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## Beyond co-design to co-evaluation

Reflections on collaborating with lived experience researchers

# Key questions

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What this presentation will cover...

What is lived experience?

What is driving the need for a lived experience workforce?

**Lived experience researcher case example: mental health service delivery**

What are the broader implications for consumer participation?

How can we best support the lived experience workforce?

# Continuum of engagement



## Communicate

- Informing stakeholders about policy/program development



## Consult

- Engaging communities to inform and influence policy/program



## Coordinate

- Consolidating different findings/perspective for shared outcome



## Collaborate

- Different people working together to achieve a shared vision



## Co-design/ co-produce

- achieves shared goals through equity, inclusivity, and the engagement of many complex and different perspectives



# Co-design to co-evaluation

## Co-design



## Principles

### EQUAL PARTNERSHIP

Consumers, families and staff work together from the beginning with an equal voice and shared ownership and control.

### OPENNESS

Work together on a shared goal, trust the process and learn together.

### RESPECT

Acknowledge and value the views, experiences and diversity of consumers, families and staff.

### EMPATHY

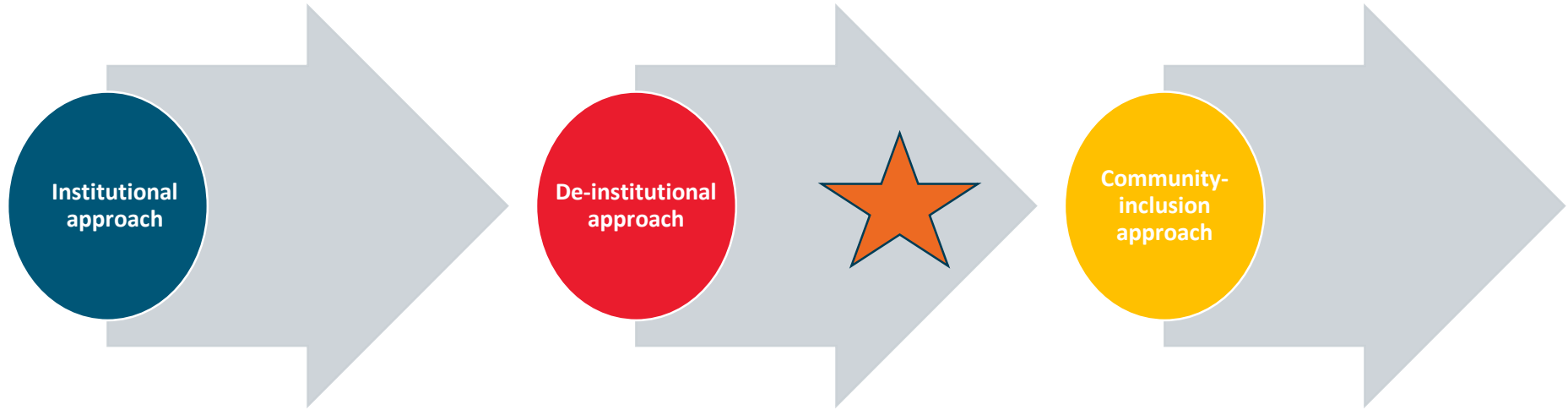
Practice empathy and maintain an environment which feels safe and brings confidence to everyone.


### DESIGN TOGETHER

Consumers, families and staff work together to design, implement and evaluation improvements, activities, products and services.

Where has consumer research come from?

## Changes in service model delivery





...the consumer researcher can act as a **useful vehicle** for maximising the unique contributions consumers can make to mental health researchers and enhancement (Case et al., 2014)

Case et al. (2014). Stakeholders' perspectives on community-based participatory research to enhance mental health services. *American Journal of Community Psychology*, 54(3-4), 397-408.

Photo: <https://www.freepik.com/free-photo/business-teamwork-join-hands-together-business-teamwork-concept>

# Working from a lived experience perspective



Meaningful use of lived  
experience



Celebrates the expertise  
of lived experience



Fosters connection with  
other lived experience  
workers



Opportunity for  
professional learning and  
growth



Increased equity and  
active citizenship for  
consumers and carers



Reduces power  
imbalance of traditional  
experts holding the  
knowledge

## Case example: mental health service delivery

- Three consortiums across Eastern Melbourne
- Delivery of mental health services for anyone with low to complex mental health needs
- Targeted at low-income consumers
- Our evaluation is looking at the staged implementation of the model as well as emerging outcomes for consumers, service providers and at the system level.
- Case studies involving data collection with a range of stakeholder groups including consumers/carers





## Our model

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Conduct data collection with consumers and carers

To provide a lived experience lens through which to analyse data

To provide their perspective as a person with lived mental ill health experience

# Lived Experience Research and Evaluation Roles

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1

Academic Lived Experience  
Researcher

2

Project-specific Lived  
Experience Researcher

3

Lived-experience  
steering/advisory group

4

Lived-experience  
advisor/consultant

# Barriers for lived experience researchers

## However lived experience researchers often experience:

- Lack of acceptance from non-lived experience colleagues
- More appropriate support requirement throughout lifecycle of engagement
- Lack of a defined role
- Lack of a defined career pathway and access to training

# Supporting the lived experience workforce

- **Formal employment support** – e.g. appropriate contracts, position descriptions, creating an enabling environment.
- **Communication and support** – e.g. regular debriefs, lived experience mentor, opportunities to decompress, peer supervision.
- **Sustainability of the lived experience workforce** – e.g. training and career pathways, national standards for remuneration.

## **Current space – some examples**

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- **Lived Experience Project** – Eastern Melbourne PHN
- **Lived Experience Evaluators Project (LEEP) Project** – Asylum Seeker Resource Centre (ASRC)
- **Consumer Reference Groups** – NDIS
- **BlueVoices** – Beyond Blue

## Q&A



# Team

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