Quality Checkers and Organisational Person Centredness: An Inclusive Research Approach

The Centre for Disability Studies Inclusive Research Network
Affiliate of The University of Sydney, NSW, Australia

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What is the Centre for Disability Studies Inclusive Research Network?

- We are a part of a group of co-researchers with intellectual disabilities, their supporters and university researchers from CDS, Sydney, New South Wales. We do research together.
- We have been working together since 2010.
- Our members have changed over time but we are all still very keen to do research together.

“Nothing About Us Without Us”
Background

• Thank you to the Endeavour Challenge Foundation!

• Person centredness important in the NDIS – but how do people with intellectual disability see person centredness and what is the fit with organisational policies?
Aims of the Study

• Aims of the study
  i) develop a set of person centredness signs gained from the views and experiences of people with intellectual disability, and
  ii) to check these signs with organisational policies

• We used ideas from the Quality Checkers work - people with intellectual disability as experts by experience who work with organisations to check various aspects of service quality
What did we do?

Two parts to our study

– Part One – conducting individual interviews with people with intellectual disability on their views and experiences of person centredness

– Part Two – checking each organisation’s policies against what the people said about person centredness
The First Part of Our Study

• Our whole group developed questions on person centredness from a brief review of some literature as well as from our own expertise – as experts by experience

• We all conducted the interviews with 30 people with intellectual disability from 3 disability organisations in Sydney NSW

• Transcripts of recordings of the interviews were our data which we then analysed
What Did we find from the Interviews?

What is person centredness?

I am recognised for who I am

I feel positive about who I am

I feel happy and a better person

I am a person

I have a life
Signs of Person Centredness

• Our participants identified 3 key signs of person centredness:

  – Choice and decision making

  – Communication

  – Relationships with staff
The Second Part of our Study

• We then checked each organisation’s policies for these three signs

• We worked in pairs to do this and spent a whole day with each organisation
First Sign of Person Centredness

**Choice and Decision-Making**

- I can choose who supports me
- I don’t feel alone
- Staff support my choices and advocate for me
- It’s my decision
- I do what I want to do, not what the staff want me to do
What did the Policies Say about Choice and Decision Making?

• All policies good on choice and decision making

• Important for people to make their own decisions and have control over their lives

• It was the person-centred planning process that helped choices and decisions to be worked on
Second Indicator of Person Centredness
Communication

*Speaking up and being listened to*

- I can speak up and get my rights heard
- I can speak up for others who can’t speak up for themselves
- I am listened to and taken seriously
- I have someone to tell if I am not being listened to
- I am not confident or I don’t know how to speak up
What Did the Policies Say About Communication?

All the policies said it is important to

• Listen to the person
• Communicate with the person how they communicate
• Ask other people who know the person well

BUT policies assume people can speak up. Many can’t or don’t feel comfortable to do so

Policies need to include guidelines to support people to develop confidence and skills in speaking up
Third Sign of Person Centredness

Close Relationships with Staff

Staff do not have enough time with me. Staff have to support other people as well.

Staff work with me to achieve my goals.

Staff are concerned for my well-being.

Staff and I talk about things that are important to me or that are worrying me.

I see the staff as still being the boss.
What did the Policies say about Staff and Relationships with Staff?

• Policies talked about the importance of respectful relationships and professional boundaries
• Policies geared to staff not clients

**BUT**

• Our participants talked about wanting different relationships in person centredness – more collaborative
• Professional boundaries in person centredness may need to be different
What Do Our Findings Tell Us?

Our findings told us lots of things. Some are:

• Staff relationships – a more collaborative relationship in a person-centred environment

• People need to be supported to have their voices heard and to make choices in their lives – choice, voice and control cannot be assumed!

• Quality checkers model a good way for the experiences of people using services help policy development
What’s Next for Us?

Our next task is to meet with the organisations to share with them our findings for their organisation.

We hope they will find them helpful!
Thank you for your attention

Add more pics of other presenters
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