

## Disability and Health Background Paper

This paper provides background information to the PHAA Disability and Health Policy Position Statement, providing evidence and justification for the public health policy position adopted by Public Health Association of Australia and for use by other organisations, including governments and the general public.

This background paper should be read in conjunction with the following policy position statements:

- Health equity
- Gender and health

### Summary

*People with disability have poorer health than the general population. This can be partly attributed to discrimination based on disability, barriers to accessing services and barriers to inclusion. People with disability are disadvantaged with respect to the social determinants of health and this also contributes to their poorer health outcomes. To improve the health of people with disability, actions must be taken to address the drivers of poorer outcomes.*

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## Public health issue

1. In Australia, the National Disability Insurance Scheme and the National Disability Strategy increased the focus on disability service, but the health of people with disability has not been fully addressed. Disability is most often viewed as an outcome to be prevented, and disability is conflated with poor health (1) however the poor health of people with disability is not always caused by their disability but by obstacles to accessing healthcare, discrimination and social determinants of health.
2. The survey of Disability, Ageing and Carers reported that there were 4.4 million Australians with disability in 2018, representing 17.7% of the population. Almost half (49.6%) of Australians aged over 65 had disabilities, and 11.6% of people aged 0 to 64 had a disability (2). Almost one quarter (24%) of Aboriginal and Torres Strait Islander people were reported to have disability (2). People with disability experience worse health than the general population across a range of health indicators (3).
3. The social determinants of health, the circumstances in which people “grow, work, and age, and the systems put in place to deal with illness” (4) are key drivers of health inequities for people with disability. People with disability are often excluded from employment and from education through direct and indirect discrimination (5) and are disadvantaged with respect to almost all social determinants but particularly education, income, and employment (2).
4. People with disability have been disproportionately affected during the COVID-19 pandemic due to increased risk of infection, increased risk of serious illness, impracticality of physical distancing, barriers in accessing healthcare, and disruptions in support services due to measures taken to reduce the spread of the virus (6, 7). Pandemic protocols to ban visitors to hospitals shut out advocates and family members who advocate for people with disability, and there has been evidence of bias and discrimination in the application of triage protocols overseas (8). COVID-19 vaccination rates for people with disability are much lower than in the general population (9).
5. The World Health Organization argues that attaining the highest possible standard of health and wellbeing for all is only possible when disability inclusion is intrinsic to all health sector priorities, including during health emergencies (6). Redressing the health and social inequities faced by people with disability - eliminating the avoidable causes of health and social inequalities - is key to improving health outcomes for people with disability (1, 10).

## Background, policy context, and priority

6. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that persons with disabilities have the right to attain the highest standard of health without discrimination on the basis of disability (11). The CRPD recognises the model of disability as outlined in the World Health Organizations’ International Classification of Functioning, Disability and Health (ICF) (12). That is, that disability is the result of ‘interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others’ (13).
7. The Sustainable Development Goals agreed by United Nations Member States includes seven targets explicitly referring to people with disability and six additional targets referring to persons in vulnerable situations, which includes persons with disabilities. These targets include equal access to education, full and productive employment and decent work (including for persons

with disabilities), removal of barriers to accessing transport and building, and social, economic and political inclusion (14). These targets align with social determinants of health.

The Sustainable Development Goals are underpinned by a commitment to 'leave no one behind', and it is recognised that the Goals cannot be achieved whilst people are excluded from opportunities and services (15, 16). This includes people with disability who often face barriers to full participation in, and benefit from, development activities (16).

8. Australia ratified the UN CRPD in 2008, and the Commonwealth, State and Territory governments signed the National Disability Agreement in the same year with this action intended to be the first step toward a cooperative approach to supporting Australians with disability. The National Disability Strategy 2010-2020 was introduced in 2011 which provided all levels of government with a high level framework of policy action areas to improve outcomes for people with disability (17), but people with disability have continued to experience poorer health outcomes and more risk factors for chronic health conditions than people without disability (18, 19). Australia's Disability Strategy 2021-2031 was launched in December 2021 and builds on the original strategy (20) including with a clearer focus on monitoring and evaluation (21).
9. Established in 2013 and rolled out nationally from 2016, the National Disability Insurance Scheme (NDIS) transformed the disability services landscape in Australia (22). The NDIS is jointly funded and governed by the Commonwealth, state and territory governments (23), whilst the independent statutory agency, the National Disability Insurance Agency (NDIA), is responsible for implementation of the scheme (24).
10. Australia has a framework of State, Territory and National discrimination laws to protect people from discrimination on the basis of disability. Efforts to introduce a religious discrimination bill undermine the effect of these laws, risking access to healthcare, and eroding the rights of people with disability (25).
11. Reasonable accommodation describes the 'necessary and appropriate modification and adjustments' to ensure people with disability can exercise their full human rights and freedoms, whilst not imposing undue burden (13). Signatories to the CRPD are required to take all appropriate steps to ensure that reasonable accommodation is provided (13). Despite this, people with disability continue to face barriers, stigmatization, and discrimination when accessing health and health-related services. One in ten disabled Australians reported they had experienced discrimination because of their disability and in 2020-21, 37% of all complaints to the Australian Human Rights Commission related to disability discrimination, more than any other form of discrimination (26).
12. Intersectional discrimination occurs when discrimination on several grounds operate simultaneously, interact and result in unique disadvantage and discrimination (27). People with disability may experience multiple and intersecting discrimination on the basis of race, ethnicity, culture, religion, class, geographic location, gender, age, sex, sexuality or other characteristics, in addition to disability. The intersection of disability with other social characteristics influences the experience of and response to violence for people with disability (28). For example, women with disability in institutional settings are at increased risk of gender-based violence, including sexual violence and forced sterilisation or abortion (28), whilst people with disability from culturally and linguistically diverse communities may face intersecting barriers in reporting violence or abuse (29).
13. The health and wellbeing of people with disability can be improved by addressing the social determinants of health, and through addressing barriers and discrimination in access to health

services. The six outcome areas set out in Australia's Disability Strategy 2021-2031 act as and are aligned with social determinants of health (19, 20), and these policy outcome areas need to be translated into action on inequities faced by people with disability.

## Current situation

### *International and Australian Recommendations*

14. The World Programme of Action concerning Disabled Persons was a major outcome of the International Year of Disabled Persons and was adopted by the United Nations General Assembly on 3 December 1982. While it is now four decades old, the recommendations for action are still relevant to the current situation. A central theme of the World Programme of Action was "equalization of opportunities", and a philosophy of achieving full participation of persons with disabilities in all aspects of social and economic life (30). The CRPD built on the World Programme of Action, but much work still remains to be done.

The 2011 World Health Organisation World Report on Disability made recommendations to assist stakeholders in overcoming the barriers the people with disability face. This report identified widespread barriers including inadequate policies and standards, negative attitudes, lack of provision of services, problems with service delivery, inadequate funding, lack of accessibility, lack of consultation and involvement and lack of data and evidence (31). The evidence in the World Report on Disability suggested that these barriers are avoidable, and made nine recommendations for action:

- Enable access to all mainstream policies, systems and services
- Invest in specific programmes and services for people with disability
- Adopt a national disability strategy and plan of action
- Involve people with disability
- Improve human resource capacity of people working in education, health care, rehabilitation, social protection, labour, law enforcement, and the media to ensure non-discrimination and participation
- Provide adequate funding and improve affordability
- Increase public awareness and understanding of disability
- Improve disability data collection
- Strengthen and support research on disability

Implementing these recommendations requires multisectoral action and the involvement of actors in government, civil society organisations, professionals, the private sector, and people with disability and their families (31).

15. The National Disability Strategy 2010-2020 directly addressed one of the World Report on Disability recommendations for action (adoption of a national disability strategy) and aimed to make progress toward at least three of the other recommendations for action: enabling access to mainstream services, increasing public awareness and understanding of disability and involving people with disability. The Strategy was developed to complement Australia's 2008 ratification of the UN CRPD and was the first time in Australian history that all governments

committed to a unified approach (17). The six policy areas covered in the Strategy were intended as outcome areas and included long-term goals for:

- Inclusive and accessible communities (physical environment, digital information and communications technologies, and civic life)
- Rights protection, justice and legislation (statutory protections, complaints mechanisms, advocacy, electoral and justice systems)
- Economic security (jobs, financial independence, adequate income support, housing)
- Personal and community support
- Learning and skills (early childhood, school, further education, transition from education to employment)
- Health and wellbeing (health services, health promotion, wellbeing) (17)

Australia's Disability Strategy 2021-2031 retains the six outcome areas of the original Strategy. These policy areas act as social determinants of health and the focus on these areas reflects the Social Model of Disability the Strategy is based on. The focus of the Strategy aligns with the UN CRPD and Social Model of Disability with an aim to removing 'attitudinal and environmental barriers hindering full and effective participation in society on an equal basis with others' (20).

16. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) was established in April 2019 in response to the 2015 Australian Senate Community Affairs Reference Committee's recommendation (32). The Letters Patent which established the Disability Royal Commission recognise Australia's 'international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability, including to protect people with disability from all forms of exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities' (33 p1). Accordingly, the Disability Royal Commission is employing a human rights-based approach to its inquiries (34).

Health forms a key area of the Disability Royal Commission's inquiry, and in 2019 an Issues Paper on health care for people with cognitive disability was released (35). The Commission recognises that people with disability may experience violence, abuse, neglect and exploitation in health settings and that 'the denial of the right to health care may also be a form of neglect' (35 p2). The Disability Royal Commission is due to deliver its final report to the Australian Government in September 2023.

17. The Australian Human Rights Commission published guidelines on the rights of people with disability in health and disability care during COVID-19 in 2020. While these guidelines have a narrowed focus, on care settings and COVID-19, they are relevant to the broader issues of avoiding discrimination on grounds of disability and avoidance of practices and acts contrary to or inconsistent with human rights of people with disability. The guidelines outline the key rights from with the CRPD that are relevant in the pandemic context (36):

- The right to protection during times of risk
- Right to health
- Right to life

- Right to equality and non-discrimination
- Right to equal recognition before the law
- Right to accessible information

The role of human rights in health care for people with disability are relevant to policies introduced to manage COVID-19. Policies to manage COVID-19 should avoid practices or acts that deny access to mobility aids, accessible communication, access to visitors and family (36). The use of limited resources, application of triage protocols to discharge patients or do not resuscitate directions must not discriminate against people with disability (36).

### *Disability and Health in Australia*

18. Among people with disability in Australia, 1.4 million have severe or profound disability, requiring assistance sometimes or always with daily self-care, mobility or communication (2). For over three quarters (77%) of Australians with disability, their primary disability is physical, most commonly being related to musculoskeletal disorders (2). For one-quarter (23%) of Australians with disability, their primary disability is mental or behavioural, which includes intellectual disability, autism, mood affective disorders and dementia. The most common disability affecting children is intellectual disability, followed by sensory and speech disability (2).
19. The most recent ABS Survey of Disability, Aging and Carers highlights stark inequities experienced by people with disability with respect to social determinants of health. In 2018 (2):
- 53% of people with disability aged 15-64 years were engaged in the labour force compared to 84% of people without disability
  - The unemployment rate for people with disability was more than double the rate for people without disability.
  - Graduates with disability were less likely to find full-time or any employment compared with graduates without disability (37)
  - Median gross personal incomes of people with disability were half that of people without disability, and half of people with disability lived in a household in the lowest two quintiles of household income.
  - One-third of people with disability aged 15 and over had completed Year 12 or equivalent, significantly lower than young people without disability (38)
  - People with disability experienced limited access to public transport, including due to physical inaccessibility, anxiety and a lack of seating

Aboriginal and Torres Strait Islander people with disability experience disadvantage with respect to social determinants of health in comparison to Aboriginal and Torres Strait Islander people without disability, non-Indigenous Australians with disability, and the general population. This includes lower educational attainment (15.8% completion of year 11 or 12) (39), lower labour force participation (43.8%) (39), higher levels of discrimination due to disability (39), over-representation in prison populations (40) and over-representation of younger people in residential aged care (18). More than a third (34.4%) of Aboriginal and Torres Strait Islander people with disability lived in a household in the lowest quintile of household income (39).

20. People with disability experience poorer health and wellbeing outcomes compared with the general population and people without disability. Examples include (18):

- The mortality rate for people using disability support services was 4.7 times higher in 2013-2018, and the rate of potentially avoidable deaths 3.6 times higher, than the general population (41)
- One quarter (24%) of adults with disability rate their health as 'excellent' or 'very good', compared with two-thirds (65%) of adults without disability (18)
- Adults with disability are four times more likely to experience a 'high' or 'very high' level of psychological distress than adults without disability (32% vs 8%) (18)
- People with disability have higher rates of modifiable risk factors for chronic disease than people without disability, including: physical inactivity, poor diet, tobacco use, and overweight and obesity (18)

21. People with disability experience higher rates of abuse, violence, and multiple incidence of violence than people without disability (18). In 2018:

- Almost half (47%) of adults with disability have experienced violence after the age of 15, compared with one third (36%) of people without disability (18)
- One fifth (20%) of adults with disability experienced abuse before the age of 15, compared with 11% of people without disability (18)
- One fifth (21%) of adults with disability have experienced intimate partner violence, compared with 13% of adults without disability
- Half (50%) of adults with severe or profound disability, and 62% of adults with psychosocial disability have experienced sexual harassment, compared with 37% of adults without disability (18)
- Three quarters (74%) of adults with disability who experienced violence experienced multiple incidence of violence, compared with 62% of adults without disability who experienced violence (18)

Despite these concerning statistics, it is recognised that the actual rate of violence and abuse experienced by people with disability is likely to be higher than reported rates due to barriers to reporting and the lack of nationally consistent data sets (28).

22. Whilst people with disability interact with the health system more frequently than the general population, they are less likely to receive preventative healthcare, and more likely to face barriers to accessing health services (18, 42-45). Furthermore, people with disability have reduced access to sexual and reproductive healthcare, and may experience denial of reproductive rights (46-49). Barriers to accessing health services include inaccessibility of buildings, waiting times, service cost, poor communication between health professionals and discrimination by health professionals (18). Such barriers are more commonly experienced by people with disability living in outer regional and remote areas, compared with those living in major cities (42). Almost 1 in 5 (18%) people with disability who need help with healthcare activities do not have this need fully met (2), including 1 in 8 who have no source of assistance (42).

23. People with intellectual disability experience specific barriers to inclusion in mainstream and preventative healthcare services (50, 51). These include insufficient support for their autonomy and decision making in healthcare settings, health professional's limited knowledge of intellectual disability, stigmatising attitudes held by health professionals, and communication barriers (50). People with intellectual disability may experience diagnostic overshadowing, whereby mental or physical health symptoms are attributed to their disability, rather than being

recognised as a separate concern (44, 50). The functional or behavioural support needs of people with intellectual disability may increase during acute hospitalisation, however, the formal supports required during hospital admissions are rarely provided (44).

24. In 2018, 2.65 million Australians were unpaid informal carers of people with disability and older people, including 235,300 young carers aged under 25 years (2). Over 70% of primary carers were women (2). Carers experience poorer health, social, economic and employment outcomes than non-carers, and over one third of primary carers have disability themselves (2, 52).

### *Populations with a high prevalence of disability*

25. Aboriginal and Torres Strait Islander people experience higher rates of disability than non-Indigenous Australians, including due to the impacts of colonisation, dispossession and racism (53-55), however actual prevalence estimates vary. Data from the 2018 ABS Survey of Disability, Aging and Carers found that almost one quarter (24%) of Aboriginal and Torres Strait Islander people have disability, including 8.8% who have severe or profound disability (2), and that over half (53.5%) of people aged over 55 years have disability (2). This survey included Aboriginal and Torres Strait Islander people living in private housing, and excluded those living in residential care, very remote areas or discrete Aboriginal and Torres Strait Islander communities - approximately 17% of the Aboriginal and Torres Strait Islander population (2). The 2019 ABS National Aboriginal and Torres Strait Islander Health Survey reported a significantly higher prevalence of disability among Aboriginal and Torres Strait Islander people, at 38% (56). This survey included Aboriginal and Torres Strait Islander people in private housing in remote and non-remote areas, including discrete Aboriginal communities (56).
26. Whilst the reported prevalence of disability among people entering prison is less than one-third (57), the actual prevalence is widely recognised as being higher; a 2018 Human Rights Watch report (58) estimated that around half of people entering prison have disability, a Victorian study found that 42% of male prisoners and 33% of female prisoners were assessed as having acquired brain injury (59), and it is estimated that 95% of Aboriginal people appearing in court charged with criminal offenses have an intellectual disability, cognitive impairment or mental illness (60). Statistics such as these have led Victoria's Office of the Public Advocate to ask in 2021 whether 'prisons are the new institutions for people with disability' (61). Additionally, serious concerns have been raised regarding the legislative framework and policies allowing the arbitrary and indefinite detention of people with disability (58, 60, 62), which disproportionately affect people with intellectual disability and Aboriginal and Torres Strait Islander people with disability (60, 62).
27. Refugees and asylum seekers are more likely to have a disability than other populations due to experiences of conflict, torture and displacement (63). Data on exact prevalence of disability among refugees and asylum seekers is not available therefore prevalence data for disability globally are often used to indicate the probable number (64). Refugees and asylum seekers are invisible in much of the disability literature, in part due to exclusion of the disabled from immigration systems of many nation-states (65). Whilst Australia has ratified both the Convention Relating to the Status of Refugees and the UNCRPD, Australia's Migration Act is exempt from the Disability Discrimination Act, meaning that people with disability are likely to be denied entry into Australia (66). Thus, refugees face difficulties in identifying children or family members with disability who require support services, whilst navigating migration pathways (67). Until 2012, people with a disability were excluded altogether from Australia's resettlement program (63). The exclusion of people with disability from resettlement programs and difficulties in estimating prevalence of disability among forcibly displaced people means the

global estimate of disability often used is likely to be an underestimate of the prevalence among refugees and asylum seekers. Australian data on refugees and asylum seekers who settled in Australia in 2013-14 indicates that almost 36% had a long term health condition that had lasted or was likely to last longer than a year (68).

### *Inadequacies of service access for specific populations*

Specific populations of people with disability in Australia experience disadvantage with respect to service access or utilisation.

28. The Royal Commission into Aged Care Quality and Safety found that older people with disability are denied equitable access to disability services (69). Unless an existing NDIS participant at age 65, older adults with disability are excluded from receiving support services under the NDIS. The services available through aged care systems may be inadequate or unsuitable to meet complex disability-related needs (69).

29. Whilst representing 49% (70) of people with disability under 65 years, females make up only 37% of all NDIS participants (71). The underrepresentation of women and girls among NDIS participants may be due in part to gender differences in relation to the prevalence or diagnosis of particular disabilities. For example:

- the types of conditions most likely to be funded under the NDIS are more commonly diagnosed in males and may be underdiagnosed in females (72). (NDIS participants with autism account for one-third of all participants, with a male to female ratio of 2.8 (71).)
- conditions such as fibromyalgia and myalgic encephalo-myelitis/chronic fatigue syndrome (ME/CFS) are more commonly diagnosed in women (73) are less likely to be funded under the NDIS.

30. Lesbian, gay, bisexual, transgender, intersex, questioning and plus (LGBTQI+) people with disability have reduced service access compared with non-LGBTQI+ people with disability and LGBTQI+ people without disability (74). Barriers impacting on service access and utilisation include discriminatory and stigmatising attitudes towards LGBTQI+ people and/or people with disability, which may be held by workers in the health and disability sectors (75, 76). LGBTQI+ people with disability may not have their identities understood or respected by health or disability service providers (75). Fears of discrimination or poor quality care may contribute to reduced service engagement and delays in seeking healthcare (75).

The number of LGBTQI+ people with disability is difficult to correctly ascertain due to a lack of national population-based data with relevant data items (77). The NDIA's LGBTQI+ Strategy (78) identifies enhancing data collection and evaluation as a strategic aim. NDIS Quarterly Reports categorise participants' gender as 'Male', 'Female' and 'Other'; participants categorised as 'Other' gender accounted for 2% of participants entering the scheme in the most recent quarter (December 2021) and represent 1% of total NDIS participants (71).

31. People with disability from culturally and linguistically diverse (CALD) backgrounds face barriers to accessing and utilising (79) mainstream and disability specific services, including the NDIS (67). Barriers include:

- Language barriers, compounded by a lack of interpreters and translated material (63, 79, 80)
- Service providers that lack cultural understanding and cross-cultural communication (63, 66). A lack of culturally appropriate services may exacerbate feelings of isolation for people with disability within CALD communities (81).

- Challenges for parents of children with disability in navigating systems, particularly for newly arrived refugees and asylum seekers (81)
- An understanding of disability in the country of origin that may persist once in Australia, including cultural stigmas around disability (66, 79, 81).
- Distrust of government agencies resulting from previous negative experiences in other countries (79)

32. Aboriginal and Torres Strait Islander people with disability often face intersecting marginalisation (82), face barriers to services access across all life stages (82) and have greater levels of unmet need for services (83). Contributing factors include:

- Low awareness of disability (82) and disability services (83), and limited access to information (53)
- Diverse perceptions and cultural conceptualisations of disability (53, 84, 85) which may differ markedly from non-Indigenous models of disability (86); traditional languages have no comparable word to disability and many Aboriginal and Torres Strait Islander people with disability are reluctant to self-identify as having disability, which may be considered a further negative label (53, 87)
- The requirement for a formal diagnosis to be eligible supports (88), in combination with under-diagnosis of conditions among Aboriginal and Torres Strait Islander people (88-93)
- Inadequate culturally appropriate support (49) and reported lack of cultural safety when engaging with services (53, 83, 84). This includes a low level of cultural competence through the NDIS assessment and planning process, exacerbating confusion of Aboriginal and Torres Strait Islander participants and distrust towards the scheme (83)
- The need for strengthening of the Aboriginal and Torres Strait Islander disability workforce and Community Controlled Disability Service Sector (86, 94, 95)
- Communities' preference to provide support for Aboriginal and Torres Strait Islander people with disability (53), which is considered part of broader family responsibilities (96)
- Lack of trust in government services (49, 84, 97), trauma resulting from the well-documented removal of children (49) and negative past experience of discrimination, racism and exclusion from mainstream and disability services (53, 84, 98) contribute to a reluctance to seek assistance and access services (49, 84, 86)
- Lack of confidence in navigating systems (83), understanding the language of the disability service system, and knowledge of rights or entitlements (53, 84)
- Language and communication barriers, particularly in remote areas (83, 84)
- Inadequate infrastructure and service provision, as well as increased costs associated with service delivery, in remote areas (53, 84, 99, 100) where approximately one in five Aboriginal and Torres Strait Islander people live (101)
- Over-representation in the criminal justice system (57) and out of home care (102), environments which lack adequate capacity to identify needs and provide disability support (40, 58, 103, 104)

33. People with disability living in rural and remote areas often face specific challenges to accessing services and are more likely to have unmet demand for services than those living in urban areas (99). The delivery of disability support services in rural and remote locations is hampered by difficulty attracting and retaining skilled workers, limited infrastructure, and the challenges associated with delivering services to small, vastly spread populations (99, 105, 106). There is concern regarding the sufficiency of provider markets in rural and remote areas, and the limited effective choice and control for people with disability in locations with few or no services (99, 100). The limited service delivery capacity of complex support in regional and remote areas is of particular concern (103). Additionally, funding allocated for services, such as through the NDIS, is

used to cover travel costs of providers (100, 105). These costs may be significant if service providers are not locally based, and potentially result in less funding available for the actual delivery of services for people living in rural and remote areas (100, 105).

The rural healthcare system also differs from that in metropolitan areas beyond the more commonly discussed issues of access. Relationships between rural people with disability, health professionals, and rural health services differ due to social and geographical proximity in rural communities (107). There can be dual personal and professional relationships which can potentially support access to healthcare or create access barriers that do not exist in metropolitan areas (for example due to concerns about anonymity) (107).

34. People with disability are at higher risk of homelessness than the general population due to low incomes, low rates of employment and restricted capacity in the private rental market, and are overrepresented among people experiencing homelessness in Australia (108). People with disability have poorer housing outcomes compared with the Australian population as a whole, and households with people with a disability frequently have difficulty securing appropriately located accommodation, often living on the urban fringe in less expensive regional housing that is some distance from services (108). Fifteen percent (27,700) of clients accessing specialist homelessness services reported that their main source of income was the disability support pension (109). Thirty-six percent of specialist homelessness services clients who identified a need for disability services did not have their needs met (109).
35. People with disability who are incarcerated often do not receive timely, appropriate and adequate services and supports due to factors including (58):
  - inadequate assessment and identification of disability and support needs due to a lack of sensitivity in assessment tools and inadequate staff training (58). The reliance of self-reporting is problematic as people who are incarcerated may not identify as having disability, be unaware of their disability, be undiagnosed prior to prison entry or choose not to disclose (40, 58). A lack of cultural relevance and safety of the assessment process contributes to additional barriers for Aboriginal and Torres Strait Islander people with disability who are incarcerated (40).
  - inadequate training for correctional staff to distinguish between disobedience and behaviour resulting from a lack of support for people with disability (58). This may result in people with disability who are incarcerated receiving punitive treatment, such as solitary confinement in detention or safety units, rather than necessary supports and medical care (58).
  - lack of disability specific services and unclear interface between the NDIS and corrective services (40)
  - variable access to assistive equipment (40)
  - overcrowding delaying access to health care for people who are incarcerated in general, compounded by the specific barriers that people with disability face such as negative staff attitudes and a lack of proper diagnoses (58).
  - people with disability who are incarcerated may not be provided with sufficient information to enable their informed decision making regarding treatment options and consent (58).
  - a lack of specialised forensic facilities (61), which are not increasing proportionally to the number of people who are incarcerated (58).
  - the prioritisation of safety over health needs in some circumstances (58).

Inadequate or non-existent post-release disability support contributes to high reincarceration rates among people with disability (110), perpetuating the cycle.

### *Additional Issues Impacting on People with Disability*

36. The Australia's Disability Strategy aligns with the social model of disability (111) and the NDIS Act (2013) was enacted with the express purpose of fulfilling Australia's obligations under numerous conventions (112), including the rights-based UN CRPD (112). Despite this, outdated models of disability including the charity and medical models continue to find expression in systems, policy and attitudes (113), negatively impacting on the experience of people with disability (53, 113). Examples include the framing of the NDIS as reliant on love, compassion and natural empathy, rather than a fulfillment of Australia's international human rights obligations (114, 115); and the requirement of a medical diagnosis to be eligible for disability supports (88, 116), preventing those who are unable to obtain an accurate or timely diagnosis from accessing support.
37. There is growing evidence of the inequity of the NDIS, both in relation to applicants gaining access to the Scheme and benefitting from available services once access has been met (99, 117-120). The administrative complexity - described as a central feature of the NDIS (118) - and the emphasis on self-advocacy (117) contribute to the inequity. That around two-thirds of NDIA decisions are overturned on appeal (121) indicates the initial exclusion of eligible people with disability to the Scheme (117, 118). This illustrates an additional barrier to service access for people with disability.
38. Whilst the NDIS provides enormous potential to support people with disability, and indeed provides benefit to most participants (99), it necessitates that individuals have the capacity to engage with the Scheme (119). Ironically, in some cases, people with disability may be prevented from accessing the NDIS due to the impact of their disability (119). For example, 9.5% of people with disability require assistance with reading and writing tasks (2), yet correct completion of the nine-page NDIS access form and compilation of supporting evidence are the first steps in seeking access (118). A recent analysis identified that over half of the NDIS access form is potentially complex for some applicants (118). The complexity of life for many people with disability presents challenges for completion of an eligibility form that makes assumptions on applicants' circumstances, including a stable home address and phone number, and consistency of support needs (118). The administrative burden of accessing the NDIS is unequally distributed and may be amplified for those who are resource disadvantaged (118, 120).
39. Personalisation schemes, such as the NDIS, place an 'unprecedented emphasis' (122) on self-advocacy, requiring participants and potential participants to effectively communicate their disability-related needs and goals (117). Education, employment, supportive networks, household income, knowledge of where to access to information, English literacy and access to advocates appear to contribute to the successful navigation, and benefit from, the Scheme (99, 117, 122). However, these skills and resources are not equally distributed (117), and individuals who can most effectively self-advocate are those who are already least disadvantaged (122). Conversely, already marginalised groups - including people who are socio-economically disadvantaged, people from CALD communities and Aboriginal and Torres Strait Islander people - are excluded or face additional barriers to accessing supports, and are at risk of further disadvantage (117, 119).
40. Whilst drawn from data prior to NDIS rollout, a study of young people in custody in New South Wales (123) provides an example of the stark disparity between assessed level of function and self-reported needs. Among this cohort, almost three quarters had difficulties in reading single words, over three quarters demonstrated severe difficulties with reading comprehension, almost half demonstrated severe difficulties with receptive and expressive language measures, and one in six obtained Full Scale Intelligence Quotients (FSIQ) below 70 (123). However, only 8.4% self-reported a need for assistance with learning and applying knowledge and 0.4% self-

reported a need for assistance with communication (123). An inability to self-report support needs, within a system that emphasises self-advocacy, places people with disability at risk of not receiving necessary disability supports (123).

41. The COVID-19 pandemic has exposed underlying inequities and discrimination faced by people with disability in accessing essential services, inadequate service co-ordination and a lack of system preparedness (124). The Disability Royal Commission formally raised concerns regarding the impact of the emerging pandemic on people with disability in early 2020, calling on Australian governments to ensure the safety, health and wellbeing of people with disability (125). In early 2022, the Disability Royal Commission issued a ‘Statement of ongoing concern’ (124) which highlighted key areas of concern, including:

- Lack of regard for the health and wellbeing of people with disability
- Significant gaps in data and reporting of vaccination, infection, and mortality rates among people with disability
- Access to vaccination and boosters for people with disability, including the earlier de-prioritisation of people living in disability residential care
- Disruptions to essential disability supports and increased isolation for people with disability
- Access to essential health services and fears of health rationing
- Lack of accessible public health information
- Inadequate consultation with the disability sector and people with disability
- Increased risk of violence, abuse and neglect in residential settings due to reduced oversight mechanisms

42. Inconsistent definitions of disability, and a lack of identifying mechanisms across data sources, limit the understanding of disability in Australia, the experience of people with disability and their engagement with mainstream services (18, 126). Administrative data on mainstream health service utilisation, such as data collected by the Medicare Benefits Scheme, the Pharmaceutical Benefits Scheme and hospitals, does not identify service users with disability (42, 45). Whilst the need for population-level data that can be disaggregated by disability has been recognised, Australia has not yet developed nationally consistent measures to collect and publicly report such data (45, 49, 127). The trial of the National Disability Data Asset to provide better understanding of how people are supported through services, payments and programs is a positive step (128), but the challenges in gathering data need to be addressed, including differences in definitions of disability across jurisdictions and data sources, as well as lack of mechanisms to determine if participants accessing mainstream services have a disability (126). Robust data on outcomes and experiences of people with disability are needed to inform government policy initiatives.

## Policy options and recommendations

43. This background paper has emphasised the poorer health outcomes of people with disability and contributors to these poorer health outcomes:

- Disadvantage with respect to almost all social determinants
- Barriers in accessing healthcare

- Discrimination on the basis of disability

To improve the health of people with disability, actions must be taken to address the drivers of poorer outcomes.

Australian, state and territory governments must:

44. Develop nationally consistent measures to collect and report population-level data disaggregated by disability. Robust data will improve understanding of outcomes and experiences of people with a disability in relation to social determinants of health, service access, experiences of violence and abuse, and health, and will better inform government initiatives.
45. Undertake multisectoral action (health in all policies) with the involvement of people with a disability to develop policies addressing disadvantage with respect to social determinants of health.
46. Always be guided by the principle 'nothing about us, without us' when taking action that aims to improve health of people with disability and reduce inequities: this means *meaningful* involvement of people with disability in policy development, in decisions that affect people with disability and not just requesting input and paying lip service to any input provided.
47. Be willing to take bold political action to address action areas in Australia's Disability Strategy 2021-2031 that act as social determinants of health, particularly income, employment (addressing unreasonably low wages and providing appropriate remuneration for people with disability who are employed in addition to providing meaningful opportunities for employment for people with disability who are able to work), housing (addressing barriers to accessing accessible and affordable housing), education (provide access to inclusive and supportive opportunities) and social inclusion.

Whilst Australia has made positive steps towards enacting the CRPD, concerns have been raised by the CRPD Committee over the past decade (62, 127) and during the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (129) which provide a basis for policy options to better comply with the CRPD and improve outcomes for people with disability.

Australian, state and territory governments must:

48. Make health services and equipment accessible and affordable for all people with disability but particularly Aboriginal and Torres Strait Islander people with disability, people with disability in remote areas, people with psychosocial or intellectual disability, people with disability living in institutions, and women and children with disability.
49. Amend the NDIS assessment process to adopt the social model of disability (not the medical model of disability) that is consistent with the CRPD and Australia's Disability Strategy.
50. Take action to ensure the NDIS assessment process provides equal opportunities for Aboriginal and Torres Strait Islander people with disability, older people with disability, people from CALD backgrounds with disability, and people with psychosocial or intellectual disability. Actions to ensure the assessment process provides equal opportunities for Aboriginal and Torres Strait Islander people should be led by Aboriginal Community Controlled Health Organisations.
51. Improve the accessibility of the NDIS by making more information and resources publicly available and accessible, reducing complexity of procedures, and improving services in remote areas.
52. Harmonise Australia's legal framework with the CRPD, including but not limited to protecting people with a disability from multiple and intersectional discrimination.

53. Abolish the guardianship system and substituted decision-making regime and implement a nationally consistent supported decision-making framework.
54. Repeal provisions allowing for the involuntary detention of people with disability in psychiatric hospitals and abolish the use of medical interventions and restrictive practices.
55. Remedy the inadequate resources for advocacy programs for people with disability.
56. Review and amend migration laws and policies to ensure people with disability do not face any form of discrimination related to migration and asylum and cease the transfer of people with disability to offshore processing.

### **ADOPTED (September 2022)**

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