![SCIA - Spinal Cord Injuries Australia]

Promoting inclusion

Spinal Cord Injuries Australia

Policy and Advocacy Team Submission

June 2021

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
Via email to DRCEnquiries@royalcommission.gov.au

Introduction

Spinal Cord Injuries Australia (**SCIA**) welcomes the opportunity to offer a submission to the Royal Commission on promotion of a more inclusive society that ensures the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. SCIA strongly supports the work of the Royal Commission recognising that people with disability are equal members of Australian society and have the right to the full and equal enjoyment of all human rights and fundamental freedoms, including respect for their inherent dignity and individual autonomy.[1]

This submission reflects SCIA's vision for a truly inclusive Australian society and makes recommendations for reforms to make this vision a reality.

About Spinal Cord Injuries Australia

SCIA is a for-purpose organisation working for people living with spinal cord injury (**SCI**) and other physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 25% of our staff, and the majority of our Board live with SCI. SCIA is a national, member-based organisation that serves 2,500 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector.

SCIA's Policy and Advocacy Team provides individual and systemic advocacy, and supports self-advocacy. The team aims to ensure that people living with SCI and other disabilities do not face barriers in exercising their independence and realising their human rights. The team strives to achieve inclusivity and change for people with disability, their family members and carers.

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[1] Letters Patent (Commonwealth), 4 April 2019 amended 13 September 2019, Preamble.

Executive summary and recommendations

This submission discusses the variety of challenges and barriers that people with disability continue to encounter in Australian society. Our collective goal is to foster a truly inclusive society that embraces and respects all peoples' differences. The following recommendations provide practical reforms to achieve this goal:

Recommendation 1:

The Australian Government, state and territory governments and local governments should implement greater enforcement measures of minimum accessibility standards as protected in the Disability Discrimination Act 1992.

Recommendation 2:

All information published by government should be made available in universally accessible formats and all non-government organisations should be supported to achieve this too.

Recommendation 3:

Initiatives should be taken to increase allocation of accessible accommodation in private and public housing and the cost of home modifications should be subsidised to allow choice for people ineligible for other government schemes (e.g. NDIS and Aged Care).

Recommendation 4:

All stakeholders should work towards eliminating segregated settings and eradicating restrictive practices, by implementing more person-centred planning and community-based support.

Recommendation 5:

Ensure that any law, policy and program affecting people with disability establishes strategies and includes taskforces that specifically focus on the impact on priority groups – including people from an ATSI or CALD background, LGBTQI+ community, women and girls, older people, people living in rural and remote areas.

Recommendation 6:

Campaigns should be launched by government and non-government stakeholders to tackle attitudinal barriers to people with disability in the workplace, school and other settings.

Recommendation 7:

*The powers of the Australian Human Rights Commission (**AHRC**) should be expanded to allow for private stakeholders to be held accountable for acts or failures to act leading to violence, abuse, neglect and exploitation of people with disability.*

Recommendation 8:

Private organisations should be supported to establish internal, robust complaints mechanisms to deal with complaints of violence, abuse, neglect and exploitation of people with disability.

Recommendation 9:

Every person with disability should have access and information about advocacy services and advocacy service providers should receive long-term funding to ensure their sustainability.

Recommendation 10:

The AHRC should act as the independent body tasked with monitoring progress toward achieving inclusion goals, reporting to Parliament and seeking feedback from people with disability.

Recommendation 11:

Sustainable consultation policies and bodies should be established to ensure input from people with disability throughout the co-design, implementation and monitoring phases of any government-led programs, laws or policies.

Recommendation 12:

General and specific training programs, tools and booklets should be provided to all public, private and community organisations to increase disability awareness. Educational campaigns should be included in curriculums in primary and secondary schools.

Recommendation 13:

The Australian Government should develop a standardised set of media guidelines on the representation of disability following guidance from people with disability.

Recommendation 14:

Public, private and community organisations should be encouraged to consider adopting affirmative action policies including outreach, hiring targets, connecting with disability employment advisors and through removing barriers to entry.

Recommendation 15:

The Australian Government should adopt Recommendations 72 and 73 of the Royal Commission into Aged Care Quality and Safety.

Recommendation 16:

People with disability from priority groups should have greater access to advocacy services and assertive outreach should be done to make them aware of their rights.

Recommendation 17:

People with disability living in rural and remote areas should have access to communications and technology to facilitate service delivery and face-to-face services should increase their coverage.

1. Understanding inclusion

Universal inclusion is a fundamental principle that should define our community. Every person and their experience of the world is unique, but we are all connected by our inherent dignity, which is realised through fulfilment of our human rights.[2] Inclusion can mean many things for different people, but at its heart inclusion centres on respect for all people's differences and ensuring all people have equal opportunities across all domains of life. If any one group is segregated, then true inclusion is not possible.

Becoming a truly inclusive society does not simply involve rhetoric, it must be supported and proactively promoted by concrete measures and actions made by all members and institutions of society. It is critical to tackle negative attitudes and behaviours that arbitrarily exclude people on the basis of their difference and recognise our interdependence to move toward a truly inclusive society for all peoples. It requires the rejection of unjust segregation and denunciation of direct and indirect discrimination. We should not just strive for genuine legal equality, it is fundamentally about establishing equity for all people by providing supports to ensure everyone has the same starting point to empower their choice and self-determination. For people with disability, one aspect of this process involves achieving universal "accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication".[3]

For SCIA, inclusion underpins all of our work. We hope to ensure that all people with disability do not face barriers, can achieve their goals and live a thriving independent life. This involves both the advancement of the rights, choices and entitlements of people with disabilities and ensuring that high quality, relevant services are readily available to fulfil their rights. It also requires robust monitoring and reporting mechanisms to respect, protect and fulfil people's rights.

Following consultation with several SCIA members in late 2020, including individuals with spinal and neurological conditions and their family members, it is evident that many people do not feel included in mainstream Australian society. Below are just a few of the comments made among our membership when asked about community attitudes:

'They've all said it, "People with disabilities should be seen, but rather not heard". And that mantra really needs to disappear…I just can't believe we're in the year 2020 and yet people with disabilities are still fighting to be accepted into mainstream society.' [SCIA member from South Australia]

'If you're in a wheelchair, the person at the counter will want to talk to the person that happens to be with you.' [SCIA member from New South Wales]

'People have a big problem with understanding other people's disabilities, ill health, abnormalities, whatever you want to call it…Now you see someone who's in a supermarket is in a wheelchair, people will go down a different aisle just so they don't have to deal with it.' [SCIA member from the Australian Capital Territory]

These comments reflect a wider sense of segregation, discrimination and disempowerment felt by people with disability. This segregation is evident when examining rates of people with disabilities' participation in different areas of life, including education, employment, healthcare, housing and justice. For example, according to recent research from the Australian Institute of Health and Welfare:

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[2] Human rights enshrined in international human rights law, specifically in the *Universal Declaration of Human Rights* (1948) and *Convention on the Rights of Persons with Disabilities* (2006).
[3] CRPD, Preamble (v).

- 53% of people with disability aged 15 - 64 participate in the labour force;
- 43% of people with disability receive a government payment as their main source of income;
- 47% of adults with disability have experienced violence after turning 15;
- 10% of people with disability aged over 15 experienced discrimination within the past 12 months;
- 33% of people with disability aged over 15 avoided situations become of their disability in the past 12 months;
- 24% of non-dependent people with disability live alone (compared with 10% of people without disability);
- Adults with disability are 6 times more likely to describe their health as 'poor' or 'fair';
- 21% of people with disability aged 15 - 64, for whom onset of disability occurred at age 14 or under, left school before age 16 (compared with 9% without disability); and
- 10% of school aged children with disability do not attend school.[4]

In light of the above, it is difficult to argue that Australia is a truly inclusive society.

The standards of an inclusive society, prioritising the human rights of people with disability, have already been articulated in the Convention on the Rights of Persons with Disabilities (**CRPD**). Australia's first National Disability Strategy (**NDS**) has established many of the goals to fulfil the rights in the CRPD, and it is hoped that the second NDS and its associated Outcomes Frameworks, will similarly provide a roadmap forward to respond to current inequities. To achieve these goals, there needs to be significant resources and commitments made by government and non-government stakeholders to effect systemic, institutional changes. Underlying this there needs to be a nationwide campaign to tackle attitudes within Australian society that disenfranchise people with disability and ensure that all organisations universally foster inclusive cultures. As recently elected Chairperson of the UN Committee on the Rights of Persons with Disabilities, Rosemary Kayess, noted:

'It's about breaking some of those cultural norms that seem to normalise the violence, abuse and neglect that people with disability experience.' [5]

2. Inclusion for people with disability

An inclusive society embraces respect for, protection of and fulfilment of the human rights of people with disability. It is also important to acknowledge the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms.[6] We must recognise a life course approach and that people with disability are entitled to all political, civil, socioeconomic and cultural rights. Fulfilling all of these rights through proactive measures is a vital element in supporting and removing all barriers to the independence, choice and control of people with disability. Additionally, the responsibility to achieve this lies with all members of Australian society.

There are several steps that government, non-government organisations and all other community members can take to support people with disability's independence, choice and control. They involve achieving equity by ensuring all people with disability have opportunities to actively participate and receive supports in all domains of life. This relates to all settings and institutions including, among

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[4] Australian Institute of Health and Welfare, *People with disability in Australia*, Australian Government, 2020, pp. 1-3, 41, 124, 218, https://www.aihw.gov.au/getmedia/ee5ee3c2-152d-4b5f-9901-71d483b47f03/aihw-dis-72.pdf.aspx?inline=true.

[5] Chloe Yang, 'Rosemary Kayess and Disability Rights at the United Nations', *Australian Human Rights Institute*, 23 July 2019, https://www.humanrights.unsw.edu.au/news/rosemary-kayess-and-disability-rights-united-nations.

[6] CRPD, Preamble (c).

others: housing, education, employment, health, political and civic activities and events, cultural events and programs, detention institutions and recourse to legal supports. At the heart of assuring people with disability enjoy equal opportunities across different domains of life is universal accessibility. This includes both physical accessibility and communications accessibility.

Physical accessibility allows people to navigate their community with freedom, without facing barriers to access services, places and supports. For example, for wheelchair users this can only be achieved through universal design, ensuring people have a barrier-free journey that is safe and continuous from the moment they leave their home to the moment they reach their *chosen* destination point. Additionally, many people have found that even if buildings have accessible features or structures, they must be functioning and repaired as needed. As one SCIA member, who is a wheelchair user, described it:

'It's just respect really I think it comes down to. Just getting into a building, you don't need to have a ramp for disabled people, it's just a ramp so anyone can access the building. It shouldn't be a separate thing. We're not special, we're just not like everyone else.' [SCIA member from NSW]

All facilities, services, information and media must be accessible for people with disability. Even if targeted services and supports exist, people with disability and their support networks need to be made aware of their availability and relevance in providing equitable opportunities to benefit from them.

This involves investing in empowering peoples' knowledge and awareness of their freedom of choice in the provision of information and media in all accessible forms. All written information and publications should have versions in accessible formats, including Plain English and different levels of Easy Read, multiple translations into other community languages, hard copy Braille documents, audio recordings, large print and files that are recognised by screen readers. Further, any video material must include Auslan translation, live captioning and other alternative formats.

> **Recommendation 1:** *The Australian Government, state and territory governments and local governments should implement greater enforcement measures of minimum accessibility standards as protected in the Disability Discrimination Act 1992.[7]*
>
> **Recommendation 2:** *All information published by government should be made available in universally accessible formats and all non-government organisations should be supported to achieve this too.*

Another aspect of accessibility and ensuring people with disability have independence is through ensuring that all people have long-term, meaningful housing options to choose from. This is facilitated by enforcing minimum mandatory accessibility standards, providing supports to make home modifications financially possible and increasing construction and allocation of accessible social and affordable housing. Without these measures, SCIA has seen many members with disability forced into accommodation, particularly aged care facilities, which have restricted their independence and weakened their ties to their families and support networks. Often these facilities are low staffed with few trained in providing supports for people with disability. As one person, with a family member in an aged care facility, described the situation:

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[7] This includes standards under the *Disability (Access to Premises - Buildings) Standards 2010* (Cth), *Disability Standards for Accessible Public Transport 2002* (Cth), *Disability Standards for Education 2005* (Cth), and pending amendments to the National Construction Code to entrench minimum standards in compliance with the Silver Level of the Livable Housing Design Guidelines.

'[They've] had so many people pass away next to [them] and [they're] frightened that [they're] going to die there. We're trying to get [them] home…the only reason [they're] there is because [they] require disabled access for hygiene…Our family has broken apart.' [SCIA member from Western Australia]

Recommendation 3: *Initiatives should be taken to increase allocation of accessible accommodation in private and public housing and the cost of home modifications should be subsidised to allow choice for people ineligible for other government schemes (e.g. NDIS and Aged Care).*

Taking a whole of life of approach means understanding that people with disability move between different life events, and each of these impact on future independence, choice and control. Significant periods in all peoples' lives include early childhood development, the transition from school to the workplace, moving homes and expanding kinship networks. As such, institutions and stakeholders should collaborate and communicate with one another to ensure that people with disability do not lose access to services or supports that empower their independence, choice and control. They should not be disadvantaged by interfacing issues or are at risk of falling through the gaps due to poor governance.

This issue is also related to working towards a society in which individuals are not forced to learn, work or live in segregated settings. Currently, segregated arrangements are often the result of a lack of alternative options, or decisions made by others on behalf of a person with disability.[8] This division often masks people with disability from the rest of society, and as will be discussed below, forces people with disability into the 'shadows'. Additionally, in these settings there is a further lack of choice and independence as many service providers choose which supports a person receives. Many older SCIA members with disability residing in aged care facilities have emphasised the disempowering effect of a lack of end-user choice. The intersectional difficulties faced by older people with disability will be further discussed in Section 4 of this submission. A person with disability and people in their support network are the experts in that person's disability and their daily needs. Removing control from them in choosing the supports and services they use is not simply disempowering, it can also pose risks to their health and wellbeing.

Another risk, especially in segregated settings, is the increased risk of restrictive practices. Restrictive practices should always be used as a last resort for the minimum possible time and regularly reported on and reviewed. They are the ultimate forms of subduing a person, repressing their autonomy and infringing on their human rights. As such, they pose an inherent intrusion on respect for a person's dignity. Many service providers have received complaints following staff using restrictive practices in wholly unjustifiable circumstances, particularly in failing to facilitate access or in establishing situations of involuntary seclusion. These practices and failures to act present danger to a person with disability both at the time and in the future as they can instil feelings of isolation, disempowerment and trauma. Following complaints many service providers have failed to instigate systemic change to ensure people are not put at risk again, and unfortunately many have not been held accountable, either legally or practically.

An inclusive society would not endanger people with disability's lives without recourse to accountability mechanisms that have genuine repercussions for people who unjustifiably use restrictive practices. First and foremost, they are a last resort, and eradicating the need for their use

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[8] Joint Position Paper between DANA, AFDO, WWDA, CYPDA, NEDA, Inclusion Australia, FPDNA and PWDA, 'Segregation of People with Disability is Discrimination and Must End', September 2020, p. 3.

should be a constant goal,[9] as they represent the ultimate restriction on a person's human rights, independence, choice and control.

> **Recommendation 4**: *All stakeholders should work towards eliminating segregated settings and eradicating restrictive practices, by implementing more person-centred planning and community-based support.*

For many people with disability, they face increased discrimination and barriers to access and supports due to intersectional characteristics (including people from an Aboriginal and Torres Strait Islander background (ATSI), culturally and linguistically diverse background (CALD) and others). This will be further discussed in Section 4, but it is important to note here that an inclusive society will support a person's independence if it addresses inequities associated with their disability and other characteristic. For example, some people with disability from a LGBTQI+ background have found that certain faith-based organisations have refused to provide disability services for them due to their identification as LGBTQI+. This is especially problematic when these service providers operate in thin market areas. As such, inclusive societies work to supporting the independence, choice and control of all people with intersectional identities, ensuring that there is no discrimination in opportunity and equitable access to supports and services.

> **Recommendation 5**: *Ensure that any law, policy and program affecting people with disability establishes strategies and includes taskforces that specifically focus on the impact on priority groups – including people from an ATSI or CALD background, LGBTQI+ community, women and girls, older people, people living in rural and remote areas.*

Ultimately an inclusive society is reflected in all individuals and communities embracing and respecting the talents and differences of all people with disability. At present, many people with disability encounter negative attitudes and stigmas, which translate to differential treatment and associated trauma and destabilising effects on mental health. In the context of the workplace, many people with disability are being put in the 'too hard basket' by employers, who fail to recognise the benefits of hiring people with disability.[10] For people with acquired disabilities, returning to work is often a very challenging, lengthy experience as they find their former employers unwilling to make reasonable adjustments in their former workplace. Further, gaining similar employment that matches their level of experience is usually impossible and many people rely on their personal network to even get their foot in the door. If there is a paradigm shift that normalises disability and increases the everyday visibility of people with disability, there will hopefully be fewer and fewer attitudinal barriers that people with disability encounter:

'Integration comes through association. If you're seen and communicating with other people they'll understand you and accept you. It's when you come out of the shadows suddenly that people don't understand, they're afraid to say the wrong thing, they don't know what to say, it's a whole new experience for them. I think

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[9] Research has shown there are many alternatives: Melbourne Social Equity Institute, 'Seclusion and Restraint Project: Report', University of Melbourne, 2018: Piers Gooding and others, 'Alternatives to Coercion in Mental Health Settings: A Literature Review', University of Melbourne, 2018; M. Gómez-Carrillo, E. Flynn and M. Pinilla, 'Global Study on Disability-Specific Forms of Deprivation of liberty', National University of Ireland Galway, 2018; The Australia Psychological Society Ltd, 'Evidence-based guidelines to reduce the need for restrictive practices in the disability sector', 2011; Lynne S. Webber, Ben Richardson, Kathryn L. White, Padraig Fitzpatrick, Keith McVilly & Sheridan Forster 'Factors associated with the use of mechanical restraint in disability services', 2019, vol. 44 (1), *Journal of Intellectual & Developmental Disability*.

[10] This has already been supported empirically in research including: Accenture, American Association of People with Disabilities, Disability:IN, 'Getting to Equal: The Disability Inclusion Advantage', 2018.

integration in the schools is a really good starting point and then there are integration in the supporting activities. Wherever that can be facilitated.' [SCIA member from New South Wales]

Reforms to try and achieve this paradigm shift will be discussed further in Section 3.

The above has mostly related to how inclusive societies should fulfil people with disability's rights to live independently. However, it is just as crucial to ensure that our society strives to respect and protect people with disability's right to live free from violence, abuse, neglect and exploitation. First, this should be achieved through proactive measures that create society-wide awareness of what constitutes violence, abuse, neglect and exploitation. This can take the form of educational and media campaigns, freely available training sessions and creating a free toolkit to disseminate to all people providing services for people with disability.

In cases where a person has experienced violence, abuse, neglect and/or exploitation, several measures should be taken by government and non-government stakeholders to establish accountability mechanisms and provide remedies to the person and serving the purpose of specific and general deterrence.

Currently, achieving positive outcomes through legal remedies is inhibited by a lack of access to advocacy and legal representation. Additionally, there is general lack of implementation and monitoring of courts and tribunals' orders, and many bodies, including the Australian Human Rights Commission (AHRC) have restricted powers in intervening in individual complaints and effecting appropriate individual and systemic remedies. For example, the AHRC should be further empowered to hold non-government entities to account and adhere to legislation protection people with disability and their families, including the *Disability Discrimination Act 1992* (Cth), as well as provisions under the CRPD and NDS. The AHRC should take on the role as a 'public prosecutor' and act as the peak accountability mechanism to address individual complaints, which result in positive systemic outcomes in the public interest and collaborate with the NDIS Quality and Safeguards Commission, the Aged Care Quality and Safety Commission and others to resolve complaints. In other words, it could become the ultimate arbiter in claims of violence, abuse, neglect and exploitation against people with disability and order appropriate remedies to implement systemic change.

This would overcome present challenges people have in addressing complaints at the AHRC if reaching settlement through conciliation is not possible, and when significant legal costs act as a disincentive from initiating a complaint in the courts. The AHRC should be empowered to take administrative and court-based compliance and enforcement actions including: formal warning letters, infringement notices, injunctions, acting to enforce an undertaking and civil penalties.

For non-government organisations, they should establish internal robust complaints mechanisms if any cases of violence, abuse, neglect or exploitation are raised. Every complaint should be thoroughly investigated and complainants informed of the progress and outcomes of any investigation and their wellbeing and privacy should be prioritised. Organisations should take concrete actions to address violence, abuse, neglect or exploitation of people with disability following complaints. These actions should be directed at the relevant staff member and at the organisation at large, by implementing organisation-wide training and education programs to protect people with disability from future risk of harm.

In achieving positive outcomes through any accountability mechanism, every person with disability should be assigned an advocate and have access to legal advice through community legal centres and other legal services, if they wish to make a complaint about service provision or other instances of discrimination they have experienced. In making complaints, people with disability's wellbeing,

privacy and confidentiality should all be protected and supported, particularly if they require psychosocial and legal supports throughout the process. In order to facilitate greater access to advocacy and legal representation, government should increase funding to disability advocacy organisations, legal aid services and community legal centres.

> *Recommendation 6*: *Campaigns should be launched by government and non-government stakeholders to tackle attitudinal barriers to people with disability in the workplace, school and other settings.*
>
> *Recommendation 7*: *The powers of the Australian Human Rights Commission should be expanded to allow for private stakeholders to be held accountable for acts or failures to act leading to violence, abuse, neglect and exploitation of people with disability.*
>
> *Recommendation 8*: *Private organisations should be supported to establish internal, robust complaints mechanisms to deal with complaints of violence, abuse, neglect and exploitation of people with disability.*
>
> *Recommendation 9*: *Every person with disability should have access and information about advocacy services and advocacy service providers should receive long-term funding to ensure their sustainability.*

Another proactive measure that should be taken is to ensure that people with disability and their support persons are directly involved in the co-design of any program, policy or law that will affect their lives. This complies with Australia's General Obligations in the CRPD in Article 4 (3) and the NDS: '[people with disability] must play a central role in shaping and implementing policies, programs and services that affect them'.[11]

3. Practical reforms

Several practical reforms have already been mentioned in Section 2 and a few additional recommendations will be included in Section 4 that specifically relate to access to services and supports and accountability mechanisms. This section will discuss further recommended accountability mechanisms; measures to guarantee consultation, engagement and co-design with people with disability; and initiatives to tackle cultural, behavioural and attitudinal changes.

3.1. Accountability mechanisms and data collection

The AHRC could also play a major role in ongoing monitoring and measurement of progress toward inclusion goals. The AHRC could collate data nationally and regularly report annually to Parliament on outcomes achieved, collaborating with State and Territory governments, private stakeholders and others. This recommendation is made in light of SCIA's past recommendations and former public consultations with stakeholders in the disability sector.[12] Actions that affect, and data that measures, progress towards achieving the outcomes set by the CRPD, NDS and NDIS, can reveal dramatic impacts on the daily lives of people with disability and their family and informal carers. In turn, this provides an opportunity to quickly address any issues that have arisen over the course of the year and monitor

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[11] Council of Australian Governments, *National Disability Strategy 2010-2020*, Commonwealth of Australia, 2011, p. 24.

[12] See Spinal Cord Injuries Australia, Submission to Department of Social Services, *A new National Disability Strategy – Stage 2 consultations* (30 October 2020) pp. 9-10; Department of Social Services, *Right to Opportunity: Consultation report to help shape the next national disability strategy – Summary Report*, December 2019, p. 6; Social Policy Research Centre, 'Review of implementation of the National Disability Strategy 2010-2020 Final Report', August 2018, p. 37 and Department of Social Services.

the progress of ongoing programs impacting people with disability and their families and carers. Reports should include identifying annual changes to funding and policy amendments to services and programs. Additionally, reports should provide all available statistics, collated from different stakeholders, relating to:

- Demographics,
- Access to disability and non-disability specific services,
- Participation in economic and social activities,
- Political agency,
- Education, and
- Accessibility and representation in the media.

Implementation and monitoring of progress toward inclusion goals should be streamlined through a single, independent body that collates information from the numerous stakeholders delivering programs and policies affecting people with disability. This will ensure transparency, independence and public accountability. All stakeholders across the disability sector, government and government agencies should commit to an ongoing process of information sharing of quantitative data and engagement and consultation with people with disability and their families and carers. This collaboration will ensure that progress towards NDS and NDIS outcomes are measured *holistically*. The independent body that could best facilitate this process is the AHRC, particularly as the Commission may draw upon its own disability expertise to align data and feedback within the context of the CRPD, NDS and NDIS.

> **Recommendation 10**: *The AHRC should act as the independent body tasked with monitoring progress toward achieving inclusion goals, reporting to Parliament and seeking feedback from people with disability.*

3.2. Consultation, engagement and co-design

The success of any law, policy or program affecting people with disability should be measured through both quantitative data and through direct consultation with people with disability and their families and carers. These consultations should be conducted throughout the life of a project, from the outset of co-design, to implementation and then to monitoring. Engagement must be *ongoing, accessible, genuine and thorough*. For example, many in the disability sector championed the NDS as: "The strength of the NDS is the disability community's sense of ownership of it, driven in part by its extensive consultation processes".[13]

Consultation and engagement can be achieved by establishing platforms and opportunities for oversight bodies (including the AHRC) to engage with as numerous and diverse individuals and organisations as possible. SCIA has received feedback from some of its members that there is enthusiasm for greater engagement through surveys and interviews (face-to-face and virtual). These surveys could be circulated through social media and via existing membership of disability organisations. Additionally, the disability sector should be engaged through regular consultations. These may include peak disability organisations, disability advocacy organisations and reference groups. Outreach should be done to individuals in regional and rural areas and to people in priority populations. These include ATSI, CALD, people experiencing homelessness, the LGBTQI+ community,

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[13] Australian Civil Society CRPD Shadow Report Working Group, *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities, UN CRPD Review 2019*, July 2019, p. 5.

and people aged over 65. This could be facilitated by developing relationships with existing disability advocacy organisations or service providers working with these priority populations.

> **Recommendation 11**: *Sustainable consultation policies and bodies should be established to ensure input from people with disability throughout the co-design, implementation and monitoring phases of any government-led programs, laws or policies.*

3.3. Education and training

People with disability and their family and carers should lead training sessions and be at the forefront of educational campaigns. Thorough training programs of staff across public, private and community organisations and educational campaigns within primary and secondary schools, universities and vocational training institutions should be regularly undertaken to promote disability awareness. Individuals in key decision-making roles should be targeted for training and understanding the disability experience and how the interests of people with disability are influenced by their activities.

Government should also lead the way by offering training sessions and tools that could be used within organisations to promote inclusion and support disability access consultants to conduct assessments of premises. A variety of other stakeholders must also be involved in training and education including: peak disability organisations, government figures and others, to improve general awareness and understanding of government and non-government entities' responsibilities.

Improving disability awareness among younger generations is an important step in creating sustainable, long-term change in community attitudes. All schools should be delivering disability awareness training and education with the aim of improving attitudes, empathy and acceptance, and hopefully eradicate or minimise bullying against children with disability. The success of bridging the empathy gap by exposing young children to disability is already anecdotally evident:

> *'When a child is confronted with something from a very young age, it's normal to them, they don't find it weird. My niece, she's seen me in a wheelchair, so she doesn't find being in a wheelchair any different, she doesn't treat me any different. In her school, they had to bring something that [represented] one change that they want to embrace. So, she brought a Barbie doll in a wheelchair because she thought that's the change she wants to see…That little girl…recognises that disability is not accepted, and she wants that to be accepted. Because she has seen me…I found that so deep.'* [SCIA member from NSW]

> **Recommendation 12**: *General and specific training programs, tools and booklets should be provided to all public, private and community organisations to increase disability awareness. Educational campaigns should be included in curriculums in primary and secondary schools.*

3.4. Media representation and fostering a language of inclusion

Visibility is a critical tool in tackling stereotypes and misunderstanding of the disability experience. During SCIA's consultation, increasing representation of people with disability in the media was the most frequently suggested reform in changing community attitudes.

This should involve actions including national advertising campaigns combating negative stereotypes and unfounded assumptions. These campaigns should address specific issues including the impact of intersectionality on different people, the need for wider access to assistive technology and more diverse representation of people with disability in the media. The Australian Government should also develop media guidelines to ensure journalists and broadcasters use positive language and depictions when describing or discussing people with disability, and include a list of acceptable positive terms and language to be used.

'If there was more on TV, so we saw more commentators with disabilities, more actors with disabilities, more normalisation of people living their lives that might not have perfect bodies or perfect minds.' [SCIA member from NSW]

'It's the visibility. If it's on TV, if it's in the newspaper, it just becomes normal. It's not an odd thing to see. Even I've noticed since the NDIS has been in, when you go to the shops, you see more disabled people out. It's just part of the community. It's not a special thing you see.' [SCIA member from NSW]

> **Recommendation 13:** *The Australian Government should develop a standardised set of media guidelines on the representation of disability following guidance from people with disability.*

3.5. Affirmative action policies

Organisations should be encouraged to consider adopting affirmative action policies to increase employment and membership of people with disability. Barriers to participation in employment is a major concern for all people with disability, and many SCIA members with acquired disabilities have highlighted the specific difficulties employers have making reasonable adjustments in the workplace or in adopting inclusive hiring policies. As a result, one member takes the following approach:

'I never identify myself at all as a person with a disability. In my resume I tried to take out all the references that could be perceived as a person with a disability. But when there's a big gap of nearly two years, and that's taking up the time that I acquired my spinal injury to the time I'm ready to go back to work. That's a big gap and employers don't like that gap.' [SCIA member from ACT]

Affirmative action measures can sometimes be a useful short to mid-term tool to increase participation in the workplace and lead to better inclusion outcomes. Such policies may include outreach to potential candidates with disability; specific hiring goals or targets; removing barriers to entry by reviewing organisational policies and premises to identify access barriers.

Presently, there is a lack of person-centred support for people with disabilities seeking meaningful, secure, long-term opportunities and the Australian government needs to focus its investment and supports on establishing a positive feedback loop between building the candidate, building opportunities and building employers. There should be a paradigm shift in connecting all stakeholders in the employment journey. Further details about SCIA's position on developing an approach to empowering with disability to find employment opportunities that match their skills and aspirations can be found in our submission on the proposed National Disability Employment Strategy.[14]

> **Recommendation 14:** *Public, private and community organisations should be encouraged to consider adopting affirmative action policies including outreach, hiring targets, connecting with disability employment advisors and through removing barriers to entry.*

4. Barriers for particular groups

Section 2 has already identified the specific intersectional inequities experienced by many people due to other characteristics, including whether they are from an ATSI, CALD, LGBTQI+ background or depending on their age, gender or where they live. Many SCIA members and clients have faced additional barriers due to above characteristics. One of SCIA's current priority advocacy area is a focus on supports for people aged over 65 living with a disability. A single illustration of the inequity facing

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[14] Spinal Cord Injuries Australia, 'Submission to the Department of Social Services on the National Disability Employment Strategy', 14 May 2021, https://engage.dss.gov.au/development_national_disability_employment_strategy-submissions/1620964155/.

people aged over 65 with a disability is a comparison between funding through the NDIS or through the aged care system. Under the NDIS, a person with a spinal cord injury has an average annual plan of $164,000,[15] whereas the most a person with a spinal cord injury acquired after age 65 can access via a Level 4 Home Care Package is $52,000 annually.[16] Following a major consultation project with members, we heard the following:

> *'We're getting offered a second-rate grab bag, a complete mishmash…there's no rhyme and no reason for it…We're put on the scrap heap, because we have no goals, we have no aspirations.'* [SCIA member from regional NSW aged over 65]

> *'We don't treat our loved ones this way…They have so much ability, we don't rob people of their ability…They're just ripped off of so much potential.'* [SCIA member from WA caring for over 65-year-old family member]

The Australian Government should adopt both recommendations in Chapter 10 of the Aged Care Royal Commission's Final Recommendations as they provide important protections that directly address the inequities experienced above.[17]

Another group experiencing additional inequity are those with a disability living in rural and remote areas. Many found after acquiring injuries that it was difficult to find appropriate accessible housing in their area and home modifications were too expensive without government support to allow them to remain at home. Others felt isolated particularly as they could not access peer support services after returning home from rehabilitation centres in metropolitan areas, leading to a sense of neglect. Service delivery was also limited for many people and they often did not have the option of face-to-face care or supports, making them feel 'very low in the priorities'.

These are just a handful of examples that illustrate the particular difficulties faced by groups due the intersection between ableism and ageism, poor communication and service delivery in rural locations. People in the other groups mentioned above face similar barriers including racism, homophobia and transphobia and an increased likelihood of experience of domestic violence among others.

These issues are further complicated as many people in these groups face additional barriers in accessing advocacy services due to a lack of computer literacy, a lack of family or carer supports, poor communication and lack of delivery of advocacy services in many locations.

Recommendation 15: *The Australian Government should adopt Recommendations 72 and 73 of the Royal Commission into Aged Care Quality and Safety.*

Recommendation 16: *People with disability from priority groups should have greater access to advocacy services and assertive outreach should be done to make them aware of their rights.*

Recommendation 17: *People with disability living in rural and remote areas should have access to communications and technology to facilitate service delivery and face-to-face services should increase their coverage.*

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[15] NDIA, 'Explore Data: Participants with Spinal Cord Injury Active Jul-Sep 2020', NDIS, https://data.ndis.gov.au/explore-data.

[16] MyAgedCare, 'Home Care Packages', Australian Government, 2021, https://www.myagedcare.gov.au/help-at-home/home-care-packages.

[17] Royal Commission into Aged Care Quality and Safety, *Final Report Volume 1: Recommendations*, Australian Government, p. 255.

5. Conclusion

Achieving genuine inclusion across Australian society will involve an array of reforms and attitudinal change, with constant consultation and co-design with people with disability. However, without an outcomes-focussed approach, in which all stakeholders are committed to achieve the vision outlined in Sections 1 and 2 for people with disability, we cannot truly call ourselves an inclusive society. The dignity of people with disability needs to be both acknowledged, respected and fulfilled through active practices and reforms. In the words of people with lived experience of disability:

'There's so many different types [of disability]. It's just a different normal' [SCIA member from NSW]

'We're just part of the community' [SCIA member from NSW]

If the Commission requires further information or has any queries about the content of this submission, please do not hesitate to contact SCIA.

Kind regards,

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