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# Experiences of the National Disability Insurance Scheme (NDIS) planning from the perspectives of Adults with intellectual disability

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# Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability

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## Abstract

The Australian National Disability Insurance Scheme (NDIS) is attempting to address long-term inequalities experienced by people with disability. Planning is central to the NDIS. People with intellectual disability will be the largest group of NDIS participants, and their perspectives are underrepresented in the literature. It is important to understand how they experience and perceive NDIS planning. Ten adults with intellectual disability participated in semi-structured interviews to explore their experiences of NDIS planning. Data were analysed using Braun and Clarke's (2006, *Qualitative Research in Psychology*, 3, 77) six stages of thematic analysis. Six themes were identified: planning preparation not fit for purpose, creating goals, goals not met, planning not meeting real needs, lack of choice and control and importance of relationship with planner. In principle, the NDIS presents a real opportunity to increase the choice and control, social and economic participation, and independence of people with disability; however, this does not always translate into practice for people with intellectual disability.

## KEY WORDS

intellectual disability, lived experience, National Disability Insurance Scheme, perspective, planning

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# BACKGROUND

- International trend – people given choice and control of lives
- “Underfunded, unfair, fragmented, inefficient and give people with disabilities little choice and no certainty of access to appropriate supports” (Productivity Commission, 2013)
- NDIS (2013) Block to individualised funding
- Focus on individualised planning
- NDIS - Person centred approaches (Collings et al 2016)

# BACKGROUND

- Intellectual disability 60 – 70% of the scheme (Productivity Commission, 2011)
- PWID most disadvantaged in Australia (Bigby and Wiesel, 2011)
- Hard for voices of PWID to be heard (Curryer et al 2015)
- Require additional assistance at all points of the planning process (O'Connor, 2014)
- PWID have exercise poorer choice and control over their supports (Mavromarus, 2018)
- Unfavourable and inequitable impacts (Mavromarus, 2018)

# AIM

- To explore the experiences of NDIS planning from the perspectives of adults with intellectual disability

# WHO DID WE SPEAK TO?

- Eight male, two females
- Verbal communication
- 22- 64 years of age
- Metropolitan area
- Five lived independently, four with family, one with a house mate
- Eight engaged in employment 2 f/t, 5 p/t, 1 self emp.
- Connected to peer-led support agency

# RESEARCH DESIGN

- Focus on experiences
- Pilot interviews
- Semi structured interviews (Liamputtong, 2007; Creswell, 2012)
- Thematic analysis (Braun and Clarke, 2016)
- NVIVO
- Trustworthiness of data – coding, moderation, themes

# THEMES

1. Planning preparation not fit for purpose
2. Creating goals
3. Goals not met
4. Planning not meeting real need
5. Lack of choice and control
6. Importance of relationship with planner

# 1. Planning preparation not fit for purpose

- Planning support with peer led disability support agency
- Engaged in practice and role play
- 9/10 felt inadequately prepared

*“but when you got there its totally different” (NATHAN, 54)*

- 9/10 felt they needed to be better prepared
- Confusion and not sure what to expect
- Everyone preferred having a support person with them

*“They can help me if I have problems understanding or have problems expressing my goals so you have to have someone there with you” (THOMAS, 42)*

## 2. Creating goals

- Positive statements about being involved with planning
- Seen as an opportunity to explore current life situations and what they would like to be doing in the future
- All had goals about socialising and increasing access to the community
- All participants had goals relating to their independence
- All participants has funding for a support worker to assist with achieving goals

### 3. Goals not met

- 4/10 not actively working toward goals

*“I didn’t do anything this year” (EMILY)*

- What is written and what happens....

*“I’ll tell you it is pretty good plan. Its just things not happening like the plan says...it happening a little bit. But not what I want to get done.” (DYLAN)*

*“See I don’t know if for sure if it’s a little bit delayed all of this stuff in the plan...nothing for sure in the plan.. Because it is all maybes and what if you knows.” (LUKE)*

## 4. Planning not meeting real needs

- All said it failed to capture and meet their real needs
- Desire to engage in long term planning but not being addressed
- Eg moving from home, formal education
- 5/10 - issues of future when parents die

*“This fine print about NDIS government support and everything and all you know, is there anything there in case Mum does go.”(LUKE)*

## 5. Lack of choice and control

- Present but not included

*“No I didn’t say anything to them... didn’t speak at all... I just listened to all they had to say” (ETHAN)*

- Being referred to in the third person

*“Stop referring me in the third person. You know I am right here” (JACINTA)*

- Question too difficult

*“I managed to get through the easy ones and then the hard ones were all a bit hard because she (the planner) wasn’t breaking them down” (EMILY)*

## 6. Importance of relationship with planner

- All participants wanted to get to know their planner better
- All participants expressed ideas about lack of continuity with planners
- All participants wanted the same planner next time

*“You know I don’t give them a hard time. But you know its silly you get to know somebody then they disappear then somebody else pops in and then you have to start all over again” (ROBERT)*

# Conclusions and implications

- Aims of NDIS not fully realised
- Lack of appropriate and relevant preparation
- Role of skilled support people
- Person centred planning approaches
- Not making a real difference consistent with the aims of NDIS to address long term inequities and barriers to inclusion
- Skills of planners
- Consistency of planner
- Large gap between desired outcomes and reality

# Where to from here

- Preparation capacity
- Supports for planning
- Co-design process and approach
- Short term vs long term planning