

Perspectives on Co-Production

Supported Decision Making

Experiences, Approaches & Preferences



Research Team



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Barbara shares her thoughts

Barbara talks about her peer researcher experience.



Why research decision making?

- Making decisions about your own life is a key part of **independence, freedom and human rights**
- Without support sometimes people are not able and/or allowed to make their own decisions
- The Mental Capacity Act (Northern Ireland) 2016 is a new law with guidance to respect everyone's rights and the need to support people to make their own decisions
- There is not enough information available about how to support decision making, especially information about peoples own experiences

How did we do the research?

- **Peer researchers** interviewed 41 people with mental ill health and/or learning disabilities
- They asked lots of questions about:
 - People's experiences of decision making
 - What types of support people have had when making decisions
 - What people liked or disliked about the support they have received

What we found

- Everyone has different experiences of decision making.
- Everyone has different feelings about support when making decisions.
- Participants identified a range of supporters with particular ‘qualities’.
- Participants identified a range of supports which were useful depending on the situation.
- There were three factors which made decision making harder.

Co-Production

Co-production is not just a word, it's not just a concept, it is a **meeting of minds** coming together to find a **shared solution**. In practice, it involves people who use services being **consulted**, **included** and **working together** from the start to the end of any project that affects them.

--Think Local, Act Personal 2011

Why Co-Production?

- To produce research which is informed by people with lived experience.
- To provide opportunities for ‘everyone’ in the team to benefit from their involvement in the project.

Keywords

A word cloud on a dark purple background. The words are in various colors (white, light blue, green, purple) and sizes. The most prominent words are 'power', 'job', 'encouragement', 'listening', 'training', 'meetings', 'democratic', and 'valued'. Other words include 'participatory', 'advisory', 'responsibility', 'employment', 'relationships', 'balance', 'choice', 'confidence', 'enjoyable', 'team', 'neutral', 'flexibility', 'dialogue', 'care', 'trust', 'safe', 'opportunity', 'communication', 'voice', 'transformation', 'egalitarian', 'hope', and 'positive'.

power job
participatory advisory
responsibility employment
relationships balance
encouragement choice
listening confidence
enjoyable
training
team neutral
care dialogue flexibility
trust safe opportunity communication
voice transformation egalitarian
hope positive meetings
democratic
valued

Process

- Reference group identifies research area for study.
- Involvement of ‘International Advisory Group’.
- Partnership Agreement.
- Open recruitment process for paid positions.

Process II

- Training for peer researchers provided.
- Development of data collection tools with accessible equivalents.
- Purposive selection of interviewees.
- Matching of peer researchers with interviewees.
- Support and debriefing following each interview.
- Regular team meetings.

Process III

...with opportunities for peer researchers to work on:

- data analysis
- report writing
- public speaking.

...according to their interests and goals.

Pros of Co-Production

- Disability can be an asset.
- Challenges stereotyping.
- Develops skills of all team members.
- Makes it possible to collect good quality data.
- Encourages dissemination which is impactful and accessible.
- Gives peer researchers the confidence to take on new projects.

Cons of Co-Production

- Time to conduct the project.
- Issues around decision making and power dynamics.
- Issues around when and how to be involved.
- Participant distress.
- Employment comes to an end when the research project is complete.
- Difficulty of facilitating involvement during the unfunded stage of project(s).
- An 'emergent' research design is a 'difficult sell'.

Removing Barriers I

- Key stakeholders need to be aware that research involving people with lived experience takes time.
- Establish how decisions will be made in the partnership agreement.
- Create a co-design checklist at the start of the project and continuously review!
- Enable people with lived experience to make their contribution in different ways and at different levels.

Removing Barriers II

- Provide thorough training.
- Lobby for the creation of funded peer researcher panels which exist beyond the life of a specific project.
- Provide signposting to benefits advice.
- Advertise the fact that the post of peer researcher exists!
- Establish a forum where peer researchers can share their reasons for doing research.

Aine shares her thoughts

Aine talks about her peer researcher experience.



Concluding Comments

Thank you!

Thank you for listening to our presentation!

The project report is available from the Disability
Research on Independent Living and Learning
(DRILL) website

<http://www.drilluk.org.uk/>