# Commentary: Client Involvement in Public Administration Research and Evaluation

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## Introduction

This issue of *The Innovation Journal* highlights ways that human services "clients" are involved in policy and practice in public sector organizations. The literature now favors a robust client voice in the planning and evaluation of services. Referring to mental health consumers, Chaney defines that voice as "meaningful participation in the design, delivery, and monitoring of health care" (Chaney, 2002).

This Commentary primarily focuses on client or consumer involvement in public administration research and evaluation in the United States. However, its central principles are applicable wherever any form of research takes place.

Public participation in health care and its benefits cannot be achieved without the direct involvement of the consumer voice and influence. The effectiveness of that involvement is determined by the characteristics of both the consumer members and the work environment (Shea et al, 2005).

### *The Value of Clients as Partners in Research and Evaluation*

The South African HIV/AIDS slogan, "nothing to us, without us" is as true for research and evaluation as it is for program management and policy development. Sadly, clients including people with disabilities are often seen as only the objects of survey research. A core flaw of our public health care system is the lack of client or consumer[1] involvement in research and intervention design. If research has anything to do with policy, then every effort needs to be made to include clients in the evaluation process as well. When clients play a significant role in planning for research and evaluation they are in a position to establish research goals that are relevant to their peers, and to advise on how findings can best be applied in their communities (Delman 2007). Clients with the right support are in fact capable of taking a collaborative and meaningful role in research, but only if they are provided with the resources to support training and infrastructure (Delman 2007).

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[1] Language is very important when talking about people who are users of public services, especially when referring to people with disabilities. Our culture is full of stigma against people with disabilities. Terms such as "the disabled", "manic-depressives", or "retarded" focus on the disability and not the many aspects of a person that primarily define him or her. Thus, "persons living with HIV/AIDS", and "persons with developmental disabilities" show the respect that client members of teams and those they study deserve. Some mental health "consumers" prefer language such as "persons with mental health and/or addiction recovery needs (MHARN)." In this paper, we use people first language. Also, for the sake of clarity and brevity in this paper, we use client and consumer interchangeably and also consider families or carers (U.K. language) within this group.

Including clients and their input leads to research questions that are of most concern and relevance. Clients can help determine whether research protocols are appropriate and likely to be acceptable to other consumers. They can facilitate the recruitment of other consumers to research projects and place consumers at ease during the work.

Clients can be excellent data collectors. Because of their personal experiences, client interviewers are often able to build a good rapport with respondents, who are then more comfortable sharing their honest opinions (Clark et al 1999).

Clients can provide insights into the interpretation of research results and expertise in setting research priorities, deciding topics, determining the need for further research and in assessing the generalizability of research results. They can provide feedback on the clarity of reports and articles, and help to translate this information into consumer-appropriate formats that can be most effectively utilized by people in the field. This creates a better chance of disseminating and implementing research findings, translating research to practice, and ensuring that evaluations will be considered and acted upon by key stakeholders (Delman 2007). Clients can be important partners in advocating for change. By mutually sharing knowledge, researchers "can benefit from wider expertise, and be reminded constantly to put people and their needs first." (Griffiths, Jorm, and Christensen, 2004)

To do so, the research must be relevant to clients. Researchers and evaluators need to respect clients and appreciate the important role that they can play in their work. Clients need to value the expertise of those in academia and the value that their work brings to program development, assessment and advocacy.

### *Partnership Models*

A continuum of client involvement in research and evaluation demonstrates the range of roles that clients can take. They can be professional consumer researchers, academic consumer researchers (ACRs), or lay (non-professional) members of research teams led by non-consumers.

*Client-Run Research Organizations*: Clients can create and manage consumer-run research organizations. An excellent example is Consumer Quality Initiatives Inc. (CQI), a mental health consumer-directed and staffed quality improvement and research organization based in Boston, Massachusetts. CQI's mission  is to give consumers a greater voice and an integral role in evaluating their treatment and to initiate changes based on data collected. A primary activity of CQI is to collect information by interviewing consumers and family members via structured or semi-structured surveys and writing in-depth data-driven reports. The interviews are conducted by consumers and/or family members. The goal is to improve service quality and to transform a flawed system into one that is recovery oriented and consumer driven.

CQI is unique in that it is a research and evaluation organization that is run by community members, in this case people with mental illness. CQI is a consumer-operated organization. According to its bylaws, at least 51% of CQI's board of directors must be, and are, mental health consumers. CQI's founding (and current) executive director is a mental health consumer, its staff is made up of both consumers and family members.  It also utilizes some non-consumer consultants. A majority of CQI's revenues are derived from two ongoing contractual

arrangements. One agreement is with the Massachusetts Department of Mental Health (DMH), and a larger one is with the state Medicaid behavioral health managed care company, the Massachusetts Behavioral Health Partnership (MBHP). Most of the work here is related to quality improvement, although needs assessments are also conducted.

***Community-Based Participatory Action Research***: CQI's approach is based on the principles of Community-based Participatory Action Research ("CPAR"), which is defined as a:

> collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CPAR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. (Minkler, Blackwell, Thompson & Tamir, 2003).

CBPR is designed to address the historical conditions of social and economic inequality that continue to disadvantage certain communities, including people with disabilities or chronic health conditions (Israel at el 2003, Strand et al 2003). CBPR thus requires the active re-allotment of power between the researchers and the community members (Ochocka et al 2002). Among barriers that must be overcome is the historic mistrust that disadvantaged communities have for health care researchers (Israel et al 2003, Springett 2003). History documents the manner in which researchers have seen community members as fodder for data, rather than partners and beneficiaries of the research process.

CBPR recognizes the community, such as members of a disability group, to be a unit of identity (Israel et al 2003). With CBPR, the community has a right to share control of the research, including ownership of the research products and co-authorship of journal articles (Israel et al 2003). Involving the community in all phases of the research ensures that researchers do not misconstrue or ignore information collected due to their lack of "lived experience." (Danley et al 1997)

The participatory process is based on the legitimacy of community expertise produced outside of the scientific community, and looks to build on that expertise. Community members are permitted to contribute their particular expertise in describing the local culture and context within which the research that is to be conducted (Israel et al 2003). In addition, community members, with their knowledge of their community, can develop strategies to improve response rates and minimize attrition (Delman 2007).

CQI's approach to survey research is considered more radical than other forms of CPAR since CQI is an organization of mental health consumers with strong ties to the grassroots, participates in survey research decision making, and aims for systems to make structural change, not just individual program change.. CQI also participates in the Boston Community-Academic Mental Health Partnership (B-CAMHP), along with the Boston University School of Public Health, the Massachusetts Department of Mental Health, the Parent/Professional Advocacy League, The Transformation Center and the National Alliance on Mental Illness- Massachusetts.

The B-CAMHP is supported by funding from the National Institute of Mental Health (U.S.) to conduct community-based mental health research in Boston.

ACRs: An increasing number of academic researchers have "come out" as academic consumer researchers (ACRs), clearly stating their identification with the larger client world. For example, Jean Campbell PhD, a mental health researcher at the Missouri Institute of Mental Health, has led several federally-funded studies. ACRs have a number of unique advantages including "acceptance by other researchers as equal partners; skills in research; access to research funding; training in disseminating research findings within the scientific community; potential to influence research funding and research policy; capacity to influence the research culture; and potential to facilitate the involvement of lay consumers in the research process." They can also help to reduce the stigma of diseases such as mental illness, substance use, cancer, and HIV/AIDS (Griffiths, Jorm, and Christensen, 2004).

***Other Research Organizations That Involve Consumers:*** Organizations and projects that are not consumer led can include clients in a variety of ways. Clients can be co-investigators or members of advisory councils. They can have input into research objectives and design and survey questions. One of their most useful roles is as phone or face-to-face interviewers or focus group leaders or co-leaders.. They can be hired for other staff roles such as data entry staff that give them needed jobs but frequently little real power.  They can help to write or review project reports and articles. They can be public presenters of results and facilitators of changes.

One pioneering effort in the health field has been that of the Cochrane Collaboration, an organization that since 1993 has actively created partnerships between researchers and consumers to identify evidence-based health care practices and which emphasizes peer reviewing in all of its work (Shea et al, 2005).

At Suffolk University in Boston, we conducted Voices of Experience 1996 (VOE '96), Voices of Experience 2000 (VOE 2000), and Voices of Experience 2003 (VOE 2003), studies of consumer experiences in accessing and using Ryan White Title I and other HIV/AIDS services in eastern Massachusetts and southern New Hampshire. For each study, Suffolk recruited Consumer Research Associates (CRAs), men and women from around the state living with HIV who for each project were trained and paid to conduct nearly 500 face to face and telephone interviews of their peers. VOE '96 was conducted in a period when many people living with HIV/AIDS were dying, and VOE 2000 took place after the introduction of the new combination therapies. In 2003, more consumers were focused on living, but they were also experiencing sharp service cutbacks as the state wrestled with a $3 billion deficit.

A work group including consumers, providers, state staff, and Suffolk researchers developed the surveys. Consumers under the supervision of Suffolk staff conducted all of the interviews and co-led focus groups. They reviewed and had input into the final report. They co-presented the findings to the community advisory board and other groups. To our knowledge, these are some of the largest consumer to consumer HIV/AIDS surveys ever conducted.

During this period, Suffolk conducted a similar but smaller survey following similar procedures with people with low to moderately severe developmental disabilities and their family members as CRAs.

*Challenges of Including Clients in Research and Evaluation*

Including health care clients in research presents special challenges, and may be scary for the researcher who has not done it before, and does present challenges.

*Academics:* Clients are included in order to provide a different perspective, and thus to challenge the established researcher to look at their research ideas differently.  Thus, researchers who have worked without much oversight will now have to utilize, and/or develop, good team-building and collaboration skills, based on the capacity to tolerate and resolve dissent.  This kind of collaboration can be difficult and can ultimately extend the time required to complete a research project. Time in particular will need to be devoted to training people (clients) with limited background the basics of research. As part of B-CAMHP, CQI lead the training of five community (client) researchers, who are now in the process of conducting qualitative interviews with people who have frequently used psychiatric emergency services in Boston. They are also learning about qualitative coding and are being trained in the use of related software.

Client research team members will need to have good collaborative skills, and be willing to learn basic research techniques, such as research interviewing..  Academic researchers will thus need to take the time to hire clients with the strongest skill level, potential to be a good researcher, and interest in doing research. The fact is that not all people, irrespective of their client status or diagnosis, are good interviewers, data collectors, or survey coders. Research team leaders must be ready to recognize that some people are clearly not suited for the job and then not hire them. If there are problems with any researcher, again irrespective of client status, every reasonable effort should be made to accommodate that person so that s/he can succeed on the job.  However, if the person is ultimately unable to do the job (after adjustments for their disability have been made) or  if they act in a way that puts the project at risk it is appropriate to terminate involvement.  . However, one should not give up working with health clients after letting a client go, as that sort of generalizing to the groups perpetuates a stigma and will rob the research leader of other rewarding opportunities

***Concerns about consumer researchers***. Some people are concerned that ACRs marginalize lay consumers and create two tiers as has happened at times in consumer advocacy organizations. Others fear biased design or reporting of research and delivery of content in training courses, conflict of interest, or that the need to publish and get grants could compromise their capacity to conduct research from a consumer perspective (Griffiths, Jorm, and Christensen, 2004). Of course, the same things could be said of non-client researchers which is an argument for care with anyone doing research or evaluation.

*Lessons Learned*

What are some of the lessons that can be learned from research and evaluation with consumer and family team members? Using an expert workshop and Delphi process involving health, social care, universities, and consumer organizations, Telford, Boote and Cooper (2004) obtained consensus on the eight principles and indicators of successful consumer involvement in UK National Health Service research (Appendix 1).

From our experience, long-standing relationships and sharing of power are critical to success. Buy-in by the funding or contracting organization to client involvement is necessary if a

project is to succeed. In the case of Voices of Experience, the City of Boston and the Ryan White Title I Advisory Board with strong consumer representation fully supported the Voices project. The Massachusetts Department of Mental Health and the Division of Medical Assistance continue to heavily fund CQI, in part due to the many years that they have worked together, established good relationships, and produced valuable results.

As part of this collaborative approach is the willingness of health care clients and researchers to learn from each other, and to adapt to this kind of collaboration.  Researchers should meet with health clients in the community setting, and spend time just getting to know them.  Clients may need to learn academic language and acronyms to fully participate in research.

In addition, work needs to be meaningful for clients, and not simply low level tasks. Clients need to be included as fully as possible in teams and informed of the project's scope, process, and value to them and their peers.

Clients need to be rewarded for their work and not expected to be volunteers. This includes pay or other form of compensation, a title that can be used on a resume, report or article co-authorship when appropriate, and other public acknowledgement of their roles.

Many clients have special needs that need to be met to accommodate their disabilities. Meeting the requirements of The Americans with Disabilities Act is as critical in research as it is in administration. Special problems may arise in research. Several team members died during our first HIV/AIDS needs assessment before the new combination therapies turned HIV/AIDS from an illness of death to a chronic illness of living. Others needed periods of time off during the study to recover from their illness and medication side-effects. Some needed help with transportation and others with day care support.

Clients have biases that need to be addressed, just as people without disabilities have their own blinders that get in the way of unbiased interviewing and interpreting. The communities of clients and their families are often small, especially when advocates are the ones who apply for research teams. Confidentiality and keeping to the questions and not digressing to more informal conversations are critical in the interviewing process and an important element of training.

Training, as with any project, is a particularly important part of the research project. This should preferably be led or co-led by clients. Open and regular communication and supervision are important because many clients have less work experience than people who are not consumers. Work habits such as reliability, appreciation that there are real deliverables and timetables, and other business practices need to be emphasized and enforced.

Training of team members who are not clients, especially student Research Assistants, is critical. Many may not be aware of or sensitive to the special needs or attitudes or culture of clients.

**Conclusion**

Involving clients as much as possible in research and evaluation can have high dividends. It strengthens the research process. It often leads to greater utilization of research findings. It improves public administration planning and management, Our experience and that of many others is that partnership with consumers is not a take it or leave it option. Consumers should be meaningful participants in any research that directly or indirectly affects their lives. Whether the research and evaluation is run by consumers themselves, by providers, by academics, or by consultants, a variety of ways of involving consumers have proven to be effective. The principles of successful participation are well known. We need to overcome the biases and resistance of many to collaborating with consumers. Researchers, just as providers and policy makers, are not gods. The new paradigm of collaboration and partnership rather than hierarchical "study them" or "do it to them" should become the norm. The result will be much more accurate, honest and useful information that will more effectively guide sound programming and policy making.

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**Appendix 1**: The Principles and Indicators of Successful Consumer Involvement in NHS Research (Telford et al, 2004)

| | **Principle** | **Indicator(s)** |
|---|---|---|
| **1** | The roles of consumers are agreed between the researchers and consumers involved in the research | The roles of consumers in the research were documented |
| **2** | Researchers budget appropriately for the costs of consumer involvement in research | Researchers applied for funding to involve consumers in the research |
| | | Consumers were reimbursed for their travel costs |
| | | Consumers were reimbursed for their indirect costs (e.g. carer costs) |
| **3** | Researchers respect the differing skills, knowledge and experience of consumers | The contribution of consumers' skills, knowledge and experience were included in research reports and papers |
| **4** | Consumers are offered training and personal support, to enable them to be involved in research | Consumers' training needs related to their involvement in the research were agreed between consumers and researchers |
| | | Consumers had access to training to facilitate their involvement in the research |
| | | Mentors were available to provide personal and technical support to consumers |
| **5** | Researchers ensure that they have the necessary skills to involve consumers in the research process | Researchers ensured that their own training needs were met in relation to involving consumers in the research |
| **6** | Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research | Consumers gave advice to researchers on how to recruit participants to the research |
| | | Consumers gave advice to researchers on how to keep participants informed about the progress of the research |
| **7** | Consumer involvement is described in research reports | The involvement of consumers in the research reports and publications was acknowledged |
| | | Details were given in the research reports and publications of how consumers were involved in the research process |
| **8** | Research findings are available to consumers, in formats and in language they can easily understand | Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille) |
| | | The distribution of the research findings to relevant consumer groups was in appropriate formats and easily understandable language |
| | | Consumers involved in the research gave their advice on the choice of methods used to distribute the research findings |