

Experiential knowledge in mental health policy and legislation:

can we ever
change
the agenda?



**Beresford, P. &
Carr, S. (2017)
Social Policy First Hand
Bristol: Policy Press**

jasna russo 2017

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TOPICS



UN CRPD and the biomedical model of 'mental illness'



Meaningful participation: challenges and prerequisites



UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

Article 4

General obligations

3.

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Mental Health
in Europe.
Promoting
Equal
Opportunities
and Social
Participation,
12 April 2017,
Brussels



FIRST-PERSON KNOWLEDGE AND STRUCTURES OF ,SOCIAL RESPONSIBILITY‘

“By speaking *for* or acting *on behalf of* those deemed mentally ill they (‘the socially responsible’) also contribute to, and perpetuate notions of the ‘dependency’, ‘passivity’ and ‘incompetence’ of people with a mental illness diagnosis; *irrespective of whether or not this is their intention.*”

Wilson, A. & Beresford, P. 1999

Surviving An Abusive System. In H. Payne and B. Littlechild (eds) *Ethical Practice and the Abuse of Power in Social Responsibility: Leave No Stone Unturned*, London: Jessica Kingsley, (emphasis in original)

“[*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

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

European Patients' Forum

Value + (2008 – 2010)



- The Value+ Handbook for Project Co-ordinators, Leaders and Promoters on Meaningful Patient Involvement

- The Value+ Toolkit for Patient Organisations on Meaningful Patient Involvement

- The Value+ Policy Recommendations

MEANINGFUL PARTICIPATION

National Survivor User Network (NSUN)

National Involvement

Partnership (2013 – 2015)



Jaysree Kalathil, 2008 /2011

Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement. London: Afiya Trust & NSUN

Peter Beresford, 2013

Beyond the usual suspects. Towards inclusive user involvement. London: Shaping our Lives

BARRIERS TO PARTICIPATION

Anti Stigma Programme: European Network (ASPEN)
2009-2011

Mental Disability Advocacy Center, Budapest:
Civil society involvement in mental health
legislation and policy



lack of accessible and timely information



lack of knowledge of participation possibilities



scarce financial resources and lack of time



low status of experiential knowledge



overall sense of participation?

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“More knowledge may be less important than a clearer sense of value [...] This shift seems paradigmatic of our times—from needing more knowledge to needing values that allow us to take a stand with respect to what we know. [...] Deciding what to do about what we know requires having an ethical standpoint. ”

Arthur W. Frank, 2000
The Standpoint of Storyteller.
Qualitative Health Research, 10(3)