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**Living with
Disability**
RESEARCH CENTRE

Supporting inclusion of people
with cognitive disability



Strategies for supporting people with intellectual disability to have choice and control over their lives

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The choice and control of people with disability is central to the NDIS but what about those with cognitive impairments?

The service commitment as outlined in the Service Charter of the National Disability Insurance Agency (NDIA) is that the agency will “provide people with choice and control to access the most appropriate support services”(NDIA, 2016)

So what does this mean for people with intellectual disability who have a range of cognitive and communication impairments?



Background

Traditional thinking is based on “individual factors”

Immanuel Kant’s thinking was those without rationality and independence are not eligible to act autonomously.

Leading to the deeply embedded western cultural belief that people with disability, particularly those with intellectual disability can not have choice and control over their lives.

In comparison, contemporary thinking focuses on “enabling environmental factors”
(Wong, 2010)

For example: the physical environments where people live
 the type of relationships they have with those around them

Aim

The aim of this study was to examine the processes that facilitate self-determination of people with moderate to severe levels of intellectual disability.

Agran, Story and Krupper (2010) define self-determination as an individual making choices and decisions and how these are “... encouraged, respected, and supported.”

Does this sound familiar?

i.e. Choice and control

Methods

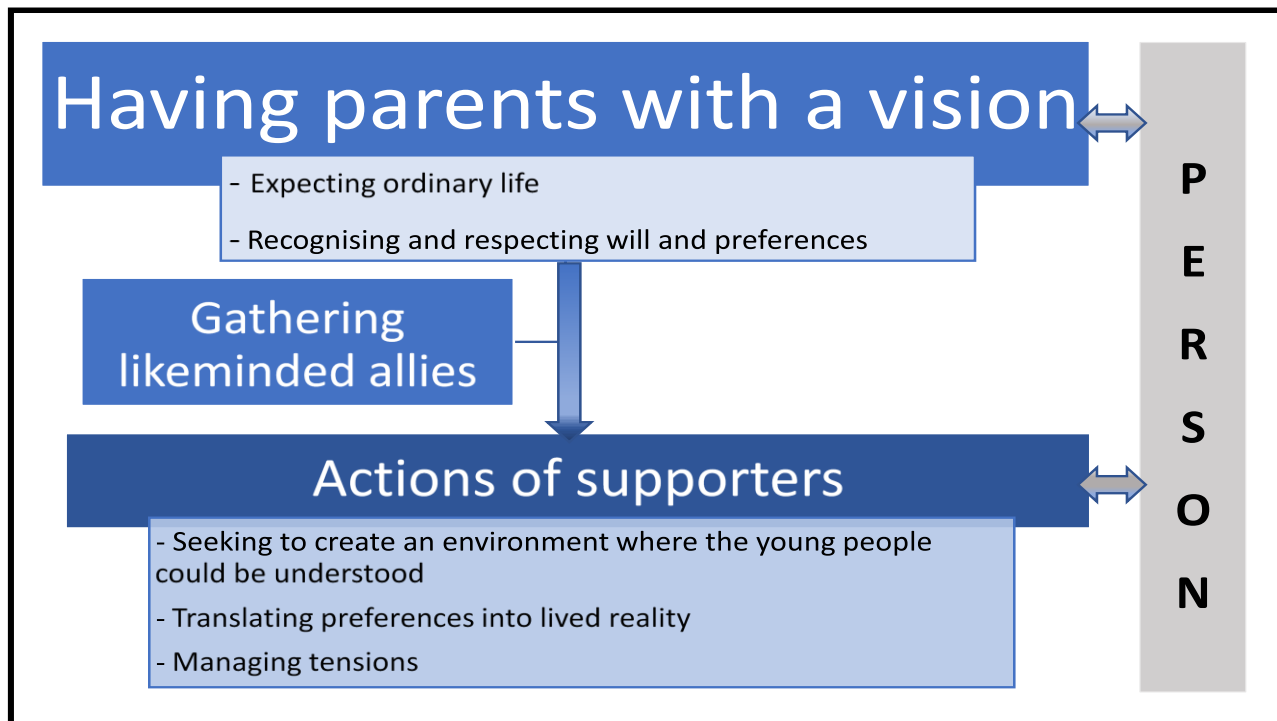
The use of a set of purposive sampling criteria enabled the recruitment of seven people with intellectual disability who were being supported to have a lifestyle that was reflective of their preferences.

Semi-structured in-depth interviews with supporters were the primary source of data.

The young people with intellectual disability also participated in the interviews, and participant observation was used to gain additional insights.

An iterative process of data analysis was used in accordance with constructivist grounded theory methodology outlined by Charmaz (2014).

Findings:- The process of guiding self-determination



Having parents with a vision

- i. Expecting an ordinary life.
- ii. Recognising and respecting will and preferences.

Gathering like-minded allies

Case study: David probably had a mild to moderate level of intellectual disability and an ASD which made his support needs quite high at times. His family were articulate with sufficient social capital to advocate for his needs.

“...we always had our own bit of vision about integration when he was at school right; he went to the local school up there - where his sisters went.” (David’s mother)

Actions of supporters

Seeking to create an environment where the young people could be understood

Parents and their allies provided encouragement, reassurance and time to each individual to ensure he or she was confident to express his or her desires.

They also took the time to observe the individual's non-verbal communication to better understand those wishes.

Individuals unable to communicate verbally relied upon parents and their allies to meticulously observe the individual's non-verbal communication and then interpret the meaning of that communication in order to determine his or her will and preferences.

Translating preferences into lived reality

- I. Learning about possibilities
- II. Providing opportunities

“... David just would not go to bed at night, so come ten o’clock we’re ready to go to bed, everyone’s ready...He’s, “I’m not going.” Screaming shouting. That was the most difficult part...”

“... two families got together and we rented a house down in a neighbouring suburb, and her daughter stayed a couple of nights a week and David stayed a couple of nights a week, so this was a step in his story that he knew there was another place to exist besides home.” (David’s father)

Managing tensions

The actions parents and their like-minded allies took to guide the young person to be more self-determined were not straight forward and tensions arose that needed to be managed during the process. Overall there were three main sources of tensions:

- i. When people disregarded the young person as an individual;
- ii. When there were inconsistencies between the young person's short-term wishes and longer-term goals;
- iii. When supporters imposed their vision upon the young person and this cut across their own preferences.

“You’ve got to listen when he’s saying, no.” (David’s mother)

Conclusions

The young people in the research require significant support to express their preferences, exercise choice, make decisions and participate in everyday activities. Despite this, they had a say in their lives and their preferences directly influenced how they lived.

The relationships between the young people and their supporters were strong, trusting and nurturing. The strength in these relationships stemmed from supporters long term knowledge of the young people's history and acknowledgment of their changing preferences over time.

Those who developed the UNCRPD and authors of the literature on supported decision making conceptualise self-determination (choice and control) as a binary opposite to paternalism (Committee on the Rights of Persons with Disabilities, 2014; United Nations, 2008; Bigby & Douglas 2016)

Guiding self-determination demonstrates the binary between individual preferences and paternalism may be misplaced, and a more nuanced understanding is required about managing self-determination and best interests together.

Implications

Are you like-minded allies of parents with a vision of a ordinary life for their son or daughter?

How can parents be supported to embrace this vision and expectations for their son or daughter for them to have greater choice and control?

What happens to people with intellectual disability under the NDIS who lack strong, trusting and nurturing relationships with their supporters for a host of reasons?

The NDIS Costs Report (Productivity Commission, 2017), the COAG Disability Reform Council and the Victorian Ombudsman who share similar concerns regardless the lack of independent advocacy

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Thank you

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