



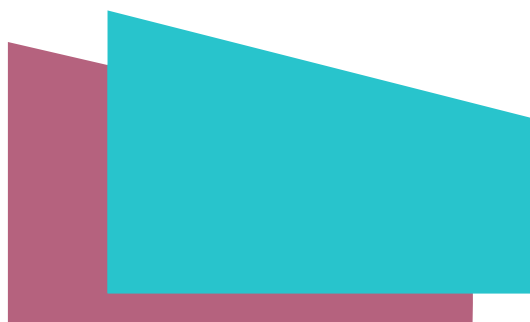
LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

2021 RESEARCH

SEMINAR SERIES

8 December



The National Disability Insurance Scheme: An Australian Public Policy Experiment


BOOK OVERVIEW PRESENTATION

8 DECEMBER 2021


Overview of the book

- The book is a public policy textbook describing the NDIS from concept through to implementation and analysing its successes and challenges.
- It is written in three parts:
 - Part One: Provides an overview of the history and philosophy of the NDIS, including its trial, transition and full scheme phases of implementation.
 - Part Two: Examines how the NDIS has interacted with particular cohorts and sectors. Chapters are authored by academics and practitioners working in relevant fields and sectors.
 - Part Three: Includes a collection of personal stories from people with disability, who have accessed NDIS services, and their families and carers.

Contributing authors

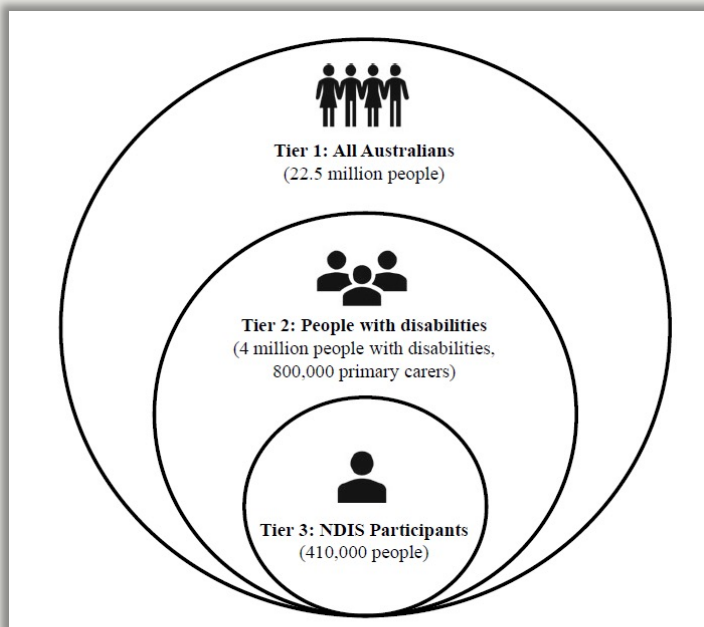
- **Dr. Gemma Carey and Eleanor Malbon** - Implementation Challenges in the NDIS.
 - **Professor Theresa Williams and Dr. Geoffrey Smith** - Mental Health and the NDIS: Making It Work for People with Psychosocial Disability.
 - **Ian Thompson** - The NDIS and Health Care.
 - **Jody Barney** - Indigenous Ways of Knowing, Being and Doing, and Responding to NDIS Thin Markets.
 - **Curated by Dr. David Henderson and Christine Bigby** - Stories from the Wild West Frontier: The NDIS Experiences of People with Severe and Profound Intellectual Disability.
 - **Curated by Samantha Jenkinson** - Individual Stories of the NDIS.
 - **Dr. Ilan Wiesel** - Housing and the National Disability Insurance.
 - **Professor Christine Bigby** - “The Scheme Was Designed with a Very Different Idea in Mind of Who a Disabled Person Is”: The NDIS and People with Intellectual Disability.
 - **Dr. Sue Olney** - Inclusion, Work and Wellbeing: Shifting Perceptions of Disability and Employability Through the NDIS.
 - **Dr. Ash Evans, Alan Greenfield, and Sarah Wood** - The Role of the Actuary in the NDIS.
 - **Penny Knight** – The NDIS and the Not-for-Profit Sector.
 - **Samantha Jenkinson** – Who Can Tell Us We Have Got It Right?” Advocacy and the NDIS.
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Why write the book?

- This is the first book to comprehensively describe and examine the NDIS from early concept through to full implementation.
 - It is cross-disciplinary, combining public policy perspectives from academics and practitioners working across multiple sectors.
 - It contains collections of stories of people with disability, told in their own words and those of their families, which track personal experiences with the scheme.
 - With the scheme fully rolled out, the time felt right to pause and reflect on the “the biggest social services shift since Medicare”
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What is the NDIS?

Three tiers of support



What's different about the NDIS?

Entitlement to 'reasonable and necessary' support (unlike the previous 'capped' system)

More choice and control through the individualised planning process

Funded like 'insurance' to meet current and future need, using actuarial modelling

A 'lifetime view' of costs, which structurally incentivises early interventions (even when expensive upfront)

Corporate governance model designed to protect the financial sustainability of the scheme.

National consistency and portability (you can move and not lose your supports).

Author reflections

Benefits of the scheme

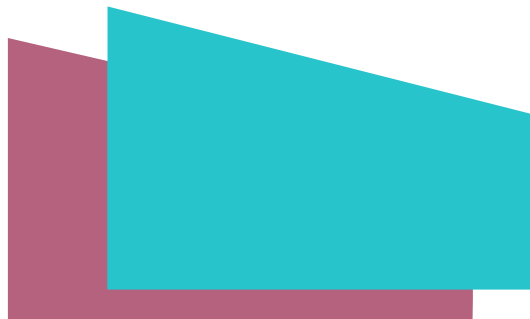
"Of the over 400,000 NDIS participants with an approved plan, 193,000 (~48%) were receiving disability support for the very first time."

- 1 A renewed public focus on the experiences of people with disability
- 2 An unprecedented entitlement to services
- 3 Good experiences for many participants
- 4 New insights on choice and control
- 5 National consistency, with some emerging flexibility
- 6 Better data to inform decision-making and innovation

Challenges ahead

"Some people with disability have found the NDIS empowering and enabling. For others, the NDIS is not working."


- 1 Outcomes for people with disability are varied in the NDIS.
- 2 National consistency must be balanced with flexibility.
- 3 The disability services market is still developing.
- 4 The true opportunity of service 'personalisation' has not yet been realised.
- 5 Difficulties remain with the interface between the NDIS and other service systems.
- 6 A sustainable funding model is essential for the NDIS to continue.




Children and the NDIS

CHAPTER BY MHAIRI COWDEN


Who are children and why do they matter?

- Children are young people under the age of 18
 - Children are not just defined by a certain age bracket, but also by the normative value we ascribed to them
 - Many of the same misconceptions we ascribe to children are shared by society's view of people with disability – lack of capacity, agency and 'otherness'
 - Public policy struggles with 'child centred' approaches
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The NDIS presented an opportunity to radically reimagine capacity

- Children primarily enter the NDIS through the early intervention pathway
 - The NDIS shifts the presumption of incapacity for people with disability and starts with a presumption of capacity and competence.
 - Conceptually it asks us to place the person with a disability at the centre and challenges liberal notions of 'capacity' and 'competence' and their centrality in a person's moral status as a rights holder
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The NDIS starts from a position of assuming incompetence for children with disabilities

- NDIS participants under the age of 18 are automatically appointed a child representative, in most cases their parents
 - The original Productivity Commission report frequently conflated the choices and decision making of the children with a disability with the choices and decision making of their parents
 - The CEO of the NDIA can make a determination that a child representative is not needed
 - There are some restrictions to the role of a child representative set out in the NDIS rules
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Some counterarguments

1. It is clear that very young children, such as newborn, do not have the capacity to make choices
2. The risk of denying rights is lower for children as they 'age out'

I would argue that these do not stand when seen in context of the way in which the NDIS should work with adults with diminished decision making capacities

There is a big but...

- The reality is that the NDIS is not delivering effective supported decision making services to those who need it
- To shift the way the NDIS views children with disability would mean a more nuanced, practiced and resourced approach to working with adults with disability – in line with the original intent of the scheme

Some concluding thoughts

- The NDIS presents principles and ways of working that give us insight into how we might do person centred approaches for children
 - But the NDIS has missed a trick by introducing a blanket assumption of incompetence for child participants
 - There is much work to be done to make the NDIS an effective scheme for those that require decision making support
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