SURVIVOR-CONTROLLED RESEARCH:
EXPLORING OUR OWN KNOWLEDGE

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ENUSP 2014
 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
“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

Hanley et al 2000

Sweeney & Morgan 2009

ESTABLISHING FIRST-PERSON KNOWLEDGE

Webb, David
2010
Thinking About Suicide: Contemplating and comprehending the urge to die, Ross-on-Wye, PCCS Books.

Fabris, Erick
2011
Tranquil Prisons: Chemical Incarceration under Community Treatment Orders
Toronto, University of Toronto Press.

Brenda A. LeFrançois, Robert Menzies, Geoffrey Reaume (Eds.)
2013
Mad Matters: A Critical Reader in Canadian Mad Studies
Toronto, Canadian Scholars’ 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


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


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