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 aspects of their lives that make self-determination possible for them. Please indicate how much you agree or disagree with each of the following statements.

1a) I have enough money to live reasonably well.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]  [ ]  [ ]  [ ]

1b) I have control over how my money is spent.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]  [ ]  [ ]  [ ]

1c) My job pays me enough to live the kind of life I want.

   Strongly Disagree  Disagree  Agree  Strongly Agree  Not Applicable
   [ ]  [ ]  [ ]  [ ]  [ ]

1d) I have mental health care coverage  [ ] YES  [ ] NO

1e) My mental health care coverage allows me to get the treatment I need.

   Strongly Disagree  Disagree  Agree  Strongly Agree  Not Applicable
   [ ]  [ ]  [ ]  [ ]  [ ]

1f) I have a choice about where I live.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]  [ ]  [ ]  [ ]

1g) I have a decent and affordable place to live.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]  [ ]  [ ]  [ ]

1h) I have choice about whether to live alone or with someone else.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]  [ ]  [ ]  [ ]
1i) I have the skills to advocate for myself in order to get what I need.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]

1j) I can do whatever I set my mind to.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]

1k) Other people in my life respect my choices, beliefs, and needs.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]

1l) I have transportation to get to places I want to go to.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]

1m) I have choice about the type of mental health treatment I receive.

   Strongly Disagree  Disagree  Agree  Strongly Agree  Not Applicable
   [ ]                 [ ]       [ ]     [ ]         [ ]

1n) I have choice about the amount of mental health treatment I receive.

   Strongly Disagree  Disagree  Agree  Strongly Agree  Not Applicable
   [ ]                 [ ]       [ ]     [ ]         [ ]

1o) Recovery is the focus of my mental health treatment.

   Strongly Disagree  Disagree  Agree  Strongly Agree  Not Applicable
   [ ]                 [ ]       [ ]     [ ]         [ ]

1p) I know ways to manage my own emotional problems.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]

1q) I have access to self-help or support groups.

   [ ] YES   [ ] NO

1r) I have friends who help me.

   Strongly Disagree  Disagree  Agree  Strongly Agree
   [ ]                 [ ]       [ ]     [ ]
1s) I have a spouse or partner who helps me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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1t) I feel that I am a real part of my community.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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1u) My basic civil and human rights are respected.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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1v) I have the freedom to live the way I want to.

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<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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2) On a scale from 0-10 how much self-determination do you have in your life right now?

<table>
<thead>
<tr>
<th>No Self-Determination</th>
<th>Total Self-Determination</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
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</tbody>
</table>

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?

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

4
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 right now.
[ ] 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 didn’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: _____________________________________________________

[SKIP TO #7]

6) Think about the mental health service provider with whom you currently have the most contact. How much do you agree or disagree that this person…

6a) respects the choices you make about your own life?

Strongly Disagree Disagree Agree Strongly Agree
[ ] [ ] [ ] [ ]

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 desire to try things for yourself?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
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6f) - works in partnership with you in your mental health treatment?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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6g) - respects the choices you make about your own mental health services?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
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6h) - allows you to change treatment goals or plans when you want to?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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6i) - avoids the use of coercion or force in your mental health treatment?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
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<td>[ ]</td>
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6j) - understands and respects your culture, gender, and other personal characteristics?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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[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) **Other than to complete this survey today**, do you ever use a computer? By computer we mean a desktop (IBM-compatible or Macintosh), laptop, PDA/handheld device, or Web-TV.

1 YES [GO TO #7A]
0 NO [GO TO #7B]

7a) Do you have access to a computer you can use whenever you want to?

1 YES [SKIP TO #8]
0 NO [SKIP TO #8]

7b) Do you have access to a computer you could use if you wanted to?

1 YES [SKIP TO #11]
0 NO [SKIP TO #12]

8) Do you own your own computer?

[ ] YES  [ ] NO

9) Where 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
6 Someone else’s privately owned computer (friend, family, etc.)
7 Commercial location (pay for use as you go -- Kinko’s, Internet café,)
8 Mental health program, drop-in center, peer-support program
9 Any place else/specify____________________________________

10) In general, 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]
11) What is the main reason you do not use a computer more often or at all? (PLEASE CHOOSE ONE RESPONSE ONLY)
1 Cost, too expensive
2 Not enough time to use it
3 Not useful
4 Confusing, hard to use
5 Too inconvenient to get to a computer
6 No technical support
7 Concern about how children might be harmed by using it
8 Don’t want it, not interested
9 Because others in my household are using it when I want to
10 Concerned about my privacy and the use of my personal information
11 Afraid to use it
11 Other: _________________________________

This next set of questions has to do with the Internet. The Internet is made up of several different types of services: e-mail, electronic discussion groups (listservs), the World Wide Web (WWW or ”the Web”), telnet or remote login, FTP or File Transfer Protocol, and Gopher. If you use any of these services, you are using the Internet.

12) 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 for free?  
1 YES [GO TO 12a]  
0 NO [SKIP TO #13]

12a) Where?  
Library
College/university/school
Mental health program/community mental health center/peer-support program or drop-in center
Church
Place of business/employment agency
Some other place (please specify): _________________________________

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 and can pay a required fee?  
1 YES [GO TO 13a]  
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]
14) *Other than to complete this survey today*, do you use the Internet?  
[ ] 1 YES [CONTINUE ON TO #15]  
[ ] 0 NO [SKIP TO #18]

15) Where do you use the Internet? (CHECK ALL 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 (friend, family, etc.)  
[ ] 7 Commercial location (pay for use as you go -- Kinko’s, Internet café,)  
[ ] 8 Mental health program, drop-in center, peer-support program  
[ ] 9 By using a cell phone or other wireless device  
[ ] 99 Any place else/specify____________________________________  
[CONTINUE ON TO #16]

16) When did you first start going online?  
Within the last six months [SKIP TO #17]  
A year ago [SKIP TO #17]  
Two or three years ago [SKIP TO #17]  
More than three years ago [CONTINUE ON TO #16a]  
If “more than 3 yrs” ---  
[ ] 16a) About how many years have you had Internet access? _________  
[CONTINUE ON TO #17]

17) In general, how often do you use the Internet/go online?  
[ ] 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]
18) What is the main reason you do not use the Internet more often or at all? (ONE RESPONSE ONLY)

1  Cost, too expensive
2  Not enough time to use it
3  Not useful
4  Confusing, hard to use
5  Too inconvenient to get to a computer with Internet access
6  Problems with Internet service provider
7  Concern about how children might be harmed by using it
8  Don’t want it, not interested
9  Because others in my household are using the computer
10 Concerned about my privacy and the use of my personal information
11 Afraid to use it
12 Other/specify

[CONTINUE ON TO #19]

19) Do you feel that your mental health problems make it harder for you to use the Internet?
[ ] YES
[ ] NO
[ ] Does not apply

[CONTINUE ON TO #20]

20) Here are some things people sometimes say about the Internet. Just based on what you have heard or experienced, 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

[IF ANSWERED ‘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?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete school assignments.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Work/do your job.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Manage household records or finances.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Play games.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Search for information about products or services.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Look for health or medical information.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Look for information from a local, state, or federal government website.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Look for information about a job.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Look for information about a place to live.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Do word processing/typing or desktop publishing.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Use a calendar or do scheduling.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Send or read e-mail.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Participate in chat rooms or listservs.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Take an educational course online.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Buy a product on line (such as books, music, toys, or clothing).</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Get news online.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Check weather reports or forecasts online.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>View TV or movies or listen to the radio over the Internet.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Look for information about movies, music, books, or other leisure activities.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Make telephone calls over the Internet.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Do online banking.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Create artwork.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Search for information on the Internet about someone you know or might meet.</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
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 online (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 services/person with emotional difficulties
- [ ] Family member of a person with mental health problems
- [ ] Government Official
- [ ] College or University Teacher
- [ ] Other Teacher
- [ ] Program Director/Manager/Supervisor
- [ ] Other, please specify:

26) What is your age?: ____________________ years

27) What is your gender?: [ ] Female      [ ] Male

27y) Are you of Hispanic or Latino origin or descent, such as Mexican, Puerto Rican, Cuban, or some other Latin American background?

Y E S [CONTINUE TO #27z]
NO [SKIP TO #28]

27z) Do you consider yourself a:

- [ ] 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
- [ ] Mixed race
- [ ] Other (please specify) __________________________
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 total household income from all sources and all household members 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/uicnrtec) IN THE COMING MONTHS FOR RESULTS.