IIMHL
International Initiative *for* Mental Health Leadership

The College for Behavioral Health Leadership

The Reality of Co-Production: Learning from Experiences of Working with Service Users as Stakeholders

May 24, 2022

9:00am PT / 10:00am MT / 11:00am CT / 12:00pm ET

Welcome! We will get started momentarily.

Please let us know who you are and where you are from in the chat box (click the chat icon at the bottom of your screen).

Welcome

2022 Leadership Exchange

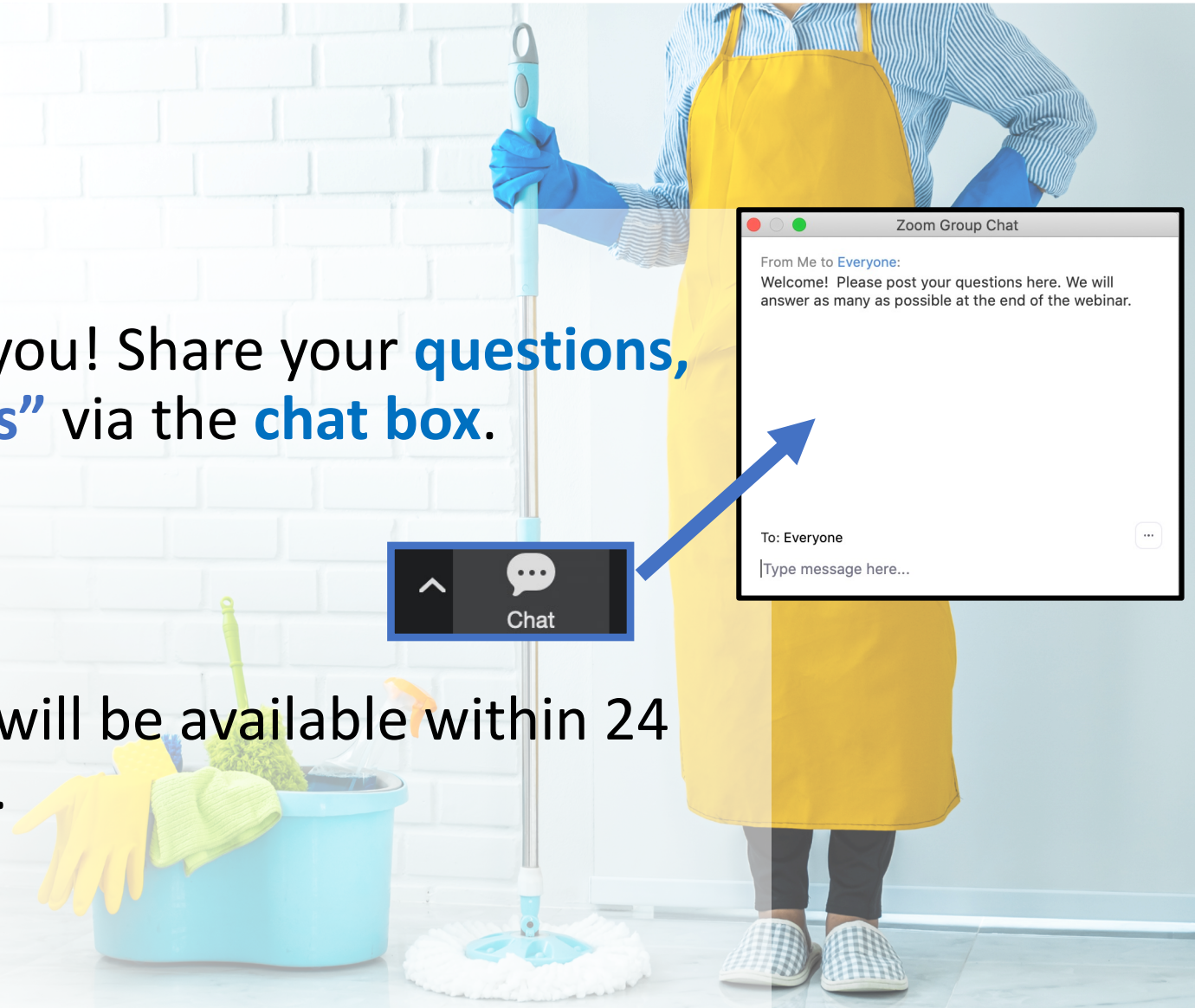
Valuing Inclusion, Resilience & Growth

- Focus on youth
- Washington DC
- Three components
  - Virtual Matches: October 3-20
  - In-Person Network Meeting: October 26-27
  - Virtual viewing
- Register now!
  - https://iimhl.com/2022-leadership-exchange-menu-iimhl

The College for Behavioral Health Leadership

Housekeeping

- We want to hear from you! Share your **questions, comments** and **“ah-ha’s”** via the **chat box**.



- A **recording and slides** will be available within 24 hours - We’ll email you.

The College for Behavioral Health Leadership

Our Time Today

- Welcome
- Speaker Presentation: The Reality of Co-Production
- Audience Q&A/Moderated Discussion

Our Presenters

Dr. Corinna Hackmann

Clinical Psychologist/Adult Services Research Development Lead | Norfolk and Suffolk NHS Foundation Trust, UK

Dr. Bonnie Teague

Head of Research and Associate Professor in Mental Health Services Research | Norfolk and Suffolk NHS Foundation Trust and University of East Anglia

The College for Behavioral Health Leadership

The Reality of Co-Production: Learning from Experiences of Working with Service users as Stakeholders

Corinna Hackmann & Bonnie Teague

Norfolk and Suffolk NHS Foundation Trust, UK.

Hello! Who we are and where we're coming from!

- We work as strategic and operational leaders in an embedded clinical research team in the NHS, UK, focused on mental health and dementia research.

- Our teams develop research and improvement projects based on the priorities and needs of service users, carers and families and clinicians.

- All of the work we do is co-produced with diverse stakeholders.

Areas to be discussed

Philosophy and values of coproduction in health and research programmes.

Examples of coproduced projects and different ways of working

The ‘how to’ of coproduction (what we have learnt so far)

Philosophy and values of coproduction

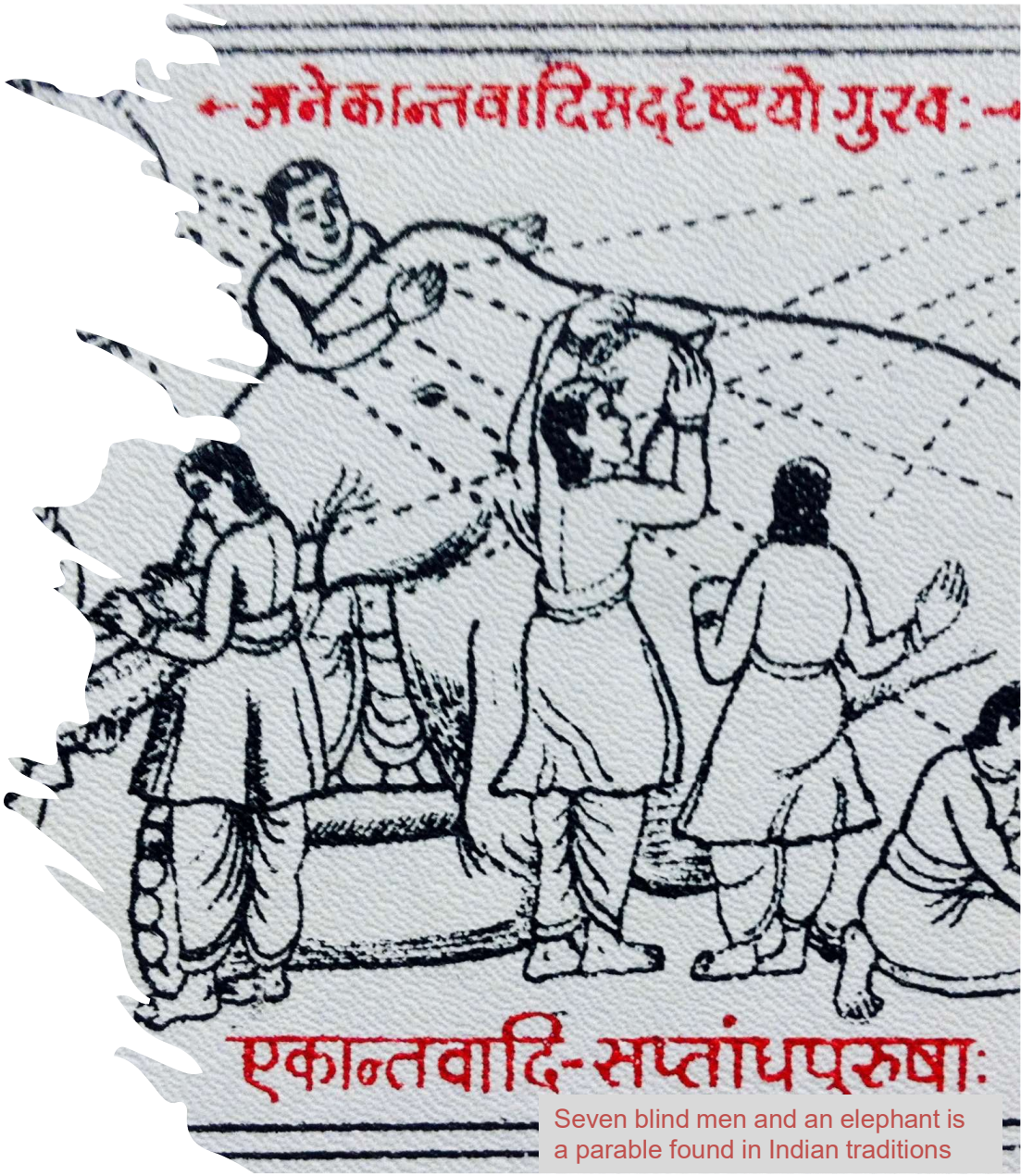
Values of coproduction

Only through multiple lenses can we see the bigger picture (blind men and elephant proverb)

It's the **integration of the lenses** where the magic happens!

Our values

- Authentic joint collaboration
- A communal and inclusive endeavour that encompass a wide range of contributions
- Equal valuing of expertise by experience and learning to create, inform, develop and refine projects



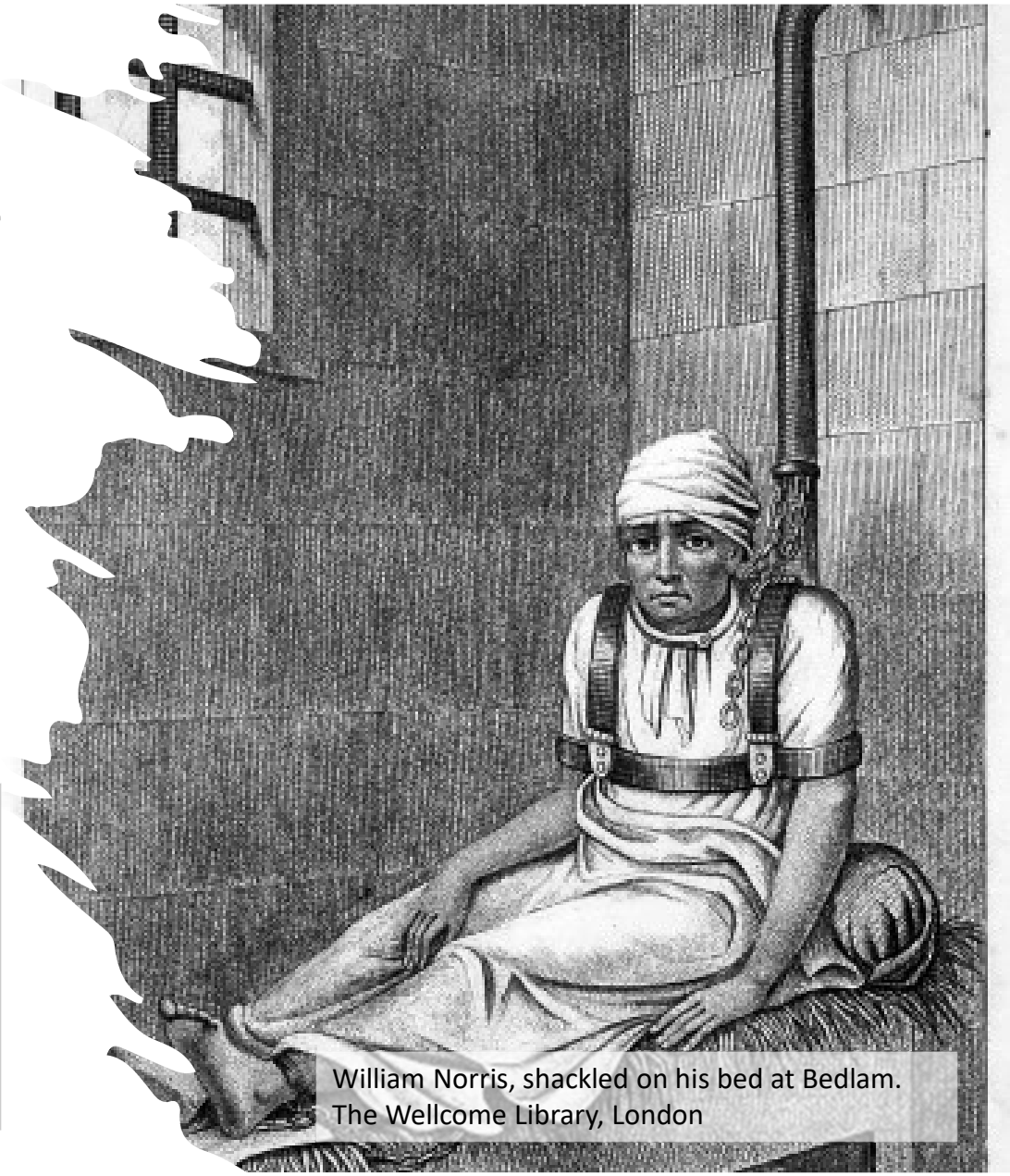
Seven blind men and an elephant is a parable found in Indian traditions

Impact of medical history of mental illness (be aware of ‘your’ baggage)

- History of the restriction of liberty and disempowerment
- Privilege as decision-making power
- Influence of physical and medical sciences
- Lack of recognition of patient perspectives
- History shapes research lens and language

Ivan Belknap’s (1956) ethnography of ECT: “the amnesia and disorientation produced by the shock treatment keeps them quiet and prevents them disturbing or hurting other patients or upsetting the ward routine”

See Andrew Scull, *Desperate Remedies*, 2022



William Norris, shackled on his bed at Bedlam.
The Wellcome Library, London

Lived-experience as knowledge

- Clinical service delivery needs to be ‘evidence-based’
- This tends to mean neutral, objective and distant
- Lived-experience has historically be treated as less valuable (anecdotal)
- However, it has been argued that

“The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted”

It’s Our Lives. A short theory of knowledge, distance and experience’ Beresford, 2003

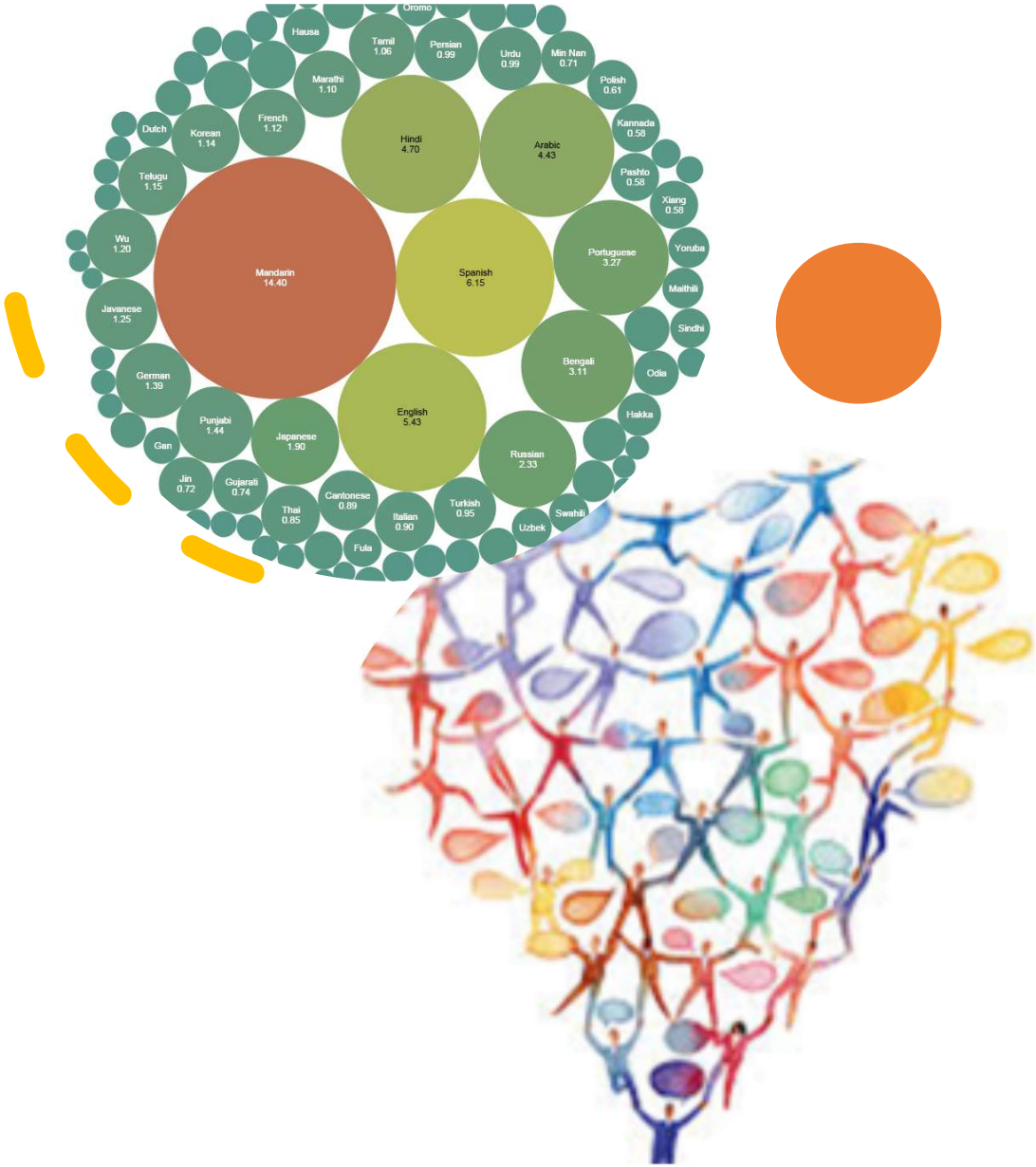
https://shapingourlives.org.uk/wp-content/uploads/2021/08/ItsOurLives-1.pdf

It’s Our Lives. A short theory of knowledge, distance and experience’ Beresford, 2003

Language

"*Language is everything*"

- Language colours our reality
- Interpellation is the process by which cultural ideas and values become internalised through language (Althusser, 1971)
- Language constructs and maintains our understanding of the world (Foucault, 1970)
- Medical, psychiatric and psychological language is coloured by medical history and underlying assumptions of who is right
- Consider the implications of language and idioms like 'non-adherence', 'lack of insight' and 'dis-engagement'



“From the vantage point of the colonized, a position from which I write, and choose to privilege, the term ‘research’ is inextricably linked to European imperialism and colonialism. The word itself, ‘research’, is probably one of the dirtiest words in the indigenous world’s vocabulary. When mentioned in many indigenous contexts, it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful. It is so powerful that indigenous people even write poetry about research. The ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the world’s colonized peoples. It is a history that still offends the deepest sense of our humanity.”

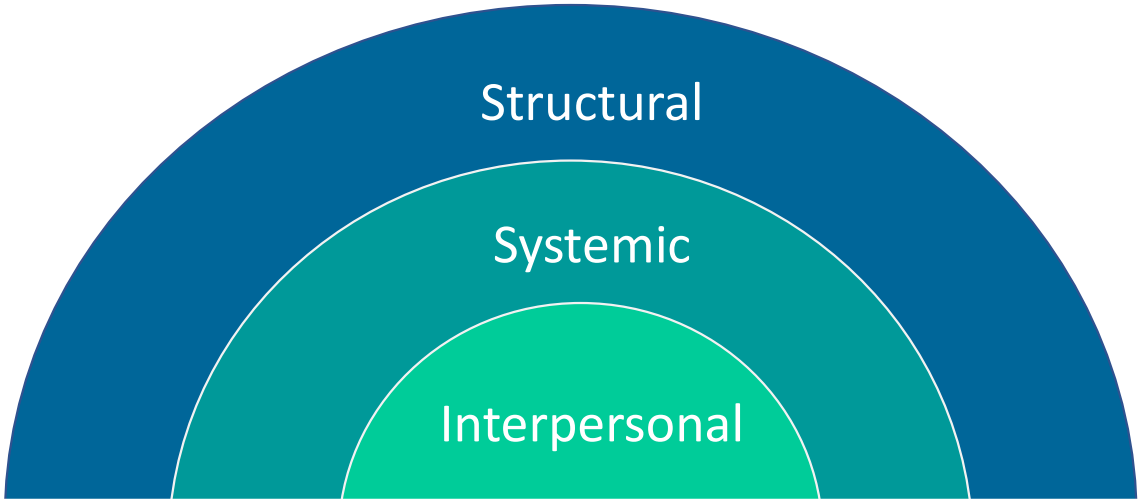
Professor Linda Tuhiwal Smith

Power

- Historical roots of medicine…
- What is considered evidence…
- Language…

All relate to power and inequality

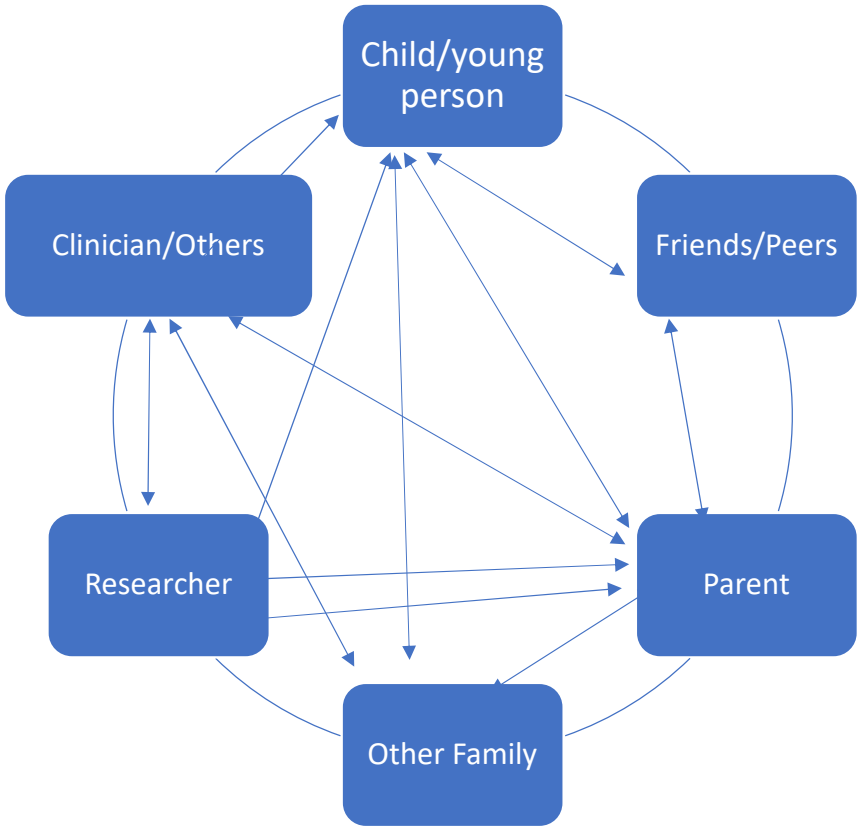
Types of power to consider

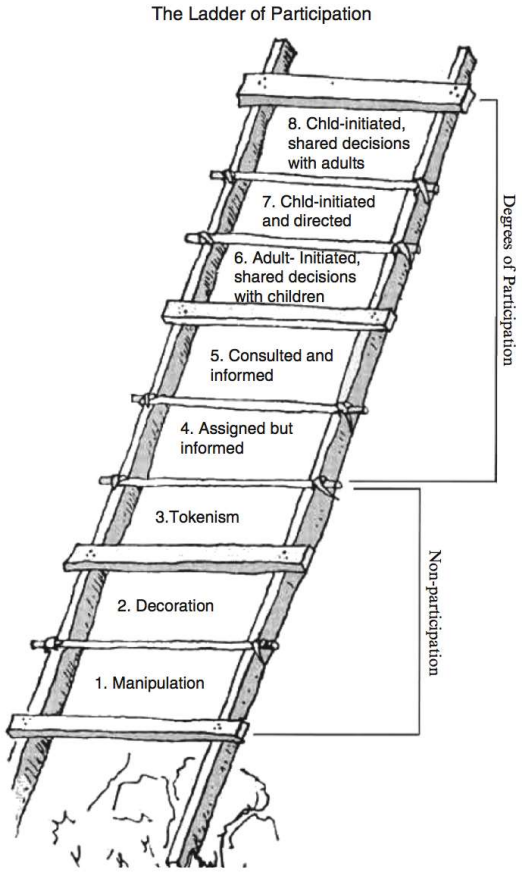


Nutrient and Integrative Power
Rollo May (1972)

Co-production power with children, young people and their families

UNDERSTANDING DYNAMIC POWER IN FAMILIES

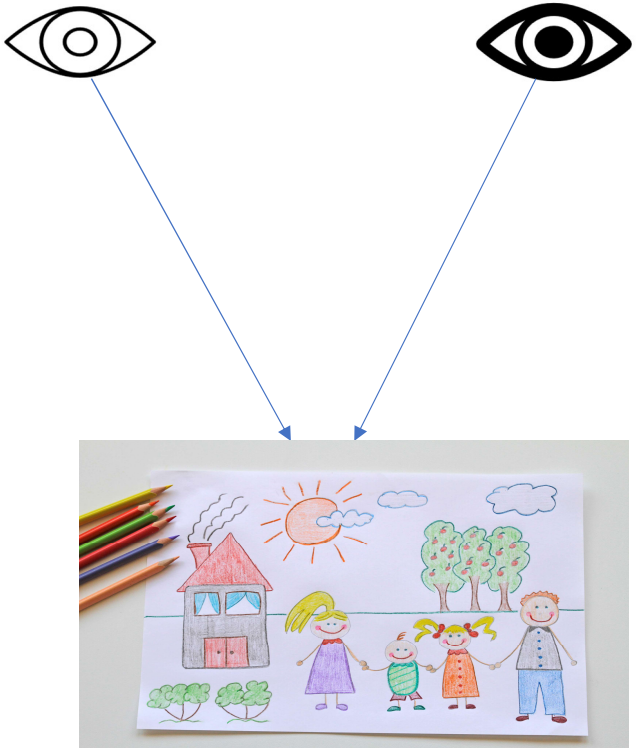




Etuaptmumk: **Two-eye seeing and young people**

Mi'kmaq Elder Albert Marshall

- Mutually respect autonomy and integrity of each person in the room and maximise 'depth perception' of a topic.
- Action-Oriented to create new paradigms.
- Synergistically grow power through reciprocating knowledge and sharing.



CO-LEARNING SPACES

- *Recognise that everyone has something different to bring and something different to learn.*

- Children, Young People and parents are individuals not a unit. But a co-learning ethos can help to move children from ‘manipulated’ to participatory.

In Summary…

- Coproduction can be done well or poorly
- It is not separate from the social, cultural and … history of both individuals and communities beyond the limited vision of clinical ‘lived experience’.
- This needs to be considered openly, as co-production can perpetuate these inequalities, or it can be transformative.

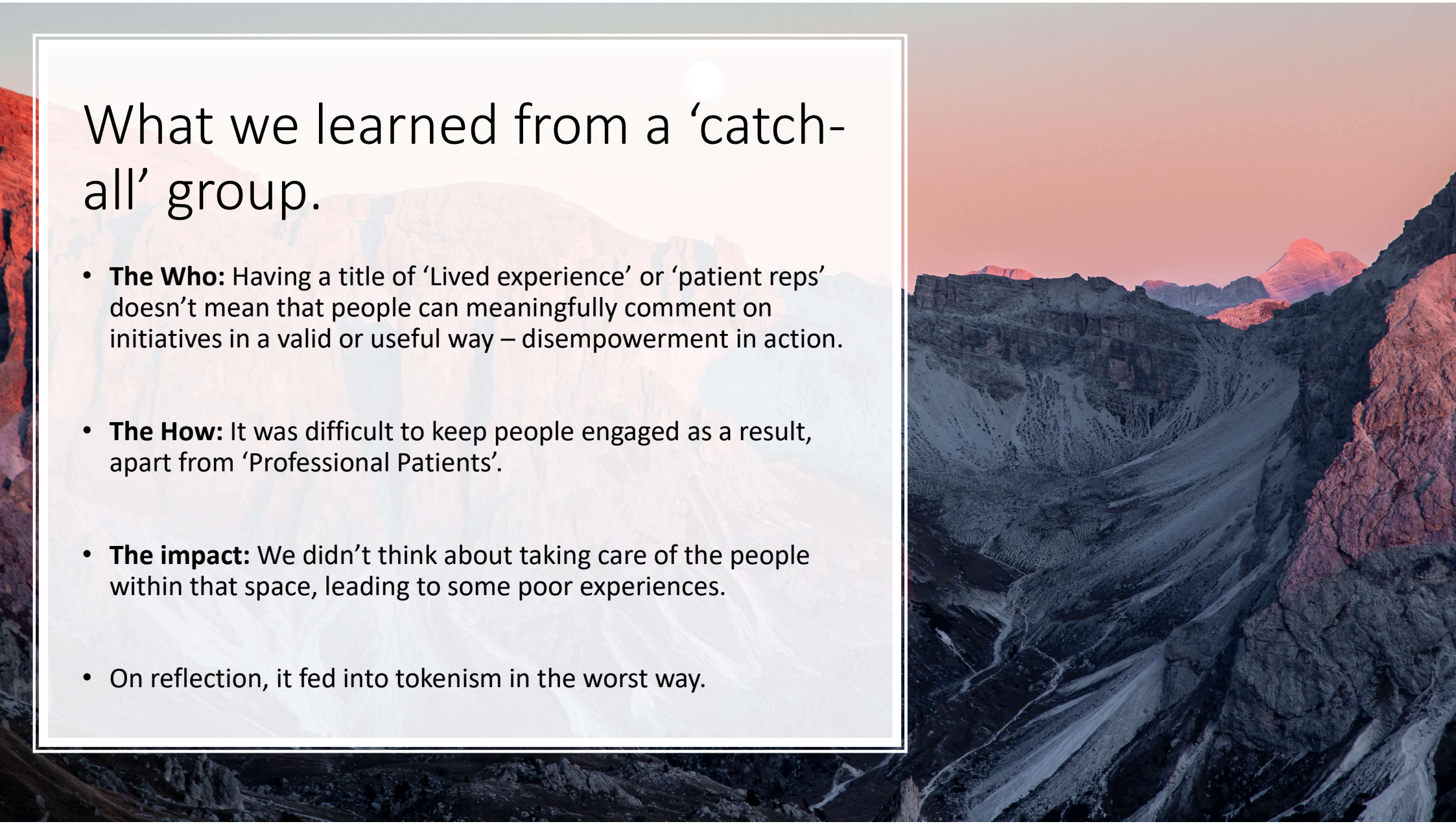
- **These issues will next be discussed in practical terms of projects and experiences we and others have had.**

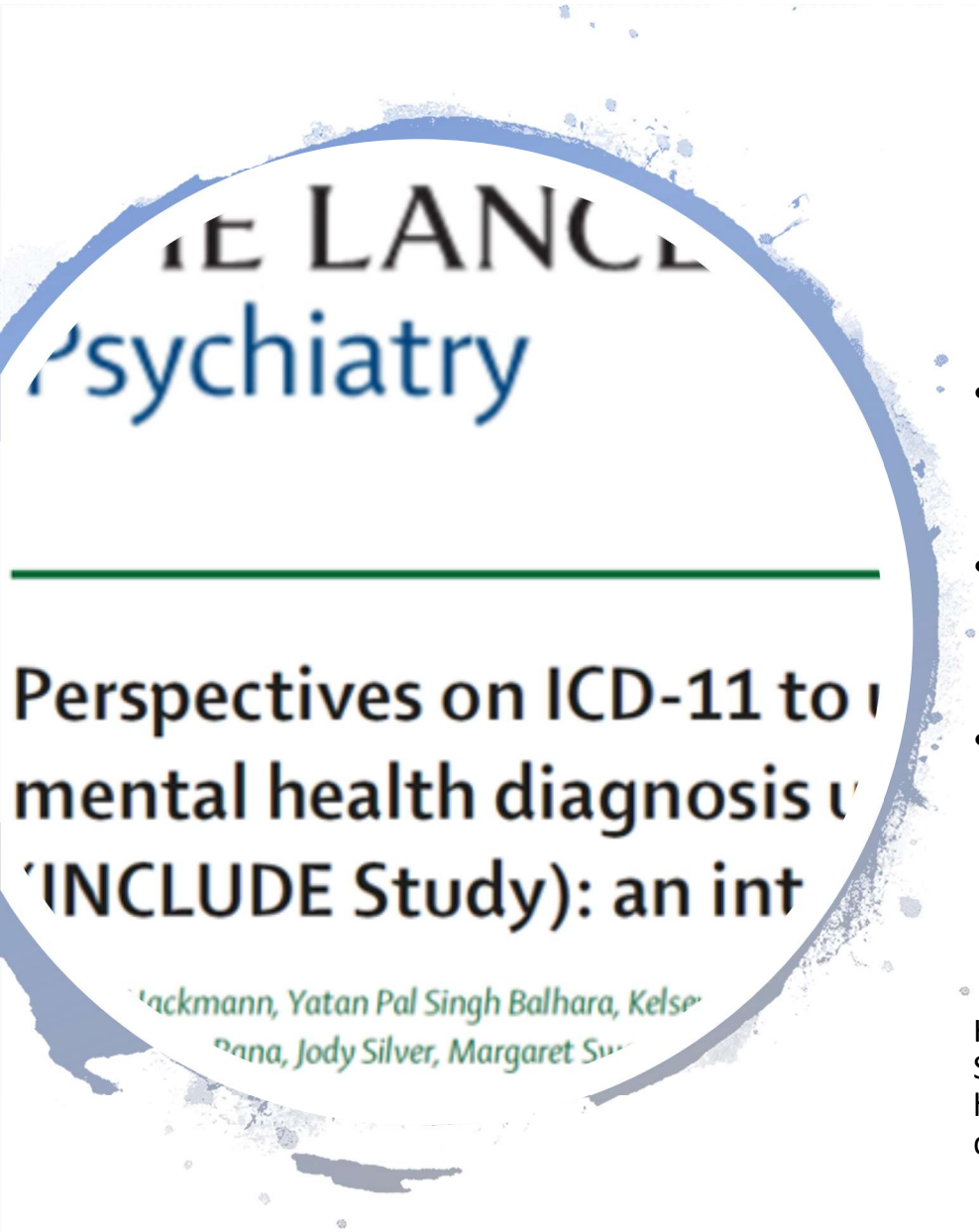
Co-production in Practice

Our initial journey with coproduction

What we learned from a ‘catch-all’ group.

- **The Who:** Having a title of ‘Lived experience’ or ‘patient reps’ doesn’t mean that people can meaningfully comment on initiatives in a valid or useful way – disempowerment in action.
- **The How:** It was difficult to keep people engaged as a result, apart from ‘Professional Patients’.
- **The impact:** We didn’t think about taking care of the people within that space, leading to some poor experiences.
- On reflection, it fed into tokenism in the worst way.





Policy development: INCLUDE study

- Perspectives on ICD-11 to understand and improve mental health diagnosis using expertise by experience (INCLUDE Study): an international qualitative study
- The INCLUDE study was the first to systematically collate and feedback service user perspectives into the development of a major diagnostic system (ICD)
- Collaborated with the WHO and Rutgers University, Columbia University and AIIMS to collate feedback from service users in the UK, US and India

Hackmann, C., Balhara, Y., Clayman, K., Nemec, P. B., Notley, C., Pike, K., ... & Shakespeare, T. (2019a). Perspectives on ICD-11 to understand and improve mental health diagnosis using expertise by experience (INCLUDE Study): an international qualitative study. The Lancet Psychiatry, 6(9), 778-785.

INCLUDE study methods

- Focus-groups to elicit feedback – included accessible language version
- Thematic analysis to develop themes
- Themes used as basis for co-produced recommendations for the WHO

Coproduction in the INCLUDE study

How did we coproduce?

- Research team
- Protocol development
- Topic guides for focus groups
- Participation in focus groups
- Analysis
- Co-production of recommendations for the WHO
- Write-up
- Dissemination to participants

INCLUDE study finding – importance of a duel perspective (who's diagnosis is it anyway?!)

- Schizophrenia diagnostic feature – '**disorganised** thinking and behaviour'

"I feel really mentally clear, and I write letters and I use words, and you know, and go really over the top, but my mind is really clear"

"What appears meaningless or disorganised to you may not be so for me... it can have a very clear meaning for me"

Supporting Young People to lead research activities

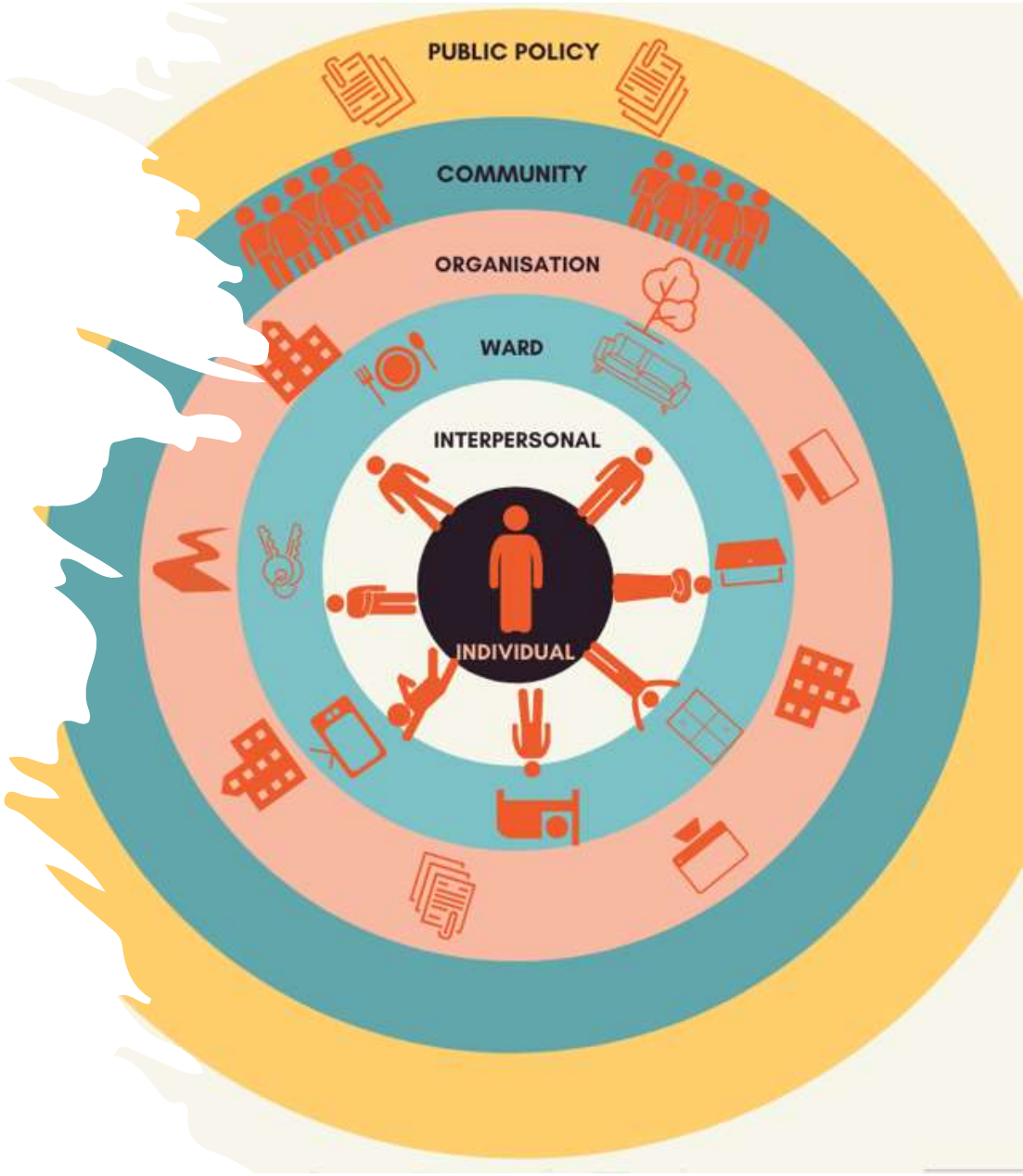
A consultation survey for young people found that they found the level of mental health support from paramedics and EMS was poor.

Young people were keen to take the lead on conducting interviews with other young people who had accessed EMS for their mental health.

So we co-developed interview topic guides and materials together, then trained young people in qualitative research methods through role-plays and rehearsals. We set up additional buddy systems so that a researcher was on call if needed.

Service development: MINDS study

- Intractable problem of poor experience of discharge from mental health hospitals
- Developed from lived-experience
- Co-produced and co-led
- Balancing perspectives of key stakeholders
- To develop a discharge approach that is designed to balance the needs of all
- Funded by the National Institute of Health Research, UK



Research evidence interventions to support discharge from mental health hospital

‘Staff establish therapeutic relationships’

‘which may help service users follow care and treatment plans’

‘Education, training and support for service users and their families about their condition and positive self-management strategies’…

‘Re-seeing’ the research evidence

‘Staff establish therapeutic relationships’

What do they mean by therapeutic relationships – and from who’s perspective? I’ve never experienced a therapeutic relationship on the ward – supportive maybe but not therapeutic

‘which may help service users follow care and treatment plans’

The emphasis here suggests that service users should blindly accept and follow care and treatment plans – where is the involvement?

‘Education, training and support for service users and their families about their condition and positive self-management strategies’…

This misses service user expertise – I’ve never met anyone on the ward who is not an expert in their own condition

“Let’s Talk Literacy”

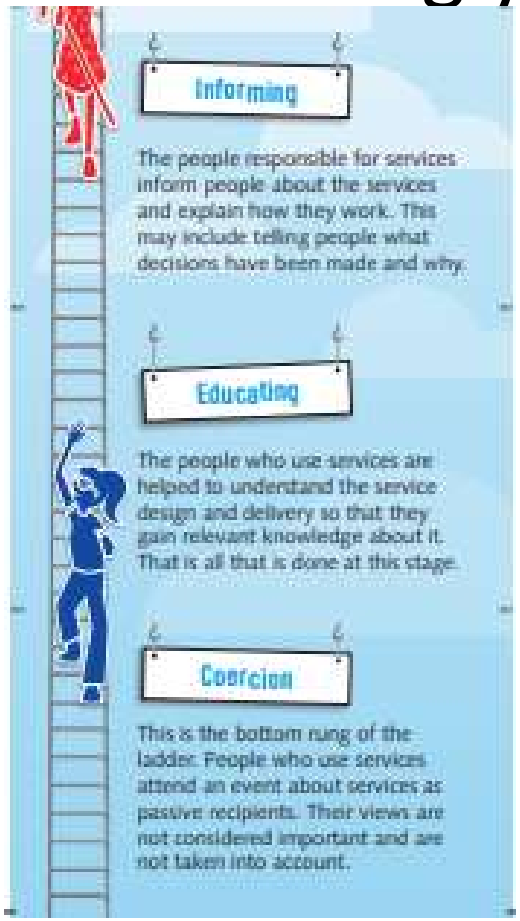
- 60 members of a learning disabilities and autism network identified that they felt reading and writing needs impacted on their mental health care negatively.

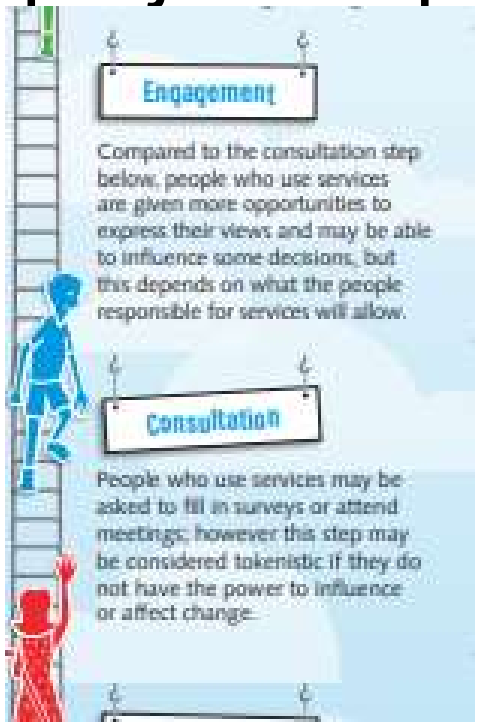
- We co-created a list of research priorities in the area of literacy and mental health within a workshop. The top priority was understanding the perspectives of healthcare professionals and how they did or didn’t embed literacy awareness into their practice.

- We established an integrated working group from clinical and lived experience of literacy needs, and provided training to help form research questions, conduct qualitative analysis using creative methods and a ‘Making Meaning’ of data workshop. At every milestone, findings were validated with the wider Network members.

The ‘How To’ of coproduction – what we have learnt so far

Ladder of co-production – think about where you're aiming your project or programme





Think Local Act Personal: Ladder of co-production

https://www.thinklocalactpersonal.org.uk/Latest/Co-production-The-ladder-of-co-production/

Thinking about the **Who**

- **Intersectionality:** People are complicated and full of different identities, not just the label that are coming in with in terms of their ‘lived experience’. Their worldviews reflect this.

- **Opening up Opportunity:** People engage differently across different platforms. Think about mixed-methods approaches to co-production and engagement i.e. surveys/groups/social media posts etc.

Opening the door (things to think about before you start)

- Think about who you are working with – what understanding do you have of their needs and lives?
- Recognise you can't *know* about anybody else's lived experience and be open to learn. **Throw out heuristics**.
- Hold onto the values of mutuality and reciprocity and equality.

- Think operationally about how the project will work with this.
- Remember that everyone walks into the 'room' feeling disempowered, possibly including you.

Think about your agenda

- Everyone will enter the room for a different reason and will have a different agenda.
- It’s good to name that – and not to see different purposes as a challenging thing, it adds a great deal to the conversation.
- Engaging children in this conversation is helpful too – it removes the parent being the dominant factor in the room if the child can name what they want out of the process.
- From the different agendas, agree the basic shared purpose and aims of the co-production.

Co-building a shared sustained purpose

- In an equitable co-learning space, one agenda or vision does not trump another.
- But fundamentally, the basic principle relates to the co-production process transforming projects, services and cultures for the better. **The end game is better health.**
- Hold onto that principle throughout and share in every interaction and documents.
- But be aware that the way to achieve the purpose may change. So it's a constant evolution – be a critical friend to yourself and the process.

Try to ‘enter the room’ together

- Recognise the hierarchy – issues of power

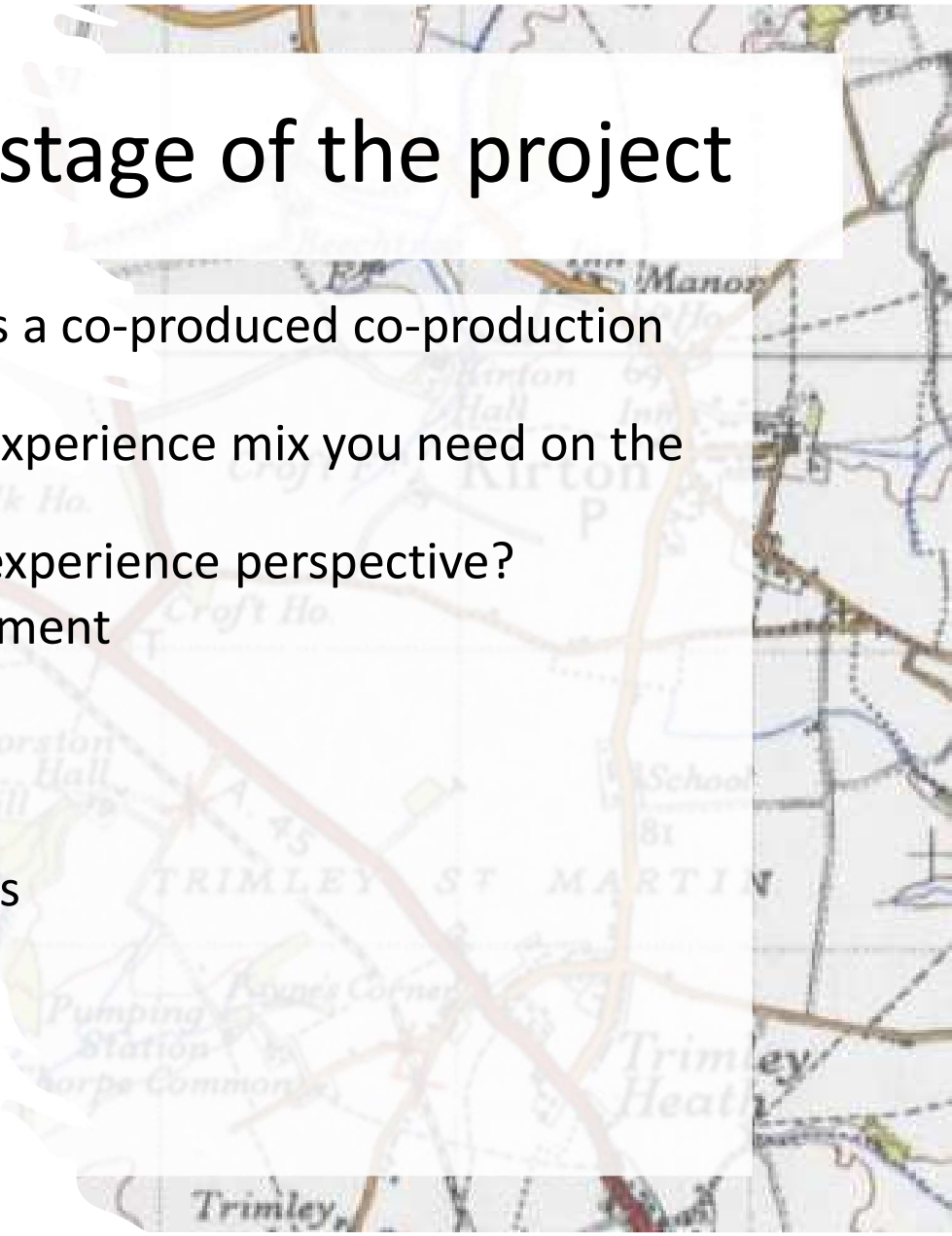
and talk about this.

- Think about what is needed to enable access to the room/conversation
- Avoid jargon, technical language, acronyms etc
- Remember your history and baggage – reflect on the possible impact of this on your project. Think of how you introduce yourself.
- Be aware of individual negative experiences and feelings of stigma
- Reflect on how the use of medical/clinical constructs and language may shape direction
- Remember nutrient power

Working together at every stage of the project

- Develop a clear project plan that includes a co-produced co-production protocol.
- Think about what skills, knowledge and experience mix you need on the team
- At what points will you integrate a lived experience perspective?
  - Conception and early project development
  - Deciding the project aims
  - Project design and planning
  - Collection of data
  - Analysis/making sense of your findings
  - Outputs and recommendations

- Think about *how* you will do this



Co-production with children and young people

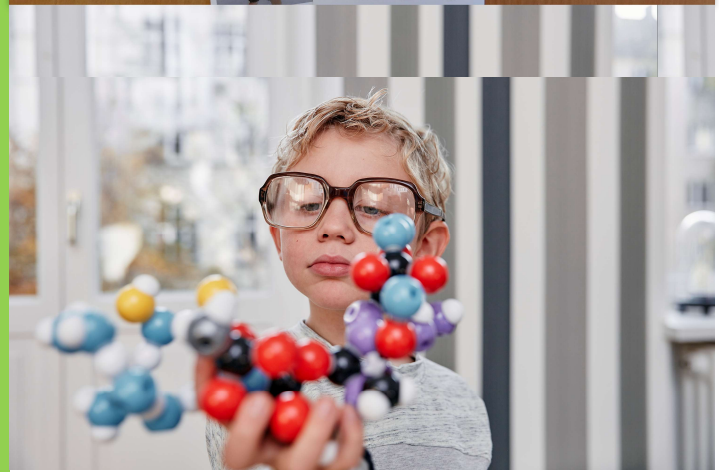
- First of all, find out why children, parents, other family members and researchers are there as individuals and collectively. What's important to them as individuals, and what recognition do people want?

- Co-develop collaboration protocols with children and their families. Don't fall back on the minimal '4 meetings a year' model.

- Developing a shared dictionary of terms and meaning for the project for parents and children i.e. What does the word 'Qualitative' mean?

- Building safe spaces and other ways of socialising for young people i.e. Whatsapp groups.

- Thinking creatively at all times , including tangible experiences and materials – redefine what lived experience means.



Setting boundaries

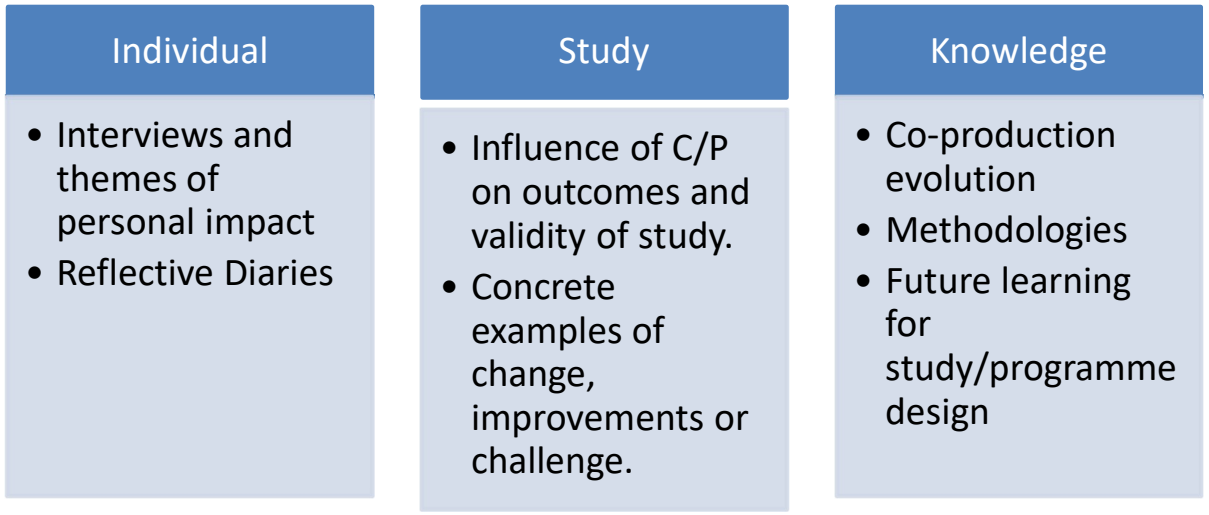
- This can be a grey area.
- People bring their lenses, not necessarily their stories.

- Clinical boundaries: Important to be clear that a co-production process isn't a clinical service, providing treatment or is a short-cut to care. But it can be helpful to prepare a signposting document with contact details of support organisations/services.
- BUT you still may need to manage distress during an interaction, so make sure there is a co-developed process for what to do.

Evaluating Co-production

- Co-develop with your team how you are going to capture and make meaning of the true impact and value of co-production on the initiative.

- Identify recordable domains of impact on the individual, study outcome and wider knowledge level.

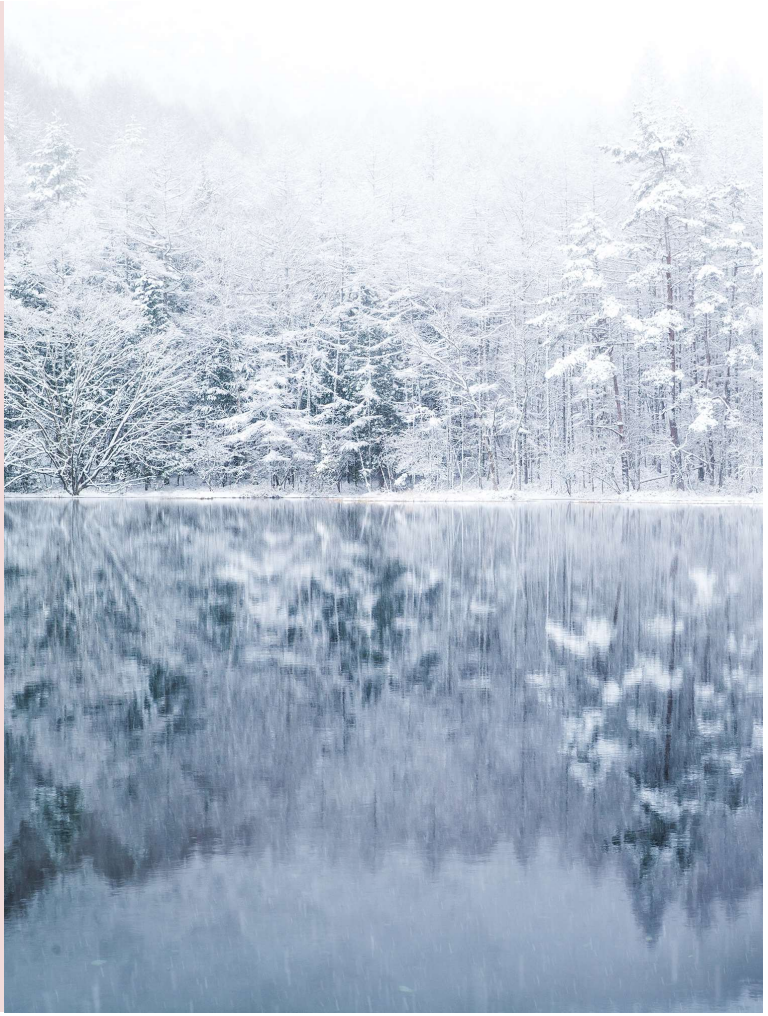


Slow down

- Genuine coproduction will always slow a project down and make things more complicated
- Recognise the need for understanding
- This also develops humility
- Build this into your project plan – e.g., the timeline
- Be flexible

Make space for reflection and feelings – you're in the room too!

- Coproduction in service development and research has challenged my clinical practice and identity
- I have also experienced a fair amount of criticism relating to how I am doing the coproduction!
- It can be easy for this to cause feelings of defensiveness
- Understand that you sometimes need to 'take it on the chin'
- However, coproduction should be the integration of different types of expertise (not the prioritisation of lived experience)
- Stay open and humble – but be aware of your expertise – be flexible and reflective about how you can work together to integrate perspectives



Recognise and allow the messy reality – there is no such thing as perfect coproduction!

- But it is still important to do!
- Coproduction tends to be a complex, iterative, flexible (messy?) process
- It can feel like a project is being ‘derailed’ (e.g. OP pathway project)
- Every so often take stock (build in time to stop and reflect)
- Try to balance flexibility with progressive pragmatism

Summary of experiences.

How our work has been enriched by working together

Values/philosophy

- Reciprocity and mutuality
- Nutrient power (Rollo May)

Process

- Tension of perspective
- Challenging each other

Outputs

- Outputs that are balanced to meet needs of different communities
- Transformative of service user experience
- Shifts the culture of service provision and research
- Educates providers, commissioners and funders

To contact us, email: research@nsft.nhs.uk

Q&A

Please use the chat box or the “raise hand” feature to ask questions.

Contact

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The College for Behavioral Health Leadership