



CRE-DH

**Centre of Research
Excellence in
Disability and Health**

SUBMISSION TO THE DEPARTMENT OF SOCIAL SERVICES

In response to the Consultation Paper: A New
Act to Replace the Disability Services Act 1986

in partnership with



About this submission

This submission is made on behalf of the Centre of Research Excellence in Disability and Health (CRE-DH) funded by the National Health and Medical Research Council, 9 February 2023.

The submission is made in response to the Consultation Paper from the Department of Social Services – ‘A New Act to Replace the Disability Services Act 1986’ released on 7 November 2022.

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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 disability in Australia. There are four interconnected research areas the CRE-DH focuses on:

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

The CRE-DH is 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.

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

This submission is from the NHMRC Centre of Research Excellence in Disability and Health in response to the Consultation Paper from the Department of Social Services – ‘A New Act to Replace the Disability Services Act 1986’ released on 7 November 2022.

Our submission is organised around the questions defined in the Consultation Paper. Our response focuses on the following key issues: defining disability and the target group to be covered by the new Disability Services Act, the need for data collection and reporting from services and supports, and ensuring that the new Disability Services Act meets Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities. We offer reflections and recommendations under these key issue areas that align with Consultation Paper questions 1, 2, 4, and 6.

RECOMMENDATIONS

Overarching recommendations

1. The Act must firmly embed the concepts outlined within Article 3, General Principles, and Article 4, General Obligations, of the CRPD.
2. The wording used in the Act needs to align with the language used in the CRPD.
3. The Act needs to be expanded to cover supports and services encompassing all life domains as detailed within the Articles in the CRPD, including both mainstream and disability-specific supports and services.
4. The Act must ensure that all existing disability supports and services conform to the new Act within a clearly specified timeframe.

Objects within the Act

5. The proposed objects are too narrow. While increasing social and economic participation is critical, the objects covered under the Act need to be expanded to include social protection, health, justice, non-discrimination, protection from violence, housing, transport and recreation.
6. An object should be added that addresses humanitarian emergencies, ensuring access to disability-specific and disability-responsive support during emergencies.

7. The objects should emphasise the importance of individual autonomy for how a person with disability chooses to participate in society, such that their life experiences are meaningful to them.
8. The objects should include enabling people with disability to exercise choice and control in the planning and delivery of their services and supports, including both disability-specific and mainstream services and supports.
9. The objects should promote a supported decision-making framework to enable people with disability to make decisions about their services and supports.
10. An object should be added about the importance of safeguarding arrangements to protect people with disability from experiencing abuse, neglect or hardships arising from poor quality or unsafe supports or services.
11. An object should be added that ensures realisation of the rights of the child so that supports and services for children and young people with disability are provided in an age-appropriate manner that enables their views to be heard and taken into consideration on all matters affecting them.
12. An object should be added to ensure that both disability-specific services and mainstream government services are required to collect consistent, high-quality data on the supports and services offered to people with disability that can be used to monitor programs and policies.
13. The objects should ensure that any decision-making body that is involved in the design, implementation, evaluation, and/or maintenance of disability services includes people with disability in its decision-making processes.

Target group covered by the Act

14. The new Act needs to define the target group inclusively and align with the CRPD conceptualisation of disability. This means disability is understood based on whether an individual’s participation in society is restricted due to interactions between their impairments and societal, physical, cultural or environmental barriers.
15. The Act must consider the diverse needs of people with disability, such that services and supports are developed and implemented from a person-centred approach, taking into account each individual’s circumstances.

16. The Act needs to consider the intersectional disadvantage that occurs for people with disability, including women, Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse people, and people in rural and remote communities.

Definition of disability within the Act

17. The new Act should include a definition of disability. It should align with the biopsychosocial model of disability of the ICF framework. The ICF provides a standard language for describing functioning and disability. This approach will include all people with disability.

Data collection and research to support monitoring and evaluation of disability services and supports

18. Data collection is essential for monitoring progress in meeting Australia's obligations under the CRPD. The Act needs to commit to collecting nationally consistent disability data and reporting at regular intervals on outcomes for people with disability.
19. All mainstream government services, whether provided by Federal or state or territory governments, need to include nationally consistent disability identifiers to permit transparent and accountable reporting of outcomes for people with disability.
20. All government disability services, whether provided by Federal or state or territory governments, need to collect and report data about (i) the nature, quantity and extent of services and supports provided, (ii) characteristics of individuals to whom services and supports are provided (including disability identifiers), (iii) the quality of services and supports provided, and (iv) associated outcomes for individuals to whom services and supports are provided.
21. The Act should recognise the importance of data linkage to capture involvement of people with disability, their pathways through supports and services, and to enable monitoring of outcomes for people with disability to drive change and decrease inequities.
22. The Act should commit to sharing de-identified data, with appropriate governance in place, for research purposes.
23. The Act should highlight the need to build disability research capacity across all disability stakeholders, including people with disability, to undertake research and to disseminate findings broadly including with people with disability and other stakeholders.

24. The Act should highlight the need to make existing disability data available to researchers with appropriate safeguards including a secure and de-identified form. For instance, NDIS data about current and past participants, as well as people who have applied to the NDIS but not met access requirements. This means that data is not limited to snapshots in time but enables independent researchers to assess whether disability and mainstream supports, services and policies are meeting the needs of people with disability and do not create or reinforce inequities.

Review of the Act

25. The Disability Services Act should be reviewed at least every 10 years to ensure that it continues to meet obligations under the CRPD and meets best practice in disability service provision.

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Overarching issues and recommendations

Our recommendations draw on the CRE-DH's expertise in the conceptualisation and definition of disability, expertise in Australian disability data, and the evidence describing the social determinants of health and health inequity for people with disability generated by the CRE-DH.

Despite ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), Australia still has a way to go in aligning disability legislation with CRPD Articles and Principles, as detailed in the most recent United Nations Concluding Observations on Australia's periodic reports related to the CRPD (hereafter referred to as UN Concluding Observations on Australia).¹

All legislation, including the Disability Services Act (hereafter referred to as the Act), must embed Article 3 General Principles and Article 4 General Obligations of the CRPD to ensure that the rights of people with disability are protected. The Act must emphasise that all services and supports provided to people with disability, whether disability-specific or mainstream, whether new or existing, must be developed, implemented, and maintained in a manner that promotes and respects the rights of people with disability.

To meet the requirements of the CRPD, the new Act must consider the needs of people with disability from a person-centred approach. While some specialist disability services will be required to enable participation in society, many of the services required are no different to those required by the rest of the community but may require additional investment to make them accessible to people with disability and meet their needs. Building an integrated and inclusionary approach to disability services will make it easier for the Australian Government to better meet its obligations of the CRPD with regards to education and employment. Article 24 highlights the need for an "inclusive education system", while Article 27 highlights the importance a "labour market and work environment that is open, inclusive and accessible to persons with disabilities".

The proposed objects in the Consultation Paper list education and employment as factors that may lead to increased social and economic

participation. However, the CRPD recognises the importance of all domains of life, enforcing that the rights of people with disability must be considered across much broader life domains than simply education and employment. Furthermore, research conducted as part of the CRE-DH has found evidence demonstrating that people with disability in Australia experience considerable disadvantage across a range of different socio-economic characteristics including employment, education, housing, social support, discrimination, and violence, which contributes to their poor health and wellbeing.²⁻¹¹

The CRE-DH developed a disability and wellbeing monitoring framework, which provides a comprehensive structure for measuring and reporting inequalities between people with and without disability in relation to health and the social determinants of health and highlights existing gaps in national disability data.¹² The analysis using the framework demonstrated inequalities between people with and without disability across most domains of health status, the social determinants of health, and access to services, with larger inequalities for people with severe disability. Thus, the Act must go beyond increasing social and economic participation through employment and education, to include all life domains as detailed within the CRPD.

Article 4 of the CRPD requires that all policies and programs must protect and promote the rights of people with disability and that this should be implemented through legislation and other policies, and that existing regulations and practices that discriminate must be modified or abolished.¹³ Thus it is essential that not only new, but also existing services and supports for people with disability meet this standard. This is needed to narrow existing inequities. The new Act must therefore provide clearly specified timeframes for when existing services and supports for people will be required to conform to the Act.

Our overarching recommendations are:

Recommendation 1: The Act must firmly embed the concepts outlined within Article 3, General Principles, and Article 4, General Obligations, of the CRPD.

Recommendation 2: The wording used in the Act needs to align with the language used in the CRPD.

Recommendation 3: The Act needs to be expanded to cover supports and services encompassing all life domains as detailed within the Articles in the CRPD, including both mainstream and disability-specific supports and services.

Recommendation 4: The Act must ensure that all existing disability supports and services conform to the new Act within a clearly specified timeframe.

Reflections and responses to the Consultation Paper

There were 7 questions within the Consultation Paper. Below we provide reflections on questions where we have specific expertise and offer recommendations for consideration.

Question 1 – Do you agree with the proposed objects for the new Act? What other objects should be included in the new Act?

The proposed objects are too narrow with their focus on increasing social and economic participation by increasing employment and education opportunities. While our research supports the importance of both education and employment, the CRE-DH Disability and Wellbeing Monitoring Framework and Indicators Baseline Data Report demonstrates Australians with disability face inequities in all aspects of life, including health, poverty, violence, discrimination, justice, housing, transport and recreation.¹²

While inequalities refer to differences in outcomes, inequities refer to the systematic differences in outcomes of different population groups that arise from the social conditions in which people are born, grow, live, work and age, and the wider set of forces and systems shaping the conditions of daily life. These are avoidable, unfair differences which require government action because they deny the human rights of people with disability. The proposed objects in the Act need to be expanded to encompass all life domains to address the existing inequities and align with the CRPD.

Article 11 of the CRPD highlights the need for protecting people with disability in situations of risk and humanitarian emergencies.¹³ The CRE-DH led research on emergency planning for people with disability for the COVID-19 pandemic and the 2019-2020 bushfires. Our research found that there was a lack of attention to emergency planning with regard to people with disability.¹⁴ Nationally consistent emergency management standards that ensure access to disability-specific and disability-

responsive support before, during, and after emergencies are urgently needed as one step in the right direction to keeping people with disability safe from violence, abuse, neglect and exploitation during emergency situations.¹⁴ As such, the Act should include an object specifically related to humanitarian emergencies.

A key principle of the CRPD (Article 3) is to provide “individual autonomy including the freedom to make one’s own choices”.¹³ The Act needs to empower and support people with disability to make informed choices about services and supports and how they choose to participate in society to ensure and promote the full realisation of their human rights and fundamental freedoms. As such, the Act should include objects specifically related to individual autonomy, including the freedom to make one’s own choices about services and supports. It should also promote a supported decision-making framework to enable people with disability to make decisions about their services and supports.

A national safeguarding framework to ensure the safety of supports and services for people with disability must be implemented given the extensive evidence about Australians with disability experiencing abuse, neglect or unnecessary hardship arising from poor quality or unsafe supports or services.¹⁵ The Act therefore needs an object that clearly articulates the importance of comprehensive safeguarding that monitors service design and implementation so that the human rights of people with disability are upheld when they are accessing services and supports.

Article 7 of the CRPD indicates additional protections are required for children with disability to ensure they “have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”.¹³ The UN Outcomes Report on Australia expresses concern about the lack of focus on the rights of children with disability within national plans and legislation.¹ As such, the Act should include an object specifically related to children and young people with disability to ensure that supports and services are provided in an age-appropriate manner that enables their views to be heard and

taken into consideration on all matters affecting them.

Article 33 of the CRPD requires national monitoring to ensure coordinated implementation across different sectors and different levels of government, while Article 31 requires that data be collected to ensure that obligations of the CRPD are being met. Thus, all services and supports for people with disability, whether disability-specific or mainstream, must be required to collect consistent and high-quality data that can be used to monitor programs and ensure the needs of people with disability are being met. An object should be included in the Act to enforce this need for evaluation.

When implementing and monitoring Australia’s progress on the CRPD, it is critical that people with disability are included in any decision-making body that is involved in the design, implementation, evaluation, and/or maintenance of disability supports and services. The UN Concluding Observations on Australia¹ recommended that a formal mechanism for meaningful engagement of people with disability and their representative organisations is necessary for the implementation and monitoring of the CRPD. This important concept should be included as an object in the Act.

We make the following recommendations regarding the objects within the Act:

Recommendation 5: The proposed objects are too narrow. While increasing social and economic participation is critical, the objects covered under the Act need to be expanded to include social protection, health, justice, non-discrimination, protection from violence, housing, transport and recreation.

Recommendation 6: An object should be added that addresses humanitarian emergencies, ensuring access to disability-specific and disability-responsive support during emergencies.

Recommendation 7: The objects should emphasise the importance of individual autonomy for how a person with disability chooses to participate in society, such that their life experiences are meaningful to them.

Recommendation 8: The objects should include enabling people with disability to exercise

choice and control in the planning and delivery of their services and supports, including both disability-specific and mainstream services and supports.

Recommendation 9: The objects should promote a supported decision-making framework to enable people with disability to make decisions about their services and supports.

Recommendation 10: An object should be added about the importance of safeguarding arrangements to protect people with disability from experiencing abuse, neglect or hardships arising from poor quality or unsafe supports or services.

Recommendation 11: An object should be added that ensures realisation of the rights of the child so that supports and services for children and young people with disability are provided in an age-appropriate manner that enables their views to be heard and taken into consideration on all matters affecting them.

Recommendation 12: An object should be added to ensure that both disability-specific services and mainstream government services are required to collect consistent, high-quality data on the supports and services offered to people with disability that can be used to monitor programs and policies.

Recommendation 13: The objects should ensure that any decision-making body that is involved in the design, implementation, evaluation, and/or maintenance of disability services includes people with disability in its decision-making processes.

Question 2 – Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

Article 1 of the CRPD conceptualises people with disability as people whose impairments interact with various barriers to hinder full and effective participation in society on an equal basis with others.¹³ It does not matter whether disability is ‘physical’ or ‘mental’, whether it was present at birth or acquired later in life, or whether it is temporary or permanent. What matters is that disability limits equal participation in society due to the interaction between people’s health conditions and impairments and existing societal barriers. Disability services and supports need to be designed to overcome societal barriers to support individuals with disability to participate in society on an equal basis with others, regardless of how old a person is, their type of disability, or the permanence of their disability. To ensure Australia meets its obligations under the CRPD, the new Act needs to define the target group inclusively to align with the CRPD.

Taking a broad definition of disability means that the target group will be diverse, including people with a wide range of support needs. In addition, it is important to acknowledge the contextual nature of disability, the experience of which will be diverse as it results from the interaction between a person’s impairments, the environment in which they live and their personal characteristics. This reflects the biopsychosocial model of disability defined by the ICF (explained in our response to Question 4). The diversity of the target group needs to be acknowledged in the design and implementation of services and supports. To do this, the Act must consider the needs of people with disability from a person-centred approach, so that services and supports are designed in a manner that takes into account each individual’s circumstances.

It is also important to recognise and address the multiple and intersectional forms of discrimination experienced by subgroups of the population of people with disability, including women, Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse people, and people in rural and remote communities. Such subpopulations were

highlighted as an area of concern in the UN Concluding Observations on Australia.¹

We make the following recommendations regarding the approach to the target group:

Recommendation 14: The new Act needs to define the target group inclusively and align with the CRPD conceptualisation of disability. This means disability is understood based on whether an individual’s participation in society is restricted due to interactions between their impairments and societal, physical, cultural or environmental barriers.

Recommendation 15: The Act must consider the diverse needs of people with disability, such that services and supports are developed and implemented from a person-centred approach, taking into account each individual’s circumstances.

Recommendation 16: The Act needs to consider the intersectional disadvantage that occurs for people with disability, including women, Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse people, and people in rural and remote communities.

Question 4 – Do you think the new Act should include a definition for disability? Do you have any additional comments?

The CRPD recognises that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.¹³ The Act should include a definition of disability that aligns with this conceptualisation of disability.

The biopsychosocial model of disability, as defined within the International Classification of Health and Functioning (ICF) framework,¹⁶ is the definition used by the World Health Organization and aligns with the CRPD. The ICF framework articulates that disability cannot be defined solely based on biological factors, such as the presence of health conditions or impairments to body functions or structures. Instead, disability is a complex phenomenon resulting from dynamic interactions between biological factors, environmental factors, and personal factors, that cause difficulty in undertaking everyday activities and limit participation within society. Consequently, the definition of disability needs to focus on people’s level of functioning within the environment in which they live, determined by individual, social and environmental characteristics.

The ICF is accepted worldwide and is a key tool used as the basis for defining disability within national data collections including in Australia by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.¹⁷ Using the ICF to define disability in the Act will assist consistent data collection about supports and services for people with disability, essential for meeting Australia’s obligations under Article 31 of the CRPD with regard to statistics and data collection.

We make the following recommendation regarding the definition of disability within the Act:

Recommendation 17: The new Act should include a definition of disability. It should align with the biopsychosocial model of disability of the ICF framework. The ICF provides a standard language for describing functioning and disability. This approach will include all people with disability.

Question 6 – Do you agree with the supports and services listed above? What other kinds of supports and services should be included in the new Act?

In response to this question, we provide recommendations relating to data collection and research.

The Act must take a broad approach when considering supports and services for people with disability, regardless of whether they are disability-specific or mainstream, whether they are provided by Federal or state or territory governments, and across all life domains. The need for better disability data applies across the full breadth of supports and services.

Article 31 of the CRPD, Statistics and Data Collection, requires the collection of statistical and research data to ensure that obligations under the CRPD are met.¹³ However this was raised as an area of concern by the 2019 UN Concluding Observations on Australia, which recommended development of an overarching “national disability data framework to ensure appropriate, nationally consistent measures for the collection and public reporting of disaggregated data across the full range of obligations contained in the Convention”.¹ This would ensure that all government services (disability and mainstream) collect consistent data that can be used to monitor outcomes and identify drivers of inequities, to develop evidence-based policies and programs.

Australia’s Disability Strategy 2021-2031 has committed to more comprehensive and visible reporting.¹⁸ However, without a rigorous and consistent methodology for identifying people with disability, it will not be possible to track progress for people with disability against the outcome areas, nor will it be possible to inform and evaluate government policies and programs. Thus, being able to identify the group of people with disability is a necessity to achieve the aims of Australia’s Disability Strategy 2021-2031 and to meet Australia’s obligations under the CRPD.

While some mainstream services collect basic disability information as part of their routine data collection, such as Services Australia for the Disability Support Pension or for people who are

temporarily incapacitated and unable to work, the data is inconsistent between different data collections and does not align with the ICF. Most mainstream services however do not routinely collect disability information, making it difficult to track the needs of people with disability within these services. This is particularly problematic within the health sector.

The CRE-DH invested in research to develop disability questions suitable for use in primary care for the Voluntary Patient Registration (VPR) scheme in general practices and Aboriginal Community Controlled Health Services across Australia.¹⁹ The questions were developed in partnership with people with disability and their representative organisations and guided by the ICF and the CRPD to ensure consistency between different data collections and alignment with the ICF. The research demonstrated that there was broad support for capturing patient disability information on the VPR form, demonstrating the potential for collection of disability data in mainstream services.

In recognition of the need for better disability data, there have recently been large government investments in improving disability data by investing in data linkage. However, because disability data are not routinely collected in mainstream services, disability information in linked datasets relies on data from disability services and supports. The CRE-DH led a research project evaluating the capacity to identify people with disability in linked administrative data for one of the five National Disability Data Asset (NDDA) test cases. The study found that some subgroups of people with disability were under-represented in linked specialist disability services and supports data including people with sensory or speech disability and acquired brain injury, older people with disability, women, and people with high education and income that were less likely to access disability payments and services.²⁰ This study clearly demonstrated an immediate need for improvement in collection of consistent disability data across all government services, including mainstream services. The study also demonstrated important difference in the types of disability data that are collected between disability-specific services, highlighting the need for a consistent approach to disability data collection in disability-specific services, as well as mainstream services. Despite the limitations of the data, the findings highlighted the huge potential for data linkage for monitoring of

outcomes for people with disability to drive change.

Article 31 of the CRPD requires that statistical and research data, which ensure confidentiality and privacy for people with disability, is disseminated and made accessible to “persons with disabilities and others” and used to help “identify and address the barriers faced by persons with disabilities in exercising their rights”.¹³ It is therefore essential that the Act commits to sharing de-identified data for research purposes, where appropriate safeguards are available to ensure data confidentiality.

It is critical that disability research capacity is built across all disability stakeholders so that all people with an interest in disability research and outcomes can meaningfully contribute to assessing and monitoring outcomes and identifying drivers of inequities that need to be addressed within new policies and programs.²¹

Data from all government services and supports should include information about (i) the nature, quantity and extent of services and supports provided, (ii) characteristics of individuals to whom services and supports are provided (including disability identifiers), (iii) the quality of services and supports provided, and (iv) associated outcomes for individuals to whom services and supports are provided. Such data are essential for transparency and accountability, to monitor compliance, effectiveness and quality of disability services and to inform ongoing improvements to improve outcomes for people with disability.

An example of where improved dissemination is required is data collected by the National Disability Insurance Agency (NDIA) on Australians who receive NDIS supports. NDIS data is made available to approved researchers via the Multi-Agency Data Integration Project (MADIP), a whole population linked data resource bringing together information on health, education, government payments, income and taxation, employment, and population demographics over time. However, only selected data about NDIS participants is available within MADIP. Furthermore, while the NDIA collects information about people with disability who applied for NDIS supports but did not meet access requirements, these data are not available via MADIP. Article 31, item 2, of the CRPD requires that statistical and research data

shall be disaggregated and used to “identify and address the barriers faced by persons with disabilities in exercising their rights”.¹³

Therefore, all data about NDIS participants and unsuccessful applicants, along with other NDIA processes, must be made available for research purposes to understand whether the NDIS is meeting the needs and rights of people with disability.

We make the following recommendations relating to data collection:

Recommendation 18: Data collection is essential for monitoring progress in meeting Australia’s obligations under the CRPD. The Act needs to commit to collecting nationally consistent disability data and reporting at regular intervals on outcomes for people with disability.

Recommendation 19: All mainstream government services, whether provided by Federal or state or territory governments, need to include nationally consistent disability identifiers to permit transparent and accountable reporting of outcomes for people with disability.

Recommendation 20: All government disability services, whether provided by Federal or state or territory governments, need to collect and report data about (i) the nature, quantity and extent of services and supports provided, (ii) characteristics of individuals to whom services and supports are provided (including disability identifiers), (iii) the quality of services and supports provided, and (iv) associated outcomes for individuals to whom services and supports are provided.

Recommendation 21: The Act should recognise the importance of data linkage to capture involvement of people with disability, their pathways through supports and services, and to enable monitoring of outcomes for people with disability to drive change and decrease inequities.

Recommendation 22: The Act should commit to sharing de-identified data, with appropriate governance in place, for research purposes.

Recommendation 23: The Act should highlight the need to build disability research capacity across all disability stakeholders, including people with disability, to undertake research

and to disseminate findings broadly including with people with disability and other stakeholders.

Recommendation 24: The Act should highlight the need to make existing disability data available to researchers with appropriate safeguards including a secure and de-identified form. For instance, NDIS data about current and past participants, as well as people who have applied to the NDIS but not met access requirements. This means that data is not limited to snapshots in time but enables independent researchers to assess whether disability and mainstream supports, services and policies, are meeting the needs of people with disability and do not create or reinforce inequities.

Concluding comments

Australia is still a considerable distance from meeting its obligations under the CRPD, as evidenced by the lengthy set of concerns and recommendations detailed in the recent UN Concluding Observations on Australia.¹ Revising the very outdated Disability Services Act (1986) is an important step forward, given that the Act is a key piece of legislation for regulating the supports and services provided for people with disability.

The CRPD requires regular monitoring and reporting to ensure that obligations are being met. Similarly, it is important that the Act is periodically reviewed alongside monitoring of CRPD regulations and revised accordingly to ensure that best practices are implemented for support and service provision and that the human rights of people with disability are being met.

We recommend the following:

Recommendation 25: The Disability Services Act should be reviewed at least every 10 years to ensure that it continues to meet obligations under the CRPD and meets best practice in disability service provision.

REFERENCES

1. United Nations Committee on the Rights of Persons with Disabilities. Concluding observations on the combined second and third periodic reports of Australia. 2019. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fCO%2fAU%2fCO%2f2-3&Lang=en.
2. Aitken Z, Simpson JA, Bentley R, Kavanagh AM. How much of the effect of disability acquisition on mental health is mediated through employment and income? A causal mediation analysis quantifying interventional indirect effects using data from four waves of an Australian cohort study. *BMJ Open* 2021; **11**(11): e055176.
3. Emerson E, Fortune N, Aitken Z, Hatton C, Stancliffe R, Llewellyn G. The wellbeing of working-age adults with and without disability in the UK: Associations with age, gender, ethnicity, partnership status, educational attainment and employment status. *Disabil Health J* 2020; **13**(3): 100889.
4. Aitken Z, Baker E, Badland H, et al. Precariously placed: housing affordability, quality and satisfaction of Australians with disabilities. *Disabil Soc* 2019; **34**(1): 121-42.
5. Devine A, Vaughan C, Kavanagh A. If I had stable housing I would be a bit more receptive to having a job. Factors influencing the effectiveness of Disability Employment Services reform. *Work* 2020; **65**(4): 775-87.
6. Aitken Z, Krnjacki L, Kavanagh AM, Lamontagne AD, Milner A. Does social support modify the effect of disability acquisition on mental health? A longitudinal study of Australian adults. *Social Psychiatry and Psychiatric Epidemiology* 2017; **52**(10): 1247-55.
7. Emerson E, Fortune N, Llewellyn G, Stancliffe R. Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study. *Disabil Health J* 2021; **14**(1): 100965.
8. Emerson E, Milner A, Aitken Z, Vaughan C, Llewellyn G, Kavanagh AM. Exposure to discrimination and subsequent changes in self-rated health: prospective evidence from the UK's Life Opportunities Survey. *Public Health* 2020; **185**: 176-81.
9. Krnjacki L, Priest N, Aitken Z, et al. Disability-based discrimination and health: findings from an Australian-based population study. *Aust N Z J Public Health* 2018; **42**(2): 172-4.
10. Krnjacki L, Emerson E, Llewellyn G, Kavanagh AM. Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study. *Aust N Z J Public Health* 2016; **40**(1): 16-21.
11. Rachele JN, Disney G, Milner A, Emerson E, Krnjacki L, Kavanagh AM. Violence and Mental Health: Does Disability Make a Difference? *Epidemiology* 2020; **31**(1): e6-e7.
12. Centre of Research Excellence in Disability and Health. Disability and Wellbeing Monitoring Framework: Baseline indicator data for Australians aged 18-64 years. Melbourne: Centre of Research Excellence in Disability and Health, 2022. <https://doi.org/10.25910/ffxs-wd42>.
13. United Nations General Assembly. Convention on the Rights of Persons with Disabilities: resolution 61/106 (24 January 2007), A/RES/61/106. Geneva, 2007.
14. Llewellyn G, Kavanagh A, Smith-Merry J, Villeneuve M, Dickinson H, Petrie D. Submission to the Disability Royal Commission on Emergency Planning and Disaster Preparedness. Melbourne: University of Melbourne, 2021. <https://doi.org/10.26188/14572317.v3>.
15. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Interim Report. 2020. <https://disability.royalcommission.gov.au/publications/interim-report>.
16. World Health Organization. Towards a common language for functioning, disability and health: ICF the international classification of functioning, disability and health. Geneva: WHO; 2002.
17. Madden R, Glozier N, Mpofu E, Llewellyn G. Eligibility, the ICF and the UN Convention: Australian perspectives. *BMC Public Health* 2011; **11**(4): S6.
18. Department of Social Services. Australia's Disability Strategy 2021-2031. 2021. <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>.
19. Bailie J, Fortune N, Gordon J, Madden RC, Llewellyn G. Making everyone count: it is time to improve the visibility of people with disability in primary care. *Med J Aust* 2022; **217**(4): 173-5.

20. Aitken Z, Fortune N, Krnjacki L, Badji C, Disney G, Kavanagh A. Methodology paper: Identification of people with disability in linked administrative data. Melbourne: The University of Melbourne, 2022. <https://ndda.dss.gov.au/wp-content/uploads/2022/12/identification-people-disability-linked-administrative-data-methodology-paper-1.pdf>.
21. Buick F, West R, Dickinson H. Building effective system-wide disability research capacity in Australia. What does it look like and how do we get there?: Public Service Research Group (UNSW), 2022. <https://apo.org.au/node/320681>.