CRE–DH

Centre of Research
Excellence in
Disability and Health

THE DISABILITY AND WELLBEING MONITORING FRAMEWORK AND INDICATORS: TECHNICAL REPORT

in partnership with

THE UNIVERSITY OF MELBOURNE

THE UNIVERSITY OF SYDNEY

UNSW CANBERRA

RMIT UNIVERSITY

MONASH University

Acknowledgements

Thanks to the members of the Expert Panel of Advice who provided invaluable input into the development of the monitoring framework and indicators, and to the NSW Council for Intellectual Disability for hosting a facilitated focus group as part of the consultation process. The authors are grateful for feedback provided by the Centre of Research Excellence in Disability and Health (CRE-DH) Partner Advisory Group and members of the wider CRE-DH research team. Thanks also to Laura Davy who developed easy-read versions of the consultation materials.

Authors

Nicola Fortune[1], Hannah Badland[2], Shane Clifton[1], Eric Emerson[3], Jerome Rachele[4], Roger J Stancliffe[1], Qingsheng Zhou[1] and Gwynnyth Llewellyn[1]

[1.] Centre for Disability Research and Policy, The University of Sydney
[2.] Centre for Urban Research, RMIT University
[3.] Centre for Disability Research, Lancaster University
[4.] Disability and Health Unit, Melbourne School of Population and Global Health, The University of Melbourne

All of the authors are affiliated with the Centre of Research Excellence in Disability and Health.

ISBN 978 0 7340 5577 4

Suggested citation

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.* Centre of Research Excellence in Disability and Health, Melbourne.

Contact information

Centre of Research Excellence in Disability and Health (CRE-DH)

Telephone	+61 3 8344 0717
Email	cre-dh@unimelb.edu.au
Website	www.credh.org.au
Twitter	@DisabilityHlth

CRE–DH
Centre of Research
Excellence in
Disability and Health

CONTENTS

ABBREVIATIONS

ABS	Australian Bureau of Statistics
AHPF	Australian Health Performance Framework
CRE-DH	Centre of Research Excellence in Disability and Health
CRPD	Convention on the Rights of Persons with Disabilities
ICF	International Classification of Functioning, Disability and Health
NHMRC	National Health and Medical Research Council
OECD	Organisation for Economic Co-operation and Development
PAG	CRE-DH Partner Advisory Group
UN	United Nations
WHO	World Health Organization

EXECUTIVE SUMMARY

This Technical Report documents the development of a comprehensive Monitoring Framework and Indicators to measure and track inequalities between people with and without disability in relation to exposure to well-established social determinants of health and wellbeing. It is produced by the Centre of Research Excellence in Disability and Health (CRE-DH), a world-first research initiative that aims to build knowledge and gather the evidence needed to guide social and health policy reform for people with disability in Australia. The CRE-DH is funded by the National Health and Medical Research Council.

The **Disability and Wellbeing Monitoring Framework** was developed by the Mapping Inequities Work Program, with input from the wider CRE-DH research team and Partner Advisory Group. Input was sought from an Expert Panel of Advice comprising people with lived experience of disability, to ensure that the Monitoring Framework and Indicators comprehensively capture the health, social, economic and wellbeing issues that are important and meaningful to people with disability.

Two complementary suites of indicators have been developed to sit within the structure of the Monitoring Framework:

Person indicators

These will be used to report national baseline data on exposure to social determinants of health and wellbeing for people with and without disability, and to track change over time, including changes in absolute and relative inequalities.

Area indicators

These will be used to explore socio-spatial patterning of social determinants of health and wellbeing, and investigate the contribution of area-level variables in the relationship between disability, health and the social determinants of health and wellbeing.

Key next steps for this work include reporting national data for the person indicators and area indicators. Analyses using the indicator data will be conducted to identify possible intervention points to address socially-produced inequalities between people with and without disability. The CRE-DH also aims to work with governments and statutory agencies responsible for data collection and reporting to address data gaps and limitations that have been identified through this work.

It is anticipated that the Monitoring Framework will be embraced by a diversity of stakeholders in the disability sector and beyond as a valuable tool to inform public discussion and effective policy responses. We will continue to actively engage with stakeholders, including people with disability and their representative organisations, to further develop and disseminate this work.

Further detail is provided in the Appendices:

Appendix A presents the full suite of person indicators, within the domain (main headings) and topic (sub-headings) structure of the monitoring framework.

Appendix B provides a summary of key data sources to be used for reporting baseline person indicator data.

Appendix C lists the area indicators for the Monitoring Framework.

Appendix D shows how the domain structure of the Disability and Wellbeing Monitoring Framework relates to two important international frameworks – the CRPD and the ICF.

Appendix E provides a summary of the input provided by the Expert Panel of Advice.

1. INTRODUCTION

1.1 Background

The vision of the WHO Global Disability Action Plan 2014–2021 is "a world in which all persons with disabilities and their families live in dignity, with equal rights and opportunities, and are able to achieve their full potential"[1]. International and Australian evidence shows that people with disability experience poorer health and increased rates of exposure to health risks when compared with people without disability [1-8]. They also have higher rates of health service use and chronic conditions such as diabetes and heart disease, and are less likely to use preventive health care [9-13]. People with disability are disadvantaged with respect to social determinants of health: these are the upstream factors that affect health through the conditions in which people are born, grow, live, work, and age, and which are, in turn, shaped by political, social, and economic forces [14]. Evidence shows that people with disability are more likely than those without to experience poverty [15-18], violence [19, 20], social exclusion [15], housing insecurity [16, 17], unemployment and economic inactivity [16, 17, 21].

We urgently need effective policy responses to reduce these inequalities between people with and without disability through action on the social determinants of health.

National and international reports and strategies recommend monitoring social, economic and health outcomes for people with disability in comparison with non-disabled people, to identify levers for policy and political action [8, 22, 23]. The UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Australia in 2008, requires States Parties to monitor implementation of the Convention and report on progress (Articles 31(2), 33(2) and 35(1)) [23]. Australia's National Disability Strategy 2010-2020 provides a framework for Australia to meet its obligations under the CRPD. The Strategy identifies indicators within six areas for policy action.[1] It states that: "Monitoring and reporting progress against the Strategy is vital to ensure that life is improving for Australians with disability". The Strategy also provides a mechanism to contribute to Australia's reporting requirements under the CRPD (p.67) [22].

Despite these obligations and undertakings at national level, there is no systematic monitoring system in place in Australia to track progress towards reducing socially-produced inequalities experienced by people with disability. A review of the implementation of the National Disability Strategy found that "the Strategy has not closed data gaps in important areas" and identified the need for "a stronger evidence base for measuring and reporting implementation progress", including to assess the impact of government initiatives on the lives of people with disability and to identify emerging policy priorities [24]. In the absence of timely and effective reporting there is a lack of public transparency and accountability in relation to Australia's progress towards achieving an inclusive society in which people with disability can fulfil their potential as equal citizens [25].

Against this backdrop, the NHMRC-funded Centre of Research Excellence in Disability and Health (CRE-DH) set out to develop a comprehensive monitoring framework and indicators to measure inequalities between people with and without disability in relation to the social determinants of health.

The CRE-DH is a world-first research initiative that aims to build knowledge and gather the evidence needed to guide social and health policy reform for people with disability in Australia (https://credh.org.au).

The multi-disciplinary research team across five universities is overseen by a Partner Advisory Group (PAG), comprising members from government and non-government organisations, statutory bodies, peak bodies and consumer representative organisations. Several members of the research team and the PAG have lived experience of disability. It is a core principle of the CRE-DH that the voices and perspectives of people with disability should be integral in shaping the research undertaken. The CRE-DH is committed to working in collaboration with people with disability, service providers, non-government organisations and other stakeholders to identify key and emerging issues affecting Australians with disability. Together, the four thematic work programs of the CRE-DH – Mapping Inequities, Social Determinants, Health Economics, and Policy Analysis and Reform – are focused on reducing disability-related inequalities that are socially-produced, inequitable, and impact on health. Achieving this will improve the health of Australians with disability, increase the overall health of the population, and reduce health and welfare expenditure.

The goals of the work presented in this report are to:

- generate knowledge of the extent, magnitude and distribution of inequalities in social, economic and health outcomes experienced by Australians with disability aged 15–64 years; [2]
- create a Monitoring Framework and Indicators to identify opportunities for policy interventions and track progress in reducing socially-produced inequalities; and
- identify what national data are available for these purposes, and data gaps that need to be addressed.

---

[1] The Areas of Policy Action in the National Disability Strategy 2010-2020 are: Inclusive and accessible communities, Rights protection, justice and legislation, Economic security, Personal and community support, Learning and skills, and Health and wellbeing.

[2] Australians aged 15–64 years are the focus of the monitoring framework and the work of the CRE-DH more broadly. Similar programs of work are needed for children and for people aged 65 years and over to build policy-relevant knowledge about disability-related inequalities in health and social determinants of health for these groups.

The Disability and Wellbeing Monitoring Framework will inform ongoing public discussion and policy action to promote the health and wellbeing of people with disability.

1.2 A rights-based, social determinants of health approach

The CRPD extends the framework of human rights enshrined in the Charter of the UN and pre-existing rights covenants and conventions to specifically articulate the rights of people with disability, recognising that "persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights" [23]. Guided by the principles and articles of the CRPD, we have sought to take an explicitly rights-based approach to development of the monitoring framework and indicators. As described in more detail below, we have operationalised this through:

- Drawing on the content of the articles of the CRPD to ensure that the monitoring framework comprehensively captures all issues of relevance to the rights of people with disability in the context of health and the social determinants of health;
- Utilising existing disability-focused, rights-based frameworks and indicator sets; and
- Seeking input from an Expert Panel of Advice comprising people with lived experience of disability.

The rights enshrined in the CRPD correspond to the fundamental aspects of life that impact people's wellbeing and on which persistent socially-generated inequalities exist between people with and without disability.

The CRE-DH research program applies a social determinants approach to understanding and acting on socially-produced health inequalities experienced by people with disability. A social determinants approach views health as a product of many interrelated factors operating at multiple levels of influence [14, 26]. Social determinants – such as socioeconomic status, early life experiences, social exclusion, social capital, housing, education, employment and access to health services – impact health at both the individual and the population level. The work of the WHO's Commission on Social Determinants of Health has been vital in providing a strong foundation of evidence and issuing a call to action on social determinants of health in order to promote health equity [14].

It is important to note that, while knowledge concerning the social determinants of health has grown rapidly in recent times, the impacts of social determinants of health specifically for people with disability have not been so thoroughly investigated.

It is possible that certain social determinants are of greater importance to the health of people with disability than to the health of the non-disabled population. Taking a dual rights-based and social determinants approach assists in broadening the range of topics considered for inclusion in the Monitoring Framework.

Discrimination and patterns of socially-produced disadvantage impact the health of people with disability and members of other marginalised groups. Some individuals are members of more than one marginalised group, and experience the combined impact of multiple disadvantaged statuses [27]. Understanding the nature, magnitude, distribution and potential causes of socially-produced health inequalities for people with disability is essential for designing policy responses and monitoring their effectiveness [28].

1.3. Process for developing the Disability and Wellbeing Monitoring Framework and Indicators

The main steps in developing the Monitoring Framework and Indicators were:

1. Developing a draft framework drawing on existing frameworks and indicator sets.
2. Consulting with the Expert Panel of Advice on the draft framework.
3. Revising the framework structure based on feedback.
4. Developing potential indicators and identifying national data sources and data gaps.
5. Consulting with the Expert Panel of Advice on the revised framework and indicators.
6. Refining the framework and indicator list based on feedback and indicator selection criteria.

At the inception of this work, members of the Mapping Inequities team, with input from the wider CRE-DH and PAG, determined the broad approach to be taken and articulated a set of guiding principles, as documented in two papers: *Frameworks and indicators for reporting on the health of working age adults with disabilities in Australia* and *Expert Panel of Advice on indicators for reporting on the social, economic and health outcomes of working age adults with disabilities in Australia* (available on request) [29, 30].

Key aspects of the development process are described in more detail in the following three sections.

2. DEVELOPING THE DRAFT MONITORING FRAMEWORK

A draft Monitoring Framework was initially developed by the Mapping Inequities team in October 2018. This was based on a review of existing international and Australian rights-based, disability-focused indicator frameworks, social determinants of health frameworks, and broader health and wellbeing frameworks. Development of the draft framework was also informed by an examination of the rights expressed in Articles of CRPD and the Environmental Factors and Activities and Participation domains in the WHO's International Classification of Functioning, Disability and Health (ICF) [31]. These source materials were selected to ensure that both social determinants of health and disability rights-based perspectives would be reflected in the monitoring framework. *Box 1 sets out the full list of sources reviewed.*

The Australian Health Performance Framework (AHPF) was the starting point for developing the framework structure [32, 33]. The AHPF has been agreed by Australian and state/territory health ministers for assessing the health of Australia's population and performance of the health system, and the Australian Institute of Health and Welfare reports data against indicators within the AHPF biennially in Australia's Health [32]. Structural consistency with the AHPF was considered desirable because of its policy currency in Australia. The AHPF has four broad domains – Health status, Determinants of health, Heath system, and Health system context – each with a number of sub-domains. The principle of equity overarches these domains. While it is not explicitly positioned as a social determinants of health framework, the AHPF Determinants of health domain covers environmental and social determinants.

Domains, themes and indicators identified in each of the sources were mapped to the structure of the AHPF. From this base, the Mapping Inequities team undertook an iterative process to develop the structure of domains (headings) and topics (sub-headings). This process involved making decisions about combining, splitting and ordering domains and topics, and the wording used. Particular considerations were the focus of the Monitoring Framework on people with disability and on social determinants of health, the Australian context, and the target population of people aged 15–64 years. The AHPF sub-domain Social inequalities was not included because indicators in all domains of the Monitoring Framework will provide information about social and health inequalities by comparing data for people with and without disability. During the development process feedback was sought from the wider CRE-DH and the PAG.

Box 1. Sources reviewed to inform development of the draft monitoring framework

Disability-focused frameworks

2010–2020: National Disability Strategy [22, 34]

A fair go? Measuring Australia's progress in reducing disadvantage for adults with disabilities [25]

Absolutely everyone. State disability plan 2017–2020 (Victoria) [35, 36]

Convention on the Rights of Persons with Disabilities [23]

Incheon Strategy Targets [37, 38]

International Classification of Functioning, Disability and Health [31]

National Disability Agreement performance indicators [39]

NDIS Outcomes Framework [40, 41]

Report on Government Services performance indicator framework [42]

World Report on Disability [8]

Social and environmental determinants of health frameworks

Closing the gap in a generation: health equity through action on the social determinants of health [14]

Creating liveable cities in Australia: Mapping urban policy implementation and evidence-based national liveability indicators [43]

Global age-friendly cities: a guide [44]

Review of social determinants and the health divide in the WHO European Region: final report [45]

Social inclusion in Australia. How Australia is faring. 2nd Edition [46]

General health and wellbeing frameworks

Australian Health Performance Framework [32]

Australia's Welfare 2017 [47]

Australia's Health Tracker [48, 49]

Global Reference List of 100 Core Health Indicators [50]

Measures of Australia's progress [51]

3. SEEKING INPUT FROM PEOPLE WITH LIVED EXPERIENCE OF DISABILITY

Input was sought from people with lived experience of disability via an **Expert Panel of Advice.** This was to ensure that the framework and indicators comprehensively capture health, social, economic and wellbeing issues that have the most meaning for people with disability. Ethical approval was granted by the University of Sydney Human Research Ethics Committee (Project number 2018/884).

Potential panel members were identified through the established networks of CRE-DH researchers, including the PAG and Disabled People's Organisations. All prospective members of the Expert Panel of Advice were sent an individual email of invitation, along with a Participant Information Statement which provided background information about the project. Participants completed informed consent forms.

The Expert Panel of Advice comprised 17 members – 14 people with disability and 3 people who had a close family member with complex disability. Members lived in six Australian jurisdictions; two members lived in non-metropolitan areas.

Two rounds of consultation were conducted:

- Round 1 (February 2019) focused on refinement of the draft monitoring framework structure.
- Round 2 (May 2019) focused on potential indicators within each framework domain.

There were 6 video conferences each involving between 2 and 6 participants, one phone feedback session, and one facilitated focus group hosted by the NSW Council for Intellectual Disability. Input received from the Expert Panel of Advice was used to inform the further development and refinement of the monitoring framework and indicators.

Our aim in forming the Expert Panel of Advice was to bring a diversity of experience and perspectives to bear on identifying framework domains and indicators for inclusion. Despite our best efforts, we were unable to secure representation of some key perspectives, in particular Aboriginal and Torres Strait Islander people with disability, people with disability from culturally and linguistically diverse backgrounds, and those living in rural and remote areas. In addition, some impairment types were not represented (e.g., hearing impairment, psychosocial impairment). These are recognised as limitations of the consultation process, and may have influenced the product presented in this report.

See **Appendix E** for a summary of the input provided by the Expert Panel of Advice.

4. DEVELOPING INDICATORS FOR THE MONITORING FRAMEWORK

Two complementary suites of indicators were developed to sit within the structure of the monitoring framework.

4.1 Person indicators

A three-stage process was used to develop the suite of person indicators.

1. An initial extensive list of potential indicators was generated based on:

i. indicators in the previously reviewed existing frameworks and indicator lists (Box 1);

ii. indicators suggested by the Expert Panel of Advice; and

iii. data items available in key national data sources (e.g., ABS surveys that contain a disability identifier, the Household Income and Labour Dynamics Survey (HILDA), and the ABS's Multi-Agency Data Integration Project).

2. Feedback on the potential indicators was sought from the Expert Panel of Advice.

3. After incorporating input from the Expert Panel of Advice, the Mapping Inequities team worked through the revised list of potential indicators, applying the indicator criteria set out in Box 2 (p.12).

The Mapping Inequities team articulated the following principles to supplement the indicator criteria and to help make consistent decisions about indicators for inclusion:

- 'Objective' measures are given preference over 'perceived' measures (e.g., 'satisfaction' measures, which are inevitably influenced by people's expectations, in turn influenced by life circumstances).
- Composite indicators should be avoided because the input variables for these may overlap with other indicators in the framework and/or span multiple framework domains.[3]
- Indicators relating to historical circumstances or inter-generational issues (e.g., witness to violence before age 15, educational attainment of parents) should not be included. This is because indicators should be responsive to changes in the phenomena of interest within a timeframe that is meaningful in a policy context; current/future policy cannot change the historical factors in people's lives.
- Indicators should enable comparison between people with and without disability; however, some indicators relating specifically to people with disability may be included to provide information about issues in the lives of people with disability relevant to the social determinants of health, such as 'Experience of disability-related discrimination' or 'Access to job design modifications'.
- Indicators relating to 'Access to support with…' will be presented together in one domain – Disability services and supports – rather than in the particular social determinant of health domains to which the support relates.
- Indicators relating to mainstream services will be presented together in one domain – Mainstream services – rather than in the particular social determinant of health domains to which the services relate.
- There should be a preference for indicators that recognise people with disability as individuals with autonomous exercise of rights (e.g., 'Personal income') over indicators that provide information about people with disability in the context of their membership of social units (e.g., 'Household income'), though both types of indicators may have value for understanding inequalities.

---

[3] For example, the Index of Relative Socio-Economic Disadvantage was calculated by the ABS from Census 2011 data using 16 variables, including household equivalised income, jobless households, dwelling internet connection, educational attainment, overcrowding.[52]

Box 2. Criteria to guide indicator selection [1]

Valid	The indicator measures the phenomenon it is intended to measure.
Relevant	The indicator relates to an issue of importance to stakeholders, in particular people with disability, and there is theoretical and/or empirical support for the indicator/topic as a social determinant of health or measure of health status.
Broadly applicable	The indicator is meaningful and comparable across different population groups to which the topic is relevant.
Reliable	The indicator is not likely to be influenced by variation in definitions or data collection methods in such a way that comparability over time or between sub-populations is compromised.
Sensitive and robust	Meaningful change in the phenomenon of interest will be reflected by a significant change in the indicator. Conversely, a change in the indicator reflects a corresponding change in the phenomenon of interest.
Easy to understand	The indicator is easily understood by decision makers and key stakeholders. (This criterion is often referred to as 'face validity'.)
Data availability and feasibility	The data needed to report the indicator can be obtained. Feasibility considerations include cost, availability of comparable data over space and time, and the burden placed on data providers.
Informative	The phenomenon to which the indicator relates can be influenced by policy action, and a change in the indicator can meaningfully inform policy action.
Parsimony and navigability	The list of indicators should be as short and concise as possible, without compromising comprehensive coverage of the social determinants of health relevant to people with disability. Indicators should be organised in a clear and logical way.

1. These criteria are closely based on a set used by the Australian Institute of Health and Welfare to select 'indicators of Australia's welfare'[52] with some modification and augmentation following a review of criteria used in the development of several other health and well-being indicator sets.

Aggregated individual-level data from national surveys and administrative data sources will be used to populate the person indicators. A national data source was sought for each indicator. For some indicators, two or more potential data sources were identified. The Mapping Inequities team agreed that Australian Bureau of Statistics (ABS) data sources should be given preference over other sources (e.g., the HILDA survey) because of consistent approach to disability identification across ABS sources and the expectation of stability and future replication of data capture methodology over time.

Three categories of ABS data sources were identified, each with different strengths and limitations[54]:

Survey of Disability, Ageing and Carers (SDAC)
Strengths: comprehensive method of disability identification; includes households and establishments providing long-term cared accommodation.

Limitations: excludes 'Very Remote' areas and 'discrete Aboriginal and Torres Strait Islander communities'; data only for people with disability for most data items.

Household surveys with short disability module
Strengths: allow comparison of people with and without disability across a broad range of variables.

Limitations: disability identification less rigorous than SDAC approach; exclude 'Very Remote' areas and 'discrete Aboriginal and Torres Strait Islander communities'.

Population Census
Strengths: high confidence in numbers because not based on a survey sample; data on the entire population (not restricted to private dwellings) and all geographic areas.

Limitations: only identifies people with 'core activity need for assistance' (intended to be conceptually equivalent to profound or severe core activity limitation in SDAC)[54].

4.2 Area indicators

A set of area indicators was developed to fit within the structure of the Monitoring Framework. This work was informed by the national liveability indicators, which were developed for monitoring spatial attributes associated with health and wellbeing across Australia's cities [43].

The area indicators are of two types:

- **Characteristics of the population** (e.g., labour force participation rate for people aged 15-64 years living within a given area).
- **Characteristics of the physical environment and infrastructure** (e.g., average distance to closest pharmacy for dwellings within a given area).

A spatial data resource will be developed containing area indicator data for Australia's 21 largest cities, capturing 90% of the Australian population. Indicator data will be produced at the spatial scale of Statistical Area Level 2 (SA2 – average population of approximately 10,000 people), designed by the ABS to reflect functional areas that represent a community that interacts together socially and economically. Where possible and meaningful, data will be produced at the scale of Statistical Area Level 1 (SA1 – average of approximately 400 people)[55].

Area indicator data will be used to explore how area-level factors related to social determinants of health vary geographically, and to identify associations between local area characteristics and health and wellbeing outcomes for people with and without disability.

5. THE DISABILITY AND WELLBEING MONITORING FRAMEWORK AND INDICATORS

The overall structure of the Disability and Wellbeing Monitoring Framework is presented in *Figure 1*. It has a hierarchical structure, with 19 domains grouped into three broader elements. Each domain has one or more topics, within which relevant indicators are specified (shown in Appendix A). There are 128 indicators in total; 113 indicators require a comparison between people with and without disability, and 15 relate specifically to the experiences of people with disability (e.g., 'Experience of disability-related discrimination').

Some topics do not have indicators assigned at this stage. In some cases this is because no relevant indicators were identified in the sources drawn upon. In other cases, indicators can be found in existing frameworks, but through discussion with the Expert Panel of Advice and the Mapping Inequities team it was concluded that these indicators were not suitable for this framework. These topics remain in the framework structure as placeholders. Further work is needed to develop appropriate indicators for these topics.

For 73% of the indicators listed in the framework an Australian national data source is available to enable reporting. For the other 27%, national data are not currently available. These indicators are retained in the framework to highlight the need for efforts to ensure that data are available in future.

Input from the Expert Panel of Advice identified three additional factors that are relevant across all the framework domains:

- Community attitudes,
- Access to opportunities, and
- Advocacy and empowerment.

Further development and consultation is needed to determine how these factors can meaningfully be represented in the framework in relation to monitoring socially-produced inequalities between people with and without disability.

Appendix A presents the full suite of person indicators, within the domain (main headings) and topic (sub-headings) structure of the Disability and Wellbeing Monitoring Framework.

Appendix B provides a summary of key data sources to be used for reporting baseline person indicator data.

Appendix C lists the area indicators for the Disability and Wellbeing Monitoring Framework.

Appendix D shows how the domain structure of the Disability and Wellbeing Monitoring Framework relates to two important international frameworks – the CRPD and the ICF.

Figure 1. Elements and related domains in the Disability and Wellbeing Monitoring Framework

ELEMENTS	DOMAINS
Health	1. Subjective health and wellbeing
	2. Morbidity
	3. Mortality
	4. Lifestyle factors
	5. Personal biomedical factors
Social determinants of health	6. Physical environment
	7. Transport
	8. Food
	9. Information and communications
	10. Income and material resources
	11. Housing
	12. Employment
	13. Education
	14. Family and relationships
	15. Social and civic participation
	16. Justice and safety
Service system	17. Health services
	18. Disability services and supports
	19. Mainstream services

6. NEXT STEPS

The Monitoring Framework provides a comprehensive, conceptually-informed basis for reporting on the social determinants of health and inequalities between Australians aged 15–64 years with and without disability. The person indicators will be used to report national baseline data on exposure to social determinants of health and wellbeing for people with and without disability, and to track change over time, including changes in absolute and relative inequalities. The area indicators will be used to explore socio-spatial patterning of social determinants of health and wellbeing, and investigate the contribution of area-level variables in the relationship between disability, health and the social determinants of health and wellbeing. In addition, by identifying national data gaps, the framework has an important role to play in highlighting the need to address deficiencies in national data.

Key next steps for this work include:

- **Reporting national baseline data** for the person indicators and area indicators.
- Seeking input about how the Monitoring Framework can be used to best **meet the needs of policy makers**. This will include consulting with a range of stakeholders and working with the CRE-DH Policy Lab, an expert panel of 30 individuals with knowledge and experience in the areas of disability and/or health policy [56].
- **Identifying priorities for more in-depth analyses,** including bringing person indicators and area indicators together to gain a more sophisticated understanding of spatial patterning and associations in relation to the social determinants of health and possible intervention points to address inequalities.
- **Data advocacy** efforts in collaboration with governments and statutory agencies responsible for data collection to address the data gaps identified.

It is anticipated that indicator data and findings will be disseminated by way of a variety of forums and communication methods aimed at different audiences. The framework may be used in its entirety, for example for reporting data at national or state level against all indicators specified. Subsets of indicators may be selected for specific purposes, for example to report on issues of special interest to a particular population group defined by impairment type or geographic location. It is anticipated that the monitoring framework will be used systematically by reporting at regular intervals, on selected indicators of topical interest and as a whole, to inform public discussion and to assist in developing effective policy responses.

To this end, we will continue to actively engage with stakeholders, including people with disability and their representative organisations, in further developing and disseminating this work.

REFERENCES

1. World Health Organization. *WHO global disability action plan 2014-2021. Better health for all people with disability.* Geneva (CH): WHO; 2015.

2. Allerton L, Emerson E. Individuals with impairments face significant barriers to accessing health services in the United Kingdom. *Public Health*. 2012;126(11):920-7.

3. Emerson E, Madden R, Graham H, Llewellyn G, Hatton C, Robertson J. The health of disabled people and the social determinants of health. *Public Health*. 2011;125(3):145-7.

4. Emerson E, Vick B, Rechel B, Muñoz I, Sørensen J, Färm I. *Health inequalities and people with disabilities in Europe*. Copenhagen: European Regional Office of the World Health Organization; 2013.

5. Emerson E. Health status and health risks of the "hidden majority" of adults with intellectual disability. *J Intellect Dev Disabil*. 2011;49(3):155-65.

6. Australian Institute of Health and Welfare. *Health of Australians with disability: health status and risk factors. Bulletin 83. Cat no. AUS 132*. Canberra (AU): AIHW; 2010.

7. Emerson E, Madden R, Robertson J, Graham H, Hatton C, Llewellyn G. *Intellectual and physical disability, social mobility, social inclusion and health: background paper for the Marmot Review*. Lancaster (GB): Centre for Disability Research, Lancaster University; 2009.

8. World Health Organization, World Bank. *World report on disability*. Geneva (CH): WHO; 2011.

9. Australian Institute of Health and Welfare. *Access to health services by Australians with disability. Cat no DIS 70*. Canberra (AU): AIHW; 2017.

10. Llewellyn G, Balandin S, Poulos A, McCarthy L. Disability and mammography screening: intangible barriers to participation. *Disabil Rehabil*. 2011;33(19-20):1755-67.

11. Chen L, Chou Y, Tsay J, Lee C, Chou P, Huang N. Variation in the cervical cancer screening compliance among women with disability. *J Med Screen*. 2009;16(2):85-90.

12. Horner-Johnson W, Dobbertin K, Andresen E, Iezzoni L. Breast and cervical cancer screening disparities associated with disability severity. *Women's Health Issues*. 2014;24(1):e147-53.

13. Ramjan L, Cotton A, Algoso M, Peters K. Barriers to breast and cervical cancer screening for women with physical disability: a review. *Women Health*. 2015;56(2):141-56.

14. Commission on Social Determinants of Health. *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva (CH): WHO; 2008.

15. Emerson E, Honey H, Llewellyn G. *Left behind: 2013. Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities 2001 – 2011. Technical Report 1, February 2013*. Centre for Disability Research and Policy, University of Sydney; 2013.

16. Kavanagh AM, Krnjacki L, Aitken Z, LaMontagne AD, Beer A, Baker E, Bentley R. Intersections between disability, type of impairment, gender and socio-economic disadvantage in a nationally representative sample of 33,101 working-aged Australians. *Disabil Health J*. 2015;8(2):191-9.

17. Kavanagh AM, Krnjacki L, Beer A, Lamontagne AD, Bentley R. Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities. *Int J Equity Health*. 2013;12.

18. Banks LM, Kuper H, Polack S. Poverty and disability in low- and middle-income countries: A systematic review. *PLoS One*. 2017;12(12).

19. 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.

20. Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, McCoy E, Mikton C, Shakespeare T, Officer A. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet*. 2012;379(9826):1621-9.

21. Milner A, LaMontagne A, Aitken Z, Bentley R, Kavanagh A. Employment status and mental health among persons with and without a disability: evidence from an Australian cohort study. *J Epidemiol Community Health*. 2014;68(11):1064-71.

22. Commonwealth of Australia. *2010–2020 National Disability Strategy. An initiative of the Council of Australian Governments*. Commonwealth of Australia; 2011.

23. United Nations. *Convention on the Rights of Persons with Disabilities*.

24. Davy L, Fisher K, Wehbe A, Purcal C, S R, Kayess R, Santos D. *Review of implementation of the National Disability Strategy 2010-2020. Final report*. Sydney (AU): Social Policy Research Centre, UNSW; 2018.

25. The Centre of Research Excellence in Disability and Health. *A Fair Go? Measuring Australia's progress in reducing disadvantage for adults with disabilities (2001-2016)*. Melbourne (AU): Centre of Research Excellence in Disability and Health; 2017.

26. Dahlgren G, Whitehead M. *Policies and strategies to promote social equity in health. Background document to WHO—strategy paper for Europe*. Stockholm, Sweden: Institute for Future Studies; 1991.

27. Brown RL, Moloney ME. Intersectionality, work, and well-being: the effects of gender and disability. *Gender & Society*. 2019;33(1):94-122.

28. Braveman P, Krieger N, Lynch J. Health inequalities and social inequalities in health. *Bull World Health Organ*. 2000;78(2):232-4.

29. Llewellyn G, Stancliffe R, Emerson E, Zhou Q, Badland H, Clifton S. *Expert Panel of Advice on indicators for reporting on the social, economic and health outcomes of working age adults with disabilities in Australia*. University of Sydney; 2018.

30. Llewellyn G, Emerson E. *Frameworks and indicators for reporting on the health of working age adults with disabilities in Australia*. University of Sydney; 2018.

31. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva (CH): WHO; 2001.

32. Australian Institute of Health and Welfare. *Australia's Health 2018*. Canberra (AU): AIHW; 2018.

33. National Health Information and Performance Principal Committee. *The Australian Health Performance Framework*. Adelaide: COAG Health Council; 2017.

34. Department of Social Services. *2010-2020 National Disability Strategy. Progress Report to the Council of Australian Governments 2014*. 2014.

35. Kavanagh A, Davern M, Krnjacki L, Llewellyn G, Emerson E, McVilly K, Madden R. *Absolutely everyone: State disability plan 2017–2020 indicators development*. University of Melbourne, RMIT University, University of Sydney; 2018.

36. State of Victoria. *Absolutely everyone. State disability plan 2017–2020*. 2016.

37. United Nations Economic and Social Commission for Asia and the Pacific. *Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific*. Bangkok (TH): United Nations; 2012.

38. United Nations Economic and Social Commission for Asia and the Pacific. *Building Disability Inclusive Societies in Asia and the Pacific: Assessing progress of the Incheon strategy*. Bangkok (TH): United Nations; 2018.

39. Council of Australian Governments. National Disability Agreement. 2010.

40. National Disability Insurance Agency. *National Disability Insurance Scheme. Outcomes framework pilot study: summary report*. 2015.

41. National Disability Insurance Agency. *National Disability Insurance Scheme. COAG Disability Reform Council Quarterly Report.* December 2017. 2017.

42. Productivity Commission. Report on Government Services 2018.

43. Arundel J, Lowe M, Hooper P, Roberts R, Rozek J, Higgs C, Giles-Corti B. *Creating liveable cities in Australia: Mapping urban policy implementation and evidence-based national liveability indicators*. Melbourne (AU): Centre for Urban Research, RMIT University; 2017.

44. World Health Organization. *Global age-friendly cities: a guide*. Geneva: World Health Organization; 2007.

45. World Health Organization Regional Office for Europe. *Review of social determinants and the health divide in the WHO European Region*: final report. 2013.

46. Australian Social Inclusion Board. *Social Inclusion in Australia. How Australia is faring. 2nd Edition*. Canberra: Commonwealth of Australia; 2012.

47. Australian Institute of Health and Welfare. *Australia's welfare 2017*. Australia's welfare series no 13 AUS 214. Canberra (AU): AIHW; 2017.

48. Australian Health Policy Collaboration. *Targets and indicators for chronic disease prevention in Australia. Technical paper No. 2015-08*. 2015.

49. Tolhurst P, Lindberg R, Calder R, Dunbar J, de Courten M. *Australia's Health Tracker. Technical Appendix. Second edition. Technical Paper 2016-03*. Melbourne: The Australian Health Policy Collaboration; 2016.

50. World Health Organization. *Global reference list of 100 core health indicators*. Geneva (CH): WHO; 2015.

51. Australian Bureau of Statistics. Measures of Australia's Progress 2013. 1370.0 Canberra (AU): ABS; 2014:

52. Australian Bureau of Statistics. *Socio-Economic Indexes for Areas (SEIFA) 2011. Technical paper. ABS Catalogue no. 2033.0.55.001*. Canberra (AU): ABS; 2013.

53. Australian Institute of Health and Welfare. *Australia's welfare 2005*. Canberra (AU): AIHW; 2005.

54. Australian Bureau of Statistics. *4431.0.55.002 - ABS Sources of Disability Information, 2012 - 2016*. Canberra (AU): ABS; 2018.

55. Australian Bureau of Statistics. *1270.0.55.001 - Australian Statistical Geography Standard (ASGS): Volume 1 - Main Structure and Greater Capital City Statistical Areas, July 2016* Canberra (AU): ABS; 2016.

56. Green C, Dickinson H, Carey G. *Debates in disability and health policy: health inequities and the social determinants of health for working-age Australians with disability*. Melbourne (AU): Centre of Research Excellence in Disability and Health; 2018.

CRE–DH

Centre of Research
Excellence in
Disability and Health

Disability and Wellbeing Monitoring Framework and Indicators: Technical Report

APPENDICES

in partnership with

THE UNIVERSITY OF MELBOURNE

THE UNIVERSITY OF SYDNEY

UNSW CANBERRA

RMIT UNIVERSITY

MONASH University

Contents

APPENDIX A

Person indicators within the Disability and Wellbeing Monitoring Framework structure

Key to data sources

Census: Census of Population and Housing, 2016

GSS: General Social Survey, 2014

HEIH: Household Expenditure, Income and Housing, 2015-16

HILDA: Household Income and Labour Dynamics Survey

NHS: National Health Survey, 2014-15 or 2017-18

PSS: Personal Safety Survey, 2016

SDAC: Survey of Disability, Ageing and Carers, 2018

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
HEALTH			
1. Subjective health and wellbeing	**1.1 Self-rated health**	Self-rated health	**NHS 2017–18** – % of people who reported their health to be 'very good' or 'excellent'
	1.2 Self-rated wellbeing	Subjective wellbeing	Current data gap: % of people who reported high level of subjective wellbeing; with/without disability
		Life satisfaction	**GSS** – % of people who rated their overall life satisfaction as 7 or higher on a scale of 0 to 10
	1.3 Self-rated mental health	Self-rated mental health	**NHS 2017–18** – % of people with low levels of psychological distress (based on Kessler 10 score)
2. Morbidity	**2.1 Incidence of selected health conditions**	Incidence of heart attacks	Current data gap: incidence of heart attacks; with/without disability
		Incidence of selected cancers (Breast; Bowel; Melanoma; Lung; Cervical)	Current data gap: incidence of specified cancers; with/without disability
		Notification rates of sexually transmissible infections and blood-borne viruses (Syphilis; HIV; Hepatitis B; Hepatitis C; Chlamydia; Gonorrhoea)	Current data gap: notification rates of specified sexually transmissible infections and blood-borne viruses; with/without disability
		Incidence of end-stage kidney disease	Current data gap: Incidence of end-stage kidney disease; with/without disability
	2.2. Prevalence of selected health conditions	Mental illness	**NHS 2017–18** – % of people who reported having a current and long-term mental or behavioural condition
		Depression	**NHS 2017–18** – % of people who reported having current and long-term depression
		Anxiety	**NHS 2017–18** – % of people who reported having current and long-term anxiety-related problems
		Diabetes	**NHS 2017–18** – % of people who reported having diabetes currently
		Asthma	**NHS 2017–18** – % of people who reported having current and long-term asthma
		Poor dental health	Current data gap: Prevalence of poor dental health; with/without disability

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
	2.3 Cause-specific hospitalisation	Hospitalisation for injury and poisoning	Current data gap: rate of hospitalisation for injury and poisoning; with/without disability
3. Mortality	**3.1 All-cause mortality**		Topic placeholder – no indicators
	3.2 Cause-specific mortality		Topic placeholder – no indicators
	3.3 Life expectancy		Topic placeholder – no indicators
	3.4 Suicide	Suicide rate	Current data gap: Suicide rate; with/without disability
4. Lifestyle factors	**4.1 Physical activity**	Physical activity level	**NHS 2017–18** – % of people who met the Physical Activity Guidelines 2014 (incl exercise and workplace)
	4.2 Smoking	Smoker status	**NHS 2017–18** – % of people who are a current daily smoker
	4.3 Alcohol consumption	Risky alcohol consumption	**NHS 2017–18** – % of people who exceeded the lifetime alcohol risk level - 7 day average (2009 guidelines)
	4.4 Diet	Fruit and vegetable consumption	**NHS 2017–18** – % of people who met both fruit and vegetable consumption guidelines (2013 NHRMC guidelines)
		Vegetable consumption	**NHS 2017–18** – % of people who met vegetable consumption guidelines (2013 NHRMC guidelines)
		Fruit consumption	**NHS 2017–18** – % of people who met fruit consumption guidelines (2013 NHRMC guidelines)
	4.5 Drug use		Topic placeholder – no indicators
5. Personal biomedical factors	**5.1 BMI/obesity**	Body Mass Index	**NHS 2017–18** – % of people who are overweight or obese based on BMI measurement
	5.2 Blood pressure		Topic placeholder – no indicators
	5.3 Blood glucose		Topic placeholder – no indicators
SOCIAL DETERMINANTS OF HEALTH			
6. Physical environment	**6.1 Air, water and noise**		Topic placeholder – no indicators
	6.2 Built environment accessibility	Difficulty accessing venues/ locations	**SDAC –** % of people with disability who had difficulty accessing buildings or facilities in last 12 months
		Access to social venues	**SDAC –** % of people with disability who had difficulty accessing social venues in last 12 months (response categories used: Restaurants or cafés; Bars, clubs or pubs; Public parks or recreation venues; Movies, concerts, theatres or other performing arts events)
		Housing visitability	**SDAC –** % of people with disability who had difficulty accessing other people's homes in last 12 months
	6.3 Access to the natural environment		Topic placeholder – no indicators
7. Transport	**7.1 Transport availability and accessibility**	Difficulty using public transport	**SDAC –** % of people with disability who could not use any form of public transport
		Public transport availability	**SDAC –** % of people with disability who said public transport is not available in their area Aim to get comparable data for people with and without disability on availability of public transport in local area

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
		Access to private motor vehicle	**GSS** – % of people who have access to motor vehicle/s to drive **SDAC** – % of people with disability who have a licence and drive monthly or more often
		Difficulty with transport	**GSS** – % of people who can easily get to places they need to go
8. Food	**8.1 Access to food**		Topic placeholder – no indicators
	8.2 Cost of food		Topic placeholder – no indicators
9. Information and communications	**9.1 Information accessibility**		Topic placeholder – no indicators
	9.2 Internet and phone access	Internet access	**Census** – % of people who live in a household in which at least one household member accesses the internet from home **HILDA** – Access to the internet at home (Wave 14)
		Internet use	**SDAC** – % of people with disability who used the internet in the last 3 months
	9.3 Health literacy	Health literacy	**NHS 2017–18** – % of people who said it was difficult to find good health information (derived from 2018 Health Literacy Survey data)
10. Income and material resources	**10.1 Income**	Household Income	**GSS** – % of people who live in households in the bottom 4 deciles of equivalised household gross weekly income
		Personal income	**HEIH** – Average weekly disposable income for people with and without disability
		Source of income	**GSS** – % of people for whom a Government pension or allowance is the principal source of personal income
	10.2 Wealth		Topic placeholder – no indicators
	10.3 Material assets	Motor vehicles	**Census** – % of people who live in a household with one or more motor vehicles
	10.4 Financial stress	Difficulty paying bills on time	**GSS** – % of people who live in a household that reported having difficulty paying bills in last 12 months
		Financial stressors	**GSS** – % of people who live in a household that had at least one cash-flow problem in the last 12 months
		Access to emergency funds	**GSS** – % of people who live in a household that could not raise $2,000 within a week for an emergency
	10.5 Future economic security		Topic placeholder – no indicators
11. Housing	**11.1 Housing affordability**	Housing stress	**HEIH** – % of people who live in a household with equivalised household disposable income in the bottom 4 deciles, where housing costs account for more than 30% of household disposable income
	11.2 Housing conditions	Overcrowding	**HEIH** – % of people who live in a household in which 1 or more additional bedroom/s is needed (Canadian National Occupancy Standard)
	11.3 Living arrangements	Younger people with disability in residential aged care	**AIHW data** – number of people aged under 55 living in residential aged care
	11.4 Housing tenure	Tenure type	**HEIH** – % of people who owned their own home (with or without a mortgage)
	11.5 Homelessness	Homelessness	**GSS** – % of people who have ever experienced homelessness

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
12. Employment	**12.1 Labour force participation**	Labour force participation rate	**GSS** – % of people not in the labour force
	12.2 Employment	Employment to population ratio	**GSS** – % of people employed
		Engagement in Employment, Education and Training	**Census –** % of people not engaged in employment, education or training
	12.3 Unemployment	Unemployment rate	**GSS** – % of people who are unemployed
		Youth unemployment rate	**GSS** – % of people aged 15-24 years who are unemployed
		Long-term unemployment ratio	**GSS** – % of people who are unemployed and have been looking for work for 12 months or more
	12.4 Under-employment	Under-employment	**SDAC –** % of people with disability who are employed and usually work 34 hours or less per week who would like a job with more hours
	12.5 Job conditions	Leave entitlements	**GSS** – % of people employed who have leave entitlements in their main job
		Employment in high skill jobs	**GSS** – % of people employed who are in high skill jobs (Main job in ANZCO categories Managers, Professionals, Technicians and Trades Workers)
	12.6 Pay		Topic placeholder – no indicators
	12.7 Employment accommodations	Access to job design modifications and reasonable adjustments	Current data gap: Access to job design modifications and reasonable adjustments; people with disability only
	12.8 Attitudes and discrimination in the workplace	Experience of disability-related discrimination in the workplace	Current data gap: Experience of disability-related discrimination in the workplace; people with disability only
13. Education	**13.1 Educational attainment**	Educational attainment	**GSS** – % of people who have completed year 12 **GSS** – % of people with post-secondary school educational attainment
	13.2 Access to education and training	Current participation in education	**GSS** – % of people currently enrolled in a course of study for any educational qualification
	13.3 Attitudes and discrimination in education	Experience of disability-related discrimination in educational settings	Current data gap: Experience of disability-related discrimination in educational settings; people with disability only
14. Family and relationships	**14.1 Intimate relationships**	Social marital status	**GSS** – % of people who are married in a registered or de facto marriage
	14.2 Parenting and caring roles	Parenting role	**HILDA** – % of people who have parenting responsibilities for any children aged 17 years or less
		Caring role	**SDAC –** % of people who are primary carers
	14.3 Involvement with child protection	Children placed in out-of-home care	Current data gap: rate of placement of children in out-of-home care; parents with and without disability
15 Social and civic participation	**15.1 Participation in social and civic activities**	Volunteering	**GSS** – % of people who did unpaid voluntary work in last 12 months through an organisation
		Participation in community or social groups or activities	**GSS** – % of people who have been actively involved in a community or social group in the last 12 months or taken part in an activity they organised

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
		Participation in cultural, recreation and leisure pursuits	**GSS** – % of people who attended selected cultural venues and events, and/or attended sporting events as a spectator, in last 12 months
		Participation in civic or political activities	**GSS** – % of people who were involved in a civic or political group in the last 12 months
		Participation in religious or spiritual group activities	Current data gap: % of people who report participating in religious or spiritual group activities; with/without disability
	15.2 Social connectedness	Contact with friends/family not living in the same household	**SDAC**– % of people who have contact with family or friends not living in same household once a week or more often (incl. by phone, email, social networking, SMS etc.)
		Social media use	**SDAC** – % of people with disability who accessed the internet in the last 3 months for social networking. Aim to get comparable data for people with and without disability on social media use
		Having people to confide in	**GSS** – % of people who have ex-household family/friends to confide in
		Availability of social network support in times of crisis	**GSS** – % of people who feel they are able to get support in times of crisis from someone living outside the household
16. Justice and safety	**16.1 Experience of discrimination**	Experience of discrimination or being treated unfairly	**GSS** – % of people who experienced discrimination or had been treated unfairly
		Experience of disability-related discrimination	**SDAC** – % of people with disability who had experienced discrimination due to disability in the last 12 months
	16.2 Experience of violence and abuse	Experience of bullying or harassment	Current data gap: % of people who have experienced bullying or harassment; with/without disability
		Experience of partner violence	**PSS** – % of people who experienced violence by a current partner and/or previous partner since age 15
		Experience of physical violence	**GSS** – % of people who were a victim of physical or threatened violence in last 12 months
		Experience of sexual violence	**PSS** – % of people who experienced sexual violence since age 15
		Experience of emotional abuse	**PSS** – % of people who experienced emotional abuse by a current partner and/or previous partner since age 15 Aim to get data on emotional abuse more broadly than partner abuse
		Experience of financial abuse	Current data gap: % of people who have experienced financial abuse; with/without disability
	16.3 Feelings of safety	Feelings of safety at home	**GSS** – % of people who feel safe or very safe at home alone after dark Aim to get comparable data for people with and without disability on feelings of safety at home during the day
		Feelings of safety in neighbourhood	**GSS** – % of people who feel safe or very safe walking alone in local area after dark

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
		Feelings of safety on public transport	Current data gap: % of people who feel safe or very safe on public transport; with/without disability
	16.4 Involvement with criminal justice system	Incarceration rate	**National Prisoner Health Data Collection** – % of prison entrants with disability
	16.5 Disaster preparedness		Topic placeholder – no indicators
SERVICE SYSTEM			
17. Health services	**17.1 Access to health services**	Blood pressure screening	**NHS 2017-18** – % of people who reported that they had their blood pressure checked in the last 2 years
		Breast cancer screening (women aged over 50)	**NHS 2014-15** – % of women aged over 50 who had been screened for breast cancer in the last 2 years
		Bowel cancer screening (people aged over 50)	**NHS 2014-15** – % of people aged over 50 who had been screened for bowel cancer in the last 2 years
		Use of GP services	**NHS 2014-15** – % of people who consulted a GP in the last 12 months
		Use of specialist services	**NHS 2014-15** – % of people who consulted a specialist in the last 12 months
		Use of allied health services	**NHS 2014-15** – % of people who consulted an allied health professional in the last 12 months
		Use of hospitals services	**NHS 2014-15** – % of people who had been admitted to hospital as inpatient in last 12 months
		Use of emergency department services	**NHS 2014-15** – % of people who had visited emergency/casualty department in last 12 months
		Difficulty accessing healthcare	**GSS** – % of people who had experienced barrier to accessing healthcare when needed in the last 12 months
		Selected potentially avoidable GP-type presentations to emergency departments	Current data gap: rate of potentially avoidable GP-type presentations to emergency departments; with/without disability
		Unmet need for GP services	**SDAC** – % of people with disability who reported unmet need to see a GP in the last 12 months Aim to get comparable data for people with and without disability on unmet need for GP services
		Unmet need for specialist services	**SDAC** – % of people with disability who reported unmet need for services of a medical specialist in the last 12 months Aim to get comparable data for people with and without disability on unmet need for specialist services
		Unmet need for allied health services	Current data gap: % of people who report unmet need for allied health services; with/without disability
		Unmet need for hospital services	**SDAC** – % of people with disability who reported unmet need for hospital admission in the last 12 months Aim to get comparable data for people with and without disability on unmet need for hospital services
		Unmet need for pharmaceuticals	Current data gap: % of people who report unmet need for pharmaceuticals; with/without disability

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
		Access to mental health services	Current data gap: % of people able to access mental health services when needed; with/without disability
		Waiting time for GP services	Current data gap: average waiting time for GP services; with/without disability
		Proportion of pregnancies with an antenatal visit in the first trimester	Current data gap: % of pregnant women who have an antenatal visit in the first trimester; with/without disability
		Access to specific hospital procedures	Current data gap: % of people able to access specified hospital procedures when needed; with/without disability
		Waiting time for elective surgery	Current data gap: average waiting time for elective surgery; with/without disability
		Use of dental services	**NHS 2014-15** – % of people who consulted a dentist in the last 12 months
		Unmet need for dental services	**SDAC** – % of people with disability who reported unmet need to see a dental professional in the last 12 months
		Waiting time for dental services	**SDAC** – % of people with disability who were on the public dental waiting list for 6 months or more before receiving dental care
	17.2 Effectiveness of health services	Selected potentially preventable hospitalisations	Current data gap: rate of selected potentially preventable hospitalisations; with/without disability
		Survival of people diagnosed with cancer	Current data gap: Survival of people diagnosed with cancer; with/without disability
		Potentially avoidable deaths	Current data gap: rate of potentially avoidable deaths; with/without disability
	17.3 Appropriateness of health services	Discrimination - health services	**SDAC** – % of people with disability who reported discrimination as the main reason they did not see a health professional when they needed to
	17.4 Safety of health services	Adverse events treated in hospital	Current data gap: rate of adverse events treated in hospital; with/without disability
		Falls resulting in patient harm in hospitals	Current data gap: rate of falls resulting in patient harm in hospitals; with/without disability
	17.5 Continuity of health care	Proportion of people with asthma with a written asthma action plan	Current data gap: % of people with asthma with a written asthma action plan; with/without disability
		Proportion of people with mental illness with a GP care plan	Current data gap: % of people with mental illness with a GP care plan; with/without disability
		Proportion of people with diabetes with a GP annual cycle of care	Current data gap: % of people with diabetes with a GP annual cycle of care; with/without disability
		Multiple health providers consulted for same health condition	**SDAC** – % of people with disability who had seen 3 or more health professionals for the same condition in the last 12 months
	17.6 Cost of health services and medicines	Bulk-billing for GP attendances	Current data gap: rate of bulk-billing for GP attendances; with/without disability
		Cost as barrier to accessing health services	**HILDA** – % of people who could not afford to get medical treatment when they needed it **SDAC** – % of people with disability who delayed seeing or did not see [GP; Medical specialist; go to hospital] in the last 12 months because of the cost

DOMAIN	TOPIC	INDICATOR	DATA SOURCE
		Cost as barrier to accessing dental services	**HILDA** – % of people who could not afford to get dental treatment when they needed it **SDAC** – % of people with disability who delayed seeing or did not see a dentist in the last 12 months because of the cost
		Cost as barrier to accessing medicines	**HILDA** – % of people who could not afford to get medicines when prescribed by a doctor
		Expenditure on medications	Current data gap: out-of-pocket expenditure on medications; with/without disability
18. Disability services and supports	**18.1 Access to disability support services**	Difficulty accessing specialist disability services	**GSS** – % of people who had difficulty accessing disability services
		Proportion of people with disability accessing disability services	Current data gap: % of people with disability accessing disability services
	18.2 Appropriateness of disability services		Topic placeholder – no indicators
	18.3 Met/unmet need for support	Unmet need for assistance	**SDAC** – % of people with disability with need for assistance only partly or not at all met in one or more area of activity (Mobility, Self-care, Oral communication, Health care, Cognitive or emotional tasks, Household chores, Property maintenance, Meal preparation, Reading or writing, Private transport)
		Need for more assistance with core activities from organised services	**SDAC** – % of people with disability who need more assistance with at least one core activity (communication, mobility or self-care) from organised services
	18.4 Met/unmet need for assistive products	Unmet need for assistive products	**SDAC** – % of people with disability who need additional aid(s)
	18.5 Quality of disability services		Topic placeholder – no indicators
19. Mainstream services	**19.1 Access to mainstream services**	Difficulty accessing services	**GSS** – % of people who had difficulty accessing services (any of: Banks or other financial institutions; Centrelink; Employment services; Family Assistance Office; Legal services; Telecommunication services; Motor vehicle registry; Utilities providers; Housing services; Other service)

APPENDIX B

Summary of key data sources for reporting person indicators baseline data

SOURCE	DISABILITY IDENTIFICATION	COVERAGE AND INFORMATION CAPTURE
Census of Population and Housing 2016 (ABS) Previous years: 2006, 2011	Census module: three questions about the need for assistance in the core activity areas of self-care, mobility and communication and the 4th question providing a reason for that need. (7% did not respond to need for assistance question) Output categories: • Has need for assistance with core activities • Does not have need for assistance with core activities "does not attempt to identify disability but rather the people who are affected by disability to the degree that they need assistance. The need for assistance measure was designed to be comparable to the profound or severe core activity limitation measure available from the SDAC and social surveys using the Short Disability Module"	Entire population. Self-enumerated forms in most areas; special forms used in remote Indigenous communities. The form used in gaols did not include any questions on need for assistance.
Survey of Disability, Ageing and Carers, 2018 (ABS) Sample: 65,805 persons Response rate: 79.7% (Household component) 90.9% (Cared-accommodation component) Previous years: 1981, 1988, 1993, 1998, 2003, 2009, 2012, 2015 Future years: 2021	166 disability identification questions. Output categories: • Profound core activity limitation • Severe core activity limitation • Moderate core activity limitation • Mild core activity limitation • Schooling or employment restriction • Without specific limitations or restrictions • All with reported disability • Long-term health condition • No long-term health condition	Private dwellings, self-care retirement villages and establishments providing long-term cared accommodation (see list of non-private dwellings excluded, such as correctional facilities). Household component all usual residents of private and non-private dwellings: 54,142 persons. Cared-accommodation component (sample of residents): 11,663 persons. Excludes Very Remote Areas. Excludes discrete Aboriginal and Torres Strait Islander communities. Household component: a responsible adult identified people with a disability. Where possible, personal interview conducted with each person with disability. Proxy interviews conducted for children aged <15 (and 15-17 depending on parental consent) and those incapable of answering for themselves due to illness, impairment, injury or language problems. Cared accommodation: questionnaires completed by a staff member for each selected occupant and mailed back.

SOURCE	DISABILITY IDENTIFICATION	COVERAGE AND INFORMATION CAPTURE
General Social Survey, 2014 (GSS) (ABS) Sample: 12,932 persons Response rate: 80.1% Previous years: 2002, 2006, 2010	Short module (14 questions) Output categories: • Profound core activity limitation • Severe core activity limitation • Moderate core activity limitation • Mild core activity limitation • Schooling/employment restriction only • No specific restriction • No disability or long-term health condition	Private dwellings only Age 15+ Excludes • Very Remote Areas. • People living in discrete Aboriginal and Torres Strait Islander communities A responsible adult provided basic demographic details, details of relationships and household information A personal, face-to-face interview was conducted with one randomly selected person aged 15 years or over per household; a proxy interview was conducted where necessary and acceptable to the selected person.
National Health Survey 2017-18 (NHS) (ABS) Sample: 21,315 persons Response rate: 76.1% Previous years: 1989-90, 1995, 2001, 2004-05, 2007-08, 2011-12, 2014-15	Short module (14 questions) Output categories: • Profound core activity limitation • Severe core activity limitation • Moderate core activity limitation • Mild core activity limitation • Schooling/employment restriction only • No specific restriction • No disability or long-term health condition	Private dwellings only Excludes Very Remote Areas. Information was obtained about one adult and one child aged 0-17 years in each selected household. A responsible adult provided basic demographic details, details of relationships and household information. Personal interview was conducted with selected adult. A parent/guardian of a selected child was interviewed on their behalf.
Survey of Income and Housing 2017-18 (ABS) Sample: 26,921 persons Response rate: 74% of selected dwellings SIH is conducted biennially and enumerated over a 12-month period	Short module (14 questions) Output categories: • Profound core activity limitation • Severe core activity limitation • Moderate core activity limitation • Mild core activity limitation • Schooling/employment restriction only • No specific restriction • No disability or long-term health condition	Private dwellings only Age 15+ Excludes Very Remote Areas. A responsible adult provided basic demographic details, details of relationships and household information. Personal interviews were conducted with all members of the household aged 15 years and over.
Personal Safety Survey 2016 (PSS) (ABS) Sample: 15,589 women and 5,653 men Response rate: 68.7% Previous years: 2005, 2012	Short module (14 questions) Output categories: • Profound core activity limitation • Severe core activity limitation • Moderate core activity limitation • Mild core activity limitation • Schooling/employment restriction only • No specific restriction • No disability or long-term health condition	Private dwellings only Age 18+ Excludes Very Remote Areas. Interviews were conducted with one randomly selected person aged 18 years or over who was a usual resident of the selected household. A responsible adult provided basic demographic details, details of relationships and household information. Personal interviews were conducted with selected adult.

SOURCE	DISABILITY IDENTIFICATION	COVERAGE AND INFORMATION CAPTURE
HILDA (Melbourne Institute) Over 17,000 people each wave Response rate: 90% and 70% for original and newer participants, respectively. Initial household response rate: 66% Conducted annually from 2001	Single question: 'Do you have any impairment, long-term health condition or disability such as these (show list) that restricts you in your everyday activities and has lasted or is likely to last for six months or more?' Information on specific impairment types was not collected until Wave 3. Information on functioning, restriction, and assistance for individuals with disability is not collected in each wave and the functional impact of disability is not assessed comprehensively.	Private dwellings. Participation in HILDA requires a moderate degree of intellectual ability in order to understand (at times) complex questions, and an ability to communicate responses to others. These factors will have led to the exclusion of some people with more severe disabilities either as a result of their intellectual or communicative impairments or as a result of their placement in institutional settings. Interviews (face-to-face or telephone) conducted with all household members aged 15 and over; plus self-completion questionnaire.
National Prisoner Health Data Collection (AIHW) 2018 Previous years: 2009, 2010, 2012, 2015	AIHW's 'Standardised Disability Flag' items: 'activity and participation need for assistance cluster', 'education participation restriction flag' and 'employment participation restriction flag'. Data on disability status for prison entrants only. 2015 was first time disability flag was included.	The collection is designed to be a census, capturing data on the entire population of interest (though this is not achieved in practice). Collected data from 76 out of 91 public and private prisons. Data were provided by prisons in all states and territories in Australia except New South Wales, which provided data on prison entrants only. Data are collected over a 2-week period. The collection is based on convenience sampling with prisoners approached for participation where possible; not all prisoners provide consent. The majority of the data collected are self-reported data.

Sources

Australian Bureau of Statistics (2015). 4159.0 - General Social Survey: Summary Results, Australia, 2014. Canberra (AU): ABS.
Australian Bureau of Statistics (2017). 4906.0 - Personal Safety, Australia, 2016. Canberra (AU): ABS.
Australian Bureau of Statistics (2018). 4364.0.55.001 - National Health Survey: First Results, 2017-18 Canberra (AU): ABS.
Australian Bureau of Statistics (2018). 4431.0.55.002 - ABS Sources of Disability Information, 2012 - 2016. Canberra (AU): ABS.
Australian Bureau of Statistics (2019). 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018. Canberra (AU): ABS.
Australian Bureau of Statistics (2019). 6553.0 - Survey of Income and Housing, User Guide, Australia, 2017-18 Canberra (AU): ABS.
Australian Institute of Health and Welfare (2019). The health of Australia's prisoners 2018. Cat. no. PHE 246. Canberra (AU): AIHW.
Melbourne Institute. HILDA survey. Available from https://melbourneinstitute.unimelb.edu.au/hilda.

APPENDIX C

Area indicators for the Disability and Wellbeing Monitoring Framework

Data for these indicators have been obtained from the following sources: Healthy Liveable Cities Group (RMIT), 2017; Open Street Map 2018; Australian Bureau of Statistics (2016 Census and life expectancy data); National Health Services Directory 2017.

Area indicators based on population data are labelled ‘(pop)’; all other indicators are based on spatial data.

FRAMEWORK DOMAIN	AREA INDICATORS
1. Subjective health and wellbeing	–
2. Morbidity	–
3. Mortality	Life expectancy at birth (pop)
4. Lifestyle factors	–
5. Personal biomedical factors	–
6. Physical environment	Average daily living destination access score for local 1600 metres walkable neighbourhoods
	Average street connectivity per square kilometre for local 1600 metres walkable neighbourhoods within area
	Average dwelling density per hectare for local 1600 metres walkable neighbourhoods within area
	Average walkability index for local 1600 metres walkable neighbourhoods, relative to 21 cities
	Average walkability index for local 1600 metres walkable neighbourhoods, relative to study region
	Percentage of dwellings within 400 metres of public open space
	Percentage of dwellings within 400 metres of public open space greater than 1.5 hectares
7. Transport	Percentage of dwellings within 400 metres of public transport stop with a frequent weekday service (at least every 30 minutes, 7am-7pm)
	Method of travel to work (active travel/driving) (pop)
8. Food	Count of fruit and vegetable grocers within 3200 metres
	Count of 'healthier' food options (supermarkets or fruit and vegetable grocers) within 3200 metres
	Healthy food choices ratio (ratio of healthier- to fast- food options within 3200 metres)
	Healthy food choices percentage (percentage of 'healthier-' relative to healthier- and fast-food options combined within 3200 metres)
	Percentage of dwellings with no availability of healthy or unhealthy food within 3200 metres
	Percentage of dwellings within 1000 metres walking distance of a supermarket
	Number of off-licence alcohol outlets counted within 800 metres
	Number of on-licence alcohol outlets counted within 400 metres
9. Information and communications	Household Internet access (pop)
10. Income and material resources	Car ownership (pop)
	Index of Relative Socio-economic Disadvantage decile (pop)
	Household income (pop)
	Personal income (pop)
11. Housing	Household tenure type (pop)
	Homelessness (pop)
	Housing affordability (pop)
12. Employment	Labour force status (pop)
	Industry of employment (pop)
	Hours worked (pop)
13. Education	Participation in education (pop)
	Educational attainment (pop)

FRAMEWORK DOMAIN	AREA INDICATORS
14. Family and relationships	–
15. Social and civic participation	Volunteering (pop)
16. Justice and safety	–
17. Health services	Average distance to closest general practitioner
	Average distance to closest pharmacy
	Average distance to closest generalist counselling
	Average distance to closest dentist
	Average distance to closest adult mental health services
	Average distance to closest family counselling and/or family therapy
	Average distance to closest psychology
	Average distance to closest hospital
18. Disability services and supports	*Note: data from ABS Survey of Disability Ageing and Carers may provide area indicator relating to access to disability services (e.g., % of people with disability who report need for more formal assistance)*
19. Mainstream services	Average distance to closest physical activity & recreation
	Average distance to closest library
	Average distance to closest Centrelink
	Average distance to closest employment service
	Average distance to closest activity centre

APPENDIX D

Mapping CRPD and ICF to the Disability and Wellbeing Monitoring Framework

Mapping of rights articulated in the Convention on the Rights of Persons with Disabilities (CRPD) and domains from the International Classification of Functioning, Disability and Health (ICF) to CRE-DH Monitoring Framework domains.

FRAMEWORK DOMAIN AND TOPICS	RIGHTS ARTICULATED IN CRPD	ICF DOMAINS[1]
1. Subjective health and wellbeing 1.1. Self-rated health 1.2. Self-rated wellbeing 1.3. Self-rated mental health	**3. General principles** (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;	
2. Morbidity 2.1. Incidence of selected health conditions 2.2. Prevalence of selected health conditions 2.3. Cause-specific hospitalisation	**25. Health** … persons with disabilities have the right to the enjoyment of the highest attainable standard of health without of discrimination on the basis of disability.	
3. Mortality 3.1 All-cause mortality 3.2 Cause-specific mortality 3.3 Life expectancy 3.4 Suicide	**10. Right to life** … every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.	
4. Lifestyle factors 4.1 Physical activity 4.2 Smoking 4.3 Alcohol consumption 4.4 Diet 4.5 Drug use		Looking after one's health (d570)
5. Personal biomedical factors 5.1 BMI/obesity 5.2 Blood pressure 5.3 Blood glucose		
6. Physical environment 6.1 Air, water and noise 6.2 Built environment accessibility 6.3 Access to the natural environment	**9. Accessibility** 1. … access, on an equal basis with others, to the physical environment, … and to other facilities and services open or provided to the public… **19. Living independently and being included in the community** (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. **28. Adequate standard of living and social protection** 2.(a) … equal access by persons with disabilities to clean water…	Design, construction and building products and technology of buildings for public use (e150) Products and technology for land development (e160) Architecture and construction services, systems and policies; Open space planning services, systems and policies; Utilities services, systems and policies (e515–e520, e530) Natural environment and human-made changes to environment (e.g., Climate; Sound; Air quality) (e210–e260)

FRAMEWORK DOMAIN AND TOPICS	RIGHTS ARTICULATED IN CRPD	ICF DOMAINS[1]
7. Transport 7.1 Transport availability and accessibility	**9. Accessibility** 1. … access, on an equal basis with others, … to transportation … **20. Personal mobility** … personal mobility with the greatest possible independence for persons with disabilities…	Products and technology for personal indoor and outdoor mobility and transportation (e120) Transportation services, systems and policies (e540) Moving around using transportation (d470–d489)
8. Food 8.1 Access to food 8.2 Cost of food	**25. Health** (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. **28. Adequate standard of living and social protection** 1. … the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions…	Food (e1100) Services, systems and policies for the production of consumer goods (e510)
9. Information and communications 9.1 Information accessibility 9.2 Internet and phone access 9.3 Health literacy	**9. Accessibility** 1. … access, on an equal basis with others, to information and communications, including information and communications technologies and systems … 21. Freedom of expression and opinion, and access to information … persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others…	Products and technology for communication (e125) Communication services, systems and policies (e535) Media services, systems and policies (e560) Communication (d3)
10. Income and material resources 10.1 Income 10.2 Wealth 10.3 Material assets 10.4 Financial stress 10.5 Future economic security	**28. Adequate standard of living and social protection** 1. … the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions…	Assets (e165) Social security services, systems and policies (e570) Economic life (d860-d879) Acquisition of necessities (d610-d629)
11. Housing 11.1 Housing affordability 11.2 Housing conditions 11.3 Living arrangements 11.4 Housing tenure 11.5 Homelessness	**19. Living independently and being included in the community** … the equal right of all persons with disabilities to live in the community, with choices equal to others… (a) … the opportunity to choose their place of residence and where and with whom they live on an equal basis with others… **28. Adequate standard of living and social protection** 2.(d) … ensure access by persons with disabilities to public housing programmes;	Design, construction and building products and technology of buildings for private use (e155) Housing services, systems and policies (e525) Acquiring a place to live (d610)

FRAMEWORK DOMAIN AND TOPICS	RIGHTS ARTICULATED IN CRPD	ICF DOMAINS[1]
12. Employment 12.1 Labour force participation 12.2 Employment 12.3 Unemployment 12.4 Under-employment 12.5 Job conditions 12.6 Pay 12.7 Employment accommodations 12.8 Attitudes and discrimination in the workplace	**27. Work and employment** 1. … the right of persons with disabilities to work, on an equal basis with others; 1.(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment… 1.(g) Employ persons with disabilities in the public sector; 1.(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;	Products and technology for employment (e135) Economic services, systems and policies (e565) Labour and employment services, systems and policies (e590) Work and employment (d840-d859)
13. Education 13.1 Educational attainment 13.2 Access to education and training 13.3 Attitudes and discrimination in education	**24. Education** 1. … the right of persons with disabilities to education. 1. … ensure an inclusive education system at all levels and lifelong learning…	Products and technology for education (e130) Education and training services, systems and policies (e585) Learning and applying knowledge (d1) Education (d810-d839)
14. Family and relationships 14.1 Intimate relationships 14.2 Parenting and caring roles 14.3 Involvement with child protection	**23. Respect for home and the family** 1. … eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships 2. …render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities	Interpersonal interactions and relationships (d7) Assisting others (d660) Family relationships (d760) Intimate relationships (d770)
15. Social and civic participation 15.1 Participation in social and civic activities 15.2 Social connectedness	**9. Accessibility** 1. … to live independently and participate fully in all aspects of life… **29. Participation in political and public life** … guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others… (a) ... ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others **30. Participation in cultural life, recreation, leisure and sport** 1. … the right of persons with disabilities to take part on an equal basis with others in cultural life…	Products and technology for culture, recreation and sport (e140) Products and technology for the practice of religion and spirituality (e145) Support and relationships (e.g., Immediate family; Friends; People in positions of authority; Domesticated animals) (e310–e350, e360) Associations and organizational services, systems and policies (e555) Political services, systems and policies (e595) Community life (d910) Recreation and leisure (d920) Religion and spirituality (d930) Political life and citizenship (d950)

FRAMEWORK DOMAIN AND TOPICS	RIGHTS ARTICULATED IN CRPD	ICF DOMAINS[1]
16. Justice and safety 16.1 Experience of discrimination 16.2 Experience of violence and abuse 16.3 Feelings of safety 16.4 Involvement with criminal justice system 16.5 Disaster preparedness	**5. Equality and non-discrimination** 1. … all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law. 2. … prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. **11. Situations of risk and humanitarian emergencies** … the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. **12. Equal recognition before the law** 1. … persons with disabilities have the right to recognition everywhere as persons before the law. 3. … access by persons with disabilities to the support they may require in exercising their legal capacity. **13. Access to justice** 1. … effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations… **14. Liberty and security of person** 1.(a) … the right to liberty and security of person; **15. Freedom from torture or cruel, inhuman or degrading treatment or punishment** 1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation. **16. Freedom from exploitation, violence and abuse** 1. … protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.	Natural events (e230) Human-caused events (e235) Civil protection services, systems and policies; Legal services, systems and policies; (e545–e550)
17. Health services 17.1 Access to health services 17.2 Effectiveness of health services 17.3 Appropriateness of health services 17.4 Safety of health services 17.5 Continuity of health care 17.6 Cost of health services and medicines	**25. Health** … ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.	e1101 Drugs (e1101) Health professionals (e355) Health services, systems and policies (e580)

FRAMEWORK DOMAIN AND TOPICS	RIGHTS ARTICULATED IN CRPD	ICF DOMAINS[1]
18. Disability services and supports 18.1 Access to disability support services 18.2 Appropriateness of disability services 18.3 Met/unmet need for support 18.4 Met/unmet need for assistive products 18.5 Quality of disability services	**16. Freedom from exploitation, violence and abuse** 3. … ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities. **19. Living independently and being included in the community** (b) … access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; **26. Habilitation and rehabilitation** 1. … to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. 1. … To that end … organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services… 3. … promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation. **28. Adequate standard of living and social protection** 2.(a) … access to appropriate and affordable services, devices and other assistance for disability-related needs	Products and technology for personal use in daily living; … for personal indoor and outdoor mobility and transportation; … for communication; … for education; … for employment; … for culture, recreation and sport; … for the practice of religion and spirituality (e115–e145) General social support services, systems and policies (e575)
19. Mainstream services 19.1 Access to mainstream services	**19. Living independently and being included in the community** (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.	Services, systems and policies (e3)

---

[1] ICF Environmental Factor domains have an ‘e’ prefix, Activities and Participation domains have a ‘d’ prefix.

APPENDIX E

Summary of feedback received from Expert Panel of Advice

First round of consultation – feedback focused on structure of draft monitoring framework

Comments on the framework not specific to a single domain

- For the overall structure of domains, it would be better to use an accepted framework, such as the CRPD; the CRPD is the framework used by a lot of advocacy organisations and for government disability policy, so using it as a base would give this framework policy currency. It has previously been used as a basis for indicator development and research projects.
- There are so many possible ways to divide up the domains and topics. There could be so many sub-categories that you could never work through it.
- Should there be a 'Family' domain, which could include family violence, reproductive coercion (incl. sterilisation), child protection issues, parenting and caring responsibilities? It's a question of whether it makes sense to group these under one heading or have them spread across other domains.
- Crowding can be an issue, e.g., an over-crowded living environment can cause stress, accessibility issues, and can make people feel unsafe.
- Community attitudes are a major barrier for people with disability; attitudes are relevant under many of the domain headings in the framework.
- The environmental domains and indicators can have links to the security of people with disability in climate events and global warming. Some universities are starting to make projections around this issue for women; knowledge around people with disability would also be helpful.
- There needs to be more emphasis on inclusion and related issues in domains such as education, physical environment, and social/civic participation. Often there is an emphasis on physical access and not deeper issues that influence inclusion, such as: How experienced are staff at local library to accept a person living with disability who might have specific needs?; Does the local supermarket receive any awareness training around how to manage 'behaviours of concern' if a person living with multiple disabilities and an overlay of mental illness uses the store and shows behaviours that are 'challenging?; Are local events held for families inclusive of families where a family member may have physical access requirements or are activities geared around everyone sitting down on the floor and bouncing the kids on their legs?
- It would be good to have an indicator that addresses inclusion in a positive sense, i.e., the fundamental experience of belonging, connection to community and being valued.
- For people with complex disabilities, who are very dependent on others for communication and many aspects of life, it is difficult to see how they fit under the headings in the framework; the framework must be able to capture issues for this group of people.
- The main headings are good and comprehensive, but the indicators need to be capable of capturing everyone, not just people who are capable of self-reporting.
- The domains are comprehensive, but some could be grouped together (e.g., the first four could be grouped as a 'health and wellbeing' domain; information and communications environment, community amenities and infrastructure, and physical environment could be grouped); having fewer top-level domains could make the framework more approachable.
- 'Advocacy' seems to be missing from the framework; this should be a domain or a major indicator, and should cover both self-advocacy and people having others advocate on their behalf. Advocacy is an issue relevant across domains for particular groups (e.g., people with high communication support needs, or from CALD backgrounds).
- Look for a term other than 'working aged people' to describe the focus of this framework; this term implies that to work is the norm. Work is something that is not attainable for some people with disability, and people's value should not be seen in terms only of their ability to engage in paid employment.

- Where does mental health fit in? Particularly the mental health of people with disability, which can be so negatively affected by systemic barriers they face (e.g., high rates of anxiety and stress, and the psychological harm done to children through the education system, which can have life-long effects).
- Regarding mental health – there is greater stigma around having a mental health issue than other types of disability.
- Religion and spirituality should be covered somewhere in the framework. It doesn't fit neatly under any of the existing domains; the definition of spirituality is complex, but it's about people feeling that they are living for meaning and purpose.
- Access to support is a major determinant of choice and participation across many domains of the framework (e.g., employment, education, food, transport, information); this is a cross-cutting issue and should not be confined to a single domain.
- Suggestion to reduce the number of domains by grouping, to make the framework a more approachable and easier to digest; suggestion:

1) Housing
    - Housing, Physical environment
2) Employment
    - Employment, Income and material resources
3) Social inclusion
    - Social, civic participation and inclusion
4) Support services
    - Disability support and assistance, Health system and services
5) Education and training
    - Education and Training
6) Transport and infrastructure
    - Transport and mobility, Community amenities and Infrastructure
7) Justice & safety
    - Justice and safety
8) Health & wellbeing
    - Health conditions, Biomedical factors, Wellbeing, Deaths, Health behaviours, Food security
9) Information
    - Information and communications environment.

Comments concerning data for reporting against indicators

- People often choose to hide their disabilities because of the negative reactions/attitudes of others. Issues of disclosure may affect the completeness and quality of data available in various data sources, so this is something that should be considered when developing indicators and presenting data (there are legal and other 'triggers' for disclosure).
- It is important to be mindful that asking people questions about sensitive subjects (e.g., social connectedness, safety) can impact negatively on people – this is an important consideration when reporting the resulting data, e.g., in presenting the data we should also advocate for this kind of information to be collected in a sensitive, safe way.
- The concept of self-reported data is problematic for people who communicate through their behaviour and are very dependent on others to acknowledge and respond to their behaviour. The expectation should be that measures are based on self-report data wherever possible, but where this is not possible some other way of capturing the information is needed so that people with high communication support needs are not left out of the picture.
- Data deemed to be self-report is not always self-report data in reality; often people do not have the opportunity to answer questions in private, and service providers sometimes answer questions on behalf of their clients.
- Contextual factors: examples given in background paper are important (proportion of the population with a disability, representation of people with disability in the health workforce), and also level of representation of people living with disability in the following roles: In community service roles such as councils, libraries; In customer-based roles.
- There is typically very little information about what is happening for people who live in cared accommodation and who don't have a strong family advocate. It is important to capture data for this group of people.
- It is important to be aware of data validity and reliability issues. Some sources of data may not be meaningful because the questions asked are not applicable to people's situations (e.g., some questions in NDIS surveys cannot be meaningfully answered for people with very complex disabilities and high communication support needs).
- Complaint mechanisms within disability services are flawed, and therefore not a good source of data on health or other issues that occur within disability services.
- It is important to be aware of intersectionality issues, e.g., issues that may be particular to Aboriginal and Torres Strait Islander people, children, people from non-English speaking background, women.
- It would be useful to have indicator data broken down by age, sex, impairment type, socioeconomic status, and also NDIS participation if possible.
- In presenting data we want to highlight inequalities, but not paint a negative picture of people with disability (i.e., avoid projecting an 'ablist' perspective).
- Contextual information, e.g., prevalence of disability by disability type, would be most useful at the local level, e.g., within a local community or a workplace; however, presenting this kind of contextual information at national level may be useful for raising awareness via national media.
- Ideas for presenting data to be accessible for people with intellectual disability: add pictures alongside the graph and a picture or symbol to show which component of the graph represents data for people with disability; have clear explanatory text next to the graph; a column graph could be described as a tower graph with 100 floors and a person on each floor; columns should show how many people out of 100 have positive and negative values for the indicator (i.e., two sections of the column, maybe with a symbol or picture in each section to aid interpretation).
- Idea for presenting the framework to people with intellectual disability: recipe analogy, with the domains as ingredients, i.e., all the things that affect health.

Comments on particular domains

Health conditions

- Consider including some of the major ones like:
    - Cardiac Disease
    - Mental illness
    - Diabetes
    - Vaccine preventable diseases
    - Diseases of poor nutrition (including obesity)
    - Addictions
- Hospitalisations for injury and poisoning: this should be broadened to cover injuries and health issues where people are not hospitalised; this is particularly an issue for people living in cared accommodation – this kind of information may need to be captured from disability services.
- Dental health can be a major issue for people with disability, because of lack of access to dental services and dental care.
- Interpreted this domain to be about health conditions associated with disability; so this may need clarification – suggested calling it, e.g., 'prevalence of physical and mental health conditions'.
- A distinction can be made between health problems that are related to a person's disability and health problems not related to disability.
- People with certain disability types (e.g., Down Syndrome) are at higher risk of particular health problems.
- Mental health (e.g., anxiety and depression) is a major area of concern for people with disability.

Wellbeing

- Wellbeing – does this mean overall wellbeing, psychosocial, physical, other? It should be specified what is meant by wellbeing. For people with disability, sense of wellbeing and how they see themselves can be affected by the expectations of others. Should 'self-rated health' be under wellbeing?
- The concept of 'self-rated health' is problematic for people with profound communication disabilities. A person may not understand a question about how they rate their own health or wellbeing; close family carers may be able to provide a rating based on interpreting the person's communication through behaviour, but for someone who doesn't have a close family carer this is not possible either.
- It is good to make a distinction between a person's disability and their health.
- The framework should include mental health issues such as anxiety, depression and stress, which are commonly experienced by people with disability because of external stressors, barriers and discrimination.
- People with disability need information and support to help them speak up and have control in their lives, including in relation to bullying and discrimination.

Deaths

- Perhaps "co-morbidities" should be listed here.
- This is not a good title for a framework domain.
- Suicide rates would be a valuable indicator to include.

Health behaviours

- Thought is needed about the definition of 'health literacy' in relation to people with disability, and appropriate ways to measure it.
- It would be good to look at drug use, both prescription and illicit drugs; over-prescription can be a problem for people with disability. For some people with disability, the issue is the health literacy of their carer/s rather than their own health literacy.
- Suggested indicators: number of times has been to a doctor/been an inpatient at a hospital in the last 12-months; illicit drug use.
- It is important to have information about the side-effects of medication.
- It is important to have information about your family medical history so that you can be tested and take preventive action against diseases you might be genetically predisposed to.
- Availability and accessibility of health information for people with disability and their families is important – e.g., information about epilepsy, autism.
- People with disability may need support to have a healthy lifestyle, e.g., meal plans to support healthy eating.

Personal biomedical factors

- Commented that this is similar to the 'health conditions' domain; the first few domains are very much health-related.

Transport and mobility

- A topic could be "availability of paid accessible transport options" – this would include how well serviced the area is in terms of access cabs, access Ubers, access transport via funded schemes (for instance some subsidised community transport schemes exist where people pay a small amount only to access community areas).
- There's a lot of emphasis on getting people with disability to use public transport, but public transport is not always suitable (e.g., it takes too long); there are many factors that can limit a person's ability to drive
- It is difficult to see how this domain relates to people with very complex disabilities; they don't fit into the 'norm' that is implied by the content currently under this heading.
- Suggested indicator: number of accessible taxi's.
- Suggestion to include NDIS and support for using public transport.

Food environment

- Food environment – this domain does not make a lot of sense from a disability perspective. For people with disability, access to and choice of food is affected by factors such as cost and care relationships (more than proximity of fresh food outlets). Choice of food is probably the first indicator you would need to consider.
- Support for accessing healthy food is an important factor for this domain; food outlets might exist, but people with certain types of disability need support to access them.

Information and communications environment

- Acknowledge importance of the 'Information and communications' technology domain
- Suggested indicator: social media user.
- Support for accessing information is an important factor for this domain; technological access is one issue, but having a support person and choice is very important.

Community amenities and infrastructure

- Related to 'Access to buildings', consider:
    - access to social venues
    - housing visitability (to visit friends).

Physical environment

- Physical environment – exposure to noise is an important factor here, especially for people for whom loud noise is a problem (e.g., people with autism spectrum disabilities)
- Both physical access and support for accessing services are important factors.

Income and material resources

- This is an important domain because many people are under a lot of financial pressure because of their disability.

Employment

- Suggested indicators: disability pay gap; disability employment gap (rename existing employment to populationn ratio) under-employment would be an indicator as two parts perhaps (proportion who would like and be willing to work more hours if they were available and over classification, i.e., people doing jobs below their capabilities); part-time/casual employment; job search duration; public sector employment; 'own account' work.
- At the level of the individual workplace it would be useful to have information on how many people have a disability; if there are multiple people with disability this may improve awareness and reduce discrimination, and people with disability can get together to share experiences and discuss solutions. This relates to the topic 'job quality and work environment'.
- 'Job quality and work environment' is very broad; a job might be great, but often there is not adequate support and this can make it stressful.
- Regarding attitudes and discrimination in the workplace, mostly this is not obvious but hidden.
- Information on labour force participation of carers raises issues of interpretation – for the person with a disability, if their carer has a job they may be less available to provide support, and this can limit choice for the person with disability.
- Employment is important for wellbeing, but job situations can also be a source of stress.
- Would be interesting to know what percentage of unemployed people across Australia have a disability.

Education

- Suggested indicator: proportion in education or training.
- Access to support is an important factor for this domain.

Housing

- Living alone can be challenging, stressful and lonely – while living independently is often regarded as a positive outcome, for many people a good shared living situation may be better.

Social and civic participation and inclusion

- Social connectedness is important – it would be interesting to have an indicator to measure actual level of social connectedness for people with disability, not just in times of crisis.
- It would be interesting to look at the degree to which people with disability have social connectivity outside their structure (this relates to question of how to operationally define social connectedness).
- Play (for children) should be included under this domain.
- Access to support is an important factor for this domain.
- Attitudes and discrimination are important factors across all domains.

Justice and safety

- People with disability often feel vulnerable – a safe living environment (home and neighbourhood) is important.
- If there isn't a Family domain added, this domain should include contact with child protection / removal of children.
- Suggested indicator: incarceration rates.
- Health needs of people with disability within the criminal justice system – often neglected or ignored (e.g., in terms of medication needs)
- Bullying is a major issue that can impact on wellbeing for people with disability, especially during schooling.
- A history of trauma during childhood can have impacts throughout the life course.

Health system and services

- Preventive health checks – there are physical accessibility issues with mammograms, bone density tests, eye tests, etc. that make it difficult for some people with disability to access these preventive health services.
- People in supported accommodation would have complicated health issues because they are not necessarily given a choice of medical practitioner nor necessarily a choice of whether to seek medical attention when necessary. They would need to rely on their support workers to identify a health concern and act appropriately.
- People with complex disabilities typically require a range of health and allied health services; access to appropriate services can be a big issue for this group.
- Inadequate access to dental services can be a problem for people with disability.
- For people who live in cared accommodation, their health care and access to health services is at the mercy of their carers.
- Whether people have their medications regularly assessed by a doctor could be important to include here.
- Communication with health providers is important. Often people with disability have difficulty conveying their health problems to providers and this can result in poor health outcomes – the 'my health matters' tool developed by CID helps to facilitate this communication.
- People with disability are often treated poorly by staff in hospitals. There is a need to educate medical staff about disability.
- Support for family members of people with disability is important in relation to health issues (especially at times of health crisis); whether or not family members are supported impacts on people with disability themselves.

Disability support and assistance

- A better reporting system for incidents that happen within disability services is needed. Many people cannot report things themselves, many don't have a strong family advocate, and often people with intellectual disabilities are not believed.
- This domain relates to support required for participation within all the other domains; for vision impairment and perhaps other disability types (e.g., learning disability and psychiatric disability) this domain is extremely important.

Second round of consultation – feedback focused on potential indicators

Comments not specific to a single domain

- Many of the topics (both health outcomes and social determinants) are heavily influenced by financial resources, including how much a person gets in their NDIS plan. NDIS is not strongly reflected in the document, and it is going to have huge influence on people's wellbeing.
- People with complex disabilities are often 'invisible'. They're the ones who need the most care, and in many instances get the least. For many of the indicators listed these people just don't fit in or would be excluded. We need to make them visible in this monitoring framework.
- Acknowledging the bounds of this project, we must ensure that important issues raised during the consultation process (such as people with complex disabilities being invisible) are not lost, and should get somewhere where they will be heard.
- In presenting the indicators, it's important to make clear that 'no data' means no national data. For some indicators data do exist at state level, and state-level data may provide a basis for advocating for national data.
- It would be useful to get access to NDIS data for some of these indicators, because some are quite disability-specific.
- Need to consider how indicators reflect or capture rights-based expectations (example of a parent responding saying that a person is happy with their employment in a sheltered workshop).
- Careful thought is needed to ensure that indicator data are presented in a way that is not disabling. This includes choice of language used.
- First People's Disability Network have worked closely with ABS and have developed some good community-based indicators – worth looking at.
- Language – preferable to use 'people with disability', as this is more consistent with the social model (rather than 'people with disabilities'). Also, prefer not to use 'lived experience', as this terminology comes from the mental health recovery model.
- The monitoring framework is really big. Its content reflects the CRPD pretty well. It will be a valuable tool in terms of the human rights framework of disability. It would be good to link the indicators back to the CRPD. PWDA would like to see the CRPD used as a basis for all policy development and anything to do with disability, because it is a human rights framework and supports transformative equality.
- There is generally insufficient research focus on the intersectionality of gender and disability.
- Measures of 'satisfaction with' are problematic because satisfaction is related to expectations. If you have come to have low expectations through your life circumstances this will affect how you respond to questions about satisfaction. Thus interpretation of the data will be problematic.
- It will be useful to cultivate contacts/allies within government departments to get policy-maker engagement around this work.
- When we say people with disability are included in the data it would be good to communicate which PWD - eg. whether the study included people in isolated settings like group homes, and whether PWD had access to supports to participate.
- Could all data be gender disaggregated when possible?
- The spatial indicators study looks good – it could include ABS data on caring responsibilities.

Comments on particular domains

DOMAIN	COMMENTS
1. Subjective health and wellbeing 1.1. Self-rated health 1.2. Self-rated wellbeing 1.3. Self-rated mental health	Concern about people with complex disabilities not being represented in self-rated measures; any measure reported that doesn't include this cohort does not properly represent people with disability. Proxy responses on self-rated measures are very problematic. 'Gatekeeping' is an issue for this domain – the ideas and choices of people with disability being monitored and controlled by others. People are being made invisible. This should be identified and drawn out. Re self-rated health, there will be a proportion of people who might be quite stoic and think they're fine, so their rating may not give an accurate indication of their actual health status. It's hard to see any inclusion of Sexual and Reproductive Health in this section - eg. access to contraception services and choices. The self measurement indicator about 'compared to others I know' seems like it would be skewed if someone lived in an isolated setting like a group home.
2. Morbidity 2.1. Incidence of selected health conditions 2.2. Prevalence of selected health conditions 2.3. Cause-specific hospitalisation	Vic has data on incidence of heart attacks. Re prevalence indicators, some things are important to one person but not another, so it's hard to decide which conditions should be in the list. Could the conditions in the list be grouped together more? E.g., there are several relating to mental health, different cancers, two on diabetes. The cause-specific hospitalisation indicator should not be limited to supported accommodation, but should at least be broadened to include other disability-specific settings (e.g., day programs). Gatekeeping is an issue for hospitalisation – there are problems with documentation of injuries for people with disability, and often things are covered up. Injuries where people don't get appropriate care/treatment is a good candidate for an aspirational indicator. Prevalence of health conditions associated with poor nutrition prevalence is a good one, because people with disability face a range of barriers to accessing a good diet.
3. Mortality and life expectancy 3.1 All-cause mortality 3.2 Cause-specific mortality 3.3 Life expectancy 3.4 Suicide	Some disabilities have reduced life expectancy, but if mortality is because of neglect that's a completely different issue.
4. Health behaviours 4.1 Physical activity 4.2 Smoking 4.3 Alcohol consumption 4.4 Diet 4.5 Drug use 4.6 Other	Disability Sport and Rec in Vic has data on physical activity. Many people with complex disabilities miss out completely on physical activities because they're unable to participate in what is available. Could NDIS data on what people are funded for in their plans be used as a source of information for physical activity? General agreement for including indicators on smoking and alcohol consumption. Diet – the indicator on freq of consumption seems to duplicate the first 3 indicators, so could be deleted. Diet – important to capture issues for people who are dependent on others for their food and may not get a reasonable diet. Diet – financial considerations affect diet: rubbish food is cheaper than fresh food, and many people with disability have low income. Other factors also affect diet, e.g., lack of transport. Sleep can be a big issue for people with certain disabilities. Re people choosing to eat unhealthy foods – there is a rights issue involved here as well (right to choose). There's good data from Glasgow around smoking and economic status. People should be allowed to do what they want and not be judged – in relation to health behaviours, monitoring is unduly focused on certain cohorts in society, comparing people against some hypothetical model citizen. The term 'behaviours' is problematic – it implies control and value-based judgements. The benefits of having data on health-related behaviours outweigh the concerns expressed about value-based judgements sometimes being made around these issues.

DOMAIN	COMMENTS
5. Personal biomedical factors 5.1 BMI/obesity 5.2 Blood pressure 5.3 Blood glucose	People with certain conditions are predisposed to being overweight – all of this information needs to be captured to have a fair understanding of the concept. General agreement for including some measure of overweight because this is an important factor that affects health (it isn't about 'fat shaming'). Is there a way of capturing data on biomedical factors via health checks? E.g., My Health Record rather than survey data? (seen as preferable to asking people about their weight). Some people who carry more weight are very healthy. Some measures will be affected by disability-related conditions, e.g., SC injury affects waist circumference. No strong view on obesity measures. This domain very much fits the 'disease model'. In SA, many people in wheelchairs are not able to get an accurate weight measurement done because the facilities are not available.
6. Physical environment 6.1 Air quality 6.2 Access to safe water 6.3 Exposure to noise 6.4 Building accessibility 6.5 Access to services within local community 6.6 Access to the natural environment 6.7 Access to support for accessing places in the built or natural environment	People with disability don't always have a choice about where they live, and so about their physical environment. Accessible toilets are very important in making it possible for people to go out (e.g., 'Changing places' program). You need everything to be in place (transport, toilet facilities, support) in order for people to be able to get out and about. The physical environment is very important, in terms of access to services like libraries and childcare, and also parks. We don't have enough information about the health benefits of green spaces; if we had better information developers couldn't get away so easily with what they do. Access to local services (e.g., library, community centre) is important. In Adelaide local advocacy has led to beaches being made wheelchair accessible, which has been a very significant thing for some people. While access to natural environment is important, the reality is that for most people accessing basic things like health services is a higher priority.
7. Transport and mobility 7.1 Public transport accessibility and adequacy 7.2 Availability of paid accessible transport options 7.3 Access to private transport 7.4 Neighbourhood mobility (e.g., footpaths and road crossings) 7.5 Access to support for transport use 7.6 Transport - general 7.7 Services - transport and mobility	Transport and mobility issues are very important. It's a human rights issue. Endorse topics and indicators listed. Wide doorways and ramps are not always sufficient to make transport accessible. Disability parking spaces are often not accessible in practice. People who are visually or hearing impaired need visual cues, platform announcements, etc. Transport means different things to different people. Many factors affect accessibility of transport, e.g., someone might have a car but can't afford petrol. It's a 'spiders web'. What is listed here doesn't capture issues for people with complex disabilities who can't use any form of transport unassisted. Transport issues are often caught in the gaps between programs and so it falls back on parents – would be interesting to know how many adults are still being driven around by their parents. The indicator on access to support for using transport (incl being taken out by support workers?) could be valuable for capturing points raised re people with complex disabilities. Public transport sometimes includes taxis, sometimes not. We don't capture whether people get a decent NDIS package to support them for all these areas – should this be in framework? Transport is a big problem – cost and accessibility issues in relation to public transport, taxis, and private cars. Some places have no public transport at all and this is a real problem for mobility for people with disability. Footpaths (quality/lack of) are often a problem. The indicator about 'not leaving home as often as you would like due to disability' is a really good one.

DOMAIN	COMMENTS
8. Food 8.1 Access to food 8.2 Choice of food 8.3 Access to support for exercising choice and control in relation to food 8.3 Cost	Some discussion for this domain was really about diet, so it is recorded in domain no. 4. Does ‘food’ cover tube-feeding directly into a person’s stomach? The question of whether people with disability are paying a higher price for their food is relevant here. Pleased to see that ‘food’ is a domain; the concept of ‘food deserts’ is an important one. A lot of people with disability live in low socioeconomic areas and convenience food is shoved in their face. The University of Adelaide has done some good research on food environments. Being able to access and prepare healthy food can be a major challenge for people living independently, and often people resort to packaged and processed food. Being able to get and prepare fresh food is a privilege.
9. Information and communications 9.1 Information accessibility 9.2 Internet and phone access 9.3 Social media use 9.4 Health literacy 9.5 Availability of support for information technology use 9.6 Services - information and communication	Very supportive of this domain being included. Online interactions are important for people with disability. The e-safety commissioner may have relevant data. How to capture when a family member uses the internet on behalf of a person with disability, e.g., to access services? It is important to view people with disability as individuals, i.e., indicators should be about individual use of internet etc, not whether household has access. Measures need to capture that the person with disability is a separate, independent person, otherwise it’s just not respectful. It would be useful to have data around people who are ‘nominees’ for a person with disability (e.g., for Centrelink, NIDS, etc). Does ‘My Health Record’ have data on health literacy? Some people have to access computer/internet at public library and this is an issue for privacy (e.g., for accessing NDIS portal or MyGov records when others can see). Support for accessing information may be available through public library, but accessibility and availability (queues) can be a barrier. Gatekeeping is an issue when people are reliant on others to access electronic resources (e.g., online forms). Software programs, algorithms etc tend to be highly gendered. Social media platforms can be very important for people with disability, for communication and connection.
10. Income and material resources 10.1 Income 10.2 Wealth 10.3 Material assets 10.4 Financial stress 10.5 Self-rated economic wellbeing 10.6 Access to emergency funds 10.7 Services - income and material resources 10.8 Other - income and material resources	Having indicators for both household income and personal income will be important. Living in a household with reasonable income and asset levels can disguise the fact that individuals themselves may have very little. Perhaps the emphasis should be on personal income – presenting data on household income could muddy the waters. Do we have financial literacy? (not a strong view that this should be in). Superannuation is a very important issue, particularly for women. If you don’t get a good NDIS package this can lead to financial stress. Economic status is about more than income and getting NDIS funding – it’s also about assets, access to emergency money, and economic security for the future. Whether people have insurance is important. A barrier to enjoying economic resources is Economic Abuse which I couldn't see listed in this section, in the justice section or in the family section.

DOMAIN	COMMENTS
11. Housing 11.1 Housing stress 11.2 Housing conditions (incl. overcrowding) 11.3 Living arrangements 11.4 Satisfaction with housing 11.5 Homelessness 11.6 Housing tenure 11.7 Housing services	Accessibility of housing is important. Suitability is important – whether your house has been modified for you, who you live with. Could get rid of 'satisfaction' indicators. Homelessness is important, and access to homelessness services. Access to utilities (water, electricity) is important. Could get rid of tenure type – this is somewhat redundant if you have a measure of financial stress, as if you're spending more than 40% of your income on housing costs this is a stress regardless of whether you are renting or have a mortgage. Data on people living in residential aged care is very important. Housing tenure is important – you're in a totally different position if you're 55 and own your own home vs 55 and renting. At a point in time it may not be so significant, but in the longer term it may be very significant. NB that a prominent form of homelessness or housing insecurity for women is living in violent intimate partner relationships. The housing alliance potentially could be another data source.
12. Employment 12.1 Labour force participation 12.2 Employment 12.3 Unemployment, long-term unemployment 12.4 Under-employment 12.5 Job quality and work environment 12.6 Pay 12.7 Flexible work arrangements and job design accommodations 12.8 Access to employment-related support 12.9 Attitudes and discrimination in the workplace 12.10 Satisfaction with employment 12.11 Services - employment 12.12 Other - employment	Complaints of employment-related discrimination made to the Human Rights Commission could be included here. Do we have data on pay below the minimum wage – i.e., actual unfair pay, rather than subjective feelings about pay? Australian Network on Disability may have data on unfair pay in sheltered workshops. Indicators of employment should reflect genuine employment, and not include working in ADEs (sheltered workshops). Under-employment and people working in jobs below their qualifications are important issues. There has been work done around wages for people in AEDs and should be data publicly available on DSS website. Flexible work arrangements and job design accommodations are important. Everybody should have flexible work arrangements. The federal gov has a 'job access' program that is part of CRPD implementation – assisting employers to ensure workplaces are accessible. Also the Australian Network on Disability may have relevant data on this. Suggest dropping indicator on satisfaction with pay. Suggest dropping indicator on satisfaction with employment. The issue of discrimination and negative attitudes in workplaces should be in the framework because it's the biggest barrier that people with disability face in accessing genuine employment. Supportive of all indicators listed. Important to pick up long-term job seeking – many people with disability find themselves in a cycle of rotating between job-search providers but never getting work. It would be good to have an indicator of satisfaction with employment service providers. Department of Jobs and Small Business may have data on this
13. Education 13.1 Participation in education 13.2 Educational attainment 13.3 Access to education/training 13.4 Satisfaction with education 13.5 Access to education-related support 13.6 Attitudes and discrimination in education 13.7 Other - education	Limiting a child's access to education is a form of abuse. May be worth looking at nationally consistent collection of schools data done by Dept of Education – but these data are quite problematic. Data on issues for students with disability in schools is relevant for this framework as there are many 15-18 yr olds still in school. How to provide more targeted and respectful support for students with disability in universities is an important issue. The word 'special' should not be used in relation to education or supports provided in any situation. 'Specific modification' is better. Supportive of all indicators listed.

DOMAIN	COMMENTS
14. Family and relationships 14.1 Intimate relationships 14.2 Parenting and caring roles 14.3 Contact with child protection / Removal of children 14.4 Family violence 14.5 Reproductive coercion (incl. sterilisation) 14.6 Family cohesion 14.7 Services - family and relationships	This is an important domain and should include indicators that view family issues through a range of lenses – caring responsibilities, parenting, violence, etc. There should be an indicator about whether the person lives alone, whether they're married or have children – that can change everything, including ability to advocate and get a good NDIS package. Reproductive coercion should include forced abortion. Could be broadened to 'reproductive choice'. Removal of children is an important one. Very pleased to see 14.2 about caring role. Include what can be included on parenting. Maintain inclusion of family / domestic violence indicators. Marriage – marital status? Is this still relevant nowadays?
15. Religion and spirituality	Suggestion that National Church Life Survey could be a source of data, but this only relates to Christian faiths. The middle two indicators look useful. Not so sure about 'participation in religious services' or 'religious affiliation'.
16. Social and civic participation 16.1 Community attitudes 16.2 Access to opportunities 16.3 Participation in social and civic activities 16.4 Access to support for social and civic participation 16.5 Trust 16.6 Social connectedness 16.7 Access to play during childhood 16.8 Advocacy and empowerment in relation to social and civic participation	Attitudes affect every touch-point of every indicator – it's a 'biggy'. Volunteering is important as a way for people not able to work to make a productive input in the community, and to be connected. Complaints re discrimination made to the Human Rights Commission could be included in the relevant domain (education, employment, etc). Online communities and social contact is very important for people with disability. Data on online social stuff could be captured by a broad question about 'access to any other social situations' – it's about having access to opportunities and being able to make informed choices. Voter enrolment is important, but likely to be very difficult to get data. (Discussion re tick-box about 'unsound mind' used by Electoral Commission as completely unacceptable.) Community attitudes is a very important one. Also attitudes towards kids with disability in schools. Whether you leave home as often as you would like is a really good one, as is avoidance of situations because of disability and social connectedness – these are all really good. Indicators around 16.8 are good, about access to self advocacy, etc Really like including the attitudes indicators. Community attitudes on violence against women are measured nationally and include disability data. This could be represented in Family, Justice or Community sections of this dataset. 'Satisfaction with how safe you feel' is great - i'd love it if it could be captured. Social and Civic attitudes towards PwD – I believe the University of Sydney had or has a project on bystander violence and PwD. Access to support for social and civic participation – NDIS data. Trust – I think this would be problematic to measure. Access to play in childhood – the Early childhood survey might have some data on this.

DOMAIN	COMMENTS
17. Justice and safety 17.1 Experience of discrimination 17.2 Experience of violence and abuse 17.3 Feelings of safety 17.4 Contact with criminal justice system 17.5 Disaster response arrangements 17.6 Justice and safety services	There should be data on abuse and neglect of people with disability. Disaster response arrangements is good – e.g., people with disability who might be stuck at home when there is a bushfire or flood. Maintain the personal safety elements. The discrimination stuff is good, it could be perhaps reduced (NB it's tricky for discrimination indicators to pick up on intersectional compounding factors like race and gender). Justice and Safety – Perhaps look at the take up of Disability Justice plans across the nation. Contact with the criminal justice system – Human Rights Watch released a report on PWD in prison. Disaster Response – The University of Sydney Centre for Disability Research and Policy is doing extensive work in this space.
18. Health services 18.1 Access to preventive health services 18.2 Access to health and allied services 18.3 Access to dental services 18.4 Appropriateness 18.5 Attitudes of health providers 18.6 Satisfaction with health services 18.7 Over-prescription 18.8 Regular review of medication 18.9 Choice and control in relation to accessing health services 18.10 Quality and effectiveness 18.11 Cost	Access to general health procedures, diagnostic procedures and health checks is an important issue – people with disability face a lot of barriers. Value-based judgements are often made in relation to people with disabilities accessing screening and diagnostic procedures – it can be seen as euthanasia by stealth. There are major service/funding gaps appearing in relation to health for people with disability, particularly in relation to medications. In SA, many people in wheelchairs are not able to get an accurate weight measurement done because the facilities are not available. This can lead to issues with incorrect medication dosage and resulting side-effects. Often people with disability are discharged from hospital into aged care and have to stay there for several weeks before being allowed to go home – this can have huge psychological impact. May be possible to get hospital discharge data to show this.
19. Disability services 19.1 Access to support 19.2 Appropriateness 19.3 Met/unmet need for services 19.4 Met/unmet need for assistive products 19.5 Satisfaction with support 19.6 Experience of problems with disability services 19.7 Quality of disability services	We don’t capture whether people get a decent NDIS package to support them for all these areas – should this be in the framework? There is a high rate of dissatisfaction with NDIS plans.

Centre of Research Excellence in Disability and Health

T. +61 3 8344 0717
E. cre-dh@unimelb.edu.au
W. www.credh.org.au
T. @DisabilityHlth

CRE–DH
Centre of Research
Excellence in
Disability and Health