# On listening to consumers with psychosocial disabilities

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# Overview

- A little about me
- User-led research and ‘psy’ science – is coproduction possible in this space?
- Welfare provision in the UK for people with mental distress
  - Assessment and ‘psychocompulsion’
  - What do we mean by ‘recovery’?

# A little about me

- ‘Service user’ all my adult life
- Academic position 1972-1986 – social science etc
- Medically retired on grounds of (mental) ill-health
- 10 years pretty grim and living on welfare benefits
- BUT
- Became involved in user / survivor movement – life changing experience and the journey has not ended
- 1996 two identities come together to do ‘user-focussed research’ which has become ‘user-led research’
- My marginalised and denigrated identity became an asset

# Colney Hatch Lunatic Asylum (est 1851)

# Friern Hospital corridor 1974 – I walked the line

# An example of user-led research from 1988

- Activist local group at time of asylum closures in England and USA most had been in Friern
- Mainstream research in both countries concerned with enumerating / estimating possible negative consequences of deinstitutionalisation – violence, murder, homelessness, imprisonment
- RCT in England, McArthur work in USA
- We also did research but different and focused on that hospital

# What did we do?

- Interviewed people about their experiences of the asylum compared to new services – DGHs and Community Mental Health Centres
- Results not simple – there were things respondents missed as well as things they liked about the move
- Point – we asked people about their experiences, in the context of fundamental policy change, people who generally were thought could not speak for themselves and **so were not listened to**

# Reaction

- Methodologically, this was not rigorous research but made a splash
- Report discussed at Maudsley Hospital in London where RCT was being conducted – a bit baffled I am told
- Platform with Leonard Stein – ACT – quantitative evaluation
- Faulkner and Layzell (2001) *Strategies for Living*
- This is our tradition, a new narrative, social experience is not structured like a regression equation, but new methods to elicit and analyse – it’s still research
  - Politically grounded
  - A silenced voice to be heard in the mainstream and elsewhere

# Increasing rigour in a university setting

- Developed new methods
  - Adapted method of systematic reviews and meta-analysis to include ‘grey literature’, **testimonies**, service user reference groups and researchers with **‘double identity**’ eg ECT
  - Turned development of outcome measures on its head so they start with people’s **experience** of what is to be evaluated - ‘bottom up’ not ‘top down’. Again, researchers share experience

# Changing the Research Relationship

- May not think that research involves a ‘power dynamic’
- Participatory research – recognises that dynamic and tries to level it
- In our case we share some of the same experiences as our participants **and so listen differently**
- Not without difficulties – slowly recognised through both theorisation and experience

# What was the status of all this?

- To demonstrate that user involvement in research could be rigorous and meticulous yet different
- To ‘add’ to the conventional evidence base
- To introduce a new ‘piece of the jigsaw’
- Sometimes to ‘challenge’
- Make research more ‘relevant’
- But implicit assumption not to change the fundamentals and that’s a constant tension.
- A continuum or a break?

# So what can go wrong - example

- RCT of Joint Crisis Plans for
  - People who self-harm
  - People with Borderline Personality Disorder

- The language – ‘manipulative’, ‘complex’, ‘demanding’, ‘difficult’, ‘sexualised’

- Very, very difficult
  - Some accepted my critiques
  - Some carried on including with regard to a student!

# What are the limitations?

- Don’t escape the diagnostic but also the slang of medical categories
- ECT patient information sheet currently on RCPsych website
  - Factually wrong but recuperated into their comfort zone
- Realisation that method is the royal road to truth for mainstream psychiatric research and there is a hierarchy of methods
- We were not just changing the method, but trying (and failing) to legitimate a different form of knowledge, the knowledge of users
- This is about power held by individuals but also the epistemic system they inhabit which makes the privileging of method seem ‘obvious’
- Epistemic injustice – we are not credible knowers
- Not good at opening this up to marginalised peoples – intersectionality, multiple identities and histories at play

# Everybody now wants stories but only certain stories will do

- Celebrity stories – how I was saved by psychiatry
- **Individual** stories of success
- Was asked to write my ‘story of resilience’
  - I’m not – but reversal of previous assumptions
    - Can’t be credible academic as a service user
    - Now you are a credible academic you must be resilient / recovered
  - The people who are marginalised and on the benefit circus that characterises austerity in the UK
  - Social justice, peer support and a wicked sense of humour
- My story politely declined

# A long, roundabout way of saying – coproduction is usually not possible

- Power dynamics persist in individual, policy and research relations and structures
- Casual use of term ‘coproduction’ **hides** these
- Be explicit about power differences before you start
- But changing knowledge in direction of listening to and giving credence to those positioned as ‘mad’ requires a different approach
- And we are not an homogenous group - intersectionalities
- Stories yes but in own terms, oral history, respect the narrative however challenging, learn to listen and learn to listen to ourselves
- Research not the only way of creating knowledge and academic spaces should be recognised as contingently privileged
- Racialised and indigenous peoples very rarely have their knowledge regarded as credible and tied to useful practices of support– power has a long history and inextricably linked to knowledge

Reflections for you – are there resonances here?

# WELFARE PROVISION FOR THOSE WITH MENTAL DISTRESS IN UK

# Commonalities

- Closure of institutions
- But ‘community services’ still position the patient as passive
- Move to choice and ‘empowerment’
  - The customer is King
- Personal budgets – social care then health
  - But tiny take up by people with mental distress
- Personal Independence Payments (PIP)
  - But part of a much wider system

# Physical and mental disabilities

- UK has an assessment (eligibility) system for different levels of ‘readiness to work’
- Long-term disability now attracts same sum as a few weeks unemployment
- The assessment is skewed towards physical disability
- People with mental health problems must have a diagnosis, be taking medication and have letter from psychiatrist
- May think unexceptional – I think spread of medical thinking into questions of financial support
- How does they system fit together – should not be only predicated on biomedicine
- PIP case 2018 – judge agreed anxiety could impede mobility
- Government unannounced changed ‘anxiety’ to ‘panic attacks’ to be documented by a doctor

# Psychocompulsion

- Term is used by Freidli and Stearn (2015)
- Work has become a health outcome
- If you miss appointments you may be sanctioned – lose money for some weeks
- 2014 Department of Work and Pensions (DWP) introduced psychologists into JobCentres
- Unemployment is a psychological condition to be ‘treated’
- Used to be argued psychological interventions cannot be compelled
- But can be sanctioned financially for missing appointments
- There is no way but work to contribute to society
- Fear of the brown envelope – qualitative research
- Media supports government – ‘strivers’ and ‘scroungers’
- People are dying

# Recovery

- Started in North America and New Zealand as a collective support to enable meaningful life
- Now in UK is in hands of professionals and it is an **individual** intervention
- Set your own goals (but only certain ones permitted)
- Unrecovery star
- The ultimate mark of recovery is work
- To be recovered is to be normal

# Normality – what's wrong with that?

- Nothing at first sight and many seek
- But instantiates divide between normal and pathological
- To be normal is to be a self-actualising individual making good for self and family
- To be 'mentally ill' is to be different, Other and pathological
- But 'mental illness' has **positive** aspects
  - Service user can sit with a suicidal person in a way a professional can't
  - Basis of peer support – shared experience
  - Mania or hearing voices can enable not only disable
  - While emphasising mental distress can be awful
- My little story of the recovery house

# Conclusion 1

- **User-led** research promotes a different way of listening to those in distress and so figuring its meanings
- It is becoming established and it is a break epistemologically and in terms of method
- Mainstream research often doesn’t listen at all – RCTs, clinician driven outcome measures, big data, ‘people’ are represented as aggregate numbers
- Psychiatry as a practice has to step aside to allow more appropriate supports to develop

# Conclusion 2

- Health is not just a medical matter
- For some mental health is not a medical matter at all
- So medicine should not be the ties that bind the different parts of the mental health system
- We have our own research now and it is both informed by and offers ‘alternative’ practices
- Psychiatry less embedded in Global South and much user / survivor activity around CRPD
- To be bemoaned or celebrated?
- The crucible of new ways of responding to distress may be in the Global South