# Do warm feelings, rather than negative feelings, obstruct support for self-determination from support workers? A literature review.

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# DEFINING THE QUESTION TERMS

Do **warm feelings**, rather than **negative feelings**, obstruct support for **self-determination** from **support workers**?

- Warm feelings
  - Liking
  - Caring about

- Negative feelings
  - Hostility
  - Contempt

- Self-determination - "acting as the primary causal agent in one's life" (Wehmeyer, 1992a, 1996 as cited in Wehmeyer, 1996, p. 24)

- Support workers
  - Within the NDIS
  - Direct support
  - One-to-one
  - Day services
  - Group homes

# OUTLINE

- The problem: support workers obstructing self-determination
- Why this is a problem: importance of self-determination
- Behind the problem: staff perceptions
- Literature on stigma and (negative) perceptions
- Warm feelings behind obstructing self-determination
- New perspectives re stigma and warm feelings
- The stereotype content model
- Next steps

# THE PROBLEM

Support workers aren't supporting self-determination enough…

*…the daily practices of deciding what disabled persons should eat, how they should spend their leisure time, whether they should be allowed to have sex, how many cups of coffee their stomachs can handle, and what specific blend of coercion, bribing, and threats should be put to work when they refuse to take their weekly shower…*

(Altermark, 2017, p. 4)
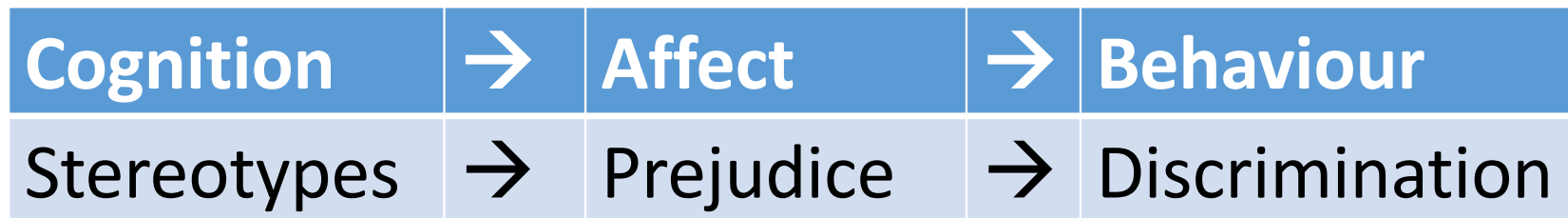
# SUPPORTING SELF-DETERMINATION IS IMPORTANT

- Self-determination is "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1992a, 1996 as cited in Wehmeyer, 1996, p. 24)

- People have an "internal need to perform intrinsically motivated behaviours" (Wehmeyer, 1996, p. 20)

- Adults with intellectual disabilities need support to exercise self-determination, e.g. with decision-making (Bigby et al., 2017)

# EXPECTATION TO SUPPORT SELF-DETERMINATION

- Support with exercising self-determination is recognised as a right in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities

- NDIS promotes choice and control, NDIS Code of Conduct guides workers to support self-determination (NDIS Quality and Safeguards Commission, 2019)

# BEHIND THE PROBLEM: STAFF PERCEPTIONS

- Multiple factors behind obstructed self-determination: organisational structure, unclear policy, competing expectations, <u>staff perceptions</u>, staff skills, insufficient resources (e.g. Bigby & Beadle-Brown, 2018)

- The stigma model shows how perceptions → behaviour

| Cognition | → | Affect | → | Behaviour |
|-----------|---|--------|---|-----------|
| Stereotypes | → | Prejudice | → | Discrimination |

# PERCEPTIONS → BEHAVIOUR

Service users are like children → Staff adopting parental roles, being protective (Clement & Bigby, 2010)

Interpretation of 'duty of care' as protecting service users from their own decisions → Overriding decisions (Bigby et al., 2009)

Staff have "*superior knowledge* as to which choices are wise and which are not" → Overriding decisions (Altermark, 2017, p. 115)

Support worker role is 'doing for' not 'doing with' → Service with poor quality outcomes (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012)

# STIGMA – NEGATIVE PERCEPTIONS

| Cognition | → | Affect | → | Behaviour |
|---|---|---|---|---|
| Stereotypes *(negative)* | → | Prejudice *(negative)* | → | Discrimination *(negative)* |

- Stereotypes can be positive or negative
- Endorsement of *negative* stereotypes leads to prejudice
- Prejudice leads to discrimination, harmful behaviour
  (Werner, 2015)
- Stigma is based on long-standing ideas that discrimination is based on antipathy / contempt (Allport, 1954/1979)

# COMPLEXITY AND TENSIONS

Support workers say they *want* to support rights, *but*…

- They have "a conflict between protecting residents and acknowledging residents' autonomy" (Hawkins, Redley, & Holland, 2011, p. 878)

- "'*There is a responsibility to follow the law [re: self-determination], but also a responsibility to cater to their wellbeing. It becomes so frustrating…*'" (Altermark, 2017, p. 115)

- "Questions arise … when is it legitimate to intervene or override preferences?" (Bigby, Douglas, & Hamilton, 2018, p. 4)

# WARM FEELINGS WITH PATERNALISTIC BEHAVIOURS

Warm (positive) feelings are evident when we look within accounts of workers failing to support self-determination...

> For example, support workers withholding distressing news appears "to stem from a genuine place of care and love for the person with learning disabilities and a sense of wanting to shield them from perceived unnecessary harm, rather than that of malice or ill-intent" (Brownrigg, 2018, p. 228).

# PATERNALISTIC DISCRIMINATION

Behaviour that is *harmful* because it reduces self-determination, but it is based on *helpful* (positive) rather than harmful or avoidant (negative) perceptions/intentions

# NEW PERSPECTIVE

- Stigma model looks at negative perceptions → harmful behaviour (discrimination)

- Descriptive literature shows warm feelings → harmful behaviour (paternalistic discrimination)

- Currently no theoretical model to guide how to address harmful behaviour based on positive perceptions/intentions – we may need to do things differently

# THE CEILING EFFECT FOR WARM PERCEPTIONS

- Intergroup contact (Allport, 1954/1979; Pettigrew & Tropp, 2011) is a highly regarded approach for addressing stigma (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012) that increases positive perceptions

- Contact is found less effective for vulnerable groups, already seen as warm and likeable, as existing warmth may put a ceiling on benefits of increasing warm perceptions (Pettigrew & Tropp, 2011)

- We may need a different approach… Need a way of conceptualising *how* warm feelings contribute

# WARM FEELINGS → *BETTER* SUPPORT, TOO

- In group homes with better outcomes, support staff have **positive regard** for residents (Bigby, Knox, Beadle-Brown, & Clement, 2015)

  "Staff not only regarded residents positively but provided care in the context of a relationship characterised by warm feelings, which for many extended into a deep emotional bond" (p. 291)

  - Doing with, not doing for

  - Seeing residents as 'like us', with essential humanness (Bogdan & Taylor, 1989) as people who can feel, think and understand

  - Applying the platinum rule – "doing unto others, wherever possible, as *they* want to be done by" (Popper, 1945/1966, p. 386)

# MIXED PERCEPTIONS → PATERNALISTIC SUPPORT

"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, 2017, p. 115)

# MIXED PERCEPTIONS → PATERNALISTIC SUPPORT

"The demonstrated main stereotypes of intellectual disabilities comprise both positive (i.e., "friendly") and negative (e.g., "unintelligent", "less independent") traits … [that] may lead to more subtle forms of discrimination … 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."

(Pelleboer-Gunnink et al., 2019, p. 7)

# STEREOTYPE CONTENT MODEL

- Developed by Fiske, Cuddy, Glick, and Xu (2002)

- Extends on stigma, stereotypes → prejudice → discrimination

- *Both* positive *and* negative perceptions contribute to discrimination

- Groups evaluated on two stereotype dimensions: warmth & competence

- Relates back to evolutionary survival (Fiske, Cuddy, & Glick, 2007)

    1. Warmth: Are the 'other' a friend or enemy? Are they for us or against us?

    2. Competence: Are they able to help us (if friend) or harm us (if enemy)?

# STEREOTYPE QUADRANTS

The quadrants HW-LC and LW-HC (in blue) are *ambivalent* because they have both negative and positive components
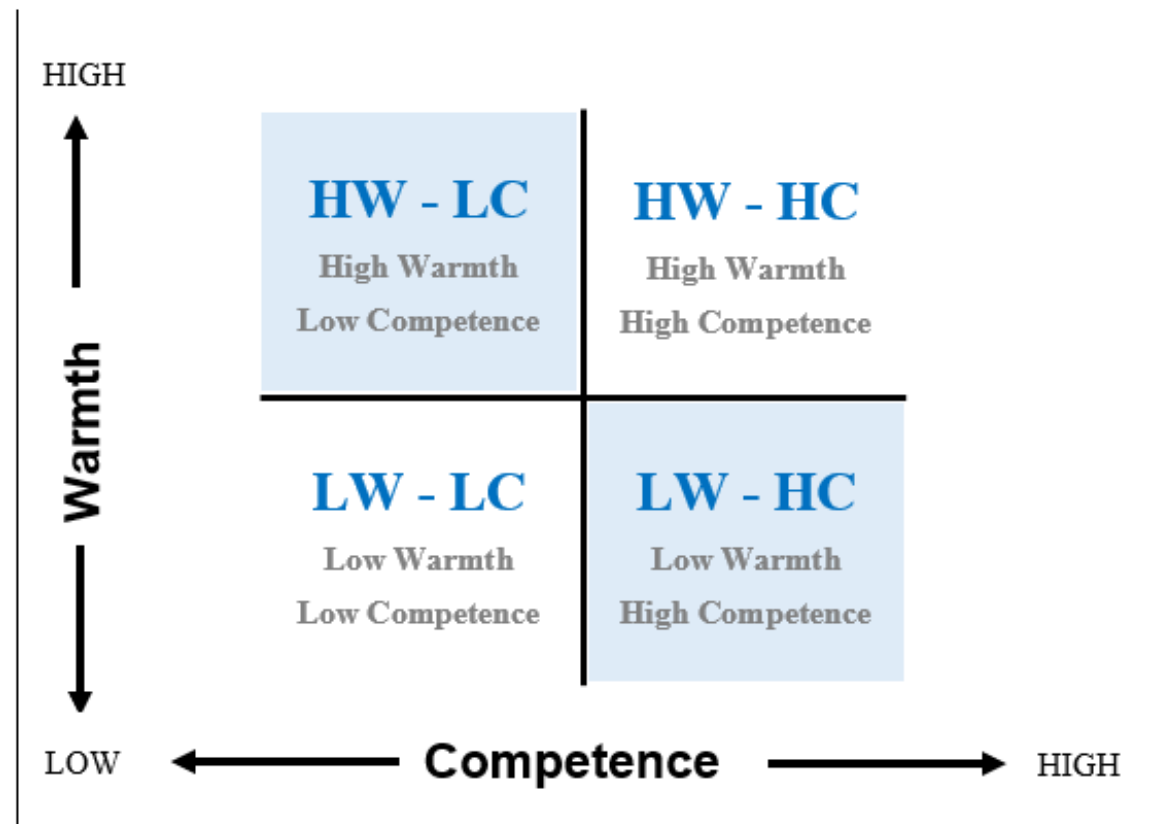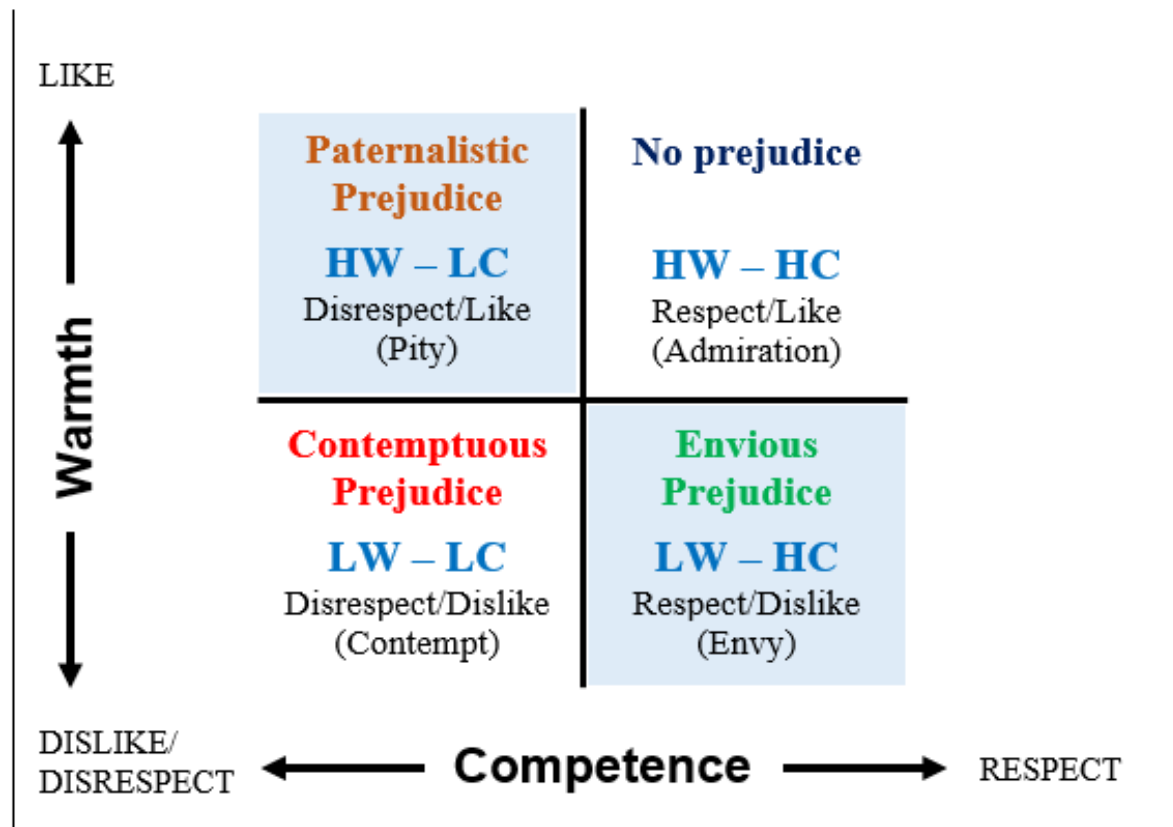


(adapted from Fiske, Cuddy, Glick, & Xu, 2002)

# PREJUDICE QUADRANTS

Ambivalent stereotypes predict ambivalent prejudice

- Warmth stereotype → liking/disliking
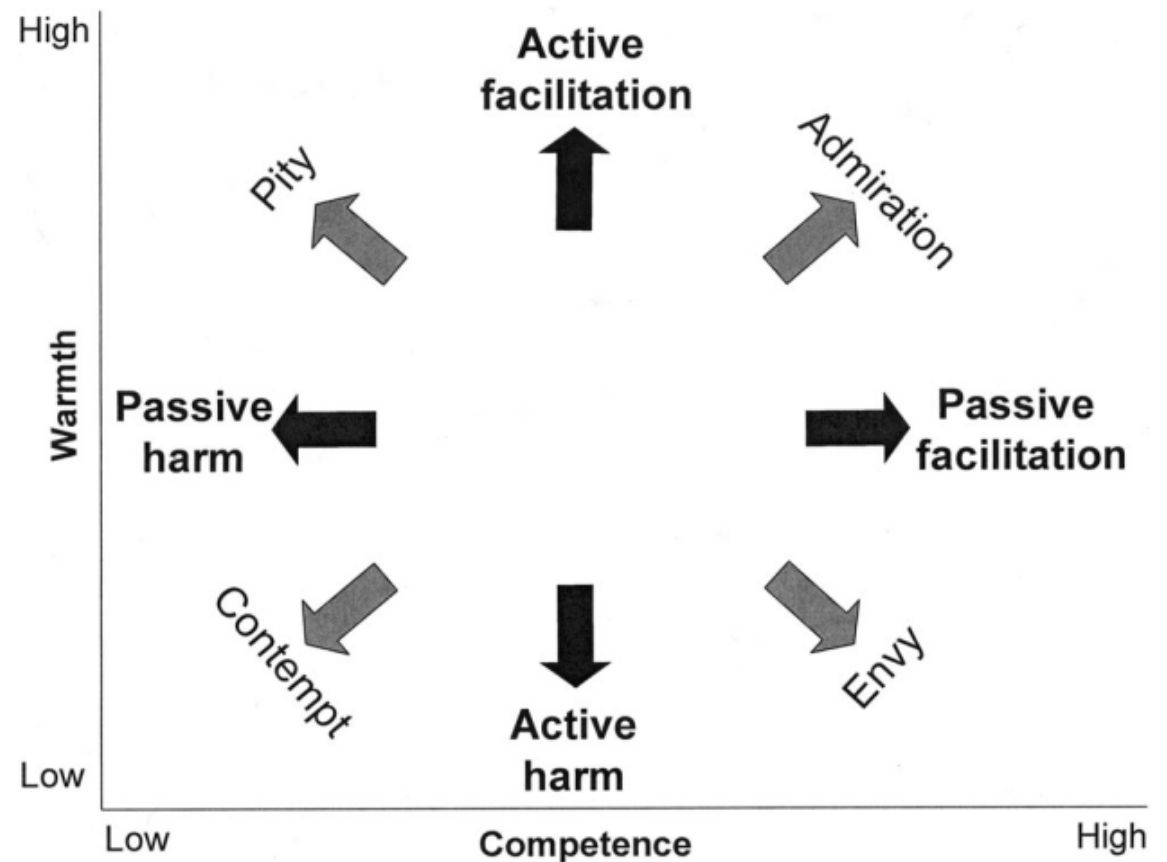
- Competence stereotype → respect/non-respect

(Fiske, Xu, Cuddy, & Glick, 1999)



(adapted from Fiske, Cuddy, Glick, & Xu, 2002)

# DISCRIMINATION

- Warmth → *active* behavior (harm or facilitation)

- Competence → *passive* behavior (harm or facilitation)

- Paternalistic prejudice (pity) → ambivalent combo, active facilitation + passive harm



(Cuddy, Fiske, & Glick, 2007, p. 634)

# PATERNALISTIC DISCRIMINATION

**Active Harm**
*Acting against*
- Explicit / overt harming
- Verbal or physical harassment
- Sexual harassment
- Bullying

**Passive Harm**
*Acting without*
- Undeliberate harm
- Neglect
- Avoidance
- Dismissing

**Active Facilitation**
*Acting for*
- Explicit / overt helping
- Defending others
- Assistance programs
- Opening doors

**Passive Facilitation**
*Acting with*
- Working together
- Hiring
- Associating together

(adapted from Cuddy, Fiske, & Glick, 2007)

# WHAT NEXT?

- Both warm feelings (liking) *and* negative feelings (non-respect) contribute to obstruction of self-determination / paternalistic discrimination

- Based on this model, how should we address paternalistic discrimination?

- How do we overcome the ceiling effect on warm feelings?

# CONCEPTS TO EXPLORE

## Emotions

Warm

Cold

Respect

Disrespect

## Behaviours

→ **Acting For**
(positive intentions)

→ **Acting Against**
(negative intentions)

→ **Acting With**
(collaborating, valuing perspective)

→ **Acting Without**
(ignoring, disregarding, leaving out)

# NEXT STEPS

- Explore the thoughts and feelings leading to wanting to support vs not wanting to support self-determination

- Qualitative exploration, as introducing concepts without indicators

- Explore what changes when support workers hear stories from self-advocates about how it feels to lose self-determination

- Explore mechanisms emerging between feelings and intention to support self-determination

  - Will empathy for situation of losing self-determination → support for self-determination?

  - Will empathy from perspective-taking → feeling of sameness / 'like us' → respect?

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# Thank you

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