The Social Construction of ‘Intellectual Disability’: Perspectives of Staff

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Overview

- Literature and limitations
- Research aims
- An overview of the research project
- Reflexivity
- Findings
- Take home message
Literature and limitations

- Intellectual disability as a stigmatised identity.

- Ascription of a stigmatised identity by researchers *apriori*.

- Failure to consider the alternative identities an individual may embody.

- Failure to include people with intellectual disabilities in the research process.
Research Aims

- To explore the social construction of ‘intellectual disability’, particularly the personhood, identities and social roles of people with intellectual disabilities.

- To increase the control, power and meaningful participation of people with intellectual disabilities in the research process.
Overview of the Research Project

How people with intellectual disabilities conceptualise their own identities and social roles?

- 18 Members
  - Photovoice and Conversational Interviewing
- 5 Advocacy Agency Staff
  - Conversational Interviewing
- 1 Member
  - Lifestory
Advocacy Agency Staff

- A number of staff members at the Advocacy Agency expressed an interest in being involved in the research.

- Five staff members from the Advocacy Agency (four female and one male).

- Held various positions within the organisation from managerial to volunteer roles.

- Conversational interviewing.

- Analysed using CLA.
Reflexivity

- Reflexivity is the process of critically reflecting on the kind of knowledge produced and how that knowledge is generated.

- Subjectivity is considered a strength or resource of the research that should be acknowledged and revealed.

- Personally revealing and at times leads to uncomfortable conclusions.

- ... But it is really important!
Theme: Low Expectations and Limited Opportunities

- Presumed incompetence or inability.

- Begin once the individual is recognised or formally diagnosed as having an intellectual disability

- Pervasive

“… well it’s not really about that person not having, you know… intellectual disability, so they can’t do it because they don’t have the intelligence. It’s about not being given the opportunity.” (Bob).
Subtheme: A Bloody Good Life?

- Rhetoric that people with the label intellectual disability lead a good life.

- A full and satisfying life was described as being achieved despite the absence of indicators of Western notions of success such as meaningful employment and close relationships.

“I get the feeling that they have a bloody good life at times, like anyone. But they don’t have to have a good car to do that, they don’t have to go overseas to do that or dress in a good suit... most of them make the most of what they have” (Bob).
Subtheme: Smiley, Happy People

- Discourse about people with the label intellectual disability being ‘happy’, ‘loving’ and ‘lovable’.

- Worldview that people with intellectual disabilities are able to have fun and can offer love and affection.

“They’re human beings and it doesn’t matter, you’re still going to love them cos they’re yours… You know, it’s not so bad. There’s still a living human being that can give you love, affection, can do things, can achieve things” (Lorraine).
Face Palm Moment  #1

Kate: So did you have anything else that you wanted to tell me about you?

Jacob: (silence)

Kate: About what you… What do you think you’re like?

Jacob: (silence)

Kate: Do you think you’re a pretty happy person?

Jacob: Yeah.
FACEPALM

Because expressing how dumb that was in words just doesn't work.
Face Palm Moment  #2

Kate: So if you were thinking about what you’re like as a person, how would you describe yourself? It’s a hard question, isn’t it?

Freya: Yeah.

Kate: What do you think you’re like? I think if I think about myself I think I’d be pretty happy. I love to hang out with my friends…

Freya: Yeah me too.

Kate: My family… are you the same?

(Freya nods).
DOUBLE FACEPALM
FOR WHEN ONE FACEPALM DOESN'T CUT IT
Theme: Imposed Identities

- The roles that people with an intellectual disability are often cast included: the deviant, the child and the disabled.

- Subthemes:
  - Deviancy and Intellectual disability
  - The Eternal Child
  - Disability as a Master Status

- Incidences of hypocrisy.
“She may get left with them and they are in control of her as they have got to look after her and they may consider she has been naughty… they will send her to the naughty corner. Another time, she will say to me that she hasn’t got her TV in her room because she's not allowed to watch TV for three weeks or six months or however long the so-called punishment or she's had a new DVD, and she is not allowed to watch that… And then she will say, 'I tell them I am thirty-three. I'm an adult. I'm an adult.' But this is kind of how she gets treated. So her voice is not heard” (Vicky).
Face Palm Moment #3

Kate: *Dusk Til Dawn*. Do you like the scary ones?

Jacob: Yeah.

Kate: Yeah. *You don’t get nightmares?*

Jacob: No.

Kate: No? *I do* (laughs)… I think it took me about ten years to get over Scream it was that scary (laughs).
TRIPLE FACEPALM
Not even double facepalm can explain how much you fail
"It doesn't matter what it is. You know, it’s like if you’ve got cancer, you’re the cancer on ward 5. I suppose when I smacked my arm, I was the smacked shoulder on ward 2, or something. I don’t know.... it's just the way this society is” (Dawn).

“They actually would identify each other and themselves probably by more of a social, like their leadership roles, so to them it’s about who’s got certain leadership roles, about who’s bossy boots, about who’s ratbag at the pub” (Liz).
Face Palm Moment #4

*Kate*: And how do you get to the venue?

*Louise*: I normally get a bus or a friend to take me and bring me home.

*Kate*: Yep. And how are you with going on the buses?


*Kate*: How do you go with your budgeting in everything? Are you good with, you know, doing your bills…

*Micellle*: Nah.

*Kate*: No. It’s hard, isn’t it?

*(Michelle nods).*

*Kate*: Yeah, it can be tough.
GODZILLA FACEPALM

When Godzilla gives you the facepalm, you know the fail is epic.

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The Take Home Message

- Our values, attitudes, personal histories and the broader social context in which we inhabit, will inevitably enter into and shape our work.

- Attempting to develop self-awareness is so important.