



What needs to change

A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Prepared by Advocacy for Inclusion, December 2022

About Advocacy for Inclusion

Advocacy for Inclusion incorporating People with Disabilities ACT¹ (AFI) is a leading independent organisation delivering reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

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Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work. We respect and celebrate the diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

¹ On March 24, 2021, Advocacy for Inclusion (AFI) officially merged with People with Disabilities ACT (PWDACT), a systemic advocacy organisation based in the ACT. Herein, reference to 'AFI' also acknowledges the values and philosophies of PWDACT.

Background

What needs to change

Our submission, focusing on recommendations for change, follows three years of work supporting private submissions and working with people in the ACT to support them to engage with the Disability Royal Commission. But it also follows five decades of institutional memory from the various organisations' which merged into AFI, including the former People with Disabilities ACT and who came together following the International Year of Disabled Persons in 1981.

We reflect on decades of attempts to improve the circumstances of people with disability across a range of issues in the nation's capital: work to improve the circumstances of people in large group houses following the Gallop Board of Inquiry; work to build a Disability Justice Strategy; efforts to create accessible spaces, places and services; attention to the circumstances of people with disability in disasters from the 2003 bushfires to the ongoing threat of COVID; campaigns to establish, found and then improve the NDIS; attempts to address falling employment rates across the Public and Private sectors; continuing campaigns for inclusive education and many other issues.

What binds many issues is the effort to shift from a medical to a social model of disability; responses to experiences of violence, abuse and neglect across services and systems; and an attempt to realise the intent of Australia's commitment to the United Nations Convention on the Rights of People with Disability.

Reflecting on the circumstances we have confronted across time we find that there are too many people with disability a few kilometres away from Parliament House who spend their whole lives in waves of crisis or an unravelling desperation, who can never make their budget balance or afford life's essentials; who experience lifecycle discrimination in domains from the family home to the workplace; who are living, studying and working in closed and deprived circumstances because of their disability; who can't access spaces, places and services that others use everyday; who can't get the equipment they need to be mobile, pain free or whole, whose talents are never used; and who are consistently failed in wider moments of crisis – be that in healthcare, in justice or in times of disaster or plague.

We've followed as the Royal Commission has received over 6,000 submissions and over a thousand private sessions with hundreds of hours of public hearings which have described the lives of Australians with disability living and, too often, dying under unacceptable conditions. This the most

expensive, extensive, and complex Royal Commission in Australian history, conducted during a pandemic which has provided direct insights in real time about threshold disability rights matters. Australia needs it to deliver transformative lasting change: we have one shot at this.

As the Royal Commission moves to develop recommendations for change, we urge it to recommend ambitious, far reaching and nation building changes that will reset and reboot the lives and circumstances of people with disability.

Specifically, we need to move the Australian approach to disability from perpetual planning and review to reboot, reset and reform.

We contend there has not been one calendar day since the start of this century that the circumstances of people with disability, the frameworks protecting our rights and/or disability services in one State or Territory or the Commonwealth have not been in the midst of a substantive jurisdiction wide review or inquiry. A mountain of reports, reviews and inquiries often capped by aspirational visions for change for people with disability sit in the National Library, the National Archives, in State libraries and bottom drawers.

Things have been like this for a very long time – when servicemen and women returned from the wars with injury and disability Hansard records the struggles of successive governments who over generations did not know how to support them, how to include them and what to do with them.

There are some very familiar [themes across time](#) in Australia's treatment of disabled people. It is telling that a thrust of advocacy by veterans and families following the Great War was to keep soldiers in military hospitals and out of State Government and charitable run asylums. Nearly a century later people told their stories of abuse, neglect and violence in disability institutions through a Senate Inquiry which led indirectly to the Disability Royal Commission.

This tells us something – the risk of misdirected effort, the scale of change needed and a lack of progress over a vast stretch of time by changes that chip away at the margins.

The historic opportunity now afforded to Australia through this Commission is to arrive at breakthrough recommendations for legislative change, safety net improvements, structural investments, structural changes and system wide upheavals in policy and practice that result in direct, lifelong improvements to the straightened, impoverished and narrowed lives of all disabled Australians.

About our Royal Commission work

The Royal Commission engagement project

Background

Advocacy for Inclusion was one of only two advocacy organisations in the ACT tasked with providing advocacy services for the Disability Royal Commission (DRC). Broadly, AFI's role was to:

- inform people about, and help them understand the purpose, of the Royal Commission; and
- provide support to people to participate in the Royal Commission whether by public hearings, private sessions or submissions.

Support was also provided to people with other related issues faced by engaging with the Royal Commission such as accessing services, finding housing, stopping discrimination or making complaints.

The remit was huge. It was a privilege to hold space for and listen to people share their stories – sometimes for the first time, sometimes for the hundredth. AFI helped to shape their stories into accounts the Royal Commission can use to inform their final report. We successfully undertook this work throughout a global pandemic.

Following is an outline of how AFI delivered on the DRC work, the outcomes of this work and the stories that remain untold.

Delivery

COVID presented challenges to delivering the work of the DRC. Early on, it was a barrier to promoting and informing people about the DRC. Planned face-to-face community events needed to be postponed. This then required more innovative approaches in relaying the DRC message to the community.

Various forms of media became the main way to promote the DRC widely including podcasts, social media and Easy English resources such as documents explaining the DRC's purpose and short videos.

COVID also necessitated abrupt, but essential, change in delivering DRC Individual Advocacy from face-to-face meetings to phone support. This proved challenging for some clients who prefer meetings in person. Technology barriers also meant that communication could be challenging.

However, despite these difficulties, AFI's work continued. Clients were happy to spend time speaking on the phone and working remotely on their submissions. Rapport and trust could still be established, even when not meeting in person.

When COVID protections were removed, AFI took a collaborative approach in informing the community about the DRC. Working alongside other funded bodies including ADACAS², NEDA³, WWDACT⁴, Relationships Australia and Your Story Disability Legal Support, AFI presented at DRC Roadshow events to both people with disability and service providers.

AFI, together with Your Story and ADACAS, successfully engaged with detainees at the Alexander Maconochie Centre (AMC) to provide information about the DRC and offer advocacy services. Ongoing fortnightly visits to the AMC were conducted.

Outcomes

AFI supported clients in different ways to share their experiences with the DRC, namely through private sessions and submissions – both phone and written.

In total, AFI provided support for:

- 9 private sessions
- 15 written submissions
- 2 phone submissions

Advocacy support often spanned many months, sometimes up to two years. The complexity of peoples' experiences, interwoven with the complexities and challenges of their day-to-day lives, meant that putting together submissions took time.

Following is an example of the type of support AFI provided:

A client asked AFI for support to tell their story to the DRC regarding building access issues. They use a mobility scooter when outside their home but cannot open doors when using the scooter, keeping them virtually locked inside their home every day.

² ADACAS – ACT Disability, Aged and Carer Advocacy Service.

³ NEDA – National Ethnic Disability Alliance

⁴ WWDACT – Women With Disabilities ACT

AFI worked with the client to develop their story for the DRC in the way they wanted it to be told, which included writing a submission to the DRC and making a video highlighting their concerns. Advocacy support was provided not only to tell their story to the DRC but also to liaise with the Human Rights Commission, to try and resolve their building access issues.

Advocacy support was of great value to the client, helping them to have their concerns heard and acted upon.

The untold stories

Despite consistent and valiant attempts made by AFI, there were people's voices we were unable to hear and stories we were unable to share with the DRC. The barriers were both systemic and personal but speak to the trauma, frayed and tangled lives some people with disability are forced to lead.

Encapsulating these stories can never truly do them justice but following are examples of people's experiences within closed settings:

People shared experiences of abuse, mistreatment and neglect within the mental health system. In times of crisis, places which should have offered a safe haven for treatment and recovery, became places to be feared and another source of abuse.

Support systems, which should have offered protection, guidance and treatment, became another source of distrust.

Living in group settings was meant to provide safety and independence but for some this was not their experience. Suffering abuse from other residents and then being scrutinised by staff was another form of abuse.

The Royal Commission must ensure that any recommendations made encompass all people with disability, whether hard-to-reach groups stories were told or not, to ensure no-one is left behind.

Our themes and focus

Our submission focuses on eight key areas which need to change to make a material, lasting difference in the lives of people with disability as well as some which address specific issues within the ACT where we work and operate.

1. Reforming Australia's Discrimination Laws
2. A path out of COVID for disabled people
3. Lifting disabled people out of poverty
4. Finding homes to thrive in
5. Making Inclusive Education Work
6. A right to justice
7. Making healthcare accessible
8. Delivering the promise of NDIS
9. Levelling up for the ACT

What needs to change

Reforming Australia's Discrimination Laws

Evidence that it needs to change:

Australia's Federal Disability Discrimination Act 1992 (DDA) is broken and after thirty years has been unsuccessful in achieving transformative change in the areas it was supposed to change, namely:

- Improving employment outcomes for people with disability
- Ending segregated schooling
- Ensuring people with disability could travel on public transport and on planes
- Creating a barrier free urban realm; and
- Improving access to physical and digital infrastructure.

The lack of transformational change in areas covered by discrimination law is a key underlying condition which places people with disability in the path of violence, abuse and neglect. Fewer people would be in poverty if we ended employment discrimination. Fewer people would be trapped in circumstances of violence, abuse and neglect if they weren't forced together by a lack of accessible and affordable housing. More people could find their way out of bad situations if we had accessible infrastructure.

The complaints-based nature of the legislation was always problematic. For the DDA to work, Australians with disabilities would need to be prepared to be mired in endless litigation with employers, airlines, shops, restaurants, schools and civic buildings.

Over time the power of Federal Disability Discrimination Legislation within the Australian Human Rights Commission has eroded to the point where it is wholly reliant on its mediation function. The Act creates a set of penalties which can no longer be enforced without litigants risking adverse outcomes and financial ruin in a court matter following the King vs Jetstar case.⁵

⁵ King v Jetstar Airways Pty Limited [2012] FCAFC 115, available <https://jade.io/article/270429>

Defendants usually have a generous armoury of defences - notably that accommodations will result in unjustifiable hardship. This is a nebulous, moveable concept that was arguably even further weighted against complainants as a result of the Jetstar decision.⁶

The DDA's mechanisms also appear half-hearted. The Commonwealth Disability Strategy was meant to deliver action plans across Commonwealth agencies, yet never really stepped up. Proof can be seen in steady decline of employment of people with disability in the Australian Public Service (APS).⁷

The DDA Standards Process, created as an engine for change, was slow and unambitious in delivering transport standards which exempt, of all things, school buses, and have timelines which step all the way out to 2032. Incorporating Access Standards into the Building Code took over a decade.

Access and inclusion are good sense and a right. Yet somehow the DDA manages to achieve neither of these mindsets. It creates a limbo which doesn't force change outright or have sufficient 'muscle' to allow people to accept access as a given and move beyond rules and compliance to good service.

Despite almost 1 in 5 Australians having a disability, it is telling that we achieved nothing like the foothold that family friendly spaces, environmentally safe products or the pink tourism dollar have gained in the corporate imagination.

The 21st century is placing strains on our infrastructure and capacity for access as the population ages and the NDIS provides people with freedom to participate. The DDA is simply not up to the job of getting Australia ready. We need to do better.

⁶ MacDermott, T. (2018). 'The collective dimension of federal anti-discrimination proceedings in Australia: Shifting the burden from individual litigants.' *International Journal of Discrimination and the Law* 18(1): 22-39.

⁷ See e.g., Williamson, P. (2019). '[An ableist public service? How to shift the underemployment of people with disability in the Australian Public Sector.](#)' December 3, 2019. Accessed 22 December 2022.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- That the Commonwealth Disability Discrimination Act 1992 be amended to provide the Federal Disability Discrimination Commissioner with enforcement powers
- That a National Disability Discrimination Commission be created to exercise, quality assure and enforce these powers to ensure consistent and high levels of accessibility to places, spaces, goods and services
- That a National Disability Inclusion Act be introduced requiring all Commonwealth Agencies to publish and operate Disability Access and Inclusion Plans for approval by the Commission and allowing the Commonwealth to preference private business and non-government providers who have approved Disability and Access Inclusion Plans. Further that work to align State, Territory and Local Government approaches to DAIPS be undertaken through the National Cabinet

A path out of COVID for people with disability

What needs to change:

The COVID-19 pandemic continues to impact all of us. Especially Australians with disability. We have high daily death rates, large numbers of people in hospital and fewer protections and supports. The ACT has had among the highest rates of COVID in Australia. 'Endemic' COVID is being experienced as a treadmill of infections and reinfections including among the vaccinated. There is growing and troubling evidence about the health consequences of long COVID. Large numbers are sick and there are disruptions to supply chains and service continuity. There are other disease outbreaks occurring in an immune compromised population.

As we head into the end of 2022 we are in a 'fourth wave' of COVID with worrying and unpredictable signs of new variants emerging from a mass outbreak across China. COVID is far from over – even though we want it to be.

COVID-19 and its management is a disability rights issue, consequential to [Articles 11](#) and [25](#) of Convention on the Rights of Persons with Disabilities (CRPD), and since 2020 there have been troubling gaps and delays in the formation of responses, the delivery of assistance and the availability of vaccines. In 2022, as BA4 and BA5 surge, many people with disabilities find themselves with a series of bad choices – forced to shield or risk interactions in a community which has largely dropped protections at the same time as the pandemic worsens.

In its hearings the Royal Commission has heard that the COVID-19 pandemic continues to threaten the lives, health, social interactions and enjoyment of social, civil and political rights of people with disability. There should be a program of work to address this involving disability ministers and health ministers. Governments need to be guided by precautionary public health principles and human rights principles, including CRPD Article 11, in managing the pandemic. AFI joins leaders in public health and across the disability community in questioning the current approach of 'living with COVID'.

We question whether the current trajectory of relying on vaccine only strategies, removing protections and moving towards uncontrolled transmission of COVID is sustainable given:

- the high mortality rate which falls on older people and people with disability;
- the ongoing levels of illness, debility and disease across the community resulting in workforce shortages in industries essential for the supply of goods and services;
- the prevalence of disability because of long COVID;
- the emergence of opportunistic breakout infections; and
- the disproportionate impact of policies which allow community transmission on the lives, health and freedoms of older people and people with disability.

There needs to be an honest conversation about the social, human rights, moral and economic implications of the current policy trajectory and the voices, rights and agency of disabled people need to be amplified and listened to. Relevant lessons need to be applied from other pandemics including HIV and AIDS including the agency of vulnerable populations.

We support the position of [OzSage](#) which aims for elimination of uncontrolled transmission with layered, whole of society protections addressing safe indoor air, respiratory protection and optimal vaccination – a vaccine-PLUS strategy

In the meantime, Governments have asked people with disability and immune compromised people to take personal responsibility for their own health care during the pandemic. This requires Governments to reciprocate with actions, policies and modes of delivery that enable people to minimise their risks and carry on.

We also flag urgent priorities in respect of Long COVID. This is Australia's next challenge for disability which will test the capacity, resilience and commitment of this country to rights, accessibility, support systems and safety nets for people with disability. Without the right policy settings and the right preparation at the right time there is a very real chance the bedrock supports people rely on will not survive until the end of the decade.

People with Long COVID join a list of other disabilities which are taking time to be recognised, understood and responded to. We know this is poor way of responding to disability. The experience

with Asperger's, Chronic Fatigue and ME CFS has shown that delays in understanding, recognising and treating conditions have long downstream costs.

We highlight the likely prevalence of Long COVID, the need to recognise Long COVID as a disability, the necessity of steps to reduce the prevalence of Long COVID, to support people with Long COVID with disability supports and to recover and rehabilitate. We particularly urge Governments to take lessons from other disabilities in responding early to improve quality of life and ensure service systems are sustainable. We also call for a research agenda around Long COVID, its management and its disability intersections.

There are urgent priorities for Governments to ensure that people with disabilities are supported, protected and treated with fairness and decency in pandemic circumstances.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- That all levels of Government embark on an honest conversation about the social, human rights, moral and economic implications of the current policy trajectory of trying to live with COVID and that this conversation include disabled people.
- That the Australian response to COVID draw on lessons from other pandemics and put people with disability at the centre of the planning of the response
- That the policy goals of National Cabinet should prioritise the safety of vulnerable people including disabled people via the elimination of uncontrolled transmission with layered, whole of society protections addressing safe indoor air, respiratory protection and optimal vaccination – a vaccine-PLUS strategy
- That National Cabinet invite trusted representatives to address it on the impact of COVID decisions on people at risk including aged, disabled and immunocompromised Australians, people who are unable to be safely vaccinated and those with Long COVID
- That the Commission finds that a failure to provide COVID safe spaces, places, schools and transport is discrimination against sick, older and disabled people
- That the Commission recommends the continuation of key protections including a requirement to isolate with requirements for safe indoor air and mask use
- That the Commission calls for full data transparency with detailed daily reporting and full disclosure in all at risk settings plus release of all health advice and unredacted minutes of

meetings concerning all decision making, including the removal of public health requirements by National Cabinet

- That Governments should provide funding and requirements to make public places including schools, hospitals, offices and community facilities COVID safe with safe indoor air and mask use
- That Governments should ensure payments and support systems are geared to ensure low income and casualised people are not forced back into work while sick
- That Governments commit to a COVID inclusion guarantee including a non-contact service framework, including for government agencies like Centrelink and covering rights to work and study and transact business from home along with equitable contributions from employers and public authorities to the costs of online access to home based work and study for those at risk
- That the Federal Government remove mutual obligations, especially for those who are at risk of severe disease or death from COVID while uncontrolled transmission continues
- That the Federal Government commit to access to telehealth for all Australians, including in-reach services and recovery support for NDIS participants, people living in congregate (group) settings and people living in aged care facilities
- That Governments implement practical community development work for those who are isolated, including ensuring access to peer support, guaranteed care workforce, essential medications and health care treatment
- That Governments maintain continued requirements for isolation and testing of all people working in care roles for any worker providing care to people at risk of health complications from COVID-19
- That Governments provide subsidies or full funding for good quality masks and HEPA filters for those who are most at risk
- That Health Ministers make a public commitment to ethical and non-discriminatory treatment of disabled, sick and immune compromised people in the COVID-19 pandemic and future pandemics along the lines of the Statement of Concern – COVID-19: Human rights, disability and ethical decision-making
- That the National Cabinet implement an agenda around Long COVID including work to recognise and reduce the incidence of Long COVID, a Medicare line item for Long COVID, along with clear definitions in line with the work being carried out in other countries; provide people with Long COVID impairment timely access to income and disability supports, research on the condition and its disability intersections, research and action on

early intervention. A focus should be early intervention, support and treatment and the implementation of the outcomes of the Federal Inquiry.

- That a National Memorial and one minutes silence in all Australian Parliaments should be observed to respect those who have died from COVID and to acknowledge the toll of Long COVID.

Lifting disabled people out of poverty

What needs to change:

Poverty is a driver of abuse, neglect and violence against people with disabilities. It places people in situations of harm, reduces their capacity to remove themselves from these situations and leaves them open to exploitation. Food insecurity, housing stress, transport disadvantage and pressures from utilities and other bills combined with additional costs that come with having a disability represent a form of systemic abuse and neglect in a country that can afford to do better.

Many people with disability experience poor economic outcomes, financial hardship un(der)employment, and poverty.⁸ Across Australia, there are approximately 2.1 million people with disability of working age (between 15 and 64). Of these people,

- Over half (53.4%) were in the labour force, compared with 84.1% of those without disability⁹
 - The labour force participation rate for people with disability has remained largely unchanged from 2003 (53%). In contrast, the labour force participation rate increased from 63.6% (2003) to 84.1% (2018) for people without disability.
 - Labour force participation was higher among men with disability than women (56.1% compared to 50.7%)¹⁰
 - Labour force participation declines with the severity of limitation
- The unemployment rate for people with disability has remained stable since 2015. By contrast, the unemployment rate for people without disability has decreased.
 - The unemployment rate is 10.3% of people with any type of disability (more than twice the rate for people without disability, 4.6%)¹¹

⁸ Meyer, B.D. and Mok, W.K., (2019). "Disability, earnings, income and consumption." *Journal of Public Economics* 171: pp. 51-69. See also Palmer, M., (2011). "Disability and poverty: A conceptual review." *Journal of Disability Policy Studies* 21(4), pp.210-218.

⁹ Australian Bureau of Statistics (2019) [Disability, Ageing and Carers, Australia: Summary of Findings, 2018](#). Catalogue number 4430.0. ABS: Canberra, Australia. Accessed 25 August 2022.

¹⁰ Ibid.

¹¹ Australian Institute of Health and Welfare (2022) [People with disability in Australia 2022](#) (cat. no. DIS 72). AIHW: Australian Government, p. 338. Accessed 25 August 2022.

- Constrained or intermittent access to paid work means people with disability face a higher risk of poverty.¹² In addition, people with disability face a greater risk of *persistent* poverty than the general population, over both a four-year (22%) and ten-year time frames (24.5%)¹³
 - Poverty is more likely to be a persistent rather than temporary phenomenon for people with disability
- Across Australia, more than half (56%) of people with disability rely on government pension or allowance as their main source of income.¹⁴ In addition, of people with disability aged 15-64, 38% with disability have a low level of personal income (\$383 or below per week)¹⁵
- In the ACT, 62.5% of people with disability were working full- or part-time.¹⁶
 - However, only one third of people with disability (33.3%) identify wages or salary as a main source of personal income¹⁷
 - An additional third (30.2%) rely on government pension or allowance
 - This increases to 57% of people with profound or severe core activity limitation¹⁸
- In 2018, the median gross personal income of people with disability was estimated as \$700 per week in the ACT, nearly half that of people with no reported disability (\$1343).¹⁹
- People with disability were more likely to live in households with a lower equivalised gross household income. Among those whose household income was known in the ACT:
 - 30.8% lived in a household in the lowest two quintiles, approximately three times that of people without disability (10.4%)²⁰
- In terms of income support, approximately 764,000 people aged 16 and over receive the Disability Support Pension across Australia²¹
 - In September 2022, there were 8697 DSP (Disability Support Pension) payments in the ACT

¹² Davidson, P., Bradbury, B., Wong, M. (2020). [Poverty in Australia 2020: Part 2, Who is affected?](#) ACOSS/UNSW Poverty and Inequality Partnership Report, No. 4. ACOSS: Sydney, p. 15

¹³ Vera-Toscano, E., Wilkins, R. (2022). [The Dynamics of Income Poverty in Australia: Evidence from the HILDA Survey, 2001 to 2019](#). Melbourne Institute: Applied Economic & Social Research, The University of Melbourne, p. 38.

¹⁴ Australian Institute of Health and Welfare (2022) [People with disability in Australia 2022](#), p. 360.

¹⁵ *Ibid.*, p. 364.

¹⁶ Australian Bureau of Statistics (2019) [Disability Ageing and Carers, Australia: Australian Capital Territory, 2018](#). ABS: Canberra, Australia, Table 8.3. Accessed 25 August 2022.

¹⁷ *Ibid.*, Table 7.3.

¹⁸ *Ibid.*

¹⁹ *Ibid.*, Table 7.1

²⁰ *Ibid.*

²¹ Department of Social Services (2022). [DSS Payment Demographic Data – September 2022](#). Australian Government, Canberra.

- The maximum rate of the DSP (including pension and energy supplements) is \$1026.50²²
- Consider a single DSP recipient in the ACT whose weekly income matches the gross median weekly income for people with disability (\$700)
 - Per fortnight this equates to an income of \$1400
 - If receiving DSP, this means an additional \$416.50 once adjusted for income.²³ Let's also include Commonwealth Rent Assistance (\$151.60)
 - Overall fortnightly income of \$1968.1, or approximately \$4264.20 per month
 - In August 2022, the weekly median rent for all properties in the ACT is \$650 per week, or \$2816 per month.
 - Current weekly grocery expenses are approximately \$123 per week for a single person
 - Utility (gas, water, electricity) expenditures are estimated at \$190-230 per month, with internet at approximately \$75 per month
- This means that, after rent, groceries, and basic utilities, a single DSP recipient earning the median weekly income would be left with \$630.21 per month, or \$20.71 per day, to spend on necessary health care, transport, and all other expenses.
- These calculations are unlikely to represent lived experience. For example, in June 2022, only 4.8% of DSP recipients across Australia reported earnings above \$250 per fortnight. In addition, only 6.8% of DSP recipients across Australia reported any earnings from income in the last fortnight.²⁴
 - A person with disability relying solely on the DSP (and Commonwealth Rent Assistance) would need to source an additional \$263 per month just to pay the median rent in the ACT.
 - While 76.5% of DSP recipients are non-homeowners, only 20% of DSP recipients receive Commonwealth Rent Assistance
- This indicates that people with disability require financial aid from others, mostly friends, family or supportive organisations just to achieve a level of equality.

What it costs to live in Canberra for a fortnight with a disability

²² Department of Social Services (2022). [Indexation Rates September 2022](#). Canberra: Australian Government. Accessed 25 August 2022.

²³ A single person aged over 21 years may earn up to \$180 per fortnight and receive the full pension. However, any earnings above \$180 per fortnight will reduce their pension by 50 cents for each dollar above \$180. Earning \$2115 or above in a fortnight will reduce their pension to \$0.

²⁴ Department of Social Services (2022). [DSS Payment Demographic Data – June 2022](#).

AFI have prepared an estimated model household Budget for a fortnight in Canberra (assumes person in rented accommodation, single, unable to drive with additional cost of disability needs for food prep, transport, heating)

Expenses	Amount (\$)
Rent	1300
Basic utilities (electricity, gas, water)	97.38
Mobile phone and home internet	13.85 + 34.62
Taxi's	246.00
Groceries + cost of disability loading	246.00 + 8.61
Personal care and pharma + cost of disability loading	54.25 + 1.90
Healthcare/pharma/dental/unanticipated event	240.00
Total Due (not incl. unanticipated event)	2002.61
Total Income (DSP + CRA + Supplements)	1178.1
Total Left Over	-\$824.51
<p><i>Commentary on sources and some assumptions</i></p> <p>Rent: \$650 per week corresponds to SQM Research Weekly Rents Index which represents the combined median weekly rent for all houses and all units in Canberra for the week 28 September 2022</p> <p>Basic utilities: figure taken from Canberra.com.au – the available cost of living material is distributed by the Australian Capital Territory Government as a general reference source. The figures also correspond with prices in Finder's Consumer Sentiment Tracker.</p> <p>Phone and internet: the average phone bill estimate represents a mid-point of \$30 p/m (\$28 for prepaid and \$33 for post-paid) (Canstar Blue, 2022). Finder (2022) states the average broad band user spends \$75 p/m on their internet plan</p> <p>Taxi's: 13% of DSP recipients live in postcode 2615. The estimated fare from this postcode to Canberra Hospital is \$70 one way, to the closest supermarket is \$15 one way, and to the city centre \$55 one way. Assuming 2 x return supermarket trips, 1 x return hospital and 2 x return city centre trips per fortnight (and taking ACT Taxi Subsidy Scheme into account). This estimate is also conservative as it does not take into account extra costs associated with Wheelchair Accessible Vehicles. For a similar estimate, see ACTCOSS's (2016) ACT Cost of Living Report: Transport, p. 56.</p> <p>Groceries + cost of disability loading: Canstar Blue research found that \$123 represents the average weekly grocery bill for a low-income household, as of July 2022. The disability loading represents the extra, hidden costs of disability. Comparing different survey responses, Frisch (2001) states that it is reasonable to anticipate additional costs between 2 and 5 percent for groceries. A conservative mid-point estimate (3.5%) was used here.</p> <p>Personal care and pharma + cost of disability loading: This figure corresponds to Hughes and Purdey's (1999) Survey results regarding median annual costs for people with disability. It has been updated to reflect 2022 values. The cost of disability loading refers to Frisch's (2001) estimate of 2-5%. A conservative mid-point estimate (3.5%) was used here.</p> <p>Healthcare/pharma/dental/unanticipated event: Household whitegood repair estimates start at \$195 in the main suburbs of Canberra. Conservative one-off estimate here equates to an appliance repair which requires additional part (+\$45.00). This cost is difficult to calculate as it could cover a large range. For example, emergency dental such as root canal can cost up to \$1100; a dental extraction may be up to \$600.</p> <p>Note: Approximately 40% of DSP recipients could not raise \$2000 within a week.</p>	

Recommendations:

That the final report of the Royal Commission recommend that the Federal Government commit to improved federal income support for people with disability, with particular attention on the following issues:

- Introduce a Disability and Illness Supplement of at least \$50 a week (for single people) that recognises the additional costs they face because of disability or illness. This supplement should be available to people with disability, as well as people with an illness that prevents them from undertaking full-time paid work.
- Remove 'fully' from 'diagnosed, treated and stabilised' assessment criteria in DSP to avoid people being denied claims when their treatment is ongoing.
- Return Treating Doctor Reports so people's doctors have a clear understanding of the Impairment Tables relevant to their patient's DSP claim and can provide a report addressing those tables, together with appropriate evidence.
- Abolish the Program of Support requirement. This requirement has only served to deny or delay access to DSP for people who need it and has failed to improve employment outcomes for people with disability.
- Grant DSP to people who do not meet the 20-point requirement under one impairment table but score at least 20 points across tables. The eligibility criteria must recognise someone's incapacity if they have multiple disabilities or illnesses.
- Simplify eligibility requirements
- Reducing claim times
- Remove the partner income test, as this can cause financial dependence in romantic relationships and increase people with disability (particularly women's) vulnerability to domestic violence, including financial abuse
- Adjustments to DSP process and requirements focus on expanding the system to better support episodic conditions, mental illness, or psychosocial disability and multiple or chronic conditions to extend support to increase capacity and sustain well-being
- There should be an end to shifting people onto the JobSeeker payment and this payment should be raised to at least \$70 a day so that everyone has enough to cover the basics while going through tough times.
- Organise the DSP in ways that are more conducive to enable economic participation for people with disabilities who are able to find work including enabling people with disability to retain DSP for a period after entering employment for up to 12 months with an option to return to the payment without needing to reapply for a grace period

Providing homes for people with disability to thrive in

The case for change:

Compared to people without disability, people with disability are more likely to face barriers to secure, accessible and affordable housing. Moreover, over one quarter (29%) of social housing tenants are people with disability, and thus they are also likely to experience a range of widely reported issues associated with ACT Housing.²⁵

Through our advocacy, we have heard Canberran's with disability express the following concerns about housing:

- People with disability want a place of their own, which is not dependent on Supported Disability Accommodation funding under the NDIS. Current housing is not designed to support disability or ageing in place, making it difficult and frustrating to live independently with choice and control over their lives.²⁶
- Lack of housing diversity is an issue when people with disability want to remain and live independently in the community close to public transport, centre complexes and support services. Most leases are short-term, which can cause people with disabilities anxiety as they may be required to move more frequently.
- Social isolation is a significant issue for people with disabilities and mental health living alone. Women with disability worry about security and feel safer living near central locations.
- High-density residential areas, including apartment complexes, are prone to being used as the default option for some people with disability, including those involved in the justice system and mental health system. This can be experienced as ghettoization and result in fraying communities with limited pools of social capital.
- Group homes and large cluster housing remains a feature of housing for people with disability in the ACT. Yet this form of housing is inconsistent with CRPD ([article 19](#)), erodes independence and capacity, limits choice, often breaks down and leaves people at risk of violence, rape, abuse and homelessness.

²⁵ ACT Housing Strategy, p 32.

²⁶ See also, Aitken, Z., Baker, E., Badland, H., Mason, K., Bentley, R., Beer, A. and Kavanagh, A.M., 2019. Precariously placed: housing affordability, quality and satisfaction of Australians with disabilities. *Disability & Society*, 34(1), pp.121-142.

- Public and social housing remains the main viable form for people with disability. There are long waiting lists for public housing (375 days for priority housing and over 7 years for a standard wait), a lack of social housing and unaffordable private rental housing. People with disability face a double disadvantage in Canberra – a lack of affordable housing and a lack of appropriate built form. These issues are amplified by low rates of Disability Support Pension and JobSeeker, and Canberra’s high-cost private rental market.²⁷

We need concerted action on housing across all markets via the ACT Disability Strategy and this is supported by the [Productivity Commission’s Study Report on the Review of the NHHA](#) which has made a recommendation that there be a targeted action plan on housing under Australia’s Disability Strategy, to look at improving the availability of affordable and accessible housing for people with disability.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- State and Territory Planning systems should prioritise the development and construction of affordable and accessible housing at scale within Greenfields and Brownfields development across Australia, including a focus on housing which is also affordable within the rental market for people in the bottom income quintiles
- All Governments should progress requirements to ensure all new housing complies with minimum accessibility standards for residential housing and apartments in the National Construction Code 2022 based on the [Liveable Housing Design Guidelines silver standards](#). Work should be undertaken to encourage more housing built to the Gold Standard.
- Governments should maintain a focus on the supply of public housing and ensuring this is available, accessible and well maintained with proximity to transport, commercial centres and services. Public Housing serves people with complex lives, is a provider of last resort and part of the safety net. In the absence of private rentals, it remains a key option for many people with disability.
- Governments should support the growth of not-for-profit, non-congregate community housing around Australia with accessible built form as a companion piece to public housing investment.

²⁷ See also, Soldatic, K, Bowman, D, Mupanemunda, M, & McGee, P. (2021). [Dead ends: how our social security system is failing people with partial capacity to work](#). Brotherhood of St. Laurence, Melbourne, p. 10-12.

- Government should work with the development industry including architects, designers, town planners, real estate developers and property owners to create more accessible private rental utilising a combination of incentives, tax levers, regulation and education. A starting point should be a shared realisation that this is a significant market failure.

Making Inclusive Education Work

The case for change:

Access to quality education is universally recognised as a key pathway to the achievement of social, economic, political and human rights, especially for children.

It is acknowledged around the world that access to education is intrinsically linked to key developmental indicators and milestones from child development to employment. Access to education is formative, underpins other rights and has impacts across the life course.

From the Shut Out Report in 2010 to the hearings of the Disability Royal Commission to the Shaddock review in the ACT, we know that too many students with disability experience barriers to education, poor completion, poor attainment and harm within education settings. Social inclusion is linked to education. People with disabilities are less likely to be employed, have lower incomes, have lower levels of tertiary entry and are less likely to participate in most forms of human interaction.

Discussions about education for students with disabilities are often poorly framed, with the starting point being a series of bad choices between segregated settings and poorly resourced, inadequate settings. There are too few examples of well resourced, universally designed education offerings in mainstream settings – discussions about choice are impossible in the absence of these.

AFI's overarching priority regarding education is to advocate for improvements to the ACT's education system, which ensure people with disability have access to quality, inclusive education, free from violence, abuse and neglect. Without an adequate inclusive education system, the rights of people with disability to education remains nominal, and they are denied meaningful opportunities for social and economic inclusion.

The ACT is a Human Rights jurisdiction bound by the UN Convention on the Rights of Persons with Disabilities (CRPD) ratified by the Australian government in 2008. [Article 24](#) of the CRPD recognises “the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life-long learning.” The ACT Government has also signed up to

Australia’s Disability Strategy 2021–2031 (the National Strategy), which prioritised building “capability in the delivery of inclusive education to improve educational outcomes for school students with disability.”

While there is work to be done, we know that the ACT Government has laid some important foundation stones in the journey to inclusive education. It has acknowledged instances of poor inclusive practice in schools through the 2015 Schools for All report²⁸ and the Government response²⁹ and laid out a roadmap for continued focus and investment via The Future of Education Strategy. In 2022 it is embarked on an Inclusive Education Strategy.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

That jurisdictions identify a goal and target for a complete transition to inclusive schooling including

- Implementing the Australian Coalition for Inclusive Education’s Roadmap for achieving inclusive education in Australia (2021).
- Implementing universal design principles across all aspects of ACT public schools and create incentives for non-government schools to implement universal design principles.
- Increasing the disability loading funding for students in mainstream schools to ensure they have access to all necessary support, including one-on-one academic, social and behavioural supports. As part of this, provide funding for one full-time position per school to coordinate the administrative workload of data collection and disability support funding applications.
- Clarify roles and responsibilities with the National Disability Insurance Agency (NDIA) for in-school supports, to ensure that students with disability are not going without necessary supports.

²⁸Shaddock, A., Packer, S., and Roy, A. (2015). [Schools for All: Children and Young People](#). Report of the Expert Panel on Students with Complex Needs and Challenging Behaviour, p. 93.

²⁹ ACT Education Directorate, Catholic Education Office, Association of Independent Schools (2016) [Schools for All Program: Responding to the needs of children and young people in Canberra Schools](#).

A right to justice

The case for change:

People with disability are over-represented at all stages of the criminal justice system – as witnesses, victims, offenders, defendants, and prisoners.³⁰

Despite forming only 18 per cent of the general population, people with disability make up at least 29 per cent of Australia’s prison population. This is a conservative estimate. Additional qualitative and case studies report a figure closer to 50 per cent.³¹

Such over-representation in the criminal justice system reflects the systematic failure to provide appropriate services and supports to people with disability. Many people with disabilities inside prisons across Australia have spent their lives being ‘managed’ in criminal justice settings, rather than being supported in the community.³²

People with disability face a wide range of systematic and structural barriers to accessing justice. Inadequate disability support is linked to cycles of offending and reincarceration for people with disability.³³ Limited access to communication support and other necessary adjustments can hinder a person with disability’s capacity to participate in health, education, employment, rehabilitation, and pre-release programs.³⁴

A study conducted in NSW revealed a rate of recidivism for prisoners with intellectual disability 2.4 times higher for prisoners without prior conviction and 1.48 times higher for prisoners who had previously been convicted.³⁵ These results mirror those found in Victoria as well.

³⁰ McCausland, R., and Baldry, E. (2017). ‘I feel like I failed him by ringing the police’: Criminalising disability in Australia. *Punishment and Society* 19(3): pp. 290-309. See also, Mackay, A. (2015). [‘Human Rights Protections for People with Mental Health and Cognitive Disability in Prisons.’](#) *Psychiatry, Psychology and Law* 22(6): pp. 842-868.

³¹ Dowse et al., (2021). [Police responses to people with disability.](#) Research report. Sydney, University of New South Wales, p. 4.

³² Sotiri, M., and Russell, M. (2020). [Locked out: The implementation of the NDIS for people in prison in NSW: 2016-2019.](#) NSW, Community Restorative Centre, p. 12

³³ Doyle, C. et al. (2022). [‘There’s not just a gap, there’s a chasm’: The boundaries between Australian disability services and prisons.](#) Public Service Research Group, UNSW Canberra.

³⁴ Yates, S. et al. (2022). [‘Where specialist and mainstream service systems collide: The National Disability Insurance Scheme in prisons.’](#) *Australian Journal of Public Administration* (early view).

³⁵ Riches, V., Parmenter, T., Wiese, M., and Stancliffe, R. (2006). ‘Intellectual disability and mental illness in the NSW criminal justice system.’ *International Journal of Law and Psychiatry* 29: pp. 386-396.

Without appropriate support and adjustments, the legal system remains largely inaccessible and can produce unjust and costly outcomes.

- A cost benefit analysis compared the actual outcome of a man with intellectual disability charged with indecent assault who received the necessary support with two typical pathways for accused persons whose fitness to stand trial is questioned.
- The actual outcome cost \$5034. The latter two pathways (unfitness to plead proceedings and entering a guilty plea to avoid such proceedings) cost at most \$393,756 and \$133,412, respectively.³⁶

Despite the importance and prevalence of these issues, there is limited data and research on the intersection of disability and correctional services. This is exacerbated by a reliance on detainees self-identifying and disclosing their disability upon entry.

- In the ACT, only 14 percent of respondent detainees reported ever being told they had an intellectual disability. Upon subsequent screening, 1 in 4 respondents screened positive.³⁷
- Common undiagnosed disabilities include foetal alcohol spectrum disorders, borderline intellectual disability and acquired brain injury. The latter are estimated to affect 25-30 per cent and 40-90 per cent of Australian prisoners respectively.³⁸

As of June 2022, there were 383 prisoners in the ACT's Alexander Maconochie Centre (AMC). A 2022 Review found that 31% of AMC's detainees identified as having a disability.³⁹

However, consistent and accurate public data regarding the number of people with disability is difficult to ascertain. This is due both to the point-in-time prison population snapshots taken as well as the reliance on disability self-reporting.

³⁶ McCausland, R., Reeve, R., Gooding, P., and Baldry, E. (2017). [Cost Benefit Analysis of Support Workers in Legal Services for People with Cognitive Disability](#). Unfitness to Plead Project. Melbourne Social Equity Institute, University of Melbourne, p. 3.

³⁷ Young, J., van Dooren, K., Borschmann, R., and Kinner, S. (2017). [ACT Detainee Health and Wellbeing Survey 2016: Summary results](#). Canberra, ACT Government, p. 31. p. 31

³⁸ Australian Human Rights Commission (2020). ['People with Disability and the Criminal Justice System.'](#) Submission to the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability, p. 30.

³⁹ ACT Inspector of Correctional Services (2022). [Healthy Prison Review of the Alexander Maconochie Centre 2022](#). Canberra.

In 2020, when asked how many inmates in the AMC have a disability, the Minister for Corrections responded: “the information sought is not in an easily retrievable form,” and collecting such information “would require a considerable diversion of resources.”⁴⁰

ACT crime rates are going down, but incarceration levels continue to rise. We know that diversion away from the criminal justice system, or appropriate diversion within it, can significantly improve the lives of people with disabilities by better respecting their human rights.⁴¹ It is also clear that prisons and imprisonment are expensive and detrimental. The ACT justice system currently costs \$270 million annually with costs expected to increase to \$337 million by 2025.

- It costs upwards of \$380 per adult prisoner per day in the ACT.⁴²
- The cost per young person per day subject to detention-based supervision in the ACT is \$3464.06.⁴³ This is upwards of \$1 million per young person per year.
- Disinvesting from criminal justice agencies and detention and reinvesting such funds into community support programs, social services, education, employment, cultural and social outcomes is one approach that could reduce criminal justice involvement.⁴⁴

The offences for which people with cognitive disability are imprisoned are overwhelmingly in the lowest severity categories, including low level non-violent offences, traffic offences, theft and breach of orders.⁴⁵ The importance of early intervention, diversion programs and appropriate adjustments and support cannot be overstated – especially when it comes to youth justice. This is critical as criminalisation often begins when young people with complex support needs are processed by the police.⁴⁶

⁴⁰ Minister for Corrections, [Legislative Assembly for the ACT: 2020 Week 01 Hansard](#) (Thursday 3 December), p. 244.

⁴¹ McCausland, R., Baldry, E., Johnson, S., and Cohen, A. (2013). [People with mental health disorders and cognitive impairment in the criminal justice system: Cost-benefit analysis of early support and diversion](#). Australian Human Rights Commission.

⁴² Report on Government Services (2022). [Part C – Justice. Section 8: Corrective Services](#). Canberra, Productivity Commission, Table 8A.19.

⁴³ Report on Government Services (2021). [Part F – Community services. Section 17: Youth justice services](#). Canberra, Productivity Commission, Table 17A.19-20.

⁴⁴ Baldry, E. (2014). ‘Disability at the Margins: The Limits of the Law.’ *Griffith Law Review* 23(3): pp. 370-388.

⁴⁵ Simpson, J. (2014). [‘Participants or just policed?’](#) Guide to the role of the NDIS – people with intellectual disability who have contact with the criminal justice system. Sydney, New South Wales Council for Intellectual Disability, p. 28.

⁴⁶ Baldry, E., Briggs, D., Goldson, B., and Russell, S. (2018). ‘Cruel and unusual punishment’: an interjurisdictional study of the criminalisation of young people with complex support needs. *Journal of Youth Studies* 21(5): pp. 636-65.

A primary prevention and early intervention pilot program within the Victorian police has revealed promising results in terms of diversion, support, and a reduction in offending.⁴⁷ Overall, avoidance of homelessness, home supports, case management, community support, and diversion programs can disrupt the pathways that put young people into contact with the criminal justice system, avoiding many of the long-term social and economic costs of detention. A recent review in the ACT offers a cost-effective comprehensive alternative response including crisis management, early intervention police programs, and different accommodation models.⁴⁸

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- There should be a National Disability Justice Strategy under Australia’s Disability Strategy with Strategies in place in all States and Territories
- A focus of investment should shift towards investments which reduce the number of people with disability entering corrections through diversion pathways for people with disability engaged with law enforcement.
- A universal design approach should be adopted in community corrections and within places of detention. All detention infrastructure, rehabilitation programs and services should meet high standards of accessibility
- Detainees within corrective facilities should have a right of access to disability advocacy to support their welfare within these places and their transition from them. This should be one focus within the National Disability Advocacy Framework and should be accompanied by resources
- Urgent attention should be given to ensure standardised work is undertaken to obtain timely and accurate information about the disability status of detainees in places of correction – this should be a priority piece of work for Justice Ministers
- Disability focussed governance, accountability and compliance goals should be included in the performance agreements and reporting requirements for senior staff in places of detention.

⁴⁷ Luebbbers, S., Pichler, A., Fullam, R., and Ogloff, J. (2019). [Embedded Youth Outreach Program Evaluation, Final Report](#). Prepared for Victoria Police by the Centre for Forensic Behavioural Science, Swinburne University of Technology, Melbourne.

⁴⁸ McArthur, M., Suomi, A., and Kendall, B. (2021). [Review of the service system and implementation requirements for raising the minimum age of criminal responsibility in the Australian Capital Territory](#). Canberra, Australian National University, pp. 63-72. See also Appendix 3.

- Work should be undertaken to improve cultural readiness and disability confidence within the justice system – police, corrections officers, public prosecutors and within the legal fraternity
- Work should be undertaken to understand and respond to hate speech and hate crime against people with disability in Australia
- Work should be undertaken to understand and respond to the promotion and commission of disability motivated filicide, senicide, involuntary euthanasia and other forms of killing of people with disabilities including inside families.

Making healthcare accessible

The case for change

Access to health care is a human right covered by the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12; the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW); the Convention on the Rights of the Child (CRC); and the Convention on the Rights of Persons With Disabilities (CRPD).⁴⁹

The World Health Organisation (WHO) recognises health as a human right, which creates a legal obligation on states to ensure access to timely, acceptable, and affordable health care of appropriate quality. It also establishes an obligation to provide the underlying determinants of health, such as safe and potable water, sanitation, food, housing, health-related information and education, and gender equality.⁵⁰

There is a range of evidence, brought together in the evidence that informed the National Disability Strategy (NDS) and the Shut Out report,⁵¹ that people with disability experience poor general health and co-morbidity outcomes at a greater rate than the general population, including for reasons unrelated to a core underlying condition. Good health status underpins a decent life and poor health affects all areas of life.

Lack of access to health services can mean people become ill, are unable to participate in and contribute to the community, and are exposed to adverse experiences including restraint and abuse. It can also complicate – and be complicated by – a person’s underlying disability, for instance, through diagnostic overshadowing.

AFI are guided by the ACTCOSS *Imagining Better* report and suite of work in our commentary of health system issues in the ACT.⁵² This report shows that people with disability self-report poor health outcomes arising from a mixture of:

- Economic disadvantage
- Diagnostic overshadowing (where a person’s disability is treated as the problem rather than a person’s presenting medical condition)⁵³

⁴⁹ Australian Human Rights Commission, [Right to health](#), Australian Human Rights Commission.

⁵⁰ World Health Organisation (2017) [Human rights and health](#), World Health Organisation.

⁵¹ National People with Disabilities and Carers Council (2009). [Shut Out: The Experience of People with Disabilities and their Families in Australia](#), Australian Government.

⁵² ACTCOSS (2019). [Imagining Better: Reflections on access, choice and control in ACT health services for people with disability](#). Report of the Appreciative Inquiry Project supported by the ACT Office for Disability. ACT: Canberra.

⁵³ Diagnostic overshadowing is the attribution of a person’s symptoms to their mental condition, when such symptoms actually suggest a comorbid condition. The term was first used to describe the underdiagnosis of

- Poor attitudes, including a lack of a social model for responding to disability or health within clinical settings
- Inappropriate digital and physical infrastructure leading to access barriers and poor communications
- Service gaps including a lack of tailored services to help manage diagnostic conditions (i.e. to understand, treat and manage the primary and secondary health impacts of different kinds of disabilities).

Recommendations:

That the final report of the Royal Commission include the following recommendations:

That work should be undertaken between Health and Disability Ministers to develop a National Disability Health Strategy within Australia’s Disability Strategy with funded Strategies at a State and Territory level. These should be developed in a consultative way with Disabled Peoples Organisations and Disability Representative Organisations. Some early areas of focus should be:

- Addressing cost issues through dedicated low-cost services, including a once-a-year free extended consultation, and information access
- Establishing specialist centres of excellence for diagnostic disabilities with wrap around services
- Auditing and improving health infrastructure to make it more fit for purpose for people with disability
- Improving workforce readiness by providing training, disability confidence and skills development work led by people with disability to the health workforce including practitioners, health and wellness services outside the formal system and, specifically, to doctors doing Centrelink assessments⁵⁴
- Strengthening the employment of people with disability in State and Territory Health systems and resourcing people with disability to develop and deliver training to doctors, nurses, ancillary staff and other wellness practitioners in the social model of disability
- Training to increase knowledge about diagnostic overshadowing and reduce its incidence.

mental illness in people with intellectual disability. In recent years, the term has also been used when physical illnesses are overlooked in people with mental illness. Read more at: S Jones, L Howard and G Thornicroft (2018) [“Diagnostic overshadowing”: worse physical health care for people with mental illness](#), *Acta Psychiatrica Scandinavica* 118, pp. 169-171.

⁵⁴ This could include use of the “Medicopoly” device developed by ACTCOSS and PWD ACT as an awareness raising and service development tool.

Delivering the promise of NDIS

The case for change:

The National Disability Insurance Scheme is a vital national reform for Australia that seeks to improve the dignity, independence and lives of all Australians with disability. The Scheme is helping hundreds of thousands of people live better lives including over 9,000 people here in the ACT. It's achievements, in difficult circumstances for reform, should not be diminished.

However, the Scheme has drifted away from the rights-based scheme delivering true choice and control to people with disability. An urgent program of reform to issues in the scheme must begin. Focus areas should include better engagement with people with disability on the ground and at a State and Territory level, cultural change to open up and improve the National Disability Insurance Agency; greater stewardship and understanding of the disability service provider markets, better planning; more disability confidence and knowledge; and greater application of common sense and judgement, instead of complex litigation and the creation of administrative burden.

Opening up the NDIS

The NDIA should open itself to the community it serves. It should foster innovation, partnerships, co-design and responsible risk taking and flexibility. Staff could be embedded (and cross embedded) in disability organisations, clients and disability advocates invited to come in and share, informal connections and gatherings should be encouraged and unnecessary walls between the sector and the agency should come down.

Staff development activities within the NDIA could focus on enhancing and building understandings of the effects of customer interactions on people with disabilities. A model could be the service improvement work undertaken in the early 2000's within Centrelink under the leadership of Sue Vardon including value creation workshops and exposure of staff to intensive client experience feedback.

There has been some improvement and greater openness, and the forums which foster this should be continued. In addition, all staff should be exposed to reflective feedback from clients to understand how interactions impact them – sessions could be designed for staff to observe clients providing candid feedback about what it was like to engage with the NDIA.

Ambitious community engagement projects that allow NDIS participants and the public to be part of the process of driving cultural change should be resumed. A very good example from the early days of the scheme was the NDIS Citizens Jury Scorecard project from 2014/15 which was the winner of a global IAP2 Award in 2015.

- What we've seen: Over time we have observed a deteriorating level of trust, collaboration, understanding and engagement between the NDIA and disability organisations as well as people on the ground.
- Early initiatives which allowed for co-design and innovation with the sector, such as the NDIS Citizens Jury or the Voice Assistant project have fallen away.

Recognising and reducing administrative burdens

The NDIS needs to reduce the administrative burden on people with disability across every aspect of applying for access, planning, review and engagement. Support coordination is one way to reduce administrative burdens on individuals. NDIS participants should be granted funding for a support coordinator in their first plan, unless they choose to opt-out.

What we've seen:

- We have seen participants being required to submit the same documents over and over again, unnecessary hoops for receiving support coordination and requirements for reports for small cost items.
- AFI has worked with adult people with disability whose families are unable to maintain full-time employment, due to the extensive administrative requirements of NDIS access applications and the planning process. In one instance, a mother reported that she no longer worked Mondays because that was her day for 'NDIS work'.
- AFI has witnessed instances in which participants are not granted support coordination, despite requesting or requiring it. In one situation, a client who did not have support-coordination was unable to access most of their supports for six months, due to the lack of support regarding their difficulties in self-management. This caused angst and difficulty in their subsequent plan review, as they were required to prove why they didn't access all their funds.
- In another situation, a client did not know how to begin organising supports in their first plan, and they were unaware that support coordinators could be funded. Despite them asking for assistance, their Local Area Coordinator (LAC) did not show them how to organise supports for the first few months of their plan.

- We have also worked with a woman with disability who had a child with disability. The mother reported that she did not apply to the NDIS because she “didn’t have time”.

High quality assurance:

The NDIA needs to take steps to improve the quality of document management, handovers between staff and other quality assurance procedures.

- What we’ve seen: There has been a small but regular stream of issues around the management of information and documents with our clients. AFI has interacted with clients where it appears the NDIA has lost participant’s documentation or where there have been errors in documents (wrong names, wrong conditions and other basic details incorrect).

Greater stewardship of the disability services market

The NDIA needs to put more energy and time into understanding the disability services market, identifying critical gaps in that market and where necessary undertaking industry development.

- What we’ve seen: In some cases people have money to spend and disability services needs but the market can’t meet them. Examples in our ACT market include customized equipment fabrication, parenting classes for adults with an intellectual disability. The provider lists operated by the NDIA and by support coordinators often bear little resemblance to the services which are actually available. Special care, consideration and investment, where necessary, should be offered to continue small, bespoke but vital services which meet a critical need in a thin market. For instance there is only one provider of disabled driver modifications in the whole of the ACT.

Greater engagement and knowledge of State and Territory Disability sectors

The national nature of the NDIA as well as headquartering in Geelong have made it hard for State and Territory based advocates to problem solve with the agency, to understand who is in charge and to build rapport. Welcome initiatives like the NDIA monthly briefings are focused on information sharing.

While the NDIS is national, Australia is still a Federation – public services like justice, education and health remain organised on State and Territory lines. Markets which serve NDIS clients contain providers and provider networks which exist solely within that State or Territory.

The NDIS needs to have some decision makers and consultative mechanisms in place at a State and Territory level. There would be value in regular grassroots advisory committee groups and the relevant NDIA State or Territory managers engaging with groups of peaks – like the Disability and Carers Policy Group in the ACT.

- What we've seen: Over time it has become clear there is mixed local market knowledge from staff at the NDIA and sometimes with Feros who don't have a good grasp of thin market issues in our region. Sometimes clients are referred to services that are full, don't provide services in the ACT or for service types that aren't offered here.

Recently the NDIA's engagement with AFI has improved with monthly catchups with advocate and policy team working through a 'traffic light' register of issues. This could be a good engagement model for other jurisdictions.

An NDIA more disability aware, confident and grounded in disability issues

The NDIA would benefit from diversifying its staff to include more people with disability, and more people with broader experiences in the disability sector including people grounded in rights-based work. The NDIS could also explore other ways of coworking and collaborating with disabled people and our organisations – embedded staff, shared projects, secondments and other mechanisms.

The NDIA needs a culture of learning about disability, its impacts and the nature of impairments. Targeted efforts must be made to increase the culture and safety of the NDIA for staff with disability. In turn, this will help attract more staff members with disability.

- What we've seen: Sometimes decisions reflect a poor knowledge of the impacts of particular disabilities on a person's need for supports – for instance accessing transport or health services. Sometimes comments about disability in planning conversations have a medical, rather than a social model approach.

Towards transparent, consistent and inclusive decision-making

Participants are much more likely to feel satisfied with a plan that they have had meaningful input into. The planning process must be much more collaborative, such that the participant should be presented with a draft NDIS plan before the final version and they should be given a funding breakdown.

Even where the funds can be used flexibly, the participant should be informed how and why the specific amount of funding has been allocated. In instances involving simple additions or alterations, the participant could 'request to add support to plan'; as opposed to applying for internal review. This would encourage the collaborative production of an NDIS plan, including more dialogue regarding the reasons for a support's inclusion or exclusion. Moreover, it will allow for small changes to plans without applicant's having to engage in the internal review process. If the applicant remains unhappy with the plan after this dialogue, they can still lodge a request for internal review.

The NDIA could provide clearer pathways for people with fluctuating conditions, such as psychosocial conditions. This may include distinct rules for the application of section 24 to psychosocial disabilities and chronic pain. It is particularly important that the NDIA reconsider the application of section 24(1)(c) to fluctuating conditions and ensures that activities such as self-management and self-care are assessed over weeks or months, as opposed to on a daily basis. The NDIA must increase the transparency of their decision-making to minimise any inconsistent and discretionary decision-making processes. As part of this, internal policy that is used to guide decision-making could be made public.

- What we've seen: A variable standard of proof seems to be felt by people with disability who have conditions that the NDIA does not automatically consider permanent or which are fluctuating. For example, AFI has been informed that the NDIA does not consider Developmental Language Disorder permanent. It's unclear how this decision has been arrived at.

Enhancing communication

NDIA staff members and LACs (Local Area Coordinator) must dedicate and allow adequate time to speak with the person with disability about the reasons for decisions, at all stages of engagement with the scheme. Staff must be equipped with correct and up-to-date knowledge of the NDIS, and the call centre must be subject to greater quality control.

To ensure accurate information is disseminated, close attention needs to be paid to the current understanding of the NDIS service market. Assessors need to do regular market sector updates and have regular check-ins with knowledgeable organisations to map the sector. As part of this, the Disability Gateway and Ask Izzy App need urgent work to ensure it is accessible and accurate.

- What we've seen: AFI did our own audit of the service providers listed for mobility aids and equipment in the ACT and found that only around a third of the providers listed for the ACT actually serviced the region at this point in time

Flexibility, common sense and judgement

The Federal and State or Territory Governments must better work together to ensure the overall aims of the NDIS and Australia's Disability Strategy are met. This will include ensuring adequate funding for mainstream systems to ensure joint and clear lines of responsibility and to prevent the NDIS from taking responsibility for everything. This also requires flexibility within the NDIS to ensure that individuals are not without support due to siloed systems in the interim. The NDIS needs to make quality judgement calls which weigh harm against risk and benefit.

- What we've seen: The COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems continue to lack clarity, and are therefore insufficient for addressing key service gaps, including in the Education sector, the Health sector and the Justice sector. For example, students are not able to get necessary support workers in school, as the NDIA states that it is the Education system's responsibility. A more flexible response might enable a judgement call to be made between the risk of a student dropping out of school and the risk of providing a support intended to be provided by a State or Territory Government.
- The 'Would we fund it: Gym membership' case study states that gym membership would not be funded by the Scheme. Despite this, AFI is aware of multiple participants with funding for gym memberships. As the NDIS is tailored around individual support needs, it is reasonable that different people would receive different supports.
- Sometimes participant's preferences are dismissed due to the application of inflexible rules which lead to problematic decisions. For example, a person may be given funding for a support worker assist them to cook, but not for ready-made meals; regardless of the latter option being cheaper, preferred and possibly more practical (especially during a pandemic). This reflects a culture of inflexibility and risk-aversion.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- That the NDIA embark on intentional strategies to open itself to the community it serves. It should foster innovation, partnerships, co-design and responsible risk taking and flexibility.

- That the NDIA reduce the administrative burden on people with disability across every aspect of applying for access, planning, review and engagement.
- The NDIA take steps to improve the quality of document management, handovers between staff and other quality assurance procedures.
- The NDIA put more energy and time into understanding local disability services markets, identifying critical gaps in that market and where necessary undertaking industry development.
- The NDIA put more energy and focus into engagement and knowledge of State and Territory Disability sectors
- The Federal and State or Territory Governments better work together to ensure the overall aims of the NDIS and Australia's Disability Strategy are met. This should include ensuring adequate funding for mainstream systems to ensure joint and clear lines of responsibility.
- The NDIA work to build capacity to exercise flexibility, common sense and judgement to ensure that individuals where there are failures of mainstream responses and to minimise the number of matters caught in litigation and the AAT (or its successors).

Leveling up in ACT

Case for change:

AFI notes a number of issues specific to the Australian Capital Territory which we would invite the Commission to consider and attend to. Beyond the National Capital Precinct is a growing metropolis of nearly half a million people as well as a region in Southern NSW to which we are adjacent. The capital region has distinct advantages but also social problems, service gaps, gaps in government servicing and a slew of issues deriving from a high cost of living. These issues are lost because of the proximity of the national capital and problematic assumptions about the wealth of the city.

Like Washington there are people living lives of poverty and desperation within sight of the Parliament House flagpole. There actually needs to be a levelling up agenda for Territory's and regions with specific gaps. We make the following observations.

- As the ACT Chief Minister has observed the ACT falls between funding classifications for some grant monies allocated to cities and regions. At times this has meant the ACT has missed out on a good share of grants which in other jurisdictions has improved the quantity of accessible physical and digital infrastructure as well as other services
- The ACT lacks dedicated social planning work aimed to build and improve access to the city – in other jurisdictions this would be undertaken by municipal access committee's but in the ACT, we have no local councils
- The ACT has at various times over the last two decades had the most unaffordable housing in Australia and this has combined with a lack of accessible built form to create a distinct disability housing crisis. From our advocacy we are aware of people with disability who have moved *out of the ACT* to access housing.
- Some disability services are simply not present in the city or operate on a fly in fly out basis which means people with disability are not well served by them. The ACT also lacks a number of specialist clinical services – there is no muscular dystrophy clinic, spina bifida clinic or Downs Syndrome Clinic in Canberra.
- The Yass, Goulburn, Queanbeyan and Southern NSW regions have low socio-economic status and high needs for disability supports but we note that disability advocacy is thin and often unavailable. Organisations like AFI are often approached for individual advocacy support outside the ACT but are not funded and do not have capacity to support people in the broader region.

Recommendations:

That the final report of the Royal Commission include the following recommendations:

- The need for specific levelling up strategies to ensure focus, attention and funding is available to support quality services, infrastructure and advocacy in regions which miss out including the Australian Capital Territory and the broader Southern NSW region.

END OF SUBMISSION