



Staff perspectives and supporting adults with intellectual disabilities to be self-determined

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RESEARCH AIMS

The overarching purpose of this research is to improve staff support of self-determination for adults with intellectual disabilities

The aim is to test an intervention based on the stereotype content model for changing staff's perceptions and intentions to support self-determination

The research questions are:

- How do staff perceive adults with intellectual disabilities?
- How do staff in disability services understand and intend to support self-determination for adults with intellectual disabilities?
- Do these understandings, perceptions and intentions change after an intervention based on the stereotype content model?

OUTLINE

Self-determination, what it is and why it is important

Issues in staff practices and the role of perceptions

Attitude change theories: stigma and contact

The stereotype content model

Methodology for perspective-taking intervention

SELF-DETERMINATION IS IMPORTANT

- Self-determination is a right for all people with disabilities through the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)
- The NDIS has an objective to uphold CRPD rights, promotes choice and control
- Acting based on one's own choice and intrinsic motivation is a psychological need (Deci & Ryan, 1985, 2015)

A CLOSER LOOK AT SELF-DETERMINATION

- Some literature describes self-determination as a **characteristic**, the skill or confidence to make choices and bring them into action
- Other literature looks at self-determination as a **process**, making choices and bringing them into action

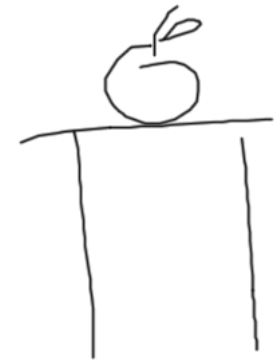
Each of these leads to different ways of thinking about how to support self-determination...

SELF-DETERMINATION — A CHARACTERISTIC/SKILL

Causal Agency Theory

- The ability to set goals
- The ability to plot a pathway toward a goal
- Belief in your ability to take action

(Shogren et al., 2015)



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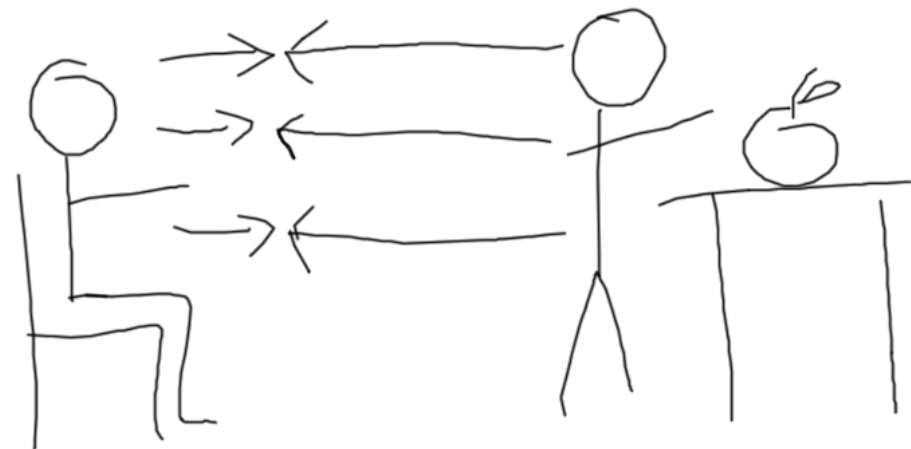


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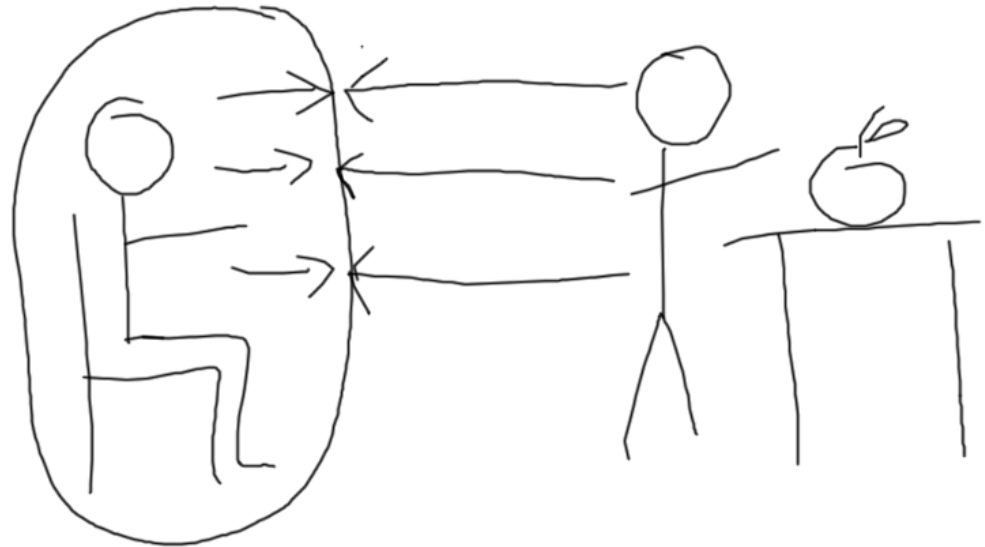


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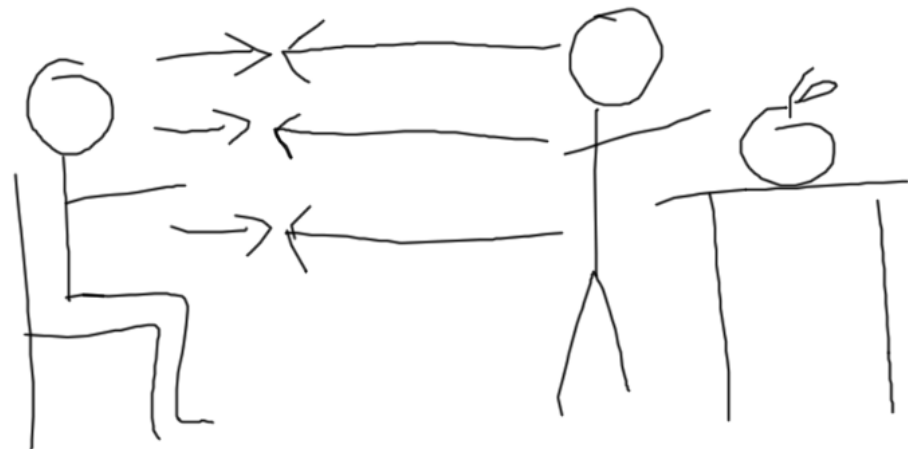
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SELF-DETERMINATION — AN ECOLOGICAL PROCESS

Self-determination is a complex *process* involving interaction between the individual and environmental factors

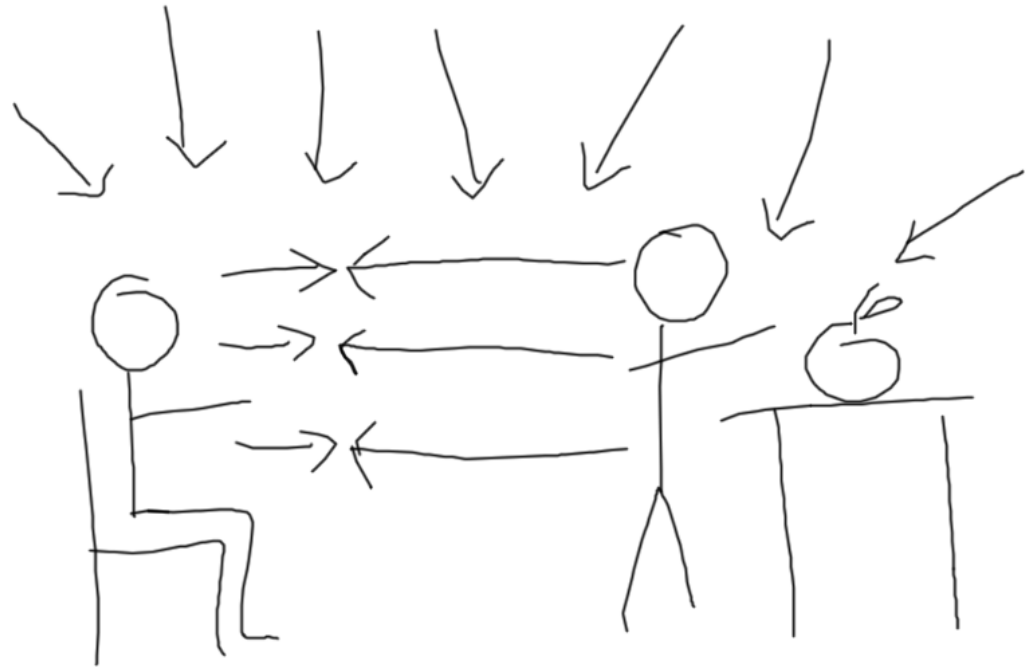
(Abery & Stancliffe, 1996)



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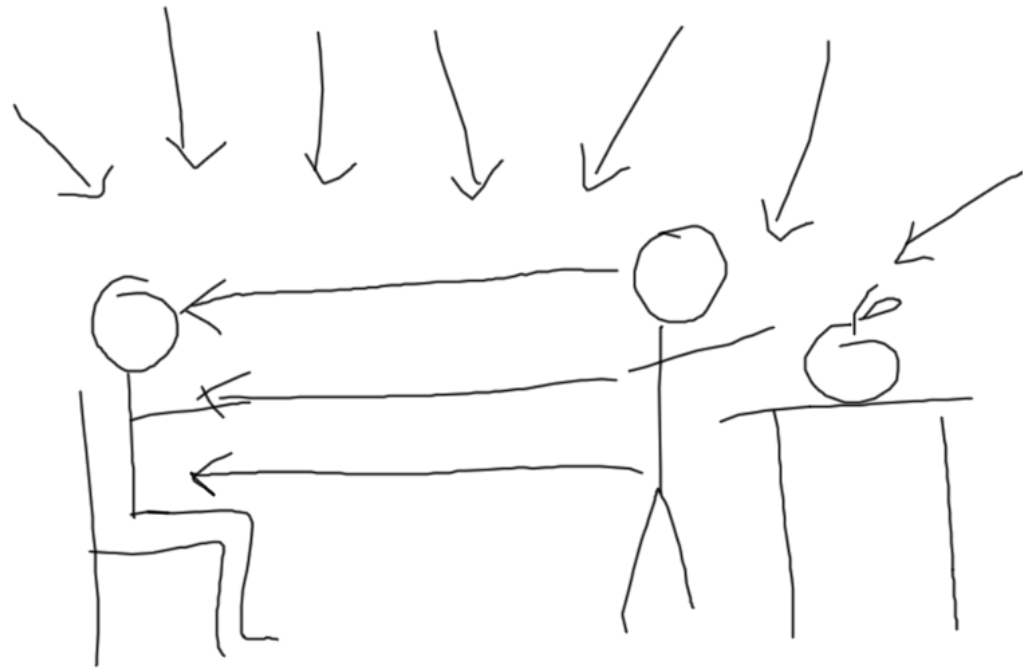
(Abery & Stancliffe, 1996)



SELF-DETERMINATION — AN ECOLOGICAL PROCESS

“... if you listen to Kloe, and to her yelling at you, there’s all different yells, and you’ll know, like there’s a yell when I walk through the door because she knows I’m here or there’s a yell that: ‘I need to go to the toilet’ ... so you need to listen.”

(Bigby et. al., 2014, p. 361)



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ISSUES IN STAFF SUPPORT FOR SELF-DETERMINATION

Literature on the experiences of adults with intellectual disabilities has evidence of poor staff support for self-determination, with examples of staff..

- Monitoring and preventing sexual relationships (Kelly et al., 2009; Sitter et al., 2019)
- Making decisions for people without asking (Nonnemacher & Bambara, 2011)
- Not giving people information they need (Kelly et al., 2009; Nonnemacher & Bambara, 2011)
- Controlling money (Björnsdóttir et al., 2015; Nonnemacher & Bambara, 2011)
- Making people adjust or change their clothes (Bigby et al., 2009; Altermark, 2018)
- Not responding to cues, not offering options, leaving people disengaged (Bigby et al., 2009; Björnsdóttir et al., 2015; Mansell et al., 2013)

FACTORS IN POOR SUPPORT FOR SELF-DETERMINATION

Themes found in the literature...

External Factors	Staff Perceptions
Limited resources (e.g., only one bus for everyone, staff allocation and training)	Dehumanising (e.g., less than human, a burden)
Policies and processes (e.g., risk, duty of care)	Defending best interests (e.g., avoiding hurt feelings, promoting a socially acceptable image)

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PERCEPTIONS WHEN LIMITING SELF-DETERMINATION

“When acting against the self-determination of people with intellectual disabilities, the interviewees see themselves as (1) *emotionally* tied to the people they work with, (2) personally *responsible* for their safety and as acting based on an (3) *informal* rather than a formal relationship. In addition, (4) they come to focus on the *individual* and their suffering rather than on overarching principles of justice, and they do so based on the presumption that they have (5) *superior knowledge* as to which choices are wise and which are not.”

(Altermark, 2018, p. 115)

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THE PLATINUM RULE VS. THE GOLDEN RULE

Studies of culture in group homes found that even in those with better cultures providing better support...

- Staff apply the 'golden rule' and imagine what *they (staff)* would want in the resident's position, which is well-meaning but does not account for the person's own values, will and preferences
- Bigby et al. (2015) suggest a 'platinum rule' would be more appropriate, trying to understand what *the person themselves* wants in that situation given their background, values, etc.

.... this requires abstract thinking & knowing the person well

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ATTITUDE CHANGE THEORIES

Attitude change literature takes the three components of attitudes and looks at the negative sides of them – the **stigma model** aims to reduce negative behaviours by changing the perceptions that influence them

Stereotypes → Prejudice → Discrimination

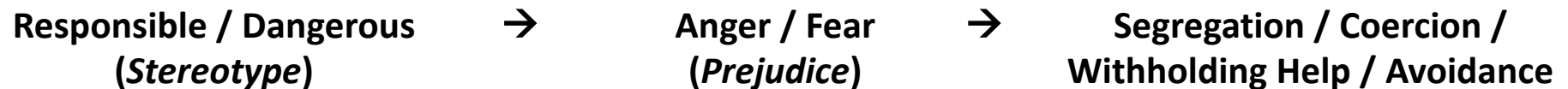
(Thoughts) (Feelings) (Behaviour)



Perceptions

APPLYING THE STIGMA MODEL

Extensive work in stigma in mental illness research (e.g., Corrigan et al., 2003):



When applied for stigma to people with intellectual disabilities, the same pathways arise as with mental illness stigma... but with low levels (Pelleboer-Gunnink, van Weeghel, et al., 2019; Werner, 2015; Werner & Araten-Bergman, 2017).

Stereotypes 'dangerous' and 'responsible' are less common for people with intellectual disabilities. Stereotypes 'friendly' and 'unintelligent' are more common, as per scoping review of stigma studies (Pelleboer-Gunnink, van Oorsouw, et al., 2019).

NON-LINEARITY - FINDINGS THAT DON'T FIT STIGMA

Study on social workers stigma toward people with intellectual disabilities, mental illness and dual diagnosis (Werner and Araten-Bergman, 2017) found...

Pity → **Helping & Coercion**

Pelleboer-Gunnink, van Weeghel, et al. (2019) found low levels of stigma due to the 'dangerous' stereotype, they proposed a different type of stigma may be happening...

“due to [ambivalent] stereotypes of being not independent ... and friendly, people with intellectual disabilities may be tolerated in the community but, not be taken seriously, not receiving possibilities for self-determination, or not having the opportunity to make their own choices” (p. 7).

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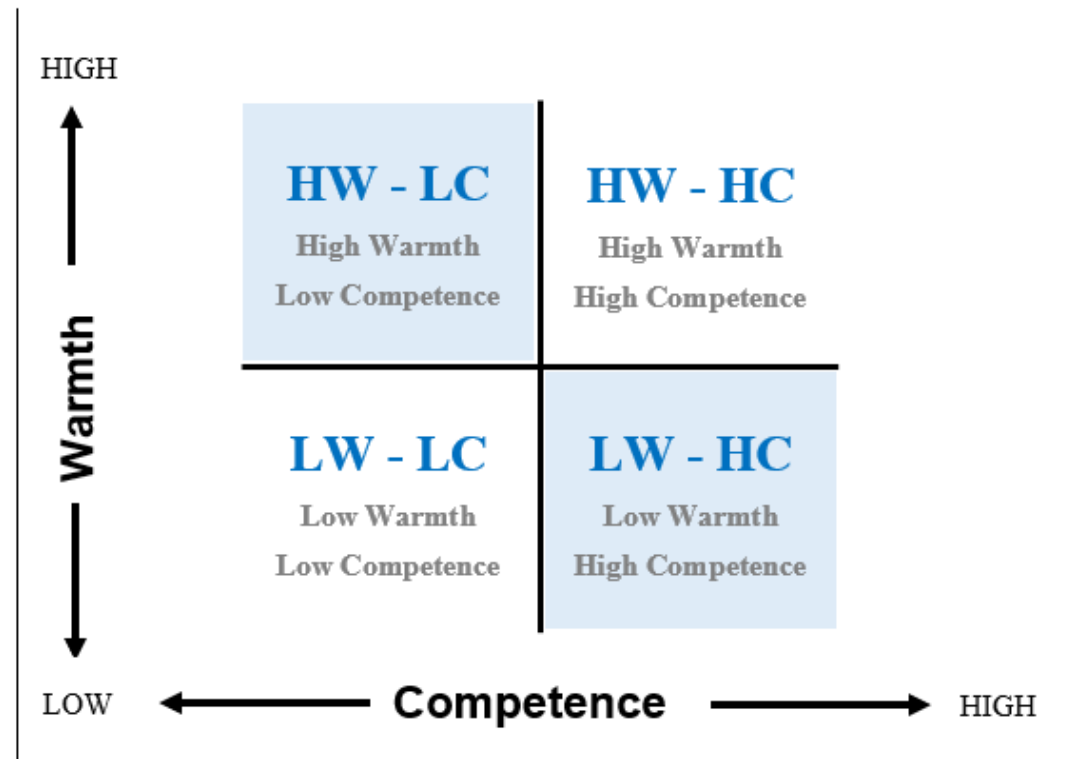
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THE STEREOTYPE CONTENT MODEL (SCM)

SCM plots two dimensions of stereotypes: warmth and competence, to create four quadrants.

The two ambivalent quadrants (in blue)

(Fiske, Cuddy, Glick, et al., 2002)

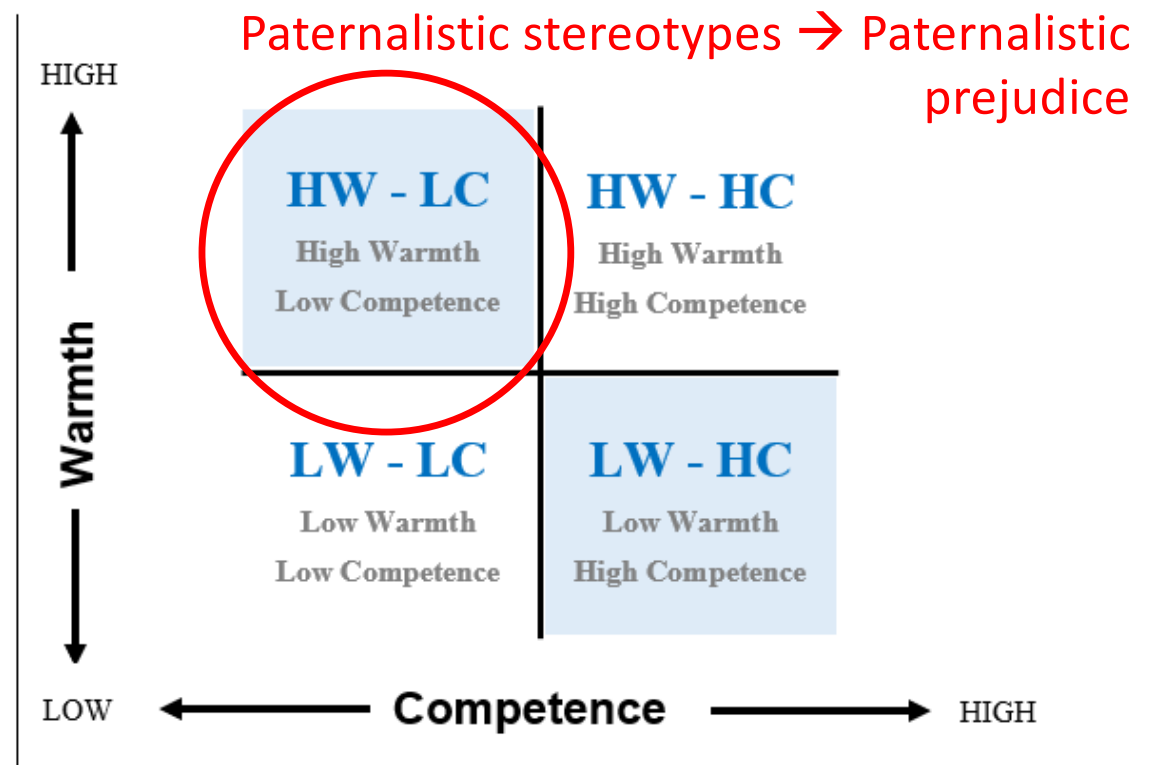


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BENEVOLENT DISCRIMINATION

Paternalistic stereotypes → Paternalistic prejudice → Benevolent discrimination

High Warmth Stereotype



Warm Feelings



Active Facilitation Behaviour

Acting for

Explicit / overt helping

Defending others

Assistance programs

Opening doors

Low Competence Stereotype



Low-esteem Feelings



Passive Harm Behaviour

Acting without

Undeliberate harm

Neglect

Avoidance

Dismissing

(Cuddy, Fiske, & Glick, 2007)

PROPOSITIONS (1-3)

1. Staff perceive adults with intellectual disabilities with **paternalistic stereotypes** - thinking of them as warm/friendly, but not competent
2. Staff perceive adults with intellectual disabilities with **paternalistic prejudice** – feelings of caring/liking, but holding them in low esteem
3. Staff have behavioural intentions that match **benevolent discrimination** - intending to provide best support (active helping), but using their own values to judge this instead of the preferences and values of the people being supported (passive harm)

To be continued...

BENEVOLENT DISCRIMINATION — WHAT TO DO?

There is little focus on interventions in SCM literature.

Researchers Connor, Glick, and Fiske (2016) for benevolent sexism observe the most promising type of intervention is explaining to the people who mean well what they're doing is harmful (e.g., Becker & Swim, 2012; Fehr & Sassenberg, 2009).

In intellectual disability literature SCM is rare, but there is growing understanding that we should listen to the perspectives of people with intellectual disabilities. So far this has not been from the theoretical perspective linking warm intentions to effectiveness. There is literature noticing these links (Pelleboer-Gunnink, 2020; Pelleboer-Gunnink et al., 2019).

PROPOSITIONS (4)

4. Staff's behavioural intentions for benevolent discrimination will be reduced by a **perspective-taking intervention** that shows staff how practices of benevolent discrimination are harmful from the perspectives of adults with intellectual disabilities

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PERSPECTIVE TAKING INTERVENTION

- 2-hour workshop for staff
- Co-delivered by self-advocates – members of human rights-based groups for people with intellectual disabilities or related impairments
- Self-advocates will tell stories from the perspectives of adults with intellectual disabilities, highlighting how it is harmful to have their self-determination limited despite staff's good intentions

INTERVENTION DEVELOPMENT WITH SELF-ADVOCATES

Building stories

- Interview 5-12 self-advocates about their experiences of staff support with self-determination
- Co-develop a narrative with each person that reflects their experience in story format, drawing from perspective-taking literature on how to present harms experienced from their perspective

Make vignettes for interviews

- Focus group exercise with 5-12 self-advocates to develop vignettes of situations where staff might limit self-determination, to be used in interviews with staff

Prepare the workshop

- Work with 2-3 self-advocates on a workshop to co-deliver to staff
- Self-advocates will be actors and read out selected de-identified stories

METHODOLOGY — LOOKING FOR CHANGE

- Staff will be recruited through the services they work for to the 2-hour workshop
- They will be invited to participate in interviews before and after
- Qualitative semi-structured interviews
 - Asking staff about how they perceive adults with intellectual disabilities
 - Using vignettes to explore how staff understand and intend to support self-determination for adults with intellectual disabilities
- Thematic coding using a hybrid inductive and deductive approach (Fereday & Muir-Cochrane, 2006; Layder, 1998)
- Looking for changes in perceptions and intentions after the intervention and what factors emerge as relevant

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