



Women
With
Disabilities
Australia
(WWDA)



ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

WWDA SUBMISSION ON RECOGNISING AND RESPECTING OUR RIGHTS: Young women, feminine identifying and non-binary Young People With Disability

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First Nations peoples should be aware that this publication may contain the names and words of people who have passed.

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Women With Disabilities Australia (WWDA) has Special Consultative Status with the Economic and Social Council of the United Nations.

Awards

Winner

National Human Rights Award 2001

Winner

National Violence Prevention Award 1999

Winner

Tasmanian Women's Safety Award 2008

Nominee

UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee

French Republic's Human Rights Prize 2003

Nominee

UN Millennium Peace Prize for Women 2000

Certificate of Merit

Australian Crime & Violence Prevention Awards 2008

Nominee

National Disability Awards 2017

Finalist

International Zero23 Award, Information and Communication Technologies (ICT)

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ABOUT WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

[Women With Disabilities Australia \(WWDA\)](#) Inc is the national Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying and non-binary people with disability in Australia. As a DPO and a NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.

WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (DPOs) are recognised around the world, and in international human rights law, as self-determining organisations led by, controlled by, and constituted of, people with disability. DPOs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.¹

ABOUT CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA (CYDA)

[Children and Young People with Disability Australia \(CYDA\)](#) are the national peak body that represents children and young people (aged 0-25) with disability. CYDA is a not-for-profit community-based organisation that was officially incorporated as a company limited by guarantee in November 2009. The organisation was initially established in 2002 as the Australian Association for Families of Children with Disability. CYDA receives its core funding under the Department of Social Services (DSS) national secretariat program. CYDA provides a link between the direct experiences of children and young people with disability and their families and the Federal Government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences of and challenges for children and young people with disability and their families.



1 RECOMMENDATIONS

1. RECOMMENDATIONS

Women With Disabilities Australia ('WWDA') submits that the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* ('Royal Commission') must address the specific forms of violence, abuse, neglect and exploitation experienced by young women and girls with disability, as separate, but inextricably linked with the ableism, structural inequality and discrimination which underpins the broader systemic problem of all forms of violence against women and girls with disability.

Drawing on direct feedback and anecdotes from young women and girls with disability, this Submission makes a number of recommendations that encompass a range of areas and issues – including access to healthcare and services, the National Disability Insurance Scheme (NDIS); education, employment, inclusion in the community, research and data collection.

This section outlines WWDA's **thirty-five** recommendations on how to improve the experiences of young women and girls with disability in two stages. It first outlines recommendations to Government that the Royal Commission can include in its Final Report, and then makes a series of recommendations about the direction and focus of the Royal Commission's work leading up to the Final Report. Sections 2 - 6 of this Submission provide context to and elaboration on these recommendations.

WWDA respectfully requests that the Royal Commission consider this Submission in conjunction with **ALL** WWDA's other submissions to the Royal Commission, particularly its submissions on Restrictive Practices, Sexual and Reproductive rights, Guardianship, Education, Employment, and Reproductive Justice for Young People.

In relation to this Submission, WWDA makes the following **thirty-five** broad Recommendations. These Recommendations are provided in no particular order of priority.

- 1.1 That the Royal Commission recommend the Australian Government establish and enact comprehensive, national, judicially enforceable human rights legislation that fully incorporates its international human rights obligations into domestic law.
- 1.2 Recognising that Australia is a signatory to seven core international human rights treaties, each of which contain obligations relating to people with disability (including women and girls with disability), and which 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, the Royal Commission should ensure that its Final Report includes recommendations which address all of the relevant recommendations made to Australia from the international human rights treaty monitoring bodies, not just those stemming from the Committee on the Rights of Persons with Disabilities.
- 1.3 That the Royal Commission recommend the Australian Government establish a nationally consistent supported decision-making framework, that strongly and positively promotes and supports women with disability to effectively assert and exercise their legal capacity and enshrines the primacy of supported decision-making mechanisms, including the right of women and girls with disability to make free, informed and responsible choices about their bodies and lives including in relation to sexual health, reproductive health, intimate and emotional relationships, and parenting. This framework must replace (rather than complement) substitute decision-making regimes and practices.²
- 1.4 That the Royal Commission recommend the Australian Government and State and Territory Governments strengthen anti-discrimination laws to explicitly recognise and address intersectional discrimination, including its aggravating and compounding effects, and to

guarantee the protection from discrimination on the grounds of disability that explicitly covers all persons with disability.

- 1.5 That the Royal Commission, consistent with recommendations made to successive Australian Government's by UN treaty monitoring bodies recommend the Australian Government withdraw its Interpretive Declarations on the United Nations Convention on the Rights of People With Disabilities (CRPD) including Article 12 [Equal recognition before the law], Article 17 [Protecting the integrity of the person] and Article 18 [Liberty of movement and nationality] and that the Australian Government review and take action to withdraw its Reservations and Interpretative Declarations to the other human rights treaties to which Australia is a party.
- 1.6 That the Royal Commission, in all areas of its work, and in its Final Report, explicitly recognise and conceptualise the segregation of people with disability as discrimination, that segregation is an underpinning enabler of violence, abuse, neglect and exploitation, that segregation constitutes systemic violence, abuse, neglect and exploitation; and the Disability Royal Commission must hold governments and other stakeholders to account for supporting, maintaining and funding segregated legal, justice, service, residential, educational, employment and other systems.
- 1.7 That the Royal Commission recommend the Australian Government ensure that the Australian Disability Strategy (ADS) 2021-2031, develop specific, gendered, data collection measures to monitor and report on, the sexual and reproductive rights violations experienced by people with disability, particularly women and girls with disability.
- 1.8 That, consistent with long-standing recommendations from the UN international human rights treaty monitoring bodies, the Royal Commission recommend the Australian Government commission and fund a comprehensive assessment of the situation of women and girls with disability, in order to establish a baseline of disaggregated data and information against which compliance with the UN treaties (to which Australia is a party) and national policy frameworks can be measured and monitored.
- 1.9 That the Royal Commission recommend the Australian Government implement a nationally consistent framework to enable the collection, analysis and public reporting of disaggregated data across all jurisdictions, on all forms of gendered disability violence, abuse, neglect and exploitation experienced by women and girls with disability.
- 1.10 That the Royal Commission, consistent with and reflecting multiple and repeated recommendations from the UN international human rights treaty monitoring bodies, recommend the Australian Government as a matter of urgency enact national, uniform and legally enforceable legislation prohibiting the sterilisation of children, and the sterilisation of adults with disability in the absence of their prior fully informed and free consent.
- 1.11 That the Royal Commission recommend the Australian Government in association with State and Territory Governments, as a matter of urgency, prohibit all forms of forced treatment and restrictive practices on and against all people with disability, including forced sterilisation, forced contraception, menstrual suppression and forced and coerced abortion. To commence this work, and in consultation with people with disability, the Australian Government must conduct a comprehensive audit of laws, policies and administrative arrangements underpinning forced treatment and restrictive practices with a view to: introducing reforms to repeal laws and prohibit practices that relate to forced treatment and restrictive practices. This audit should extend to guardianship laws, family and child protection laws, mental health laws and common law *parens patriae* doctrine.
- 1.12 That the Australian Government require and enforce mandatory disability access and inclusion policies and intersectional disability inclusivity training for all health services and providers, including hospitals, GP surgeries, medical specialists, allied health workers, clinics etc.

- 1.13 Recognising that barriers to diagnosis, especially for young women and girls who are neurodivergent, and that prevent young women and girls with disability from being able to access adequate healthcare and support services; the Royal Commission recommend the Australian Government develop national strategies to target the underdiagnosis and misdiagnosis of conditions such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) in girls and young women. This should include:
- Resourcing a comprehensive inquiry, informed by evidence-based research, aimed at revising the diagnostic criteria used by practitioners to identify ASD and ADHD at all ages, but particularly among children and young people.
 - Increasing Medicare rebates for the assessments required for ASD and ADHD diagnoses.
 - Ensuring that the recently announced development of a 'National Autism Strategy' is gendered, and ensures a co-design approach with women and girls with disability.
- 1.14 That the Royal Commission recommend the Australian Government make available mobile, accessible sexual and reproductive health checks and screening services for women and girls with disability, including those in institutional settings and regional and remote geographic locations.
- 1.15 That the Royal Commission recommend the Australian Government introduce and fund sexual and reproductive health education curriculum at all levels that is inclusive of the sexual and reproductive health and rights of women and girls with disability.
- 1.16 That the Royal Commission recommend the Australian Government commit to resourcing, maintaining and expanding Telehealth services on an ongoing basis across all states and territories.
- 1.17 That the Royal Commission recommend the Australian Government, in consultation with key stakeholders, fully resource a national system such as My Health Record³ that creates and streamlines communication pathways between different practitioners.
- 1.18 Recognising that National Disability Insurance Scheme (NDIS) participants only account for 10% of people with disability across Australia, the Royal Commission recommend the Australian Government Review of the NDIS, includes a focus on the eligibility criteria that excludes cohorts of people with disability, including some neurodivergent people, people with chronic illness, people on temporary visas and people aged over 65.
- 1.19 Recognising the gender inequity in the NDIS whereby the percentage of female participants has remained at 37% or lower since the Scheme's inception, the Royal Commission recommend the NDIA, in consultation with women with disability and their representative organisations, urgently develop an NDIS Gender Strategy.
- 1.20 That the Royal Commission recommend that the NDIS provide gender disaggregated data across all its data collection processes and frameworks, and this data should be published in all NDIS Quarterly Reports.
- 1.21 That the Royal Commission recommend that the NDIS, in consultation with people with disability and their representative organisations, develop a risk assessment process for identifying and responding to all forms of violence against people with disability, including identifying and responding to gender-based violence. Inherent in this, is the need for the National Disability Insurance Agency (NDIA) to develop pathways to safety for NDIS participants escaping violence.

- 1.22 Recognising that NDIS processes are inaccessible and overwhelming for many people with disability, especially young people with disability, the Royal Commission recommend that Australian Governments expand and fully fund independent advocacy services to support individuals to apply for and navigate the NDIS.
- 1.23 Acknowledging that Government pensions are the main source of personal income for 42% of people with disability; the median gross weekly personal income of people with disability is half that of people without disability; and more than 45% of people with a disability live in poverty, the the Royal Commission recommend that the Australian Government act urgently to increase the rate of all government payments, including the Newstart Allowance, Youth Allowance and the Disability Support Pension (DSP).
- 1.24 Acknowledging that the Centrelink eligibility requirements exclude many people with disability from being able to access adequate income support, the Royal Commission recommend that the Australian Government urgently abolish discriminatory eligibility tests, such as the DSP 20-point eligibility test based on special Impairment Tables.⁴
- 1.25 Acknowledging that means testing individuals based on the income of their partner, caregivers or parents increases the risk of women and girls with disability, especially young women and girls with disability, experiencing violence, the Royal Commission recommend that the Australian Government urgently amend the Centrelink criteria to consider all people with disability independently of any other individual from the age of 18.
- 1.26 That the Royal Commission recommend Australian Governments develop and implement a national Action Plan for Inclusive Education which includes:
- A nationally consistent legislative and policy framework that fully complies with CRPD article 24 and General Comment No. 4;
 - Specific actions to recognise and respond to intersectionality, including for women and girls with disability;
 - Measurable actions and rigorous accountability mechanisms for the transition from segregated models of education to inclusive education;
 - Reallocation of resources and funding from segregated education models to inclusive education;
 - Explicit recognition of the right to be free from violence, abuse, neglect and exploitation, including behaviour management that constitutes torture and ill-treatment, such as restrictive practices⁵.
- 1.27 That the Royal Commission recommend the Australian Government, as part of all educational curricula, develop a comprehensive suite of human rights based educational programs and delivered across the life span (including in childhood) with the aim of:
- Fostering and valuing diversity and inclusion;
 - Challenging ableism and intersecting forms of inequality and discrimination, including for women and girls with disability;
 - Building knowledge, skills and strengths in recognising rights to bodily integrity and to be free from all forms of violence, abuse, neglect and exploitation;
 - Increasing opportunities and participation in decision-making, self-advocacy and in speaking up about rights.

- 1.28 That the Royal Commission ensures, in its Final Report, the recognition that segregation of people with disability in employment – including through Australian Disability Enterprises (ADEs) – remain State sanctioned practices that enable violence, abuse, neglect, and exploitation to flourish.
- 1.29 Recognising Australian Disability Enterprises (ADEs) and other segregated models of employment as being in contravention of the CRPD, and reflecting recommendations made to Australia by the Committee on the Rights of Persons with Disabilities, the Royal Commission recommend the Australian Government urgently develop and implement a national, time bound strategy and framework for the closure of all ADEs and segregated models of employment, and provide services to transition people with disability from ADEs into open inclusive and accessible forms of employment, ensuring equal remuneration for work for equal value.
- 1.30 That the Royal Commission recommend the Australian Government pursue the actions identified by DPO Australia in its position paper ‘Segregation of People with Disability is Discrimination and Must End’⁶ and adopt the principles in that position paper in order to guide its disability policy and service provision more broadly.
- 1.31 That the Royal Commission recommend that the Australian Government develop and implement a national, time bound Deinstitutionalisation and Disability Housing Strategy aimed at closing institutional living arrangements for people with disability; preventing the building of new institutional living arrangements, including the building of new group homes through NDIS Specialist Disability Accommodation (SDA); repurposing existing group homes into genuine community-based housing options; providing resources to increase the supply and range of accessible social and public housing stock; and amending the National Construction Code to mandate minimum universal accessible housing design standards for all new and extensively modified housing. The national, time bound Deinstitutionalisation and Disability Housing Strategy must reflect and be consistent with the CRPD Committee Guidelines on Deinstitutionalisation.
- 1.32 That the Royal Commission recommend the Australian Government recognise, support and strengthen the role of women with disabilities organisations, groups and networks in efforts to fulfil, respect, protect and promote their human rights, and to support and empower women with disability, both individually and collectively, to claim their rights. This includes the need to create an environment conducive to the effective functioning of such organisations, groups and networks, including adequate and sustained resourcing. Inherent in this, is the need for financial and political support to enable the establishment and recurrent funding of a peak DPO for women with disability in each State and Territory.
- 1.33 That the Royal Commission recommend all Australian Governments agree on and implement an inclusive definition of ‘violence against women’ that is consistent with, and reflects Australia’s international human rights obligations and acknowledges that violence against women occurs on a continuum that spans interpersonal and structural violence; manifests itself on a continuum of multiple, interrelated and recurring forms, in a range of settings, from private to public (including technology-mediated settings); acknowledges the structural aspects and factors of discrimination, including structural and institutional inequalities; and analyses social and economic hierarchies between women and men (inter-gender inequalities) and among women (intra-gender inequalities).
- 1.34 In line with long-standing recommendations to Australia from the CEDAW Committee,⁷ and recognising the gendered nature of violence, the disproportionate, multiple and intersecting forms of violence experienced by women and girls with disability, and the lack of legislative, policy and service responses to prevent and address violence against women and girls with disability, the Royal Commission recommend the Australian Government develop and enact national legislation on prevention of all forms of gender-based violence, and this should extend to reproductive violence and restrictive practices

(including non-consensual and coercive sterilisation, menstrual suppression, contraception and abortion). Such legislation could be modelled on the Istanbul Convention.⁸

- 1.35 That the Royal Commission recommend the Australian Government commit to providing comprehensive, long-term funding and resourcing to improve the accessibility and resourcing of front-line disability, crisis and domestic and family violence services to ensure they are equipped to support women and girls with disability, in all of their diversity.



2 BACKGROUND TO THE ROYAL COMMISSION

2. BACKGROUND TO THE ROYAL COMMISSION

- 2.1 The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission)⁹ was established after many years of campaigning by people with disability and our representative organisations at both the domestic and international level.¹⁰
- 2.2 Women With Disabilities Australia (WWDA) played a leading role in these advocacy efforts, and in particular, in exposing the gendered nature of violence against people with disability.
- 2.3 In 2015, our collective campaign efforts led to the establishment of the *Senate Inquiry into Violence, Abuse and Neglect Against People with Disability in Institutional and Residential Settings*, including the gender and age-related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.¹¹ The priority Recommendation from that Senate Inquiry was that a Royal Commission into violence against people with disability be established.¹²
- 2.4 However, it was not until 2019, following further concerted advocacy efforts that the Royal Commission was finally established by the Australian Government. The urgent need for a Royal Commission into all forms of violence against people with disability, was a key recommendation from the 2017 review of Australia’s compliance with the International Covenant on Economic, Social and Cultural Rights (ICESCR); and was also addressed at the September 2019 review of Australia’s compliance with the Convention on the Rights of Persons with Disabilities (CRPD).
- 2.5 The Terms of Reference for the Royal Commission are contained in the Commonwealth Letters Patent that were signed by the Governor General on 4 April 2019.¹³ The Terms of Reference explicitly state that:
- “Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability, including to protect people with disability from all forms of exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities.”*
- 2.6 The Terms of Reference reflect our campaign calls that the Royal Commission should have regard to ‘all forms of violence against, and abuse, neglect and exploitation of, people with disability, whatever the setting or context’.¹⁴
- 2.7 The Terms of Reference also reflect our calls for recognition of the intersectional dimensions of people with disability that make the experiences of violence, abuse, neglect and exploitation specific, unique and diverse:
- the specific experiences of violence against, and abuse, neglect and exploitation of, people with disability are multi-layered and influenced by experiences associated with their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, including the particular situation of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people with disability.¹⁵*
- 2.8 The intersectional analysis required by the Terms of Reference and enshrined in the CRPD, is critical to ensuring that **all** forms of violence experienced by people with disability, including women and girls with disability, in all settings and context, is identified, understood and addressed.

2.9 Despite our collective calls for the Terms of Reference for the Royal Commission to include provision for a **redress scheme**, this was not included. In September 2019, the Committee on the Rights of Persons with Disabilities adopted its Concluding Observations following its review of Australia's compliance with the CRPD. The Committee expressly recommended that the Australian Government:

*ensure [adequate resources and] a **redress mechanism** for the Royal Commission.*¹⁶

2.10 To date, there has been no response from the Australian Government in response to this recommendation, and it therefore remains unclear as to whether the Australian Government will adopt this critical recommendation.

2.11 As noted in the Royal Commission's *Accessibility and Inclusion Strategy*, and through research commissioned by the Royal Commission and through its Public Hearings, it is now well established and recognised internationally and domestically that women and girls with disability are 'far more likely to experience violence and abuse than women and girls without disability, and they are less likely to report this abuse for both personal and systemic reasons'.¹⁷ CRPD General Comment No. 3 on Women with Disabilities, published by the Committee on the Rights of Persons with Disabilities (CRPD Committee) in 2016, elaborates on this fact, and draws particular attention to the structural and institutional forms of gender-based violence related to law, the state and culture that women and girls with disability not only experience, but are more at risk of.¹⁸

2.12 Australia has received numerous recommendations over many years from the United Nations (UN) to investigate, address and remedy this situation for women and girls with disability. Very few of these recommendations have ever been implemented by successive Australian governments.



3 INTRODUCTION

3. INTRODUCTION

- 3.1 In 2021, recognising that the Royal Commission had provided limited specific methods or strategies to engage with young people with disability about their experiences; WWDA collaborated with Children and Young People With Disability (CYDA) to set up opportunities for young women, feminine identifying and non-binary people with disability to provide us with direct information and feedback about their experiences that could be relayed to the Royal Commission.
- 3.2 This submission is based on feedback provided from young women, feminine identifying and non-binary people with disability via three focus groups as well as a national survey, which both asked questions about their experiences accessing healthcare, supports and services, navigating education, employment and the community.
- 3.3 To date, there have been no Royal Commission Hearings or Issues Papers dedicated directly to investigating the experiences of young people with disability. Thanks to ongoing advocacy from WWDA, there has been one hearing on the experiences of women and girls with disability generally. Public hearing 17: The experience of women and girls with disability with a particular focus on family, domestic and sexual violence (Part 1) was held online on 13 and 14 October 2021 and Public hearing 17.2: The experiences of women and girls with disability with a particular focus on family, domestic and sexual violence (Part 2) was held in Hobart on 28 March 2022 to 1 April 2022.
- 3.4 While these hearings are a vital aspect of the Royal Commission's work exploring intersectional dimensions of women and girls with disability's experiences of violence, abuse, neglect and exploitation, it is vital that the Royal Commission thread intersectionality and specific experiences of women and girls with disability throughout all its work and make specific efforts to explore the experiences of young women and girls with disability. To date, there has been little to no focus on intersections between disability, gender and age and there has been a lack of identification and deeper exploration of gendered dynamics of violence, abuse, neglect and exploitation and specific experiences of women and girls with disability. Public Hearings, Community Forums and Issues Papers have been largely gender and age neutral, perpetuating the consequences of age and gender-based discrimination and contributing to misleading analyses of issues and inaccurate assessments of likely policy outcomes. As such, we are concerned this neutrality in much of the Royal Commission's public work will lead to the Royal Commission making recommendations that do not respond to the specificities of young women and girls with disabilities' experiences.
- 3.5 While the focus and the title of the Royal Commission's only hearing into the experiences of women and girls with disability changed dramatically throughout the time WWDA was conducting research for this submission, the research questions for this were developed according to the original focus of Public Hearing 17 'The Health and Safety of Women and Girls with Disability.'
- 3.6 Based on the feedback received from research participants, this submission details the experiences of young women and girls with disability in regards to accessing healthcare, supports and services, navigating education, employment and the community and analyses these in relation to the international human rights of women and girls with disability.
- 3.7 To be true to the feedback given by participants, this submission incorporates direct quotes and anecdotes from young people who participated in the survey focus groups. All quotes are de-identified for the safety and protection of participants. Consent was obtained by the participants to include their contribution in the report.
- 3.8 Throughout this submission, we refer to 'disability' as it is defined under the Human Rights Model of Disability¹⁹ which is codified in the CRPD and is distinct from the Medical Model of Disability, which views disability as a 'deficit' within the individual.²⁰ As explained by the United Nations CRPD Committee:

The human rights model of disability recognizes that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights. It acknowledges that disability is one of several layers of identity. Hence, disability laws and policies must take the diversity of persons with disabilities into account. It also recognizes that human rights are interdependent, interrelated and indivisible.²¹

- 3.9 Consistent with the Human Rights Model of Disability, young women and girls with disability, who are the subject of this submission, have fundamental human rights as individuals and under international human rights instruments, including the CRPD, the Convention on the Rights of the Child (CRC), the CEDAW and all four other human rights treaties to which Australia is signatory: the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), and the United Nations Declaration on the Rights of Indigenous Persons (UNDRIP), which Australia endorsed in 2009.²²
- 3.10 In this submission, we draw on these instruments as the basis to which Australia must adhere as a signatory and discuss how actions must be taken to improve the experiences of young women and girls with disability which were highlighted in WWDA's and CYDA's research findings.



4 RESEARCH DESIGN AND PARTICIPATION

4. RESEARCH DESIGN AND PARTICIPATION

- 4.1 The research project conducted to inform this submission was a collaborative effort between Women with Disabilities Australia (WWDA) and Children and Young People with Disability Australia (CYDA) to collect information on the experiences of young women, feminine-identifying and non-binary young people with disability that could be provided to the Royal Commission.
- 4.2 This project used a mixed-methods study, which was co-designed with people with lived experience of disability, including young women, feminine-identifying and non-binary youth under 30 years of age. Focus groups and an open-ended survey were the primary methods of data collection, selected for their suitability for capturing qualitative data on the lived experiences of participants.
- 4.3 Purposive sampling was used to recruit focus group participants, according to predetermined criteria. Participants were required to be young women, feminine-identifying or non-binary people with disability living in Australia, aged between 15-30 years.
- 4.4 The study was advertised via WWDA and CYDA's social media platforms, newsletters, websites and emails; and participants were able to register for the focus group via a form offered in multiple accessible formats, including online and in downloadable word documents and Easy Read.
- 4.5 Three focus groups were conducted over Zoom in September 2021, each with facilitators from WWDA and CYDA. There were 36 focus group participants in total - 16, 8 and 14 respectively. Each session consisted of introductions, an ice breaker exercise, information about the Royal Commission and the intended project outcomes, break for accessibility and a lengthy discussion on the experiences of participants. The discussion section was co-facilitated by a member of WWDA's Youth Advisory Group and participants were encouraged to engage at a capacity they were comfortable with, switching cameras off when required, and contributing via speech and/or by using the chat function. A health and wellbeing officer (who had experience and qualifications as a counsellor) attended each session to provide support throughout and post-session.
- 4.6 A mixed-methods survey was also included to offer young people with disability an alternative format to share their experiences. The survey was collaboratively designed by WWDA and CYDA and distributed using Survey Monkey. The survey was live between 6 September 2021 and 30 September 2021 and consisted of 10 multiple choice questions and 12 open-ended questions. There were 21 survey respondents.
- 4.7 Quantitative data about the demographics and intersectional identities of participants was captured via a consent form for focus group participants, and via multiple choice questions for the survey respondents. Thematic analysis was used to elucidate key themes in the data.
- 4.8 In total, 60 young women feminine-identifying and non-binary young people with disability from every state and territory across Australia participated in the focus groups and the survey. It must be noted that the composition of this sample reflects specific, lived experiences of disability. While it is not a representative sample of all young Australians with disability, it provides a "rich snapshot" of the experiences, issues and challenges faced by young people with disability.²³

Research Questions

- 4.9 The research questions for the focus groups and survey were designed in accordance with the Royal Commission Terms of Reference, and were centred on developing an understanding of:

- The intersectional experiences of young women and girls with disability;
- All forms of violence against, abuse, neglect and exploitation experienced by women and girls with disability in a range of settings and contexts, including the home, workplace, and when accessing health and support services;
- The quality and safety of these services;
- What can be done by governments, institutions and the community to prevent and better protect young women and girls with disability and promote a more inclusive and supportive society.

4.10 In designing the research, WWDA and CYDA recognised that the terms ‘violence’, ‘abuse’, ‘neglect’ and ‘exploitation’ are complex, and that their meanings and relevance to lived experience are subjectively and diversely interpreted. In some cases, these terms may not be familiar or recognisable to people with disability, and in other cases they may be disconcerting, upsetting or triggering, particularly for young people.²⁴ To address the barriers that using these terms may place on the study, this project framed research questions in a more generalised way, using words such as ‘barriers’, ‘challenges,’ ‘safety’ and ‘experiences.’

Ethical Considerations

- 4.11 Key ethical considerations pertain to the risks associated with participants who experience multiple forms of marginalisation, and to the sensitive and potentially distressing nature of the topics discussed.
- 4.12 Throughout the research, a number of measures were taken to minimise risk of harm and discomfort to research participants and ensure research was conducted in the spirit of beneficence. When organising the focus groups, it was ensured that all facilitators had a basic understanding of trauma-informed care and valid Working with Children or equivalent certification. In each of the focus groups, an experienced counsellor was also present and available to support participants and provide referral to specialist services where required.
- 4.13 Participants were able to contact facilitators throughout the process to ask questions and make informed decisions about their participation, with the option to withdraw at any time. All participants have been de-identified in this report, and data will be held securely as per WWDA’s Privacy Policy, which is in accordance with the Australian Privacy Principles and 1988 Privacy Act.

Representation

- 4.14 In total, 60 young women feminine-identifying and non-binary young people with disability from every state and territory across Australia participated in the focus groups and the survey.

Geographical Location

- 4.15 Of the focus group participants, 52.5% were from Victoria (VIC); 12.5% from Tasmania (TAS); 12.5% from the Australian Capital Territory (ACT); 7.5% from New South Wales (NSW); 3.75% from Queensland (QLD) and 2% from Western Australia (WA). Of the survey respondents, 33% were from VIC; 23.81% from TAS; 9.52% from NSW; 9.52% from WA; 9.52% from QLD; 4.76% from ACT; 4.76% from South Australia (SA) and 4.76% from Northern Territory (NT). 23.1% of focus group participants and 19.04% of survey respondents identified as being from a regional or remote area.

Age

4.16 Of focus group participants, 5.13% were under 18; 38% were between 18-25 and 56% were between 25-30. Of survey respondents, 15.79% were under 18; 31.58% were between 18-25 and 52.63% were between the ages of 25-30.

Gender

4.17 Of focus group participants, 74.3% identified as female, and 25.6% identified as non-binary (including 2.6% who also identified as gender queer, and 2.6% who also identified as a trans-woman). Of survey respondents, 76.19% identified as female, 9.52% identified as non-binary and 4.76% chose not to respond.

Cultural Background

4.18 Of focus group participants, 15.4% identified as culturally and linguistically diverse (CALD); 5.1% identified as a refugee; 2.6% identified as a migrant and 2.6% identified as Aboriginal or Torres Strait Islander. Of survey respondents, 9.5% identified as CALD, and 24% identified as a migrant.



5 INTERSECTIONALITY

5. INTERSECTIONALITY

- 5.1 Throughout the consultations, young people made clear that consideration of intersectionality is important when considering their experiences. In particular, participants highlighted how their gender combined with their disability had contributed to their experiences of discrimination throughout their lifetime.

“I have found that being a woman, female presenting, has had a big impact on my experience of disability. I was only recently diagnosed with ADHD, which is really, common for neurodiverse women, and non-binary people as well. It is not the stereotyped view of the condition that everybody has, so it was just never picked up.”

“As somebody who is non-binary and asexual, it makes me quite nervous to even disclose my sexuality and gender identity, because a lot of people think that is a disorder of itself.”

- 5.2 Additionally, many participants discussed their experiences as not only young women and girls with disability, but also as young people who are LGBTIQ+, culturally and linguistically diverse, First Nations, from low socio-economic backgrounds and rural and regional locations; exemplifying that understanding their experiences requires intersectional analysis.

“It is hard to summarise what the key issues, barriers or challenges are, because being a multiply marginalised person is obviously incredibly hard and elements of your identity are constantly erased. But I think the biggest thing for me has been that whenever trying to access support or community for a specific element of my identity there is not the capacity for services supposedly to engage the other parts of myself.”

- 5.3 Intersectionality is an analytic tool which enables us to better understand both the multiple identities of an individual, and the compounding effect of these identities on their lived experiences. Intersectionality allows us to understand how an individual’s identities relate to systemic processes and subjective experiences of disadvantage, marginalisation and exclusion.²⁵ People with disability face significant barriers to having their needs met across all areas of healthcare, education and employment, placing them at a higher risk of developing co-morbidities and secondary conditions which can have devastating impacts on both quality of life and risk of premature death.²⁶ People with disability also experience violence, abuse, neglect and exploitation at higher rates than the general population, often in ways that pertain directly to their disability.²⁷ These experiences are compounded upon by intersectional dimensions such as age, sex, gender, sexuality, intersex status, religion, class, and ethnic and racial background.

- 5.4 For instance, women with disability experience unique intersections of social attributes which increase their vulnerability to experiencing particular kinds of violence, such as much higher incidence of sexual and physical abuse.²⁸ The transgender community have higher levels of disability than the rest of the population, and trans people are more prone to suffer from mental health issues related to dysphoria and experiences of prejudice.²⁹ Transgender people also face increased risks of physical and sexual assault, and face greater discrimination when accessing housing;³⁰ and report significant issues with accessing supports and healthcare when managing disabilities and chronic conditions.³¹ In consultations with young people which informed this paper, numerous participants spoke about these difficulties:

“I’ve found that organisations in general are not very LGBTIQ+ or trans friendly. Things like Centrelink only having male and female options for gender. Organisations only have gender titles like Miss or Mister, and no option not to put one down. Same

with organisations where they don't use your preferred name they will only use your legal name to communicate with you. That is an issue I've had a someone that is non-binary trying to access [supports]."

"[Queer] networks are really economically and emotionally under-resourced. These are typically communities that have less stable economic frameworks for anything more divergent than heterosexual couples, who have steady legal agreements. The further you get away from that concept, the greater your economic risks are. And the fewer opportunities you have to access things like financial stability, and housing stability and security, which then lets you access formal or informal disability support. The fact that I don't have a primary partner ... means that I don't have what, for example, the NDIS considers a built in informal support system and that, even though I do have an amazing support network in some ways, we are not backed up by frameworks and structures that actually make that efficient enough to do, and keep doing, without just continually burning each other out."

"Most LGBTIQ+ places aren't accessible to those with disability in a variety of ways and that needs to change."

"As a disabled woman, I find I am supposed to do research to get around in my life. For example, I have physical access needs, Cerebral Palsy. But also, autism, and I am a member of the LGBTIQ+ community. I find focus a lot on my physical needs, so my other needs are not considered."

"Pride events are also usually very inaccessible."

"Most LGBTIQ+ services are not accessible physically and in other ways."

"So I think when you are young and disabled and if you are queer, you cannot be those things at once because we are too complicated."

- 5.5 Young people also face specific barriers, with approaches to change-making often centred on the needs of adults or organisations rather than those of youth.³² This is compounded by a confluence of factors that prevent their active participation in change-making activities, such as social and cultural attitudes towards disability, low expectations and assumptions about their capability, negative stereotypes, issues of inaccessibility and intersectional dimensions of identity.³³

"Children and young are systematically marginalised. Especially, and this might be one of my collection of soap boxes, that we actively restrict children and young people from having diverse communities and networks. So, we actually prevent children and young people from seeing people who are like them and knowing people who are like them. And when you cannot see yourself reflected in the world around you, you have no framework to understand where it goes."

"I think there also needs to be much more emotional support for young people with disabilities, particularly if they develop a disability later in life (15-25ish). I didn't really become disabled until 19, which was obviously extremely traumatic, yet I could not access any support or therapy at all."

"I feel like sometimes people - especially older people in my case parents, teachers and doctors - don't actually want to acknowledge my disability because they think it's too sad to have me, a 16-year-old, identify as disabled because I am young and should be living my life freely. But with this thought they treat me like I put this on myself or like I chose to be disabled. This makes me feel like less of a person because now, according to them, my situation is too sad to be acknowledged as real?"

- 5.6 For young women and girls with disability, who also experience other forms of marginalisation, the situation is even more complexed and multi-layered. This is clear in the following anecdotes from young people who talked about being culturally and linguistically diverse, First Nations, from low socio-economic backgrounds and rural and regional locations.

“I am a person of colour and from a refugee migrant background, [which influences] how gender and disability play into how situations and support play out. There really is none. It is really hard to get that nuanced support because there are so many moving parts in delicate situations. And it doesn’t help that in the advocacy space, it is heavily dominated by white people. And that is not really comforting or representative of such a diverse population.”

“Something I want to touch on is how culture and how people from CALD or refugee/ migrant backgrounds experience disability and especially how it plays into their gender roles within a certain culture and how it is dealt with and supported and so on and so forth. Because when you go to a disability support organisation or service, and you say, “I need to do this in my daily life.” There is often little understanding as to why that is if it pertains to gender specific roles within your culture. And then even more if it is a kind of specific ritual, tradition, or religious practice, and oftentimes communities are not supported in making cultural events accessible.”

“While we can’t hide our skin colour as people of colour, there are still two closets that we live under. One is the LGBTIQ+ closet that we live under and the other is the disability closet. So while I came out as a bisexual Muslim woman in the community, I can never imagine opening my disability closet and going openly about my disability in the community. I always think it was a mistake to come out as a bisexual woman, because that is all that I am now. It is very difficult with the way the media approaches you with interviews and starts harassing you and misconstruing a lot of what you say. This year for example they published an article about queer people from Muslim backgrounds and that had to be deleted the same day because of the amount of backlash they got from people on Facebook comments. Whereas a similar article was posted about a white Christian man who was also having experiencing issues with being queer and dating, but everybody saw him as an inspiration. It didn’t make any sense to me. With regards to disability, it is something I can never say out loud to anybody in my community and in my family. They also live with that orthodox belief that it has to be something like losing a leg or losing an arm, that is considered a disability ... It gets very difficult, partially also because I don’t understand what their plan is. I have ageing parents and my mum is developing arthritis, so now it will be like a disabled young woman looking after a disabled mum. That’s becoming a very common thing amongst migrants and many young Australians, because we have so much experience with our own disability, that we become carers of other elders in our families with disability.”

“There are a lot of challenges as a person of colour talking about disability because... you think ableism in Western society is extreme, it is so much worse and more taboo and more stigmatised [for us] ... Ableism is rife. It is very internalised, particularly if you come from a refugee background, if your parents came to Australia and escaped a war, and you have a roof over your head and food on the table and no matter what you are going through it cannot be as bad as escaping the war. So not getting the support because you are not going through anything nearly as hard as what you would be going through if your parents had not escaped.”

“I’m too Pakistani for Australians, too Australian for Pakistanis, too Muslim to be Bi, too Bi to be Muslim.”

“I think one of the biggest issues for me is having come from a low socio-economic background, my mum is very disabled as well, and doesn’t have much money. And then, myself, also being a low socio-economic person, as a lot of disabled people are, they are forced into. It has been really hard, you’re either at the mercy of the public system, which is not well-funded, long wait times, or you have to try and scrounge money for the private system, or find some very caring doctors ... I found that is very hard, you can not just go out and get the things you need, you need to make choices about whether you buy medication, or other things in your life.”

- 5.7 From these quotes, it is clear that in seeking to understand and improve upon the lived experiences of young women, feminine-identifying and non-binary youth with disability, and to address the complexity of multiple barriers and forms of discrimination they face, it is imperative that an intersectional approach be implemented.
- 5.8 While the Terms of Reference establishing the Royal Commission require examination of the intersectional dimensions of violence, abuse, neglect and exploitation, we note that to date there has been minimal dedicated focus on the intersection between disability and gender. The Hearings, community forums and the Issues Papers have been gender neutral with little to no identification of the specific experiences of women and girls with disability.
- 5.9 Intersectionality is a key element of the human rights approach to disability required by the CRPD.
- 5.10 People with disability, including women and girls with disability have their rights articulated and upheld through all the international human rights treaties to which Australia is a party. However, until the development and adoption of the CRPD, the application of human rights to the issues and concerns of people with disability were largely invisible and not addressed.³⁴ The CRPD is a response to this lack of recognition of the rights of persons with disability.
- 5.11 Until the CRPD, the specific issues and concerns for women and girls with disability were mainly articulated, in varying degrees, within the jurisprudence developed under the CEDAW and the CRC.
- 5.12 However, the CRPD explicitly acknowledges different layers or intersections of identity, through its preamble paragraph (p):
- “Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple and aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status”.*
- 5.13 Intersectional discrimination acknowledges that people with disability do not experience discrimination in the same way as a homogenous group. It recognises the “multidimensional layers of identities, statuses and life realities” that “interact with each other at the same time in such a way as to be inseparable.”³⁵
- 5.14 Intersectional discrimination is specifically articulated for women and girls with disability and children with disability in the CRPD through the inclusion of article 6, Women with disabilities and article 7, Children with disabilities.
- 5.15 Intersectional discrimination recognises the diversity of women and girls with disability:
- “They include indigenous women; refugee, migrant, asylum-seeking and internally displaced women; women in detention (hospitals, residential institutions, juvenile or*

correctional facilities and prisons); women living in poverty; women from different ethnic, religious and racial backgrounds; women with multiple disabilities and high levels of support; women with albinism; and lesbian, bisexual and transgender women, as well as intersex persons.”³⁶

- 5.16 Article 6 recognises “that women and girls with disabilities are subject to multiple discrimination”, which establishes “the first binding intersectionality clause in a human rights treaty.”³⁷
- 5.17 Importantly, article 6 is a cross-cutting article that relates to all other articles of the CRPD.³⁸ This means that the issues and concerns of women and girls with disability must be included in all actions to implement the CRPD, including the implementation of
- “positive measures... to ensure that women with disabilities are protected against multiple discrimination and can enjoy human rights and fundamental freedoms on an equal basis with others.”³⁹*
- 5.18 Guidance on interpretation and implementation of article 6 has been developed by the CRPD Committee in its General Comment No. 3 (2016) on women and girls with disabilities.
- 5.19 This General Comment highlights that women and girls with disability experience the “same harmful practices”⁴⁰ committed against women without disability but also experience specific and unique forms of violence. This includes the absence of free and informed consent and legal compulsory detention and treatment, economic exploitation, violations of sexual and reproductive rights, and forms of violence that constitute torture and ill-treatment, such as forced or coerced sterilisation, the administration of electroshock treatment and the use of chemical, physical or mechanical restraints, and isolation and seclusion.⁴¹



6 KEY ISSUES

6. KEY ISSUES

- 6.1 Throughout the survey and consultations which informed this submission, participants raised a number of issues, which we have thematised in this section under five key headings: Healthcare, Access to Supports and Services, Education, Employment, Community Inclusion and Safety from Abuse and Violence.
- 6.2 While participants rarely talked specifically about violence, it must be recognised that many of the experiences discussed throughout this section constitute forms of violence, abuse, neglect and exploitation under the CRPD.
- 6.3 Importantly, the Royal Commission needs to recognise that violence, abuse, neglect and exploitation of women and girls with disability cannot be confined to an examination of domestic and family violence, which is often the only area where there is focus on women and girls with disability. Violence abuse, neglect and exploitation is often used in non-domestic settings including group homes, institutions and hospitals.
- 6.4 It must also be recognised that the issues, barriers, discrimination and human rights violations that are discussed in this section disproportionately affect young women and girls with disability and must be identified, analysed and addressed by the Royal Commission.

Healthcare

- 6.5 The key issues raised by participants in regard to accessing health services were facing barriers to diagnosis, experiences of discrimination and dismissiveness when interacting with medical professionals, and difficulties associated with a lack of holistic health care.

Discrimination and Dismissiveness

- 6.6 One of the most common experiences shared by participants was being dismissed and discriminated against by healthcare professionals when seeking diagnoses, medical treatment and support, which reflects a broader pattern of ableism in society, where the systemic discrimination against and devaluation of people with disability, perpetuates harmful and ingrained negative perceptions, misconceptions, patronising attitudes and unjust behaviour towards people with disability across all areas of community life, including among medical professionals and service providers.⁴²
- 6.7 Many participants stated that medical professionals generally lack awareness and understanding about disability and lack the capacity to work with patients with disability in a way that is informed, safe and empowering. Overwhelmingly, participants use words such as “gaslit”, “belittled”, “infantilised” and “disbelieved” to describe the way they are treated when discussing their symptoms with and seeking help from medical staff. Overwhelmingly, participants emphasised how their age and gender as young women and girls with disability prevented them from having their agency respected in healthcare.

“With having invisible disabilities - people say ‘but you don’t look sick, you don’t look disabled’ or saying ‘you’re too young to be sick and or disabled.’”

“When you disclose something [with doctors], they then check with your parents to make sure we aren’t ‘lying’”

“When you talk to the professional about something concerning your parents and they then go and disclose almost everything if not everything you said about them to your parents.”

“I have had doctors say that I am just too young to be feeling this kind of pain, and I am searching for pain medication to get high on,”

“I have experienced a lot of dismissiveness about my levels of pain. I got a really bad allergic reaction, which you would not think would be put down to mental health issues, but when I got sent to an allergy specialist to review it he said, “Are you sure it was not just a panic attack?”... I have had a lot of experiences with medical sexism. There is a lot of gas lighting, and minimisation of symptoms.”

“I called lifeline during crisis one day, I was told to calm down, have a cup of tea and talk to my doctor.”

“I often feel like I’m being infantilized because of my disability or disbelieved because I’m a woman when I attend health services. If I express discomfort with a plan for managing my health, I’m treated as if I’m being defiant or a “fraidy cat” instead of having my concerns addressed. And I don’t feel safe making complaints about these interactions because there are only a few services available for my disability in the adult sector and I feel trapped with these providers because there’s literally no one else who has the knowledge to help look after me. Doctors need to understand that I’m the only person in the world who’s been to every one of my appointments and that that means I know more about my disability than they do. They don’t go to all my different specialists and therapists and allied health appointments - they only see things from their single perspective. But I have the breadth of knowledge about my entire disability and that needs to be respected and believed.”

“People talk about me like I am not in the room. I want to be treated like a human who can make decisions about my own life.”

“Believe us. When we say we’re experiencing symptoms, when we’re worried about something, when we say something won’t work. We know our bodies and we deserve to be active participants in the decision-making process about what happens to our bodies.”

“I have something called Lambert-Eaton syndrome which is similar to MS but not really. As well as having that, I have recently been diagnosed with a functional neurological disorder so that is something that doesn’t have a root physical cause but is more related to the software of the brain. I was diagnosed with that by a psychiatrist, and I’m lucky enough to be treated by a psychologist now for complex PTSD for medical trauma and all the gas lighting and stuff that I endured getting that physical diagnosis. So I deal with that, and the chronic pain issue. Being a young person, having to go through four or five appointments a week with all the different doctors in all of the different hospitals and I have had so many people tell me that what I am going through, their exact words of course weren’t always this, but that it is not real. It hurts, it really does.”

“Medical professionals being unfamiliar with my conditions and me having to advocate for my medical needs when unwell has been challenging. We need more open medical professionals who are willing to listen to a patients experience that may contradict the textbook.”

“I had an absolutely horrific time in hospital before I got my endometriosis surgery, where a practitioner said to me “your pain is not real, you’re making it up, we need to get you out of hospital right now because you’re wasting resources”. And I managed to convince them to do the surgery and I had the worst, most severe endometriosis that you could have, and it was a four-hour surgery and he said, “I wasn’t expecting it to be that long.” And I was like “that is because he did not take me seriously”, you know?”

“Disabled women deserve to feel safe and comfortable in all aspects of life but especially when it comes to accessing healthcare. We do not need to be belittled and gaslit by doctors and nurses.”

“It is exhausting. I fight for myself every day to get the care, to look after myself, to convince people of my illnesses.”

“I struggle with mental health. Some doctors and nurses discriminate against me because of my disability, and they just say “this is bad behaviour and just stop acting this way” when I have a meltdown because of sensory overload. And they expect me to just stop behaving that way. You see a lot of nurses and doctors in hospitals, and they don’t understand disabilities and mental health, they just think you are behaving badly, really.”

“[There needs to be] a focus on bodily autonomy, more explanation of medical procedures, especially when conducted by male doctors, and what clothing will be removed/body parts touched”

“It feels humiliating to have to ‘prove’ what is part of my day-to-day life again and again”

“The re-telling and need to neatly and eloquently package our experiences to be believed is soul sucking”

“Doctors saying nothing is wrong with you because one test came back normal.”

“The professionals have a catchphrase “it’s all in your head.”

- 6.8 These experiences not only reflect the specific discrimination faced by young women and girls with disability in healthcare, but also speak to the broader experiences of women and girls with disability generally. As discussed at length in WWDA’s previous work,

[Women with disability] continue to represent one of the most excluded and marginalised groups of women, subject to widespread discrimination, systemic prejudice, paternalistic and ableist attitudes that denigrate, devalue, oppress, limit and deny their potential and their rights and freedoms. They are often not afforded dignity, recognition, respect, agency and/or autonomy. Regrettably, women and girls with disability in Australia continue to be denied the right to participate in, and remain largely excluded from, decision-making, participation and advocacy processes, about issues that affect their lives and those of their families, communities and nations. Too often, they have their views ignored or disregarded in favour of ‘experts’, ‘professionals’, parents, guardians, and carers, as well as representatives of organisations not controlled and constituted by people with disability themselves.⁴³

- 6.9 In the consultations with young people that informed this report, it was clear that other aspects of intersectionality also impacted upon their experiences of discrimination and being denied agency in healthcare. Alternative-appearing participants, particularly those who are gender diverse, share experiences of being dismissed as “drug seeking” when attempting to access treatment and medication. Assigned female at birth (AFAB) participants talked about experiencing medical sexism as their symptoms are constantly dismissed as anxiety, depression or other mental health issues; trans-women and non-binary participants shared similar experiences, noting that their gender often becomes the point of focus, even when it is unrelated to their disability and medical concerns; and CALD individuals and their families said they had been the recipients of racism.

“After doctors find out that English is not my and my family’s first language, we

experience racism as they seem to suddenly need to treat me, and particularly my parents, differently in a very negative way. Because my parents often need to come to appointments with me and they struggle to understand the doctors, so I often end up explaining these complex medical terms between my doctors and my parents.”

“In telling a Dr what my pronouns were, the first response was, “Are you seeing a therapist for that? There is something wrong with you? What is a pronoun? There is something wrong with you, you better see a therapist about that.” So, telling me I am wrong, that I cannot possibly be non-binary and it cannot possibly be who I am simply because of his social constructs, he was an old white man and I know I am generalising but you know, it happens. I have had nurses.”

“Doctors and other health professionals openly misgender me and choose to and know for a fact - I will have signs on my door, when I spend extended periods of time in hospital, literally signs on my door saying “hi, these are my pronouns, if it is too difficult for you just use my name” you know. And they would just purposely misgender me, saying “ahh you’re making my life too difficult”. Like it’s so difficult. So, you have that component of who you are and that identity.”

“Whenever I mention my trans-ness in appointments, it becomes the focus when I’m there for something different, and their focus on it is still transphobic.”

“Often people with complex health issues sacrifice queer/trans-friendly health services for services that can treat their complex issues. Essentially you have to choose to expose yourself to medical trauma to receive treatment.”

- 6.10 In the consultations, it was made clear that many doctors and other medical service providers are not informed about or accommodating of the intersectional identities of their client-base, i.e., the spaces are not autism friendly, gender-diverse friendly or LGBTQIA+ friendly.

“Having more diverse and lived experience medical professionals would be such a game changer for diagnosis and treatment/care.”

Service fragmentation and inefficiency

- 6.11 Another recurring shared frustration among participants is the inadequate and fragmented nature of healthcare services. Most participants had a considerable number of different practitioners that they need to consult with on a regular basis, with very little communication between different providers. The lack of connection between different specialists presents a number of challenges, placing a high amount of pressure on young, disabled people to keep on top of planning, paperwork and correspondence.

“It would be exhausting enough without being disabled, to constantly be chasing up doctors, making phone calls and trying to coordinate different services while struggling with day-to-day life and work.”

“So, I talk about this specific thing with this specific practitioner because I know they are cool with basic feminism, maybe, but not so good on pain medication or whatever. So I will talk to this other person about this other thing, and you compartmentalise your life down and then the big trends of your health that should be picked are not picked because you know you can’t talk to anyone about the whole picture, and also no one is talking about the whole picture.”

“My biggest disability is my autism and my mental health, but it seems that any time I mentioned my mental health with autism it gets disregarded as a co-morbidity and this is a huge problem because throughout this year I’ve accessed psychiatric services so often, like going into hospital and stuff, it is not autistic friendly at all let alone disability friendly. It is so frustrating to go into the services because you are really desperate but then not have anyone there who can actually help you let alone understand you”

“Correspondence and records are ridiculous to keep track of! I have in excess of 300 pages and a long history of practitioners which makes it so hard when you’re trying to cover off everything with new health practitioners”

““Care” lol is so dang fragmented”

“I often say I’m a full-time sick person because I spend so much time on calls, organising and attending appointments, paying for and claiming benefits, coordinating with different practitioners and clinics - that’s not even just being sick and disabled!”

“It would be exhausting enough without being disabled, to constantly be chasing up doctors, making phone calls and trying to coordinate different services while struggling with day-to-day life and work.”

“I have been lucky this year to find at the Royal women’s Hospital they have a pain clinic, so they actually do a little call where four or five of my different professionals will talk about where they are at with me in the various facets of my treatment. I think that has helped from one perspective, but then that is only professionals who are related specifically to my women’s pain issues. My rheumatologist is not linked to that, and my GP isn’t either. I have been thinking about ways to coordinate that.”

“So I talk about this specific thing with this specific practitioner because I know they are cool with basic feminism, maybe, but not so good on pain medication or whatever. So, I will talk to this other person about this other thing, and you compartmentalise your life down and then the big trends of your health that should be picked are not picked because you know you can’t talk to anyone about the whole picture, and also no one is talking about the whole picture.”

“Not having your care put into one spot. I purposely didn’t opt out of My Health record because I wanted all of my crap together which is the whole point of my health record, and all my crap is not together, it is so ridiculous! As an example of how ridiculous this is, if you have multiple chronic illnesses and complex issues like Ehlers Danlos Syndrome etc. Doctors do not include you in the correspondence. They talk to each other and send things to other GPs, they assume that whoever they send correspondence to will do their job and follow-up. The thing is, not including the patient in their care actually backfires.”

- 6.12 This fragmentation is exacerbated for young women, feminine identifying and non-binary young people with disability who identify with additional marginalised cohorts. As WWDA has often discussed in its ongoing advocacy and submissions, women with disability often struggle to access appropriate services for their needs, as too often services cater to women, or people with disability, or LGBTIQ+ or CaLD people, but are almost never equipped to support women and girls who sit across multiple identities. As stated in previous WWDA submissions, women with disability seeking support are caught in a cycle of successive referral, without ever receiving appropriate or timely interventions.⁴⁴

“It is so difficult to find spaces, whether they are medical spaces, or allied health spaces, or social spaces or anything, that are safe and informed across all my identities. If I found a space that is queer friendly, I then have to go through, and check

is it fat friendly? Is it disability friendly? Is it neuro-divergence friendly? And frankly, finding something that sums up all of those in medical and allied health and support fields in general, is very, very small ... if I'm in a crisis, the crisis services that are technically available to me, are unlikely to be safe spaces ... I have to avoid accessing services that could be useful to me, because of the sheer risk involved."

"When looking to access a service/specialist/system, my decision-making process is centred around what is the LEAST harmful and violent as opposed to what is emotionally, physically and spiritually safe."

6.13 One area in which fragmented healthcare results in severe inadequacies for women with disability is in sexual and reproductive health services. Too often, sexual and reproductive health services and information excludes young women and girls with disability.

6.14 The UN CRPD Committee in its General Comment 3 (Women and Girls with Disabilities) has noted that women with disabilities face barriers in accessing health services, particularly those related to sexual and reproductive health:

"Women with disabilities face barriers to accessing health and rehabilitation services; these include but are not limited to: lack of education and information on sexual and reproductive health and rights; physical barriers to gynecological, obstetric and oncology services; and attitudinal barriers to fertility and hormone treatments. In addition, physical and psychological rehabilitation service provision, including counselling for acts of gender-based violence, may not be accessible, inclusive, age or gender sensitive."⁴⁵

6.15 The CRPD Committee notes that these barriers are associated with a number of factors, including service fragmentation, a lack of training for providers and entrenched ableism based on harmful stereotypes which assume they are asexual; all of which are reflected in anecdotes from youth participants.

"One of the biggest issues that I have faced as a femme-presenting (disabled) person is sexual health and reproductive health and where we can get that kind of information, how readily it is available, and how inclusive it is of all body types. I have a physical disability, and so it is hard to find that kind of information."

"And doctors recommending disabled people don't have children if their disability is genetic."

"I don't feel represented in sex education. All het normative, without any recognition of differences in gender and sexual identities."

6.16 In such a fragmented system, major health trends are often missed when different practitioners fail to interact, placing additional responsibility on young people with limited medical literacy to catch what practitioners fail to. This is made even more difficult when doctors "dump" their patients, and new practitioners need to be brought into the fold, an experience a number of participants shared.

"Getting ghosted by doctors is a CONSTANT!"

"Getting dumped as a patient seems to happen far too often."

Barriers to diagnosis

- 6.17 Another key theme that was discussed by participants at length was facing barriers to assessment or diagnosis, most commonly as neurodivergent people who were Assigned Female at Birth (AFAB).
- 6.18 Thirty-six percent (36%) of focus group participants shared experiences of being diagnosed with ADHD and/or ASD in early adulthood, often after years of confusing and harmful misdiagnosis and negative interactions with medical staff.

“Issues with medical professionals questioning “why” you need a diagnosis. I.e., questioning why you need a tilt table test or why you want to seek a diagnosis for Autism. Isn’t it enough that you want to know what’s going on with your own body?”

“Even just trying to be diagnosed as an AFAB (Assigned Female at Birth) person is extremely difficult. Especially if you look healthy like I do, I’ve been told a number of times by many different doctors that I was faking it, that it is just anxiety or some kind of mental disorder.”

“I think it is really appalling that to get a diagnosis of adult ADHD, many people have to bring parents into their diagnosis process. When you consider the levels of depression and anxiety in people who have ADHD, and are diagnosed later in life, while it is not obviously always connected, this quite often is because of parents. So, I am increasingly hearing stories of people having to bring abusive parents into their diagnosis, into their appointments, to gain access to the accommodations that they need, and I just find it so appalling. Like, I intentionally have not told my mom about my diagnosis, and I am financially OK, but I did not have to. But there are many people who do not have the choice, and I think the trauma it creates about living with that...it makes me really upset to think about how scared I am just to tell my mum. She is not abusive either, she is just a problematic human, and to tell her that I have ADHD is so stressful and traumatic, I can’t imagine what it would be like, if you had a parent who is actually abusive, and you had no other choice.”

“Being a woman, female presenting, has had a big impact on my experience of disability. I was only recently diagnosed with ADHD, which is really really common for neurodiverse women, and non-binary people as well. It is not the stereotyped view of the condition that everybody has, so it was just never picked up. I’m nearly 30 now. It is a long time of not getting support which would have been hugely impactful for me.”

“I was sexually assaulted when I was 17. I am 21 now. It was not until I was in hospital, a mental health hospital with post-traumatic stress that they said, “You might be autistic.” And they were able to diagnose that for me when I was 19. But I think if I had had the diagnosis earlier, my boundaries would have been better, and perhaps so would not have been sexually assaulted. And I think it is really sad, and I think it is just really terrible, but I think it is also something that is common.”

“I was misdiagnosed with a bunch of stuff for years, a whole long list of depression and complex PTSD, I was having an autism assessment at one point. And anxiety. Just the whole list of everything you could find in the DSM. And it turns out that pretty much the whole time it was ADHD because it doesn’t present the same sometimes in AFAB people as it does in AMAB people. And all those issues that I have been having for years and years could have been fixed if they were just listening to me and seeing what was happening in my life. Instead, I was given horrible medication. I was given really strong antipsychotics at one point because they were like “This will make her quiet and stop talking at us” It was horrible.”

“The barriers to diagnosis in the first place can be really challenging as well! I find it fluctuates between assuming I cannot do [insert task here] and then expecting me to be able to do things that I find highly challenging!”

“Also let’s remember the problematic nature of so many standardised assessments, particularly for people with disability with complex communication/support needs and CALD individuals!”

- 6.19 Participants overwhelmingly described gendered misconceptions and stereotypes about ADHD and ASD as the main reason for their missed or incorrect diagnosis. ADHD is commonly missed among young people who were Assigned Female at Birth (AFAB). The diagnostic criteria for ADHD, which was developed for children, has a strong gender bias and focuses heavily on expressions that are common to young people who are Assigned Male at Birth (AMAB). As AMAB people are more likely to exhibit symptoms that are more outwardly disruptive in social environments they are more frequently referred for assessment, while AFAB people remain underdiagnosed and undertreated. Similarly, young AMAB people are around four times as likely to receive referrals for an ASD assessment and be diagnosed than their AFAB counterparts, who are generally more adept at masking their symptoms.⁴⁶ Like ADHD, AFAB presentations of ASD are more subtle than those of AMAB youth, showing fewer stereotypical behaviours resulting in missed diagnoses or misdiagnoses.

“I had a formal assessment when I was six. They did an IQ test or whatever the autism screener was in 1997. And they said, “Cool, you are a girl, and you like people and can make eye contact.” So you are not autistic, but clearly gifted based on your other scores ... Only to come to be 27 a couple of years ago and have a better psychologist say, yes you are also autistic - completely and absolutely— I don’t know why you’re asking, it is ridiculous. And actually having to go back and do a sense of self work, and the perception of self in a cognitive way. For autism, and all the lingo that comes with autism, which I had actually done successfully with all that gifted stuff, because we had been talking and reading about it since I was six. And I knew people. And I talked to other people, and to then get to 27 and be like, “Fuck, I could have done this already”

“The whole idea of diagnosis and functioning labels based on how neurotypicals or non-disabled people experience us and how ‘difficult’ we are in their spaces, is so problematic because I burnt out. I was functioning at the sacrifice of my mental wellbeing, and my home life, and because I was able to get things in at the 11th hour and because I got excited about learning. I just managed to sit through enough, enough, enough and by the time I hit uni, straight out of school, I couldn’t manage it. I had no coping strategies, no awareness, I was trying neuro-typical learning techniques that were not working, and that became internalised as blame and shame, which turned into anxiety that I had to treat without knowing what was going on underneath it. My report cards were great, but we are looking for these little, white boy presentations of [ADHD] when there is so much more to the experience than that. And the ripple on from [me finally being diagnosed] is my sister getting diagnosed and my mum going in for a diagnosis, because they didn’t know any different, it was normalised because my mum didn’t know any different, that’s just how it is, so you do all these counterstrategies which turned into maladaptive, intense anxiety, just to be able to function at a level without getting the help. Unpacking that is a lot of work. It would have been so much better to have been supported in that from the start, rather than unlearn it all, then expecting me to be able to do things that I find highly challenging!”

“As soon as you mention you are a girl with autism people will look at you bewildered because they don’t think it can be true. Just the number of specialists or professionals that I have come across where I tell them I am autistic but also a girl, they do not

comprehend that. There is a myth behind it. I got diagnosed really late as I am almost 21, and I was diagnosed at 19 because professionals were not educated about the fact that girls could also be autistic. That frustration alone going through high school in primary school and nearly my entire life up to this point being undiagnosed, having so many issues, I wonder why the fuck this is? And going to places like headspace where you expect to find help and support and it is covered by Medicare, but they are uneducated as well, psychologists and psychiatrists don't have a clue about disability or anything like that. So, you have to find outside services without realising that is what you actually need. I happened to fall upon getting my disability diagnosis, it did not occur to anyone let alone professionals that I was autistic. And that this was why I was having so many issues throughout my entire life. So, the whole system is uneducated."

- 6.20 Adjusting to a diagnosis later in life can have a significant impact on the mental health and sense of identity among participants, and their ability to form meaningful and supportive social networks⁴⁷. As evidenced by the quoted anecdotes from participants, barriers to diagnosis, treatment and care can have significant negative effects on young people with disability. Denying access to much needed and potentially life-changing medical care, social and psychological support is a form of neglect and can have a significant impact on the mental health and sense of identity among young people.
- 6.21 Additionally, it is already well known that late diagnoses of impairments in women and girls with disability can lead to significant gender inequities in access to supports and services⁴⁸.
- 6.22 For example, while there is no scientific evidence to suggest that men and boys are more likely to be Autistic than women and girls, men and boys make up over three quarters (76%) of National Disability Insurance Scheme (NDIS) participants whose primary diagnosis is ASD;⁴⁹ a statistic which is also reflected across other conditions, and the fact that women and girls still make up less than 37% of total NDIS participants across all states and territories.⁵⁰ While this major gender gap does slightly decrease with the age of participants, individuals who access late diagnoses often still face barriers finding services that are catered to their needs as women with disabilities.

"Another thing is trying to access services specifically for autism as an adult who is AFAB and a level one autistic person. 99% of services for autism are for people that are under 16. It is hard to find services that cater to adults. And then who cater for a level 1 adults who are able to live independently and just need a little bit of extra support, and because of that a lot of the information of autism out there is centred around the male experience of autism, and not women, femme identifying or AFAB people. And that is an issue that I have had."

"There are not enough services for neurodiverse people. We need an understanding that my health is just as important as my education and that not everyone can manage their health around their education."

Cost and inaccessibility of healthcare

- 6.23 Another key, theme that came up during the consultations was the inaccessibility and unaffordability of healthcare in Australia.
- 6.24 Across Australia, poverty is a major structural barrier to accessing adequate services for women with disability. Forty-five per cent of people with a disability in Australia live in poverty.⁵¹ 11.2% of people with disability experience deep and persistent disadvantage,

more than twice that of the national prevalence.⁵² This rate is significantly higher for Indigenous people with disability. 61% of people with disability cannot afford to cover their basic needs on their current income.⁵³

- 6.25 Government pensions are the main source of personal income for 42% of people with disability of working age.⁵⁴ By comparison, wages or salary is the main source of personal income for 68% of people of working age without disability.⁵⁵ The median gross weekly personal income of people with disability is half that of people without disability.⁵⁶ Income, welfare and taxation systems in Australia do not recognise the significant costs of disability that people with disability incur throughout their lifetime.⁵⁷ For eg: research indicates that women with disability spend more of their income on medical care and health related expenses than men with disability.⁵⁸ Women with disability between the ages of 18 and 44 have almost 2.5 times the yearly health care expenditures of non-disabled women. Women with disability between the ages of 45 and 64 have more than three times the average yearly expenditures of their non-disabled counterparts.⁵⁹
- 6.26 While this research is largely based only on adults with disability, it is expected that the barriers to accessing healthcare because of cost and availability would be even more pronounced for young women and girls with disability, who are more likely to be relying on government support, families or carers for their income. The following quotes reflect some of these difficulties.

“I have a medication that is about \$70 and is a little bit cheaper with all brands but even then it is super expensive. If I think about my Trans medical prescriptions, there are certain things that are on the PBS but it is because of cisgender people... Because cisgender people need it, it is on the PBS, but because trans people need certain medications, sometimes they are just not covered. And it is absolutely frustrating.”

“It is very difficult and expensive to access the proper services needed for healthcare. Many people with disabilities are unable to work so have limited money for things like transport to appointments and even booking appointments at all. It is very difficult in rural communities to access things like psychiatric and psychological services as well as even basic health services like a GP. And the journey to then go to the nearest services cost fortunes to drive to and from the centers. [We need] more remote access to health care services and lowering the costs of services such as psychiatry. Possibly even make a payment accessible to people with disabilities in rural communities so that we are an afford fuel and transport costs to get to our appointments”

“Mental health is not actually recognised if you are disabled. So it is a comorbidity, something to do with your disability and not a significant thing, which in fact it is significant always. Mental health is not recognised and it needs to be. It is its own disability within itself and the reason that psychosocial disability exists is because mental health is severe and significant. It is not recognised by the NDIS or Medicare, the 10 sessions you get with a psychologist on Medicare and even though we got extra last year, are not enough to actually have proper care and proper help with your mental health. This is a constant and ongoing problem. Because there are not services that know how to cater towards disabled people which causes more anxiety - it is a horrible circle.”

“Australia needs to sign a Healthcare treaty and Social Security treaties for migrants from non-white majority countries to help people like us as healthcare is too expensive in this country. Telehealth psychiatry is not available in different languages and they tell us that we have to be in rural areas to access E-psychiatry. - E-psychiatry [needs] to be available beyond rural/regional folks.”

6.27 There were also a number of other barriers beyond cost which participants said prevented them from accessing adequate healthcare and services.

“Access to female healthcare providers. Access to advocates to help us attend appointments and make sure we’re getting the care and respect we deserve.”

“Telehealth should be made a permanent service and option available for all health services. This makes appointments much more accessible ... It has been so helpful for me. Noting that I am still seeing my GP in NSW because I haven’t been able to find someone in VIC who can take on all my ‘issues’ and be my champion.”

“Kids Help line to extend the age cut off till 30 for young people with disability.”

“All medical access is audible (GP/HOSPITAL), I am deaf, therefore find these areas difficult to navigate. [We need things like] options for text msg when called by doctors in waiting rooms.”

6.28 In addressing these barriers, it is essential that the Royal Commission include provisions in its Final Report to call on Australian Governments to provide universal access to adequate, affordable and accessible health services, including sexual and reproductive health services and services that provide specialised support to different groups of girls and women.

6.29 The Royal Commission should also examine what other measures need to be taken by Australian governments to ensure that Australia is meeting its obligations under International Human Rights instruments such as the CRPD.

6.30 Article 25 of the CRPD provides for the right to ‘the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’, and States Parties must ‘take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive’.

6.31 The right to health is also found in other international human rights treaties. Article 12 of CEDAW specifically requires States Parties to ‘eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning’ and to also ‘ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period’. Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) provides for the ‘right of everyone to the enjoyment of the highest attainable standard of physical and mental health’. Article 24 of CRC provides for the ‘right of the child to the enjoyment of the highest attainable standard of health’.

6.32 Reflecting on the experiences of the young people who informed this submission, it is clear that a number of actions need to be taken in order to ensure the healthcare rights of young women, feminine identifying and non-binary people with disability to are upheld. While a comprehensive list of recommendations is provided in section 1 of this submission, consideration should also be given to:

- Providing evidence-based training and resources to educate and promote awareness about disability and intersectionality among medical practitioners
- Revising the diagnostic criteria used by practitioners to identify ASD and ADHD at all ages, but particularly among children and young people
- Resourcing systems that create and streamline communication pathways between different practitioners

- Providing accessible information and resources to promote and increase health literacy among young women, feminine-identifying and non-binary people with disability, including in relation to their sexual and reproductive health
- Resourcing the expansion of Telehealth services across all states and territories.

National Disability Insurance Scheme (NDIS)

6.33 In addition to healthcare, many participants shared frustrating experiences about accessing supports through government systems like Centrelink and the NDIS. Overwhelmingly, participants expressed that these services, despite existing to provide essential support to people with disability, are inaccessible.

“NDIS and Centrelink need to be more accessible and not so stingy! We need to be able to live over the poverty line.”

“The NDIS and Centrelink feel structurally created to be hard to access.”

“The whole “there’s too much going on with you, you clearly need more help but we can’t offer it” from services happens ridiculously often. It would be exhausting enough without being disabled, to constantly be chasing up doctors, making phone calls and trying to coordinate different services while struggling with day-to-day life and work.”

6.34 As mentioned previously, it is clear from NDIS participation rates that there are significant barriers preventing women and girls from accessing supports under the NDIS.

6.35 Across Australia, women and girls only make up less than 37 percent of all NDIS participants, and less than 30% of participants are girls under 14 years of age and these statistics have mostly remained unchanged since the commencement of the NDIS, despite ongoing calls from both domestic and international human rights bodies to the Australian Governments to address the poor status of women and girls with disability in Australia.⁶⁰

6.36 The Committee on CRPD, through CRPD General Comment 3 [Article 6: Women with Disabilities], for instance⁶¹ has provided clear and authoritative guidance to States Parties (including Australia) regarding the imperative to employ targeted, extra and specific measures to ensure that women and girls with disability can realise and enjoy their rights on an equal basis as others.⁶² This includes their right to access and receive services and programs – including through the NDIS.

6.37 In line with this guidance, WWDA has repeatedly called on the Australian Government and the National Disability Insurance Agency (NDIA) to implement an NDIS Gender Strategy. However, these calls to date, have not been actioned.

6.38 While there are numerous reasons for the low participation of women and girls in the NDIS, key themes that came up in the consultations included: difficulties accessing diagnosis, paying for the required assessments and reports needed for NDIS applications, the NDIS not recognising certain conditions as disabilities and the emotional and practical pressures associated with navigating complex government systems.

Diagnostic Barriers

6.39 As discussed in the earlier section on health, there are a number of barriers that prevent young women and girls from accessing diagnoses for their disabilities or chronic health

conditions, including diagnostic criteria based on male presentations of conditions and a tendency for certain women and girls to be dismissed by practitioners.

- 6.40 While there is an increasing recognition of the underdiagnosis of certain conditions such as ASD and ADHD in women and girls, young women and girls still reported in the consultations that barriers to diagnosis prevented them from accessing the NDIS.

“If you are waiting to get funding and this requires a diagnosis, how are you supposed to access a diagnosis in the first place? And unfortunately, a lot of universities require this for an EIP. For people that are struggling to get appropriate healthcare, it is very difficult even knowing who to go to. If you go to a regular GP, they might not know anything about autism or specific disabilities ... To me it is quite concerning, as a training allied health therapist, that we still rely heavily on these services and then expect a lot of these young people or autistic adults or disabled adults to source this themselves when they might not have then just make the means to.”

“Often people can’t get on NDIS because they don’t have a diagnosis, but they can’t access a diagnosis without the kind of assistance being on NDIS would provide. I.e., case management, follow up, community transport to appointments. This leads to people putting themselves in dangerous positions, and their health degrading throughout the diagnostic process. It’s assumed people are healthy until proven otherwise and there’s no support such as ongoing case management, disability-informed emotional support/therapy and community transport for people going through this process.”

“Something I want to touch on quickly is what I found with a lot of disability support services that they get caught up on the name of your diagnosis rather than actually the symptoms. For me, I have quite a lot of different disabilities and they all give me very similar to someone who has MS, but because I have not been diagnosed with MS (Multiple Sclerosis) I can’t access those support even though I have the same symptoms as them. Rather than looking at your symptoms and how it affects them, they look at the name. Also, if one of your disabilities gives you a symptom that is not as well-known in connection to that then they will not give you any help with that because it is not as widely as accepted as a symptom.”

“Often people can’t get on NDIS because they don’t have a diagnosis, but they can’t access a diagnosis without the kind of assistance being on NDIS would provide. I.e., case management, follow up, community transport to appointments. This leads to people putting themselves in dangerous positions, and their health degrading throughout the diagnostic process. It’s assumed people are healthy until proven otherwise and there’s no support such as ongoing case management, disability-informed emotional support/therapy and community transport for people going through this process.”

- 6.41 Participants also raised concerns with the eligibility criteria of the NDIS. Under the current eligibility requirements, it is stipulated that NDIS participants must have a permanent, life-long disability, be an Australian citizen or hold a permanent visa, and be under the age of 65. Additionally, there are a number of disabilities considered to be lifelong that the NDIS either does not cover, or only covers under exceptional circumstances. These include some neurodivergent conditions, such as ADHD and Dyslexia, some psychosocial disabilities, and many chronic illnesses.

“The NDIS qualification is insane. My partner experiences paralysis attacks and has days they cannot walk; we still can’t work out why this is happening. They can’t get on NDIS due to this even though it’s incredibly disabling, however they can get on NDIS with an autism diagnosis (which is much less disabling in their case). The definition of

what is/isn't long term is also absolutely skewed. For instance, POTS isn't considered a long-term condition even though it's incredibly disabling and stops people from working regular job."

"I have been eligible for every other service, every other funding, eligible and received the funding for equipment, wheelchair etc. and it is the same eligibility as NDIS but the NDIS is being ridiculously difficult to get on even though it was exactly the same criteria. One specific thing about NDIS is "have you exhausted every single treatment option?" or something along those lines. A majority of doctors aren't going to say "yes this person has exhausted everything that has possibly existed" for you, and doctors that don't know NDIS very well won't put their reputation on the line by saying something like that. So, I have been going through hoops and hoops and hoops and hoops with NDIS, I have an OT and a social worker and all the people who are supposed to support me receiving support but can't seem to get access to it, which is really ironic because I can get access to everything else but the thing I need the most I can't get access to."

"I agree with people that have spoken about NDIS. I think NDIS is again designed for people with physical disability, I don't think is designed for people with mental health issues and mental health disabilities. I say this also because their entire thing is about 'are you having difficulty eating?' Are you having difficulty showering? No. As a mental health person, I don't need someone to help me shower and feed me. But I do need someone to come and check me at home. I would need that. I don't think the NDIS is designed to help people like us. It is a very difficult system."

"I am only on NDIS for my Cerebral Palsy at the moment. I am working at including other things as well. I think it is justifiable that someone who has a lot of anxiety around things like falling or about being in the community because of my physical disability, to have support from a psychologist, but they say it's not part of my physical disability and is better funded elsewhere and I cannot afford to go see a psychologist elsewhere. So, it's these sorts of things the NDIS can be very rigid on. And systems in general. I think a lot of systems are very black and white and they do not fit into what actually is a reality for disabled people. For example, NDIS like yes or no answers, can you shower yourself? Well, I can do some of it but I do need some assistance or some set up or whatever it may be. Some days I can do more myself and some days I need a lot of help. They do not understand that subtlety, that grey area, they like things to be black and white."

Inaccessible processes

6.42 In addition to experiencing difficulties accessing diagnoses, many participants talked about not being able to pay for the appointments and reports that the NDIS requires with applications.

6.43 Ironically, participants highlighted that NDIS participants get access to funding to pay for appointments and reports that are needed prior to submitting an application.

"And needing pay to get diagnosed to get financial assistance from things like NDIS. Spending money to get money. Make it make sense!"

6.44 Participants also said the processes for applying, maintaining and reviewing funding are inaccessible and had serious implications for their physical and mental health.

"I applied for NDIS and typically they asked for more information on how it impacted on me and my daily functioning. I had to pay out of pocket for an OT and had a functional assessment of 8 pages and that got me into the NDIS. But from the moment I started engaging it was inaccessible. I wanted to use videoconference but 10 minutes into the appointment, they asked if I had a phone instead, they could call me on because it worked better for them. I stood my ground and I said no, it had to be a video call. They said they had Microsoft Teams and Skype. I didn't have either of those and I said could not have been discussed prior to the meeting instead of when we were 15 minutes late already? I had a severe meltdown. People say that NDIS is bad and I didn't realise how bad. I decided to push through with the meeting, and I was two hours into it, and the funding came back as not adequate. So, I used what I had to get more reports and went in for a review four months later. I spoke to the LAC about it and while we were on the phone, he essentially said to me, "Well, I will have to take it up with my manager," but he said he doubted he they would give me a review unless I took it further because he had to be honest with how I presented at the video conference at the original presentation. I was very high functioning and he said I didn't need the support that I was stating in the original reports. I ended that phone call in tears and ended up going through another review to the NDIS. I asked for so much and it came back with 15 pages about why support workers were denied and why I couldn't have access to more consumables for low-cost assistive technology and why they didn't think I was as disabled as I was claiming to be, so that gave me a seven-month interim plan with adequate funding and support more funding in place to keep me off the NDIS. It ends in two weeks and I don't know what is happening"

"This year my psychologist said, "I think you are eligible for NDIS." And I said I got rejected last time three years ago. It is a lot of work, a lot of mental stuff. I don't know if I'm capable of going through all that. And she is like "You have worked so hard and fought for yourself so much. You have got all the support around you that will help you now." So, I got a referral from an exercise physiologist, I got my gym to write a reference, I got the psychologist, the doctor, everything. NDIS sent it back like three times, and I got rejected again. But then they just said what happened with your rheumatologist, we need that report? So, I got the report from the rheumatologist, and they finally accepted. It was only today, this morning actually, they called me to tell me what I got in my plan. So now I'm wrapping my head around what's all in that. I have fears - what if they look at the fact that - because I am a specialist teacher now, I work for myself, I teach children maths and English and science and all that kind of stuff. But physically I wouldn't be able to stand in a classroom, I can only work with kids one and one or two or something. I have fears like what if they start looking more at the fact that I am working, and they go "She is too capable. Maybe we shouldn't have her NDIS in two years." What do they do if you get married? What happens with all that kind of stuff? I don't know."

"Every time I try to apply for NDIS I get overwhelmed and melt down. I then can't tackle it again for weeks. I guess they hope the process is too hard, so people won't bother. I don't have power-parents or money to have someone to take it on for me, I wish someone could sweep in and take it on for me..."

"[We need] help. After diagnosis many of us are then left to flounder, particularly if we are diagnosed as adults. The NDIS is a confusing mass of nebulas where money sits in an unused account that no one has any idea what to do with. Give referrals, and people will follow up. Say 'look for a service provider', and people with executive function difficulties are not going to make good use of their money when faced with a choice of 40 providers and a mountain of jargon. LACs don't do anything, and please remember that IQ is not the same thing as being able to make decisions. Also, more

needs to be done to recognise disabling illness. Many people cannot access the NDIS for such things even though they are unable to manage their household or require therapy which they cannot afford”

“I heard somebody mention that they had a service animal and were getting different therapies. And that is something that I haven’t been able to access because I haven’t been able to get leave for that. Because I have tried, but they have got such strict guidelines as to who can access that kind of funding, quite often the people who actually really need it cannot get it because they don’t tick a certain box. The NDIS is just an absolute minefield an impossible to navigate”

“The NDIS is the main cause of declining mental health for disabled people who are rejected, then giving up hope, and eventually becoming depressed and suicidal. This is my lived experience & what I have witnessed in my disabled friend group”

“I’m lucky enough to have NDIS funding and that has been good for me and has been very helpful in my life, but there is a lot of stress that comes around planning, with things like when they are approving equipment and where they are going to cut my funding.”

“Funding through the NDIS is a minefield. I still don’t have funding for Freya (support dog) despite training her through MindDog and having a plethora of evidence of her progress. I was rejected the first time around... so difficult.”

“I was hoping to get a service animal for my complex-PTSD but I would have to jump through so many hoops. I gave up and was told I am better off training a service animal myself and just have the service animal for home use only.”

- 6.45 A number of young people in the consultations said that the complexity of navigating NDIS has become too overwhelming and has pushed them to give up and avoid the system altogether.
- 6.46 In order to address the various issues with the NDIS, there are a number of actions that the Royal Commission should consider for inclusion in its final recommendations. These include:
- Developing an NDIS Gender Strategy in consultation with with women with disability and their representative organisations,
 - Revising the NDIS eligibility criteria to include conditions that predominantly impact girls and women.
 - Resourcing independent advocacy services specifically for the purpose of supporting young people with NDIS applications.

Centrelink

- 6.47 Similar to their experiences with the NDIS, many consultation participants said that they found Centrelink to be inaccessible and that the criteria for support payments to be too restrictive to adequately support them as young women and girls with disability.

“Help is often capped by age i.e., if you’re under 21 on Centrelink you receive less payments, and if you’re not elderly but experience hearing loss then hearing aids are incredibly expensive.”

“It should be literally the first hurdle they clear. It’s FOR people with disabilities, it

should be accessible, it should be paid quickly.”

“I have ADHD and really struggled with the levels of reporting and paperwork.”

“I had to leave my full-time job because my health was declining rapidly. And once I started the [application] process, I couldn’t do it. It was two months till I got my first jobseeker payment, and relentless calls, turning up to Centrelink in person, and I am fortunate enough to have mobility and go into Centrelink in person, but a lot of people do not have access to that. I have thought about what that would have meant for me, if I was not able to go into Centrelink multiple times; I would not have been able to pay my rent, and I would need more and more medication. Because I was having to withdraw from many things. Multiple things each week, because I cannot afford my medication. But the process, how confronting it is, how degrading it is. In some ways I think, if I were not to pursue this, what would I do? And would actually be that much worse? Tossing up between putting myself through that harm, or going to a different kind of harm, for a payment that is just so subpar for people who live with disability.”

“The DSP, the process is just so... for me, it was pretty horrific, the evidence that I needed to supply, and when I first applied it was about six years ago. I went in for meetings that were pretty confronting. At the time I was living through agoraphobia as well. I needed to turn up to face to face meetings. I needed to supply bucketloads of evidence to prove why I was unable to work. And I was fortunate enough to have support with that. My mum was my carer for a period of time. And she was the person who got all the information together. If it were not for her, I would have fallen further into homelessness, and finding accommodation. And me being physically and mentally unwell, I would have drastically declined further. Which would have needed more services and systems access. So, the process is designed for people to be unable to self-advocate, and then tap out.

“If you present as “functioning enough” to get through the [Centrelink’s] ridiculous barriers you’re too abled bodied to get it, but if you can’t, you can’t go through the barriers to get it.”

“We need advocates and supportive structures that are embedded within Centrelink to support people in the process of accessing the payment”

Eligibility Criteria

- 6.48 While it is understood that government support payments must have eligibility criteria and restrictions for sustainability purposes; countless anecdotes from women with disability, including those quoted above, suggest that current processes restrict many individuals from accessing income support they have a right to. Under the CRPD Article 28 for instance, it is emphasised that persons with disability have a right to an adequate standard of living and social protection. Article 28 2(b) specifically refers to the obligations of state parties:

“to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes.”⁶³

- 6.49 However, despite these obligations, the Centrelink system continues to create hurdles for people with disability, which not only deny them access to payments, but also increase their risk of experiencing discrimination, abuse and violence.

“If you are able, at least in my sense, once I was able to get the application in, the

entirety of the submission done, the wait time was truly outrageous. It was nearly 10 months before I received my first cheque. I got back paid, but it was 10 months. And that meant I was further exposed to family violence. The process, in and of itself, was so damaging that I wish I had not applied. And that is something that I have experienced again this year”

“I got kicked off [Centrelink] at a time when it was incredibly hard to get back on and I ended up sticking it out for one year without any payments. I was lucky I was living with a partner who was earning a decent amount of the time but that put me at a huge risk for domestic violence because I can’t leave in any way. He is fine and it was fine but acknowledging that risk that disabled people have disproportionately. ... The system is actively created to make it hard for people with ADHD, and anyone else with any level of executive function issues, schizophrenia is another one where it is really hard. Like, thought organisation is just hard. It is really difficult, and it is really hard for them, not to mention people who deal with fatigue and stuff. So, for me, it is structurally created to be incredibly difficult, such that if anyone has any opportunity to not be on it, even if it is relying on someone who is incredibly, incredibly bad for you, that might be what you do.”

6.50 In addition to Centrelink waiting times and the inaccessibility of application processes, this risk of violence and abuse is also further exacerbated by requirements that applicants be means tested based on the income or their partners or parents.

6.51 As noted in other submissions written by WWDA, there are also a number of specific barriers preventing women and girls with disability from accessing the Disability Support Payment (DSP). In order to reach the criteria for the DSP, individuals are required to have a permanent condition that does not improve over time or with treatment and that meets measures 20 points or more according to a standardised assessment.

6.52 Due to the restrictions associated with these criteria, many people with disability settle for other government support payments such as Newstart or Youth Allowance, which require significant mutual obligations to retain and are paid at a lesser rate than the DSP, which makes it extremely difficult to cover the additional costs associated with having disability.

“It is a low amount of money for any person to live in our world, but the additional costs that come with being disabled - it leaves you with minimal.”

“I think the entire country is well aware that Centrelink is drastically underfunded, under-resourced and that is intentional.”

6.53 In 2019, the Committee on the Rights of Persons with Disabilities, in its concluding observations⁶⁴ on the combined second and third periodic report of Australia, expressed concern that a significant proportion of people with disability in Australia live near or below the poverty line. As a means to address this, the Committee recommended that the rate of government income support payments be increased to ensure an adequate standard of living for people with disability. ever, despite these observations, the rate of payments in relation to indexation, have not been raised.

6.54 In order to address these Centrelink system failures, there are a number of actions that the Royal Commission should consider for inclusion in its final recommendations. These include:

- Abolishing or revising the discriminatory eligibility tests for accessing Centrelink support payments such as the Disability Support Pension (DSP)
- Remove provision that means tests applicants based on the income of their

partner, caregiver or parents.

- Providing free advocacy and support services to assist individuals to apply for and maintain income support payments.

Education

- 6.55 Throughout the consultations, and survey, many participants talked about experiencing exclusion and discrimination in education settings relating to a severe lack of understanding around disability among both teachers and peers.
- 6.56 As noted in WWDA's previous submission in response to the Royal Commission Issues Paper on Education, the right to inclusive education is guaranteed in article 24 of the CRPD. Guidance on interpretation and implementation of article 24 is provided in General Comment No. 4 on the right to inclusive education. General Comment No. 4 makes clear that segregated models of education, including special schools or separate units within mainstream schools contravene the CRPD.⁶⁵
- 6.57 This is reinforced in General Comment No.6 on equality and non-discrimination, which states that segregated models of education contravene the CRPD, and the failure to provide inclusive education is discrimination and a direct contravention of articles 5 and 24.⁶⁶
- 6.58 People with disability rarely receive a genuine inclusive educational experience in Australia.⁶⁷ Over the past decade, segregation of students with disability has increased significantly, with a 35% increase in students with disability attending special schools.⁶⁸ Funding incentives support this increase, with higher funding going to children with disability if they attend a special school rather than a mainstream school.⁶⁹
- 6.59 While the previous National Disability Strategy 2010-2020 (NDS), which was the national plan for CRPD implementation for over a decade, did commit to "an inclusive high-quality education system;"⁷⁰ the intended outcome has not been achieved.
- 6.60 The Disability Discrimination Act 1992 (Cth) (DDA) and the Disability Standards for Education (2005) do not provide a legislative or policy framework for inclusive education that fully complies with article 24 and General Comment No. 4.⁷¹ The DDA also does not protect against systemic and intersectional discrimination.⁷²
- 6.61 The failure of these national measures to protect students from discrimination and adequately implement the rights of students with disabilities under the CRPD are reflected in the following anecdotes from participants:

"There is the stigma and low expectations that comes with showing a diagnosis"

"I struggled a lot in school, when I first started it was a public school, it was absolutely awful, there were fights everywhere, I was being sexually and physically harassed. It was quite literally a jungle ... I hear the 'r' slur being thrown around a lot and there are rude things being said about people with disabilities by some of the students. I have struggled a lot to get the people around me to understand how I work, I guess. Teachers used to try to force me to make eye contact. Teachers would tell me I needed to look them in the eyes when talking to them. It is so hard. I have to do it, but it made me break down. I am still in school, and I struggle to find motivation for school. I am in lockdown now but when I was at school, I took lots of days off because I would get so overwhelmed"

"I finished school last year. I was at a specialist school with students aged 12-18 due to living semi-rural. At school they didn't understand my "yes" or "no" or when I was

upset. When I got upset or anxious, they put me facing the wall. It was not good and made me feel dirty. It still makes me sad. I don't want to go back at all. I am good now that I have left and have my own supports"

"I only knew two people other than me with disabilities in my physiotherapy degree and they were actively shamed for it which was horrible. They received less help than other students and were never used as student models at the front of the class, even though their body types were more likely to be seen in a physio clinic"

"In regard to invisible disabilities and being misunderstood, I was at this VET hospitality course and this teacher actually bullied me. My mum explained that I had Autism Spectrum Disorder, but he actually still bullied me because I was different in the classroom. He embarrassed me in front of the students, he bullied me in front of the class. Invisible disabilities aren't understood and a lot of students in high school don't understand people's differences, and I think there needs to be more education for those people in school because that is where the bullying started for me"

"I've just completed a Bach in social work and I was marked down in one area of learning as I couldn't help set up a play area. This was because I use crutches! This was during placement"

"For me I have found that I experienced a lot of racism when I was in high school and primary school. Because I am dyslexic and it is a shift in understanding when you see an Asian person struggling with maths and English. And I found that I had very little support from teachers when it came to that, and they didn't even consider the idea of me being dyslexic. Because I was Asian and the stereotype is that Asians are smart and they could get through it because they are Asian."

"One of the main reasons my parents never sought out an assessment for me is because they were genuinely worried that me being diagnosed with autism or ADHD would mean that I would get pigeonholed as a dumb kid who cannot do anything and cannot be successful in school. But I was quite successful at school ... Because my parents were generally concerned that getting me diagnosed and telling the school about the diagnosis, even if they would help me in some ways, would hurt me more than it would help me. There is something that needs to change there."

6.62 The marginalisation, stigma and discrimination that these students faced is reflected in the broader community, where evidence has shown that young people with disability are twice as likely to be dissatisfied with their studies when compared to their non-disabled peers, three times as likely to leave school before age 16 and less likely to attain a tertiary education.⁷³

6.63 Additionally, a tendency for students with disability to be funnelled into 'special schools' demonstrates that Australia is not only not complying with its obligations under article 24, it is also taking regressive measures that are not compliant with international human rights standards of implementation. The right to inclusive education needs to be progressively implemented over time and within the maximum extent of available resources. It is not permissible to take regressive or 'backward' steps.⁷⁴

6.64 The Australian Government clearly does not hold that segregated education is discrimination. In its most recent report to the CRPD Committee, Australia stated that it is meeting its obligations under article 24 by providing:

"an education system that allows for funding of different education modalities so students with disability are able to participate in a range of education options

*including enrolment in mainstream classes in mainstream schools with additional support, specialist classes or units in mainstream schools and specialist schools”.*⁷⁵

- 6.65 The reported quote above goes on to suggest that the CRPD Committee should clarify that education can be offered through specialist classes or schools consistent with article 24.⁷⁶ This is of grave concern because Australia appears to be rejecting and/or misunderstanding internationally agreed human rights obligations, which recognise segregation as a form of discrimination.
- 6.66 In WWDA’s consultations with young people with disabilities, students asserted views in line with the CRPD, noting the needs of students with disabilities should not be segregated into their own schools or curriculums.

“I hate the term, but my specialisation was ‘special education’. But the things I was learning about teaching students with disabilities, I was shocked that it had to be a specialisation. What I was learning, every teacher who is going to teach students with disabilities needs to know. In my degree, there was only one time that I touched something that was special needs related. And it is just not good enough. It is terrible. It is not going to prepare teachers for kids with disabilities in schools”

- 6.67 While many families with children with disabilities do send their children to segregated schools to ensure their disabilities are supported; anecdotes from young people who did participate in mainstream education suggest that these decisions are rarely based on choice, but rather, are the only options for students who can’t get their accessibility needs met without being segregated.

“When I was still studying, I found it very difficult to secure accommodations and accessibility due to the episodic nature of my disabilities. I could operate more-or-less as an able-bodied person for a period of time and then all of a sudden need help to access my education. This sudden need for accommodation was always treated with rudeness and frustration by the staff and once, when I needed surgery in the middle of Year 12, it led to me being told I should drop out for the rest of the year and try again the following year. I also experienced a lot of discrimination for needing to take time off school to attend appointments and physical therapy, being told by teachers that I was disrupting the classroom when my parents collected me. I would feel more safe and included if there was an understanding that my health is just as important as my education and that not everyone can manage their health around their education.”

“I was also told that I could not access Disability Services at TAFE due to my status as an International Student, so I was therefore unable to receive the accommodations (e.g. extensions, reasonable adjustments and support) students with disabilities usually do. I felt like this was discriminatory and exclusionary.”

“I have studied my bachelor’s degree online via correspondence but have been studying a diploma with TAFE NSW and have felt unsafe and excluded due to my health conditions. For example, with discussion around returning to face-to-face delivery in the coming weeks, immunocompromised individuals have not been considered.”

“[I would feel more safe and included if there were] reasonable adjustments and accommodations for when my health issues put me into difficult situations. E.g. numerous occasions I’ve had to justify absenteeism due to hospital visits or doctor visits. It would be helpful if there was a standard letter of accommodation for people with ongoing chronic health conditions in education.”

“We need greater ease of access to accessibility options. The process to get [disability concessions] during my degree was a bit confusing, and it was only until online education was available at my university during COVID that I was able to attend more often.”

“UTAS is really hard to get support, Sometimes I use a cane and it’s very hard to use around the campus as classes are so far spread out which causes a flare up.”

“I was at TAFE this year. When I rocked up at TAFE I had many issues of physical access and also just issues with getting onto people and asking for accommodations and assistance with things like placement. I studied mental health at TAFE. It has been really upsetting to me how difficult it has been to find a placement as a wheelchair user. And it really made me think a lot more about how difficult it has been over time for me as someone who has a physical disability, to access mental health services. I think that that is a big issue, and I am sure that it is a shared experience with other disabilities, having services that are not suitable for your needs.”

- 6.68 A critical starting point for the Royal Commission in examining the area of education and learning must be to explicitly recognise segregated models of education in both ‘special’ and mainstream schools as discrimination; and make recommendations to ensure that mainstream schools and educators are equipped to understand and support students who require accommodations.

“I think that there is a massive lack of communication and information available to professionals and services given by people from those experiences. For example, in the school system, the Teachers dealing with children in the classroom with undiagnosed or badly treated disorders, for me especially with Aspergers and ADHD, are not fully prepared to deal with or be considerate of those difficulties in that situation, especially because of harmful stereotypes that many people categorise those disorders with that they then believe can’t be worked with or helped. So, when they come into contact with people like me and they don’t know how they might be able to communicate and deal with the challenges that come with being around me and what they can do to help me.”

“There is a lack of communication between the teachers and students. The teachers seem to be very underprepared when it comes to dealing with or understanding disabilities such as ASD or even ADHD despite it being a very common disorder. [There needs to be] more preparation for teachers and how to deal with children with disabilities. As well as a more open and inviting atmosphere when educating children with disabilities.”

“We need education of students and teachers on issues such as LGBTQIA+, disability, neurodiversity, ATSI, CALD and mental health.”

“I work in education in the disability education sector, and I think one thing we need to look at is providing educators, whether that be LSA, teachers or whatever, with the cultural awareness that needs to be around how some cultures will react differently to diagnoses.”

“We need better education within schools regarding access to options. I know of many school experiences where students were not taught about HOW to reach out for help i.e. how to access a mental health care plan; that medical decisions will be kept confidential between a doctor and patient at age 14+; how to advocate when a doctor does not listen to our needs/pain.”

“There is an assumption by so many teachers that if mental health issues/

neurodivergence/disability is undiagnosed, then it does not exist in a student. Teachers must be equipped to deal with, confront their ableism, and help students who may be struggling with something undiagnosed.”

“That is a huge area that needs a massive overhaul. And I think getting the education system right is so important because that will influence our ability to advocate for ourselves and the learned helplessness and all these things, even just students without disabilities or anything, them then having that inclusive mindset instilled in them in school, it’s so important and so hard to instill later in life if we don’t have it in education.”

- 6.69 Many participants shared that the most supportive experiences in education was flexibility around approaches to study. However, most also reported that there was a lack of information around alternative approaches and adaptations to learning, and that greater clarity of information and support from education providers is necessary.

“Free TAFE with disability support and assignment extensions have been helpful.”

“Having live captioning and transcript of slides would be very helpful.”

“For me, learning from home was a way more efficient way for me to complete my work in an environment where I wasn’t at risk of sensory overload or distractions that I couldn’t control.”

“My university, Charles Sturt University, actually came up with free audiobook access so I don’t have to read online, I can listen to my audiobook and that helps relieve my anxiety. They are very generous with giving assignment extensions. They generally try to help me with my online study.”

“I go to Deakin University and the disability department is fully run and headed by people with disabilities and students with disabilities. The disability liaison officers all have lived experience with disability. When you enroll in the university, you click a button “I identify as having a disability.” And they call you, they request one letter from your GP, and they sign you up for the whole thing and you go in for a consultation on the chat to you and it is chilled. And very inclusive and they give you a letter that you just wave at your uni professor and say that you need an extension, and it says here and I don’t have to explain myself. And it is a one-off thing, and all of the Deakin University staff know about it and they do not question you about it. And if you wave this piece of paper at them, they will just shut up. And that is something that is great.”

“I guess understanding what sort of support might be helpful in an educational context, often at universities you might get an education inclusion plan, they might put things like extensions or additional time but sometimes I need a bit more. For example, if a rubric is very open ended, I might not be able to follow it, I might need further clarification on what the words mean and the difference in what the marks are, and even simple things, because people assume I am neurotypical just looking at me, they get quite surprised when I say I do not do well in group work. Not that I can’t socialise with people, but the more unfamiliar people that are added to a situation, the more I have to rely on other forms of functioning, like executive function and emotional regulation, and those things I struggle with, and I find it hard to explain that to people because it is not their experience, but other neurodiverse people get it immediately.”

“In terms of showing other symptoms, and people not necessarily understanding it is a disability, I used to have some horrible issues in high school around processing, whether it is auditory, written or processing it has not been my thing. And the

school, because the school did not have understanding that with autism comes a lot of processing issues, my parents used to push for me to use a laptop for taking notes and all that kind of stuff. And the school just did not want to budge, because they were not willing to look at the overall side of autism, that people could have different issues in different areas and will need support in these kinds of areas. It took them until I got an actual diagnosis of dyspraxia that they could go, "OK, she has reasonable evidence to use a laptop." But I think there needs to be further understanding and further education that yes, this child might have X, but XYZ can look different with everyone. What works with one child A might not necessarily work with child B."

"Don't get me started on the general education about different opportunities that are available. I got most of my education about different opportunities that have been available around support, from Facebook ads. That is how shocking it is. I get Facebook ads for headspace, and all of that stuff. In year 12 I was in New South Wales, it's different for every state and everything, but I had to do HSC part time over two years, it was the best thing for me. But I only knew about that when it got to the point where I was hospitalized and the social worker at the hospital said it was an option. And I thought, oh my god, doing it part time and everything was such an amazing experience, it made everything so much easier. And nobody had heard of it, nobody at my school had heard of it, none of my teachers had heard of it, nobody was doing it that way."

- 6.70 Additionally, many participants highlighted that a lack of investment in and financial support for students with disabilities created additional barriers to them pursuing and succeeding in education.

"Only being able to study part time and having to work part time has a financial impact in both the short term and long term and affects career entry and progression. [We need] stronger government financial support and greater flexibility from the university in regards to deadlines and timeframes in which work can be completed"

"If there was actually some support through the system or financial support, and I didn't have to pay double the rent I was already paying to go on placement, and some safety measures were put in place, textbooks did not cost \$500, you would maybe have a more informed and diverse field. So, I think in terms of prevention for a lot of what we are dealing with right now, actually investing in students is so important going forward. Because I wish I could've made it through the degree, but it is what it is."

"Students are not invested in enough. They experience huge financial, social and existential pressures whilst studying which leads to heaps of people dropping out or not working after they've finished their degrees. Allied health and medical students need further assistance to become the best practitioners possible; they need to be incentivised to study and enter the workforce. Instead of being saddled with higher expectations they should be taught in a holistic fashion and have assistance available to ensure they're living as stable a lifestyle as possible to help facilitate study."

- 6.71 All of these barriers contribute to the situation in Australia where people with disability are more likely to leave school at younger ages and to have a lower level of educational attainment.
- 6.72 One thing that was very clear from WWDA and CYDA's consultations is that in order to further and adequately address the multitude of issues in education, the Royal Commission must allow for more evidence to be provided by people with disability, including children

with disability themselves. This would allow examination of how this systemic neglect is experienced by people with disability, including women and girls with disability, in terms of poor educational outcomes, the culture of low expectations and ongoing segregation, marginalisation and disadvantage, and the exposure to harmful educational practices, such as seclusion, forms of restraint and other restrictive practices.

6.73 Additionally, there are a number of key recommendations which can be taken from the consultations for the Royal Commission to consider in its final recommendations, including:

- Transitioning away from all forms of segregated education
- Investing in training for educators in how to work with and support students with disability
- Increasing understanding reasonable accommodations and promoting flexible learning environments in all educational settings.
- Streamlining processes for accessing reasonable accommodations in education to alleviate pressure of constantly chasing up and providing documentation
- Education within schools for disabled students to learn about medical autonomy and consent, their rights, how to access services etc.
- Education reform to address entrenched ableism and promote inclusion and understanding among educators and students
- Promoting greater representation of people with disability in the classroom - disabled bodies being used as classroom examples
- Providing additional financial support for students with disability to continue their education.

Employment

6.74 Another key issue that was discussed by participants throughout the consultation was a lack of sustainable and flexible employment for young people with disability.

“Getting access to sustainable work is a cluster fuck. It makes us have to rely on the systems that wish we weren’t existing. I feel like we all saw that when the pandemic happened, all of a sudden, a lot of people were able to work from home, whereas before that was not an option ... I am 30, and I have only had two years of work in a row, the amount that burn out does to my system, and how I basically have had to choose between burning out, and becoming more disabled? And just unlocking more, extra diagnoses or putting myself at the mercy of the system which wants me to live below the poverty line. It’s a choice we shouldn’t have to make, but here we all are making the decision ... I have had job opportunities in the past, where I know a lot of people through the whole career’s thing, it is simply inaccessible for a lot of reasons. This idea that there is so few part-time jobs, and jobs with flexible hour arrangements, it is ridiculous to expect people to work 40–60-hour weeks.”

“Most disabled folks CAN work part-time for life. But they keep employing us as casuals so no superannuation. Disability Youth exploitation is high. We are asked to volunteer for years before scoring a part time paid job.”

- 6.75 While there is limited further research available on the experiences of young women and girls with disability in the workforce, the experience cited by consultation participants reflect the broader experiences of women with disability in the Australian workforce.
- 6.76 Although there is an acute lack of gender-disaggregated data in Australia on the economic position of women with disability, available data shows that Australians with disability are more likely to be unemployed (10.0% compared with 5.0% for those without disability) and face significantly longer periods of unemployment than people without disability.⁷⁷ Women with disability in Australia are also significantly disadvantaged in employment in relation to access to jobs, in regard to remuneration for the work they perform, and in the types of jobs they gain.⁷⁸
- 6.77 Working-age women with disability who are in the labour force have lower incomes from employment; are more concentrated than other women and men in precarious, informal, subsistence and vulnerable employment, and are much more likely to be in lower paid jobs than men with disability.⁷⁹ Of those who are in the workforce, women with disability have a much higher rate of part-time employment (56%) than men with disability (22%) and are much more likely to be underemployed.⁸⁰
- 6.78 Many women with disability are often given marginal jobs far below their capacity. They are denied opportunities for further training and job advancement. They are often unable to enforce industrial rights. Women with disability have reported being typically treated like children and not given credit when they have performed well on the job because attitudes in their workplace were such that no one believed that they could have actually done the job on their own.⁸¹
- 6.79 These experiences, and those highlighted in the consultations, largely reflect the sexist and ableist attitudes that are still embedded in the Australian workforce and result in the persistent devaluing of women with disability and their potential. While many women and girls with disability are capable and willing to work, ableist practices and attitudes too often deny them the opportunity and flexibility to be able to prove their potential. As consultation participants explained:

“People in workplaces with neurodiverse issues are discriminated against as employers do not know the different strategies for different people for success.”

“I have tended not to disclose my health conditions to employers or in interviews if I can avoid it as I live with a hidden disability and I have always felt that disclosure of my conditions may make my employer see me as less capable or productive which worries me. I would also feel safer and included if employers had special policies in place for people with invisible disability’s such as diabetes; sick days or sick leave policies tend to be intimidating for me in full-time roles.”

“I feel safe in the workforce, but I don’t feel included. I am not outgoing and can feel excluded from workplace friendships and conversations, I feel excluded in the workforce as my skills and abilities are not recognised. I would like to experience self-actualising work that aligns with my education level and skills. We would also benefit from recruitment processes and selection criteria that do not indirectly exclude people with certain disabilities.”

- 6.80 Despite the existence of disability discrimination policies and requirements on employers to provide reasonable accommodations, women and girls with disability too often experience reluctance from employers to provide flexibility on the basis of chronic health conditions or disability.

“I hide my disability at all costs. I asked for access adjustments to the lifts to be able

to get into the building this year. It took 6 months and a full performance review and investigation before HR granted it. They're fearful and suspicious of disabled people and see us as a weakness for the organisation."

"The pandemic has enabled work from home and more flexible options for work which should be permanent too! It shouldn't have taken a pandemic to provide better working options for people with disability."

6.81 Given that Article 27 of the CRPD sets out that persons with disability must be afforded the right to work on an equal basis with others and be provided with opportunities to gain a living by work freely chosen; it is essential that the Royal Commission view these experiences as evidence of a failure of Australia to meet its obligations as a CRPD signatory.

6.82 In order to address these failures, consultation participants provided a number of recommendations, including the provision of disability awareness training among employers and stronger protections for disabled employees against discrimination.

"As an invisibly disabled person, more awareness in the work force of people like me would make me feel much safer when seeking and participating in work."

"[We need] Less platitudes, more diversity and inclusion of disabled people. More disabled people hired, a disability advocate employed, policy to protect disabled employees from harassment, bullying and unfair treatment, better training for HR / people and culture."

6.83 Additionally, participants highlighted that they would benefit from more workplace visibility of people with disability and mentoring from more experienced individuals.

"There is no mentoring program where you can slowly integrate yourself into a teaching career ... Just thinking about anxiety and the pressure to perform. Let alone having the disability on top makes it a very interesting situation. It burns people a lot faster."

"I'm at uni becoming a teacher and honestly a mentoring slow approach into my career would be perfect but obviously isn't a thing."

"There is a real lack of disabled leaders in my profession and it is so hard to keep going, or know there is a path."

"We need peer type mentors and people with lived experiences."

"There needs to be more opportunities for disabled adults to connect to disabled youth, to empower younger disabled people."

6.84 Considering the feedback from participants, as well as broader evidence about the inclusion of disabled people in employment, the Royal Commission should consider including the following recommendations:

- Resourcing mentoring programs for students with disability to transition into employment;
- Developing a plan to transition away from all forms of segregated employment and providing services to transition people with disability from segregated systems into open inclusive and accessible forms of employment;

- Providing training for employers to implement inclusive workplace practices, including the provision of reasonable accommodations, and implementing accountability mechanisms for compliance failures; and
- Commissioning and adequately resourcing mechanisms for the collection of disaggregated data and intersectional evidence on the employment of women and girls with disability in Australia.

Community Access and Inclusion

6.85 Another specific, but cross cutting theme that came up during the consultations were persistent experiences of ableism and a lack of inclusion in the community. Throughout the survey and consultations, participants cited a lack of understanding and awareness about disability, particularly, but not exclusively invisible disability, within the community and related experiences of discrimination and stigma.

“I hate misinformation that is spread around and the way that disability is taught, that forms negative perspectives and also leads to unsafe and inaccessible environments.”

“A lot of people misunderstand me, which can make relationships difficult. They expect me to achieve things like everyone else and put unrealistic expectations on me. People expect that I will behave like everyone else, but I can’t always act like everyone else.”

“There are so many barriers with invisible disabilities and invisible illnesses. You are not seen and you are dismissed constantly.”

“I’ve had negative experiences with emergency services like police and people like that. They should have training in invisible disabilities because they really don’t understand. Because I look normal and they talk normal and they really don’t understand that, then they treat me badly because of that.”

“Growing up and even now I’ve had people say not to use the word disabled and that I’m not disabled, and I can do heaps of things and to focus on that. But what these people don’t realise is that it’s okay to be disabled. Being disabled is part of our lives and nothing will change that. Like I am disabled but what disables me more is society more so than my health issues!”

“As a young person my local council doesn’t acknowledge that young people can have a disability, they prefer older people having a disability helping them over young people with a disability and supporting them. The youth services are just crap. The government needs to do more to support young people with disability in local areas, as well as obviously nationally.”

“I guess the biggest issue that I have faced is being in unfamiliar environments and being around people who do not get my hidden disabilities. Something I’ve learned when I mention my assistance dog is that people don’t understand what assistance animals are, they just see a cute dog in a vest and they think they have the right to come and pet her, even though she is serving a purpose. When it is not stereotypical forms of disability, people do not necessarily know how to help you.”

“I was in the city with my friends at night after it got dark, none of us had drunk anything or taken anything, and we were stopped by a police patrol. I’m guessing they noticed the way I walk - I have something very similar to multiple sclerosis. They asked me to walk heel to toe in a line to prove I wasn’t drunk. My balance is very bad, I use a cane most days but this day I didn’t have them so after obviously not being

able to walk like this, they didn't believe me when I said I had a physical disability and thought I was just trying to get out of being intoxicated in public. They took me to the city police station and waited for my parents to pick me up and actually bring a doctor's note to confirm I wasn't drunk ... It was very scary because I'm 16 and I have never had anything to do with the police before being picked up like that, and they were talking to me like I had really done something wrong. Having more support in the community and from community services would be really, really nice."

- 6.86 While varying in their nature, these experiences all reflect a need for attitudinal change and awareness raising; but also, the way that ableist attitudes are embedded within structures and institutions.

Housing

- 6.87 One area in which this entrenched ableism was cited, was in housing and accommodation.
- 6.88 Compared to men with disability and other women, disabled women experience substantial housing vulnerability, are more likely to experience and face homelessness, and are much more likely to be affected by the lack of affordable housing; which was reflected in the consultations.⁸²

"The people I live with often treat me as a burden or that I'm too difficult to accommodate. When I get frustrated by this, they treat me like I'm being difficult or rude instead of understanding that they're hurting my feelings and making me feel excluded."

"Trying to get access to a rental when you are disabled is an absolute nightmare. You do not get the choice to find something with rails, accessibility, no stairs, anything like that. And you can't tell the agent, "Hey, can we get a railing installed?" Because, sure, they can't say no you can't get a rail installed and you're getting kicked out because you are disabled, because a tribunal would love that. But there are so many ways to out someone while still being right. For example, they can say that the landlord needs to occupy the property, and then they will stay for three days, and they have technically occupied the property so that's fine. There are so many loopholes in that respect. So trying to find a place that is single-story where you have more space will be more expensive because it is not high density living but there is no assistance for this increased cost whatsoever."

"Another thing that comes up in that safe environment question, is trying to find suitable accommodation. I'm someone that uses a wheelchair, I can walk independently but I do rely on my wheelchair at home, and I'm having a hard time to find wheelchair accessible accommodation that is actually affordable. I been living on my own for quite a while, and I'm finally in a place that does not have stairs on it, and that is only because it is my university accommodation. Once I leave my university, I'm not sure how I will be able to find accommodation that is safe for me. So far, I have had to put up with accommodation that is mainly unsafe. I think that accommodation services and support for disabled people is very lacking."

"I know some universities even at mine, the accommodation is not actually wheelchair accessible is I been working at the moment with my friend who uses a wheelchair and literally cannot get herself into the room. Which has completely excluded that as an option."

“I live in a three-bedroom, three-bathroom house and I have been sleeping on my couch for over a year and a half because I can’t get my own bedroom. The OT was hoping that the NDIS would support me and I would get funding for home modifications, et cetera, but I applied back almost a year ago and it just keeps going around and around in circles and so I’m just sleeping on the couch, which is not good for chronic pain, joint issues, all of that sort of stuff, fatigue, etc. So, I have a house that I can’t even access because of how ridiculously inaccessible things are, let alone society and not being able to get into places. So that’s a bit of a brain dump and a bit of everything. It’s quite bleak.”

- 6.89 While CRPD article 19, recognises the equal right of people with disability to live in the community, to be fully included and to participate in community life, with choices equal to others⁸³; it is clear from these experiences that these rights are not being afforded to many young women and girls with disability.
- 6.90 In order to address these experiences, consultation participants provided a number of recommendations to be considered by the Royal Commission, including increasing community awareness of disability and co-designing support services and structures with people with lived experience.

Education and Autonomy

- 6.91 Overwhelmingly, participants emphasised the importance that the wider community be educated about the rights and capabilities of women and girls with disability, stating that more education is needed around the experiences and accessibility needs of disabled people, as well as how services, institutions and non-disabled people can be more inclusive.

“[We need to] education to improve understanding around not only the identity, barriers and chance of abuse for young disabled women but of their carers, family, friends and the role they play in mitigating negative outcomes for disabled women. More accessible places to go out to that are also safe from a woman’s perspective I see well lit, visible and easy to access and leave if need be.”

“There needs to be more education about the unique needs facing us; being reassured that we have bodily autonomy (whether they may push sterilisation based on our disability, OR assume we desire children); less gendered language around reproductive health, but also centres dedicated for women (with emphasis on trans, cis and nonbinary acceptance and education) to offer safe spaces; more discussion, education, and money being spent on preventing sexual assault and ensuring safety; LGBTIQA+ training; understanding and education about the intersection of identity, cultural background, and disability.”

“I guess I want to weigh in on what would be helpful, I guess. Things like working out and problem-solving how we can educate the wider community on inclusive practices, whether it is through national campaigns, or greater opportunities for people with personal experiences to share their consultation with other organisations. I think that this is an important discussion to be had, and I think that whilst we have awareness of a lot of different forms of disabilities, that understanding and true inclusion is something that we still need to work on.”

“Feeling like your disability/ies is not enough is so tough. More resources and knowledge sharing about how disabilities can take form (visible vs invisible, for

anyone young or old) would be so useful to prevent ableism (for both us and the rest of society)."

- 6.92 Participants reflected on the fact that women and girls with disability are often denied basic rights to make fully independent or supported choices about their own lives, bodies and goals. Due to widespread ableist and paternalistic attitudes, women and girls with disability are frequently excluded from participating in decisions that affect their lives on a daily basis, including as active agents in their own sexual and reproductive rights and sexual and reproductive health.⁸⁴
- 6.93 Reflecting on this evidence, participants stated that education and awareness raising is needed to reinforce that women and girls with disability have a right to fully participate in their community, make their own decisions and hold autonomy over their lives and bodies.⁸⁵
- 6.94 Additionally, participants agreed that professionals, service providers and community members need to be trained in how to implement inclusive practices in their respective areas.
- 6.95 Despite the fact that the federal Disability Discrimination Act, as well as state and territory based anti-discrimination legislation,⁸⁶ have, for decades, required governments, councils, institutions and community groups to be inclusive of people with disability, direct, indirect and intersectional discrimination and prejudice on the basis of sex, disability, race, colour, ethnicity, sexuality, gender identity, social origin and access to economic resources, continue to impede the full and meaningful participation of women and girls with disability.⁸⁷
- 6.96 In order to prevent these forms of discrimination, consultation participants emphasised the importance of providing education and resources to inform the implementation of inclusive practices, including through the provision of accessible and appropriate information, accessibility measures for public spaces and flexibility to account for the diversity of disabilities.
- 6.97 To ensure that this education is inclusive and reflects lived experience, participants also emphasised they need to be co-designed with disabled people.
- "The services for disabled people need to be co-created or have involved disabled people with lived experience."*
- "Even more than co-designed and co-created, but actually designed and created **by** us. Not just us being included to confirm they involved us."*
- "In general, companies need to consult actual disabled people to write their "how to treat disabled people like humans" section."*
- 6.98 While young girls with disability – particularly adolescent girls - are rarely given opportunities to participate in participation and advocacy processes, about issues that affect their lives;⁸⁸ there is significant evidence that involving young people and people with disability in the design and implementation of the services they access improves their success and suitability for purpose. In the disability sector, these practices are usually referred to as co-design.⁸⁹
- 6.99 While supporting the full inclusion and participation of women and girls with disability in the community will require long-term and radical solutions, participants recommended a number of specific actions to be considered by the Royal Commission which can be

summarised into the following:

- Providing comprehensive and targeted education and awareness raising about the rights and capabilities of disabled people to combat widespread and systemic ableism and paternalistic attitudes;
- Providing training to frontline service providers in recognising disability and offering practices that are disability inclusive;
- Commissioning the development of accessible and affordable; accommodation services for disabled young people across Australia; and
- Co-designing services and support programs with people with disability.

Safety from all forms of discrimination, abuse and violence

6.100 The right to live free from all forms of violence and abuse is consistently identified by women and girls with disability in Australia as the most urgent and unaddressed human rights issue they face. Compared to their peers, women and girls with disability, at all ages, experience significantly higher levels of all forms of violence more intensely and frequently and are subjected to such violence by a greater number of perpetrators. Their experiences of violence last over a longer period of time, they experience more severe injuries as a result of the violence, and they have considerably fewer pathways to safety.⁹⁰

6.101 While, due to the design and nature of the consultations discussed earlier in this submission, experiences of violence and abuse were not explicitly discussed as an issue facing young women and girls with disability, some participants did disclose their specific experiences and how their disability had contributed.

“I think violence is a big part of it, and obviously disproportionately affects women, feminine-identifying and non-binary people with disabilities. In part people don’t talk about it, I think people talk about it in the sense you are obviously more disadvantaged and you are likely to be a recipient of violence if you are in a relationship, particularly in a relationship with your partner who is also your carer, and there is financial violence and abuse. But disability acquired as a result of intimate partner violence or family violence is not talked about. My spinal injury, which does not go well with Ehlers Danlos syndrome, is a result of intimate partner violence. That is a challenging component because when I am a part of a violence prevention forum it is not considered - acquired disability as a result of violence. If you have a disability, you are more likely to be in the position of violence. Particularly if you are young, it is not taken into consideration. I think there is not anything that really exists for young people with disability in violence or about violence in that sort of way. There is so much work being done around violence prevention and intimate partner violence and all of that, but there is not a lot of discussion with young people about violence. I guess the ongoing challenges associated with that, particularly if you acquired your disability as a result of the trauma and having to deal with the physical challenges of your disability but the emotional challenges of being reminded - long story short, every time I am in pain, my back hurts, every time I experience nerve damage and nerve pain and have to go in to get my third or fourth or fifth or sixth or seventh spinal surgery - it always comes back to the violence. That person moves on and lives their life but there is no real justice or way of support moving forward for survivors of violence - particularly young people. I think this is a major gap as well particularly when there is a lot of work being done around the disability sector in violence”

“Probs need a session just on violence and exploitation of people with disabilities.

Child sexual abuse happening overseas on holidays or prior to coming to Australia as a migrant and refugee is a very complex issue but disability emerges out of this trauma.

- 6.102 Additionally, many participants did talk about feeling unsafe and the importance of creating safe spaces to support their full inclusion and participation.

“if I’m in a crisis, the crisis services that are technically available to me, are unlikely to be safe spaces ... I have to avoid accessing services that could be useful to me, because of the sheer risk involved.”

“Being listened to and believed when giving our opinion on matters involving us. Being able to have a safe space created by people including those in our situations.”

“People having dual diagnosis of disability and mental health need more support safe places to go and more professionals need to understand dual diagnosis and how hard it can be to have multiple issues.”

“For me, a safe environment looks like a place where my intersectionality is recognised. I am really lucky to be part of a fitness program, and it is full of queer people, but they are also really understanding of my access and support needs, so I do not feel like I have to explain myself to go into the space, it is very sensitive friendly and all at your own pace. I would really like to see more of those environments. As a person with disability who is also queer, when I go to the spaces it is either one or the other and there is no in between spot where you can find people like yourselves, and I think that for me, both are important for my own lived experience. My non-binary gender is a bit like my autism in a funny way in that it is not necessarily obvious to the outsider and a lot of assumptions are made as well. Even simple things like misgendering me can be very frustrating, so having more understanding that disabled people can be sexually and gender diverse as well, it is very simple thing.”

“I want to have a space for me, as an intersectional person, for all my identities that are equally as important to me.”

“I think really, a safe environment to me looks like one that includes us. As in, disabled people.”

- 6.103 Overwhelmingly, participants stated that places they considered safe included people and environments that understood and included their identities and experiences, in all of their diversity. Commonly, participants referred to the importance of individuals and services understanding intersectionality and disabled identities.

- 6.104 As is the case with inclusion in the broader community, participants also emphasised the importance of co-design with people with disability for the purpose of creating spaces that are inclusive and safe.

“A safe environment does not exist unless we created ourselves, and the safe spaces are one’s that only have people like me in them. We talk about allies a lot and that is obviously appreciated but a lot of the time it is a label people give to themselves when they have not earned it. So, services, treatments, institutions, education and employment places are not safe environments no matter how much they say: “We understand disability, we have worked with autistic people before, and we have a rainbow tick accreditation” and what have you. ... And I guess I want the Disability Royal Commission to know that, while well-meaning, a lot of the services and supports and systems that exists are not made for people like me, no matter how much they try to adapt from their original thing there needs to be new spaces created exclusively

for people like us in this call, rather than trying to change ableist and transphobic and misogynistic systems for us.”

- 6.105 In 2012, through the Human Rights Council, the UN Special Rapporteur on Violence against Women, its Causes and Consequences, Rashida Manjoo, tabled the report of her global thematic study on violence against women with disability.¹³⁵ She made several strong recommendations to States, including urging them to respect, involve and enhance support for, Disabled Peoples Organisations (DPO's) in all efforts combat violence against women with disability, including in related dialogue, strategy and institution-building processes.⁹¹
- 6.106 In order to ensure women and girls with disability have the opportunity to engage in processes of co-design, be represented and listened to, WWDA and the broader disability sector has advocated for the full and sustainable resourcing of DPO's that are run by and for disabled women and girls.
- 6.107 While DPO's work tirelessly to promote and protect the rights and dignity of people with disability, represent and promote understanding of the diversity of people with disability, promote and support the active participation of people with disability in decision-making processes and all aspects of community life, foster strategic partnerships with other disability and human rights organisations and groups, and foster co-operative and respectful relationships with all levels of government; even for DPO's that have long-standing, established presences and relationships with their communities, funding arrangements continue to be largely inadequate, insecure, and unsustainable.
- 6.108 While addressing the epidemic of violence against women and girls with disability requires significant long-term and systemic change, there are a number of key actions that young people from the consultations wanted to the Royal Commission to consider in relation to making the community safer. These include:
- Improving the accessibility and resourcing of front-line disability, crisis and domestic and family violence services to ensure they are equipped to support women and girls with disability, in all of their diversity;
 - Reviewing the eligibility criteria for government supports through Centrelink and the NDIS to ensure that women and girls with disability are not put at increased risk of experiencing violence through being forced to rely on partners, parents or caregivers as their sole source of income.
 - Requiring frontline service providers to undergo comprehensive and mandatory training around disability inclusion and intersectionality, so that disabled women and girls can feel safe to access supports
 - Providing adequate and sustainable resourcing to Disabled People's Organisations (DPO's) and networks run by and for women and girls with disability.



7 ENDNOTES

7. ENDNOTES

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Winner

National Human Rights Award 2001

Winner

National Violence Prevention Award 1999

Winner

Tasmanian Women's Safety Award 2008

Nominee

UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee

French Republic's Human Rights Prize 2003

Nominee

UN Millennium Peace Prize for Women 2000

Certificate of Merit

Australian Crime & Violence Prevention Awards 2008

Nominee

National Disability Awards 2017

Finalist

International Zero23 Award, Information and Communication Technologies (ICT)