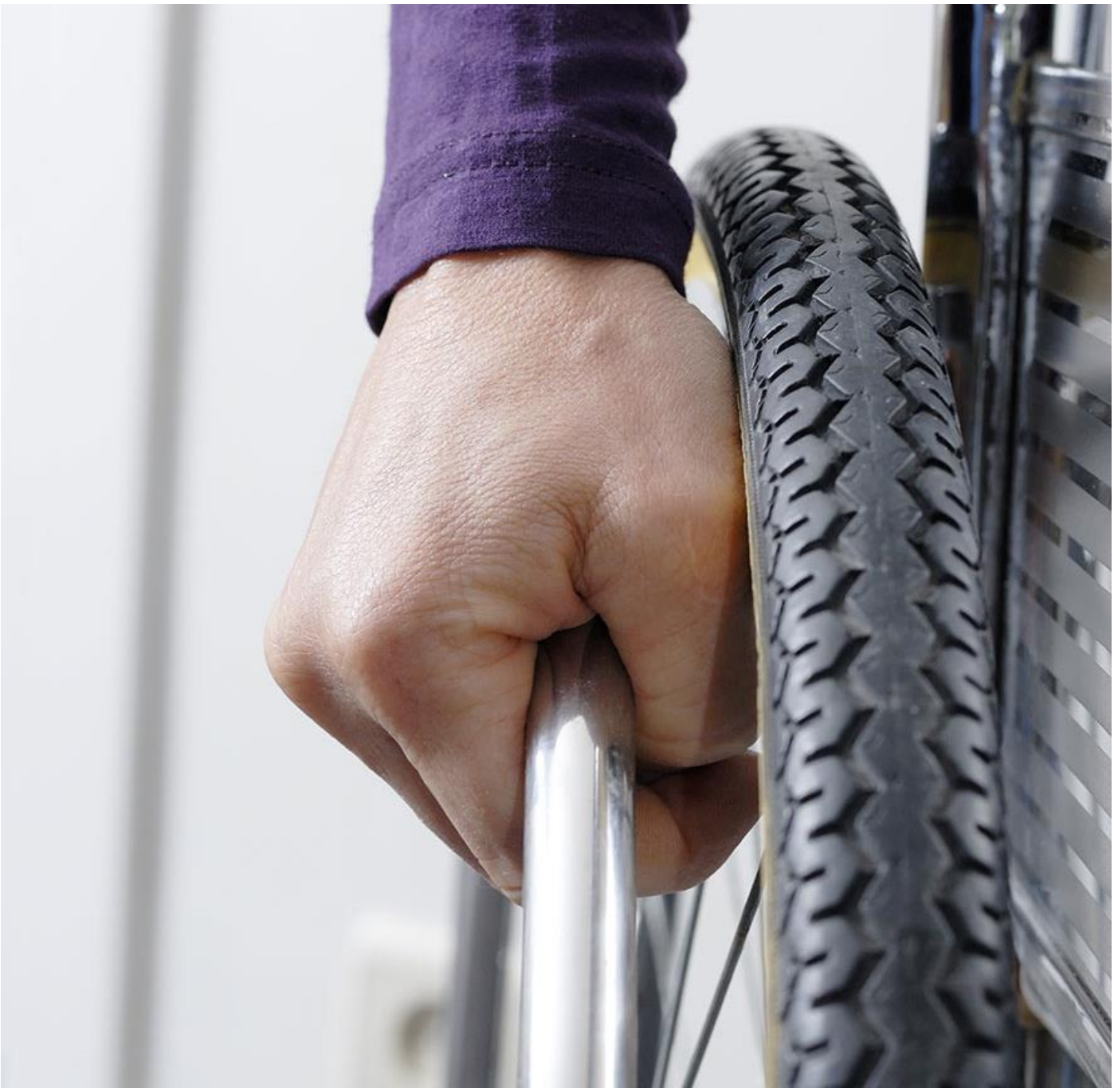
scia

Spinal Cord Injuries Australia

# Submission to the Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability

## Advocacy and Representation



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Spinal Cord Injuries Australia

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## 1. About Spinal Cord Injuries Australia

Thank you for inviting Spinal Cord Injuries Australia (SCIA) to provide this submission to the Disability Royal Commission (Royal Commission) on the importance and role of advocacy and representation on behalf of the many people with spinal cord injury and similar physical disability who use our services.

SCIA has been providing a dedicated advocacy service for people with spinal cord injuries and similar disability since 1967. We currently employ – staff across services nationwide including 14 staff dedicated to our Policy and Advocacy work in New South Wales. Some of our staff provide advocacy services from our regional office in Alstonville, in Northern NSW. SCIA provides specialty knowledge in Spinal Cord Injury and similar neurological conditions, and broader knowledge and experience across physical disability. SCIA was founded by people with acquired spinal cord injury and continues to employ many people with spinal cord injury and similar physical disability. Having people with spinal cord injury and similar physical disability on our staff creates a vast knowledge base that helps us to meet the individual needs of the people who use SCIA's services.

## 2. Introduction

While the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is, in and of itself, a demonstration of the power of advocacy and self-advocacy, the weight of evidence presented to the Royal Commission has emphasised the acute vulnerability of people with disability when they are denied access to strong representation and the skills to promote, protect and defend their own rights.

The Royal Commission's Interim Report (Interim Report) rightly acknowledges the historical significance of the disability rights movement and the momentum that has built since the 1970s and 80s for substantial and positive changes in Australian legislation, policy, and practice. People with disability and their families, with the support of advocates, have taken great strides towards achieving a more accessible and inclusive society – the most significant of those achievements being the National Disability Insurance Scheme (NDIS). But there is still a long way to go before we can say that people with disability have anything like equal rights, equal recognition, and the same opportunities as others.

Advocacy services like SCIA exist to create a more inclusive and accessible society for people with disability. Our role is critical to ensuring the promotion, protection, and security of people's rights. On behalf of people with disability and their families, we address the barriers, discrimination, mistreatment, and inequalities that people with disability contend with every day.

The preamble to the Convention on the Rights of Persons with Disabilities states "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." [1] Yet people with disability in Australia continue to experience attitudinal and environmental barriers when they use public transport or attend a hospital; when they go shopping in a supermarket or try to withdraw money from a bank. In some way, there is always an impediment for people with disability when they try to access the services that most people take for granted.

Unlike many disability service providers and health professionals who increasingly operate almost exclusively in the NDIS space, advocacy groups provide their services to all people with disability in all settings and contexts regardless of their age or disability. With more funding we could reach more people including people with disability, who for reasons of remoteness, Aboriginal and Torres Strait Islander heritage, culture, incarceration, economic and or social disadvantage, age, gender and more, are unable to access the NDIS or other types of funding suitable to their needs that should and would be available to them with appropriate advocacy.

Only a minority of people with disability (about 10%) are NDIS participants. Most people with disability are either ineligible for the NDIS or unable to access the advocacy services that they need to complete the application and eligibility process. For many the application process is far too complicated and intimidating.

For instance, according to Australian Bureau of Statistics data (ABS), psychoses and mood affective disorders are the second largest long-term health condition in Australia, yet only 10% of NDIS participants identify psychosocial disability as their primary disability.

Importantly, the Interim Report has acknowledged the increased vulnerability of people with disability who are not NDIS participants and the number of incidents of violence, abuse, neglect, and exploitation that go unreported.

The intention of the NDIS was to provide more choice and control for people with disability to increase their inclusion and participation in society and to be actively involved in the decisions that affect their lives. To a large extent, and to varying degrees, for NDIS participants this has happened. Many people with disability who have accessed the NDIS have far more choice and control over the services that they use and when and how they are provided.

The principle of choice and control that underpins the NDIS is complemented by a code of conduct and quality and safeguards assurances. Those safeguards include compulsory reporting obligations and service standards that give transparency to the activities of service providers and hold them accountable. This accountability is a safeguard against violence, abuse, neglect, and exploitation for NDIS participants that does not apply to people with disability who are not NDIS participants. This includes people with disability aged over 65, who are seriously impacted by gaps in disability and aged care funding, especially people with disability over 65 with high and complex support needs.

More funding for advocacy could increase NDIS or My Aged Care participation rates and provide quality and safeguard protections to more people with disability.

NDIS participants also experience difficulties due to a lack of advocacy services particularly in achieving positive outcomes in their support plans and through the plan review and appeals process. Despite the exponential growth and seismic changes that have occurred in the disability sector particularly since 2013 when the NDIS was introduced, funding for advocacy and representative services has reduced to such an extent that SCIA and other similar organisations are unable to meet the volume of requests for advocacy that we receive [2].

A survey by the disability sector's peak body, National Disability Services (NDS) in their annual "State of the Disability Sector Report 2021" [3] said that only 18% of respondents believed there was sufficient advocacy for the people they support, and that advocacy was considered by respondents to be the most important 'sector building activity' that the disability sector could collaborate on.

Poor outcomes experienced by NDIS participants are caused by many of the same problems that have, for a long time, beset the disability sector and people with disability. They include skilled staff shortages; cost; lack of funding; discrimination; intersectionality; isolation and lack of access to advocacy services.

Evidence from the Royal Commission tells us that an increase in funding for advocacy services is urgently required. That includes funding for peer advocacy services that connect people with disability with advocates who either share or have had the same experiences, and programs that promote and develop the skills of people with disability to self-advocate; that is, the ability of people with disability to understand and communicate their own rights and needs.

Over the past 12 months especially, SCIA has been inundated with requests for individual advocacy support, particularly in the NDIS space. Because of the amount of funding, regulation and resources that are applied to the NDIS, that is from where most of our advocacy work is generated. Most requests relate to the complexity of the eligibility and application processes to access the NDIS; NDIS plan reviews and appeals; and our ongoing systemic advocacy work to make sure legislation, policies and practices support the rights and interests of all people with disability. In the past, when our case load exceeded our capability we would refer clients to other advocacy services, but that option is no longer available to us because they, like us, are also at capacity.

The funding we receive is nowhere near adequate to meet current demand and a fraction of what is required to meet future needs if the sector, including the NDIS, continue to grow at the same level. As a result, people with disability who require advocacy are either unable to receive it or they are waiting inordinate amounts of time for advocacy services which, in the case of people with high and complex needs, can mean surviving on NDIS plans that are inadequate or unsuitable to their needs.

Yet our greatest concern is for the people with disability who are unable to access advocacy as promptly as they need it. We know that people with disability are more at risk of experiencing violence, abuse, neglect, and exploitation and that the perpetrators are often in positions of trust. People with disability experiencing violence, abuse, neglect, and exploitation should have the confidence and ability to access advocacy if and whenever it is required – especially if intervention is required promptly.

Throughout this submission, SCIA will identify systemic issues within the disability sector that are denying fair treatment and social justice to people with disability and leaving many people with disability in situations where they continue to experience violence, abuse, neglect, and exploitation. We will also demonstrate how increased advocacy could mitigate some of the risk that people with disability experience.

For the safety, wellbeing, and protection of people with disability, funding for advocacy services should be restored to levels sufficient to meet demand with proper consideration given to the growth of the NDIS and funding for people with disability who are not receiving either the funding or supports that they are entitled to.

### 2.1 Advocacy and representation

Advocacy is essential to any system of services and supports that are designed to assist people to a life of full inclusion and participation. People with disability describe their feelings of exclusion and being undervalued that are imposed by inaccessible services, buildings, and structures; societal and institutional norms that undermine the right to inclusion and self-determination; and systemic discrimination that continues to create barriers to active participation in society.

Disability Advocacy groups promote and protect the rights and interests of people with disability. We assist people with disability to identify personal goals and to take the necessary initiative to achieve them. For people with disability to live the fully inclusive and fulfilling lives that they aspire to, they must be protected from the violence, abuse, neglect, and exploitation that has for too long, been present in too many lives. Whenever a service or system is created, advocacy support should be made available to those for whom the service is constructed and particularly to those who are most at risk within it [4].

## 3. Recommendations

1. Increase community awareness of the role of advocacy in the lives of people with disability and improve accessibility to advocacy services for people with disability.

2. Promote the need for community support and skill development for people with disability to self-advocate.

3. Explore models of peer advocacy training/qualifications for people with disability to be advocates.

4. Representation and participation: Strengthen the inclusion and involvement of people with disability in decision making, co-design and organisational governance.

5. Service Capacity Enhancement: Increase the capacity of disability advocacy services to meet demand and support clients in a timely and consistent manner. This Funding enhancement would be used to increase reach, efficiency, and the quality of advocacy services.

6. Provide additional funding to advocacy services funded by Federal and State and Territory government programs to meet unmet demand, address complex needs, access hard to reach people, reduce waiting times and waiting lists:
    - Funding to ensure people with disability who are at greatest risk receive prioritised support
    - Funding to ensure face to face support is available to those who need it the most
    - Support for staff training and ongoing professional development, supervision etc. include allocations for assertive outreach (and in-reach)
    - Culturally appropriate support to people and communities identified as hard to reach e.g. First Nations people, CALD community members, socially isolated, closed settings etc, rural and remote areas.

7. Annual CPI funding increases to ensure continuity and sustainability of advocacy services:
    - Funding grants with 5-year timeframes to enable planning and development and staff retention
    - Apply an agreed funding formula to grant allocations to adequately cover staff and other costs e.g., consultation/liaison with other service providers or lawyers, educators, and therapists.

8. Additional targeted funding to improve advocacy organisations system capacity and efficiency to:
    - Streamline functions and free up resources for direct client support
    - Implement a nationally consistent and compatible Customer Relationship Management (CRM)
    - Funding to support tailoring of services and workforce development.

9. Funding to improve workforce training and development to:
    - Develop the disability advocacy sector
    - Enhance professionalism and consistency of advocacy support for all people with disability
    - Develop nationally consistent professional competencies and practitioner accreditation for disability advocates similar to existing work being developed in Western Australia
    - Develop nationally consistent tools and resources to support high quality disability advocacy practices
    - Explore opportunities for articulating disability advocacy specialisation e.g., complex communication, supported decision making skills etc.
    - Establish a national peer workforce network that draws on collective skills, knowledge and expertise to share knowledge and evidence nationally
    - Support establishment of disability advocacy communities of practice
    - Explore models of peer advocacy training/qualifications for people with disability to be advocates.

10. Increase recognition and awareness of disability advocates by:
    - Developing a promotional strategy to raise the profile and roles of disability advocates to disseminate across related professionals, services, communities etc.
    - Increase community awareness and uptake of citizen advocacy
    - Implement the National Disability and Older Persons Advocacy Standard (currently being developed by OPAN and DANA)
    - Establish equitable staff wage levels for disability advocates (equitable with advocates in other sectors)
    - Develop a national benchmark for disability advocacy case loads
    - Establish an information and awareness program for service providers and related professionals to raise awareness and understanding about the importance of advocacy for people with disability; the role of advocates, advocacy services and benefits of advocacy.

11. TARGETED ADVOCACY: Support the development of tailored advocacy approaches to increase access and support for identified high risk population groups to address their specific needs.
    - First Nations people with disability
    - Culturally and Linguistically Diverse people with disability
    - LGBTIQA+ people with disability
    - Children and young people with disability
    - Older people with disability
    - Women and girls with disability.

12. Address issues arising from intersectionality that impact people with disability including housing, poverty, mental health, justice, abuse, vulnerability
    - Provide funding for National Centre for Advocacy to develop with other relevant stakeholders, comprehensive advocacy models for addressing impacts of intersectionality.
    - Provide funding for National Centre for Advocacy to develop and deliver training and workforce development resources that support effective advocacy for people with disability who are experiencing intersectional impacts.

13. Commonwealth and State and Territory Cooperation:
    - Streamlining of Commonwealth and state and territory funding and administrative systems to increase access, efficiency, improved outcomes to ensure that "no door is the wrong door" for people with disability
    - Establish a national Disability Advocacy round table of federal and state and territory funders, peaks, and other key stakeholders to:
        - Review current barriers and identified gaps and systemic issues for people with disability accessing advocacy
        - Develop a joint/collaborative strategy to address barriers and fragmentation in access to disability advocacy support to reflect population demographics
    - Establish an expert taskforce to design a disability advocacy funding model that can be applied at federal, state and national levels to ensure an equitable and population based allocation of resources
    - Consider collaborative funding models that support people with disability who experience multiple factors of disadvantage and intersectionality
    - Consider options to streamline funding and reporting to reduce administrative burdens on disability advocacy services

14. Establish a National Disability Advocacy Data Taskforce with relevant expertise to:
    - Develop agreed national and jurisdictional data collection systems that:
        - Enable greater efficiency and consistency of data collection
        - Define agreed priority data sets
        - Yield robust data with potential for aggregation, cross-system data linkages and systemic analysis
        - Implement agreed processes for data release and protection of confidentiality
        - Enable transparency and public sharing of high-level information

- Support building an evidence base of effective disability advocacy models and systems

**4. The case for a National Advocacy Data Taskforce**

In accordance with our CRPD obligations Australia seeks to eradicate discrimination from all areas of the life of a person with disability including, but not limited to, employment, education, health services, transportation, and access to justice.

Evidence presented to the Royal Commission has identified the causes, complexity, and difficulties in detecting the extent of the violence, abuse, neglect, and exploitation against people with disability. One of the fundamental problems with detection is the lack of suitable, disaggregated data that can report with any accuracy the true state of participation, access, and equity for all people with disability [5].

As a signatory to the Convention on the Rights of Persons with Disabilities (CRPD) Australia agrees to "undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. [1]"

Australia has an obligation to the CRPD to collect statistical and research data for the purpose of implementing policies that deliver on the many rights that exist under the convention. This includes, identifying data gaps and limitations that might be preventing policy development and adding to the ever-increasing amount of unmet need of people with disability.

In referring to data and its role in preventing violence, abuse, neglect, and exploitation against people with disability, The Interim Report states:

"Without high quality data, it is difficult for governments and organisations to plan policies and programs that will prevent violence against, and abuse, neglect, and exploitation of, people with disability. Data is needed to set goals and measure success against these goals, and to allow others to hold governments and organisations accountable for delivering on these goals. Data helps track progress on important action plans, such as the National Disability Strategy, and whether the Australian Government is meeting its responsibilities under the United Nations Convention on the Rights of Persons with Disabilities (CRPD)."

There is currently no accurate way to record precisely how many people with disability there are in our society. Australian Bureau of Statistics (ABS) data is unable to identify how many people with disability live in boarding houses, hostels for the homeless, aged care facilities and nursing homes, or other institutions like jails, and hospitals including psychiatric hospitals [5]. Those forms of accommodation all fall into the broad category of 'non-private dwellings' yet for the purpose of protecting people with disability from violence, abuse, neglect, and exploitation, the context and living environment is essential information. There have been numerous examples provided in evidence to the Royal Commission of young people with disability living in residential aged care facilities because they are unable to access the advocacy to find them more suitable and less expensive accommodation.

Similarly, the ABS do not record data for people with disability who live in very remote areas or discrete Aboriginal and Torres Strait Islander communities [5]. The circumstances and needs of people with disability in these settings are largely unknown.

Australian Survey of Disability Ageing and Carers (SDAC) data, surveys people with disability every three years and issues results based on the sample population chosen. Neither the ABS or SDAC integrate data from Medicare or the Pharmaceutical Benefits Scheme in a standard data structure that could inform on disability, ethnicity, or intersectionality [5].

Disaggregated data must be focused on the analysis of more complex and intersecting dimensions of identity to increase the visibility of those who are most vulnerable and most at risk [6]. Collecting data from health services across all settings, including segregated institutions like jails where we know people with disability are over-represented, could help to locate people with disability who may be experiencing multi-layered discrimination and exclusion.

Without suitable data including disaggregated data by disability status, interventions run the risk of being poorly conceived and misdirected. For instance, people with disability may be relying on health services or unsuitable residential care when funding for personal care or assistive technology may be more appropriate to their needs and a less expensive alternative

## 5. Health and Access to Health Services

Health and access to health services is a key measure of participation by people with disability across all facets of their lives. Submissions to the Royal Commission have demonstrated that poor health and limited access to health services leads to impacted accessibility to other services and diminishes quality of life for people with disability.

A November 2021 article from the International Journal of Environmental Research and Public Health on Health and Access to Health Services for People with Disability in Australia: Data and Data Gaps [5] concluded that the rights of people with disability to the highest attainable standard of health is not currently being realised.

According to Fortune N et al: “A key principle that must guide future disability data development is that people with disability and their representative organisations must be involved and participate fully in the development of data and statistics, and in their use [5].”

“It is clear that work is needed to address existing data gaps and limitations and to more fully understand the experiences of people with disability in relation to health and health services, to measure disability related inequities, and to monitor implementation of Article 25 of the CRPD [5].”

## 6. Assistive Technology

The use of assistive technology (AT) for improving health outcomes for people with disability, particularly for people with disability over 65, is largely underutilised [7]. Recommendation 72 in the Aged Care Royal Commission final report states:

“By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids, and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.”

For individuals, AT is a clear and obvious investment to prevent unnecessary future costs. The empirical evidence case for the benefits of assistive technologies and their wide application is well known particularly for older people with disability who may be able to live independently for longer and with greater quality of life [7]. The impact of AT has been evidenced as effective and necessary for improved safety, independence, mobility, physical function, wellbeing, and overall quality of life [7].

Awareness of the importance of AT and the consequences of increased long-term costs due to dependence on the health system and other services dates to the 2009, Disability Investment Group (DIG) report: The Way Forward – A New Disability Policy Framework for Australia [8]. DIG said the provision of aids and equipment was a fiscally responsible investment, to be realised by the National Disability Insurance Scheme (NDIS) and the National Injury Insurance Scheme (NIIS) [8].

## 7. Covid-19 and crisis response

For many people with disability, the Covid-19 pandemic was both a health crisis and a crisis of social isolation. People with disability are more vulnerable to the Covid-19 pandemic than the general population. Older people with disability; Aboriginal and Torres Strait Islander people with disability; people with disability who are dependent on ventilators or have compromised immunity are at the highest risk of contracting Covid-19 and developing a serious illness [9].

For many people with disability, the health crisis and the experience of isolation were compounded by acute interruptions and changes to their supports and services and poor communication from government agencies on the policies, protocols and procedures that needed to be adhered to. There were also examples of service providers introducing risk management protocols that undermined the human rights of people with disability by denying access to essential services and in some cases, their homes [10].

Older people with disability, often with chronic health issues, who are already subjected to even greater levels of discrimination because of their disability and age fared worst of all. This is the demographic who are most susceptible to gaps in funding, services, and access to advocacy. Covid-19 was another example of services being prioritised for the majority with little consideration given to those at the margins, like people with disability. While advocacy groups did their best to support people with disability, especially those with chronic health conditions and people with high and complex support needs, we too were grappling with the impact of lockdowns, illness, insufficient resources, and chronic communication issues. In fact, during the Covid-19 crisis disability advocacy organisations experienced a 70% increase in requests for information related to support services, NDIS plans and accessing government payments [10].

'Recovery' from the impact of Covid-19 is far from over for people with disability. The Victorian Council of Social Service (VCOSS) in their submission to the Royal Commission - Emergency Planning and Response Issues Paper - stated that people and communities who are socially vulnerable are "more at risk of the immediate, medium and long-term effects of disasters, such as loss, injury, and social and economic hardship [10]."

On how Covid-19 is continuing to compound the accessibility and safety issues that many people with disability experience, VCOSS added: "Even under normal circumstances, persons with disabilities are less likely to access health care, education, employment and to participate in the community. They

are more likely to live in poverty, experience higher rates of violence, neglect and abuse, and are among the most marginalised in any crisis-affected community. Covid-19 has further compounded this situation, disproportionately impacting persons with disabilities both directly and indirectly."

Article 11 of the CRPD affirms Australia's obligation to ensure the protection and safety of people with disability during times of risk, including emergencies, natural disasters, and armed conflict. In cooperation with advocacy groups Australia could learn from the Covid-19 crisis and our response to the 2019/2020 bushfires by including people with disability in emergency and crisis response initiatives to ensure financial assistance and essential supplies and services are immediately available [10].

Co-design principles applied to emergency responses and in advance of an emergency or crisis allows people with disability to engage their own networks and prepare in a manner that directly addresses their individual needs. For instance, people with spinal cord injury or similar disability may need to be evacuated from their home in an emergency. This would require accessible transport and alternative accessible accommodation – both would be difficult to coordinate in the middle of a crisis.

Understanding issues and risks and developing personal strategies with the cooperation of advocacy services reduces the reliance on emergency and universal services who may be unable to prioritise the needs of people with disability.

Similarly, healthcare professionals should be trained in disability awareness and be aware of the services their patients will require in an emergency or crisis. These will include mainstream health services and specialist services related to their disability. Peer advocacy groups are an essential resource for people with disability, their families, and carers so they too are aware of what they need to do to engage emergency services.

People with disability impacted by Covid-19 and other emergencies like the bushfires of 2019/2020 and the 2022 floods continue to need support and specialist advocacy. New strains of Covid, calls for additional rounds of boosters and ongoing social distancing and isolation measures all take their toll. Advocacy, including peer advocacy, give continuity to the social and community connections that are lost or suspended during an emergency or crisis. Advocacy is an essential formal and informal resource for disseminating information, sharing knowledge and emergency planning [10].

## 8. Impacts of Intersectionality

Intersectionality recognises the many ways that people with disability may experience discrimination, exclusion, and violence, abuse, neglect, and exploitation.

People with disability experience intersectional discrimination when factors such as race, culture, incarceration, economic and or social disadvantage, age, gender and gender identity, and sexual orientation overlap with a person's disability to compound their experience of exclusion [11]. If a person with disability has other marginalised identities, then the combination of the two will exacerbate the inequities they experience. These "aggravated forms of discrimination" often eventuate in lower quality services, particularly where resources are scarce already as is the case with Aboriginal and Torres Strait Islander people with disability and people with disability in regional and remote areas [9].

Intersectionality refers to the identity of individuals and the structures and systems that an identity must exist in. For people from culturally and linguistically diverse backgrounds that can mean our immigration policy; for other identities it will mean incarceration, labour rights, health, social services and more. An alternate identity can disguise a disability and therefore deny the human rights of a person with disability [11].

The experience of Aboriginal and Torres Strait Islander people with disability is a prominent example of intersectional discrimination. Evidence to the Royal Commission by the National Aboriginal Community Controlled Health Organisation (NACCHO) demonstrates how Aboriginal and Torres Strait Islander people with disability miss out on culture because of their disability or, conversely, they are deprived of services and programs because of their culture [12].

"Often service provision forms have a 'tick box' for Aboriginal and Torres Strait Islander people or disability, but not both."

And Aboriginal and Torres Strait Islander people with disability are often falsely incarcerated on the belief they are intoxicated rather than having a disability. Once they appear in court there are few alternative pathways for the courts to consider other than jail [12]. The same applies to young people who are not transitioned from Early Childhood Early Intervention (ECEI) services into the NDIS when they turn nine (9). Without the necessary supports, they too are risk of entering the child protection system [13].

The responsibilities and the rights of people with disability under the CRPD include equal access to the highest standard of health and rehabilitation services; equal access to the physical environment including transport, information, justice, communications and other facilities and services; equal access to employment and education; an adequate standard of living which includes access to appropriate housing; and many more [1].

Analysis of each of those rights against the accessibility that people with disability currently have to health services, employment, education, and housing, and delivery on fundamental supports like personal assistance and care and assistive technology, shows that for most people with disability, those standards are not being met. If people with disability identify with more than one group – disability and Aboriginality or disability and gender as examples - then they are likely to experience multi-layered discrimination [11].

For instance, we know that women with disability experience violence more frequently and for longer periods than women who do not have a disability [11]. Because of sexual and or gender diversity, people with disability are excluded from multiple social systems including limited access to information and services. We also know that people with disability are over-represented in jails and that some people with disability from culturally and linguistically diverse backgrounds cannot access services due to language barriers or feel excluded based on beliefs and customs associated with their culture. Aboriginal and Torres Strait Islander people experience disability at twice the rate of other Australians yet their participation rate in the NDIS is disproportionality low.

People with disability experience poverty and unemployment at significantly higher rates than other people and have significantly lower levels of educational attainment. In 2015 the United Nations estimated that living with a disability increased the cost of living by about a third of the average income.

Unfortunately, disaggregated data to support this theory is not available because statistics identify people with disability as a homogenous group [5]. It stands to reason however, that if employers make recruitment decisions based on certain stereotypes, the further that people with disability are from those stereotypes, the longer and deeper that inequality is perpetuated.

Because education is such a significant determinant to a person's current and future income and job security, the lack of access to education is a major factor in the living standards, savings, and financial future of people with disability [14].

Education will also determine the ability of people with disability to use technology and afford technology. Poor or limited access to technology increases the experience of isolation and contributes to the vulnerability of people with disability.

Meeting the individual needs of people with disability who are also representative of other minorities highlights some of the market-based limitations of the NDIS, particularly in the way providers serve thin markets where economies of scale and operational costs are prohibitive [12].

Thin markets exist whenever there is disparity between the needs of people with disability and the services available in the market. Likewise, thin markets can emerge when markets cease to be viable [15]. Ultimately the Australian Government must be accountable for not only the efficient use of resources but their equal distribution to meet our CRPD commitments. Providers must be incentivised to increase their presence in thin markets and their accessibility to people with disability who experience exclusion [15]. Within the NDIS it is possible to use market-based mechanisms to guarantee demand or supply, as the case may be.

For people who are not NDIS participants the challenges are significant. If people with disability are not NDIS or Disability Support for Older Australians (DSOA) participants, there are no policy or legislative settings that guarantee their protection.

These are structural issues in the disability sector that have never been adequately resolved. Some issues have disappeared or diminished with individualised funding and the increased choice and control experienced by participants, but other issues have compounded through the transition to a new market-based service model. Not least, the reliance that non-NDIS participants have on state-based health, housing, aged care, justice, child protection, education, and other services. Where some cooperative interface between these agencies and the NDIS exists, there does not appear to be any state based framework to identify and support people with disabilities within these services if they are not NDIS participants.

## 9. Very vulnerable population groups – Aboriginal and Torres Strait Islander People with Disability

The NDIS is designed for high population, metropolitan settings. It does not easily translate to regional, rural, or remote community settings. The expansion and density of services targeted at metropolitan areas detracts from services in regional and remote communities. For these reasons and more, the current disability system excludes most Aboriginal and Torres Strait Islander people with disability especially in regional and remote communities [12].

Aboriginal and Torres Strait Islander peoples are more than twice as likely to experience a disability than other Australians (9% with a severe condition compared to 4% for non - Indigenous) [16]. In 2018, according to Disability, Ageing and Carers Australia, part of the Australian Bureau of Statistics, 24% or 139,700 Aboriginal and Torres Strait Islander people had a disability. The proportions of men and women were very similar [16].

Currently 6.9% of NDIS participants are Aboriginal and Torres Strait Islander peoples (32,396 active participants as of 30 June 2021) which is considerably less than the percentage of Aboriginal and Torres Strait Islander people believed to have a significant disability.

The First People Disability Network (FPDN) estimated that the number of Aboriginal and Torres Strait Islander people nationally eligible for participation in the NDIS in 2019 was closer to 60,000.

Remoteness is often identified as the main practical impediment to service delivery for Aboriginal and Torres Strait Islander communities and peoples by service providers, the NDIS and the Australian Government. Governments recoil from the true costs of providing culturally appropriate support to Aboriginal and Torres Strait Islander communities and peoples.

Government response to remoteness invariably leads to:

- A scaling down of services to compensate for poor economies of scale and workforce and funding inadequacies.
- Dependence on digital infrastructure to address geographic accessibility issues.
- Poor coordination between agencies - Aboriginal and Torres Strait Islander people with disability are denied funding and services because the system often fails to recognise they have a disability [12].

An unwillingness by the Australian Government and the NDIS to develop a cultural competency framework has tarnished the experiences of Aboriginal and Torres Strait Islander people in accessing the NDIS, developing appropriate plans, and receiving support.

According to the National Aboriginal Community Controlled Health Organisation (NACCHO), “Aboriginal and Torres Strait Islander peoples will not access a service (or at least defer accessing) if they perceive that, or have an experience where their cultural safety is compromised.”

To increase NDIS participation by Aboriginal and Torres Strait Islander people with disability particularly in regional communities, the NDIS should consider exemptions to rules preventing family members providing support to NDIS participants.

This is a fundamental misunderstanding of the importance of kinship in the lives of Aboriginal and Torres Strait Islander people. Expectations that Aboriginal and Torres Strait Islander people should relocate away from their communities to access services disregards the impact that dislocation has on the wellbeing of a participant and their family and carers.

The 2016 Census included a question about whether people had provided unpaid assistance to someone with disability, a long-term health condition or a problem related to old age in the 2 weeks before Census night.

In 2016, of Indigenous Australians aged 15 and over for whom responses to this question were provided:

- 15% (58,500 Indigenous Australians) had provided unpaid assistance to someone with disability, a long-term health condition or a problem related to old age in the 2 weeks before Census night.
- 18% (36,500) of females had provided unpaid assistance, compared with 12% (22,000) of males.
- The proportion of Indigenous Australians who had provided unpaid assistance was similar among Indigenous Australians living in remote and non-remote areas (16% or 11,600, and 15% or 46,700, respectively) (ABS 2019b)

Growth needs for the entire disability workforce is estimated to be 14.2% or 249,500 to 2025. An additional 80,000 workers are required for regional and remote communities. For Aboriginal and Torres Strait Islander disability support workers to make up a modest 3.3% of that forecast growth, the sector will require an additional 8,233 workers.

**10. Housing and supported accommodation**

Under article 19 of the CRPD, person with disabilities have the right to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement [1].

The roll-out of accessible, social and or affordable housing has been far too slow to protect people with disability from more incidents of violence, abuse, neglect, and exploitation. The largest residential institutions for people with disability are now gone but group homes remain as part of the disability sector and the housing system - including supported disability accommodation funded by the NDIS - despite the incidents of violence, abuse, neglect, and exploitation that occur in group homes [17].

Prior to the NDIS and ever since the implementation of the NDIS, people with disability have been compelled to live in group homes, boarding house style accommodation or hostels, and residential aged care facilities, for lack of a suitable alternative.

At the end of June 2021, there were 3,899 younger people living in residential aged care according to Statistics from the Department of Health and Aged Care. Of the younger people living in residential aged care over 95% were NDIS participant living in non-remote areas [18].

In just three months between 1 July 2019 and 30 September 2019, there were 8,595 serious incidents lodged with the NDIS Quality and Safeguards Commission. While the vast majority of those incidents were reports of unauthorised restrictive practices, 1,236 of those incidents or approximately 14%, were reports of alleged sexual, physical, verbal and financial abuse, and neglect. Despite the volume of incidents, group homes are continuing to be built as the standard form of housing for people with disability who are assessed as eligible for SDA funding [17].

Reported incidents that have come to the attention of the DRC through NDIS incident reporting obligations and the NDIS Quality and Safeguards Commission are but a small proportion of a much bigger problem. People with disability who are eligible for SDA funding represents only 6% of NDIS participants and the NDIS represents only 10% of all people with disability, approximately [17].

People with disability who are not eligible for the NDIS or unable to access the NDIS are particularly vulnerable in the housing market. Many people with disability live in accommodation that is both unsuitable to their needs and not of their choosing, yet they are bound to their circumstances because there is insufficient accessible social and affordable housing. And for people with disability who are experiencing violence, abuse, neglect, and exploitation and need to be relocated because they are at risk, there are too few portable or interim housing options [17].

The lack of affordable and accessible properties in the private and social housing markets, and supported disability accommodation funded under the NDIS, continues to negatively impact people with disability.

For NDIS participants, the assessment and eligibility processes for SDA and Supported Independent Living (SIL) funding are often onerous and undertaken at the participant's expense without any guarantee of success. And rather than allocating accommodation vacancies to those who are most in need, people with disability who have the means to pay for their assessments are advantaged because they do not have to join the queue for community health funded assessments. Additionally, if participants are in hospital waiting to be discharged, between homes or are without suitable housing during their assessments, there is limited funding for short and medium-term accommodation.

Many people with disability in group homes have little to no choice about where and with whom they live. They take the accommodation that is available and once there, they do not complain for fear of losing what they have and becoming homeless. The Royal Commission has received many submissions and other evidence of people with disability enduring violence, abuse, neglect, and exploitation in group homes and remaining silent because they have nowhere else to go. More recently, the Royal Commission has received evidence of people with disability being told that due to the risk of contracting and spreading Covid-19, if they leave their home, they will lose their accommodation [10].

The risk of violence, abuse, neglect, and exploitation is heightened in group homes where the same provider is responsible for accommodation and supports. This practice is reflective of older models of disability support and runs contrary to the principles of the NDIS – particularly the principles of choice and control [17].

This risk was highlighted in the recently released: Joint Standing Committee on the National Disability Insurance Scheme: Report into Supported Independent Living [19].

The committee found that: "Allowing a single entity to exercise control over both tenancy and service delivery may have significant negative impacts for participants, including reductions in service quality; increased risks of abuse and neglect; and reduced housing security [19]."

SCIA and other advocacy services already contribute significant resources in supporting people with physical disability through the SDA eligibility process. However, this is a structural problem that precedes the NDIS, and it is an issue that will continue to compound as the demand for all types of accommodation grows. The scope for advocacy in this area could be expanded to include advocacy groups working with housing providers and service providers on solutions that meet the individual needs of the people they support.

Advocacy services play a major role in recognising and responding to violence, abuse, neglect, and exploitation of people with disability. It is essential that advocacy services are suitably funded to ensure that vulnerable people in group homes and other forms of public and private accommodation

are protected. The need for this advocacy is supported by the substantial evidence that has been presented to the Royal Commission by advocacy services and residents.

Given the opportunity and with adequate funding, advocacy - including education resources to encourage self-advocacy and peer advocacy services - could play a much larger role in the correction of these issues and by extension, reduce the incidents of violence, abuse, neglect, and exploitation experienced by people with disability in group homes and other congregated living environments.

## 11. Conclusion

All governments: Federal, State and Territory have a responsibility to uphold the purpose of the United Nations Conventions on the Rights of Persons with Disabilities which is: 'To promote protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity [1].'

However, in contrast to Australia's CRPD obligations and according to the evidence and the many submissions provided to the Royal Commission, the voice of people with disability is not being heard and their rights to inclusion and equality are not being upheld.

In fact, there is a strong correlation between the continued inequities experienced by people with disability and the under prioritising and underfunding of advocacy services. The social and economic benefits of advocacy, in all its forms, is being ignored and neglected despite the important role it plays in the lives of people with disability and by affecting systemic change in legislation, policy and practice.

Systemic advocacy informs responses to the needs and aspirations of people with disability. Individual advocacy stems violence, abuse, neglect, and exploitation and acts in the interests of those who cannot act for themselves. A Review into Disability Advocacy by the NSW Ageing and Disability Commissioner in 2019, estimated that the value of independent advocacy for people with disability to the Australian economy in 2017 dollars, was close to $600 million [20].

Currently, the lack of investment in advocacy services combined with the inadequacies in our data collection systems, are concealing the true extent of the violence, abuse, neglect, and exploitation of the most disadvantaged and vulnerable people in our society.

This is evident in settings where people with disability should feel safest - in their own homes. There continues to be a crisis in the lack of appropriate and accessible accommodation for people with disability. Despite evidence to the Royal Commission on the violence, abuse, neglect, and exploitation occurring in group homes, this form of congregated accommodation is continuing to be built by SDA providers who, in many instances, provide both accommodation and support services – a conflict of interest that not only limits choice and control for people with disability but increases their vulnerability to violence, abuse, neglect, and exploitation often perpetrated by people in positions of trust [17].

Unfounded and inaccurate assumptions are made about people with disability, including assumptions about productivity and competence. These assumptions manifest in the low rates of participation by people with disability in employment and education. Only 53.4% (approximately 1 million) of working age people with disability are employed. The statistics are worse in the public sector where only 4% of the workforce have a disability [21]. There are similar disparities in education; only 17% of people with disability have a bachelor's degree or higher compared to 35% of people without disability according to the Australian Institute of Health and Welfare.

To build aspiration and increase participation in employment, education, technology, and other settings where people with disability are underrepresented, the cultural and contextual needs of people with disability who experience intersectional discrimination need to be understood.

Intersectional disadvantage and discrimination are not just barriers to education, employment, technology, and other services, they influence the high levels of poverty experienced by people with disability. One in six people with disability are living in poverty compared to one in ten Australians without a disability. Those figures do not reflect the additional costs of having a disability which the United Nations estimated as being about one third of the average wage. In Australian terms that is between $87 and $173 per week on average, depending on the disability [21].

When multiple characteristics overlap with disability, they become intrenched and replicated in our social structure [14]. These systemic and structural impediments to equality against people with disability contradict our CRPD obligations. Inclusivity for people with disability should begin with inclusion at all levels of decision making, and co-design principles need to be ingrained in the design of supports and services. All levels of government should be required to consult with people with disability when making policy that affects them.

And the role of advocacy needs to be acknowledged, valued, and funded appropriately. Advocacy groups need assurances that long-term sustainable funding will be available for staff recruitment and retention, program evaluation and development including programs to increase NDIS participation along with the work we do to improve the individual circumstances of people with disability.

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