

Consumer Research Activities in the States

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Executive Summary

The Kentucky Center for Mental Health Studies, Inc. (KCMHS), with technical assistance from The Evaluation Center@HSRI (TEC), held organized discussions to gather information about consumer research activities in the states. In particular, KCMHS inquired about 1) the consumers' involvement in evaluation and research, 2) the areas in which consumers desire technical assistance in these fields, and 3) consumers' familiarity with a consumer grant program that funds consumer evaluation and research activities entitled The Consumer Evaluator Network. The purpose of this project is to inform technical assistance centers, such as TEC through its Consumer Evaluator Network, where to direct resources in regards to consumer research and evaluation activities.

To collect information, KCMHS chose to hold discussions with individuals knowledgeable of consumer research activities. The majority of discussions included directors of the State Office of Consumer Affairs in 2003. However, when these individuals could not be contacted, non-consumer state employees and individuals positioned in consumer or state research offices were engaged in the discussions. KCMHS staff engaged 34 individuals in discussion. The discussions revealed helpful information.

Consumers' involvement in evaluation and research. Informants indicated that they and/or the consumers they represent were involved in some research or evaluation activity in most states. More than half of the informants identified the type of research/evaluation that they were involved in to be program evaluations or satisfaction surveys. The role of consumers in these activities, as indicated by the informants, was closely divided, with little over half of the informants indicating that they or the consumers they represent control the research and evaluation activities.

Desired technical assistance. The majority of informants indicated that they or the consumers that they represented were interested in technical assistance in twelve out of twelve research and evaluation areas. The high priority areas for technical assistance, as indicated by at least half of the informants, include the following:

- Measuring recovery
- Understanding and explaining evidence-based practices
- Introductory training on evaluation and research
- Assessing the cultural competency of services

Awareness of the Consumer Evaluator Network. The majority of informants indicated that they were not familiar with the Consumer Evaluator Network.

The information reported here suggests that consumers are involved in research and evaluation at various capacities. Regardless of their involvement in these activities, there is an overwhelming desire expressed by informants for increased knowledge and technical assistance in the areas of research and evaluation. Because centers currently exist to provide technical assistance and disseminate knowledge with regard to research and evaluation, information from the discussions suggests the need for centers to increase outreach to consumer directed offices and organizations.

Introduction

The Kentucky Center for Mental Health Studies, Inc. (KCMHS), with technical assistance from The Evaluation Center@HSRI (TEC), set out to investigate consumer research activities in the states in 2003. Through organized discussions with individuals knowledgeable of consumer activities, the project aimed to identify information concerning consumer involvement and interest in mental health research and evaluation. Mainly, directors of the State Office of Consumer Affairs (OCA) acted as informants, but when they could not be contacted non-consumer state employees and individuals positioned in state mental health research offices were engaged in discussion. The project revealed the current involvement and role of consumers in mental health research and evaluation activities, the assistance needed by consumers in research and evaluation activities, and the ways that technical assistance centers, such as TEC through its Consumer Evaluator Network, might provide assistance.

Organizational Overview

The Evaluation Center at Human Services Research Institute (TEC)

The Evaluation Center@ HSRI (TEC) is a national technical assistance center for the evaluation of adult mental health systems change. TEC provides technical assistance in the area of evaluation to States and nonprofit public entities within the States for improving the planning, development, and operation of adult mental health services. Funding for TEC is provided by Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CMHS). TEC funds the Consumer Evaluator Network, which was started in 1997, and is managed by the KCMHS. The Consumer Evaluator Network provides small grants to consumers, enabling them to participate in evaluation and research activities. Interested consumers provide an application to KCMHS, which consults with TEC on the review of the application. The Consumer Evaluator Network recently provided funding for a national research project for the development of system performance indicators and measures of recovery.

The Kentucky Center for Mental Health Studies, Inc (KCMHS)

The Kentucky Center for Mental Health Studies, Inc. (KCMHS) is a consumer-governed research institute that was established to give consumers opportunities to conduct, participate in, and collaborate on mental health research initiatives and projects. The center is organized as an independent, non-profit entity that began operations on July 1, 1998. It is located in the historic district of Georgetown, Kentucky.

Office of Consumer Affairs (OCA)¹

The Office of Consumer Affairs (OCA) began development within state mental health agencies in the late 1980s and early 1990s. Their development came about as a method to insure meaningful consumer involvement in the public mental health system. The OCA's mission is "to serve and improve state mental health systems by working to support and expand the consumer voice within mental health policymaking, planning and practice" (Jorgenson & Schmook 2000,p.3). While the OCA's mission is shared by all OCAs, regardless of state, the implementation of the mission varies by state, depending on system and stakeholder influences. Jorgenson and Schmook (2000) point out six areas for which OCAs are generally responsible:

¹Jorgenson, J. & Schmook, A. (November 2000). *Offices of Consumer Affairs: A Pathway to Effective Public Mental Health Services*. National Association of Consumer/Survivor Mental Health Administrators

- Policy and regulation development
- Program planning
- Evaluation and monitoring
- Training
- Finance and contract management
- Addressing complaints and grievances

Approach to Gathering Information

Identifying Informants. Information for this study was gathered through discussions KCMHS staff held with OCA directors or other individuals knowledgeable of consumer research and evaluation activities. KCMHS staff identified potential informants through the most recent list at that time (October 2003) of OCA directors provided by the National Association of Consumer Survivors Mental Health Administrators (NACSMHA) (See Appendix A). KCMHS staff contacted each state, plus the District of Columbia and Puerto Rico, to schedule a phone call. Staff found that the listed contact information of OCA directors was frequently outdated, making identifying informants and scheduling discussions a time-consuming process. When an OCA director could not be reached or was not listed for a state, non-consumer state employees and individuals positioned in consumer research offices were identified as potential informants.

Staff identified forty-four potential informants. However, they were unsuccessful in establishing contacts for discussions in seven states and one territory in the brief window for the study. Discussants attempted to contact informants multiple times. If informants could not be reached after multiple attempts or the set discussion deadline, individuals were categorized as “no response.” Out of the forty-four (44) potential informants, KCMHS staff gathered information from thirty-four (34).

Description of Informants

The informants could be divided into three basic groups:

- Directors of State Offices of Consumer Affairs (22)
- Directors of statewide or other consumer organizations (6)
- Non-consumer state employees (6)

Directors of State Offices of Consumer Affairs. KCMHS staff engaged twenty-two directors of State Offices of Consumer Affairs in discussions. All twenty-two were the recognized spokespersons for consumer affairs for that particular state. They may have had the title of “Director,” “Acting Director,” “Interim Director,” “Consumer Specialist,” or similar title. Nonetheless, these individuals were self-identified consumers who represented the consumer community within state government.

Directors of Statewide or Other Consumer Organizations. These persons were those whom the mental health authority directed KCMHS staff to if there was no consumer in the state government who specifically represented consumers. KCMHS staff called six individuals representing this category. Sometimes these individuals were leaders of a statewide consumer organization or a regional consumer group that was widely recognized within the state by consumers as an acceptable representative.

Non-consumer State Employees. When a state did not have a consumer representative in state government, a consumer contact could not be reached, or an office of consumer affairs was vacant, KCMHS called a non-consumer staff member of the mental health agency who knew about the research activities sponsored for consumers within the state. This group consisted of researchers, ombudsperson, bureau chief, program manager and regional consultant. KCMHS held discussions with six (6) non-consumer state employees about consumer research activities.

Table 1. Persons Engaged in Discussion

	N	%
Persons Contacted	44	100
Persons Engaged	34	77
Consumers Engaged	28	82
Non-Consumers Engaged	6	18

Discussions

KCMHS discussants prepared for the discussions prior to contacting informants. Preparatory activities were designed to educate discussants of the current state mental health policies and planning activities in the states and review a discussion strategy. It also allowed time for discussants to rehearse discussion scenarios, and plan for handling a variety of situations that might occur during the discussion. Following each discussion, discussants assessed their conversation: they compared notes with each other, troubleshoot problems with the discussion questions, and developed new strategies to improve discussions.

The discussants engaged thirty-two informants via the telephone, leaving two of the informants to answer discussion questions in a written format. Discussants used the questions developed by the staff of KCMHS and the Evaluation Center to guide discussions. Some phone calls were held without informants having knowledge of the discussion questions prior to the discussion. In other situations, informants asked to receive a copy of the questions prior to the discussion. For those completing the questions in a written format, questions were faxed to the contact person and, once completed, returned by fax. In these situations, the responses were also discussed over the phone.

Findings

The findings² are divided into three sections: *Consumer Research and Evaluation Activities*, *Consumer Technical Assistance Priorities* and *Awareness of the Consumer Evaluator Network Program*. **Section One**, *Consumer Research and Evaluation Activities*, identifies the types of research and evaluation activities in which informants indicated that they or the consumers they represent are involved and discusses the roles of consumers in these activities as well. **Section Two**, *Consumer Technical Assistance Priorities*, indicates the types of technical assistance consumers would like to receive in research and evaluation, according to the informants. **Section Three** discusses the familiarity of informants with the Consumer Evaluator Network Program.

² Numbers are based on the number of informants that responded. Informant's responses might be representative of themselves or the consumers which they represent in research and evaluation activities.

Section One: Consumer Research and Evaluation Activities

Based on the discussions, all informants and/or the consumers they represent are involved in some type of research or evaluation activity. Informants indicated that consumers are involved in research and evaluation at the state level in a number of areas: satisfaction surveys, program evaluation, consumer organization evaluation, needs assessment, and other areas. Consumers were most likely to be involved in conducting consumer satisfaction surveys (85%) and program evaluations (68%) (Refer to Table 2).

When asked to describe the program evaluations that they or the consumers they represent are involved in, some informants described these activities in general terms, noting that consumers are involved in all program and service evaluations or Block Grant funded program and service evaluations. Other informants' named the specific types of program evaluation in which they or the consumers they represent are involved: inpatient programs, day programs, consumer operated residential programs, crisis services, community mental health services, nutritional services, assessment teams, mandated care, managed care, outcome evaluations, focus groups, performance indicators, and courses (i.e. leadership academy, recovery education and Dialectical Behavior Therapy program).

Less than half of the discussants noted that they or the consumers that they represented were involved in needs assessments (35%), other research/evaluation activities (35%), or consumer organization evaluation (21%). The description of research/evaluation activities identified as "other" fall into the following categories: performance data monitoring, qualitative research studies, survey development, quality improvement, development of program standards, identification and development of outcome measures, and activity research.

Table 2.
Consumer Involvement in Research/Evaluation Activities*

Research/Evaluation Type	N	%
Satisfaction Surveys**	29	85
Program Evaluation**	23	68
Needs Assessments**	12	35
Other**	12	35
Consumer Organization Evaluation**	7	21
None**	0	0

* The numbers are based on the number of informants that responded. Informant's responses might be representative of themselves or the consumers that they represent in research and evaluation activities.

** Categories are not exclusive.

Based on informants' responses, consumers seem to be involved in various research and evaluation activities in their states. When asked if they would like to see more consumer involvement in research and/or evaluation projects almost half of the informants, forty-seven percent (47%), said "no" while twenty-nine (29%) of informants noted that there are evaluation or research projects in their state for which they would like to see more consumer involvement. Almost a quarter of informants (24%) did not respond to this question. Some informants suggested projects that they believe need more consumer involvement. Informants identified the following projects:

- Consumer participation in the evaluation of all projects
- PATH and Homeless Program
- Co-Occurring Disorders Project
- Consumer Outcomes in State Quality Improvement Projects
- Coordination of Medicaid/non-Medicaid individuals in support activities

*Consumers' Roles in Research and Evaluation Activities*³. Informants reported that they and/or the consumers they represent are generally involved in collaborative relationships with the state in (1) planning, (2) administering, (3) conducting, and (4) reporting research and evaluation activities.

Respondents were asked to describe the role of consumers when it pertained to general control of research and evaluation activities. Respondents reported that fifty-six percent (56%) of the informants understood that consumers lead research and evaluation activities in their state. Forty-seven percent (47%) reported that non-consumers lead these activities. Typically, professional research/evaluators are involved too. Specifically, sixty-eight percent (68%) of informants indicated that these activities involved professional researchers/evaluators, while eighteen percent (18%) of informants indicated that these activities did not involve professional researchers/evaluators. Informants explained that while consumers were frequently in control of the activities, typically professional research/evaluators worked side-by-side as mentors. When asked if the researchers or evaluators were consumers, fifty-three percent (53%) of the informants stated researchers in the states are not consumers and forty-four percent (44%) stated that the researcher or evaluators are consumers.

An informant noted that consumers most often did not involve themselves in study design and statistics. Because of a “discomfort level” with these professional areas, they generally preferred professional staff to provide the expertise in these areas. However, a couple of informants reported active involvement at this level.

Section Two: Technical Assistance Priorities in Research

KCMHS staff asked informants to indicate if they or the consumers they represented desired technical assistance in any of twelve areas:

- Assessing the cultural competency of services
- Measuring recovery
- Designing or implementing a needs assessment
- Understanding evidence-based practices
- Introductory training on research and evaluation
- Interpreting program evaluations or performance information
- Designing or interpreting a program or research evaluation
- Designing or evaluating a consumer satisfaction survey
- How to participate in consumer satisfaction activities

³ A small number of informants marked opposing categories. This suggests informants were confused with the questions or that they were aware of both types of situations: 1) activities in a state that are lead by consumers and that are lead by non-consumers 2) activities that involved researchers/evaluators and activities that do not involve researchers/evaluators 3) activities in which the researchers/evaluators are not consumers and activities in which researchers/evaluators are consumers.

- Reviewing the evidence for services
- Evaluating managed care
- Measuring other outcomes

The majority of informants reported an interest in receiving technical assistance in all twelve areas, thus indicating demand exists in the consumer community for technical assistance in research and evaluation activities (See Table 3).

Table 3. Technical Assistance Topic Areas*

Topic Area	Marked as a Priority		Not Marked as Priority	
	N	%	N	%
Assessing the cultural competency of services	30	88	4	12
Measuring recovery	30	88	4	12
Designing or implementing a needs assessment	29	85	5	15
Understanding Evidence-based practices	29	85	5	15
Introductory training on research and evaluation	29	85	5	15
Interpreting program evaluations or performance information	27	79	7	21
Designing or interpreting a program or research evaluation	25	74	9	26
Designing or evaluating a consumer satisfaction survey	25	74	9	26
How to participate in consumer satisfaction activities	25	74	9	26
Reviewing the evidence for services	24	71	10	29
Evaluating managed care	23	68	11	32
Measuring other outcomes	21	62	13	38

*The numbers are based on the number of informants that responded. Informants’ responses might be representative of themselves or the consumers that they represent in research and evaluation activities.

If the informants stated an interest in technical assistance, they were then asked to prioritize the items. Respondents indicated whether the topic area was a *very high priority*, *high priority*, *medium priority*, or *very low priority*. Priority levels were then recoded to indicate whether an item was a high (combined responses marked as very high and high), neutral (responses marked as medium), or low priority (responses marked as very low) (See Table 4).

The topics marked as a technical assistance high priority by at least half of all informants include four areas:

- Measuring Recovery
- Understanding Evidence Based Practices
- Introductory training on research and evaluation
- Assessing the cultural competency of services

It is worth noting that the high priority areas noted above are consistent with many of the goals and objectives identified in the President’s New Freedom Commission on Mental Health Report entitled *Achieving the Promise: Transforming Mental Health Care in America*.⁴ Specifically, the Commission Report recommends

⁴ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Executive Summary*. DHHS Pub. No. SMA-03-3831. Rockville, MD: 2003.

transforming the mental health system into one that is recovery-oriented, consumer and family driven, and where excellent care is delivered, research is accelerated, and disparities in care are eliminated.

Table 4. Technical Assistance Topic Areas By Priority Level*

Topic Area	Priority Level					
	High		Neutral		Low	
	N	%	N	%	N	%
Measuring recovery	25	74	2	6	3	9
Understanding Evidence-based practices	21	62	4	12	4	12
Introductory training on research and evaluation	19	56	8	24	2	6
Assessing the cultural competency of services	17	50	6	18	7	21
Reviewing the evidence for services	16	47	4	12	4	12
Measuring other outcomes	13	38	6	18	2	6
Interpreting program evaluations or performance information	12	35	10	29	5	15
Designing or interpreting a program or research evaluation	11	32	11	32	3	9
Designing or implementing a needs assessment	11	32	12	35	6	18
How to participate in consumer satisfaction activities	10	29	4	12	11	32
Designing or evaluating a consumer satisfaction survey	7	21	5	15	13	38
Evaluating managed care	4	12	8	24	11	32

*Numbers are based on the number of informants that responded. Informants' responses might be representative of themselves or the consumers that they represent in research and evaluation activities.

In addition to gathering information on priority and priority level, discussants asked informants to identify specific technical assistance interests for three out of the twelve technical assistance topic areas: 1) reviewing the evidence for services; 2) measuring other outcomes; and 3) designing or interpreting a program or research evaluation.

Reviewing the evidence for services. When asked to specify programs/services for which they would like to review the evidence, informants indicated that they are interested in reviewing the evidence of a wide variety of programs/services: evidence-based practices, consumer operated services, rehabilitation services, clinical services including medication management and electric shock therapy, and recovery-oriented services.

Measuring other outcomes. Informants reported that they or the consumers they represent are interested in measuring numerous outcomes in addition to recovery. The outcomes that informants expressed an interest in measuring include satisfaction, employment, housing, voter registration, quality of life, community integration, general health, hospitalization, and clinical outcomes. Although this question asked for outcomes in addition to recovery, recovery was noted several times by informants.

Designing or interpreting a program or research evaluation. Informants indicated that they or the consumers they represent are interested in evaluating a variety of consumer-operated services. While some informants provided a general response of "consumer-operated services" or "consumer-run services," others identified specific program models or types of service. The specific program/services listed include clubhouse, drop-in center, peer support, consumer-run leadership organizations, The Wellness Recovery Action Plan, Double

Trouble in Recovery, Advanced Directives, Palmetto Pride Recovery Retreat, warm-lines, recovery projects/systems of care, jail diversion, and citizen organizer/coordinator programs.

Section Three: Awareness of the Consumer Evaluator Network Program

Close to three-fourths of the informants, seventy-four percent (74%), were not aware of the Consumer Evaluator Network, leaving twenty-six percent (26%) of individuals aware of the program. Of all the informants KCMHS engaged in discussions, seventeen of the informants (50%) recommended that KCMHS contact other consumers and consumer groups to inform them of the Consumer Evaluator Network and provided relevant contact information. Less than half of the informants, thirty-eight percent (38%), did not recommend consumer or consumer groups for KCMHS to contact, and twelve percent (12%) did not respond.

Conclusion

The information generated from discussions suggests that consumers are involved in research and evaluation at various capacities. Regardless of their involvement in these activities, the majority of informants indicated that they or the consumers that they represented were interested in technical assistance in all twelve research and evaluation areas discussed. The high priority areas for technical assistance, which were indicated by at least half of the informants, include the following:

- Measuring recovery
- Understanding and explaining evidence-based practices
- Introductory training on evaluation and research
- Assessing the cultural competency of services

The majority of informants indicated that they were not familiar with the Consumer Evaluator Network.

Limitations

While the discussions with informants provided a lot of interesting information about consumers' research and evaluation activities in the states, we believe the project has several limitations:

Availability of Informants. The discussion component of the project was conducted during the vacation period for most state employees, making reaching these individuals difficult and sometimes impossible. As a result, KCMHS was not able to engage representatives from all the states and territories in discussions.

Incomplete Discussions. The informants who were engaged in the discussions did not respond to all questions, thus limiting the amount of information gathered.

The Number of Consumers the Informants Represent. The questions posed by discussants asked informants to comment on behalf of themselves or the consumers they represent, e.g. what types of evaluation or research activities are you or the consumers you represent involved in? However, staff did not distinguish whether informants were referring to themselves or the consumers they represent when responding to questions. Thus, it is possible that the informants' responses vary from representing one individual, themselves, to a varying numbers of consumers they represent.

Unfamiliarity with Discussion Questions. Due to the unfamiliarity of informants with the questions being asked prior to being engaged in discussions, informants' knowledge concerning the consumers they represent might be subject to unintentional inaccuracies. KCMHS staff believes that in future studies of this nature, it would be best to provide all informants with the discussion questions prior to the discussion. This would provide an opportunity for discussants to ponder the questions, prepare responses, and gather information.

Recommendations

Based on the information generated through discussions, KCMHS makes the following recommendations for future directions of the Consumer Evaluators' Network. The recommendations are presented in a random order.

Recommendation 1: INCREASE OUTREACH TO CONSUMERS

Consumer Evaluator Network. The majority of informants were not aware of the Consumer Evaluator Network. Thus, we recommend that the Consumer Evaluator Network perform routine outreach activities, disseminating information about the Consumer Evaluator Network, grant opportunities and previous work to OCAs and like organizations.

Technical Assistance Centers. The high demand for technical assistance reported by informants suggests informants are unaware of technical assistance centers (TACs), such as TEC and KCMHS, and their products, which are designed to provide technical assistance in the areas of research/evaluation to individuals. We recommend that TEC, through its Consumer Evaluator Network, actively work to disseminate information to consumer organizations and OCAs about available technical assistance resources.

Recommendation 2: CURRICULUM AND MATERIALS DEVELOPMENT

In addition to the general technical assistance available through centers, with the majority of consumers being involved in research or evaluation and the overwhelming request for technical assistance, it is important for efforts to continue to support the development of materials that are specifically designed to address consumer issues/obstacles in evaluation and research. We recommend supporting efforts to develop toolkits and/or guides, which are specifically geared towards educating and assisting consumers or laypeople in evaluation and research activities. These guides might identify common obstacles experienced by consumers or the untrained person in evaluation and research and methods used to avoid or overcome them.

Recommendation 3: CONTINUE FUNDING FOR PROJECTS

Meaningful consumer involvement is an important component to developing a mental health system that is recovery-oriented. Thus, we believe the Consumer Evaluator Network's role in supporting consumer involvement in research and evaluation activities is an important one. We suggest that the Consumer Evaluator Network continue to provide grants to support consumers' involvement in research and evaluation. The Network may take into consideration past involvement of consumers in a particular type of research and evaluation project when distributing grants, making projects that have seen little or no consumer involvement in the past a priority.

Recommendation 4: FUND A CONSORTIUM OF CONSUMER RESEARCHERS

In 2000, consumer researchers met under the auspices of HSRI and the NASMHPD Research Institute with the assistance of Drs. Steve Leff and Noel Mazade for two days in Alexandria, Virginia, to create an agenda for consumer research. Since that time, there has been a need for consumer researchers to be brought together on a yearly or biannual basis to bring cohesion to consumer research activity and thought. The Consumer Evaluation Network, if funded appropriately, could seed that, setting up a more definitive body of technical assistants and consultants for consumer projects.

Appendix A: Directors of Offices of Consumer Affairs – Updated October, 2004

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