



Women  
With  
Disabilities  
Australia  
(WWDA)



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

# **WWDA SUBMISSION ON GUARDIANSHIP AND FINANCIAL MANAGEMENT**

**Our Right to Decide:  
Equality and Autonomy for Women with Disability**

**December 2022**

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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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This document was written by Dr. Linda Steele, (University of Technology Sydney) ([ORCID ID: 0000-0001-6944-7888](https://orcid.org/0000-0001-6944-7888)), Carolyn Frohmader, (WWDA Chief Executive Officer), Hope Siciliano (University of Technology Sydney), Dr Evelyn Rose (University of Technology Sydney) and Emily Gosden-Kaye (University of Technology Sydney) for and on behalf of Women with Disabilities Australia (WWDA).

Formatting, editing and design by Carolyn Frohmader (WWDA) and Jacinta Carlton (WWDA).

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ABN: 23 627 650 121

ARBN: 621 534 307

### Contact

Women With Disabilities Australia (WWDA)  
Contact: Carolyn Frohmader, Executive Director  
PO BOX 407 Lenah Valley, Tasmania, 7008 Australia

+61 438 535 123

[carolyn@wwda.org.au](mailto:carolyn@wwda.org.au)

[officeadmin@wwda.org.au](mailto:officeadmin@wwda.org.au)

[www.wwda.org.au](http://www.wwda.org.au)

[www.facebook.com/WWDA.Australia](https://www.facebook.com/WWDA.Australia)

[twitter.com/WWDA\\_AU](https://twitter.com/WWDA_AU)

**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)

## 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.<sup>2</sup>

## ABOUT THE UNIVERSITY OF TECHNOLOGY SYDNEY (UTS) FACULTY OF LAW

The UTS Faculty of Law is a dynamic and innovative law school. Since its commencement in 1977 it has achieved great success for the quality of its legal education and its commitment to practice-oriented learning. In more recent years it has built a strong reputation for research excellence, engagement, and researcher development. Dr Linda Steele (Associate Professor, Faculty of Law), and co-author of this Submission, is a socio-legal researcher working at the intersections of disability, law and social justice. She has been researching disability law and social issues for over a decade, having previously been a solicitor with the Intellectual Disability Rights Service. Dr Steele's research focuses on the roles of law, human rights and transitional justice in perpetration and redress of violence against disabled people. Dr Steele reflects on how to engage with legal methods (such as litigation, redress schemes, truth commissions and law reform) to work with disabled people to achieve social justice. Dr Steele explores these concerns in a range of contexts including institutionalisation, sterilisation, criminal justice incarceration, restrictive practices, and segregated ('sheltered') employment.

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## ABBREVIATIONS

AGAC	Australian Guardianship and Administrative Council
CEDAW	Convention on the Elimination of Discrimination Against Women
CEDAW Committee	Committee on the Elimination of Discrimination Against Women
CPRD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee Convention on the Rights of Persons with Disabilities
Disability Royal Commission	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICESCR Committee	Committee on Economic, Social and Cultural Rights Committee
LARC	Long-acting reversible contraception
NSWLRC	New South Wales Law Reform Commission
QLRC	Queensland Law Reform Commission
Van Boven Principles	Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law
WWDA	Women with Disabilities Australia (WWDA) Inc





# 1 RECOMMENDATIONS

# 1. RECOMMENDATIONS

WWDA prefaces our recommendations with a clear call to action to the Disability Royal Commission:

- (a) That the Disability Royal Commission must recognise that guardianship and financial management laws and other substitute-decision making regimes, continue to enable violence against women with disability and undermine their equality and autonomy.
- (b) That the Disability Royal Commission must make recommendations for guardianship and financial management to be replaced with supported decision-making and other measures that facilitate disabled women's equality and autonomy, including through deinstitutionalisation, desegregation, and reparations.

WWDA makes the following **seventeen** broad Recommendations:

1. 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. That the Royal Commission recommend the Australian Government repeal existing guardianship and financial management laws and all other laws that enable substitute decision-making regimes and practices. The CRPD Committee has made it clear that the development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.
3. Recognising that the common law doctrine of *parens patriae* is a patriarchal framework that rests on gendered assumptions, the Royal Commission recommend that Federal, State and Territory Governments, as a matter of urgency, repeal substitute decision-making laws, including guardianship law and mental health law, and legislate to limit the scope of the common law *parens patriae* doctrine so it does not apply to people with disability.
4. That the Royal Commission recommend that, as a matter of urgency, and until substitute-decision making laws are abolished, courts and tribunals exercising the *parens patriae* jurisdiction, including state and territory Supreme Courts, guardianship tribunals and mental health tribunals be subject to greater levels of public transparency and accountability on their hearings and decisions on 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, including through public access to their decisions and quantitative data.
5. That the Royal Commission recommend the Australian Government fully resource supported decision-making, including investing in research, and programs and practices that support women with disability to exercise their legal capacity. In so doing, all forms of support for decision-making must incorporate key provisions, as detailed in CRPD General Comment 1, to ensure compliance with article 12 of the CRPD.

6. That the Royal Commission recommend that, as well as reforming laws to prevent substitute decision-making, laws prohibiting interventions that have been enabled through guardianship, notably forced sterilisation, forced abortion, forced contraception, menstrual suppression, restrictive practices, and other forced interventions, must also be developed and enacted.
7. That the Royal Commission recommend that legislated frameworks for individual and collective redress and other forms of reparations for those harmed through substitute decision-making laws and practices must be developed. Access to justice and redress for victim-survivors must be consistent with the *International Principles and Guidelines on Access to Justice for Persons with Disabilities*, and the *Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law* (Van Boven Principles). Redress and reparations must include an individual redress scheme (e.g., compensation, counselling, individual apology, access to legal, financial and social support) and collective measures (e.g. law reform, truth-telling, national apology, community education).
8. 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*'<sup>1</sup> and adopt the principles in that position paper in order to guide its disability policy and service provision more broadly.
9. 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.
10. 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.
11. That the Royal Commission 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.
12. 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.
13. That the Royal Commission recommend Australia fully implements the recommendations from Australia’s reviews under the seven human rights treaties to which it is a party.
  14. 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.
  15. That the Royal Commission recommend the Australian Government establish a national, accessible, oversight, complaint and redress mechanism for all people with disability who have experienced violence, abuse, exploitation and neglect (including sexual and reproductive violence) irrespective of the setting in which they occurred and when they occurred. This mechanism should be capable of redressing sexual and reproductive violence (both historical and contemporary violations), including measures for victim-survivors of reparation, satisfaction and guarantees of non-repetition as well as compensation, rehabilitation and recovery, as well as structural and community-based redress such as apologies, memorialisation and community education.
  16. That the Royal Commission recommend that the Australian Government develop and implement a national, time bound Action Plan for Inclusive Education which includes specific strategies for people with disability to realise their human rights.
  17. That the Royal Commission, in all areas of its work, 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.



### **3 INTRODUCTION: ABOUT THIS SUBMISSION**

### 3. INTRODUCTION: ABOUT THIS SUBMISSION

- 3.1 We are witnessing a time in Australia of an increased commitment to and action on women's rights. This is particularly pronounced in relation to women's rights to equality and autonomy concerning their bodies, their safety and their lives.
- 3.2 That women in Australia are to have full control over a range of matters that historically were decided by others, such as their fathers, husbands, or the government is increasingly unquestionable and non-negotiable. These matters include choice, control and consent in relation to: who a woman is intimate with, which and how many sexual partners she has, when, and or if a woman starts and raises a family, if and how a woman manages her menstruation and fertility, where a woman lives and with whom she lives, and how a woman manages her property and finances and spends her money.
- 3.3 We have witnessed considerable change over the past two decades in Australia. Laws have been reformed to give greater recognition of women's rights to equality and autonomy (such as reform of sexual consent laws, decriminalisation of abortion, introduction of apprehended domestic violence orders and introduction of coercive control laws). Resources and services (such as domestic violence support services, assisted reproductive technology services, and abortion services) have been increased to support many (but not all) women to realise equality and autonomy. Government-led media campaigns have raised broader awareness about women's equality and autonomy (such as sexual consent, domestic violence, sexual assault, and respectful relationships).
- 3.4 There is increasing focus in Australian law, policy and service delivery that women have the right to live free from all forms of gender-based violence, and this is confirmed by the *Australian National Plan to End Violence against Women and Children 2022–2032* which is driven by the vision of ending violence against women in one generation.<sup>3</sup> When women are subjected to violence or threats of violence, there is recognition that women should no longer be silenced, disbelieved, blamed, punished or disadvantaged. Instead, women must have the freedom to safely speak out about their experiences. They must be listened to, believed and supported, and it is the perpetrator, government and society at large that need to be the site of intervention, action and change. There is recognition that supporting women who are experiencing violence must be framed in terms of empowerment, rather than paternalism, and recognise women as the experts and leaders of their own lives. In particular, women should have the choice to remain in their homes or have access to sustainable housing if they leave, and have access to services, resources and laws that will support their choices and enable them to live free from further violence.
- 3.5 Ultimately, there is now recognition that violence against women is never okay, it is never the woman's fault, it is women who must decide what happens to their bodies and lives, and that supports provided to women by government and the broader community must be informed by women's needs, rights and perspectives.
- 3.6 Yet, women with disability, particularly women with cognitive and psychosocial disability, continue to be denied rights to equality and autonomy and miss out on these progressive social and legal shifts in the understanding of and response to violence against women. Indeed, this marginalisation and exclusion is not happenstance but is largely by design with legal, justice and service systems being set up to operate in ways that remove their freedom to make choices and decide what happens to their bodies and their lives, and that legally and socially sanction others to instead make these decisions. One key area of law and service delivery through which this occurs is guardianship and financial management.
- 3.7 Guardianship and financial management are forms of substitute decision-making in

Australia whereby the law essentially determines a person incapable of exercising their right to legal capacity and transfers their decision-making rights and powers to another person or group of people. It is also known in some overseas jurisdictions as conservatorship or wardship. All forms of substitute decision-making remove voice, choice and autonomy from women with disability. Legally and socially sanctioning others – tribunal members, guardians and financial managers – to make decisions about fundamental issues concerning all facets of life results in multiple human rights violations against women with disability, multi-faceted violence against women with disability, and profound and lifelong impacts on women with disability.

- 3.8 Guardianship and financial management have wide-ranging impacts on women with disability. Their impacts are particularly pronounced in sexual and reproductive contexts. In particular, through guardianship and financial management, women with disability can be subject to interventions such as non-consensual sterilisation, contraception, and menstrual suppression that violate their bodily integrity and deny to them the ability to make profoundly personal and significant life decisions.
- 3.9 Guardianship and financial management contradict many of the key features that have characterised the considerable positive change in women’s equality and autonomy over the past couple of decades in Australia which we introduced above. Guardianship and financial management deny to women with disability the opportunity to exercise choice and control over their bodies and lives, empowers others to make decisions about the bodies and lives of women with disability, enables non-consensual interventions in the bodies of women with disability, protects from civil liability and criminal punishment those who perpetrate these non-consensual interventions, excludes women with disability from recognition as victims/survivors of violence and accessing redress, enables paternalistic responses to women with disability considered at risk of violence or exploitation by others (including being institutionalised, having all money taken out of their control, and being isolated from families and friends), and can respond to their protests, distress and demands expressed in relation or resistance to their experiences through detention and physical and chemical restraint.
- 3.10 Women with disability and their representative organisations such as Women with Disabilities Australia have for decades been advocating for equality and autonomy for women with disability, including through prohibition of sterilisation and abolition of substitute decision-making laws.<sup>4</sup> And, there are signs that this advocacy is having impact. There is increasing recognition by Australian governments that violence against women with disability – in all its forms – must end. For example, the Australian *National Plan to End Violence against Women and Children 2022–2032* (The National Plan) explicitly recognises that: ‘Women with disability experience specific forms of gender-based violence including reproductive coercion, forced sterilisation and forced medical interventions.’<sup>5</sup> It further observes:

*there is a need to address gender-based violence for victim-survivors with disability. While women with disability face many of the same forms of domestic, family and sexual violence as other women, they also experience and are at more risk of particular forms of violence. For example, women with disability may experience forced sterilisation, seclusion and restrictive practices, and violence in a range of institutional and service settings such as residential institutions and aged care facilities.*

*There are additional ableist drivers of violence against women and children with disability including:*

- *negative stereotypes about people with disability*
- *accepting or normalising violence, disrespect and discrimination against*

- *people with disability*
- *controlling people with disability's decision-making and limiting their independence*
- *social segregation and exclusion of people with disability.*<sup>6</sup>

3.11 Some of the objectives of the National Plan are particularly relevant to women with disability and can be applied to guardianship and financial management:

**Objective:** Challenge the condoning of violence against women and embed prevention activities across sectors and settings.<sup>7</sup> **Application to guardianship and financial management:** Address the condoning of violence against women with disability through guardianship and financial management in the legal, justice, health and disability and aged care service systems.

**Objective:** Advance gender equality and promote women's independence and decision-making in public life and relationships.<sup>8</sup> **Application to guardianship and financial management:** Introduce laws and provide resources for supported decision-making for women with disability and abolish laws and practices that deny to women with disability their independence and decision-making.

**Objective:** Enhance accountability of people who choose to use violence.<sup>9</sup> **Application to guardianship and financial management:** Abolish laws and practices that legally, socially and clinically sanction non-consensual interventions in the bodies and lives of women with disability through guardianship and financial management, reform laws to ensure criminal and civil legal accountability of people who perpetrate harm through substitute decision-making in the future, ensure access to redress for women with disability subjected to guardianship and financial management in the past and into the future, and provide access to advocacy and legal assistance to participate in accountability processes and obtain redress.

**Objective:** Ensure women and children escaping violence have safe and secure housing, from crisis accommodation to longer-term, sustainable social housing.<sup>10</sup> **Application to guardianship and financial management:** Cease practices of detaining or otherwise moving women with disability, to disability segregated housing (such as group homes or residential aged care facilities) when they are subject to or are at risk of violence. Instead give them the opportunity to remain in their home or support their access to alternative sustainable housing in the community, and focus on intervening in perpetrators' conduct and addressing environmental and structural factors that contribute to violence.

**Objective:** Improve justice responses to all forms of gender-based violence.<sup>11</sup> **Application to guardianship and financial management:** Reform laws to ensure criminal and civil legal accountability of people who perpetrate harm through substitute decision-making in the future and ensure access to redress for women with disability subjected to guardianship and financial management in the past and into the future.

**Objective:** Ensure victim-survivors are well supported in all aspects of their daily lives through trauma-informed, culturally safe and accessible services that support long-term recovery.<sup>12</sup> **Application to guardianship and financial management:** Cease practices of taking control of women with disability's property and money and detaining or otherwise moving women with disability to disability-segregated housing (such as group homes or residential aged care facilities) when they are at risk of violence. Instead, provide women with disability with support to continue to exercise autonomy over their finances and housing, including by providing them with the opportunity to remain in their home or support their access to alternative sustainable housing in the community, and listening to and acting on their protests,



distress and demands expressed in relation or resistance to their experiences of violence rather than pathologising and punishing this behavior through using detention and physical and chemical restraint.

- 3.12 In this submission, WWDA argues that the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission') must not regress these positive developments on violence against women. Instead, it must accelerate progress on violence against women so that guardianship and financial management are key areas of transformative change in order to prevent, respond to and redress violence, abuse, neglect and exploitation of women with disability.
- 3.13 Guardianship and financial management are disability rights issues impacting people with disability of all genders, and in-depth exploration of the intersections of gender and guardianship and financial management is important to understand the diverse ways in which guardianship and financial management are rationalised and operate in relation to people of different genders yet ultimately still with the same outcome of being violent and oppressive. In this submission, we focus on women with disability and show how guardianship and financial management impact women with disability in very particular ways and that reform is necessary as a matter of disability rights and women's rights.
- 3.14 Our call to action is twofold:
- (a) **The Disability Royal Commission must recognise that guardianship and financial management are currently enabling violence against women with disability and undermining their equality and autonomy.**
  - (b) **The Disability Royal Commission must make recommendations for guardianship and financial management to be replaced with supported decision-making and other measures that facilitate women's equality and autonomy, such as deinstitutionalisation, desegregation and reparations.**
- 3.15 This call to action is necessary to realise the full human rights of women with disability. The call is also necessary to ensure women with disability are equal beneficiaries of the decades of advances in women's rights and violence prevention which too often are only enjoyed by some non-disabled, privileged women. We also deserve equality and autonomy in relation to our bodies and lives.

## Structure of this Submission

- 3.16 This submission is structured in **ten** major sections and one Appendix:

**Section 1:** Outlines our **seventeen** recommendations.

**Section 2:** Provides a brief overview of Women with Disabilities Australia (WWDA) and the University of Technology Sydney (UTS) Faculty Of Law (who worked collaboratively to produce this Submission).

**Section 3:** Provides an Introduction and overview of the Submission, including our Call to Action to the Disability Royal Commission (DRC).

**Section 4:** Argues that guardianship and financial management are violent. It first outlines WWDA's approach to violence, then briefly applies this approach to guardianship and financial management.

**Section 5:** Discusses socio-cultural dynamics: harms associated with guardianship and financial management, guardianship and financial

management as ableist and sexist, the anachronism of guardianship and financial management, and examples where similar mechanisms applying to other marginalised populations have been abolished. (NB: Sections 5-7 present some of the dynamics of guardianship and financial management that provide depth and context to our argument that guardianship and financial management are violent and violate human rights).

**Section 6:** Discusses legal dynamics: guardianship and financial management legal frameworks as discriminatory and segregating, operation of guardianship and financial management laws in discriminatory and unjust contexts, the need to explore ableism in tribunal decision-making, specific issues with guardianship law as it relates to sexual and reproductive decision-making, the problems with the concepts of ‘best interests’ and ‘last resort’, the silencing of people under guardianship and financial management, and the lack of accountability and redress for harms associated with guardianship and financial management, and women with disability being silenced and prevented from speaking out about their experiences under guardianship and financial management.

**Section 7:** Discusses economic and bureaucratic dynamics: lack of resources for supported decision-making, specific issues with the public guardian, and the financial benefit to others through guardianship and financial management.

**Section 8:** Argues that guardianship and financial management violate international human rights norms, including those specifically articulated in relation to people with disability and women.

**Section 9:** Argues for changes to guardianship and financial management. These changes draw on international human rights norms discussed in Section 8 and respond to the issues identified in Sections 5-7. These changes relate to abolition of guardianship and financial management, introduction of supported decision-making, provision of reparations, and broader deinstitutionalisation and desegregation.

**Section 10:** Identifies key concerns with the Disability Royal Commission’s document ‘Roundtable: Supported decision-making and guardianship: proposals for reform’.<sup>13</sup>

**Appendix 1:** Provides endnotes.

## Method

3.17 This submission draws on **four** bodies of knowledge.

### Lived experiences

Our submission draws on lived experiences of people with disability, particularly women with disability. These lived experiences are found in government inquiry reports, submissions to government inquiries, NGO reports, and academic literature. We draw on lived experiences in recognition that women with disability are the experts on their bodies and lives in a context where guardianship and financial management silences and disempowers them, and to centre the impacts of guardianship and financial management on women with disability. We note, however, that there are limited sources available because ‘gag’ laws prevent people from speaking publicly about their experiences under guardianship and financial management (see Section 3).

## Human Rights

Our submission draws on international human rights norms relevant to women with disability and guardianship and financial management, particularly in the UN Convention on the Rights of Persons with Disabilities (CRPD)<sup>14</sup> and the UN Convention on the Elimination of Discrimination Against Women (CEDAW).<sup>15</sup> We draw on international human rights norms in order to highlight how guardianship and financial management violate the human rights of women with disability and to make human rights-based recommendations for reform.

## Legal Decisions

Our submission draws on decisions of state and territory tribunals and boards that administer guardianship and financial management legislation. Considering the limited published tribunal and board decisions (see Section 3) the submission also draws on annual reports both of these tribunals and boards, and of public guardians and public trustees. However, this source is also problematic because these annual reports do not provide a breakdown of data in relation to women with disability. The only demographic that was clearly discussed in some of these reports was the older population where many jurisdictions made note that the ageing population is resulting in increasing guardianship and financial management applications. We draw on legal decisions and related documents in order to demonstrate the discriminatory and unjust legal frameworks and social contexts in which guardianship and financial management operate.

## Scholarship

Our submission draws on socio-legal, critical disability and feminist scholarship. We draw on scholarship to highlight the power dynamics and broader contexts in which guardianship and financial management operate in relation to women with disability.

## Data on guardianship and financial management

- 3.18 There is a dearth of disaggregated data on violence against women with disability, as we discussed in our earlier submission on sexual and reproductive rights.<sup>16</sup> This dearth of data is particularly pronounced in relation to guardianship and financial management. There are no publicly available data consistently available across all state and territory jurisdictions on guardianship and financial management orders, including quantitative data on how many people are currently subject to these orders and qualitative data on the specific scope of those orders and the nature of the decisions guardians and financial managers are making, sometimes for years after these orders being made. There is a lack of published data on how many people on these orders are using specific systems (e.g., it is impossible to see how many people are participants in the NDIS, or are in residential aged care), and this limits our understanding of how guardianship and financial management orders relate to individuals' experiences of specific systems.
- 3.19 There are limited published decisions of state and territory tribunals and boards. Guardianship and financial management tribunal and board decisions are not routinely published. The Queensland Law Reform Commission ('QLRC') considered public access to information about tribunal decision-making in the context of its project on confidentiality in guardianship law. In its final report published in 2007, the QLRC made a series of recommendations directed to enhancing public access to information about Guardianship Tribunal matters. For example, the QLRC recommended that the Guardianship and Administration Act 2000 (Qld) should be amended so that 'a person may generally publish information about a Tribunal proceeding', although this cannot identify the individual subject to the proceedings.<sup>17</sup> In making its recommendations, the QLRC identified 'the principle of open justice' as one of three principles guiding its recommendations.<sup>18</sup> In explaining the importance of 'open justice' in the guardianship context, the QLRC noted:

*... the need for the community to have confidence in the guardianship system. The submissions as a whole revealed some mistrust in the system, and issues of confidentiality often underpinned those concerns. The Commission is of the view that an effective guardianship system must not only be functioning properly, but be seen to be doing so. It considers that greater openness will bring both the accountability and transparency that will strengthen community confidence. Further, an integral part of community confidence in the guardianship system is increasing public awareness of its role, and greater openness will also facilitate the achievement of this goal.<sup>19</sup>*

- 3.20 The QLRC was of the view that the benefits of greater transparency and accountability outweighs the potential impacts on privacy:

*the Commission is of the view that insufficient weight has been given to the important role that open justice [plays] in promoting and safeguarding the rights and interests of adults with impaired capacity, both individually and as a group. Open justice fosters greater accountability and transparency which can improve decision-making by and for the adult. ... In giving greater weight to the role that openness in decision-making can play in promoting and safeguarding the adult's rights and interests, the Commission acknowledges that there may be less priority given to some of the adult's interests, such as his or her privacy. It nevertheless considers such an approach, which enhances the quality of decision-making, will serve to advance the adult's interests overall.<sup>20</sup>*

- 3.21 In contrast, the New South Wales Law Reform Commission (NSWLRC) inquiry into the *Guardianship Act 1987* (NSW) did not consider open justice and instead focused on the issue of privacy, stating:

We consider that the current law sufficiently protects the privacy of parties by allowing the Tribunal to:

- *hold hearings in private where necessary*
- *prohibit the publication of the identities of participants without the Tribunal's permission, and*
- *prohibit or limit the publication or broadcast of any report of a case.*

*The current law also prohibits the disclosure of information obtained in connection with the administration or execution of the Guardianship Act without the consent of the person from whom the information was obtained, or other lawful excuse. Submissions consider that these provisions sufficiently protect the privacy of the parties. NCAT notes that the discretion to hold hearings in private "is exercised sparingly", but argues that the current non-disclosure provisions, and the Tribunal's powers to "make non-disclosure orders ... strikes an appropriate balance between the public interest in open justice and the need to protect the personal information of the parties to proceedings". Several submissions support the current approach.*

*We also consider that the current law sufficiently protects the interests of the parties to proceedings by allowing:*

- *parties to inspect documents in their case held by the Tribunal registry, and*
- *a person who is not a party to apply to inspect "public access documents" from a finalised proceeding.<sup>21</sup>*

- 3.22 Recently, the limited publication of decisions was additionally justified by the NSWLRC on the basis of cost and resources. The NSWLRC was in part responding to a legal scholar submitting that these decisions should be published by reason of the significant

interventions they enable which are similar in severity to criminal justice interventions:

*The Guardianship Division also publishes significant decisions concerning particular aspects of the division's jurisdiction and decisions that represent the majority of applications before the division. This approach assists people appearing before the division and explains the workings of the division to the public. ...*

*[A submission by Linda Steele] suggested that decisions in the Guardianship Division, as well as in the Protective List of the Supreme Court, should be "publicly accessible on an equal basis to other jurisdictions", because this:*

*is central to gaining a comprehensive understanding of the justice system's role in restrictive practices, in order to more fully address the systemic issue of violence against people with disability and ensure equality in the justice system for people with disability.*

*There should not be changes to the current practices of the Consumer and Commercial Division and Guardianship Division. Consultations indicated that published reasons for decisions in these divisions appropriately function like guideline judgments on important or unique issues. In addition, any reasons for decisions in the Guardianship Division must be published in an anonymised or de-identified form, as legislation prohibits publication of the identity of people involved in guardianship proceedings. Consultations indicated that this is a difficult and time-consuming process.*

*A presumption in favour of publishing reasons for decisions, or a requirement to publish a minimum percentage of decisions, would be arbitrary and impractical given the large number of matters heard by NCAT.<sup>22</sup>*

- 3.23 Tribunal and board decisions that are published do not reflect a cross-section of those subject to guardianship and financial management orders, as we discuss in Section 6. The absence in the reported tribunal and board decisions of a representative sample of women subject to guardianship and financial management orders in terms of different demographics and contexts (let alone a comprehensive dataset) means it is impossible for the public to have comprehensive understanding of the scope and diverse impacts of guardianship and financial management on women with disability. On top of the secrecy surrounding tribunal decision-making, there is an additional layer of secrecy related to the substitute decisions guardians and financial managers make pursuant to the tribunal and board orders empowering them as substitute decision-makers. There is no comprehensive reporting of the substitute decisions of guardians and financial managers, and the level of secrecy is particularly the case for private guardians and financial managers who are not members of public government agencies that produce annual reports or can be subject to freedom of information requests.
- 3.24 Moreover, state and territory guardianship laws also 'gag' people under guardianship and financial management by prohibiting them from speaking out about their experiences, as we discuss in Section 6.
- 3.25 There is limited data specifically on sexual and reproductive substitute decision-making. In 2015, the Victorian Office of the Public Advocate produced a report on a project which was conducted at the request of the Australian Government 'on sterilisation data collection practices' which 'relates to sterilisation applications and medical procedures that result in sterilisation of persons with cognitive across all Australian jurisdictions'.<sup>23</sup> One of the goals of the project was to: 'enable Boards and Tribunals to be able to report back against the data indicators'.<sup>24</sup> One of the project's objectives was to: 'standardise data collection practices of state and territory courts and tribunals regarding sterilisation applications and medical procedures that result in sterilisation, and determine the most appropriate place for annual publication'.<sup>25</sup> One of the outputs of the project was an agreed, 'consistent set



of indicators for data collection on sterilisation applications and medical procedures that result in sterilisation across all state and territory jurisdictions', including 'a consistent approach to data on the number of applications, the nature of the procedures applied for, the age of patients, the nature of disabilities, alternate treatments considered, the categories of parties to the proceedings, the outcome of applications and any other relevant data.'<sup>26</sup> The indicators for data collection purposes are: number of applications, age and age bracket of person, gender of person, primary disability of person, applicant, proposed procedure, alternative treatment/s considered, other parties to the application (including whether Public Advocate/ Guardian is a party), primary reason for application, outcome of application, date application received, date application heard, and date decision made.

- 3.26 There are annual 'Australian Sterilisation Data Reports'<sup>27</sup> available on the Australian Guardianship and Administration Council's (AGAC) website,<sup>28</sup> but these *only* report on number of sterilisations authorised per jurisdiction, and do not provide the level of detail reflected in the indicators discussed in the previous paragraph. The AGAC reports are an important source of data, but they do not extend to menstrual suppression and contraceptives that have long-term but not permanent effects. Moreover, the reports do not extend to sterilisation of women with disability other than those with cognitive impairment. These data do not provide *any* qualitative information about the personal and legal circumstances of the decisions. These limitations aside, for present purposes the data do indicate higher applications than have been reflected in published decisions. Annual reports on data provided by State and Territory Tribunals between June 2016-June 2020 show that 31 applications for sterilisation of adults with cognitive impairment were approved. These 31 decisions are not all published and publicly available via Austlii.
- 3.27 By not providing comprehensive (or at least representative) data on guardianship and financial management, we do not have the necessary depth and breadth of information to understand the structural elements and frameworks that dictate these frameworks. The lack of quantitative and qualitative data on guardianship and financial management is problematic for four specific reasons. First, it is problematic given the significance of non-consensual interventions in the bodies and lives of women with disability, including related to sexual and reproductive decision-making. The low level of data available in relation to guardianship and financial management is inconsistent with the greater level of data available in relation to criminal justice incarceration and non-consensual interventions (including public data in the form of judicial decisions on conviction and sentencing), which is of similar or sometimes even less severity and length compared to non-consensual interventions through guardianship and financial management.<sup>29</sup> We have argued in our earlier sexual and reproductive rights submission that the lack of public transparency on tribunal and board decision-making is highly gendered, in that it relates to assumptions about the inherent benevolence of tribunal and board decision-making and vulnerability of women with disability.<sup>30</sup>
- 3.28 Second, guardianship and financial management laws that prohibit women from speaking out about their experiences (see Section 6) contradict and undermine women's right to voice their demands for change that has been central to activism of women and the feminist movement, including in the specific context of violence against women (e.g., the '#MeToo' and '#LetUsSpeak'/'#LetHerSpeak' movements).
- 3.29 Third, an absence of data can then result in lack of action on human rights violations.
- 3.30 Fourth, lack of data can also contribute to the cultural status of women with disability as not mattering, which then gives further social sanction to violence against them. It sends the message that individuals who experience these forms of violence do not count as victims: 'We count what matters, and what matters counts'.<sup>31</sup>



## **4 GUARDIANSHIP AND FINANCIAL MANAGEMENT ENABLE VIOLENCE AGAINST WOMEN**

## 4. GUARDIANSHIP AND FINANCIAL MANAGEMENT ENABLE VIOLENCE AGAINST WOMEN

4.1 In this section we argue that guardianship and financial management are violent. We begin by presenting WWDA's approach to violence, and we then apply this approach to guardianship and financial management.

### WWDA's approach to violence

4.2 WWDA has outlined its approach to violence, abuse, neglect, and exploitation in considerable detail in its earlier submission to the Disability Royal Commission on sexual and reproductive rights.<sup>32</sup> In summary:

- What individual women with disability perceive of and experience as violence is specific to each individual and contingent on that individual's current circumstances and past experiences, and each individual is the expert on and must be believed in their perceptions and experiences of violence.
- Violence against women with disability must be understood at the intersections of ableism and sexism, and other dynamics of oppression such as racism and heterosexism.
- Violence against women with disability can be understood as structural in the sense that it is perpetrated through how systems – legal, justice, service, economic and support systems – are designed, organised, and operate and through cultural understandings and social hierarchies of disability, as well as gender, sexuality, Indigeneity, race, and age.
- Violence against First Nations women with disability is interconnected with settler colonial violence and the dispossession of and denial of self-determination and sovereignty to First Nations people.
- Violence against women with disability is enabled by the cultural devaluing of women with disability as incapable of experiencing pain and harm, being of no social and economic value to society, and being less than full humans.
- Violence against women with disability includes interpersonal physical and sexual violence that is prohibited by criminal law.
- Violence against women with disability is not always legally prohibited, and sometimes it is lawful (legal violence), or is medically or socially authorised (medical violence).
- Violence against women with disability is not only physical – it extends to denying a woman voice and status as knower (epistemic violence) or status as human and a legitimate place in the world (ontological violence).
- Violence against women with disability is not always identifiable as a discrete and sudden act, it might instead take place over a long period of time, with its impacts accruing slowly (slow violence).
- Violence against women with disability harms, disadvantages, and disempowers those who experience it and can also advantage, financially benefit, and empower those who perpetrate it and condone it (economic violence).

- Violence against women with disability is sometimes justified as being in a woman’s best interests or for the protection of that woman or others.
  - Violence against women with disability can be concealed and silenced by preventing a woman from making complaints or taking legal action, preventing them from speaking out in public, or by discounting their knowledge and perspectives or punishing them when they do speak out.
- 4.3 Violence against women with disability as described above violates human rights, and some of this violence even constitutes torture and might also constitute crimes against humanity (see Section 9), yet, this violence is rarely officially recognised as grave human rights violations and is rarely the subject of legal redress or social repair.
- 4.4 In our earlier sexual and reproductive rights submission,<sup>33</sup> we proposed the concept of ‘gendered ableist violence’ to understand violence against women with disability. This concept refers to violence that enforces norms of ability and gender. We also proposed the concept of ‘gendered ableist legal violence’ to refer to violence enabled by legal and justice systems.

### **Guardianship and financial management as violence against women with disability**

- 4.5 Guardianship and financial management enable violence against women with disability, in five ways:
- (a) Appointment of a guardian or financial manager.
  - (b) Substitute decisions by a guardian or financial manager and denial to women with disability the opportunity to make their own decisions.
  - (c) Non-consensual intervention pursuant to decisions of tribunals and boards (e.g., serious medical procedures such as sterilisation generally require specific tribunal or board authorisation) or substitute decisions of guardians and financial managers.
  - (d) Exposure to further violence through institutionalisation, restriction and segregation related to substitute decisions of guardian or financial manager.
  - (e) Use of guardianship and financial management by partners, family members or care partners as part of a wider practice of domestic violence.
- 4.6 Appointment of guardians and financial managers to women with disability authorises other people to make decisions about the bodies and lives of women with disability and denies to women with disability the opportunity to decide what happens to their bodies and lives. This denial constitutes epistemic violence in empowering third parties to interpret these women’s experiences and circumstances, determine what is best for them and make decisions about what will happen to their bodies and lives. As Claire Spivakovsky and Linda Steele state: ‘It denies disabled people the opportunity to have their own perceptions and views of their experiences and needs recognised by others, and it negates their status as political actors, capable of exercising resistance to legal and medical authority’.<sup>34</sup> Appointment of guardians and financial managers additionally constitutes ontological violence because denial of autonomy negates their status as full legal subjects, citizens and humans.
- 4.7 The decisions made by tribunals and boards, and guardians and financial managers about the bodies and lives of women with disability in substitution of and in the absence of the consent of women with disability results in non-consensual interventions in their bodies



and lives. These interventions constitute physical and psychological violence against and coercive control of women with disability. These non-consensual interventions are harmful to women with disability (see discussion in Section 5). In Section 8 we will outline that various United Nations human rights bodies and officials have observed that non-consensual interventions pursuant to substitute decision-making are forms of violence against women with disability.

- 4.8 The legal and social sanctioning of the decisions on non-consensual interventions in the bodies and lives of women with disability made by tribunals and boards, guardians and financial managers gives rise to legal violence against women with disability. These non-consensual interventions are done pursuant to guardianship and financial management law and thus are not considered unlawful, harmful and unjust. In turn, these interventions are not viewed legally or culturally as deserving of legal redress and necessitating broader social repair.
- 4.9 Guardianship and financial management can be a form of settler colonial violence for First Nations women with disability because the imposition of substitute decision-makers and the making of decisions for non-consensual interventions denies self-determination and continues settler colonial practices of paternalistic control of First Nations people's bodies and lives.
- 4.10 Guardianship and financial management can also give rise to economic violence and exploitation. This is by reason of the economic efficiency and related financial gain for service providers associated with some of the non-consensual interventions authorised by guardians and financial managers (e.g., use of restrictive practices) and use of substitute decision-making in lieu of expenditure on reasonable accommodations and resources to facilitate supported decision-making by reason of decision-making. Financial managers receive financial gain through charging fees for financial management services that women with disability have not consented to (see discussion in Section 7). It is important to recognise that others are financially benefitting from the violence against and harms to women with disability through guardianship and financial management particularly for understanding issues of accountability and reparations.
- 4.11 Guardianship and financial management are a form of slow violence because they set up ongoing interventions in or limitations on the bodies and lives of women with disability that can operate for years and even decades, and can have longer term impacts on women's economic, social and health outcomes.
- 4.12 In this section and Section 3 we have outlined how guardianship and financial management enable violence against women with disability. And, have outlined how denial of equality, personal integrity and autonomy to women and the high levels of control and coercion that can be exercised by guardians, financial managers, service providers (including disability services and aged care services), and the medical profession (particularly in relation to reproduction and sexuality) represent a serious regression on decades of Australian feminist activism and recent Australian government action to prevent violence against women as a key strategy in enhancing women's equality and autonomy. In so doing, we have provided a basis for prioritising guardianship and financial management in responding to violence against women with disability, which we will turn to further develop by examining socio-cultural, legal, and economic and bureaucratic dynamics of guardianship and financial management.





## **5 SOCIO-CULTURAL DYNAMICS**

## 5. SOCIO-CULTURAL DYNAMICS

- 5.1 In this section we discuss some of the socio-cultural dynamics of violence against women with disability through guardianship and financial management.

### Harmful to women with disability

- 5.2 In Section 4 we outlined why guardianship and financial management are violent. Here we identify specific harms to women with disability by reason of that multi-faceted violence, drawing where available on lived experiences of women with disability. It is important to note that harm through guardianship and financial management is denied or justified on the basis that guardianship and financial management is legally sanctioned and is framed in legislation, tribunal and board decision-making and public discourse as being directed towards protection and inclusion of people with disability.<sup>35</sup>

- 5.3 Guardianship and financial management are harmful because they subordinate women with disability by operating through a dynamic of dominance and subordination. To draw on the words of Anna Arstein-Kerslake et al, guardianship and financial management laws operating in many jurisdictions:

*create relationships of dominance between the individual with disabilities and the state or other actor that is vested with their decision-making power – the individual with disabilities is subordinated because their decision-making power is removed.*<sup>36</sup>

- 5.4 In a similar vein, Margaret Bushko writing in the context of United States of America (US) conservatorship laws states that this dynamic of dominance and subordination is specifically patriarchal in nature:

*the power dynamic and transfer of rights involved in the fundamental structure of conservatorships ... indicate that abuse – perpetuated by a long history of patriarchal dominance in the legal system itself – is potentially occurring under the guise of conservatorship laws.*<sup>37</sup>

- 5.5 Guardianship and financial management are also harmful because they deny to women with disability the opportunity to make decisions about their own lives, ranging from routine aspects of daily life through to serious medical decisions and all the way through to major life decisions. For example, the Center for Public Representation in has explained in the context of US conservatorship laws that: ‘Guardianship and conservatorship take away fundamental rights people have to direct their own lives’.<sup>38</sup> Spivakovsky and Steele argue that guardianship legitimates diverse and significant disenfranchising, intrusive, coercive, harmful, and violent interventions that may include a person with disability being forced to live in a specific setting or type of setting, with specific people or indeed no one, to be locked or secluded in their room or home at the determination of others, and to be involuntarily physically, mechanically, or chemically controlled, restrained, or rendered docile or incapacitated.<sup>39</sup> A woman with intellectual disability, Claire Hendrick, expressed her experience of being a Ward of Court in Ireland as similar to a prisoner:

*Now that I look back, Wardship is a disgrace. It is like mental torture. I was a prisoner. People are playing games with you every day. They take away your power, your power to make your own decisions.*<sup>40</sup>

- 5.6 Relatedly, guardianship and financial management are harmful in impacting on the privacy of women with disability. Guardianship and financial management are ‘invasive’ and ‘intrusive’ in the lives of women with disability<sup>41</sup> in stepping into areas of women’s lives that

are deeply private, personal and intimate and which women might not otherwise choose to share with others except those whom they have a strong connection to and can trust. For example, the Center for Public Representation has explained in the context of US conservatorship laws that:

*guardianship orders routinely authorize third parties to make decisions about the most personal and important decisions in an individual's life—choices that impact the person's own body and reproductive health; how and where they receive medical, psychiatric, and psychological treatment; how the money and resources they work to earn are spent; and even with whom they associate.<sup>42</sup>*

5.7 Guardianship and financial management are harmful because they instil fear and insecurity in women with disability who are subject to them, involve extreme surveillance and control, and limit life possibilities of women with disability and because women with disability are legally prohibited from speaking about their experiences.

5.8 Guardianship and financial management can also instil fear and insecurity in women with disability where its use forms part of a broader experience of domestic violence. Queensland Advocacy Incorporated provide the example of Wendy, who experienced the psychological harms of coercive control by her two brothers, through guardianship:

*Wendy is a 55-year-old woman who lives in regional Queensland. Unfortunately, Wendy suddenly lost her life-long partner and became unwell and was admitted as an inpatient to a mental health unit. During this time, Wendy's two brothers made applications for an interim and substantive order seeking to appoint them both as Wendy's guardians and administrators under the Guardianship and Administration Act 2000 (Qld). Wendy's brothers did this without consulting her. In accordance with these applications, the Queensland Civil and Administrative Tribunal made an order appointing her brothers as her guardians for most personal matters and administrators all financial matters.*

*Wendy and her brothers had an amicable relationship prior to this order, however, after the order was made, Wendy began to feel as though her brothers were controlling all aspects of her life and not consulting with her prior to doing so. Because her brothers were appointed as guardian for the personal matter about who Wendy could contact, her brothers became controlling over who Wendy could contact and made attempts to prevent Wendy contacting her new partner. Wendy was also denied access to her savings account and had noticed money was being spent from her accounts by her brothers without any communication or justification of the expenses. This level of control left Wendy feeling incredibly anxious and upset and as though her relationship with her family had significantly changed. To remove herself from this level of control by her brothers, Wendy made an application to remove them as her guardians and administrators and was ultimately successful.<sup>43</sup>*

5.9 Guardianship and financial management are harmful because they dehumanise women with disability. This is because guardianship and financial management undermines core liberal ideals of autonomy, personal integrity and equality that are central to understandings of full humanness and citizenship. The experience of dehumanisation is recounted by 'Sarah' in an ABC news story. Sarah is a 59-year-old woman who is under financial management of the Queensland Public Trustee:

*Sarah said she is too scared to call and ask for more money because she has been intimidated by the Public Trustee office in the past.*

*"They are a dictatorship [unto] themselves. They have their own laws, which are inhumane. They have taken away my voice, my character, my decision making. They have no respect to be treating me as a human being," she said. ...*

*"I would have more rights in jail."<sup>44</sup>*

- 5.10 Moreover, non-consensual interventions through guardianship and financial management subject women with disability to a standard of mistreatment that would not be tolerated for people without disability (e.g., sterilisation, locked accommodation, and degrading living conditions or violence in accommodation or services selected by the guardian and which women with disability are sometimes required to remain at and will be coercively returned to by police or ambulance officers if they leave).
- 5.11 Guardianship and financial management are also harmful because they can prevent women from having children. This might be by reason of sterilisation being ordered by a tribunal or board, but it can also be the impact of substitute decisions that guardians can make (with no tribunal or board oversight) such as authorising use of contraception through which women are – in the words of US disabled legal scholar Robyn M Powell – ‘in effect sterilized since they cannot reproduce’<sup>45</sup> or deciding where a woman lives and who she can and cannot have social contact with. Relatedly, when guardianship involves decisions that deny supports and resources for women with disability to experience positive sexual experiences and intimate relationships, it is harming women in denying to them intimacy and pleasure.
- 5.12 Guardianship and financial management are harmful because of the longer-term impacts that women with disability experience, which might not be immediately visible at the time when guardians make their substitute decisions and slowly deplete their living conditions, sense of self, economic wellbeing, social networks, identity and health.<sup>46</sup> Women with disability can be under guardianship and financial management for long periods of time – years and even decades. During that time, they can be subjected to extreme restrictions on whether they menstruate, whether they can become pregnant, where they live, who they have social contact with, how they spend their money, and what healthcare and services they receive. Yet, even after any guardianship or financial management orders cease to operate (if they do ever cease), women with disability can continue to live with the legacies of those orders. This is for a number of reasons. One reason is that living and service arrangements set up through substitute decisions can remain in place even if women with disability cease to be under guardianship, and women with disability might not have the social networks or economic security to access other accommodation or support (this also being caused by the failure of guardians to enhance the social capital and economic wellbeing of women with disability). A second is that it might be impossible for women with disability to repair social and family networks that have been broken through substitute decisions, such as decisions limiting social contact. A third reason is that women’s self-confidence, self-worth, sense of self and ability to trust others is irretrievably damaged after having been denied autonomy for years under guardianship and financial management. On Day 2 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Julie Bury spoke of the ongoing impact of her revoked interim financial management order, imploring

*I want them to know that what has happened to me, this Public Trustee, has actually changed my life completely. ... And I’m constantly looking behind me waiting for the next attack, the next stab in the back, and sometimes it may not be the way it should be, but I’ve learned that quite often I have to trust my instinct and I know when it’s coming. And that shouldn’t be the way a person moves. That’s the way an animal lives.*

- 5.13 Fourth, by the time women with disability are free of guardianship they might have passed the window of years in which they can become pregnant, or have had the capacity to become pregnant permanently removed through sterilisation. Fifth, women with disability might live with harmful physical and mental health impacts of the medical decisions of tribunals and boards or guardians (e.g., the longer-term impacts of sterilisation, long

acting reversible contraception or psychotropic medication) or the substitute decisions that guardians have made (e.g., deciding that a woman live in degrading or unsafe accommodation) or have failed to make (e.g., not arranging regular medical and dental check-ups). On Day 1 of the Public Hearing 30 on guardianship, substituted and supported decision-making, the Disability Royal Commission heard from Anthony (a pseudonym) who spoke of his experiences assisting his mother, Killara (a pseudonym), a First Nations woman placed under the Western Australian Public Advocate and Public Trustee in 2015. Killara lived in a facility from late 2015 to June 2022 following an accommodation decision made by the Public Advocate. Anthony provided details of the medical neglect suffered by Killara over this period in the facility. Killara had been displaying physical signs of untreated diabetes including blurry eyesight, poor condition of her feet and black teeth which led to her needing ‘on one occasion, eight teeth removed one day. The next day, healing, seven teeth. She’s got dentures now’ noting her diabetes was not confirmed until Anthony took over as medical guardian and ran the relevant blood tests. Killara also had an untreated hepatitis C infection that led to moderate cirrhosis of her liver.<sup>47</sup>

- 5.14 The wealth of lived experiences of sterilisation (explored in detail in our earlier sexual and reproductive rights submission)<sup>48</sup> illustrates the broad range and depth of harms that can be experienced by women with disability when subjected to non-consensual interventions related to their reproduction and sexuality. While it is not clear that guardianship law was used in all of these lived experiences below, sterilisation can be the subject of substituted decision-making in guardianship law and thus we include some examples here as indicative of the kinds of harms that are possible, particularly the way they endure and become further entrenched over one’s life:

*“I was devastated when my doctor advised me that the previous surgeon had done more than tie my tubes. He had actually removed parts of my reproductive system that could never be replaced.....I was shocked and furious.”*

*“Because I have had important parts of my body taken away it is hard to find out what is really going on in my body.”*

*“We have the right to control what happens to our own bodies.”*

*“Because I will not go through obvious menopause, in my culture that means I have no marker for becoming an ‘elder’.”*

*“Surgery of a healthy body is mutilation.”*

*“I am...taking a big risk on behalf of myself and my family in speaking up. I would like to know what is being done for us who have had this done twenty or thirty years ago? I don’t have an intellectual disability and it was done before I started having a period. What research is being done to help us who were young children that went through this, and when we go through menopause? It can affect our health in the future. I think of this as my real disability – the physical one that you see isn’t real – the one I had happen to me when I was 12 is the main one and I don’t have anyone to turn to.”*

*“It has resulted in loss of my identity as a woman, as a sexual being.”*

*“I have been denied the same joys and aspirations as other women.”*

*“It stops us from having children if we want to.”*

*“I worry about the future health effects like osteoporosis and other problems.”*

*“The fact that services are not there is no reason for sterilisation.”*

*“Sterilisation takes my choice away.”*



*"I'm angry."*

*"I want to experience a period."*

*"Sterilization is a terrible thing to do to a woman. They had no right to do that to me. They never ask you about it. They told me that it was just for my appendix and then they did that to me."*

*"If they'd told the truth and asked me, I would have shouted 'No!' My sterilisation makes me feel I'm less of a woman when I have sex because I'm not normal down there.....When I see other mums holding their babies, I look away and cry because I won't ever know that happiness."*

*"Sterilisation takes away your womanhood."*

*"I do want to have children but I can't now."*

*"I got sterilised at 18, my mum said I had to – she said that if I ever had a child, she'd probably have to help look after it. She said: "I went through hell bringing you up and I will not do it again". It's more than 30 years now since I was sterilised and the pain is still unspeakable. It is the biggest regret of my life."*

*"For me it has meant a denial of my womanhood."*

*"I was sterilised and I wasn't ever told when I was getting it done. The specialist told mum about it but I didn't know I'd had it done until I was 18."*

*"I have always had a fear of speaking out about it – it's been very isolating."*

*"I want to help others who don't have a voice, to stop it happening to them – I feel powerless to do that."*

*"I will have no way of knowing about the onset of my menopause."*

*"I know it has resulted in hormone changes in my body that wouldn't have happened otherwise."*

*"It can lead to the break-up of relationships."*

*"Other people don't understand what it means in your life and it's very hard to explain that to people."*

*"Other women don't understand what it's like for us – it sets us apart from them."*

*"For me it is about living with loss."*

*"It really affects my self-esteem."*

*"It has stopped me having a normal life."*

*"It's about loss of control."*

*"For me it has meant a loss of trust – especially of doctors – those who women with disabilities often have to place their trust."*

*"I have a blockage of emotions."*

*"It's a great emotional upheaval."*

*“I feel alone and isolated.”*

*“The pain is hard to bear.”*

*“I have a fear of not being seen as a sexual identity – of sexual rejection.”*

*“I have feelings of rejection.”*

*“There is no information available for us.”*

*“There are not enough services or people to listen”.<sup>49</sup>*

- 5.15 Academic research has also established the harms to women’s health caused by sterilisation and use of long acting reversible contraception (LARC), these being non-consensual interventions that can be the subject of guardianship law. The impacts of LARC can include certain gynaecological cancers, osteoporosis, increased weight gain, elevated prolactin concentrations (which can cause infertility, menopausal symptoms, milk discharge from the breasts, hyperprolactinemia, hypothyroidism).<sup>50</sup> In a 2020 report on menstrual suppression, the Victorian Senior Practitioner summarised some of these risks:

*Depo-Provera decreases estrogen levels, which leads to reduced bone density and strength. For those women who may not be able to exercise, or have limited exercise, there is an increased risk of losing overall bone strength. Reduced bone strength is likely to lead to bone fractures and breaks. Taking the oral contraceptive pill (ethinyloestradiol) can increase the risk of blood clots by three to five times, which can cause heart attacks and stroke. Similarly, those who are unable to exercise, or have limited exercise, are at increased risk of blood clots. Considering the prevalence of complex communication needs in this population, people may be unable to report pain or injury. This compounds the health risks, as people may be experiencing severe pain on a daily basis.<sup>51</sup>*

- 5.16 A current boxed warning for Depo-Provera directed towards US residents states:

**Warning: Loss of Bone Mineral Density**

*Women who use Depo-Provera Contraceptive Injection (Depo-Provera CI) may lose significant bone mineral density. Bone loss is greater with increasing duration of use and may not be completely reversible ... .*

*It is unknown if use of Depo-Provera CI during adolescence or early adulthood, a critical period of bone accretion, will reduce peak bone mass and increase the risk for osteoporotic fracture in later life ... .*

*Depo-Provera CI is not recommended as a long-term (i.e., longer than 2 years) birth control method unless other options are considered inadequate ... .<sup>52</sup>*

- 5.17 Pfizer’s prescribing information for medical practitioners additionally notes:

*Depo-Provera CI can pose an additional risk in patients with risk factors for osteoporosis (e.g., metabolic bone disease, chronic alcohol and/or tobacco use, anorexia nervosa, strong family history of osteoporosis or chronic use of drugs that can reduce bone mass such as anticonvulsants or corticosteroids). ...*

*Women who have or have had a history of breast cancer should not use hormonal contraceptives, including Depo-Provera CI, because breast cancer may be hormonally sensitive ... . Women with a strong family history of breast cancer should be monitored with particular care. ...*

*Monitor patients who have a history of depression and do not re-administer Depo-Provera CI if depression recurs. ...*

*Return to ovulation and fertility is likely to be delayed after stopping Depo-Provera CI.*  
...

*A woman who is taking hormonal contraceptive should have a yearly visit with her healthcare provider for a blood pressure check and for other indicated healthcare.<sup>53</sup>*

- 5.18 The information on Depo-Provera makes clear that there are significant health risks with use of this LARC, particularly for longer-term use, and that this can be exacerbated for women with pre-existing conditions such as depression. Moreover, the information emphasises the importance of doctors monitoring usage of Depo-Provera, including through annual medical check-ups. Unfortunately, some women with disability who are under guardianship and subject to non-consensual contraception can be in a state of ‘set and forget’ and not have regular medical check-ups let alone regular review of contraception prescriptions. This is particularly the case if women are additionally socially isolated, financially disadvantaged and in insecure housing such as boarding houses or in disability group homes (all circumstances that might themselves have been enabled through the substitute decisions or neglect of guardians and financial managers). These circumstances are demonstrated by Killara’s experiences from Day 1 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making which we discussed earlier in this section. By way of further example, on Day 1 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Alice Barter of the Aboriginal Legal Service of Western Australia discussed how decisions made by the Public Advocate and Public Trustee are very reactive where, for example, ‘it would only be once someone takes a decision to the Public Advocate that they will make a decision, rather than proactively making sure their clients have got housing or have got medical services’. Barter illustrates the consequences of this approach through a case study:

*She was very, very special. She had experienced every single type of trauma that our clients had experienced. She was involved in a motor vehicle accident when she was quite young, and she had lost the feeling in her legs, so she was a wheelchair user. She also had an acquired brain injury, which made her quite difficult to communicate with. The way she communicated is she used the F and the C words. That was just the way that she spoke, and I think a lot of carers and service providers found that quite disrespectful, despite her not meaning any disrespect. It was just the way that she communicated.*

*And she would get very dysregulated very easily. She had a lot of trust issues from all the things that she had been through. But she would come to the ALS and say, “No one else is helping me.” Despite being under orders. There was one time where she was the - the police had taken her from her home because her carers were not able to calm her down and she needed serious medical attention. She had very bad pressure sores that had progressed to septicaemia.*

*And the police took her to a hospital in Perth and the hospital workers didn’t want to help her because she was being “difficult” in inverted commas. And she had nowhere else to go so she came to the Aboriginal Legal Service office, which, you know, we are not a medical service, but we calmed her down and called an ambulance. She ended up passing away due to those pressure sores, and it was so heartbreaking for us because she should have had help. She needed help. She needed help to make her decisions, and she needed support workers who were patient and kind, and she needed medical staff who were going to help her deal with these pressure sores.*

*But because it was so difficult for her to get assistance she got really sick and she passed away. And it was one of those examples where we as lawyers had tried to engage the Public Advocate in her care. We tried to connect both the hospital and the Public Advocate together to talk about the decisions in relation to her treatment, but often the Public Advocate didn't even know she was in hospital. And sometimes the hospital staff didn't know to talk to the Public Advocate about decisions. And so we saw that as a very big gap in the way that the system could be working in a proactive way to actually make sure that someone is getting the support they need. But, unfortunately, she didn't get it.*

- 5.19 Guardianship and financial management are harmful to First Nations women with disability because they are a form of settler colonial violence. The denial of self-determination through substitute decision-making and the role of government authorities in guardianship and financial management can be experienced as having continuities with other forms of settler state violence such as state child removal. These settler colonial dynamics of financial management were considered in relation to the Civil and Administrative Tribunal New South Wales Appeal Panel decisions concerning 'ZOF'. ZOF is described as a '59-year-old man who identifies as a member of the Ngarbal people and is from regional NSW' and is 'a survivor of the Stolen Generations'. ZOF had received an *ex gratia* payment under the NSW Stolen Generations Reparations Scheme, and a cousin of ZOF had made an application for a financial management order on the basis that others might take ZOF's reparations payment.<sup>54</sup> The Civil and Administrative Tribunal New South Wales Appeal Panel considered the potential impact of financial management on the Aboriginal cultural practice of 'sharing and caring', with ZOF submitting that 'an order should not be made and that it would "take away his identity"'.<sup>55</sup> The Civil and Administrative Tribunal New South Wales Appeal Panel also considered financial management as a form of government and institutional control of Aboriginal people, in light of ZOF's solicitor's submissions that:

*the very existence of the order, despite it seemingly as yet having not deprived the appellant of self-management of any of his estate, had been detrimental to the Appellant due to his cultural heritage which in turn was linked to personal history of having been part of the Stolen Generations since the age of three months.*<sup>56</sup>

- 5.20 ZOF's experience as part of the Stolen Generations, had 'amplified his negative perception of the existing order'.<sup>57</sup> Ultimately, the Civil and Administrative Tribunal New South Wales Appeal Panel dismissed the application for a financial management order.
- 5.21 Guardianship and financial management can also contribute to poverty and social exclusion experienced by women with disability. For example, the Intellectual Disability Rights Service observes the impact of financial management orders in NSW as making it difficult for people with intellectual disability to enjoy cultural rituals such as birthdays and everyday experiences that are otherwise taken for granted and are important for a sense of belonging and identity:

*Many of the people contacting IDRS about financial management orders find the restrictions very distressing, frustrating and detrimental to their lives. They are often limited in many aspects of their lives – for example, some clients have not been able to access funds for food, transport and other necessities. For many others, negotiating for money to enjoy some special event or occasion, outside their usual routine (for example, a gift for a friend's birthday or to attend a special event, like a concert or dinner) proves to be impossible.*<sup>58</sup>

- 5.22 Moreover, some of the non-consensual interventions in the bodies and lives of women with disability authorised through guardianship and financial management expose women to further harms. For example, non-consensual contraception and sterilisation can increase

women and girls' vulnerability to sexual violence because they can be victimised without the possibility of pregnancy and perpetrators can more easily evade detection (as noted by the CRPD Committee).<sup>59</sup> Guardianship substitute decisions to place or even detain women with disability in disability group homes, residential aged care facilities or other segregated and closed accommodation settings can then expose these women to the physical and psychological harms associated with sexual and physical violence and use of restrictive practices which are heightened in such settings. Guardianship substitute decisions about accessing services that provide degrading standards of accommodation, personal care and support can expose women with disability to physical and psychological harm. Guardians who have medical decision-making authority but do not ensure regular medical and dental check-ups and timely responses to health concerns can then result in longer-term health issues and even premature death. Financial management which denies to women with disability access to sufficient funds to meet their needs for accommodation, food and other necessities can result in harms associated with sexual and labour exploitation as they might find other ways to meet their needs. The increased opportunity for contact with police and ambulance services that women with disability are exposed to when they are subject to guardianship orders that empower emergency services to coercively return them to their accommodation also exposes some women with disability to greater risk of criminalisation and to incarceration in police custody, prison and mental health facilities.<sup>60</sup>

- 5.23 Guardianship and financial management also cause socio-cultural harms to all women with disability. These harms are perpetrated through the messages about women with disability as less than human and as violable which are reflected in the legally and socially sanctioned violence and control enabled through guardianship and financial management, and the lack of accountability and redress in the aftermath of these experiences. Guardianship and financial management instil fear and insecurity in women with disability more broadly because the possibility for their use is legally and socially sanctioned. The Beijing Platform of Action explained more broadly that:

*Acts or threats of violence, whether occurring within the home or in the community, or perpetrated or condoned by the State, instil fear and insecurity in women's lives ... . The fear of violence [and restriction and coercion, particularly for women with disabilities] ... is a permanent constraint on the mobility of women and limits their access to resources and basic activities.*<sup>61</sup>

- 5.24 The discussion in this section of the diverse and sometimes lifelong harms to women with disability underscores the importance of recognising guardianship and financial management as violence against women as part of the broader Australian National Plan to End Violence against Women and Children 2022–2032 to end violence against women in one generation. Failure to do so gives rise to an additional harm – at the level of law and policy – in treating women with disability less favourably than other women in giving them less protection from violence and less opportunities for equality and autonomy. Indeed, this additional harm at the level of law and policy has already manifested in abortion law reform where a narrow focus on decriminalising consensual abortion for women through specific legislative reforms of criminal law has overlooked the legality of non-consensual abortion specifically for women with disability at the intersections of disability-specific legislation and criminal legal principles on consent.<sup>62</sup>

## **Ableist and sexist**

- 5.25 Guardianship is ableist and sexist.

## **Ableism**

- 5.26 Former UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas-Aguilar elaborates that ableism is:

*a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives.*

*The hegemony of ableism in society has perpetuated the idea that living with a disability is a life not worth living. There is a deep-rooted belief, carved with fear, stigma and ignorance, that persons with disabilities cannot enjoy a fulfilling life, that their lives are incomplete and unfortunate ...<sup>63</sup>*

- 5.27 Devandas-Aguilar explains that ableism ‘leads to social prejudice, discrimination against and oppression of persons with disabilities, as it informs legislation, policies and practices’.<sup>64</sup> She explains that ableism endures: ‘Despite the significant advances in the recognition of the rights of persons with disabilities at international and national levels’ and persists as ‘deeply rooted negative perceptions about the value of [people with disabilities]’ lives’ and which reproduces fundamental obstacles to this group’s capacity to recognise and enjoy their rights.<sup>65</sup>

- 5.28 Devandas-Aguilar observes that ableist assumptions have underpinned and constrained the notion of autonomy in a manner that excludes people with disability from exercising their legal capacity and rights. She explains:

*Traditionally, both individual autonomy and personal independence were based on ableist assumptions, such as possessing certain mental capacity or not needing assistance to carry out everyday activities. As a result, persons with disabilities were seen as less autonomous and independent than others and even as having no autonomy or independence.<sup>66</sup>*

- 5.29 Devandas-Aguilar argues that substitute decision-making and many of the non-consensual interventions associated with guardianship are grounded in ableism:

*Ableist assumptions lie at the root of discriminatory practices, such as the sterilization of girls and women with disabilities, the segregation, institutionalization and deprivation of liberty of persons with disabilities in disability-specific facilities and the use of coercion on the basis of “need of treatment” or “risk to self or to others”, the denial of legal capacity on the basis of mental capacity, the denial of treatment on the basis of disability, or the failure to consider the extra costs of living with a disability.<sup>67</sup>*

- 5.30 Ableism is associated with ‘medical’ models of and approaches to disability, which

*prevent the application of the equality principle to persons with disabilities. Under the medical model of disability, persons with disabilities are not recognized as rights holders but are instead “reduced” to their impairments. Under these models, discriminatory or differential treatment against and the exclusion of persons with disabilities is seen as the norm and is legitimized by a medically driven incapacity approach to disability.<sup>68</sup>*

- 5.31 Talila A Lewis – an abolitionist community lawyer, educator, and organiser – offers an expansive definition of ableism that emphasises the connections between different forms of structural oppression:



*A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, 'health/wellness', and/or their ability to satisfactorily re/produce, 'excel' and 'behave'.<sup>69</sup>*

- 5.32 Through an ableist lens, disability is understood as a negative attribute associated with abnormality, burden, unfitness and incapacity. When used as a lens through which to view individuals and entire marginalised groups, ableism provides a justification for them to be devalued, violated and dehumanised. Through ableism, people with disability are relegated not simply to the status of socially undesirable in and of themselves, but as socially and economically burdensome on others and as having a depleting impact on the prosperity of their families, the wider population and the nation. It is by reason of this impact on others that people with disability are rendered undeserving of access to property, resources, and legal protections to survive and flourish.
- 5.33 When understood through the lens of ableism, autonomy is not simply a characteristic that certain individuals and groups possess naturally. Rather, autonomy is an entitlement that is granted selectively to individuals and groups based on their economic and social deservedness. Thus, the denial of autonomy to people with disability is an effect of their status as abnormal, unproductive, incapable and unfit which in turn renders their bodies legitimately violable, and thus is a political (and legal) act that is based on cultural assumptions about people with disability. The centrality of autonomy to Western legal, political and cultural understandings of personhood (and relatedly control of one's body and ownership and control of property) also means that denial of autonomy is an act that denies people with disability recognition in law and society as persons.<sup>70</sup> This selective granting of capacity is also seen in the context of other marginalised groups in contemporary and historical contexts such as First Nations peoples and women.
- 5.34 The ableist nature of guardianship and financial management continues eugenics logics associated with earlier laws that enabled the sterilisation and institutionalisation of people with disability, and other marginalised populations.<sup>71</sup> For example, disabled health researcher Michaela Kathleen Curran has argued that eugenics endure in contemporary US conservatorship laws that allow others to control reproductive and sexual decision-making.<sup>72</sup>
- 5.35 Canadian scholar Joshua Shaw argues that substitute decision-making laws (and specifically Canadian parens patriae jurisdictions) rely on an ableist medical-legal construct of mental competence which is premised upon a highly individualised conception of autonomy:

*focusing on the capacity of an individual without assistance to make and exercise decisions that will obtain self-realization. It ignores the role of relationships, including the support and influences these bring, by atomizing the individual. In its fixed preference for individualized autonomy, reliance on a biomedical-oriented lifeworld can deprive a person with intellectual disability of the opportunity to make decisions that might be possible with assistance, especially where that individual is deemed mentally incompetent at law.<sup>73</sup>*

- 5.36 In a similar vein, Arstein-Kerslake et al argue that guardianship and financial management are ableist because they devalue the abilities of people with disability:

*ableist notions ... de-value the decision-making skills of people with disability and justify the imposition of ... guardianship, conservatorship, interdiction, and other*

*such measures ... to constrain the legal personhood and agency of an individual with disabilities, or, in some jurisdictions, ... to wholly remove an individual's legal personhood and vest their decision-making power in another individual or in the state.*<sup>74</sup>

- 5.37 Bushko argues (in the US context) that '[a]s an institution, guardianships and conservatorships require separating those who are "competent" and able to care for themselves and their property from those who are not' and 'defining who is mentally ill or incompetent can be problematic, because these categories are socially and culturally variable'.<sup>75</sup>
- 5.38 Spivakovsky and Steele argue that guardianship is constructed as necessary mechanisms for people with disability to be in the community and thus are based on a conceptualisation of people with disability as not part of the community, or as only conditionally part of the community. Guardianship therefore constructs and enforces a hierarchical, transactional relationship between people with disability and the remaining 'normal' people of society because the former must give up their rights *in exchange for* being considered part of the community. In effect, it functions as a framework for 'graciously allowing the person to remain in the community by denying them legal recognition of their decisions'.<sup>76</sup>
- 5.39 Guardianship and financial management are also ableist because they de-value and deny the decision-making skills of people with disability<sup>77</sup> and deny the reality that people (irrespective of disability) are interdependent in their decision-making and lives more broadly. Erin O'Donnell and Arstein-Kerslake argue that the dominant approach to legal personhood (which we argue underpins guardianship and financial management) 'is largely in line with liberal political values that prioritise individualism and often ignores the relational nature of our socio-legal world. ... [and] the inherent interdependence that we all live within and benefit from'.<sup>78</sup> Similarly, Shaw argues that 'the concept of individualized autonomy [that underpins guardianship law] contributes to an understanding of the human condition that is divorced from reality'.<sup>79</sup> Autonomy is more accurately understood 'as a relational social process'; therefore, as Shaw argues:

*a person's competence to make decisions should not be assessed according to his ability to fulfil the legal and social fiction of an autonomous individual. Instead, positive efforts should be made to empower a person ... , enabling the individual to make decisions and make those decisions known.*<sup>80</sup>

- 5.40 The ableism of guardianship and financial management is connected to the historical oppression of other marginalised populations. For example, O'Donnell and Arstein-Kerslake argue that legal personhood (which is inextricably bound up with legal capacity) reflects a 'white, European, able-bodied, cis-gender male approach to legal personhood ... has dominated much of the world and excluded and marginalised other groups'.<sup>81</sup> O'Donnell and Arstein-Kerslake argue that this approach to legal personhood 'assumes that the individual has the power and privilege necessary to move deftly through the socio-legal world to secure their rights and interests. It disadvantages most groups and individuals that are not experiencing high levels of power and privilege'.<sup>82</sup> This approach to legal personhood 'was developed throughout the last several centuries and has largely met the needs of feudal lords, slave owners, colonial settlers, husbands, capitalists, and others that have held positions of social privilege and had the power and freedom to influence the development of theory and law'.<sup>83</sup> O'Donnell and Arstein-Kerslake observe that this concept of personhood was developed by 'legal and philosophical thinkers [who] were white, able-bodied, cis-gender men' and these privileged men who developed the law were sexually and racially exploitative, since they 'were largely supported by the often unacknowledged labour of women and people of colour'.<sup>84</sup>

## Sexist

- 5.41 Guardianship and financial management are also sexist. Recognising this sexism is important in order to highlight the particular impact of guardianship and financial management on women with disability and that guardianship and financial management contribute to gender inequality. Concerningly, in its Roundtable document on supported decision-making and guardianship, the Disability Royal Commission itself did not specifically address the circumstances of women with disability nor the intersections of guardianship and financial management with sexuality and reproduction (although, nor did it consider ableism), only noting in a cursory manner:

*We have heard that some people with disability face additional barriers to exercising their autonomy, based on their type of disability, cultural and socio-economic background, gender or gender identity, sexuality, and age.<sup>85</sup>*

- 5.42 The CRPD Committee has described forms of ‘substituted decision-making’ as ‘patriarchal systems’ that oppress and disenfranchise all people with disability but which disproportionately harm women and girls.<sup>86</sup>
- 5.43 Feminist legal scholars have long argued that legal systems are patriarchal. Bushko, writing in the context of a feminist legal critique of US conservatorship laws, argues that ‘the legal system, even when promulgating gender-neutral laws, perpetuates society’s patriarchal systems’<sup>87</sup> and that ‘laws perpetuate historically problematic power dynamics in society, particularly pertaining to gender’.<sup>88</sup> Bushko argues that because of the inherent sexism of law, there is always ‘the potential for gender-biased abuse underlying supposedly neutral laws’, including specifically in the case of conservatorship laws.<sup>89</sup> Although ‘conservatorship laws ... are gender-neutral on their face’, Bushko argues that they ‘involve the protective-yet-restrictive legal structure that feminist theorists have often observed, cautioned against, and advocated to change’.<sup>90</sup> Therefore, there is a strong ‘potential for gender-based abuse under conservatorship laws’.<sup>91</sup> Bushko argues that, in the context of a ‘patriarchal legal structure [which] has historically already given men control of women’s sexuality and reproductive choices’, ‘Conservatorships ... allow a legally appointed conservator to control the social lives and reproductive freedoms of individuals’ and can therefore easily extend patriarchal control and perpetuate further sex-specific harms.<sup>92</sup>
- 5.44 In making the non-consensual treatment of people with disability legally permissible,<sup>93</sup> guardianship parallels the sexist hierarchy of knowledge and decision-making in law and medicine that has normalised the paternalistic treatment of women and their subjection to non-consensual sexual and reproductive medical practices and interventions. This sexist hierarchy has disenfranchised women whether they are disabled or not. For example, Sonya Charles’ research<sup>94</sup> into sexism and violence against women in obstetric practice documents pregnant women’s routine subjection to ‘patronising and paternalistic’<sup>95</sup> attitudes from physicians who did not respect their right to receive balanced information nor recognise their capacity to make informed decisions. Women’s experiences also extended to medico-legal violence when, in some cases of caesarean surgery, obstetricians had obtained court orders that literally imprisoned women in a particular hospital and forced them to undergo this procedure, rather than allowing the women to seek various medical opinions, weigh risks and benefits, and make an informed choice. Via medico-legal power, the threat of further coercion, and ultimately, the direct physical and sexual violation of forced surgery, women were subjected to ‘legitimate’ violence, rooted in oppressive sexist ideas about their inferior capacity and need for paternalistic and protectionist treatment.

5.45 When situated in the context of this sexism in law and medicine more broadly, guardianship and financial management are sexist because they explicitly enable control of sexuality, reproduction and menstruation of women with disability. This control is premised on sexist assumptions about women as irrational and incapable, compounded with ableist assumptions that women with disability are ‘incapable of adequate parenting’ and that their children will ‘inevitably be a financial burden on the state’.<sup>96</sup> These ideas reflect a continuation of ideas often associated with early twentieth century eugenics (such as articulated in the famous US Supreme Court sterilisation decision of *Buck v Bell*),<sup>97</sup> but are now recast in person-centred rationales of community inclusion and participation. As US disabled legal scholar Powell argues, ‘reproduction is still weaponized to subjugate people with disabilities’.<sup>98</sup> The control of women’s sexuality, reproduction and menstruation through guardianship and financial management is greater than what is possible in relation to males with disability. For example, while it is lawful to remove or damage physical parts of women’s bodies, this is not possible in relation to males with disability (instead chemical castration is possible). Our point is not that this level of physical intervention and destruction should also be possible for males with disability, but rather to show the extremes of control and intervention enabled on women’s bodies in relation to their reproduction, sexuality and menstruation. As Powell argues, sterilisation interweaves ableism and sexism because it is about the control of disabled people and of female reproduction and sexuality.<sup>99</sup> Renu Addlakha et al further explain:

*While it goes without saying that people with disability have equal rights to sexual and reproductive desires and hopes as non-disabled people, society has disregarded their sexuality and reproductive concerns, aspirations and human rights. People with disabilities are infantilised and held to be asexual (or in some cases, hypersexual), incapable of reproduction and unfit sexual/marriage partners or parents. The sexual and reproductive health and rights (SRHR) of people with disabilities continue to be contested, and there are particular concerns in relation to women with disabilities. For women, disability often means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood.<sup>100</sup>*

5.46 The operation of guardianship and financial management is sexist in outcome because women with disability are disproportionately affected. For example, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) has stated in its general comment on women and girls with disability:

*Women with disabilities are more likely to be subjected to forced interventions than are women in general and men with disabilities. Such forced interventions are wrongfully justified by theories of incapacity and therapeutic necessity, are legitimized under national laws and may enjoy wide public support for being in the alleged best interest of the person concerned. Forced interventions violate a number of rights enshrined in the Convention, namely: the right to equal recognition before the law; the right to freedom from exploitation, violence and abuse; the right to found a family; the right to the integrity of the person; the right to sexual and reproductive health; and the right to freedom from torture or cruel, inhuman or degrading treatment or punishment.<sup>101</sup>*

5.47 The CRPD Committee goes on to state that:

*Women with disabilities, more often than men with disabilities and more often than women without disabilities, are denied the right to legal capacity. Their rights to maintain control over their reproductive health, including on the basis of free and informed consent, to found a family, to choose where and with whom to live, to physical and mental integrity, to own and inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit are often violated through patriarchal systems of substituted decision-*

*making.*<sup>102</sup>

- 5.48 Older women with disability (including those living with dementia) are also disproportionately impacted. Devandas-Aguilar has observed that older women with disability are more disadvantaged and institutionalised than other people with disability:

*Older women with disabilities have consistently worse life prospects and outcomes than older women without disabilities and older men with disabilities. Gender roles and expectations often push these women into economic dependency. As a result, older women with disabilities are considerably poorer; are likely to be subject to violence, abuse and neglect; and have higher chances of facing unmet needs and human rights violations. In addition, older women with disabilities are more likely to be institutionalized or incapacitated owing to the higher life expectancy of women compared with men.*<sup>103</sup>

- 5.49 The Independent Expert on the Enjoyment of all Human Rights by Older Persons (Claudia Mahler) has argued that dementia is a gendered phenomenon:

*Dementia disproportionately affects women, but little research has been conducted directly involving women with dementia as participants and focusing on the gender issues associated with this condition. The voices of women with dementia remain largely unheard, and more needs to be done to dispel misconceptions and stigma associated with dementia. This is of particular concern given the higher vulnerability of persons with dementia to denial of their basic rights and freedoms.*<sup>104</sup>

- 5.50 Mahler has noted that older women are particularly subjected to ageism:

*Ageist attitudes disadvantage older women more than men. ... Other societal and cultural norms expect that older women are respected and cared for by their family, which can make it socially unacceptable to speak out and report violence, abuse and neglect.*<sup>105</sup>

- 5.51 Also, Mahler recognises that older women are subject to disadvantage and violence in relation to their property ownership:

*This means that access to safe and secure housing can be especially challenging for older women and can lead to further violations of human rights, including the rights to liberty and security of the person, independent living, privacy and health. Owing to limited income and savings, unequal access to property and assets and a lack of affordable community-based care services, older women can be at particular risk of losing their homes, being institutionalized or living in inappropriate and unsafe housing.*<sup>106</sup>

- 5.52 Mahler notes that older women are also at greater risk of violence because of '[e]conomic insecurity, challenges in access to quality and affordable health and care services, limited autonomy and independence and other disadvantages'.<sup>107</sup>

- 5.53 Ultimately, guardianship and financial management can be understood through a lens of 'gendered ableism', which we explained in our sexual and reproductive rights submission as:

*paying specific attention to the particular ways women and girls with disability are positioned as economic and social burdens, how women and girls with disability are disempowered access to embodied and social experiences that are gendered as female – such as menstruation, child birth and mothering, and gender-based violence – and the particular role of sexual and reproductive violence against women and girls with disability in settler colonial and neoliberal nation building.*<sup>108</sup>



## Guardianship and financial management are anachronistic

- 5.54 Guardianship and financial management legislation were introduced over thirty years ago in the late 1980s, and at a specific moment in Australian disability history. Specifically, guardianship and financial management legislation emerged at a time of escalating deinstitutionalisation, where large residential centres that congregated and segregated people with disability were closing and individuals with psychosocial and cognitive disability (particularly intellectual disability) were moving out of these institutions and living in the community. These individuals had previously been subject to profound control in institutions where decisions about all aspects of their lives were made by others. These decisions included where they lived, whether they worked, how they spent their money, who they had social contact with, what healthcare they received, what they did each day, what they could eat and what kind of personal care they received. At that point in time, guardianship and financial management were seen as a necessary, but paternalistic, response to the challenges it was assumed people with disability (particularly people with intellectual disability) would encounter in making their own decisions as part of living in the community.<sup>109</sup>
- 5.55 For example, The Victorian Law Reform Commission reflects that:
- The development of modern guardianship laws accompanied the deinstitutionalisation of services for people with cognitive disabilities in Victoria during the late 1970s and the 1980s. These reforms to Victorian law were part of a growing international interest in formally recognising the human rights of people with a disability.*<sup>110</sup>
- 5.56 Similarly, the NSW Law Reform Commission reflects that
- The Act developed out of concern with the limited legal mechanisms that existed for protecting and promoting the rights of people with intellectual disabilities. ... There was also a greater awareness of the rights of people with a disability to live as normal lives as possible in the community rather than in an institution.*<sup>111</sup>
- 5.57 Thirty years later, that time in 20<sup>th</sup> century Australian history has well passed. At a domestic level, the National Disability Insurance Scheme (NDIS) has marked a significant shift in how supports and funding are provided, and how inclusion and participation are understood. The objects of the *National Disability Insurance Scheme Act 2013* (Cth) include to support social and economic participation of people with disability and enable them to exercise choice and control<sup>112</sup> and extend to giving effect to Australia's obligations under the CRPD and other international human rights instruments.<sup>113</sup> Moreover, at an international level, and as we detail in Section 8, the CRPD gives rise to an expectation of not simply opportunity of a better life within the community compared to institutions, but of equality and autonomy within the community.<sup>114</sup> The CRPD Committee has explicitly called for abolition of guardianship laws and introduction of supported decision-making.<sup>115</sup> The UN Special Rapporteur on the Rights of Persons with Disabilities (Gerard Quinn) has made clear that 'protection' of people with disability must no longer be framed in paternalistic terms but rather should be framed in terms of 'personhood, human agency and the right of persons with disabilities to participate in and help to reshape their own societies'.<sup>116</sup>
- 5.58 Spivakovsky and Steele have critiqued guardianship law's orientation towards supporting community participation and inclusion, as evident in the principles contained in many of the state and territory guardianship Acts. They argue that this framing of guardianship law as delivering inclusion and participation is perverse, because these purported goals are arrived at through physical and epistemic violence:



*First, guardianship law emerged from, and continues to work within, the temporal dynamics of a medicalised, curative imaginary. Not only is the appointment of a substitute decision-maker under guardianship law seen as necessary for producing a better future for the 'lacking' individual – graciously allowing the person to remain in the community by denying them legal recognition of their decisions. But additionally, this promise of a better, more 'inclusive' future in the community through guardianship, is pitted against what Altermark (2017) calls, the 'dark past' of institutionalisation.*

*Second, the future brought forth by guardianship law is one filled with (more) curative violence. To continue to be 'included' in the community going forward, disabled people deemed lacking decision-making capacity are not only denied legal recognition of their decisions, but they are also expected to receive and accept significant coercive, violent and harmful interventions in their bodies and lives. In the name of 'inclusion', they are expected to welcome having no choice in where they live, with whom they can reside, or indeed, when they can leave their place of residence. They are also expected to welcome having someone else consent to them being physically and/or mechanically restrained, to being chemically rendered docile, and to being secluded in their room or home.<sup>117</sup>*

- 5.59 Therefore, guardianship and financial management is outdated and has no place in 21<sup>st</sup> century Australian society and law and policy.

### **Similar mechanisms for other marginalised groups have largely been abolished**

- 5.60 The CRPD Committee has observed that other marginalised populations have historically been denied legal identity or capacity:

*Legal capacity has been prejudicially denied to many groups throughout history, including women (particularly upon marriage) and ethnic minorities.<sup>118</sup>*

- 5.61 Indeed, at various times in human history, marginalised populations such as women, children, racial, ethnic and religious minorities, lower castes, and slaves, have been excluded from legal personhood.<sup>119</sup> Eilíonóir Flynn and Anna Arstein-Kerslake explain the foundation of these distinctions and inequalities:

*... many categories of persons have been regarded as less deserving of equal rights, and indeed as 'less human', than others. This approach to personhood has been used throughout history to justify discriminatory treatment for various individuals and groups.<sup>120</sup>*

- 5.62 These same authors further observe that assumptions about intellect are often used to justify exclusion of diverse marginalised groups from legal personhood, stating that when

*... legal agency has been denied to certain groups, while the core justification for the removal of legal agency in these situations was the individuals' status, these approaches were often rationalised by reference to the supposedly inferior intellect of individuals of these groups.<sup>121</sup>*

- 5.63 Women are the largest group that have been systematically denied legal status. In common law countries, they were not historically afforded full and independent legal personhood, as Blackstone's early English common law commentary makes clear:

*By marriage, the husband and wife are one person in law: that is, the very being or legal existence of the woman is ... incorporated and consolidated into that of the husband.<sup>122</sup>*

- 5.64 This was also known as the common law doctrine of coverture, and it meant that wives had no individual legal rights but instead had their legal identities subsumed within their husbands'.<sup>123</sup> Coverture positioned women as their husband's property to control rather than as autonomous human beings or rights-holders, and thus made legally permissible a range of controlling, coercive, abusive, and violent behaviours by men against women in the private sphere.<sup>124</sup> This situation persisted in most common law jurisdictions up until last century; eventually shifting due to political activism by early Western feminist and pro-feminist activists, who successfully petitioned for women's rights to be recognised and enshrined in law.
- 5.65 Guardianship of women still exists in some countries such as Saudi Arabia, where women struggle with a system that has oppressed them for centuries and continues to legally endorse 'men's authority over important aspects of women's lives, including marriage, travel, work, study, and moving from the family home'.<sup>125</sup> However, these laws and practices are widely considered human rights violations by international civil society, and abolition campaigns continue in earnest.<sup>126</sup>
- 5.66 Historically, First Nations Peoples have also had their legal capacity denied and have been subjected to regimes of guardianship and financial control. In the US, Bushko details
- horrifying, racially-charged ... conservatorship abuse ... in the early-1900s practice of putting Native Americans into guardianship, particularly when oil and gas were discovered under their land. Lawyers and conservators had themselves appointed as guardians over Native Americans with full fiduciary authority to spend their wards' money, or lease and sell their lands, allowing them to essentially steal lands and funds with court-appointed authority. ... Wards were often left to struggle financially while their funds and lands were depleted by excessive guardianship fees, negligence, deception, and other forms of abuse.*<sup>127</sup>
- 5.67 Racially-motivated denial of personhood was of course a cornerstone of slavery systems as well. Until this practice was abolished, 'under the law of the American colonies, slaves were only thought of as three-fifths of a person' and thus not as legal subjects nor as possessing legal capacity.<sup>128</sup>
- 5.68 In Australia, First Nations Peoples have also been historically denied legal personhood based on racist ideology concerning their inferior status and capacity. Indeed, by designating Australia *terra nullius* ('land belonging to no one') and its human inhabitants as fauna, European invaders and their laws set the scene for the systematic race-based subjugation of the lands of First Peoples. This subjugation underpinned numerous controlling policies across Australia's short white history, which can be understood under guardianship and financial management. For example, Bielefeld and Beaupert explain some of the foundations of early financial management of First Nations Peoples:
- In the context of Australian colonialism, Indigenous peoples were portrayed as possessing an inferior place in the human hierarchy, with child-like capabilities and minds stuck in a stage of partial development. This portrayal of First Peoples as incompetent and unworthy of access to rights afforded to others in the burgeoning colony had economic and other benefits for colonists intent on land acquisition and profits from slave labour. These racist attitudes were reflected in earlier colonial legislation. For instance, Indigenous peoples in Queensland were affected for years by 'slow worker' clauses in legislation that permitted gross underpayment of wages. This was a way of ensuring that minimal cash was transferred into Indigenous hands. Historically, every Australian jurisdiction adopted paternalistic legislation that made it difficult for Indigenous peoples to obtain access to money. ...*

*There were also other laws enacted in the early 1900s that denied Indigenous Australians civil rights and legal personhood, including laws preventing individuals from sitting on a jury, preventing them from engaging in military service, and preventing them from voting.<sup>129</sup>*

- 5.69 First Nations Peoples still experience enduring injustice and inequality directly stemming from this history. For example, it has been argued that the ‘Northern Territory Intervention’, which included laws for compulsory income management, has continued historical practices of excluding First Nations Peoples from legal personhood.<sup>130</sup>
- 5.70 These examples highlight the unethical foundations and moral dangers in excluding individuals or groups from legal rights frameworks. As Flynn and Arstein-Kerslake explain, legal frameworks that denying legal personhood to diverse marginalised groups are fundamentally discriminatory because they were based on the erroneous notion that ‘those of a different race or gender to the dominant group were ... not only socially, but biologically and cognitively, inferior’.<sup>131</sup> Even when under the banner of supposedly benevolent paternalism or protectionism, all these approaches and examples are profoundly problematic because they lead to human beings being treated as ‘objects to be pitied and cared for rather than as subjects before the law’.<sup>132</sup>
- 5.71 Ultimately, race and gender-based denial of legal personhood has been recognised as discriminatory and unjust and has been abolished in most parts of the world. It is now largely accepted that skin colour and gender, among other categories, are not indicative of individuals’ capacity to engage in decision-making, and are therefore not legitimate reasons for denying legal personhood.<sup>133</sup> Legal reforms can also be understood as part of broader strategies to recognise human rights and universal equality.
- 5.72 It is not only historically that people with disability have been perceived and treated as unworthy of legal capacity and ‘as a group which must be paternalistically protected by the law’ through mechanisms like guardianship.<sup>134</sup> In contrast to some positive legal reforms in relation to other marginalised populations, people with disability continue to be excluded from legal personhood through anachronistic guardianship and financial management laws. In line with these positive shifts, we therefore argue that it is now time for a similar process of change in relation to people with disability and to move from guardianship and financial management to supported decision-making frameworks. The examples discussed above demonstrate that there can be recognition that laws and practices are not set in stone forever but can be removed as societal attitudes and political status change, and that changing these laws is itself part of what contributes to this change. Change should be possible in relation to people with disability through abolishing guardianship and financial management laws and practices at our current time of focus on enhancing autonomy and equality for people with disability, particularly given these laws emerged at a very different point in the evolution of disability rights. If such transformative changes can be achieved for other marginalised populations, there is no reason why they cannot be achieved for people with disability. As noted by Flynn and Arstein-Kerslake, ‘disability is the last frontier (or at least one of the last) in the struggle for civil rights’.<sup>135</sup> The CRPD Committee has documented that ‘persons with disabilities remain the group whose legal capacity is most commonly denied in legal systems worldwide’.<sup>136</sup> Addressing their inequality is well overdue.



## **6 LEGAL DYNAMICS**

## 6. LEGAL DYNAMICS

- 6.1 In this section we discuss some of the legal dynamics of violence against women with disability through guardianship and financial management.

### Segregating and discriminatory legal framework

- 6.2 At a structural level, guardianship and financial management laws are segregating and discriminatory.
- 6.3 First, guardianship and financial management legislation is disability-specific legislation, insofar as it applies to individuals who are considered to lack decision making capacity by reason of their disability. Only people with disability (and particularly people with cognitive and psychosocial disability) can ever be subjected to the legislation, and have their legal capacity denied through substitute decision-making. Therefore, guardianship and financial management law creates the structural possibility for denial of autonomy and personal integrity of people with disability who come within the scope of the legislation. The legislation is then interpreted and applied in separate tribunals, tribunal lists or boards, thus introducing a further layer of segregation.
- 6.4 Second, the availability in law of guardianship and financial management runs counter to the general liberal approach in law to recognise individual freedom to consent to matters related to their bodies, lives and property. Individuals without disability can have their autonomy denied only in very narrow circumstances (e.g., criminal conviction, bankruptcy, medical emergency). Therefore, guardianship and financial management law creates a legally-sanctioned space for numerous non-consensual, coercive and violent medical interventions and procedures specifically in relation to people with disability.
- 6.5 Third, guardianship and financial management law is premised on narrow expectations about how people access, understand and process information, make decisions, and communicate those decisions. These expectations reflect the experiences of abled people. This is in contrast to addressing attitudes and stereotypes that inform these expectations and providing accommodations to support people with disability to make decisions (we discuss this further in Sections 7 & 8).
- 6.6 Fourth, some of the non-consensual interventions that can be authorised pursuant to guardianship and financial management law go beyond what would otherwise be legal, politically just, or even comprehensible in relation to people without disability. For example, non-consensual sterilisation, menstrual suppression and chemical castration are widely recognised as gravely wrong in relation to other groups (such as in response to such historical and even recent practices in relation to transgender people, racialised minorities and prisoners).<sup>137</sup> Thus, what is anticipated as appropriate and necessary non-consensual interventions in the bodies and lives of people with disability is different to and greater than what would be anticipated in the broader population, including other marginalised populations.
- 6.7 Fifth, guardianship and financial management law is paternalistic and positions people with disability as dependent, vulnerable and even child-like. In some jurisdictions this paternalism is not merely implied – it is explicitly stated in law. In Western Australia, a plenary guardian has the same functions as are vested in a person under the *Family Court Act 1997* in relation to a parenting order which allocates parental responsibility for a child ‘as if the represented person were a child lacking in mature understanding’.<sup>138</sup> Similarly, the Tasmanian guardianship legislation provides that: ‘A guardianship order



appointing a full guardian confers on the full guardian in respect of the represented person all the powers and duties which the full guardian would have in Tasmania if he or she was a parent and the represented person his or her child'.<sup>139</sup> Indeed, a 2021 Tasmanian Civil and Administrative Tribunal decision demonstrates how unproblematic tribunals consider equating in law of an 81 year old woman and a child. This decision concerned a guardianship order to provide consent to the use of a keypad lock on a door to restrict the ability of an 81 year old woman 'CBE' to leave her residential aged care facility, the Tribunal specifically considered the law on whether 'a parent [has] a right to lawfully restrict the freedom of movement of a child that would otherwise constitute a false imprisonment'.<sup>140</sup> It concluded that 'the granting of authority to a guardian to consent to or withhold consent to the use of the keypad lock on the front door of the facility for the purposes of an environmental restraint within the Principles is analogous to the power of a parent to his or her child and is within power under section 25'.<sup>141</sup>

- 6.8 Sixth, guardianship and financial management law is discriminatory by reason of the kinds of interventions that are enabled specifically in relation to women with disability. Legislation enables non-consensual sterilisation, abortion and contraception in relation to women with disability. Sterilisation and contraception can be authorised for non-medical reasons, this going beyond what might be considered possible in emergency situations for non-disabled women (e.g., sterilisation in the context of traumatic childbirth or detection of serious cancer). This is a significant denial of autonomy and personal integrity to women in a context of longstanding feminist activism on reproductive rights for women, these reproductive rights being considered most recently in the context of decriminalisation of abortion in Australia. For example, state-based law reform reviews of abortion law have focused on decriminalisation of consensual abortion in crimes legislation and have not recommended prohibition of forced and/or coerced abortion in relation to women and girls with disability, and indeed some have even affirmed the appropriateness of existing mental health and guardianship laws on non-consensual abortion. For example, in the course of recommending decriminalisation of abortion under Queensland criminal law, the QLRC recommended 'consequential amendments' to guardianship legislation which would reflect criminal law reform to consensual abortion but sustain the substitute decision making arrangements for non-consensual abortion, stating 'the draft legislation is not intended to affect the laws that regulate health practitioners or that govern consent to medical treatment, including consent to medical treatment for minors and substitute decision-making for adults with impaired capacity. If the draft legislation is enacted, those general laws will continue to apply'.<sup>142</sup> In an earlier 2008 report on abortion law in Victoria, the Victorian Law Reform Commission stated that 'The law governing consent to medical treatment by adults, children, young people, and people who do not have the capacity to provide their own consent because of disability is clear and appears to operate well in practice. The commission believes there is no demonstrated need to consider any changes to this body of law in the context of abortion law reform'.<sup>143</sup> Similarly, a Tasmanian review of criminal law on consensual assault did not consider or make any recommendations in relation to medical consent, observing that 'It is understood that consent to assault is generally accepted in areas like sport, correction of children and medical intervention'.<sup>144</sup> Most recently, the South Australian Law Reform Institute in recommending decriminalisation expressed its agreement 'with the reasoning of the Victorian Law Reform Commission and Queensland Law Reform Commission and considers that no changes are necessary to the existing laws in South Australia that govern consent to medical treatment for minors and adults with impaired decision-making capacity'. In the next paragraph the report went on to consider 'reproductive coercion' without any consideration of non-consensual abortion for women and girls with disability.<sup>145</sup> While women with disability have been marginalised in mainstream action on reproductive justice, US disabled scholar Powell has specifically argued for abolition of guardianship for achieving reproductive justice for women with disability, stating 'to achieve reproductive justice, legal and policy efforts must protect the autonomy and self-determination of

people with disabilities, including ensuring that they receive the least restrictive supports and abolishing guardianship'.<sup>146</sup> It is important to see abolition of guardianship and financial management as key strategies for preventing and responding to violence against women, as well as their broader function in realising human rights for all people with disability.

- 6.9 Seventh, guardianship and financial management law is discriminatory because it is available to be used as a violence prevention mechanism. As a violence prevention mechanism, guardianship and financial management law is antithetical to the approach taken in the key violence prevention law available for use in relation to women generally – apprehended violence order laws. Apprehended violence order laws take a non-paternalistic and victim/survivor-centred approach to violence prevention. Apprehended violence order laws place restrictions on perpetrators' behaviour (e.g., not contacting, residing with or coming within a close proximity of a victim/survivor), rather than punishing or disadvantaging the victim/survivor by legally coercing *them* to restrict their social networks and movements and change their residence, let alone legally requiring them to move into segregated or locked accommodation and relinquish control of their finances. It would be incomprehensible for a key response to violence against non-disabled women to be that they are put under control of someone else, moved into segregated and locked accommodation where they are exposed to a higher risk of violence including use of restrictive practices, and coercively brought back to their accommodation by police or ambulances if they do happen to leave (which might in turn expose them to criminalisation and incarceration).
- 6.10 As such, the approach under apprehended violation order laws is in contrast to the approach when guardianship and financial management law is used as a violence prevention tool, where it is used to 'protect' a woman with disability by moving her out of her existing accommodation and into segregated and locked accommodation, controlling who she has social contact with and taking control of her finances. This is a particular issue for older women living with dementia. The use of guardianship and financial management as a violence prevention tool effectively punishes victim/survivors, rather than intervening in and punishing the behaviour of perpetrators. Moreover, this particular use of guardianship and financial management law does not end a woman's subjection to violence and control, rather it simply transfers the violence and control from one person (marked as illegitimately using violence and control) to another (the guardian, who is marked as legitimately and legally using violence and control) and sustains the idea of the women with disability as an object to be moved around and lacking in agency. Further, through use of guardianship and financial management as a violence prevention tool, women can be exposed to greater risk of violence when they are moved into segregated and even locked accommodation.
- 6.11 Last, guardianship and financial management is discriminatory because it can be used to satisfy what is in the best interests (including the financial interests) of others. Substitute decision-making, particularly 'best interest' approaches, are intrinsically value-laden.<sup>147</sup> As noted by the Australian Law Reform Commission:

*The 'best interests' principle was seen to reflect the idea of 'beneficence'—a dominant theme in medical ethics, in which the 'primary imperatives were for doing good for the patient, the avoidance of harm and the protection of life'. A best interests standard was identified as associated with paternalistic approaches to persons with disability. ... The 'guiding philosophies' that became 'strongly entrenched in Australian laws for guardians, financial managers or administrators' by the 1990s were: the presumption of competence; normalisation; the least restrictive option; respect for autonomy; and fostering self-management. Even in a reformed context of being committed to advancing individuals' rights, 'best interests' standards were still retained.<sup>148</sup>*

- 6.12 In practice, the ‘best interest’ approach most often serves the interests of guardians, families, carers and service providers.<sup>149</sup> As stated by Professor Ian Kennedy:

*The best interests formula may be beloved of family lawyers but a moment’s reflection will indicate that although it is said to be a test, indeed the legal test for deciding matters relating to children, it is not really a test at all. Instead, it is a somewhat crude conclusion of social policy. It allows lawyers and courts to persuade themselves and others that theirs is a principled approach to law. Meanwhile, they engage in what to others is clearly a form of ‘ad hocery’.<sup>150</sup>*

### Operating in discriminatory and unjust contexts

- 6.13 Guardianship and financial management law operate in discriminatory and unjust contexts in relation to its application to individual women with disability.
- 6.14 In exploring the operation of guardianship and financial management, we are limited by the available data, a point we explained in Section 3. Thus, our ability to be fully across the experiences of women with diverse demographics (particularly younger women with disability) is limited. With those limitations noted, we surveyed all tribunal and board decisions in state and territory jurisdictions 2020-2022 concerning the making of orders appointing guardians and financial managers, which were publicly available on Austlii. Austlii is Australia’s online free-access resource for Australian legal information.
- 6.15 The method for identifying relevant tribunal and board decisions to include in the survey involved going to the tribunal or board decision page for each of the relevant years in relation to each state and territory tribunal or board responsible for making guardianship and financial management orders. Each decision was read to determine its relevance for inclusion in the survey. Decisions were included when the represented person was a woman and it involved a first instance application for the appointment of a guardian or financial manager.<sup>151</sup> Decisions were excluded where they were strictly applications concerning a review or rehearing of a previous decision, an enduring guardian or power of attorney, medical treatment decision maker appointments, consent to medical treatment, application for a tribunal’s advice about the exercise of a power, and emergency (Tasmania) or interim (Queensland) applications for guardianship and/or financial management.
- 6.16 There was a total of 90 decisions identified, as presented in the table below.

First instance tribunal and board decisions appointing guardians and/or financial managers to women with disability: Tribunal and board decisions published on Austlii				
	2020	2021	2022 (Jan-July)	Total
<b>ACT</b> ACT Civil and Administrative Tribunal	0	0	1	1
<b>NSW</b> NSW Civil and Administrative Tribunal	23	5	1	29
<b>NT</b> Northern Territory Civil and Administrative Tribunal	1	0	0	1
<b>QLD</b> Queensland Civil and Administrative Tribunal	4	1	0	5
<b>SA</b> South Australian Civil and Administrative Tribunal	0	0	0	0
<b>TAS</b> Tasmanian Civil and Administrative Tribunal (decisions published from November 2021) Tasmanian Guardianship and Administration Board (decisions published to October 2021)	4	2	4	10
<b>VIC</b> Victorian Civil and Administrative Tribunal	10	11	8	29
<b>WA</b> State Administrative Tribunal of Western Australia	4	10	1	15
<b>Total</b>	46	29	15	90

6.17 As a preliminary note, the total number of published tribunal decisions on appointment of guardians and financial managers to women with disability can be contrasted with the available data on the number of tribunal decisions actually made. Available data varies between jurisdictions – including how decisions are categorised and the timeframes for data collection – but the table below illustrates that a very small minority of decisions are being published. None of the jurisdictions provide a breakdown of their decisions based on gender. It is important to observe the limitations of analysing guardianship and financial management by reference to tribunal and board decisions, particularly that these decisions provide the official, state representation of the tribunal and board process and of the woman with disability rather than how individual women with disability understand themselves and their circumstances and how they are experiencing the tribunal and board process.

<b>First instance tribunal decisions appointing guardians and/or financial managers to people with disability: All decisions made by tribunals<sup>152</sup></b>			
	<b>Timeframe</b>	<b>Number of tribunal decisions</b>	<b>Explanation</b>
<b>ACT</b>	01/07/2019 to 30/06/2021	310	This number excludes emergency guardianship or financial management applications
<b>NSW</b>	01/07/2019 to 30/06/2022	23,427	
<b>NT</b>	01/07/2019 to 30/06/2021	490	
<b>QLD</b>	01/07/2019 to 30/06/2022	39,694	This number includes all guardianship and financial management applications, including interim, first instance and review applications
<b>SA</b>	01/07/2019 to 30/06/2022	11,941	
<b>TAS</b>	01/07/2019 to 30/06/2022	1,890	This number excludes emergency guardianship or financial management applications for FY20 and FY21. This number may include emergency applications made in FY22 as the data available did not distinguish between normal and emergency applications
<b>VIC</b>	01/07/2019 to 30/06/2021	11,537	
<b>WA</b>	01/07/2019 to 30/06/2022	15,566	This number includes all guardianship and financial management applications, including first instance and review applications

6.18 There were several key trends that emerged from the available data. First, NSW, Tasmania, WA and Queensland annual reports indicate that Australia's ageing population is causing an increasing rate of guardianship and financial management orders, noting that in NSW and Tasmania the majority of applications involved people over 65-years-old.<sup>153</sup> Second, dementia is a disability that is often identified in applications for guardianship and



financial management.<sup>154</sup> Specifically, some tribunals and boards have noted disability demographics in their annual reports:

- **ACT Civil and Administrative Tribunal:** The 2020-2021 annual review provides a breakdown of the disability demographics for the previous five years. Since 2016-2017, dementia has been recorded as the primary condition affecting people the subject of new applications. The identification of dementia in applications has gradually increased over this period from 38% in 2016-2017, 37% in 2017-2018, 49% in 2018-2019, 54% in 2019-2020, to 58% in 2020-2021.<sup>155</sup> The data for the 2021-2022 period has not yet been published.
- **NSW Civil and Administrative Tribunal:** The last three annual reports provide that dementia is the most common disability identified in applications followed by intellectual disability, mental illness, other, neurological, brain injury, then alcohol / drug related disability.<sup>156</sup> The identification of dementia in applications has gradually increased from 39% in 2019-2020, to 40% in 2020-2021, to 42% in 2021-2022.<sup>157</sup>
- **Tasmanian Guardianship and Administration Board:** The 2019-2020 annual report states that the most common disability in applications before the Board was dementia, noting that the modelling showed predicted growth in application numbers will continue due to increased dementia and mental health disabilities, and an ageing population.<sup>158</sup> There was no discussion of disability demographics in the 2020-2021 annual report.<sup>159</sup>
- **Tasmanian Civil and Administrative Tribunal:** There was no discussion of disability demographics in the 2021-2022 annual report.<sup>160</sup>
- **Northern Territory Civil and Administrative Tribunal:** There was no discussion of disability demographics in the 2019-2020 and 2020-2021 annual reports.<sup>161</sup>
- **South Australian Civil and Administrative Tribunal:** There was no discussion of disability demographics in the 2019-2020, 2020-2021 and 2021-2022 performance reports.<sup>162</sup>
- **State Administrative Tribunal of Western Australia:** There was no discussion of disability demographics in the 2019-2020, 2020-2021 and 2021-2022 annual reports.<sup>163</sup>
- **Victorian Civil and Administrative Tribunal:** There was no discussion of disability demographics in the 2019-2020 and 2020-2021 annual reports.<sup>164</sup>
- **Queensland Civil and Administrative Tribunal:** There was no discussion of disability demographics in the 2019-2020, 2020-2021 and 2021-2022 annual reports.<sup>165</sup>

6.19 Third, NSW, Tasmania, WA and ACT annual reports indicate there is an increasing rate of applications concerning the use of restrictive practices, particularly in relation to residential aged care facilities.<sup>166</sup>

6.20 While the published tribunal and board decisions are not comprehensive nor representative, they do reflect a number of the above trends that are important for the Royal Commission to consider in relation to guardianship and financial management as violence against women with disability.

6.21 The majority of the published tribunal and board decisions that we surveyed (61%, 55 out of 90 decisions) involved older women diagnosed with dementia, or a suspected diagnosis of dementia. This highlights the importance of exploring the particular experiences of women living with dementia in relation to guardianship and financial management. However, we know that younger women with disability are also subject to guardianship orders, including in such circumstances as when they are: transitioning from of out of home care and into the NDIS framework at 18 years old,<sup>167</sup> being diverted from the criminal justice system,<sup>168</sup> and, in accessing NDIS services. In the absence of access to comprehensive or representative tribunal and board decisions, it is likely that certain groups of women with disability are not reflected in the published decisions.

### **Discriminatory and inaccessible tribunal and board processes**

6.22 Guardianship and financial management tribunal and board processes are generally understood as playing a protective function as they provide the legal oversight in the appointment of guardians and financial managers. This is problematic for four reasons.

6.23 First, through making guardianship and financial management orders, tribunals and boards in effect are given the legal authority to expose women with disability to violence and human rights violations. As US disabled legal scholar Powell observes, through guardianship laws 'disabled people experience threats to their reproductive freedom even with supposed judicial protections'.<sup>169</sup>

6.24 Second, there is recognition that just because judges have jurisdiction to make decisions concerning women's bodies and lives does not mean they will make decisions that support their autonomy, personal integrity and equality. Judges can and do make decisions that are harmful to women. This includes about reproductive and sexual aspects of their lives. Indeed, various projects have re-written judgments from a feminist perspective as one example, in recognition of the sexism and paternalism of judicial decision-making.<sup>170</sup>

6.25 Third, extensive research over decades in Australia and overseas has established sexism and racism in the design and operation of the justice system. Rather than seeing sexism and racism as an issue of individual prejudice of a few 'bad eggs', research understands judicial sexism and racism as a systemic issue. Moreover, a recent Australian Law Reform Commission report on judicial impartiality and bias observed that:

*social and cultural factors will inevitably influence the decision-making of judges. Stakeholders have raised concerns about how social and cultural factors can improperly impact on decision-making, negatively affecting some groups more than others.*<sup>171</sup>

6.26 The Australian Law Reform Commission engaged in a detailed consideration of social and cultural bias in the context of First Nations Australians' contact with justice systems.<sup>172</sup> It noted the possibility for explicit expressions of impartiality and bias (e.g., jokes and offensive comments), as well as 'prejudice, and judges' social and cultural world views, interact with the social environment and act as "subtle, ambivalent, generally unintentional biases".<sup>173</sup> There is no reason to assume that there is not also ableism, sexism and other prejudice (whether explicit and intentional or otherwise) in the context of tribunal and board decision-making on guardianship and financial management. The Disability Royal Commission itself has recognised negative cultural attitudes about disability in the context of professionals and service staff in other service systems. The Disability Royal Commission has observed this in the contexts of disability support, criminal justice and health systems and how these in turn can result in discriminatory and harmful service provision. Unfortunately, the Disability Royal Commission has not publicly explored

discriminatory and harmful attitudes about disability in the justice systems, including the attitudes and conduct of lawyers, tribunal members, judges, and public servants. This is a concerning, unusual and unfortunate omission by the Disability Royal Commission, given that so much violence, abuse, neglect and exploitation of people with disability is enabled by law (including by tribunals in the context of guardianship and financial management law).

- 6.27 Fourth, guardianship and financial management tribunal processes are not accessible. There is no comprehensive use of Easy Read (including in the Easy Read translation of all documents and evidence in tribunal matters) nor is there universal access to legal advice and representation and support persons for tribunal matters.
- 6.28 Fifth, the medical evidence supporting applications for guardianship and financial management can also be discriminatory and unjust. On Day 3 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Naomi Anderson from Villamanta Disability Rights Legal Service Inc discussed issues with the medical evidence provided to the Victorian Civil and Administrative Tribunal in relation to assessing capacity. Anderson states that the tribunal ‘requires a medical report to be completed and they provide a template for that medical report and that medical report asks yes/no questions about capacity. It doesn’t provide any context or any background, and it most commonly is completed by a general practitioner’. This is problematic as ‘a general practitioner does not diagnose intellectual disability, does not do any of the work around understanding cognitive functioning. It generally doesn’t talk to their client or their patients about what happens in their day-to-day life and who makes their decisions. ... Very rarely is that evidence tested at VCAT.’ In his lived experience evidence on the same day, Uli Cartwright expressed his dissatisfaction that a medical report was obtained from his local GP to support the application for a financial management order as he does not discuss his financial decision-making with any of his medical professionals, rather ‘[w]e talk about keeping me alive and keeping me moving.’

## Reasons for applications

- 6.29 In the 90 surveyed decisions, there are common reasons for applications being made for appointment of guardians and/or financial managers, and these differ depending on who is making the application.
- 6.30 One of the key reasons family members made applications is due to pressure or advice from service providers, including aged care and disability providers, to apply for guardianship so that the family members can access disability or residential aged care services or so disability and aged care services can receive consent for the use of restrictive practices, this being triggered by recent NDIS and residential aged care legislative changes to regulation of use of restrictive practices. In *DZG*, the son made an application on the direction of the residential aged care facility having given an ‘irrevocable undertaking’ to the facility that he would make the applications for guardianship and financial management orders as a precondition to signing the Resident Agreement.<sup>174</sup> The Tribunal dismissed both applications and noted that the irrevocable undertaking appeared to be of ‘questionable legal validity’.<sup>175</sup> Another key reason for family members’ applications is longstanding fractured relationships between family members, particularly among a woman’s adult children. There are often disagreements about decision-making in relation to the woman, accusations of violence, abuse, neglect and exploitation towards the woman, and allegations that attorneys have improperly exercised their powers under a woman’s Enduring Power of Attorney or Enduring Power of Guardianship.

- 6.31 Hospital staff (including social workers, mental health case workers, and medical treating team members) have made applications after a woman with disability is hospitalised. This is for three reasons. One is concern about discharging the person from hospital, including where a woman cannot safely be supported by community services or by family due to their high support needs, a woman refuses to be discharged into a residential aged care facility and insists on returning home, or a woman is seen to be in denial about her high care needs and need for services. A second is concerns about family members, such that family members are unable to meet the woman's care needs, there is violence, abuse, neglect or exploitation by family members towards the woman, and there is observed family conflict including animosity between family members and disagreements about decision-making in relation to the woman. A third concern is about the health and welfare of the woman such as when she is refusing medical treatment or services, she is in denial of her high support needs and refuses to accept that these increasing supports cannot be met by family or home services, perceived decline in a her self-care (e.g. welfare check exposed poor living conditions), she needs to make large life decisions (e.g. potential need to sell home) but is perceived to have declining capacity, and concern about a woman's pregnancy.
- 6.32 Service providers, including aged care and disability providers, also made applications. A key reason was the need for consent for the use of restrictive practices. Additional reasons include suspected abuse or neglect towards the person by family members, concern that the woman's attorneys (usually family members) appointed under an Enduring Power of Attorney or Enduring Guardian are making decisions contrary to her wishes, and perceived decline of the woman's capacity to make important decisions, including clinical decisions.
- 6.33 Other decisions in the context of NSW were made by the NSW Ageing and Disability Commissioner (which is an officer described as 'promoting the rights of older people and adults with disability to live free from abuse in their family, home and community')<sup>176</sup> including where there was concern that a woman was being exploited by others, her home was not appropriate to her needs, and she was missing medical appointments and assessments of services.
- 6.34 In another decision, a financial institution made an application on the basis of concern about financial exploitation due to significant withdrawals made by the person's family member.
- 6.35 Applications to facilitate access to services are perverse because it renders access to support, accommodation and care conditional on subjugation through denial of autonomy. Such applications are also contrary to the stated respect for autonomy in these service contexts – both disability and residential aged care services are (to varying degrees) framed in terms of personal autonomy: one of the objects of the *National Disability Insurance Scheme Act 2013* (Cth) is to enable people with disability to exercise choice and control<sup>177</sup> and the Charter of Aged Care Rights provides that individuals receiving aged care services have the right to 'control over and make choices about' their care, personal and social life, and personal aspects of their daily life, financial affairs and possessions.<sup>178</sup> Applications in response to risk or actual harm are problematic because women with disability are being penalised by having their autonomy denied because of the illegal or dangerous behaviour of others, rather than those who perpetrate this behaviour being regulated or punished. Similarly, applications related to family conflict show how monetary concerns can influence the conduct of their family members. Applications being made to facilitate admission to residential aged care facilities show older women with disability being responsibilised and penalised for lack of supports within the community beyond that provided by family members, in a context of the failure of government to fund sufficient accessible community housing and support such that institutionalisation is not the only option. The mercy of women with disability to family members' conflict reflects Quinn's critique of the idea of people with disability as inherently vulnerable:

*... there is no such thing as an inherently vulnerable person, but only persons with disabilities placed in vulnerable situations. ... this [is] imposed vulnerability<sup>179</sup>*

- 6.36 Other reasons reflect paternalism in assuming what is best for a woman in a context where people without disability are allowed to ignore medical advice, refuse assistance, and choose what medical treatment and supports they access. Making applications due to restrictive practices is concerning at two levels: that restrictive practices themselves can be used non-consensually, and that the regulation of restrictive practices triggers need for guardianship which can involve a broader denial of autonomy beyond consent to restrictive practices.
- 6.37 While not apparent in the 90 surveyed tribunal and board decisions, an observable trend from the public guardian and public trustee annual reports and the Disability Royal Commission Public Hearing 30 on guardianship, substituted decision-making and supported decision-making is that the rollout of the NDIS is resulting in an increase in guardianship and financial management applications. Many applications are being initiated by NDIS service providers who seek the appointment of the Public Guardian and/or Public Trustee for two key reasons. First, NDIS service providers want to transfer risk and uncertainty by seeking contractual agreements with decision-makers that officially have legal capacity, or they incorrectly believe there is a need to formalise decision-making arrangements and/or who view this as a mechanism to fulfil their administrative goals.<sup>180</sup> Second, NDIS service providers have a vested interest in maintaining service agreements with participants with substantial funding packages and may make applications for the appointment of a Public Guardian and/or Public Trustee following disagreement with the participant and/or their familial guardian.<sup>181</sup> Evidently, NDIS service providers are motivated to request the appointment of a substitute decision-maker by prospects of financial gain and are guided by ill-informed understandings of decision-making capacity.<sup>182</sup>
- 6.38 Of course, women with disability should live free from violence and exploitation, live in the community and have access to the housing, support and personal and medical care they need – these are all human rights. However, to make access to these circumstances and enjoyment of human rights conditional on denial of their autonomy treats women with disability unequally to others in the community who do not risk being put under guardianship simply by, for example, accessing routine medical care or seeking assistance for violence.

### **Least restrictive alternatives**

- 6.39 Consideration of whether the appointment of a guardian or financial manager is the least restrictive alternative is an important limitation on the circumstances in which such orders are made. This ensures that guardianship and financial management orders are only made where more informal and less intrusive and coercive options are unavailable. However, the least restrictive alternative is not an objective and fixed concept but rather is contingent on what options are currently materially and practically – rather than theoretically or ideally – available to a specific individual. The availability of alternative options is not experienced equally across the population. Rather, what alternative options (if any) are available will depend on an individual's personal circumstances, including their access to social capital, existing family and social networks, and access to and eligibility for support services. Moreover, under guardianship and financial management law, a tribunal or board has no power to order third parties (including the government) to provide alternative options that might be relevant to an individual, nor does the tribunal or board have power to change the structural conditions or cultural attitudes that shape what alternative options are available to an individual. This means that women with disability for whom alternative



options are unavailable then bear the burden of their circumstances and become responsabilised and punished for these through being subjected to non-consensual interventions, noting that the non-consensual interventions pursuant to guardianship and financial management are similar to and even at times more extreme than what people who are in the criminal justice system might be subjected to. In turn, guardianship and financial management accommodate socioeconomic inequalities, illegal or harmful conduct by others (such as family members), and government irresponsibility.

- 6.40 The 90 surveyed decisions highlight that family conflict was a significant barrier to implementing less restrictive alternatives. For example, the availability of a less restrictive alternative other than an order can depend on whether the person's needs can be met informally, such as established family or community supports that have assisted the person to make decisions thus far. Where there is significant family conflict, tribunals have demonstrated preference to make a formal appointment, rather than allow for informal decision-making, often viewing it necessary to make 'independent' appointments of the Public Guardian or Public Trustee. Similarly, the 'person responsible' framework for medical decision-making is generally considered by tribunals and boards to be unavailable where there is significant family conflict. Where such a conflict exists, it is considered more appropriate to formally appoint a guardian with medical/dental consent power.
- 6.41 As such, the availability of a less restrictive alternative other than an order can be out of the control of a woman with disability and depend upon the conduct of her family and, indeed, whether she has any family or social networks on which she can draw. This issue underscores the importance of resources for supported decision-making, so women with disability are not unfairly disadvantaged by their personal familial and social circumstances.
- 6.42 The possibility of supported decision-making as a least restrictive alternative is legally and practically fraught because substitute decision-making in guardianship and financial management operates in a context where the alternative of supported decision-making is not legally mandated nor resourced. This seems contrary to the provision of reasonable accommodations as an established practice and legal principle in domestic anti-discrimination law and in international disability human rights law. Writing in the Irish context, Hendrick and McNamara suggest that this failure to provide supports arises from a 'paternalistic or protectionist approach to disability, arising from the medical model of disability, which focuses on a person's impairment rather than the barriers imposed by society or the environment'.<sup>183</sup> The failure to provide supports operates in a wider context of denial of autonomy and choice to people with disability across their life course. As children and young people, people with disability are not necessarily taught decision-making, including in relation to sexual and reproductive decision-making, managing money and navigating bureaucratic and service systems. Indeed, they might be excluded from many significant life decisions, such as where they go to school, what job they have, what medication and health services they receive, where they live, where they work and what disability support services they receive. As adults, they might be in residential, employment and other service relationships where decisions taken away from them. Not only are people with disability not prepared for decision-making, but broader society is not prepared for having people with disability as part of the community and as equal rights bearers. For example, US disability studies scholars David Mitchell and Sharon Snyder write 'two hundred years of institutionalisation and/or isolation within one's home actively produces social unfamiliarity with embodied difference'. The physical separation of people with disability has created an othering : 'this lack of shared space with disabled persons has ill prepared social contexts for integrative life and results in a variety of inflexibilities that tend to be argued as overly expensive to rectify'.<sup>184</sup>
- 6.43 In 2019, Victoria introduced the *Guardianship and Administration Act 2019* (Vic) enabling the Victorian Civil and Administrative Tribunal to appoint a supportive guardian for

personal matters or supportive administrator for financial matters, recognising that the person may be able to make some types of decisions themselves with the right support.<sup>185</sup> Pursuant to s 87 *Guardianship and Administration Act 2019* (Vic), a supportive order may only be made where the person consents to the supportive order, the person has decision-making capacity when practicable and appropriate support is provided, and the supportive order will promote the person's personal and social wellbeing. The option of making supportive guardianship and administration orders is argued to be the closest to CRPD-compliant legislation (although the enduring existence of substitute decision-making is contrary to the CRPD). However, in all of the Victorian decisions surveyed, this less restrictive alternative was discussed but not implemented in any of the decisions. The most common justification for not making supportive orders was that, on the basis of the medical evidence provided to the Victorian Civil and Administrative Tribunal, the person lacks the requisite decision-making capacity even when supported because of their disability. In *VDX (Guardianship)*, a supportive guardianship order was revoked one month later in favour of a formal guardianship order by a different Tribunal Member. This Member considered the supportive guardianship order as an attempt to make decision informally which had met with very limited success. This Member was satisfied that this less restrictive alternative was no longer available because the medical evidence provided by VDX's psychiatrists indicate there is no likelihood VDX would have decision making capacity even when supported.<sup>186</sup> The resort to substituted decision-making in these decisions highlights how the continued existence of substituted decision-making as an option can undermine the introduction of options that are less restrictive and more aligned to supported decision-making. There are also resource issues with supported decision-making in Victoria which we return to in Section 7.

## Human rights considerations

- 6.44 Human rights were only explicitly considered in some surveyed tribunal and board decisions which were made in those jurisdictions with human rights legislation (i.e. Queensland, ACT and Victoria).
- 6.45 In Queensland, s 48 of the *Human Rights Act 2019* (Qld) requires the tribunal to interpret statutory provisions, to the extent possible that is consistent with their purpose, in a way that is compatible with human rights. However, pursuant to s 13 of the *Human Rights Act 2019* (Qld), the Queensland Civil and Administrative Tribunal can make a decision that limits human rights if it is satisfied that the limits imposed by the decision of the Queensland Civil and Administrative Tribunal are reasonable and justifiable. In 4 of the 5 of the surveyed decisions by the Queensland Civil and Administrative Tribunal where human rights were explicitly considered, the tribunal decided to make a decision that would limit a woman's human rights.
- 6.46 In *IHC*, the Queensland Civil and Administrative Tribunal was of the view that IHC's right to privacy, freedom of movement and property are engaged and limited by the decision of the Tribunal to appoint a guardian and administrator. However, on the other hand it was thought that this decision ensures IHC's finances are managed so she can receive accommodation and care commensurate to her increasing needs in the context of her advancing dementia. As such, the tribunal concluded that the benefits of this decision outweigh any limitations imposed on IHC's human rights and the limits imposed by the decision are reasonable and demonstrably justified.<sup>187</sup>
- 6.47 In *DKM*, the Queensland Civil and Administrative Tribunal was of the view that DKM's rights to property and privacy are engaged and limited by the administration appointment. However, the Queensland Civil and Administrative Tribunal was of the view that the limits imposed by the decision are reasonable and demonstrably justified considering that

DKM has income that requires management to ensure funds are available for her needs, including accommodation, lifestyle and care requirements, at the present time and into the future. The Tribunal noted that there must be an adequate and effective decision-making regime in place for DKM in order to meet her financial needs and protect her financial interests and, due to the tribunal's declaration of invalidity of her Enduring Power of Attorney (on the basis that the EPOA was not properly certified by the witness as 'he did not ascertain the adult's understanding of the nature and effect of an Enduring Power of Attorney'), an administrator appointment was necessary.<sup>188</sup>

- 6.48 In *DLD*, the Queensland Civil and Administrative Tribunal noted that limitations on DLD's human rights must only be that which are reasonable having regard to the purpose of the limitation and whether there is any less restrictive way of satisfying that purpose. These rights include recognition and equality before the law, freedom of movement including choosing where to live, property rights, privacy and reputation including not to have the person's family interfered with, protection of families and children, right to liberty and security of person, humane treatment when deprived of liberty, fair hearing, and right to health services. The Tribunal found that in terms of the *Human Rights Act 2019* (Qld), DLD does not have capacity to make decisions in regard to accommodation, with whom she has contact with and/or visits, and the provision of services. These decisions are required as her care and welfare are currently not being adequately met and there is no less restrictive way of ensuring this without the appointment of a guardian so that the decisions are made appropriately.<sup>189</sup>
- 6.49 In *GCS*, the Queensland Civil and Administrative Tribunal was of the view that GCS's rights to property, freedom of movement, privacy and protection from being subject to medical treatment without her full, free and informed consent are engaged and limited by the guardianship and administration appointments. The tribunal was satisfied that the limits imposed by the decision are reasonable and demonstrably justified considering that there is a need for decisions in relation to accommodation, health care and financial matters. GCS has income, assets and expenses that require management to ensure funds are available for her accommodation and care requirements. Accordingly, there must be an adequate and effective decision-making regime in place for GCS in order to meet her needs and protect her interests. Due to allegations of abuse towards GCS, the tribunal determined that her current attorney would not discharge effective decision making for personal, health and financial matters and consequently the Enduring Power of Attorney was overtaken by the guardian and administrator appointments.<sup>190</sup>
- 6.50 In the ACT Civil and Administrative Tribunal decision of *Re Frieda (Guardianship)*, the tribunal noted that the human rights contained in s 13 (freedom of movement) and s 18 (right to liberty and security of a person) of the *Human Rights Act 2004* (ACT) are not unconditional and, pursuant to s 28, may be subject to reasonable limits set by laws. In this case, Frieda's human rights are subject to limits set by the *Quality of Care Principles 2014* that regulate and authorise the use of restrictive practices. Therefore, if an environmental restraint can be imposed in accordance with the *Quality of Care Principles 2014*, it would also be lawful under the *Human Rights Act 2004* (ACT). The application for guardianship was dismissed on the basis that the Enduring Power of Attorney empowers Frieda's daughter to give consent to the use of an environmental restraint.<sup>191</sup>
- 6.51 In the Victorian decision of *LWW (Guardianship)* the tribunal considered s 13 of the *Charter of Human Rights and Responsibilities Act 2006* (Vic). Section 13 provides that a person has the right not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with. The Victorian Civil and Administrative Tribunal noted that very serious allegations have been raised that LWW's relationships with her family and her access to correspondence have arbitrarily been interfered with. LWW's daughter was restricting LWW's access to other family and friends but LWW wishes to have contact with

these family and friends. It was the Victorian Civil and Administrative Tribunal's view that safeguarding LWW's human rights by the appointment of a guardian is an important aspect of promoting her personal and social wellbeing.<sup>192</sup> This was the only Victorian decision out of 26 surveyed Victorian Civil and Administrative Tribunal decisions that refers to human rights legislation.

- 6.52 These decisions highlight the negligible impact of human rights legislation on guardianship and financial management, and suggest that the interpretation of when human rights violations are justified is done through a paternalistic and ableist lens which ultimately subjects women with disability to a lower standard of human rights than non-disabled people. The fact that legislation legally sanctions guardianship and financial management and restrictive practices is itself a barrier to full enjoyment of human rights through human rights legislation, and is a further layer of the legal violence inherent to guardianship and financial management.

### Sexual and reproductive circumstances

- 6.53 There were only four decisions in the 90 surveyed which involved sexual and reproductive circumstances.

- 6.54 The Western Australian State Administrative Tribunal decision of *EC* concerned a 19-year-old woman with intellectual disability. *EC* has been a patient of the Child and Adolescent Health Service since coming to Australia as a child refugee and is due to be discharged because of her age. *EC* experienced severe trauma both before and after arriving in Australia. She is estranged from her family of origin and has had little contact with them. She is the sole parent of a 5-year-old daughter who was conceived from a sexual assault at 13-years-old. At the time of hearing, *EC* was pregnant and a victim of domestic violence perpetrated by the baby's father. The Child and Adolescent Health Service made an application for guardianship and financial management orders. The financial management application was dismissed. A guardianship order was made appointing the Public Advocate as limited guardian with functions including medical treatment and services decisions, as well as functions relating to any investigation or proposed legal proceedings under the *Children and Community Services Act 2004 (WA)*. The State Administrative Tribunal was of the view that the guardianship order was needed due to *EC*'s vulnerability to domestic violence and her lack of appreciation of that risk; the risk of Department of Communities child protection intervention; the possibility of complexities around the upcoming birth of her child; and the absence of any friends or family to act as supports or give substitute consent for treatment decisions. The State Administrative Tribunal stated:

*EC is due to have a baby in July 2021. In normal circumstances EC may, as many women do, be faced with complex decisions in her pregnancy and delivery of her baby. Her previous pregnancy and delivery of her daughter M occurred overseas in a refugee camp when EC was aged 13 or 14. Although it is speculation, it is possible that this history may create further complexity or have implications for EC's health and the management of her current pregnancy and delivery.*<sup>193</sup>

*EC's care of M is described in very positive terms by everyone who has contact with her: she is described as a loving, devoted and caring mother putting M's needs above her own. However there have been two referrals to [Department of Communities child protection] regarding child safety concerns related to violence perpetrated against EC and there is an*

*open investigation which is said to continue until EC's baby is born in July 2021.*<sup>194</sup>

- 6.55 The New South Wales decision of *PZI* concerned a 38-year-old woman with schizophrenia and polysubstance abuse. At the time of hearing, she was a patient in the Mental Health Rehabilitation Unit at a public hospital. She was involuntarily admitted with 'an exacerbation of schizophrenia' and had been in breach of her mental health Community Treatment Order. *PZI* was estimated as 36 weeks pregnant and although *PZI* was due to give birth in four weeks' time, she could go into labour at any time. A guardianship application was made by a social worker with the Mental Health Rehabilitation Unit asking for an urgent hearing. The Public Guardian was appointed as limited guardian with functions including health care, medical/dental consent, and restrictive practices (physical restraint by way of holding down *PZI*'s arm/s for the shortest period possible in order to administer intramuscular sedation and/or for taking blood). The Public Guardian also had authority to override *PZI*'s objection to medical treatment. The order was made for 3 months and was not reviewable, in order to apply for the period of birth and postpartum recovery. The New South Wales Civil and Administrative Tribunal stated:

*PZI's evidence clearly indicated to us that she remains focussed on only one possible pathway, namely an induced birth with the possible use of an epidural, and a short labour. As a consequence, and due to the exacerbation of her mental illness at the current time, we were satisfied that PZI is severely restricted in making decisions as to her medical and health care concerning the birth of her child to such an extent that she requires supervision in this regard.*<sup>195</sup>

- 6.56 The New South Wales Civil and Administrative Tribunal decision of *EZN* concerned a 31-year-old Aboriginal woman diagnosed with either Bipolar Affective Disorder or Schizoaffective Disorder. At the time of hearing, *EZN* was 37 weeks pregnant and detained in hospital under the *Mental Health Act 2007* (NSW) after she was found wandering the streets responding to unseen stimuli. An urgent application for guardianship was made by a social worker with the hospital. The Public Guardian was appointed as limited guardian with functions including health care and medical/dental consent. The Public Guardian also had authority to override *EZN*'s objection to medical treatment. The tribunal was of the view that, due to mental illness, *EZN* was not in a position to provide consent for treatment associated with her pregnancy, there may be some complexity with the procedure given her past history including two miscarriages, and there was the strong probability she may object to treatment. The order was made reviewable after one month to allow for a substitute decision-maker to be in place over the course of *EZN*'s pregnancy and delivery.<sup>196</sup>
- 6.57 These three decisions raise concerns around the autonomy of women with disability in relation to their experiences of their pregnancy and childbirth. Noting the earlier discussion in Section 5 of the broader paternalism of medicine and law concerning pregnant and birthing women, these tribunal decisions demonstrate how guardianship law provides an additional option, only available in relation to women with disability, to enable reproductive control and violence of women.
- 6.58 The Victorian Civil and Administrative Tribunal decision of *VLX* (*Guardianship*) concerned a woman described as having treatment resistant mental illness (no other identity details provided in the decision). An application for appointment of a guardian to make decisions regarding medical treatment decisions i.e. contraception by Implanon insertion. Medical professionals wanted *VLX* to receive the Implanon, however *VLX* would not consent to Implanon insertion. *VLX* was prepared to take birth control instead and continue using condoms. The treating psychiatrist had a major concern as to the fullness or depth of



VLX's ability to consent to contraception, and a concern that VLX may change her mind. The psychiatrist acknowledged that VLX had agreed to take the pill and knew that VLX had condoms in her purse, but believed the Implanon as the most effective and efficient contraception because there was no means for monitoring and ensuring the contraceptive pill had been taken by VLX. There was no information as to what the treating team's specific concern was with VLX becoming pregnant, nor recognition that there are many women who choose not to use contraception or who do not consistently maintain their contraception use. The Victorian Civil and Administrative Tribunal was satisfied that VLX is making her own reasonable decisions regarding contraception.<sup>197</sup>

*I am satisfied VLX has a disability but I am not satisfied she lacks capacity to make decisions about her contraception. I acknowledge VLX's decision-making requires the medical professionals managing her treatment to be creative, her independent nature means she needs more time to make her decisions which requires significant patience of her medical practitioners.*<sup>198</sup>

*I appreciate the concern expressed by VLX's treating psychiatrist Dr Egan and the difficulty, and to some extent the intrusiveness required by the treating team to be convinced VLX is using contraception, however, I am not satisfied VLX needs a guardian as she is making her own reasonable decisions in relation to contraception. She has agreed to take her treating psychiatrist's advice regarding the pill; she does not want and will not consent to implanon insertion.*<sup>199</sup>

- 6.59 The Victorian Civil and Administrative Tribunal also considered supportive decision-making regime, but the tribunal stated

*In the present case this less restrictive alternative was not appropriate because VLX was, and continues, to make her own decisions about contraception and has agreed to take the pill. VLX believes it is her right to make contraceptive decisions which, although those not preferred by the medical practitioners, suit her and are decisions which she says she will follow through.*<sup>200</sup>

- 6.60 While it is notable that the Victorian Civil and Administrative Tribunal decided not to make this order, it is concerning that such an application was brought at all, thus highlighting the ableism and sexism in the medical profession, including by treating doctors with whom women with disability are expected to have a safe, constructive and trusting relationship.

## Restrictive practices

- 6.61 There were 12 decisions in the 90 surveyed that concerned applications for appointment of guardians specifically to authorise restrictive practices, including physical restraint (holding down to administer medicine, locked doors), environmental restraint (locked doors, surveillance cameras) and chemical restraint.
- 6.62 In the NSW decisions of *DZD* and *PZI*, applications were brought by hospital social workers as *DZD* and *PZI* were objecting to medical treatment while in-patients at public hospitals. In both decisions, guardians were appointed with a restrictive practices function to consent to the use of physical restraint, including the authority to override any objections to major or minor medical treatment.
- 6.63 The majority of the remainder of applications were brought by family members after



receiving advice from a residential aged care provider or disability service provider, or brought by the service providers themselves. Guardianship was considered necessary due to residential aged care and NDIS regulatory frameworks requiring guardians to provide consent for the use of restrictive practices. For example, in the ACT decision of *Re Frieda (Guardianship)*, an application was made to appoint a guardian to make decisions about environmental restraint to prevent Frieda from ‘wandering around the Memory Support Unit and getting lost’. The ACT Civil and Administrative Tribunal dismissed the guardianship application stating ‘I concluded that the appointment of a guardian is not necessary because the [Enduring Power of Attorney] empowers Jill [the applicant and Frieda’s daughter] to give consent to [Goodwin Residential Care] restraining Frieda from leaving the [Goodwin Residential Care residential aged care facility], meaning to give consent to [Goodwin Residential Care’s] use of an environmental restraint’.<sup>201</sup> The ACT Civil and Administrative Tribunal noted that this application was among many applications recently made in similar situations and to whom the residential aged care provider had given the same advice due to the changes to Commonwealth legislation.

*Jill’s application was among many applications recently made to the tribunal by other attorneys who were in the same or a similar situation and to whom Goodwin had given the same advice. Goodwin’s advice to Jill, and the other attorneys, arose from recent significant changes to Commonwealth legislation regulating the use of environmental restraints and other restrictive practices by approved providers (such as Goodwin) of residential aged care accommodation.*<sup>202</sup>

- 6.64 In the Tasmanian tribunal decision of *CBE (Application for Guardianship)* which concerned a guardianship order to enable consent to use of a keypad lock on the front door of a residential aged care facility as a form of environmental restraint, the tribunal accepted that the use of a keypad lock that CBE cannot operate on a door that would otherwise be her only means of egress from the facility in circumstances where, from time to time she seeks to use that door to exit the facility unaccompanied, could amount to a false imprisonment. This highlights the significant human rights and legal issues at stake in guardianship matters, the legal actions and remedies that are denied to individuals through substitute decision-making, and the likelihood there are many women with disability in closed and institutional residential settings who have been subject to false imprisonment or assault but have no means of accessing legal assistance or even being alerted to their legal rights.
- 6.65 A similar view on false imprisonment was expressed in the NSW Civil and Administrative Tribunal decision of *FNX* which involved a centre manager of a residential aged care facility where FNX (a woman living with dementia) was confined in a dementia specific unit. In *FNX*, the NSW Civil and Administrative Tribunal found that appointing a guardian to decide upon the circumstances of FNX’s environmental restraint in a residential aged care facility would promote her welfare and interests. The NSW Civil and Administrative Tribunal was of the view that the conditions under which FNX resides at her residential aged care facility involve a total restraint on her freedom of movement as she is unable to lock the door or the memory support unit or the front door and gate of the facility. FNX is not able to exit the memory support unit unless permitted to do so by a staff member and, if she were to exit the unit or the facility, she would be unable to do so unless she was accompanied and would be returned to the facility if she left. The NSW Civil and Administrative Tribunal found that FNX is restrained even though she is unaware of being restrained and has not asked to leave the memory support unit or the facility or attempted to leave these areas of her own accord. She is restrained even though physical force is not required to prevent her from leaving. As such the NSW Civil and Administrative Tribunal was of the view that FNX’s circumstances could constitute a tort of false imprisonment.<sup>203</sup>
- 6.66 The earlier 2020 decision of *JFL* (which sits outside of the time period of our surveyed

decisions) concerned the same applicant and circumstances as *FNX*. In *JFL* the NSW Civil and Administrative Tribunal considered whether to make an order to appoint a guardian to consent to restrictive practices in the form of restraint through a keypad locked door. *JFL* is a woman with Alzheimer's dementia living in a secure and locked dementia specific unit within a residential aged care facility. The unit was locked by a keypad and *JFL* had not been given the passcode. *JFL* was in the unit 'due to her tendency to wander and the potential for her to be aggressive towards other residents and staff'.<sup>204</sup> (at [68]). The manager of the residential aged care facility in which *JFL* lives applied for a guardian to be appointed on the basis that *JFL* was being restrained by the use of the coded keypads. As *JFL* did not have any family or friends in her life, the NSW Civil and Administrative Tribunal appointed the Public Guardian to give or withhold consent to this restrictive practice.<sup>205</sup>

- 6.67 In the 90 surveyed decisions, those on chemical restraint highlighted the fragile boundary between chemical restraint and medical treatment. Medical treatment is generally easier to authorise either via person responsible frameworks or because there is no need for a behaviour support plan in order to appoint a guardian for medical decision-making. We raised issues with this boundary in the context of our sexual and reproductive rights submission in relation to non-consensual contraception and menstrual suppression.<sup>206</sup>
- 6.68 In the NSW Civil and Administrative Tribunal decision of *NZT* there was confusion about the purpose of medication (whether restrictive practice or medical treatment) and lack of awareness about the reason for the high dosage. It was clear that a major medication had been prescribed for *NZT* for many years without anyone providing lawful consent for the administration of this medication, at least for any period over which *NZT* has been unable to provide her own informed consent to the medication. This medication had been prescribed at a relatively high dosage. *NZT*'s treating practitioner was unable to explain the reason for the administration of this medication. The NSW Civil and Administrative Tribunal thus decided to appoint a guardian to seek specialist advice as to *NZT*'s medical treatment and, in particular, whether quetiapine should continue to be administered at its current dosage or at all. On the basis of this advice, the NSW Civil and Administrative Tribunal was of the view the appointed guardian is likely to be in a better position to provide evidence to the NSW Civil and Administrative Tribunal on the next occasion as to whether the medication is being used to treat a medical condition or whether it is being used as a form of chemical restraint. A 6-month order was made to allow for *NZT*'s general health and medical treatment to be reviewed, with another hearing to occur at the end of this period.<sup>207</sup>
- 6.69 A similar situation arose in the Tasmanian Guardianship and Administration Board decision of *MDN (Guardianship)*. The Tasmanian Guardianship and Administration Board considered whether the use of a psychotropic medication is being prescribed as medical treatment to treat a diagnosed medical condition or for the purpose of behaviour management and who, if anyone, is providing consent to its use. While not bound to do so, the Tasmanian Guardianship and Administration Board adopted the definition of chemical restraint used in the NDIS Rules given there is no relevant State legislation providing such definition (this in itself showing a lack of definitional clarity around restrictive practices). The Tasmanian Guardianship and Administration Board appointed a guardian with the power to give or withhold consent to the use of chemical restraint. The Tasmanian Guardianship and Administration Board found:

*On the evidence before it, the Board finds that the use of Largactil is prescribed and administered for the behaviour management of MDN. The psychotropic medication is being prescribed when there is no evidence of a mental illness warranting treatment by it. The evidence of the diagnosis of Autism Spectrum Disorder does not indicate Largactil is being prescribed to treat this condition. The prescribing medical practitioner*

*Dr Baker is not able to identify any medical condition the medication is treating and believes it is for the purpose of behaviour management. The Board notes it is the intention of the Applicant [MDN's sister] and QNN [MDN's mother] to obtain further psychiatric review by a psychiatrist for MDN.<sup>208</sup>*

## Response to violence

- 6.70 Guardians and financial managers are appointed in response to violence against women with disability.
- 6.71 In the 90 board and tribunal decisions surveyed, use of guardianship and financial management in response to violence was particularly apparent in relation to older women with disability exposed to family violence. For example, in the Tasmanian Guardianship and Administration Board decision of ZGS (*Guardianship and Administration*), the Public Guardian and Public Trustee were appointed to ZGS after an application was made on the basis that ZGS had consistently reported financial, physical and emotional abuse including damage and destruction to her home and property by family members who reside with her. The applicant also reported that as ZGS is physically frail and cognitively impaired, she has no ability to protect herself in her home environment and that abusive behaviour towards her has been recorded over numerous hospital admissions and specifically during the last two hospital admissions in 2020.<sup>209</sup> In the Western Australian decision of EC, EC had been subjected to domestic violence by her boyfriend. EC was described in the Western Australian State Administrative Tribunal decision as having minimised the seriousness of domestic violence incidents and said that they were her fault. There was concern that if a guardian was not appointed, EC's boyfriend might exercise substitute decision-making on behalf of EC including in relation to her present pregnancy. The Western Australian State Administrative Tribunal accepted that EC is not able to engage in a meaningful way with more complex issues, including the risk of domestic violence and the consequent risk of intervention by Department of Communities child protection because of her failure to appreciate or acknowledge the risk associated with domestic violence. It was thought there may be cultural reasons for EC's views about domestic violence but the Western Australian State Administrative Tribunal accepted that EC's vulnerability is heightened due to her intellectual disability.<sup>210</sup>
- 6.72 Sometimes the family violence can be alleged in broader family conflict. In the Victorian decision of YSA (*Guardianship*), the daughter/applicant provided that YSA's partner was abusive, and that this abuse isolated YSA from the daughter. The daughter believes that the YSA's sons and partner purposely damaged the trust between YSA and daughter. The daughter said that the Magistrates' Court had recognised that YSA was being subjected to family violence through making an intervention order. The granddaughter and daughter's husband supported the daughter's allegations of abuse. YSA's sons had a different perspective. They said that there was not and had never been family violence, that ZJK was an attentive and caring partner for YSA, and that YSA wanted to live in her home with him there taking care of her. They had been together for over 40 years and he was not a threat or a risk for her, but a support and comfort. Another family member wrote in support of the perspective of YSA's sons, saying that YSA was happy and well cared for in her home with the support of her partner and her sons, and that she was at no risk whatsoever.<sup>211</sup>

## Lack of accountability on services and guardians

- 6.73 There is an absence of recognition and action on accountability in relation to individuals and service providers who are currently harming or putting women with disability at risk of harm, or in relation to guardians and financial managers whose actions (or inaction) are exposing women with disability to degrading living conditions and physical and psychological harm.
- 6.74 *NZT* and *MDN (Guardianship)* raise significant issues around medical neglect and patient safety, and also questions about accountability and redress for the time that *NZT* and *MDN* had been subjected to the medication without any lawful authority, nor with any clear indication as to its therapeutic purpose. It is concerning that there might be many more women with disability in similar situations whose tribunal and board decisions are not published. It is not clear women with disability in these situations of long term, ambiguous and unlawful medication are provided access to legal assistance to bring any complaints or obtain redress. It is unclear if they are provided with any immediate medical assistance to check they have not been impacted by the medication nor any immediate attempts to resolve the use of the medication. In *NZT*, the NSW Civil and Administrative Tribunal's failure to order for *NZT*'s medical treatment to be reviewed over the next 6 months does not resolve the issue of the current administration of quetiapine on older woman living with dementia, noting that a current boxed warning for Seroquel (a brand name under which quetiapine is sold) directed towards US residents states:

*Warning: Increased Mortality in Elderly Patients with Dementia-Related Psychosis*

*Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. SEROQUEL is not approved for elderly patients with dementia-related psychosis<sup>212</sup>*

- 6.75 AstraZeneca's prescribing information for medical practitioners additionally notes:

*Cerebrovascular Adverse Reactions: Increased incidence of cerebrovascular adverse reactions (e.g., stroke, transient ischemic attack) has been seen in elderly patients with dementia-related psychoses treated with atypical antipsychotic drugs.<sup>213</sup>*

- 6.76 The information on quetiapine makes clear that there are significant health risks with use of this antipsychotic medication in elderly patients with dementia. Irrespective of the risks associated with these medications, ultimately, in *NZT* and *MDN*, the approach seems to be that it is the guardian's role to provide consent (*MDN*) or investigate the use of medications (*NZT*) and the tribunal or board has no role in recognising and addressing the potential ongoing harms and injustices associated with these medications.
- 6.77 Related to the paternalistic approach of using guardianship and financial management in response to violence against women with disability, there is no indication in the tribunal and board decisions related to violence which were surveyed – including those discussed above – that anyone will be tasked with advising the women of their exposure to violence and rights to support and redress and to assist them in accessing legal assistance, counselling and other victim support. There is also no mention of processes of accountability (including of service providers), such as police investigations. However, there were a few decisions in which apprehended violence orders had been taken out on behalf of a woman with disability.<sup>214</sup> Thus, guardianship and financial management law can accommodate and ultimately condone violence against women with disability.

- 6.78 For example, in the Tasmanian Guardianship and Administration Board decision of SC (*Guardianship and Administration*) an application for guardianship was triggered when members of another person’s family at the disability supported accommodation facility raised concern that SC had been physically harmed in the home. The Public Guardian suggested to those people that their concerns should be raised with other agencies. The Public Guardian said that initially SC had expressed to the her that she was scared living where she was, but more recently she had been saying that she wishes to move to the new accommodation being built by the supported accommodation facility. The board observed that the person ‘had been physically harmed and, while the [proposed representative person] is currently expressing a wish to move to different [the supported accommodation facility] accommodation that is still being built, that had not always been her wish.’<sup>215</sup> However, their reasoning largely dealt with a conflict of interest issue because the same service provider was providing SC’s accommodation, all of her support services, was the employer of her NDIS support coordinator, and also appeared to be managing her money.<sup>216</sup> The Public Guardian was appointed as limited guardian with the power to decide where SC is to live whether permanently or temporarily, and advocate on SC’s behalf and make any decisions required in respect of any NDIS plan development, plan implementation and/or plan review. The Public Trustee was appointed as administrator of SC’s estate. As we discuss below, there was no recognition of accountability on the part of the Public Guardian to respond to the violence.
- 6.79 In the decision of SC (*Guardianship and Administration*) there was no indication of accountability of Public Guardian for failing to address safety concerns by simply referring the issue on to others, nor was there any indication of any action being taken in relation to the accountability of the service provider, nor to assist SC with her legal and psychological needs in the aftermath of harm. In fact, the decision states:
- the Chairing Member pointed out that the Board was not suggesting that anything improper had been done by [the supported accommodation facility] but noted the distinction between a perception or possibility of a conflict of interest and an actual conflict of interest. In this regard, the Board could understand why the NDIS Commission might be of the view that it is not best practice to have a support coordinator employed by the organisation providing significant services to the person concerned. The Board also noted that having a support coordinator working in a different building did not remove the perception of a conflict of interest.*<sup>217</sup>
- 6.80 In this quote, the Tasmanian Guardianship and Administration Board makes it seem like nothing wrong really happened, thus underscoring our earlier point on the lack of accountability.
- 6.81 While the Public Guardian in initiating the application expressed concern that SC had not had any independent advocacy support, this concern was not mentioned or addressed in the decision. The Public Guardian in her initial investigation ‘expressed concern that the [proposed representative person] had not had any independent advocacy support’ and this idea of independent advocacy support was not mentioned again in the Tasmanian Guardianship and Administration Board decision.
- 6.82 Spivakovsky and Steele discuss a NSW Civil and Administrative Tribunal decision. This decision falls outside of the timespan of the 90 decisions surveyed for this submission. This decision was to amend a guardianship order of an older First Nations woman with disability (UZX) in the early months of the COVID-19 illustrates a further issue of use of guardianship orders to facilitate continued access to disability support services. UZX is a 69-year-old Aboriginal woman living in Housing NSW accommodation in Regional NSW who was under the NSW Public Guardian. The NSW Public Guardian was granted ‘accommodation’ and



'services' functions of guardianship. However, UZX's primary clinician at the Older Persons Mental Health Service applied to the tribunal to have the guardianship order varied to have the accommodation function varied to the coercive accommodation function (the latter enabling UZX to be coercively brought back to her accommodation by ambulance or police). The application was brought because UZX was not considered to be socially distancing and thus putting herself and her support workers at risk of COVID-19, and in turn giving rise to risk of her disability support service withdrawing.<sup>218</sup> Six months later, UZX's guardianship order with the coercive accommodation function was confirmed.<sup>219</sup> As Spivakovsky and Steele have explained, this decision raises serious concerns with the accountability of disability service providers who withdraw services. One issue is

*the shallow expectations that appear to be held for the delivery and quality of disability services in the community. There is no indication in [UZX that UZX's] contracted service providers had attempted to work with UZX ... to develop accessible, personalised strategies for these individuals to voluntarily comply with the restrictions under the NSW Public Health Order. In fact, there is no time for either service provider to have done this work. UZX's provider suspended their in-home services to UZX on the same day that the NSW Public Health Order came into effect...*<sup>220</sup>

6.83 A second concern identified is

*the accountability of disability service provision in the community. There is no indication within NCAT's decision that there has been, or will be, any consequences for [UZX's] service providers suspending or threatening to withdraw their contracted services. This is despite NCAT noting that ongoing provision of these services is what allows [UZX] to remain within their current accommodation, and enjoy their current levels of freedom under guardianship. Indeed, in the case of UZX, NCAT explicitly indicates that 'without a considerable degree of personal care support on a daily basis [as had been delivered by the provider who has now suspended their contracted services], UZX's general health, hygiene and well-being will deteriorate further' (UZX [2020] NSWCATGD 3[38]).*<sup>221</sup>

6.84 The threatened actions of UZX's service providers are particularly concerning because UZX lives in a regional area and withdrawing services could leave UZX unsupported. This decision highlights the precarity of people with disability within the current service landscape. Persons are vulnerable to systems and to specific moments of crises. To draw on critical disability scholars Mitchell and Snyder, people with disability 'serve as canaries in the coal mine of government-funded initiatives in that their situation as the objects of proliferating service provision opportunities expose their vulnerability within economically fragile social assistance systems'.<sup>222</sup>

6.85 A third concern relates to the accountability of guardians:

*Finally, the responses of [UZK's guardian] to the suspension or threat of withdrawal of contracted disability services raise another set of troubling questions. Why was it that [UZK's] guardians could locate and engage alternative service providers for UZX or GZK through their pre-existing 'services functions' of guardianship? Surely at a time when all disability service providers across Australia were in the process of having to actively change their practices to support disabled people to comply with public health orders, there would have been a service provider able to determine strategies for UZX ... to voluntarily adhere to the restrictions of the NSW Public Health Order? And yet, once again, NCAT does not query whether the [UZK's guardian] could have done more to advocate*



*for the individuals for which they are responsible. Nor for that matter does NCAT query whether the seemingly automatic shift of these guardians to seeking restrictive and coercive practices renders their guardianship inappropriate.*<sup>223</sup>

- 6.86 The subjection of women with disability to guardianship and financial management orders, including to increased levels of coercion within existing orders, in response to the illegal, unethical or neglectful conduct of services and guardians is discriminatory, punitive and unjust. Moreover, it is clear that there are no clear pathways for women with disability to be told when they have experienced legal wrongs, and no support to access legal and advocacy assistance and psychological and other support in the aftermath of such wrongs in order to obtain redress and to heal. Nor is there any indication that tribunal decisions identify systemic problems in disability and aged care service systems and in the guardianship and financial management systems and have a feedback loop to compelling or even informing structural change.
- 6.87 The observations made here about *UZX* speak to a broader problem of lack of legal accountability on disability, aged care service providers and guardians, and financial managers. For example, the lack of any clear pathways to legal advice and psychological support and access to redress in the aftermath of the use of unauthorised restrictive practices by NDIS providers (which are illegal violence and thus capable of redress), including in the context of 1,032,064 reports of unauthorised restrictive practices in 2020-21<sup>224</sup> and the recent 2022 law reforms to residential aged care provider liability with use of unauthorised restrictive practices.<sup>225</sup>
- 6.88 Guardianship and financial management law provide that guardians and financial managers are protected from liability when they act in good faith. And, even if they do not act in good faith (noting this is a problematic concept in an ableist, paternalistic system), there are inconsistent laws between jurisdictions in relation to legislated and accessible processes to seek redress for harm caused by guardians and financial managers. For example, ABC News recently reported a story of Michael Burles, a man in Tasmania who ‘allegedly cancelled his funeral plan and sold his belongings without his consent’ after being placed on an emergency guardianship order following a fall in 2020 and placed in a dementia unit in a residential aged care unit. Burles did not feel the \$10,000 in compensation reflected the extent of loss and impact on him. The story reports calls by advocates for an accessible compensation scheme:

*Advocacy Tasmania chief executive Leanne Groombridge said the payment was a “hollow victory”.*

*“Just consider how much our client had to go through to actually receive a few thousand dollars from the Public Trustee,” she said.*

*“Years of suffering and a team of pro bono lawyers lodging court applications and negotiating for 10 months.*

*“The Public Trustee must be celebrating that they got out of it so cheaply. This in no way compensates our client for the pain, suffering and loss that he has endured through the guardianship system that destroys so many Tasmanians year after year.”*

*Ms Groombridge called on the government to establish an accessible compensation scheme for people wronged by the Public Trustee and Public Guardian and said they should be required to pay penalties when they were found to fail to comply with their statutory obligations.*<sup>226</sup>

- 6.89 It is also important to note that being on a guardianship order or not having access to proper supported decision frameworks can result in women not being recognised as capable of reporting crime, as noted by Jane Maree Maher et al:

*Given extensive evidence that the criminal justice system struggles to respond effectively to gendered violence, the obstacles faced by women with disability are seemingly multiplied and compounded. Without well devised supported decision-making frameworks and well-resourced processes brought into effect throughout the criminal justice system, women with disability are too readily dismissed as lacking capacity and credibility, and their cases rarely achieve a form of legal 'justice'.<sup>227</sup>*

### Sexual and reproductive decision-making

- 6.90 There are specific issues about guardianship law as it relates to sexual and reproductive decision-making. In this section we provide an overview of key aspects of the guardianship legal framework as it operates in relation to women's sexual and reproductive decision-making (noting that we discussed this in detail in our sexual and reproductive rights submission), followed by discussion of specific published decisions on sterilisation and contraception.
- 6.91 The guardianship legal framework related to sexual and reproductive decision-making is inconsistent between jurisdictions, with considerably lower thresholds for non-consensual sterilisation and contraception in some. Turning first to sterilisation, sterilisation must have tribunal or board authorisation, rather than the decision being made by a guardian who has previously been appointed by the tribunal (as is the case with most contraception). While this means there is significant tribunal or board oversight of the specific decision on sterilisation, there is great variation between jurisdictions in relation to the basis on which sterilisation can be authorised by the tribunal or board, as we now turn to discuss.
- 6.92 In New South Wales, the focus is on what is necessary in relation to health. Sterilisation is categorised as 'special treatment'.<sup>228</sup> Special treatment can only take place pursuant to authorisation of the NSW Civil and Administrative Tribunal. The NSW Civil and Administrative Tribunal must not consent unless it is 'satisfied that the treatment is the most appropriate form of treatment for promoting and maintaining the patient's health and well-being' and 'it is satisfied that the treatment is necessary (a) to save the patient's life, or (b) to prevent serious damage to the patient's health'.<sup>229</sup> The NSW Civil and Administrative Tribunal must also be satisfied that 'the treatment is the most appropriate form of treatment for promoting and maintaining the patient's health and well-being'.<sup>230</sup>
- 6.93 In contrast, under Queensland and South Australia guardianship law sterilisation can be authorised where it is medically necessary, or for contraceptive or menstrual purposes. Section 70 of the Guardianship and Administration Act 2000 (Qld) provides that the Queensland Civil and Administrative Tribunal can consent to sterilisation of 'an adult with impaired capacity' only if it is satisfied that 'the sterilisation is medically necessary', 'the adult is, or is likely to be, sexually active and there is no method of contraception that could reasonably be expected to be successfully applied', and 'if the adult is female: the adult has problems with menstruation and cessation of menstruation by sterilisation is the only practicable way of overcoming the problems'. Additionally, Queensland Civil and Administrative Tribunal must be satisfied that 'the sterilisation can not reasonably be postponed' and 'the adult is unlikely, in the foreseeable future, to have capacity for decisions about sterilisation'.<sup>231</sup> The ground of medical necessity will not be met if the sterilisation is 'for eugenic reasons' or 'to remove the risk of pregnancy resulting from

sexual abuse'.<sup>232</sup> Although a reading of this provision suggests that eugenics reasons or risk of sexual abuse-related pregnancy can be reasons in relation to the contraception or menstruations grounds for sterilisation. In making its decision to consent to sterilisation, QCAT must take into account 'alternative forms of health care, including other sterilisation procedures, available or likely to become available in the foreseeable future', and 'the nature and extent of short-term, or long-term, significant risks associated with the proposed procedure and available alternative forms of health care, including other sterilisation procedures'.<sup>233</sup> Section 61(2) of the Guardianship and Administration Act 1993 (SA) provides that the South Australian Civil and Administrative Tribunal cannot consent to sterilisation unless the sterilisation is 'therapeutically necessary' or alternatively 'there is no likelihood of the person acquiring at any time the capacity to give an effective consent', 'the person is physically capable of procreation', and either that 'the person is, or is likely to be, sexually active, and there is no method of contraception that could, in all the circumstances, reasonably be expected to be successfully applied' or 'cessation of [a woman's] menstrual cycle would be in her best interests and would be the only reasonably practicable way of dealing with the social, sanitary or other problems associated with her menstruation'.

- 6.94 The difference between the New South Wales and Queensland/South Australia approaches is striking. Of particular concern is that in Queensland and South Australia, sterilisation can be authorised for contraception or menstrual management. It is incomprehensible that non-consensual sterilisation would be allowed for women without disability for contraception or menstrual management. It is also concerning that in Queensland and South Australia sterilisation can be for eugenics or sexual abuse risk related reasons for menstruation or contraception grounds of sterilisation. The mere fact of the availability of legal non-consensual sterilisation only for women with disability itself reflects eugenics logics embedded within the legislation at a structural level,<sup>234</sup> irrespective of how the legislation might be applied in relation to a specific individual.
- 6.95 A third approach to tribunal authorisation of sterilisation under guardianship law is found in Western Australia, Australian Capital Territory and Tasmania which focuses on 'best interests'. For example, in Tasmania, sterilisation is a 'special medical treatment' which must be consented to by the Tasmanian Guardianship and Administration Board, and such consent can only be given where the 'person is incapable of giving consent' and it would be in the 'best interests' of the person.<sup>235</sup> In determining that the sterilisation is in the individual's best interests, the Tasmanian Guardianship and Administration Board will take into account 'the wishes of that person, so far as they can be ascertained', 'the consequences to that person if the proposed treatment is not carried out', and 'any alternative treatment available to that person'.<sup>236</sup> The ACT, TAS and WA 'best interests' approach sets a low threshold for authorising sterilisation, because of judgements of what constitutes 'best interests'.
- 6.96 Fourth, in Victoria, a slightly different approach is taken. Under the Guardianship and Administration Act 2019 (Vic), the Victorian Civil and Administrative Tribunal can consent to 'sterilisation' as a 'special medical procedure' about an individual who 'does not have decision-making capacity in relation to giving consent' and 'is not likely to have decision-making capacity in relation to giving consent within a reasonable time'.<sup>237</sup> However, instead of the best interests requirement that applied under the state's previous guardianship legislation, the question is now whether 'the patient would consent to the carrying out of the special medical procedure if the patient had decision-making capacity in relation to giving consent'.<sup>238</sup> If the individual has not expressed their preferences then the Victorian Civil and Administrative Tribunal 'must give consideration to the patient's values whether— (i) expressed other than by way of a values directive; or (ii) inferred from the patient's life'.<sup>239</sup> While the Victorian test uses different wording than 'best interests' and is directed towards trying to identify what the woman herself might want, ultimately it is still a system of substitute decision-making that privileges the views and insights of third parties (including

their interpretations of what women might want). Entrenched structural ableism in health, disability service and legal systems means it is likely the views and insights of third parties will be informed by gendered ableist approaches to women with disability.

- 6.97 Contraception is subject to lower but varying standards of tribunal and board oversight. Guardianship legislation enables substitute decision-making about medical interventions. This is because contraception is categorised in different ways within and between jurisdictions in relation to the hierarchy of guardianship tribunal oversight of medical procedures. At one end, there are forms of contraception that are categorised as less significant medical interventions where guardianship law recognises the authority of third parties close to the individual (ranging in a hierarchy from guardians to family and friends) to consent whenever the need for consent arises without obtaining tribunal or board authorisation. In the mid-range there are medical interventions that can be authorised by guardians who have been formally appointed under guardianship law whenever the need for consent arises without obtaining tribunal or board authorisation. And, at the other end of the spectrum, the most significant medical interventions (similar to sterilisation) require tribunal or board authorisation for each specific intervention. We now turn to discuss some examples which highlight differences between jurisdictions.
- 6.98 In New South Wales, ‘major treatment’ is defined as including administration of a ‘long-acting injectable hormonal substance for the purpose of contraception or menstrual regulation’, such as Depo-Provera and ‘any treatment used for the purpose of eliminating menstruation’.<sup>240</sup> Major treatment can be consented to by NSW Civil and Administrative Tribunal or the ‘person responsible for the patient’<sup>241</sup> which is the guardian (if one is appointed for medical treatment decisions) or otherwise someone else close to the person such as a parent or partner (according to a legislative hierarchy).<sup>242</sup> However, forms of contraception which are not injectable, such as the contraceptive pill, would sit outside the definition of ‘major treatment’ and can be consented to by NSW Civil and Administrative Tribunal or the ‘person responsible for the patient’,<sup>243</sup> or even be administered without any such consent if ‘there is no person responsible for the patient’ or ‘there is such a person but that person either cannot be contacted or is unable or unwilling to make a decision concerning a request for that person’s consent to the carrying out of the treatment’ and the doctor certifies ‘the treatment is necessary and is the form of treatment that will most successfully promote the patient’s health and well-being’ and ‘the patient does not object to the carrying out of the treatment’.<sup>244</sup>
- 6.99 In South Australia, ‘medical treatment’ is defined as ‘the provision by a medical practitioner of physical, surgical or psychological therapy to a person (including the provision of such therapy for the purposes of preventing disease, restoring or replacing bodily function in the face of disease or injury or improving comfort and quality of life) and includes the prescription or supply of drugs’.<sup>245</sup> This is quite a broad definition which would include a range of contraception and menstrual suppression – implanted/inserted and oral. Consent to medical treatment is through the guardian or (if no guardian) the person responsible.<sup>246</sup>
- 6.100 In Victoria, guardians can make decisions about a ‘medical treatment decision’, which is defined as ‘a decision to consent to or refuse the commencement or continuation of medical treatment or a medical research procedure’.<sup>247</sup> ‘Medical treatment’ is defined as: ‘any of the following treatments of a person by a health practitioner for the purposes of diagnosing a physical or mental condition, preventing disease, restoring or replacing bodily function in the face of disease or injury or improving comfort and quality of life—(a) treatment with physical or surgical therapy; (b) treatment for mental illness; (c) treatment with prescription pharmaceuticals; (d) dental treatment; (e) palliative care—but does not include a medical research procedure’.<sup>248</sup> If a guardian is not appointed, a decision can instead be made by the relevant ‘medical treatment decision maker’ (e.g., spouse or primary carer).<sup>249</sup>

6.101 Another complexity is that additional to being regulated by guardianship law as medical treatment (as per the discussion above) contraception is also regulated and authorised as a restrictive practice, where done for behavioural rather than medical reasons. Restrictive practices are generally consented to by a guardian (who must have the restrictive practices function) and generally also require a Behaviour Support Plan (BSP). The requirement for a BSP does elevate the standard of tribunal or board oversight as compared to contraception that can be authorised as medical treatment by guardians or other persons responsible. Some of our concerns with restrictive practices were raised earlier in the context of the NDIS, and in WWDA's earlier submissions to the Disability Royal Commission on restrictive practices and sexual and reproductive rights. For present purposes, contraception as a restrictive practice is problematic for four reasons. One is that the binary between therapeutic and non-therapeutic is unclear (as we discussed in our earlier sexual and reproductive rights submission to the Disability Royal Commission). The second is that contraception would not be given for behavioural reasons non-consensually to non-disabled women. The third is that the kinds of behavioural reasons that restrictive practices are used can actually be related to others' convenience or financial benefit. The fourth is that, as noted by a 2020 report on menstrual suppression by the Victorian Senior Practitioner, there are considerable issues related to oversight of use of contraception as restrictive practice. A review of 23 behaviour support plans in a study by the Victorian Senior Practitioner in relation to menstrual suppression found a lack of specificity with the purpose and timeframes for use of LARC as a restrictive practice:

6.102 Reported themes of menstrual suppression use in the BSPs were:

- to reduce distress or anxiety
- to reduce hygiene risk
- to address behaviours of concern related to menstruation
- to address pain or feeling unwell
- by choice of the person
- for contraception.

6.103 Though some uses of menstrual suppression were reported to be for the purpose of managing behaviours of concern (i.e. risk of harm to self or others), many were reported for other reasons (such as choice, distress or contraception), or no information was provided for purpose.<sup>250</sup>

6.104 Moreover, five of the behaviour support plans did not even comply with the *Disability Service Act 2006* (Vic) requirements in relation to behaviour support plans, which included requirements to provide details:

- Evidence is provided of physical harm to the person or another person.
- Evidence is provided of physical harm to the person or another person from property destruction.
- An explanation is provided of how the restraint or seclusion is used for behaviour support.
- An explanation is provided as to how the restraint or seclusion will be of benefit to the person.
- A demonstration is provided as to how the restraint or seclusion is least restrictive of the person as is possible in the circumstances.<sup>251</sup>

6.105 The report found that five of the reports were non-compliant:

*Five of the [behaviour support plans] were identified as being non-compliant with legislation. All five that were non-compliant did not demonstrate how the restraint or seclusion is least restrictive of the person*

*as is possible in the circumstances. One BSP was non-compliant with the first five points as listed above, as there was no behaviour of concern identified.<sup>252</sup>*

- 6.106 The Victorian Senior Practitioner report found that of the 82 women subjected to menstrual-related restrictive practices, nine women had been subject to the restrictive practice for 11 years (the entirety of the study period, and possibly further back in time prior to the data collection) and 44 women for 5-11 years.<sup>253</sup>
- 6.107 A final complexity across guardian decision-making on sexual and reproductive matters is that these are deeply personal and intimate issues which people do not generally speak about to others. Making decisions in ways that will not draw on the substitute decision-maker's own views or what they consider socially appropriate is difficult. While some women with disability might have a family member or close friend as their guardian, women who do not have access to a guardian from their own networks (e.g., because they are socially isolated or who have been in out of home care as a child) will be appointed the Public Guardian. We return to discuss the Public Guardian in Section 7. The problems with decision-making on contraception is then compounded by the fact that there is a lack of trained staff in disability services which are dedicated to understanding these issues in positive ways. Very few NDIS service providers specifically have services for women with disability, many provide general services which further ignores and diminishes that this is important to women with disability.
- 6.108 A recent search of Australian Legal Information Institute (Austlii) and Australian legal case citation databases identified the following decisions on tribunal authorisation of sterilisation, contraception and menstrual suppression:



<b>Sterilisation and contraception guardianship matters involving women with disability</b>			
	<b>Decision</b>	<b>Procedure</b>	<b>Outcome</b>
<b>NSW</b>	<i>JZL</i> [2021] NSWCATGD 13	Sterilisation (Laparotomy with bilateral salpingo-oophorectomy and hysterectomy)	Application approved
	<i>MCF</i> [2020] NSWCATGD 77	Sterilisation (Abdominal hysterectomy and bilateral salpingo-oophorectomy)	Application approved
	<i>TZV</i> [2020] NSWCATGD 76	Sterilisation (External beam radiotherapy to pelvis and para aortic lymph nodes)	Application approved
	<i>Re OBD</i> [2016] NSWCATGD 58	Sterilisation (Endometrial ablation)	Application dismissed (applicant can consent without tribunal approval)
	<i>Re QMI</i> [2016] NSWCATGD 59	Sterilisation (Hysterectomy)	Application approved
	<i>Re NKI</i> [2015] NSWCATGD 59	Sterilisation (Abdominal hysterectomy and bilateral salpingectomy)	Application approved
	<i>Re UMG</i> [2015] NSWCATGD 54	Sterilisation (Hysterectomy)	Application dismissed (applicant can consent without tribunal approval)
	<i>Re UBE</i> [2015] NSWCATGD 57	Sterilisation (Laparoscopic tubal ligation)	Application dismissed (applicant can consent without tribunal approval)
	<i>Re UFH</i> [2015] NSWCATGD 58	Sterilisation (Laparoscopic hysterectomy and bilateral salpingectomy)	Application dismissed (applicant can consent without tribunal approval)
	<i>Re MMW</i> [2014] NSWCATGD 34	Sterilisation (hysterectomy with ovarian conservation)	Application dismissed (applicant can consent without tribunal approval)
	<i>Re NXM</i> [2014] NSWCATGD 52	Sterilisation (Hysterectomy)	Application dismissed (not necessary to save patient's life or prevent serious damage to patient's health)
	<i>Re NXM (No 2)</i> [2014] NSWCATGD 53	Sterilisation (Hysterectomy)	Application approved
	<i>PYR</i> [2012] NSWGT 30	Sterilisation (Endometrial ablation)	Application dismissed (need to consider less invasive treatment options)
	<i>LDS</i> [2012] NSWGT 9	Sterilisation (Hysterectomy)	Application approved
	<i>Re XTV</i> [2012] NSWGT 5	Sterilisation (endometrial ablation)	Application dismissed (not necessary to save patient's life or prevent serious damage to patient's health)
	<i>TAC</i> [2010] NSWGT 23	Sterilisation (Hysterectomy)	Application dismissed (applicant can consent without tribunal approval)
	<i>WAK</i> [2010] NSWGT 25	Sterilisation (Hysterectomy with bilateral salpingo-oophorectomy - with Postoperative radiation treatment if required)	Application approved
<i>MNY</i> [1996] NSWGT 1	Sterilisation (Hysterectomy)	Application approved	

<b>QLD</b>	<i>In an application about matters concerning CM</i> [2022] QCAT 263	Sterilisation (Laparoscopic hysterectomy with bilateral salpingectomy and laparotomy)	Application approved
	<i>EKF</i> [2017] QCAT 434	Sterilisation (Hysterectomy)	Application approved
	<i>CEN</i> [2012] QCAT 387	Sterilisation (Tubal ligation)	Application approved
	<i>CN</i> [2012] QCAT 11	Sterilisation	No decision finalised (insufficient information available to make decision)
	<i>TN</i> [2012] QCAT 713	Sterilisation (Hysterectomy)	Application approved
	<i>HGL (No 2)</i> [2011] QCATA 259	Sterilisation	Application approved
	<i>Re AAE</i> [2007] QGAAT 59	Sterilisation (Hysterectomy)	Application approved
	<i>Re CMH</i> [2004] QGAAT 7	Sterilisation (Hysterectomy)	Application approved
	<i>Re AX</i> [2000] QGAAT 4	Sterilisation (Hysterectomy)	Application approved
<b>TAS</b>	<i>UI (Consent to Special Medical Treatment)</i> [2020] TASGAB 48	Sterilisation (Tubal ligation)	Application approved
	<i>MZS (Consent to Special Medical Treatment)</i> [2019] TASGAB 40	Sterilisation (Laparoscopic total hysterectomy and salpingectomy)	Application approved for laparoscopic total hysterectomy and salpingectomy, but not oophorectomy
	<i>QN (Medical Consent)</i> [2018] TASGAB 13	Sterilisation (Salpingectomy)	Application approved
	<i>KI (Medical Consent)</i> [2018] TASGAB 12	Sterilisation (Laparoscopy with ligation of fallopian tubes with filschie clips or removal of fallopian tubes)	Application dismissed (not the necessary and the least restrictive way to achieve the purpose of preventing pregnancy)
	<i>MG (Medical Consent)</i> [2004] TASGAB 5	Sterilisation (Hysterectomy)	Application dismissed (not in a position to say that no other less restrictive treatment will work as other option untested)
<b>VIC</b>	<i>ZEH (Guardianship)</i> [2015] VCAT 2051	Sterilisation (Tubal ligation)	Application dismissed (no compelling justification for the special procedure and not the least restrictive option)
	<i>SBM (Guardianship)</i> [2014] VCAT 1654	Sterilisation (Tubal ligation)	Application dismissed (applicant can consent without tribunal approval)

WA	EW [2021] WASAT 111	Sterilisation (Tubal ligation)	Application approved
	JS v CS (2009) 63 SR (WA) 23	Sterilisation (Hysterectomy)	Application dismissed (applicant can consent without tribunal approval)
	AD [2007] WASAT 123	Sterilisation (Hysterectomy)	Application dismissed (no compelling justification for procedure)
	Re P (1993) 12 SR (WA) 255	Sterilisation	Application dismissed
	Re S (1993) 12 SR (WA) 258	Sterilisation	Application dismissed (Public Guardian appointed for purpose of administering contraception and develop self-help skills)
	Re D (1998) 24 SR (WA) 163	Sterilisation	Application approved

6.109 Four observations can be made about these decisions in relation to the legal dynamics of guardianship.

6.110 The first is that reproductive and sexual substitute decision-making remains a live issue in the guardianship jurisdictions. This is at a time when there is increased advocacy on the role of legal and justice systems in women's sexual and reproductive rights, such as advocacy around decriminalisation of abortion.

6.111 The second is that use of guardianship in the context of sexual and reproductive decision-making to facilitate inclusion (one of its stated aims) comes at the cost of other rights. For example, in *QN (Medical Consent)*,<sup>254</sup> the Tasmanian Guardianship and Administration Board decided it was in QN's best interests to be sterilised to prevent pregnancy related to her being in an intimate relationship. Dr Keating, QN's treating gynaecologist, made an application to TASGAB to provide consent for QN to have a sterilisation procedure as a form of permanent contraception. QN is described in the judgment as a 19-year-old woman with Tristomy 21 (Down syndrome). Dr Keating reported that QN had been trialled on a number of oral contraceptives which were not well tolerated and resulted in significant dysphoria and mood disturbance. The Board heard evidence from FH (QN's mother) that QN enjoys male company more than female company and had shown interest in particular male persons in the past. FH advised that her daughter had fallen in love a number of times and had experimented with romantic relationships, kissing and cuddling. FH also indicated that her daughter has requested that her boyfriend be allowed to come over and sleep in her bed with her. Dr Keating indicated that QN had sexualised behaviour and the chances of QN having sexual activity were high. Dr Keating indicated it would be impossible for QN to be able to keep and care for a baby. Dr Williams, a paediatrician, reported that: 'A pregnancy would be disastrous and life threatening for QN is vulnerable to non-consensual sexual intercourse'. The Tasmanian Guardianship and Administration Board concluded that the sterilisation would be in her best interests, particularly because this would allow her to remain included in the community:

*The Board gives weight to the fact that QN appears to be participating as fully as she is able in life, enjoying socialising with others and living a life significantly less isolate than one she previously enjoyed. The Board acknowledges QN's human right to freely engage in contact with persons of both sexes and the right to enter intimate relationships if she so chooses. The Board notes the views of those present at hearing that it*

*is highly likely that QN may engage in sexual relationships and appears to have opportunity to do so. The least restrictive option is therefore to allow her to enjoy her current lifestyle and not to socially isolate her from male persons so as to ensure she does not have sexual relationships and therefore to prevent pregnancy. To do so would result in a severe reduction of QN's quality of life and freedom to engage in social activity.<sup>255</sup>*

- 6.112 The reasoning by the Tasmanian Guardianship and Administration Board highlights a core tension in guardianship law as identified earlier in this submission – that the interventions in guardianship law are necessary to bring about future wellbeing, while the intervention itself depletes wellbeing and excludes individuals from full legal personhood and citizenship. As in QN's case, her human rights, community inclusion, and happiness and fulfillment in the context of her intimate relationship is given as a justifiable basis from which to authorise her sterilisation even when this very intervention could be the cause of ongoing trauma and long-term health impacts. Furthermore, sterilisation permanently denies to her the possibility of her having children which many women in intimate relationships might wish to do. The Tasmanian Guardianship and Administration Board also rules out that QN could learn about contraception, including that she could access services through the NDIS that could support this learning.
- 6.113 The third is the board and tribunal decisions that highlight how sexual and reproductive decision-making can be contingent on the availability of disability support (provided informally by family members or formally by paid services) or the preferences of those providing support. For example, in *Re AX*, sterilisation of AX was authorised by Queensland Civil and Administrative Tribunal for the purpose of menstrual management. AX was described as 31 years old and with an intellectual disability and epilepsy. AX was unable to manage her personal care needs independently during periods of menstruation and was reliant on her mother for assistance. The aim of AX's parents was for AX to have some level of independence but this was impossible when she was so physically reliant on her mother for her care during her periods. This was a key consideration in QCAT authorising the sterilisation:

*The Tribunal also notes that Ms AX is also incapable of independent living whilst she continues to experience menstrual difficulties. The Tribunal accepts the evidence of Ms AX's parents that they are aging and would like to see Ms AX in an independent living situation. Ms AX's activities during menstruation are also limited due to the fact that she is totally dependent on her mother for assistance. The Tribunal also notes the impact that this dependence has on Ms AX's mother. The Tribunal also notes that in the normal course of events Ms AX would continue to have periods for the next twenty years.<sup>256</sup>*

- 6.114 Here the Queensland Civil and Administrative Tribunal portrays AX as suffering by the act of menstruating which casts menstruation in a negative light.
- 6.115 Fourth, some decisions are not being made because there is no jurisdiction to make an order because the tribunal or board decides the woman actually has capacity. For example, in the decision of the NSW Civil and Administrative Tribunal,<sup>257</sup> UMG (a woman described as having learning disability) sought a hysterectomy in response to chronic pelvic pain related to endometriosis. Her obstetrician applied for the NSW Civil and Administrative Tribunal's consent because they were unsure of UMG's capacity to provide her own consent. The NSW Civil and Administrative Tribunal ultimately decided she did have sufficient consent; however, this was not until a tribunal hearing that explored in detail her disability, capacity and her reproductive health (including through multiple expert reports), well beyond what women without disability would ever be subjected to in accessing reproductive healthcare.

This decision is significant because it highlights assumptions at the intersection of gender and disability where women with disability are assumed to be incapable. Eight of the 17 applications detailed in the table above which were dismissed were dismissed on the basis that the woman had capacity to make her own decision about the procedure and in some of these decisions it was the woman herself who had gone to the doctor seeking the procedure. These decisions where sterilisation has *not* been authorised on the basis a woman possesses capacity highlights the problematic denial of reproductive autonomy to women with disability by reason of assumptions made by healthcare and social care professionals. This observation reflects broader concerns about women with disability being denied autonomy to make their own decisions about reproductive healthcare for endometriosis and chronic pelvic pain. Many women with disability such as those with endometriosis or adenomyosis request endometrial ablation and want to consent to this procedure but health professionals deny them this opportunity to receive this care. Research on chronic pelvic pain experienced by women more broadly documents the challenges women encounter in having their pain recognised by health professionals, the invisibilisation of chronic pelvic pain, and the impact of gendered stereotypes about women as being hysterical or difficult on the failure of health professionals to provide the medical treatment women seek.<sup>258</sup> The failure of health professionals to listen to and believe the experiences and needs of women in relation to endometrial ablation demonstrates the gendered ableism underpinning the role of the legal and health systems in sterilisation. We cannot simply assume that health or legal professionals are acting in the best interests of women with disability by reason of their professional status and role. These issues around healthcare professionals disregarding women with disability's attempts to access and consent to surgery related to chronic pelvic pain might be particularly pronounced in relation to women with intellectual disability. These women might be considered incapable of consenting, with healthcare or social care professionals involved in these women's lives seeking an order from a guardianship tribunal or board in lieu of the woman's own consent.

## Silenced

- 6.116 Guardianship and financial management law silence women with disability. This silencing is in stark contrast to feminist campaigns in support of women speaking out about their experiences of violence, such as #MeToo and #LetUsSpeak/#LetHerSpeak.
- 6.117 Women with disability experience barriers to speaking out about their experiences in official forums. The interventions in the bodies and lives of women with disability authorised pursuant to guardianship and financial management law (either by decisions of guardians and financial managers, or decisions by tribunals or boards in the case of sterilisation) are legally sanctioned. Yet the women with disability subject to these interventions have not consented. In other situations, the non-consensual nature of these interventions would generally render these interventions unlawful. However, in the context of guardianship these interventions do not constitute illegal violence, imprisonment, and stealing of money and property, and there is a profound aberration from established legal principles that recognise the right to bodily autonomy and bodily integrity. The legality of these interventions (irrespective of being non-consensual and harmful), prevent women with disability from seeking protection from police, applying for apprehended violence orders, taking civil legal action or seeking victims' support and payments under state and territory victims' support legislation. The legality of these interventions might also be an impediment to women with disability recognising that they are victims of violence and dealing with associated trauma or negative feelings from such harm.
- 6.118 Women with disability are also prevented from speaking publicly about their experiences of guardianship and financial management. State and territory guardianship laws 'gag'

people under guardianship and financial management by prohibiting them from speaking out about their experiences. For example, in order for ABC Four Corners to report in its 2022 episode 'State Control: Australians Trapped, Stripped of Assets and Silenced' on individuals' experiences of financial management in Queensland, the ABC had to apply to the Queensland Supreme Court, as explained by journalist Anne Connolly:

*Laws in every state and territory (except for the ACT) stop the media from identifying these people — even after they have died. The penalties: tens of thousands of dollars and/or six months in jail or more. Hence, the ABC's applications to two Supreme Courts to lift the ban and tell these stories.<sup>259</sup>*

- 6.119 It was recently reported that John Chesterman, Queensland's Public Advocate, released a report recommending repeal of the 'gag' law in Queensland that prohibits publication about tribunal proceedings that discloses adult's identity (section 114A of the *Guardianship and Administration Act 2000* (Qld)). In discussing this recommendation, Chesterman is reported to have stated:

*The analogy is with victims of sexual assault not being able to tell their stories, and that's changed. For a similar reason, I think this one should change too. ...*

*Enabling people to talk about their own guardianship experiences outweighs the protective benefit of retaining the restriction. That's why I've recommended its repeal. ...*

*I do think it's an important issue in terms of human rights and self-actualisation and transparency.<sup>260</sup>*

- 6.120 Moreover, the inaccessibility of tribunal and board processes can also have a silencing effect on women with disability. Women with disability will not be able to speak and participate in tribunal and board processes if they have not been provided with accessible information on guardianship and financial management and if tribunal and board processes themselves are not inclusive, accessible and trauma-informed.

## Trapped

- 6.121 Guardianship and financial management laws operate to trap women with disability, sometimes for years and decades, in substitute decision-making arrangements. In part this is because guardianship and financial management orders can be made for a number of years, and financial management orders can even be made for an indefinite period. Moreover, orders can be difficult to revoke. For example, the Intellectual Disability Rights Service has observed:

*once a person is under formal orders, it is difficult for the person to have those orders varied or revoked — the evidentiary onus lies with them to prove they have re-gained capacity to manage their affairs or there is no longer a need for an order or that it is not in their best interests to have one;*

*in some jurisdictions orders are not automatically reviewed and so a person (whose decision-making skills or other circumstances may have improved) can be left languishing for years unnecessarily bound and limited in their lifestyle and financial choices;<sup>261</sup>*



- 6.122 The Intellectual Disability Rights Service explains how orders can be easier to make than revoke, by reference to NSW:

*In New South Wales a financial management order can be revoked by the Guardianship Tribunal if:*

- a) *it is satisfied that the protected person is capable of managing his or her affairs, or*
- b) *it considers that it is in the best interests of the protected person that the order be revoked (even though it is not satisfied that the protected person is capable of managing his or her affairs).*

*The onus of proof lies with the person making the application (usually the protected person) to lead evidence and establish either of the limbs. Leaving to one side the evidentiary difficulties for a person with decision-making disability to meet the onus of proof, there is an inherent unfairness in this ‘test’ for revocation in New South Wales. That is, there is no alternative limb in the test allowing the applicant to argue there is no longer a ‘need’ for their affairs to be managed by another person, even though there is a ‘need’ limb in the test to determine whether that person should have been under the financial management order in the first place. In other words, in New South Wales, it is easier to be put under a financial management order than it is to be removed from one.<sup>262</sup>*

- 6.123 Women with disability can also be trapped in guardianship and financial management arrangements because financial managers can control access to funds to pay for legal assistance, as noted by disability rights lawyer Natalie Wade in an ABC News story:

*“When people with disability approach me as a lawyer, they express a sincere and genuine fear of “the government”, as they call it, which refers to ... the Public Trustee, coming to make decisions for them, “ said Natalie Wade, founder and principal lawyer at Equality Lawyers.*

- 6.124 Lawyers say it is almost impossible to escape the Public Trustee because it controls a person’s bank account and can refuse to release funds for them to hire a lawyer.

*“They are up against a government department with all of the resources that it entails, including representatives from the Crown Solicitor’s Office, some of the best lawyers in the land,” Ms Wade said.*

*“If you’re going to have a law that is going to actively offend the human rights of people with disabilities, you would really want to have a system in place that supports those people to defend their human rights. And at the moment, we don’t have either. We have a law that breaches their human rights, and we have a system that does not allow them to defend them.”<sup>263</sup>*

- 6.125 Women with disability who are under guardianship and financial management can also be trapped when they are unable to access independent advocacy or legal representation to assist them to seek revocation of orders. For example, on Day 5 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted decision-making and supported decision-making, Craig Gear from the Older Persons Advocacy Network noted significant problems with independent advocates being blocked and threatened with legal action by attorneys under Enduring Powers of Attorney and suggested a legislated right to third party advocacy. Gear explains:

*We have had situations and we have had the power of attorney go to legal representation and have letters written to us to say that they - that we are not to speak to the person. And that's when we know that there's a situation or a risk of abuse by the person appointed as power of attorney. We need to have in legislation that we have the right under law to speak to the individual and to educate them about their access to rights and the availability of independent third-party support through an advocate.*

*If that was done, we would then be able to work with a person to identify risks, educate them on their rights, and then if they said they didn't want advocacy, we would absolutely respect that, but we would actually be able to make sure that people have been informed of their rights and can exercise that and know of other options such as mediation to have some of the family relationship issues resolved that might be going on there. It needs to be a legislated right to aged care advocacy.*



## **7 ECONOMIC AND BUREAUCRATIC DYNAMICS**

## 7. ECONOMIC AND BUREAUCRATIC DYNAMICS

- 7.1 In this section we discuss some of the economic and bureaucratic dynamics of violence against women with disability through guardianship and financial management.

### Lack of resources for supported decision-making

- 7.2 Once a guardian or financial manager is appointed there is no one clear legislated requirement on the guardian, financial manager, or a third-party agency, to be actively working with a woman with disability to develop their capacity so that they can apply to have the order revoked. There is no automatic access to support services to develop the skills and conditions in which supported decision-making can operate and guardianship and financial management orders might be revoked.
- 7.3 Moreover, there are broader issues with supported decision-making that can render it an impossible alternative to substitute decision-making. Supported decision-making is not resourced or supported in the community. For example, on Day 4 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Colleen Pearce of the Office of Public Advocate, Victoria gave evidence about the limitations of implemented supportive decision making in the *Guardianship and Administration Act 2019* (Vic). Pearce talked about resourcing issues noting that supported decision-making requires ‘more resources, more time, more decisions to be made’ and ‘it is a limitation on the ability for everyone to be able to implement the new Act when there were limited resources, or no resources given to the implementation of the Act’, advising the Disability Royal Commission that no funding was given to the Office of the Public Advocate or State Trustees to implement the new Act. In particular, there have been challenges in identifying supportive guardians or supportive administrators. Pearce advised that the tribunal ‘is often unable to appoint a supportive guardian because there’s no one available to take up that role. And so, you put this into an Act but then you don’t create a system where you can identify supportive guardians.’ Consequently, the tribunal in the year 2020 to 2021 made 68 supportive guardianship orders and 62 supportive administration orders, however only 18 supportive guardians and 30 supportive administrators were appointed.
- 7.4 Concerns have been raised that without proper planning, supported decision-making mechanisms will become part of a tick-box exercise that will satisfy bureaucratic requirements to show concern for choice rather than helping persons to achieve better outcomes. The following passage shows quotes from a participant with a disability at a Symposium called the Future Directions in Supported Decision-Making Research Symposium held by the University of Melbourne in 2015 as written about by Arstein-Kerslake et al:
- “I think we are at risk of supported decision-making becoming another thing that services are just required to do, like planning. There is no real focus on how and why, just that it is done”. Another participant replied to this comment with, “Yes, I think you’re right... there needs to be focus on the how. How do we really work out what people want? A written plan or a supported decision-making agreement is well and good, but how do we get there?”<sup>264</sup>*
- 7.5 There is also concern that there is little focus on the specific mechanism of how to do supported decision-making, as noted by Rhonda Galbally:

*Many people are completely unaware of the concept and process of*

*support for decision making. A systematic approach to raising awareness and providing targeted information is required for people with disability, families, informal supporters, NDIA and outsourced staff and service providers. Consistent messages that address the varied interests and challenges of different audiences including audiences ‘on the margins’ will need to be crafted.<sup>265</sup>*

- 7.6 Moreover, supported decision-making needs to focus on the individual as well as systemic and policy-based interventions that focus across all levels of society, as Emily DiMatteo and co-authors describe in recommendations to the legal system in America:

*Federal and state-level policymakers must increase oversight; develop a set of basic rights for people under guardianship; provide funding for training and education for courts, attorneys, and parents; adjust transitional planning efforts; and improve data collection.<sup>266</sup>*

- 7.7 Furthermore, little focus has been on creating supported decision-making frameworks within service systems such as the NDIS and residential aged care, including to lodge claims, articulate needs, make decisions, identify and exercise control over service delivery, and, when necessary, make complaints.<sup>267</sup> Inclusion Australia reports on the case of Grace, who turns to her local advocacy service for support for supported decision-making as this is not part of the NDIS:

*Grace is a 21-year-old female with intellectual disability who is a participant of the NDIS. A strong self-advocate and representative of others with intellectual disability, Grace is a very independent person with well-established social networks and friendship groups who enjoys ‘being herself’. She is on many statewide committees and her committee colleagues report Grace is a great self-advocate – for herself and others with an intellectual disability. Grace’s mother is the nominee of her NDIS plan. Grace’s mother and the coordinator of supports do not involve Grace in the decision making related to her NDIS plan. There have been times when they have attended the NDIS meetings without her being present. Grace’s goal is to move out of the family home and live independently, but she is constantly told by her family that she is not capable of living independently. Grace knows that she is capable of this with some capacity building supports but she has not put this as one of her goals as the nominee will not allow it. At times Grace needs some support around making decisions. As she feels this is not something her nominee does well, she contacts her local advocacy service for this support around her rights and supported decision making.<sup>268</sup>*

- 7.8 On Day 3 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Uli Cartwright and John O’Donnell discussed their experiences under the Queensland State Trustee. O’Donnell expressed that it is important for people to receive financial counselling opportunities ‘before they get on to State Trustees, before they get taken away their independence’. Once a person is subject to a financial management order, there is limited opportunity to build financial capacity. According to Cartwright, ‘it just feels like it’s – once you are in it is set and forget. It’s just done. It’s over. There’s - there’s - this is just an assumption that you can’t learn anything and, because of that, they don’t know where to start’.
- 7.9 Lack of resources and other issues concerning supported decision-making contributes to the state of women with disability being trapped.



## Specific issues with public guardians and trustees

7.10 Women with disability under the guardianship or financial management of public agencies are subject to disadvantage. This is particularly problematic because these agencies function as last resort options and thus are typically applied to individuals who do not have access to family members or friends who could act as guardians and financial managers (e.g., socially isolated and financially disadvantaged or are subject to familial conflict). However, the public guardian annual reports across all jurisdictions have noted that the rollout of the NDIS has created a considerable administrative burden for public guardians where the need to make decisions about, and undertake reviews of, NDIS services is a significant portion of their workload.<sup>269</sup> Concerningly, this administrative use of guardianship has led to an increase in longer-term public guardianship appointments, more reappointments and fewer revocations of appointments for clients under the NDIS.<sup>270</sup> The relationship between guardianship orders, financial management orders and the NDIS was discussed at length during the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making with Chair Sackville commenting at the end of Day 4 that ‘the use of a guardian to assist in this [NDIS] process would seem to be a sledgehammer to crack a nut’, highlighting that this increasing trend of appointing public guardians and public trustees to assist people with disability to navigate the NDIS is inappropriate.

7.11 Government agencies, public guardians and public trustees fulfil their role as guardian or financial manager through delegation of tasks to public servants who typically ‘manage’ a high number of ‘cases’. These public servants do not have the time, nor do they have the personal connections or emotional and moral obligations of family and friends to develop a deeper insight into the individual’s preferences and needs. It also gives rise to poor quality service provision, as observed by the Intellectual Disability Rights Service:

*IDRS consistently receives complaints from people who are subject to formal orders where a government body is their financial manager and/or their guardian. Common complaints include:*

- use of ‘client service teams’ leading to no particular person being responsible or accountable for any particular client;
- inconsistent service delivery and information to clients which understandably leads to incredible levels of stress and frustration for those clients;
- slow (to no) responses to requests from clients;
- bills not being paid;
- slow decision-making;
- an unwillingness to spend the time needed to understand the needs, changing circumstances and idiosyncrasies of clients;
- a lack of individualised service to the needs and wishes of each client;
- clients being left for extensive periods of time ‘on hold’ when they telephone the offices and being forced to leave voicemail messages that do not get returned or answered, and
- concerning cynical and pejorative attitudes displayed by some of the staff in these offices to their clients and to disability generally.<sup>271</sup>

7.12 The Intellectual Disability Rights Service have noted in relation to financial management by the public trustee in NSW that:

*Few, if any, clients under the financial management of the NSW Trustee and Guardian have individualised financial plans and budgets specifically*

*tailored to their lifestyle needs and aspirations. Few clients have regular direct personal contact with staff, and for those reasons it is not possible for the NSW Trustee and Guardian to really know if the person's assets are being used for their benefit or in their best interests.<sup>272</sup>*

7.13 Ultimately, women with disability become reduced to a case file number and thus become de-individualised and dehumanised and exposed to the risk of harm through the neglect or uninformed decisions of their guardian or financial manager. This dehumanisation is illustrated by Killara's experiences from Day 1 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making which we discussed in Section 5. For example, People with Disability Australia's submission to the Disability Royal Commission Public Hearing 30 discussed the experiences of Beverley:

*Beverley was in the care of her state's child protection system until eighteen years old and was then under the guardianship of the OPG and Public Trustee (PT) until the Administrative Tribunal removed guardianship orders when she was 30 years old. Beverley states there was no supported decision making with OPG and PT and they made all decisions in her life. Beverley says there was a high turnover of staff in OPG and PT. Staff were not trauma informed. She did not feel heard or respected. State disability services and OPG worked closely together but Beverley felt they ignored what she wanted. Beverley noted:*

- They tried to control who she could see, tried to stop her from seeing her then boyfriend, now husband, who also has a mild intellectual disability, and spoke with her boyfriend's father without her consent.*
- OPG neglected to support her health needs when she had chronic pain and repeat hospital stays.*
- Beverley had to ask PT permission to take a holiday and received a minimum amount for living expenses.*
- When reporting an assault, OPG supported the accommodation provider and not her.*
- When pregnant, OPG said she made up the pregnancy and threatened that child protection services would get involved. This scared her and she made alternative arrangements with someone to look after her children because she was afraid her children would grow up in the child protection system.*

*A disability organisation made a complaint to the Ombudsman on her behalf. Her general practitioner supported her to have OPG and PT guardianship orders removed by stating she could look after herself and had capacity to make decisions in her own life. She still lives in fear that OPG and PT will somehow get control over her life again.<sup>273</sup>*

7.14 The Public Guardian has high caseloads and does not have ongoing and meaningful involvement with the represented person. The National Standards of Public Guardianship specify that guardianship staff making legal decisions 'will endeavour to meet in person or use audiovisual technology to have direct contact with the represented person at least once a year'.<sup>274</sup> A meeting, potentially not even face-to-face, once a year is not sufficient opportunity to develop a deep knowledge and understanding of a person's circumstances and develop a strong connection with the person, to then be consenting to such significant interventions in their bodies related to such personal and intimate matters as menstruation, reproduction and sexuality. The lack of ongoing contact, engagement with, and consideration for the lives of people with disability under public guardianship

can exacerbate the dominance that is inherent to guardianship and financial management because, as explained by Arstein-Kerslake et al, this increases the risk of substitute decisions that do not align with an individual's needs and experiences:

*the mere dependence of a person with disabilities on others ... can give rise to situations of dominance, leading to disempowerment and dehumanisation. One of the reasons for this is inherent to the concept of 'guardianship' and its assumption that the guardian can act in the best interests of the individual. By articulating those 'best interests' as distinct from the will and preference of the individual, guardians are encouraged to substitute their interpretation of the best interests of their wards. This substitution becomes especially likely in situations where communication between guardian and ward is extremely limited, such as in cases of severe physical and/or intellectual disability.<sup>275</sup>*

- 7.15 The use of public guardians and public trustees as last resort options for women with disability who are socially isolated is additionally problematic because these women might experience distrust and fear and be triggered by being under the control of a government authority. For example, the Intellectual Disability Rights Service has observed:

*formal orders may appoint government bodies as the financial manager and/or the guardian and these bodies are often difficult to contact and engage with, creating poor relations and distrust.<sup>276</sup>*

- 7.16 Indeed, negative and harmful experiences of public guardians and public trustees can themselves destroy women's ability to trust, and result in feelings of loss of autonomy and control. People with Disability Australia's submission to Disability Royal Commission Public Hearing 30 discussed the experiences of Margie:

*Margie was placed under the Office of the Public Guardian (OPG) and Public Trustee (PT) in a large Australian state. She spent six months in hospital waiting for suitable accommodation to be organised. An OPG guardian visited her in hospital two months after she was admitted. Margie also accumulated a long stay hospital debt.*

*Margie was not given a choice of accommodation providers when arrangements were made following the hospital stay. Margie said that she did not feel safe where she was living. The OPG did not initially respond to her pleas to move accommodation providers, but eventually found her a new accommodation provider. Margie continues to feel frustrated with the OPG and PT regarding the lack of communication, lack of supported decision making and constant staff changes.*

*Margie asked for more stakeholder meetings, but these were not forthcoming. Margie said she wanted regular stakeholder meetings to express her goals and concerns in a safe environment. She feels that the OPG listens more to the National Disability Insurance Agency and accommodation providers, rather than listening to her.*

*Margie feels like her voice is not heard, she feels controlled and wants to remove guardianship from her life.<sup>277</sup>*

- 7.17 Chris, a person with a disability under a guardianship order told reporters in an Australian Broadcasting Corporation Four Corners investigation into the Queensland Public Trustee:

*I don't believe that they act in people's best interest. I don't think they care. They're a body answerable to themselves only, apparently. And there doesn't seem to be any oversight of the Public Trustee and what they do to people.<sup>278</sup>*

## Others are profiting from guardianship and financial management

- 7.18 Financial managers and disability services financially benefit from guardianship and financial management.
- 7.19 Financial managers – including public trustees – are paid for their role from the funds of people with disability. This is so even though the people under financial management have not requested or agreed to this service. The fact that women with disability need to pay for this service is inconsistent with the approach in relation to other coercive frameworks. People in prison and immigration detention do not pay for their incarceration, nor do people receiving involuntary mental health treatment and detention pay for these services they have imposed on them.
- 7.20 The financial benefit to financial managers for their role then creates a conflict of interest in two respects. First, financial managers are balancing financial interests of their operations with being required to act in the best interests of the individual under management and thus will not necessarily make financial decisions that will meet the emotional, social and other needs of a woman with disability under their management. Second, there is no incentive to support women with disability under their financial management having orders revoked.
- 7.21 There are also issues of mismanagement of funds and the charging of high fees. For example, an Australian Broadcasting Commission Four Corners investigation into the Queensland Public Trustee found 'mismanagement and extraordinary fees'.<sup>279</sup> There have also been media reports of issues with public guardians and financial managers. The Australian Broadcasting Corporation published an article highlighting how the Public Trustee in Queensland charges high fees for their services:

*Sophie — not her real name — wants to tell the story of the high fees and the unnecessary charges she said her mother has been forced to pay since coming under the control of Queensland's Public Trustee three years ago due to dementia. Over three years, she said her mother has paid \$28,000 in personal administration and asset management fees.<sup>280</sup>*

- 7.22 To recoup these fees, the money is taken from the personal accounts of people under financial management. Australian Broadcasting Commission reports that these problems are often unreported as the Office of the Public Trustee forbids persons from speaking out about their guardianship orders; in Queensland, it is an imprisonable offence punished by six months in prison and, in some cases, a \$50,000 fine which dissuades persons from reporting these issues.<sup>281</sup>
- 7.23 Additionally, financial management orders are tricky to undo as laws allow the Public Trustee to use the person with a disability's money to pay the legal fees of court cases and keep the financial management order in place. A report by the Australian Broadcasting Commission on such cases tells the story of Peter:

*Peter fought to return to his family home he inherited in Canberra. With the help of legal advocates, he had the authority of Queensland's Public Guardian, and Public Trustee revoked. Until we showed Peter his statement, he had no idea that two weeks after he won his hearing, the Public Trustee deducted \$18,000 from his account for its solicitor.<sup>282</sup>*

- 7.24 Disability and aged care services can also financially benefit from guardianship by reason of the resource and labour cost savings associated with some of the interventions authorised by guardians. For example, authorisation of menstrual suppression and sterilisation reduces resource and labour costs associated with personal care of women who menstruate. Authorisation of chemical or physical restraint in group homes or residential aged care settings reduces labour costs associated with providing social and physical support to people with disability because they are physically contained or immobilised. For example, research on people living with dementia in residential aged care recounts experiences of people being ‘parked’:

*The most commonly mentioned factor affecting freedom of movement was the removal of means of mobility. This includes not providing mobility aids, opportunities for physical exercise, or meaningful activities to prevent decline and distress.*

*The first thing they do with people with walking frames is take the walking frame away from them and put them in a wheelchair because they don't have the staff to support them while they're walking. And they sat in the wheelchair, and then they just ... they're parked. (focus group 1, care partner)*

*Several participants mentioned people being seated (“parked”) in front of televisions:*

*They're parked ... No, I'm not talking about them being restrained. I'm talking about them being put in an area like the common area, where the TV's on, and, essentially, just left there. And they're supposed to occupy themselves, I suppose, by looking at the TV for endless hours. Or, alternatively, they're left in their room, perhaps in their bed or in their chair, but with no real way of them getting up and being able to move about and interact. (interview 3, lawyer)<sup>283</sup>*

- 7.25 Disability and aged care services can also financially benefit from guardianship and financial management by reason of not needing to spend time and resources that might be necessary to support an individual to exercise their autonomy and make their own decisions.

### Pipelines into guardianship

- 7.26 Guardianship and financial management might also be entrenched in the connections and pathways between systems.
- 7.27 New South Wales Supreme Court decisions evidence the transition of young people in out of home care from the parental responsibility of the Minister and related coercive *parens patriae* orders for restrictive accommodation into guardianship arrangements associated with accessing the NDIS.<sup>284</sup>
- 7.28 As we have discussed in other sections of this submission, guardianship and financial management can also be required by disability and aged care services prior to people with disability access supports and accommodation.
- 7.29 Writing in the US context, DiMatteo and co-authors describe a ‘school-to-guardianship pipeline’:

*Many students with intellectual and developmental disabilities enter the school-to-guardianship pipeline through high school transition planning. Under the Individuals with Disabilities Education Act (IDEA) of 1990, students leaving high school are supposed to work with schools and their parent or guardian to go through a transition period during which rights are transferred directly to the student. However, this “transfer of rights” process often results in school officials suggesting that parents become legal guardians of their young adult children. According to some studies, almost 60 percent of people with intellectual and developmental disabilities ages 18 to 22 who receive publicly funded services have guardians and report that schools often present guardianship as the main or default option to support young adults in decision-making. Some school professionals may not provide parents any information on alternatives to guardianship.*

*When guardianship is explored at this juncture, school officials and parents are often unaware of the potential long-lasting consequences of guardianship. For instance, a disabled student under guardianship loses their rights to make decisions about their future education and plans after high school, which counteracts IDEA’s promotion of self-determination and independence.<sup>31</sup> Parents who speak English as a second language or who are from low-income and marginalized communities may have even more difficulty accessing the necessary information about less restrictive alternatives to long-term guardianship.<sup>285</sup>*

- 7.30 It is important to explore if this is also occurring in Australia, including as young people with disability transition into employment services or Australian Disability Enterprises, or in the context of the NDIS. This issue also raises the issue of whether schools (mainstream and segregated) are supporting the development of decision-making skills for students with disability and are maximising their opportunities to exercise their choice and agency in the school setting. On Day 1 of the Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making, Christine Grace of Kin Disability Advocacy Inc discussed the concerning trends observed in First Nations communities over the past 12 months:

*Some of the issues around when a young person is leaving the care of the Department of Child Protection and Family Service, and there’s an assumed - an assumption is made that the person leaving care (1) needs a guardian and (2) the guardian should not be a family member. Even when the - the person being cared for has been in stable care since they were infants.*

*And at no stage is there a conversation - like, transition planning, the conversation with the kinship carers that actually they could do this role for the person they are caring for and what sort of supports might they need if they were taking - if they were to take on that role. The assumption was made that they need someone outside of the family, either an independent community guardian or an Office of the Public Advocate-appointed guardian.*

- 7.31 Elaborating upon why this trend might be the case, Grace states:

*The common denominator is in relation to making decisions, especially around what supports should be put into someone’s NDIS plan. There are other concerns around administration, especially if the person has*



*a compensation payment for different reasons, but mainly as far as guardianship goes, it's around making decisions in relation to NDIS supports.*



## **8 GUARDIANSHIP AND FINANCIAL MANAGEMENT VIOLATE WOMEN'S HUMAN RIGHTS**

## 8. GUARDIANSHIP AND FINANCIAL MANAGEMENT VIOLATE WOMEN'S HUMAN RIGHTS

- 8.1 In this section we argue that all of the violence, harms and injustice outlined in Sections 4-7, violate the human rights of women with disability subject to guardianship and financial management.
- 8.2 Guardianship and financial management violate human rights of women with disability. Violation occurs through a variety of aspects of guardianship and financial management: the orders appointing substitute decision-makers, the substitute decisions that are made pursuant to the orders, and the non-consensual interventions done pursuant to these decisions. The nature of some of the decisions made by substitute decision-makers (such as that women live in segregated and closed settings, that they be sterilised) then places women with disability at greater risk of violence and other human rights violations.
- 8.3 In this section we present United Nations commentary identifying human rights issues with guardianship and financial management and discuss specific human rights that are violated through guardianship and financial management. We more fully address human rights violations associated with non-consensual interventions done pursuant to guardian decisions in our earlier submissions on restrictive practices<sup>286</sup> and sexual and reproductive rights.<sup>287</sup>
- 8.4 We have a particular focus on international human rights norms found in the CRPD and CEDAW in order to highlight how women with disability have their rights violated both as people with disability and as women. Such an approach aligns with the 2018 joint observations of the CRPD Committee and the Committee on the Elimination of Discrimination Against Women (CEDAW Committee) on the intersection of disability rights and gender equality:

*... gender equality and disability rights are mutually reinforcing concepts and States parties should guarantee the human rights of all women, including women with disabilities. As such, States parties have an obligation to respect, protect and fulfill the rights of women, including women with disabilities, in relation to their sexual and reproductive health and rights ... without any form of discrimination.*<sup>288</sup>

- 8.5 In this section we begin with the right to legal capacity because this right goes to the heart of the denial of autonomy inherent to guardianship and financial management. We show that the right to legal capacity is an important human right itself and is also foundational to the realisation of other human rights. In the context of guardianship, this means the denial of legal capacity through substitute decision-making is a violation, as well as providing conditions for other human rights violations concerning liberty, personal integrity, independent living and freedom from violence.

### Legal capacity and autonomy

- 8.6 Guardianship and financial management violate the right of women with disability to equal recognition before the law and legal capacity. Guardianship and financial management are forms of substitute decision-making that deny legal recognition of women's own decisions about their bodies and lives and instead legally authorises others to make decisions about women's bodies and lives which enable interventions in women's bodies and lives without the consent of those women.
- 8.7 The right to legal capacity reiterates in the specific context of people with disability the

right in Article 16 of the International Covenant on Civil and Political Rights (ICCPR) that individuals have to equal recognition ‘as a person before the law’. The CRPD reaffirms in Article 12(1) the right of persons with disabilities ‘to recognition everywhere as persons before the law’. Article 12 of the CRPD requires States Parties to ‘recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. To this end, Article 12(3) of the CRPD requires States Parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. Article 12(4) of the CRPD provides that States Parties must also ensure ‘appropriate and effective safeguards to prevent abuse’ in exercise of legal capacity including that ‘measures relating to the exercise of legal capacity respect the rights, will and preferences of the person’, ‘are proportional and tailored to the person’s circumstances’, ‘apply for the shortest time possible’ and ‘are subject to regular review by a competent, independent and impartial authority or judicial body’. States Parties are also required pursuant to Article 12(5) of the CRPD to take measures to ensure ‘the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit’, and to ‘ensure that persons with disabilities are not arbitrarily deprived of their property’.

- 8.8 In guardianship and financial management, women with disability are denied legal recognition of their own decisions about their bodies, lives and finances because of assumptions about their mental capacity associated with disability (particularly when they have cognitive or psychosocial disability). The CRPD Committee acknowledges the problematic nature of ‘mental capacity’, being the basis on which legal capacity is conventionally denied to people with disability:

*The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.*<sup>289</sup>

- 8.9 Guardianship and other substitute decision-making regimes are recognised as violating Article 12. Devandas-Aguilar has stated:

*the existence of guardianship and other substitute decision-making regimes present great challenges for persons with disabilities ... These practices not only deprive them of the possibility to choose their supports, but also contribute to perpetuating their isolation, forced treatment and institutionalization.*<sup>290</sup>

- 8.10 The CRPD Committee identifies discriminatory laws, such as guardianship and financial management, as central to denial of legal capacity to people with disability:

*States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others. Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.*<sup>291</sup>

- 8.11 The CRPD Committee has noted that people with cognitive and psychosocial disability are particularly impacted by substitute decision-making:

*All persons with disabilities, including those with physical, mental, intellectual or sensory impairments, can be affected by denial of legal capacity and substitute decision-making. However, persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity.<sup>292</sup>*

- 8.12 Legal capacity is universal and thus cannot be denied based on disability, as it is in guardianship and financial management. Article 12 does not create any new human rights, but simply reiterates the universal human rights to equal recognition before the law, as articulated by the CRPD Committee:

*Equality before the law is a basic general principle of human rights protection and is indispensable for the exercise of other human rights. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights specifically guarantee the right to equality before the law. Article 12 of the Convention on the Rights of Persons with Disabilities further describes the content of this civil right and focuses on the areas in which people with disabilities have traditionally been denied the right. Article 12 does not set out additional rights for people with disabilities; it simply describes the specific elements that States parties are required to take into account to ensure the right to equality before the law for people with disabilities, on an equal basis with others.<sup>293</sup>*

- 8.13 The CRPD Committee has explained in its general comment on equal recognition before the law that legal capacity is a universal attribute which cannot be denied:

*The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others. Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights. It acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work.<sup>294</sup>*

- 8.14 Thus, legal capacity cannot be denied because of disability:

*The Committee reaffirms that a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in article 12.<sup>295</sup>*

- 8.15 As explained by Arstein-Kerslake and Black, the right to legal capacity is not a right that only applies to people with disability. Rather, it is part of a broader framework within which 'all rights apply to all people and all groups equally'. This framework means that:

*no person's legal capacity should be denied on the basis of their membership in any protected group. For example, legal personhood or legal agency should not be denied on the basis of a person's gender – a woman should not lose the legal capacity to inherit on the basis that she is a woman.<sup>296</sup>*

- 8.16 The CRPD Committee has noted the importance of reaffirming 'that the legal capacity of women with disabilities should be recognized on an equal basis with others.'<sup>297</sup> Articles

15(1)-(3) of CEDAW also provide that women have the right to equality with men before the law. This means that women are to have accorded to them a legal capacity in civil matters identical to men. And private instruments (including contracts) which restrict the legal capacity of women shall be deemed null and void.<sup>298</sup> This is recognised in the General Comment 1 on Article 12.

8.17 In short, as the CRPD Committee states: ‘Legal capacity means that all people, including persons with disabilities, have legal standing and legal agency simply by virtue of being human.’<sup>299</sup>

8.18 The CRPD Committee has specifically reiterated that women with disability have an equal right to legal capacity as others:

*women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. ... it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others.*<sup>300</sup>

8.19 However, the CRPD Committee recognises that women with disability are subject to multiple and intersectional forms of discrimination and thus are more likely to be denied their right to legal capacity. Denial of legal capacity has significant impacts on other rights – including the right to maintain sexual and reproductive autonomy, to found and maintain a family, to choose where and with whom to live, to be free from violence, to maintain bodily and mental integrity, and to realise their right to work in the open labour market, in work that is freely chosen, and that provides just, favourable conditions of work on an equal basis with others.<sup>301</sup> The CRPD Committee states:

*In practice, the choices of women with disabilities, especially women with psychosocial or intellectual disabilities, are often ignored and their decisions are often substituted by those of third parties, including legal representatives, service providers, guardians and family members, in violation of their rights under article 12 of the Convention. All women with disabilities must be able to exercise their legal capacity by taking their own decisions, with support when desired, with regard to medical and/or therapeutic treatment, including by taking their own decisions on retaining their fertility and reproductive autonomy, exercising their right to choose the number and spacing of children, consenting and accepting a statement of fatherhood and exercising their right to establish relationships. Restricting or removing legal capacity can facilitate forced interventions, such as sterilization, abortion, contraception, female genital mutilation, surgery or treatment performed on intersex children without their informed consent and forced detention in institutions.*

*Forced contraception and sterilization can also result in sexual violence without the consequence of pregnancy, especially for women with psychosocial or intellectual disabilities, women in psychiatric or other institutions and women in custody. Therefore, it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with that of others and that women with disabilities have the right to found a family and be provided with appropriate assistance to raise their children.*<sup>302</sup>



- 8.20 The choices of women with disability are often substituted by third parties such as legal representatives, service providers, guardians and family members, and can violate these women's decision-making rights around. For example, the CRPD Committee notes:

*retaining their fertility, reproductive autonomy, their right to choose the number and spacing of children, to consent and accept a statement of fatherhood, and the right to establish relationships. Restricting or removing legal capacity can facilitate forced interventions, such as: sterilisation, abortion, contraception, female genital mutilation, or surgery, or treatment performed on intersex children without their informed consent and forced detention in institutions.<sup>303</sup>*

- 8.21 Devandas-Aguilar has observed that denial of legal capacity can impact the services that people with disability are able to access:

*The denial or restriction of legal capacity, a widespread human rights violation worldwide, has a direct impact on the possibility for persons with disabilities to exercise choice and control over the support they receive and contributes to the imposition of services that are contrary to their dignity and rights.<sup>304</sup>*

- 8.22 Devandas-Aguilar has highlighted the impacts of substitute decision-making on older people with disability:

*Given the intersection between disability and age, older persons with disabilities experience an increased risk of limitations on their right to autonomy and on the exercise of their legal capacity. Grounds for the denial of legal capacity are not limited to the existence or perception of an impairment but include other factors such as negative perceptions (e.g. being perceived as "frail and senile"), loss of income and family abandonment. As a result, older persons with disabilities are more likely to be subject to guardianship, institutionalization, home confinement and involuntary treatment than those without disabilities. Persons with dementia in particular have been assumed to possess weak or even no agency. The diagnosis of Alzheimer's disease or dementia alone is often the justification for the denial of the exercise of rights such as the right to marry or to make a will. Persons with psychosocial disabilities continue to be exposed to forced treatment as they age, with increased vulnerability to guardianship and permanent institutionalization and with less access to alternative mental health services or to social support under the independent living model.*

*Even when there is no substitute decision-making regime in place, in practice many older persons with disabilities are de facto deprived of their legal capacity. For example, they are often restricted from making autonomous decisions without the consent of their family members, or their informed consent is not sought for medical treatment and social care, including palliative care and end-of-life decisions. The will and preferences of older persons with disabilities regarding daily living arrangements, such as what to eat, what to wear, what time to go to bed or even whether and when to use the bathroom, are sometimes completely disregarded. Older women with disabilities face particular challenges in relation to their legal capacity. They may not have the right to inherit and administer marital property upon the death of their spouse, or their legal capacity is deferred by law or de facto to lawyers or family members without their consent.<sup>305</sup>*

- 8.23 The former Independent Expert on the Enjoyment of all Human Rights by Older Persons, Rosa Kornfeld-Matte, has also recognised the importance of the right to legal capacity for older persons, including in the context of guardianship:

*Legal capacity is a key aspect of autonomy, allowing older persons to exercise civil, political, economic, social and cultural rights. In circumstances where an older person is partially or completely unable to look after their own interests because of a mental condition, such as dementia, or an extreme state of physical frailty, there may be a need for supported decision making. There is a need to ensure, however, that in such instances a person is not stripped of his or her legal capacity by guardianship measures, which remove their ability to make decisions about certain aspects of their lives. It is important to note in this regard that the Convention on the Rights of Persons with Disabilities provides that a person's status as a person with a disability or the existence of impairment must never be a ground for denying legal capacity. In its general comment No. 1 on article 12 of the Convention, the Committee on the Rights of Persons with Disabilities highlighted that the Convention does not legitimize the denial of legal capacity based on perceived or actual deficits in mental capacity.<sup>306</sup>*

- 8.24 Mahler has elaborated on the impacts of denial of legal capacity on older people, particularly older women:

*Older persons with disabilities face an increased risk of being placed in institutions and denied legal capacity. Persons with dementia are further perceived as possessing limited agency. As a result, they tend to be more exposed to “guardianship, institutionalization, home confinement and involuntary treatment than those without disabilities”. Their daily living arrangements are usually controlled, and their preferences denied, violating their right to adequate housing.*

*Older persons with intellectual or psychosocial disabilities are at increased risk of being subject to substitute decision-making regimes and denial of legal capacity, which may, in some cases, lead to dispossession and insecure housing by preventing the persons concerned from buying or selling property without their consent. It also increases the risk of institutionalization in long-term facilities without the consent of older persons with disabilities.*

*The denial of legal capacity on the basis of disability violates articles 12 and 19 of the Convention on the Rights of Persons with Disabilities, as it limits individuals' capacity to control their choice of residence option, thereby limiting their right to independent living and inclusion within the community. Disability must never be grounds for denying legal capacity, and reduced legal capacity should not be invoked to deny or limit the right to independence and independent living in the community.*

*The denial of legal capacity has even greater consequences on older women with disabilities in relation to their housing situation, as they may face difficulties with regard to inheriting and administering marital property upon the death of their spouse, or see their legal capacity “deferred by law or de facto to lawyers or family members without their consent”. Considering the overrepresentation of women among older persons with dementia, gender-responsive action is currently overlooked and*

*undervalued in policy development and plans addressing dementia in older age. Older women with disabilities are therefore more likely to be institutionalized.*<sup>307</sup>

- 8.25 Devandas-Aguilar has rejected the idea that some older people with disability ‘naturally’ relinquish their legal capacity as they age:

*Having high support needs cannot justify the denial of autonomy and legal capacity. Loss of autonomy is not a natural process, but a social process that results from the failure of society to respect and support the will and preferences of all people. Older persons with disabilities have the right to maintain their legal capacity and to have access to supported decision-making, and their agency needs to be recognized and facilitated. Furthermore, all health and social care services should be based on the free and informed consent of the individual concerned, and all laws that allow involuntary treatment or placement in residential care upon the authorization of third parties, such as family members, or on the basis of an actual or perceived mental health condition or other impairment, should be repealed.*<sup>308</sup>

- 8.26 Legal capacity underpins personhood,<sup>309</sup> and is central to realising other human rights. The general comment by the CRPD Committee on equal recognition before the law has made clear the importance of legal capacity as its own right and in realising other rights in the CRPD, such as the right to independent living and community inclusion, the right to liberty, and the right to equality and non-discrimination.<sup>310</sup> People with disability are recognised as currently experiencing widespread denial of the right to legal capacity which gives rise to other human rights violations. For example, the CRPD Committee has explained in its general comment on equal recognition before the law that:

*The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.*<sup>311</sup>

- 8.27 In its general comment on equality and non-discrimination, the CRPD Committee describes the right to legal capacity as a ‘threshold right, that is, it is required for the enjoyment of almost all other rights in the Convention, including the right to equality and non-discrimination’.<sup>312</sup> Thus, preventing violations of Article 12 through guardianship and financial management will have flow on effects to realisation of other human rights for women with disability.

- 8.28 The effect of Article 12 is to recognise universal legal capacity and focus on the provision of support to ensure people with disability have their decisions legally recognised and are not abused while exercising their legal capacity. The CRPD Committee stated in its general comment on equal recognition before the law:

*All practices that in purpose or effect violate article 12 must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.*<sup>313</sup>

- 8.29 The CRPD Committee has also stated that, ‘Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.’<sup>314</sup>

8.30 The CRPD Committee has explained that the right to equality before the law is a civil and political right thus giving rise to an obligation on States Parties to immediately realise the right. As such, the obligation ‘to provide access to support in the exercise of legal capacity is an obligation for the fulfilment of the civil and political right to equal recognition before the law’.<sup>315</sup>

8.31 The CRPD Committee states that abolishing laws that deny legal capacity is central to the realisation of Article 12: ‘In order to fully recognize “universal legal capacity,” whereby all persons, regardless of disability or decision-making skills, inherently possess legal capacity, States parties must abolish denials of legal capacity that are discriminatory on the basis of disability in purpose or effect.’<sup>316</sup> Thus, in implementing Article 12, States Parties should:

*Recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities.*<sup>317</sup>

8.32 The CRPD Committee has made it clear that States Parties’ obligation to replace substitute decision-making regimes with supported decision-making requires both abolition of substitute decision-making regimes and development of supported decision-making alternatives.<sup>318</sup> Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disability and should never amount to substitute decision-making. Further details on supported decision-making is provided in Section 9.

8.33 Abolition of substitute decision-making must occur simultaneously to the introduction and development of supported decision-making, as explained by the CRPD Committee:

*States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.*<sup>319</sup>

8.34 The International Guidelines and Principles on Access to Justice for Persons with Disabilities provide in Principle 1 that:

*All persons with disabilities have legal capacity and, therefore, no one shall be denied access to justice on the basis of disability.*<sup>320</sup>

8.35 The Guidelines to this Principle 1 explain that this requires:

*States shall guarantee that persons with disabilities enjoy legal capacity on an equal basis with others and, where necessary, shall provide the support and accommodations necessary to exercise legal capacity and guarantee access to justice.*

*To that end, States shall: (a) Ensure that all persons with disabilities are considered to have legal capacity, and the right to act on and exercise legal capacity; (b) Recognize and assume the full capacity and right of persons with disabilities to participate in the proceedings of all courts, tribunals and forums; (c) Ensure that constructs such as “cognitive incapacity” and “mental incapacity”, as determined, for instance, by*

*functional or mental status assessments, are not used to restrict a person's right to legal capacity; (d) Repeal or amend all laws, regulations, policies, guidelines and practices that directly or indirectly restrict the legal capacity of persons with disabilities, including those that allow for substituted decision-making and those that require that a person be "of sound mind" to take any action, thereby excluding persons with disabilities from equal access to justice;*<sup>321</sup>

8.36 Thus, guardianship and financial management violates the human rights of women with disability in denying to them legal recognition of their own decisions on their bodies, lives and finances and legally empowering others to make these decisions instead. In order to realise Article 12, States parties must abolish guardianship and financial management laws. States parties must also introduce laws and provide support and resources that will both enable legal recognition of women with disability's own decisions about their bodies, lives and finances and prohibit other people from making decisions on their behalf without their consent.

8.37 Denial of legal capacity through guardianship and financial management in turn undermine the autonomy of women with disability. The CRPD Committee has recognised that realising Article 12 restores autonomy to people with disability.<sup>322</sup> The preamble to the CRPD recognises the importance to people with disability of individual autonomy and independence, including the freedom to make choices. The very first principle of the CRPD, found in Article 3(a) of the CRPD, is: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'. Autonomy is not included in the CRPD as a specific right, but rather is threaded throughout other rights provided by the CRPD. Autonomy is also understood by the CRPD Committee as one of the foundations of the right to live independently and be included in the community in Article 19 of the CRPD.<sup>323</sup> Autonomy is also reflected in Article 17 of the CRPD which provides the right for people with disability to respect for physical and mental integrity on an equal basis with others.<sup>324</sup> The CRPD Committee recommends that States Parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned.<sup>325</sup>

8.38 Autonomy is also expressed in the CRPD and CEDAW in the specific context of sexual and reproductive rights. Article 23(1)(b) of the CRPD provides that:

*States Parties shall ... ensure that ... The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.*

8.39 Article 23(1)(c) of the CRPD provides:

*States Parties shall ... ensure that ... Persons with disabilities, including children, retain their fertility on an equal basis with others.*

8.40 Article 25(d) of the CRPD provides that health professionals are required:

*to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities.*

- 8.41 Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) provides for the right to health. The Committee on Economic, Social and Cultural Rights (ICESCR Committee) has explained that Article 12 of ICESCR requires States to ‘take affirmative measures to eradicate social barriers in terms of norms or beliefs that inhibit individuals of different ages and genders, women, girls and adolescents from autonomously exercising their right to sexual and reproductive health’.<sup>326</sup> And Article of ICESCR also requires States to:

*eliminate discrimination against individuals and groups and to guarantee their equal right to sexual and reproductive health ... by repeal[ing] or reform[ing] laws and policies that nullify or impair the ability of certain individuals and groups to realize their right to sexual and reproductive health. There exists a wide range of laws, policies and practices that undermine autonomy and right to equality and non-discrimination in the full enjoyment of the right to sexual and reproductive health ... . States parties should also ensure that all individuals and groups have equal access to the full range of sexual and reproductive health information, goods and services, including by removing all barriers that particular groups may face.*<sup>327</sup>

- 8.42 CEDAW provides for autonomy in relation to family planning. Article 16(1)(e) of CEDAW provides that women have equal rights to ‘decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights’. Article 10 of CEDAW provides that women’s right to education includes ‘access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning’. The Beijing Platform for Action states that ‘the human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence’.<sup>328</sup>

- 8.43 Devandas-Aguilar has explained autonomy as the freedom to make choices and be in control of one’s life:

*Individual autonomy and personal independence (art. 3 (a)) are essential values associated with human dignity. Autonomy means to have the freedom to make one’s own choices, independence and to be in charge of one’s own life. Traditionally, both individual autonomy and personal independence were based on ableist assumptions, such as possessing certain mental capacity or not needing assistance to carry out everyday activities. As a result, persons with disabilities were seen as less autonomous and independent than others and even as having no autonomy or independence. However, the human rights model of disability frames autonomy and independence in a way that takes into account the interdependence of human experiences and accepts reliance on others as a fundamental aspect of these values. Respect for individual autonomy means that persons with disabilities are recognized as rights holders, capable of making their own decisions, with adequate support if required. Having high support needs cannot justify the denial of autonomy and self-determination.*<sup>329</sup>

- 8.44 In their 2018 joint statement, the CRPD Committee and CEDAW Committee stated the importance of autonomy in sexual and reproductive health:

*States parties should ensure non-interference, including by non-State actors, with the respect for autonomous decision-making by women, including women with disabilities, regarding their sexual and reproductive health well-being. A human rights-based approach to sexual and*



*reproductive health acknowledges that women’s decisions on their own bodies are personal and private, and places the autonomy of the woman at the center of policy and law-making related to sexual and reproductive health services, including abortion care. States should adopt effective measures to enable women, including women with disabilities, to make autonomous decisions about their sexual and reproductive health and should ensure that women have access to evidence-based and unbiased information in this regard. It is also critical that these decisions are made freely and that all women, including women with disabilities, are protected against forced abortion, contraception or sterilization against their will or without their informed consent. Women should neither be stigmatized for voluntarily undergoing abortion nor forced to undergo an abortion or sterilization against their will or without their informed consent.*<sup>330</sup>

- 8.45 The CRPD Committee in the context of its general comment on equality and non-discrimination highlights the role of laws – and the paternalism underpinning them – as sustaining inequality and violence against people with disability:

*... laws and regulatory frameworks often remain imperfect and incomplete or ineffective, or reflect an inadequate understanding of the human rights model of disability. Many national laws and policies perpetuate the exclusion and isolation of and discrimination and violence against persons with disabilities. They often lack a recognition of multiple and intersectional discrimination or discrimination by association; fail to acknowledge that the denial of reasonable accommodation constitutes discrimination; and lack effective mechanisms of legal redress and reparation. Such laws and policies are commonly not regarded as disability-based discrimination because they are justified as being for the protection or care of the persons with a disability, or in their best interest.*<sup>331</sup>

- 8.46 Quinn has connected autonomy to personhood and to resistance of paternalism:

*emphasis [in the CRPD] on personhood has massive implications for traditional power relationships and seeks to restore both the visibility of persons and their power over their own lives. Rather than conceptualizing persons with disabilities as objects to be managed or cared for, this newer framing sees persons with disabilities as full moral agents capable of directing and willing to direct their own lives. It is a useful antidote to the rampant paternalism of the past.*<sup>332</sup>

- 8.47 In the context of the CRPD, Quinn has emphasised the importance of ‘rebalancing ... the traditional protection agenda’.<sup>333</sup> Quinn states that while ‘[p]rotection ... is embraced by the Convention’, it ‘is now shorn of its paternalistic roots’.<sup>334</sup> He explains that in terms of ‘“protection” in the Convention’, we urgently need

*to purge it of its legacy of paternalism, to ground it on active human agency and the participation rights of persons with disabilities and to link it with broader goals of inclusion and development. The anchor norms in this regard have to do with personhood, human agency and the right of persons with disabilities to participate in and help to reshape their own societies.*<sup>335</sup>

- 8.48 Quinn has noted, ““protection” in the [CRPD] is part of a broader agenda of personhood, inclusion and participation: a vision of active human agency’.<sup>336</sup> Protection must not slip into paternalism, as he noted:

*Protection, as such, has not gone away. It is embraced by the Convention (see art. 16, on freedom from exploitation, violence and abuse). However, it is now shorn of its paternalistic roots. In a way, it is acknowledged in the Convention that there is no such thing as an inherently vulnerable person, but only persons with disabilities placed in vulnerable situations. The need to deal with this imposed vulnerability is therefore highlighted. ... An end to impunity is also demanded in article 16. Accordingly, the historic invisibility of persons with disabilities in law enforcement is acknowledged and its reversal sought.*

*The Convention therefore does not eliminate the need for protection, but places it on fundamentally different predicates. This has clear implications for laws and policies along the peace continuum that seem to overemphasize the medical condition of disability and downplay the moral agency of persons with disabilities, as well as the broader skein of rights into which protection should be understood.<sup>337</sup>*

- 8.49 While Quinn made these comments in the context of armed conflict, his analysis is significant in explaining that protecting women with disability should always be in an empowering rather than paternalistic framework. Thus, using guardianship and financial management to protect women with disability from violence would reflect a paternalistic rather than empowering approach. Certainly, this resistance to paternalism aligns with contemporary approaches to preventing and responding to violence against women, including in the Australian National Plan to End Violence against Women and Children 2022–2032 (discussed in Section 3) which has as one of its objectives to: ‘Advance gender equality and promote women’s independence and decision-making in public life and relationships’<sup>338</sup> and which ‘envisages a future where our comprehensive and coordinated crisis response system: ... hears and validates victim-survivors, and supports and empowers their choices’.<sup>339</sup>

- 8.50 Mahler has explained the significance of autonomy in relation to older women, including older women with disability:

*Autonomy and independence are critical for a life in dignity, well-being and enjoyment of all human rights. Gendered inequalities, discrimination and ageism impede the right of older women to make free and informed decisions about their lives, including in terms of living arrangements, family life, participation in the community, income and asset management and access to health and care services. Some older women describe being disempowered in family affairs, decisions about money and resources or even leaving their homes freely. Moreover, requirements for independent living, such as personal assistance, access to adequate housing and mobility aids receive insufficient attention. Older women, including older women with disabilities, may face barriers in retaining and exercising their legal capacity owing to discriminatory inheritance and property laws or in cases of dementia and psychosocial disabilities.<sup>340</sup>*

- 8.51 Mahler has explained:

*Although older age should not be considered as grounds for the limitation of rights, the autonomy and independence enjoyed by older persons earlier in life are often denied in older age. As such, the right to personal liberty for older persons must also be understood in the context of their right to autonomy and independence. The Convention on the Rights of Persons with Disabilities clearly defines the understanding of a person’s*

*rights to autonomy and independence, and while ageing should not be associated with disability, the Convention offers a solid legal framework applicable to older persons with disabilities deprived of liberty.*

*As recognized in article 3 (a) of the Convention, persons with disabilities have the right to individual autonomy and independence, including the freedom to make their own choices. Article 14 of the Convention states that persons with disabilities shall enjoy the right to personal liberty on an equal basis with others and cannot therefore be deprived of liberty unlawfully or arbitrarily. Respect for the right of older persons to free and informed consent to choice of treatment, services and care is also crucial to prevent deprivation of liberty. States have a duty to establish safeguards to ensure informed consent of older persons, especially in the context of guardianship, and to build their capacity to fully understand and make use of care and health-related information.<sup>341</sup>*

- 8.52 Therefore, in denying to women with disability legal recognition of their own decisions and in turn enabling non-consensual interventions in women's bodies and lives, guardianship and financial management undermines women with disability's autonomy. Repealing guardianship and financial management laws and providing reparations for human rights violations associated with those laws, introducing supported decision-making laws and providing access to support and resources for making decisions will help realise autonomy of women with disability, and in turn contribute to realisation of other human rights such as rights to personal integrity, privacy, health and independent living.

## **Equality and non-discrimination**

- 8.53 Guardianship and financial management violate the right to equality. Appointing substitute decision-makers because of assumptions about mental capacity associated with disability discriminates against women with disability in exposing them to a legal avenue for denial of legal capacity and non-consensual interventions in their bodies, lives and finances which is not available to people without disability.
- 8.54 International human rights conventions provide for non-discrimination in the enjoyment of the rights they provide.<sup>342</sup> The CRPD specifically provides for equality and non-discrimination are found in the CRPD, both as a general principle in Article 3 and as a right in Article 5. The CRPD preamble also recognises that 'discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person'.
- 8.55 Articles 5(1)-(3) of the CRPD requires States parties to recognise that 'all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law', and to 'prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds' including through provision of reasonable accommodation. Article 5(2) of the CRPD provides that States parties must prohibit 'all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.'
- 8.56 'Discrimination on the basis of disability' is defined in Article 2 of the CRPD as: 'any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.' 'Discrimination on all grounds' is defined by the CRPD Committee as:

*... all possible grounds of discrimination and their intersections must be taken into account. Possible grounds include but are not limited to: disability; health status; genetic or other predisposition towards illness; race; colour; descent; sex; pregnancy and maternity/paternity; civil; family or carer status; gender expression; sex; language; religion; political or other opinion; national, ethnic, indigenous or social origin; migrant, refugee or asylum status; belonging to a national minority; economic or property status; birth; and age, or a combination of any of those grounds or characteristics associated with any of those grounds.*<sup>343</sup>

8.57 Moreover, Article 8 of the CRPD places obligations on States parties to ‘adopt immediate, effective and appropriate’ awareness raising measures to foster respect for rights and dignity, combat stereotypes and harmful practices, and promote awareness of the contributions and capabilities of people with disability. Such measures include rights awareness training for persons with disability.

8.58 Devandas-Aguilar has discussed the role of ableism in discrimination and inequality, as introduced in Section 5. Devandas-Aguilar draws on the principle of inherent dignity in the CRPD to resist ableism and re-assert the entitlement of people with disability to full humanity:

*Life with a disability is a life worth living equal to others. Every person has a unique set of unrepeatable characteristics and experiences that make them irreplaceable and valuable. The lives of persons with disabilities are human lives and, consequently, endowed with inherent dignity. Persons with disabilities can live fulfilling lives and enjoy what gives life meaning.*<sup>344</sup>

8.59 She argues that addressing ableism is not simply about ‘awareness raising’, but rather requires ‘cultural transformation’:

*Given the cultural and societal challenges posed by ableism, neither awareness-raising programmes nor the generalization of anti-discrimination measures will alone suffice. What is needed is a cultural transformation of the way society relates to the difference of disability. That is a commitment to the recognition of persons with disabilities as equals on all terms, with the same rights and opportunities as everyone else in society. It is thus vital to reduce the distance between society’s views of disability and the narratives of those living with a disability. The devaluation of the lives of persons with disabilities comes partly from a historic inability to listen to what persons with disabilities have to say about themselves.*<sup>345</sup>

8.60 Article 6(1) of the CRPD also places obligations on States Parties specifically in relation to addressing the multiple discrimination experienced by women with disability. In its general comment on women and girls with disabilities, the CRPD Committee specifically recognises that women and girls with disability are more likely to be discriminated against than men and boys with disability and women and girls without disability.<sup>346</sup> This General Comment highlights that women and girls with disability experience the ‘same harmful practices’<sup>347</sup> 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.<sup>348</sup> The CRPD Committee recognises the significant barriers encountered by women and girls with disability:

*There is strong evidence to show that women and girls with disabilities face barriers in most areas of life. These barriers create situations of multiple and intersecting forms of discrimination against women and girls with disabilities, particularly, with regard to ... the ability to exercise control over their own lives across a range of contexts, for example: with regard to healthcare, including sexual and reproductive health; and where and with whom they wish to live.<sup>349</sup>*

- 8.61 Also relevant to women with disability, CEDAW provides for the right to equality and non-discrimination for all women. It provides that ‘States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women’. To this end, Article 2 of CEDAW requires States Parties to take such measures as prohibiting discrimination against women, including through legislation. Article 1 of CEDAW defines ‘discrimination against women’ as:

*any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.*

- 8.62 Relevant to First Nations women with disability, Article 22 of the Declaration on the Rights of Indigenous Peoples<sup>350</sup> provides that:

*Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration.*

*States shall take measures, in conjunction with indigenous peoples, to ensure that indigenous women and children enjoy the full protection and guarantees against all forms of violence and discrimination.*

- 8.63 The CRPD Committee also emphasises the importance of recognising and addressing stigma and stereotypes pertaining to women with disability, even though they might seem ‘benign’:

*Ensuring the human rights of women requires, first and foremost, a comprehensive understanding of the social structures and power relations that frame laws and policies, as well as of economic and social dynamics, family and community life, and cultural beliefs. Gender stereotypes can limit women’s capacity to develop their own abilities, pursue professional careers and make choices about their lives and life plans. Both hostile/negative and seemingly benign stereotypes can be harmful. Harmful gender stereotypes need to be recognized and addressed in order to promote gender equality. The Convention enshrines an obligation to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life.<sup>351</sup>*

- 8.64 Devandas-Aguilar observes that older women with disability are particularly disadvantaged:

*Older women with disabilities have consistently worse life prospects and outcomes than older women without disabilities and older men with*

*disabilities. Gender roles and expectations often push these women into economic dependency. As a result, older women with disabilities are considerably poorer; are likely to be subject to violence, abuse and neglect; and have higher chances of facing unmet needs and human rights violations. In addition, older women with disabilities are more likely to be institutionalized or incapacitated owing to the higher life expectancy of women compared with men.*<sup>352</sup>

- 8.65 More broadly, Devandas-Aguilar explains intersections of ageism and ableism in relation to older people with disability as follows:

*Although ageism and ableism share common roots and consequences, inequality in older age is not the mere result of ableist biases. Ageism – the stereotyping of, and prejudice and discrimination towards, older people and older age – is a distinct form of oppression that affects older persons, including older persons with disabilities. Older persons are often perceived as a burden, dependent, unproductive, undeserving or helpless. While disability is increasingly understood as a social construct, inequalities due to old age are predominantly seen as “natural” or “inevitable.” Therefore, older persons with disabilities are discriminated against and disadvantaged not just because they have a disability, but also because of stereotypes about older people.*<sup>353</sup>

- 8.66 She notes the significance of stigma in relation to older persons with disability:

*Stigma and stereotypes represent a major concern affecting older persons with disabilities. Both ableism and ageism are deeply rooted in popular thinking, policies, laws, institutions, attitudes and beliefs. Older persons with disabilities experience unique human rights violations owing to the intersection of these forms of discrimination. As impairments among older persons are often seen as a natural aspect of ageing, the barriers to participation that they experience are perceived not as a social construct, but as a normal fact of life. Therefore, efforts are not focused on eliminating barriers or generating options to promote participation, but rather are framed mainly under a medical lens. Furthermore, low expectations regarding ageing with a disability lead to the assumption that it is not worthwhile to support the participation of older persons with disabilities. As a result, differential treatment on the basis of disability and age is not only widespread but also considered necessary and unproblematic, leading to the normalization of practices that would be considered unacceptable for other groups, such as younger persons with disabilities.*<sup>354</sup>

- 8.67 Guardianship and financial management can be understood as discrimination against women with disability. Women with disability can be impacted by guardianship and financial management in specific ways at the intersections of ableism and sexism and for older women with disability, additionally at intersections with ageism. Guardianship and financial management enable denial of legal capacity and non-consensual interventions in relation to the bodies, lives and finances of women with disability because of assumptions about their mental incapacity. These assumptions are grounded in ableist, sexist and ageist deficit approaches to women with disability, that position them as incapable of agency and devalue them in economic and social terms as not worth the effort and resources to facilitate them exercising control over their bodies and lives and supporting realisation of their autonomy and equality.



8.68 States parties are obligated to prohibit discrimination against women with disability. The CRPD Committee has stated that ‘there should be no laws that allow for specific denial, restriction or limitation of the rights of persons with disabilities, and that disability should be mainstreamed in all legislation and policies.’<sup>355</sup>

8.69 States Parties’ obligations in relation to equality and non-discrimination extend to the abolition of discriminatory laws. As the CRPD Committee states:

*States parties shall modify or abolish existing laws, regulations, customs and practices that constitute such discrimination. The Committee has often given examples in that regard including: guardianship laws and other rules infringing upon the right to legal capacity; mental health laws that legitimize forced institutionalization and forced treatment, which are discriminatory and must be abolished; non-consensual sterilization of women and girls with disabilities; inaccessible housing and institutionalization policy; segregated education laws and policies; and election laws that disenfranchise persons with disabilities.*<sup>356</sup>

8.70 As well as abolishing discriminatory laws, in implementing Article 5 of the CRPD the CRPD Committee has explained that States parties are also required to: ‘[e]stablish accessible and effective redress mechanisms and ensure access to justice, on an equal basis with others, for victims of discrimination based on disability.’<sup>357</sup>

8.71 Article 6 of the CRPD obliges Governments to take positive actions and measures to ensure that women with disability enjoy all human rights and fundamental freedoms. Article 6 of the CRPD clarifies the need to ensure that national policies, frameworks and strategies explicitly recognise the impact of multiple discriminations caused by intersections of gender and disability, and that such policies and frameworks include focused, gender-specific measures to ensure that women and girls with disability experience full and effective enjoyment of their human rights.<sup>358</sup> Article 6 is a cross-cutting article that relates to all other articles of the CRPD.<sup>359</sup> This means that the issues and concerns of women 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.’<sup>360</sup> In its general comment on women and girls with disabilities, the CRPD Committee clarifies that Article 6 is a binding non-discrimination and equality provision that unequivocally obligates Governments to outlaw discrimination against women with disability and promotes equality of opportunity and equality of outcomes.

8.72 In order to combat multiple discrimination against women and girls with disability, States parties must abolish discriminatory laws and introduce laws that will promote equality:

*Repealing discriminatory laws, policies and practices that prevent women with disabilities from enjoying all the rights enshrined in the Convention, outlawing gender- and disability-based discrimination and its intersectional forms, criminalizing sexual violence against girls and women with disabilities, prohibiting all forms of forced sterilization, forced abortion and non-consensual birth control, prohibiting all forms of forced gender- and/or disability-related medical treatment and taking all appropriate legislative steps to protect women with disabilities against discrimination.*

*Adopting appropriate laws, policies and actions to ensure that the rights of women with disabilities are included in all policies, especially in policies related to women in general and policies on disability.*<sup>361</sup>

- 8.73 On the basis of Articles 5 and 6 of the CRPD, States parties have the obligation to repeal guardianship and financial management laws and provide reparations for human rights violations associated with those laws and introduce supported decision-making laws that will enable women with disability to exercise their legal capacity and enjoy their personal integrity, liberty and other human rights on an equal basis to others.
- 8.74 The right to equality and non-discrimination can be understood in the context of the approaches to equality and disability that underpin the CRPD. The CRPD Committee explains in its general comment that the CRPD promotes an ‘inclusive equality’ model of equality and a ‘human rights’ model of disability. The CRPD Committee explains the inclusive equality model as:
- a new model of equality developed throughout the Convention. It embraces a substantive model of equality and extends and elaborates on the content of equality in: (a) a fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity. The Convention is based on inclusive equality.<sup>362</sup>*
- 8.75 The approach of inclusive equality underscores the importance of not simply replacing guardianship and financial management law with supported decision-making laws, but to address the broader structural, social, economic and cultural dynamics that shape the opportunities women with disability have to exercise control over their bodies and lives.
- 8.76 The CRPD Committee explains the human rights model of disability as:
- 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.<sup>363</sup>*
- 8.77 This model of disability ‘values impairment as part of human diversity and human dignity.’<sup>364</sup> The inherent dignity of the human being is the focus of the human rights model of disability, rather than any impairment. The model ‘clarifies that impairment does not derogate human dignity nor does it encroach upon the disabled person’s status as a rights-bearer.’<sup>365</sup>
- 8.78 Inclusive equality and the human rights model of disability underscore the need for laws and practices that provide diverse support and resources to women with disability to facilitate them exercising control over their bodies, lives and finances, rather than making enjoyment of human rights conditional on meeting certain norms, including norms of cognition and rationality and cultural and socioeconomic norms of ready access to social capital and financial resources, and fitting in a singular model of decision-making.
- 8.79 Non-discrimination includes the right to reasonable accommodation in the exercise of legal capacity (art. 5, para. 3). Reasonable accommodation is defined in article 2 of the Convention as ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons

with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'. The right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to support in the exercise of legal capacity. States parties are required to make any necessary modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden. Such modifications or adjustments may include, but are not limited to, access to essential buildings such as courts, banks, social benefit offices and voting venues; accessible information regarding decisions which have legal effect; and personal assistance. The right to support in the exercise of legal capacity shall not be limited by the claim of disproportionate or undue burden. The State has an absolute obligation to provide access to support in the exercise of legal capacity.<sup>366</sup>

## Liberty

8.80 Guardianship and financial management violate the right to liberty for women with disability, because through substitute decisions of guardians, women with disability can be confined in group homes, residential aged care facilities and other secure accommodation. Importantly, the discussion in this section makes clear that the decisions of tribunals and boards and substitute decisions of guardians and financial managers are inextricably connected to human rights violations related to deprivation of liberty, irrespective of the physical proximity of these decisionmakers to the places where women with disability are segregated and confined.

8.81 Article 9(1) of the ICCPR provides for the right to liberty and security of the person, including not to be subjected to arbitrary arrest or detention. Article 10(1) of the ICCPR provides that persons who are deprived of liberty have the right to be 'treated with humanity and with respect for the inherent dignity of the human person'. Article 14(1) of the CRPD provides that persons with disability should enjoy the right to liberty on an equal basis with others, and their disability cannot justify deprivation of liberty.

8.82 In its Guidelines on Article 14, the CRPD Committee has explained that the provision is grounded in equality and non-discrimination:

*Article 14 of the Convention is in essence a non-discrimination provision. It specifies the scope of the right to liberty and security of the person in relation to persons with disabilities, prohibiting all discrimination based on disability in its exercise. Thereby, article 14 relates directly to the purpose of the Convention, which is to ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect of their inherent dignity.<sup>367</sup>*

8.83 These Guidelines also make clear that any deprivation of liberty on the basis (whole or in part) of disability is prohibited by Article 14:

*... article 14 does not permit any exceptions whereby persons may be detained on the grounds of their actual or perceived impairment ...*

*[Article 14] prohibits the deprivation of liberty on the basis of impairment even if additional factors or criteria are also used to justify the deprivation of liberty...<sup>368</sup>*

8.84 Deprivation of liberty includes being placed in a setting without one's own consent: 'Individuals are deprived of their liberty when they are confined to a restricted space or placed in an institution or setting, not free to leave, and without free and informed consent'.<sup>369</sup> Thus, deprivation of liberty occurs when a third party (such as a guardian)

consents to an individual being placed in a setting, rather than the individual their self. For example, the CRPD Committee's General Comment on Article 12 explains that recognition of the right to legal capacity is vital to realising the right to liberty, and that Article 14 will be violated if individuals are detained pursuant to substitute decisions:

*Respecting the right to legal capacity of persons with disabilities on an equal basis with others includes respecting the right of persons with disabilities to liberty and security of the person. The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention.<sup>370</sup>*

- 8.85 Mahler reinforces the interconnection of Articles 12 and 14 in relation to older people, explaining that the State must provide supported decision-making rather than deprivation of liberty:

*Deprivation of liberty through institutionalized care occurs in countries where older persons are placed in care or health-related facilities or institutions against their will and preference. In some countries, older persons are more likely to be de facto deprived of liberty in care facilities than in prisons. In this context, older persons are often seen as lacking the legal and mental capacity to consent to these care arrangements, and decisions on such matters are made by others, often relatives. Older persons are unable to leave such institutions and are fully dependent on their caregivers for daily activities. However, neither older age nor a diagnosis of mental disorder is sufficient to determine their lack of capacity to make meaningful decisions. In any case, if there is diminished capacity, it is the obligation of States to ensure that systems of supported decision-making are in place, as opposed to the systems and practices of substituted decision-making that are often employed.<sup>371</sup>*

- 8.86 The CRPD Committee has acknowledged that enjoyment of the right to liberty is also essential to realising the right to independent living in Article 19 of the CRPD.<sup>372</sup> Devandas-Aguilar has noted that institutionalisation through substitute decisions will violate Article 14:

*Placing a person with disabilities into an institution, either without their consent or with the consent of a substitute decision maker, contradicts the right to personal liberty and the right to live independently in the community (art. 19).<sup>373</sup>*

- 8.87 Devandas-Aguilar has challenged the idea that deprivation of liberty is inevitable for people with disability, instead arguing it results from a failure to provide supports to make decisions and live in the community:

*Deprivation of liberty on the basis of impairment is not a “necessary evil” but a consequence of the failure of States to ensure their human rights obligations towards persons with disabilities. As this report illustrates, deprivation of liberty of persons with disabilities is rooted in intolerance, and in States’ inaction to implement human rights, particularly the rights to legal capacity, integrity, access to justice, living independently in the community, the highest attainable standard of health, an adequate standard of living and social protection. In the absence of appropriate*

*support and livelihoods, persons with disabilities are sent to institutions and mental health facilities as if there were no other option. As designed, institutional care and mental health services will only add to this accumulated structural discrimination.*<sup>374</sup>

- 8.88 Devandas-Aguilar has noted that non-consensual institutionalisation exposes people with disability to violence and other harm:

*Persons with disabilities deprived of their liberty are invariably placed into an extremely vulnerable position. They are at serious risk of sexual and physical violence, sterilization and human trafficking. They also experience a higher risk of being subjected to torture and inhuman and degrading treatment, including forced medication and electroshock, restraints and solitary confinement. They are even denied medical care and left to die. Moreover, persons with disabilities deprived of their liberty are often formally stripped of their legal capacity, without opportunities to challenge the deprivation of liberty, and in the long run invisible and forgotten by the wider community. Indeed, due to the mistaken belief that those practices are benevolent and well intentioned and do not constitute deprivation of liberty, the situation of persons with disabilities deprived of their liberty is hardly monitored by national preventive mechanisms or national human rights institutions.*<sup>375</sup>

- 8.89 The CRPD Committee in its general comment on women and girls with disabilities has noted that women and girls with disability can be exposed to sexual violence whilst deprived of their liberty in institutional settings:

*Violations relating to deprivation of liberty disproportionately affect women with intellectual or psychosocial disabilities and those in institutional settings. Those deprived of their liberty in places such as psychiatric institutions, on the basis of actual or perceived impairment, are subject to higher levels of violence, as well as to cruel, inhuman or degrading treatment or punishment and are segregated and exposed to the risk of sexual violence and trafficking within care and special education institutions. Violence against women with disabilities in institutions includes: involuntary undressing by male staff against the will of the woman concerned; forced administration of psychiatric medication; and overmedication, which can reduce the ability to describe and/or remember sexual violence. Perpetrators may act with impunity because they perceive little risk of discovery or punishment given that access to judicial remedies is severely restricted, and women with disabilities subjected to such violence are unlikely to be able to access helplines or other forms of support to report such violations.*<sup>376</sup>

- 8.90 Also, in this general comment, the CRPD Committee has stated that '[w]omen with disabilities are more likely to be subjected to forced interventions than are women in general and men with disabilities' and these interventions 'are wrongfully justified by theories of incapacity and therapeutic necessity, are legitimized under national laws and may enjoy wide public support for being in the alleged best interest of the person concerned.' However, it states that such forced interventions 'violate the right to personal integrity'.<sup>377</sup>

- 8.91 Mahler has recently observed that older people are particularly subjected to deprivation of liberty:

*Older persons may be considered to have been deprived of their liberty if they are confined to a specific space or placed in a public or private institution, for different reasons, without permission to leave at will, and when the arrangements taken to restrict their freedom were made without their free and informed consent. Such instances usually involve more restrictions than mere interference with freedom of movement. Decisions of this nature are usually made by order of, or under the de facto control of, a judicial, administrative or other authority.<sup>378</sup>*

8.92 Mahler elaborates:

*Deprivation of liberty based on age or disability, or both, is prevalent and common around the world. Such forms of deprivation usually involve the limitation or denial of the right to legal capacity and consent of older persons, based, in particular, on perceived or actual needs of care, treatment or hospitalization. Such situations are usually enforced based on existing laws, policies and practices allowing such deprivation of liberty and are also fuelled by ageism and ageist attitudes. Like disability, youth, gender or older age should not be used to justify depriving persons of their liberty and when the law authorizes such deprivation on the grounds of older age, alone or in combination of other grounds, it violates international human rights law.*

*Whether older persons are deprived of liberty in the context of care, States have the duty to take appropriate measures to protect their right to liberty, including by non-State actors and in private settings (including private care, health facilities and private homes).<sup>379</sup>*

8.93 Mahler also notes the significance of intersectional factors in deprivation of older person's liberty, particularly in relation to gender and disability:

*Intersectional factors, such as sex, gender, gender identity and sexual orientation, disability, race, ethnicity and class should also be taken into account when analysing the root causes of the deprivation of liberty of older persons. The intersection between such factors and older age may exacerbate older persons' risk of being deprived of their liberty because of legal and policy frameworks in force. These factors also shape the experience of older persons in detention, placing them at heightened risk of discrimination, isolation, ill-treatment and violence.*

*Gender discrimination, in intersection with ageism, has a particularly unique and aggravating effect on the right to personal liberty of older women. Gender stereotypes and attitudes associated with the persistence of patriarchal norms, which do not disappear with older age, may lead to and justify the unlawful deprivation of liberty of older women. In its 2019 thematic report, the Working Group on the issue of discrimination against women in law and in practice concluded that "Deprivation of liberty is deeply gendered. While there are many forms, they are all tied to causes rooted in discrimination against women". Such forms are based on harmful stereotypes created to belittle and silence them, punish them for perceived deviance or to over protect them. Ageing women may also be perceived as "dangerous" and "in need of control" in some societies, resulting in forced confinement and banishment from their communities....*



*Disability represents an additional risk factor for justifying the deprivation of liberty of certain groups of older persons, and stigma and misconceptions are often the cause. As analysed in a 2019 report of the Special Rapporteur on the rights of persons with disabilities, a disability-specific deprivation of liberty occurs when laws or policies provide for or permit such deprivation based on an apparent or diagnosed disability or where specific places of detention are designed solely or primarily for persons with disabilities. This may result in involuntary commitment to mental health institutions, institutionalization for “specialized care”, as well as detention as a result of diversion from the criminal justice system. The deprivation of liberty of older persons with disabilities represents a failure by the State to protect their rights as guaranteed by the Convention on the Rights of Persons with Disabilities.<sup>380</sup>*

- 8.94 Deprivation of liberty gives rise to further human rights violations, as explained by Mahler in the context of older people:

*Older persons are exposed to heightened risks of violence, abuse and neglect when they are forcibly placed and deprived of their liberty. This may take several forms, including physical ill-treatment, verbal abuse or disrespectful behaviour by staff; violence among residents, including gender-based sexual violence; lack of adequate medical care; and prolonged use of physical, mechanical and/or chemical restraints.*

*The overuse of medication to control the behaviour of older persons with dementia without a proper therapeutic purpose remains a widespread and abusive practice that may lead to health complications and even death by overdose. During the COVID-19 pandemic, the use of psychotropic medication has dramatically increased in a number of residential care establishments, justified by the prolonged social isolation and feelings of loneliness experienced by older residents during lockdowns.*

*The shortage of adequately trained staff in age-related issues, including health, in institutionalized care further exposes older persons to the risk of being abused by both staff and other residents. Inappropriate arrangements may further contribute to risks to the safety of older persons, for example they are mixed with residents who engage in what is characterized as “aggressive” behaviours, or do not have access to separate and protected bedrooms and sanitary facilities for men and women.*

*The absence or low availability of adequate medical care, especially of palliative care, in care settings has also raised concerns. The denial of palliative care and pain relief is a human right violation, as recognized by international and regional experts. Poor or limited health care, as well as limited access to essential medication and other support, have been exacerbated during COVID-19 lockdowns and have had a disproportionate impact on older persons deprived of liberty in care facilities.*

*Deprivation of liberty in care and health-related facilities significantly subvert the quality of life and living conditions of older persons. Serious concerns about the rights of residents to dignity, privacy, autonomy and participation have been raised in several instances, including the locking*

*of older persons in their rooms without the possibility of opening the door from the inside; disrespecting their privacy and intimacy, especially when undressing and bathing; lack of appropriate heating or ventilation; insufficient food and incontinence products (to save money); and the removal of necessary aids such as glasses, crutches and walkers necessary to help prevent falls.*

*Social isolation and loneliness are also common among older persons deprived of liberty in care facilities, increasing risks of stress, anxiety and depression. Since the beginning of the COVID-19 pandemic, reports have emerged about the devastating impacts of contact restrictions, quarantine and isolation on the health and well-being of older persons living in care facilities. Rules not allowing overnight visits of partners or not allowing couples to live together may have further exacerbated their social isolation and loneliness.*

*While in some facilities, complaint mechanisms are available to report mistreatment, older persons may be less likely to assert their rights or to file a complaint about the conditions in which they are held or about their treatment.<sup>381</sup>*

- 8.95 People who have been deprived of their liberty must have access to reparations, as noted by the CRPD Committee in its Guidelines on Article 14:

*Persons with disabilities arbitrarily or unlawfully deprived of their liberty are entitled to have access to justice to review the lawfulness of their detention, and to obtain appropriate redress and reparation.<sup>382</sup>*

- 8.96 The United Nations Basic Principles and Guidelines on remedies and procedures on the right of anyone deprived of their liberty to bring proceedings before a court, adopted by the Working Group on Arbitrary Detention identify as one of the measures that 'shall be taken to ensure procedural accommodation and the provision of accessibility and reasonable accommodation for the exercise of the substantive rights of access to justice and equal recognition before the law':

*Persons with disabilities are provided with compensation, as well as other forms of reparations, in the case of arbitrary or unlawful deprivation of liberty. This compensation must also consider the damage caused by the lack of accessibility, denial of reasonable accommodation, lack of health care and rehabilitation, which have affected the person with disability deprived of liberty.<sup>383</sup>*

- 8.97 Thus, guardianship and financial management violate the right to liberty because they enable non-consensual detention of women with disability, including in group homes and residential aged care facilities. Being deprived of liberty in turn violates the right to independent living. Deprivation of liberty also violates the right to freedom from violence because women who are detained are exposed to greater risk of violence, including sexual and physical violence and use of restrictive practices and forced treatment. Relevantly for present purposes, realising the right to liberty requires abolition of substitute decision-making such as guardianship and financial management, provision of supported decision making and associated support and resources, and access to reparations for deprivation of liberty.

## Independent living and community participation

- 8.98 Guardianship and financial management contribute to violations of the right to independent living for women with disability. When a guardian has the power to make accommodation decisions women with disability are denied the opportunity to decide where they live. Women with disability can be confined in accommodation or have limited or no opportunities to participate in the community through the substitute decisions of guardians. Importantly, the discussion in this section makes clear that the decisions of tribunals and boards and substitute decisions of guardians and financial managers are inextricably connected to human rights violations related to independent living and community participation, irrespective of the physical proximity of these decisionmakers to the places where women with disability are segregated and confined.
- 8.99 Article 19 of the CRPD provides for the right to independent living and community participation. It provides for the ‘equal right of all persons with disabilities to live in the community, with choices equal to others’. States Parties have the obligation to take measures to facilitate ‘full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community’, including by ensuring that persons with disability have ‘the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement’, and ‘access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’. Article 19 of the CRPD also provides that States Parties should also ensure that ‘[c]ommunity services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs’.
- 8.100 The CRPD Committee in its general comment on Article 19 clarifies that any institutional form of support services which segregates and limits personal autonomy is not permitted by Article 19(b).

*Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions.<sup>384</sup>*

- 8.101 The CRPD Committee explicitly and unequivocally states that Article 19 requires Governments ‘to phase out institutionalisation’<sup>385</sup> through ‘adopt[ing] clear and targeted strategies for deinstitutionalisation, with specific time frames and adequate budgets, in order to eliminate all forms of isolation, segregation and institutionalization of persons with disabilities.’<sup>386</sup> States parties to the CRPD ‘must adopt a strategy and a concrete plan

of action for deinstitutionalization’ and that deinstitutionalisation ‘requires a systemic transformation’.<sup>387</sup>

8.102 The CRPD Committee has explained that the right ‘means exercising freedom of choice and control over decisions affecting one’s life with the maximum level of self-determination and interdependence within society’.<sup>388</sup> As noted by the CRPD Committee in its general comment on Article 12, one of the core elements of Article 19 is ‘[t]o ensure the right to legal capacity, in line with the Committee’s general comment No. 1, to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment’.<sup>389</sup>

8.103 In its later general comment on independent living, the CRPD Committee emphasises that Article 19 applies irrespective of disability, including in the context of those who might be denied legal capacity:

*Article 19 explicitly refers to all persons with disabilities. Neither the full or partial deprivation of any “degree” of legal capacity nor the level of support required may be invoked to deny or limit the right to independence and independent living in the community to persons with disabilities.*<sup>390</sup>

8.104 In its general comment on Article 19, the CRPD Committee also noted that while there have been advancements in implementing article 19 in the last decade, one of the remaining barriers to implementation is ‘[d]enial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements’.<sup>391</sup>

8.105 The recently adopted CRPD Committee Guidelines on Deinstitutionalisation emphasise that institutionalisation per se violates human rights:

*States parties should abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a “choice”.*<sup>392</sup>

8.106 The CRPD Committee Guidelines on Deinstitutionalisation state that abolition of substitute decision-making must occur simultaneously to deinstitutionalisation:

*The reform of legislation on legal capacity, in accordance with general comment No. 1 (2014), should be carried out immediately, and simultaneously with deinstitutionalization. Where persons with disabilities, including those placed in institutions, are subjected to guardianship, forced mental health treatment or other substituted decision-making regimes, those measures should immediately be lifted. To prevent forced mental health treatment, affirmative, free and informed expression of consent by the person concerned is required. The exercise of decision-making by persons with disabilities who are currently placed in institutions should be respected within the deinstitutionalization process. They should be provided with the accommodation and support that they require to exercise their legal capacity, with full effect given to their will and preferences. Support to exercise legal capacity should continue, if required, after persons with disabilities have established themselves in the community.*<sup>393</sup>

8.107 The CRPD Guidelines on Deinstitutionalisation identify a specific role for reparations in deinstitutionalisation, stating that governments should ensure legal and policy frameworks.<sup>394</sup>

- 8.108 The CRPD Committee grounds the right to independent living and community participation in the human rights principle of dignity:

*The foundation of the article is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth.<sup>395</sup>*

- 8.109 The CRPD Committee states that institutionalisation is inherently discriminatory:

*Institutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities, who are forced to relinquish their participation in community life to receive treatment. The institutionalization of persons with disabilities as a condition to receive public sector mental health services constitutes differential treatment on the basis of disability and, as such, is discriminatory.<sup>396</sup>*

- 8.110 The CRPD Committee also notes that independent living and community participation is ‘a basic concept of human living around the globe’ that, through Article 19, is applied to the context of disability.<sup>397</sup> In its general comment on equality and non-discrimination the CRPD Committee has emphasised the importance of Article 19 applying without discrimination:

*Article 19 reaffirms non-discrimination and recognition of the equal right of persons with disabilities to live with full inclusion and participation independently in the community. In order to realize the right to live independently and be included in the community, States parties must take effective and appropriate measures to facilitate the full enjoyment of the right and the full inclusion and participation of persons with disabilities in the community. This involves implementing deinstitutionalization strategies and, in accordance with the Committee’s general comment No. 5 (2017) on living independently and being included in the community, allocating resources for independent living support services, accessible and affordable housing, support services for family carers and access to inclusive education. Article 19 of the Convention recognizes the right not to be obliged to live in a particular living arrangement on account of one’s disability. Institutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities, who are forced to relinquish their participation in community life to receive treatment. The institutionalization of persons with disabilities as a condition to receive public sector mental health services constitutes differential treatment on the basis of disability and, as such, is discriminatory.<sup>398</sup>*

- 8.111 And, that it should apply equally to people of all genders:

*Persons with disabilities of all genders are rights holders and enjoy equal protection under article 19. All appropriate measures should be taken to ensure the full development, advancement and empowerment of women.<sup>399</sup>*

- 8.112 It has been recognised that denial of the right to independent living and community participation can give rise to violence in institutional settings. The substitute decision of a guardian can often be the precursor to a woman with disability being non-consensually moved into and confined in an institutional setting. While the guardian is not themselves

perpetrating the harms within the institution, the guardian's substitute decisions have a key role in enabling the coercive conditions in which this violence, harm and injustice occur.

- 8.113 The CRPD Committee identifies a clear link between institutional settings *per se* and violence:

*The cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalization of persons with disabilities.<sup>400</sup>*

- 8.114 In its Thematic Study on the right of persons with disabilities to live independently and be included in the community, the United Nations High Commissioner of Human Rights similarly explains how institutionalisation *per se* creates the conditions for violence to flourish:

*Cutting a person off from family, friends, education and employment through institutionalization results in social exclusion, creates barriers to inclusion in the community and reduces or denies the capacity of persons with disabilities to choose and plan their lives. That inhibits their autonomy by fostering dependency, preventing persons with disabilities from reaching their full potential in terms of independence and social participation. In addition, it has been widely documented that institutionalization may render persons vulnerable to violence and abuse, with women with disabilities particularly exposed to such risk. The risk of abuse is further exacerbated by the absence of public scrutiny, a lack of access to remedies, a fear of reporting violations, and disability-related communication barriers. Instances of abuse are in direct contradiction to the State's obligation to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects (art. 16).<sup>401</sup>*

- 8.115 Devandas-Aguilar has discussed the exposure of older people with disability to violence in institutional settings:

*In long-term care settings, in which older persons with disabilities represent a significant proportion of the residents, elder abuse is a critical issue. Numerous reports and studies have shown high rates of elder abuse in institutions, which are likely to be underestimated owing to the lack of proper detection and/or reporting. Persons with dementia are particularly at risk owing to their high support needs and communication difficulties. They, along with persons diagnosed with mental health conditions, are often administered neuroleptics and other psychotropic drugs as a form of chemical restraint or in the guise of therapeutic "treatment" against their will. Furthermore, residents of nursing homes and assisted living facilities are often poorly informed of existing adult protective services and remain uncertain about options when care is not optimal. Older women with disabilities who are survivors of sexual violence face particular barriers to disclosure and access to justice, resulting in their experiences remaining hidden. When they do report abuse, older women, in particular those with cognitive disabilities, may be viewed as poor witnesses owing to memory problems.<sup>402</sup>*

- 8.116 The CRPD Committee has acknowledged that women with disability are particularly



disadvantaged in relation to institutionalisation:

*Often, women and girls with disabilities (art. 6) are more excluded and isolated and face more restrictions regarding their place of residence as well as their living arrangements owing to paternalistic stereotyping and patriarchal social patterns that discriminate against women in society. Women and girls with disabilities also experience gender-based, multiple and intersectional discrimination, greater risk of institutionalization and violence, including sexual violence, abuse and harassment. ... Therefore, when implementing the right to live independently and be included in the community, particular attention should be paid to gender equality, the elimination of gender-based discrimination and patriarchal social patterns.<sup>403</sup>*

- 8.117 In its general comment on Article 19, the CRPD Committee recognises the inherent risk to women with disability in segregated settings:

*Since institutions tend to isolate those who reside within them from the rest of the community, institutionalised women and girls with disabilities are further susceptible to gender-based violence, including forced sterilization, sexual and physical abuse, emotional abuse and further isolation. They also face increased barriers to reporting such violence. It is imperative that States include these issues in their monitoring of institutions and ensure access to redress for women with disabilities who are exposed to gender-based violence in institutions.<sup>404</sup>*

- 8.118 Violence in institutions is also gendered, as observed by Mahler:

*The prevalence of violence, abuse and neglect is estimated to be higher in institutional settings, where women often form the majority of residents. The way gender shapes related risks, forms and consequences has not been sufficiently explored. Abuse and neglect in care homes have been documented in many countries, including during the COVID-19 pandemic. Concerns were raised, for example, about the overmedication of residents, especially those with dementia, and the administration of antipsychotic drugs without free and informed consent to “manage” residents in care homes with inadequate staff numbers and training.<sup>405</sup>*

- 8.119 And, lesbian, bisexual, transgender and intersex women might experience discrimination and violence, as noted by Mahler in the context of older women:

*Many older lesbian, bisexual, transgender and intersex women report social isolation, loneliness and a feeling that they have no one to rely on for care as they age. Moving to care homes brings anxiety over losing their identity and facing stigma if they reveal their sexual orientation, gender identity and sex characteristics, particularly for older transgender women who may be at risk of more extreme experiences of discrimination and abuse. Staff in care homes are often not trained or sensitive to the specific health-care needs of older lesbian, bisexual, transgender and intersex women, while such settings generally remain heavily heteronormative and in some contexts even hostile to lesbian, gay, bisexual, transgender and intersex individuals, with cases of violence and abuse reported.<sup>406</sup>*

- 8.120 Devandas-Aguilar explains that older people with disability might be more subjected to institutionalisation, particularly because of lack of appropriate supports and housing

in the community. She notes the greater use of institutionalisation in relation to older persons with disability, particularly at a time when ‘younger persons with disabilities are increasingly encouraged and provided with support to live independently.’<sup>407</sup> She sees the lack of support services in the community for older people with disability as a key driver of institutionalisation, including by reason of age limits on accessing disability supports.<sup>408</sup> She states that institutionalisation should not be the solution to an absence of care in the community and that ‘States need to transform their institutional forms of care for older persons with disabilities and to provide support and services within the community.’<sup>409</sup> In a similar vein, Mahler has stated:

*In some contexts, the lack of adequate and affordable home and community based care services may mean that there is no alternative other than to move to care homes, where older women are the majority of residents and where choices over care, life and daily routines may be limited. Older women with disabilities are more likely to be institutionalized, also owing to a lack of support and financial resources to live in the community.*<sup>410</sup>

- 8.121 Mahler has noted that sexual violence can be a driver for institutionalisation of older women, and even lead to early death:

*Sexual violence against older women has long been hidden because of pervasive taboos and stereotypes and is believed to be significantly underreported. The limited studies on the topic show that the perpetrators are predominantly men, most commonly an intimate partner, a family member or a caregiver. Older women with cognitive impairments or physical care needs appear to be particularly at risk, while their ability to express consent and resist coercion can be more limited. The consequences of sexual violence against older women are often devastating and include serious bodily injury, severe emotional trauma, long-term health problems, loss of independence, moving to a care facility and accelerated death.*<sup>411</sup>

- 8.122 The recognised connection in international human rights law between institutionalisation and violence, and the role of guardian’s substitute decisions in facilitating the institutionalisation of women with disability (including older women with disability) is contrary to current Australian approaches to preventing and responding to violence against women are grounded in the empowerment and support of survivors of violence, rather than blaming, punishing and detaining them. For example, the Australian National Plan to End Violence against Women and Children 2022–2032 (discussed in Section 3) has as two of its objectives ‘Enhance accountability of people who choose to use violence’<sup>412</sup> and ‘Ensure women and children escaping violence have safe and secure housing, from crisis accommodation to longer-term, sustainable social housing’.<sup>413</sup> It is deeply concerning that women with disability, including older women with disability, are being subjected to violence after being non-consensually detained in group homes and residential aged care facilities, including when they are put in these places in order to ‘protect’ them from violence.

- 8.123 The CRPD also contains other rights related to community participation. Article 26(1) provides for the right to habilitation and rehabilitation, requiring States Parties to take measures, ‘to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’, including through organising, strengthening and extending comprehensive habilitation and rehabilitation services and programmes. Moreover, in order for people with disability to live independently and participate fully in

all aspects of life, Article 9 of the CRPD provides that States Parties shall take measures to ensure equal access to the physical environment, transportation, information and communications, and public facilities. Guardianship and financial management violate this aspect of Article 19 when the substitute decisions of guardians and financial managers prevent women with disability from making their own decisions about participating in the community, including because substitute decisions deny them access to their money, access to family and friends, or the opportunity to freely leave their residence and access the community.

- 8.124 Thus, guardianship and financial management violates rights to independent living and community participation because decisions of tribunals and boards and substitute decisions of guardians enable the segregation and confinement of women living with dementia and prevent them from choosing where they live and how they participate in the community. Commentary on these rights makes clear that realising this right for women with disability must extend to guaranteeing legal capacity to all, repealing laws that deny legal capacity or that enable women with disability to be non-consensually moved and detained in accommodation, and providing access to resources and supports both to enable supported decision-making in the community and to enable women to live where they choose.

## Freedom from torture and violence

- 8.125 Guardianship and financial management violate the rights of women with disability to freedom from violence and from cruel, inhuman or degrading treatment and torture. This is because guardianship tribunals and guardians can consent to interventions in the bodies of women with disability to which the women themselves have not given their consent.
- 8.126 Turning first to torture and cruel, inhuman or degrading treatment, Article 7 of the ICCPR provides for freedom from torture and cruel, inhuman or degrading treatment or punishment. Article 2(1) of the *Convention Against Torture* provides that: 'Each State Party shall take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction'.<sup>44</sup> Article 15 of the CRPD reiterates the right to freedom from torture and cruel, inhuman or degrading treatment or punishment, and requires States Parties to take 'all effective legislative, administrative, judicial or other measures' to ensure people with disability enjoy this right on an equal basis with others.
- 8.127 The kinds of non-consensual interventions that can be the subject of substitute decisions by guardians or serious medical decisions by tribunals and boards (e.g., for sterilisation) have been identified as amounting to torture or cruel, inhuman or degrading treatment of people with disability. The CRPD Committee has observed in its general comment on women and girls with disabilities that certain forms of violence can constitute 'cruel, inhuman or degrading treatment or punishment and as breaching a number of international human rights treaties', including:

*forced, coerced and otherwise involuntary pregnancy or sterilization; any medical procedure or intervention performed without free and informed consent, including procedures and interventions related to contraception and abortion; invasive and irreversible surgical practices such as psychosurgery, female genital mutilation and surgery or treatment performed on intersex children without their informed consent; the administration of electroshock treatment and the use of chemical, physical or mechanical restraints; and isolation or seclusion.*<sup>45</sup>

- 8.128 The CEDAW Committee has observed that non-consensual interventions concerning women’s sexuality and reproduction – many of which can be authorised through substitute decision-making – might constitute torture:

*Violations of women’s sexual and reproductive health and rights, such as forced sterilizations, forced abortion, forced pregnancy, criminalisation of abortion, denial or delay of safe abortion and post-abortion care, forced continuation of pregnancy, abuse and mistreatment of women and girls seeking sexual and reproductive health information, goods and services, are forms of gender-based violence that, depending on the circumstances, may amount to torture or cruel, inhuman or degrading treatment.*<sup>416</sup>

- 8.129 Devandas-Aguilar provides examples of torture and cruel, inhuman and degrading treatment, including some relevant to sexual and reproductive violence: ‘forced sterilization, contraception and abortion’ and ‘the use of chemical, physical or mechanical restraints’.<sup>417</sup>

- 8.130 The former Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Juan Méndez) identifies forms of sexual and reproductive violence as forms of torture:

*Some women may experience multiple forms of discrimination on the basis of their sex and other status or identity. Targeting ethnic and racial minorities, women from marginalized communities and women with disabilities for involuntary sterilization because of discriminatory notions that they are “unfit” to bear children is an increasingly global problem. Forced sterilization is an act of violence, a form of social control, and a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment. The mandate has asserted that “forced abortions or sterilizations carried out by State officials in accordance with coercive family planning laws or policies may amount to torture”.*<sup>418</sup>

- 8.131 Méndez has also described as torture or ill-treatment ‘medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose [and] when enforced or administered without the free and informed consent of the person concerned’, ‘notwithstanding claims of good intentions or medical necessity.’<sup>419</sup> He calls for an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including: ‘the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics’;<sup>420</sup> ‘all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, ... in all places of deprivation of liberty, including in psychiatric and social care institutions’;<sup>421</sup> and the ‘institutionalisation of persons with disabilities on the grounds of their disability without their free and informed consent.’<sup>422</sup>

- 8.132 The CRPD also provides for the right to freedom from exploitation, violence, and abuse. Article 16 of the CRPD requires Governments: (a) ‘protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects’; (b) ‘prevent all forms of exploitation, violence and abuse’; (c) ‘promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse’; and (d) ‘put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.’

- 8.133 In relation to women with disability, the CRPD Committee has defined violence as being ‘interpersonal’ or ‘institutional and/or structural violence.’ The latter is defined as ‘any form of structural inequality or institutional discrimination that keeps a woman in a subordinate position, whether physically or ideologically, compared with other people in her family, household or community’.<sup>423</sup> Guardianship and financial management can be understood as structural violence as per this definition, because the denial of autonomy and the oppressive nature of substitute decisions keeps women with disability in a subordinate position.
- 8.134 According to the CRPD Committee, specific examples of violence against women with disability that will violate Article 16 include those that can be associated with substitute decision-making by tribunals and guardians: ‘the absence of free and informed consent and legal compulsion’; ‘neglect, including the withholding or denial of access to medication’; ‘the denial of personal mobility and accessibility by, for example, removing or destroying accessibility features such as ramps, assistive devices such as white canes or mobility devices such as wheelchairs’; ‘the refusal by caregivers to assist with daily activities such as bathing, menstrual and/or sanitation management, dressing and eating, which hinders enjoyment of the right to live independently and to freedom from degrading treatment’; and ‘the exercise of control, for example by restricting face-to-face or virtual access to family, friends or others’.<sup>424</sup>
- 8.135 The CRPD Committee notes that enjoying freedom from violence can be hindered by harmful stereotypes about women with disability: ‘Harmful stereotypes that infantilize women with disabilities and call into question their ability to make judgements, perceptions of women with disabilities as being asexual or hypersexual’.<sup>425</sup>
- 8.136 The Beijing Platform for Action defines violence against women as ‘any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life’.<sup>426</sup> It extends to ‘[p]hysical, sexual and psychological violence perpetrated or condoned by the State, wherever it occurs’ and ‘forced sterilisation and forced abortion, coercive / forced use of contraceptives’.<sup>427</sup>
- 8.137 In a Resolution titled ‘Accelerating efforts to eliminate all forms of violence against women and girls: preventing and responding to all forms of violence against women and girls with disabilities’ adopted on 13 July 2021, the Human Rights Council calls upon States to ‘take immediate and effective action to prevent and eliminate all forms of violence against women and girls’, including by:
- Reviewing laws and policies that perpetuate the outdated understanding of disability present in charity and medical models and ableism, and incorporating a human rights-based approach to disability.*<sup>428</sup>
- 8.138 Other strategies include: awareness-raising and addressing stereotypes and stigma, strengthening inclusive policies, allocating resources to support women and girls with disability and ‘address historical, structural and underlying causes and risk factors of violence against women and girls’, support participation and inclusion of women and girls with disability in decision-making processes and leadership, ensuring accessible and inclusive services and programs for prevention and elimination of violence against women, and enhance social protection measures.<sup>429</sup>
- 8.139 The Human Rights Council also calls upon States to ‘take immediate and effective action to respond to all forms of violence against women and girls and to support and protect all victims and survivors’, including relevantly for present purposes:
- Guaranteeing equal recognition before the law of persons with disabilities, inter alia older women with disabilities, persons with disabilities belonging*

*to minorities, including persons with disabilities of African and Asian descent, migrants with disabilities and indigenous persons with disabilities, and ensuring that they have the opportunity to exercise their legal capacity on an equal basis with others in all aspects of life, as recognized in article 12 of the Convention on the Rights of Persons with Disabilities;*

*Repealing legislation and regulatory provisions that restrict legal capacity or permit forced sterilization, forced abortion and forced contraception and ensuring that any medical procedure or intervention is performed with due regard for the right to respect for physical and mental integrity on an equal basis with others and to bodily autonomy and is not performed without the free and informed consent of women and girls with disabilities;<sup>430</sup>*

8.140 The Human Rights Council also calls for access to justice and reparations:

*Ensuring access to justice and accountability mechanisms and timely and effective remedies for the effective implementation and enforcement of laws aimed at preventing and eliminating all forms of discrimination and gender-based violence, including by informing women and girls about their rights under relevant laws in an accessible way, providing procedural accommodation for women and girls with disabilities, improving legal infrastructure and mainstreaming age- and gender-responsive and disability-inclusive training into justice systems to ensure equality before the law and equal protection of women and girls with disabilities by the law;*

*Providing victims and survivors of violence with effective remedies, including victim- and survivor-centred and age- and gender-responsive legal, medical, psychological and confidential counselling services and legal protection that avoid revictimization and retraumatization and are inclusive of and accessible to women and girls with disabilities, and providing support services, information and education in accessible formats, including on how to prevent, recognize and report instances of exploitation, violence and abuse in any setting;<sup>431</sup>*

8.141 Thus, guardianship and financial management violate rights to freedom from torture and violence because decisions of tribunals and boards and substitute decisions of guardians enable non-consensual interventions in the bodies of women with disability. Commentary on these rights makes clear that ending violence against women with disability must extend to guaranteeing legal capacity to all, repealing laws that deny legal capacity or that enable non-consensual interventions, and providing access to reparations.

## Access to justice

8.142 Guardianship and financial management violate the right of women with disability to access to justice and remedy, because the interventions authorised pursuant to tribunals and boards or guardians and financial managers are legal and thus are not considered unlawful and justiciable and in turn are beyond remedy and redress. Guardianship and financial management also violate the right to access to justice



because the tribunal processes through which guardians and financial managers are appointed are inaccessible.

- 8.143 The ICCPR provides that persons have the right to be ‘equal before the courts and tribunals’. Article 13(1) of the CRPD provides the right to access to justice for persons with disability on an equal basis to others, noting the importance of accommodations and support to facilitate their participation in the justice system:

*States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*

- 8.144 Guardianship and financial management violate the right to access to justice because the process through which guardianship and financial management orders are made are not accessible to women with disability.

- 8.145 The International Principles and Guidelines on Access to Justice for Persons with Disabilities provide guidance on realising the right to access to justice in Article 13 of the CRPD. These Principles are:

**Principle 1:** All persons with disabilities have legal capacity and, therefore, no one shall be denied access to justice on the basis of disability.

**Principle 2:** Facilities and services must be universally accessible to ensure equal access to justice without discrimination of persons with disabilities.

**Principle 3:** Persons with disabilities, including children with disabilities, have the right to appropriate procedural accommodations.

**Principle 4:** Persons with disabilities have the right to access legal notices and information in a timely and accessible manner on an equal basis with others.

**Principle 5:** Persons with disabilities are entitled to all substantive and procedural safeguards recognized in international law on an equal basis with others, and States must provide the necessary accommodations to guarantee due process.

**Principle 6:** Persons with disabilities have the right to free or affordable legal assistance.

**Principle 7:** Persons with disabilities have the right to participate in the administration of justice on an equal basis with others.

**Principle 8:** Persons with disabilities have the rights to report complaints and initiate legal proceedings concerning human rights violations and crimes, have their complaints investigated and be afforded effective remedies.

**Principle 9:** Effective and robust monitoring mechanisms play a critical

role in supporting access to justice for persons with disabilities.

**Principle 10:** All those working in the justice system must be provided with awareness-raising and training programmes addressing the rights of persons with disabilities, in particular in the context of access to justice.<sup>432</sup>

- 8.146 Principle 2 of the International Principles and Guidelines on Access to Justice for Persons with Disabilities provides that '[f]acilities and services must be universally accessible to ensure equal access to justice without discrimination of persons with disabilities', and this includes access to information and communication.<sup>433</sup> Principle 3 provides for the right to procedural accommodation which includes:

*gender and age-appropriate individualized procedural accommodations for persons with disabilities. They encompass all the necessary and appropriate modifications and adjustments needed in a particular case, including intermediaries or facilitators, procedural adjustments and modifications, adjustments to the environment and communication support, to ensure access to justice for persons with disabilities.*<sup>434</sup>

- 8.147 Principle 4 provides for accessible legal information, and this would include information in preparation for a tribunal hearing:

*clear understandable information about how a procedure works, what to expect during a process, what is expected of a person, where to get help with understanding the process and the person's rights in the process, in language that is not merely a repetition of the statute, regulation, policy or guideline – for example, plain language.*<sup>435</sup>

- 8.148 Accessible legal information also includes real time information to assist in understanding a tribunal hearing as it is occurring:

*support is available in real time for individuals who need assistance to understand notices and information by providing, for instance, interpreters, guides, readers, intermediaries and facilitators, and other forms of support.*<sup>436</sup>

- 8.149 Guardianship and financial management also violate the right to access to justice because women with disability have limited avenues for redress in relation to the conduct and decisions of guardians and financial managers, and the decisions of guardians concerning violations in the bodies of women with disability are lawful even though non-consensual which thus means women with disability cannot seek access to justice for assault through criminal and civil law. Moreover, women with disability under guardianship and financial management might also be perceived as lacking the capacity to have legal standing to bring civil actions and to give sworn evidence in criminal and civil trials, thus reducing the opportunity to pursue any legal action that might be available.

- 8.150 The CRPD Committee in its general comment on women and girls with disabilities explains that women with disabilities face barriers in accessing justice in relation to violence:

*due to harmful stereotypes, discrimination and lack of procedural and reasonable accommodations, which can lead to their credibility being doubted and their accusations being dismissed. Procedures or enforcement attitudes may intimidate victims or discourage them from pursuing justice. These can include: complicated or degrading reporting procedures; referral of victims to social services rather than legal remedies; dismissive attitudes by police or other enforcement agencies. This can lead to impunity and invisibility of the issue, resulting in violence lasting for extended periods of time. Women with disabilities may also fear reporting violence, exploitation or abuse because they are concerned they may lose their support requirements from caregivers.*<sup>437</sup>

- 8.151 Devandas-Aguilar has noted the importance of access to justice for older persons with disability:

*States must take all appropriate legislative, administrative, social, educational and other measures to protect older persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects. States have an obligation to prevent and investigate all acts of violence and abuse and to prosecute and, when convicted, punish the perpetrators, as well as to protect the rights and interests of the victims and survivors. All protection services must be age-, gender- and disability-sensitive.*<sup>438</sup>

- 8.152 Devandas-Aguilar has specifically identified the importance of eliminating denial of legal standing and other barriers to accessing justice for older people with disability:

*States must ensure effective access to justice for older persons with disabilities. Access to effective remedies is critical to combating all forms of exploitation, violence or abuse against older persons with disabilities in the public and private spheres. States must eliminate all restrictions preventing older persons with disabilities from obtaining access to justice, including denial of legal standing and accessibility barriers. States are required to provide age- and gender-appropriate procedural accommodations to facilitate the effective participation of older persons with disabilities in all legal proceedings.*<sup>439</sup>

- 8.153 Mahler has also emphasised the importance of access to justice and remedies in relation to older persons:

*States have an obligation not only to prevent and punish human rights violations in State-managed institutions, but also to take all necessary measures to protect older persons from violations of such rights by non-State actors. They must also investigate all allegations of violations of the rights of older persons, notably the right to life, including through arbitrary detention and torture and other ill-treatment, as well as violations perpetrated by private entities. Investigations should be effective, prompt, thorough and impartial. Effective accountability mechanisms also provide ways to ensure access to justice and reparations for older persons. Caregiving and health-related facilities should have mechanisms in place allowing residents to file complaints if they believe their human rights have been violated, which is also a good way to improve the quality and efficiency of health services and maintain client satisfaction. Failure*

*to ensure accountability for the negligence of care-home staff resulting in the death of an older individual should amount to a violation of the right to life. This should also apply within the criminal justice system.<sup>440</sup>*

8.154 As well as access to justice as a right, some conventions also recognise a right to remedy in relation to violations of the rights in those conventions. Article 2(3) of the ICCPR requires that when individuals are subject to violations of the rights in the ICCPR, States Parties undertake to ensure that persons have an effective remedy, and that this remedy is determined by judicial, administrative or legislative authorities and is enforceable. Violation of some specific rights also give rise to entitlements to redress. For example, Article 9 of the ICCPR provides that individuals who are deprived of their liberty are entitled to go to court to seek release from detention, and victims of unlawful detention 'shall have an enforceable right to compensation'. Article 17(2) of the ICCPR provides that individuals who experience arbitrary or unlawful interference with their privacy, family, home or correspondence have the 'right to the protection of the law against such interference or attacks'. States Parties are required pursuant to Article 14(1) of the Convention Against Torture to 'ensure in its legal system that the victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible'.<sup>441</sup>

8.155 The CRPD Guidelines on Deinstitutionalisation identify a specific role for reparations in deinstitutionalisation, stating that governments should ensure legal and policy frameworks:

*enable the full inclusion of all persons with disabilities and guide deinstitutionalization processes towards the closure of institutions. Such frameworks should enable the development of inclusive community support systems and mainstream services, the creation of a reparations mechanism, and guarantee the availability, accessibility and effectiveness of remedies for survivors of institutionalization.<sup>442</sup>*

8.156 The CRPD Guidelines on Deinstitutionalisation state that governments:

*should provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability.<sup>443</sup>*

8.157 The CRPD Guidelines on Deinstitutionalisation provide that reparations for institutionalisation should include formal apologies, financial compensation, include restitution, habilitation and rehabilitation, and establishment of truth commissions.

<sup>444</sup>

8.158 The International Principles and Guidelines on Access to Justice for Persons with Disabilities provide in relation to Principle 8 (affording of legal remedies) that States Parties should ensure that 'effective remedies are in place for human rights violations, including the right to be free from disability-based discrimination and the rights to restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition'. These remedies should be 'enforceable, individualized and tailored to meet the needs of claimants', '[e]nsure that victims are protected from repeat violations of their human rights', and '[a]ddress the systemic nature of human rights violations'.<sup>445</sup>

8.159 Thus, guardianship and financial management violates rights to access to justice because women with disability have little recourse to police, civil remedies and victim support in relation to the decisions of tribunals and boards and substitute decisions of guardians and financial managers that enable non-consensual interventions in the bodies, lives and finances of women with disability. Commentary on these rights makes clear that realising access to justice for women with disability must extend to guaranteeing legal capacity to all, repealing laws that deny legal capacity, and providing access to reparations.

## Freedom of expression

8.160 Article 21 of the CRPD provides for freedom of expression. It provides in part that: 'States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice'.

8.161 Guardianship and financial management violate the right of women with disability to freedom of expression, in three respects. First, appointing guardians and financial managers to women with disability denies to them the opportunity to express their needs, perspectives and choices and have these legally recognised as decisions. Second, women with disability under guardianship or financial management are generally legally prohibited from speaking publicly about their experiences of guardianship and financial management. Third, guardians can be authorised to make decisions about medical treatment, restrictive practices and detention, all of which can be used as a pathologising and punitive response to women with disability who express resistance, distress and anger in response to their experiences under guardianship and financial management, including their experiences in segregated and closed settings.<sup>446</sup>

## Crimes against humanity

8.162 The harms of guardianship, including denial of legal capacity and non-consensual interventions, might constitute crimes against humanity. Both a crime against humanity and a broader state crime conceptual frame illuminates the significance and severity of the various harms uniquely perpetrated against women with disability, as legally-sanctified and state-endorsed structural violence that causes systematic harms against this group. 'Crime against humanity' is defined as any one of a list of specified acts which are committed as part of a widespread or systematic attack directed against any civilian population, with knowledge of the attack.<sup>447</sup> The list of specified acts includes 'imprisonment or other severe deprivation of physical liberty', 'torture', 'enforced sterilization, or any other form of sexual violence of comparable gravity', 'other inhumane acts of a similar character intentionally causing great suffering, or serious injury to body or to mental or physical health'. Article 7.2(a) clarifies that 'Attack directed against any civilian population' means 'a course of conduct involving the multiple commission of acts ... against any civilian population, pursuant to or in furtherance of a State or organizational policy to commit such attack'.<sup>448</sup>

8.163 Understanding guardianship and financial management as crimes against humanity illuminates that the legality of the substitute decisions of guardians and tribunals, and the oversight by tribunals and boards of guardianship and financial management underscores the systematic and state-sanctioned nature of this attack on women with disability.

- 8.164 Pons et al have observed that appointment of guardians and the kinds of interventions authorised by guardians might constitute crimes against humanity:

*To cite but a few examples of proscribed conduct consistent with the CRPD and too often visited upon persons with disabilities with impunity: ... the imposition of plenary guardianship removing legal capacity in relation to any and all decision making; or forced treatment ... absent consent. Such treatment is not protection, therapy, or science. The CRPD and the dynamic treaty practice it has brought about clarify that such conduct is unacceptable, contrary to human rights law, and, in certain situations, may amount to crimes against humanity.<sup>449</sup>*

- 8.165 In specific relation to women with disability being subjected to legally authorised non-consensual sterilisation and abortion, there is growing literature in relation to reproductive violence against women more broadly as a crime against humanity.<sup>450</sup>

- 8.166 The topic of people with disability and crimes against humanity, and the specific topic of disability-specific laws and interventions as crimes against humanity are under-explored and under-researched. The Disability Royal Commission is encouraged to fully explore this issue as part of its work on international human rights.

- 8.167 This section has demonstrated that guardianship and financial management violate human rights of women with disability. In order for Australia to meet its international human rights obligations, it must repeal guardianship and financial management laws and provide reparations for human rights violations associated with the operation of those laws and the substitute decisions made pursuant to those laws. Australia must also introduce supported decision-making laws and provide access to support and resources for making decisions. More broadly the Australian Government must end segregation and institutionalisation, in order to create a wider environment and culture in which women with disability can enjoy equality and autonomy. In Section 9 we will present a series of recommendations that are informed by these human rights.





## **9 SUPPORTING LEGAL CAPACITY FOR TRANSFORMATIVE CHANGE**

## 9. SUPPORTING LEGAL CAPACITY FOR TRANSFORMATIVE CHANGE

- 9.1 In Sections 4-8 we outlined a series of reasons why guardianship and financial management enable violence against women with disability and violate their human rights. We explained how violence, harm, injustice and human rights violations against women with disability occur in the context of laws and practices that: are ableist and sexist towards women with disability, responsabilise and punish women for family violence and conflict and a lack of resources and supports within the community, accommodate under-resourced services that do not support choice and autonomy, silence women with disability and lack transparency, and fail to provide the opportunities, resources and conditions across women's life course to develop and facilitate their decision-making and broader autonomy and equality.
- 9.2 We have shown that guardianship and financial management enable forms of violence against women that must be addressed by the Disability Royal Commission in order to fulfil its Terms of Reference. We have also shown that guardianship and financial management are themselves forms of violence and their use as a response to violence against women with disability is fundamentally at odds with contemporary approaches to preventing and responding to violence against women more broadly and undermines the vision driving the Australian National Plan to End Violence against Women and Children 2022–2032 to end violence against women in one generation.
- 9.3 In this section we present some key actions to prevent and respond to the violence against women with disability associated with guardianship and financial management. The foundation for these recommendations is a shift from a paternalistic, ableist, sexist and dehumanising approach to women with disability, to one that is grounded in recognition of the equality, autonomy and inherent value and humanity of women with disability. The importance of this shift is underscored by statements by successive Special Rapporteurs on the Rights of Persons with Disabilities. Devandas-Aguilar has emphasised the importance of a starting point where people with disability are valued and supported to live and flourish:
- Life with a disability is a life worth living equal to others. Every person has a unique set of unrepeatable characteristics and experiences that make them irreplaceable and valuable. The lives of persons with disabilities are human lives and, consequently, endowed with inherent dignity. Persons with disabilities can live fulfilling lives and enjoy what gives life meaning.<sup>451</sup>*
- 9.4 Quinn has emphasised the importance of rejecting paternalism and supporting the agency of people with disability, arguing that the concept of protection needs to be:
- purge[d] ... of its legacy of paternalism, to ground it on active human agency and the participation rights of persons with disabilities and to link it with broader goals of inclusion and development. The anchor norms in this regard have to do with personhood, human agency and the right of persons with disabilities to participate in and help to reshape their own societies.<sup>452</sup>*
- 9.5 We begin by discussing reforms specifically to guardianship and financial management law – supported decision-making, repealing substitute decision-making laws and access to justice and redress. We then turn to transformations to law and society more broadly – ending segregation and institutionalisation and supporting autonomy and equality.

## Supports and supported decision-making

9.6 For women with disability to be able to exercise agency and enjoy autonomy and equality which has been robbed of them by guardianship and financial management, they must have access to supports to make their own decisions about their bodies, lives, and finances, including through supported decision-making.

9.7 Article 12(3) of the CRPD provides:

*States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

9.8 There are three preliminary points to note about Article 12(3) of the CRPD. The first is that Article 12(3) of the CRPD does not use the terminology of ‘supported decision-making’, although the provision is typically associated with this term. Rather, it uses the wider term of ‘support’. The CRPD Committee has defined ‘support’ expansively and as taking a variety of forms:

*Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. ‘Support’ is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility — for example, requiring private and public actors, such as banks and financial institutions, to provide information in an understandable format or to provide professional sign language interpretation — in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.*

*The type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities.*

*This is in accordance with article 3 (d), which sets out ‘respect for difference and acceptance of persons with disabilities as part of human diversity and humanity’ as a general principle of the Convention. At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.<sup>453</sup>*

9.9 The second point is that ‘there is no limit on the obligation under article 12 (3)’, in the sense of only providing what is considered ‘reasonable’ (Article 5 of the CRPD on reasonable accommodation). Therefore, the ‘fact that support to exercise capacity may impose a disproportionate or undue burden does not limit the requirement to provide it’.<sup>454</sup> The unlimited nature of article 12(3) is significant given the current economic and bureaucratic dynamics enabling guardianship and financial management.

9.10 The third point is that the CRPD Committee identifies supported decision-making as an important aspect of realising legal capacity. It states:

*To ensure consistency between articles 5 and 12 of the Convention, States parties should: (a) Reform existing legislation to prohibit discriminatory denial of legal capacity, premised on status-based, functional or outcome-based models. Where appropriate, replace those with models of supported decision-making, taking into account universal adult legal capacity without any form of discrimination.<sup>455</sup>*

9.11 The connection between supported decision-making and legal capacity means that supported decision-making will not realise human rights of women with disability if it forms part of substitute decision-making laws that enable guardianship and financial management to continue, even if with reduced scope.

9.12 Thus, the Australian Government must 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 (such as guardianship and financial management frameworks) and as such all substitute decision-making laws must be abolished.

9.13 In its general comment on equal recognition before the law, the CRPD Committee has explained that there is no one-size-fits-all model of supported decision-making, stating that an individual’s supported decision-making regime needs to be tailored and flexible, comprising

*various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.).<sup>456</sup>*

9.14 Moreover, as Hendrick and McNamara explain, supported decision-making arrangements can include both formal and informal arrangements which vary in intensity depending on individual needs and circumstances and:

*Importantly, persons with disabilities must be allowed to decide the*

*nature of the supports which should be provided, in accordance with their individual autonomy. If support is not requested or desired, the person's will and preferences must be respected.*<sup>457</sup>

- 9.15 As Flynn and Arstein-Kerslake explain, 'the philosophy of Article 12 [of the] CRPD ... posits that supports to exercise legal capacity can only be offered to people with disabilities, never imposed against the person's will'.<sup>458</sup> Similarly, People with Disability Australia note that it is important that the 'supported person must consent to the supporter signing or acting on their behalf on each and every occasion'.<sup>459</sup> Thus, while the state should offer support, this should never 'override the person's autonomy if the person refuses to accept help'.<sup>460</sup> Moreover, the purpose of any state intervention should be 'to explore the individual's circumstances, and to determine what can be offered by way of support, rather than imposing unwanted protection or restricting the individual's liberty'.<sup>461</sup>
- 9.16 While supported decision-making regimes can take many forms, the CRPD Committee has proposed that all forms of 'support in decision-making' should 'incorporate certain key provisions to ensure compliance with article 12 of the Convention, including the following:
- (a) Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making;
  - (b) All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;
  - (c) A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
  - (d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned;
  - (e) In order to comply with the requirement, set out in article 12, paragraph 3, of the Convention, for States parties to take measures to "provide access" to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
  - (f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;
  - (g) The person must have the right to refuse support and terminate or change the support relationship at any time;
  - (h) Safeguards must be set up for all processes relating to legal capacity and support in



exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.

- (i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.<sup>462</sup>

9.17 In its general comment on Article 12 the CRPD Committee notes that realising the right to legal capacity requires that persons with disability 'have the opportunity to live independently in the community and to make choices and to have control over their everyday lives, on an equal basis with others, as provided for in article 19' and that 'support in the exercise of legal capacity should be provided through a community-based approach'.<sup>463</sup> To this end, 'communities are assets and partners in the process of learning what types of support are needed in the exercise of legal capacity, including raising awareness about different support options' and 'States parties must recognize the social networks and naturally occurring community support (including friends, family and schools) of persons with disabilities as key to supported decision-making'.<sup>464</sup>

9.18 Supported decision-making must not strip people of their legal capacity, as Kornfeld-Matte has explained in relation to older people:

*Legal capacity is a key aspect of autonomy, allowing older persons to exercise civil, political, economic, social and cultural rights. In circumstances where an older person is partially or completely unable to look after their own interests because of a mental condition, such as dementia, or an extreme state of physical frailty, there may be a need for supported decision making. There is a need to ensure, however, that in such instances a person is not stripped of his or her legal capacity by guardianship measures, which remove their ability to make decisions about certain aspects of their lives.*<sup>465</sup>

9.19 Creating a cultural context for supported decision-making requires re-framing interdependency as needed for most persons, irrespective of disability. Nair explains this in relation to menstruation:

*Applying a supported decision-making model to menstruation facilitates the creation of a community around menstruators with disabilities. Rather than stripping away autonomy or penalizing individuals with disabilities because of the support they may require during menstruation, we can recognize that all menstruators require assistance and support. Supported decision-making, with respect to menstruation, could explicitly address the individual's menstruation management needs and the support system that they can rely upon to make decisions about reproduction or menstrual suppression.*<sup>466</sup>

9.20 As Flynn and Arstein-Kerslake note, many of the 'new approaches to support people with disabilities to exercise their legal capacity ... long pre-date the CRPD, but have come to international prominence more recently'.<sup>467</sup> Examples of supported decision-making practice include open dialogue, family group conferencing and circles of support.<sup>468</sup> Flynn and Arstein-Kerslake explain that these strategies, 'are ideally implemented on a proactive and "ongoing basis ... to prevent ... state intervention', rather than being 'activated during a crisis'.<sup>469</sup>

9.21 There is emerging research on supported decision-making and women with disability.



Flynn and Arstein-Kerslake explain how ‘circles of support’ have been successfully used with women with intellectual disability and reflects feminist understandings of friendship and support:

*Circles of support were initially developed to foster friendship and connections between disabled people and their non-disabled peers (Uditsky, 1993) and are made up of an intentional group of supporters, often invited by the individual’s immediate family, but extending beyond family members to include neighbours, peers and friends. Gold (1994) explores the operation of one particular circle, for a young woman with significant intellectual disability, Leslie, where some members were initially invited by Leslie’s mother, but all had independent friendships with Leslie prior to the formation of the circle, and Leslie’s immediate family members were not involved in the group. Gold describes how circles such as this one can be viewed as part of a ‘sociology of acceptance’ and also within feminist understandings of friendship and support. This practice therefore has significant potential, especially when used on an ongoing basis to avoid the need for state intervention in the private lives of adults in emergency situations.<sup>470</sup>*

9.22 Prianka Nair explains how supported decision-making could be used in the context of menstruation:

*While guardianship is premised on the notion that the individual is incapable of making independent decisions, thereby requiring a surrogate decision maker to stand in their shoes to make those decisions, supported decision-making dismantles the falsehood that people are islands. Rather than supplanting the decisions of the individual, supported decision making involves the creation of a plan that allows the individual to retain their decision-making capacity, while selecting trusted advisors, such as friends, family members, or professionals, to understand, consider, and communicate decisions about health care and financial or property management. Supported decision-making values community and interdependence over the false narrative of independence.<sup>471</sup>*

9.23 Supported parenting programmes can help to allow for women with intellectual disability who are often the target of child protection services, to access the proper support in giving birth and provide training to staff members. A report by the Scottish Commission for Learning Disability describes a practice that helps support women in pregnancy, childbirth and parenting, which involves the following elements:

- Support should be available right from the start i.e. from pre-birth onwards
- Families might need ongoing support i.e. support at every stage of the child’s development
- Support must be based on respect for the parents and for the emotional bond between the parents and their children
- Parents should be seen as a resource, not a problem
- Support should be for the family as a whole rather than individuals
- Parents should be supported to feel in control and to experience being competent
- Support should focus on building strengths
- Making mistakes as a parent is forgivable: support should help parents learn from them
- Families are best supported in the context of their own extended families, neighbourhoods and communities.<sup>472</sup>

- 9.24 Health promotion tools that provide information on supports and services in Easy Read and accessible ways can be an excellent way to promote decision-making about a woman's body and health needs. Such tools can also provide specific training to women with disability to them in making the decision.<sup>473</sup>
- 9.25 There are many examples of the positive impacts on women with disability of being free of guardianship and financial management, and having supports to exercise legal capacity.
- 9.26 For example, the National Resource Centre for Circles of Support and Microboards provide the example of Anouk's positive experiences of supported decision-making:

*Anouk is 19 years old and lives with her family close to a major city. Anouk and her family immigrated to Australia 5 years ago from Finland. Anouk attended school until she was 17 and then was in a supported work environment for 18 months. Anouk's family are very connected to each other and the local Finnish community. Anouk and her family have recently been talking about the future and are beginning to explore opportunities for both Anouk and her family.*

*Anouk works part time in a café close to her family home. Anouk works in the kitchen, washing dishes and food preparation, peeling and chopping vegetables. Anouk says that she enjoys working at the cafe, but has not really made any friends amongst staff.*

*Anouk often talks with her family about having friends to do things with, like going shopping, spending time at the beach and going to the movies. Anouk says that she would love to go on a holiday to Queensland and visit other parts of Australia as well. Anouk's family are very busy, Anouk's sister is at university, works part time and has a busy social life. Anouk's family are keen for her to have her own friends.*

*Anouk decided it was time to do the things that she has been dreaming about and discussing with her family. Anouk and her family were not sure where to begin so they decided to talk with a local advocacy organisation. Anouk met with an advocate who mentioned circles of support. Anouk said that one of her friends mentioned that she has a circle, but Anouk was not sure what they do. After further discussion, Anouk said she wanted to know more about circles. The advocate and Anouk decided to send an email to the local circle organisation.*

*Within a few days, Anouk received an email from Janet, a circles facilitator asking if Anouk would like to catch up. Anouk asked if her advocate could also attend the meeting and they set a date to talk.*

*At the meeting, Anouk asked Janet lots of questions about how circles work, who could join and also talked about her future dreams. Anouk thinks that a circle is a great idea, so together they begin to plan. The first thing they discussed, was why Anouk wanted a circle, then they discussed who could Anouk ask to join her circle. Anouk said there is someone at the café that she would like to invite. Together they make a list of people's names and decide to email invitations and deliver some personally. In the invitation, they write the details of the place and time of the first meeting.*

*Anouk invited her mum along with three others, including Susan from the café. Anouk was pleased that two of the three people said yes, including*

*Susan. Anouk and her sister prepared for the first meeting to be held at Anouk's family home. At the first meeting, Anouk and Janet thanked everyone for coming and then Anouk talked about her life in Australia, and then shared some of her dreams. Janet was very helpful encouraging everyone to join the conversation. Susan was surprised to hear about Anouk's life and was very interested to become involved. The meeting ended and everyone agreed to meet again in 3 weeks' time.*

*The next day at the café Susan was talking with Anouk about the meeting and said she would like to do something with Anouk. Anouk was happy and they discussed maybe they could go shopping and maybe even visit a travel agent to look at holiday options. They both decided that they would go shopping together on the next weekend. That evening Anouk told her mum about the conversation that she had with Susan. This was the beginning of some amazing changes in Anouk's life. Anouk said to her mum that she was really looking forward to her future and could not wait for the next circle meeting.<sup>474</sup>*

- 9.27 Many people with disability have positive outcomes and experiences due to the support of a circle of persons to help them with decision-making and to provide guidance, Di explains what she thinks of her circle of support in a report by Resourcing Inclusive Communities (Family Advocacy, NSW):

*The circle helps me to see that the challenges coming up are not mountains but molehills, especially when they help me break them down into do-able steps. People in the circle offer support in other ways that is often a natural extension of things they would typically do.<sup>475</sup>*

- 9.28 Supported decision making allowed for Katie Alcorn to move to her own accommodation. To do this her mother founded 'Kate's Crew' as a group of people around her who would provide and plan to make these ideas happen, Kate and her mum Carolyn share these ideas:

*All the members of Kate's Crew bring a mix of skills, interests and opportunities. "We go around the circle and talk about each member's gifts. For example, Martin is very practical, so he puts ads in the paper, fixes things at Kate's unit and things like that. We rely on Peter for his computer skills. My brother and sister in law live at the Sunshine Coast [and living so far away] there's lots of things they can't do, but we value their input and Chris (Peter's wife) shares in facilitating the meetings. This facilitation role is an important one. They are responsible for keeping the conversation going and making sure Kate's vision is at the centre of all decision making. Others help out with taking minutes, interviewing prospective housemates and being part of sub committees to solve in-depth problems.<sup>476</sup>*

- 9.29 There are also overseas examples of the benefits of supported decision-making. For example, Emily DiMatteo and co-authors describe the experience of Emma:

*protecting disabled people's legal rights means allowing them to make their own reproductive decisions. Emma Budway, a nonspeaking autistic woman in Virginia, is working to transition out of her guardianship once she receives an assistive technology device. When the authors recently interviewed her with the communication assistance of her guardian, Emma was passionate about using alternatives to guardianship as she works to transition out of her current arrangement: "I have the ability and agency to make decisions about my life. I am in full control. For example, I take a birth control pill for cessation of menstruation; that is my decision."<sup>477</sup>*

- 9.30 DiMatteo and co-authors also write that supported decision-making in healthcare can have positive impacts on health outcomes for women with disability, drawing on examples from the USA:

*While it is difficult to establish causality, outcome data for people with intellectual and developmental disabilities, as captured by the NCI, indicate an interesting correlation between a state's concerted shift to comprehensive shared decision-making arrangements and its reproductive health outcomes, such as rates of Pap smears and mammograms. For example, available data from the NCI show that Texas and Delaware—which both codified supported decision-making policies into statute in 2015 and 2016, respectively—had among the highest percentages of women with intellectual and developmental disabilities who had received either a Pap smear or mammogram in the past two years.<sup>478</sup>*

- 9.31 In the Irish context, Claire Hendrick once free from Irish Wardship and with appropriate supports in place,

*has taken back control of her life, she has been able to enter into a relationship, go on holidays, start a college course, find a job and buy her first house. This story demonstrates that all persons can make decisions and we may all need a certain level of support to do so, but only if we choose to seek such supports. It also portrays the dangers of substituted decision-making and the need for persons with disabilities to have their legal capacity recognised and their will and preferences respected.<sup>479</sup>*

- 9.32 Hendrick describes how, after leaving state Wardship, she was assisted to buy a house by her cousin. Because she was supported by these people, she explains she now has broader independence and freedom:

*I am now an independent member of society, managing my household and I have a childcare level 6 degree. I have a job, no mortgage and I'm doing what I love. My aunt and cousin still help me with big decisions when I ask them and we see each other regularly. No one else should ever have to go through Wardship again. Just because you have a disability does not make you any less human. You are a person with rights, but Wardship takes those away from you.<sup>480</sup>*

### Repeal guardianship and financial management legislation

- 9.33 As well as introducing supports to realise legal capacity, such as supported decision-making, existing guardianship and financial management laws and other substitute decision-making regimes must be repealed.

- 9.34 The CRPD Committee has made clear that it is not possible to retain substitute decision-making alongside supported decision-making:

*The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.<sup>481</sup>*

- 9.35 The CRPD Committee has explained that '[r]ecogniz[ing] persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others'

*... requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities. It is recommended that States parties create statutory language protecting the right to legal capacity on an equal basis for all.*<sup>482</sup>

- 9.36 In a subsequent 2018 general comment on equality and non-discrimination, the CRPD Committee again emphasised the necessity of abolition of substitute decision-making:

*States parties shall modify or abolish existing laws, regulations, customs and practices that constitute such discrimination ... including: guardianship laws and other rules infringing upon the right to legal capacity; mental health laws that legitimize forced institutionalization and forced treatment, which are discriminatory and must be abolished; non-consensual sterilization of women and girls with disabilities; ...*<sup>483</sup>

- 9.37 The CRPD Committee has also stated:

*Reform existing legislation to prohibit discriminatory denial of legal capacity, premised on status-based, functional or outcome-based models. Where appropriate, replace those with models of supported decision-making, taking into account universal adult legal capacity without any form of discrimination.*<sup>484</sup>

- 9.38 The CRPD Committee also states in its general comment on equal recognition before the law, that in its concluding observations on States parties' initial reports, it has repeatedly stated that States parties must

*review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences.*<sup>485</sup>

- 9.39 Similarly, Devandas-Aguilar has stated that it is necessary to replace (rather than supplement) substitute decision-making laws:

*The Convention on the Rights of Persons with Disabilities explicitly recognizes that States have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity (art. 12 (3)). States must replace regimes of substitute decision-making with regimes of supported decision-making that respect the rights, will and preferences of persons with disabilities, such as support agreements, peer support groups, self-advocacy support and advance directives, among others.*<sup>486</sup>

- 9.40 Devandas-Aguilar has reiterated this obligation on States in the specific context of older people with disability:

*States have an obligation to immediately repeal all legislation that allows the denial of legal capacity, deprivation of liberty, institutionalization and involuntary treatment of older persons with disabilities on the basis of disability and/or age.*<sup>487</sup>

- 9.41 Mahler has also emphasised the importance of repealing substitute decision-making laws in relation to older people:

*Legislation or practices that enable substitute decision-making, especially in the context of forced institutionalization, must be repealed and replaced by laws guaranteeing supported decision-making, as set out in the Convention on the Rights of Persons with Disabilities.<sup>488</sup>*

- 9.42 The international human rights commentary is phrased in broad terms of substitute decision-making – rather than referring only to guardianship and financial management. Therefore, governments must remove *all* laws enabling substituted decision-making, not only guardianship and financial management laws, as noted by the CRPD Committee:

*Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.<sup>489</sup>*

- 9.43 For example, mental health laws will also need to be repealed to the extent they enable substitute decision-making and non-consensual interventions. To this end, the CRPD Committee has stated that:

*States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment.<sup>490</sup>*

- 9.44 Writing in the Australian context, John Chesterman has noted that the CRPD Committee’s call:

*bluntly for the abolition of all substitute decision-making regimes. In Australia, this would involve every state and territory removing key elements of their guardianship, mental health, powers of attorney and medical treatment laws.<sup>491</sup>*

- 9.45 Moreover, even if mental health, guardianship and financial management laws enabling substitute decision-making were completely abolished, the common law doctrine of *parens patriae* would continue to apply to people with disability unless explicitly excluded through legislation. The common law doctrine of *parens patriae* is rarely discussed and scrutinised in government inquiries and academic discussion of substitute decision-making, with the focus instead being on guardianship and mental health legislative frameworks. The common law doctrine of *parens patriae* is a patriarchal framework that rests on gendered assumptions in four respects:

- (a) it is a highly gendered model based on the assumed familial, patriarchal authority of the father over the vulnerable child in the private sphere of the home.
- (b) it assumes the incapacity and vulnerability of people with disability, their submission to dominance, and the inherent positivity of the familial, patriarchal protection of the father/judge.



- (c) it is based on a patriarchal construction of the father, family, and private sphere whereby a father figure is automatically loving, kind and protective to his family; and of the justice system and court similarly, i.e. as a space of safety and non-violence.
  - (d) it positions the court as an inherently benevolent father figure that comes to the rescue of helpless and vulnerable people with disability who are positioned as children.
- 9.46 Feminist advocacy and scholarship on violence against women in the home and Quinn’s arguments for a rejection of paternalism towards people with disability, undermine these core assumptions on which the *parens patriae* jurisdiction rests and provide a strong basis on which to extend any abolition of substitute decision-making to this jurisdiction.
- 9.47 As well as reforming law to prevent substitute decision-making, laws prohibiting interventions that have been enabled through guardianship, notably non-consensual sterilisation, abortion and contraception must also be introduced. For example, the CRPD Committee states that:
- Repealing discriminatory laws, policies and practices that prevent women with disabilities from enjoying all the rights enshrined in the Convention, outlawing gender- and disability-based discrimination and its intersectional forms, criminalizing sexual violence against girls and women with disabilities, prohibiting all forms of forced sterilization, forced abortion and non-consensual birth control, prohibiting all forms of forced gender- and/or disability-related medical treatment and taking all appropriate legislative steps to protect women with disabilities against discrimination,*<sup>492</sup>
- 9.48 Abolition of substitute decision-making can draw on experiences of successful repeal of laws in the context of other marginalised groups who have historically been subjected to discriminatory and paternalistic laws (as discussed in Section 5). If transformative change can be brought about for women and First Nations people, there is no reason such change cannot also be achieved in relation to women with disability (to think otherwise is itself discriminatory and speaks to the low expectations society and lawmakers have for people with disability).

### Access to justice and redress

- 9.49 As well as transforming decision-making laws for future benefit of women with disability, women with disability who were harmed through guardianship and financial management must also have access to justice and redress. Justice and redress are particularly important given the harms outlined in Section 5 can be severe and lifelong and, as discussed in Section 8, constitute human rights violations potentially amounting to torture and crimes against humanity.
- 9.50 As such clear, accessible and inclusive pathways for making complaints and reporting abuses of power and violence are necessary. Legislated frameworks for individual redress and other forms of reparations need developing to support complaint making.
- 9.51 Additional to the guidance on access to justice provided by the International Principles and Guidelines on Access to Justice for Persons with Disabilities (discussed in Section 8), the ‘Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law’ (Van Boven Principles) also provide guidance on redress and support

for victims-survivors of violence that constitute gross violations of human rights. In general, the 'obligation to respect, ensure respect for and implement international human rights law' includes the duty to:

- (a) Take appropriate legislative and administrative and other appropriate measures to prevent violations;
- (b) Investigate violations effectively, promptly, thoroughly and impartially and, where appropriate, take action against those allegedly responsible in accordance with domestic and international law;
- (c) Provide those who claim to be victims of a human rights or humanitarian law violation with equal and effective access to justice, as described below, irrespective of who may ultimately be the bearer of responsibility for the violation; and
- (d) Provide effective remedies to victims, including reparation, as described below.<sup>493</sup>

9.52 Specifically, the Van Boven Principles provide that remedies for gross human rights violations include the victim's right to 'equal and effective access to justice'; 'adequate, effective and prompt reparation for harm suffered'; and 'access to relevant information concerning violations and reparation mechanisms'. 'Reparation for harm suffered' 'should be proportional to the gravity of the violations and the harm suffered'.<sup>494</sup>

9.53 Victims of gross violations of international human rights law should 'be provided with full and effective reparation'.<sup>495</sup> The forms of reparations provided by the Van Boven Principles consist of:

- (a) Restitution: This 'should, whenever possible, restore the victim to the original situation before the gross violations of international human rights law or serious violations of international humanitarian law occurred'. Examples of restitution are 'restoration of liberty, enjoyment of human rights, identity, family life and citizenship, return to one's place of residence, restoration of employment and return of property'.
- (b) Compensation: This should be 'provided for any economically assessable damage, as appropriate and proportional to the gravity of the violation and the circumstances of each case'. The damage can include: 'physical or mental harm', 'lost opportunities', including employment, education and social benefits, 'material damages and loss of earnings, including loss of earning potential', and 'moral damage'.
- (c) Rehabilitation: This includes 'medical and psychological care as well as legal and social services'.
- (d) Satisfaction: This should include, where applicable, such forms as: 'effective measures aimed at the cessation of continuing violations', 'verification of the facts and full and public disclosure of the truth', 'an official declaration or a judicial decision restoring the dignity, the reputation and the rights of the victim and of persons closely connected with the victim', 'public apology, including acknowledgement of the facts and acceptance of responsibility', 'judicial and administrative sanctions against persons liable for the violations', 'commemorations and tributes to the victims', and 'inclusion of an accurate account of the violations that occurred in international human rights law and international humanitarian law training and in educational material at all levels'.
- (e) Guarantees of non-repetition: These measures, which 'will also contribute to prevention', can include: reviewing and reforming laws contributing to or allowing gross violations of international human rights law and serious violations of international humanitarian law'.<sup>496</sup>

- 9.54 At an individual level, reparations for women with disability who have been harmed by guardianship and financial management must include individual redress payments in recognition of the wrong and harm done through guardianship and financial management and additionally payment of compensation for financial loss (e.g., payment of fees for financial management, mis-management of money), compensation for physical and mental harm related to being under substitute decision-making and related to the specific non-consensual interventions authorised, and compensation for lost opportunities for employment and education (particularly where women with disability have been put in segregated settings pursuant to guardian's decisions). Reparations at an individual level must also include restitution including in the form of restoration of liberty for women who have been institutionalised or subjected to restrictive practices, and access to rehabilitation to address all physical, psychological, social and legal needs associated with the harms of guardianship and financial management. Individual recognition such as apologies must also be available.
- 9.55 At a collective level, reparations for guardianship and financial management must include truth-telling, government and professional association apologies, guarantees of non-repetition and involvement of women with disability in law reform, public education and memorialisation.
- 9.56 As we discuss in our submission on sexual and reproductive rights, the delivery of individual redress and other forms of reparations for women with disability can draw on the design and lived experiences of other redress schemes for women with disability (e.g., sterilisation redress) and for people who have experienced institutional harm (e.g., institutional child abuse and Stolen Generations schemes).<sup>497</sup>

### Ending segregation and institutionalisation

- 9.57 Ending segregation and institutionalisation is another core dimension of supporting legal capacity and realising equality and autonomy of women with disability, in two respects.
- 9.58 First, denial of legal capacity is associated with entry into institutionalisation and experiences of violence in institutions (particularly restrictive practices), as noted by the CRPD Committee:

*The segregation of persons with disabilities in institutions continues to be a pervasive and insidious problem that violates a number of the rights guaranteed under the Convention. The problem is exacerbated by the widespread denial of legal capacity to persons with disabilities, which allows others to consent to their placement in institutional settings. ... In order to comply with the Convention and respect the human rights of persons with disabilities, deinstitutionalization must be achieved and legal capacity must be restored to all persons with disabilities, who must be able to choose where and with whom to live (art. 19). A person's choice of where and with whom to live should not affect his or her right to access support in the exercise of his or her legal capacity.*<sup>498</sup>

- 9.59 Second, realising legal capacity requires an individual to live within and have support of the community, as explained by the CRPD Committee:

*To fully realize the transition to supported decision-making and implement the rights enshrined in article 12, it is imperative that persons with disabilities have the opportunity to develop and express their wishes and preferences in order to exercise their legal capacity on an equal basis*

*with others. To achieve this, they have to be a part of the community. Furthermore, support in the exercise of legal capacity should be provided using a community-based approach which respects the wishes and preferences of individuals with disabilities.*<sup>499</sup>

- 9.60 Deinstitutionalisation and desegregation are particularly important for women with disability who can be more subject to institutionalisation, as the CRPD Committee has noted:

*Often, women and girls with disabilities (art. 6) are more excluded and isolated, and face more restrictions regarding their place of residence as well as their living arrangements owing to paternalistic stereotyping and patriarchal social patterns that discriminate against women in society. Women and girls with disabilities also experience gender-based, multiple and intersectional discrimination, greater risk of institutionalization and violence, including sexual violence, abuse and harassment. States parties must provide affordable, or free, legal remedy and support services for victims of violence and abuse. Women with disabilities who face domestic violence are frequently more economically, physically or emotionally dependent on their abusers, who often act as caregivers, a situation that prevents women with disabilities from leaving abusive relationships and leads to further social isolation. Therefore, when implementing the right to live independently and be included in the community, particular attention should be paid to gender equality, the elimination of gender-based discrimination and patriarchal social patterns.*

*Cultural norms and values may adversely restrict the choices and control of women and girls with disabilities over their living arrangements, limit their autonomy, oblige them to live in particular living arrangements, require them to suppress their own requirements and instead serve those of others and take certain roles within the family. States parties should take measures to tackle discrimination and barriers against women in accessing social services and support, as well as ensure that various policies, programmes and strategies concerning access to social services and support take due consideration of the equality between women and men.*<sup>500</sup>

- 9.61 States are obligated under Article 19 of the CRPD to reform any laws that impede an individual's right to live independently in the community, including laws which directly or indirectly restrict the options of persons with disabilities to choose their place of residence or where, how and with whom to live, or their autonomy.<sup>501</sup>
- 9.62 The recently adopted CRPD Committee Guidelines on Deinstitutionalisation describe deinstitutionalization as comprising 'interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live'. These guidelines emphasise the importance of deinstitutionalization being 'led by persons with disabilities, including those affected by institutionalization', and that they should not be led 'by those involved in managing or perpetuating institutions'. Moreover, the guidelines state that deinstitutionalization must not involve measures that simply enable the evolution of segregation and confinement:

*Practices that violate article 19 of the Convention should be avoided, such as renovating settings, adding more beds, replacing large institutions with smaller ones, renaming institutions, or applying standards such as the principle of the least restrictive alternative in mental health legislation.*<sup>502</sup>

9.63 The CRPD Committee has stated that government must:

*Repeal all laws that prevent any person with disabilities, regardless of the type of impairment, to choose where and with whom and how to live, including the right not to be confined on the basis of any kind of disability.<sup>503</sup>*

9.64 Governments are also required to have a strategy and plan for deinstitutionalisation:

*States parties must adopt a strategy and a concrete plan of action for deinstitutionalization. It should include the duty to implement structural reforms, to improve accessibility for persons with disabilities within the community and to raise awareness among all persons in society about inclusion of persons with disabilities within the community. Deinstitutionalization also requires a systemic transformation, which includes the closure of institutions and the elimination of institutionalizing regulations as part of a comprehensive strategy, along with the establishment of a range of individualized support services, including individualized plans for transition with budgets and time frames as well as inclusive support services. Therefore, a coordinated, cross-government approach which ensures reforms, budgets and appropriate changes of attitude at all levels and sectors of government, including local authorities, is required.<sup>504</sup>*

9.65 Governments are also required to ‘phase out institutionalization’. This means:

*No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents’ physical safety. Institutions should not be extended, new residents should not enter when others leave and “satellite” living arrangements that branch out from institutions, i.e., those that have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established.<sup>505</sup>*

9.66 Deinstitutionalisation also means governments not allocating new funds to institutionalisation, as explained by the CRPD Committee:

*States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization.<sup>506</sup>*

9.67 The recently adopted CRPD Committee Guidelines on Deinstitutionalisation also emphasise the importance of no new funding and investment in institutions:

*Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently. States parties should refrain from suggesting that persons with disabilities “choose” to live in institutions, or using similar arguments to justify the maintenance of institutions.*

*States parties should stop using public funds for the construction and renovation of institutions and should allocate them, including those from international cooperation, to ensure the sustainability of inclusive community support systems and inclusive mainstream services.<sup>507</sup>*

9.68 In a similar vein, Mahler has recommended:

*States should refrain from allocating funding to services that allow for the deprivation of liberty of older persons based on advanced age or on perceived or actual disability or need of care; funding should be increasingly allocated to fund research and technical assistance to end all forms of deprivation of liberty in the context of care.<sup>508</sup>*

9.69 Deinstitutionalization also requires access to social support and housing in the community, this being particularly important to prevent poverty and emergence of new forms of segregation, as explained in the CRPD Committee Guidelines on Deinstitutionalisation:

*States parties should provide persons with disabilities, including children with disabilities, leaving institutions with a comprehensive compensatory package comprising goods for daily living, cash, food vouchers, communication devices and information about services available, immediately upon departure. Such packages should provide basic security, support and confidence to persons with disabilities leaving institutions, in order that they can recover, seek support when they require it, and have an adequate standard of living in the community without risk of homelessness or poverty. ...*

*States parties should ensure safe, accessible and affordable housing in the community, through public housing or rental subsidies, for persons leaving institutions. Aggregating persons leaving institutions into communal housing arrangements or in assigned neighbourhoods, or bundling housing with medical or support packages, are incompatible with articles 19 and 18 (1) of the Convention. ...*

*The reference to residential services in article 19 of the Convention should not be used to justify the maintenance of institutions. The term “residential services” refers to community-based support services aimed at ensuring equality and non-discrimination in the exercise by persons with disabilities of their right to adequate housing. Examples of residential services are social housing, self-managed co-housing, free matching services, and assistance in challenging housing discrimination. For housing to be considered adequate, it must meet minimum criteria concerning legal security of tenure, availability of services, materials, facilities and infrastructure, affordability, habitability, accessibility, location and cultural adequacy.<sup>509</sup>*

9.70 Similarly, Mahler has stated in the context of older persons:

*Age-related adequate care arrangements should be developed and appropriately funded by States to ensure that older persons may live independently in their communities, with dignity, in line with their will and preferences, in accordance with the concept of “ageing in place” and with the objective of ending the institutionalization of older persons,<sup>510</sup>*

9.71 Abolition of ‘policies and measures that allow the spatial segregation of older persons’,<sup>511</sup> access to ‘adaptation of housing’ and ‘a range of services to support them in their daily activities’<sup>512</sup> as well as ‘adequate funding ... to ensure the availability of age-friendly support and services at home and within the community’ are all vital to supporting independent living of older people with disability.<sup>513</sup>



- 9.72 The recently adopted CRPD Committee Guidelines on Deinstitutionalisation emphasise the importance of taking an intersectional approach to deinstitutionalisation, including being alert to the specific needs of women with disability:

*States parties should adopt an intersectional approach to tackling discrimination, segregation, isolation and other forms of ill-treatment of persons with disabilities living in and leaving institutions. The personal identities of persons with disabilities are multifaceted, and disability is only one characteristic. Other characteristics include race, sex and gender, gender identity and expression, sexual orientation, sexual characteristics, language, religion, ethnic, indigenous or social origin, migrant or refugee status, age, impairment group, political or other opinion, experience of imprisonment or other status, and these characteristics intersect to shape a person's individual identity. Intersectionality plays an important role in the lived experiences of all persons with disabilities. ...*

*States parties should acknowledge that women and girls with disabilities are subjected to multiple discrimination on the grounds of gender and disability, and that they are not a homogeneous group. Women with disabilities are at a heightened risk of violence, exploitation and abuse compared with other women, and of gender-based violence and harmful practices, such as forced contraception, forced abortion and sterilization, during institutionalization. They are denied the right more often than men with disabilities and more often than other women to exercise their legal capacity, leading to denial of access to justice, choice and autonomy. These risks should be considered when designing and implementing deinstitutionalization plans.<sup>514</sup>*

### Supporting autonomy across the life course

- 9.73 As well as introducing formal supported decision-making, women with disability must also have opportunities to develop understanding of decision-making and human rights and develop decision-making skills and to make decisions across their life course, starting in childhood.

- 9.74 The CRPD Committee has stated:

*States parties are encouraged to develop effective mechanisms to combat both formal and informal substitute decision-making. To this end, the Committee urges States parties to ensure that persons with disabilities have the opportunity to make meaningful choices in their lives and develop their personalities, to support the exercise of their legal capacity. This includes, but is not limited to, opportunities to build social networks; opportunities to work and earn a living on an equal basis with others; multiple choices for place of residence in the community; and inclusion in education at all levels.<sup>515</sup>*

- 9.75 Specifically, children and young people with disability must be given opportunities to develop their autonomy, rather than waiting until people with disability reach adulthood. Children must also be made aware of supported decision-making, as one option for supporting autonomy. Learning needs to begin in childhood, including in schools. Relatedly, parents and teachers of children with disability must also be equipped with the knowledge, resources and support to facilitate learning and skills development. Disability and aged care service, and other services accessed by girls and women with disability must also be premised on supporting autonomy and independence, including providing opportunities and spaces for developing decision-making capacity.<sup>516</sup>

9.76 Careful attention needs to be paid to specific systems: How can decision-making skills and opportunities be integrated into curriculum and learning in mainstream and segregated education? How can decision-making skills and opportunities be integrated into service planning and day-to-day living in disability service provision? How can decision-making opportunities be designed into key transition points – leaving out of home care, education into employment or other programs? How can decision-making opportunities be designed into healthcare? How can the professionals and staff working in all of these systems be educated about human rights and trained in the skills to support legal capacity (including this knowledge being integrated into higher level secondary subjects and tertiary degrees)?

9.77 In order to develop social which can be an important element of women with disability exercising autonomy, women and girls with disability need to have support to create and build relationships that are more integrated into the community and are not formal paid support relationships, as argued by Epstein-Frish:

*Service models that group people with disability significantly impede independence. Group homes and day programs have developed under the guise that people with disability are better off with ‘their own’ and because limited imagination anticipated that all support had to come from paid workers. Research affirms better quality of life without necessarily additional cost occurs when paid support is used to compliment informal support of family and friends to enable even people with high support needs to live in their own homes and enjoy valued roles in the community. What is often not recognised in funding formulae is that many people with disability do not easily form relationships with people who want to play a role in their lives and so investment in the development of informal support is required in order to enable this type of lifestyle.<sup>517</sup>*

9.78 Rights training is also important, as Devandas has noted in the context of older people with disability:

*States must adopt immediate, effective and appropriate measures to raise awareness throughout society of older persons with disabilities from a rights-based perspective. Older persons with disabilities should not be seen as “ill” or as “patients”, but as rights-holders in the same way as other members of society. States should take measures to promote positive perceptions and greater social awareness of older persons with disabilities and to combat stigma, stereotypes and harmful practices against them, including harmful medical and legal practices. ...*

*States must also foster respect for the rights and dignity of older persons with disabilities through awareness-raising among and the training of professionals and staff working with them. Family members and informal caregivers should be trained to improve the provision of assistance to older persons with disabilities from a rights-based perspective. Training should address the multiple and intersecting forms of discrimination that affect older persons with disabilities.<sup>518</sup>*

9.79 Broader society must also be educated on rights, as noted by the CRPD Committee:

*Discrimination cannot be combated without awareness-raising among all sectors of government and society. Thus, any non-discrimination and equality measure must be accompanied by adequate awareness-raising measures and measures to change or abolish compounded pejorative*

*disability stereotypes and negative attitudes. In addition, violence, harmful practices and prejudices must be tackled by awareness-raising campaigns. States parties should undertake measures to encourage, inter alia, the media to portray persons with disabilities in a manner consistent with the purpose of the Convention and to modify harmful views of persons with disabilities, such as those that portray them unrealistically as being dangerous to themselves and others, or sufferers and dependent objects of care without autonomy who are unproductive economic and social burdens to society.<sup>519</sup>*

### Greater disaggregated data

9.80 The discussion in Sections 3 & 6 highlighted significant gaps in quantitative and qualitative data about guardianship and financial management, including as it applies to women with disability.

9.81 Tribunal and board decisions on guardianship and financial management must be publicly available (including with de-identification if needed). The current rationales for keeping most decisions confidential are not appropriate. Sensitive and private details can be addressed through de-identification of decisions. Cost should not be a barrier to publishing of court decisions related to significant interventions in bodies, lives and finances of members of marginalised communities.

9.82 More data in relation to service delivery of public guardians and public trustees is also necessary. The importance of data collection and public access to data is supported by international human rights commentary. For example, the Human Rights Council has called upon States to ‘take immediate and effective action to respond to all forms of violence against women and girls and to support and protect all victims and survivors’, including by:

*Strengthening or establishing systems to regularly collect, analyse and publish statistical data disaggregated by sex, age, disability and other relevant characteristics on all forms of violence against women and girls, and using these data to inform more effective efforts across all sectors to prevent and respond to violence, while respecting human rights principles, including participation, transparency, privacy and accountability;<sup>520</sup>*

9.83 In the context of older persons, Mahler recently recommended:

*A system of systematic data collection with age-based disaggregation at the national level should be established, involving all relevant ministries and other State agencies, to efficiently inform laws, policies and practices with regard to the situation of older persons in all places of detention; data should be disaggregated by gender, ethnicity, disability, health conditions and needs and should be made widely available to inform the public about the realities faced by older persons deprived of liberty.<sup>521</sup>*

9.84 The UN has also clarified that Article 31 of the CRPD (*Statistics and Data Collection*) is not solely concerned with collection of demographic statistics on prevalence and types of disability or impairment, but also with data on the extent of compliance or otherwise with the requirements of the CRPD. It is inherently difficult for States Parties to report on CRPD implementation without benchmarking data on initial levels of compliance. The UN has made clear that Australia must develop nationally consistent measures for data collection and public reporting of disaggregated data across the full range of obligations contained in

the CRPD, and that *all* data must be disaggregated by gender.

- 9.85 For more than a decade, the UN has been critical of Australia for its neglect of women and girls with disability in all aspects of data collection, information and research,<sup>522</sup> and has repeatedly called on the Australian Government to address this neglect as a matter of urgency. For example, following her mission to Australia, the Special Rapporteur on Violence Against Women, its causes and consequences recommended the Australian Government:

*Implement the recommendation made by the Committee on the Rights of Persons with Disabilities that the Government commission and fund a comprehensive assessment of the situation of girls and women with disabilities, in order to establish a baseline of disaggregated data against which future progress towards the implementation of the Convention could be measured.*<sup>523</sup>



**10 RESPONSE TO DISABILITY ROYAL  
COMMISSION ROUNDTABLE  
DOCUMENT  
'SUPPORTED DECISION-MAKING  
AND GUARDIANSHIP:  
PROPOSALS FOR REFORM'**

## 10. RESPONSE TO DISABILITY ROYAL COMMISSION ROUNDTABLE DOCUMENT ‘SUPPORTED DECISION-MAKING AND GUARDIANSHIP: PROPOSALS FOR REFORM’

- 10.1 WWDA does not support the proposals for reform. This is because of core flaws and limitations in the overarching approach of the document which are fundamentally inconsistent with our position that guardianship and financial management are violence against women with disability. In this section we summarise these flaws and limitations.
- 10.2 First, there were not enough people with disability and Disabled People’s Organisations involved in the roundtables where the proposals for reform were discussed. Rather, the ‘stakeholders’ participating in were largely bureaucrats operating the current system. Giving primacy to the voices and perspectives of those who perpetrate or are complicit in violence is inconsistent with current approaches to development of policy around violence prevention and response, particularly in the context of violence against women where the voices of survivors are foregrounded.
- 10.3 Second, the proposals for reform were developed without being informed by Disability Royal Commission Public Hearing 30 on guardianship, substituted and supported decision-making (held on for 21-25 November 2022).
- 10.4 Third, the proposals for reform do not recommend the abolition of substitute decision-making. The document proposes that supported decision-making be introduced into law as a supplement to substitute decision-making. At best this will result in *some* individuals who might otherwise have been subjected to substitute decision-making having access to supported decision-making. Thus, supported decision-making is not a guarantee or right of access to all women with disability. Whether individual women with disability have access to supported decision-making will ultimately depend on the decisions of others (such as tribunals and boards), the nature of the non-consensual interventions (e.g., non-consensual restrictive practices and sterilisation will likely still be enabled pursuant to substitute decision-making) and the individual circumstances of women (e.g., women with disability who are considered to have more complex circumstances such as family conflict and lack of social networks might be less likely to access supported decision-making). Many of the dynamics we outlined in Sections 5-7 will continue to shape inconsistent and unequal access to supported decision-making. Substitute decision-making must be abolished and replaced with supported decision-making.
- 10.5 Fourth, the proposals for reform do not specifically consider substitute decision-making in relation to sexuality and reproduction, nor do they consider reproductive and sexual justice for women with disability. In particular, the proposals for reform do not specifically consider substitute decision-making for serious medical treatment – which includes sterilisation – which is a decision-making generally reserved to tribunals and boards rather than guardians.
- 10.6 Fifth, the proposals for reform do not propose cessation of use of substitute decision-making for restrictive practices nor do they propose prohibition of restrictive practices. Instead, the document only proposes ‘robust safeguards ... to ensure appropriate oversight and monitoring’ of restrictive practices which ‘should enable improvements in practice, including reducing and eliminating the use of restrictive practices’. The use of ‘should’ instead of ‘must’ and the use of ‘reduce and eliminate’ instead of ‘prohibit’ demonstrates an ambivalence towards use of restrictive practices in a context where guardianship law has a key role in the legality and continued use of these interventions. The approach to restrictive practice relies on individual circumstance and the decisions of others rather than providing an absolute guarantee or right to be free from restrictive practices.



- 10.7 Sixth, the proposals for reform do not recommend individual redress and collective reparations for people who have been subjected to substitute decision-making, including guardianship and financial management. While there are some accountability measures contained in the proposals for reform these do not meet the standards required by international human rights.
- 10.8 Seventh, the proposals for reform are not framed in a broad understanding of the interconnected human rights in the CRPD and in mainstream human rights instruments, including rights to freedom from torture, violence and deprivation of liberty, to access to justice and remedies, and to independent living. The interconnectedness of human rights in the context of legal capacity was discussed in Section 8, and is also noted by Flynn and Arstein-Kerslake:
- the implications of the removal of legal capacity are great - from both a legal and moral perspective. In fact, legal capacity is the backbone of a plethora of other human rights because an individual who is not recognised as a person before the law is automatically deprived of other rights. This demonstrates the inter-connectedness of human rights concerns.*<sup>524</sup>
- 10.9 Instead of an interconnected human rights approach, in the document there is a narrow focus on Article 12 of the CRPD which focuses more on the act of deciding rather than also the consequences of the kinds of decisions that are made by guardians and financial managers. Ultimately the absence of a human rights framing in the proposals for reform decontextualises guardianship and financial management from the broader lives of women with disability and its longer-term impacts.
- 10.10 Eighth, and related to the last point, the proposals for reform have not recommended deinstitutionalisation and desegregation which are widely recognised in the international human rights commentary as essential to realising legal capacity and the broader human rights of people with disability, as explained in Section 8.
- 10.11 Ninth, the proposals for reform are explicitly contrary to the Australian National Plan to End Violence against Women and Children 2022–2032 insofar as they propose that guardians and other substitute decision-makers can serve a violence prevention or advocacy function. Violence prevention and advocacy should never be conditional on removal of legal capacity. This would not be acceptable for people without disability, and speaks to the profound inequality women with disability are still subjected to.
- 10.12 Tenth, the proposals for reform do not engage with the issue of ableism, nor do they propose addressing ableism in the justice and legal system. Moreover, the proposals for reform do not engage with intersectional oppression, such as ableism, sexism, ageism and racism.
- 10.13 Eleventh, the proposals for reform do not recommend comprehensive quantitative and qualitative data collection and publicly available data on tribunal decisions and activities of guardians and financial managers. Statistical information does not provide the depth of detail required to ensure transparency and accountability.
- 10.14 Therefore, for the reasons outlined above, the proposals for reform would continue to enable violence against women with disability and violation of human rights of women with disability.



## 11 ENDNOTES

## 11 ENDNOTES

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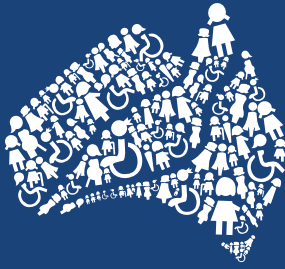
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Women  
With  
Disabilities  
Australia  
(WWDA)

Women With Disabilities Australia (WWDA)  
PO BOX 407 Lenah Valley, Tasmania, 7008 Australia

[+61 438 535 123](tel:+61438535123)

[+61 438 535 535](tel:+61438535535)

[carolyn@wwda.org.au](mailto:carolyn@wwda.org.au)

[officeadmin@wwda.org.au](mailto:officeadmin@wwda.org.au)

[www.wwda.org.au](http://www.wwda.org.au)

[www.facebook.com/WWDA.Australia](https://www.facebook.com/WWDA.Australia)

[www.twitter.com/WWDA\\_AU](https://www.twitter.com/WWDA_AU)

**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