



Measuring Outcomes in the National Disability Insurance Scheme From Theory to Reality

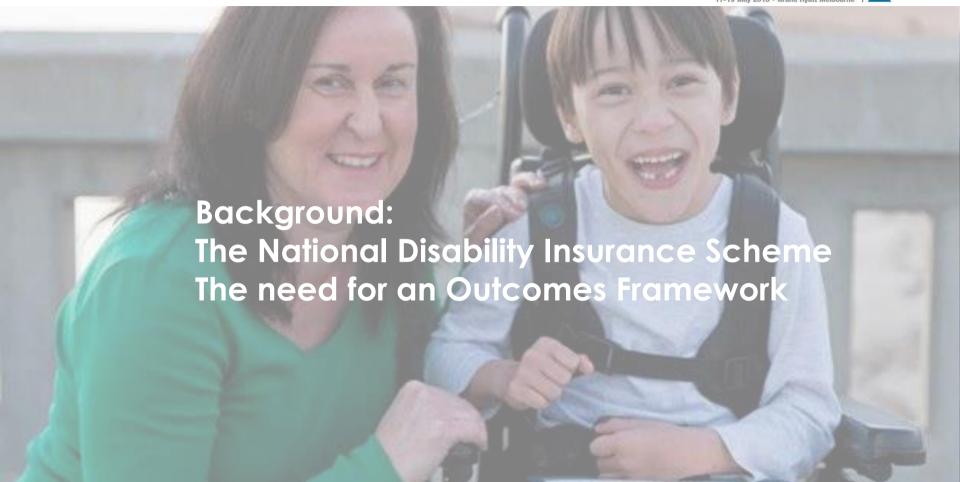
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The National Disability Insurance Scheme (NDIS)

- Became fully operational on 1 July 2013 with the commencement of trial sites across Australia
- Represents a fundamentally new approach to supporting Australians with disability
 - Shifts the existing welfare system to an insurance-based model
 - Promotes choice and control, early intervention, and community inclusion
- Further detail: concurrent session 4e



- 1 Barwon region, Victoria
- 2 Hunter region, New South Wales
- 3 South Australia (age 13 and under on 1 July 2014)
- 4 Tasmania (age 15-24)
- 6 Australian Capital Territory
- 6 Barkly region, Northern Territory
- Perth Hills area, Western Australia





The need for an outcomes framework Legislation: NDIS Act 2013

- Section 3 lists the objects of the Act, such as supporting the independence and social and economic participation of people with disability, and refers to Australia's obligations under some other instruments, including the UN Convention on the Rights of Persons with Disabilities (CRPD)
- Section 4 sets out 17 general principles guiding actions under the Act. For example, the first principle is: "People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development"



The need for an outcomes framework NDIA Strategic Plan



People with disability are in control and have choices, based on the UN Convention on the Rights of Persons with Disabilities.

Goals

The National Disability Insurance Scheme is financially sustainable and is governed using insurance principles.

The community has ownership, confidence and pride in the National Disability Insurance Scheme and the National Disability Insurance Agency.

The need for an outcomes framework Other policy documents

- Intergovernmental agreement
 - Performance Reporting Framework
- National Disability Strategy: six broad outcome areas
 - Inclusive and accessible communities, Rights protection, justice and legislation, Economic security, Personal and community support, Learning and skills, Health and wellbeing
- National Standards for Disability Services: six standards
 - Rights, Participation and inclusion, Individual outcomes, Feedback and complaints, Service access, Services management



The need for an outcomes framework Monitoring progress

 Are we meeting our obligations – under legislation/ policy guidelines, and more broadly to participants and families/carers? Are we making a difference?

Muir & Bennett (2014) put the general case:

"Our social progress has arguably been stymied because we haven't concentrated enough on outcomes. Together we've created a social purpose system that has good intentions, but more often focuses, counts and funds what and how much we do, rather than whether we are making a difference"

Terminology: output, outcome, impact

- Outputs: services, products, funding provided to participants
- Outcomes: the difference these outputs make to participants
 - "Changes in targeted attitudes, values, behaviors or conditions between baseline measurement and subsequent points of measurement"
- Impact: long term, deeper changes that arise from achieving outcomes



socrates.berkeley.edu/~pbd/pdfs/Evaluation Terminology.pdf

Terminology: outcome, indicator

"there is considerable confusion about the meaning of the terms **outcomes** and **indicators** ... In a research setting, an outcome usually refers to a result, whereas in a policy context an outcome most commonly refers to what an action plan/program/project expects to achieve through implementation... The most common definition of an indicator is information collected to monitor progress towards achievement of an outcome"

 National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000

NDIA Strategic Plan: goals, outcomes, deliverables, success indicators

Goal 1: People with disability are in control and have choices, based on the UN CRPD

Outcome A: Build the capacity of people with disability to exercise choice and control in the pursuit of their goals

Deliverable 1: Encourage, enable & challenge people with disability to take control & self-manage their supports

Success indicator 1: People with disability plan & exercise choice



Measureable indicator: the proportion of people who self-manage their supports, and how this proportion changes over time

Monitoring progress

- Tracking progress of individual participants and families/carers over time
 - are things improving for our participants?
- Linking outcomes to supports received, other risk factors, and participant characteristics
 - what types of supports lead to good outcomes?
- Benchmarking
 - how do we compare to Australians without disability, and to other OECD countries?

Comparison with insurance and traditional disability systems

- Insurance: insurer must satisfy all valid claims
- Traditional disability systems: block funding, capped budget
- NDIS shares features of both
 - Must provide reasonable and necessary support
 - Supports participants and families/carers to achieve their goals over their lifetime – concerned with participant outcomes as well as financial result

Comparison with insurance and traditional disability systems: Outcomes

- Insurance
 - For short tail classes, focus is on speed and efficiency of settling claims
 - For long tail classes, claimant outcomes become more important. For example, in accident compensation schemes, rehabilitation and RTW outcomes are important for claims management
- Traditional disability systems: service delivery tended to be monitored by measuring inputs (funds, staffing) and outputs (hours of care, numbers of clients)
- NDIS: participant outcomes play a crucial role in scheme monitoring. Lifetime view of costs/benefit.

Outcome measurement in compensation schemes Workers' Compensation

- Workers' compensation schemes around Australia are focused on return to work (RTW) as an outcome measure
- New Zealand and all Australian jurisdictions except for ACT take part in the Safe Work Australia – RTW Survey
- The RTW Survey focuses on Work, with some questions on Health (general health, medical treatment, resilience) and a couple of questions related to Choice & Control
- Although there are some overlapping domains, the survey questions reflect the different nature of the schemes
 - Work-related questions in the NDIS outcomes framework concentrate on whether the participant was able to find work and on work stability, whereas the RTW survey questions focus on the client return to work experience
 - The experience of families/carers is not captured in the RTW Survey



Outcome measurement in compensation schemes Motor Accident Compensation

Several states conduct participant satisfaction surveys and fund research on client outcomes. For example:

- In NSW, studies funded by the Motor Accidents Authority (MAA) include
 - The Brain Injury Outcomes Study (BIOS) (Tate et al. 2004), a longitudinal study of outcomes for 198 people with newly-acquired traumatic brain injury, along with 160 close relatives
 - A longitudinal study of health outcomes for claimants with whiplash (Rebbeck et al. 2006)
 - The Life After Injury study, looking at quality of life for people with traumaticallyacquired brain injury and spinal cord injury, including the experience of family carers (Gething et al. 2002)
- Also in NSW, the Lifetime Care and Support Authority's annual participant satisfaction survey measures overall satisfaction with the scheme, whether participants feel part of community, have worked or studied post-accident, spend time with friends



Outcome measurement in compensation schemes Motor Accident Compensation

Examples (continued):

- In VIC, the Transport Accident Commission (TAC) is conducting a longitudinal client research study of outcomes for ~1500 clients to allow better understanding of pathways to recovery. TAC also funds a Longitudinal Head Injury Outcomes Study
- In QLD, as well as conducting an annual CTP claimant survey, the Motor Accident Insurance Commission have also funded a longitudinal study on the physical and mental health of Queensland CTP claimants with predominantly minor injuries

Outcome measurement under State Disability Schemes

- Increasing focus on outcome measurement, with Individual Outcomes introduced as one of the six standards in the revised National Standards for Disability Services 2013 (NSDS)
- Implementation is conducted separately by each state. Examples of state approaches include:
 - NSW: Have aligned their standards to the 6 NSDS standards. Practice requirements and KPIs released to support person-centred decision making and achievement of each individual's personal goals / outcomes
 - VIC: Have a set of 4 standards that apply across all social services.
 Requires goal-oriented plans for support, regular review and update of plans
 - TAS: Currently developing an Outcomes Purchasing Framework that will apply across social services. This will complement its existing service standards



Outcome measurement under State Disability Schemes

- Outcomes measurement approaches vary
 - Variations in state approaches
 - NDS analysis (2012) suggested a variety of approaches were used by service providers, including state government frameworks and independent frameworks (e.g. CQL Personal Outcomes Measures). Some providers also did not measure outcomes at time of survey
- Nationally consistent outcomes data is currently limited. The National Minimum Dataset (NMDS) contains some outcomes-related fields (e.g. workforce participation) but it is not comprehensive. Difficult to draw comparisons of outcomes achieved
- The structure of state systems means outcomes are measured separately for each service received. To some extent this can reduce the focus on the person as a whole and their overall goals

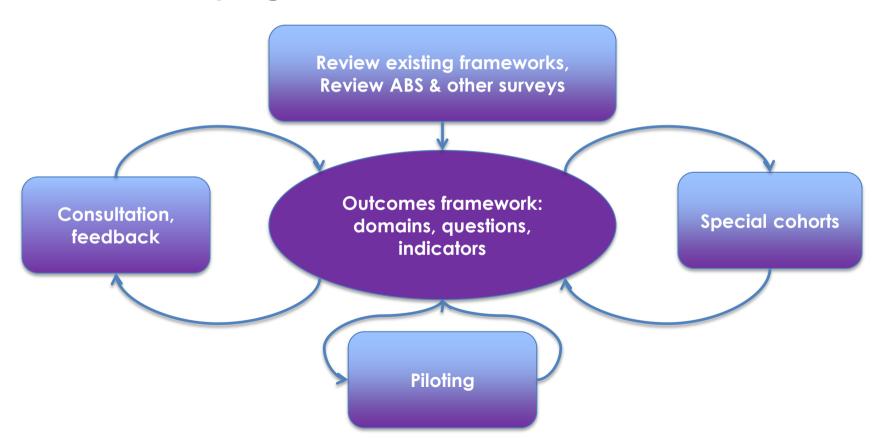


Developing the NDIS Outcomes Framework Guiding Principles

- Two ways of measuring progress
 - The distance from "an ordinary life"
 - Progress towards an individual's own goals
- Indicators must be
 - Meaningful: widely accepted as important measures of progress
 - Informative: able to indicate what is working to improve outcomes and what is not
 - Feasible to collect and report: avoid over-surveying participants and undue burden on staff



Developing the NDIS Outcomes Framework



Review of existing frameworks

US: National Core Indicators (NCI), The Council on Quality and Leadership Personal Outcome Measures (CQL POM)

UK: Fulfilling Potential, Life Opportunities Survey, Adult Social Care
Outcomes Framework, Personally Controlled Budgets
Republic of Ireland: National Disability Survey,
The Intellectual Disability Supplement to the Irish Longitudinal
Study of Ageing (TILDA)

Canada: The University of Toronto Quality of Life Profile (QLP)

NZ: Ministry of Social Development "Investing in Services for Outcomes"

Australia: Transport Accident Commission, National Disability Services

Population information

ABS Surveys

- Survey of Disability, Ageing and Carers (SDAC) 2012
- General Social Survey (GSS) 2010
- Survey of Mental Health and Wellbeing (SMHWB) 2007
- Personal Safety Survey (PSS) 2012
- 2011-13 Australian Health Survey (AHS)

Other

- Household, Income and Labour Dynamics in Australia (HILDA) Survey
- Longitudinal Study of Australian Children
- Longitudinal Study of Indigenous Children
- Australian Social Inclusion Board (2012) report: Social Inclusion in Australia: How Australia is faring

The NDIS Outcomes Framework: Lifespan approach

- Independent Advisory Council (IAC) report: Reasonable and necessary support across the lifespan
- The lifespan approach recognises that participants, their families and carers have the potential to grow and develop at any stage of life
- The lifespan approach guides the NDIS to enable each participant to positively experience the key features of a life stage that their peers without disability take for granted
- Reasonable and necessary support by age group required for participants to meet the same milestones and achieve the same goals and aspirations as their peers without disability

Outcomes across the lifespan



Children from birth to school entry



Children from school entry to age 15



Young people aged 16 to 24



Adults aged 25 to 55



Older adults aged over 55

Adults: Participant Domains

- 1. Choice and control
- 2. Daily activities
- 3. Relationships
- 4. Home
- 5. Health and wellbeing
- 6. Lifelong learning
- 7. Work
- 8. Social, community and civic participation

Adults: Family Domains

- 1. Families have the support they need to care
- 2. Families know their rights and advocate effectively for their family member with disability
- 3. Families are able to gain access to desired services, programs, and activities in their community
- 4. Families have succession plans
- Parents enjoy health and wellbeing

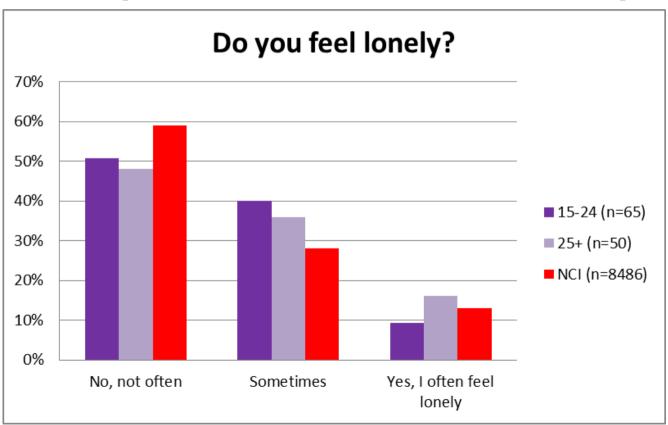


Pilot study

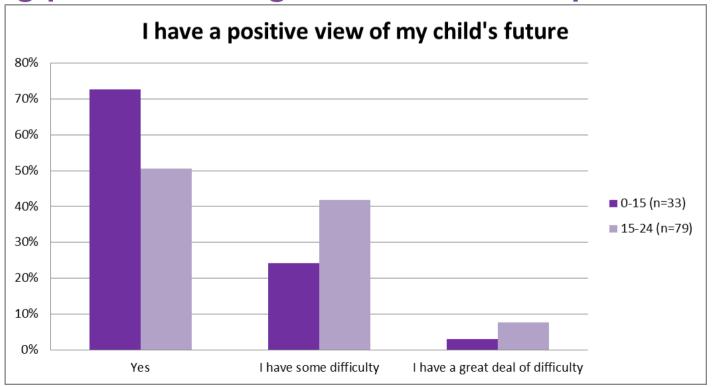
- Piloting was undertaken in the Barwon, Hunter and Tasmanian trial sites
- Design: stratified on questionnaire type (except Tas) (effective stratification on age and whether participant had an intellectual disability)
- Almost 400 interviews were conducted (both participants and family members/carers), either face-to-face or by phone



Participant domain 3 – Relationships



Family domain 1 – Families understand their child/ young person's strengths, abilities and special needs



A plug for longitudinal data

- Age group comparisons presented are crosssectional: people of different ages at a fixed time
- Longitudinal studies: follow the same people over time as they age
- Estimates of age-related change obtained from a cross-sectional study can be biased due to cohort effects
- Cohort effect: systematic difference between people born at different times

Cohort effects

Lucke et al. (2010) Health Across Generations: Findings From the Australian Longitudinal Study on Women's Health
Biological Research for Nursing 12(2)

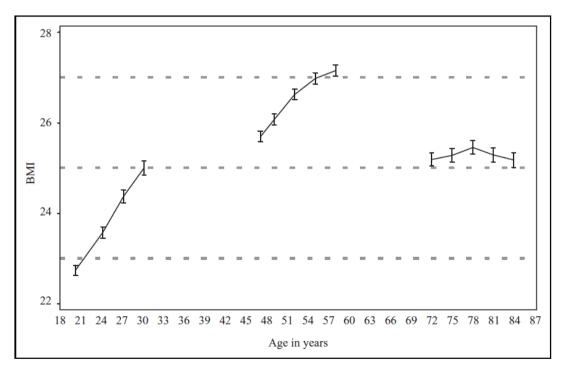
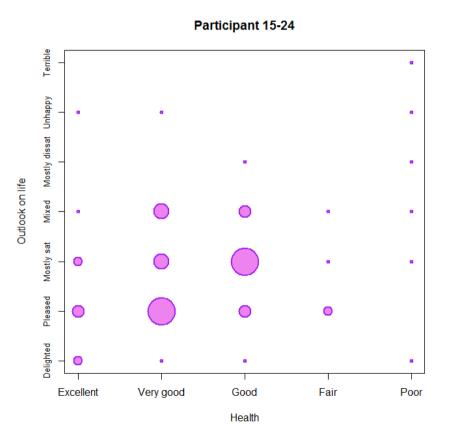


Figure 1. Mean body mass index (BMI; with 95% confidence limits) by age in the three cohorts. Cohorts were born in 1973–1978, 1946–1951, and 1921–1926. BMI was calculated at each survey over a period of 10–12 years.

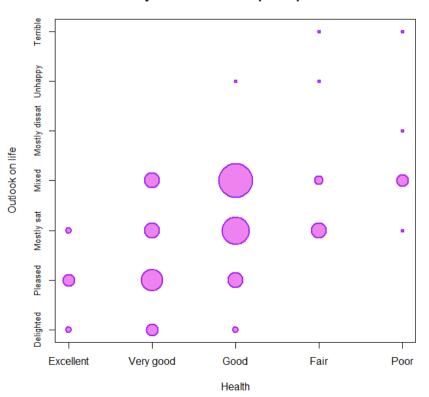


Outlook on life versus health



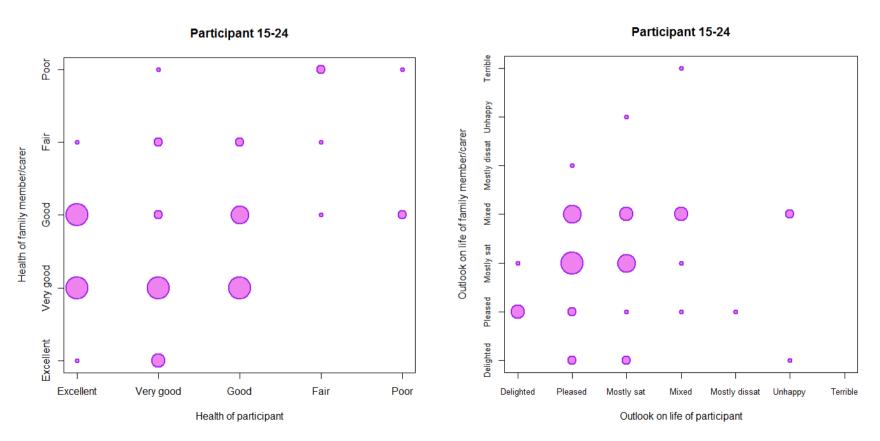


Family member/carer of participant 15-24





Matched Participant/Family Analysis



Where to from here?

- Finish pilot analysis
- Analyse feedback from March 2015 workshop
- Incorporate pilot analysis and feedback into questionnaires
- Decide on implementation
- Start collection!

Questions?