

Joint submission from Disability Representative Organisations

Identified gaps in the scope of work
undertaken by the Disability Royal
Commission as at November 2022



21 November 2022

Introduction

This submission to the Disability Royal Commission (the Royal Commission) outlines collective views from the national Disability Representative Organisations on gaps in the scope of work undertaken by the Royal Commission to date and identifies issues requiring further examination.

As noted in our previous correspondence, the Royal Commission provides a critical, once in a lifetime opportunity for Australia to understand the context, impact and extent to which violence, abuse, neglect and exploitation of people with disability occurred, and still occurs, in our society. It is an opportunity to lay bare systemic ableism and make concrete recommendations to effect change through a human rights framework, consistent with Australia's international human rights obligations under the seven international human rights treaties to which Australia is a party.

These treaties, along with their Optional Protocols, General Comments and recommendations adopted by the bodies monitoring their implementation, provide the framework to delineate the obligations and responsibilities of governments and other duty-bearers to comprehensively promote the human rights of people with disability, including their right to freedom from all forms of violence, abuse, neglect and exploitation. Critically, implementation of these treaties is not mutually exclusive. They are expected to be viewed and implemented as complementary mechanisms through which to create a holistic framework of rights protection and response for all people with disability experiencing, or at risk of experiencing, violence, abuse, neglect and exploitation.

We thank the Royal Commission for the significant work it has undertaken to date which has begun to shine a light on the widespread issues of violence, abuse, neglect and exploitation which people with disability, advocates and organisations have relentlessly advocated to be addressed over many years.

In addition to this considerable work, DROs have identified several settings, structures and contexts that still require examination by the Royal Commission to give full effect to its Terms of Reference. We outlined these key areas in our previous correspondence and again below. They reflect and are consistent with commitments made by the Royal Commission through its Terms of Reference, opening hearing, Interim Report, other hearings, and commissioned research reports. Without interrogation of these settings, structures and contexts, Australians cannot be confident that the recommendations of the Royal Commission will be fully informed and sufficient to prevent future violence, abuse, neglect and exploitation. This is an opportunity that cannot be lost.

On 21 September 2022, we sent a letter to the Commission Chair and other Commissioners asking the Commission to confirm how it will examine the following priorities:

- Lawful forms of violence and abuse against people with disability, including restrictive practices, forced medical treatment and procedures, and lawful discrimination against people with disability in Australia's migration system
- Independent advocacy and representation, including funding to address
 - currently unmet demand and need
 - targeted approaches to meet the needs of marginalised demographic groups
 - access barriers to advocacy and representation for people with disability in segregated or isolated settings such as boarding houses, group homes, mental health services, prisons and any other settings where access can be denied/limited by the service provider or government body responsible for the service.
- Over-representation and indefinite detention of First Nations people with disability in the criminal justice system
- Over-representation of children and young people with disability or parents with disability involved in the child protection system, and connections with other service systems, and
- Options for a resourced redress and reparation scheme for people with disability who have experienced systemic violence, abuse, neglect, and exploitation.

We note that these issues have arisen through various public hearings and no doubt also through other forms of information gathering conducted by the Royal Commission, however we are concerned that they have not been examined in sufficient depth and that this may lead to insufficient consideration in the recommendations.

This submission builds on our previous two letters to the Royal Commission and provides a more detailed list of the gaps we have identified and which we ask the Commission to address before its conclusion. We note that guardianship, substitute decision-making, and supported decision-making are not mentioned in this submission, in anticipation of Public hearing 30 commencing on 21 November 2022.

This submission is provided on behalf of the following organisations:

- Australian Federation of Disability Organisations (AFDO)
- Children and Young People with Disability Australia (CYDA)
- Disability Advocacy Network Australia (DANA)
- First People's Disability Network (FPDN)
- Inclusion Australia
- National Ethnic Disability Alliance (NEDA)
- People with Disability Australia (PWDA)
- Women with Disabilities Australia (WWDA)

Priority areas requiring further examination by the Disability Royal Commission

We acknowledge that research and literature reviews have been commissioned by the Royal Commission into some of the areas listed below, through *A Flourishing Future: The Disability Royal Commission Research Agenda*. We also recognise that some of these areas have been mentioned or raised by witnesses in public hearings. However, in our view, significantly more work is required for the Commission to fully explore and understand these issues.

The below list is organised according to the Outcome Areas in *Australia's Disability Strategy 2021-2031*.

<i>Employment and financial security</i>
<p>Examine and address the impact of structural, institutional economic neglect on people with disability</p> <ul style="list-style-type: none">• We note mention in the DRC Interim Report on p. 414: ‘...will explore the relationship between poverty, unemployment and underemployment, and violence against, and abuse, neglect and exploitation of, people with disability’• We acknowledge that this has been touched on in previous employment public hearings, but it remains a considerable gap. This is particularly the case for some cohorts of people with disability, including:<ul style="list-style-type: none">○ People with disability who are on the JobSeeker payment rather than the Disability Support Pension (DSP)○ People with an intellectual disability who are often employed at pay rates below the minimum wage, via the Supported Wage System○ First Nations people with disability living in rural and remote communities, including the impact of income management○ Young people with disability, who are one of the most disadvantaged cohorts in the labour market.
<p>Link evidence on violence, abuse, neglect and exploitation in disability employment with evidence on institutional abuse and neglect in the DSP</p>

Examine the impact detention has on access to the DSP, including investigation of the current DSP payment suspension arrangements that only allow people who have been in custody (including on remand) to suspend their DSP and resume access, without reapplying, for up to two years

Research into, and consideration of, social protection and income support as a mechanism for inclusion

Ensure that the content of the Senate Inquiry report on the purpose, intent and adequacy of the Disability Support Pension and its recommendations are properly analysed and considered

Examine what would be required to transition Australian Disability Enterprises (ADEs) into open inclusive mainstream employers in terms of funding, timeframes, grandfathering arrangements

Determine what would be required to pay people with disability the minimum wage both within ADEs as they are phased out and within mainstream employment

Interrogate whether the current government subsidies and funding models of ADEs are a disincentive to achieving inclusion of people with disability in mainstream employment settings

Consider what would be required to ensure that organisations receiving government funding and/or grants are required to employ people with disability as a condition of their receipt of funding

Explore whether and how other models of employment, such as micro enterprise and social firms should be funded and made widely available for people with disability

Inclusive homes and communities

Examine what changes need to be made to enable residents to transition out of group homes to alternative models such as shared houses (choosing who you live with, disabled or non-disabled), living alone, salt and pepper developments, homeshare, keyring models etc. by examining:

- The adequacy of Individualised Living Options including NDIS funding
- How to reorientate Specialist Disability Accommodation (SDA) to support non group homes options
- How to separate accommodation from support services
- Independent support coordination for residents of group homes to facilitate transition out of group homes, including advocates (paid and volunteer), to support this transition
- Whether current funding models are a disincentive to achieving individualised living models
- The funding changes that would be required for these transitional plans/models
- Time frames and grandfathering options to transition people with disability out of group homes into individualised living choices

Examine the issue of separation of housing and supports and single-entity providers, to address conflict of interest, including in the NDIS, as indicated on p. 255 of the Interim Report

Examine the relationship between adequate affordable and accessible housing and violence, abuse, neglect and exploitation against Aboriginal and Torres Strait Islander people with disability, with a focus on:

- The housing crisis for Aboriginal and Torres Strait Islander people, and the impact this has on Aboriginal and Torres Strait Islander people with disability the intersectional barriers to accessing affordable and accessible housing for Aboriginal and Torres Strait Islander people with disability
- The availability of affordable and accessible housing for Aboriginal and Torres Strait Islander people with disability
- The impact of being forcibly relocated from Country in order to access supported accommodation
- How overcrowding affects rates of violence and abuse against Aboriginal and Torres Strait Islander people with disability

<ul style="list-style-type: none"> • Community-led solutions to housing issues.
<p>Consider and evaluate mechanisms for providing people with disability with the support services, including decision support, and individual advocacy necessary to identify and express their housing preferences and to obtain accommodation that matches their preferences, as indicated on p.255 of the Interim Report</p> <p>Identify supported decision-making needs and opportunities around housing choices</p>
<p>Explore strategies to increase the stock of suitable accommodation, as indicated on p. 255 of the Interim Report, so that people with disability can choose where and with whom they live (per UN CRPD Article 19)</p>
<p>identify the changes that need to be made by the NDIS to give people with disability currently living in group homes choice and control over where, how and with whom they live within the community</p>
<p>Consider experiences of people with disability who are locked out of the commercial housing and rental markets</p>
<p>Examine lack of accessible housing options for children and young people with disability and their families</p>
<p>Consider experiences of people with an intellectual disability who have lived in large residential institutions, including their experiences transitioning to the community</p>
<p>Consider the impact of segregated employment systems, like ADEs and the Supported Wage System, on people’s financial capacity and their ability to find housing options they can afford.</p> <ul style="list-style-type: none"> • Low wages provided to people with disability through the Supported Wage System limit their purchasing power and ability to choose where and with whom they would like to live, contributing to the prevalence of group and congregate housing settings, which can contribute to higher rates of violence and abuse.
<p>Challenge any assumptions that people with disability will continue to live in congregated and segregated settings such as group homes, explore a CRPD-compliant end to these settings, and investigate how people with disability living in congregated and segregated settings such as group homes can be supported in the transition to alternative forms of accommodation, as indicated on p. 257 of the Interim Report</p>

Consider what the research, literature reviews and lived experience have identified as approaches to enabling people with disability being included and participating in the community alongside people without disability

Examine Australia's transport systems and the need for safe, consistent accessible transport for people with disability and link between lack of transport options and isolation and barriers to inclusion

Safety, rights and justice

Address the important role of disability advocacy in safeguarding the rights of people with disability, including:

- Investigation of unmet demand and need for independent disability advocacy support including specialised or targeted approaches to meet the needs of demographic groups that have been identified as experiencing disadvantage and increased risk of violence, abuse, neglect and exploitation
- Exploration of support for children and young people with disability to develop their voice and self-advocacy rights and opportunities
- Exploration of the need for human rights education and awareness raising across the community, including about what constitutes violence, abuse, neglect and exploitation
- Exploration of support for a legal advocacy specialisation focused exclusively on the cohort of First Nations peoples with disability in Australia's prisons
- Investigation and consideration of investment in the creation of independent, First Nations owned and operated individual advocacy services
- Investigation and consideration of *“measures, including increased funding, needed to ensure that all residents of group homes and other supported accommodation have access to individual advocacy”* and self-advocacy programs (to implement as medium-term safety strategies during transition away from segregated settings), as indicated on p.257 of the Interim Report.

Further examine how supporters, families, advocates, and workforce can facilitate the independence and autonomy (choice and control) of people with disability, including exploration of how representation and advocacy may help prevent and better respond to violence, abuse, neglect (as indicated on p. 481 of Interim Report)

Interrogate lawful forms of violence and abuse against people with disability, including restrictive practices, forced medical treatment and procedures, income management and quarantining of income support

Examine the impact of 'capture' of an NDIS participant by a limited number of providers and how this affects safeguards and access to informal supports

Address the over representation of children and young people with disability or parents with disability involved in the child protection system, and the lack of disability identification, NDIS support, and systemic abuse they are facing

- It is acknowledged that some work has commenced in this area, however we believe it needs further examination as it has a cascading effect in other systems and life dimensions.

In-depth examination of the significant overrepresentation of First Peoples with disability involved, or at risk of being involved (as children, young people or and/or parents), within all aspects of the child protection system. This includes:

- The institutionalised forms of discrimination, including racism and ableism, that underpin the child protection system
- The systemic issues that lead up to interactions with the child protection system, including;

Justified fear of accessing disability diagnosis, services and formal supports due the increase of surveillance, intervention and over -representation of child removal by the child protection system for First Peoples.

Lack of culturally appropriate (that include acknowledgment of the over-surveillance and over- representation) supports for families

An overhaul of the child protection system and related legislation, policy and practices that continue to be coercive, controlling and punitive, and are underpinned by racist perceptions.

- The need for accurate data about the numbers of First Peoples with disability (including children, young people and parents with disability) in the criminal justice system.
- The removal of First Nations children with disability from, and lack of reunification back into their families, kinship groups and access to cultural needs by the child protection system.

Examine the need for greater access to justice for people with disability, including current inequality before the law experienced by people with disability regarding 'legal capacity' assessments, and removal of the interpretive declaration on Article 12 of the CRPD in order for people with disability to achieve equality before the law

Examine the need for greater legal recourse for people with disability who experience multiple and intersecting forms of discrimination, including amending Australia's *Disability Discrimination Act 1992* and existing complaints mechanisms. For example, First Nations people with disability who experience discrimination that is co-constitutive of both racism and ableism cannot pursue legal redress on the basis of both racial discrimination and disability discrimination, and must only choose one

Examine, in depth, the significant overrepresentation of First People with disability within all aspects of the criminal justice system.

This includes:

- Ongoing deaths in custody¹
- The contribution of the criminal justice system to violence and abuse against First People with disability, including the use of restrictive practices such as spit hoods, restraints chairs and solitary confinement
- The increasing 'management' of First Peoples with disability by police, courts and prisons in the absence of access to critical community-based services
- What is happening for First Peoples with disability when they're in prison and what happens when they leave prison
- Further examination of the prevalence and implications of Indefinite detention
- Interactions with the police, including the violence, abuse and police brutality First Peoples with disability experience
- The institutionalised forms of discrimination, including racism and ableism, that underpin the criminal justice system
- The barriers First Peoples face when accessing disability supports, including the NDIS, across the criminal justice system
- The barriers First Peoples face when accessing health care, including Medicare and the PBS, across the criminal justice system
- The systemic issues that lead up to entering the criminal justice system
- Accurate data about the numbers of First Peoples with disability in the criminal justice system, at all ages
- The impact of the criminal justice system on Aboriginal and Torres Strait Islander children and young people with disability, including the disproportionate rates of First Nations children with disability within youth detention

¹ Acknowledging that over 40 per cent of all deaths in custody since the 1991 Royal Commission into Aboriginal Deaths in Custody have involved the deaths of First Nations people with psychosocial or cognitive disability. Source: <https://www.theguardian.com/australia-news/ng-interactive/2018/aug/28/deaths-inside-indigenous-australian-deaths-in-custody>

- The ongoing human rights abuses occurring in youth detention, and the incarceration of First Nations children with disability in adult prisons
- The need for a legal advocacy specialisation focused exclusively on the cohort of First Peoples with disability in Australia's prisons.

Acknowledge the need for intersectional, quantitative data on First People with disability in detention, including youth detention

Explore accountability issues with:

- Not upholding children's rights to reasonable adjustments and application of Disability Standards for Education
- Breaches of the Disability Discrimination Act
- Removal of exemptions to disability standards, such as school bus exemption to Disability Transport Standards
- Implementation of the UN Convention Against Torture and the Optional Protocol

In-depth exploration of sexual and reproductive violence, specifically forced or coerced sterilisation, abortion, adoption and contraception, and use of the law in deprivation of liberty

- See Interim report p.402: *"Throughout the course of our inquiry we will examine the nature and extent of violence against, and abuse, neglect and exploitation of, people with disability in the context of relationships, including abuse related to sexual and reproductive rights, and violence between people with disability"*

Explore systemic issues underpinning how gender inequality, sexism, and queerphobia combine with ableism to drive violence and abuse against women, girls, non-binary, and gender diverse people with disability

Examine the challenges faced by people with disability in reporting instances of violence, abuse, neglect and exploitation, including complaints being minimised, not believed, ignored or unreported

- This must include consideration of:
 - The proliferation of regulatory bodies in the lives of people with disability and confusion / lack of clarity about where to report what
 - The inaccessibility of various reporting mechanisms and communication by regulatory bodies

- The lack of culturally appropriate reporting mechanisms
- The time taken by many regulatory bodies in addressing reports
- The impact perpetrator misidentification has on people with disability, especially First Nations people with disability, when making police reports
- We acknowledge the 'Accessible and Inclusive Complaints' research project commissioned by the Royal Commission the recent release of this report.
- We note the Interim Report said the DRC would consider: *“whether the approach of the NDIS Quality and Safeguards Commission (NDIS Commission) to identifying, reporting, investigating and responding to cases of violence against, and abuse, neglect and exploitation of, people with disability living in group homes or supported accommodation is adequate and, if not, how it can be improved”* (p.257).

Address the critical need for and benefits of a redress scheme for people with disability who have experienced violence, abuse, neglect and exploitation

- An options paper for redress to be developed for consideration by Commissioners.

Personal and community support

Interrogate whether the current funding models for day programs are a disincentive to achieving inclusive community participation and if so, what would need to change

Examine how individualised arrangements, such as one on one support and provision of assistance to mainstream community to include people with disability, could be implemented

Explore time frames and grandfathering options to transition people with disability out of day programs into individualised community participation

Consider systemic neglect in the disability service system, including the NDIS, My Aged Care, TAC, and WorkCover programs, and the services available for people with disability who are not eligible for the NDIS. Specifically consider:

- Issues of NDIS access and the disability services available for people who are denied access
- The experiences of people with psychosocial or other forms of episodic disability, people with an intellectual disability, children and young people, and older people.
- Conflict of interest and the impacts of provider capture, where NDIS participants have multiple services (including housing and supports) provided by a single-entity provider

Investigate barriers to parenting experienced by people with disability, as indicated on p.402 of the Interim Report, including examination of access to parenting supports (including specialist supports for parents with intellectual disability, through the NDIS and other systems)

- Consider the flow-on impacts of this for children and parents who are involved in the child protection system and the violence, abuse, and neglect experienced by many

Further examine the experiences of violence, abuse, neglect and exploitation of people with disability living in regional, rural and remote communities, with a targeted focus on First Nations people with disability living in rural and remote communities

Further explore emergency preparedness and systemic responses for people with disability, particularly with regards to neglect and care rationing

Consider how people with disability can be supported and included in the community by a workforce that meets their needs, including:

- Whether the current training and certificated models are effective in (i) reducing violence, abuse, neglect and exploitation of people with disability and (ii) empowering and supporting people with disability to make their own decisions, choose their own support services, and manage their own support workers
- Whether staff have the necessary values, knowledge and skills to recognise and develop the potential of the people they support
- Whether staff are adequately trained and supported to design and implement behaviour support plans and other specialised plans (including health and relationship development) effectively
- What disability service providers need to do or change to ensure they have an appropriately trained workforce in areas such as support for decision making, community inclusion, cultural safety, trauma-informed care, relationship development and support
- How government might better assist services to invest in staff training and development systems that are fit for the purpose of achieving the NDIA goals of self-determination, community inclusion, choice and control
- Whether the National Quality and Safeguards Commission support worker workforce capability framework is a useful starting point
- How the voices of people with disability can be included meaningfully in workforce training and development
- How a community controlled First Nations disability sector can be developed

Education and learning

Identify the actions that need to be taken by State and Territory governments so all children with disability are educated in inclusive mainstream educational settings alongside children without disability, in line with the UN CRPD

- In its Interim Report, the DRC indicates it *“will continue to examine the issue of inclusive education, including measures that will encourage more effective programs of inclusive education in mainstream schools”* (p.239).

Examine the grandfathering arrangements and timeframes to transition mainstream schools into inclusive schools and then to transition away from segregated special schools into inclusive mainstream schools

Consider what supports a child with disability requires to be educated in the same settings as their non-disabled peers, including early interventions and early education

Interrogate what can be done to prevent violence, abuse, neglect of development, and restrictive practices in special schools

Further explore the rights of children, specifically the right to inclusive education under Article 24, to supersede parental decision making

Explore the life trajectory of First Peoples with disability, including the:

- Experiences in the education system of Aboriginal and Torres Strait Islander children and young people with disability
- Experiences, incidence and data about expulsion and suspensions of Aboriginal and Torres Strait Islander children and young people with disability
- Connections between the criminal justice system and expulsion and suspension from school.

Address equal access for children and young people with disability to education on respectful relationships, body autonomy and other areas that set them up for safe, equal and respectful sexual expression and experiences

- Interim Report p.283: *“The Royal Commission will investigate the measures required to establish a planned process for the transition of young people with cognitive disability into the adult health system, including a process for addressing sexual and reproductive health.”*

Consider the right to inclusive early childhood experiences and what is required to achieve these

Identify required improvements in transition planning and resourcing for moving from child to adolescent to adult education and training services and supports, including access to tertiary education

Examine participation rates and resourcing of supports in tertiary education (vocational training and university) and how to improve these

Examine disproportionate rates of sexual assault and violence experienced by disabled students in tertiary education settings

Health and wellbeing

Further examine *“the means by which people with cognitive disability, their families, carers and supporters can be supported in advocating for health care and treatment, including support for independent advocacy and self-advocacy”*, as identified on p.42 of the Interim Report

Identify what is needed to improve transition planning and resourcing for people with disability as they move from child to adolescent to adult health services and supports

Further explore the impacts of the COVID-19 pandemic response on people with disability and their families, including:

- The lack of COVID-19 recommendations for children and young people and their families
- Systemic neglect from health systems
- Instances of care rationing within health systems, including the formalisation of care rationing within policy and procedures
- Experiences of people with disability who are immunocompromised, following the removal of public health measures such as public mask-wearing
- Disability and health services available for those disabled by Long COVID
- Specialist healthcare and elective surgery waitlist blow-outs

As per the Interim Report, *“investigate the measures required to establish a planned process for the transition of young people with cognitive disability into the adult health system, including a process for addressing sexual and reproductive health”* (p.283)

Fully explore sexual and reproductive health violations against all people with disability, including women and girls, men and boys, and non-binary and gender diverse people. This includes practices such as forced and coerced sterilisation, menstrual management, forced and coerced vasectomies, and with medications that have the effect of chemical castration.

Address the lack of accessible and inclusive mental health support (including eating disorder services), considering especially the supports available for Autistic people and for people with an intellectual disability

- The Interim Report talks about specific actions the Royal Commission will take in relation to mental health care and notes the Commission will seek updates from both Commonwealth and NSW governments (p.283)

Additionally, investigate and address the use of seclusion, restraint and forced treatment in mental health inpatient services – including taking steps to hear directly from people currently in these settings and those with past experiences

Investigate measures needed to prevent referrals to palliative care where medical care can and should be provided, as indicated on p.284 of the Interim Report, and strategies to improve palliative care for patients with disability

Further examine preventable deaths of people with disability within healthcare systems, including public reporting requirements and the role of discrimination (such as ableism and racism) in these deaths

Identify what is needed to improve hospital discharge planning for people with disability, especially those at risk of homelessness and institutionalisation

Investigate violence, abuse and neglect experienced by older people with disability, including elder abuse and neglect experienced in aged care settings

Investigate systemic discrimination and neglect against older people with disability, including by their exclusion from the NDIS

Specifically explore the experiences of LGBTQIA+ people with disability relating to the majority of life domains, and the violence, abuse, neglect and exploitation they experience

Community attitudes

Clearly articulate the ways community attitudes towards disability, including ableism and stigma, drive violence, abuse, neglect and exploitation of people with disability, and how this is compounded by intersectional discrimination and prejudice

Identify clear recommendations of the government investment required to improve community attitudes towards people with disability and promote inclusion, including through:

- Active presence of people with disability
- Leadership
- Targeting multiple levels and multiple types of policy and intervention
- Long-term approaches with adequate resources
- Measuring and monitoring change (as identified by the final report from the Royal Commission's Research Project 14).

This should include exploration of the potential role and resourcing of:

- Advocacy and disability representative organisations
- Peer support groups and networks
- Self-advocacy groups, networks and resource units
- Disability leadership development programs and opportunities
- Co-design in policy and program design, implementation and evaluation.

Further areas to be explored

Consider which models, both domestic and international, show potential to achieve transitions away from segregated settings and into inclusive mainstream settings for people with disability?

Consider the requirements to extend the coverage of effective models across Australia

Facilitate a greater number of submissions from closed settings, including Supported Independent Living arrangements, group homes, prisons, youth detention, forensic hospitals, immigration detention

Conduct outreach to people facing difficulty accessing advocacy services, into service settings, and to people without access to technology or social media

Ensure views represented to the DRC are widespread enough to be genuinely reflective of the whole population of people with disability and represent the broad intersectional issues

Explore the experiences of 12 to 17-year-old young people with disability

Include people with disability and Disability Representative Organisations in development and testing of Royal Commission recommendations