



Mad Studies Group Notes

Thursday 7 February 2019, 5pm – 6.30pm @ Java Lounge, Moseley, Birmingham

Attendees: 12

Papers Considered:

The group discussed Professor Peter Beresford's recent work which highlights the greater difficulty that grassroots, service user led initiatives face in gaining funding when compared to larger Mental Health organisations or charities. Click on the links below for a copy:

Austerity is denying patients and care service users a voice (Guardian article):

<https://goo.gl/wnHGy9>

Public Participation in Health and Social Care: Exploring the Co-production of Knowledge:

<https://goo.gl/vcVccn>

PST Mad Studies Blog: www.pinkskythinking.com/blog

PST YouTube Vlog: <https://youtu.be/Kj5dco4RUkw>

Next Meeting: Thursday 7 March, 5pm – 6.30pm @ 52 Pritchatts Road, University of Birmingham, Birmingham, B15 2SA – check website for confirmation of room details

Papers for consideration:

User-led sector 'faces threat of extinction' – John Pring (Disability News Service):

<https://www.disabilitynewsservice.com/user-led-sector-faces-threat-of-extinction/>

Madness and the Demand for Recognition – Mohammed Abouelleil Rashed (Introduction):

https://www.researchgate.net/publication/322641352_Madness_the_Demand_for_Recognition_A_Philosophical_Inquiry_into_Identity_Mental_Health_Activism



Notes & reflections from attendees:

Public Participation in Health and Social Care: Exploring the Co-production of Knowledge

David Gibbs:

“It gives a good analytical and historical overview while reflecting the current reality with a glimpse into the future. He gives a realistic picture but also gives one hope for what might happen. The article also highlights the multi-disciplinary nature of what is done in practice, teaching and research. Some progress has been made but there is lot to do done including grassroots movements like Mad Studies fighting intersectionality.”

Caroline Fox:

First step to advancing public participation in health is to put it in the context of developing modern democracy more generally.

This article will seek to do this by identifying four key stages in the development of public participation in health and social care. These phases will be headlined as:

- Working for universal suffrage in representative democracy and the achievement of social rights, like the right to decent housing, education and health;
- Provisions for participatory democracy and community development;
- Specific provisions for participation in health and social care;
- State reaction and service user-led renewal as conflicts and competing agendas develop.

Liberal democracy is a set of representative institutions, guided by certain values; deliberative democracy is a way of getting, or trying to get, agreement about policies in the political arena...The important thing is that the participants reach a judgement on the basis of what they have heard and said (Giddens, 1994, p. 113).

Democratization “as the (actual and potential) extension of dialogic democracy...where such communication forms a dialogue by means of which policies and activities are shaped” (Giddens, op cit, pp. 114–115).



Isolating participation from its ideological and political relations—particularly its relations with ideas, theories and practices of democracy and democratization.

Key areas which have emerged from service users themselves are user involvement in professional training, learning and education; the development of user led research and knowledge production and the development of user-controlled initiatives and approaches. These have made it possible to:

- Develop the kind of learning and training for health and social care professions consistent with supporting people's rights and needs, informed by and respecting service users' understandings of their identities and worlds (SCIE, 2009);
- Challenge the exclusion and marginalization of their perspectives and experience (Faulkner, 2010);
- Advance the evidence base for the social understandings of service users and the issues they experience which they themselves have developed, rather than being tied solely to other people's interpretations and understandings of them (Beresford and Croft, 2012);
- Develop as service users their own organizations, histories, cultures, collectivities and independent action (Beresford, 2016);
- Develop as service users ideas, policy and practice consistent with their own models and philosophies (Campbell and Oliver, 1996).

What generally seems to define the key elements of mad studies is that:

- First, it is definitely divorcing us and itself from a simplistic biomedical model, making possible a necessary rupture from it. It allows other understandings and disciplines to come into it instead of solely medical dominance—sociology, anthropology, social work, cultural studies, feminist, Queer studies, disability studies, history—everything.
- Second is the value and emphasis it places on first person knowledge—centring on the first person knowledge of everyone, not just those psychiatrised. If you want to talk about yourself, then you have a right to, it is ok to include yourself. This is positioned/situated research—you can't just be talking from nowhere, as if you had no place in the proceedings—as it has been in psychiatry.
- And finally of course Mad Studies treats survivors' first hand knowledge with equality. But Mad Studies values and has a place for all our first hand experiential knowledge; that's why such a wide range of roles and standpoints can contribute equally to Mad Studies—if they are happy to sign up to its core principles. It isn't only us as survivors/mental health service users, but allies, professionals, researchers, loved ones, and so on, This is a venture we can all work for together in alliance. So it includes the experiential knowledge of service users, the practice knowledge/wisdom of workers



and the knowledge from those offering support, of family carers as important bases for future research and development (Beresford and Russo, 2016).

Conclusion:

Therefore, key recommendations to achieve more effective and inclusive participation are to:

- strengthen the funding basis of user led organizations, which have played a key role in user involvement innovation, to ensure that they are viable and sustainable (ULO);
- ensure that both ULOs and service-led schemes for user involvement/PPI are adequately resourced to be more inclusive and address diversity with greater equality;
- Equalize access to funding for user controlled research, particularly within ULOs, to support the development of service user experiential knowledge and to challenge the traditional dominance of so-called “expert” or professional knowledge.