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 LGBTIQA+ 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 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 LGBTIQA+.

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 LGBTIQA+; 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 Commission[1] Final Report

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[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.

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 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

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 LGBTIQA+ 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 young people apart from any conditions or labels, focusing on the person's skills, abilities, and strengths (West et al., 2015).

Cognitive Disability

This study utilises the term 'cognitive disability' as an umbrella term to describe several conditions, that is, intellectual disability, acquired brain injury, and autism spectrum disorder. These separate conditions are explained below as a point of reference for the reader, noting that clinical descriptors of conditions can provide general understandings of the functional impact of a person's impairment and, in this case, can be an important consideration when examining the experiences of transition. However, it is also vital to note that young people with such labels are a heterogeneous group, and therefore clinical definitions may be poor indicators of young people's experiences. Indeed, many of the young people in this study did not identify with these labels, and their experiences of disability are not adequately summarised by these diagnostic categories.

Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities, 'intellectual disability' is a term used to describe significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills, with the age of onset prior to twenty-two years (Schalock et al., 2021, p. 439). The World Health Organisation's (2022) International Statistical Classification of Diseases (and related health problems) (ICD-11) further divides intellectual disability into degrees of severity, namely, 'mild', 'moderate', 'severe', and 'profound' disorders of intellectual development. Another category of intellectual disability that is not documented in diagnostic manuals, yet nonetheless refers to a group of people who experience significant social, emotional, and psychological vulnerabilities, is 'borderline' intellectual disability (Wieland & Zitman, 2016).

Acquired Brain Injury

The term 'acquired brain injury' (ABI) refers to any damage to the brain that happened after birth (Australian Institute of Health and Welfare, 2007). The causes of ABI are varied, and can include abusive head trauma, accidents, lack of oxygen, stroke, and degenerative neurological disease. A person's cognitive, physical, emotional, and independent functioning can be impacted by having an ABI (Legano et al., 2021).

Autism Spectrum Disorder

The term 'autism spectrum disorder' has been described in the *Diagnostic and Statistical Manual of Mental Disorders: DSM-5-TR* as a condition 'characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviours used for social interaction, and skills in developing, maintaining and understanding relationships' (American Psychiatric Association, 2022). A diagnosis of autism spectrum disorder also requires the presence of repetitive, restricted patterns of behaviour, activities, or interests. Diagnoses such as Asperger's syndrome and pervasive developmental disorders have been subsumed under the broad category of autism, but many people continue to use these terms out of personal preference. Other young people prefer to consider autism in social terms of human rights and identity, rather than as a deficit-focused medical term (Kapp, 2020). The neurodiverse movement advocates for people whose sensory and cognitive experiences fall outside the norm, that is, people who are neurodivergent (Gratton, 2021).

Violence

Acts of abuse, neglect, and exploitation of and violence to young people with cognitive disability represent extreme examples of prejudice, discrimination, and marginalisation that can and do occur on a daily basis (Richardson et al., 2016). While these acts occur at an individual level and must be addressed on a person-to-person basis, they are also indicative of broader societal values and beliefs that permeate relationships, communities, services, and institutions (Goodley & Runswick-Cole, 2011).

The authors in this book were conscious that some language which refers to acts of abuse can serve to minimise or silence the experiences of young people with cognitive disability who are victims of such acts (Healy, 2020; Thorneycroft & Asquith, 2015). Consequently, the term 'violence' has been used as an overarching concept to describe the many different types of abuse experienced by young people. Violence, it is felt, best encapsulates the oppressive material, structural, systemic, and cultural conditions young people with cognitive disability encounter, as well as the practices that are committed against the person. Violence is used not only to describe extreme acts of violation of human rights, but also so-called smaller acts of abuse and neglect against young people with cognitive disability. In some respects, it is those 'smaller' acts that are at greater risk of becoming normalised by those who have the authority and power to change them. As will be seen throughout this book, these 'smaller' acts of violence can set the scene for further criminal behaviour (Burch, 2021).

Defining Transition to Adulthood

The path to adulthood for all young people in contemporary Western societies is often defined as an opportunity for young people to become autonomous and to exercise their right to citizenship (Bekken, 2022). As previously mentioned, the traditional markers of 'successful' transitions, such as finding full-time work, achieving financial independence, marriage, and parenthood, reflect cultural values about adulthood, but fail to account for the complexity of youth experiences (Pearson et al., 2021). These cultural values imposed on youth transition construct young people as individual actors who are aiming to meet an ideal version of adulthood, rather than understanding who young people are and how they feel in the present (Pearson et al., 2021).

A more accurate descriptor of youth transition used in this book is one in which there is a change in role or status. This change can potentially occur over many different contexts and involves moving between or within a variety of social structures (Strnadová & Cumming, 2016). For any young person, becoming an adult is not a step-by-step, linear process, nor does the transition necessarily have a predetermined end (Smith & Dowse, 2019). Applying a uniform and simplistic framework for understanding change in young people is therefore problematic, and especially so for young people with cognitive disability, who are likely to face multiple and interlocking disadvantage throughout their life (Ellem et al., 2019).

The 'most normal' way of becoming an adult is often out of reach for young people with cognitive disability (Bekken, 2022). Social expectations around independence can fail to consider young people with cognitive disability who may be dependent on others for daily personal care (Jacobs et al., 2020), who may have difficulties setting goals and organising activities (Schalock et al., 2021), who may require support with social interaction (American Psychiatric Association, 2013), and who may have co-occurring medical and psychiatric conditions that can create barriers to community inclusion (Wisner-Carlson et al., 2020). These individual difficulties, related to a young person's impairment, are compounded by structural inequalities in society, which position young people with cognitive disability as defective and incomplete in achieving the ideals of adulthood (Midjo & Aune, 2018). This group of young people may therefore be excluded from receipt of transition supports.

Approaching Youth Transition through an Intersectional Lens

Having a cognitive disability can be considered as one social identity among many others that can impact on youth transition (McLaughlin, 2023). Intersectionality, a theoretical framework first coined by Crenshaw (1989) and foregrounded by African American feminist scholars, examines the simultaneous lived experience of multiple facets of social identity (Thill, 2019). According to this theory, identity categories such as those related to gender, sexuality, ability, ethnicity, and culture are interconnected, creating overlapping and interdependent systems of discrimination and disadvantage (Hill Collins & Bilge, 2016). By using intersectionality as an analytical tool for understanding youth transition in this book, the experiences of young people with cognitive disability of youth transition no longer just relate to their disability, but also to other social identities. This study also considered Aboriginal and/or Torres Strait Islander young people with cognitive disability, young people with cognitive disability from culturally and linguistically diverse backgrounds, and LGBTIQA+ young people with cognitive disability.

Transition Experiences of Aboriginal and/or Torres Strait Islander Young People with Cognitive Disability

The relationship between youth transition and social disadvantage is very apparent for Aboriginal and/or Torres Strait Islander young people with cognitive disability, yet little is known in Australia about how many Indigenous young people have a cognitive disability nor how this group fares in transition. An Australian Institute of Health and Welfare (AIHW) analysis of self-reported data on disability from the 2014–2015 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) found that, while the majority of Indigenous young people did not have a disability, 20 per cent (or 13,500) young people reported having an intellectual disability (AIHW, 2018). This proportion of young people with intellectual disability warrants further attention.

Many Aboriginal and/or Torres Strait Islander young people with cognitive disability may never have had their disability appropriately diagnosed or recognised and may never have received any support from disability services (McCausland & Dowse, 2020). Aboriginal and/or Torres Strait Islander young people with cognitive disability may be unable or unwilling to identify with a having a disability, as such diagnostic labels may seem culturally or socially inappropriate. Those who do receive disability support may experience interactions with service providers that lack cultural awareness and sensitivity (Green et al., 2018).

There are likely to be multiple structural and practical barriers to Aboriginal and/or Torres Strait Islander young people with cognitive disability in receiving the services and supports they need as they transition to adulthood (McCausland & Dowse, 2020). The effect of intergenerational trauma, racism, and socioeconomic disadvantage can impact on adult transition, and this group of young people may have poor access to education, income, shelter, and food security (AIHW, 2018). Aboriginal and/or Torres Strait Islander young people are over-represented in child protection and criminal justice systems; are disproportionately exposed to risk factors such as grief, loss, and discrimination; have higher rates of suicide and risk of suicide than other groups of Australian young people; and are at greater risk of abuse, neglect, and exploitation (Cuervo et al., 2015).

Transition Experiences of Culturally and Linguistically Diverse Young People with Cognitive Disability

Another group of young people with cognitive disability who can experience added barriers and challenges in transitioning to adulthood are culturally and linguistically diverse young people with cognitive disability. 'Culturally and linguistically diverse' is used here to refer to a diverse group of young people that includes migrants, refugees, or multicultural young people (Wyn et al., 2018).

The act of migration presents challenges for any young person, requiring adaptation to a new environment, language, and culture, as well as having to negotiate changes in growth and development as the young person matures into adulthood (Khawaja & Carr, 2020). Departing one's country of origin also involves leaving established support networks behind and experiencing associated grief and loss (Jorgensen et al., 2021). Culturally and linguistically diverse young people with cognitive disability may also experience intergenerational conflict with their family members as they settle into the new country and seek to navigate two cultures, that of their country of origin and that of the host country (Khawaja & Ramirez, 2019). For young people with cognitive disability who are refugees, past experiences of displacement, war, torture, and persecution can also shape their settlement processes, and adversely impact on their physical and psychological health and their ability to fully participate in society on an equal basis with others (Stein & Lord, 2012; Federation of Ethnic Communities' Councils of Australia et al., 2019).

Culturally and linguistically diverse young people with cognitive disability have been described as a hidden population (Burns, 2020), and many authors have documented common experiences of social isolation for this group of young people (King, Edwards, Correa-Velez, Darracott, et al., 2016). There may be intense feelings of shame, guilt, and stigma within the young person's family regarding cognitive disability (Amparo Advocacy, 2016), and the family may feel unsupported emotionally and socially from their country-of-origin community in Australia (King, Edwards, Correa-Velez, Hair, et al., 2016). In addition, a family may be distrustful of, or lack awareness of, formal supports and services regarding disability (Jorgensen et al., 2021; Zhou, 2016).

Advocacy services for culturally and linguistically diverse people with disability view Australia's immigration law and policy as discriminatory to migrants with disability (National Ethnic Disability Alliance, 2023). An assessment of Australia's compliance with the CRPD by the CRPD committee raised concerns about the *Migration Act (1958)* (Cth) and the health requirement in *Migration Regulations (1994)* (Cth) that allow immigration authorities to refuse entry to refugees and migrants on the basis of their disability and its perceived economic cost (Committee on the Rights of Persons with Disabilities, 2019). It was recommended that these laws be amended, that the ten-year qualifying period for migrants to access the Disability Support Pension be removed, and that refugees with disability are not transferred to the neighbouring country, Papua New Guinea, or other 'regional processing countries'.

Discrimination and neglect of young people from culturally and linguistically diverse backgrounds with cognitive disability can also occur on a daily basis, in public places such as shopping centres, schools, and workplaces (Wyn et al., 2018). In addition, disability services have been known to turn away clients from culturally and linguistically diverse backgrounds on the basis that agencies do not feel they have the resources to work with people with limited English language skills (Federation of Ethnic Communities' Councils of Australia et al., 2019). The failure of the Australian community and supports and services to adequately cater to culturally and linguistically diverse young people with cognitive disability undermines their health and well-being and is likely to increase their risk of experiencing abuse and exploitation.

Transition Experiences of LGBTIQA+ Young People with Cognitive Disability

The acronym LGBTIQA+ refers to many identity categories, including lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual, and other terms. It is a collective term that people use to express their gender, sexuality, identity, and relationships. This descriptor acknowledges the diversity of people's identities and the unique ways in which people describe their histories and experiences (O'Shea et al., 2020).

Very little research has been conducted on the prevalence of LGBTIQA+ young people who have a cognitive disability in Australia. An online survey of 6,418 LGBTIQA+ young people in Australia aged between fourteen and twenty-one found that almost two-fifths of the sample reported having a disability or a long-term health condition (39%, $n =$ 2,500) (Hill et al., 2021). Participants self-identified as having neurodiversity/autism (6.6%, $n = 422$), intellectual disability (0.1%, $n = 10$), and acquired brain injury (2.1%, $n = 132$). There are limitations to these findings, being a non-representative sample, and therefore comparisons cannot be made with general population data. This highlights the importance of further research.

The task of negotiating one's identity and making sense of one's place in the world is particularly challenging for young people with cognitive disability who identify as LGBTIQA+ (Bates, 2020). A safe transition to adulthood for this group of young people is dependent upon acceptance from others, support to develop a positive self-image, and opportunities to build connections with peers (Dinwoodie et al., 2020). The process of coming out to others about one's sexuality may be a constant negotiation, where young people need to make safety-based decisions about others' responses (Toft et al., 2019).

Many young people with cognitive disability have been historically regarded as non-sexual, incapable, or uninterested in sex (Wilson et al., 2016). These social attitudes can be compounded when a young person identifies as LGBTIQA+. Disability service providers may show more support to the sexuality of heterosexual young people with cognitive disability than to LGBTIQA+ young people (Dinwoodie et al., 2020). This group of young people may struggle to belong in disability services, yet also feel unsupported in LGBTIQA+ services (Miller et al., 2021).

LGBTIQA+ young people with cognitive disability are at higher risk for depression, anxiety, substance abuse, and suicidal ideations and attempts than other groups of young people (Dinwoodie et al., 2020; Stoffelen et al., 2018). They may be subjected to bullying, abuse, and violence from both strangers and acquaintances, and subsequently internalise homophobic attitudes, seldom reporting matters to police. LGBTIQA+ young people may assume that police will be homophobic and discriminatory if they were to disclose their experiences of violence (Pickles, 2021).

1.4 Structure of This Book

Each chapter of this book is prefaced with an accessible Easy English summary. This section provides a road map to the twelve chapters in this book.

Accessible Chapter Summaries

Each chapter of this book is prefaced with an accessible Easy English summary. Easy English is a form of written communication that has been developed within Australia for the last twenty years (Basterfield, 2019). In other countries, such as the United States, United Kingdom, and Scandinavia, the term 'Easy Read' is often used to denote the same process. Easy English is targeted towards people who have limited literacy. This can include people with a cognitive disability, and therefore, the addition of this communication style is important for this book in order for it to reach young people with cognitive disability. These Easy English summaries use short sentences, everyday words, a minimum size fourteen font, and bullet points (Anderson et al., 2017). The summaries have been reviewed by co-researchers with cognitive disability to guide their development.

Chapter Road Map

This work is organised into several thematic chapters. In Chapter 2, 'Violence against Young People with Cognitive Disability', we examine what is known about the nature and extent of abuse experienced by young people with cognitive disability and consider the implications for transition to adulthood. We draw upon both Australian and international literature to look at the difficulties in ascertaining the prevalence of abuse in young people with cognitive disability, and the personal, environmental, service, and system factors that can increase the risk of abuse in this group.

In Chapter 3, 'Working in Partnership with People with Lived Experience: An Inclusive Methodology', we speak to the participatory nature of this study, and outline the research aims, the theoretical framework, and research methods involved in this study. This chapter is an honest reflection on the processes of engaging in inclusive research in an area that is highly sensitive and presents significant ethical complexities. We discuss inclusive research principles and how they relate to our work and include insights from co-researchers with disability on the study.

Chapter 4, 'Amethyst's Story', is an account of one young woman's experience of violence. Amethyst is an Aboriginal and South Sea Islander woman with cognitive disability who shared her account of domestic and family violence, sexual and physical abuse, degradation, coercive control, and exploitation. Her story sets the scene for our book and illustrates how violence cuts across multiple systems and is intimately related to ableism, racism, and gender bias. The story is explained through an ecological intersectional lens, the key theoretical framework of this book.

Chapter 5, 'The Experiences of Young People with Cognitive Disability: The Complex Road to Adulthood', shares the many barriers that young people in our study encountered in emerging adulthood. Ableism in many guises impacted on young people's struggles to assert independence, to develop meaningful relationships, and to navigate adulthood safely. The chapter also highlights the need for cultural safety and respect as well as the need to depart from heteronormative assumptions to allow some young people to explore their sexuality in their own way.

Chapter 6, 'The Many Faces of Violence', outlines violence in many forms. We reveal many incidents of abuse of young people with cognitive disability, including domestic and family violence, physical abuse, emotional and psychological abuse, neglect, exploitation, and sexual assault. While it may appear that the examples given are separate and discrete events, the violence was likely accompanied by other acts of harm. The impact of these events on the transition to adulthood can be cumulative, enduring, and disruptive, and require young people to reclaim their power from the persons and contexts that led to the abuse.

In Chapter 7, 'Young People and the National Disability Insurance Scheme: "The Standard Cookie Cutter Approach"', the reader is introduced to the ways in which service systems may set the context for abuse, neglect, and violence to occur for young people with cognitive disability. Section 7.2 discusses the ways in which the concerns of young people with cognitive disability may be problematised by service systems. The chapter describes the difficulties that can occur when fiscal and managerial considerations of services override fundamental needs of young people. Section 7.3 examines the National Disability Insurance Scheme (NDIS)[2] from the perspective of young people with cognitive disability, family members, and practitioners. Many participants report challenges in accessing the scheme and ensuring supports were appropriate. While many young people were grateful for the supports on offer, further change was needed to ensure

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[2] The National Disability Insurance Scheme is a scheme of the Australian government that provides funding to eligible people with disability.

young people exercised meaningful choice and control over their lives as they transitioned into adulthood.

Chapter 8, 'Don't Give Up on Us: Young People's Experiences of Education and Employment', explores the transition from education to work for young people with cognitive disability. The desire to belong, to have friendships, and to have some certainty and direction when leaving school was evident in young people's accounts. Some young people were able to find paid work after school, but this often did not meet their aspirations. Education and employment experiences often failed to provide the stability and support young people needed to navigate young adulthood.

Chapter 9, 'Housing, Home, and Mental Well-Being: The Need for Self-Determination and Safety', discusses the complexity involved for young people with cognitive disability to access their fundamental rights for safe housing and appropriate mental health support. Many young people were denied access to appropriate, stable, and affordable housing where they could live safely and independently. Others had no choice about whom they lived with, and the combination of these further exacerbated exposure to violence for the young people. The challenges of receiving appropriate mental health support that recognised and accommodated the particular needs of the young person with cognitive disability were also highlighted.

In Chapter 10, 'Young People's Experiences of the Child Protection and Criminal Justice Systems', the complexities involved for young people with cognitive disability who come to the attention of both systems is discussed. The lack of recognition and accommodation of a young person's disability when entering the child protection and criminal justice systems resulted in experiences of abuse, neglect, exploitation, and violence, reflecting systemic level gaps. The cognitive disability of parents was seen as a defining factor in determining their 'fitness to parent', resulting in children being removed from their care. Young people's experiences of the criminal justice system were shaped by the system's lack of understanding of their cognitive disability and an absence of appropriate skills in authorities to respond effectively to this group, thus resulting in further violence and harm.

Chapter 11, 'Having Someone in Your Corner', identifies the importance of appropriate positive social supports for young people with cognitive disability. Access to support at the micro and meso levels was identified as vital to creating a sense of safety, belonging, and connection. Such supports included informal support through family and friends, but also pets, and at a formal level through organisations and services. Importantly, the young people shared that having these supports was key to enabling them to navigate the complexities of multiple systems.

In Chapter 12, 'In the Voices of Participants: What Needs to Change', we come back to the profound human rights violations that young people with cognitive disability have experienced. We focus on what it is that young people with cognitive disability, their families, and practitioner stakeholders say is needed to reduce the violence experienced. We recommend that an integrated strategy across life stages and government agencies is critical to redressing the human rights violations experienced by young people with cognitive disability transitioning to adulthood.

1.5 Conclusion

While the young people who participated in this research desire to be free from violence, they desire more than just that. They desire and are entitled to exercise all their rights and to operate as empowered and equal actors in society. The young people have struggled against profound barriers to exercise family, housing, educational, and economic rights.

This book reinforces and reiterates findings from past research and inquiries in Australia and overseas. This is a stark reminder and, the authors hope, a wakeup call of the devastating impact of current disabling discourses that underpin structures, systems, and processes. These discourses create a culture where violence can thrive and construct young people with cognitive disability as vulnerable and powerless. Australia and other countries need to address unequal power relationships between young people with cognitive disability and others. Young people are our future, and we need to afford them the opportunity to transition into the next great leaders. Laws and policies must protect them, but also empower young people with cognitive disability to become full and equal citizens in society.