

**SURVIVOR-CONTROLLED
RESEARCH:
EXPLORING OUR OWN
KNOWLEDGE**

JASNA RUSSO

**Centre for Citizen Participation
Brunel University London**

**SURVIVOR-CONTROLLED RESEARCH:
EXPLORING OUR OWN KNOWLEDGE**

CONTENTS

- ★ First person knowledge
in psychiatry
- ★ Service user involvement
in mental health research
- ★ Working towards paradigm shift
and our own model
(paradigm = distinct concept or thought pattern in
science)

FIRST VS. THIRD - PERSON KNOWLEDGE

“The essential experiential data of consciousness are subjective, invisible and unmeasurable first-person data which cannot be reduced to third-person data without losing their most important properties, which are the subjective *value and meaning* of an experience to those who live it. The reductive, third-person methods of traditional science will simply not help us to understand, describe and explain the first-person, lived experience of consciousness.”

David Webb, 2010 (emphasis in original)

Data = information collected in research

DIFFERENT WAYS OF KNOWING AND EPISTEMIC VIOLENCE

“The dominant epistemology has worked to prohibit mental health service users from being producers or knowers of their own knowledges. Psychiatric knowledge has been based on the ‘knowledge claims’ of others about the experience of mad people and mental health service users. They have played the key role in interpreting service users’ experience, while the latter’s own interpretations have, as has been argued, been excluded or devalued.”

Beresford and Boxall, 2013

“For psychiatrized people, being constructed as ‘incompetent’ and ‘dangerous’ becomes a powerful mechanism leading to their disqualification as legitimate knowers.”

“[*Epistemic violence*] is a very denial of a person’s legitimacy as a knower – their knowledge and their ways of knowing – that renders that person out of existence, unable to be heard and to have their interest count.”

Maria Liegghio, 2013

Epistemology = the theory of knowledge

WAYS OF INCLUDING THE EXPERIENTIAL KNOWLEDGE OF USERS/SURVIVORS

CONSULTATION

COLLABORATION

CONTROL

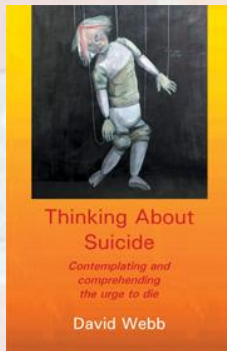
CONTRIBUTION

Hanley et al 2000

Sweeney & Morgan 2009

BERESFORD, P. 2002. User Involvement in Research and Evaluation: Liberation or Regulation. *Social Policy & Society*, 1, 95-105.

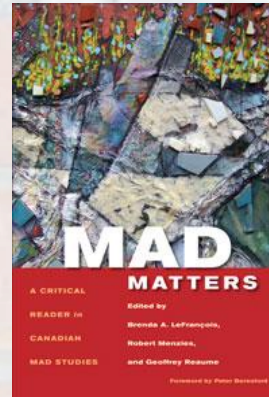
ESTABLISHING FIRST-PERSON KNOWLEDGE



Webb, David

2010

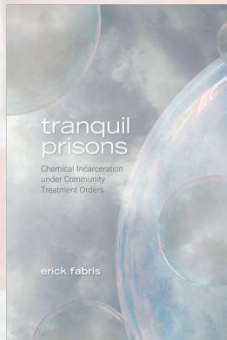
Thinking About Suicide: Contemplating and comprehending the urge to die, Ross-on-Wye, PCCS Books.



**Brenda A. LeFrançois,
Robert Menzies,
Geoffrey Reaume (Eds.)**

2013

Mad Matters: A Critical Reader in Canadian Mad Studies Toronto, Canadian Scholars' Press



Fabris, Erick

2011

Tranquil Prisons: Chemical Incarceration under Community Treatment Orders Toronto, University of Toronto Press.

“Working against the dominant psychiatric paradigm, the course places the perspectives of the ‘mad, insane or mentally ill’ at the centre of knowledge formation.”

Kathryn Church, 2013

SURVIVOR-CONTROLLED RESEARCH

MAIN FEATURES

- ★ Shared identity and closeness to the research topic
- ★ Joint analysis and interpretation

MAIN CHALLENGES

- ★ Lack of resources and recognition
- ★ Lack of the underpinning theory

As people who *know* madness and distress, and have also experienced dominant societal responses to it, we are responsible for further exploring, advancing and sharing our knowledge to achieve a different, non-damaging and non-medical framework. Inspired and encouraged by the social model of disability, we also see no one better equipped for this task than ourselves. Our joint efforts in this direction could lead us beyond divisions based on psychiatric assessments to “a society brave and moral enough to eschew the whole paradigm of mental health and illness, replacing it with a creation of real community, and real help” (Shimrat 2013).

Russo & Shulkes 2015

REFERENCES

BERESFORD, P. & BOXALL, K. 2013. Where do service users' knowledges sit in relation to professional and academic understanding of knowledge? In *Mental Health Service Users in Research: Critical sociological perspectives*, ed. P. Staddon, Bristol: The Policy Press, pp. 69-86.

CHURCH, K. 2013. Making Madness Matter in Academic Practice. In B. LeFrancois, R. Menzies & G. Reaume (Eds.) *Mad Matters: A Critical Reader in Canadian Mad Studies*, Toronto: Canadian Scholars' Press, pp. 181-190

HANLEY, B. et al 2000. *Involving Consumers in Research & Development In the NHS: Briefing Notes for Researchers*. London: INVOLVE Support Unit

LIEGGHIO, M. 2013. A Denial of Being: Psychiatrization as Epistemic Violence. In B. LeFrancois, R. Menzies & G. Reaume (Eds.) *Mad Matters: A Critical Reader in Canadian Mad Studies*, Toronto: Canadian Scholars' Press, pp. 122-129

RUSSO J. & SHULKES, D. (forthcoming) What we talk about when we talk about disability: Making sense of debates in the European user/survivor movement. In Spandler H, Anderson J, Sapey B (Eds.) *Madness, Distress and the Politics of Disablement*, Bristol: The Policy Press.

SHIMRAT, I. 2013. The Tragic Farce of "Community Mental Health Care" in LeFrancois, B. A., Menzies, R. and Reaume, G. (eds.) *Mad Matters: A Critical Reader in Canadian Mad Studies*, Toronto: Canadian Scholars' Press Inc., 144-157.

SWEENEY, A. & MORGAN, L. 2009. The Levels and Stages of Service User/Survivor Involvement in Research. In J. Wallcraft, B. Schrank & M. Amering (Eds.) *Handbook of Service User Involvement in Mental Health Research*, West Sussex: Wiley-Blackwell