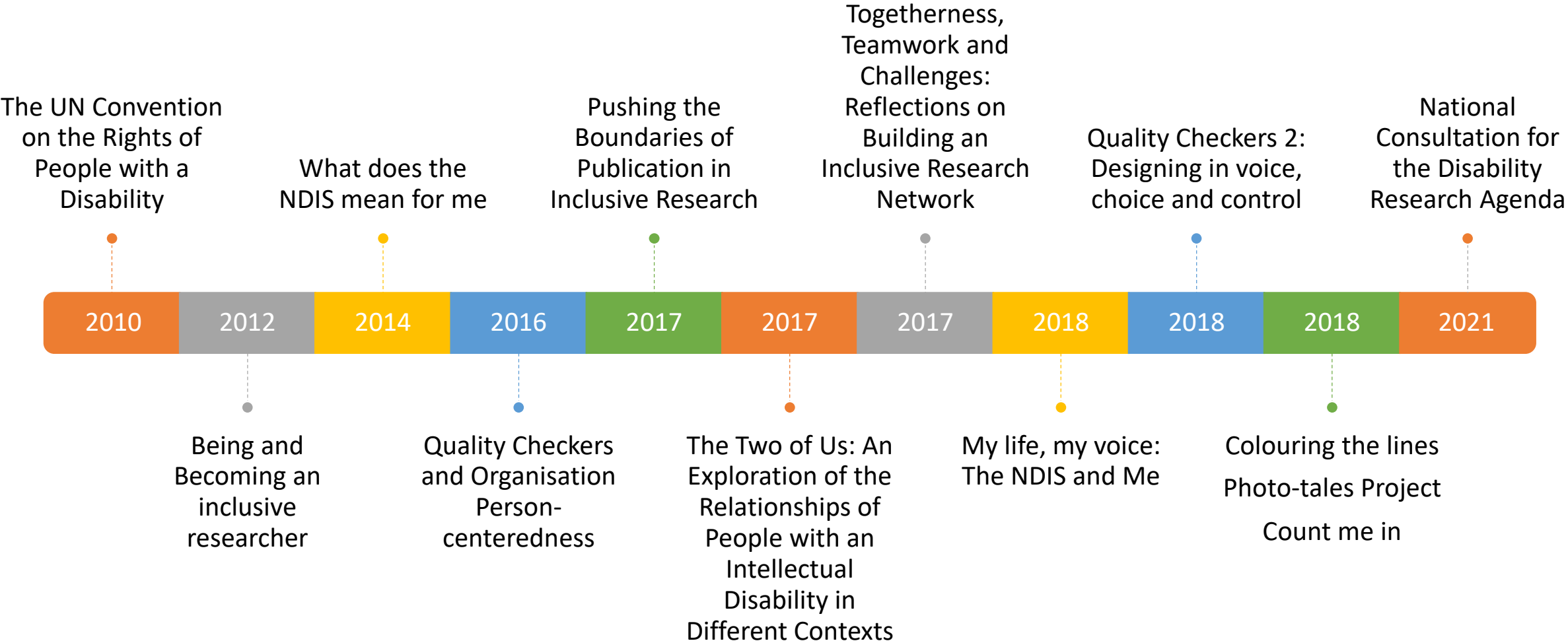


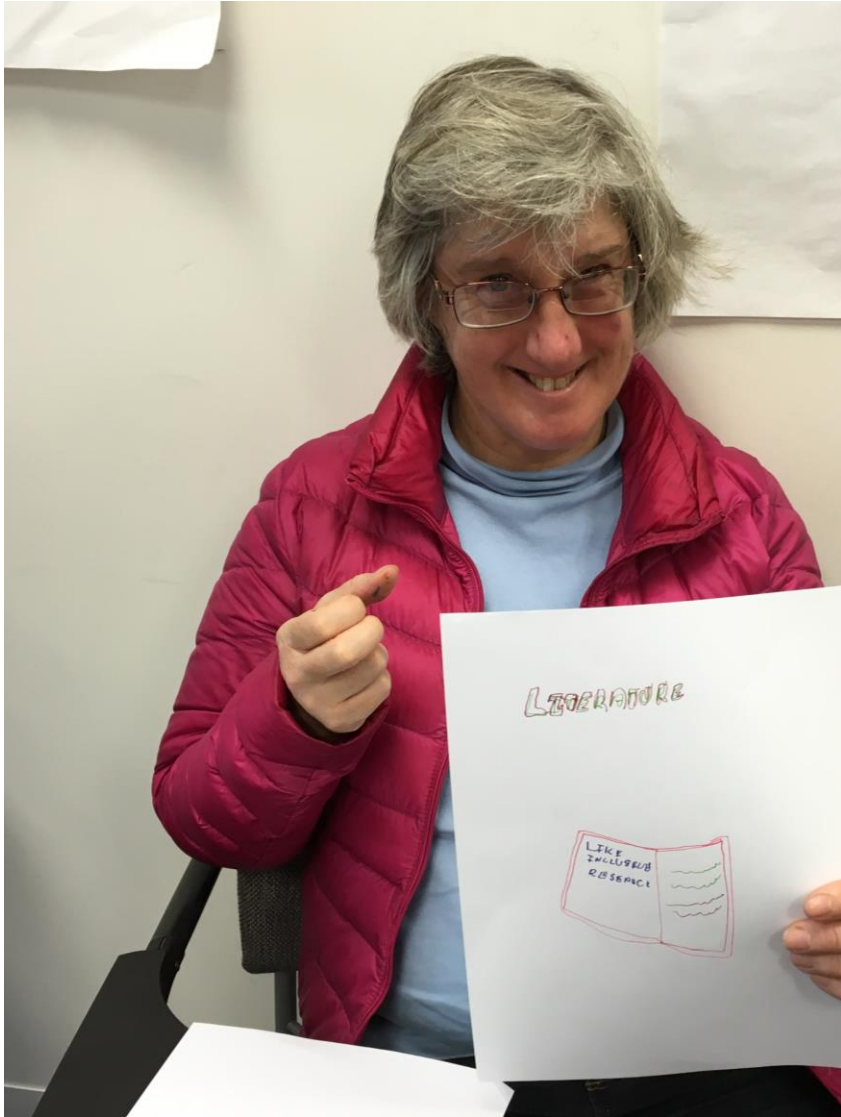


A mental health support program for us by us

Presented by: Bruce, Elizabeth and Erin

Timeline of the IRN Projects





What is inclusive research?

- Inclusive research means people with intellectual disability doing research about people with intellectual disability
- From a paper we wrote about inclusive research (Westermann 2022):
 - Inclusive research is best practice
 - People with disability should drive research about themselves and be involved in that research
 - We should be included in every part of research, from the beginning to the end

What are we doing?

- The aim of the project is to create an inclusive, peer to peer, support project about mental health for people with intellectual disability
- Our goal is to make sure that the research that we do and the program that we make are accessible and inclusive for everyone
- We are trying to create awareness of mental health problems with and for people with intellectual disability
- We want to create guidelines or a resource manual for people with intellectual disability, to help them support people in their lives
- We have thought of a few different things, like a first aid kit with tea and tissues, or a toolkit to help people

Why are we doing it?

- Mental health problems are very common for everyone, especially people with intellectual disability
- Everyone is affected by mental health, particularly people with intellectual disability
- Not enough is known about mental health for people with intellectual disability
- There are many resources for people without a disability, but very few for people with intellectual disability
- The ones that we have found are not designed by people with intellectual disability
- People who don't have good support might have difficulty accessing resources
- We want to know how we can support our friends and family
- Peer support also teaches people skills, like listening

Why is it important to do it inclusively



- People with intellectual disability have lived experience of mental health problems. We are the ones who are really living with it
- We also know what needs to be done. We know what gaps exist, from our own experience, and what can be done to improve it
- It is also easier for us to do things accessibly. Sometimes when academics ‘translate’ things into plain English or easy read they don’t always do a great job
- We can make sure every part of the project is accessible, not just the end result
- Nothing about us without us!

How are we doing it?

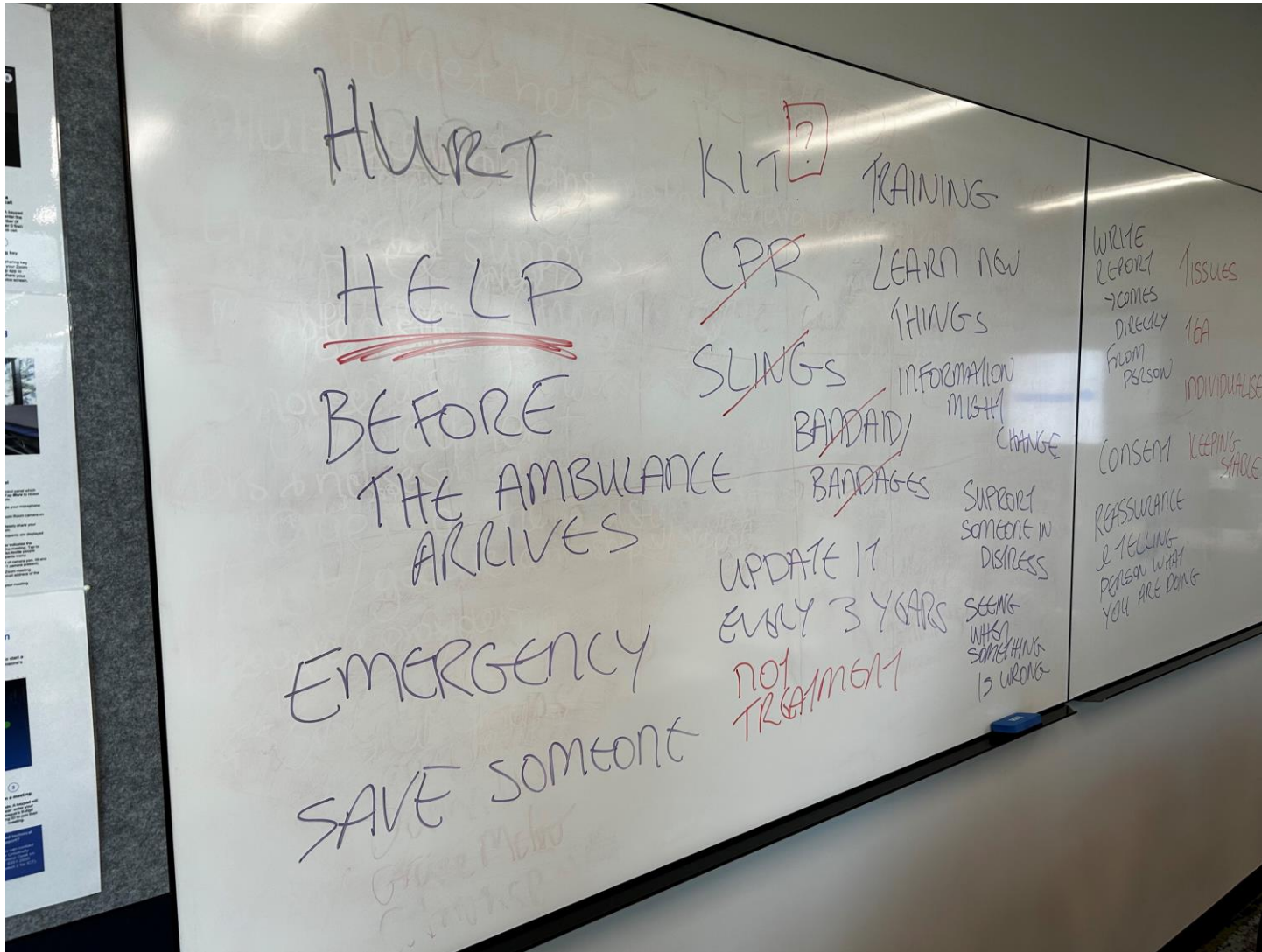
There are two parts to this:

1. how we are doing the project
2. how we are doing it inclusively

Part 1:

- We are asking people about their lived experience of mental health
- We are asking them questions like
“What has helped with your mental health?”
“What has helped when you have been having a hard time?”
“Do you have any tips?”
- We are using interviews and focus groups to get this information

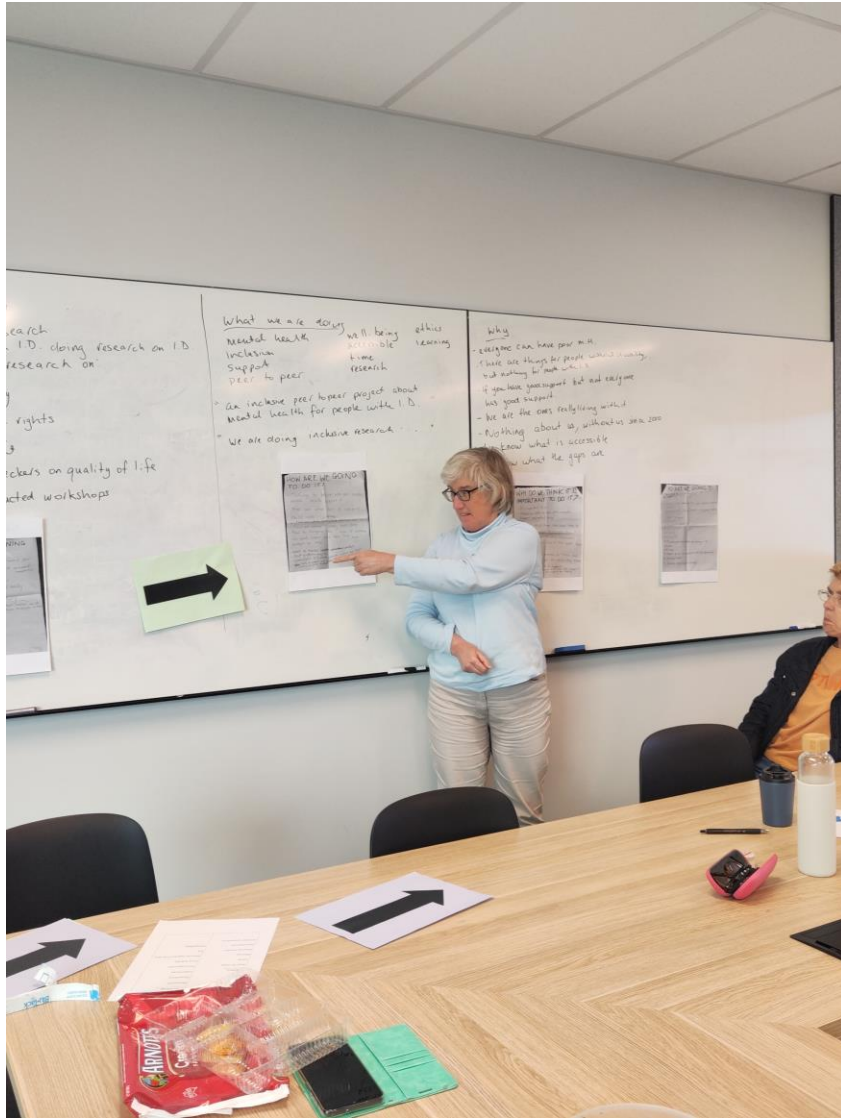




How are we doing it inclusively?

Part 2:

- Multiple steps:
- We started with a big list of ideas, everything we were interested in
- We did a vote on which ideas are important – kept the most popular
- A bus stop to generate ideas about our specific topic
- Who, what, where, how and why



What is a bus stop?

- A bus stop is a tool we use a lot to help us make decisions
- A bus stop is where we set up 'bus stops' around the room
- A bus stop can be a question, or a prompt
- We break into groups and each group takes a turn to answer each question
- We move around the room and brainstorm together

Who are we going to work with?

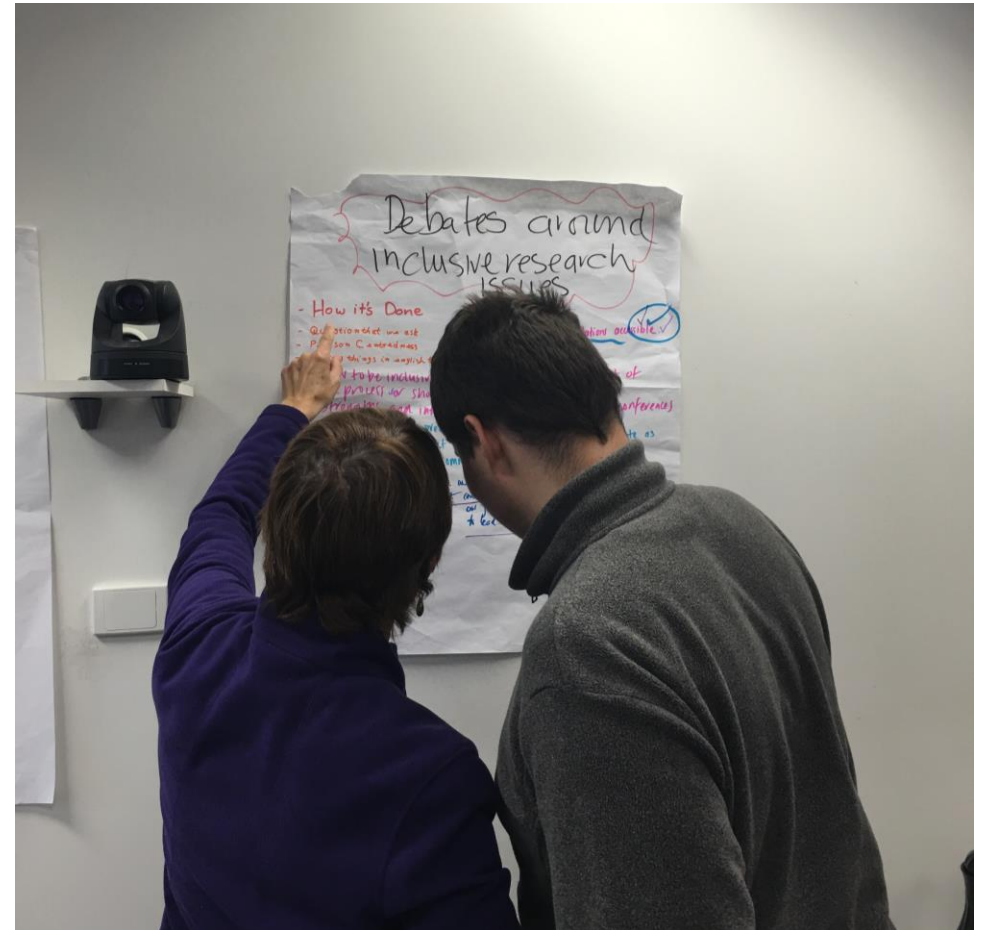
- People with intellectual disability who have experienced poor mental health
- Service providers
- Health professionals
- Support people (friends, family)



Difficulties and challenges

What are the difficulties and challenges we have faced?

- Ethics – not an accessible process
- Takes a long time to make group decisions
- Not enough time together – only meet once a month
- Money
- Grant applications are not accessible, especially the timeline – they are too quick. Not inclusive – we want the entire process to be inclusive



Next steps



Search literature



Summarise findings



Translation of findings into interview/focus group/survey questions



Host focus groups/interview



Survey shared throughout network



Analysis of research findings



Presentation of findings



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