

9. Research

INTRODUCTION:

Can research enhance consumer choice, power and knowledge? Important issues have been raised concerning researching the effectiveness of peer-run alternatives, involving consumers as research partners, and protecting consumers who are subjects of research and data collection.

- **Effectiveness of peer-run alternatives**

ISSUE:

There has been scant research on peer-run alternatives, which has hindered the acceptance of such programs by the traditional mental health community. This situation has also limited the capacity of peer-run programs to generate funding through grants and direct appropriations. Further, the lack of research and suitable research tools has prevented them from discovering and documenting what works for whom and at what cost, as well as preventing them from applying this knowledge to improve and enhance existing program models. Support is needed to assist peer-run programs that desire to collect service and satisfaction data or are being required to report such information. Finally, using rigorous scientific methods may not always be possible when studying programs that embrace principles of voluntariness and respect for recipients' desire for anonymity. The research process could change peer-run programs or create an excessive burden for them and the people who attend.

BACKGROUND:

Since the beginning of the consumer/survivor/ex-patient movement, people diagnosed with a mental illness have asserted that help and support are best received when programs are voluntary and there is reciprocity between the provider and recipient of services. The value of both providing support to and getting support from people who have had similar experiences, and the widespread use of force and coercion in traditional mental health services, led to the development and proliferation of peer-run alternative programs. These include self-

help support groups, drop-in centers, educational programs, and peer specialists who work within traditional service systems.

Some studies have shown that participation in peer-run programs can help people improve the quality of their lives and can reduce the need for mental health care and hospitalization. Therefore, research can help promote peer-run alternatives as a promising way to reach more people and better support their recovery and respond to their social needs.

However, the valuable role of peer-run alternatives has received little legitimatization from traditional mental health services research. Neither the identification of the qualities that consumers bring to service provision, nor the outcomes related to peer support, have been generally recognized as important research topics. In addition, peer-run programs need data to continue receiving funding, as many are being pressured to show cost savings, effectiveness, satisfaction, and utilization. However, scientific methods, such as randomization and tracking, and professionally developed scales are often at odds with the values and fundamental strengths of peer-run alternatives.

Two large federal research efforts are currently underway, one to identify the number of peer-run programs in the United States and the other to study their cost-effectiveness. However, it is not clear how many peer-run programs want to or can accommodate such investigations, or if the methods of science as now practiced can successfully respond to the needs and values of consumers.

- **The involvement of consumers/survivors as research partners**

ISSUE:

Throughout history, consumers have been largely ignored in research projects except as objects to be studied. Their questions, insights, values, needs, and rights are seldom addressed. On the other hand, with the growing recognition of the value of consumer perspective and insight by the research and provider community, the results from consumers' involvement have increasingly become contested property in

a struggle over ownership of the key definitions of consumer experience.

Without constructive ways for dialogue and shared decision-making to take place, the involvement of consumers in research reinforces a turf war over control of the consumers being studied, power within the research process, and interpretation and use of research findings. Access to research is sometimes denied, and lack of adequate pay and reimbursement of expenses has undermined trust, cooperation, and sustained commitment. Further, there is little technical assistance available for consumers in conducting research or using its findings. At this point, there is a danger that consumer involvement in research is creating stigma, exploitation, and tokenism even as researchers attempt to be inclusive.

BACKGROUND:

Because the questions that people ask are inextricably linked with the answers that are produced, science is always a social construction: partial, colluded, and inscribed with power, bias and stereotype. For example, mental health researchers often lack the insight to ask questions that would capture the negative effects of psychotropic medications, restraints, or ECT.

The absence of consumers in research has had a profound impact on what was studied, how it was studied, how the research treated the people being studied, and what actions were taken based on the findings. Clearly, consumer perceptions about the effects of treatment, as well as the way services are delivered, determine what programs consumers will use and which outcomes will be valued. Involving consumers in research can make studies more meaningful, more useful for improving service delivery, more sensitive to consumer values, and more scientifically convincing.

In the past decade, growing numbers are taking leadership roles in assessing housing and support needs, defining outcome measures and report card indicators, and developing methods for determining service satisfaction. The formation of assessment teams, the use of focus groups, and studies on recovery and empowerment have been key activities.

- **Human subject protections in research and data collection**

ISSUE:

Since the repudiation of the atrocities committed by Nazi scientists, academic practice, and federal regulations have required that research proposals go through an initial ethical review process to protect those involved as the subjects of the research. Despite this, research projects have raised concerns about informed consent, justification of studies proposed, and the privacy and confidentiality of the participants involved.

BACKGROUND:

Few consumers have had the opportunity to be involved in a review of the protections of a research study or to serve on a committee that establishes such protections. Consequently, consent documents that are often used to promote participation are often difficult to understand, do not adequately discuss risks of participation, and are designed to shield the researcher from liability rather than inform and protect participants. Consent is usually a one-time event at the beginning of a study, and compliance to the terms of consent is seldom monitored. Participation is sometimes coerced through threats or excessive rewards. When data is collected as part of a service provider's information system, people are given no choice about participating, except to go without services, even though analysis of the information may be published in a research journal.

Failures to protect data privacy through inadvertent breaches in confidentiality, health data searches and data-merging activities have caused people to lose jobs, custody of children, and housing. Studies that require people to go off their medications, and those that intentionally provoke psychiatric symptoms, involve great risks without established benefits for the individual being recruited. Researchers justify many of these abuses by deciding that the rights of the individual are subordinate to the good of society. However, as experience has shown, it is problematic to make scientists the judges of social good, or to value social good over the worth of each human being.

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FACILITATOR:

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CO-FACILITATOR:

Jeanne Dumont, Ph.D., is principal investigator of the Crisis Hostel Research Demonstration Project at Well Beings, Inc., in Ithaca, New York, where she has worked for nearly the last decade. Previously, she taught in high school and junior high, as well as at Cornell University, where she has also consulted in curriculum development and educator training. She has written a number of papers and monographs and has made a variety of presentations on mental health issues.