

Voice for the Voiceless: Methodological Pluralism as an Ethical Imperative in Mental Health Services Research?

Ted Schrecker schrecker@usask.ca

Saskatchewan Population Health and Evaluation Research Unit



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What do I mean by methodological pluralism?

Incorporation of diverse methodologies, crucially including

- qualitative and narrative, as well as quantitative approaches
- multiple perspectives

into study designs

Why multiple perspectives?

- Knowledge and power are inseparable; research takes place in a context that reflects broader power relations.
- People with serious mental illness (SMI) tend to be multiply marginalized and subordinated by stigmatization, poverty, and the asymmetry of power relations with health professionals.

- Front-line care providers' view of mental health service needs, adequacy is very different from that of planners, hospital executives, etc.
- Most health researchers and system decision-makers, and many health professionals, live in a completely different world from the one inhabited by people with SMI.
- All these considerations more important given current vogue for 'evidence-based' system planning, resource allocation

Background

Public mental health systems throughout North America are in crisis.

- In US, Bazelon Center report warned:
“Increasingly, across America, mental health services are simply unattainable through disintegrating public systems” (Bernstein & Koyanagi, 2001).

Comparably systematic Canadian assessments are lacking but ...

- “We have 175 people on the waiting list for services in Ottawa, and one half have attempted suicide while they are waiting for services.” (B. Everett, CEO, Canadian Mental Health Association-Ontario, January, 2003).
- Waiting list before CMHA London assigns a case manager to a new client: 3-4 months (Pers. comm., February 2003)

(Local CMHA chapters are among the 370 “transfer payment agencies” (TPAs) that provide services in the community under agreements with provincial Ministry of Health; TPAs have not had an increase in their base budgets since 1992.)

Ontario has embarked on a long (at least since 1988) process of mental health system 'reform' (Hartford et al., 2003). Key features:

- Commitment to reduce number of psychiatric beds in hospitals, shift ratio of institutional:community mental health funding from 68:32 percent (in 1997) to 40:60 percent by 2003 (ratio was 54:46 in 2002);

- Since 1993, designation of people with “serious [or “severe”] mental illness” (SMI) as a priority population,* based on “3 Ds” (diagnosis, disability, duration); “diagnoses of predominant concern are schizophrenia, mood disorders, organic brain syndrome, and paranoid and other psychoses” (Ontario, 1999)

* Official estimates of the size of this population have ranged from 75,000 to 300,000 (!)

- Since 1995, “divestment” of provincial psychiatric hospitals (PPHs), with governance shifting to local general hospitals.

Two case studies in methodological pluralism

- Multistakeholder workshops in southwestern Ontario
- A multi-state focus group study in the United States

A word of caution: presentation of results here is *highly* selective. I urge you to consult full reports (all available on the Web); the narrative dimension of the US report as it deals with issues of poverty and service quality is especially important.

Case study 1: Multi-stakeholder workshops (“colloquia”) as part of a study of deinstitutionalization

Southwestern Ontario – the ‘natural laboratory’:

- Population: 1,324,775
- Combines almost entirely rural counties with two mid-sized CMAs, London (432,451) and Windsor (307,977)
- Two PPHs now divested to St. Joseph’s Health Care London
- Wide intra-regional variations in service availability (Velamoor *et al*, 1999)

The Colloquia

- Two invitational colloquia (November 1999 and November, 2000), involving
- System clients, care providers (purposive sample), members of research group (including clinicians, full-time academics, health planners)
- Proceedings audiotaped and transcribed (Ethics approval from UWO REB; consent forms obtained from all participants)

- Narrative summary identified major themes based on transcripts, flip charts, written comments solicited from participants
- Care taken to avoid quotations that would reveal identity of any participant
- Summary circulated to all participants for comments in draft form, then
- Mailed out and
- Made available on the Web:
<http://www.uwo.ca/fammed/pchu/coreport1.pdf>
<http://www.uwo.ca/fammed/pchu/coreport2.pdf>

Selected themes

- (a) Administrative vs. clinical definitions of target populations
- (b) Accessibility, availability, organization and continuity of care
- (c) Money (and especially the lack of it) matters
- (d) Perspective matters

(a) Defining target populations

- For research purposes: need to move beyond previous history of hospitalization
- For service provision: 3 Ds approach for defining SMI as implemented in Ontario too narrow, may mean clients 'not yet sick enough' and deteriorate until a crisis occurs

“People who are clinically suffering a burden of illness, but don’t fit a particular certain diagnosis are being excluded.”

“It seems as if the society wants you to get sicker and sicker.”

“[Clients] have to reach ‘rock bottom’ to get help in many circumstances.”

(b) Accessibility, availability, organization and continuity of care

- Deinstitutionalization requires (lots of) coordination:

“When divestment takes place, coordination is broken because divestment is on the principle of what is the least number of services that can be tolerated and costed within the institutional setting. So government then withdraws from the responsibility of coordinating everything else.”

- Service availability and accessibility highly variable, with transportation a major problem outside cities.

“The situation that I work in which is a small town ... the resources are very, very different. There’s not drop-in centres, there’s not employment opportunities run by consumers. The nearest psychiatrist is forty minutes away.”

“No respite or crisis shelters in my community; very limited geared to income housing.”

“In [my] county we have two psychiatrists; GP s don’t bother to refer any more, and in the court system we have no access to a psychiatrist referral unless we wait the six months ... so those clients don’t even get referred so they just serve their time, then are discharged.”

“No doctors taking new patients; only three psychiatrists for 110,000 population.”

(c) Money matters

With remarkable clarity and consistency, client ('consumer/survivor') participants identified inadequate income support and inadequate housing as two of the most significant problems they face.

Money matters: some specific concerns

- Ontario Disability Support Benefit (ODSP) cuts when clients are hospitalized
- 'Clawback' of ODSP benefits limits employment income, and therefore contribution of employment to recovery
- Affordable housing scarce, in undesirable/unsafe areas

“Once you are in hospital for over three months, Disability cuts you back to \$100 a month. If a person has a place, a decent place to live before they go into hospital, they are going to lose that place unless they have somebody to keep it for them and keep on top of the rent.”

“We stack the deck against people with mental illness, and other disabilities too. Because when you look at every single person who gets a disability pension, they live in poverty. The fact that you can't have a proper diet or take care of those things, that shortens people's life expectancy as well.”

“The way in which income is distributed and eligibility criteria [are] set creates a cycle of being housed, hospitalized and perhaps homeless at discharge simply because of the way MCSS [the provincial Ministry of Community and Social Services] provides the shelter allowance.”

“If you are in the hospital more than three months and your disability cheque gets cut ... that means your family is packing up your apartment; you are losing your house. Then you have to start all over again.”

“This person I knew left a hospital and got a place in one of the most notorious parts of the city ... he spent much of his time locking the door so people would not try to kick it in trying to get crack cocaine.”

Observations:

- Ontario Disability Support Program (ODSP) income (2001) for a single, disabled person in London or Windsor: C\$11,160 (includes maximum housing allowance of C\$4,968)
- Statistics Canada Low Income Cut-Off (LICO) for such a person: C\$16,167
- People with serious mental illness may have no option but to live in high crime areas, increasing the chances that they will become victims of crime (*cf.* Hiday, 1997).

- The ‘silo problem’ means that deinstitutionalization may be generating *cost shifting* rather than *cost savings* (cf. Hogan, 2002):

“If you add up all the peripheral stuff, we are spending more on mental health than it would appear Ministries, if they are going to work, should work as a team.”

“We have very poor information about the number of people who make use of more than one system As a result, a big hidden is the amount of money these services actually cost.”

A key lesson: the need for explicit consideration of system level variables that are outside the control of care providers, and often outside the control of ministries of health (or their equivalent), but may nevertheless exert a decisive influence on outcomes.

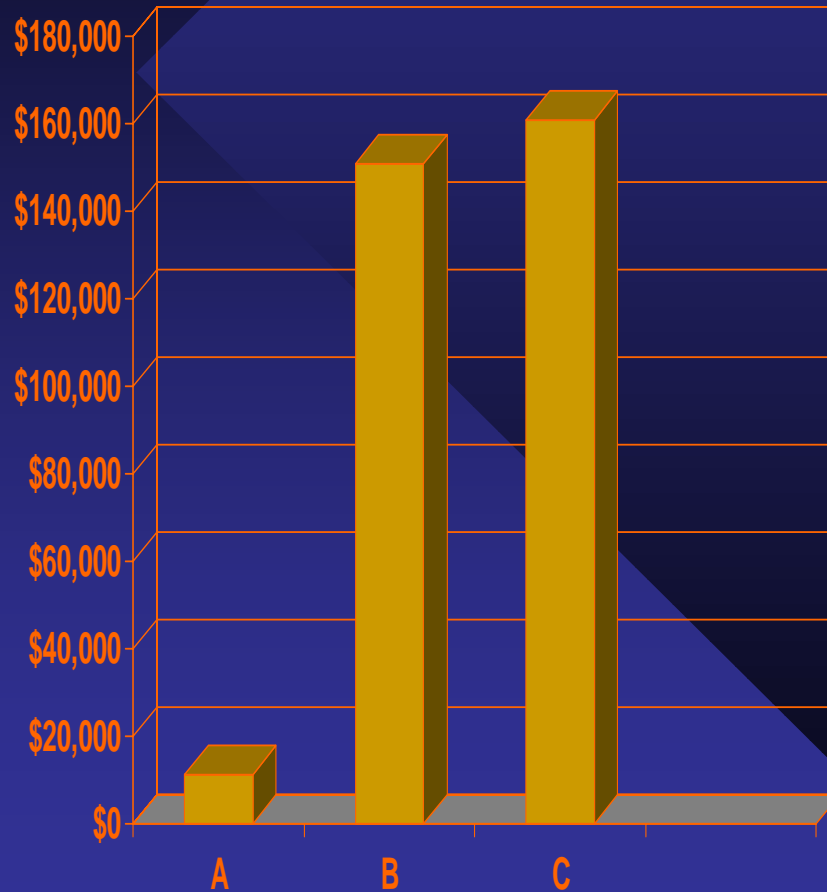
(d) Perspective matters

“Historically, when there has been any kind of research done like this and it has been all about us, the clients have historically been left out of the funding And every time it happens people say, you know, there is not a budget for focus groups for consumers or involvement.”

“I have a really good friend who has schizophrenia He and I go out for coffee and I noticed that he became bigger and bigger and bigger. He finally said to me, ‘You know I have gained 128 pounds in the last 3 years.’ I am just trying to figure how the physician could first and foremost let somebody gain 128 pounds without going, ‘Hey, I think there is something wrong with the medication here; maybe there should be a change’.”

“Whose insight is it?”

Different lives, different worlds



- A. Maximum income under ODSP
- B. Avg. salary + taxable benefits of most senior MoHLTC bureaucrats with mental health planning responsibilities (n=3), 2002
- C. Avg. salary + taxable benefits of staff psychiatrists at St. Joseph's Health Care London (n=29), 2002

“There is a belief at [client peer support organization] that if all the money taken, less was spent on providing services, paying professionals and medication and instead divided up amongst consumers, and the money was used to solve issues like the poverty issue and the housing issue and they could hire the live in companion if that was needed -- you solve all those problems, the mental health problems would actually literally go downwards.

Case study 2: Multi-state focus group study on barriers to recovery

Onken SJ, Dumont JM, Ridgway P, Dorman DH, Ralph RO. (2002) *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators* (Washington, DC: National Technical Assistance Center for State Mental Health Planning, October; http://www.nasmhpd.org/general_files/publications/ntac_pubs/reports/MHSIPReport.pdf)

The study

- Grew out of a 16-state indicators project, part of Mental Health Statistics Improvement Project (MHSIP)
- Purposive sampling strategy used to recruit 115 focus group participants (10 groups, 9 states)
- Common format and question set
- Data analyzed using multiple coders and common set of codes
- Preliminary report mailed to focus group participants, with telephone followup

Key themes

- Basic material resources
- Self/whole person
- Hope, meaning and purpose
- Choice
- Independence
- Social relationships
- Meaningful activities
- Peer support
- Formal services
- Formal service staff

Just a few illustrative quotations (from focus group participants)

“Like if you are not Medicaid-eligible you might as well go to Hell. You have to be absolutely destitute before you can get something.”

[There is a] “need to take a more holistic view so that choices are available so far as not only treating our illness but our housing, our transportation, our training, our employment.”

“It seems every day we lose. The waiting lists are getting bigger ... It’s bleak.”

“It would be nice if a mental health center would say ‘These are the services that we should be able to provide to you. We can’t because of funding. But if we could, they might actually be more helpful to your recovery process than what we do have to offer.’ Because, there’s something that’s really empowering in having at least that knowledge.”

“Affordable housing is independence to me.”

“I had a Dr. introduce himself and say you need ECT. I’d never seen him before in my life.”

“I’ve got another consumer who died from lack of somebody following up, making sure she was all right. Her air condition broke, called up the Center. Five days later she was found on the floor with a 107 degrees temperature with brain damage right off the bat. Four months later she did not recover.”

Discussion, part 1: Why an *ethical* imperative?

The canonical “four principles” of bioethics (Beauchamp & Childress, 5th ed., 2001):

- Beneficence (doing good)
- Non-maleficence (not doing harm)
- Respect for autonomy
- Justice

The “four principles” have been criticized for being too individualistic and US-oriented, yet they provide a worthwhile ‘anchor’ for expanding discussions about ethics outside the usual frames of reference.

Application:

- *Beneficence*: primary purpose of health services research should be to generate improvements in quality of care and quality of life.
- Qualitative research yields data of a kind that cannot be obtained through, e.g., epidemiological investigations or clinical trials (*cf.* Donenberg *et al.*, 1999).
- Multiple perspectives make possible 'triangulation' of findings, and ...

- “[T]here is good reason to believe vision is better from below the brilliant space platforms of the powerful” (Haraway, 1988).
- Studies like the ones summarized here focus attention on important determinants of (not just mental) health that are unrelated to the activities of health care providers and health systems.
- In age of evidence based practice, methodological pluralism provides a valuable antidote to fiscally attractive “therapeutic nihilism” (Lowe, 2000): nothing works (at a 95% confidence level), so why fund anything (*cf.* Schrecker *et al.*, 2001).

- Distributive *justice*: Enhanced sensitivity to disparities in power and resources.
- Need for special attention to voices and perspectives of the marginalized or subordinated?? (cf. Haraway, again)

Source of image: <http://www.peoplewho.org>;
Used by permission of Sylvia Caras



Discussion, part 2: The way forward

When such research methods are available and their viability has been demonstrated, why the persistence of the remarkable disconnect between the lived experiences of clients and care providers and the abstract discourses of mental health service planning? What, if anything, can or should be done?

Possible responses in research design and governance:

- Focus on variables that are outside control of health systems (and usually most visible to clients and care providers in daily contact with them).
- Routine involvement of clients and care providers in defining outcome variables.
- Explicit interrogation of 'resource scarcities' and their impacts, at all levels.

- Participatory action models that incorporate multiple perspectives into the design of research projects before protocols are finalized.*
- For larger scale research projects, organizational structures that specify and formalize the roles of care providers and clients (e.g. through steering committees, research advisory committees).*

* Along lines pioneered by Social Sciences and Humanities Research Council Canada (SSHRC) in its Community-University Research Initiative (CURA) program: http://www.sshrc.ca/web/apply/program_descriptions/cura_e.asp

A key question: Should funding agencies award extra points for these, or even require them, in mental health services research proposals? Should some, or all, of these responses be generalized to research that involves or affects other marginalized or subordinated populations?

A recent Ontario report recommends:

- “Develop strategies for the meaningful involvement of mental health consumers and their family members in research.”
- “*Mandate* that research be collaborative and use consumer participation” (Provincial Forum of Mental Health Implementation Task Force Chairs, 2002; emphasis added).

A final question: Can we expect health system and social policy design actually to respond to 'the evidence,' or are they driven by other influences such as the persistence of stigma, the politics of tax revolt?

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