

Consumer Involvement in Research

Suzanne Garverich, BA, Lorna J. Simon, MA, Albert J. Grudzinskas, Jr., JD,
James McDonald, Jr., AA & John Grillo

Consumer involvement in research has become increasingly important, especially in mental health services research. CMHSR embraces the importance of consumers' experience and knowledge in enhancing quality research. Consumers at CMHSR are involved in all aspects of the research process, from the conceptualization of a research topic to the dissemination of research findings. Consumers are involved in training, statistical analysis, interviewing, data entry, database management, and managing research studies. They also present and publish findings.

Center Initiatives to enhance consumer involvement

In the past year, CMHSR has launched three new consumer initiatives: the creation of a Consumer Workgroup, the formation of a Consumer Advisory Council, and an initiative to disseminate information to consumers, their supporters and advocates.

The Consumer Workgroup, a consumer-run group, meets with faculty to conceptualize studies and review grant submissions. The Workgroup meets with Principal Investigators and discusses the consumer involvement in the proposed study and ways that consumer participation can be increased. This review process has become part of the mandated review procedure for all grants initiated by CMHSR faculty.

The Consumer Advisory Council is comprised of consumers and other stakeholders across



Massachusetts (e.g., M-Power and NAMI) and is designed to provide input into the CMHSR research agenda, including developing research questions, evaluating instruments, identifying funding sources, and disseminating research findings.

The Dissemination of Information Initiative is targeted toward consumers, their supporters and advocates. A committee of staff and faculty, including consumers, work to develop informational pamphlets for consumers on topics identified by consumers such as suicide prevention, clubhouses, consumers' rights and adolescents in the criminal justice system.

Involvement of Consumers in Research: Participatory Action Research at CMHSR

CMHSR has a long history of consumer involvement in research studies. These studies use the principles of Participatory Action Research (PAR), which is an approach to research in which consumers are included in all stages of a study.¹ We discuss the research of Joanne



Nicholson, PhD, Colleen McKay, MA, CAGS, Albert Grudzinskas, Jr., JD, and Charles Lidz, PhD to illustrate this approach.

Dr. Nicholson has directed many projects in which consumers are heavily involved, all of which have been informed by a statewide advisory group, consisting of psychosocial rehabilitation clubhouse members, parents, Massachusetts Department of Mental Health (DMH) and Massachusetts Department of Social Services (DSS) staff and advocacy group members. Dr. Nicholson's work with consumers began in 1997 as part of the Parenting Options Project, for which Transitional Employment (TE) and Supported Employment (SE) research positions were utilized.² The use of TEs and SEs has allowed CMHSR to expand consumer roles in research. Dr. Nicholson involves consumers not only in the development of research methods, but also in the dissemination of study findings. Her group developed materials to help parents with mental illness in raising their children. The book, *Parenting Well When You're Depressed*,³ came out of this project. Other products of this research included the Clubhouse Family Legal Support Project, a newsletter, and a website (<http://www.parentingwell.info>).

Dr. Nicholson also directed the Women and Violence Project, for women with co-occurring mental illness and substance abuse and histories of violence. This study was completely infused with consumer input. Consumers were involved in training the entire study team. Consumers had a voice in what types of questions the study participants were asked. Consumers were also trained to be research interviewers. The measures developed for this project continue to be used in current research.

The Program for Clubhouse Research (PCR), directed by Colleen McKay, MA, CAGS, also includes considerable consumer input in every study conducted. The PCR Team includes two consumers, one holding a TE position and one holding a SE position. Together, they perform a variety of tasks, including data entry, data cleaning, and mailings. Most importantly, these consumers provide feedback on the development of instruments and databases. Clubhouse members and staff also provide input into the research agenda for the program. The PCR director meets with clubhouse staff and members who are participating in trainings, solicits feedback on research being conducted in the Program for Clubhouse Research, and discusses

directions for future research (http://www.umassmed.edu/clubhouse_research.aspx).

The Massachusetts Mental Health Diversion and Integration Program (MMHDIP) directed by Albert Grudzinskas, Jr., JD has provided training to law enforcement and criminal justice personnel for over ten years. This program involves consumers in research development and delivery of the mental health training curricula. Consumers have presented at national conferences regarding their role in educating law enforcers in what it is like to live with a mental illness, as well as dispelling myths and stigma about mental illness (<http://www.umassmed.edu/massdiversion/index.aspx>).

The Consumer Satisfaction Survey, directed by Charles Lidz, PhD, and funded by the Massachusetts Department of Mental Health for the past three years, is another project in which consumers are involved. In the first year of the survey, there were four consumers on the interviewing team. In three years the number of consumer interviewers tripled. Additional tasks in which consumers participated in after the data collection included mailings, data entry, and data analysis.

Recommendations

Consumer involvement in research makes instruments more reliable and the results more relevant to consumers. The role of consumer input in all aspects of the research process is essential to creating quality research. CMHSR's dedication to consumer involvement in shaping and conducting research will continue as they progress in their research efforts to enhance mental health services.

Reference

1. Minkler M & Wallerstein N (2003). *Community-Based Participatory Research for Health*. San Francisco, CA: John Wiley & Sons, Inc.
2. Henry AD, Nicholson J, Clayfield J, Phillips S, & Stier L (2002). Creating job opportunities for people with psychiatric disabilities in a university-based research center. *Psychiatric Rehabilitation Journal* 26(2): 181-189.
3. Nicholson, J., Henry, A.D., Clayfield, J. & Phillips, S. (2001) *Parenting Well When You're Depressed: A Complete Resource for Maintaining a Healthy Family*. Oakland, CA: New Harbinger Publications, Inc.

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