



CRE-DH

Centre of
Research Excellence in
Disability and Health



SUBMISSION TO THE NSW AGEING AND DISABILITY COMMISSION POSITION PAPER

in partnership with



About this submission

This submission is made by Dr Nicola Fortune on behalf of investigators within the Centre of Research Excellence in Disability and Health (CRE-DH) funded by the National Health and Medical Research Council.

In responding to the questions set out in the position paper, we draw on our collective knowledge and research expertise in relation to health and wellbeing inequalities experienced by people with disability, and particularly on our recent experience with:

- Developing the Disability and Wellbeing Monitoring Framework and Indicators, with input from people with lived experience of disability; and
- Organising, in partnership with the Australian Human Rights Commission, a Zoom webinar as part of consultations for the next National Disability Strategy.

Monitoring implementation of and outcomes related to the National Disability Strategy is essential for ensuring that the Strategy is effective in improving the lives of people with disability in NSW and achieving a fair and inclusive society in which people with disability can fulfil their potential as equal citizens. We congratulate the ADC for undertaking this important work.

About the CRE-DH

The Centre of Research Excellence in Disability and Health (CRE-DH) aims to identify cost-effective policies to improve the health of people with disabilities in Australia. There are four interconnected research areas in the CRE-DH focused on:

1. mapping the health inequities between Australians with and without disabilities,
2. analysing the social, economic and environmental factors that contribute to the poorer health of people with disabilities,
3. modelling the cost-effectiveness of health policy interventions, and
4. policy analysis and reform.

The CRE-DH is funded by the National Health and Medical Research Council. We are an interdisciplinary research group comprised of academics from five universities, a team of international advisors and a Partner Advisory Group of stakeholders from the disability and health sectors.

The CRE-DH Co-Directors are Professor Anne Kavanagh (University of Melbourne) and Professor Gwynnyth Llewellyn (University of Sydney). The CRE-DH includes Chief Investigators from the University of Melbourne, University of Sydney, Monash University, UNSW Canberra and RMIT with multidisciplinary skills in epidemiology, health economics, health and social policy, psychology, psychiatry, public administration and public health. In addition, we have Associate Investigators from a range of national and international universities and the World Health Organization. We work in collaboration with key stakeholders including DSS, ABS, AIHW and peak bodies in the disability advocacy and service sector through our Partner Advisory Group. Several members of the CRE-DH research team and the Partner Advisory Group also have lived experience of disability.

We hope our input is helpful. Please do not hesitate to contact us if we can be of further assistance..

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Submission to the NSW Ageing and Disability Commission (ADC) in response to the position paper ‘Establishing a Standing Review to Monitor, Assess and Report on the implementation of the National Disability Strategy in NSW’

THE APPROACH

Question 1. What do you think about the approach of the Standing Review, outlined in section 2, for monitoring, assessing and reporting on the implementation of the Strategy in NSW?

Overall, the Standing Review approach looks good.

In relation to the Stakeholder Engagement Framework, we suggest that researchers and research groups, and also the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW), should be included in the list of stakeholders. The research community has much to offer, including knowledge concerning existing evidence on particular topics that can provide important context for monitoring implementation and outcomes, understanding of the strengths and limitations of different data sources, and practical expertise in collecting and analysing both qualitative and quantitative data.

The biennial timeframe seems sensible, given that the frequency of availability of updated data varies by data source. Biennial reporting should enable updated data to be presented on a good proportion of the measures each time.

In relation to ‘examining available data sources to assess how NSW is progressing and achieving outcomes under the Strategy’, it is important to articulate a commitment to addressing data gaps and improving data over time. Working in partnership with ABS, AIHW and the research community will be of particular relevance here.

We note that a firm commitment to the ongoing adequate resourcing of both stakeholder engagement and data capture and analysis will be necessary to ensure that the planned biennial public reporting can be effective in holding the government to account on NDS implementation and driving positive change for people with disability.

STANDING REVIEW FRAMEWORK

Question 2. What principles should guide the development of the Standing Review Framework, including: How you think the ADC should fulfil its function to ‘monitor, assess and report’ on the NSW implementation of the Strategy?

People with disability and their representative organisations should be integrally involved in developing the Standing Review Framework from the outset. Importantly, the full diversity of people with disability should have input, including Indigenous and culturally and linguistically diverse groups, those who need support with communication, and children and young people with disability. In developing the Disability and Wellbeing Monitoring Framework and Indicators, the CRE-DH’s experience consulting with an ‘Expert Panel of Advice’ highlighted the valuable input provided by lived expertise. This consultation led to changes to the language, shape, and detail of the Framework, resulting in a stronger product that was better fit-for-purpose.¹

Question 3. How should the ADC ensure accountability and transparency in its reporting on the implementation of the Strategy in NSW? How can the Standing Review best add value to the implementation process for the Strategy in NSW?

Using statistical data to track inequalities between people with and without disability on key measures across all outcome areas will be an essential component of the Standing Review Framework. In addition, there should be attention to outcomes for different sub-groups of people with disability, and outcomes relating only to people with disability (e.g., experience of disability discrimination, physical and information accessibility, access to disability support services and assistive devices).

1. Clifton S, Fortune N, Llewellyn G, Stancliffe RJ, Williamson P (2020). Lived expertise and the development of a framework for tracking the social determinants, health, and wellbeing of Australians with disability. *Scandinavian Journal of Disability Research* 22(1): 137–146.

Reporting should be high profile, in order to raise awareness of the NDS across stakeholder groups and the broader community, and to meaningfully achieve transparency and accountability.

At the recent webinar on the next NDS, participants suggested there should be a high-level NDS focal point in government (at both national and state/territory levels), and NDS champions within all government departments. If put in place, such a structure could be used for effective dissemination of reporting, and to promote commitment to implementation and buy-in across portfolios.

The Standing Review Framework should be consistent with, and should complement, the national NDS outcomes framework (currently under development), while also being tailored to the NSW context. This includes ensuring that data item definitions are consistent wherever possible, so that data reported in the NSW context can be meaningfully compared with data reported nationally. In developing the Standing Review Framework there should also be consideration of how it will contribute to Australia's reporting to the UN Committee on the Rights of Persons with Disabilities on implementation of the CRPD.

STAKEHOLDER ENGAGEMENT FRAMEWORK

Question 4. What principles should guide the development of the Stakeholder Engagement Framework?

It is important to have people with disability integrally involved in developing the broader Stakeholder Engagement Framework. An advisory committee with broad membership, along the lines of the National Disability Data Asset Disability Advisory Council, could be an effective approach. People with disability should be in paid roles both within the ADC and on any advisory committee that is established. There should also be input from people with expertise in collecting and analysing data, and using data to inform policy. Input from the ABS, AIHW and the research community should be sought.

Before consultation and engagement is undertaken, there should be clear articulation of how input will be used to inform development of the Framework. After the process is completed a summary of feedback received should be published, highlighting how this was used to inform development of the Framework. This will help ensure accountability to those who provide input.

A variety of approaches should be taken to consulting and engaging with people with disability, their supporters, and

the broader disability sector, to ensure the process is as accessible as possible. The recent Zoom webinar on the next NDS was an effective way of engaging with people with disability and other stakeholders. It involved both pre-recorded and live video presentations from a range of speakers, and participants were invited to respond to specific questions via an online engagement tool. Many participants did take this opportunity to provide their responses, and some commented that this was an effective way to facilitate input.

FOCUS AREAS

Question 5. Should the Standing Review focus on specific aspects for in depth review?

In the context of biennial reporting, most recent data for an agreed set of key indicators should be presented every time, so that the report provides an authoritative repository that stakeholders can refer to for the latest data.

In addition to this, it may work well to select specific outcome areas, aspects of the implementation process, and/or portfolio areas for more in-depth review.

Arguably, as well as reporting available data, the first biennial report should include an in-depth review of data sources, identifying gaps and priority topics for data development. Developing reliable sources of disability data requires an enduring commitment over time, so it would be desirable to make this a focus early on.

Question 6. Other questions

It would be valuable to cover all these questions in consultations. In addition to the first question on indicators, it would be useful to ask, in connection with answers given to each of the following questions, what measures could be used to track progress. Responses might suggest opportunities for future data collection.

Regarding available and accessible indicators, the CRE-DH has developed the Disability and Wellbeing Monitoring Framework, in consultation with people with lived experience of disability, to measure and track inequalities between people with and without disability in relation to exposure to social determinants of health and wellbeing². The Framework has a hierarchical structure, with 19 domains grouped into three broad elements (Health and wellbeing, Social determinants, and Service system), within which 128 indicators are specified. It is possible to report nearly three-quarters of these indicators using existing Australian national data sources. For the remainder,

2. Fortune N, Badland H, Clifton S, Emerson E, Rachele J, Stancliffe RJ, Zhou Q, Llewellyn, G (2020). The Disability and Wellbeing Monitoring Framework and Indicators: Technical report. Melbourne, Centre of Research Excellence in Disability and Health. Available at: <https://credh.org.au/publications/reports/>

national data are not currently available, highlighting the need for data development efforts³. The CRE-DH is currently preparing to report national data comparing people with and without disability, for all indicators where such comparison is applicable.

Further information about the development, structure and content of the Disability and Wellbeing Monitoring Framework and Indicators can be found on the CRE-DH [website](#).

We suggest that the Framework is a valuable resource to inform development of the ADC NDS monitoring framework for NSW.

3. Fortune N, Badland H, Clifton S, Emerson E, Rachele J, Stancliffe RJ, Zhou Q, Llewellyn G (2020). The Disability and Wellbeing Monitoring Framework: data, data gaps, and policy implications. *ANZ Journal of Public Health* 44(3): 227-232.