

To what extent is the National Disability Insurance Scheme achieving its aims and objectives from the perspective of people with disability?

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Public Service Research Group

- Interdisciplinary research group with a focus on the implementation of policy nationally and internationally.
- Our work comprises research, teaching and executive education/professional development.
- Organized according to three major themes:
 - Large Scale reform and system change
 - Diversity, inclusion and equity
 - Public service capability
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A range of disability-related research projects

- NHMRC-funded Centre of Research Excellence in disability and health.
- ARC-funded Linkage project (with Department of Social Services and National Disability Services) exploring thin markets.
- ARC-funded Linkage project with a range of Disability Employment Service providers on improving employment outcomes for individuals with psychosocial disability.
- International comparative work with colleagues in UK, Europe, North America
- Choice, control and the NDIS looking at consumer experience



The NDIS promise



“the National Disability Insurance Scheme (NDIS)...will support a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers”



<https://www.ndis.gov.au/about-us.html>

ACT spends thousands bailing people out of crisis under NDIS

By [Sherryn Groch](#)

26 November 2018 – 12:00am



The ACT government has spent more than \$88,000 in the past four months on e for people falling through the cracks in the National Disability Insurance Scheme as a looming market failure in the sector grows louder.

The [new lifeline fund, part of \\$1.8 million set aside in the most recent ACT budget](#)



Advertisement

There are now more Canberrans leaving NDIS than there are joining it

By [Sherryn Groch](#)

30 May 2018 – 9:54pm



The number of Canberrans leaving the National Disability Insurance Scheme has doubled in just three months, for the first time eclipsing the number joining the scheme in the same period.

The [latest NDIS snapshot](#) was published on the same day representatives from the agency behind the scheme fronted an ACT parliamentary inquiry.



2 View all comments



National Disability Insurance Scheme systems and processes not working well, providers say

By [Lexi Motherell](#)
Updated 19 Nov 2018, 2:10pm



Grieving parents to fulfil vow to late son at NDIS inquiry

By [Fiona Blackwood](#)
Updated Thu at 6:53pm



The research landscape

- Research on provider perspectives (e.g. National Disability Services work)
- Research on policy maker perspectives (e.g. Gemma Carey's NHMRC fellowship exploring the implementation of the NDIS).
- But where is the consumer voice?
 - Independent evaluation of the NDIS at National Institute of Labour Studies at Flinders University.



Our research team



Our research

- Is the NDIS giving people with disabilities ***more choice and control*** over their care?
- Is it making the funding and organising of disability services ***less complex and more efficient?***
- Is it promoting ***equity of access*** to services and support?

TOTAL NUMBER OF INTERVIEWS	42
People with disability: physical, cognitive and psychosocial disabilities	25
Family carers	17

Positives of the NDIS

- Experiences of the NDIS varied with people's individual needs and circumstances
- Some people told us what had changed for the better:

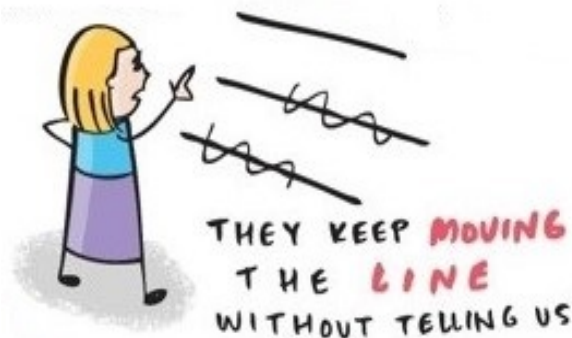


There used to be a waiting list for years for people trying to get care. So, with the introduction of NDIS, all these people who were waiting for care won. That was good, that was a positive thing. (interview 38)

Negatives of the NDIS

Some people talked about negative or mixed experiences in the NDIS:

- Complex system
- Bureaucratic
- Difficult to navigate



Piers Gooding

@P_Gooding

Replying to @drhdickinson @DisabilityHlth @Parl...

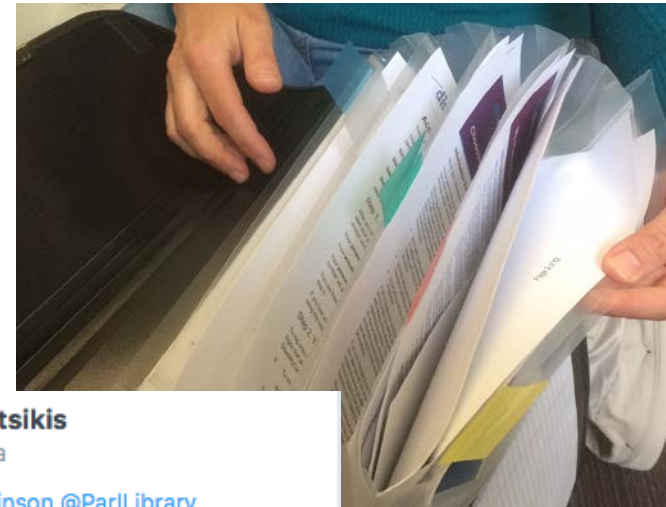
In my personal exp: assessment process opaque, participant faced lottery depending on assessor, request for review taken 6 mths despite deteriorating conditions, enormous uncertainty in mental health context, appreciated greater ability to choose providers w available funds.

1:26pm · 26 Nov 2018 · Twitter for Android

Difficulties navigating the scheme

Some people were unhappy with care planning processes. They talked about lots of paperwork, high turnover of planning staff, and planners not understanding their day to day life and disregarding their preferences for services and support.

If we can't get the planning right, we can't get the scheme right (interview 33)



Georgia Katsikis
@KatsGeorgia

Replying to @drhdickinson @ParLibrary
I'll have my first planing meeting this week. The amount of preparation needed (e.g. support letters in 'NDIS language'), and the uncertainty of what the outcome will be (fear of losing existing supports), is nothing less than stressful.

1:21pm · 26 Nov 2018 · Twitter for iPhone

specific funded supports. The planners' training isn't very effective to provide sufficient knowledge to tackle even common disabilities. Asking amputees if their condition is permanent, or asking someone with Downs Syndrome when they acquired their disability are reasonably common examples.



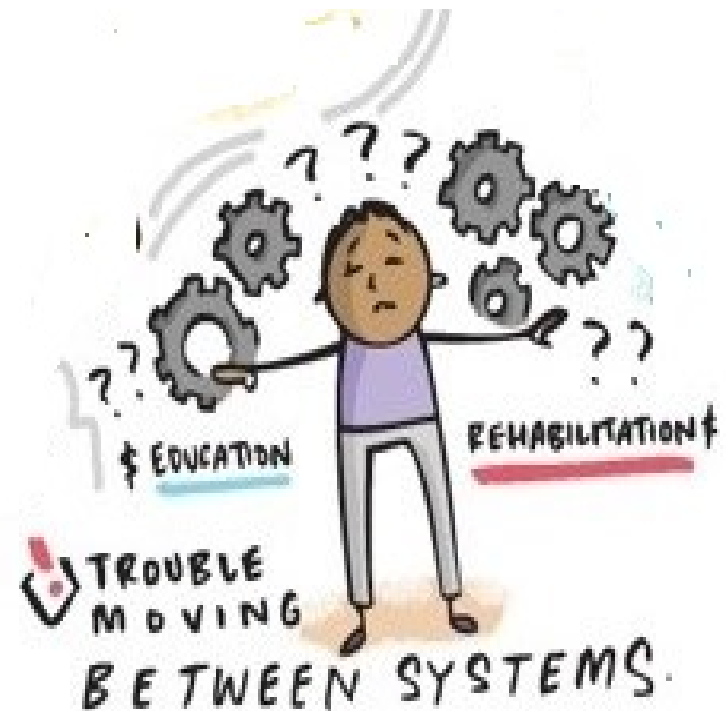
Need to trust people in decision-making

Some people said they thought the NDIS didn't trust people with disabilities to make decisions, and wasted money checking on things that didn't cost much



Boundaries with mainstream services

Some people described problems moving between different service systems – for example education, health and housing – when they wanted to combine services and support



In my case, I'm looking for funded support to address my poor physical health. 2/3 planners have said that, as my disability is primarily psychosocial in nature, and poor physical health is a very common outcome for people in that circumstance, naturally they would immediately allocate funds for things like Physiotherapy, Dietician, Exercise Physiologist, Personal Trainer etc. The one I saw (of course) said that the side effects of my medication are a medical condition that is more appropriately funded through the Primary Health system. So despite having a goal of improving my physical health, I am not going to get any funds to help me achieve that goal unless I take the issue to the AAT. Interestingly, if I wait 6 months for the new Psychosocial plan stream to be implemented, according to the recommendations from

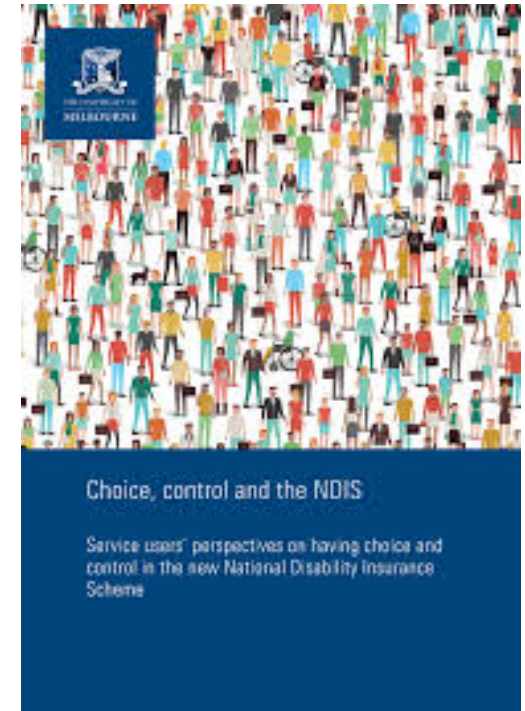
Key messages

- **Choice and control** varied with people's needs and individual circumstances
- Views on the **complexity and efficiency** of the NDIS were shaped by people's expectations of the scheme, their experience of the planning process, and communications with the scheme
- Access to information, services and support was inconsistent, flagging **equity** issues in the scheme



What do we learn from this?

- There is a lot of good will and optimism around the NDIS. Change is needed in terms of Australian disability services. Difficulty matching up rhetoric and reality
- Large scale change is difficult and the scale of change around the NDIS is significant (comparable with Medicare) and happening much quicker than other countries.
- Some of the teething issues are being identified and addressed by the NDIA.
- Care planning is a crucial component and needs to be done well (not just the NDIS).
- Real question over interface with mainstream services and LAC function
- People with disability feel like they aren't listened to.



Thank you for listening

