

The influence of stories on disability staff's support for choice and control

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Overview

1. Rationale

2. Workshop

3. Preliminary results

The overarching purpose of this research is to improve disability staff's support of choice and control for adults with intellectual disabilities

How does listening to stories about how it feels to be unsupported with choice and control change the perspectives of disability support staff?

1. Rationale

A short overview of the theory and literature review behind the workshop



The need for choice and control

Self-determination, acting based on one's own choice and intrinsic motivation, is a psychological need
(Deci & Ryan, 1985, 2015)

Self-determination = having choice and being in control



Benevolent discrimination

Well-meaning intentions, yet harmful actions

This is different from the usual attitude change theories / stigma theory

Ordinary discrimination : Negative stereotypes → Contempt: prejudice → Deliberately harmful actions: discrimination

Benevolent discrimination : Mixed stereotypes: warm / not competent → Pity: paternalistic prejudice → Well-meaning harmful actions: benevolent discrimination (Fiske et al., 2002; Cuddy et al., 2007)

Interventions for benevolent discrimination

Interventions for ordinary discrimination: Encourage participants to feel warmth and liking toward the target group so that their actions will no longer be hostile.

- Unlikely to work for benevolent discrimination as the warmth is already there (Pettigrew & Tropp, 2011).

Intervention idea for benevolent discrimination: Build upon participants' *existing* feelings of warmth and liking for the target group, and redirect how they are acted upon, by showing participants which actions cause harm (Becker & Swim, 2012; Fehr & Sassenberg, 2009, Connor et al., 2016).

Idea behind the workshop - if disability support staff hear about the harms of not having choice and control and examples of how this can happen, will their existing warmth redirect them into understanding and intending to provide better support for choice and control?

Research questions and propositions

1. How do staff perceive adults with intellectual disabilities?

- PROPOSITION: with paternalistic stereotypes: seeing them as warm and friendly, but not competent; and with paternalistic prejudice: feeling care and liking, but holding them in low esteem

2. How do staff in disability services understand and intend to support choice and control for adults with intellectual disabilities?

- PROPOSITION: with benevolent discrimination: intending to provide best support (active helping), but using own values instead of values of the people being supported (passive harm)

3. Do these understandings, perceptions and intentions change after an intervention (workshop) based on the stereotype content model?

- PROPOSITION: yes, behavioural intentions of benevolent discrimination will change

2. Workshop

A two-hour workshop for disability staff, using stories by adults with intellectual disabilities about how they feel when unsupported with choice and control

 **LA TROBE** UNIVERSITY | LIVING WITH DISABILITY RESEARCH CENTRE



Supporting choice and control

**SEE THE WHOLE PERSON,
TUNE IN TO THEIR FEELINGS**

Featuring video stories from people with intellectual disabilities on how they feel about support with choice and control

Workshop development

Work with self-advocates



Rachael



Kathryn

Collect stories

- Interviews with < 10 self-advocates on their experiences of staff support for choice and control
- Co-develop a narrative with each person that reflects their experience in story format

Prepare the workshop

- Work with 2 self-advocates on a workshop to co-deliver to disability support staff
- Stories filmed and read by actors with intellectual disabilities

Deliver the workshops

- We delivered the workshop 12 times, to 62 participants who were disability support staff and students of disability support courses

Key messages in the workshop

It feels bad if you don't have choice and control over your life – it is a human need

When you are supporting a person, think about how they experience a situation, from their point of view

- how do they feel about the choices they have?
- how do they feel about how they are being supported?

Thinking about the situation from the person's point of view you need to:

- See the whole person
- Tune in to their feelings



Instructions for workshop participants

For each story, consider the situation as it is experienced by the person telling the story, from their point of view - how do they feel about how they are being supported?

Answer three questions:

- How does the person feel about how they are being supported?
- Which responses from staff are making the person feel this way?
- What were the staff intending to do?

Jamie's story



1. How does the person feel about how they are being supported?



Collecting data

Interviews with 22 disability services staff or students before and after the workshop

To answer these research questions:

1. How do staff perceive adults with intellectual disabilities?
2. How do staff in disability services understand and intend to support choice and control for adults with intellectual disabilities?
3. Do these understandings, perceptions and intentions change after an intervention (workshop) based on the stereotype content model?

Approach:

- Qualitative, semi-structured format, using vignette scenarios to explore how staff understand and intend to support choice and control for adults with intellectual disabilities
- Analysis in different layers, deductive and inductive

Scenarios

Participants were asked in interviews how they would respond to different scenarios:

Interview 1:

John – likes trains and wants to be a train driver as a job

Nancy – wants access to more of her money for going out drinking with friends

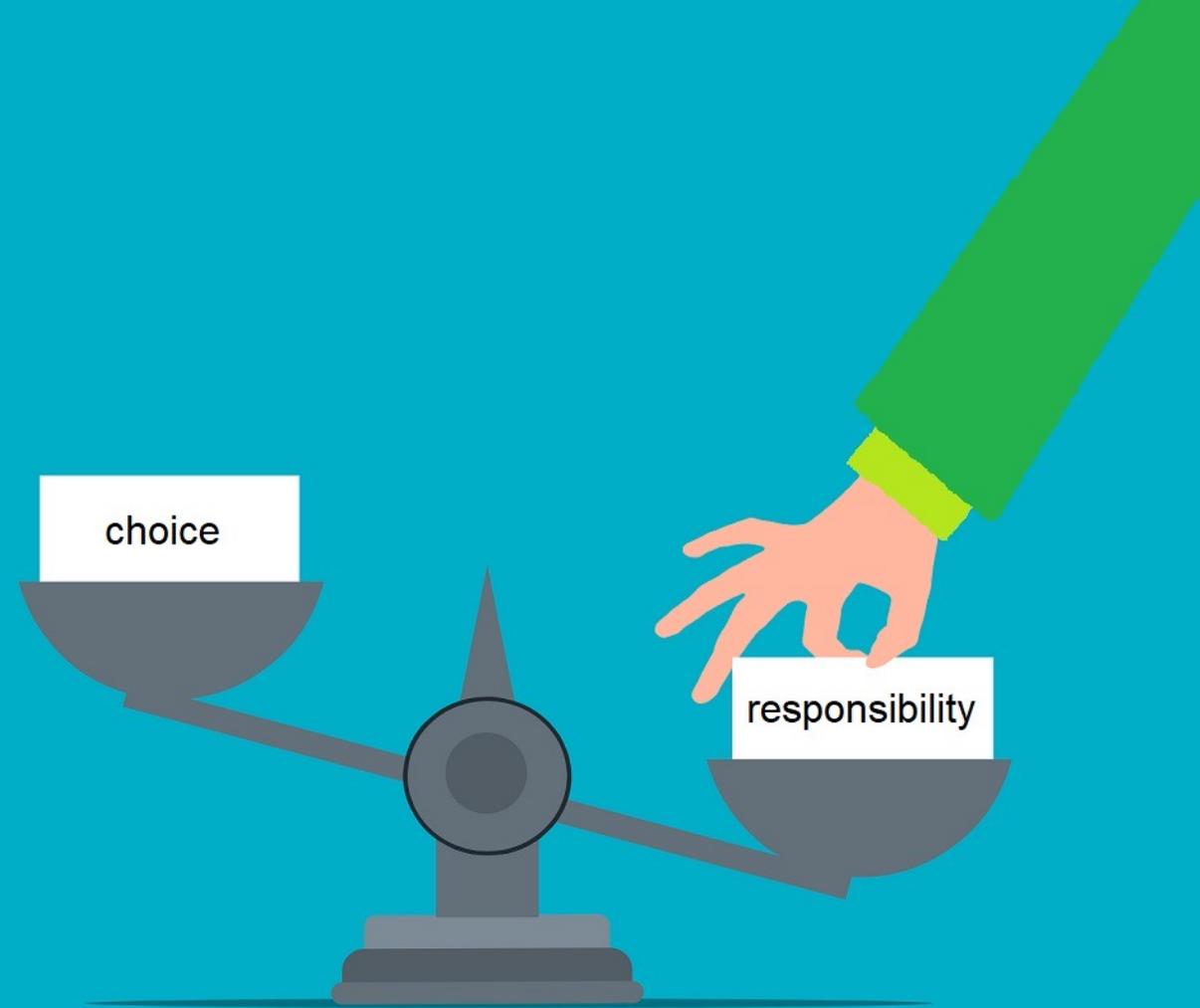
Interview 2:

Michelle – when asked what she wants to do, always says she wants to go to the shops

Carl – met a man online a few weeks ago and wants to go interstate to meet him

3. Preliminary results

What changed for staff who attended the workshop?



Q1 - How do staff perceive adults with intellectual disabilities?



Warmth & Positive Feeling

Consistent result - Staff have positive perceptions of people or positive motivations for support



Competence & Esteem

Staff reluctant to acknowledge differences, avoiding negative stereotype about competence

Q2 - How do staff understand and intend to support choice and control?

Looking for benevolent discrimination - actions of active helping with passive unintentional harm (or lack of this)

Using inductive analysis, unsure what actions or patterns will consistently indicate this.

Initial thoughts – predict that getting to know the person will be an indicator of good support for choice and control

Supporting the person to get what they want

Gathering information
about the person



Support
the person to get what they want

“I guess I'd start with Michelle, what is it that you like doing when you go shopping? What do you...? What is it...? Start to ask questions to help understand what it is that she's getting out of that.” (Staff 66)

Provide alternative options for their preference

Gathering information
about the person

Provide alternative options
that the person might prefer

“Then I probably could ask more broader life questions like, do you have any friends? Is there anyone you want to get to know better? Maybe there's a budding relationship at work that we don't know about, that we could be supporting ... does she have any goals that we're not aware of?”
(Staff 66)

Provide alternative options for constraints

Gathering information
about the person

Provide alternative options
to meet external constraints

“Helping her explore the options and, you know, being realistic about the pros and cons and what is and isn't possible ... she might go to swimming twice a week, and she might be prepared to give up the swimming so that she can go out with her friends and have a drink more often.” (Staff 76)

Provide alternative options to match capability



“He might not have the capacity to be a train driver, but he might really think that that is what he wants to do. So you would really have to think about creative supports and how you might be able to come to something in the middle that works. Whether it would be linking in to a volunteer thing where he could be with the volunteer train driver in the cabin or...”

(Staff 47)

Persuade the person away from their choice



“What it is she likes about the bars and the clubs – is it the loud noise, is it the environment, is it socialising with people and that sort of thing? What input Nancy is enjoying from that, and are there other environments she could do that as well ... similar sensory input, but a different social activity that might take the focus a bit more off of drinking.” (Staff 36)

Example 1 – Supporting Carl’s choice to meet Paul

“So for Carl, relationships are obviously important to him ... we've got to be mindful that we're supportive, but not limit his options on the grounds of safety and all of those sorts of things. So, travelling interstate, whether he wants to do that independently or whether he wants to have a support worker go with him, how that can be facilitated, his preferred form of travel. Does he want to go in a car, does he want to go on the train, does he want to go on the bus, does he want to fly?” (Staff 76)

Example 2 – Supporting Carl’s choice to meet Paul

Supporting an end goal

“That's not to say that you couldn't help plan a trip, but rather than planning a trip for next week I would be more inclined to encourage a trip for maybe three months’ time ... then just see how their relationship goes. If Carl and Paul are still talking when you get to that three months ... they really got to know each other, and then you can go on a trip. And have just one part of that trip being meeting Paul, maybe not focus the entire trip on him.” (Staff 36)

Ways staff interpret choice and control

How staff support people with choice and control may be a function of how they interpret what it means to have choice and control over your life.

Navigating the processes of your life
toward goals, choosing how much of it you do for yourself

Getting the end goals that you want
defining the goal then getting to it, however that happens

Example 3 – Supporting Nancy’s choice to get money

Building capacity

“What do we need to do to get Nancy to have more control over her funds? ... Does she need to learn more about budgeting, about banking? All that sort of stuff, making shopping lists, making sure of savings ... if she was able to learn those skills and able to understand them, then there really shouldn't be an issue of why she's not in control of her funding.”

(Staff 53)

Ways staff interpret choice and control

How staff support people with choice and control may be a function of how they interpret what it means to have choice and control over your life.

Navigating the processes of your life
toward goals, choosing how much of it you do for yourself

Doing as much for yourself as possible
and being supported to fill in the gaps

Getting the end goals that you want
defining the goal then getting to it, however that happens

Ways staff intend to support choice and control

getting to end goals

Promoting the process that is safest or best for the person's interests.

Setting out all the steps for them to take, teaching them skills, or taking steps on their behalf – whatever works.

building capacity

Providing information and resources, including safety, around the multiple paths the person may take, prioritised to their *abilities*.

Teaching the person skills to take the steps for themselves, filling in gaps according to their abilities.

navigating a process

Providing information and resources, including safety, around the multiple paths the person may take, prioritised to their *preference*.

Checking how much support the person wants along the way, how much control they want to take.

Q3 – Do perceptions change after the workshop?

Have workshop participants changed how they think about what it means to have choice and control, and how to support it? Not clear yet. Still exploring.

Participants did get the message it feels bad to be unsupported with choice and control, and they were motivated to reduce harm felt by the person

They intend to change things about how they work, e.g., be more critical, check how their actions are being received, use non-judgemental language.

Good news – analysis uncovering a lot about how disability support staff think about what it means to have choice and control and its relationship to support.

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