

Policy Document

Disability Care and Support (2022)

Position Statement

AMSA believes that:

1. People with disabilities can experience barriers to participation in society, and have the right to support maintaining self-determination and promoting wellbeing, independence, health and social inclusion;
2. The NDIS in its current implementation aspires to support all people with a disability but poses barriers to access for all Australians with a disability throughout their life
3. The NDIS requires continual evaluation, in consultation with its consumers, to ensure it runs to its intended effect;
4. There are fundamental inequities in the ability of particularly vulnerable communities to access and utilise services;
5. Early intervention provides children with a disability or developmental delay with the best possible outcome and quality of life;
6. Alongside the NDIS, support and ongoing education for healthcare professionals is needed to assist with multidisciplinary care and to best support patients to achieve their care goals;
7. Medical education should have mandatory teaching activities that provide students with a strong understanding of the perspectives and priorities of people with a disability and their support network
8. Informal carers are a critical element of disability care and should have access to specialised support groups, counselling, and financial support;

Policy Points

AMSA calls upon:

1. **The Commonwealth Government of Australia to:**
 - a. Expand the access of the NDIS to cover a person's entire life as needed;
 - b. Ensure those who are not eligible for the NDIS to are able to access adequate care and support from other support services;
 - c. Continue to commit funding to the NDIS and other support services to achieve Australia's Disability Strategy 2021-2031;



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- d. Fund research into addressing societal accessibility barriers and:
 - i. Require that people with disabilities are consulted throughout, or directly involved in, the conceptualisation, design and implementation of research projects that relate to disability;
 - ii. Continue to provide funding for research into informal carer wellbeing and necessary interventions that are effective;
- e. Increase and expand the Integrated Carer Support Service Model to have a wider variety of services, including but not limited to:
 - i. Identifying subdivisions of carers and their specific needs for support groups, including but not limited to: young carers, carers with a disability, CALD carers;
 - ii. Providing different types of support groups available across different modalities and locations;
 - iii. Identifying and funding effective education and training programs for carers to fulfil their care roles;
 - iv. Ensuring that carers and people with disabilities have adequate home support including but not limited to cleaning and transport services;
- f. Review the Carer Payment and Carer Allowance in recognition of carers' barriers to workforce participation in line with the recommendations by Carers Australia;
- g. Fund and develop free, readily available training services for carers and self-dependent persons with disabilities to achieve technological proficiency and NDIS engagement;
- h. Continue to consult and fund Aboriginal and Torres Strait Islander advocacy and research groups such as First People's Disability Network Australia in order to:
 - i. Facilitate Aboriginal and Torres Strait Islander engagement in the NDIS;
 - ii. Increase support for existing community-focused NDIS services liaising in inclusive and culturally relevant ways with First Nations communities and mainstream agencies whose services have proven successful engagement with Aboriginal and Torres Strait Islander communities;
 - iii. Developing safe and community controlled services for Aboriginal and Torres Strait Islander people and carers;
- i. Allocate funding to services, such as the National Ethnic Disability Alliance (NEDA) working with Culturally and Linguistically Diverse (CALD) communities to increase interactions with the NDIS by:
 - i. Developing an advocacy position that focuses on CALD people with disability engaging with the NDIS;
 - ii. Including funded translation services within individual NDIS plans/service packages for CALD clients where required;
 - iii. Marketing material specifically for CALD communities with attention to cultural diversity representation, and inclusion of a CALD contact on promotional material;

- j. Fund research regarding LGBTQIA+ people with disability that meaningfully includes them at all stages of the research process, including design, data collection and analysis, write up and dissemination;
 - k. Increase transparency and support for the needs of non-permanent Australian residents with a disability and their families such that:
 - i. Decisions regarding the Health Requirements process, particularly with costs assessments is clearly explicated to prospective visa applicants;
 - ii. Families are not unfairly disadvantaged under the Health Requirement as a result of a member of that family being a person with a disability;
 - l. Assessment of diseases and medical conditions are addressed separately from the assessment of conditions as part of a disability when applying for permanent residency or citizenship;
- 2. The National Disability Insurance Agency (NDIA) to:**
- a) Facilitate the expansion of access of the NDIS to cover a person's entire life;
 - b) Clarify the eligibility criteria for people with disabilities to receive NDIS support;
 - c) Continue to ensure those who are not eligible for the NDIS receive adequate care and support from other mainstream services by:
 - i) Continuing to provide information about eligibility for the NDIS and other choices of mainstream services on the NDIS website;
 - ii) Ensuring service providers have adequate knowledge regarding the eligibility for the NDIS and other mainstream services to ensure participants are well-informed with their choices;
 - d) Provide clear, transparent and appropriate information and guidelines to help participants with navigating and advocating for themselves:
 - i) Develop consistent guidelines and criteria so service providers can provide more consistent plans across participants with similar experiences and needs;
 - ii) Improve the clarity on what is included within service coverage compared to other government services so participants are well-informed with the support they are able to receive;
 - iii) Continue to update with transparency the standard for NDIS applications;
 - e) Broaden the scheme for people living with psychosocial disability who are currently ineligible but require access to NDIS support services:
 - i) Including scheme engagement and application processes, assessments, planning, plan activation and review;

- ii) Including service delivery to those living with severe mental illness who will not be eligible for the Scheme and therefore need to keep receiving services outside of the NDIS;
- f) Ensure the development of new strategies under the Aboriginal and Torres Strait Islander Engagement Strategy and CALD Strategy to provide better awareness and access to NDIS services for Aboriginal and Torres Strait Islander and CALD communities:
 - i) Implement educational and informational campaigns in collaboration with CALD, Aboriginal and Torres Strait Islander communities;
- g) Acknowledge LGBTQIA+ people with disability as a priority community for focussed outreach or enhanced access support within the NDIS:
 - i) Establish a review process for engagement, planning, plan review and policy reform;
 - ii) Promote opportunities for collaborative research development, including funding advocacy services;
 - iii) Follow up the impact of the priority actions proposed in the LGBTQIA+ Strategy;
- h) Acknowledge the varying diagnoses amongst genders to ensure NDIS services are equitable, accessible and tailored to these populations by;
 - i) Acknowledging the sociocultural factors contributing to this;
 - ii) Acknowledge the need for different diagnostic approaches for vulnerable populations and ensure NDIS services are accessible, provided for and tailored to these populations by;
 - iii) Establishing a specialist psychosocial disability gateway to the NDIS to assess and work with applicants with a psychosocial disability;
 - iv) Increasing training for key workers to better understand the fluctuating demands of psychosocial disability;
 - v) Ensuring all diagnostic approach is culturally responsive and appropriate;
- i) Develop a responsive system which supports the fluctuating demands associated with the varying degree of need throughout an individual's life; including but not limited to streamlining plan review requirements of people with disabilities throughout life stages;
- j) Develop a public monitoring and reporting strategy on rates of application, acceptance, plan activation, timeframes, plan contents and rates of review for people with a disability in relation to targets, including a streamlined and easily accessible reporting avenue for mistreatment or dissatisfaction;
- k) Continue to fund and provide emergency and planned respite services for people with disabilities;
- l) Ensure the smooth functioning of the Regional Delivery Partners program to overcome geographical barriers and shortage of local

services, such as but not limited to, needs assessments and financial and crisis support;

- m) Continue to work closely with local services in remote and very remote areas to ensure equitable and consistent provision of care and services;
 - i) Focussing on capacity building in those areas in the context of their local communities, families and friends to build trusting relationships;
 - ii) Working with local councils in providing support and access to the NDIS in the community;

3. NDIS Service providers and delivery partners to:

- a) Provide emergency and planned respite services covering a large geographical area, encompassing regional and rural areas;
- b) Provide simple digital pathways to access services, specifically for carers and people with disabilities without technological or language proficiency;
- c) Provide clear and transparent self-advocacy guidelines and criteria to ensure that participants have enough information to advocate for themselves;
- d) Provide information about other mainstream services for those who are not eligible for the NDIS;
 - i) Ensure well-informed choices for people with a disability to receive adequate care;
 - ii) Liaise with other mainstream disability support services to streamline referrals
- e) Continue to educate themselves on knowledge and understanding of the needs of people with disabilities to provide an environment with cultural sensitivity and safety, empathy and compassion;
 - i) Continual education regarding appropriate language to use when providing, educating, and discussing disability and associated care;
 - ii) Updated staff training, resources and other supports regarding non-judgemental, culturally appropriate, empathetic and compassionate communication;
 - iii) Co-design services alongside people with disabilities to ensure supports are tailored to their needs

4. Australian State and Territory governments to:

- a) Fully cooperate with the Commonwealth on the implementation and continued operation of the National Disability Insurance Scheme;
- b) Fund and develop readily available training services that are at minimal costs to carers to achieve technological proficiency;
- c) Ensure the uninterrupted care and services provided for patients as they transition between state-based schemes and institutions, and the NDIS:
 - i) Providing sufficient protections and safe spaces to people who are victims of disrupted care;

- ii) Ensuring continuity of care for individuals with fluctuating eligibility for the NDIS, that have had disruption in their services;
- d) Continue their commitment to the welfare and wellbeing of people with disabilities, including:
 - i) Maintaining existing services or providing sufficient replacements should services be terminated;
 - ii) Ensuring services designed to protect people experiencing hardship are accessible to and inclusive of people with disabilities;

5. Medical Schools to:

- a. Provide disability education, in both preclinical and clinical years, that covers a wide range of contexts, giving students a broad understanding of how best to provide care for patients with disabilities, and to:
 - i. Consult the disability community when developing teaching plans;
 - ii. Involve disability self-advocates in providing this teaching, where appropriate and volunteered by the individual;
 - iii. Incorporate teaching specific to vulnerable communities such as CALD people and LGBTQIA+ individuals with a disability;
- b. Educate medical students about the barriers of communication and how to communicate with people with disabilities in a respectful and non-judgemental way by:
 - i. Including providing opportunities for students to acquire specialised communication skills, such as AUSLAN and how to use non-verbal communication boards;
 - ii. Including teaching students how to appropriately work with interpreters, so that the patient is still at the centre of their care;
- c. Educate medical students on how to involve people with disabilities, and, where appropriate, their carers or other healthcare professionals, in developing care plans;
- d. Educate medical students on the functioning of NDIS and other disability support services, particularly how to refer patients to the appropriate services;
- e. Educate medical students on the specific health and wellbeing challenges and barriers to healthcare access that people with disabilities and their carers face, as well as potential solutions that can be implemented;
- f. Educate students about the importance of autonomy and self-determination;
- g. Educate students on disability etiquette, such as not moving mobility aids;

6. Australian Medical Council to:

- a. Implement mandatory curriculum objectives in medical schools to identify and understand the experiences and needs of individuals with physical and mental disabilities, including intellectual disabilities, by:
 - i. Requiring direct contact with individuals with a variety of disabilities in the provision of these objectives;
 - ii. Including an emphasis on the individuality of each patient's personal disability experience;

7. Medical, Nursing and Allied Health Professionals to:

- a. Advocate for an environment of respect and equal opportunities for people with disabilities in the healthcare setting and wider community including:
 - i. Increased clarity about the NDIS and the assistance that may be available to them through this scheme;
 - ii. Continue to educate themselves about the evolving disability landscape in Australia and the community in which they practise;
- b. Remain respectful and non-judgemental when interacting with and referring to people with disabilities:
 - i. Including consulting with patients on their preferred terminology (ie person-first or identity-first language);
 - ii. Including consulting with patients on their preferred pronouns;
- c. Ensure their practices are respectful to people with disabilities and any alternative needs:
 - i. Ensure clinical practice environments are accessible, inclusive and disability-informed;
 - ii. Consult patients with a disability about their specific support and accessibility needs, and ensure that where possible their clinical practice and the clinical environment caters to these needs;
- d. Incorporate formal cultural competency and inclusivity training to create respectful and inclusive practises in caring for vulnerable communities with a disability;
- e. Increase level of expertise with using translator services among staff;
- f. Promote and prioritise the autonomy and self-determination of all patients;

8. Medical, Nursing and Allied Health Students to:

- a) Remain respectful and non-judgemental when interacting with and referring to people with disabilities, including:
 - i) Consulting with patients on their preferred terminology (ie person-first or identity-first language, pronouns);
 - ii) Maintaining respectful and inclusive communication with CALD communities, LGBTQIA+ people and Aboriginal and Torres Strait Islander peoples.

Background

Disability is a broad term describing a wide range of long-term conditions affecting physical, mental, intellectual or sensory impairments that, in conjunction with various barriers, may hinder an individual's ability to participate in society to the same extent as people without disabilities (1). This definition utilises the social model of disability, where disability is not viewed as the inherent cause of any limitations one may face. Instead, the onus is placed on barriers in society that prevent people with disabilities from accessing the same services and quality of life offered to those without disabilities (2). A prime example of this is that people with wheelchairs are often unable to access certain locations, not due to their requirement of a mobility aid, but rather the lack of ramps, elevators and other infrastructure that would make it accessible for all.

Disabilities can be present at birth, although this does not guarantee diagnosis early in life, or acquired later on in life, and may be the result of one or many factors. The United Nations Convention on the Rights of Persons with Disabilities asserts that all people with disability have a right to equality of opportunity, accessibility, dignity and individual autonomy, as well as full and effective participation and inclusion in society. All individuals, regardless of disability status, are equal before and under the law (1). The nature and severity of disability, as well as one's age, does not preclude them from the aforementioned rights. This is also upheld by Australia's Disability Discrimination Act of 1992 (3). Refer to AMSA's Human & Human Rights Policy for more information on human rights generally. (4)

According to the Australian Bureau of Statistics Summary of Findings on Disability, Ageing and Carers, Australia, there were 4.4 million Australians, in 2018, who indicated they had a disability (5). This equates to 17.7% of the total population. It was also found from the same data that disability prevalence increased with age and was relatively proportional between sexes, with more pronounced differences in early childhood and adolescence (5). Despite the existing legislature, approximately one in ten individuals with a disability experienced discrimination, which was an increase from the previous survey date (5).

Language to address disability community:

Language has an important role in shaping human interactions, hence it is important to use respectful terminology when referring to members of the disability community. A key application of this is the use of either 'identity-first' language (e.g. disabled people) or 'person-first' language (e.g. people with disabilities). Since each individual with a disability is different, one's preferences cannot be assumed. Hence, it is best practice to ask and use whichever terminology the individual prefers (6). To contextualise the importance of terminology-sensitivity, the implications of both languages should be identified. Person-first language is intended to highlight that the individual is not defined by their disability, and that they are a person before they are seen as someone with a

disability. This has been proposed as a means to place all people, with or without a disability, on the same level (7).

However, many disability-advocates argue that this justification is an admission that disabilities are seen as inherently negative and detract from a person's worth, and that it implies disability is something to be ashamed of and to hide (8). This provides the basis of identity-first language, which proposes that one's disability is a part of their identity, and hence it should be affirmed and validated (9). It should be noted that person-first language is the current preference in academia and professional circles, including healthcare (9). As such, most sources and official documents follow this convention, including this policy. However, this does not mean that person-first language should be considered the default language. It is imperative to always reflect on the preferences of the audience being addressed and the intentions of the text.

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was implemented in 2013 to provide support for children over the age of seven and adults under the age of 65 with permanent and significant disabilities. Since 2013, the NDIS has provided over \$22 billion per year in funding to support more than 500,000 people (10). The NDIS is a key part of the support network for Australians with a significant disability up to the age of 65 (10). Governed by the National Disability Insurance Agency (NDIA), the NDIS continues to be a key part of Australia's Disability Strategy 2021-2031 to improve the quality of life and create a more inclusive society for people with disabilities (11). In the 2021-2022 Budget, the government has committed an additional \$13.2 billion over the next four years (12). It is expected that the entire budget will be \$122 billion over the next four years with contributions from the Commonwealth, States and Territory governments (12).

It was highlighted in the NDIS 2020-2021 annual report that significant milestones were achieved in the preceding 12 months: 74,620 new participants, of which 10,296 were children aged under 6 years and 13,400 were children who received support through the Early Childhood Early Intervention (ECEI) program (13). In the same report there are 32,396 participants who identified as Aboriginal and Torres Strait Islander and 44,113 participants who identified as Culturally and Linguistically Diverse (CALD) (13). Compared to the previous year, there is an increase of 27 percent amongst Aboriginal and Torres Strait Islander participants and 22 percent in CALD participants (14). This is a key achievement of the NDIS, empowering the development of new strategies under the 'Aboriginal and Torres Strait Islander Engagement Strategy' and 'CALD Strategy' within 2022 (14). The NDIA intended to engage with key stakeholders including participants, families, and carers to develop these strategies (14). However, the overall projected increase in the number of participants challenges the budget of the NDIS directly (15). Thus, this challenges the functioning of the NDIA and NDIS where expense for staff and service providers is limited, and directly affects the affordability of services provided (14). The annual budget of \$22 billion was sufficient during the

2013-2020 period, however, there was a significant increment in participants between 2015-2016 and 2016-2017 (15). Hence, the estimated costs grew to \$30.6 billion and \$41 billion in 2024-2025 and 2029-2030, respectively (15).

In 2020, the NDIA introduced the Participant Service Guarantee and Service Improvement Plan to explain how they would achieve participants' expectations (13). The NDIA also implemented the 'Specialist Disability Accommodation' scheme and made several changes to the 'Support Independent Living' scheme to ensure equity including publishing information and guidelines and setting price limits (13). Throughout the COVID-19 pandemic, the NDIS has provided additional support including regular telephone checkups, opportunities to claim the cost of personal protective equipment and priority deliveries of resources (13). However, there are many carers involved in NDIS services, this poses a significant risk of transmission as more carers move amongst households to provide services (16).

It was announced that in 2020 that the Australian Government would provide \$5.9 million over the following two years for the National Aboriginal Community Controlled Health Organisation (NACCHO) to improve access and service outcomes within the Aboriginal and Torres Strait Islander communities (15). In 2021, NACCHO delivered \$1.25 million in grants to 57 Aboriginal Community Controlled Organisations (ACCOs) to support the implementation of NDIS services (17). This funding provides ACCOs with the resources to expand and deliver NDIS services and workforce in Aboriginal and Torres Strait Islander markets (17).

Early childhood approach

The NDIS have partnered with early childhood partners, who are local organisations of professionals who have clinical experiences with children with disabilities and connect families with appropriate support services. Parents of children younger than seven with developmental delays are recommended to apply for NDIS as they are more likely to meet the NDIS developmental delay criteria. They can access services that provide more information, connect to mainstream services, and receive support from allied health professionals without a diagnosis, a process known as "early connections"(18).

The NDIS provides support for people aged over seven, who have a permanent and significant disability that affects their ability to take part in everyday activities (19). They will have their eligibility checked then fill in the access form and contact local area coordinator services that can link them to community support services in the local area. They will help create a NDIS support plan that is then approved by the NDIA and will be in charge of implementing and reviewing the plan annually.

NDIS barriers

One of the key issues is the inconsistencies in services, care provision and funding by the NDIS (4). The Australian Bureau of Statistics (ABS) indicated that women and girls form 49% of the eligible population for NDIS, however, the NDIS female



participation rate in 2021 was only 37% (20). The key factor contributing to this is that women are under-diagnosed for NDIS-funded disabilities such as autism spectrum disorder (20). Furthermore, the NDIS does not provide funding for disabilities that women are more likely to be diagnosed with, such as myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia (20). It is also indicated that NDIS participants with similar diagnoses and needs receive different levels of funding and services (20). An identified key causal factor is the difference in experience and health literacy in recognising participants' needs of planners and local area coordinators (20). The inconsistencies were reported in fundamental services including the Auslan services and were acknowledged by the NDIA (21).

The NDIS is only accessible to those under the age of 65 when applying, which has led to inequity in receiving disability support and care (22). Those who did apply prior to being 65 continue to be supported by the NDIS. However, many older people with disabilities who were 65 and over during the rollout of the NDIS are ineligible for the scheme. Out of an estimated 2 million persons with disabilities who are over 65, there are currently 19 430 NDIS participants as of December 2021 (23, 24).

In addition, the risk of acquiring a disability increases with age, thus this limitation effectively prevents older people from receiving the required help when they are most at risk (25). The central source of aged care support for those over 65 who are ineligible comes primarily via Home Care Packages (HCP) and Commonwealth Home Support Programs (CHSP) through the My Aged Care Scheme (26). However, these services severely lack the funding and individualisation of services offered by the NDIS (27, 28). Thus, in order to continue receiving the same services supplied by the NDIS, most will have to pay out of pocket. This means that access to disability support and care has become increasingly inequitable with respect to age. The Royal Commission into Aged Care Quality and Safety published a final report in 2021 recommending that those over 65 should receive the support and outcomes equivalent to those under 65 with the same conditions (29).

Another key issue of NDIS accessibility is the lack of transparent information regarding the function and management of the system, therefore requiring strong self-advocacy, health literacy and navigation skills from participants to ensure they receive adequate support (30).

It was indicated by service providers that many NDIS participants and their carers were not equipped with the knowledge and skills to advocate for services and support required (21, 31). Participants themselves also expressed concerns that the complexity of the NDIS might affect funding for ill-equipped families or participants that are applying independently (21, 31)). However, many participants demonstrated more satisfaction with the increased choices that promoted their autonomy despite further support is required to navigate the complexity (20).

Language within the NDIS is considered as 'culturally insensitive', 'jargon-heavy' and 'inappropriate' by carers and parents (32). Specifically, in a study about parents' experience with the NDIS, communication and support were not

personalised nor appropriate for children's needs, stage of planning and diagnosis (32). The NDIS' language of permanence limits eligibility for conditions that are fluctuating, stereotypically less severe or conditions that are dynamic with age or can be 'grown out of' (33). Overall, the lack of consistency in language used across the different stakeholders of disability care provision can cause confusion and is a general obstacle in receiving adequate disability support.

As acknowledged by the government, NDIS participants face difficulty during planning, which can be largely attributed to their experiences with NDIA staff and providers exposing a lack of experience and knowledge of living with and alongside disability (21, 33). Participants have noted the lack of empathy and compassion from the staff, and indicated that they focused more on maintenance rather than helping them overcome challenges (20, 22). The need to repeatedly explain individual circumstances places a significant burden on carers and parents' well-being (21). This poses the risk for inconsistent planning, wrongful rejection and lack of access to services, especially in remote areas, Aboriginal and Torres Strait Islanders and CALD communities (20, 22). Notably, there was a significant increase in the number of applications to the Administrative Appeals Tribunal over NDIS decisions and anecdotal claims that participants were turned down wrongfully (34). These problems could easily be managed when approached with empathy and compassion (31, 33). This has become even more significant during COVID-19, as people with disabilities require substantial additional support (26).

In 2019, The Minister for the NDIS acknowledged how geographical, educational and socio-economic barriers can influence participants' experience of the NDIS (32). However, this issue has existed since prior to the NDIS rollout and has not been addressed entirely (35). Many participants and carers facing geographical disadvantages have reported limited access and control over support to the NDIS service, describing extensive delays in accessing therapy support, essential goods, care products, assistive technologies, and shortage of staff and cases of neglect (35). These participants further identified many barriers to access including the need for additional financial support, community capacity building issues and the lack of alignment between participants' needs and services provided (32). Participants further noted that additional financial support in the short term can help to overcome geographical barriers, for example, cost of travelling to access services that are not available in that area (32). Reasons identified were lack of basic services and product deliveries available making it harder for families to locate (35).

Vulnerable communities

Australia is home to many diverse populations including, but not limited to Aboriginal and Torres Strait Islanders, CALD people, LGBTQIA+ people and those with complex support needs. These mentioned groups have been historically marginalised in the disability support system of Australia and continue to report unmet demand and underutilisation of disability support services (36).

Psychosocial disabilities and mental illness

The NDIS eligibility criteria supports 460,000 people described to have significant and permanent disabilities, which accounts for approximately 10% of Australia's population living with a disability (37). Unlike previous programs such as Partners in Recovery (38), this narrow definition calls for disability to be significant and permanent, limiting eligibility for NDIS support and thereby excluding those with fluctuating, episodic or periodic mental illness or psychosocial disabilities (39). It is estimated that of the 3.7 million Australians who experience mental illness, 690,000 Australians live with severe mental illness (39), yet only 64,000 people with a primary psychosocial disability will be eligible for support (39). This lack of engagement stems from overwhelming difficulty acquiring evidence for assessment, lack of understanding and support from services towards psychosocial disabilities, and language of disability and permanence that is incompatible with psychosocial recovery language (38), leaving a significant portion of those with severe mental illness unsupported.

Aboriginal and Torres Strait Islander peoples

The impact of historical and continuing harm of government policies and intervention of Aboriginal and Torres Strait Islanders has resulted in profound or severe activity limitations at more than twice the rate of non-Indigenous counterparts (14). Alongside disproportionate rates of disability, on average Aboriginal and Torres Strait Islander people also experience lower socioeconomic outcomes, and the remoteness of many communities further hinders their engagement with disability planning and support services (14). As a result of historic and continued harm due to government and welfare services, and culturally insensitive practices, barriers to access have emerged. These include the substantial proportion of Indigenous Australians situated in rural and regional areas that lack accessible disability services, housing and transport limitations, and disproportionate high rates of incarceration. Inconsistencies in the perception of disability across Indigenous populations, and the healthcare system complicates the functioning and success of disability populations; there is no word for disability in many Aboriginal languages (14) and people with disabilities are not labelled this way in the culture (14), therefore there is no ubiquitous view on disability among Aboriginal and Torres Strait Islander peoples. Strategies such as the "Access Program" implemented through the Aboriginal Community Controlled Sector evidence that application of self-determination principles and culturally appropriate services from well-educated staff result in successful connection of eligible Aboriginal and Torres Strait Islander people with disabilities and support (40).

Culturally and Linguistically Diverse (CALD) populations

Despite rates of disability amongst people from CALD backgrounds mirroring those of Non-CALD people, CALD communities' utilisation of disability services has a substantial accessibility gap (36). 21.9% of NDIS participants should come from a CALD community as estimated by the National Ethnic Disability Alliance (41), however the NDIS annual report demonstrated that CALD people only constituted

9% of participants receiving a plan (7). This underrepresentation comes as a result of intersecting cultural and systemic disadvantages such as language barriers, unfamiliarity or distrust of Western healthcare systems, unsuitable information delivery, and clashing cultural beliefs surrounding disability (41). The demands of CALD people with a disability are often unmet, unreported and underutilised, with CALD participants reporting negative experiences when they do engage with the scheme (41). Language and literacy are the largest barriers in engaging with NDIS services, likely due to the inappropriate delivery of information; written materials are provided to people with low literacy skills and limited language range. An overreliance on family or children as informal and often biased translators exists due to the bureaucratic paperwork requirements for NDIA funded translators, and lack of support for free professional translators (27). In many CALD belief systems, the definition of what constitutes a disability clashes with the Western definition, often connoting stigma and shame to disability, resulting in refusal to seek support (41).

Further, those living with a disability and without a permanent residency cannot receive NDIS support, unless on permanent humanitarian visas (13). These immigrants with a disability, and their families have their visa applications refused because they are unable to meet the strict health requirement set out under the Migration Act 1958 (Cth) and Migration Regulations 1993 (35). The health requirement specifies that an applicant for permanent residency must be free of a disease or condition that would be significantly costly or put the general public's health at risk. This not only excludes immigrants with a disability but also their families, due to a "one fail all fails" rule (42). Despite a parliamentary inquiry in 2010 (42) into the discriminatory disability policy and a special entry pathway instigated in 2012 (42) no changes and there continues to be severe limitations for those who are not Australian citizens or permanent residents.

LGBTQIA+ peoples

For LGBTQIA+ people with a disability, experiences of discrimination and oppression are exacerbated by multiple social identities (43). An intersectional approach is required to understand the health of LGBTQIA+ people with a disability, support their wellbeing and access to services. LGBTQIA+ people have a higher incidence of disability, psychological distress and anxiety than the general community, compounded with decreased social support, an antagonistic relationship with medical professionals, and a perception of health services as judgemental (43). The LGBTQIA+ Strategy released by the NDIS in 2020 (44) recognised the disparities in supporting the LGBTQIA+ community and the barriers preventing access to support, and in response has introduced LGBTQIA+ cultural inclusion training to over 7000 staff as well as other promising priority actions to reduce discrimination against the LGBTQIA+ community. Whilst this is an important step, collaboration with LGBTQIA+ people with a disability and their communities is crucial in understanding the intersectional disadvantages they face. However, there is still minimal research regarding the specific demographic of LGBTQIA+ people with a disability due to the NDIA neglecting gender identity information.

Education About Disability in Medical Schools

Providing teaching specific to disability care and support in medical schools, especially that which directly exposes students to people with disabilities, is shown to improve empathy, competency and attitudes of students towards patients with disabilities (45). Possessing these attributes as a healthcare practitioner directly contributes to the quality of care provided to patients (45). Furthermore, disability education will help protect people with disabilities against violence, abuse and neglect. This will occur directly by giving healthcare professionals the skills to avoid using constraints and restrictive practices, which is considered as abuse according to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (46). It will also work indirectly, through ensuring healthcare providers have the skills to identify risk and the appropriate channels through which this can be managed, in all patients (46). It follows that these practices will also be beneficial in the education of other healthcare providers, including, but not limited to, nurses, physical therapists and social workers.

A 2020 review of teaching on intellectual disability (ID) in medical schools found that while there was no significant change in the number of hours of compulsory ID content, there was a significant decrease in students' direct clinical contact with people with ID since 1995 (47). People with ID present to the emergency department and hospitals more than those without ID and experience poorer health outcomes, however the medical school accreditation standards set by the Australian Medical Council (AMC) make no specific mention of ID and ID teaching (47). This is exemplified by a retrospective study on mortality and its causes in adults with ID, which found 38% of deaths in the ID cohort were potentially avoidable, compared to 17% in the comparison cohort (47). This result was achieved through reanalysing deaths previously attributed to the aetiology of the disability, demonstrating that health practitioners are not thoroughly aware of the different ways in which people with ID may present for care (47). Given these inequities, compulsory medical education on ID would be a significant step in improving the quality of healthcare provided, and hence the quality of life for people with ID.

Although, ID is certainly not the only area of disability education that is lacking, as there is in fact no mention of disability of any kind, in the context of patients and their carers, in the AMC accreditation standards (47). This means that providing education on the needs, challenges and perspectives of patients with disability, and their carers, is provided entirely at the discretion of each individual medical school.

Informal Carers

An informal carer is someone who provides care to another person with a disability without payment. Informal carers are also commonly referred to as "carers." As of

2018, there were 2.65 million people (10% of Australians) who provided informal care for their loved ones (48). They are an invisible workforce, receiving limited support or compensation for their labour. Informal carers often perform tasks such as healthcare facilitation, household maintenance, personal hygiene, meal preparation, and transport (49).

Informal carers have lower levels of wellbeing, employment and health compared to the average Australian (48). Carers are frequently underemployed due to having limited availability and flexibility to work when juggling caring for another. Young carers (under 25 years of age) often have higher psychological distress and lower confidence in their care role when compared to older carers (48). Older carers frequently have fewer technological skills to facilitate access to the NDIS and other essential services (49). These age-related barriers impact overall accessibility of the NDIS, which can be further compounded by factors such as socioeconomic status and rurality.

Carers from vulnerable populations, such as Aboriginal or Torres Strait Islander or CALD communities have very few tailored services enabling access to support for those they care for (50). In Aboriginal and Torres Strait Islander communities, there are higher numbers of carers; 12.4% of the Aboriginal and Torres Strait Islander population are carers, compared to 10.5% of the non-Indigenous Australian population (50). Upstream factors can influence Indigenous Australians' health and their care roles, such as socio-economic status or rurality which are linked with limited health literacy or decreased access to culturally competent local support (50). With higher rates of carers, targeted services are required to meet the complex needs of these communities.

There is some support for informal carers, though limited. The Department of Social Services provides an Integrated Carer Support Service Model for all carers which enables access to support groups, counselling, and financial support (51). The NDIS provides respite care for people with disabilities, allowing carers to have time off from their care roles. Carers are also entitled to the Carer Payment or Carer Allowance (based on whether they provide constant or additional care to an individual with a disability, respectively), granted they meet certain criteria, though it does not fully supplement an income (52). The Regional Delivery Partners network also provides recently expanded and streamlined support services for carers in rural and regional areas, redressing geographical barriers to aid (53).

Key data on carer wellbeing and support is cyclically studied by surveys such as the Carer Wellbeing Survey. Despite the aforementioned supports being available, this survey found the vast majority of carers do not access formal support, with only 31.4% accessing psychological care and 22.2% accessing skills training in the last 12 months (54). So despite these supports, carers still report higher levels of financial stress and lower well being due to the model's fundamental gaps. Research has shown that carers require additional support to live rich lives outside of their care roles. Beneficial activities include recreational clubs, support groups, employment and health services (54). It was also found that increased and diverse



support is directly linked with better wellbeing (54). Carers Australia recommends reviewing the amount and process of accessing the Carer Allowance and Carer Payment, as this is another pertinent barrier to care. This is in the hopes of increasing financial freedom to support many carers to participate in the workforce or education if they wish to do so (55).



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