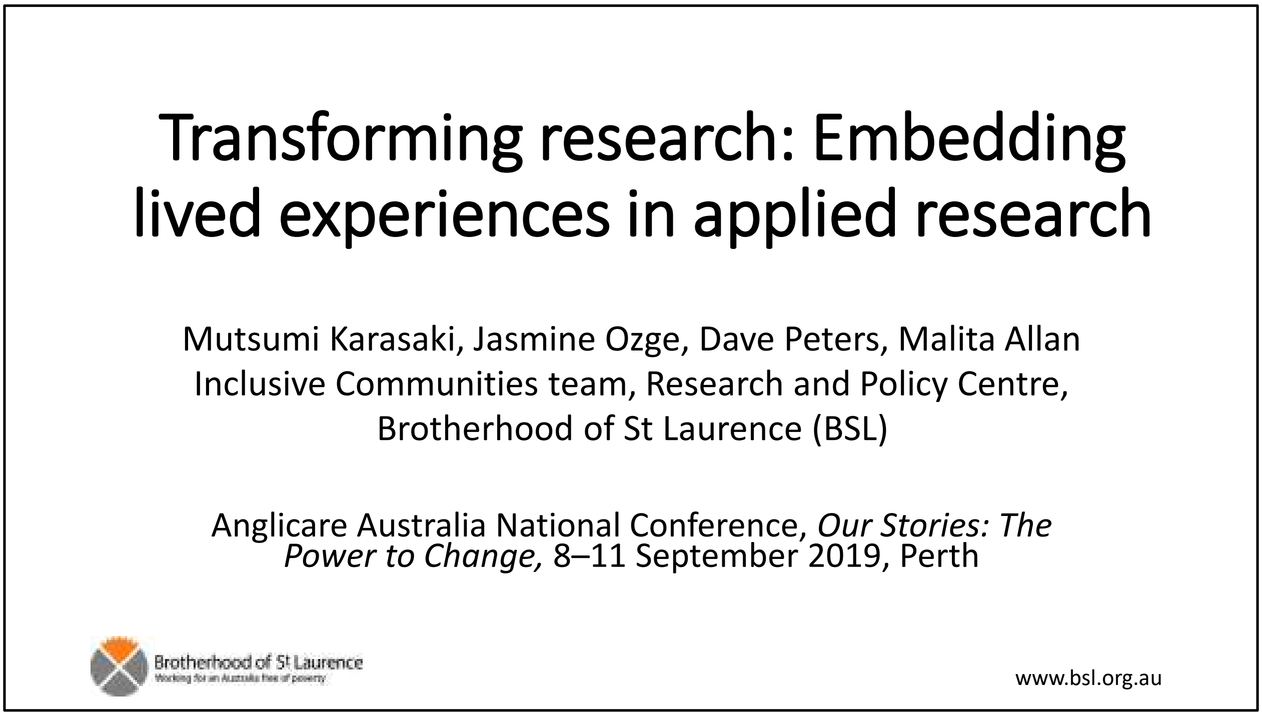

Transforming research: Embedding lived experiences in applied research

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Brotherhood of St Laurence
Working for an Australia free of poverty

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Hello my name is …. [everyone says their own first name]

We are researchers in the Inclusive Communities team in the Research and Policy Centre at the Brotherhood of St Laurence. The four of us are a new project team within Inclusive Communities that has been working together since the start of this year.

[Mutsumi says] two of us are men and one of us is a parent
[Jas says] two of us speak multiple languages fluently
[Dave says] one of us is a chair of a research committee
[Malita says] two of us have a PhD and three of us have peer reviewed journal articles

These attributes are typical among our colleagues in our workplace where the main focus of our work is publishing research and policy papers.

What is different about our team is that two of us have little experience of working in a research centre yet personally live with the conditions that we do research on – which are disability and mental illness.

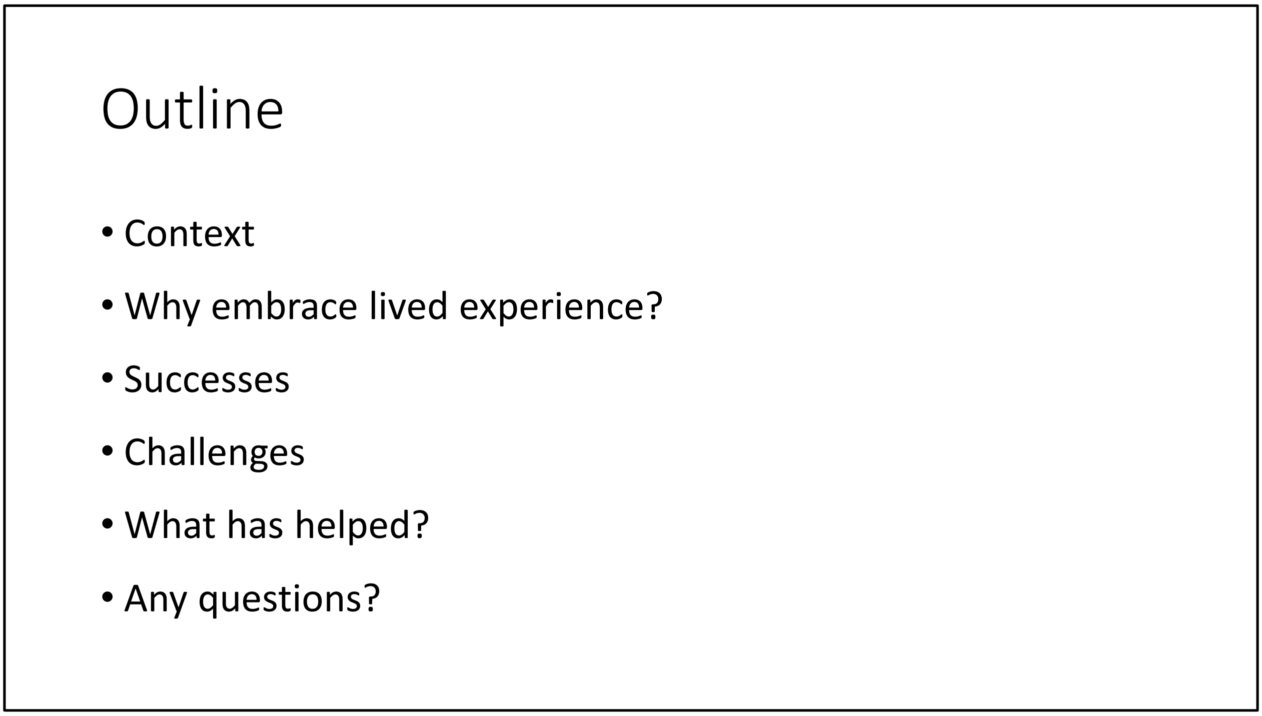
What is our talk about?

- Embedding lived experiences:
  - Into research practice
  - Within an organisation
- Embedding lived experience:
  - Challenging
  - Right thing to do
  - Improve quality and outcomes
  - Commitment and capacity building at all levels

Our presentation is about embedding lived experiences into research practice among team members and within an organisation. By lived experience, we mean using personal experience as a form of evidence.

There is recognition in our organisation of the importance of including the voices of people who have historically been sidelined. However meaningful inclusion requires everyone actively committing to practice inclusion in everyday interactions and work, and this undoing of historical injustice is a slow process.

We argue that embedding lived experience, *whilst challenging, i*s not only the right thing to do but can improve the quality of research to produce better outcomes for people with disability. This needs thinking at all levels of the organisation where all parties involved - including individuals, the research team and the leadership group - share a need for capacity building.



Outline

- Context
- Why embrace lived experience?
- Successes
- Challenges
- What has helped?
- Any questions?

We will first talk about the context, then why it is important to embrace lived experience and the successes and challenges in doing this. Then, we will share our learnings about what has helped. After that we will have 20 minutes for questions and discussion.

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Context

- Inclusive communities team
  - ‘Applied’: research – policy – practice
  - Projects with BSL NDIS services
- Lived experience and/in research
  - Object of study (what)
  - Way of knowing (how)
  - An attribute of researcher and/or ‘researched’ (who)

In the Inclusive Communities team we work on projects about the NDIS. Our work is situated in the intersection of policy, research and practice. Because our organisation provides NDIS services, our research has the potential to inform both NDIS policy and service delivery.

Our talk today is about the four of us, and our manager, Amanda who could not be here today, as well as the wider organisational context. When Amanda recruited our team to work on NDIS projects, she decided to have a mix of researchers with and without lived experience, for the reasons we are going to discuss.

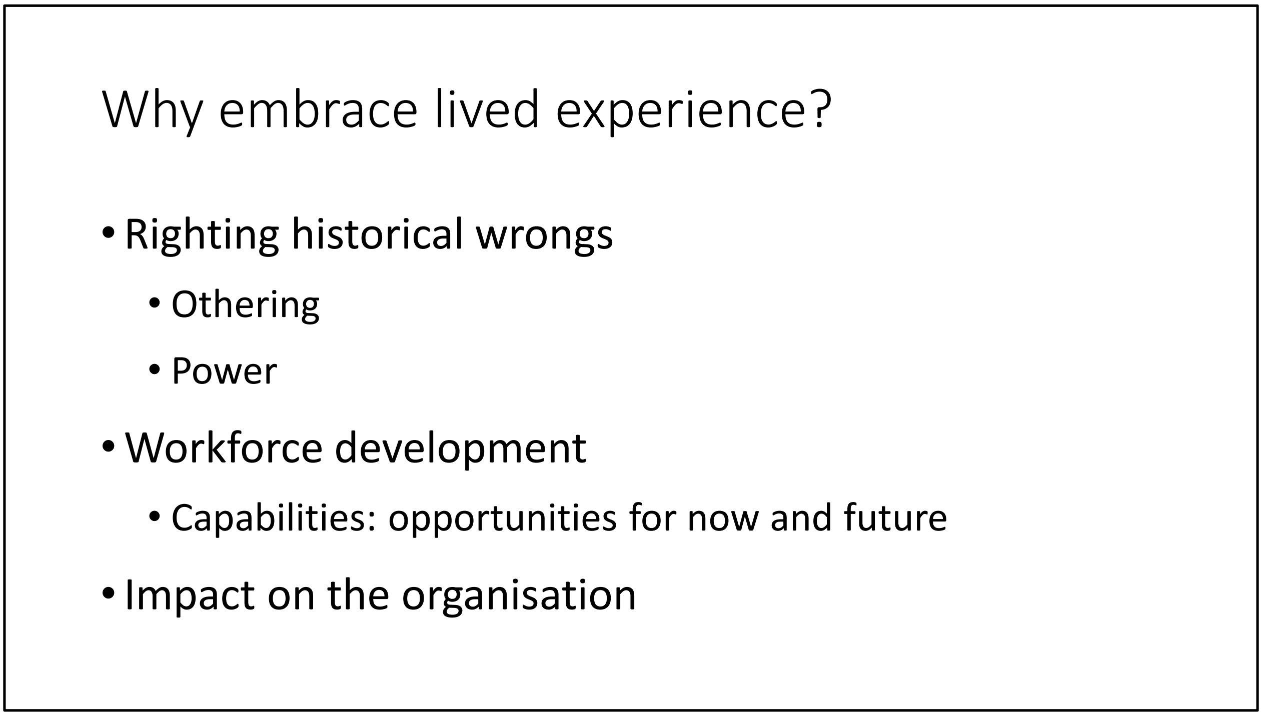
But before that, we will talk briefly about what has already been written in the literature about incorporating lived experience in the research process. Broadly speaking, lived experience has been incorporated into research in three overlapping ways: as an object of study, as a way of knowing, and as an attribute of people.

Literature

- Incorporating lived experience:
  - Quality: Design, recruitment, data collection and analysis (Barber 2011)
  - Credibility: Wider, more accessible and authentic dissemination (McLaughlin, 2006; Smith et al. 2008)
  - Power: Decision making, mutual learning (Brenda et al. 2018; Staley & Barron 2019)
  - Challenges: Time and cost (Boote et al. 2010), further disempowerment (Bochel et al. 2008), distress (Cotterell et al. 2010), how to evaluate outcomes (Staley & Barron, 2019)
- Our Inclusive Communities team:
  - Not co-researchers, but rather colleagues in workplace

Lived experience as an object of study is the basis of much qualitative research. So, our work is based on the idea of obtaining and disseminating lived experience to a wider audience, usually through publications. But who is involved and how they are involved, matters in what kind of knowledge is produced. The literature shows incorporating lived experience can impact on quality, credibility and power dynamics of the research process. However, there are also challenges around time, cost, and potential disempowerment and distress.

This literature often focuses on the overall successes with limited attention paid to nuances of everyday practice and dynamics in achieving these successes. Also the literature is mostly from ‘service user involvement’ in health and mental health care contexts, or community-based participatory research. Their discussions are often around engaging co-researchers, who are treated distinct from academic researchers who lead the projects. This is the common understanding of lived experience research in university settings, but we are trying to do something different because none of us are co-researchers. We are all colleagues in a team.



Why embrace lived experience?

- Righting historical wrongs
  - Othering
  - Power
- Workforce development
  - Capabilities: opportunities for now and future
- Impact on the organisation

We are embracing lived experience because we believe it is the right thing to do. Historically, people with disability or mental illness have had limited voice in research, policy and service development processes. They are either the ‘researched’, or invited to an advisory committee that may not lead to a meaningful contribution, because of the power imbalance not only in interpersonal relations but also deeply embedded at a structural level.

People with disability and mental illness have been previously spoken about and for by people without disability, with little benefit in return for them, such as genuine salary and career advancement, as opposed to tokenistic reimbursement such as a supermarket voucher.

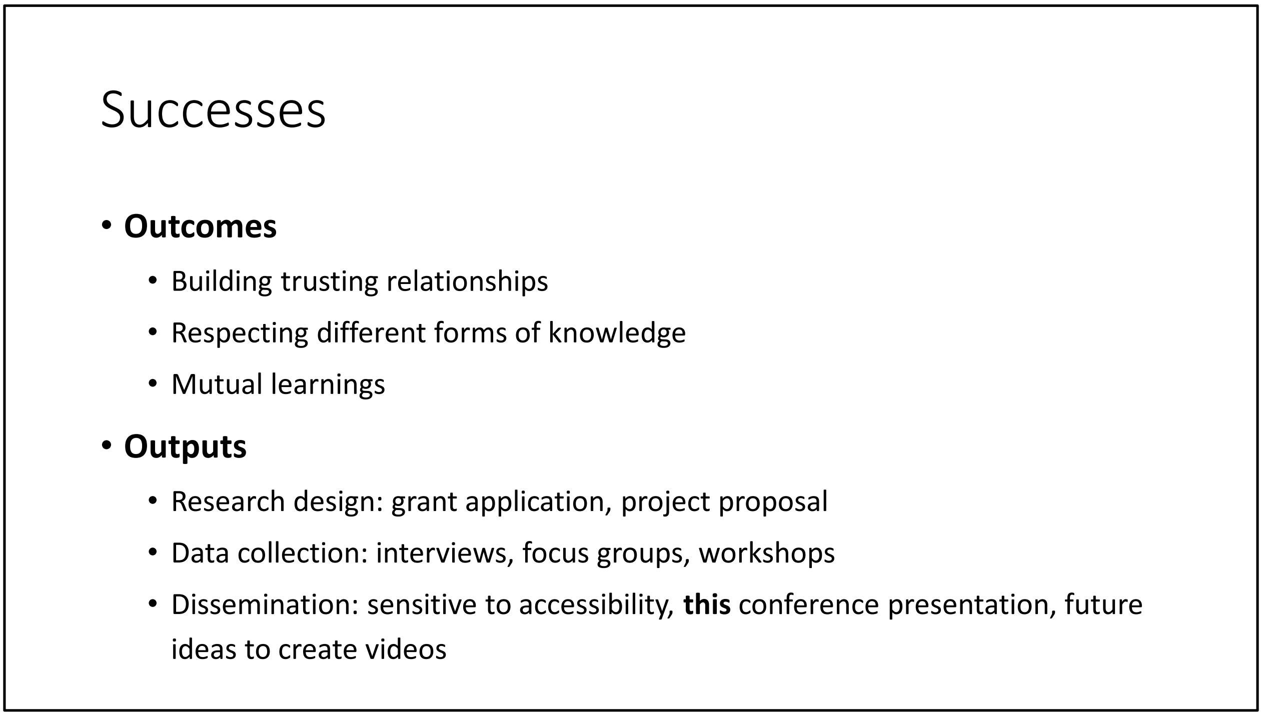
By having team members with lived experience of disability or mental illness working on research projects about the NDIS, we are working to move beyond tokenism. There are several elements to this.

Having team members with lived experience involved in the knowledge formation process, from research design, to data collection, analysis and dissemination can facilitate conversations of mutual learning. Even though the power imbalance is still with us, we are creating a sense that we are doing this together as team members, SLIDE 6 cont.

rather than community researchers working for academic researchers.

We also think of this as a way of developing the workforce. Rather than having co- or community researchers who are recruited on a project basis, we have team members employed on a longer-term contract. We hope that this allows for better possibilities for career development beyond that of work experience or upskilling.

Having people with disability or mental illness as part of the team can change organisational practice and structures and we are hoping that this will form a basis for genuine opportunities to develop into future leaders in the field of research and policy.



Successes

- **Outcomes**
  - Building trusting relationships
  - Respecting different forms of knowledge
  - Mutual learnings
- **Outputs**
  - Research design: grant application, project proposal
  - Data collection: interviews, focus groups, workshops
  - Dissemination: sensitive to accessibility, **this** conference presentation, future ideas to create videos

We have had successes of embedding lived experiences in our research practice.

We have been able to establish trusting relationships as a team, by figuring out how to provide and receive hands-on support without this becoming micro-management. For example, in a grant application we prepared recently those of us in a more senior position provided a mix of direction and guidance whilst relinquishing control. The outcome of this is that we sweated together as a team to make the deadline exceeding our expectations, and we have just found out that we have been awarded the grant.

In sharing an idea based on lived experience, through discussions we work to capture and articulate the idea, transforming a collection of different forms of knowledge into outputs. For example, in preparing this presentation we started with a personal story shared by one of us and collectively and collaboratively turned it into something new. This also leads to mutual learnings. Through regular team discussions we have started to develop a shared language around our work.

We are at the stage where we are starting to see products of our efforts, including writing a grant application, a project proposal and this presentation. We have also collected data, with future plans to disseminate them through publications such as

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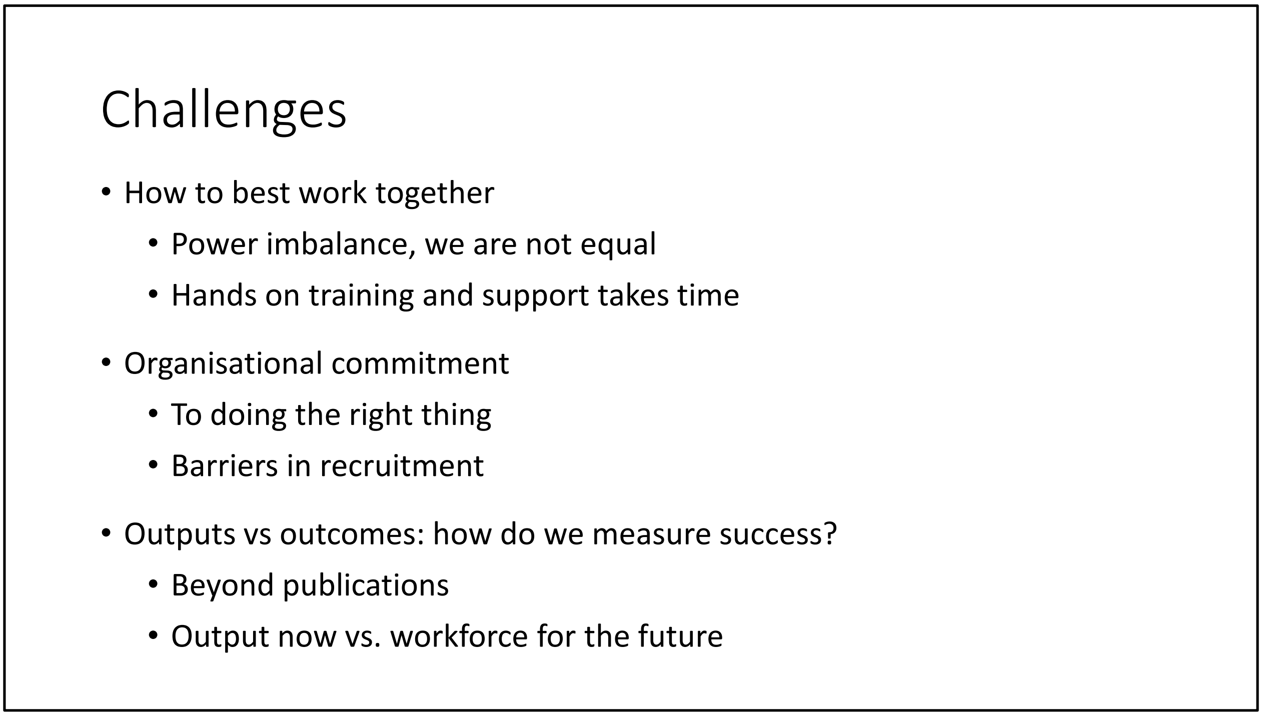
multimedia and other accessible formats.

What we have experienced so far has been consistent with the literature. Involving people with lived experience has improved research design and data collection. For example, connections made between lived experience researchers and participants with disability were useful for recruitment and gaining candid and raw responses in interviews.



Challenges

- How to best work together
  - Power imbalance, we are not equal
  - Hands on training and support takes time
- Organisational commitment
  - To doing the right thing
  - Barriers in recruitment
- Outputs vs outcomes: how do we measure success?
  - Beyond publications
  - Output now vs. workforce for the future

The successes we have been talking about are outcomes of the challenges we face in our everyday work.

First of all, it is important to situate our team not only in an organisation but also in a wider social and political context. In working together we find that the power imbalance is ever present. The reality is, we are not equal.

- The traditional researchers are in higher positions with higher pay because they have had education opportunities
- They are privileged to be able to say that good research practice is remaining objective and not getting caught up emotionally in interviews
- They are also privileged to be able to expect their body and mind to be functioning in order to turn up to work next week

In finding ways to best work together, we have to remind ourselves of these realities.

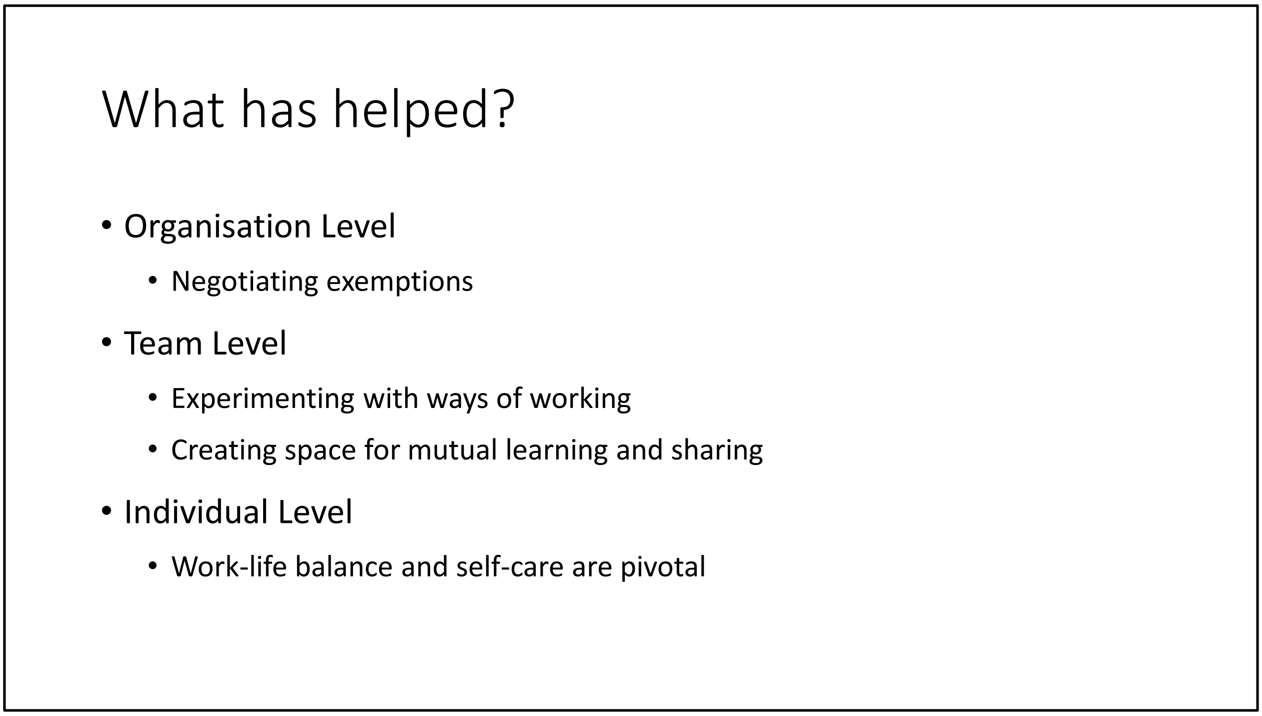
Working together has practical implications. All of us need to put in significant time and effort in learning the best way to support and communicate with one another. This involves a great deal of collective emotional management amongst us. Living life can be difficult enough when you are stressed. When you add in chronic conditions such as mental illness or paralysis of the body, accommodating this complexity requires the whole team to be understanding, patient, compassionate and flexible.

Our team is trying to practice this inclusivity but this can’t happen in a vacuum. We need the organisation and leadership at all levels to embrace the value of doing the right thing and maintain their commitment. This is not easy because they are also part of a larger picture about what a successful organisation might be. This means that the recruitment process has been skewed towards hiring traditional researchers, usually without disability. Amanda wanted to avoid reproducing these historical wrongs. However, she faced organisational barriers during recruitment. She had to challenge the standard recruitment procedure with HR in order to hire researchers with lived experience.

Another challenge is how success is measured. Traditionally in research settings the most valued performance measure is based on publication outputs. As we said, moving beyond tokenism means the research process can be slower. This means the demand for publications places stress on the research team, and it makes it difficult for everyone involved to maintain the commitment.

For the organisation to fully embrace lived experience, this tension needs to be recognised and respected by the leadership. One way of doing this might be considering different ways of measuring outputs and outcomes. Examples may include relationship building, creating future opportunities for people with disability, and ways of sharing our experiences with the rest of the organisation.

An unresolved tension is how best to balance the demand for outputs now with our longer term ambition of developing a lived experience workforce.



What has helped?

- Organisation Level
  - Negotiating exemptions
- Team Level
  - Experimenting with ways of working
  - Creating space for mutual learning and sharing
- Individual Level
  - Work-life balance and self-care are pivotal

So, what has helped?

As discussed, the HR process was not easy. Our new project team has been made possible by making exemptions and we need to acknowledge the organisation’s willingness to invest in us.

Within our team, we have developed a space for experimenting with ways to work together. For example, in order to strike the right balance between hands on support and micro-management, we have tried different ways of structuring our time and priorities. One strategy is that we have a morning huddle every day where we break down the work into small and more manageable tasks to assist with focusing and avoid being overwhelmed.

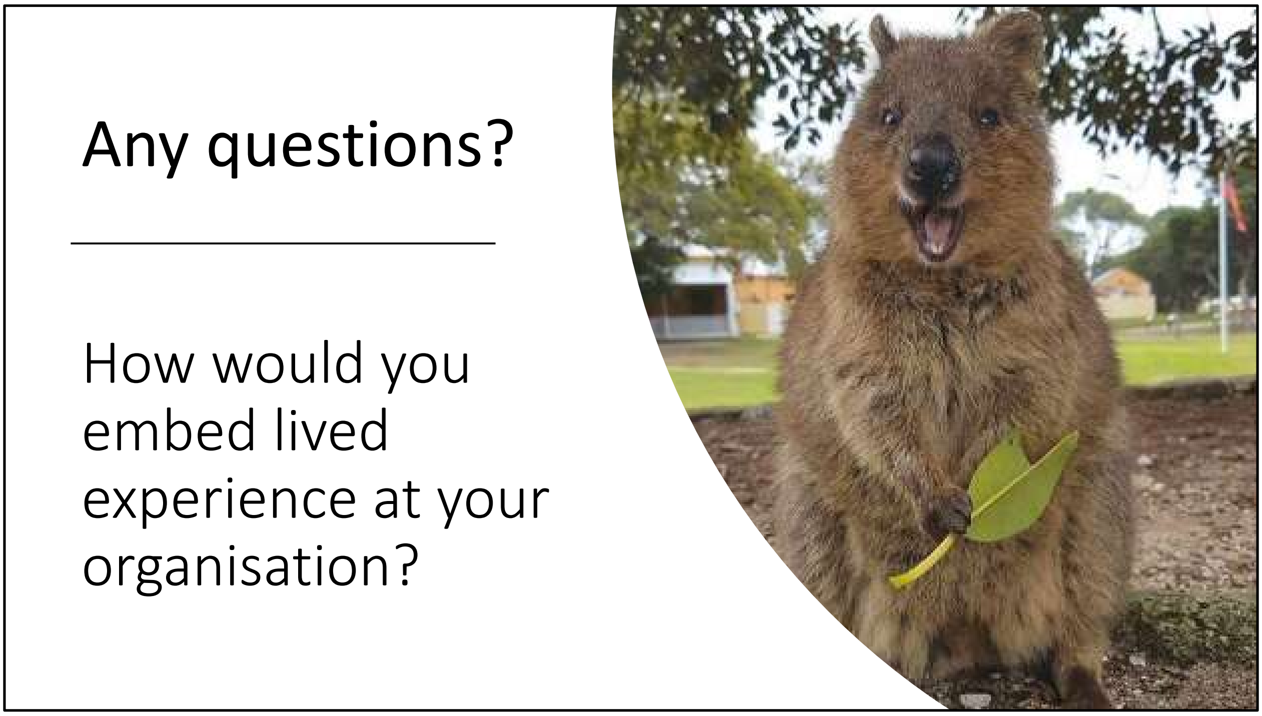
We have dedicated time to have regular discussions about different approaches to conducting research, as well as learning about each other and our working styles.

We have also created a shared online space to record and document different resources, contacts and reflections.

We share the sentiment in the literature that working in a lived experience role can be triggering and re-traumatising at times. This means that the separation between work and home life can be blurred.

For these reasons, it is particularly important to implement a strict self-care regime to try and manage the stress and potential distress.

These are strategies that we are using in our work, but it is not easy. It takes commitment from everyone, and it takes time. But we believe it is worth it.



Any questions?

How would you embed lived experience at your organisation?

Thanks for listening! Do you have any questions?