Involving people with lived experience of intellectual disability - In reviewing and monitoring of services.

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Who are we?

- We are a group of co-researchers, with 2 of us having lived experience of intellectual disability.
- We live in 3 different countries, Australia, Northern (U K) and Republic of Ireland.
- All five of us have experience and membership of different inclusive research networks.
- We have collaborated on 2 articles for *Social Sciences* one on inclusive research an another on inclusive evaluation and regulation

- Patricia O'Brien & Edurne Garcia Iriarte & Roy Mc Conkey & Sarah Butler & Bruce O'Brien, 2022. "**Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled**," Social Sciences, MDPI, vol. 11(10), pages 1-14, October.

We met at Circular Quay in **2024**

We discussed recent **Royal commissions into, abuse neglect and violence** of people with intellectual disabilities

We wondered if people with intellectual disabilities were involved in evaluation of services whether their "**insider knowledge"** would pick up on issues that were missed.

Shared a set of questions

- Are there articles we should read before we start?
- Who should be interviewed and by whom?
- How will we go about discussing what people tell us?
- How will we write up what people say?

Aims of exploratory study

To identify where and how persons with the lived experience of intellectual disabilities were involved in inclusive evaluations activities.

To discover from various perspectives the advantages and the challenges of taking an inclusive evaluation approach.

To explore the prospects of inclusive evaluation activities being undertaken within service and regulatory organisations.

Where OUR conversations happened both on-line face to face.

In Australia.

- Three interviews.

In Northern Ireland.

- Four interviews. One focus group (N=3).

In Republic of Ireland.

- One interview.

In New Zealand

- One interview

Who we had conversations with

Co-Evaluators	Regulators	Service Managers	Support professionals
• Two interviews with co-evaluators with intellectual disabilities	Three interviews with regulators from Government Departments.	One interview and one focus group of managers of services for people with intellectual disability. and one focus group of	• Three interviews with supporters of co- evaluators.

What did we find out?

There were three ways people worked as co-evaluators

An evaluation team member

A technical expert

A storyteller

Also, people with intellectual disabilities were supported as co-evaluators through

Training

Use of Easy English

Working with a supporter in twos

- *What people said*

- *(From a Co-evaluator with intellectual disability)*

So, I tell them (the people in the residential service) ... I'm here as one of yous (sic), because I've been through this. Because I've got that more of the t-shirt, you know. So that helped them, because they knew I understood what (Their place) was like. I could have empathy. Is that the right word? I know what they're going through

We also identified what people saw as advantages of people with intellectual disabilities being co-evaluators

Met obligations of Australia re Convention on rights of persons with disabilities

Greater empathy & trust towards those being interviewed

Service users have more confidence to raise difficulties

Opportunities for paid employment

Co-evaluators gained confidence from being valued for their opinions

What people said (From a Regulator)

- *If you want to make [it] real, the Convention on the Rights of Persons with Disabilities and in terms of Article 21 and the saying "Nothing about us without us" it will bring to life our own international obligation to an international treaty to include people with disability into all aspects of the government's work. I would say that there is advantage in having that experience as part of an evaluation in house team, people with the lived experience of disability can bring in insight.*

The challenges of people with intellectual disabilities being co-evaluators covered

- Need for accessible materials and resources
- Need for change in attitudes towards the capacity of people with intellectual disabilities
- Need for whole organisation system change

What people said

- *(Regulator)*

There are several challenges, the first being a cultural challenge, not of the people with disability but of the professionals.

(Supporter).

- *There needs to be inclusive systems …organisations need to change how they do things, whether that's day-to-day communication and/or online … I feel strongly that people with lived experience need to be brought into the centre of the evaluation process not as a separate side piece*

People spoke about how to overcome the challenges

- Awareness raising of potential of people with intellectual disabilities within services to be evaluators
- Training of evaluators with intellectual disabilities in communication, confidentiality, what can be said in public, use of data gathering tools
- Training inclusively with all team members together, with intellectual disabilities and without.

They also spoke about what would be the first steps in actioning inclusive evaluation

Lobby government to fund a quota of people with lived experience as evaluators

Share news about successful employment of people with lived experience as evaluators

Pilot all aspects of the job of being an evaluator

Further first steps were

Develop accessible guidelines for the evaluator role

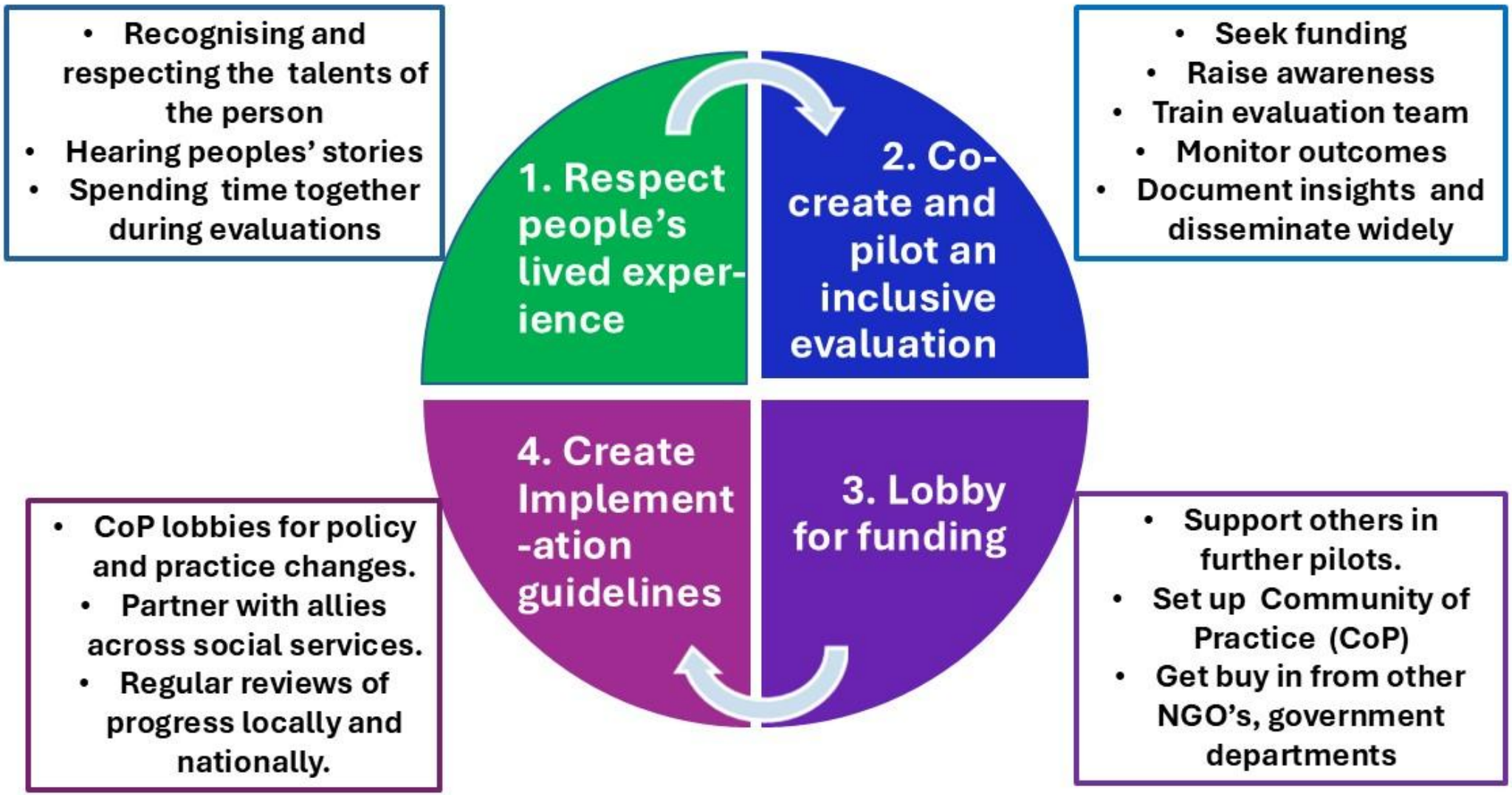
People with intellectual disabilities supported by experienced mentors

Training of evaluators with intellectual disabilities alongside peers without disabilities

What people said

Service manager

- *We made a deliberate decision that this was a paid job … we were asking people to be professionals. They were doing the kinds of jobs that we would normally employ people without a disability to do and so we paid them an award wage … It's given them gainful employment, professional employment and award wages. So, I think they've been advantages all around in doing things like this for our board, hearing from people with lived experience about the experience of our service users.*


• Recognising and respecting the talents of the person
• Hearing peoples' stories
• Spending time together during evaluations
1. Respect people's lived exper-ience
2. Co-create and pilot an inclusive evaluation
• Seek funding
• Raise awareness
• Train evaluation team
• Monitor outcomes
• Document insights and disseminate widely
4. Create Implement-ation guidelines
3. Lobby for funding
• CoP lobbies for policy and practice changes.
• Partner with allies across social services.
• Regular reviews of progress locally and nationally.
• Support others in further pilots.
• Set up Community of Practice (CoP)
• Get buy in from other NGO's, government departments

From Inclusive Research to Inclusive Evaluation: Empowering People with Intellectual Disabilities to Shape the Services They Use.

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Under review

Thank you for listening

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Link: Special editions on inclusive research
https://www.mdpi.com/journal/socsci/announcements/12798