Empowerment and the power of experiential knowledge

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Overview of presentation

- Positioning myself
- What is empowerment?
- Whose knowledge counts?
- Experiential knowledge
- Survivor (user-led) research
- The role of peer support
- Concluding thoughts
Positioning myself

- Experiences as a service user and researcher
- Work primarily in the community and voluntary sector
- PhD by publication: the role and value of experiential knowledge in mental health research
What is empowerment?

- Multi-dimensional
- A process
- Contextual
- Fluctuating
- Subject to restrictions
Things that empower people

- Information, knowledge
- Respect
- Affirmation
- Equal rights
- Skills
- Being listened to
- Support
- Having choices
- Having control, a sense of agency
- Being able to make decisions
- Resources
Attributes of Empowerment

- Having decision-making power.
- Having access to information and resources.
- Having a range of options from which to make choices (not just yes/no, either/or.)
- Assertiveness.
- A feeling that the individual can make a difference (being hopeful).
- Learning to think critically; learning the conditioning; seeing things differently; e.g.,
  - Learning to redefine who we are (speaking in our own voice).
  - Learning to redefine what we can do.
  - Learning to redefine our relationships to institutionalized power.
- Learning about and expressing anger.
- Not feeling alone; feeling part of a group.
- Understanding that people have rights.
- Effecting change in one’s life and one’s community.
- Learning skills (e.g., communication) that the individual defines as important.
- Changing others’ perceptions of one’s competency and capacity to act.
- Coming out of the closet.
- Growth and change that is never ending and self-initiated.
- Increasing one’s positive self-image and overcoming stigma.

Judi Chamberlin, USA, 1997
Empowerment needs to take place simultaneously at the population and the individual levels.
Empowerment is a multidimensional social process through which individuals and groups gain better understanding and control over their lives.

1. self-reliance
2. participation in decisions
3. dignity and respect
4. belonging and contributing to a wider community.
Incorporation of empowerment

COMMUNITY CARE FROM FRAN

I'd like to thank you all for your contributions to our new client empowerment policy.

I think you hit it on the head when you said consulting clients without giving them real power was patronising and prevented true empowerment.

So, when will it be put into practice?

God knows... that's for the top brass to decide!
Restrictions to empowerment...

- Mental health legislation
- Mental health services
- Poverty
- Stigma and discrimination
- Racism
- Invalidation...

The closing down of stories in mental health services

- Telling our stories is *both a routine experience and an impossibility* (Morgan et al, 2016)
The most significant cause of our continued oppression is...

'the societal belief that people with psychiatric diagnoses or mental health challenges are not credible reporters or witnesses of our own experiences. When we speak we are not believed...'

Wilda White
Whose knowledge counts...?
What knowledge counts?

Traditional hierarchy of evidence
The dominance of psychiatric knowledge
White, eurocentric frameworks of understanding and researching
Based on research that:
- Prioritises pseudo-scientific methodology: randomised controlled trials
- Is based on biomedical psychiatric frameworks
- Marginalises/silences the experience of service users
- Does not engage with alternative sources of knowledge
Telling our stories

- Central to the history of the user/survivor movement
- Being heard, having a voice can validate one’s identity
- Narratives are one way in which we 'make sense of our lives, our identities and our worlds' Morgan et al, 2016
- Telling our stories to challenge dominant narratives and discredited notions of (mad) identity
- The foundation of experiential knowledge…
The value of experiential knowledge

- '...specialised knowledge, grounded in an individual’s lived experience' (Borkman, 1990).
- Starts with the individual experience: what we know based on our lived experience...
- Experience of living with distress and discrimination, of services and treatments, of strategies and what helps
- Often pragmatic, holistic with a focus on everyday needs and issues
- What we begin to understand about ourselves and our experiences through sharing our stories with others...
- Rediscovering or re-forming identity
Socially and politically situating our experiences:

'The raw experience of an individual has to undergo a reflexive process before it is changed into experiential knowledge...' (Borkman, 1990, p.25)

'As we discover how particular experiences are mediated through social relations, we can connect the 'immediate' experience we started with to the larger social organization.' (Gorman, 2013; p.274)
Transformation of experience into experiential knowledge

- ‘Experiential authority’ as legitimising or giving credibility to the knowledge gained through personal experience – gained through the practice of sharing and exchanging experiential knowledge and expertise
  - E.g. Hearing Voices Network, Self-harm Network, Survivors Speak Out, local user groups, Recovery in the Bin, self-help, self-care, community groups
- Collective knowledge, survivor research
Survivor research

- User-led/Survivor research recognises experiential knowledge as a valuable source of evidence
- Research provides opportunity for service users and survivors to influence the knowledge base their treatment is rooted in
- **User-led v Services-led**
  - Democratic, bottom-up, participant driven v consumerist, top-down, research-driven
Survivor research

- Experiential knowledge as the ‘bedrock of survivor research’ (Sweeney, 2013)
- ... potential to transform knowledge about mental health (Beresford, 2013; Russo, 2013)
- ‘committed to challenging the disempowerment of mental health service users/survivors and supporting them to have a greater say in their lives and influence in the world in which they live’. (Beresford and Rose, 2009, p.18)
- Builds and consolidates experiential knowledge and can achieve ‘experiential authority’
- The emergence and growth of ‘Mad Studies’ (Lefrancois et al, 2013; Costa, 2014)
A global project led by Diana Rose to map:
- History
- Current configuration
- Knowledges
  From users/survivors and persons with psychosocial disabilities around the world.

Still We Rise: a UK project led by Jayasree Kalathil, mapping:
- History
- Knowledges—advocacy and activism - by African, African Caribbean, and Asian mental health service users and survivors.
Interviews with key figures

- Main project – ~80 users/survivors: historical and current, activists and survivor researchers
- ~20 non-users/survivors: supporters, facilitators, policy-makers
- Privilege less visible communities and knowledges

Knowledge and literature

Archival analysis

www.eurikha.org
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The significance of peer support and self-help spaces

- The closing down of stories in mental health services
  - Telling our stories is ‘both a routine experience and an impossibility’ (Morgan et al, 2016)
- Safe spaces where we can share our stories and expect to be heard
- Experiential knowledge emerges from our relationship and connectedness: from the peer support and self help spaces that we (as service users & survivors) find & create
- It is this connectedness that forms the basis of our social movement, our power to transform and create

“…self-help can be, and is, a meaningful progressive civil rights and protest social movement.”
Emerick, 1996, p.138
National Survivor User Network

We are a network of people and groups living in England who have and do experience mental distress and want to change things for the better. By connecting our members, and amplifying their experiences and aspirations, we influence policy, practice and perception, in order to reduce disadvantage and discrimination and stop people being ignored and isolated.

www.nsun.org.uk
NSUN Principles of Peer Support

- Commonality
- Trust
- Diversity
- Hope
- Empathy
- Solidarity
- Mutual benefit
- Equality
- Self-determination
Finding our voices and validating our own experiences is a fundamental basis for empowerment; it is a route to citizenship.

Structural change is needed for genuine lasting empowerment: challenging poverty, racism, stigma and discrimination...

but also the dominance of particular types of knowledge.

Preserve the spaces for experiential knowledge to grow and develop – community and collective endeavour.

Survivor research (or user-led research) is one key route towards validating our knowledges, but it is not the only one...

We need to listen to other forms of knowledge: activism, campaigns, the work of local groups and organisations...
THANK YOU!

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References