CRE–DH

Centre of
Research Excellence in
Disability and Health

SUBMISSION ON THE NATIONAL DISABILITY STRATEGY OUTCOMES FRAMEWORK

in partnership with

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About this submission

This submission is made on behalf of investigators within the Centre of Research Excellence in Disability and Health (CRE-DH).

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. The CRE-DH also aims to identify cost-effective policies that improve the health of people with disability in Australia. The CRE-DH is funded by the National Health and Medical Research Council. https://credh.org.au/

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

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Submission to the Australian Government Department of Social Services (DSS) on the draft National Disability Strategy (NDS) outcomes framework

Monitoring implementation of and outcomes related to the National Disability Strategy (NDS) is essential for ensuring that the Strategy is effective in improving the lives of people with disability and achieving a fair and inclusive society in which people with disability can fulfil their potential as equal citizens. We welcome the opportunity to have input into the development of the NDS outcomes framework.

Our comments set out in this document are based on the materials provided to participants at the 'Researcher Roundtable - National Disability Strategy beyond 2020', 3 December 2020.

In providing our comments, we draw on our collective knowledge and research expertise in relation to health and wellbeing inequalities experienced by people with disability, and particularly on our recent experience with:

- Developing the Disability and Wellbeing Monitoring Framework and Indicators, with input from people with lived experience of disability;[1] and
- Organising and contributing to, in partnership with the Australian Human Rights Commission, a Zoom webinar as part of consultations for the next National Disability Strategy.[2]

Australia has previously lacked a comprehensive approach for monitoring and reporting on social, economic and health outcomes for people with disability in comparison with non-disabled people. Research published by CRE-DH in 2017 revealed that, across many aspects of life, inequities between working-age Australians with and without disability persisted, and in some areas worsened, over the period 2001 to 2016.[3] Monitoring, using reliable sources of data, is crucial to highlight inequalities that must be addressed and to identify levers for more effective policy action.

The CRE-DH developed the Disability and Wellbeing Monitoring Framework, in consultation with people with lived experience of disability, to measure and track inequalities between people with and without disability in relation to exposure to social determinants of health and wellbeing. The Disability and Wellbeing Monitoring Framework has a hierarchical structure, with 19 domains grouped into three broad elements (Health and wellbeing, Social determinants, and Service system), within which 128 indicators are specified.

It is possible to report nearly three-quarters of these indicators using existing Australian national data sources. For the remainder, national data are not currently available, highlighting important data gaps and the need for data development efforts. The CRE-DH is currently preparing to report national baseline data comparing people with and without disability, for all indicators where such comparison is applicable.

In **Section 1**, we provide specific comments on each NDS outcomes framework domain and list relevant indicators from the Disability and Wellbeing Monitoring Framework. Where appropriate, we suggest measures that may be considered for reporting as 'headline indicators' (these are in bolded text).

In **Section 2**, we provide input concerning the following key issues and overarching considerations relating to the outcomes framework and its use over the life of the NDS:

- Co-design with people with disability, facilitated by inclusive processes, is essential in all aspects of the outcomes framework, including development, review and reporting.
- Indicators must relate explicitly to Articles of the Convention on the Rights of Persons with Disability (CRPD).
- The outcomes framework must provide a comprehensive basis for monitoring outcomes for people with disability compared with outcomes for people without disability in order to track inequalities.
- A commitment to regular public reporting is necessary for transparency and accountability.
- The outcomes framework has a crucial role to play in improving national data relevant to people with disability, and should be developed and used with this in mind.
- All measures must be fit-for purpose and should inform more effective policy and practice; therefore, the rationale for each measure must be clear.
- The content of the NDS outcomes framework should be conceptually consistent and clearly presented.

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[1] Fortune N, Badland H, Clifton S, Emerson E, Rachele J, Stancliffe RJ, Zhou Q, Llewellyn, G (2020). The Disability and Wellbeing Monitoring Framework and Indicators: Technical report. Melbourne, Centre of Research Excellence in Disability and Health. Available at: https://credh.org.au/reports-and-submissions/
Fortune N, Badland H, Clifton S, Emerson E, Rachele J, Stancliffe RJ, Zhou Q, Llewellyn G (2020). The Disability and Wellbeing Monitoring Framework: data, data gaps, and policy implications. *Australian and New Zealand Journal of Public Health* 44(3): 227-232.
Clifton S, Fortune N, Llewellyn G, Stancliffe RJ, Williamson P (2020). Lived expertise and the development of a framework for tracking the social determinants, health, and wellbeing of Australians with disability. *Scandinavian Journal of Disability Research* 22(1): 137–146.

[2] Centre of Research Excellence in Disability and Health (2020). National Disability Strategy: beyond 2020. Webinar report. Available at https://credh.org.au/reports-and-submissions/

[3] The Centre of Research Excellence in Disability and Health (2017). A fair go? Measuring Australia's progress in reducing disadvantage for adults with disabilities (2001-2016). Melbourne: University of Melbourne.

1. Comments on specific NDS outcome framework domains

Relevant indicators from the CRE-DH Disability and Wellbeing Monitoring Framework are listed for each outcomes framework indicator (dot points). Where appropriate, we suggest measures that may be considered for reporting as 'headline indicators' (these are in bolded text). Note that all indicators should be reported for both people with and without disability, so inequalities can be monitored over time (except those indicators that refer specifically to 'people with disability').

Key to data source abbreviations: **SDAC**: ABS Survey of Disability, Ageing and Carers; **GSS**: ABS General Social Survey; **NHS**: ABS National Health Survey; **SIH**: ABS Survey of Income and Housing; **PSS**: ABS Personal Safety Survey; **HILDA**: Household, Income and Labour Dynamics in Australia Survey

Domain 1 – Inclusive and accessible communities

Outcome: People with disability live in accessible and well-designed communities with opportunity for full inclusion in social, economic, sporting and cultural life

Indicators	CRE-DH Comments
The built and natural environment are accessible	• **Accessing venues/locations: SDAC – % of people with disability who had no difficulty accessing buildings or facilities in last 12 months** • Access to social venues: SDAC – % of people with disability who had no difficulty accessing social venues in last 12 months • Housing visitability: SDAC – % of people with disability who had no difficulty accessing other people's homes in last 12 months • Access to mainstream 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) The key system measure ('% People with disability unable to visit shops and banks due to disability') is in fact a population measure – suggest delete. Compliance with accessibility standards should be reported when data are available and noted as a data gap until then. Key systems identified for this domain should include urban and land use planning systems. Over the course of the NDS, it should become feasible to use spatial or geocoded data to report measures of local access to amenities (e.g., social infrastructure services, public transport, public open space) for people with disability compared with people without disability, and/or accessibility of public facilities.
Access to suitable and secure housing	• Overcrowding: SIH – % of people who live in a household in which 1 or more additional bedroom/s is needed (Canadian National Occupancy Standard) • Younger people with disability in residential aged care: AIHW data – number of people aged under 55 living in residential aged care • Homelessness: GSS – % of people who have ever experienced homelessness The population measure listed ('% of people with disability whose home is suitable and accessible') is a good headline indicator and should be noted as a 'data gap' until data are available. The NDIS measure here should not be included under 'Population measures'.

Transport systems are navigable	• **Transport: GSS – % of people who can easily get to places they need to go** • Public transport use: SDAC – % of people with disability who could use some form of public transport • Public transport availability: SDAC – % of people with disability who said public transport is available in their area • 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 '% of people with disability who have/would have no difficulty with some or all forms of public transport' should not be included as a key system measure. Suggest that 'accessible' rather than 'navigable' should be used in wording of this indicator; it is a broader and clearer concept.
Information and communication systems are accessible	• 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 • Internet use: SDAC – % of people with disability who used the internet in the last 3 months The population measure listed (% people with disability who can access communication and information networks when they need to) is a good headline indicator and should be noted as a 'data gap' until data are available. Re key system measure '% Government websites that meet WCAG 2.0 accessibility standard or above (Annual Reports)', compliance with accessibility standards must be independently assessed for data published in annual reports to be reliable.
Social inclusion and participation	• **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** • **Contact with friends/family not living in the same household: SDAC– % of people with disability 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.)** • **Having people to confide in: GSS – % of people who have ex-household family/friends to confide in** • Social marital status: GSS – % of people who are married in a registered or de facto marriage • 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 • Volunteering: GSS – % of people who did unpaid voluntary work in last 12 months through an organisation • 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 • Social media use: SDAC – % of people with disability who accessed the internet in the last 3 months for social networking • 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 The key system measure '% NDIS participants who spend free time doing activities that interest them' does not specifically relate to social inclusion and participation – suggest delete. The NDIS measure here should not be included under 'Population measures'.

Domain 2 – Economic security

Outcome: People with disability have economic security, enabling them to plan for the future and exercise choice and control over their lives

Indicators	CRE-DH Comments
Economic participation	• **Labour force participation rate: SDAC – % of people in the labour force** • **Employment to population ratio: SDAC – % of people employed** • Engagement in employment, education and training: SIH – % of people not engaged in employment, education or training • Unemployment rate: SDAC – % of people who are unemployed (Denominator = people who are in the labour force) • Long-term unemployment rate: SDAC – % of people who have been looking for work for 12 months or more (Denominator = people who are in the labour force) • Under-employment: SDAC – % of people with disability who are employed who usually work 34 hours or less per week and would like a job with more hours (Denominator = people who are employed) • Leave entitlements: GSS – % of people employed who have leave entitlements in their main job (Denominator = people who are employees) • Employment in high skill jobs: SDAC – % of people employed who are in high skill jobs (Denominator = people who are employed) This indicator should be worded in terms of 'employment' rather than 'economic participation' – improved employment outcomes are widely recognised as fundamental to improving wellbeing for people with disability. See suggestion in Section 2, below, that all indicators should be worded as positive statements, e.g., 'People with disability have equal employment opportunities'. The two key systems listed – DES and NDIS – relate to a relatively small proportion of people with disability. Additional systems with roles in delivering better outcomes for <u>all</u> people with disability should be listed (e.g., Centrelink). The planned National Disability Employment Strategy should also be listed. The NDIS measure here should not be included under 'Population measures'.

Economic independence	• **Personal income: SIH – Average weekly disposable income for people with and without disability** • **Financial stressors: GSS – % of people who live in a household that had no cash-flow problem in the last 12 months** • Household Income: GSS – % of people who live in households in the top 6 deciles of equivalised household gross weekly income • Source of income: GSS – % of people for whom a Government pension or allowance is the principal source of personal income • Motor vehicles: Census – % of people who live in a household with one or more motor vehicles • Paying bills: GSS – % of people who live in a household that reported no difficulty paying bills in last 12 months • Access to emergency funds: GSS – % of people who live in a household that could raise $2,000 within a week for an emergency This indicator should be worded in terms of 'adequate income'. Key system measures should relate to the adequacy of DSP and other income support payments for people with disability. The key system outcome 'The Commonwealth and state and territory public service supports people with disability to find and maintain employment' relates to the 'employment' indicator, above. Note that operational definitions of disability may differ between jurisdictions for this measure, so data may not be comparable.
Transition to Work	• Youth unemployment rate: SDAC – % of people aged 15-24 years who are unemployed (Denominator = people aged 15-24 who are in the labour force)
Housing affordability/ stress	• **Housing stress: SIH – % 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** • Tenure type: SIH – % of people who owned their own home (with or without a mortgage)

Domain 3 – Personal and community support

Outcome: People with disability have access to a range of well-coordinated and effective services and supports that are appropriate for their needs.

Indicators	CRE-DH Comments
Availability of support	• Difficulty accessing specialist disability services: GSS – % of people who had difficulty accessing disability services • **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** This indicator is stated extremely broadly, so it is not clear what it aims to cover. Further input from people with disability should be sought regarding how this indicator can be more clearly specified or split up (e.g., support for accessing mainstream services; support for undertaking daily activities; support for participating in social, cultural and recreational activities). '% extent to which need for assistance met' and '% People with disability receive the supports they need' should not be included as key system measures. System measures for this indicator should relate to more specifically identified support systems/services (this may be more appropriately done at state/territory level).
Informal and carer supports	
Availability of assistive technology*	• Met/unmet need for assistive products: SDAC– % of people with disability who do not need additional aids
People with complex high needs are supported*	• 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 The NDIS measure here should not be included under 'Population measures'.

Domain 4 – Health and wellbeing

Outcome: People with disability attain highest possible health and wellbeing outcomes throughout their lives

Indicators	CRE-DH comments
Health and wellbeing	Subjective health and wellbeing: • **Self-rated health: NHS 2017-18 – % of people who reported their health to be 'very good' or 'excellent'** • Life satisfaction: GSS – % of people who rated their overall life satisfaction as 7 or higher on a scale of 0 to 10 Morbidity: • 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 Lifestyle factors: • Physical activity level: NHS 2017-18 – % of people who met the Physical Activity Guidelines 2014 (incl exercise and workplace) • Smoker status: NHS 2017-18 – % of people who are a current daily smoker • Risky alcohol consumption: NHS 2017-18 – % of people who exceeded the lifetime alcohol risk level - 7 day average (2009 guidelines) • 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) • Body Mass Index: NHS 2017-18 – % of people who are overweight or obese based on BMI measurement Access to health services: • 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 • **Difficulty accessing healthcare: GSS – % of people who had experienced a barrier to accessing healthcare when needed in the last 12 months** • 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 • Unmet need for hospital services: SDAC – % of people with disability who reported unmet need for hospital admission in the last 12 months • 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 Cost of health services and medicines: • Cost as barrier to accessing health services: HILDA – % of people who could not afford to see a GP when they needed to; 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

	• 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 Health literacy: • Health literacy: NHS 2017-18 – % of people who said it was not difficult to find good health information Continuity of health care: • Multiple health providers consulted for same health condition: SDAC – % of people with disability who reported no issues caused by lack of communication between health professionals (Denominator = people who had seen 3 or more health professionals for the same condition in the last 12 months) '% of people see a medical specialist, wait longer than they feel is acceptable to get the appointment' is not a system measure (it relies on person's own perceptions/expectations) – suggest delete. Access to rehabilitation services and supports is critical for people with disability, to support functioning across all life domains, and should be included as a separate indicator in this domain.
Mental health	• **Self-rated mental health: NHS 2017-18 – % of people with low levels of psychological distress (based on Kessler 10 score)** • 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 '% of people with disability in psychological stress' is not a system measure – suggest delete. The NDIS measure here should not be included under 'Population measures'.
Prevention and early intervention	• 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 emergency department services: NHS 2014-15 – % of people who had visited emergency/casualty department in last 12 months • Unmet need for GP services: SDAC – % of people with disability who reported unmet need to see a GP in the last 12 months System measures relating to access to primary care for people with disability are needed – this is a data gap that should be urgently addressed. % of people admitted to hospital with a 'potentially preventable hospitalisation' could be used as proxy measure of primary care effectiveness (https://www.aihw.gov.au/reports/primary-health-care/potentially-preventable-hospitalisations/). With advances in data linkage, it may be soon be possible to report this measure for people with and without disability. The NDIS measure here should not be included under 'Population measures'.
Emergency responses	Re system measure '% (and number) of local governments and disaster management services that have disability inclusive plans in place', independent accreditation of disability inclusive plans is essential for this to be meaningful. '% of state and territory emergency services that comply with WCAG 2.0 accessibility standards or above' should be listed as a system measure, not a population measure. Disability inclusiveness of emergency response is an important area for data development. An effective approach may be to develop methods for data capture on outcomes for people with disability in the context of specific emergency situations (e.g., COVID, bushfires).

Domain 5 – Rights protection, justice and legislation

Outcome: People with disability feel safe and have their rights promoted, upheld and protected.

Indicators	CRE-DH comments
People with disability are safe from violence, abuse, neglect and exploitation	• 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 not a victim of physical or threatened violence in last 12 months** • Experience of sexual violence: PSS – % of people who had not experienced sexual violence since age 15 • Experience of emotional abuse: PSS – % of people who had not experienced emotional abuse by a current partner and/or previous partner since age 15 • **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** • Feelings of safety in neighbourhood: GSS – % of people who feel safe or very safe walking alone in local area after dark The key systems listed relate to a relatively small proportion of people with disability. Additional systems with roles in delivering better outcomes for all people with disability should be listed (e.g., social services, police, anti-discrimination laws). '% of children with disability who are 'On Track' in one or more domains of the AEDC (Australian Early Development Census)' is not appropriate as a system measure for child protection – suggest delete. Re 'Rate of children with disability aged 0–17 years who were the subject of a child protection resubstantiation in a given year', this does not directly measure the effectiveness of the child protection system in protecting children with disability, so should not be included in outcomes framework. When reporting population data on experience of violence it is important to state that many people who may be particularly at risk are not included in national survey data (see Section 2).

The rights of people with disability are protected and upheld	- Experience of discrimination or being treated unfairly: GSS – % of people who have not experienced discrimination or been treated unfairly - Experience of disability-related discrimination: SDAC – % of people with disability who had not experienced discrimination due to disability in the last 12 months - Workplace discrimination: SDAC – % of people with disability who experienced unfair treatment or discrimination due to disability in the past 12 months from their employer and/or work colleagues '% NDIS participants who feel able to advocate (stand up) for themselves' is not a good system measure – suggest delete. '% complaints related to disability discrimination lodged with the AHRC that are investigated and resolved (current AHRC)' does not get at the crucial issue of accessibility of the complaints process. The rate of placement of children in out-of-home care, comparing for parents with and without disability, would be an important measure to add; this is currently noted as a 'data gap' in the Disability and Wellbeing Monitoring Framework.
Access to justice for people with disability	
Equitable treatment for people with disability in the criminal justice system	- Incarceration rate: National Prisoner Health Data Collection – % of prison entrants with disability. '% people with disability who receive formal support when accessing the criminal justice system' – this is listed as a population measure, but is very similar to key system measure for the Justice system.

Domain 6 – Learning and skills

Outcome: People with disability achieve their full potential through education and learning.

Indicators	CRE-DH Comments
Participation in early childhood education	'% and rates of attendance at ECEC for children with disability' should be listed only as a population measure (not also as a system measure). For reporting, this should be broken down by segregated and not segregated ECEC settings. 'Percentage of mainstream ECEC services accessing the Inclusion Support Program' should be listed as a system measure, not a population measure.

Participation in formal education	- **Educational attainment: SDAC – % of people who have completed year 12**; SDAC – % of people with non-school educational qualification - Current participation in education: SDAC – % of people currently studying Measures to monitor progress towards providing adequate support to enable more students with disability to participate in inclusive educational settings are needed here. The need to break down systems and structures that segregate and promote ableism was identified by panellists and participants at the NDS webinar (24 Sept 2020) as a key issue for the next NDS. This should be reflected in the outcomes framework, e.g., by reporting students with disability as a percentage of all students across educational settings.
Pathways to further education	Re ‘Number of students …’ system measures, to allow meaningful interpretation these should be reported as %s with relevant denominators. Note that operational definitions of disability may differ between jurisdictions for measures that use state/territory administrative data, so data may not be comparable.
Participation in informal education (life skills)	The NDIS measure here should not be included under ‘Population measures’.

Domain 7 – Community attitudes

Outcome: Changing community attitudes toward people with disability to improve outcomes in housing, education, employment, community participation, social inclusion, health and justice

Indicators	CRE-DH comments
Employers understand benefits of hiring people with disability Supporting inclusion through greater community awareness and understanding of disability People with disability can exercise their rights and receive equal recognition before the law Personal and community supports provide assistance people need Educators are confident and supported to respond positively to students with disability Health professionals are confident and supported to meet the needs of people with disability	At the NDS webinar (24 Sept 2020), participants and panellists identified attitudes towards disability, at personal, organisational and structural levels of society, as a key issue that should receive more focus in the next NDS. However, measuring and monitoring community attitudes in a way that is meaningful and constructive poses particular challenges. This is an area of the NDS outcomes framework where it is fundamentally important for people with disability to lead development, and for input from the full diversity of people with disability to be sought and facilitated.

2. Key issues and overarching considerations for the NDS outcomes framework

Co-design and inclusive processes are essential in all aspects of the outcomes framework, including development, review and reporting

CRPD Article 33(3) requires that 'Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process': A genuine commitment to co-design and inclusive processes is essential. People with disability must have a leading and central role both in the development of the outcomes framework and the monitoring and reporting process throughout the life of the NDS.

DSS should continue to consult closely with the research community: The research community has much to offer, including:

- knowledge concerning existing evidence on particular topics that can provide important context for monitoring implementation and outcomes;
- understanding of the strengths and limitations of different data sources; and
- practical expertise in collecting and analysing both qualitative and quantitative data.

The NDS outcomes framework must relate explicitly to the Convention on the Rights of Persons with Disability (CRPD)

Indicators must be linked to Articles of the CRPD: The NDS is a key mechanism by which Australia upholds its obligations as a signatory to the CRPD. It is crucial for accountability, therefore, that each indicator in the outcomes framework be explicitly linked to the relevant Article/s of the CRPD. Of particular importance, there must be indicators that specifically address the recommendations made by the Committee on the Rights of Persons with Disabilities in *Concluding observations on the combined second and third periodic reports of Australia*, 19 October 2019.[1]

Reporting outcomes for children with disability: A point made strongly by panellists and participants at the NDS webinar (24 September 2020) was that the next NDS must pay more attention to children with disability. Throughout the outcomes framework, where applicable, measures should be reported specifically for children with disability. This reporting should be explicitly related to Australia's obligations concerning children with disability under Art. 7 of the CRPD and Art. 23 of the Convention on the Rights of the Child.

The NDS outcomes framework must provide a comprehensive basis for monitoring outcomes for people with disability compared with outcomes for people without disability

Tracking inequalities: the NDS aims to reduce inequalities between people with and without disability. To fully understand how inequalities are changing over time, it is important to consider the overall prevalence of an outcome (e.g., unemployment rate) and both absolute (difference) and relative (ratio) inequalities. For example, relative inequalities in unemployment (the rate for people with disability over the rate for people without disability) could rise in the context of falling unemployment and stable absolute differences between people with and without disability. Over the life of the next NDS, it must be possible to determine where inequalities are reducing, remaining unchanged, or worsening for people with disability compared with their non-disabled peers.

Tracking inequalities for diverse groups of people with disability: The nature and extent of disadvantage experienced varies between different groups of people with disability. There should be a commitment to monitoring outcomes and inequalities for key groups of people with disability, including women, Aboriginal and Torres Strait Islander people, people who need support with communication, children and young people, people with less visible disability, people from culturally and linguistically diverse backgrounds, and refugees and people seeking asylum.

Tracking outcomes relating only to people with disability: As well as reporting on inequalities, it is necessary to report on outcomes that relate specifically to people with disability, for example, experience of disability discrimination, physical and information accessibility, access to and quality of disability support services, and met/unmet need for assistive devices.

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[1] Committee on the Rights of Persons with Disabilities (2019). Concluding observations on the combined second and third periodic reports of Australia, 19 October 2019. Available at: http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnzSGolKOaUX8SsM2PfxU7sdcbNJQCwlRF9xTca9TaCwjm5OInhspoVv2oxnsujKTREtaVWFXhEZM%2F0OdVJz1UEyF5IeK6Ycmqrn8yzTHQCn

There should be a commitment to regular public reporting

Transparency and accountability require commitment to a regular reporting schedule: Biennial reporting against the NDS outcomes framework over the 10-year life course of the NDS is essential for holding key actors to account. While the frequency of availability of updated data varies by data source, a biennial timeframe for reporting should enable updated data to be presented on a good proportion of the measures each time. The most recent data should be presented for all headline indicators every time (even if updated data are not available), so that the report provides an authoritative repository that stakeholders can refer to for the latest data.

Reporting should be public and high profile: High-profile public reporting against the outcomes framework is key for transparently tracking progress against the commitments made by Australian governments, embodied in the NDS, to uphold the rights of and improve outcomes for people with disability. Participants at the NDS webinar (24 Sept 2020) suggested that regular NDS outcomes reports should be delivered by the Prime Minister and Premiers/Chief Ministers to parliaments at national and state/territory levels, respectively.

The outcomes framework must drive data improvement

This point relates to the recommendation made by the Committee on the Rights of Persons with Disabilities to Australia in October 2019 in relation to Articles 31-33:[2]

> “58. The Committee recommends that the State party, in conjunction with the Office of the National Data Commissioner, develop a national disability data framework to ensure appropriate, nationally consistent measures for the collection and public reporting of disaggregated data on the full range of obligations contained in the Convention, especially with regard to women, children and Aboriginal and Torres Strait Islander persons with disabilities.”

Data gaps should be highlighted: The NDS outcomes framework is critically important for highlighting data gaps and priority topics for data development. For this reason, it is desirable to include ‘aspirational measures’ for which data are not currently available.

Data on outcomes and inequalities must be reported for ALL people with disability: A commitment to monitoring outcomes and inequalities for all people with disability should be clearly articulated. All data sources have limitations, and key groups of people with disability are often missing from specific administrative and survey data sources. For example, people who live in ‘non private dwellings’ (e.g., disability group homes, prisons, and boarding houses) are not included in most population surveys; and people who are not able to answer survey questions for themselves are often also missing. This must be acknowledged when data are reported, and efforts made to get data on outcomes for these groups of people who are often particularly disadvantaged and at risk.

Spatial data sources should be used where available: Spatial and geocode data are increasingly becoming available and can provide powerful insights concerning geographic aspects of disadvantage and inequality experienced by people with disability. For example, CRE-DH recently published research using liveability indicators produced by the Australian Urban Observatory[3] together with data from the 2016 Census. Results showed higher disability prevalence in neighbourhoods with lower walkability and lower local availability of various amenities (e.g., public transport, healthier food options, public open space, and mental health services).[4] This pattern of lower liveability in areas of higher disability prevalence was evident in major cities but not regional cities. Such information can potentially be used to more effectively target or tailor policy action and interventions. Spatial data sources should increasingly be utilised for outcome reporting over the 10-year life course of the NDS.

Progress on data improvement should be reported: Where indicators are listed as ‘Future version’ it should be made clear when data are expected to be available (e.g., from next GSS). Regular reporting using the outcomes framework should include reporting on progress to fill data gaps and improve data on people with disability.

Commitment to regular review of the outcomes framework: The outcomes framework should be reviewed every two years over the course of the NDS. As well as driving data improvement, the outcomes framework should take advantage of data improvements by adding new measures when data become available (e.g., when the National Disability Data Asset comes online).

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[2] Committee on the Rights of Persons with Disabilities (2019). Concluding observations on the combined second and third periodic reports of Australia, 19 October 2019. Available at: http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnzSGolKOaUX8SsM2PfxU7sdcbNJQCwlRF9xTca9TaCwjm5OInhspoVv2oxnsujKTREtaVWFXhEZM%2F0OdVJz1UEyF5IeK6Ycmqrn8yzTHQCn

[3] Australian Urban Observatory. Available at: https://auo.org.au/

[4] Fortune N, Singh A, Badland H, Stancliffe RJ, Llewellyn G (2020). Area-level associations between built environment characteristics and disability prevalence in Australia: an ecological analysis. *International Journal of Environmental Research and Public Health* 17(21): 7844.

All measures must be fit-for purpose and should inform more effective policy and practice

Apropriate measures should be used, and data gaps highlighted: In some instances in the draft outcomes framework population measures are used as proxies for system measures, and vice versa. This should be avoided. Data gaps should be noted where there is no appropriate system or population measure available. Where it is decided that it is preferable to report an imperfect proxy measure than nothing, it should be clearly noted that it is a proxy measure.

System measures should include measures of co-design and inclusive process: A point made strongly by panellists and participants at the NDS webinar (24 Sept 2020) was that co-design by people with disability and inclusive processes across different policy areas will be fundamental to the success of the next NDS. Therefore, measures of co-design and inclusive process should be included as key system measures across all outcome framework domains.

Measures should enable identification of variation in outcomes that can inform effective intervention: Outcomes on certain indicators may vary geographically or according to particular sociodemographic factors. Measures should enable identification of 'hot spots' and 'at risk groups', so that policy action and interventions can be targeted and tailored effectively. In some cases, it may be more feasible to capture this level of detail at state or territory level. However, reporting of outcomes at this more detailed level should be consistent with the national outcomes framework, and data consistency and comparability between jurisdictions should be promoted.

Include outcome measures that relate to specific policy actions: The outcomes framework should include measures at different levels of generality and specificity. High-level population measures should certainly be included and tracked over time. In addition, measures designed to evaluate the impact of specific policy actions should be included where appropriate and feasible.

Reporting must clearly show where things are getting better, getting worse, or staying the same for people with disability: As a general principle, measures should be framed positively, as attainment measures (i.e., % of people with positive outcome), so that increasing rates and a narrowing of the gap between people with and without disability over time indicate improvement. However, it may be decided that some deficit measures should also be included. In all cases, reporting should clearly highlight where outcomes are improving, staying the same, or becoming worse over time.

Varying definition of disability in different data sources affects interpretation of data: Because of the different ways disability is identified in different data sources, the number and characteristics of people identified as 'with disability' vary between data sources. This has implications for the interpretation of data, including with respect to inequalities between people with and without disability. All data reported should include information about how disability is identified in the data source. Data should only be compared between sources if the same definition of disability is used. This will be an issue particularly where state and territory administrative data sources are used (e.g., for % of students with disability in schools). A key data development objective should be to harmonise disability identification across data sources at state, territory and national level.

The content of the NDS outcomes framework should be conceptually consistent and clearly presented

Consistency in the wording of indicators: Currently, some indicators are framed as statements of what is desired, e.g., 'Information and communication systems are accessible'. We suggest all indicators should be worded as positive statements in this way. For instance, the Domain 2 indicator 'Economic participation' could be reworded to read 'People with disability have equal employment opportunities'.

Outcome domains should match outcome areas in the NDS: We note that the order and wording of outcome domains in the detailed draft framework is different to outcome areas listed in the synopsis document. To avoid confusion, the naming of domains in the outcomes framework should match the outcome areas in the National Disability Strategy, once these are decided.

There should be a clear distinction between 'Person' and 'Population' outcomes. The NDIS outcome measures should be positioned with the 'Person outcomes' and not included in the 'Population outcomes' column. This will make clearer which measures are being used to monitor outcomes for all people with disability, and where there are gaps.

The rationale for key system measures should be clearly articulated. For each key system measure it is necessary to (i) explain why it provides a good basis for assessing the effectiveness of the relevant system or program, and (ii) explicitly set out the logic by which improvements in the system measure can be inked to improved outcomes for people with disability. This is essential to ensure appropriate interpretation of changes over time in key system measures.

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