

2019 Online KT Conference: Innovative KT Strategies That Work

Hosted by AIR's Center on KTDRR

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Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■

Panel Presentation 1:

Research Informing Policy and Practice: Recent Examples From Australia at the Micro, Meso, and Macro Levels

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**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

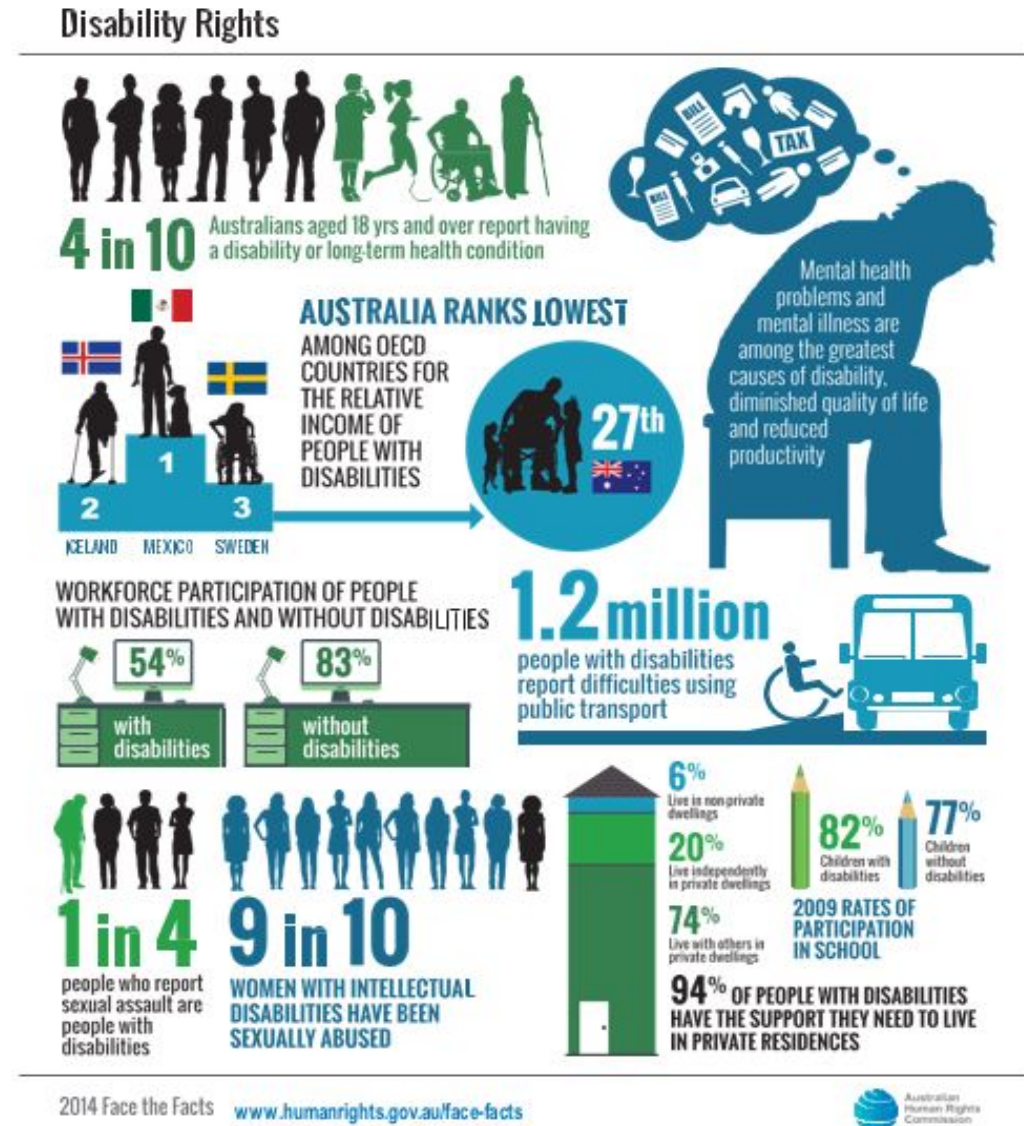
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Outline

- Some Australian context: outcomes for people and the evidence base
- Three recent examples of evidence synthesis to support contemporary best practice and system improvement, within the same (national) context, but at different levels:
 - @ Macro (industry or sector) level, complete service system redesign, replacing 8 different jurisdictions with nationally consistent arrangements
 - @ Meso (subsector) level, supporting a network of organisations providing early childhood intervention
 - @ Micro level, for practice leaders in one service type (community participation)
- Common features?
- Enablers and impediments to impact?
- Observations and discussion

Q: A fair go?
A: No!

Pressure for change >



What some people said about their services

‘can’t always get the support they need’

‘Lot of different ways of doing things in different parts of Australia’

‘not enough money available to meet people’s needs’

‘there are long waiting lists’

‘difficult to know where to go to get the services they need’

‘not enough information and not enough choice’

What some people said about their services

CONFUSOPOLY

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Audit of Australian Disability Research

Key findings of an Audit undertaken in 2014 and updated in 2017.

- ☹️ The evidence base is fragmented and diverse across topics and study designs.
- ☹️ No critical mass of research on topics of priority in disability reform agenda.
- ☹️ Australian disability research is not easily accessible. There is underutilisation of open-access journals and websites difficult to negotiate.
- ☹️ The invisibility and lack of free access to good research severely limits usefulness to inform the disability reform agenda, people with disability, their family, and carers.
- ☹️ There is not a mature sustainable research base for the purposes of the reform being undertaken.
- ☹️ The disability reform agenda leans heavily on human rights and social equity principles with a values base about choice and control, empowerment, and person-centred support. But these key concepts are relatively absent from the research evidence base.
- ☹️ Most study designs essentially describe “the problem,” not testing interventions or solutions.

Example 1: National System Reform—National Disability Insurance Scheme (NDIS)

- Principles
 - Based on UN Convention on the Rights of People with Disability (UNCRPD), grounded in lived experience
- Design
 - Person-centred planning
- Funding
 - Lifelong legal entitlement to funded “reasonable and necessary” supports
 - Early intervention preferred/where possible
 - Insurance/actuarial approach to lifetime costs and outcomes
- Other supports
 - Local area coordination
 - Supported decision making

Australia's NDIS: Core Design Principles

- ✓ Flexibility
- ✓ Portability
- ✓ Choice and control
- ✓ Personalisation
- ✓ Continuity/certainty
- ✓ Investment in capability

Evidence for Individualised Funding

“What the evidence suggests is that despite initial enthusiasm for these schemes, there is growing skepticism as to their efficacy. Concerns have been expressed about the ability of these schemes to achieve their aims of being more cost effective, improving choice and control for consumers, and improving outcomes for individuals with disability. What is not clear from the literature is whether these are inevitable features of these schemes, or whether these factors relate to the ways in which they have been **implemented and the degree to which they have been appropriately supported.**”

Source: Dickinson, 2017, p. 11.

Where's the Evidence, What Type, and How Much?

Experience: Stories

YouTube

Lots, goes way back...

"Grey" Literature

Policy pilots and action research

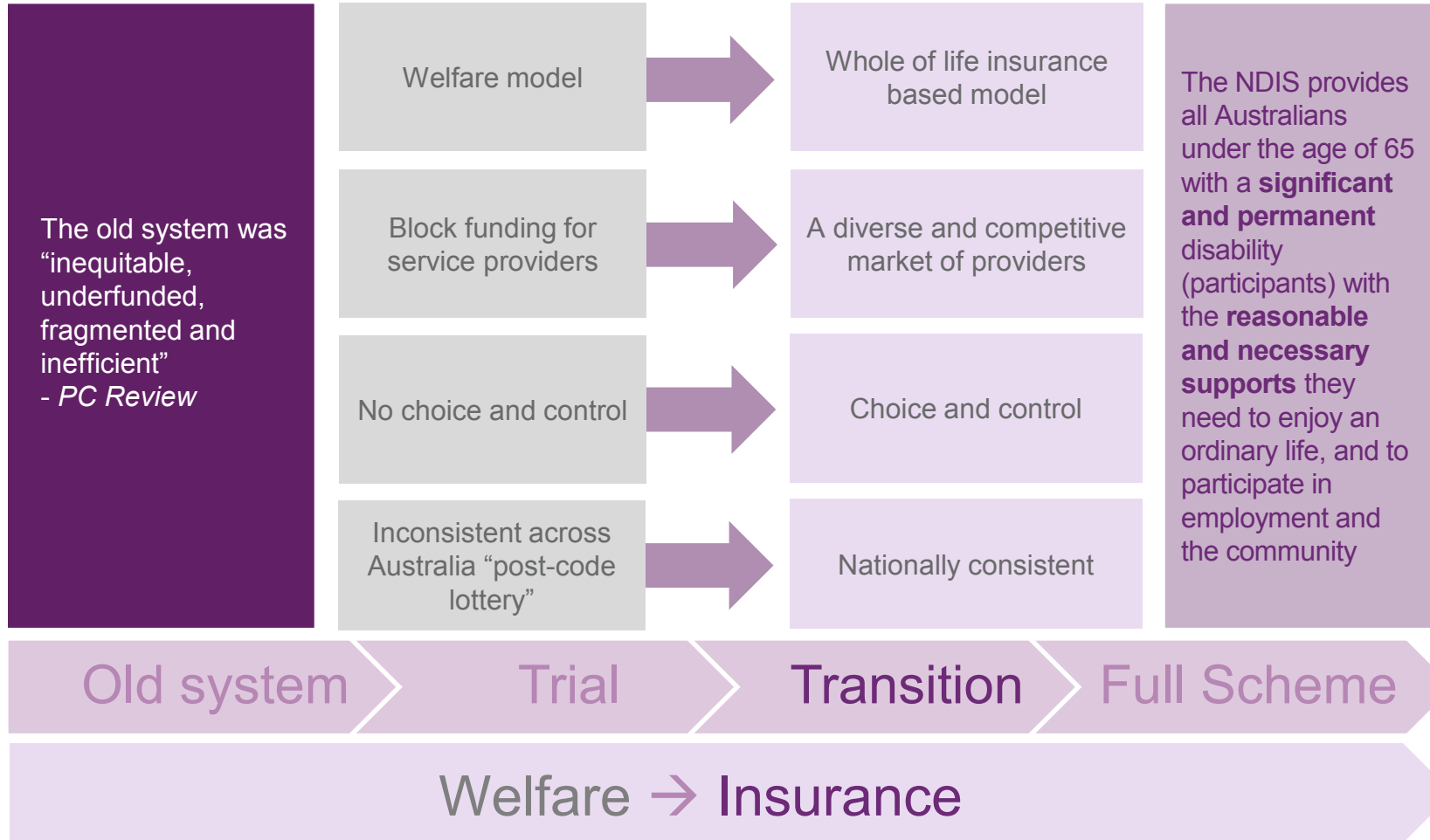
Some, more recently

Academic

Peer reviewed, "first-tier" journals
(Longitudinal, RCT)

Not enough

Evolution of the NDIS



“Reasonable and Necessary” Supports

- Assist the Participant to pursue the goals, objectives, and aspirations included in the Participant’s statement of goals and aspirations
- Assist the Participant to undertake activities, so as to facilitate the Participant’s social and economic participation
- Represents **value for money** in that the costs of the support are reasonable, relative to both the **benefits achieved** and the cost of alternative support
- Support **will be, or is likely to be, effective and beneficial for the Participant, having regard to current good practice**
- Takes account of what it is reasonable to expect families, carers, informal networks, and the community to provide
- Not more appropriately funded or provided through other general systems of service delivery or support services

Example 2: Early Childhood Intervention (ECI)

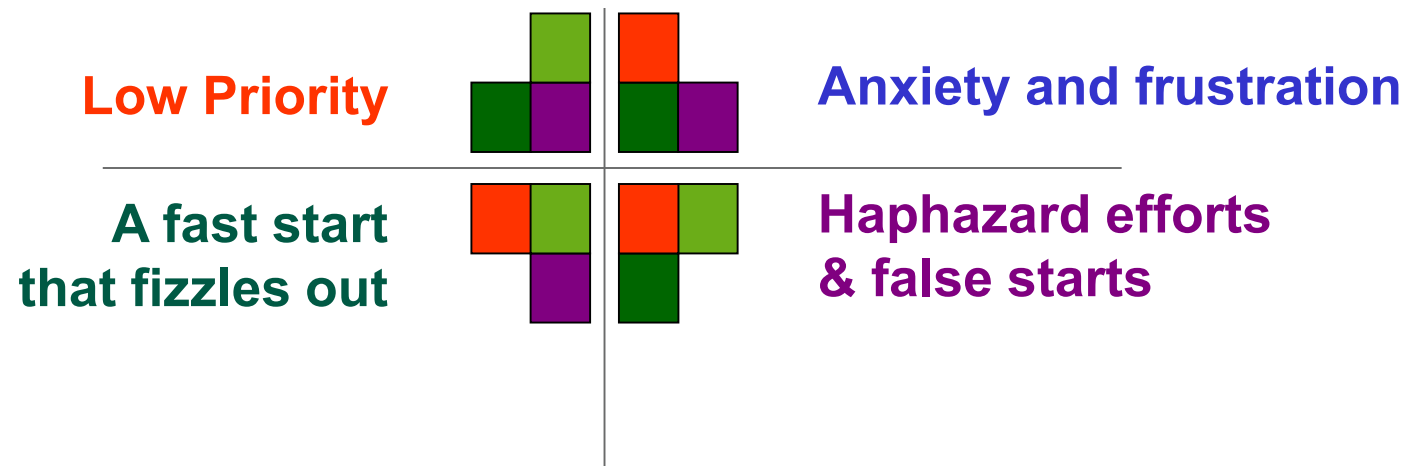
- Problem/pressure for change
 - Reflecting national inconsistency, plethora of models, policy frameworks, and program guidelines
- Best practice guidelines
 - Process [discussion paper, workshops, expert advisory groups (60 experts)]
 - Developed by a scientific committee of Australian ECI academics and researchers
- Endorsement (commissioning) by National Disability Insurance Agency (single national payer)
- Knowledge mobilisation by “apex” organisation (peak industry body)

Example 3: Community Participation

- Problem/pressure for change:
 - Range of policy frameworks, programmatic approaches
 - Poor conceptualisation of **what it is**, isn't, could be, and should be...
 - Language?
 - Theory of change?
 - Impact of individualised funding and “deconstruction of programs?”
 - Limited real-world examples of costed service models in a new “fee-for-service” environment
- Approach to refreshing the evidence base
 - International literature review > model or heuristic
 - Organisational case studies that demonstrate elements of best practice
 - Translational research resources (webinars, podcasts, guides, etc.)
 - National conversation (TBC)?

Prerequisites for Successful Change and the Effect When One Is Missing

Pressure for change	Capacity for change
A clear, shared vision	Actionable first steps



Common Enabling Features

- ✓ Pressure for change and a clear shared vision, national context
- ✓ Participant/consumer and provider involvement—credibility
- ✓ The experience of delivering and receiving services and supports
- ✓ Calibrating to existing practice = understanding the gap, leap, chasm to best practise?
- ✓ Key roles for independent (academic) subject matter experts
- ✓ Endorsement by commissioner (payer/funders) and peak (consumer and advocacy) bodies—a pull factor

Common Impediments

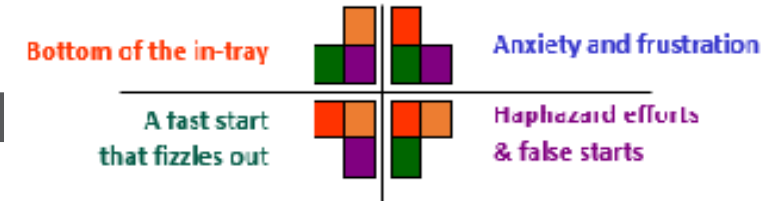
- Insufficient capacity for change

ECl e.g.: peak industry body leading change defunded

NDIA e.g.: poor market stewardship,
no national research agenda or entity responsible taking actionable first steps

- Lack of clarity about roles and responsibilities and therefore “who needs to do what to make things happen” and “first steps that lead to action”

Pressure for change	Capacity for change
A clear, shared vision	Action-able first steps



>>> the importance of research infrastructure that effectively mobilises research-backed evidence in a range of creative ways

NDIS: More Info, Resources, and References

- Background to NDIS: ‘Disability Care and Support’, Productivity Commission, Australian Government, 2011, [access here](#)
- General information on NDIS: <https://www.ndis.gov.au/>
- Political leadership. Listen to Ms. Jenny Macklin, former Federal Minister for Social Services, talk about how the Australian National Disability Insurance Scheme came into being (about 30 mins)
 - <https://www.abc.net.au/radionational/programs/bigideas/jenny-macklin-and-the-creation-of-the-ndis/11405054>
- Introduction to the NDIS
 - https://www.youtube.com/watch?v=1DMqCzdDzKM&list=PLTwZ-K9vkmo7XM8NM4Z_aP8_lxuFU48ww
- How an NDIS plan works:
 - <https://www.youtube.com/watch?v=QzzTFm4McpQ>
- Implementation issues
 - Dickinson, H. (2017). Individual funding systems: What works? *Evidence Base*, 2017(3). [Open access here](#).
 - Carey, G., Weier, M., Malbon, E., Dickinson, H., Alexander, D., & Duff, G. (2019). [How is the disability sector faring?](#) Sydney, Australia: Centre for Social Impact.
 - Duff, G. (2017). Commentary by Gordon Duff on “Knowledge translation: bridging the disability research-to-practice gap” (Dew & Boydell, 2017). *Research and Practice in Intellectual and Developmental Disabilities*, 4(2), 158–163. [Open access article here \(Duff, 2017\)](#)

ECI: More Info, Resources, and References

- Early childhood intervention resources
 - Find the Guidelines [here](#)
 - Family resources [here](#)
 - Best practice in more detail [here](#)
 - Research project inquiring into the adoption of best practice principles in ECI services. You can find the report [here](#).

Community Participation: More Info, Resources, and References

- Project information
 - Literature review and published papers are [here](#)
 - [Podcast](#) with Professor Christine Bigby, the Chief Investigator from La Trobe University Melbourne, about the need for the work internationally and in the context of the NDIS, the process, and the resources
- Research-to-action guides
 - Practice leadership
 - Person-centred active support

Contact Details

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- [National Disability Services](#) is the industry association for over 1,000 disability service providers in Australia
 - www.nds.org.au
- The [Melbourne Disability Initiative](#) at Melbourne University is leading the development of the new National Disability Research Partnership, a NIDILRR type entity that will coordinate research, knowledge mobilisation, and capacity-building activities
 - <https://disability.unimelb.edu.au/>

Disclaimer

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