

CHAPTER 1

*Introduction***Accessible Summary**

- This chapter explains what this book is about.
- Becoming an adult is different for everybody.
- Young people with cognitive disability can find it hard to get the right supports to become an adult.
- Many young people can experience violence and abuse.
- This book tells the stories of young people with cognitive disability from different backgrounds.
- Family members and practitioners also talk about stories of young people with cognitive disability.

1.1 Introduction

The transition to adulthood for any young person can be a time marked with both opportunities and challenges. Successful adulthood, according to a normative Western perspective, is often seen as achieving independence, such as attaining full-time employment, financial independence, and a home of one's own (Ravenscroft et al., 2017). However, defining adulthood according to these narrow terms serves to exclude many young people who are not always afforded the personal or social resources to achieve such markers of independence. Young people with cognitive disability are one group whose needs and experiences are often overlooked by society.

This introductory chapter is divided into three sections. Section 1.2 introduces the paradigm and purpose of this book. This section describes the aims of this book and the disability human rights paradigm that has guided the entire project. The disability human rights frame is then

explored. The Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), being the first United Nations (UN) specialised disability human rights convention, states that old approaches of exclusion and rights denials are unacceptable, and that new norms of inclusion and equality are now required (United Nations, 2006, Article 3). Section 1.3 defines and clarifies key concepts used throughout this book. In addition to defining key terms, this part defines key concepts, such as youth transition and the analytical framework used to understand the transition to adulthood for young people with cognitive disability. Further, Section 1.3 includes analysis of the circumstances surrounding youth transition for Aboriginal and/or Torres Strait Islander young people with cognitive disability, young people with cognitive disability from culturally and linguistically diverse backgrounds, and LGBTIQ+ young people with cognitive disability. Finally, Section 1.4 includes a road map on how the content is presented across this book.

1.2 The Paradigm and Purpose of This Book

This section first sets out the aims of this book. People with lived experience of cognitive disability are central to the research design, implementation, and writing process for this book. The CRPD has swept in a new disability human rights paradigm that empowers young people with cognitive disability. CRPD jurisprudence illustrates the global nature of the research presented in this book.

Aims of This Book

This book arose out of a concern to expand the landscape of youth transition research. Through making those with lived experiences co-researchers, this book explores the diverse experiences of young people with cognitive disability, bringing into sharp focus the ways in which young people with cognitive disability have been subjected to violence, abuse, and neglect in their transitions to adulthood. While this book gives voice to young people's views and the views of those who support them, it also highlights the part that services, systems, and communities play in either supporting or stifling young people's aspirations for a fulfilling adult life. This book examines the dark side to emerging adulthood and to the ways in which others have failed this group of young people. The young people with cognitive disability in this book have overcome adversity and demonstrated resilience. The reader is challenged to think about what

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change is needed within individuals, relationships, and communities to afford young people with cognitive disability the life they deserve, free from abuse and exploitation.

International disability jurisprudence and scholarship are used throughout this book to illustrate the common challenges across jurisdictions. To unpack the challenges confronting young people with cognitive disability transitioning to adulthood, this book presents the findings of an Australian study undertaken between 2020 and 2021. The primary research presented in this book had the following aims:

- To present an understanding of the nature and experiences of violence against, as well as abuse, neglect, and exploitation of, young people with cognitive disability.
- To consider the factors that increase the risk of, or prevent, violence against young people with cognitive disability.
- To examine safeguarding measures that mitigate violence against young people with cognitive disability.
- To consider experiences related to a young person's gender, sexuality, and cultural identity – in particular, the experiences of First Nations Australian young people with cognitive disability, young people with cognitive disability from culturally and linguistically diverse communities, and young people with cognitive disability who identify as LGBTIQ+.

In Their Own Words: Nothing about Us without Us

Research on persons with disability should be led by those with lived experience of disability. The method that underpins this book is analysed in more detail in Chapter 3; however, the underpinning importance of the disability human rights informed inclusive method requires attention requires specific attention at this point. As analysed in Chapter 3 of this book, the UN Convention on the Rights of Persons with Disabilities has swept in a paradigm that requires that research on persons with disability must genuinely involve them at all stages of the research process and at all levels. This creates rights and ethical obligations on all involved in the research process to ensure the voices of those researched are also represented in the research design, implementation, and leadership of research.

Reflecting the 'nothing about us without us' paradigm towards research, the majority of the researchers have a disability and/or have children with a cognitive disability. Considering the focus in this book on young people

with a cognitive disability, the research presented in this book has adopted a design, data collection, and analysis that involved collaboration with four co-researchers with intellectual disability and physical disability. The stories of nineteen young people with cognitive disability transitioning to adulthood show the diversity found in youth transitions and have applicability to jurisdictions beyond Australia. The young people included in this study were young people with intellectual disability, autism, and acquired brain injury. Many young people also had mental health concerns. Some young people were parents; others had transitioned out of state care; others identified as LGBTIQ+; and several young people were Aboriginal and/or Torres Strait Islander young people. Three young people had complex communicative support needs and their story was told by their mother or father. Young people spoke of a myriad of changes that occurred for them during emerging adulthood – for example, changes in much needed medical support, disruptions in family relationships, departing systems such as child protection and youth justice systems where the young person was an involuntary client, and cycling in and out of short-term employment.

Given that services and systems are influential in the lives of young people with cognitive disability, this book also includes the accounts of twenty-seven practitioners from disability support agencies, mental health services, domestic and family violence services, legal and advocacy services, and Aboriginal and/or Torres Strait Islander community health services. Practitioners were able to add further detail on how services and systems operate in relation to young people with cognitive disability. This includes the ways in which formal supports can both impede and facilitate a young person's transition to adulthood, and a sober assessment of how well these services and systems protect this group of young people from abuse.

The CRPD and Young People with Cognitive Disability

Introducing the CRPD

The CRPD is the first disability-specific UN human rights treaty and has created a tipping point in how states and other actors approach disability laws, policies, and practices (Harpur & Stein, 2022A). Furthermore, the CRPD is driving disability rights reform agendas across the globe. Illustratively, the Australian Disability Royal Commission¹ Final Report

¹ The Disability Royal Commission, officially known as the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, was established in April 2019 to investigate violence and abuse against people with disability.

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adopted the CRPD and the disability human rights paradigm as a frame to guide its operation and recommendations (DRC, 2023, 11).

The way in which the international human rights regime has approached the rights of young people with cognitive disability has profoundly shifted following the adoption of the CRPD. The modern international human rights regime provided persons with disability little to no specific protection prior to the CRPD. Illustratively, the so-called International Bill of Rights, adopted by the United Nations at the end of World War II, including the Universal Declaration of Human Rights; the International Covenant on Economic, Social and Cultural Rights; and the International Covenant on Civil and Political Rights, provides protection to persons with disability as part of humanity, yet provides no specific disability protections (Harpur & Stein, 2018). The only United Nations attribute-specific human rights treaty to expressly include protection for persons with disability, prior to the CRPD, was the Convention on the Rights of the Child (Harpur & Stein, 2019). Article 23 of the Convention on the Rights of the Child provides children with disability protection during their primary education but is otherwise silent on the rights of persons with disability.

To redress the omission of disability-specific human rights protections in the United Nations human rights treaties, the United Nations General Assembly adopted a resolution to establish an Ad Hoc Committee to draft a disability convention (Harpur & Stein, 2022). Ultimately, in December 2006 the CRPD convention drafted by the Ad Hoc Committee was adopted by the United Nations General Assembly and shortly received sufficient ratifications to commence operation.

The CRPD includes a sweeping disability human rights regime, which aims to transition society from dominant and disempowering laws, policies, and practices to a new world where ability diversity is celebrated and disability inclusion realized (Stein & Lord, 2007). In part the CRPD advances this transformational agenda through its comprehensive rights catalogue. The CRPD includes disability-specific rights that spread across all aspects of humanity, including rights to equality and non-discrimination, to privacy, to health, to education, to work, to family, to participating in culture, and to participating in and holding public office, as well as related transition rights (Bantekas, Stein, & Anastasiou, 2018). The way in which the CRPD rights empower young people with cognitive disability in their transitions will be analysed in each chapter to help inform this book.

*The CRPD Illustrates the Global Challenges Confronting Young People
Transitioning to Adulthood*

Although much of the research in this book is sourced from primary research performed in Australia, an analysis of the CRPD, and the jurisprudence arising from this convention, illustrates the global nature of the challenges addressed in this book. Although the substantive rights relevant to this book will be analysed in subsequent chapters, the global implications of this book can be demonstrated by analysing the CRPD and related jurisprudence. This section will draw from the United Nations body that governs and interprets the CRPD, the Committee on the Convention on the Rights of Persons with Disabilities (CRPD Committee) (CRPD Article 34). As part of its mandate, to report on states' compliance with the convention, the CRPD includes a governance framework to inform and monitor convention compliance by state parties (CRPD Articles 35–37). Part of this governance framework includes the CRPD Committee providing interpretative guidance on articles through the issuing of General Comments (United Nations Committee on the Rights of Persons with Disabilities 2014, 2014A, 2016, 2016A, 2017, 2018, 2018A, 2022). These General Comments will be referred to throughout this book.

Additionally, the CRPD governance framework requires state parties to provide reports and cooperate with the CRPD Committee. Through this process, the CRPD Committee produces periodic Concluding Observations on state parties to the CRPD. In addition to directly informing the primary research (United Nations Committee on the Rights of Persons with Disabilities, 2019, 2019A), these Concluding Observations can be used to illustrate how the issues raised in this book concerning young people with a cognitive disability are experienced in common with other jurisdictions. Therefore, this section will include a representative selection of Concluding Observations from across the globe. In the below sample the CRPD Committee refers to persons with cognitive disability with various labels, including autism, intellectual disability, and psychosocial disability. For consistency, this section will use the term 'cognitive disability'.

This book deals with the challenges people with cognitive disability encounter in transitioning to adulthood. The CRPD Committee has specifically addressed challenges encountered by persons with a disability in transitioning through various domains of life. Illustratively, in the Concluding Observation on Mexico, the CRPD raised a concern about the high dropout level of children with disability from the education

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system after age fifteen (United Nations Committee on the Rights of Persons with Disabilities, 2022A, Para. 54(c)). Relatedly, in the Concluding Observation on Germany, the CRPD Committee raised concerns about the high number of people with a disability in sheltered workshops and the slow rate of transitioning from such work arrangements to the open labour market (United Nations Committee on the Rights of Persons with Disabilities, 2023, Para. 61(a)).

In addition to addressing transition concerns, the CRPD Committee has addressed many specific challenges confronting young people with cognitive disability analysed throughout this book. This can be evidenced with respect to how intersectionality increases vulnerabilities for young people with cognitive disability (United Nations Committee on the Rights of Persons with Disabilities, 2016, Para. 47). The CRPD specifically addresses intersectionality in its articles on age and on women (Articles 6 and 7). In addition to CRPD Articles 6 and 7, the CRPD Committee has expanded upon the heightened vulnerability caused by intersectionality in a number of areas, which can be connected to age or gender, such as in the Concluding Observation on Hungary, addressing Roma children (United Nations Committee on the Rights of Persons with Disabilities, 2022B, 48(f)), or the Concluding Observation on New Zealand, addressing Māori children (United Nations Committee on the Rights of Persons with Disabilities, 2022C, 47(c)). In other examples, the vulnerabilities associated with intersectionality are not linked to Articles 6 or 7. This has occurred, for example, with respect to minority cultural status, such as being from an ethnic minority in Georgia (United Nations Committee on the Rights of Persons with Disabilities, 2023A, Para. 49(c)), or having indigenous or Afro-Peruvian status in Peru (United Nations Committee on the Rights of Persons with Disabilities, 2012, Para. 36).

The CRPD Committee has specifically addressed concerns against people with cognitive disability in a range of areas of life. Illustratively, the CRPD Committee has raised concerns about the violence confronting people with a cognitive disability in the Concluding Observations on India, Japan, Malawi, and Austria (United Nations Committee on the Rights of Persons with Disabilities, 2019A, 2022D, 2023B, 2023H). Violence is often more prevalent when persons with disability are subjected to institutionalisation (United Nations Committee on the Rights of Persons with Disabilities, 2017, Para. 82), and has been addressed when reporting on state parties, such as the Concluding Observation on India (United Nations Committee on the Rights of Persons with Disabilities, 2019A, Para. 32(c)). The reporting on violence can also draw from

research published in the state party, for example, the CRPD Committee supports its concerns about the high rates of violence against people with cognitive disability in Austria, by citing 2019 research published by the state party Federal Ministry of Employment, Social Affairs, Health and Consumer Protection (United Nations Committee on the Rights of Persons with Disabilities, 2023H, Para. 39).

Violence against people with cognitive disability has many causes. In Japan, for example, prejudice and violence against people with cognitive disability is connected with eugenic principles (United Nations Committee on the Rights of Persons with Disabilities, 2022D, Para. 19). Equally harmful, in Malawi, for example, the CRPD Committee observed that disability stereotypes and prejudices relating to people with cognitive disability, including those that portray them as in need of protection or as mystical or abnormal, underpin harmful practices according to the CRPD Committee, such as confinement, abductions, forced sterilizations, and killings (United Nations Committee on the Rights of Persons with Disabilities, 2023B, Para. 17). The discounting of people with cognitive disability is also connected with failures to recognise and engage with organizations of persons with cognitive disability – a challenge noted in the CRPD Committee’s Concluding Observations on Myanmar, Djibouti, the Lao People’s Democratic Republic, and Israel (United Nations Committee on the Rights of Persons with Disabilities, 2019G, Para. 64(c); 2021, Para. 60(c); 2022G, Para. 63(c); 2023E, Para. 9(b)).

Despite the prevalence of violence against people with cognitive disability, the CRPD Committee has identified that state parties are failing to appropriately intervene. For example, the CRPD Committee’s Concluding Observation on China raises concerns, inter alia, regarding people with a cognitive disability when they engage with the justice system as complainant and defendant, in areas including procedural accommodation, the lack of accessible information and communication in the context of legal procedures, and the inaccessibility of buildings (United Nations Committee on the Rights of Persons with Disabilities, 2022E, Para. 30). The CRPD Committee has raised similar concerns pertaining to laws and policies’ failures to prevent, investigate, and punish violence against people with a cognitive disability in Concluding Observations on Ecuador, Venezuela, and Mongolia (United Nations Committee on the Rights of Persons with Disabilities, 2019B, Para. 30(a); 2022L, Para. 30(a); 2023C, Para. 31).

In addition to the justice system, social security provides an additional avenue of protection for people with cognitive disability. In Concluding

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Observations, such as that on Slovenia, the CRPD Committee has noted that people with a cognitive disability live in poverty (United Nations Committee on the Rights of Persons with Disabilities, 2018B, Para. 47). The CRPD Committee has observed that the poverty of people with cognitive disability is not addressed due to budgetary, policy, and regulatory social security responses (United Nations Committee on the Rights of Persons with Disabilities, 2019C, Para. 45). Impoverishment and states' failures have contributed to degrading treatment. This is illustrated by the CRPD Committee's Concluding Observation on Malawi, where concerns were raised about children with cognitive disability who are 'subjected to begging, including by their guardians and in absence of a dignified opportunity for self-realization' (United Nations Committee on the Rights of Persons with Disabilities, 2023B, Para. 33(e)).

Education is a means to escape from poverty (United Nations Committee on the Rights of Persons with Disabilities, 2016A, Para. 10 (c)). But young people with cognitive disability can encounter barriers enrolling in a school. For example, the CRPD Committee noted that young people are denied access to education, in its Concluding Observations on the Lao People's Democratic Republic, who have either intellectual disability or autism; on Switzerland where they have either 'intellectual or psychosocial disabilities'; on Togo an 'intellectual impairment'; and on Great Britain and Northern Ireland, where a student is deemed 'disruptive to other classmates' (United Nations Committee on the Rights of Persons with Disabilities, 2022G, Para. 44(e); 2022H, Para. 47(c); 2023D, Para. 47; 2017B, Para. 52(c)). Even if young people with a cognitive disability are enrolled in a school, as the CRPD Committee has noted in its Concluding Observations on Hungary and Austria, this does not mean that they are provided reasonable accommodations/adjustments or supports they need to enjoy educational equality (United Nations Committee on the Rights of Persons with Disabilities, 2022B, Para. 48(e); 2023H, 55(c)). Related to the lack of supports is the lack of protection for students with cognitive disability against bullying in the CRPD Committee's Concluding Observations on Australia (United Nations Committee on the Rights of Persons with Disabilities, 2019, Para. 45(c)).

Links between a lack of education, poverty, and inadequate housing are heightened for people with cognitive disability. Illustratively, the CRPD Committee noted in its Concluding Observation on Canada, that almost 15 per cent of people with a disability lived in poverty or extreme poverty and that many persons with cognitive disability face homelessness

(United Nations Committee on the Rights of Persons with Disabilities, 2017A, Para. 49). The CRPD Committee has expressed concerns, in its Concluding Observations on South Africa and Indonesia, that where housing has been provided to people with cognitive disability, that such housing is group homes, institutionalised and unsafe (United Nations Committee on the Rights of Persons with Disabilities, 2018C, Para. 34; 2022I, Para. 44(b)). The analysis of CRPD jurisprudence in this section has illustrated the global nature of the challenges confronting young people with cognitive disability. The next section will provide key terms and explain how this book is structured.

1.3 Defining Concepts and Terms Used in This Book

This section defines key terms used throughout this book. Cognitive disability impacts on how young people transition to adulthood. This transition is complicated by intersectional vulnerabilities. The heightened impact of intersectionality is especially apparent for young people with cognitive disability who are Aboriginal and/or Torres Strait Islanders. Young people from cultural or linguistically diverse communities experience different heightened vulnerabilities. Similarly, young people who are LGBTIQ+ also experience heightened vulnerabilities.

Important Terms Used in This Book

Intentional Inconsistency: In Their Own Words

The ability of people with cognitive disability to speak in their own voices means that there are situations in this book where the language will appear inconsistent. For illustration, even though the authors prefer the umbrella term ‘cognitive disability’, where a participant uses a different term to describe themselves, then the preferences of young people with cognitive disability will be respected.

Person-First Language

There are global differences in the way in which language is used for disability. This book is written in ‘person-first’ language to describe persons with disability, as this was the majority preference of those with lived experience in the study. ‘Persons with disability’ is used as a generic term to align with the CRPD. ‘Young people with cognitive disability’ is the term adopted in discussions about the participants in this study. The merit of this approach to language is that it recognises the personhood of