO
Search for information about products or services.	1	YES	0	NO
Look for health or medical information.	1	YES	0	NO
Look for information from a local, state, or federal government website.	1	YES	0	NO
Look for information about a job.	1	YES	0	NO
Look for information about a place to live.	1	YES	0	NO
Do word processing/typing or desktop publishing.	1	YES	0	NO
Use a calendar or do scheduling.	1	YES	0	NO
Send or read e-mail.	1	YES	0	NO

Participate in chat rooms or listservs.	1	YES	0	NO
Take an educational course online.	1	YES	0	NO
Buy a product on line (such as books, music, toys, or clothing).	1	YES	0	NO
Get news online.	1	YES	0	NO
Check weather reports or forecasts online.	1	YES	0	NO
View TV or movies or listen to the radio over the Internet.	1	YES	0	NO
Look for information about movies, music, books, or other leisure activities.	1	YES	0	NO
Make telephone calls over the Internet.	1	YES	0	NO
Do online banking.	1	YES	0	NO
Create artwork.	1	YES	0	NO
Search for information on the Internet about someone you know or might meet.	1	YES	0	NO
Search for information on mental health diagnoses/treatments/medications.	1	YES	0	NO
Search for information on job accommodations/supports.	1	YES	0	NO
Search for information on the Americans with Disabilities Act (ADA), Social Security Work Incentives, etc.	1	YES	0	NO
Search for information on service providers.	1	YES	0	NO
Any other purpose. Specify:	1	YES	0	NO

We'd like to ask you a few final questions about yourself... 24) What country do you live in? (Select from list) 25) Which of the following describes you? (Please check *all* that apply): [] Consumer/survivor/client/user of mental health [] Researcher services/person with emotional difficulties [] Family member of a person with mental health [] Student problems [] Government Official [] Psychiatrist or Physician [] College or University Teacher [] Other Service Provider [] Other Teacher [] Advocate [] Program Director/Manager/Supervisor [] Employer [] Consultant Other, please specify: 26) What is your age?: ______ years [] Female [] Male 27) What is your gender?: 27y) Are you of Hispanic or Latino origin or descent, such as Mexican, Puerto Rican, Cuban, or some other Latin American background? YES [CONTINUE TO #27z] NO [SKIP TO #28] Do you consider yourself a: 27z) [] Black Hispanic/Latino [] White Hispanic/Latino [] Other Hispanic/Latino [SKIP TO #29] 28) What is your race?: [] White [] Black/African-American [] Asian or Pacific Islander

[] Other (please specify)

[] Mixed race

29) What is your marital status? [] Married [] Living as married [] Divorced [] Separated [] Widowed [] Never married
30) Formal education: [] Less than high school [] Some high school [] High school graduate or GED certificate [] Business, technical, or vocational school AFTER high school [] Some college [] College graduate (A.A. or other Associate degree) [] College graduate (B.S., B.A., or other 4-year degree) [] Post-graduate training/professional school after college (Master's degree, Ph.D., law school, medical school, etc.)
31) How would you describe your current work status? (PLEASE CHECK ONLY ONE) [] employed 35 or more hours per week [] employed less than 35 hours per week [] not working, but have looked for work in the past 4 weeks [] not working and not currently looking for work [] a student who is not working [] retired from the labor force [] on a temporary leave or layoff from a job [] other (please specify):
32) Last year, that is in 2002, what was your <u>total household income</u> from <u>all sources</u> and <u>all household members</u> before taxes?: [] \$0 - \$4,999 [] \$5,000 - \$9,999 [] \$10,000 - \$14,999 [] \$15,000 - \$19,999 [] \$20,000 - \$24,999 [] \$25,000 - \$29,999 [] \$30,000 - \$39,999 [] \$40,000 - \$49,999 [] \$50,000 - \$69,999 [] \$70,000 and over

33) How would you describe the area you live in?[] Urban[] Suburban[] Rural
34) Do your mental health problems currently keep you from participating fully in work, school housework, or other activities? []YES [] NO
35) Does any other type of disability, handicap, or chronic disease currently keep you from participating fully in work, school, housework, or other activities? []YES []NO
36) At what age did you first experience mental health difficulties:
37) Have you ever been told you have a psychiatric diagnosis or label? [] YES [] NO
If YES 37a) Would you mind telling us what that label was?
38) Have you ever been hospitalized for mental health reasons? []YES [] NO
39) Have you ever been hospitalized for substance abuse problems? []YES [] NO
40) Have you ever taken psychiatric medications? []YES [] NO

THANK YOU FOR SHARING YOUR VALUABLE EXPERIENCES BY COMPLETING THIS SURVEY. PLEASE ENCOURAGE OTHERS WHO ARE ELIGIBLE TO COMPLETE THE SURVEY. BE SURE TO VISIT OUR WEBSITE (http://psych.uic.edu/uicnrtc) IN THE COMING MONTHS FOR RESULTS.