

Barriers for Mental Health Consumers Seeking Services in Illinois in the 1990s

National Conference on Mental Health Statistics
Washington, D.C.

May 30, 2001

Andrea M. Cooke
Mental Health Consumer Education Consortium
University of Chicago
acooke2@aol.com

OVERVIEW/BACKGROUND

- This project asked consumers what they felt were their barriers to seeking treatment
- The project did not start out as scientific research
- We found that consumers thought that services were available in Illinois, but that they weren't always helpful.

METHODS

- The survey was one page long and contained 24 questions which were both yes/no and fill in the blank.
- It was a self-report

DATA COLLECTION

The data was collected between 1994 and 1996 in several ways:

- mailed to those on our mailing list
- mailed to all grant-in-aid agencies in Illinois
- mailed to day treatment programs
- distributed at consumer self help meetings

Evidence that a small amount of coaching had taken place

Data entered into SPSS

Variable relationships assessed using chi-square analysis

DEMOGRAPHICS₁

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Age	177		43	+/-13
Marital Status				
married	32	18%		
single	73	41%		
divorced/ widowed/ separated	59	36%		

DEMOGRAPHICS₂

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Sex				
male	74	43%		
female	99	57%		
Race				
white	118	71%		
nonwhite	49	29%		

DEMOGRAPHICS₃

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Employment Status				
unemployed	42	38%		
student/retired	17	15%		
professional/ nonprofessional	52	47%		

DEMOGRAPHICS₄

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Education Level				
below high school	39	23%		
high school grad	60	36%		
some college	46	27%		
college grad	24	14%		

DEMOGRAPHICS₅

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Area of Residence				
Chicago	57	35%		
Central & NW Illinois	93	56%		
Southern Illinois	15	9%		

DEMOGRAPHICS₆

<u>Category</u>	<u>Number</u>	<u>Percent</u>	<u>Mean</u>	<u>S.D.</u>
Know About LANs				
Yes	88	67%		
No	43	33%		
Informed Of Rights				
Yes	139	83%		
No	28	17%		

BARRIERS TO SEEKING SERVICES

	<u>Number</u>	<u>Percent</u>
Don't know about services	55	37.4%
No transportation	54	36.7%
No money for services	54	36.7%
Hours bad	115	78.2%
Fear of labeling	36	24.5%
Embarrassed about receiving services	49	33.3%
Feel can help self	72	49.0%
Provider competence	107	73.8%
Provider courtesy	112	77.2%
Culture/race/language	111	76.6%

DEMOGRAPHIC VARIABLES AND BARRIERS₁

Relationships Tested	Trends Towards Significance	
	<u>Confidence Levels</u>	
	95%	90%
Race & Don't Know About Services		X
Race & Hours Bad		X
Race & Labeling		X
Work Status & Provider Competence	X	
Education Level & Don't Know		X
Education Level & Provider Competence	X	

DEMOGRAPHIC VARIABLES AND BARRIERS₂

Relationships Tested	Trends Towards Significance	
	<u>Confidence Levels</u>	
	95%	90%
Education Level & Courtesy		X
Residence & Labeling		X
Know About LANs & Don't Know	X	
Know About LANs & Hours Bad	X	
Sex & Transportation	X	
Sex & Provider Courtesy	X	

FINDINGS₁

Relationships found to be significant at the 95% confidence level:

- Most unemployed consumers (67%) felt that their providers were not competent. Employed consumers did not.
- Most consumers with a high school education or less(76%) felt that their providers were not competent; only 50% college graduates felt that way.
- Most Illinois consumers (63%) felt that there was adequate transportation to mental health services.
- Twice as many consumers (49%) who knew what LANs were as those who didn't (24%) said not having knowledge about services was a barrier to seeking them out.
- 78% of those knowledgeable about the mental health system(knew LANs) felt that bad services hours was a barrier to seeking services
- The majority of consumers (77%) felt that provider courtesy was a barrier to them seeking services

FINDINGS₂

Relationships found to be significant at the 90% confidence level:

- race and not knowing about services
- race and hours being bad
- race and fear of being labeled
- education level and not knowing about services
- education level and provider courtesy
- residence and fear of being labeled
- residence and provider courtesy
- knowing what a LAN is and being embarrassed to receive services
- knowing what a LAN is and provider competency

CONSUMERS' VERBATIM COMMENTS

"I am concerned about emergency shelters for the chronically mentally ill people."

"Medicaid needs to reimburse doctors at a more reasonable rate to encourage them to participate in the program."

"Service agencies don't welcome families with open arms when we finally get the courage to ask for help."

"We need more recreation and (consumer) dating services."

"We need a vegetarian Old Country Buffet in our neighborhood."

"Give us the benefit of the doubt when it comes to meds, physical problems, etc., and don't assume you have all the answers about our diagnosis and treatment. You too can be wrong."

"People with mental illness are like anyone else but with a chemical imbalance... They can do many amazing things and are worthwhile people to know and have as good friends."

OVERALL FINDINGS

- consumers want a life like everyone else (restaurants, dating, respect)
- consumers do not all endorse an empowerment perspective
- most consumers expressed some misgivings about their providers; those with insight and knowledge(knew LANs) communicated their concern regarding provider competence
- consumers with insight and knowledge about the mental health system are more likely to feel that their concerns are important
- stigma effects (fear of being labeled and embarrassment to seek treatment) are important concerns that consumers have and deserve to be further studied