



The University of Notre Dame Australia

Submission to the Parliamentary Joint Standing
Committee on the National Disability Insurance
Scheme: General Inquiry

November 2022



About Notre Dame

The University of Notre Dame Australia (UNDA) welcomes the opportunity to make a submission to the general issues inquiry of the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme (NDIS). As a national university with health programs ranked by the Federal Government's Education Quality Indicators (QILT) as number one for teaching quality¹, the University is well placed to contribute to this important inquiry.

This submission has been prepared by Dr Rachel Skoss, Senior Research Fellow at UNDA's Institute for Health Research. Dr Skoss has a considerable history as an academic and advocate embedded in the disability sector. She has been a Board Member of the Disability Services Commission, and past chair of the WA Ministerial Advisory Council on Disability. She is currently a member of the executive advisory group of the Disability Health Network and is a consumer representative for the Royal Australian College of Physicians. She also has lived experience via being the primary carer for a teen with intellectual disability who is a participant in the NDIS.

Background

This submission focuses on the need for reform of NDIS planning guidelines and health promotion strategies to facilitate greater integration of preventative health care into care plans for people with intellectual disability living in supported independent living (SIL) accommodation and in the community.

Clients in this category often have complex health needs and are high health service users. There are many reports highlighting poor health outcomes of people with intellectual disability, and the resultant cost to the health system. However, people with intellectual disability need support from their service provider to access health services, including those that support preventative health care. To date there is limited understanding of what this support entails. Further, there is limited understanding of the health literacy skills required of caregivers to provide this support, nor the cost of providing such support.

Our recommendations are multi-faceted and aim to strengthen:

- Health outcomes for those with intellectual disabilities
- Skills and training in the care economy
- The quality and effectiveness of the NDIS

¹ Australian Government's Quality Indicators for Learning & Teaching, 2021 Graduate Outcomes Survey— qilt.edu.au



Notre Dame Landmark Health Literacy Study

These views are formed from an evidence-based approach through the recent conclusion of a two-year UNDA study² funded by a WA Department of Health Translation Research Grant. The key foci of this study explored the following attributes of independent living support:

1. Quantification of health services used for people living in supported accommodation (including hospital and community-based health and mental health services), and organisational support provided. This study recorded all health service events attended by people living in supported accommodation at a large service provider in Perth, WA over a period of 18 months. Cost of support was estimated for each type of health service.
2. An inability for large parts of the care workforce to provide health care to people with intellectual disabilities. This included lived experience perspectives from people with intellectual disability and caregivers, together with professional perspectives from GP's and disability service provider executives.
3. Health literacy of support workers and their confidence to support health behaviours of people with intellectual disability.

We believe the research findings are relevant to the Australian Government's current review into the National Disability Insurance Scheme.

Key findings and Recommendations

1. When an individual with disability accesses health services, a staff member generally attends with them (96%). This is resourced by the care organisation, with the average cost estimates per service event (inclusive of staffing, transport) \$78.51. The aggregated weekly cost of supporting access to health services was estimated at \$3,835. Considerations for this inquiry:
 - a. The SIL provider is generally responsible for supporting the health of the NDIS participants they support. SIL funding does not cover transport or other living costs, yet the provider funded 94% of the travel, and the staff.
 - b. For some participants living in congregate settings, consideration must be given to retaining adequate staffing ratios. Our data showed that the impact of a house mate attending a health service resulted in reduced supervision within the group home (79%), longer timeframes to complete care needs (32%), and loss of opportunity for others (30%). During the study period, the organisation supplied 704 hours additional resourcing via overtime or staff backfill. Note: this has been incorporated into the cost estimates above.

Recommendation 1: That supported independent living funding be increased to cover the costs associated with supporting NDIS participants accessing health care, including preventative care.

² Skoss R (2022) Health Care For People Who Need Extra Support: A health literacy guide to support the health of people with a cognitive impairment or intellectual disability. Fremantle: Institute for Health Research, The University of Notre Dame Australia



2. A participant's health and wellbeing must be central to their care planning:
 - c. Evidence from the sector highlights that attempts to include support to access 'health' services in participants' NDIS plans were unsuccessful. It is important that NDIA planners understand the support is to enable the participant to access mainstream health services, rather than delivering the health service.
 - d. The evidence highlights that attempts to include 'health and wellbeing goals' in participants' NDIS plans were generally unsuccessful. It is important that clear guidance is developed to communicate how health and wellbeing can be supported via NDIS plans. While it is a key performance indicator for the Agency, there is no consistent support to improve health and wellbeing of participants, nor accurate measurement of outcomes.
 - e. There is opportunity for participants to include specific health literacy skills as part of 'capacity building' in their NDIS plans (e.g., skills such as goal setting for healthy living, supported decision-making).

Recommendation 2: In addition to providing acute health care services, the NDIS plans need to be more wholistic and also support the provision of preventative care aimed at maintaining health and wellbeing. The inclusion of specific health literacy skills should be built into a participant's NDIS plan.

3. Health literacy of support workers is critical to how they support the health of people with intellectual disability. Amongst other key skills, workers may need to support 'healthy living', manage chronic health conditions, identify when an individual is in pain or has a change in their health status, support communication with health professionals (or communicate on the individual's behalf), and/or effectively communicate about follow-up requirements (e.g., medication changes, referrals) following health service events. Support workers also have the potential to help build the health literacy skills in the person they support. The study confirmed that the worker's health literacy knowledge and skills directly relate to their confidence to support different aspects of health. Currently, training is only funded for a narrow range of skills as part of a participant's individual NDIS plan (e.g. mealtime management, subcutaneous injections). Consistent training regarding health is not available for the workforce. Considerations for this Committee:
 - a. A health-literate workforce would likely improve health outcomes of people with intellectual disability. Currently, there is no relevant training for support workers regarding health literacy. The Certificate III does not provide the required detail. The 'health guide' was developed as a response to the lack of a useful resource in the sector. The guide can be accessed [here](#).

Recommendation 3 (a): Specific health literacy training needs be developed, considering all the skills and knowledge required to support the health of a person with intellectual disability, and that the training is a requirement of the existing and future workforce.



- b. Training needs to be delivered in a way that is cost-effective and can be immediately translated to work practice. A hybrid model of training is required, combining ‘train-the-trainer’ approaches with short digital learning modules and relevant resources for the support workers can use in practice. Currently there is no state or federal mechanism to fund the development or delivery of general health training. While the Commonwealth Department of Health’s Roadmap for Improving the Health of People with Intellectual Disability highlights improving health literacy of caregivers as a strategy to improve health outcomes of people with intellectual disability, the responsibility for action gets lost between the Commonwealth, state health agencies, and the NDIS.

Recommendation 3 (b): That funding be made available for both the development of, and delivery of a nationally accredited general health literacy training program for caregivers that will improve the timeliness and relevancy of healthcare services accessed by people living with an intellectual disability.

Further Engagement

- [Release](#) of the University of Notre Dame Health Literacy Guide (4 October 2022)
- Talking Health Literacy with [ABC TV Evening News](#) (3 October 2022)

The University of Notre Dame has considerable expertise in this field and would welcome the opportunity to partner with the NDIA to improve health literacy guidelines and to ensure they are effectively embedded in participants’ plans.

Dr Skoss is available to present directly to the inquiry if there is interest in learning more about the health literacy research program and recommendations for reform. There has been significant interest in the guide and how it can be utilised within the health and disability sectors from service providers, peak agencies, primary health networks, and other relevant organisations across jurisdictions in Australia, and internationally.