



CRE-DH

Centre of
Research Excellence in
Disability and Health



SUBMISSION TO **NATIONAL DISABILITY STRATEGY** BEYOND 2020 CONSULTATION

in partnership with



About this submission

This submission is made by Dr Laura Davy 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.

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.

Contact details

Dr Laura Davy
l.davy@unsw.edu.au
Centre of Research Excellence in Disability and Health
The University of Melbourne VIC 3001
cre-dh@unimelb.edu.au || credh.org.au || @DisabilityHlth

SUMMARY

Given the majority stakeholder view that the vision and outcome areas of the current National Disability Strategy are still the right ones, this submission focuses on the implementation and governance of the next iteration of the Strategy. The submission addresses in particular the following three areas:

1. Leadership of people with disability

Facilitating the participation of people with disability and their representative organisations in the development and implementation of law and policy that impacts them is an obligation under Article 4 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). People with disability must be represented in all aspects of the Strategy's governance structures and agenda setting and decision-making processes.

2. Coordination of the Strategy

Reviews of the current Strategy showed that it was not effectively implemented across all levels and portfolios of government. Outlining government responsibilities is not enough; the effective coordination of government responsibilities for implementing the Strategy by an appropriately resourced and representative agency or body is also necessary.

3. Quality data collection and reporting

Collecting quality data to inform policy development and implementation is an obligation under Article 31 of the CRPD. Funding will need to be allocated to developing suitable national data frameworks and to the oversight, collection and analysis of this data. The CRE-DH has developed the Disability and Wellbeing Monitoring Framework to measure and track inequalities between people with and without disability in relation to the social determinants of health and wellbeing which may be a valuable input to the development of a monitoring framework for the next Strategy.

Question 1. During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

The Government's intent to retain the current vision and six outcome areas of the Strategy is positive and reflects the majority views of stakeholders consulted so far.

We suggest that important priority issues within these 6 outcome areas include:

- **Health equity in a post COVID 19 environment;** and the need to better include people with disability in Australia's responses to potential future health emergencies and other disaster planning.
- **Measures to address and prevent violence, abuse and neglect** in reference to current and future findings of the Disability Royal Commission. The Strategy should adopt an intersectional approach to addressing and preventing violence and abuse, including by linking with other relevant policy such as the National Plan to Reduce Violence against Women and their Children, and committing to gender-transformative, tailored violence response and prevention strategies.
- **Interface issues with NDIS.** Despite government commitment to clarify roles and responsibilities and address these issues, many groups continue to fall between the gaps of existing support systems including people with psychosocial disability, family carers, and older people with disability.
- **Accessibility of mainstream government service systems** such as health, transport, and education. Previous reviews of the Strategy^{1 2} have found that mainstream public service systems are yet to fully integrate a consideration of disability within their core business and practice. Education at different levels of government to ensure personnel understand the disability policy and service environment and their human rights obligations to people with disability is required, and this requires leadership and investment.

1 SPRC, 2019, p31: <https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020>

2 Senate Community Affairs Committee Secretariat, 2017, p72 Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities, https://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/AccessibleCommunities/Report

Ideally, people with disability themselves will take a leading role in communications and education around the Strategy.

- **Enabling the leadership of people with disability** across all aspects of developing, implementing, monitoring and governing the Strategy.

Question 2. What do you think about the guiding principles proposed here?

- **Involve and engage:** has the policy process or program design engaged with and listened to people with disability at all stages of planning and implementation and provided accessible information and opportunities for feedback?
- **Design universally:** have the principles of universal design been applied where possible and has the project taken advantage of accessible and assistive technology where available?
- **Engage the broader community:** how has the broader community been informed of, involved in and been made responsible for removing barriers and supporting the inclusion of people with disability?
- **Address barriers faced by priority populations:** how have the priority populations noted by the National Disability Strategy been identified and what action has been taken to specifically address the barriers they may experience?
- **Support carers and supporters:** how have the needs of the family, carers and circles of information and formal support for the person with disability been considered in the development of the policy or program?

The five guiding principles outlined in the position paper are good, but in some places they are ambiguous and should be elaborated further and strengthened to ensure that the guidance is meaningful and can be translated into practice. For example:

Involve and engage

Previous consultations with the disability sector have found that meaningful engagement with people with disability, families and carers involves responding to the priorities identified by these groups and involving them from the outset in governance structures, agenda setting and decision-making processes (not just seeking feedback after the fact). There is a need to amplify the voice of people with disability in national discourse, and the full diversity of people with disability must have a voice, including Indigenous and culturally and linguistically diverse groups, those who need support with communication, and children and young people with disability.

Design universally

What this means in the context of policy and program development is unclear. There is considerable debate in disability studies as to whether an environment can ever be designed to be truly 'universal' as the accessibility needs of some groups may in some cases be incompatible. 'Inclusive design' is a more appropriate principle as it stresses leaving no individual or group behind.

Address barriers faced by priority populations

The design and delivery of policy and programs should take into account not just the barriers faced by priority populations, but also their impact on these groups – will the policy or program impact priority groups equitably and avoid exacerbating existing disadvantage?

Question 3. What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Having a stronger emphasis on improving community attitudes is a positive move. Critical questions remain around how this outcome will be implemented, measured and reported on. While specific actions and initiatives under the Strategy were described as beyond the scope of the position paper, it did aim to describe the overall architecture of the Strategy. Public awareness campaigns require funding commitments and measuring community attitudes requires research, both areas which are yet to be addressed in any detail in the government's position paper. In terms of tracking progress, we suggest that people with disability, their representative organisations, families and supporters are best placed to assess whether community attitudes are improving or not.

The most effective way to improve community attitudes is to increase levels of inclusion of people with disability in all aspects of society, particularly education, employment, leadership roles, and the media. There is a clear role for government to lead by example here. For example, in the outcome area of employment, public service organisations should aim to increase the representation of people with disability within their workforce.

Question 4. How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

The position paper states that ‘The new Strategy presents an opportunity to clarify the roles and responsibilities of various levels of government in disability policy and service delivery’. However, a missing piece of this puzzle is how to encourage implementation of the Strategy across all levels and portfolios of government. This question can likely only be answered through the development of a new National Disability Agreement as well as a new Strategy.

Outlining government responsibilities is not enough; the effective coordination of government responsibilities for implementing the Strategy is also necessary.

While the government’s position paper notes that many people with disability who participated in the public consultation were unaware that the current Strategy existed, the SPRC review also found that there was a considerable lack of awareness about the Strategy within government³.

Leadership is central to effective *coordination* and implementation. A Strategy implementation group or ‘coordination agency’⁴, sufficiently funded and resourced, could be charged with the responsibility for awareness raising, knowledge sharing, and fostering the creation of communities of practice. This group or office, comprised of government and disability sector representatives, could coordinate initiatives that span portfolios and levels of government and provide advice on topics such as ensuring policies and programs are CRPD compliant, how to engage people with disability in decision making processes, and so on.

Question 5. How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

Realising the full vision of the Strategy is everyone’s responsibility, and there are important roles for the business sector, the community sector, research organisations, and cultural and arts organisations to play. For many people with disability, the non-government sector in fact provides the majority of their support.

There is also a clear role for government in leading and coordinating these efforts and educating all sectors about their responsibilities and ways they can meet them.

Question 6. What kind of information on the Strategy’s progress should governments make available to the public and how often should this information be made available?

The progress reports made public for the current Strategy (2010 – 2020) were perceived by the disability sector to be piecemeal and descriptive rather than comprehensive and evidenced. They were criticized for listing policy and program outputs rather than measuring concrete progress on specific outcomes⁵.

The quality and rigor of reporting is therefore as important as the frequency. Quality reporting is dependent on 1) governments setting concrete and measurable targets for progress on NDS outcomes (in collaboration with the disability sector), and 2) the adoption of national approaches to the collection of disability data. This includes service use information (from specialist disability and mainstream services) including qualitative data on service user experiences, as well as data on priority topics such as national and jurisdictional information on incidences of abuse and neglect in disability services.

3 SPRC, 2019, p31: <https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020>

4 Senate Community Affairs Committee Secretariat, 2017, p72 Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/AccessibleCommunities/Report

5 SPRC, 2019, <https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020>

Collecting quality data to inform policy development and implementation is an obligation under the CRPD (Article 31). Funding will need to be allocated to developing suitable national data frameworks and to the oversight, collection and analysis of this information. More policy and program initiatives need to include a funded evaluation component to measure impact.

Reporting on the Strategy's progress should be a) public, and b) made available to the public in a timely fashion. We support the Productivity Commission recommendation that performance reporting under the NDA and Strategy be merged, with a biennial National Disability Report tabled in the Australian Parliament by the relevant Commonwealth Minister responsible for disability, to report on outcomes progress under both instruments.

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 wellbeing⁶. 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, national data are not currently available, highlighting the need for data development efforts.

The CRE-DH is currently preparing to report data comparing people with and without disability, for all indicators where such comparison is applicable. We suggest that the Disability and Wellbeing Monitoring Framework may be a valuable input to the development of a monitoring framework for the next NDS. We also emphasise that a national level commitment is required to address identified data gaps, so that it is possible in future to determine whether the NDS is succeeding in reducing inequalities between people with and without disability across all areas of life.

Question 7. What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time?

Targeted Action Plans are a good proposal. The identification of specific areas for action and the development of the Targeted Action Plans should be

led by people with disability and their representative organisations to ensure they meet the needs and priorities of the target beneficiaries of these activities.

There is the potential to focus on short term issues rather than long term goals in a two or three year plan so it is important that the actions proposed in Targeted Action Plans have clear alignment with the longer-term aims of the new Strategy.

The Plans should also build in an evaluation component to ensure that the outcomes for people with disability of these actions can be measured and reported. The risk of not assessing the outcomes of Targeted Action Plans is that the focus becomes the activities that have been undertaken rather than what impact these have had on people's lives, which was a major criticism of the reporting that took place under the current Strategy.

Question 8. How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

Facilitating the participation of people with disability and their representative organisations in the development and implementation of law and policy that impacts them is an obligation under the CRPD (Article 4). The proposed engagement plan must ensure that the governance arrangements that underpin the Strategy (which as yet are unspecified in the position paper) include a leading role for disability representative organisations across the sector. This means not relying on one-off consultations whether they are in the form of face to face workshops or inviting written submissions. It means integrating people with disability with the ongoing leadership and steering of the Strategy at all stages: planning and agenda-setting, implementing, evaluating, and reporting.

Given the diversity of the disability community, the engagement plan must include provisions for involving diverse groups, particularly Indigenous and culturally and linguistically diverse groups, and be flexible enough to at times tailor engagement with different groups to successfully implement different actions.

⁶ 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/>