

The Disability and Wellbeing Monitoring Framework: data, data gaps, and policy implications

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Abstract

Objective: To develop a framework and indicators to monitor inequalities in health and the social determinants of health for Australians with disability.

Methods: The development drew on existing frameworks and input from people with lived experience of disability.

Results: The Disability and Wellbeing Monitoring Framework has 19 domains. Australian national data are available for 73% of the 128 indicators in these domains. Data gaps and limitations include absence of national data and absence of disability identifiers in some data sources.

Conclusions: The framework will be used to report baseline data for people with and without disability and to monitor inequalities over time in Australia. It will also be used to locate policy priorities and focus efforts to address data gaps.

Implications for public health: Inequality between people with and without disability in relation to health and the social determinants of health is a public health issue that warrants greater attention than it has received to date. The Framework provides a robust, evidence-informed tool to address the health inequalities of people with disability, inform the development of effective policy and practice responses, and monitor change over time.

Introduction and objectives

People with disability experience poorer health and higher rates of health risk factors compared with people without disability.¹⁻⁹ They also have higher rates of health service use, are less likely to use preventive health care, and experience greater barriers to accessing health services.^{5,8,10-14} People with disability also experience greater disadvantage with respect to their exposure to well-established social determinants of health: 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.¹⁵ Evidence shows that people with disability are more likely than those without disability to experience poverty,¹⁶⁻¹⁹ violence,^{20,21} social exclusion,¹⁶ housing insecurity,^{17,18} unemployment and economic inactivity.^{17,18,22}

Differences between people with and without disability on measures of health and social determinants demonstrate the existence of inequalities. National and international reports recommend monitoring social, economic and health outcomes for people with and without disability to identify areas for policy and political action to reduce socially-produced disadvantage.^{7,23,24} 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.²⁵ Australia's National Disability Strategy 2010-2020 provides a framework for Australia to meet its CPRD obligations. The Strategy identifies indicators within six areas for policy action, and acknowledges the importance of monitoring and reporting progress.²³

Despite Australia's undertakings, there is no national, systematic monitoring system in place to determine whether life is improving for people with disability, and whether inequalities between people with and without disability are reducing. 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.^{26(p35)} Without timely and effective reporting, there is a lack of public transparency and accountability concerning Australia's progress towards achieving an inclusive society.²⁷

An estimated 4 million Australians (18%) live with disability; 2.2 million (14%) aged 15-64 years. Disability-related inequalities in health and social determinants of health are important issues that have not received the level of attention they warrant in mainstream public health discourse.²⁸⁻³⁰ Despite the prominence social determinants of health have achieved in the academic literature, there remain barriers to the implementation of social determinants policy approaches to improving health and reducing inequalities.³¹ Effective policy responses are urgently needed to reduce inequalities between people with and without disability through action on the social determinants of health.

It is in this context that the Centre of Research Excellence in Disability and Health (CRE-DH), funded by the National Health and Medical Research Council, set out to develop a monitoring framework supported by indicators to identify and track inequalities by comparing measures of health status and exposure to social determinants of health between people with and without disability. The aims of this work were to:

1. 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;
3. Identify what national data are available and data gaps that need to be addressed.

In this paper, we describe the development process and introduce the Disability and Wellbeing Monitoring Framework and indicators. In discussing the potential utility of the framework, we also consider data gaps, limitations, and implications.

Method

We drew on various sources of expert knowledge when developing the Disability and Wellbeing Monitoring Framework:³² existing frameworks and indicator sets, themselves informed by research evidence and the knowledge of those involved in their development; collective knowledge and experience of CRE-DH researchers and the CRE-DH Partner Advisory Group; and knowledge and expertise of people with lived experience of disability. For information about the CRE-DH and its Partner Advisory Group see www.credh.org.au.

An Expert Panel of Advice provided detailed input on all aspects of the framework via two rounds of consultation. The Panel comprised 17 people with lived experience of disability. Our definition of 'lived experience of disability' encompasses people with disability and people who have a close family member with disability. Ethical approval for the Expert Panel of Advice consultation process was granted by the University of Sydney Human Research Ethics Committee (Project number 2018/884). Several members of the CRE-DH research team and the Partner Advisory Group also have lived experience of disability.

The main steps in developing the Framework were: developing a draft framework drawing on existing frameworks and indicator sets; consulting with the Expert Panel of Advice on the draft framework; revising the framework based on feedback; identifying national data sources and developing potential indicators; consulting with the Expert Panel of Advice on the revised framework and indicators; and refining the framework and indicator list based on feedback and indicator selection criteria.

The Australian Health Performance Framework (AHPF) was used as the starting point for developing the framework structure.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. Structural consistency with the AHPF was considered desirable because of its policy currency in Australia. In all, 20 existing Australian and international frameworks were drawn upon – 10 rights-based, disability-focused indicator frameworks, 5 social determinants of health frameworks, and 5 broader health and wellbeing frameworks (see Supplementary file 1). Among these, key sources were the CRPD and the World Health Organization's International Classification of Functioning, Disability and Health (ICF).³⁴ Domains, themes and indicators identified in each of the sources were mapped to the structure of the AHPF. From this base, the research team undertook an iterative process to develop a structure of domains (headings) and topics (sub-headings). Input from the Expert Panel of Advice was crucial during this process, informing the high-level domain structure, content of topics within domains, and the terminology used.³⁵ Further detail about the process is provided in a technical report available upon request from the first author.

An initial list of potential indicators was based on: (i) indicators in the existing frameworks and indicator lists reviewed; (ii) indicators suggested by the Expert Panel of Advice; and (iii) data items from key Australian

national data sources that aligned with indicator topics in the framework. This list was refined in light of feedback from the Expert Panel of Advice. The refinement process was aided by applying indicator selection criteria, based on a set used by the Australian Institute of Health and Welfare.³⁶ In selecting indicators, the emphasis was on including those likely to indicate socially-produced inequalities, rather than inequalities that may be produced directly by impairment of body structure or function. The majority of indicators were chosen to enable measurement of inequality between people with and without disability aged 15–64, but some indicators relating specifically to the experiences of people with disability were also included.

Four categories of national data sources were considered: the Australian Census, surveys conducted by the Australian Bureau of Statistics (ABS), other national surveys, and administrative data collections. Where more than one national data source was available for an indicator, ABS data sources were chosen over other sources (e.g., the Household Income and Labour Dynamics Australia survey) because of the consistent approach to disability identification across ABS sources and the expectation of stability and future replication of data capture methodology over time. Most indicators require a data source allowing comparison between people with and without disability to enable inequalities to be quantified. The ABS Survey of Disability, Ageing and Carers (SDAC) is Australia’s national source of disability prevalence data. For many questions in this survey, data are only collected for people with disability, carers, and people aged 65 years or over, so it is not possible to make comparisons between people with and without disability. Nonetheless, SDAC is a rich source of information on the experiences of people with disability and can complement data sources that allow comparison between people with and without disability.

A set of area-level indicators was also developed to fit within the structure of the framework. This work was informed by the national liveability indicators developed for monitoring spatial factors associated with health and wellbeing across Australia’s cities.³⁷ The area indicators will be discussed in a subsequent paper.

Results

The Disability and Wellbeing Monitoring Framework has a hierarchical structure. The top level of this structure comprises three elements: Health and wellbeing, Social determinants, and Service system. The next level is domains, which are broad areas of information grouped within the three elements (Figure 1). At the next level down (not shown in Figure 1), each domain has one or more topics, within which relevant indicators are specified. As an example, topics and indicators for domain 16 ‘Justice and safety’ are shown in Box 1.

Indicators

The framework has 128 indicators in total, and for 93 of these (73%) an Australian national data source is available; this includes 12 indicators for which only data for people with disability are currently available, but

comparison data for people without disability are needed (Table 1). For the remaining 35 indicators (27%), national data are not currently available; about half of these are indicators identified for national reporting in the AHPF. For some indicators, SDAC data for people with disability can be used to complement data from a source that allows comparison by disability status. For example, for the indicator 'Feelings of safety at home', the ABS General Social Survey provides data on the percentage of people who feel safe at home alone after dark, by disability status, while the SDAC provides data on the percentage of people with disability who feel safe at home alone during the day. In future, it would be desirable to have data on feeling safe at home alone during the day for people with and without disability.

Of the 113 indicators that require a comparison between people with and without disability, data by disability status can be reported for 70 indicators. For the remaining 43 indicators, either population data exist but cannot be disaggregated by disability status ($N=17$), data are available only for people with disability ($N=12$), or there is no national data source ($N=14$). There are 15 indicators that relate specifically to the experiences of people with disability, for which comparison with people without disability is not needed, for example, 'Experience of disability-related discrimination'.

It is important to note that operational definitions of disability vary between data sources.³⁸ Differences in the number and wording of questions used to identify disability can affect the size and characteristics of the population identified as having disability (ABS 2018).³⁹ Possible implications of this for data comparability should be acknowledged when indicator data from different sources are presented together.

Future indicator development

There are 17 topics in the framework that do not currently have indicators. In some cases, this is because no relevant indicators could be identified. In others, existing indicators were deemed unsuitable. For example, life expectancy at birth is commonly reported as a high-level health outcome indicator (e.g., in comparing health outcomes among OECD countries⁴⁰). However, interpreting life expectancy for people with and without disability presents challenges because of the differing ages at which people acquire disability and the health conditions associated with some types of disability that influence life expectancy. Topics without indicators are retained in the Framework as 'placeholders'; further work is needed to develop appropriate indicators for these topics.

Input from the Expert Panel of Advice identified three additional factors relevant to people with disability: community attitudes, access to opportunities, and advocacy and empowerment. These factors influence the extent to which people with disability, individually and collectively, can achieve good health and wellbeing outcomes within the context of an ableist society. Some indicators speak to these factors, for example, 'Experience of disability-related discrimination in the workplace'. Further consultation is needed to determine if and how these factors could be meaningfully represented in the framework.

Figure 1: The three elements and 19 domains of the Disability and Wellbeing Monitoring Framework

HEALTH	
Subjective health and wellbeing	Lifestyle factors
Morbidity	Personal biomedical factors
Mortality	
SOCIAL DETERMINANTS OF HEALTH	
Physical environment	Employment
Transport	Education
Food	Family and relationships
Information and communications	Social and civic participation
Income and material resources	Justice and safety
Housing	
SERVICE SYSTEM	
Health services	Mainstream services
Disability services and supports	

Table 1: Disability and Wellbeing Monitoring Framework indicators by current national data availability

	<i>N</i>
<i>Indicators for which national data can be reported:</i>	
Data available to report indicator by disability status	70
Data available for people with disability only; comparison data needed	12
Data available for people with disability; comparison not needed*	11
<i>Indicators for which national data cannot be reported:</i>	
Data available, but no disability identifier	17
No national data available; data with disability identifier needed	14
No national data available; data needed for people with disability only*	4
Total	128

* Of the 128 indicators, 15 are relevant only to people with disability, e.g., 'Experience of disability-related discrimination'.

Box 1: The framework domain ‘Justice and safety’, showing topics (numbered), indicators (listed under topics) and Australian national data sources^{1, 2} (in right hand column).

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
- 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
Future aim: get data on emotional abuse more broadly than partner abuse
- Experience of financial abuse *Current data gap*: % of people who have experienced financial abuse

16.3 Feelings of safety

- Feelings of safety at home *GSS* – % of people who feel safe or very safe at home alone after dark
SDAC – % of people with disability who feel safe or very safe at home alone during the day
Future 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
SDAC – % of people with disability who feel safe or very safe walking alone in local area after dark
- Feelings of safety on public transport *Current data gap*: % of people who feel safe or very safe on public transport

16.4 Involvement with criminal justice system

- Incarceration rate *National Prisoner Health Data Collection* – % of prison entrants with disability

16.5 Disaster preparedness *No indicators for this topic currently*

1. GSS = General Social Survey;⁴¹ PSS = Personal Safety Survey;⁴² SDAC = Survey of Disability, Ageing and Carers.⁴³

2. Data for all measures can be broken down by disability status, allowing comparison between people with and without disability, except those worded as ‘% of people with disability...’.

Data gaps

In the course of developing the framework and indicators, four types of data gaps were identified. The first is the absence of any national data source for some indicators. For example, no national data on the experience of bullying and harassment are currently available for people aged 15-64 years. The second is the absence of disability identifiers in some national data sources. For example, the National Hospital Morbidity Database does not include a disability identifier, so potential inequalities cannot be determined (e.g., for rates of hospitalisation for injury and poisoning).

The third type of data gap concerns national data sources that include disability identification, however certain groups of people with disability are not represented. This is because the survey sample frames for many ABS surveys do not cover people living in Very Remote Areas, in discrete Aboriginal and Torres Strait Islander communities, or in non-private dwellings. The ABS list of non-private dwellings includes boarding houses, hospitals, psychiatric hospitals or institutions, hostels for the disabled, nursing homes, accommodation for people who are homeless, prisons, and other welfare institutions (including group homes for people with disability).⁴⁴

The fourth type of data gap concerns inadequate representation of people with disability who are not able to answer survey questions themselves. ABS survey user guides advise that, in the case of a selected adult not being able to answer for themselves due to significant long-term illness or disability, 'a person responsible for them was interviewed on their behalf, provided the interviewer was assured that this was acceptable to the selected person'.⁴⁵ Where an acceptable proxy person is not available, the interview may not go ahead. Use of proxy respondents can compromise data validity,⁴⁶ and the Expert Panel of Advice expressed concern about the potential for misrepresentation of a person's situation and views when someone else answers questions on their behalf.

Discussion

Drawing on the expertise of people with lived experience of disability as well as existing frameworks and indicator sets, we have produced a new monitoring framework and set of indicators to measure inequalities between people with and without disability in Australia. Work is underway to report national data for people aged 15-64 years. This will provide a baseline for monitoring progress on reducing inequalities and improving health and wellbeing for people with disability into the future. The aim will be to produce an informative and empowering resource that highlights areas where action is needed.

The voices and perspectives of people with disability were integral in shaping the framework and indicators, through input from the Expert Panel of Advice as well as those members of the CRE-DH research team and Partner Advisory Group who have lived experience of disability. A distinctive feature of the framework is that

it includes both indicators relating to aspects of life that are important to the population broadly, which are key for measuring inequalities, and indicators of particular relevance to people with disability, such as experience of disability-related discrimination and access to job design modifications. While this framework focuses specifically on people aged 15 to 64 years, disability-related disadvantage also affects people aged under 15 and people aged 65 and over. Future work needs to address socially-produced inequalities for these age groups, and the current framework could be used as a starting point for this.

The analysis of data availability for the indicators (Table 1) shows that Australia has a strong foundation of national data sources that enable comparison between people with and without disability. However, for 43 indicators that require comparison between people with and without disability, national data are not available. For such indicators, it is not possible to: know whether people with disability are disadvantaged relative to non-disabled people; measure the magnitude of inequality; track change over time; or identify factors that might inform effective policy responses.

Regarding the 17 indicators for which population data exist but cannot be disaggregated by disability status, all involve an administrative data source without a disability identifier. The Australian Institute of Health and Welfare has developed a standard 'disability flag' for use in administrative data collections related to mainstream services, but to date this has only been implemented in the Specialist Homelessness Services Collection and the National Prisoner Health Data Collection.⁴⁷⁻⁴⁹ Data linkage offers a potential alternative to including a disability identifier in all data collections.⁵⁰

The impact of incomplete representation of some groups of people with disability in key national data sources requires exploration. This may not have a large effect on overall measures of inequality between people with and without disability, because relatively small numbers of people live in geographic areas and dwelling types excluded from survey sample frames. However, data sources that exclude particular groups of people with disability (e.g., people living in supported accommodation) cannot be used to identify inequalities for those groups in order to inform policy responses. Work is needed to find meaningful ways to capture data on health, wellbeing and social determinants for all people with disability.

The capacity of the framework to comprehensively monitor inequalities between people with and without disability is hampered by the data gaps identified. However, by highlighting these data gaps, the framework will have an important role to play in expounding the need to address deficiencies in national data. Other future uses for the framework include investigation of the effects of intersectionality and multiple disadvantage, the mechanisms and causal pathways by which social determinants influence health outcomes for people with and without disability, and the most effective ways to intervene to reduce inequalities.

In addition to presenting national data to quantify inequalities between people with and without disability, we plan to conduct analyses of spatial data for area-level indicators that have been developed to fit within

the framework structure. This will enable us to explore how area-level factors related to social determinants of health vary geographically, and identify associations between local area characteristics (e.g., local area employment rate, local food environment, access to health services) and health and wellbeing outcomes for people with and without disability. Social and physical environmental factors are recognised to play a central role in the experience of disability (WHO 2001), and in individual- and population-level health outcomes. Area-level indicator data will be of particular value for informing geographically-targeted policy responses to address inequalities.

We recognise that people with disability are not a homogeneous group. As well as presenting broad comparisons between people with and without disability for each indicator, it will be important to explore differences among people with disability associated with factors such as type and severity of impairment, life-course stage, age at onset of disability, socioeconomic status, and geography (e.g., people living in urban versus rural and remote areas). Understanding this variation will inform effective policy responses.

Implications for public health

Inequalities between population groups are a major concern for public health, and understanding inequalities is essential for informing the development of effective policy and practice responses. Disability-related inequalities in health and wellbeing warrant greater attention than they currently receive.^{28,29} The framework provides the much-needed tool for measuring inequalities for Australians with disability aged 15-64 years, and for exposing gaps in the evidence base to be addressed. The use of robust indicators provides a systematic approach to utilising existing national data to track Australia's progress towards redressing disability-related inequalities in health and wellbeing.

The Disability and Wellbeing Monitoring Framework has been developed in an Australian context, informed by a range of Australian and international frameworks and indicator sets, and with expert guidance from people with lived experience of disability. There is an opportunity to adapt this framework and indicator set for use in other countries or internationally – with modification as needed to suit country requirements and data sources – to monitor inequalities between people with and without disability, to drive improvements to data, and in a range of related research and policy applications.

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Supplementary file 1

Sources reviewed to inform development of the Disability and Wellbeing Monitoring Framework

Disability-focused frameworks

2010–2020: National Disability Strategy.^{23,51}

A fair go? Measuring Australia's progress in reducing disadvantage for adults with disabilities.⁵²

Absolutely everyone. State disability plan 2017–2020 (Victoria).^{53,54}

Convention on the Rights of Persons with Disabilities.²⁵

Incheon Strategy Targets.^{55,56}

International Classification of Functioning, Disability and Health.³⁴

National Disability Agreement performance indicators.⁵⁷

NDIS Outcomes Framework.^{58,59}

Report on Government Services performance indicator framework.⁶⁰

World Report on Disability.⁷

Social and environmental determinants of health frameworks

Closing the gap in a generation: health equity through action on the social determinants of health.¹⁵

Creating liveable cities in Australia: Mapping urban policy implementation and evidence-based national liveability indicators.³⁷

Global age-friendly cities: a guide.⁶¹

Review of social determinants and the health divide in the WHO European Region: final report.⁶²

Social Inclusion in Australia. How Australia is faring. 2nd Edition.⁶³

General health and wellbeing frameworks

Australian Health Performance Framework.³³

Australia's Welfare 2017.⁶⁴

Australia's Health Tracker.^{65,66}

Global Reference List of 100 Core Health Indicators.⁶⁷

Measures of Australia's progress.⁶⁸

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