Voicing the Unsayable – The Unspeakable Truths of 'Personality Disorder' Services

Who are we?

- Melanie Anne Ball @melanieanneball
- Hollie Berrigan @Hoppypelican
- Keir Harding @keirwales

Why are we here

- There was an English woman, a Welshman and a Welsh woman in a bar….

The rules

On stepping into this room it is assumed that you are no longer yourself. Anything that is said isn’t said by you, merely the part that you are playing in our drama. We won’t judge anyone’s views or repeat them outside. People will not own the words that they say any more than Ian McKellen can claim the words of Shakespere are his.

Part 1

- Everything we are doing is making things worse – And its your fault!

The debate

It's all their fault

It's not my fault

6 mins each – 7 mins for questions

In Summary…

<u>“Voicing the Unsayable”</u>

Notion #2:

“*Service User Involvement is a Waste of Time and Money*”

Firstly…

- What do we mean by SUI?

SUI…

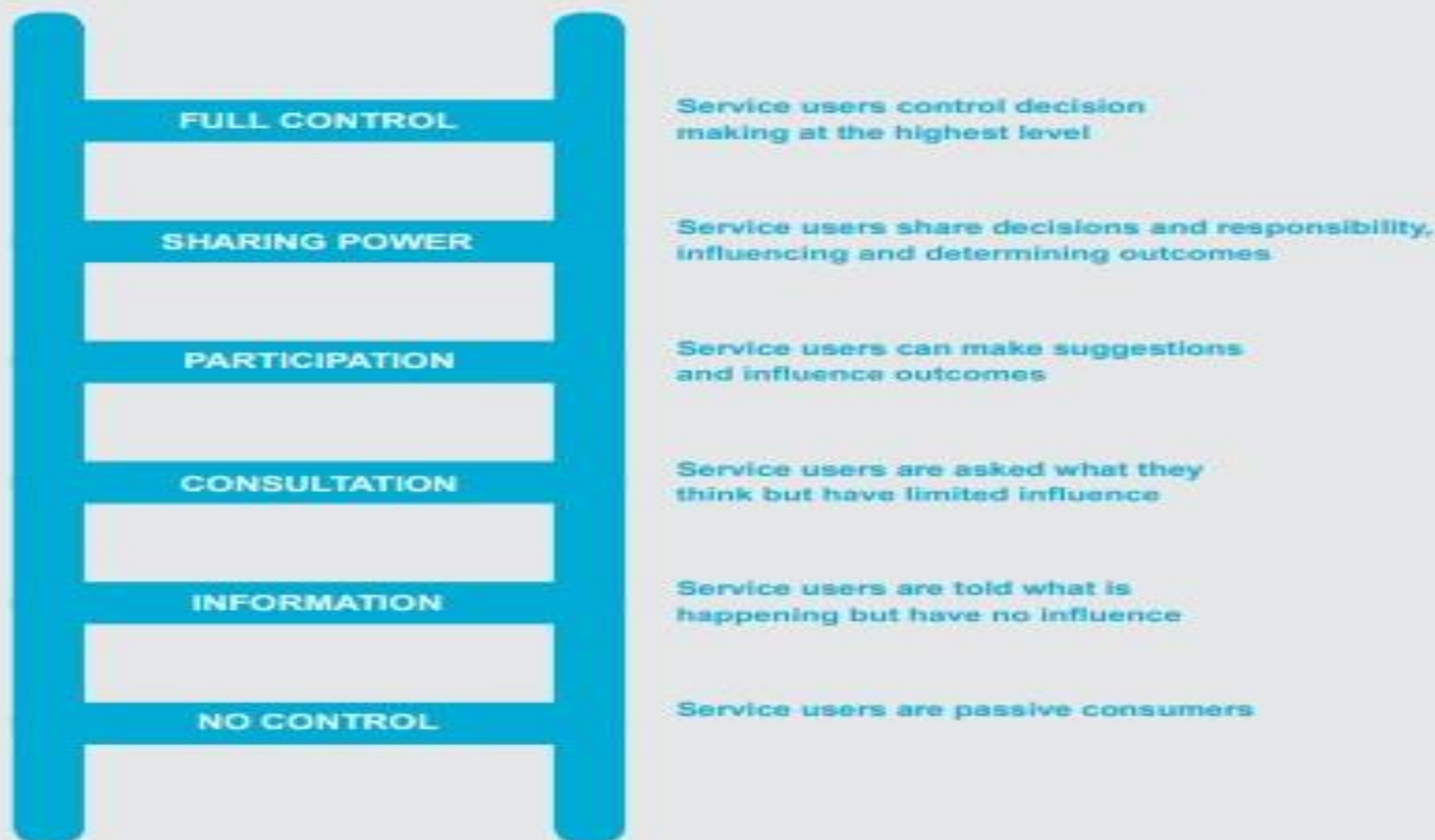
- Serious Untoward Incident or Service User Involvement?
- Our relationship with risk can be crucial to consider when thinking about Involvement and Coproduction as it can feel threatening and risky, for many reasons

Maybe we find it harder to consider what's at risk for us…?

A reminder on terms: NHS England say…

- "Service user involvement refers to the process by which people who are using or have used a service become involved in the planning, development and delivery of that service. There is a growing recognition that because of their direct experiences of using services, service users have a unique insight into what works, which can be used to improve services."

There are a number of ways of thinking about involvement. One of the best known approaches is 'the Ladder of Participation', developed by Sherry Arnstein.



This has its limitations as it sees different levels in a hierarchy when the right level of involvement can depend on a number of factors including the service user, the task and the time frame.

Strong history of coproducing in "Personality Disorder-ville"

- Therapeutic Community approach
- Non-coercive nature of therapeutic interventions
- KUF
- Emergence Plus CIC
- BIGSPD Co-presidency

And perhaps the most influential use of lived experience within Personality Disorder-ville…

- "But I suppose it's true that I developed a therapy that provides the things I needed for so many years and never got."
- "I decided to get supersuicidal people, the very worst cases, because […] I understood their suffering because I'd been there, in hell, with no idea how to get out."

Ok, so what? Don’t you know our budgets are more punishing than ever?

"A review of evidence on co-production in mental health identified a number of studies (both small scale evaluations and trials) that reported an association with reduced health care costs, e.g. for medications and specialist mental health services."

"The review also identified benefits from improved social functioning outcome, e.g. employment and reduced dependency on public services."

14. Recovery: the Business case

Mike Slade[1], David McDaid[2], Geoff Shepherd[3], Sue Williams[4] and Julie Repper[5]

More evidence…

- NESTA think the People Powered Health* approach could reduce the cost of managing patients with long-term conditions by up to 20 per cent.
- The NHS in England could realise savings of at least £4.4 billion a year if it adopted People Powered Health innovations that involve patients, their families and communities more directly in the management of long term health conditions.

(The People Powered Health approach involves five areas of practice: More than medicine (new services); people helping people (peer support); redefining consultations, networks and partnerships; and **user co-design and co-delivery.)*

whom?

So, if we can agree that copro might not be a waste of money, for whom is it a waste of time?

A Question….

What might lead a registered professional to feel that something that saves their department or service money in such times of financial hardship, and improves outcomes for current and ex-service users/ the local community is "a waste of time"…?

A task in groups…

- On your tables, read the thought cards
- Notice and discuss the first reaction you have in relation to the statement
- Notice whether the group have different responses to the statement, in thoughts and/or feelings
- Feel free to record thoughts and ideas that you might imagine a “copro-sceptic” or “copro-curious” colleague might hold in relation to the statement, as well as or instead of your own

Thought bubbles:

1. David Gilbert writes "people affected by health conditions bring insights and wisdom to transform healthcare – 'jewels from the caves of suffering' [and yet] traditional patient and public engagement relies on (child–parent) feedback or (adolescent–parent) 'representative' approaches that fail to value this expertise and buffers patients' influence." Adhering to more tokenistic forms of PPI as opposed to meaningful involvement or coproduction is preferable for us as professionals, because it means as figurative parents our 'children' never grow up: and thus our power, authority or purpose is never called into question.
2. Freud writes that the "uncanny effect of [...] madness [...] sees a manifestation of forces that [the layman] did not suspect in a fellow human being, but whose stirrings he can dimly perceive in remote corners of his own personality." Therefore, the distressing nature of the presence of an individual who journeys from one 'side' of the service to another is in the potential they hold- and that the therapeutic professional may have seen in especially sharp focus- to be 'mad'.

More thought bubbles

- “I see Peer Support Workers doing all the things that used to be the nicest bits of my job. Now all I have left is the paperwork.”
- Royal College of Psychiatrists in 2010:

“one-quarter of the psychiatrists said they avoid disclosing their profession in social situations. One-third said their family was disappointed in their career choice”.

Given these troubling findings, is it surprising that after so much gruelling study, a psychiatrist might find it especially difficult to accept that an uneducated patient has as much to offer a service design or delivery process as they do?

More Thought Bubbles…

- If it was worth anything everyone would be doing it.
- If it was worth anything people would pay for it.
- Mechanics don't ask the driver how they think their car should be fixed. Especially if the driver is mental.
- It's just too much pressure for these unwell people to work in stressful MH systems.
- What about confidentiality?
- What if they go nuts?
- I've trained for years, why should they be telling me how to do my job?
- Service Users/Peer Workers are coming for our jobs.

If you were going to kill yourself you'd have done it by now…

What is the grain of truth that underlies this view?

- In groups of x take 10 minutes to discuss…

What supports this view?

What assumptions is it based on?

Why isn't it said (or said in a disparaging way)?

“NOTHING IN THE WORLD
IS EVER COMPLETELY WRONG
EVEN A STOPPED CLOCK
IS RIGHT TWICE A DAY”

PAULO COELHO

MOSQUOTES.COM

Some ideas…

- “Suicidal” isn’t binary
- Anyone telling you “I’m going to kill myself” is inviting you to do something different
- Multiple attempts…what has happened??? (blind chance or something less sinister?)
- Letting people know is a strength
- Not taking/doing enough is a strength
- We will obviously be less worried about the 100th time someone is suicidal compared to the 1st

Should these ideas come into our discussions?

- In your groups think about the value (or not) of these ideas being part of our work?
- Are they present but not acknowledged?
- Are they acknowledged but unspoken?
- How can we have these conversations without invalidating the person in front of us?

Wrapping up…

You Have been listening to

Keir Harding - @keirwales
Keir.harding@nhs.net
Keir@beamconsultancy.co.uk
https://thediagnosisofexclusion.wordpress.com

Hollie Berrigan @hoppypelican

Melanie Anne Ball @melanieanneball