UTS UNIVERSITY OF TECHNOLOGY SYDNEY

“My main goal is to get into university”: Post-secondary education journeys of people with Down syndrome

by Fievel Tong

Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

under the supervision of Dr Keiko Yasukawa, Dr Kirsty Young, Dr Roslyn Appleby, and Emeritus Professor Alastair Pennycook

University of Technology Sydney

Faculty of Arts and Social Sciences

June 2025

Certificate of original authorship

I, Fievel Tong, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of International Studies and Education in the Faculty of Arts and Social Sciences at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature: Production Note:
Signature removed prior to publication.

Date: 29/06/2025

Acknowledgements

As much as a great deal of self-determination was required on my part to complete this thesis, the research would not have been accomplished without the widespread support I gratefully received.

I would like to thank Dr Keiko Yasukawa, my principal supervisor, who has been an enduring source of guidance and encouragement over the past four years. Keiko spent countless hours meeting with me, keeping me on track, and reading my work with a keen and critical eye. She could always be counted on to provide timely feedback and advice. Keiko was patient and understanding of the difficulties I faced, while also prodding me to get this thesis done. In all sincerity, Keiko's manner of supervision was the perfect fit for me.

I would like to thank all the members of my supervisory team. Dr Kirsty Young provided many valuable insights from a disability studies perspective. Kirsty's advice throughout the ethics application process was particularly helpful. Dr Roslyn Appleby helped me get started on the PhD journey in 2020 with all the challenges of the COVID-19 pandemic. The ongoing interest that Ros showed towards my work greatly fuelled my confidence and self-belief. Emeritus Professor Alastair Pennycook offered critical and constructive feedback on my research, sharpening my thinking and writing. Alastair's extensive knowledge in the social sciences (and more) provided me with ideas and perspectives that I had not considered.

I have had the privilege of meeting many wonderful people throughout this research. I must thank all the people with Down syndrome and the parents who participated in the interviews. The research would not have been possible

without the time and openness of heart which they gave to me. Not only have I learnt so much from people with Down syndrome and their parents, but I have been incredibly moved and inspired by their stories and experiences. As a parent of a child with Down syndrome, I treasure the words that people with Down syndrome and their parents have shared with me. Participating in the 2024 World Down Syndrome Congress and meeting some of the families in person there was one of the greatest highlights of my candidature. This work has been so much more than just a project, and I hope that this research will contribute to improving the quality of life of people with Down syndrome.

Without the support of a range of stakeholders, this research would not have come to fruition. Professor Rhonda Faragher AO and the team of researchers with Down syndrome offered invaluable feedback on how the research information could be made clearer and more accessible. I would also like to acknowledge the organisations and people who promoted this research within various communities. Down Syndrome Australia, Down Syndrome New South Wales, Down Syndrome Queensland, Celebrate T21, and Council for Intellectual Disability all helped to engage people with Down syndrome and their families with this research. National Disability Coordination Officers (NDCOs), namely Jessica Buhne, Elicia Ford, and Devan Nathan, also assisted in circulating this research throughout their networks.

My parents, Tom and Jaime, have supported me and my family unceasingly. Without their love and care, especially towards our children, this research (and many other things) would still be unfinished. Likewise, Thomas and Lorna, my in-laws, have loved and supported my family immeasurably.

My family have journeyed with me through all the joys and challenges of completing this thesis. Claudia, my wife, always listened with interest to my research. She always believed in me to finish this work. Our children are also to be acknowledged. Ethan helped me stay connected with the world as we cheered and yelled at football and cricket matches in the stadiums.

Meanwhile, Harriet, reminded me of the more tender side of life as we conversed while going shopping or going on walks. And of course, Micah, who lives with Down syndrome, has been the inspiration behind this research. Micah lives in this project and it in him. Not only so, but our family is all the richer because of him.

I dedicate this thesis to people with Down syndrome and their families and supporters all around the world. Your hope, strength, and kindness spur me on.

Statement indicating format of thesis

This thesis is a conventional thesis.

Table of contents

Certificate of original authorship ..... **i**

Acknowledgements ..... **ii**

Statement indicating format of thesis ..... **v**

Abstract ..... **x**

Chapter 1: Breaking down barriers **1**

People with Down syndrome today 1

Self-determination and capital in quality of life 5

Reading Down syndrome research critically 7

Towards a critical sociology of Down syndrome 9

Self-determination and capital in post-secondary journeys 17

Research questions 18

Outline of thesis 19

Chapter 2: Further education fields **22**

Introduction 22

Bourdieu's "field" theory 22

The field of vocational education and training (VET) 26

The field of higher education 39

Implications for research 48

Chapter 3: Living with Down syndrome **51**

Introduction 51

What is "Down syndrome"? 52

Colonialist and neo-colonialist constructions of "Down syndrome" 53

Down syndrome and quality of life 56
Down syndrome and development..... 62
Family background and living with Down syndrome 71
Conclusion 73
Chapter 4: Learners with Down syndrome..... 75
Introduction 75
Inclusive education and learning 76
Characteristics of learners with Down syndrome 79
Early childhood and school-based learning 81
Post-school transitions 87
Post-secondary education 92
Conclusion 102
Chapter 5: Self-determination and capital 104
Introduction 104
Self-determination as “socially formed dispositions and behaviours” 105
Capital as “socially valued resources” 120
Bridging Bourdieu and the self-determinists 135
Conclusion 143
Chapter 6: “I don’t think I’m going to ask that question any more” 145
Introduction 145
Framing the research project..... 147
Reflecting on researcher positionality 153
Introducing the participants 158
Ethical considerations 161
Applying inclusive research principles 164
Doing the interviews 173

Interpreting the interviews 179
Conclusion 184
Chapter 7: "No way could a university drop its bar" 186
Introduction 186
"Just like everybody else" 187
"The course really wasn't appropriate for her" 192
"They're the only avenues for me" 198
Conclusion 206
Chapter 8: "My decision was that I wanted to go to TAFE" 208
Introduction 208
"My decision was that I wanted to go to TAFE" 210
"I'll have to ask mum for that opinion" 219
"I was a bit nervous to go up to the teachers" 231
Conclusion 243
Chapter 9: "It's a bit of whom-you-know" 245
Introduction 245
Family capital 247
Personal embodied cultural capital 264
Conclusion 280
Chapter 10: Navigating post-secondary education fields 283
Introduction 283
Review of research aims 283
Key findings 285
Conclusion 312
Chapter 11: Self-determination and capital in further education journeys 314

Wrapping up the thesis 314
Relating capital and self-determination 314
Summary of main argument 327
Contributions of the research 328
Implications of the research 333
Recommendations for future research 336
Closing remarks 338
References 340
Appendices 381
List of appendices 381
Appendix 1: Research flyer 382
Appendix 2: Participant information sheet and consent form (People with Down syndrome) in Easy Read 383
Appendix 3: Participant information sheet and consent form (People with Down syndrome) 396
Appendix 4: Participant information sheet and consent form (Children with Down syndrome) 402
Appendix 5: Participant information sheet and consent form (Parents and Carers) 408
Appendix 6: Distress and referral protocol 414
Appendix 7: Participant backgrounds 417
Appendix 8: Interview guide (People with Down syndrome) in Easy Read 418
Appendix 9: Interview guide (Parents and Carers) 437
Appendix 10: Sample interview coding 440

Abstract

People with Down syndrome are increasingly participating in mainstream post-secondary education. Yet, the voices and lived experiences of post-secondary learners with Down syndrome remain under-explored. Specifically, little is known about how people with Down syndrome navigate the barriers to further education which are commonly encountered by "disadvantaged learners" in higher education and vocational education and training (VET) fields in Australia. In view of this, the research in this thesis explored the question: How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?

The research adopted a critical disability studies perspective, which entails approaching "disability" as a multifaceted phenomenon unique to each person with disability. An interdisciplinary approach was, therefore, undertaken by integrating "self-determination" (from psychology and disability studies) and "capital" (from Bourdieusian sociology). These concepts formed the theoretical lens for interpreting the interviews with people with Down syndrome and their parents. To ensure that the research would be undertaken ethically and sensitively, important principles from the field of inclusive disability research were applied.

People with Down syndrome and their parents in this study were found to have the capital and self-determination that enabled them to navigate challenges to participating in further education. In this regard, the participants with Down syndrome were seen to hold relative advantages as "disadvantaged learners" within VET and higher education fields. Although self-determination in people with Down syndrome was highly important for their post-secondary learning journeys, it was the capital of people with Down

syndrome and their families that ultimately facilitated further education opportunities and experiences. Family cultural capital was found to be the most important form of capital in fulfilling the self-determination of people with Down syndrome towards further study. Parents who were of professional and well-educated backgrounds were well positioned to support their child's university and VET journeys. At the same time, forms of embodied cultural capital found in people with Down syndrome themselves were also advantageous for further education journeys.

This research proposes a novel way of understanding the post-secondary education journeys of people with Down syndrome by integrating sociological and psychological perspectives. Moreover, the research offers a much-needed sociological emphasis to Down syndrome research more broadly. There are significant implications of the study for a range of stakeholders, including people with Down syndrome and their families and communities, as well as practitioners and policymakers within education fields.

Chapter 1: Breaking down barriers

Introduction and significance

People with Down syndrome today

People with the disability known as "Down syndrome" have, in recent decades, been increasingly participating in and contributing to society across many different social fields. To live with Down syndrome in the 21st century is to live with "greater expectations" (Gothard, 2011). This is because, globally, "[t]he last 60 years have seen significant changes – educational, medical and social – in the lives of people with Down syndrome" (Carr, 2011, p. 28). So significant are the shifts from the individual and societal perspectives that the history of Down syndrome has been referred to as "the story of two syndromes" (Whitten, 2018). There is a major contrast between the institution-era, during which people were segregated from society, and the post-institution-era (beginning from the 1970s and 1980s), which now sees many people with Down syndrome being active citizens in society.

Yet, it is not as though Down syndrome as a chromosomal condition has changed (Wong, 2002). Biologically speaking, Down syndrome has always been a genetic condition in which a person has an extra chromosome 21 (hence the name "trisomy 21"). So, whilst the syndrome itself remains the same, it is the changes in legislation and social attitudes (Carr, 2008) and advances in science and medicine (Brown et al., 2020) that have brought about the increased lifespans and improved quality of life of people with Down syndrome. The reality that sociopolitical developments can impact so significantly on individual potential and well-being is worth reflecting on:

> On a global basis, the availability of early intervention and general services in the lives of people with Down syndrome… has led to outcomes in terms of realising individual potential undreamed of by parents in the early postwar years. International shifts in attitudes to intellectual disability…[,] the potency of training and skill development, the commitment of parent-based support organisations… and the role of the state in providing services cannot be overestimated. Together they continue to raise expectations and generate hope. (Gothard, 2011, p. 183)

In Australia, the National Disability Insurance Scheme (NDIS), while it is not without its shortcomings, has facilitated greater well-being and independence in people with Down syndrome (Down Syndrome New South Wales, 2024).

International and national agreements and legislations have also contributed to greater quality of life for people with Down syndrome and people with disability more generally. The United Nations (2006) Convention on the Rights of Persons with Disabilities (UNCRPD) has provided impetus in signatory countries to promote the full participation of people with disability in all forms of civic life, though much more can still be done in this regard (Tilly & Walmsley, 2024). In Australia, the *Disability Discrimination Act 1992* (Australian Government, 2024) has sought to eliminate discrimination against persons with disability in the areas of education, employment, housing, and other social contexts. Yet, the recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has found that "people with disability continue to be excluded from participating in many areas of life" (Commonwealth of Australia, 2023a, p. 37).

When people with Down syndrome and, more broadly, people with disability are included and supported in and by society, they can attain greater personal outcomes and participation in society. Globally, there has been growing engagement of individuals with Down syndrome across different social fields

and life domains. In the education space, learners with Down syndrome can be found participating in mainstream pre-schools (McCormick et al., 2003), primary schools (Runswick-Cole, 2008), secondary schools (Mullan et al., 2018), and post-secondary education contexts (Faragher, 2023). There have also been significant improvements in the employment participation of people with Down syndrome (Carr, 2011), including in open employment contexts (Brown, 2014). Independent and semi-independent living are also becoming more common among people with Down syndrome (Dalprà et al., 2018; Illarramendi et al., 2002). In the general community, people with Down syndrome are engaging in a range of leisure, sports, and recreational activities (Adorno et al., 2022; Jobling, 2001). As a result of these positive developments, people with Down syndrome are generally experiencing an improved quality of life. The sentiment of "I have a good life" (p. 1296) is shared by many (Scott et al., 2014).

Post-secondary education

Specifically, the field of post-secondary education is one where some people with Down syndrome today are engaging purposefully. Further education is a key post-school transition outcome that contributes to quality of life for adults with Down syndrome (Faragher et al., 2020). People with Down syndrome are participating in further education in ways that challenge the deficit-based assumption that their learning reaches a plateau in adolescence (Moni & Jobling, 2001). Many people with Down syndrome wish to participate in post-secondary education for reasons similar to people without disability, namely to gain employment, to learn something of interest, and to discern what they want to do with their lives (Faragher, 2023).

There is an emerging body of research from the UK (Thomson et al., 1995), the US (Casale-Giannola & Kamens, 2006; Faragher, 2023; Hamill, 2003; Woodward, 2022), Spain (Calderón-Almendros & Calderón-Almendros, 2016), and Australia (Faragher, 2023; High & Robinson, 2021; Messenger et al., 2018;

O'Rourke, 2011) exploring the further education experiences of people with Down syndrome. (This literature is reviewed in detail in Chapter 4.)

Vocational education and training (VET) is the most common type of formal post-compulsory education undertaken by people with Down syndrome in Australia (Down Syndrome Western Australia, 2015; Foley et al., 2013). University is, nonetheless, now regarded as "increasingly possible" (Faragher et al., 2020, p. 36). Rachel High from Australia (High & Robinson, 2021), Charlotte Woodward from the US (Woodward, 2022), and Rafael Calderón-Almendros from Spain (Calderón-Almendros & Calderón-Almendros, 2016) are all recent university graduates with Down syndrome. People with Down syndrome have also participated in university inclusion programs as audit students (Casale-Giannola & Kamens, 2006; Hamill, 2003; Messenger et al., 2018; O'Rourke, 2011).

In Australia, people with Down syndrome can participate in further education programmes specially designed for people with intellectual disability. These initiatives include the community-based adult literacy and numeracy programme called Latch-On (Moni et al., 2018) and two university-based inclusion programmes, namely The Up the Hill Project (Rillotta, Arthur, et al., 2020) and uni 2 beyond (Gadow & MacDonald, 2018). Evidently, then, people with Down syndrome can engage in post-secondary education when provided with the right supports.

Despite the expansion of literature in the past two decades, the voices and lived experiences of post-secondary learners with Down syndrome remain relatively under-explored. More importantly, the field remains under-theorised. There is a need, therefore, to further research the VET and higher education journeys of people with Down syndrome, using theoretical concepts that can produce novel knowledge on this topic. "Self-determination" and "capital" are two concepts suitable for this task. Indeed, whether explicitly or implicitly, self-determination and capital have both been

used in research concerning people with Down syndrome and their quality of life.

Self-determination and capital in quality of life

The well-being of people with Down syndrome is shaped by a range of different factors (Haddad et al., 2018). Some determinants relate closely to personal characteristics and behaviours, whereas others are sociocultural and sociological in nature. The individual and social factors are, however, interrelated. In this thesis, both "self-determination" and "capital" are defined in individual and social terms. Self-determination is defined as "socially formed dispositions and behaviours", whilst capital is defined as "socially valued resources". (See Chapter 5 for a detailed discussion.) Both self-determination and capital are vital for personal well-being and quality of life for people with Down syndrome.

As self-determination theorists in disability research like Wehmeyer (2003a) argue, quality of life can come about as a person with disability lives in ways that are determined by oneself. For instance, being able to make choices about work improves the employment outcomes of people with Down syndrome (Bush & Tassé, 2017). Satisfaction towards one's housing status is shaped by the degree of choice towards where and how one prefers to live (McGinley, 2002). Young people with Down syndrome who are involved in decision making are more likely to have "better" post-school outcomes (i.e. to be engaged in VET and/or open employment) (Foley et al., 2013). Yet, self-determination cannot be seen as solely an individual construct. Disability theorists also argue that self-determination can be supported and/or hindered by one's social environments (Abery & Stancliffe, 2003a; Wehmeyer & Abery, 2013).

Moreover, quality of life is dependent on the resources (i.e. capital) that a person with Down syndrome has access to. As Bourdieu (1986) theorises,

possessing capital provides one with advantages for navigating social fields. As such, enhanced well-being has been reported by people with Down syndrome whose families have higher levels of income, have access to savings, and/or live in or near a city (economic capital) (Haddad et al., 2018). Having supportive social networks (social capital) enables families to have greater resilience and well-being (Choi & Yoo, 2015). Meanwhile, being part of a non-White ethnicity in the US (i.e. not having a particular type of cultural capital) has been found to impact negatively on the health care received by people with Down syndrome (Krell et al., 2023). Clearly, thinking in terms of Bourdieu's "capital" uncovers the reality that there are social inequalities across different families within Down syndrome communities.

Since capital and self-determination both shape personal well-being and outcomes in people with Down syndrome, it is necessary to explore the interrelationships between these two determinants of quality of life. A particular consideration is how capital and self-determination interrelate to shape post-secondary education journeys of people with Down syndrome. This issue was alluded to in Taylor et al.'s (2019) research, which explored how an individual's self-determination is supported by family resources. The research found that the decision of a young person with Down syndrome to attend college (self-determination) was fulfilled only because the family had the financial resources to relocate to live closer to the college (capital). Similarly, Foley et al. (2013) have found that young people with Down syndrome who undertake further education, namely VET, tend to be those who engage in decision making and who come from non-disadvantaged backgrounds.

Therefore, self-determination in people with Down syndrome towards further education requires the support of both family and personal capital for it to be fulfilled. As Trainor (2008) states in relation to post-secondary transitions for young people with disability, "[i]n order for students to practice self-

determination, both social and cultural capital are necessary" (p. 154). When it is defined in individual terms, self-determination alone is, therefore, not sufficient to ensure that people with Down syndrome gain access to VET and higher education opportunities.

The ways in which self-determination and capital interrelate to facilitate further education for people with Down syndrome remain in need for further study. Addressing this issue can contribute to the much-needed theorisation of VET and higher education journeys that people with Down syndrome undertake. Significantly, exploring post-secondary education in such a multidimensional manner requires the use of a research approach, such as critical disability studies, which can draw critically from varied academic disciplines. Before explaining what a critical disability studies approach in this thesis entails, it is necessary to justify the need for such an approach in Down syndrome research. By doing so, the significance of this research within the existing field of Down syndrome research is also stressed.

Reading Down syndrome research critically

The field of "Down syndrome research" is a rather diverse one. Researchers of many different disciplines engage in research on the condition itself and/or the lived experiences of people with Down syndrome. The position taken in this thesis is that, as per the critical disability studies approach, it is valuable to explore the many varied aspects of living with Down syndrome by drawing upon a range of explanatory theories. Undoubtedly, a researcher has their own subjectivities and research purposes, but this reality should not prevent them from engaging with literature emerging from other fields. There can be value in gleaning from others who are potentially ontologically, epistemologically, and/or methodologically at odds with one's own position/s.

The history of Down syndrome developmental research has been helpfully outlined by Burack et al. (2023) and can be summarised as follows. There have been two distinct (but not mutually exclusive) streams within research on the development of people with Down syndrome, both of which continue to shape contemporary study. The first was initiated by Janet Carr, a clinical psychologist who joined a longitudinal study in 1963 researching newborns and infants with Down syndrome in the UK. Carr's work spanned more than half a century and explored "virtually all areas of functioning for persons with Down syndrome from infancy to 50 years of age" (Burack et al., 2023, p. 21). Her holistic research covers diverse domains of life, such as personal growth, relationships, education, and employment, as well as environmental factors that impact on these life domains. The global Down syndrome communities continue to be indebted to Carr's expansive work (Faragher, 2023).

The second major tradition in Down syndrome developmental research, as Burack et al. (2023) explain, derives from Edward Zigler and Dante Cicchetti, both developmental psychologists. At around the same time as Carr's early work, Zigler theorised a developmental approach to the study of people with intellectual disability. Importantly, Zigler argued that developmental theory should and could be applied to all children, counter to the "defect theories" that sought to differentiate people with intellectual disability from the general population. Like Carr, he also took a whole-person approach in his work. Drawing upon Zigler's ideas, Cicchetti and Beeghly (1990) applied the developmental approach to people with Down syndrome specifically.

While this thesis owes much to the quantitative research derived from the above developmental approaches to Down syndrome research (see Chapters 3 and 4), it also engages with this literature through a critical and interpretivist lens.

In this regard, the work of Christopher Kliewer is worth discussing. Kliewer's research does not appear to receive much attention by others in Down

syndrome research, save for Moni and Jobling's (2014) chapter, which draws on both Kliewer's and Carr's work. Kliewer (1998) is concerned that research from developmental traditions can inadvertently be used as justification for excluding people with Down syndrome from literacy opportunities. Importantly, Kliewer (1995) references some of the authors within the developmental traditions but in a somewhat critical manner. In contrast to positivist developmental research that tends toward essentialising learners with Down syndrome, Kliewer's critical-interpretivist ethnography argues that disabled identities are always contested and contingent:

> Rather than creating a cohesive categorical illustration of understanding regarding practices for the education of children with Down syndrome, a common approach in Down syndrome texts (Cicchetti & Beeghly, 1990…), my observations yielded unstable, shifting, fluid images rife with tension over who belonged in particular classrooms, exposed to what content, and taught in what manner. (Kliewer, 1995, p. 340)

Towards a critical sociology of Down syndrome

The scholarly field known as "critical disability studies" provides a useful framework for investigating the further education experiences of people with Down syndrome. Critical disability studies represents a shift in disability research towards interdisciplinarity and postconventionalism (Shildrick, 2020). Within the framework, "disability" is conceptualised as a complex, multifaceted phenomenon. Disability is bodily and personal but, at once, also sociocultural, political, and structural (Meekosha & Shuttleworth, 2009).

Notably, critical disability studies draws heavily upon the "social model" of disability (Goodley, 2013; Meekosha & Shuttleworth, 2009). This model contends that "disability" is not caused by a person's impairment but by the structural barriers and social discrimination mounted against people with

impairment (Oliver, 1996). To research disability-related issues in this way is to adopt a critical sociology (Shuttleworth & Meekosha, 2012). Disability is not simply one's physiological makeup, but it is the product of being rendered disabled by social and institutional norms and structures, particularly within capitalist and late-capitalist societies (Goodley, 2011). At the heart of critical sociological disability studies is "a conviction that the world is an inherently unequal place" (Goodley, 2011, p. 57). This thinking is in concert with a central tenet of French sociologist, Bourdieu, that the values and norms of the dominant groups in society are legitimised and (re)produced in and through social fields (Bourdieu & Passeron, 1977). The benefit of adopting a Bourdieusian frame of reference to disability inquiry is stated by Paterson (2020): "Applying Bourdieu to disability, one can take account of the ways in which socio-structural inequalities between disabled and non-disabled bodies are 'naturalised' and viewed as pre-social" (p. 213).

One must, therefore, critique the socio-politics of Down syndrome operating today. Notwithstanding the positive developments in their participation in society, people with Down syndrome continue to face prejudicial discourses and inequalities across social fields. At birth, infants are discursively framed as "deviance" and "a tragedy", as Gabel and Kotel (2018) have found. Deficit discourses and "othering" discourses are routinely reproduced by medical texts such as the MSD Manual: "Down syndrome affects multiple systems and causes both structural and functional defects" (Powell-Hamilton, 2023). Furthermore, such institutional ableism is mirrored in everyday ableist discourses. "Downs people are just a drain" and "DS PEOPLE – NEVER live a proper quality life vs someone without – that is FACT" (p. 294) are just two of the many prejudicial Facebook comments uncovered by Johnson and West (2021). Additionally, some ableist discourses are shaped by capitalist and neoliberal ideologies. As Lalvani (2011) argues, "in a society that holds financial worth as a criterion for success, individuals with Down syndrome are unlikely to be valued as citizens" (p. 286). So, whilst people with Down

syndrome and their allies have broken down many significant barriers to their participation in society, stigma and discrimination persist in social fields.

Sociology and critical disability studies are both interested in hope, resistance, and social transformation, as much as they are concerned with power and ideology (Goodley et al., 2019). Discourses of a "positive" or "resistant" nature do exist. Declarations by people with Down syndrome such as "I have a good life" (Scott et al., 2014, p. 1296) encapsulate a challenge to dominant deficit-based discourses. Families might initially be "shocked" by the "diagnosis" that their newborn has Down syndrome, but they may soon be able to contest the normative discourses on Down syndrome which had once shaped their own attitudes (Ordem, 2018). Advocating for people with Down syndrome is, however, an uneven playing field. Some families are better positioned than others to resist deficit discourses. Lalvani (2011) and Gabel and Kotel (2018) have found that mothers who are well educated and of White, middle- to upper-middle-class backgrounds are better equipped to challenge discriminatory stereotypes.

It is essential that more Down syndrome research be carried out in this critical sociological vein. The research in this thesis explores the post-secondary education journeys of people with Down syndrome in such manner. By doing so, the thesis can expand the field of Down syndrome research in novel ways. A significant aspect of the study's originality lies in its integration of two concepts derived from rather divergent disciplines, namely sociology and psychology.

Intersecting Bourdieu's sociology with psychology

Introduced earlier were two key concepts, "capital" and "self-determination", that give insight into quality-of-life concerns for people with Down syndrome, including in their participation in further education (e.g. Taylor et al., 2019). Capital and self-determination both have a broad range of meanings,

depending on the fields in which they are referred to. As used in this thesis, however, the two concepts are derived from the fields of sociology and psychology, respectively. Specifically, "capital" has been theorised by the French sociologist, Pierre Bourdieu (1986), whereas "self-determination" has been conceptualised by disability scholars such as Wehmeyer, Abery, Mithaug, and Stancliffe (Wehmeyer et al., 2003).

As a sociological construct, "capital" explains how individuals are advantaged (or disadvantaged) in social fields depending on the resources they have (or do not have) to compete with other people in those fields (Bourdieu, 1986; Wacquant, 1989). This state of affairs contributes to the social reproduction of inequalities, since those without the dominant forms of capital will continue to be less competitive and accomplished or be misrecognised as such by the dominant groups (Bourdieu & Passeron, 1977). Moreover, human behaviour (e.g. choice making and decision making) is always constrained by one's access to capital (Bourdieu, 1998).

In contrast, "self-determination", as a psychological construct, refers to volitional actions that enable a person with disability to act as the main causal agent in their life (Wehmeyer, 2005). To live in a self-determined way is to exercise one's fundamental human rights, including freedom and the power to act (Abery & Stancliffe, 2003a). At the same time, self-determination can be facilitated and/or obstructed by one's environment (Abery & Stancliffe, 2003a, 2003b). Much more can be said about self-determination theories (see Chapter 5). It would appear, however, that self-determination theories are strongly shaped by liberal theories of the self. For self-determination theorists, Mithaug et al. (2002), behaviours such as choice making and decision making are understood from the viewpoint of political theorist, Jon Elster (1986). Elster's rational choice theory states that individuals have agency to make decisions that they perceive will generate the most gain. Clearly, there are inherent tensions between Bourdieu and the theorists of

self-determination and rational choice. In fact, Bourdieu (1998) and Elster (1986) have each critiqued the perspective of the other.

Intersecting sociology and psychology can, therefore, be problematic because of their somewhat divergent histories and viewpoints, and doing so can risk eroding the disciplinary distinctions of each field (Brossard & Sallée, 2019). In very broad terms, psychology has traditionally tended to focus on the human individual, whereas sociology has traditionally investigated how society and culture determine human psychology (Harlak, 2022).

One issue with traditional psychology is that it has had a tendency to construct disability as a pathological problem and as a deficiency within an individual (Goodley, 2020). Traditional psychology typically defines "what is *required* to be an individual… the accepted individual of contemporary society" (Goodley, 2020, p. 366, emphasis in original). Psychological treatment and intervention tend to target the individual, leaving the social world in its status quo.

There are, nonetheless, critical and sociological strands of psychology that are more aligned with Bourdieusian thinking. Goodley (2018, 2020), who is himself a psychologist-turned-sociologist, has outlined how psychology might be useful for critical disability studies. Critical psychology (Goodley, 2011) can, for instance, deconstruct the notion of "resilience" by rejecting an individualistic understanding founded on ableist norms and by reconceptualising "resilience" as "having access to a range of resources which allow a person to describe themselves as living well" (Runswick-Cole & Goodley, 2013, p. 76). Similarly, community psychology recognises not only that people with disability wish to live with autonomy and self-determination, but that attaining such a life is a communal project and not an individual one (Goodley et al., 2017). Finally, sociological psychology involves macro analyses of power and ideologies, with attention to how social identities and positions impact on human psychology (Crawford & Novak, 2018).

So, possibilities exist for critically integrating sociology and psychology in critical disability research. Doing so is to adopt Shildrick's (2020) "postconventionalist" approach, which requires a disability researcher to "consciously engage with all the theoretical resources available" (p. 34). Interdisciplinary research, as undertaken by this thesis, helps to capture the uncertainties and contradictions of living with disability (Goodley, 2018). To analyse the VET and university experiences of people with Down syndrome, this study draws upon both psychology and sociology but with an emphasis on the latter.

Bourdieu's "habitus"

Notably, Bourdieu himself has called for psychology and sociology to find common ground to strengthen analyses of the social world: "Sociology and psychoanalysis should unite their efforts (but it would be necessary for them to overcome their mutual prejudices) to analyze the genesis of the investment in a field of social relations" (Bourdieu, 1997, p. 198-199, as cited in Lahire, 2019, p. 69). Bourdieu's own work, particularly his theorising of "habitus", can be interpreted as an attempt to bridge the two disciplines (Wagner & McLaughlin, 2015).

For Bourdieu (1977b), "habitus" refers to "a *predisposition*, *tendency*, *propensity*, or *inclination"* (p. 214, emphasis in original) of one's body and mind (Bourdieu, 1977b). It is, at once, also a social and sociological phenomenon. Habitus is the product of the internalisation of society's objective structures into the human body. It is "the social made body" (p. 127) and "the social embodied" (Bourdieu & Wacquant, 1992, p. 128). From a psychological perspective, habitus refers to how people tend to think and behave in certain areas of life. From a sociological perspective, habitus is structurally oriented, because human psychology is always constrained by culture and society. The family and school environments are the most

significant social fields in which one's habitus is shaped in a long-lasting manner (Bourdieu & Passeron, 1977).

Significantly, Bourdieu's framing of habitus in terms of "predispositions" provides a crucial link between his sociology and the self-determination theories of disability scholars. As stated earlier, this thesis defines self-determination as "socially formed dispositions and behaviours". This understanding is derived from the work of Wehmeyer (2003a), who explains, "We have categorized self-determination as a dispositional characteristic; that is, people who consistently engage in 'self-determined behaviors' can be described as self-determined" (p. 179). These and other theoretical concerns are explored at length in Chapter 5.

The main point to understand, at this stage, is that the implication for this thesis is to explore whether some people with Down syndrome might be "predisposed" towards post-secondary education. Furthermore, how those predispositions are formed within home and school contexts also need to be researched.

Bourdieu's "field" and "capital"

Habitus is closely connected to Bourdieu's concept of "field", because it is "the product of the work of inculcation and appropriation" (p. 85) of the norms and values of social fields (Bourdieu, 1977b). Bourdieu's notion of "habitus" operates alongside "capital" and "field" as "thinking tools" for analysing the social world, particularly the reproduction and maintenance of social inequalities (Grenfell, 2012b). It is helpful, therefore, to briefly explain Bourdieu's "field", along with "capital". The discussion is not only of theoretical interest. On the contrary, the concepts inform the research questions in this thesis, which are soon to be outlined.

In Bourdieu's thinking, a "field" is a social space in which human actors operate (Thomson, 2012). A field consists of structured and hierarchised

relations between groups and individuals (Wacquant, 1989). Each field (e.g. the education field) has particular ways of operating, which are determined by the hierarchical positions of the human actors and their unequal relations with one another. Bourdieu's "field" emphasises, therefore, the inequalities that exist within social spaces and, more importantly, the reproduction of social inequalities within society. Thinking in Bourdieu's way can uncover the persistent barriers and inequities faced by people with disability within VET and higher education fields in Australia (Department of Education, 2024b; Parliament of Victoria, 2021). This topic is examined in Chapter 2. The implication of understanding analysing VET and higher education sociologically as fields is that research must be undertaken to explore the systemic barriers that hinder people with Down syndrome from participating in further education.

Like players on a sporting field, human actors compete for what is at stake in a field, namely "capital" (Thomson, 2012). Some players (the "dominant") enter the field with an advantage, because they already possess more of the very capital on which that field is established. In education systems, students of the dominant social class are at an advantage, because they hold the appropriate cultural capital for performing well academically (Bourdieu & Passeron, 1977). Meanwhile, students of "lower" classes are disadvantaged by not having been socialised with/by those norms on which education systems are built (Bourdieu & Passeron, 1977). So, cultural capital serves to explain the inequalities that cause students of "lower" social classes to have less academic success compared to learners of "higher" classes (Bourdieu, 1986). Moreover, students whose families have access to economic and social capital possess additional advantages within education fields (Bourdieu, 1986).

By utilising Bourdieu's notion of "capital", this thesis can generate new knowledge on how some people with Down syndrome might possess forms of

capital that are advantageous for participating in further education. That is, some people with Down syndrome might be better positioned to navigate barriers within VET and university fields because of their family and personal resources.

Self-determination and capital in post-secondary journeys

Before outlining the research questions of this thesis, it is beneficial to apply the concepts of "self-determination" (Wehmeyer, 2003a) and "capital" (Bourdieu, 1986) to just one existing study on post-secondary journeys for people with Down syndrome. A recent study by Taylor et al. (2019), already mentioned earlier, has made a significant finding that is useful for putting together several key issues explored in this introductory chapter. The study foregrounds the self-determination of Kimberley, a young Canadian with Down syndrome, towards going to college. Concurrently, the actions of the family in helping Kimberley to fulfil her self-determination are also emphasised. Initially, the goal of going to college was difficult to attain, because the family lived in a rural area two hours away from the college. The family overcame this barrier using their capital:

> They belong to racial and linguistic majorities, benefit from formal and informal support networks and have high socioeconomic statuses. Their resources to rent… new housing proved essential to successful transitions… The young adults with [intellectual disability] in these families are high functioning, verbal and physically healthy. (Taylor et al., 2019, p. 1125)

Bourdieu's (1986) understanding of "capital" holds explanatory power for further theorising Taylor et al.'s (2019) conclusion. That is, Kimberley's family held "cultural capital" (by being part of racial and linguistic majority groups), "social capital" (by having support networks), and "economic capital" (by having high socioeconomic status). Kimberley herself possessed "embodied

cultural capital" in the form of being "high functioning, verbal and physically healthy". These forms of capital all enabled Kimberley's self-determination towards college to be realised.

A question that needs to be further explored is how these forms of capital interrelate to facilitate the post-secondary learning experience. It is crucial to research, for instance, whether one form of capital (i.e. economic, social, or cultural capital) is particularly effective in enabling further education journeys for people with Down syndrome. Furthermore, it is also necessary to understand the interactions between family capital and personal capital in facilitating these post-secondary journeys.

Research questions

Considering the above analysis, the research questions addressed in this thesis are now outlined. The main purpose of this research is to explore the lived experiences of people with Down syndrome within the field of post-secondary education.

The main research question addressed is:

- How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?

Exploring this question can contribute significant knowledge by theorising a topic that is currently both under-researched and under-conceptualised in the existing literature.

The principal question is supported by several sub-questions concerning self-determination, capital, and the fields of further education in Australia. The order of the sub-questions follows a particular logic: Post-secondary education fields (sub-question 1) are contexts in which self-determination (sub-question 2) and capital (sub-questions 3 and 4) operate:

1. How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?

2. How do people with Down syndrome exercise and develop self-determination throughout their further education journeys?

3. How do different forms of capital (i.e. economic, cultural, and social) interrelate to enable post-secondary education journeys for people with Down syndrome?

4. How does embodied cultural capital in people with Down syndrome facilitate further education opportunities?

Outline of thesis

Chapter 1 situates this research within the context of the growing participation of people with Down syndrome in society, including in the field of post-secondary education. The chapter presents the need to explore further education journeys of people with Down syndrome within a critical disability studies framework, incorporating sociological and psychological concepts, namely capital and self-determination respectively.

Chapter 2 surveys the fields of vocational education and training (VET) and higher education in Australia. The chapter presents the contextual background of the study, emphasising the barriers and opportunities that people with disability encounter in these fields according to VET and higher education reports.

Chapter 3 analyses the existing literature on the broad topic of living with Down syndrome by using a lifelong and lifewide approach to research. The chapter explores topics surrounding the quality of life and developmental outcomes of people with Down syndrome with reference to how these are shaped by self-determination and capital.

Chapter 4 analyses the existing literature on the topic of learners with Down syndrome. The chapter places an emphasis on post-secondary students with Down syndrome, highlighting the roles that self-determination and capital play in further education journeys.

Chapter 5 establishes the theoretical framework within which the research is conducted. The chapter explores in detail the ideas of "self-determination" (a psychological construct adopted by disability theorists) and "capital" (as used by the French sociologist, Pierre Bourdieu), which form the lens through which the interview data is analysed.

Chapter 6 outlines the research methodology used in this project, drawing attention to the unexpected challenges and opportunities that arose during the participant interviews. The chapter highlights the importance of inclusive disability research and how this study was made more accessible for people with Down syndrome and their parents.

Chapter 7 presents findings on how the research participants with Down syndrome and their parents perceived and experienced post-secondary education as a "field". The chapter examines how notions such as "meritocracy", "excellence", "equity", and "inclusion" were constructed and/or contested by the interviewees.

Chapter 8 presents findings on how people with Down syndrome exercised and developed self-determination in further education contexts. The chapter explores some of the complexities surrounding how that self-determination was supported and/or redirected by parents and other stakeholders.

Chapter 9 presents findings on how various forms of family and personal capital facilitated post-secondary education journeys for people with Down syndrome. The chapter examines how capital was acquired and whether some forms of capital were more productive than others in supporting further education experiences.

Chapter 10 summarises the key findings of the research with reference to the four sub-questions which guide the study. The chapter discusses how the key findings relate to existing literature in Down syndrome research, literature on post-secondary education fields in Australia, and existing theories on self-determination and capital.

Chapter 11 addresses the overarching research question by explaining how self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome. The chapter also proposes several implications of the research and suggests areas in need of further investigation.

Chapter 2: Further education fields

Background of VET and higher education in Australia

Introduction

This chapter outlines the contextual background of this study by surveying the fields of VET and higher education in Australia. It begins with an explanation of Bourdieu's understanding of "field" as sites on which social injustices are produced and maintained. The concept is then used to analyse reports and discourses on further education systems in Australia. In particular, the chapter highlights the longstanding barriers and inequities that people with disability have encountered in their access of and participation in university and VET in Australia, as well as their outcomes gained from these fields. The chapter, moreover, provides further background to the first sub-question in this thesis: How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?

Bourdieu's "field" theory

As explained in the previous chapter, a "field" is essentially a social space in which human actors operate and interrelate (Thomson, 2012). Examples of social fields include the economic field and the education field. According to Bourdieu, a field is governed by hierarchised relations between groups and individuals (Wacquant, 1989). In a field, human relations are defined in terms of "domination, subordination, or equivalence" (Jenkins, 1992, p. 53). Each field (e.g. the education field) has particular ways of operating, which are determined and imposed by the dominant groups in the field.

Fields are sites of competition and contestation, where "[t]hose who dominate in a given field are in a position to make it function to their advantage" (Wacquant, 1989, p. 40). Because the dominant groups already possess more of the very capital on which a field is established, they are better positioned to further accumulate capital in that field. Inequality is, therefore, socially (re)produced through the unequal distribution and acquisition of capital within fields.

The field of education is a focal point of Bourdieu's critique. Bourdieu perceived education as "a mechanism for consolidating social separation" (Robbins, 2012, p. 28) between social classes. Students of the dominant social class are advantageously positioned to perform well academically, because they have already been socialised by the norms and values upon which education systems are built (Bourdieu & Passeron, 1977). The separation between the dominant and non-dominant classes would, therefore, continually be reproduced in the social structure through what appeared to be a purely merit-based system. Although his research revolved around social class, Bourdieu's critique can rightly be extended to disability identities (Paterson, 2020). That is, through their structures and pedagogies, education fields can be said to privilege "able-bodied" students, with the result that students with disability face persistent barriers and inequities in their learning (e.g. Australian Institute of Health and Welfare, 2024).

The field of education, while appearing democratic and inclusive, is not free from the workings of power and ideology. Within the context of post-war France in which Bourdieu worked, education (particularly university) became seemingly more open and accessible for all but, in reality, the rules and standards that were imposed upon all students were modelled on upper- and middle-class norms (Schubert, 2012). Bourdieu himself experienced education as "a double-edge sword" (Grenfell, 2012a, p. 17), a field in which one simultaneously faces inequality, discrimination, inclusion, and

opportunity. Completing his university education required Bourdieu to migrate from a rural area to Paris, which caused him to feel a sense of otherness because his attire, accent, and social standing all differed from his peers who had been brought up in Paris (Grenfell, 2012a). Indeed, Bourdieu had not appeared to be a likely candidate for higher education because of his family background (Grenfell, 2012a). In contrast to his parents' education attainment, however, Bourdieu's academic potential earned him entrance into a prestigious preparatory school followed by a distinguished university.

At first glance, there are tensions between Bourdieu's own education experiences and his later scholarly theorising. As Thomson (2012) notes, Bourdieu's social mobility as a university student with a rural background was facilitated by the very system that he eventually critiqued, particularly with reference to the ideology of meritocracy. Bourdieu's own experience seems to run counter to his central idea that some individuals gain academic advantages because of certain economic, social, and/or cultural privileges which they inherit from their family, since he himself succeeded without many of those forms of capital. These tensions, however, can be explained using the idea of "controlled mobility" (Bourdieu & Passeron, 1977, p. 54). That is, social structures operate in such a way that those who attain social mobility are those who can assimilate to the dominant norms and values of social fields. By allowing only select members of dominated groups to be socially mobile and denying it "to the class as whole" (p. 54), education fields perpetuate class structures and inequalities within the social world (Bourdieu & Passeron, 1977).

Bourdieu's work dispels conventional ideas on the education system as being a "meritocracy", a system where student performance is the sole determinant of academic success (Thomson, 2012). Those who succeed in education are, in fact, those who are "privileged" (p. 210) and mistakenly believe that they entirely merited their achievements (Bourdieu & Passeron, 1977). What

renders a person privileged is their prior possession of the forms of capital on which education fields are built. For Bourdieu (1998), the idea of "learner aptitude" cannot be separated from social, economic, and cultural disparities that give rise to differences in aptitude between social classes.

Although he has a strong emphasis on the social reproduction of inequalities, Bourdieu's perspective is not to be understood as being entirely deterministic (Thomson, 2012). All social fields are sites of struggle and potential change, as brought about by "the resistance of the dominated" (Bourdieu & Passeron, 1977, p. viii). All fields possess a "dynamism and malleability that avoids the inflexible determinism of classical structuralism" (Bourdieu & Wacquant, 1992, p. 18). The improvements in the quality of life and social inclusion of people with Down syndrome in recent decades are evidence that social fields can and do change for the better.

Now that a working understanding of Bourdieu's sociology of "field" has been established, the chapter can now explore the primary field of the thesis, namely post-secondary education in Australia. A Bourdieusian perspective on "field" is adopted in the following analysis to emphasise the inequities and barriers that are encountered by post-secondary learners with disability. The possibilities of inclusion and equity for people with disability in Australian VET and higher education fields are also discussed.

In Australia, post-secondary education consists of VET and higher education. It has, however, been recognised that holding a strict distinction between the two tertiary systems is a somewhat outdated perspective (Gonski & Shergold, 2021), reproducing societal perceptions towards the two fields, namely that VET is less valuable than higher education (Hodge et al., 2022). For instance, higher education degrees can be undertaken in VET colleges, though such qualifications are often devalued compared to degrees gained at universities (Webb, 2022). These issues aside, VET and higher education in Australia are

each governed by their own regulatory systems, so they are discussed in turn, with a focus on learners with disability.

The field of vocational education and training (VET)

The VET sector is considered to be a "pillar" in the Australian education system, economy, and society (Joyce, 2019; Productivity Commission, 2020). VET provides a range of benefits to individual learners, business and industry, and the government and economy (Griffin, 2016). The national VET system, established in 1992, is designed to be centralised and coordinated but also flexible and responsive to the training needs of individuals, communities, and industries (Bowman & McKenna, 2016).

Equity in VET

Equity has long been a focus of VET policies and reforms. The sector plays a key role in improving education and employment outcomes for "disadvantaged groups" (Lamb et al., 2018). Specifically, VET can close the gap between people with and without disability because of VET's relatively high accessibility, compared to the university sector (Polidano & Mavromaras, 2011). Yet, equity in and through VET remains unfinished business. Butler and Ferrier (2022) have charted the progress of equity frameworks and documents in Australia from the 1970s to today, stating that the past decades of VET reform have seen "grand statements, greats hopes and far too many disappointments" (p. 1).

Additionally, the notions of "equity" and "disadvantaged learners" are both contested within VET discourses. As Butler and Ferrier (2022) argue, "[w]here 'equity' can be found, it is most often framed within deficit discourses" (p. 7). Deficit discourses within VET frame "disadvantage" as a problem located within the individual (Butler & Ferrier, 2022). The deficit-based view is directly

challenged by the now-dissolved National VET Advisory Council (NVEAC) in their equity blueprint:

> Rather than positioning disadvantaged learners as the problem and requiring them to change to fit VET's current systems..., NVEAC contends that these systems... themselves need to change. A more equitable VET system will enable... [disadvantaged learners] to... participate... and achieve outcomes in the same way as people who... are not disadvantaged by our social, cultural and economic systems. (National VET Equity Advisory Council, 2011, p. 3)

Whilst VET discourses have sought to delineate distinct categories of "disadvantaged learners" (e.g. people with disability and First Nations peoples), it is essential to understand that disadvantaged groups cannot, in reality, be neatly categorised. To be a "disadvantaged learner" is a complex phenomenon, especially since many learners experience multiple forms of disadvantage (National VET Equity Advisory Council, 2011). In theoretical terms, the idea of "intersectionality", as developed by Crenshaw (1989), explains that a person's markers of social identity (e.g. gender, class, ethnicity, and disability) interrelate in complex ways to produce various experiences of disadvantage and oppression, including within VET contexts (Butler & Ferrier, 2022).

This is an area of concern that some VET reviews have acknowledged (e.g. Bruniges et al., 2023), but one that remains relatively under-explored. There is a need, therefore, to investigate how some people with disability in VET might be further disadvantaged because of their social backgrounds, whilst other people with disability might actually be advantaged (relative to others with disability) because of their other identity markers. This issue is important in this thesis because, as mentioned earlier, people with Down syndrome experience different life outcomes depending partly on their sociocultural and economic backgrounds.

Barriers to VET participation

Despite the grand narrative of VET being a place of inclusion, inequities continue to operate in the field (Butler & Ferrier, 2022). Several issues have been identified as barriers that hinder people, particularly those from disadvantaged backgrounds, from accessing and participating in VET.

The need for prospective learners to have an adequate level of literacy and numeracy skills is an issue highlighted in multiple VET reports (e.g. Bruniges et al., 2023; Joyce, 2019; Productivity Commission, 2020). Language, literacy, numeracy, and digital (LLND) skills are known as "foundation skills" within the VET sector, because they enable a person to engage in employment and further study (Bruniges et al., 2023, 2024). Since people with disability tend to have lower levels of prior educational attainment (Cavallaro et al., 2005; Karmel & Nguyen, 2008), it is expected that they would be particularly disadvantaged when encountering literacy and numeracy barriers within VET. Significantly, literacy and numeracy barriers can be structurally and institutionally produced, as in the case of "training methods that are not tailored to… Indigenous Australian learners" (Joyce, 2019, p. 107). Therefore, it is necessary to provide wide-ranging supports to learners who face difficulties with foundation skills, instead of viewing the learners as the "problem" (Lamb et al., 2018).

Another barrier to VET participation relates to aspects of self-determination, chiefly learner choice making and decision making. As Woolcott Research (2017) has found, poor VET participation and completion can be caused by poor student choices, which themselves may be due to students' lack of direction before enrolling, inadequate support given to students' decision making, and/or the lack of required information to inform students' choice making. The Productivity Commission (2020) has identified a number of systemic issues that hinder people, particularly disadvantaged groups, from making informed VET decisions. Within the VET field, there is, paradoxically,

“too much and yet not enough” (p. 200) information on courses and colleges. People have reported being unable to access key, basic information that would aid in their decision making. Prospective learners “navigate through a maze of information sources” (p. 191) while trying to commence their VET journey. Every individual learner has unique information needs, so it is necessary for VET colleges and practitioners to provide person-centred study and career guidance (Bruniges et al., 2023), especially to disadvantaged groups (Productivity Commission, 2020).

Other stakeholders also play a role in students’ choice making. Parents and carers significantly shape learner choices, so it is important that families have accurate information about and correct perceptions of VET (Bruniges et al., 2023; Hodge et al., 2022). Schools are another important source of VET information and guidance for young people (Joyce, 2019).

While increasing student agency is a cornerstone of VET policy, prospective learners are often restricted in their choice making (Brown, 2017). The shortcomings of rational choice theory, as it has been applied to VET research, have been discussed by Brown (2017). From a rational choice perspective, people make decisions towards vocational training with full knowledge and capacity. In reality, one’s choice making is always constrained by external factors such as location, timetables, fees, and course content (Brown, 2017). According to Albright et al. (2018), research on VET student aspirations has predominantly been undertaken using rational choice theory, so there is a need to adopt a critical Bourdieusian sociology to inform future research.

The recent VET Review in the state of New South Wales (NSW VET Review) has noted several other structural barriers faced by learners. One is the weakening of the connections between TAFE (Technical and Further Education colleges are the major public providers of VET in Australia) and their local communities (Bruniges et al., 2023). The issue is exacerbated by the

"customer service approach" in TAFE NSW, whereby enquiries are forwarded to a centralised call centre, where there is usually limited understanding of local contexts. The Review has heard feedback such as: "There is a lot of mixed messaging… get the wrong person on the end of the phone at TAFE and people look elsewhere…" and "We've had lots of difficulties engaging with TAFE NSW… [I]t is a behemoth… [W]e've no idea who the right contact is…" (Bruniges et al., 2023, p. 22). Another barrier is the complexity of the enrolment system, with some stakeholders stating, "TAFE forms are way too hard" (Bruniges et al., 2023, p. 23). Additionally, there is often uncertainty as to whether a particular course will actually be offered, with some courses being cancelled with late notice (Bruniges et al., 2023).

It is necessary to research whether and how the above barriers are experienced by people with Down syndrome specifically, but also how they might be navigated by people with Down syndrome and their families.

Inequities facing VET learners with disability

Having discussed some of the broad obstacles to VET participation faced by the general population, the discussion now focuses on learners with disability. Since very little is known about VET students with Down syndrome, the following analysis is drawn from literature on VET learners with disability more broadly.

In theory, there is legislation in Australia that protects the rights of people with disability within the VET field. Access and equity are fundamental values in the *Standards for Registered Training Organisations (RTOs) 2015* (Australian Government, 2019). In the glossary, educational and support services are specifically said to include "equipment, resources and/or programs to increase access for learners with disabilities". The Standards recognise that individual VET learners with disability, like all learners, have their own individual needs that should be catered for by RTOs. Yet, in reality, people

with disability have been continually found to be “under-represented” in VET and to experience unequitable outcomes in and from their training (Australian Institute of Health and Welfare, 2024).

The idea that people with disability are “under-represented in VET” is partly based on statistical measures. The problems associated with using statistical data to glean insights into learners with disability have long been recognised (e.g. Australian National Training Authority, 1998). The data relies on the self-disclosure of disability (i.e. the figures reflect the willingness to disclose disability, rather than the actual incidence of disability). So, an apparent statistical increase in “learners with disability” in VET does not guarantee that actual participation has improved, much less the quality of that participation (Griffin & Nechvoglod, 2008). Furthermore, statistics provide little insight into the actual lived experiences of students with disability. Nonetheless, quantitative data can provide a basis for exploring disability issues and to evaluate policy and practice (Griffin & Beddie, 2011).

Statistically, people with disability are considered “under-represented” in VET in that their participation rate falls below their percentage makeup of the general population (4% and 18% respectively in 2021) (National Centre for Vocational Education Research, 2023). Furthermore, they have reported lower satisfaction with overall quality of training and lower achievement of their main reason for undertaking training, compared to students without disability (Australian Institute of Health and Welfare, 2024). Vocational students with disability also have a lower qualification completion rate and subject load pass rate (National Centre for Vocational Education Research, 2023). Furthermore, they might be less likely to undertake higher-level qualifications (e.g. Diplomas and Certificate IIIs) (Cavallaro et al., 2005). This results in further disadvantage for people with disability with regards to employment. The reason being that, given the evolving need of the economy, the Australian Government considers Certificate III qualifications as the entry-level

qualification for skilled workers in Australia (Department of Education, 2024a).

Relatedly, VET graduates with disability seem less likely to have improved employment status after training (Australian Institute of Health and Welfare, 2024). Even compared to other equity groups, it was once found that people with disability have the lowest levels of educational achievement and employment outcomes from VET (Cavallaro et al., 2005). Because of these employment prospects, people with disability face the possibility of becoming "perennial course doers" (Woolcott Research, 2017, p. 45).

Notably, VET learners with intellectual and/or learning disabilities, such as those with Down syndrome, are especially disadvantaged within the field. Learners from these two cohorts were found by Cavallaro et al. (2005) to be the least likely to study qualifications at Certificate III and higher and also least likely to complete their qualifications, as well as having lower employment outcomes. For these reasons, Cavallaro et al. (2005) described learners with intellectual and/or learning impairments as having "well below average levels compared with all students with a disability" (p. 24). It is important, then, to explore whether this "profile" holds true for VET learners with Down syndrome.

Disability can impact on learning outcomes in varied ways (Karmel & Nguyen, 2008). Some disability types (e.g. a medical condition) might have more direct impact on attendance and attrition rates compared to other disability types (Miller & Nguyen, 2008). Interestingly, the study by Karmel and Nguyen (2008) has argued that it is not necessarily disability itself that affects a person's VET outcomes, but the fact that people with disability tend to have lower prior education. As Polidano and Vu (2011) have pointed out, "[e]ducation begets education" (p. 3). VET students with disability are more likely to have lower schooling education levels (i.e. leaving school before finishing Year 12) (Cavallaro et al., 2005). People with learning and/or intellectual disabilities

are especially disadvantaged in that they might have the lowest overall levels of school education and, hence, low VET achievements compared to people with other disabilities (Cavallaro et al., 2005).

Disability onset is another topic within VET research. People who have an early onset of disability at childhood are at greater disadvantage, because their skill and knowledge acquisition would have been impacted at a young age, with the result that "their accumulation of human and social capital was disrupted" (Polidano & Mavromaras, 2010, p. 32). This is a relevant issue for people with Down syndrome, since the condition is congenital (Down Syndrome Australia, 2022).

While some research studies on VET learners with disability cited here might seem dated, they still provide valuable insight into this cohort. The recent findings published by the Parliament of Victoria (2021) are evidence that the inequities faced by learners with disability have been long-standing.

VET journeys of learners with disability

The barriers and opportunities faced by people with disability in training can be further discussed in three distinct parts: access, participation, and benefits/outcomes. Although it is beneficial to separate these topics for analytical purposes, these areas are interdependent (Griffin & Nechvoglod, 2008).

Accessing VET

People with disability have expressed positive attitudes towards accessing vocational training (Nechvoglod & Griffin, 2011). Their stated reasons for undertaking training include gaining work skills, finding a job, and increasing self-confidence (Nechvoglod & Griffin, 2011).

Yet, people with disability face barriers to accessing training. Some people lack awareness of possible pathways and/or the self-confidence to commence their VET journey (Parliament of Victoria, 2021). This obstacle relates to the issue of accessing appropriate information on training options (Griffin & Nechvoglod, 2008). The lack of accessible and user-friendly information has long prevented people with disability from making informed choices towards VET (Australian National Training Authority, 2000; Barnett, 2004). Additionally, the enrolment system, particularly online, has been found to be complex and inaccessible, causing some prospective learners with disability to abandon enrolment (Parliament of Victoria, 2021).

For people with disability, the opportunity to be self-determined and to make choices for oneself can be hindered by stakeholders' attitudes. Training organisations, teaching staff, and even the families of a person with disability may hold deficit-based perceptions towards that person's learning potential (Barnett, 2004). Stakeholders' advice significantly shapes the prospective student's understandings of self and the VET choices available to them (Griffin & Nechvoglod, 2008). Even long before beginning the VET journey, people may have internalised the low expectations that others have had of them while growing up (Parliament of Victoria, 2021). In other words, their predisposition (habitus) may have already become deficit focused.

In contrast to these barriers, several facilitators to access have been identified. One enabler is transition planning during secondary school, which is a process that should be undertaken by well-informed practitioners (Barnett, 2004). VET in Schools also contributes to improved post-school VET access. It is a strategic pathway for young people with disability to transition into further study and/or employment (Cocks & Thoresen, 2013b). VET in Schools and other transition programs are vital for school students with disability, since they are at risk of leaving school early (Cavallaro et al., 2005). Additionally, the social networks developed through work placements enable

young people to further participate in their communities (Cocks & Thoresen, 2013b). Yet, the long-term benefits of VET programs delivered in schools, especially in enabling access to higher-level post-secondary qualifications, are not certain (Circelli & Siekmann, 2022; Gonski & Shergold, 2021).

Participating in and completing VET

People with disability benefit the most from VET when they successfully complete their training (Cocks & Thoresen, 2013a). Yet, learners with disability have lower subject completion rates than students with no declared disability (Cavallaro et al., 2005; National Centre for Vocational Education Research, 2023). It has been observed that learners with disability face greater challenges in completing VET than simply participating in VET (Polidano & Mavromaras, 2011).

One reason for their relatively low completion rate might be related to learners' backgrounds. VET learners with disability often have lower prior education attainments, which then impacts on their training (Griffin & Beddie, 2011). Low literacy and numeracy skills can impede the learning process (Parliament of Victoria, 2021). Health issues also impact on completion (Cocks & Thoresen, 2013a). It should also be remembered that VET students with disability usually require more time to complete their training (Australian National Training Authority, 2000).

Yet, there are also structural barriers that hinder people with disability from completing their training. For apprentices and trainees with disability, a lack of resources, inadequate training wages, and the cost of equipment needed for training negatively affect VET completion (Cocks & Thoresen, 2013a). The lack of institutional support (i.e. limited interaction with lecturers and tutors) is another barrier to completion (Cocks & Thoresen, 2013a). In other words, the learning process for people with disability is impeded or facilitated by not only their academic capability, but also by their material and social resources.

Benefitting from VET

Given that discourses on VET proclaim the economic and social benefits that come with attaining training (e.g. Productivity Commission, 2020), the actual gains obtained by learners with disability must be analysed. Broadly speaking, completing a VET qualification enhances the employment probability of people with disability (Polidano & Mavromaras, 2010). Graduates attain industry-specific skills, confidence, and people skills needed for employment, while the VET qualification itself functions as a form of "external validation" (Polidano & Mavromaras, 2010, p. 21).

Employment-related outcomes are enhanced through work placement. Placements enable learners to gain workplace experience, build social connections, and increase their confidence (Parliament of Victoria, 2021). Employers favour applicants who have work experience and often source information concerning the job seeker with disability from their work experience provider or employer (Waterhouse et al., 2010). Yet, not all learners with disability receive the opportunity to gain work experience, often because employers themselves lack the knowledge and confidence to receive workers with disability (Parliament of Victoria, 2021).

There are also important personal and social benefits gained by participating in VET. Overall wellbeing and quality of life for people with disability can be enhanced, especially by developing their independence (Parliament of Victoria, 2021). Participating in VET can also open pathways to further study, including university (Parliament of Victoria, 2021). Moreover, VET enables marginalised learners to develop their social capital, as they engage with staff and other students, building up their capacity to participate in society (Priest, 2008).

Assessing the benefits of VET participation should be done on a case-by-case basis. Since there is a range of reasons for which training is accessed, a primary consideration is whether people with disability feel satisfied that they

have achieved their learning goals (Australian National Training Authority, 2000).

More research is needed on how specific disabilities, such as Down syndrome, might shape the VET journeys of learners with disability.

Supporting VET learners with disability

Providing support to VET learners with disability is fundamental for their successful participation. Support should be comprehensive as in a "wrap-around" approach, where the student as a whole person is given attention to (Parliament of Victoria, 2021).

Yet, the issue of support is a complicated one. Students themselves need to exercise agency to seek disability support services. In the case of "mental illness", a reluctance to disclose one's disability or to seek support impacts negatively on VET attainments (Miller & Nguyen, 2008; Polidano & Mavromaras, 2010). At the same time, VET practitioners need to set aside deficit-focused views and develop their skills in supporting learners with disability (Barnett, 2004; Griffin & Nechvoglod, 2008). The ability to communicate with and relate to learners significantly shapes the learning experience (Australian National Training Authority, 2000). An environment of trust and inclusion can facilitate sharing and openness from students with disability (Robertson et al., 2004).

Support can take many different forms but, at its core, it is relational. It can include formal supports such as disability employment services, training institutes themselves, and employers, but also informal supports from family, friends, and co-workers, especially when formal supports are insufficient (Cocks & Thoresen, 2013a). Peer networks can help students to stay motivated and engaged (Parliament of Victoria, 2021). Cocks and Thoresen (2013a) argue, therefore, that "social capital or personal networks" (p. 9) significantly enhance course completions. VET providers can build up the

social capital of learners by developing connections with communities, schools, and employers (Priest, 2008).

Reasonable adjustment is another key support strategy. Reasonable adjustment refers to measures taken by a training provider to enable students with disability to participate “on the same basis as learners without disability” (Queensland Government, 2018, p. 5). Adjustments are based on the individual’s needs and capabilities, and can include the provision of interpreters, readers, or notetakers, as well as physical supports such as adjustable desks (Robertson et al., 2004). Learning content can be adjusted by presenting information through a range of different modes, while assessments can be modified in terms of time flexibility (Robertson et al., 2004). Additional supports such as tutoring are a major enabler of course completion (Cocks & Thoresen, 2013a).

It should also be mentioned that the National Disability Insurance Scheme (NDIS) offers rather limited support to people with disability in VET. The National Disability Insurance Agency (2025) claims responsibility for supports that are needed for “everyday activities” that “aren’t related to learning”. Supports that are related to learning are said to be the responsibility of VET providers.

In summary, the VET field in Australia is one where people with disability face varied opportunities and challenges in their access, participation, and outcomes. Whilst VET participation may have improved over the years for people with disability, there are still significant barriers faced by this population. Similar issues can be noted in field of higher education in Australia.

The field of higher education

The university sector is considered to be another "pillar" (p. 102) in Australia's economy and society (Department of Education, 2024b). The Final Report of the Australian Universities Accord (Department of Education, 2024b) has framed higher education as being beneficial for many aspects of society: "Higher education is vital to Australia's future: the knowledge, skills and research it produces enable us to be an economically prosperous, socially equitable and environmentally sustainable nation" (p. 1).

As with the VET discussion above, the following discussion analyses the field of higher education in Australia from a Bourdieusian perspective. This involves examining how inequalities persist within the field of higher education (Webb et al., 2017). The analysis focuses on issues surrounding equity for people with disability in accessing and participating in higher education, similar to what was analysed in the VET field. Notably, the discussion in this section is slightly shorter than the VET discussion. One rationale is that participation in higher education for people with Down syndrome in Australia is less common than participation in VET (Down Syndrome Western Australia, 2015; Foley et al., 2013). That is, however, not to say that higher education is a less relevant topic for people with Down syndrome.

Equity in higher education

Increasing the participation and completion rates of university learners has long been a key concern for Australian governments and institutions. Australia was one of the leading countries to restructure its higher education field to enable "wider participation" (Bradley et al., 2008, p. xii). Whilst the university reforms of the 1970s and 1980s did significantly improve overall access and attainment, several population groups have continued to be under-represented in the field (Department of Education, 2024b).

In recent decades, equity has become a fundamental priority for Australian higher education (Gale & Tranter, 2011). The 2008 Review of Australian Higher Education (Bradley et al., 2008) is regarded as a milestone moment in the "widening participation" agenda to include more learners from disadvantaged groups. The Bradley Review was significant in that it argued for the expansion of the higher education sector against "the previous orthodoxy" (p. 4) held by policymakers that there was no such need for this expansion and that efforts should focus on expanding VET instead (Birrell & Edwards, 2009). A decade after Bradley's report, the Australian Government proclaimed the successes of widening participation for people with disability (Department of Education, 2020). The Government was cautious, nonetheless, in its celebration of the increased student numbers, recognising that "it could also be that more students identify themselves as living with disability" (Department of Education, 2020, p. 1). As was discussed in relation to VET (Griffin & Beddie, 2011), it is not entirely possible to assess the actual participation of people with disability in higher education using statistics derived from self-disclosure. Besides, even if their participation has numerically increased, stigma and attitudinal barriers might be persistent in the university experiences of people with disability (Ryan, 2011).

Importantly, as with the VET sector (Butler & Ferrier, 2022), both "equity" and "equity groups" have been subject to contestations within the university field (Gale & Tranter, 2011; Rizvi & Lingard, 2011). The widening participation agenda has been criticised for being framed within neoliberal and meritocratic ideologies, which ultimately place the responsibility on the individual to prove themselves capable and deserving of higher education opportunities (O'Shea, 2020). So long as higher education is framed in terms of "quality" and "excellence", there will inevitably be limits to its equity agenda (Rizvi & Lingard, 2011).

Although it is somewhat dated, the 2008 Bradley Review continues to shape current discourses on higher education (see e.g. the 2024 Australian Universities Accord – Final Report). Because of this, it remains significant to analyse how some key concepts are contested therein. Fundamentally, Bradley et al. (2008) appear to overlook people with disability in their "widening participation" discourse: "[W]e must also look to members of groups currently under-represented…, that is, those disadvantaged by… their birth: Indigenous people, people with low socio-economic status, and those from regional and remote areas" (p. xi). The exclusion of people with disability in significant parts of the report is legitimated by several discursive moves. Firstly, Bradley et al. (2008) construct a category of learners labelled "the seriously under-represented" (p. 27). Then, people with disability are omitted from this group since "[g]ood progress has been made" (p. 29) in their participation rates. The claim is partly true, but it is also contrary to the data presented on page 28 of the Bradley Review, where people with disability had, in fact, the second lowest participation ratio in 2007.

More problematically, the Review's selective use of the quantitative data leads to the exclusion of people with disability from its discourse on "capable students" (pp. 10, 27). The section titled "Providing opportunities for all capable students to participate" argues that:

> Australia needs to make the most of the talents of all its people… An effective higher education sector which makes greater use of Australia's human capital enhances national productivity and global competitiveness.
>
> However, Australia has not provided equal access to all groups from society. People from lower socio-economic backgrounds, those from regional and remote Australia as well as Indigenous Australians are under-represented in higher education… (Bradley et al., 2008, p. 27)

It is worth asking, firstly, whether the Bradley Review implies that people with disability are "incapable" to participate in higher education and, secondly, whether the Review also deems that people with disability are less "valuable" to the Australian economy.

Rizvi and Lingard (2011) have rightly levelled significant criticisms towards the Bradley Review's "widening participation" discourse. The Bradley Review is "an assemblage" (p. 5) that attempts to unite several contrasting and competing values surrounding education through a "neo-liberal imaginary" (Rizvi & Lingard, 2011, p. 20). The Review's notion of "equity" is rather incompatible with true social justice values, since "[e]quity is thus re-articulated in terms of a human capital theory that assumes a necessarily competitive view of human nature and social relations" (Rizvi & Lingard, 2011, p. 17). Such criticisms of the widening participation agenda in higher education fields are not limited to the Bradley Review nor to the Australian context (Archer, 2007; O'Shea, 2020).

It is clear from the recent Australian Universities Accord report that neoliberal values continue to frame equity discourses within the education field. The Department of Education (2024b) uses the phrase "skills through equity" (p. 2) to frame its widening participation agenda. The Accord states on page 2, "[e]quity… provides an answer to meeting Australia's skills needs." When speaking of the benefits of higher education afforded to individual learners, the Accord swiftly links these gains back to economic gains for the nation: "Every Australian should have the opportunity to experience the life transforming benefits of tertiary education. This is vital for Australia's future. Only by expanding access to tertiary education… can the nation meet its projected skills needs" (p. 111). Unsurprisingly, then, the Accord makes numerous references to the Bradley Review, echoing the human-capital emphasis in its equity agenda (see pp. 53, 110).

Unlike the Bradley Review, however, the Accord recognises that people with disability are amongst the "substantially under-represented" (p. 60) in higher education (Department of Education, 2024b). Interestingly, though, the report recommends only "maintaining participation rates for students with disability" (p. 21, 122), as opposed to increasing their participation. This is in contrast to the recommendations to increase the participation rates of other equity groups. The reason seems to be that, in 2022, people with disability had apparently already "exceed[ed] this group's expected enrolment share of 8.4%" (p. 114). So, in the end, both the Accord and the Bradley Review could be said to minimise the need to increase the participation of people with disability in higher education.

Regardless of these issues and ambiguities, equity is strongly foregrounded by the Australian Universities Accord. Significantly, the Accord argues that equity in higher education is not solely the responsibility of the university sector, but that it can only be achieved when equity in pre-university learning contexts and broader social and economic equities are addressed (Department of Education, 2024b). Equity in higher education is a lifelong and lifewide issue and must, therefore, be researched as such.

Inequities facing higher education students with disability

As in the VET sector, there is legislation which protects the rights of people with disability in Australian higher education. The *Higher Education Standards Framework (Threshold Standards) 2021* enshrines the values of diversity and equity, as well as wellbeing and safety of all university students. Section 2.2.1 of the Framework stipulates that learners from disadvantaged cohorts need to be particularly accommodated for: "Institutional policies, practices and approaches to teaching and learning are designed to accommodate student diversity, including the under-representation and/or disadvantage experienced by identified groups, and create equivalent opportunities for academic success regardless of students' backgrounds." Meanwhile, Section

2.3.3 explicitly refers to students with disability and their right to be supported by higher education providers: “The nature and extent of support services that are available for students are informed by the needs of student cohorts, including mental health, disability and wellbeing needs.” Despite this legislative backing, the experiences that people with disability have within higher education fields are greatly varied.

It should also be noted that, as in the VET sector, the NDIS offers limited support to people with disability in higher education. The National Disability Insurance Agency (2025) does not claim responsibility for supports that are related to learning, but holds higher education institutions to be responsible for such supports.

A broad overview of learners with disability in Australian higher education can be drawn from recent reports. Statistically, enrolments of domestic undergraduate students with disability have increased significantly since 2011 (Cadby et al., 2024). As mentioned earlier, however, this may be more a reflection of increased self-disclosure rather than an actual increase in participation. Significantly, the addition of “mental health conditions” as a disability type in 2020 has likely effected more self-disclosures, hence driving up the disability participation rates (Cadby et al., 2024). Regardless, people with disability remain not only under-represented in the university sector, but are also disadvantaged in their rates of retention, success, and completion (Pitman, 2022).

The “disability types” used in university reporting have recently changed (Cadby et al., 2024). Essentially, in 2020, the disability categories were made more detailed, with “learning disability” being replaced by “intellectual disability” and “specific Learning Disability (SLD)”. This change is significant in that it has revealed the extent to which people with intellectual disability, such as people with Down syndrome, are under-represented in higher education. Between 2007 and 2019, students with “learning disability” quite

consistently comprised roughly 15% of all university students with disability (Kilpatrick et al., 2016; Pitman, 2022). With the post-2020 replacement of "learning disability" with "specific Learning Disability" and "intellectual disability", however, it has been reported that people with intellectual disability comprised only 2.1% of all university students with disability in 2022 (Cadby et al., 2024). In other words, learners with intellectual disability are a minority within a minority, meaning they are severely under-represented in higher education.

Higher education journeys of learners with disability

Issues relevant to people with disability can be drawn out of the Australian Universities Accord report and other similar reports. The barriers and opportunities that people with disability face in higher education fields are varied. The following discussion is somewhat brief, but similar issues have been analysed in the earlier VET discussion.

Accessing higher education

Equity groups, such as people with disability, who are under-represented in higher education tend to access university through a variety of pathways, including through VET, university diploma and foundation year programs, and non-award university courses (Department of Education, 2024b). People with intellectual disability often do not attain an Australian Tertiary Admission Rank (ATAR) when finishing high school or have an ATAR that is not sufficient for direct university admission (Gadow & MacDonald, 2018). Roughly two-thirds of university students with disability in 2019 had accessed alternative pathways (Jackson et al., 2023). So, having access to alternative pathways is particularly vital to this cohort.

The possibility of transitioning from VET to university is an important issue to consider, since people with Down syndrome predominantly participate in VET

and not university (Foley et al., 2013). The transition into higher education can be difficult for disadvantaged learners to undertake. Learners with disability mostly attain lower-level VET qualifications (Cavallaro et al., 2005), but transition from VET to university is more likely for people who have completed higher-level VET qualifications (Griffin, 2014). Furthermore, there needs to be better integration of VET and higher education overall to facilitate this transition (Gonski & Shergold, 2021).

People with intellectual disability can potentially experience university as non-award audit participants in specially designed programs. In Australia, however, the opportunities are scarce because there are only two such inclusion programs (National Disability Services, 2021). The two initiatives are The Up the Hill Project at Flinders University (Rillotta, Arthur, et al., 2020) and uni 2 beyond at the University of Sydney (Gadow & MacDonald, 2018).

Since higher education is becoming a greater possibility for people with Down syndrome (Faragher et al., 2020), it is essential to understand the university pathways that people with the disability might undertake.

Participating in and completing higher education

University students with disability have the greatest chance of success when they are provided adequate, holistic support (Kilpatrick et al., 2016). A holistic approach to support is needed, taking into account the broad, complex challenges faced by people with disability (National Centre for Student Equity in Higher Education, 2017). Supporting students with disability is most effective when a range of stakeholders are involved. Linkages between universities and schools, disability networks, and other organisations enable positive university experiences (Kilpatrick et al., 2016). Having a strong personal network (social capital) is often found in academically successful students with disability (Ganguly et al., 2015).

Learner agency and self-determination also facilitate successful higher education experiences for people with disability (Coyle et al., 2018). Individual qualities such as motivation and commitment are vital for positive participation in university, though these attributes are difficult to develop through formal support systems (Griffin, 2014). Students who seek support for their disability tend to attain greater retention and completion rates (National Centre for Student Equity in Higher Education, 2017). It has been found that high-achieving students with disability (i.e. having a Grade Point Average ≥ 5.5 out of 7) display key characteristics of self-determination, namely perseverance, resourcefulness, personal responsibility, and have pragmatic expectations of themselves (Ganguly et al., 2015). These learners also have positive feelings regarding their choice of degree and their employment goals, enabling them to be resilient throughout their studies (Ganguly et al., 2015).

Acting in self-determined ways is also self-reinforcing. Students with disability who reach out for personal, social, academic, or other supports usually report stronger feelings of empowerment and self-efficacy (Rooney, 2019). Yet, the students in Rooney's (2019) research also shared frustrations in finding information about available supports within university structures. This issue highlights the need to analyse interactions between learner agency and social structures in higher education journeys of people with disability.

Benefitting from higher education

University graduates with disability have been found to face "significant labour market disadvantage" (National Centre for Student Equity in Higher Education, 2017, p. 8). Compared to most other equity groups, graduates with disability "have consistently worse employment outcomes" (Andrewartha & Harvey, 2017). The disadvantage facing these graduates is complex. University students with disability seem to under-utilise careers services, but such services also need to be better resourced and more strongly promoted to this student group (Andrewartha & Harvey, 2017). Stronger connections

between employers seeking to recruit workers with disability and careers services providers at universities could also improve employment outcomes (Andrewartha & Harvey, 2017). Although the past 20 years have seen very little improvement in labour market inclusion for people with disability, it is also true that having a university degree provides people with disability with a higher probability of being in work (Buckland et al., 2024).

Li et al. (2016) have noted that there is a dearth of literature on the employment outcomes of graduates with disabilities. Yet, the issue appears to remain unaddressed in recent reports, such as the one by Australian Universities Accord. Meanwhile, the literature on the disability inclusion programs at two Australian universities has found gains in employment skills, self-determination, academic learning, and social relationships among the participants, who have experienced university life as audit participants (Gadow & MacDonald, 2018; Rillotta, Arthur, et al., 2020; Walker & MacDonald, 2018). Nonetheless, the employment and other outcomes of higher education for people with disability remain under-researched.

In brief, the field of higher education in Australia is somewhat similar to that of VET in that people with disability face varied potentialities and barriers in their access, participation, and outcomes in their studies. Whilst university participation may have improved over the years for people with disability, there are still significant barriers faced by this population, arguably more so than in VET. This is especially true for people with intellectual disability, such as Down syndrome.

Implications for research

Thinking with Bourdieu, the above analysis has shown that VET and higher education in Australia are constructed to be fields that are supposedly inclusive of learners from all backgrounds. Yet, “equity” is a central but contested notion within both fields. Although there are learners with disability

undertaking higher education and VET, they have for decades continued to be under-represented in these fields. The inequities faced include barriers to accessing, participating in, and completing their training and study, as well as gaining the benefits that further education is meant to offer. It is important to analyse barriers such as literacy and numeracy skills (i.e. forms of cultural capital) and learner choice making (i.e. agency and self-determination) as being both individually oriented and socially and institutionally produced. The formal and informal supports provided by stakeholders are essential for addressing the disadvantages that hinder post-secondary learners with disability. Significant concepts such as "self-determination" and "capital" have been referred and/or alluded to in the existing literature as facilitators of VET and higher education participation and completion.

Several implications for VET and higher education disability research are borne out of the above discussion. Firstly, notwithstanding the emphasis on the barriers analysed above, post-secondary education research should not only be problem-focused but also solution-oriented (Griffin & Nechvoglod, 2008). That is, future research should attend to how people with disability overcome barriers within post-secondary learning fields. The research in this thesis responds to this need by focusing on how some people with Down syndrome navigate barriers to studying in VET and university. Specifically, "self-determination" and "capital" both offer helpful theoretical framings for such research (see Chapter 5). It might be the case that people with Down syndrome who are self-determined and have access to capital are advantageously positioned to navigate barriers within further education fields. The main research question in this thesis (i.e. How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?) aims to explore this issue.

Secondly, a lifelong approach to disability research is necessary, because one's experiences of post-secondary education are inevitably shaped by

one's previous life experiences, particularly within the field of education. That is, early childhood learning and primary and secondary schooling all impact on post-compulsory learning. Many people with disability face challenges within higher education and VET partly because of their prior challenges in school. The research in this thesis can shed light on how people with Down syndrome might accumulate learning skills and experiences that ultimately lead into further education. Along with a lifelong perspective, a lifewide approach to research is also needed. Every individual performs a range of different identity markers (e.g. disability, gender, culture, ethnicity, and class), all of which interrelate to produce positions of relative disadvantage or advantage within further education contexts. Moreover, a person's life domains (e.g. education, employment, leisure, health, and relationships) all impact on their post-secondary education participation and outcomes. The research in this thesis contributes insights into how various aspects of living with Down syndrome interrelate with the post-secondary education experiences of people with Down syndrome. This research also explores how the family backgrounds of people with Down syndrome intersect with their university and VET journeys.

Finally, the voices and lived experiences of learners with disability must be foregrounded in further education research. Much of the existing literature is quantitative in nature and, while useful to a degree, they are limited in enabling deep exploration into this group of learners. It is imperative that disability research be undertaken ethically, respectfully, and as inclusively as possible (Griffin & Beddie, 2011). The research in this thesis amplifies the stories of people with Down syndrome and their families in the fields of VET and higher education in a way that reflects the concerns of inclusive disability research (see Chapter 6). Additionally, it has been recognised by reports on higher education and VET that further research is needed to explore how specific disability types impact on learning experiences (Ferrier & Selby Smith, 2010; National Centre for Student Equity in Higher Education, 2017). The

research in this thesis aims to produce knowledge on how Down syndrome and its commonly associated impairments can shape the post-secondary education experiences of people with Down syndrome.

Chapter 3: Living with Down syndrome

Literature review (Part I)

Introduction

This thesis explores the post-secondary education journeys of people with Down syndrome. The literature review in this chapter and the next adopt a lifelong and lifewide approach to researching this main topic.

This chapter focuses on the topic of living with Down syndrome. It builds upon several arguments made in the introductory chapter. From a critical disability studies perspective, "Down syndrome" is a complex, multifaceted phenomenon. It is a bodily and personal experience, but also a sociocultural, political, and structural one (Meekosha & Shuttleworth, 2009). Significantly, one's experience of living with Down syndrome is directed shaped by their family's socioeconomic, cultural, and education backgrounds (Gabel & Kotel, 2018; Lalvani, 2011). It is, therefore, not only a diverse experience across individuals with the disability, but one that is affected by social disparities and inequalities. As Bourdieu contends, social fields are sites of inequality, because human agents have access to unequally distributed amounts of "capital", which affect their success within those fields (Wacquant, 1989). It is necessary for this chapter to draw out the many factors, both individual and ecological, that impact on life with Down syndrome (not limited to further education experiences).

Accordingly, a primary purpose of the literature review is to exemplify an interdisciplinary, postconventionalist approach to critical disability research (Shildrick, 2020). Notwithstanding the tensions inherent in employing both sociology and psychology within the one study (Brossard & Sallée, 2019), the two fields offer useful concepts that can be related to inform the thesis. Specifically, Bourdieu's (1986) notion of "capital" and the psychological-developmental construct of "self-determination" as used by Wehmeyer et al. (2003) can together provide insight into the lifewide and lifelong experiences of people with Down syndrome, including those related specifically to VET and higher education. The following literature review draws attention to how "self-determination" and "capital" have, whether explicitly or implicitly, informed research into the topic of "living with Down syndrome". This chapter and the next also function, therefore, as a bridge to the theoretical framework chapter, where the "self-determination" and "capital" are analysed in detail.

This chapter begins by critically reflecting on what "Down syndrome" is as a contested, multifaceted phenomenon. Following this, the existing literature on quality of life and developmental outcomes for people with Down syndrome is analysed. Finally, the influence of family background on both personal well-being and developmental outcomes for people with Down syndrome is discussed. Importantly, doing all this enables the thesis to be situated within the broad field of Down syndrome research, while also bringing to the field a much-needed critical and sociological perspective.

What is "Down syndrome"?

In this thesis, the term "Down syndrome" refers to the genetic condition whereby a person's cells have three copies of chromosome 21. This, one might say, is the simple "biological fact" of the disability. It is the definition of "Down syndrome" that is, arguably, as free of the workings of power and ideology as one can provide. In recent decades, significant changes have

occurred in society's inclusion of people with Down syndrome, resulting in improvements in their quality of life. Yet, Down syndrome itself as a chromosomal condition has remained the same throughout history (Wong, 2002).

Three distinct forms of Down syndrome exist, namely trisomy 21, translocation Down syndrome, and mosaic Down syndrome (Healthdirect Australia Limited, 2024). Most people with Down syndrome have trisomy 21, meaning there are three copies of chromosome 21 in every cell of their body. In translocation Down syndrome, the 21st chromosome is attached to another chromosome, while a person with mosaic Down syndrome has a third copy of that chromosome in only some of their cells. Throughout this thesis, "Down syndrome" is used to cover all three forms of the condition without differentiation. (The exception is when speaking of one research participant who expressly shared that they have mosaic Down syndrome.)

Colonialist and neo-colonialist constructions of "Down syndrome"

From a critical disability studies perspective, the label "Down syndrome" signifies a troubling history of how people with the condition were (and continue to be) "othered". This is because the chromosomal condition is named after John Langdon Down (1866), the British physician commonly credited with being the first person to medically describe the condition. In his report, *Observations on an ethnic classification of idiots*, Down (1866) problematically referred to the condition as "Mongolism", reproducing colonial, prejudicial discourses on both race and disability. In his words, people with this "disease" were evidence that it is possible for some people to "degenerate" from one race (i.e. "Caucasian") to another (i.e. "Mongolian"). The former "race" was considered by Down and many other Europeans of his day to be inferior to every other "race". These prejudicial beliefs towards

people with Down syndrome were in spite of Down's rather progressive and compassionate care towards the "patients" in his asylum, which is the side of the doctor that most people prefer to emphasise (e.g. Kutzsche, 2018; Ward, 1999). For a detailed critique of Down's (1866) medical report, refer to my peer-reviewed article published in *Critical Discourse Studies*, a Taylor and Francis journal (Tong, 2022).

The use of the problematic labels, "Mongolism" and "Mongols", began to lose currency after Lejeune, Gautier, and colleagues discovered, in 1959, that the condition was chromosomal and entirely unrelated to "race". Eventually, the term "Down syndrome" (and not "trisomy 21") was chosen by the World Health Organization (WHO) to replace Down's colonialist label, in response to the request put forward by multiple doctors (see Allen et al., 1961). The terms "trisomy 21" and "T21" do see some use in contemporary society, including in medical discourses and by grassroots organisations such as Celebrate T21. It is unfortunate that the name "Down syndrome" reflects the troubling history of how people with the condition were discursively and structurally marginalised. Nonetheless, the term continues to be used in and by global Down syndrome communities, so it is maintained in this thesis.

Whilst the colonialist discourses on Down syndrome have largely been relegated to the past, there are, arguably, still remnants of it present today. From the perspective of disability-focused, postcolonial theorists like Erevelles (2006), this is because colonialism has become a transhistorical phenomenon. The detrimental effects of imperialism continue to be maintained and reproduced through contemporary neoliberal ideas and policies surrounding globalisation. A neo-colonialist framing of the human self inevitably devalues people with disability, since the ideology positions the human individual as "a self-defining entrepreneur, engaging in a range of activities to build their human capital so that they are an effective resource, highly sellable, within the marketplace" (Soldatic & Meekosha, 2012, p. 196).

Within capitalist/late-capitalist societies, people with Down syndrome are (de)valued based on their economic worth (Lalvani, 2011).

From a critical postcolonial perspective, one can see that Langdon Down's racialised discourse lingers as a "ghost" (p. 406) in assumed understandings of and perceptions towards people with the condition (Borthwick, 1996). Particularly, the notion of "mental deficiency" continues to persist in deficit-based discourses that construct people with Down syndrome as needing to be "civilised" (Erevelles, 2006). One example of this can be found in the MSD Manual, which was cited in the introductory chapter: "Down syndrome is an abnormality of chromosome 21 that can cause intellectual disability, microcephaly, short stature, and characteristic facies" (Powell-Hamilton, 2023). The text further defines intellectual disability as a "defect" by using the construct of intelligence quotient (IQ): "Down syndrome affects multiple systems and causes both structural and functional defects… Most affected people have some degree of cognitive impairment, ranging from severe (IQ 20 to 35) to mild (IQ 50 to 75)". Another statement in the MSD Manual claims, "As affected children grow, delay of physical and mental development becomes apparent… The mean IQ is about 50, but this varies widely." What is backgrounded in such statements is that the "intelligence" of people with Down syndrome has undergone a period of increase due to social and educational changes in past decades and, more importantly, that the construct of "intelligence" is itself inherently problematic (Borthwick, 1996).

The history and practice of IQ testing have been widely critiqued. One of the precursors to standardised IQ testing was the work of Francis Galton, the English statistician who coined the term "eugenics". Galton claimed that "intelligence" is genetic and inherited (Strunk, 2024). His interest was in comparing the "intelligence" of people across different "races", which led him to claim that Whites were intelligent and capable, while non-Whites were average, if not degenerate (Tabron & Thomas, 2024). As a proponent of White

supremacy, Galton's ultimate aim was to eliminate those who would "impair the racial qualities of future generations" (Galton, 1909, p. 81, as cited in Tabron & Thomas, 2024, p. 404). As evidenced by the MSD Manual, IQ testing has been reified, at least in some circles, without regard to its problematic history.

As a summary to the argument made thus far that "Down syndrome" is a site of contestation, Whiteaker's (2013) argument is worth quoting:

> [T]here is now broad agreement as to what intellectual disability is, …as having a measured intellectual ability below a specified point, usually IQ 70 or 75, [and] a deficit in adaptive functioning… Intellectual disability is not, however, a naturally occurring condition such as… Down's syndrome; it is a social construct, devised to do a job. It is a condition created by definition. (Whitaker, 2013, p. 122)

Down syndrome and quality of life

As explained in Chapter 1, the broad field of Down syndrome research draws much from psychological-developmental research traditions (see Burack et al., 2023). Undoubtedly, significant insights on people with Down syndrome and advocacy for people with Down syndrome have been generated by that emerging body of literature (Faragher, 2023). There is also, however, a need to approach Down syndrome research critically, as Kliewer (1995, 1998) does. That is, literature on people with Down syndrome must not be interpreted nor utilised in an essentialising manner.

With this critical perspective in mind, the chapter now analyses literature on the theme of "living with Down syndrome", focusing on issues that can be related to further education. A broad overview of quality-of-life issues across numerous life domains is painted. Then, issues surrounding Down syndrome, development, and learning are explored. Along the way, attention is drawn to

how “self-determination” (Wehmeyer, 2003a) and “capital” (Bourdieu, 1986) can be seen to shape experiences of living with Down syndrome.

This section presents a broad overview of the lived experiences of people with Down syndrome across different life domains. Notably, the domain of education is not discussed in this chapter but in the following one. Instead of focusing solely on the area of further education, a holistic approach to living with Down syndrome is taken in this chapter. One rationale for this approach is that post-secondary education should not be taken as a research topic in isolation from other aspects of one’s life. The different domains in one’s life inevitably overlap and affect each other. For example, how a person with Down syndrome perceives and experiences post-secondary education is presumably shaped, in part, by their health. The converse is also true, namely that experiences of further education impact on one’s health and well-being.

The idea of “quality of life” relates to the holistic well-being of people with Down syndrome across all domains of their lives. Every individual with Down syndrome is unique, meaning that they each have different needs and priorities in each life domain. Regardless, each person with Down syndrome should be given opportunity to find fulfilment in life as they see fit (Carr, 2008). In contrast to normative discourses on Down syndrome as “tragedy”, some people with the disability have shared emphatically, “I have a good life” (Scott et al., 2014, p. 1290). In a survey of 284 teenagers, young adults, and adults with Down syndrome, almost all of them stated that they are happy with their lives and have a positive sense of self (Skotko et al., 2011c).

Quality-of-life issues for people with Down syndrome across various life domains are now explored.

Health

For people with Down syndrome, the presence of medical conditions can negatively affect their perceived quality of life (Haddad et al., 2018). Medical

issues can often be compounded by the fact that conditions can be co-occurring (Baksh et al., 2023). Some health challenges have evident effects on learning and development for people with Down syndrome. Hearing impairments (McNeill et al., 2015) and visual impairments (Charleton & Woodhouse, 2015) can both impact directly on learning and language development. Respiratory conditions such as sleep-disturbed breathing can also impact on cognitive development and learning (Evans et al., 2015). It is also common for people with Down syndrome to have thyroid conditions, particularly hypothyroidism (Leshin, 2002). The symptoms of hypothyroidism, such as lethargy and decreased muscle tone, can affect learning (Donaldson & Leyland, 2015). Mental health issues can also be more prevalent amongst people with Down syndrome (Raffaele et al., 2022).

At the same time, health issues do not entirely determine the quality of life of people with Down syndrome. Interestingly, one study finds that health status does not seem to affect post-school transition outcomes for young people with Down syndrome, compared to factors such as daily living and communication skills (Foley et al., 2013).

Family

Throughout the lifespan, families play an essential role in the lives of people with Down syndrome. The family unit is the primary ecological context in which people with Down syndrome are nurtured (Cuskelly et al., 2008). Accordingly, family harmony and cohesion are important to the well-being of people with Down syndrome (Cuskelly et al., 2001). People with the disability usually feel supported and empowered by their families: “My parents have helped me practice to live by myself. Things like cooking and shopping. My Dad and carer give advice about relationships…” (Scott et al., 2014, p. 1292).

People with Down syndrome usually bring a sense of joy to their families (Skotko et al., 2011b). One parent has shared, “I’ve redefined the way I

measure success in my life. It's not based on material things… It is based on family happiness, taking care of each other…" (Skotko et al., 2011b, p. 2339). Such sentiments can be interpreted as resistance discourses that challenge the dominant ideologies of ableism and neoliberalism, which both tend toward devaluing people with Down syndrome (Lalvani, 2011).

Families are also important facilitators to experiencing well-being in other areas of life for people with Down syndrome. Significantly, some family variables can enhance quality of life for people with Down syndrome (discussed towards the end of this chapter). For starters, it should be noted that families with positive perceptions of their members with Down syndrome tend to be more educated and socio-economically advantaged (Skotko et al., 2011a, 2011b; Van Riper et al., 1992).

Relationships

Being socially connected to others increases one's quality of life for people with Down syndrome (Haddad et al., 2018). Many people with Down syndrome desire and are able to have meaningful relationships with others, including ones of an intimate nature (Brown, 2014). As one person with Down syndrome says in Scott et al.'s (2014) study, "I like going out with friends, meeting them at the pub for beers." (p. 1294) Significantly, it has been found that social relatedness is an area of strength for many people with Down syndrome (Fidler & Daunhauer, 2011). The social lives of people with Down syndrome are, however, quite varied (Carr, 2008, 2011; Dolva et al., 2019).

Social networks not only provide feelings of connectedness and belonging, but they can also function as valuable resources (i.e. social capital). The study by Roll and Koehly (2020) on the social networks of people with Down syndrome has made several important findings: Those with relatively small networks and weak connections to others have fewer resources and opportunities for social inclusion. The quality and nature of specific social

networks are another consideration. Professional staff such as social workers play a key role in helping people with Down syndrome to participate meaningfully in society. Roll and Bowers (2019) find that professional stakeholders can act as “bridge builders” who connect individuals with Down syndrome to other stakeholders and services that can contribute to well-being.

Housing

The living situation of people with Down syndrome is another important aspect of their well-being. From a self-determination perspective, issues surrounding housing are related to one’s independence (i.e. having some degree of choice towards where and how one prefers to live) and one’s integration (i.e. being part of the community and not segregated from society), as McGinley (2002) explains. Many people with Down syndrome now live independently or semi-independently. Doing so enables young adults and adults to develop a sense of self that is more separate from their parents and carers (Scott et al., 2014).

Leisure

Quality of life also consists of participation in leisure activities. There is a wide range of interests in recreational activities among people with Down syndrome (Jobling, 2001). Listening to music, watching TV, going to concerts and films, playing sports, reading, and drawing are some of the common leisure activities that people with Down syndrome enjoy (Carr, 2008). The benefits of engaging in recreation include physical and mental health benefits, as well as community participation when people with Down syndrome are included in community-based programs (Jobling, 2001).

Leisure activities are important across the lifespan of people with Down syndrome. For children, in particular, play contributes significantly to learning

and development (Oates et al., 2011). For adults, doing physical activity may reduce the risk of health issues commonly associated with ageing and Down syndrome (Fleming et al., 2022). In contrast to physical recreation, activities that are “cognitively stimulating” (e.g. computer games and puzzles) can also be beneficial for adults by potentially reducing the rate of decline in memory (Mihaila et al., 2019).

Employment

Employment is an important aspect of life for people with Down syndrome. There are important economic, social, and personal benefits of having work. Adults with Down syndrome share sentiments such as “I like work and getting paid then I can save my money” and “Not having enough money stops me from doing what I want to do like buying a house.” (Scott et al., 2014, p. 1295) Apart from economic and social benefits, meaningful employment also enables adults with Down syndrome to continue their learning and development post-school (Faragher et al., 2020). Having a job that is more “complex” (i.e. involving problem solving and/or critical thinking) can help to mitigate the onset of dementia and cognitive decline that is common in Down syndrome (Piro-Gambetti et al., 2023).

Self-determination is an important contributor to employment well-being. Higher levels of job satisfaction are reported when people with Down syndrome find a supportive job that suits their interest and abilities, as well as having opportunities to socialise in the workplace (Channell et al., 2023; Jevne et al., 2022). Choice making is an important aspect of exercising one’s self-determination within occupational contexts (Bush & Tassé, 2017). Many adults with Down syndrome and their families express preferences for a wide range of interesting and challenging jobs in open employment (Bottroff et al., 2001).

Summary of quality-of-life topics

The lived experiences of people with Down syndrome across various life domains have been explored. Some people with Down syndrome express goals and desires toward personal well-being in areas such as health, family, relationships, housing, leisure, and employment. Post-secondary education experiences for people with Down syndrome can shape and be shaped by these life domains.

Down syndrome and development

This section discusses some of the general or common characteristics found in people with Down syndrome in relation to behaviour, cognition, language, and literacy and numeracy. It draws largely upon psychological and developmental studies, which have strongly shaped Down syndrome research (Burack et al., 2023). Although this thesis is more aligned with critical sociological perspectives, it is still beneficial to situate this project within the broader field of Down syndrome research. The thesis acknowledges that significant insights into Down syndrome have been generated through quantitative research within psychological and developmental traditions. The aim of the following discussion is to provide a more holistic understanding of people with Down syndrome in a non-essentialising manner. Gaining such knowledge can give insight into the experiences of post-secondary education specifically.

Shaping the “Down syndrome phenotype”

Every human individual has their own unique genotype, that is the complete set of genetic material inherited at conception. A person’s phenotype is the observable expression of their genotype, and it is the product of the interaction between their genotype and their environment (Garvan Institute of Medical Research, n.d.). This means that a particular genetic condition, such

as Down syndrome, can vary considerably in its “presentation” from one individual to another. As Brown (2014) states: “Despite Down syndrome being a genetic condition, there is great room left for the impact of the genome as a whole and the interplay with environment.” (p. 33) The implication is that issues concerning human psychology and development are not solely located within the individual.

For Buckley et al. (2006), there is a strong belief that “we can change the profile” (p. 52) (i.e. the phenotypic features) of Down syndrome in a person. The emphasis is not so much on treating the individual as it is on changing the environment. Holding the principle that “development is social” (p. 51), Buckley et al. (2006) find that students with Down syndrome in inclusive education make optimal progress, particularly in terms of communication, compared to their counterparts in segregated education. Buckley et al. (2006) argue, therefore, that inclusive mainstream education ought to be the norm for students with Down syndrome, stating that teaching methods should be adapted to work with students’ strengths.

The family context also plays a significant role in shaping the development of a person with Down syndrome. Positive developmental outcomes in people with Down syndrome are promoted when the family ecology is cohesive and engaging (Head & Abbeduto, 2007). Significantly, some family variables (i.e. forms of capital) can provide advantages to the developmental outcomes of people with Down syndrome (discussed towards the end of this chapter).

The discussion now proceeds to critically explore several interconnected aspects of development in people with Down syndrome. The developmental areas are analysed because they can all be relevant to understanding post-secondary learning experiences of people with Down syndrome. As highlighted by the VET and higher education literature, there is a need to understand how disability and impairment might impact on further education journeys.

Behavioural development

Down syndrome can impact on the neurobehavioural development of individuals in varied ways. In the field of psychology, a "maladaptive behaviour" is one that "interferes with adapting to environmental and social conditions and fulfilment of the person's potential" (Levy, 2025, p. 312). According to Dykens et al. (2002), maladaptive behaviours can be internal (e.g. being withdrawn, anxious, or depressed) or external (e.g. being aggressive or delinquent). Dykens et al. (2002) found that most children with Down syndrome do not seem to experience significant maladaptive behavioural issues, whereas younger adolescents might display low-level externalising behaviours and older adolescents might show internalising behaviours. Meanwhile, adults with Down syndrome seem more likely to exhibit internalising maladaptive behaviours than externalising ones (Dykens, 2007). While levels of maladaptive behaviour vary between individuals with Down syndrome, such behaviours can "impede health, wellbeing, educational and occupational outcomes" (Channell et al., 2021, p. 3).

Importantly, behavioural "profiles" of people with Down syndrome are not fixed nor static. Rather, they develop and change throughout the lifespan, along with one's cognition, self-regulation, and maturity (Capone et al., 2006). Social and environmental factors affect one's behavioural development and functioning. For instance, family stress and/or dysfunction, overly rigid and/or permissive parenting styles, and experiences of loss or trauma can give rise to behavioural challenges for people with Down syndrome (Capone et al., 2006).

From a sociological perspective, the notion of "behavioural issues" needs to be approached critically. For people with Down syndrome, there is the threat of being excluded from community contexts such as education settings on the basis of perceived "problem behaviours" (Brown, 2014). The ways in which "good" and "bad" behaviours are constructed by standardised assessments can exacerbate this issue. For instance, the School Function Assessment

(Coster et al., 1998) attempts to measure student functional performance, using a "Compliance" domain to judge a learner's "ability to follow rules, directions, and conventional behavioral expectations" (Will et al., 2016, p. 332). Arguably, labelling behaviours in terms of "compliance" and "non-compliance" can position people with Down syndrome in problematic ways, which can then impact on their inclusion in mainstream education settings. It is necessary to consider the reason for a child's supposed non-compliance. As Esbensen et al. (2018) reason, children with Down syndrome might act in supposedly non-compliant ways when faced with a challenging task, but also when they might not understand an instruction or are tired from facing too many demands or transitions through activities. The pedagogical practices used within a particular learning environment are, thus, major contributors to arousing apparent maladaptive behaviours in learners with Down syndrome.

Cognitive development

With respect to their cognitive development and functioning, people with Down syndrome are considered to have a degree of intellectual impairment. Generally, they are said to be in the range of "mild" to "moderate" intellectual disability (Hodapp et al., 1999, as cited in Fidler & Daunhauer, 2011). The categorisations of "mild", "moderate", "severe", and "profound" intellectual disability are based on the construct of IQ, which was problematised earlier in the chapter (Whitaker, 2013), so they are referred to here rather reluctantly.

"Executive functioning" is a neurocognitive construct that is often used to study cognition in people with Down syndrome. It consists of "a number of mental processes which allows individuals to use thought to govern behavior and to perform complex activities" (Goldstein & Naglieri, 2012, p. ix). These complex, higher mental activities include "planning, working memory, attention, inhibition, self-monitoring, self-regulation, and initiation carried out by prefrontal areas of the frontal lobes" (Goldstein et al., 2012, p. 3). Since Down syndrome affects particular neural structures, including the prefrontal

cortex, people with the condition are typically said to be relatively lacking in some aspects of executive functioning (Fidler & Daunhauer, 2011).

Importantly, executive functioning can be understood as an aspect of self-determination. This is because executive functioning consists of cognitive processes that enable goal-directed behaviour in people with Down syndrome (Tomaszewski et al., 2018). Some researchers have found possible links between self-determination and cognition functioning. For example, Landuran et al. (2022) note that "the most self-determined individuals with DS [Down syndrome] have better skills in many areas such as memory, motor and language skills" (p. 89). At the same time, having an intellectual impairment does not preclude a person from thinking and acting in self-determined ways (Wehmeyer & Palmer, 2003). Through explicit teaching and modelling, students with intellectual disability can develop goal-setting, decision-making, problem-solving, and self-regulation skills (Agran et al., 2000).

"Adaptive behaviour" is another important aspect of cognitive development in Down syndrome (Fidler et al., 2023). Adaptive behaviour refers to "a set of learned skills necessary for everyday living and independence" (Sabat et al., 2020, p. 2). These skills are categorised into three domains: conceptual skills (e.g. language, literacy, numeracy, and academic skills), social skills (e.g. interpersonal skills, relational problem solving, and self-esteem), and practical skills (e.g. daily living skills, personal care, safety, use of transportation, and following schedules). People with Down syndrome generally have strong social and emotional skills, which Grieco et al. (2015) identify as being "assets". Given that adaptive behaviours are framed around notions of "autonomy" and "independence" for people with Down syndrome (Onnivello et al., 2022), they can be seen as important aspects of self-determination.

It is fundamental to explore the idea of cognitive functioning from sociocultural and sociological perspectives. Using Vygotsky's "zone of

proximal development", Nilholm (1999) contends that developmental studies which focus solely on what a child with Down syndrome is capable of doing are inadequate and that, instead, the emphasis should be on what a child might be able to accomplish "with the help of a more capable member of the culture" (p. 266). Additionally, the cognitive functioning of people with Down syndrome is significantly affected by their learning environments. The formal, institutional education environment places significant demands on executive functioning, because there are frequent transitions and many task demands (Esbensen et al., 2021). The expectation for learners to stay seated, for instance, poses challenges to the cognitive functioning of people with Down syndrome (Esbensen et al., 2021). Furthermore, education environments change significantly across one's lifespan, as learners progressively receive less and less individual support and greater self-determination is expected of learners themselves (Sabat et al., 2020). Accordingly, such learning contexts make it challenging for people with Down syndrome to engage in traditional learning.

Language development

Within the field of Down syndrome research, the main approach to understanding language and language development seems to be a cognitive one. Abbeduto et al.'s (2023) recent review of literature on language development in Down syndrome reflects a cognitive approach: "Language is among the most affected domains of neurocognitive functioning in persons with DS and is arguably the greatest barrier to independent living and meaningful inclusion in the community" (p. 335). While useful to some extent, there are limitations to a purely cognitive approach to researching language. As Lightbown and Spada (2013) explain, it is necessary to also hold a sociocultural understanding of language, which posits that language is fundamentally a social practice. Language is a product of culture and society, and language development occurs through social interaction.

From a cognitive stance, people with Down syndrome generally face language "delays", and their receptive language skills usually outweigh their expressive language competencies (Fidler & Daunhauer, 2011). The speech of people with Down syndrome is typically considered to be less clear and less intelligible (Martin et al., 2009). Importantly, however, people with Down syndrome draw upon a range of communicative resources, including gestures and visual checking, to navigate communication difficulties (Franco & Wishart, 1994).

It is necessary, therefore, to further explore sociocultural dimensions of language development in people with Down syndrome. Research shows that people with Down syndrome make greater gains in language development when they are in supportive family relationships and environments. Significantly, well-educated mothers contribute to greater "conversational talkativeness" (del Hoyo Soriano et al., 2020, p. 1) and vocabulary development in people with Down syndrome (Deckers et al., 2019). These two studies suggest that well-informed parents and carers are better equipped to modify their own language to best support the receptive and expressive skills of people with Down syndrome.

Literacy development

From a cognitive perspective, language development is understood to have effects on literacy and numeracy development in people with Down syndrome (Abbeduto et al., 2023). Taking a predominantly cognitive approach to language can, however, lead to a rather traditional view on what "literacy" and "numeracy" entail. Consequently, people with Down syndrome might be framed in rather deficit-based terms: "Although literacy rates are not known for people with DS, the research literature suggests that many people with DS never learn to read" (Abbeduto et al., 2007, p. 255). It is important, therefore, to challenge prevailing assumptions towards readers with Down syndrome.

Cologon (2013) has debunked several myths related to Down syndrome and literacy, concluding:

> People with Down syndrome commonly have a relative strength in reading… People with Down syndrome can develop advanced early reading abilities, but can also learn to read later in life… People with Down syndrome are capable of understanding what they read. People with Down syndrome… can engage in reading alongside their peers in inclusive educational settings. (Cologon, 2013, p. 147)

From a sociological perspective, it is the environment (i.e. whether it is inclusive or not) that strongly shapes literacy outcomes of learners with Down syndrome. Evidently, "literacy" is a highly contested issue that affects the lives of people with Down syndrome. Kliewer (1998) uses the notion of "literate citizenship" to problematise social and pedagogical practices that exclude people with Down syndrome from literacy opportunities. Unlike the many quantitative studies that attempt to measure literacy as a cognitive skill, Kliewer's (1998) ethnography finds two conflicting definitions of "literacy" existing in classrooms: The first, "literacy as conformity", essentially serves to position learners with Down syndrome as the "other" because of their nonnormative behaviour and language use. Students who are not able to conform to socially accepted literacy practices are excluded from other literacy activities. In contrast, the second definition of literacy as "a web of constructed relationships" sees that students with Down syndrome have "symbolic value" in that they are able to negotiate relationships with texts, peers, and teachers to construct meaning.

Drawing on Kliewer et al.'s (2006) notion of "literate invisibility", Moni and Jobling (2014) argue that the literacy goals, needs, and strengths of people with Down syndrome have typically been overlooked. Adopting a sociocultural lens, Moni and Jobling (2014) argue that the narrow, traditional view on literacy as a school-based reading skill fails to capture the multiliteracies that

people with Down syndrome have and require to participate in society. Moni and Jobling (2008, 2014), thus, promote the use of digital technologies and multiliteracies-based pedagogy to develop the literacies of adults with Down syndrome.

Numeracy development

Numeracy development directly impacts on the quality of life of people with Down syndrome (Faragher & Brown, 2005). For people with Down syndrome, emerging research suggests that their challenges in mathematics and numeracy are the result of dyscalculia, an impairment that affects one's understanding of quantity (Cuskelly & Faragher, 2019). It is, however, important to ensure that learners with Down syndrome are not excluded from school-based mathematics and numeracy learning on the basis of their impairment (Faragher, 2023). Some secondary students with Down syndrome have shown their ability to engage with a standard mathematics curriculum, if they are provided with the appropriate support and accommodations (Faragher, 2014; Monari Martinez & Benedetti, 2011).

Summary of developmental topics

Individuals with Down syndrome might have a tendency to face particular challenges and strengths in their development. Whilst it might be possible to draw a general "profile" of people with Down syndrome in terms of their behaviour, cognition, language, and literacy and numeracy skills, there is also the possibility of changing the profile (Buckley et al., 2006). The potential for personal development can be facilitated or hindered by the person's surrounding contexts, depending particularly on how inclusive and supportive those fields are towards people with Down syndrome. It is the home environment that, arguably, plays the most significant role in shaping the "Down syndrome phenotype".

Family background and living with Down syndrome

Both the quality of life and the personal development of people with Down syndrome are strongly influenced by one's family background. Because of their family backgrounds, some individuals with Down syndrome have access to socially valued forms of "capital", as Bourdieu (1986) would theorise, that enhance their personal well-being and development.

Family capital and quality of life

A number of family variables have been identified as "determinants" of quality of life for people with Down syndrome (see the scoping review by Lee et al., 2021). One study finds that individuals with Down syndrome have enhanced well-being if their family lives in/near a city, has a relatively high income, and/or has access to savings (Haddad et al., 2018). Both family income (i.e. economic capital) and parents' education levels (i.e. cultural capital) influence children's well-being (Alrayes et al., 2024). Additionally, parents in the US who engage in advocacy for their children with Down syndrome in education and healthcare settings have been found to be usually White, well educated, and of higher socioeconomic status (Krueger et al., 2019).

The ethnic backgrounds of families can, therefore, affect the lived experiences of people with Down syndrome. In the past, it was found in the US that Black children with Down syndrome who had congenital heart defects were at increased risk of mortality than their White peers because of their reduced access to specialised health services (Rasmussen et al., 2006). In a recent study, Krell et al. (2023) find that people with Down syndrome in non-White families in the US continue to receive suboptimal health care.

A family's social capital also impacts on quality of life for people with Down syndrome. Interpersonal connections developed by family members can include peer, social networks, but also professional, service-oriented networks (Roll & Bowers, 2019; Roll & Koehly, 2020). Post-secondary college

experiences for people with Down syndrome can be facilitated by families' social connections (Roll & Bowers, 2019). Family members often prioritise building relationships with professional stakeholders because of their potential to function as resources in times of need (Roll & Koehly, 2020). Significantly, family social capital can also be linked to family cultural and economic background. Roll and Bowers (2019) have noted that well-connected families in their research "were mostly White and belonged to the middle class" (pp. 147-148).

Family capital and developmental outcomes

Similar issues of sociological concern can be noted in the literature on developmental topics. Executive functioning in Down syndrome might be shaped by one's socioeconomic status (Sabat et al., 2020). Lower cognitive functioning in individuals with Down syndrome has been associated with lower household income (Channell et al., 2021). In Chile, Arango et al. (2018) have observed slower rates of cognitive, socioemotional, and language development in children with Down syndrome of low-socio-economic-status (SES) families compared to those of high-SES backgrounds.

Families' cultural capital also impacts on developmental outcomes. Wasant et al. (2008) find that parent education levels can predict the "developmental quotient" of people with Down syndrome in terms of their language development and visual-motor problem solving. Similarly, researchers across different decades (Evans & Uljarević, 2018; Golden & Pashayan, 1976) have highlighted the evidence pointing to the "heritability of IQ". Similarly, the literacy development of people with Down syndrome is strongly influenced by their home literacy environment. Young children with Down syndrome experience positive literacy development when they inhabit literacy-rich home environments (Al Otaiba et al., 2009). Language development in children with Down syndrome is supported when parents adapt their language to better engage their children during book reading (Hilvert et al., 2023). There are,

however, inequalities that exist across the varied home literacy environments of people with Down syndrome (Arango et al., 2023).

To summarise, the personal well-being and developmental outcomes of people with Down syndrome are strongly influenced by their family background and home environment. As critical sociologists like Goodley (2014) argue, disability always intersects with other social identity markers (e.g. social class and ethnicity) in complex ways. Whilst some individuals with Down syndrome might experience some advantages because their family has access to various forms of capital (i.e. economic, cultural, and/or social), other people with Down syndrome are disadvantaged in their quality of life and developmental outcomes because of a relative lack of resources. Significantly, such issues are noted even within quantitative developmental studies but remain under-explored therein. There exists a need, therefore, to qualitatively explore how family capital shapes the development outcomes and quality of life of people with Down syndrome, particularly in post-secondary learning fields.

Conclusion

This chapter has explored the idea of "living with Down syndrome" from a lifewide and lifelong perspective. This approach has been taken to address the need for whole-of-life disability research that the fields of vocational education and training (VET) and higher education in Australia have called for.

How people with Down syndrome might experience quality of life in the domains of health, family, relationships, housing, leisure, and employment have been discussed. These broad domains of life are important topics for this thesis, because they inevitably shape how people with Down syndrome experience post-secondary education. Quality of life issues are, in turn, moulded by issues surrounding self-determination (Wehmeyer, 2003a) and capital (Bourdieu, 1986) in people with Down syndrome. Personal well-being

is enhanced when people with Down syndrome have the opportunity to make choices and decisions about their lives. At the same time, a range of economic, cultural, and social resources are often needed for families to implement those choices and decisions.

This chapter has also explored developmental topics within Down syndrome research. The behavioural, cognitive, language, and literacy and numeracy development of people with Down syndrome have been discussed. Importantly, it has been emphasised that the developmental characteristics are not to be essentialised. The analysis of the developmental literature has been undertaken with a sociological lens.

Importantly, personal well-being and developmental outcomes in people with Down syndrome are closely tied to family background. Those who possess or have access to various forms of family capital experience more positive quality of life and developmental outcomes. Such findings stress the need for more qualitative, sociological research on the topic of “living with Down syndrome”.

The next chapter, which forms the second part of the literature review, focuses specifically on education-related topics for people with Down syndrome. It continues to illuminate the interrelationships between “self-determination” and “capital” as they impact on the lifelong education journeys of people with Down syndrome.

Chapter 4: Learners with Down syndrome

Literature review (Part II)

Introduction

This thesis explores the post-secondary education journeys of people with Down syndrome. This chapter forms the second part of the literature review by focusing on the topic of learners with Down syndrome. It presents the case for the inclusion of learners with Down syndrome in mainstream learning environments, highlighting the benefits and challenges of inclusion. The common characteristics of learners with Down syndrome are discussed, noting the typical strengths and challenges they possess. These "learner profiles", like with the developmental profiles discussed in the previous chapter, are not to be interpreted in an essentialised manner. It is, nonetheless, beneficial to develop an understanding of common learner attributes among people with Down syndrome to provide insight into their post-secondary education experiences specifically.

This chapter analyses the learning experiences of people with Down syndrome throughout early childhood, primary and secondary schooling, and post-secondary education and learning. A lifelong approach to Down syndrome education research is needed because experiences of post-secondary education are inevitably shaped by earlier experiences of education fields. In Australia, the higher education and vocational education and training (VET) sectors have both highlighted the need to understand learners with disability from a whole-of-life perspective (see Chapter 2).

The post-school transition and post-secondary education experiences of people with Down syndrome are given particular attention in this chapter. Specifically, the literature review draws out how "self-determination" (Wehmeyer, 2003a) and "capital" (Bourdieu, 1986) play vital roles in post-secondary transition and education.

Inclusive education and learning

Both in Australia and internationally, inclusive education for people with disability has been advocated. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognises the right to inclusive education for all people with disability (UNICEF, 2017). The UNCRPD takes a lifelong perspective on education, which encompasses preschool, primary, secondary, tertiary, vocational, and lifelong learning. Inclusion occurs when education environments adapt their structures, methods, curriculum, culture, and policies, so that they become more accessible to all students without discrimination. Inclusion occurs when people with Down syndrome are valued and supported to engage in learning alongside their peers with and without disability (Faragher, 2023). In the UNCRPD, a three-fold case is presented for inclusive education: the pedagogical case (i.e. all students learn more effectively in inclusive environments), the social case (i.e. societies at large also become more inclusive), and the economic case (i.e. it is more cost-effective than special schools) (UNICEF, 2017).

In Australia, the *Disability Discrimination Act 1992* (Australian Government, 2024) aims to eliminate discrimination against persons with disability in education fields. The obligations of education and training providers under this Act are further clarified by the *Disability Standards for Education 2005* (Australian Government, 2005). The Standards stipulate that persons with disability are to have the same rights to participate in education and training as the general population. According to the Standards, providers are required

to make reasonable adjustments to enable persons with disability to access and participate in education and training on the same basis as people without disability. The *Final Report of the 2020 Review of the Disability Standards for Education 2005* (Australian Government, 2020) has found that, despite some progress in the field, there is still widespread unawareness of and noncompliance with the Standards among education and training providers. In Australia, several significant obstacles to inclusive education have been identified, including the lack of systemic clarity around what counts as "inclusive education", as well as bureaucratic struggles and the policy–practice gap (Mavropoulou et al., 2021).

People with disability continue to face inequalities and disadvantage within education fields. Recently, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has found that: "Today, Australian schools do not consistently deliver an inclusive education… Students with disability face multiple barriers to inclusive education, underpinned by negative attitudes and low expectations. Schools systematically exclude students with disability… by not providing appropriate adjustments and supports…" (Commonwealth of Australia, 2023b, p. 10). Clearly, then, the social model of disability (Goodley, 2013; Oliver, 1996) remains highly relevant for analysing and challenging the barriers faced by people with Down syndrome within the uneven playing fields of education institutions. Inequalities persist in what are meant to be democratic and inclusive systems, thus demonstrating the ongoing relevance of Bourdieu's work (Bourdieu & Passeron, 1977).

The inclusion of people with Down syndrome in mainstream learning environments has a history of several decades. Based in the UK, Buckley and Bird (1998) were among the pioneers who advocated the inclusion of learners with Down syndrome. In the early 1980s, Buckley discovered that children with Down syndrome could learn more effectively when their visual learning

strengths were targeted and, from 1988, Buckley and colleagues worked to place children with Down syndrome into mainstream classrooms (Buckley et al., 2006). Their study shows that the teenagers who had gone through mainstream schooling attained better communication skills than other teenagers with Down syndrome who had attended special education. This serves as evidence that the "Down syndrome phenotype" can be moulded through inclusion and support in mainstream settings (Buckley et al., 2006).

The recent *International Guidelines for the Education of Learners with Down Syndrome* (Faragher et al., 2020), published by Down Syndrome International, explain that inclusive education is a major goal for global Down syndrome communities. Learning also occurs outside formal classrooms, so people with Down syndrome should find inclusion in mainstream lifewide settings, including employment, sports, the arts, and community and religious contexts (Faragher, 2023). The guidelines also acknowledge, though, that "special" schools and classes might be the only available option in some contexts. Research has shown, however, that students with Down syndrome learn most effectively within inclusive settings (Faragher, 2023). Many concrete recommendations for including learners with Down syndrome are found in Faragher's (2023) *A Practical Guide to Educating Learners with Down Syndrome: Supporting Lifelong Learning*.

Throughout the journey of lifelong learning, parents and carers of people with Down syndrome play a fundamental role in advocating inclusive learning opportunities (Eloff & Kriel, 2003). Advocacy often involves building collaborative partnerships between families, schools, therapists, and other professionals to ensure that the needs of the person with Down syndrome are holistically and effectively addressed within mainstream education fields (Faragher, 2023). Not all families, however, are equally resourced nor positioned to advocate for their children in education fields. As Lalvani (2013) argues, parents who are less familiar with educational laws or inclusive

education practices are more likely to concur with the decisions of those in power to place their children with Down syndrome in separate, non-inclusive classrooms.

Characteristics of learners with Down syndrome

Several common characteristics of learners with Down syndrome can be identified. Each individual with Down syndrome is unique, so the following attributes identified by Faragher et al. (2020) are to be understood as common tendencies rather than as essential properties of every learner: Learners with Down syndrome tend to have strengths in reading, receptive vocabulary, and visual-spatial working memory. On the other hand, they usually face challenges with verbal working memory, phonological awareness, and grammar. It is, therefore, important for learners with Down syndrome to be provided with necessary language supports, including sign language, keyword sign, visual supports, and other multimodal supports (Faragher et al., 2020).

In identifying these learner characteristics, Faragher's (2023) central pedagogical mantra is "building on strengths" and "working around challenges" (p. 36). The strengths of learners with Down syndrome are, according to Faragher (2023), related to their long-term memory, dedication to and perseverance through tasks, visual learning, reading, and being good company within and outside of the classroom. To work around some of the common learning challenges, Faragher (2023) advises educators to allow for more processing time and to segment the learning into small steps.

Several learner attributes, namely motivation, behaviour, and imitation, require closer, critical analysis. Motivation is a psychological construct that has been studied in learners with Down syndrome, as Gilmore and Cuskelly (2014) discuss in their review. It is often assumed that people with Down syndrome have deficits in motivation, but this has been found to not always be the case (Gilmore & Cuskelly, 2014). As with all learners, there are great

variances in levels of motivation between individuals with Down syndrome. Some learners have high levels of motivation and perseverance, as well as a strong desire to try new things, leading them to experience greater "success" in multiple life domains (Li et al., 2006). Drawing on Morgan et al.'s (1990) work, Gilmore and Cuskelly (2014) argue that "mastery motivation" is necessary for sustaining interest towards learning. This means that people with Down syndrome must feel the need to accomplish things that suit their interests and abilities, in order to be driven towards further challenges.

Classroom behaviours of learners with Down syndrome are another area that has been researched. On the topic of difficult classroom behaviours, Jones et al. (2014) raise several important points: Learners with Down syndrome might avoid task demands that are challenging and/or uninteresting. Avoidance might be expressed in throwing objects, crawling under a desk, or physically escaping the room. Consideration must, however, be given to what influences a learner with Down syndrome to engage in perceived inappropriate behaviour. According to Jones et al. (2014), behavioural issues can arise due to environmental factors, including the setup of the physical space, noise levels, and the presence of other people. For these reasons, they argue that behavioural "interventions" should be directed at both individuals and their environments.

The learner characteristic of imitation or modelling also requires careful analysis. Interestingly, John Langdon Down (1866), whose medical text was critiqued in the previous chapter, identified an area of strength in people with "Mongolism" which researchers and educators in the global Down syndrome communities still hold to be true today. In Down's words, "imitation" and "mimicry" are learning strengths that can be employed to good effect: "They have considerable power of imitation, even bordering on being mimics… This faculty of imitation may be cultivated to a very great extent" (Down, 1866). Indeed, imitation is still perceived to be "an exceptional strength" (p. 40) of

people with Down syndrome (Faragher, 2023). From a sociocultural perspective on learning, researchers have explained that Down's idea can be applied in inclusive classrooms, "where learners with Down syndrome are surrounded by students on whom they can model learning behaviour" (Faragher et al., 2020, p. 8).

At the same time, one must reflect critically on what exactly it is that learners with Down syndrome are being asked to imitate and what the implications of not imitating those things are. For sociologists like Bourdieu, education serves to reproduce particular ways of being that are considered valuable in society (Bourdieu & Passeron, 1977). Inevitably, since it is the ideologies of the dominant groups that are reified through education fields, people who are in the minority are at a disadvantage. Non-dominant groups, such as people with disability, are at risk of social exclusion because of their bodily "otherness" (Lalvani, 2011). So, for people with Down syndrome and, indeed, for all people in society, there is a tension between "fitting in" to succeed in social fields and "being yourself" without conforming to dominant norms and values that may run counter to notions of "diversity" and "equity". With this caveat in mind, it is recognised that imitation and modelling are learning strengths of people with Down syndrome.

More research on how post-secondary learning experiences are shaped by the common learner characteristics of people with Down syndrome needs to be undertaken.

Early childhood and school-based learning

The literature review now analyses learning and education for people with Down syndrome from a lifelong perspective. Early childhood learning and formal education in primary and secondary schooling are discussed to generate potential insight into how these education experiences can impact on post-secondary education for people with Down syndrome. Researching

further education in this way has been encouraged by reports on further education in Australia (e.g. Department of Education, 2024b), as noted in Chapter 2. The following discussion draws upon academic sources but also community resources from organisations such as Down Syndrome Australia and Down's Syndrome Association in the UK.

Early childhood learning

For all people, learning begins immediately after birth (if not in the womb). In the first two years, although they usually attain "developmental milestones" later than their peers, infants with Down syndrome begin to develop motor, social, cognitive, and linguistic skills (Mills et al., 2015). Soon after birth, infants with Down syndrome tend to begin "early intervention" with various professional therapies, all of which are important for longer-term educational outcomes (Kendall, 2019). Early intervention provides a foundation in the child for formal schooling (Faragher, 2023).

Several factors can contribute to positive early development in people with Down syndrome. Relationships, particularly within the family, have significant impact on all areas of early childhood learning (Mills et al., 2015). Additionally, exploratory behaviour is to be encouraged in infants with Down syndrome because of its positive link to cognitive, language, and motor developmental outcomes (Fidler et al., 2019). Engaging infants with simple goal-directed activities can improve their executive functioning for future volitional and goal-oriented behaviours (i.e. their self-determination) (Schworer et al., 2020).

Preschools and childcare centres play an important role in early childhood development. Young children with Down syndrome should be included in the full range of activities offered in these education settings, albeit with additional support (Down's Syndrome Association, 2021). To facilitate inclusion, collaboration needs to occur between families, therapists, and preschools and childcare providers, so that the child can be best supported in

their learning (Down Syndrome Australia, 2018). As one primary aim of preschools and childcare centres is to prepare young children for formal schooling, Down's Syndrome Association (2021) advises that developing independence, self-help skills, and social skills (i.e. self-determination) be targeted. Attending preschool provides children with Down syndrome opportunities to independently put belongings in designated areas, practise personal hygiene, follow instructions, and eat, drink and play with their friends (McCormick et al., 2003). Gaining some of these skills will facilitate the transition into primary education.

Primary education

All children with Down syndrome have, in theory, the right to access mainstream education. Nevertheless, it is important that families choose the right "fit" for their children, and some may decide on specialist schools or home-schooling (Down Syndrome Australia, 2018). Some children begin their education journey in mainstream education but later change to special education because of poor experiences of inclusion (Runswick-Cole, 2008). The imperative, as Faragher et al. (2020) argue, is to improve the quality of inclusive education, lest students with Down syndrome be pushed into segregated settings.

As they enter primary education, children with Down syndrome tend to be focused on learning how to "do school" (Faragher et al., 2020). Students with Down syndrome should be given the same rules and expectations as students without disability with regard to classroom behaviour (Faragher, 2023). While some children begin to display "problem behaviours" in primary school, many are able to mature and adjust to the learning environment. Therefore, decisions to transfer children from mainstream to special schools on the basis of "problem behaviours" should not be made hastily (Faragher et al., 2020).

Several curricular issues applicable to both primary and secondary schooling need to be discussed. Whilst adjustments to the curriculum need to be made for people with Down syndrome, the learners should still engage with the same year-level, age-appropriate curriculum (Faragher et al., 2020). This means that students might work at a different level to their peers but cover the same topics and objectives of the learning (Down's Syndrome Association and Down's Syndrome Scotland, 2013). Furthermore, it has been advised that educators plan lessons with a variety of ways for learners to be taught and assessed, with consideration towards the likely barriers to learning for people with Down syndrome (Faragher, 2023).

Family involvement and advocacy are crucial for the successful education of children with Down syndrome. Families and schools need to be in open, regular communication regarding the needs and strengths of the learners (Down Syndrome Australia, 2018). This highlights, again, the influence of family background on developmental outcomes and quality of life for people with Down syndrome.

Secondary education

As they enter high school, people with Down syndrome face many new opportunities and challenges, that most are able to adapt to quite well (Bird & Buckley, 1999). Managing timetables, navigating large school sites, and shifting between classrooms, teachers, and subjects are all important competencies that mainstream secondary education affords to adolescents with Down syndrome (Bird & Buckley, 1999). Since children with Down syndrome can find change and transition quite difficult, extra preparation and support are needed when entering high school (Down's Syndrome Association, 2023). A positive transition into secondary school depends, in part, on a successful and supported experience that a child with Down syndrome may have had in primary school (Faragher et al., 2020). As

expected, communication between family and school are, again, vital for the successful inclusion of learners with Down syndrome (Mullan et al., 2018).

It has been noted that, compared to primary school, there are fewer students with Down syndrome transitioning into and completing their education within mainstream secondary schools (Cunningham et al., 1998; Lightfoot & Bond, 2013). Advocates of inclusive high schooling note that there is a general assumption that specialist schools are more suitable for adolescents with Down syndrome, because of the perception that curriculum subjects are more difficult in secondary education for these learners (Faragher et al., 2020). These prevailing beliefs have, however, been challenged by researchers (Faragher, 2014; Monari Martinez & Benedetti, 2011).

Students with Down syndrome have the right to access the same curriculum, albeit differentiated, as their peers, rather than "being segregated to focus on 'life skills' or social skills programs" (Faragher, 2023, p. 157). When high school students have the opportunity to select subjects, people with Down syndrome should have agency to choose subjects based on their aptitude and interests (Faragher, 2023). Promoting self-determination in learners enhances positive educational outcomes.

The benefits of inclusive education for high school students with Down syndrome are many. As Buckley et al.'s (2006) research shows, teenagers with the disability make greater gains in their development, particularly their communication skills, when participating in inclusive schools. This is because of the social learning and peer modelling, which people with Down syndrome especially benefit from, alongside "typically developing" students in mainstream schools (Bird & Buckley, 1999).

In the existing literature, there are several accounts of students with Down syndrome completing high school in Australia (Down Syndrome New South Wales, 2023; Faragher, 2023; Mcneilage, 2014). In New South Wales, most learners with intellectual disability complete the Higher School Certificate

(HSC) through the alternative pathway, Life Skills (Gadow & MacDonald, 2018). Since the pathway does not have external HSC examinations, Life Skills courses cannot be used to calculate the learners' Australian Tertiary Admission Rank (ATAR), according to the NSW Education Standards Authority (2024a). Moreover, the ATARs of adolescents with intellectual disability who do complete the mainstream HSC exams are often not sufficient for direct university admission (Gadow & MacDonald, 2018). So, young people with Down syndrome who do not possess the institutionalised ranking of the ATAR will face barriers in accessing some forms of post-secondary education.

Vocational education and training (VET) courses can be completed as part of the HSC (State of NSW, 2024). The benefit of accessing VET courses at school and/or through TAFE or other training providers is that it prepares students for further education and employment (NSW Education Standards Authority, 2024b). For teenagers with Down syndrome, Faragher (2023) encourages that they engage in some way with VET during their secondary schooling, because it will help them to make informed decisions on their post-school future. Work experience in community settings, in particular, helps prepare adolescents with Down syndrome for adult life by developing their emotional and behavioural skills in real-world contexts (Faragher et al., 2020).

Finally, it must be emphasised that learning does not cease once formal secondary schooling ends. As Faragher (2023) states, many young people with Down syndrome may be just "hitting their stride" (p. 181) when they finish high school. The myth that people with Down syndrome reach a plateau in their learning during adolescence has been disproved (Moni & Jobling, 2001).

In summary, this section has discussed early childhood learning and formal schooling for people with Down syndrome. The central points are well summarised by these words:

> All children have the right to an inclusive education; however, making this happen is not always straightforward. Parents are at the heart of

> their children lives and parental experiences and perceptions are vital if we are to understand and support children with DS. (Kendall, 2019, p. 145)

It is necessary for research to be undertaken to explore how early childhood and school-based learning experiences might influence further education experiences for people with Down syndrome.

Post-school transitions

After leaving high school, young people with Down syndrome encounter a range of opportunities and challenges. Post-school pathways are shaped by a range of individual, family, environmental, and structural factors.

Conceptualising "transition"

The transition out of compulsory education has been characterised as a transition from childhood to adulthood (Ward et al., 1994). Leonard et al. (2016) define the post-school transition as "the process of moving from the protected life of a child to the autonomous and independent life an adult" (p. 1370). Even as self-determination theorists like Abery and Stancliffe (1996) point out, however, one never lives with full autonomy without influence from and dependence on others (nor should one necessarily aim to live in such a way).

For any teenager, the transition out of high school can be a challenging time. This is even more so for people with disability because their post-school transitions are further complicated by issues of impairment (Foley et al., 2012). For some people with disability, important transition milestones such as getting a driver's licence or studying in post-secondary education might be delayed, modified, or not occur at all (Griffin et al., 2013). What the post-school transition entails for people with disability cannot be taken for granted.

Some families might characterise it as a period of the “continuation” of caring for their child as opposed to a “transition” into “independence” (Murray, 2007).

Transition planning

Due to the complexities surrounding their post-school transitions, people with disability begin their transition in the senior years of high school. In Australia, Shergold et al. (2020) recommend that every senior secondary student with disability should have an individualised post-school transition plan. Because of the relatively complex nature of post-secondary transitions for people with Down syndrome, schools are advised to begin transition planning by the age of 16 and continue conversations and planning with families on an ongoing basis (Channell et al., 2023).

Three main recommendations are offered by Faragher et al. (2020) concerning school-based transition programs for people with Down syndrome. The first is that such programs should give young people opportunities to gain work experience in the community. Secondly, information about post-secondary education and employment should be provided to people with Down syndrome. Thirdly, mainstream teachers, career officers, and school counsellors should be the ones delivering the transition training.

Down Syndrome Western Australia (2015) strongly advocates the use of person-centred planning in the transition process. This involves keeping the person with Down syndrome at the centre of planning, while family members and other stakeholders are positioned as “partners” in planning. The transition plan should reflect what the person with Down syndrome values and desires, as well as their capacities and the support required to action the plan: “Young people with Down syndrome have dreams and aspirations for their future, and should be fully engaged in planning for transition from school” (Scott et al., 2014, p. 1290).

Transition outcomes

Young adults with Down syndrome report having "a good life" when they have meaningful relationships with family, friends, and intimate partners; engage in community in further education, employment, and recreation; and live with a degree of autonomy and independence (Scott et al., 2014). Transition outcomes for people with disability are affected by individual and environmental factors (Loveall et al., 2022). Individual factors can include the various aspects of development discussed in Chapter 3. Loveall et al. (2022) find that young adults with Down syndrome who have higher levels of adaptive behaviour (i.e. daily living skills) tend to have better employment outcomes and also greater community engagement. Similarly, Foley et al.'s (2013) research finds that those with better functioning in self-care, communication, and social skills have a higher chance of being in open employment and/or participating in VET.

Young people with Down syndrome who are more involved in decision making throughout the transition process are also more likely to be in VET and/or open employment (Foley et al., 2013). During the transition period, the concept of "self-determination" becomes increasingly important: "Often young adults want more choices, increased decision making, greater independence, and with this comes more responsibility" (Down Syndrome Western Australia, 2015, p. 10). In recent decades, self-determination has been influential in shaping transition programs in Australian schools (Laragy, 2004). It is observed by self-determination theorists, such as Wehmeyer and Palmer (2003), that young people with intellectual disability who are more self-determined fare better across multiple life domains, including employment, financial independence, and independent living. Shogren et al.'s (2015) research on self-determination and post-school employment and community engagement has found the same.

Acting with self-determination does not, however, mean “doing it alone”. Rather, self-determined behaviour involves drawing upon one’s social networks for advice and support (Abery & Stancliffe, 1996). Thus, to optimise post-school transition outcomes, it is important for the young person with Down syndrome, their family, and school to work in collaboration (Down Syndrome Western Australia, 2015). Social capital (in terms of social skills and supports) is identified by Brown et al. (2017) as being critical to post-secondary transitions for young people with disability.

The transition outcomes of people with Down syndrome are directly shaped by their family backgrounds. Loveall et al. (2022) observe that parent involvement in transition planning contributes significantly to greater community engagement for young adults with Down syndrome. Family income is found to also impact on post-school outcomes (Foley et al., 2013). The influence of family resources or capital is explored in Pascall and Hendey’s (2004) study concerning people with disability: “Respondents also described parents’ material, cultural and social support starting in the nursery and continuing into adulthood” (p. 172). Parents might have “inside knowledge” (p. 173), because of their professional backgrounds as teachers, for instance, that can enhance transition outcomes. Families have been found to be concretely involved in transitions to post-secondary learning: “I certainly know that I wouldn’t have gone to college if it hadn’t been for my Mum’s pushing… She was the one that… sorted it all out and did all the paperwork and the applications” (Pascall & Hendey, 2004, p. 173).

Supporting the self-determination of people with Down syndrome can be a complex undertaking. Some parents have reflected on their conflicting roles as both “gatekeepers” and “facilitators” in their children’s journey to adulthood (Docherty & Reid, 2009). Parents and carers might feel the need to play a gatekeeping role, because they perceive their adult children with Down syndrome as being somewhat lacking in judgement: “He sees himself as more

able than he is. He's not always all that realistic" (Docherty & Reid, 2009, p. 461). Sometimes, parents and carers have to redirect the person with Down syndrome towards practical and realistic options, such as from universities overseas to local vocational programs (Taylor et al., 2019). In the event that it is not possible to fulfil their goals for further education and/or employment, the person with Down syndrome can be redirected to an alternative that is still aligned to their interests (Faragher, 2023). This means that their self-determined choices and decisions are still taken into consideration.

One's past experiences of formal schooling are another environmental factor that affects post-school transition outcomes. People with Down syndrome who have been included in mainstream formal education are, according to Faragher et al. (2020), more likely to have more positive transition outcomes (i.e. to be employed, studying in further education and/or living independently or semi-independently). Davies and Beamish (2009) observe that young adults with intellectual disability who graduate from specialist schools are, conversely, less likely to have had work experience and be in paid employment but more likely to be in day programs.

In Australia, the post-school employment outcomes of people with Down syndrome are also facilitated by external supports. School Leaver Employment Supports (SLES) helps Year 12 students with disability to become job ready by developing a range of skills and knowledge needed for employment (National Disability Insurance Scheme, n.d.). Inclusive Employment Australia, which replaced Disability Employment Services (DES) in July 2025, emphasises person-centred planning and support for people with disability to find and maintain work (Department of Social Services, 2025). As Down Syndrome Australia (2025) argues, the guiding principle of such employment services ought to be that "anyone who wants to work in open employment can do so with the right job and the right supports" (p. 4). In short, the post-school transition period for young people with Down syndrome

can be complex. Self-determination and family support are both significant factors that influence post-school outcomes. The post-secondary transition experiences of people with Down syndrome still requires further research.

Post-secondary education

Having explored the broad topic of "living with Down syndrome" in the previous chapter and topics surrounding learners with Down syndrome in this chapter, the literature review now analyses the topic of post-secondary education proper. The preceding discussions have sought to provide background information on the varied lived experiences of people with Down syndrome, all of which are intricately linked to post-secondary education experiences.

Further education is a key post-school transition outcome that contributes to quality of life for adults with Down syndrome (Down Syndrome Western Australia, 2015; Thomson et al., 1995). In recent decades, people with Down syndrome have been increasingly participating in further education (Carr, 2008), challenging the assumption that their learning reaches a plateau in adolescence (Moni & Jobling, 2001). Young adults with Down syndrome have demonstrated gains in language and literacy development by participating in post-school literacy programs (Moni et al., 2018). In Australia, there are programs specifically designed to provide post-secondary learning experiences to people with Down syndrome and other disabilities (e.g. Latch-On) and university programs that include people with Down syndrome as audit participants (e.g. uni 2 beyond and Up the Hill). People with Down syndrome also engage in mainstream, non-disability specific learning contexts.

The literature on the lived experiences of people with Down syndrome in post-secondary education has been expanding in recent decades. Interestingly, research in this area is strongly qualitative in nature, in contrast to the

quantitative studies that dominate the field of Down syndrome research more broadly. As stated in Chapter 1, this growing field of research originates from the UK (Thomson et al., 1995), the US (Casale-Giannola & Kamens, 2006; Faragher, 2023; Hamill, 2003; Woodward, 2022), Spain (Calderón-Almendros & Calderón-Almendros, 2016), and Australia (Faragher, 2023; High & Robinson, 2021; Messenger et al., 2018; O'Rourke, 2011).

Vocational education and training (VET)

In Australia, information provided to people with Down syndrome and their families concerning post-secondary learning tends to be focused on VET as opposed to university (e.g. Down Syndrome Western Australia, 2015). Research tends to show that there are people with Down syndrome in VET but not university (e.g. Foley et al., 2013). It is, therefore, somewhat surprising that, globally, there is less literature on VET learners with Down syndrome than on university or college learners with Down syndrome.

One of the earliest studies to explore further education experiences of people with Down syndrome is Thomson et al.'s (1995) research. The historical context of this study is significant because the young adults had attended special schools or units in Scotland between 1986 and 1987 (i.e. before the time when inclusive education was widely implemented). Two particular young people with Down syndrome were found to differ greatly in "their socio-economic status and the severity of their learning difficulties" (Thomson et al., 1995, p. 334). The one who was considered "more able" (p. 335), because of their enhanced personal independence and social competence, had more positive experiences of further education and also better employment prospects.

Several experiences of more recent vocational college students are recounted by Faragher (2023), the first being of Ruth, her daughter. Faragher (2023) herself encountered significant access barriers when she tried to enrol Ruth

into VET: “I found the information really confusing. I spent a lot of time on the phone, on online chats and at the counter of the student centre trying to figure it out.” (p. 186) Ruth now has a Certificate III in Childcare and works full-time in a childcare centre. Faragher (2023) also describes the story of Bobby Pate, another young Queenslander with Down syndrome. Bobby has attained a Certificate in Design and, sometimes, he produces designs and artworks for public display and/or sale.

Compared to the time of Thomson et al.’s (1995) research, it would appear that it is now more commonplace for people with Down syndrome to engage in further education and to attain positive employment outcomes as a result of that learning. Such outcomes, however, are not guaranteed for all individuals with Down syndrome. As Kerry Hands of Down Syndrome Victoria says, there are challenges to converting education into employment for this population: “It seems for some, that partaking in further study has become an occupation in itself.” (Kutchel, 2016, para. 28)

It is also important to discuss the community-based adult literacy and numeracy program called Latch-On, which was once aligned to the Certificate II in Literacy and Technology (Latch-On, 2021b). Many young people with Down syndrome have participated in and benefitted from Latch-On (Moni et al., 2018). Moreover, a significant number of research studies on post-secondary learners with Down syndrome have been published by the Latch-On team (see Latch-On, 2018). The Latch-On program was established in 1998 by the University of Queensland (UQ) and, since 2004, has expanded to community-based settings around the world (Latch-On, 2021a). Using a multiliteracies approach, Latch-On (Literacy and Technology Hands-On) aims to improve the quality of life of its participants with intellectual disability by developing their literacy, numeracy, and digital skills, as well as their self-confidence and independence (Moni & Jobling, 2001, 2014).

Higher education

The field of inclusive higher education for people with intellectual disability is relatively novel, particularly in Australia (Rillotta et al., 2018). While it is more common for people with Down syndrome to participate in VET, it is also recognised that higher education is "increasingly possible" (Faragher et al., 2020, p. 36) and "emerging as an option" (Faragher, 2023, p. 188) for people with Down syndrome.

Globally, people with intellectual disability can access higher education either through the traditional path as enrolled students or through a non-traditional path as audit or non-credit participants (Hart et al., 2010). Inclusion programs at universities and colleges enable people with intellectual disability to experience academic and social aspects of higher education as non-enrolled participants. In the US, such opportunities are plentiful due, in part, to the 2008 *Higher Education Opportunity Act*, which stipulates that people with intellectual disabilities be given access to higher education (Grigal & Papay, 2018). Canada has also seen increasing participation in inclusion programs at universities and colleges (Uditsky & Hughson, 2012). In Australia, however, inclusive higher education for people with intellectual disability is still a relatively new field (Rillotta et al., 2018). There is currently no legislative motivation to establish such inclusion programs in Australia (Gadow & MacDonald, 2018). The two existing Australian initiatives, namely the Up the Hill project and uni 2 beyond, were both initiated by academics and families of people with intellectual disability (Gadow & MacDonald, 2018). The few opportunities for participating in university-based inclusion programs in Australia have, nonetheless, been modelled after the US-counterparts (Gadow & MacDonald, 2018; Rillotta et al., 2018).

The Up the Hill Project was established in 1999 with the goal of supporting people with disability to experience the social and educational life of Flinders University (Rillotta, Gobec, et al., 2020). Throughout the three-year program,

the participants identify learning goals and select topics of relevance to them (Flinders University, 2023; Rillotta et al., 2018). Importantly, the range of topics offered has broadened over time, reflecting the recognition of the decision-making rights of people with intellectual disability as stipulated in the UNCRPD (Rillotta et al., 2018). Peer mentoring is a fundamental way of supporting the Up the Hill participants. Each semester, a different peer mentor is paired with each participant, with all the mentors being undergraduate students studying a human service degree (Rillotta et al., 2018).

The uni 2 beyond program is an initiative of the Centre for Disability Studies at the University of Sydney (Centre for Disability Studies, 2025). uni 2 beyond was established in 2012 to enable people with intellectual disability to participate in university life. Through person-centred planning with the uni 2 beyond staff, the participants audit units according to their learning needs and interests (Gadow & MacDonald, 2018). Additionally, participants have the opportunity to engage in an internship placement (Walker & MacDonald, 2018). These work placements are critical because transitions from inclusion programs like uni 2 beyond to meaningful careers are still lacking (Riches et al., 2018).

The following discussion draws on literature on adults with Down syndrome participating as either audit or enrolled students in universities and colleges around the world. To preserve the particularities of their individual narratives, the studies are discussed one-by-one. Concurrently, the themes that are of particular interest to this thesis (i.e. those related to “self-determination” and “capital”) are foregrounded in each narrative, as they have been above.

Audit students

Jacqueline is a 21-year-old with Down syndrome who completed a Speech Communication subject at a private university in the US (Casale-Giannola &

Kamens, 2006). Her mother, a professor in economics, approached the Communications Department chair at her university to discuss the possibility of Jacqueline taking a college subject. Although the idea was initiated by her mother, Jacqueline was eager to participate. The subject in Speech Communication was chosen, because Jacqueline was verbal, friendly, and confident. It provided Jacqueline with the opportunity to develop her academic skills, particularly in preparing and delivering speeches. Importantly, several key stakeholders made Jacqueline's inclusion possible. An experienced professor in communications with a "kind and caring disposition" (p. 346) was a key contact. Jacqueline's mother also approached two special education professors to coordinate the inclusion. Jacqueline was supported by a peer, a pre-service teacher who had completed special education subjects. This peer mentor worked closely with Jacqueline and Jacqueline's mother to adapt the assignment and to reinforce home study of the materials. Jacqueline had, therefore, a strong social network with stakeholders who supported her inclusion.

Megan is a 26-year-old who joined an existing inclusion program at a private liberal arts Jesuit college in the US (Hamill, 2003). Megan is outgoing, has strong social skills, and is a self-advocate. For Megan, studying at college was one of two important life goals, which she framed in self-determination language: "I wanted to go to college and to be independent away from home" (p. 345). Importantly, she wanted to follow the example set by her older sisters, who both went to college. The widespread support received by Megan helped her to succeed academically. Megan's lecturers had extensive experience in the university field. Her "study buddies" (i.e. peer mentors), one of whom was taking a major in special education, provided support inside and outside the formal classrooms. Megan's family communicated with university staff regarding assessment tasks so that they could support Megan's learning at home. Megan herself was described as a successful, self-determined learner. Significantly, her classmates believed that she was capable to study

in college for credit, but they noted the inequalities in the field of higher education: “Megan said she wouldn’t be able to pass the entrance requirements to get credit for the course. I don’t think it’s fair… [Universities] should have a special test for people like Megan so they can have the same opportunities” (Hamill, 2003, p. 346).

Belle is a 21-year-old Australian with Down syndrome who entered Edith Cowan University (ECU) as a “voluntary guest” (O'Rourke, 2011). Belle wanted to pursue post-secondary education to become an education assistant within schools. Belle’s inclusion at ECU was facilitated by O'Rourke (2011) himself, who maintained close communication with Belle and, significantly, advocated for her in the face of disabling bureaucracies within the university. Throughout her university experience, Belle was supported by six peer mentors, who were all studying secondary education. She received modified course notes and delivered a presentation to achieve the course outcomes. The quality of her work was assessed as being “well structured, appropriate and delivered in a manner expected at university” (O'Rourke, 2011, p. 28). Nonetheless, the academic experience was sometimes overwhelming for Belle.

Kerri-Ann Messenger is a much older Australian with Down syndrome, who participated in the Up the Hill Project, some 22 years after finishing high school (Messenger et al., 2018). After completing Year 12, Kerri-Ann found employment but had to resign in 1994 due to ill health. She then entered TAFE to learn typing and computing: “TAFE was great until it came to an end, as there was nothing more they could offer me” (p. 173). Beginning in 1998, Kerri-Ann worked as the Assistant Chairperson of a disability organisation. When she realised that the volunteers were Flinders University students, she began to dream of being a university student herself but thought that “it would never be allowed” (p. 174). In 2012, Kerri-Ann was unexpectantly introduced to Up the Hill: “Over the next three years I was in heaven. I was so thrilled… to be given the opportunity to attend university” (p. 175). Throughout the program,

Kerri-Ann developed her academic literacy skills, such as referencing sources for assignments. Undergoing work experience at a high school special education unit fulfilled part of Kerri-Ann's dream to help people with disability and further confirmed this career goal for her.

Enrolled students

For some people with Down syndrome, the higher education journey does not conclude at the auditing stage. In the past decade, several people with Down syndrome have graduated with college and university degrees.

Charlotte Woodward (2022) is a recent graduate with Down syndrome, completing a Bachelor of Sociology majoring in Inequality and Social Change. She graduated in 2022 from George Mason University in the US. Charlotte recounts that, when she was born in 1989, her mother was told by the doctors, "I would not be able to read or write and that in the future I would most likely have a job in a sheltered workshop." (p. 732) Charlotte's mother, being a teacher and coming from a line of teachers in her family, resisted those deficit discourses. Having attained her degree, Charlotte has followed her lecturers' advice to work in public sociology to drive social change (George Mason University, 2022).

Rafael Calderón-Almendros is a young adult who became the first Spaniard with Down syndrome to graduate with a degree in music (Calderón-Almendros & Calderón-Almendros, 2016, p. 108). Rafael's music degree was long and intensive, involving four years of foundation studies followed by six years of professional studies (Calderón-Almendros & Habegger-Lardoeyt, 2017). Music had always been a major pillar in his life, so attaining a music degree was a significant highlight for him. The pathway, however, was not without barriers. Throughout his schooling, Rafael's family had to resist deficit-based discourses that sought to exclude him from mainstream education (Calderón-Almendros & Calderón-Almendros, 2016). Additionally,

Rafael's family background was, on the surface, one that would have rendered it unlikely for him to access higher education: "They are a family of fighters… working class, a modest family, nine brothers and sisters… many of them went on to study, and they have been able to help Rafael, who is the youngest one" (Calderón-Almendros & Calderón-Almendros, 2016, p. 106). Notably, despite their working-class background, Rafael's home environment was predisposed to further education.

Dylan Kuehl is another university graduate with Down syndrome (Faragher, 2023). In 2022, he graduated in the US with a Bachelor of Liberal Arts. As he explains, education is a lifelong journey: "I also went to community college… where I learned basic adult education and sharpened all my skills for a four-year university" (Faragher, 2023, p. 5). Dylan has diverse interests including music, video games, dance, and theatre. His story highlights that "literacy" should be conceptualised as "multiliteracies", instead of being confined to traditional academic skills: "My reading level and comprehension has grown and grown in college… I need to read books for my college courses. I read graphic novels, too." (p. 6)

One other recent university graduate is Rachel High, a 47-year-old Australian with Down syndrome who completed a Bachelor of Arts (High & Robinson, 2021). In her co-authored autoethnography, Rachel explains that her education journey has been long and unpredictable. Rachel attended primary and secondary schools where she was included in mainstream classes for some subjects. She completed the Duke of Edinburgh's Award from age 14 to 21. Importantly, the director of the Award then introduced Rachel to the Up the Hill program. Importantly, Rachel's formal learning journey did not cease once Up the Hill concluded. Rachel was invited to stay at the university to write and direct a film. It was then suggested that she enter the Foundation Studies Course at Flinders University. At the age of 35, Rachel gained entry into the Bachelor of Arts, which she completed over a ten-year-long journey.

Summary

Throughout the VET and higher education narratives recounted above, there are several important common themes that emerge. Firstly, many people with Down syndrome desire to access post-secondary education for reasons similar to their peers without disability, namely for employment, learning, and self-development. Accordingly, positive academic and employment outcomes have been attained by some post-secondary learners with Down syndrome. The post-school aspirations of people with Down syndrome are profoundly shaped by their home and school environments. By growing up in social contexts that value further education, people with Down syndrome become more predisposed towards VET and higher education.

Secondly, for people with Down syndrome to succeed in their access of, participation in, and outcomes from further education, there needs to be a range of resources available to them. People with Down syndrome themselves can possess important traits and abilities that facilitate post-secondary journeys. Moreover, support from and collaboration between many different stakeholders is vital. Families, in particular, play a crucial role in facilitating VET and higher education journeys. Educators and other practitioners within further education also perform vital roles in supporting learners with Down syndrome.

Thirdly, further education journeys can come about through multiple means. Whilst some opportunities arise because of the intentional choice and planning by people with Down syndrome and/or their families, some people with Down syndrome might find themselves in further education by “chance and opportunity” (Faragher, 2023, p. 183). This usually occurs when significant players within VET and higher education fields prompt people with Down syndrome towards such opportunities.

Conclusion

Spread over two chapters, the literature review has explored the broad topic of living with Down syndrome and topics specific to people with Down syndrome as learners, particularly in post-secondary education settings. The previous chapter has focused on quality-of-life issues and typical developmental strengths and challenges of people with Down syndrome. Family background and forms of capital (e.g. education, income, and culture), as well as self-determined attributes (e.g. choice making and decision making), have significant influence on both quality of life and developmental outcomes for people with Down syndrome. In the previous chapter, these topics have been explored to provide insights into lifewide and lifelong issues that might impact on the post-secondary education journeys of people with Down syndrome. Research of this nature has been called for by VET and higher education reports in Australia.

This chapter, meanwhile, has focused more narrowly on topics surrounding people with Down syndrome as learners. In a non-essentialising manner, the general characteristics of learners with Down syndrome have been analysed. A lifelong approach has also been adopted in this chapter, meaning that early childhood learning and primary and secondary education have been analysed to generate knowledge on how these stages of learning might impact on post-secondary education for people with Down syndrome. The topic of further education for people with Down syndrome proper has been given significant attention in this chapter.

It has been argued that self-determination and capital are both vital for facilitating these post-secondary education journeys. Although self-determination is found to determine further education opportunities to some extent, the capital (i.e. financial, cultural, and social resources) that people with Down syndrome and their families have access to ultimately determine post-secondary outcomes. As fundamental as the concept is for disability

studies and advocacy, self-determination alone might not be sufficient in enabling further education journeys.

It is necessary, therefore, to establish a strong understanding of self-determination and capital as integral parts of the theoretical framework in this thesis. This is the focus of the next chapter.

Chapter 5: Self-determination and capital

Theoretical framework

Introduction

This chapter presents the theoretical framework through which the post-secondary education journeys of people with Down syndrome are analysed. To address the main research question of this thesis (i.e. How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?), it is necessary to explore "self-determination" and "capital" as integral parts of the theoretical framework.

This chapter builds upon several key points from the preceding chapters. Firstly, the theoretical framework is situated within a broader critical disability studies framework, which was explained in Chapter 1. Theorising disability-related issues requires a postconventionalist approach, gleaning from a diversity of theories (Shildrick, 2020). In this chapter, a move towards interdisciplinarity involves drawing upon two scholarly fields (i.e. psychology and sociology) which have traditionally been somewhat divergent. A sociological perspective to Down syndrome research is critically needed, since the field is predominantly shaped by quantitative psychological studies (Burack et al., 2023).

Secondly, this chapter stems from the need to understand "self-determination" and "capital" in detail, as identified by the literature review in Chapters 3 and 4. Self-determination is positively linked to quality of life and developmental outcomes in people with Down syndrome (Faragher et al.,

2020; Jevne et al., 2022; Landuran et al., 2022). At the same time, resources and capital, particularly from one's family, are also necessary for facilitating such positive outcomes (Evans & Uljarević, 2018; Hilvert et al., 2023; Krueger et al., 2019). People with Down syndrome require a range of personal, family, and other resources to fulfil their self-determination towards participating in further education (Casale-Giannola & Kamens, 2006; Hamill, 2003; Taylor et al., 2019).

This chapter is, accordingly, focused on exploring self-determination and capital, which are concepts primarily derived from psychology and sociology, respectively. Self-determination can be theorised as "socially formed dispositions and behaviours", while capital can be conceptualised as "socially valued resources". After theorising self-determination and capital in turn, the chapter explains the potential commonalities between the theorists of the two concepts. In particular, this chapter highlights the contributions that the sociology of Bourdieu can provide to the self-determination theories of Wehmeyer, Abery, Stancliffe, and other disability theorists. In other words, the chapter intends to move self-determination theories closer towards critical sociology. It does this by drawing out aspects of self-determination theories that are already sociologically inclined. As crucial as the construct of self-determination is for disability research and advocacy, it would be beneficial for the concept to be more explicitly sociologically informed.

Self-determination as "socially formed dispositions and behaviours"

"Self-determination" is a key concept that informs the theoretical framework of this thesis. While it appears to be largely an individual-oriented trait, self-determination has significant social dimensions. The definition of self-determination as "socially formed dispositions and behaviours" attempts to encapsulate both the individual and social aspects of the construct.

Background

While the term has a range of meanings, "self-determination" is used in this thesis in the way that it has been theorised by disability scholars such as Wehmeyer, Abery, and Stancliffe.

Conceptually, the idea of self-determination has its roots in philosophy and psychology. Philosophical debates concerning determinism and free will have shaped Wehmeyer's (2003d) use of the concept. The "soft" determinism held by the British philosopher, John Locke, appears to be adopted by Wehmeyer (2003d). In this view, human behaviour is understood to be the result of individual free will, as well as being caused by a range of determinants. In other words, both "structure" and "agency" (terms more commonly used in the social sciences) are important for understanding human behaviour. Locke's contention that notions of freedom, equality, and power to act volitionally are fundamental rights for all humans underpins the argument that people with disability, like all people, have the right to self-determination (Abery & Stancliffe, 2003a).

Psychology is the predominant scholarly field that has influenced understandings of self-determination within disability studies. For Wehmeyer (2003d), the work of Angyal (1941) in the field of personality psychology is particularly significant. Angyal posits that autonomy and self-governance are fundamental characteristics of living organisms. Autonomous behaviours are said to include choice, self-regulation, and adaptation, which are concepts fundamental to Wehmeyer's functional theory of self-determination (as shall be explained). Significantly, Angyal (1941) also reasons that agency and autonomy are never absolute: "Self-determination is restricted by outside influences…" (p. 37).

Motivational psychology is another branch within psychology that has shaped the concept of self-determination within disability studies (Wehmeyer, 2003d). There is, according to psychologists, Deci and Ryan, a strong link

between intrinsic motivation and self-determination in human behaviour. Intrinsic motivation is seen to be "the energy source that is central to the active nature of the organism" (Deci & Ryan, 1985, p. 11). Human beings are intrinsically motivated to act to satisfy their needs. Two such needs are the needs for self-determination and competence. These needs cause humans to continually pursue and overcome challenges. Similar to Angyal's thinking, the idea of self-determination in Deci and Ryan's (1985) view relates closely to "choice" and is built on notions of "volition" and "intentionality". Again, self-determination is not exercised within a vacuum: "Although we define self-determination as a quality of human functioning, we also emphasize that it can be either supported or hindered by environmental forces" (Deci & Ryan, 1985, p. 39). This ecological strand within motivational psychology is, as shall be seen, the defining feature of the ecological theories of self-determination.

"Self-determination" in disability studies

Nirje's (1972) chapter titled "The right to self-determination" is regarded to be one of the first writings within disability studies to speak of self-determination explicitly. Its primary contention is that people with disability have the right to be self-determined. As Nirje states, self-determination is a particularly important notion for people with intellectual disability because, historically, they have been rendered voiceless and devalued by society. Promoting self-determination in people with intellectual disability has the positive effect of "normalizing their conditions of life and increasing its quality" (p. 189).

The idea of self-determination has been defined by Wehmeyer in several ways over the years. Initially, the term referred to "the attributes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (Wehmeyer, 1992, p. 305). This definition emphasises that self-determined people are able to cause things to happen in their lives. The phrase "free from

undue external influence" is also significant, signalling that self-determination is not about absolute freedom (Wehmeyer, 2003a).

Later, the idea of "quality of life" was added to the definition of self-determination (Wehmeyer, 1996). Self-determination and quality of life are seen to be mutually reinforcing. People with disability exercise self-determination to improve areas of their life, but being able to act in self-determined ways is also an indicator of having a positive quality of life (Wehmeyer, 2003a).

Wehmeyer's conceptualisation of self-determination was further clarified by introducing the notion of "volition". Wehmeyer (2005) states that: "Self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117). Volitional actions are actions which are performed intentionally and purposefully with a specific end in mind (Wehmeyer, 2007).

Theories of "self-determination"

Three distinct theoretical models of "self-determination" have been explicated by the work of Wehmeyer et al. (2003). The functional theory focuses more on individual actions and behaviours, whereas the ecological theory and the tripartite ecological theory both give more consideration to environmental factors that impact on a person's self-determination. The three models are not, however, regarded as being conflicting nor mutually exclusive.

The functional theory

The first model for understanding self-determination in this thesis is the functional theory. The theory is "functional" in that it argues that self-determination is defined according to the function served by a person's actions and behaviours (Wehmeyer, 2003a). Self-determination is not merely

to do with outward actions but the purpose and intent behind those actions. For instance, a person with disability might decide to speak assertively for oneself in one scenario but decide, in another context, that it is more beneficial to remain quiet (Wehmeyer, 2003a). In both scenarios, the person can be said to act in a self-determined manner.

Significantly, self-determination is conceptualised as a "disposition" within the functional theory: "We have categorized self-determination as a dispositional characteristic; that is, people who consistently engage in 'self-determined behaviors' can be described as self-determined" (Wehmeyer, 2003a, p. 179). People who are considered self-determined are those who have an enduring tendency to perform self-determined behaviours. Moreover, self-determination is an embodied disposition: "Dispositional characteristics involve the organization of cognitive, psychological, and physiological elements in such a manner that an individual's behavior in different situations will be similar" (Wehmeyer, 2003a, p. 179). Self-determination is, thus, affected by one's physiological body. Accordingly, the self-determination of a person with disability is always influenced in some way by their "capacity" (Wehmeyer, 2003a, p. 179).

In the functional theory, Wehmeyer (2003a, 2003b) lists a number of "component elements" of self-determined behaviour. The list is an attempt to operationalise the psychological construct, so that it might be better understood and measured and so that people with disability might be better supported in concrete ways to develop their self-determination. Several components of self-determined behaviour are related to achieving or obtaining things in life: The first component is choice making and is an important one since people with disability have tended to be at risk of having their preferences not acknowledged. Through choice making, people with disability identify and act upon their preferences according to their interests and abilities (Wehmeyer, 1995). Decision making, the second component, is

related to choice making. Decision making is a more complex process, as it requires evaluating various options before implementing a plan of action. Problem solving, meanwhile, involves responding to an issue where it is not immediately clear what the possible solutions are. Goal setting and goal attainment involve setting specific and measurable goals and monitoring one's progress towards the goals. It should be noted, however, that acting in a self-determined and goal-oriented manner does not mean that one's goals will necessarily be achieved. Therefore, self-determination is not to be equated purely with "success" (Wehmeyer, 2005).

In addition to the above list, Wehmeyer (2003a, 2003b) outlines some components of self-determined behaviour that are more related to self-reflection: Self-observation, evaluation, and reinforcement are all aspects of self-regulation. These behaviours involve reflecting upon and evaluating oneself. Self-awareness and self-knowledge enable a person with disability to recognise their own strengths, weaknesses, abilities, and limitations. Meanwhile, self-reinforcement involves a person with disability self-administering positive or negative consequences for actions done (or not done). Self-advocacy and leadership involve speaking up for oneself, another person, or a cause. Another component of self-determination is internal locus of control, which exists when a person with disability feels in control of their own life, rather than feeling that their life is determined by luck or by other people. In short, Wehmeyer's functional theory identifies behaviours such as goal setting, decision making, problem solving, self-knowledge, and self-evaluation as notable indicators of self-determination.

Although it tends toward foregrounding the actions and behaviours of individuals with disability, the functional theory also has a social and structural dimension. According to Wehmeyer (2003a), the primary factors influencing self-determination are individual capacity, opportunities to develop and exercise self-determination, and supports and accommodations

that facilitate self-determination. Individual capacity to be self-determined is related to learning and developmental outcomes, such as those discussed in Chapter 3 of this thesis. For example, people with Down syndrome who have higher levels of executive functioning usually also have greater self-determination (Landuran et al., 2022). Capacity is not, however, the only determinant, since having an intellectual impairment does not preclude a person from thinking and acting in self-determining ways (Wehmeyer & Palmer, 2003). Through explicit instruction, students with intellectual disability can increase their goal-setting, decision-making, problem-solving, and self-regulation skills (Agran et al., 2000). So, although they might face difficulties in exercising self-determination, people with intellectual disability are able to develop different aspects of self-determination when they are provided opportunities and supports to do so (Wehmeyer, 2003c).

In short, the functional theory of self-determination foregrounds the personal dispositions and behaviours that exemplify personal autonomy and volition. Yet, the theory also acknowledges that people are inevitably shaped by their environment. This latter idea is given more emphasis in the two ecological theories of self-determination.

The ecological theory

The second model for understanding self-determination in this thesis is the ecological theory. The ecological perspective is not incompatible with the functional view, though their emphases differ. Its theorists, Abery and Stancliffe (2003a), clarify that "an ecological approach includes the individual and all of his or her personal capacities" (p. 26). The individual with disability is, therefore, still an important agent within the ecological model. Nonetheless, the ecological view places more emphasis on self-determination as "the product of both the person and the environment" (Wehmeyer & Abery, 2013, p. 400). Importantly, the ecology surrounding a

person with disability can support and/or hinder their self-determination (Abery & Stancliffe, 1996).

There are several key tenets that underpin the ecological perspective (Abery & Stancliffe, 2003a): Firstly, all individuals with disability are capable of exercising self-determination. Whilst they have differing "levels" of self-determination depending on their age, education, and life experience, the ecological theory stresses that every person with disability has the potential to be self-determined. Secondly, as with most personal characteristics, self-determination exists along a continuum. The specific point on which a person with disability occupies on the spectrum is determined by their personal disposition, knowledge, and ability, as well as by their environments and networks. In addition, a given individual may have different levels of self-determination, depending on the contexts and relationships in which self-determination is exercised. Thirdly, self-determination is a lifelong process, one that is initiated soon after birth. As people grow, their self-determination becomes more complex as they navigate personal control, collaborative decision making, and allowing trusted others to assume control. Since self-determination is a developmental process, people with disability should be afforded both time and opportunity to build up their self-determination.

In light of these central principles of the ecological theory, self-determination needs to be theorised as a fluid and contingent construct. Self-determination is performed and co-constructed interpersonally within social fields. Even when it is understood as a "disposition" (Wehmeyer, 2003a), self-determination cannot be described as a trait that is intrinsic to one's biological make-up. Rather, it is a disposition that is acquired and developed throughout the lifespan as a person with disability is provided opportunity and support to do so (Doll et al., 1996). Developing the disposition and behaviours associated with self-determination involves working with the individual with disability but also intervening in their social environments (Abery & Stancliffe,

1996). Enabling people with disability to become more self-determined requires changing the social fields in which they inhabit, such that the fields themselves become more inclusive and accessible for people with disability.

Bronfenbrenner's ecological systems theory

A major theory underpinning Abery and Stancliffe's (1996, 2003a) ecological theory of self-determination derives from the ecological psychology of Urie Bronfenbrenner. As a developmental psychologist, Bronfenbrenner (1979) is interested not only in individual-oriented psychological processes but in how these processes are moulded by one's environment. His tenet is that "behaviour evolves as a function of the interplay between person and environment" (Bronfenbrenner, 1979, p. 16). The interaction between humans and their ecologies is one of "*progressive*, *mutual accommodation*" (Bronfenbrenner, 1977, p. 514, emphasis in original). In other words, individuals and their thoughts and behaviours both shape and are shaped by their ecological environments. Any given individual is active across numerous environments throughout their life, so it is important to consider how numerous fields might interrelate in shaping the individual. According to the ecological theory, people live and act within four concentric contexts at any given time. Bronfenbrenner's (1977) framework of ecosystems as being comprised of the micro, meso, exo, and macro is used by Abery and Stancliffe (1996, 2003a) in their theory of self-determination.

Firstly, the individual with disability exists within a microsystem. The microsystem consists of a person's immediate contexts, such as their family, school, and work. The relationships and social networks that people with disability have access to in their microsystem serve as "resources that are critical to optimal development" (Abery & Stancliffe, 2003a, p. 35). The first and most fundamental micro-context within which a person's self-determination is learned and developed (or not) is their family and home environment. The influence of the family unit begins immediately from birth (if

not prior). As stated in the literature review chapters, family background significantly shapes the quality of life (Alrayes et al., 2024) and developmental outcomes (Channell et al., 2021) of people with Down syndrome. As people with disability progress through life, education and employment contexts become important fields in which their self-determination is supported and/or hindered (Abery & Stancliffe, 2003a).

The second level of a person's ecosystem is the mesosystem. The mesosystem consists of the interactions and intersections between various micro-contexts (Abery & Stancliffe, 1996). The development of a person with disability is impacted by both the quantity and quality of the connections between the different fields of their microsystem (Abery & Stancliffe, 2003a). For instance, a student's learning is benefitted when collaborations between home and school exist. The ecological view posits that the facilitation of self-determination in people with disability is a shared responsibility. In particular, family involvement and advocacy in and across the individual's micro-contexts are usually what enables positive linkages to be established (Abery & Stancliffe, 1996). In other words, families of people with disability play a vital role in establishing and maintaining social networks that can contribute to the self-determination and well-being of people with disability. For people with Down syndrome, it has been shown in the literature review chapters that collaborations between families, schools, and other key stakeholders contribute to positive lifelong learning outcomes (Faragher, 2023). At the same time, not all families are well resourced to advocate for their family member with Down syndrome (Lalvani, 2013).

The third level of a person's ecosystem is known as the exosystem. Bronfenbrenner (1977) defines the exosystem as the broader social structures that "do not themselves contain the developing person but impinge upon… the immediate settings in which that person is found" (p. 515, emphasis removed). The economy, governments, and the media are examples of social

structures in the exosystem. These are broader social settings where people with disability are not necessarily included as direct nor "active participant[s]" (Abery & Stancliffe, 1996, p. 127) but are, nonetheless, affected by the decisions and actions stemming from these exo-settings. For example, the financial support afforded to a person with disability can be directly affected by economic changes and/or government policy changes. The exosystem can also include fields that are nearer to the individual's experience, such as their parents' workplaces and social networks (Bronfenbrenner, 1979). As explained in the literature review, parents and carers might possess insider knowledge and social networks because of their professional backgrounds, particularly within the education field, that can benefit their children with disability (Pascall & Hendey, 2004).

The fourth level of a person's ecosystem is the macro level. The macrosystem is fundamentally distinct to the micro-, meso-, and exosystems, because it relates to "general prototypes" (p. 515) that permeate throughout culture and society (Bronfenbrenner, 1977). The macrosystem determines the structures and activities found in the other systems. This explains, for instance, why schools within a particular culture operate in rather uniform ways, being structured by the dominant norms and values of a given society. The neoliberal framing of education, particularly within higher education and VET fields (Chapter 2), can be understood as an example of a macrolevel influence. The macrosystem operates at the level of values and beliefs, "often unwittingly, in the minds of the society's members as ideology made manifest through custom and practice in everyday life" (Bronfenbrenner, 1977, p. 515). The macrosystem has a significant impact on people with disability. Throughout history, the lives of people with disability have undergone significant changes due, in large part, to attitudinal and ideological changes in society (Abery & Stancliffe, 2003a). Deinstitutionalisation, the greater inclusion in society of people with disability, and the development of legislation that uphold the rights of people with disability are prime examples

of positive macro-level shifts. As outlined in the introductory chapter, many barriers to participating in society have been broken down by and for people with Down syndrome in recent decades (Carr, 2011; Gothard, 2011).

In summary, the ecological theory of self-determination places its analytical focus on the interactions between people and their environments. The theory upholds the notion of "reciprocal determinism" (p. 40) in that social ecosystems both shape and are shaped by individuals (Abery & Stancliffe, 2003a).

The tripartite ecological theory

The third model for understanding self-determination in this thesis is the tripartite ecological theory. The distinctive feature of the tripartite model is that it focuses on the notion of "control" in people with disability (Abery & Stancliffe, 2003b). In this theory, self-determination is defined as "individuals exercising the degree of control they desire over those areas of life they consider important" (Abery & Stancliffe, 2003b, p. 44). The model is tripartite in the sense that it positions self-determination at the intersection between three circles of "control": firstly, a person's desired degree of personal control over various areas of their life; secondly, that individual's actual degree of personal control in those areas; and thirdly, the degree of importance ascribed to the areas of life in which the individual with disability desires and exercises control (Abery & Stancliffe, 2003b).

In the tripartite model, the nature of control is shown to be complex and fluid (Abery & Stancliffe, 2003b): Firstly, the exercise of control exists on a continuum, from total control at one end to no control at the other. Generally, most people (with disability or otherwise) occupy the middle area of the continuum, where there is shared control, joint decision making, and collaboration with other individuals. Viewing self-determination in this way is particularly helpful for people with intellectual disability, because they often

have the potential to exercise self-determination when they are supported in the decision-making process. Secondly, most people do not desire to fully control all areas of their lives. Commonly, people desire to control the areas of their lives in which they perceive to be knowledgeable or skilled and in which they have definite preferences. Thirdly, people have varied priorities in their decision making. For many people with disability, major life decisions such as employment and housing are perceived to be highly important. Yet, these are sometimes precisely the areas over which people with disability have little or no control.

The tripartite theory is ecological in that it constructs the idea of "control" in social terms. It is common for individuals with and without disability alike to collaborate with others in joint decision making. An understanding of tripartite theorists is that "people may voluntarily cede or share control in certain areas of their life and still retain their self-determination" (Curryer et al., 2018, p. 189). Acting interdependently is, therefore, an act of self-determination itself. For people with disability, family members and other trusted individuals are often the ones with whom control is shared (Wehmeyer & Abery, 2013). Control might be shared when, for example, the person with disability requires support to carry out a certain decision (Curryer et al., 2018). Importantly, the interests of the person with disability should be taken into account by those with whom control is shared (Wehmeyer, 2005).

Sociological aspects of "self-determination"

In the tripartite ecological model, the individual behaviours of self-determination are framed in more social and sociological terms compared to in the functional model. The list of self-determination competencies outlined by Abery and Stancliffe (2003b) appears much the same as that of Wehmeyer's (2003a) component elements of self-determined behaviour (e.g. choice making and self-knowledge). What is given more attention in the ecological theory, however, is how these competencies are shaped by one's

environment. Several personal characteristics of self-determination in the tripartite ecological theory are worth highlighting. These are knowledge of the environment, knowledge of self, communication and social skills, and personal finances.

People with disability need to possess “a knowledge base for self-determination” (p. 62) to live in self-determined ways (Abery & Stancliffe, 2003b). Knowing one’s environment consists of knowing the systems and resources that are available to people with disability, as well as knowing one’s rights and responsibilities within social fields. Without such knowledge, people with disability face disadvantages in exercising their self-determination. Concurrently, self-determination requires knowledge of oneself regarding “their capacities and limitations, abilities and potential, as well as their interests, feelings, and personal values” (Abery & Stancliffe, 2003b, p. 64). Importantly, self-knowledge is also based on feedback from others (Abery & Stancliffe, 2003b). If people with disability experience mostly negative feedback from others and society at large, they will likely adopt a deficit-based view of themselves and, in turn, experience lower levels of self-determination.

Interpersonal skills are also fundamental for self-determination. Communication and social skills, which enable a person with disability to advocate for oneself and access supportive resources, are labelled by Abery and Stancliffe (2003b) as “competencies” (p. 56). Being well versed in communicative and social practices can help people with disability to develop meaningful relationships, as well as to influence others and to gain support to act in self-determined ways. An implication of thinking about communication skills as “competencies” is that not every person with disability will attain the same levels of “competence” and, as a result, there will inevitably be disparities between them in how they can be self-determined. At the same time, Abery and Stancliffe (2003b) point out that the

onus is not to be placed on the individual with disability to communicate in socially accepted ways, since social practices are multi-directional: "[C]ommunication partners must learn to apprehend, and respond appropriately to the messages" (p. 57).

Personal finances are, interestingly, included in the tripartite ecological theory's list of self-determination competencies: "While an individual's financial situation is technically not a personal characteristic..., the availability of spending money is likely to have a significant impact upon self-determination" (Abery & Stancliffe, 2003b, p. 64). Financial resources afford a person with disability not simply more choices but the ability to make choices based on their preferences with less financial stress. Significantly, then, self-determination theories recognise that material resources and assets shape and facilitate one's self-determination. This, again, emphasises that self-determination is not solely a personal characteristic.

In short, the tripartite ecological theory explains that "control" exists at the intersection of three circles: a person's desired level of control, their actual level of control, and the level of importance ascribed to that area of life over which they exercise control. Fundamentally, self-determination consists of voluntarily sharing control with trusted individuals, most notably family members. Moreover, the tripartite ecological model discusses many of the same self-determined behaviours as the functional model does, though framing them in more social terms. The self-determination of people with disability can be supported by their access to support social networks and material resources (or hindered by the lack of such resources).

Summary of "self-determination" theories

In disability studies, "self-determination" has its roots in the philosophical stance of "soft" determinism, which posits that human beings possess the power and right to act volitionally, though not entirely without external

influence. Self-determination in disability studies draws heavily upon various branches of psychology (motivational, developmental, and ecological) to describe individuals acting as causal agents to enhance their quality of life. The construct is both individual-oriented (the functional theory) and social-oriented (the ecological and tripartite ecological theories). This thesis, therefore, defines self-determination as "socially formed dispositions and behaviours".

Significantly, self-determination theorists all acknowledge that self-determination does not exist solely within an individual with disability. Rather, it is considerably constructed by a person's access to social connections and material and other resources (or hindered by a shortage of such resources). For this reason, it is reasonable to state that "self-determination alone is not enough" for people with disability to fulfil their desired goals to enhance their quality of life.

It is, therefore, now necessary to introduce Bourdieu's "capital" as something of an enabler of self-determination. The sociological idea can provide further insight into the personal, social, and material resources that people with disability need to live self-determined lives. It can also raise awareness of potential inequalities and disparities between people with disability, as such resources are inevitably unevenly distributed across society.

Capital as "socially valued resources"

"Capital" is another key concept that informs the theoretical framework of this thesis. The definition of capital as "socially valued resources" might seem to portray the concept in a positive light. Yet, the predominant purpose of the idea is to explain the privileges and inequalities that different individuals face within the social world.

Background

Pierre Bourdieu, the French sociologist, has developed a number of interrelated "thinking tools" for analysing the social world (Grenfell, 2012b). Chief among Bourdieu's theoretical concepts are "field", "habitus", and "capital". As explained in Chapter 2, Bourdieu uses "field" to signify a social space consisting of hierarchal relationships between social actors, who compete for what is at stake within the space, namely "capital" (Thomson, 2012; Wacquant, 1989). Meanwhile, "habitus" refers to the product of the internalisation and appropriation of the norms and values of social fields into the human mind and body (Bourdieu, 1977b; Bourdieu & Wacquant, 1992). Habitus can be regarded as the most psychological of Bourdieu's concepts (Wagner & McLaughlin, 2015). It refers to "a *predisposition*, *tendency*, *propensity*, or *inclination"* (p. 214, emphasis in original) of one's body and mind (Bourdieu, 1977b). Finally, the idea of "capital" serves to explain not only what is competed for within social fields, but that some players are advantaged because they enter the field already holding higher levels of the very capital on which the field is built (Bourdieu, 1986).

Although it might appear to be somewhat dated, the concept of capital is still vital for analysing the reproduction of social inequalities in the world today (Calderón Gómez, 2020). The preceding chapters have foregrounded a number of persistent inequalities for people with disability, specifically people with Down syndrome, within all forms of education fields.

The broadest definition of "capital" that Bourdieu (1986) gives is that of "accumulated labor" (p. 241), meaning it is the product of human effort (Mohseni, 2022). It can be thought of as "assets" (Moore, 2012, p. 99) and "goods or resources" (Jenkins, 1992, p. 53). Clearly, the term "capital" has an economic background, but Bourdieu (1986) expands its meaning beyond economic theory by stating that there are three different forms of capital (i.e. economic, cultural, and social).

Economic capital

"Economic capital" is essentially money (Thomson, 2012) but it also includes that which can be most readily converted into money (Bourdieu, 1986). Compared to social and cultural capital, the distinctive feature of economic capital is that it is transparent that people seek to gain it because of self-interest (Moore, 2012). To put it simply, it is taken for granted that money is desired by all people. On the other hand, both social and cultural capital suppress and disguise their instrumentalism, presenting themselves to have intrinsic (non-economic) worth (Moore, 2012). For instance, human agents might enjoy art or gain education qualifications (i.e. cultural capital) or build relationship networks (i.e. social capital) on the basis that these practices are inherently valuable, without regarding what economic benefit might be gained from them. In reality, however, all three forms of capital are connected. Bourdieu (1986) stresses that "economic capital is at the root of all the other types of capital" (p. 252). This is because social and cultural capital can be converted into economic capital.

The possession of economic capital can be advantageous for the accumulation of cultural capital (Bourdieu, 1986). Some families have greater financial means to support their members in the acquisition of cultural capital. Individuals in such families can be more devoted to capital-accruing activities (e.g. education), because they are not burdened by financial concerns: "the length of time for which a given individual can prolong his acquisition process depends on the length of time for which his family can provide him with the free time, i.e., time free from economic necessity" (Bourdieu, 1986, p. 246). A specific field in which this advantage (or disadvantage) can be observed is that of education. Some individuals might not progress beyond compulsory education, because their families are unable to support them materially, since "all agents do not have the economic and cultural means for prolonging their children's education beyond the minimum necessary" (Bourdieu, 1986, p. 245). Such individuals are disadvantaged in

further education fields, because they face the necessity of work to support their livelihoods.

Cultural capital

Of the three different forms of capital, it is cultural capital that is given the most attention in Bourdieu's (1986) analysis. In general terms, "cultural capital" can be understood as "legitimate knowledge of one kind or another" (Jenkins, 1992, p. 53). What is considered "legitimate" is arbitrary in that its legitimacy is socially determined and not intrinsic to the thing itself. For instance, a particular way of speaking or writing might be valued as "linguistic capital" (e.g. formal, academic language) not because it is intrinsically superior to other linguistic forms, but because it has been culturally and structurally deemed to be more valuable. The arbitrariness of what is valued as cultural capital points to inequalities in social fields, since it is ultimately the dominant class who dictate what is deemed legitimate cultural capital.

Cultural capital serves as a "theoretical hypothesis" (p. 243) to explain the inequalities that cause school students of "lower" social classes to have less academic success compared to learners of "higher" classes (Bourdieu, 1986). The students of dominant classes enter education fields at an advantage, since they already possess cultural capital in the form of the middle- and upper-class norms and behaviour on which education systems are founded. So, education fields are uneven playing fields since "working-class students are competing against the fraction of privileged students who have made the most profitable academic use of their linguistic and cultural capital" (Bourdieu & Passeron, 1977, p. 83). Far from being a meritocratic system where student performance is the sole determinant of academic success, education actually serves to reproduce social inequalities, because learners who are rewarded by the system are those who have already been socialised according to the system's ideologies from their family background (Thomson, 2012).

According to Bourdieu (1986), cultural capital exists in three distinct states (i.e. embodied, objectified, and institutionalised). Of these, embodied cultural capital is given the most attention in this chapter, because it is the "fundamental state" (p. 244) of cultural capital (Bourdieu, 1986).

Embodied cultural capital

"Embodied cultural capital" is the capital which exists in the body of its possessor (Bourdieu, 1986). Embodied capital is found "in the form of long-lasting dispositions of the mind and body" (Bourdieu, 1986, p. 243). Bourdieu's use of the term "dispositions" to describe both habitus and cultural capital can cause some confusion. Edgerton and Roberts (2014) explain that speaking of "dispositions" as a form of capital highlights the cultural value attached to certain dispositions and their potential to produce gains for the possessor. In contrast, the emphasis in "habitus" is on the process of socialisation by dominant ideologies and norms. As Moore (2012) explains, habitus and embodied cultural capital are "continuous with each other, as 'moments' of one thing" (p. 103).

To acquire embodied capital, an individual must work on oneself (Bourdieu, 1986). The extent to which a person can accumulate embodied cultural capital is, according to Bourdieu (1986), somewhat constrained by the characteristics of their body: "It cannot be accumulated beyond the appropriating capacities of an individual agent; it declines and dies with its bearer (with his biological capacity, his memory, etc.)" (p. 245) This quotation is of particular interest to disability researchers. Since capital is linked with capacity, it follows that there will be inequalities within social fields. Different human agents possess different levels of "capacity", as well as levels of capital that can increase that "capacity".

Physical capital

Embodied cultural capital can be subdivided into three forms, namely physical capital, behavioural capital, and linguistic capital. The attention given to the human body in Bourdieu's work has prompted some scholars to theorise the idea of "physical capital" (e.g. Gao, 2015; lisahunter et al., 2015; Shilling, 1991; Shilling, 2004). Bourdieu (1978) himself uses the term "physical capital" in his analysis of sport and social class. Later authors, such as Shilling (1991), tend to depart from Bourdieu's categorisation of physical capital as a form of cultural capital, arguing that the body should be considered "as a form of capital in its own right" (p. 654).

The idea of "physical capital" signifies that there is "value placed upon the size, shape and appearance of the flesh" (Shilling, 2004, p. 474). For Bourdieu (1990), "[t]he body is in the social world but the social world is also in the body" (p. 190). The body is the interface between individuals and the society. The implication of the body being "culturally constituted" (Jenkins, 1992, p. 20) is that the ways in which one uses their body is shaped and judged by the culture/s around them. For instance, dominant conceptions of femininity and masculinity might encourage females to restrict their body size (as a form of "beauty") but encourage males to build up their bodies (as a sign of "strength") (Shilling, 2004). Physical capital is also classed. Working-class bodies have value in relation to physical labour, but their posture, accent, and dress are generally devalued by the dominant classes in society (Shilling, 2004).

Disability scholars have taken to Bourdieu's concept of embodiment to theorise "disability" (Edwards & Imrie, 2003; Gibson et al., 2007). Bodies with disability are often considered "less than valuable" (p. 252) and, thus, are marginalised by society (Edwards & Imrie, 2003). Yet, these devalued bodies also resist their devaluation by the dominant classes: "Those stigmatized within a community because of a disability… may reflect on their 'spoiled

identity', having discovered they are more capable than society assumes, and reject this identity in favour of an alternative" (Shilling, 2004, p. 480). The value of disabled bodies is, thus, contested, especially in relation to neoliberal and (late-)capitalist ideologies. Edwards and Imrie (2003) pose the important questions, "How, then, do social fields ascribe value to disabled people, and how do disabled people manage their bodies in seeking to acquire social and cultural capital?" (p. 244) The concept of "physical capital" can increase awareness towards the inequalities and barriers that people with disability face in their engagement within social fields, since they enter these fields with culturally devalued bodies.

Behavioural capital

Related to "physical capital" is a second form of embodied cultural capital, one that is termed "behavioural capital" in this thesis. The predispositions and propensities of the mind, as well as physical features such as body language and stance, are all important aspects of cultural capital (Moore, 2012). One's lifestyle choices regarding clothing, sport, and cuisine are also indicators of embodied cultural capital (Jenkins, 1992). Embodied cultural capital entails, therefore, particular ways of being and behaving in the social world, hence the term "behavioural capital". Bourdieu (1977b) uses "bodily hexis" to describe ways of using one's body which are, ultimately, influenced by culture and society: "Bodily *hexis* is political mythology realized, *em-bodied*, turned into a permanent disposition, a durable manner of standing, speaking…" (p. 93, emphasis in original). Embodied behaviour is not primarily transmitted through "discourse or consciousness" (p. 87) but through imitation:

> [I]n all societies, children are particularly attentive to the gestures and postures which… express everything that goes to make an accomplished adult - a way of walking, a tilt of the head, facial expressions, ways of sitting and of using implements, always

> associated with a tone of voice, a style of speech… (Bourdieu, 1977b, p. 87)

Importantly, a person's behaviours can determine how they are evaluated by others. This is particularly true within education fields, which are ultimately sites of inequality. In an oral academic examination, for instance, the assessment of one's knowledge is not "uncontaminated by the… system of *manners* characteristic of a social position" (Bourdieu & Passeron, 1977, pp. 118-119, emphasis in original). That is, an individual is judged not only by their skill and knowledge in relation to the learning content, but also by their behaviour and appearance in general. The body becomes, therefore, part of "the unconscious criteria", as one's knowledge is assessed "through the infinitesimals of style or manners, accent or elocution, posture or mimicry, even clothing and cosmetics" (Bourdieu & Passeron, 1977, p. 162).

Linguistic capital

A third significant form of embodied cultural capital is "linguistic capital". Language is, according to Bourdieu (1977a), a "body technique" (p. 660). One's accent and pronunciation, for instance, depend on the use of the mouth and tongue. Linguistic capital is tied to one's social class through the physical body. Bourdieu posits that people of differing socioeconomic classes use their bodies in contrasting ways and such bodily distinctions give rise to different ways of using language, particularly in phonology: "the bodily schema characteristic of a social class determines the system of phonological traits that characterize a class pronunciation… This articulatory style is part and parcel of a lifestyle that has become embodied…" (Bourdieu & Wacquant, 1992, p. 149). Linguistic norms and practices are, therefore, classed (and, by extension, gendered, racialised, and disabilised) (see Paterson, 2020).

In Bourdieu's (1986) analysis, the ability to read is identified as a form of "cultural competence" (p. 245). Literacy, as a form of embodied cultural capital, has a "scarcity value" (p. 245), because not all members of society possess or have access to literacy in similar levels nor forms. Additionally, not all linguistic practices are equally valued in social fields. Bourdieu (1991) differentiates between "ordinary speech" and "written discourse worthy of being published" (p. 57), such that those who can produce the latter will possess "a power over language and thereby over the ordinary users of language" (p. 58). Fundamentally, literacy is not merely concerned with skills of doing language. Rather, literacy is bound up in "the relational structures between individuals and the field itself" (p. 156), because it concerns the question of who is sanctioned to speak the "legitimate language" (Hardy, 2013).

Language receives some attention in Bourdieu's (1986) paper on capital, but it is in some of his other works that the term "linguistic capital" is explicitly developed (e.g. Bourdieu, 1977a, 1991; Bourdieu & Passeron, 1977; Wacquant, 1989). The concept signifies that certain linguistic codes are ascribed greater value in society compared to other linguistic codes. The linguistic code of highest value is language that is considered "correct" and, therefore, normative and legitimate, which is the form of language transmitted and imposed by formal education systems (Bourdieu & Passeron, 1977, p. 116). Reproducing such linguistic norms is a form of "linguistic coercion" (p. 652), as they are imposed by those who have the power and means to impose them, but also to appropriate them (Bourdieu, 1977a). The ease or difficulty with which one might acquire or gain "mastery" (p. 116) of these linguistic codes is determined by the linguistic practices of their family social background and how similar or different those are to the linguistic norms reproduced in the school system (Bourdieu & Passeron, 1977). Since mastering the legitimate language requires exposure and direct instruction, those who are less exposed to it will be at a disadvantage (Bourdieu, 1991).

In summary, embodied cultural capital is the fundamental form of cultural capital. It is a particularly salient concept for disability research using Bourdieusian thinking. The term "embodied" signifies that cultural capital exists within and is accumulated through the use of one's body. The potentialities and limitations of one's physiological body also facilitate and/or constrain the accrual of capital within social fields. Different types of bodies are judged in contrasting ways in society according to ideologies such as neoliberalism and capitalism. This means that marginalised bodies (e.g. disabled bodies) face barriers and disadvantages in their attempts to access capital within social fields. One's physical capital, behavioural capital, and linguistic capital are all forms of embodied cultural capital which are subject to appraisal and valuation in relation to dominant forms of such capital.

Objectified cultural capital

The second state in which cultural capital exists is the "objectified state". Objectified cultural capital consists of tangible cultural goods such as art, books, instruments, and machines (Bourdieu, 1986). Writing is regarded by Bourdieu (1986) as "the form *par excellence*" (p. 256, emphasis in original) of objectified cultural capital. Indicators such as the number of culturally valuable books and desks for reading and writing at home have been used as measures of objectified cultural capital in some education research studies (Byun et al., 2012; Ma & Wu, 2020; Yamamoto & Brinton, 2010). Possessing cultural goods within the home environment is related to higher academic achievement (Kraaykamp & van Eijck, 2010).

Objectified cultural capital can be likened to raw materials (Moore, 2012) in that they are physical entities that can be appropriated in various ways. Like raw materials, cultural goods have monetary value, but they can also be appropriated in ways that differ in symbolic value (Bourdieu, 1985). This means that objectified cultural capital is transmissible in its materiality, but it becomes effective cultural capital only when it is appropriated in culturally

sanctioned ways. For instance, only economic capital is required to gain legal ownership of an objectified form of cultural capital (e.g. a dictionary or an artwork), but embodied cultural capital (e.g. knowledge) is necessary for the consumer to benefit from it.

Consequently, the appropriation of objectified cultural capital is related to inequalities within social fields. How objectified capital is culturally appropriated by different consumers and the cultural-capital returns gained by those consumers will both vary based on the pre-existing unequal possession of cultural capital between individuals (Moore, 2012).

Institutionalised cultural capital

The third state in which cultural capital exists is the "institutionalised state", that which is formally recognised and conferred by social institutions (e.g. the education system). Education qualifications are the most prominent form of institutionalised cultural capital (Bourdieu, 1986). Throughout *Distinction*, Bourdieu (1984) uses the term "educational capital" to refer to various education qualifications. An academic qualification is, fundamentally, a "certificate of cultural competence" (p. 248) that confers cultural value to its holder, whilst also providing a standard by which different individuals might be compared (Bourdieu, 1986). For instance, individuals might be evaluated on the basis of where their qualifications were gained and/or the levels of achievement attained in their qualifications.

Although education qualifications essentially guarantee the conferral of some level of cultural capital (Bourdieu, 1986), they do not necessarily lead to jobs that return an expected level of material and economic capital. Certificates and degrees do not necessarily bring about the social mobility of learners that is often promoted by governments and institutions (Ronnie, 2023). Structural inequalities in the workforce can render one's educational capital as less valuable. Identity markers such as age, gender, and socioeconomic status

might operate as “tacit requirements” (p. 103) for particular job positions (Bourdieu, 1984). The issue of embodiment is, again, relevant because institutionalised cultural capital “has the same biological limits as its bearer” (Bourdieu, 1986, p. 247).

Like other forms of cultural capital, there is a process of intergenerational reproduction, whereby parents’ institutionalised cultural capital affects the children’s capital (Kraaykamp & van Eijck, 2010). The level of education completed by parents and carers can set the standard that the children themselves will attain. Not only so, but highly educated parents also tend to invest in their children’s education, providing them with the necessary resources to achieve academic success (Kraaykamp & van Eijck, 2010). Parents’ levels of education have the effect of forming the habitus and embodied capital of children which, in turn, influence children’s levels of education (Koustourakis et al., 2018).

Social capital

Following economic and cultural capital, the third major form of capital discussed by Bourdieu (1986) is “social capital”. Jenkins (1992) defines social capital as “valued relations with significant others” (p. 53). In contrast to the ideology of “rampant individualism” (Grenfell, 2009, p. 21), the idea of social capital argues that human agents never truly act independently within social fields, nor can their academic, employment, or other success be solely attributed to their own personal efforts. Rather, it is through interpersonal support and collaboration that people often achieve desired outcomes within social fields.

Social capital is accumulated by holding membership in particular groups (e.g. a family, a class, and/or a school). The amount of social capital held by an individual depends on both the size of their social networks and the amount of capital owned by the individuals in those networks (Bourdieu,

1986). It is not simply about having social connections but having them with important actors within relevant fields. Social capital operates on the principle of mutuality, which involves "mutual knowledge and recognition" (p. 250) between different members of a social group (Bourdieu, 1986). At the same time, social capital is not merely transactional. Rather, it involves human subjectivities, including "feelings of gratitude, respect, friendship, etc." (Bourdieu, 1986, pp. 249-250).

Social capital operates together with economic capital and cultural capital in multiple ways. Firstly, an individual's embodied cultural capital in terms of their speech and behaviour are indicators of their social capital (Bourdieu, 1986). This is because different social groups tend to have marked ways of speaking and being. Indeed, Bourdieu's (1986) analysis states that some embodied cultural capital might be considered a subset of social capital: "Manners (bearing, pronunciation, etc.) may be included in social capital insofar as... they indicate initial membership of a more or less prestigious group." (p. 256)

Secondly, in its relationship to economic capital and cultural capital, social capital functions as a "multiplier" (Bourdieu, 1986, p. 249). Grenfell (2009) uses the term "accelerator" (p. 23) to the same effect. These terms denote that, if two individuals possess the same amount of economic and/or cultural capital, the person with more social capital will be able to employ their economic and/or cultural capital more effectively than the person with less social capital (Eloire, 2018). For example, a form of institutional cultural capital might not fully benefit a person if they "lack the social capital to extract the full yield from their academic qualifications" (Bourdieu, 1984, p. 147). Social capital is highly valuable, because it consists of "lasting, useful relationships that can secure material or symbolic profits" (Bourdieu, 1986, p. 249). In other words, the accumulation of economic and cultural capital is facilitated by one's social capital. At the same time, having social capital can

enable someone to offset their relative lack of academic qualifications (Bourdieu, 1984).

The existence of social networks and relationships is not a given but arises only through the "unceasing effort of sociability" (Bourdieu, 1986, p. 250). Accumulating social capital requires labour of a social nature, which includes relational practices such as exchanging gifts, letters, and visits (Bourdieu, 2007 as cited in Eloire, 2018). Such "socializing techniques" (p. 152) are essential for maintaining relational capital (Bourdieu, 1984). Whilst labour is necessary for accruing and maintaining social capital, social capital is not entirely attributable to one's efforts to acquire it. Instead, like all forms of capital, social capital is unequally distributed within uneven playing fields. Social inequalities persist when the responsibility to acquire social capital is placed entirely upon "individuals' ability to integrate into normative structures" (Rudick et al., 2019, p. 452).

The access to social capital is, therefore, unequally distributed between human agents, resulting in the reproduction of inequalities in the social world (Field, 2017). Like other forms of capital, social capital has an intergenerational dimension as it is usually transmitted within the family unit (Bourdieu, 1986). Social capital is primarily an "elite resource" (Field, 2017, p. 6), one used by the dominant class to preserve their social position at the exclusion of people from non-dominant groups (Pena-López et al., 2021). In essence, social exchange "re-produces the group… and reaffirms the limits of the group" (Bourdieu, 1986, p. 250). Not only does social capital operate to draw boundaries between social groups, but it also produces hierarchies within social groups (Alecu et al., 2022). So, Bourdieu's conception of social capital is rather pessimistic, because social capital contributes to structured inequalities in the social world by facilitating the selective transmission of economic and cultural capital (Rogošić & Baranović, 2016).

The utilisation of social capital as an "elite resource" can be observed in education fields (Green et al., 2015; Heffernan, 2021). Social networks provide parents with valuable insider knowledge that aid with school choice and school applications, but "vulnerable" families tend to not have access to such connections and knowledge (Yoon, 2020).

To summarise, similar to Bourdieu's other thinking tools, "social capital" cannot be taken at face value. As Faucher (2018) argues, "Social capital has little to do with open inclusion: it is an instrument of exclusion" (p. 3). Moreover, social capital acts as a "multiplier" to other forms of capital and this, too, can further uphold inequalities in the social world.

Summary of Bourdieu's "capital"

Bourdieu's sociological idea of "capital" refers to resources and assets within social fields that people seek to acquire and compete for. The value that a form of capital has is not intrinsic to the capital itself but is socially and culturally ascribed by dominant groups in society. This thesis, therefore, defines capital as "socially valued resources". Three forms of capital are outlined by Bourdieu (1986), namely economic, cultural, and social capital.

Cultural capital is the most significant capital in Bourdieu's analysis. Cultural capital consists of knowledge and competencies that are considered legitimate according to the norms and values of the dominant classes in society. Cultural capital exists in three distinct states, namely the embodied, the objectified, and the institutionalised. The latter two are comprised of cultural objects and institutionally granted qualifications, respectively. Embodied cultural capital is intricately tied to one's body, and takes the form of physical capital, behavioural capital, and linguistic capital. How a person thinks, looks, walks, acts, behaves, speaks, and writes (amongst other actions) are all judged and appraised in comparison to dominant ways of being in the social world. The value ascribed to these forms of capital is

dependent on the value ascribed to the body of their bearer. Since cultural capital is classed (Bourdieu's primary concern) and, by extension, also gendered, racialised, and disabilised (see Paterson, 2020), bodies that are identified as minorities within these social categories are marginalised and devalued.

The primary concern that Bourdieu has in theorising "capital" is to analyse how some people are better positioned than others to succeed in education systems, not because of their own merits and capabilities but because of the capital they possess. Because of their family and social backgrounds, some human agents already possess the dominant norms and values (i.e. cultural capital) of education fields when they enter these fields. These individuals will have significant advantages within social fields compared to people from disadvantaged backgrounds who are lacking in these socially valued resources.

Bridging Bourdieu and the self-determinists

The preceding sections have explained in detail "self-determination" and "capital" as distinct concepts from contrasting schools of thought. In this thesis, the idea of self-determination derives from the theories of disability scholars such as Wehmeyer, Abery, and Stancliffe, and has its roots in philosophy and psychology (primarily the latter). The idea of capital, in contrast, is drawn from the work of Bourdieu, the French sociologist. Despite the theoretical differences between Bourdieu and the self-determinists, there are several important commonalities between them that can be noticed. This section aims to establish theoretical connections between self-determinists and Bourdieu, particularly drawing out the elements within self-determination theories that are already more sociologically inclined.

Possible tensions

It might appear that there is little common ground between Bourdieu and the self-determination theorists. As mentioned in the introductory chapter, Wehmeyer and colleagues are influenced by the rational choice theory of political theorist, Elster (1986), which states that humans have agency to make choices that they perceive will bring about the most gain (Mithaug et al., 2002). This understanding of human agency is challenged by Bourdieu (1998), who argues that humans are not "conscious and knowing subjects acting with full knowledge of the facts, as the champions of *rational action theory* believe" (p. 24, emphasis in original). Bourdieu criticises the underlying belief within rational choice theory that human actors are "economically and socially unconditioned" (Bourdieu & Wacquant, 1992, p. 123). Human choices and decisions are, Bourdieu argues, always shaped and constrained by culture, society, and ideology. What people consider to be rational and preferred choices are shaped by their predispositions (i.e. habitus and embodied cultural capital) which are, in turn, structured by the social fields in which they inhabit. So, human agency is always limited: "We can always say that individuals make choices, as long as we do not forget that they do not choose the principle of these choices" (Wacquant, 1989, p. 45).

Significantly, from a Bourdieusian perspective, self-determination is never unconditioned nor absolute. Since social fields are built upon structural hierarchies, individuals always find themselves within power relations that "undermine their capacity to think and act in self-determining ways" (Thorpe, 2018, p. 107).

Important commonalities

Despite these distinctions in thinking between Bourdieu and self-determination theorists, several significant commonalities can be highlighted. From a philosophical perspective, both sides can be said to adopt a "soft"

determinist stance. Wehmeyer (2003d) builds his theory of self-determination specifically upon Locke's soft determinism, which posits that human behaviour is the product of both individual freewill and environmental determinants. Although his functional theory of self-determination seemingly places more focus on individual characteristics and behaviours, Wehmeyer (2003a) also argues that structural supports and opportunities determine the extent to which people with disability can be self-determined. Meanwhile, Bourdieu's philosophical stance could also be perceived as soft determinism, despite his emphasis that human actors are constrained by social structures and ideologies. As Thomson (2012) argues, Bourdieu's perspective is not to be understood as being entirely deterministic (see also Yang, 2014). The context of the quote from Bourdieu (1998) explains his view on structure and agency, stating that human agents "are not particles subject to mechanical forces and acting under the constraint of *causes*; nor are they conscious and knowing subjects acting with full knowledge of the facts" (p. 24, emphasis in original). In short, both structure and agency are important constructs within a Bourdieusian analytical framework. Bourdieu, in fact, has sought to jettison the structure–agency dichotomy that pervades the social sciences (Bourdieu & Wacquant, 1992).

In addition to their perceivable shared philosophical stance of soft determinism, Bourdieu and the self-determinists have other important commonalities. Ecological theories of self-determination hold that self-determination in people with disability are the product of the individual and their social environments (Wehmeyer & Abery, 2013). One implication is that a person's ecology can support and/or hinder their development of self-determination (Abery & Stancliffe, 1996). This environmental perspective is based on the ecological psychology of Bronfenbrenner (1977), which states that human psychology and behaviour are profoundly shaped by one's micro-, meso-, exo-, and macrosystems. Operating at the level of ideologies and social norms, the macrosystem significantly affects people with disability,

including their self-determination and quality of life (Abery & Stancliffe, 2003a).

The macrosystem is understood in similar but also contrasting ways by self-determination theorists and Bourdieu. According to both Bronfenbrenner (1977) and Bourdieu (Bourdieu & Passeron, 1977), social contexts such as schools are patterned after broader ideologies, norms, and values that operate in society. Both theorists speak of a (re)productive effect of education systems. Bronfenbrenner's (1979) point, however, is concerned with how social settings across different "cultures" (his example being a comparison of French classrooms and US classrooms) are distinct because of the different values and beliefs that give rise to them. Bourdieu, on the other hand, is primarily focused on how education fields within the one "culture" are founded upon and further reproduce the dominant norms and ideologies of the middle- and upper-classes and, importantly, how this reality perpetually disadvantages the non-dominant classes in society (Bourdieu & Passeron, 1977). It could be said, then, that the notion of ideology as power and oppression is given much more attention within Bourdieusian sociology. The idea of power seems relatively under-theorised in Bronfenbrenner's theory, as Houston (2017) states, so there is scope to move it "in the direction of a critical ecology" (p. 60).

These issues aside, emphasising the "social" can serve as a bridge between Bourdieu and the ecological self-determination theorists. The relationships and networks that people with disability have access to can positively (or negatively) impact on their self-determination: "the ecosystem has the potential to… create many additional resources or risks that either support self-determination or hinder [it]" (Abery & Stancliffe, 2003a, p. 41). Self-determination is, therefore, not to be taken as an individualistic construct. Rather, it can be seen as an interpersonal project, whereby the resources available within communities and institutions are mobilised to support the

choices, decisions, and lifestyles of people with disability. It must be acknowledged, then, that self-determination on the part of the individual is not enough. As Trainor (2008) states in relation to post-secondary transition outcomes for young people with disability, "[i]n order for students to practice self-determination, both social and cultural capital are necessary" (p. 154). It would appear that thinking about self-determination from Bourdieu's (1986) perspective of social capital, as Trainor (2008) does, is a relatively uncommon occurrence within disability research. From a sociological perspective, human agents cannot successfully navigate and compete in social fields as sole individuals. Having access to social capital (in both quality and quantity) provides individuals with an advantage over other players on the field in their accumulation of all forms of capital (Bourdieu, 1986). A sense of criticality towards social capital as an elite resource (Field, 2017) that facilitates the reproduction of social inequalities (Rogošić & Baranović, 2016) can enrich self-determination theory.

According to both Bourdieu and the self-determinists, one's family background greatly influences one's development and participation in the social world. The family context is the first and, arguably, most influential microsystem that impacts on the overall development of a person with disability (Abery & Stancliffe, 2003a). Not only can self-determination be promoted within the home environment (Abery & Stancliffe, 1996), self-determination in people with disability can also be supported by family resources. As a rather extreme example, if one's basic necessities are not met because of their impoverished family environment, then it would be rather difficult for that person to develop and/or maintain their self-determination (Abery & Stancliffe, 2003b). Even in a less extreme sense, personal finances are seen by Abery and Stancliffe (2003b) as being facilitators of self-determination, particularly in choice making and decision making. Finances provide both more choice and the ability to choose based on personal preference and not financial constraint. Similarly, Bourdieu (1986) argues that

people from families with access to economic capital are afforded more choice, specifically, to pursue further study rather than immediate employment. Significantly, Wehmeyer and colleagues (Meral et al., 2022) have recently used Bourdieu's notion of capital to conduct a study in Türkiye, reporting that higher levels of self-determination in children with intellectual and developmental disabilities are found in families with higher socioeconomic backgrounds. It is, therefore, possible and beneficial to include Bourdieu's economic capital in self-determination studies in disability.

A person's family background also provides non-economic resources that facilitate self-determination and personal development in people with and without disability. This is another important point that self-determination theorists and Bourdieu can agree on. Drawing from Bourdieu's (1986) work, Trainor (2008) argues that "capital is transmitted… from parent to child", such that "[f]amily resources affect the extent to which youth with disabilities have and adeptly use the types of cultural and social capital that schools and society require for successful postsecondary transition" (p. 156). People who attain academic success are usually those who possess from their family background the dominant forms of cultural capital upon which education fields are established (Bourdieu & Passeron, 1977). Family cultural and social capital can enhance self-determination in people with and without disability in numerous ways. Parent education and professional backgrounds, as well as their education and career aspirations for their children, are forms of cultural capital (Albright et al., 2018). According to the tripartite ecological theory, individuals with disability whose families value employment are themselves more likely to exercise greater decision making concerning vocational training and work placements (Abery & Stancliffe, 2003b). Furthermore, families who are active in establishing social connections and networks (i.e. social capital) with schools, organisations, service providers, and other stakeholders within the mesosystem contribute to supporting self-

determination in their family member with disability (Abery & Stancliffe, 2003b).

Finally, the human body is given attention in both self-determination and capital theories. According to Wehmeyer (2003a), the "capacity" of a person with disability in terms of their learning and development is one factor that influences their self-determination. Although a deficit-based view is not to be held towards people with disability (Wehmeyer, 2005), it is still important to consider how issues of impairment might impact on their self-determination. Executive functioning and adaptive behaviour, which have been discussed in Chapter 3, are linked to self-determination, meaning that impairments in the former can affect the latter (Landuran et al., 2022; Onnivello et al., 2022; Sabat et al., 2020). Within self-determination theories, interpersonal skills are framed as "competencies" that facilitate self-determination (Abery & Stancliffe, 2003b). Additionally, knowledge and understanding of oneself and one's environment are vital aspects of self-determination (Abery & Stancliffe, 2003b). The body also features in Bourdieu's sociology. Cultural capital exists, most importantly, in an embodied state (i.e. in the human body and mind) in relation to one's knowledge, education, behaviour, language, and skills (Bourdieu, 1986). The body always constrains the extent to which one might be able to acquire capital, since each human agent has a particular "biological capacity" (Bourdieu, 1986, p. 245).

A Bourdieusian perspective on self-determination

What Bourdieu's concept of capital might offer to self-determination theory is three-fold.

The first contribution is a conceptualisation of "self-determination" as a form of cultural capital. Self-determination is a disposition in that it refers to the propensity that self-determined people possess to think and behave in self-determined ways (Wehmeyer, 2003a). Dispositions, meanwhile, are forms of

cultural capital, because how a person usually thinks and behaves can be a valuable asset for accumulating capital within social fields (Bourdieu, 1986; Edgerton & Roberts, 2014). Specifically, self-determination can be understood as a form of embodied cultural capital. This is because self-determination is formed according to one's "capacity" (Wehmeyer, 2003a, p. 179), similar to how embodied cultural capital is accumulated according to one's "biological capacity" (Bourdieu, 1986, p. 245). Although their emphases differ, both self-determination and capital are seen to be necessary for human agents to make gains in their lives within social fields.

A second contribution of Bourdieusian thinking is a greater recognition that not every person with disability might attain self-determination in the same way nor to the same extent. This is because the nature and level of capital that each person has access to differ. Individuals with disability will differ in terms of their overall "capacity", their communicative and social "competencies", their understanding of self and society, their financial resources, and their family backgrounds. Appropriating the concept of self-determination for sociological research would involve giving greater attention to the reproduction of social inequalities within disability communities (e.g. the Down syndrome communities), as some people with disability have the means to become "more self-determined" than others, hence experiencing greater developmental outcomes and quality of life. Promoting self-determination in people with disability is an important undertaking, but it is also vital to be cognisant of how it might inadvertently contribute to maintaining disparities within disability groups.

A third contribution of Bourdieusian thinking is an increased awareness that the value attributed to self-determined dispositions and behaviours in modern society are culturally and ideologically produced. Arguably, self-determination can be at risk of being framed in neoliberal terms because of its emphases on "self" and "autonomy" (Furlong, 2003). The disposition to be

self-determined is an unchallenged requirement for one to compete successfully within neoliberal social fields. When thought of in this way, the idea of self-determination might raise concerns because of the dominant underlying belief within society that people with disability need to attain a particular form of cultural capital (i.e. self-determination) to be "successful" in society. People with disability already tend to be devalued by society, because the physical capital in their impaired body is considered a form of otherness in relation to dominant forms of "normality" (Edwards & Imrie, 2003; Shilling, 2004). Without doing away with the concept entirely, it is at least necessary to be aware of the potential dangers that arise when self-determination is "over-performed" (Furlong, 2003, p. 192). Taking a Bourdieusian perspective on self-determination is one important way of critically appropriating the concept for disability research.

Conclusion

This theoretical framework chapter has examined two concepts that are central to this thesis. As theorised by disability scholars such as Wehmeyer, Abery, and Stancliffe, "self-determination" has been conceptualised as "socially formed dispositions and behaviours" that enable people with disability to live with a degree of autonomy to attain well-being and quality of life. To some extent, self-determination is centred around individual dispositions and actions (as the functional theory states). It is, however, a largely social construct, because individuals with disability can be significantly supported and/or hindered by their relationships and environments in their development and exercise of self-determination (as the ecological and tripartite ecological theories state). Since people with and without disability alike require a range of resources to think and act in self-determined ways, it is necessary to acknowledge that personal self-determination is not adequate.

It is from this perspective on self-determination that this chapter has examined another key concept. As developed by Bourdieu, “capital” has been theorised in this chapter as “socially valued resources” that enable human agents to compete within social fields for more capital. Economic capital consists of financial resources, whereas social capital consists of relational networks. These two types of capital both facilitate the accumulation of cultural capital. The most fundamental form of cultural capital is “embodied cultural capital”. Physical capital, behavioural capital, and linguistic capital are important resources that exist within the bodies and minds of their possessors. Importantly, capital is distributed unequally throughout society and is dependent upon one’s social and cultural backgrounds. Because social fields operate according to the norms of the dominant groups in society, individuals from these groups already possess more socially valued capital and are, therefore, at an advantage when competing within fields. This, inevitably, leads to the reproduction of social inequalities.

Significantly, the chapter has sought to bridge the apparent differences between Bourdieu and the self-determinists. Aspects of self-determination theory that are inherently more sociological in nature can be useful for bridging that gap. Considering self-determination from Bourdieu’s perspective fosters an awareness of inequalities within disability communities, such as the Down syndrome communities. These social inequalities stem from the reality that not every person with disability has access to the economic, cultural, and social capital that can facilitate their self-determination. In and of itself, self-determination is not able to secure the developmental outcomes and quality of life, including in post-secondary education, that people with disability and their families seek to attain. The concept of self-determination remains highly important for disability research and advocacy, but a move towards critical sociology is a vital next step for self-determination theories.

Chapter 6: “I don’t think I’m going to ask that question any more”

Research methodology

Introduction

This chapter explains the research methodology used in this study to explore the post-secondary education journeys of people with Down syndrome. Due to the complexities and sensitivities of disability-related research, it is necessary to explain in detail how the study has been undertaken. The chapter outlines many important decisions that were made by me as the researcher throughout the design and implementation of the research. The methodological decisions, which are often taken for granted, stemmed from the need to conduct this study in an inclusive and accessible manner for people with Down syndrome and their families. Some decisions were initiated by me, whilst others were made in response to participant feedback (as my words, “I don’t think I’m going to ask that question any more”, in the chapter title suggests). Given that researcher positionality and reflexivity are significant themes in this chapter, it is fitting that first-person pronouns are used to refer to me as the researcher and interviewer.

This chapter builds upon several concerns from the preceding chapters. Chapter 2 has analysed the place of people with disability within the higher education and vocational education and training (VET) sectors in Australia from the perspective of Bourdieu’s “field” theory (Wacquant, 1989). Several implications for disability research within post-secondary education fields have been outlined. Firstly, it is crucial to engage disability research within further education fields in an ethical and sensitive manner (Griffin & Beddie,

2011; Pitman, 2022). This concern is central to the discussion in the present chapter. Secondly, the existing quantitative data on post-secondary students with disability are limited in their ability to provide insight into the experiences of these learners (Griffin & Beddie, 2011; Pitman, 2022). For this reason, it has been necessary to foreground the voices and lived experiences of people with Down syndrome and their families in this thesis.

The discussion in Chapters 3 and 4 on living with Down syndrome and learners with Down syndrome respectively has also shaped the research methodology. The existing literature suggests that people with Down syndrome have a range of communication skills (Fidler & Daunhauer, 2011; Martin et al., 2009) and that visual, multimodal supports can enhance their communication and understanding (Faragher et al., 2020). From the theoretical perspective of Chapter 5, people with Down syndrome have a range of "linguistic capital" (Bourdieu, 1977a), which are to be valued within social fields. The research has, therefore, utilised several communication strategies to promote the participation of people with Down syndrome. In addition, the existing literature has highlighted the centrality of the family context in the lives of people with Down syndrome (Hilvert et al., 2023; Scott et al., 2014; Taylor et al., 2019). For this reason, the research has been undertaken within family settings, not only by interviewing parents and carers but, more importantly, by including them as support people to facilitate the engagement of the participants with Down syndrome when necessary. Doing research in this way also aligns with the social and ecological perspectives on "self-determination" (Abery & Stancliffe, 2003a, 2003b) and with the idea of "social capital" (Bourdieu, 1986), which have just been explained in the theoretical framework chapter.

This chapter begins by broadly framing the study in terms of its research paradigm, research approach, research method, and research questions. It then explores complex issues surrounding researcher positionality, which is a

particularly salient topic in this study because I myself am a parent of a child with Down syndrome, in addition to other subjectivities that I inevitably bring to the research. The chapter also argues for the need to perform disability research ethically and inclusively, and it explains how the research has sought to achieve this. Finally, the process of interviewing people with Down syndrome and their parents is outlined, beginning with the "recruitment" of the participants through to the analysis of the participant interviews. Throughout this chapter and the whole thesis, the research participants are referred to using pseudonyms.

Framing the research project

In this section, the overall framework of this research project is laid out. The research paradigm, research approach, and research method are explained. The research questions, which have already been outlined in Chapter 1, are also revisited.

A qualitative, critical-constructivist study…

In terms of its broad paradigm, this research is a qualitative study. Qualitative research aims to develop a complex, holistic picture of a particular research problem or issue (Creswell & Poth, 2016). Qualitative studies strive to describe and interpret a phenomenon in detail (Flick, 2014). Adopting a qualitative approach to exploring the lived experiences of post-secondary learners with Down syndrome can contribute valuable knowledge to the existing literature. As discussed in Chapters 1 and 3, the broad field of Down syndrome research has been predominantly shaped by quantitative research from psychological traditions (Burack et al., 2023). Whilst the present study owes much to this body of literature, quantitative research has its inherent limitations (Strunk, 2024), as does qualitative research. Interestingly, as mentioned in Chapter 4, the literature on people with Down syndrome in post-

secondary education is overwhelmingly qualitative in nature, compared to the field of Down syndrome research more broadly.

Some researchers, such as Kidder and Fine (1987, as cited in Braun & Clarke, 2019, p. 594), have drawn a distinction between “small q” and “Big Q” qualitative research. The former uses qualitative tools within a positivist paradigm, whereas Big Q qualitative research is “fully qualitative” (Braun & Clarke, 2021, p. 39) in both methodology and paradigm. Since the present study adopts the approach of critical-reflexive thematic analysis (Braun & Clarke, 2006, 2019), it is Big Q in nature. That is, the research does not set out to “discover” or “prove” a particular truth about the further education journeys of people with Down syndrome. Rather, the study presents one particular interpretation of those journeys. From the viewpoint of Big Q qualitative research, a different researcher would inevitably draw out different narratives from the same interview data.

What separates the two major schools of qualitative research are their research paradigms, in which issues surrounding ontology, epistemology, and research positionality and subjectivity are theorised. Research paradigms are interpretive frameworks that influence how a researcher conceptualises, designs, and conducts their research (Creswell & Poth, 2016). Essentially, research paradigms are worldviews that guide research design (Patton, 2015). Five distinct research paradigms have been identified by (Hatch, 2023), namely positivist, post-positivist, constructivist, critical, and poststructuralist. Positivist and post-positivist ontologies and epistemologies both hold that there is an objective, external reality that can be known objectively by a researcher (Merriam & Tisdell, 2015). A (post-)positivist study might, for instance, make quantitative assessments on levels of self-determination and capital in people with Down syndrome to determine how degrees of self-determination and capital “objectively” affect further education journeys.

The present study, in contrast, adopts a critical-constructivist paradigm. Constructivist and critical schools of research have been said to "fit comfortably together" (p. 231) because of their shared understanding that reality and knowledge are never "objective" (Lincoln et al., 2017). In a constructivist paradigm, reality is understood to be plural, not singular, such that "multiple realities exist that are inherently unique because they are constructed by individuals who experience the world from their own vantage points" (Hatch, 2023, p. 18). Knowledge, therefore, is never entirely "objective" because truths are constructed by individuals in diverse contexts. The role of the researcher is, accordingly, not to discover knowledge but to construct it (Merriam & Tisdell, 2015). Similarly, a critical paradigm also holds that there are multiple realities and, moreover, that all realities are situated in sociocultural and political contexts, wherein one particular version of reality is often privileged over others (Merriam & Tisdell, 2015). According to a critical view, reality consists of a material world in which there are "historically situated structures that have a real impact on the life chances of individuals" (p. 19), depending on one's race, gender, social class, disability, and other identity markers (Hatch, 2023).

The implication is that the present research constructs one particular interpretation of the further education journeys of people with Down syndrome. Specifically, the interpretation is influenced by the concepts of "self-determination" and "capital", derived from psychology and sociology respectively (Chapter 5). Moreover, the research adopts a critical stance in that is shaped by a critical understanding of VET and higher education fields in Australia, with a particular concern towards the barriers that people with disability encounter in these social fields (Chapter 2). The study is also critical in that it reflects on how "Down syndrome", as a disability, intersects with other social identities to produce relative advantage and/or disadvantage for a person participating in VET and higher education.

… using critical reflexive thematic analysis…

In keeping with its critical-constructivist paradigm, this study adopts a research approach known as "critical-reflexive thematic analysis" (Braun & Clarke, 2006, 2019). Thematic analysis has a relatively short history as an established way of doing research (Braun et al., 2019). Although thematic analysis is usually not listed alongside other major research approaches such as phenomenology (see e.g. Creswell & Poth, 2016), Braun and Clarke (2006) have argued that thematic analysis is an approach in its own right and that it should not be subsumed under another approach as merely an analytic method. In essence, thematic analysis involves identifying, analysing, and interpreting themes (i.e. patterns of meaning) within qualitative research data (Clarke & Braun, 2017). More specifically, reflexive thematic analysis involves interpreting and constructing themes from the data (Braun & Clarke, 2019), whilst critical thematic analysis involves uncovering issues of power and ideology that underpin and give shape to the data (Lawless & Chen, 2019).

In reflexive thematic analysis, a researcher's subjectivity and positionality are seen as valuable resources for the research and not as biases to be avoided (Braun & Clarke, 2019). In contrast to what a (post-)positivist analyst might assume, themes do not simply "emerge" from the data, nor do they simply need to be "discovered" by the researcher (Braun et al., 2019). Rather, the researcher assumes the role of a storyteller, constructing themes as "creative and interpretive *stories* about the data" (Braun & Clarke, 2019, p. 594, emphasis in original). In the present study, this means that the interviews with people with Down syndrome and their parents form the basis for the further education narratives that are told by the researcher. Unavoidably, there exist within the data other important stories that are not told for the purposes of this research.

In critical thematic analysis, meanwhile, the researcher seeks to connect "everyday discourses" (p. 93) with broader social and ideological practices

which give rise to those discourses (Lawless & Chen, 2019). Critical thematic analysis involves looking beyond a research participant's explicit words to "identify or examine the *underlying* ideas, assumptions, and conceptualizations – and ideologies" (Braun & Clarke, 2006, p. 84, emphasis in original). In the current study, this means that the interview data is analysed with attention towards broader values and ideologies that are often found within discourses on further education. As argued in Chapter 2, ideas such as "equity" and "excellence" are contested within VET and higher education discourses in Australia (Butler & Ferrier, 2022; Rizvi & Lingard, 2011). Accordingly, it is necessary to analyse the perceptions of people with Down syndrome and their parents and carers towards VET and higher education fields to uncover how they might reproduce or contest such notions.

... to examine participant interviews...

This research uses interviews with people with Down syndrome and their parents as its research method. Interviewing is commonly used within qualitative research approaches (Creswell & Poth, 2016). An interview is quite literally an "*inter-view*" (p. 6, emphasis in original) whereby conversation parties engage in an interchange of views on common interests (Brinkmann & Kvale, 2018). Interviews are, however, distinct from naturally occurring conversations, because they are conducted by interviewers with specific purposes in mind (Lichtman, 2014).

In terms of research paradigms, interviews can be accommodated in positivist, constructivist, and critical studies alike (Merriam & Tisdell, 2015). These paradigms differ in whether they conceptualise the interview as being simply a data collection instrument or as a social practice that structures what is said by the interviewees and how it is said (Brinkmann, 2018). In a critical-constructivist study, a central focus is on how issues of power and ideology are reflected in the interviews, as well as on how ideas and meaning are co-constructed by the interviewer and interviewees (Lincoln et al., 2017).

For this present study, it is fundamental to interrogate how my subjectivities shaped each interview and the resulting "data" in distinct ways. Researcher positionality and reflexivity are discussed in subsequent sections of this chapter.

... exploring post-secondary education journeys

The main purpose of this research is to explore the lived experiences of people with Down syndrome within the field of post-secondary education. The research questions have already been explained and substantiated in Chapter 1, so they are simply referred to here. The main research question addressed is:

- How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?

The principal research question is supported by several sub-questions concerning self-determination, capital, and the fields of further education in Australia:

1. How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?

2. How do people with Down syndrome exercise and develop self-determination throughout their further education journeys?

3. How do different forms of capital (i.e. economic, cultural, and social) interrelate to enable post-secondary education journeys for people with Down syndrome?

4. How does embodied cultural capital in people with Down syndrome facilitate further education opportunities?

In short, this research is a qualitative study that explores the voices and lived experiences of people with Down syndrome within post-secondary education fields. The study is closely aligned with the constructivist and critical research paradigms. Accordingly, it adopts critical-reflexive thematic analysis as its research approach to construct stories based on interviews with people with Down syndrome and their parents on the topic of the post-secondary education journeys.

Reflecting on researcher positionality

In qualitative research, especially of the critical and constructivist kinds, "positionality" and "reflexivity" are central, interconnected concepts. Both terms foreground issues surrounding the role of the researcher in a research study. "Positionality" refers to the researcher's social position (e.g. gender, age, race, disability, class, and sexual orientation), as well as their background, values, and beliefs (Berger, 2015). "Reflexivity" refers to the ongoing process of critically reflecting on how one's positioning shapes and is shaped by the research project (Creswell, 2014). Practising reflexivity in qualitative research is vital because the researcher themself is a primary research instrument (Lichtman, 2014). Every stage of a research project is influenced by the researcher's positionality. As Lichtman (2014) and Braun and Clarke (2019) argue, it is not necessary nor possible for a researcher to eliminate their subjectivity. Instead, a researcher should acknowledge their subjectivities and employ them as positive resources that can enrich the research.

Whilst this entire chapter is itself a product of reflexive work, there are particular issues concerning researcher positionality that I wish to highlight here. Far from providing guidelines on "how to do reflexivity" which, as Finlay (2002) analogises, is like wading through a muddy swamp, I aim to uncover how my research identities were co-constructed through interaction with the

participants and how that, in turn, potentially affected the research data and findings.

Undoubtedly, the most crucial dimension of my positionality is that I am the father of a young child with Down syndrome. Micah, my five-year-old son, has been the fundamental inspiration behind this research. Meanwhile, my professional experience as an English language teacher to adult learners provided the interest in researching VET and higher education fields. This research project was, therefore, the product of integrating my personal and professional identities and various academic interests.

My identity as a parent made me an "insider" of the broader Down syndrome community. Being an insider brings various benefits to a research project (Berger, 2015). I have experienced that it is generally easier for a researcher to engage participants and develop trust with them when important aspects of the researcher's positionality are similar to the participants' positionality (Merriam & Tisdell, 2015). In the research flyer (Appendix 1) circulated during "recruitment", my personal and parental identities were foregrounded by using a profile photograph, along with a statement of my positionality as a father. This was done to address issues of power that are inherent to doing research. As an "insider", it is conceivable that I was able to more effectively recruit research participants from Down syndrome communities. Moreover, the participants were likely to be more open to share their experiences with me, as they likely perceived me to be a person who was understanding of their situation and lived experiences.

The insider-outsider binary is helpful, to an extent, in understanding the nature of the relationship between the researcher and the participants. Yet, the categories are far from being definite or fixed (Merriam & Tisdell, 2015). A researcher's position is fluid, such that they can experience being both an insider and outsider in relation to the participants' context (Berger, 2015). Although I am an insider in the Down syndrome community, the unfolding

relationships between me and each individual participant were often complex and unpredictable.

When I spoke with Adam, a 39-year-old with Down syndrome, and his mother, Kate, I became particularly aware of my positionality and how it influences and is influenced by the research. Unsurprisingly, there was often much in common between me and the parent participants like Kate. The excerpt below shows a humorous connection that was established between me and Kate:

Interviewer:	Great, so, what number is Adam? You said you had four [children]?
Kate:	Number 3.
Interviewer:	Number 3.
Kate:	Yeah.
Interviewer:	Yeah, great alright, thanks.
Kate:	Same as Micah.
Interviewer:	Yeah. Well, we have absolutely no intentions of having a fourth one!
Kate:	Well, funnily enough, Fievel, we didn't either!
Interviewer:	Oh gosh, I won't ask you anymore about that! [laughter]

My interview with Adam, Kate's son, was a turning point in my research and personal journey, because it profoundly changed my perception of people with Down syndrome. As I shared with Kate, when I was interviewing Adam, there was "a really nice moment where I didn't feel like I was just the interviewer". Adam and I were both in our late-30s and shared similar experiences and interests growing up. It dawned on me that, under different

circumstances, Adam and I could have been school mates and good friends. This insight came about as Adam initiated conversations with me about video games, as seen below. Coincidentally, Adam's strong interest in gaming was also a significant aspect of his further education goals.

Adam:	Have you ever played Ghost Recon? Or ever considered it?
Interviewer:	No, I mean I used to play one RPG [role-playing game] called Final Fantasy. But that was a long time ago now.
Adam:	Oh. Did you have any other – What console did you have for it?
Interviewer:	PlayStation One, if I remember correctly.
Adam:	Have you ever considered going back to it – those sorts of things?
Interviewer:	Sometimes. I feel like when my son gets older – Then, I feel like he will drag me back into it.
Adam:	Yeah, that sounds like your son for sure.

Despite its many benefits, doing insider research also carries potential "risks". One such risk is the blurring of boundaries between the researcher and the participants which, as Berger (2015) shares, can create tensions for the researcher: "I found myself constantly struggling with the questions of how much to disclose, in which manner, when, and to whom" (p. 225). As a parent of a child with Down syndrome, I often found myself empathising with the parents whom I interviewed. At times, I would verbalise that empathy and disclose how the research impacted my personal identities. As seen below, a researcher's disclosures can prompt further sharing from their participants:

Interviewer:	Well, that's really lovely to hear. It's a very moving story as well. I must confess, during these interviews, I often get a little bit teary, hearing everyone's different stories. [laughter]
Leanne:	[laughter] Yeah, naturally, there's that... This journey into adulthood and everything – initially, you do go through a bit of "Oh, it's so sad. Her friends are going off to uni. They've moved away, and her life is here. And her life becomes a little bit more closed."

Another issue I encountered was that, whilst I strove to construct a particular type of researcher identity (i.e. one who values respect and inclusion), the participants might have perceived my position as "interviewer" in terms of power and dominance. I became aware in a real way that researcher positionality is co-constructed by researchers and participants alike. I felt uncomfortable with the reality that "research participants are not passive recipients of our identity, in spite of how we may think of ourselves or how we may assume to be presenting a particular identity" (Day, 2012, p. 72).

One parent, Irene, shared that her 17-year-old daughter with Down syndrome thought of me as an interviewer who wanted to hear the "right answers". Elise's construction of my researcher identity impacted on her responses throughout the interview: "So, with you, she wanted to please you. She wanted to have the right answer, even though she didn't know what it was. So, she was just going on, one sentence after another." I experienced first-hand that the desire to "save face" and "get it right" can cause communication difficulties for people with Down syndrome and their conversation partners (Bray, 2017). It is necessary, therefore, to carefully consider the words of the participants with Down syndrome when analysing the "data", recognising that the "data" itself may not be entirely transparent at times.

To summarise, reflecting on researcher positionality is an indispensable part of doing critical-constructivist research. While I approached the study as a father-researcher, I experienced that my fluid, co-constructed identities impacted on me, my research, and the participants in complex, unexpected ways.

Introducing the participants

From the perspective of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), people with disability have a right to participate and be involved in research (Ollerton & Horsfall, 2013). This study, accordingly, foregrounds the voices and lived experiences of people with Down syndrome on the topic of post-secondary education. The participants (n=15) in the research were people with Down syndrome aged 16 to 45 and their parents. Appendix 7 presents a summary of the participants' backgrounds.

Regarding the participants with Down syndrome, the broad age range of 16 to 45 was chosen because existing literature shows that people with Down syndrome tend to study in further education at various points in their lives. The planning for transition into post-secondary education (and employment) usually begins in senior secondary school (Foley et al., 2013). Yet, it is not uncommon for people with Down syndrome to access further education, particularly university, in their 30s and 40s (High & Robinson, 2021; Messenger et al., 2018). So, it has been important for this research to engage the diverse lived experiences of people with Down syndrome by interviewing people of wide-ranging ages. The research was largely successful in recruiting participants across the age range of 16 to 45. There was, however, a notable gap in the mid-20s to mid-30s age range.

The post-secondary education experiences that the participants with Down syndrome had had were somewhat similar. The people with Down syndrome

who were interviewed had all studied at TAFE, whilst two people had had university experiences. I had hoped to interview more people with Down syndrome without further education experiences, because it would be important to hear their perspectives. This plan, however, did not come to fruition. It may have been that parents and caregivers receiving information about the research decided that their family member with Down syndrome would not be suitable for the interviews. The participants who have been interviewed could be seen to represent the "success stories" of post-secondary education for people with Down syndrome.

Another noteworthy feature of my participants were their genders. (The people with Down syndrome and the parents alike used cisgender pronouns.) Interestingly, the overwhelming majority of the participants was female. Only one out of the seven people with Down syndrome was male, and only two out of the eight parents were fathers. I had expected to interview more fathers, since my positionality as a father was made explicit in the information circulated among Down syndrome communities. The relative lack of male participants might reflect the current state of Down syndrome research, in which fathers' perspectives are seemingly under-researched in some topics (How et al., 2019; Sheldon et al., 2021).

With regard to ethnicity, the participants were all Australians of White European backgrounds. This was another somewhat surprising outcome. I had expected greater ethnic diversity among the participants not only because of the multicultural nature of Australia but also because of my own background as a Chinese Australian. As with the issue of gender, it appears that there is a lack of ethnic diversity in Down syndrome research in countries such as Canada and the US (Channell et al., 2023; Krueger et al., 2019; Onnivello et al., 2023; Skotko et al., 2016).

The families who participated in this research lived in several different parts of Australia. Four of the eight families lived in New South Wales, with only one

family living in Sydney, the most populous Australian city. One of the opportunities that the COVID-19 pandemic provided was the ability to conduct online interviews with people from across Australia. Accordingly, Brisbane, Melbourne, Perth, and Adelaide each had one family participate in the study.

Parents have had an important voice in this research, because they play a vital role in post-school transitions for people with Down syndrome (Leonard et al., 2016). Parents usually facilitate and coordinate the entry into further education for their children with Down syndrome (Casale-Giannola & Kamens, 2006; Taylor et al., 2019). In this research, the parent interviews have been invaluable for understanding the experiences of people with Down syndrome. Parents usually shared in much greater detail than the participants with Down syndrome. This may have been due to issues related to communication and/or memory in the participants with Down syndrome.

Finally, the participants were "recruited" through several channels. Disability peak organisations, namely Down Syndrome Australia (DSA), Down Syndrome New South Wales (DSNSW), Down Syndrome Queensland (DSQ), and the Council for Intellectual Disability (CID) were asked for their support in the recruitment process. These organisations promoted the research through emails, Facebook posts, and/or personal contact. Celebrate T21, a social enterprise that advocates for the Down syndrome community through photography and storytelling, also supported the recruitment process. In addition, several participants were contacted directly by me. Since these participants were quite active in the public sphere, their contact details were publicly available online.

In all this, it is conceivable that my unique positionality as a father-researcher enabled me to establish connections with stakeholders and participants more effectively. It is likely that they not only recognised the importance of the research but also desired to support me as a fellow member of the Down

syndrome community. There may also have been the perception that the research, because it was “in-house”, would be conducted in a respectful and empowering manner.

Ethical considerations

It is of utmost importance for qualitative researchers to critically examine the ethical dimensions of their work. Historically, people with disability have been marginalised in and by research concerning their lives (Walmsley & Johnson, 2003).

Brinkmann (2018) has rightly pointed out the dangers of erroneously assuming that qualitative research is inherently ethical and/or more ethical than quantitative research. Simply including people with Down syndrome and giving them voice in a research project does not automatically make the research ethical nor inclusive. As Gothard (2001) contends, even the well-intended sentiment of “giving voice” to people with Down syndrome can itself be a patronising one. This section, therefore, explains the need for the research to be undertaken ethically and inclusively. Importantly, it outlines the concrete ways by which the sensitivity and accessibility of the research were strengthened.

This research study has been approved by the UTS Human Research Ethics Committee (HREC). Its approval number is UTS HREC REF NO. ETH21-6453.

The research has been designed and conducted in accordance with the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council [NHMRC], 2023). According to Chapter 4.5 of the statement, people with Down syndrome would be “vulnerable people” because their capacity to give informed consent to participate in research can be impacted by their cognitive and intellectual impairments. Children with Down syndrome, then, would be considered doubly vulnerable because, as

noted in Chapter 4.2, their level of maturity can also affect their capacity to give informed consent.

When seeking consent from people with disability to participate in research, it is vital to use simple language and visual support to provide information about the research (Cameron & Murphy, 2007). As noted in Chapter 4, people with Down syndrome often have strengths in reading and visual-spatial working memory, meaning that information should be provided to them in visual and multimodal forms (Faragher et al., 2020; Faragher, 2023). To address these concerns, the present research has sought to provide clear and accessible information about the research to people with Down syndrome by using Easy Read (explained later in the chapter). In this study, people with Down syndrome and their parents alike indicated that the Easy Read documents were effective in communicating the research.

The potential risks and benefits of the research for the participants have also been considered. “Risk” is defined in Chapter 2.1 of the NHMRC’s (2023) statement as “a potential for harm, discomfort or inconvenience”, including its likelihood and severity. In this study, the parents were expected to experience some general stress and discomfort of a small magnitude by being interviewed. On the other hand, it was anticipated that people with Down syndrome would experience more emotional discomfort during the interviews but that the magnitude would likely not be severe. When faced with conversations that are outside of their comfort zone, people with Down syndrome might experience anxiety (Bray, 2017). This seemed to be the case, particularly with the younger participants with Down syndrome. One parent shared that their daughter was happy to have participated in the interview, but that she was also relieved when it was finished: “[A]part from taking a while to thaw, I think she was happy enough. She was more cheerful about it after the event than during it. [laughter] Once it was out of the way, 'That's good.’”

There was also one incidence of a participant with Down syndrome feeling inconvenienced by having to be interviewed. As mentioned in Chapter 3, tiredness and fatigue can be common aspects of living with Down syndrome (Donaldson & Leyland, 2015). This issue was reflected on by one parent: "[S]he came home and said 'No, I'm going to go and have a sleep. I'm exhausted.' I said, 'No, you're not. You're supposed to be doing this.'" Although the person with Down syndrome did eventually engage enthusiastically in the interview, it is necessary to acknowledge that physiological conditions can contribute to people with disability feeling inconvenienced by research studies.

Several strategies were used to minimise the likelihood and magnitude of emotional discomforts. Fundamentally, the use of Easy Read documents and interview guides increased the participants' understanding of the research and helped them not to feel overwhelmed by the interview questions. The participants were also provided with the Easy Read interview questions beforehand, so that they could prepare their responses and use them as notes during the interview. Meetings were also held with each family online for informal conversations prior to the interviews, in order to build trust and rapport. These short, casual meetings helped me and the participants to feel more comfortable with each other. Importantly, a distress and referral protocol (Appendix 6) was created to provide step-by-step guidelines on how to minimise the risk of a participant experiencing distress during an interview and what to do if such distress occurred. During the interviews, I also periodically checked in with the participants. No participant expressed emotional distress in the interviews.

In addition to minimising potential risks and harms, researchers also need to consider the potential benefits that their research brings. According to Chapter 2.1 of the NHMRC's (2023) statement, a research benefit can include gains in knowledge, as well as improved individual wellbeing and social

welfare. By participating in this research, people with Down syndrome and their parents have been able to share their lived experiences relating to post-secondary education for people with Down syndrome. This is currently an under-explored area in the literature. In addition, the participants have spoken of the barriers encountered in university and VET contexts, as well as how those barriers were navigated. The research has potential to bring benefits to a range of stakeholders, including people with Down syndrome and their families, Down syndrome communities, and educators, practitioners, and policymakers within education fields, as the conclusion in Chapter 11 argues.

Applying inclusive research principles

To enhance the sensitivities and accessibility of the study, this research has been shaped by inclusive research principles. "Inclusive research" is defined by Walmsley and Johnson (2003) as "research which includes or involves people with learning disabilities as more than just subjects of research" (pp. 61-62). From this perspective, research should not be done on people with disability, but with and by people with disability. As such, inclusive research has ethical imperatives, as well as the benefits of having the knowledge and lived experiences of people with disability to shape and lead research (Smith-Merry, 2017). Fundamentally, inclusive research is emancipatory in nature. Often, there is an intermingling of researcher and advocate roles, because "[u]nderpinning much of what inclusive researchers do is a commitment to values which are focused on social justice, equity and fairness" (Walmsley & Johnson, 2003, p. 203). Accordingly, part of my reason for undertaking this research is to contribute to improving the participation of people with Down syndrome in further education fields.

Inclusive research involves people with disability in significant research roles as "instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Walmsley & Johnson, 2003, p. 10). In

other words, research can be done inclusively at all stages, from beginning to end. Significantly, in recent years, people with Down syndrome have been increasingly conducting research as co-researchers on topics related to disability and Down syndrome (Faragher et al., 2024; Morgan et al., 2014; Morgan et al., 2015; White & Morgan, 2012).

In practice, inclusive research lies on a continuum, as Nind (2014) explains, along which power is less or more shared between the academic researchers and the co-researchers with disability. Research that is researcher-led is considered less inclusive than research that is participant-led (Nind, 2014). Inclusivity can range from being consultative to collaborative to consumer/participant-led, as Smith-Merry (2017) explains, drawing on the work of Rose (2003). Importantly, there is no single correct way of doing inclusive research (Walmsley, 2004), even if some ways might be seen as more inclusive than others. As Walmsley and Johnson (2003) state, research that is researcher-led is still valuable to people with disability and disability research, so long as it is undertaken reflexively. Although this present research has been researcher-led, it has applied several inclusive research principles to increase its accessibility and sensitively. The following discussion outlines how stakeholder consultation, Easy Read, visual research methods, inclusive communication and interpersonal skills, support people, and support documents were utilised to strengthen the inclusivity of the study.

Consultation

Consultation with stakeholders and participants occurred throughout important phases of the research. Prior to “recruitment”, I sought feedback from important stakeholders on the research ideas and information documents. Professor Rhonda Faragher and a person with Down syndrome provided invaluable feedback on the Easy Read participant information sheet and consent form. The information was said to be generally clear for people

with Down syndrome, though several suggestions were made and adopted. For example, they suggested that the research refer to “TAFE” rather than “VET”, because the former is more commonly used within Down syndrome communities and the latter can be misunderstood as “veterinarian”. Suggestions were also made to shorten some of the sentences to enhance their clarity. For instance, “You can bring someone you trust to support you in the interview” was shortened to “You can bring someone with you.”

During the recruitment and interviewing process, I also consulted the participants (especially the parents) regarding the method and the content of the interviews. The purpose was to adapt the interviews to suit each participant with Down syndrome. Providing the interview questions in advance was an important way of refining and individualising the research interviews. As the title of this chapter (“I don’t think I’m going to ask that question any more”) suggests, decisions were made to omit particular interview questions when they were deemed to be too burdensome. For instance, I was interested to find out the participants’ perception of what Down syndrome is and what it means to live with Down syndrome. One parent, however, indicated that her adult daughter did not exactly address these questions when they talked, because she found them too “in your face”. In some interviews, therefore, I decided to not ask about Down syndrome explicitly. Knowing this information before the interviews enabled me to minimise the risk of participants experiencing emotional discomfort or distress.

Accessibility

In inclusive research, accessibility is “an absolutely fundamental principle” (Walmsley & Johnson, 2003, p. 172), and one that I have sought to rigorously apply. People with intellectual disability have a right to receive clear, accessible information about research that is about their lives (Goodwin et al., 2015). Being provided with accessible information enables people to

participate in research in meaningful and informed ways. The accessibility of this research has been strengthened by using Easy Read, visual research methods, inclusive communication and interpersonal skills, support people, and support documents.

Easy Read

Easy Read is a unique way of presenting information using text and images to make information clearer and more accessible for readers from diverse backgrounds, such as people living with intellectual disability (Commonwealth of Australia, 2025). There are two columns in the layout of an Easy Read document, with visual aids on the left supporting clear, short sentences on the right. Easy Read was used in this project to present the research information (Appendix 2) and interview questions (Appendix 8) to people with Down syndrome.

Several actions were taken to enhance the effectiveness of the Easy Read documents. Firstly, I received training from the Council for Intellectual Disability (CID) on guidelines on producing Easy Read documents. The guidelines provided suggestions on how to use language more clearly, such as using active rather than passive voice, limiting sentences to one key idea, using words with no more than three syllables, and avoiding contractions. The training also provided best practices relating to Easy Read formatting, including font sizes, document lengths, colours, and page margins. Using appropriate formatting provides readers with intellectual disability with the necessary “thinking space” to process the information within an Easy Read document.

Additionally, I paid for a subscription to Photosymbols, an online photo library with over 5000 images that can be used in Easy Read documents. The benefit of using Photosymbols is that their photos are commonly used in Australia and around the world within disability communities. Some parts of the

research documents, therefore, became immediately recognisable to readers within Down syndrome communities. The images from Photosymbols have a distinct style in that they all have a white background to reduce visual clutter and to emphasise a key point in each photograph. I also selected some photos from a free library called Pexels, because it contains images of models with Down syndrome who commonly feature in social media posts and publications within Down syndrome communities.

Visual research methods

The accessibility of the research was also enhanced by using visual research methods, namely the sharing of photographs and artefacts from the participants with Down syndrome. The privileging of verbal communication in taken-for-granted research methods like interviewing can hinder people with intellectual disability from participating in research (Milne & Muir, 2020). Visual research methods, on the other hand, can promote the agency and competencies of participants with intellectual disability (Aldridge, 2015), while also providing rich data. Photographs (Gothard, 2001) and personal artefacts (Mannay, 2020) are invested with personal meaning, and are valuable resources that participants can use to share their identities and lived experiences.

In this study, participants with Down syndrome were invited to share photographs and objects to enrich their written and spoken responses. Although not every participant with Down syndrome chose to engage with the visual research methods (notably, the older participants did not), the ones who did were noticeably more engaged during those moments of the interviews. Moreover, the visuals were found to facilitate unscripted discussions more effectively than verbal follow-up questions alone did. Below is an interview excerpt where a participant's photograph promoted further discussion.

Interviewer:	Great. We have this other lovely photo you shared. Can you tell me what's happening in this photo?
Melissa:	OK. It was my first day.
Peter:	That was your enrolment day at [TAFE], wasn't it?
Melissa:	Yes. I was a bit nervous to go up to the teachers. [laughter]

Despite the benefits gained from using some visual research methods, the photographs shared by the participants have not been formally analysed. Because the photographs were discussed during the interviews, some analysis and interpretation of the images are already present in the interview transcripts.

Inclusive communication and interpersonal skills

Issues to do with communication and social interaction can impact on research involving people with intellectual disability. As discussed in Chapter 3, people with Down syndrome have varied communication skills and styles (Fidler & Daunhauer, 2011; Martin et al., 2009). It has been noted by Bray (2017), a speech therapist, that "people with Down syndrome can be competent communicators despite a high level of unintelligibility… and many are highly skilled in one or more communicative strategies" (p. 136). The participants with Down syndrome in this study did, indeed, have a range of communication levels. It appeared that the older participants in their 30s and 40s were more at ease during the interviews and conversed more freely compared to the younger participants in their late-teens and early-20s. Nonetheless, it is difficult to know what factors (e.g. age, personality, and communication ability) affected each participant's communication skills.

Regardless, it was crucial for inclusive communication strategies to be used with all participants.

A number of practices for inclusive communication have been outlined by Williams (2011). These include not sidelining people with intellectual disability nor pursuing them for answers that they do not wish to provide, as well as being open and friendly, allowing for social chat, and sharing mutual interests. People with Down syndrome might find formal conversations such as interviews to be confrontational, so it is important to allow for time and space for conversations and responses (Bray, 2017). When listening to people with Down syndrome, I would wait for several seconds of silence before responding with a remark or asking another question. Sometimes, the participants would share more during this silence. To provide feedback, I smiled and nodded in response to the participants. Since the interviews were conducted on Zoom because of the COVID-19 pandemic, it was important to make such body language clear and obvious. Although communication difficulties did arise (discussed later), the parents remarked that my communication with the person with Down syndrome was appropriate and effective.

Support people

The participants with Down syndrome were invited to bring a support person to the interview. This proved to be beneficial because, when there are challenges in communication, people with Down syndrome might use the strategy of asking a parent to step in (Bray, 2017). Of the seven participants with Down syndrome, four had a parent with them (either beside them or somewhere in the room listening).

One parent deliberately did not intervene even when it was apparent that her 17-year-old daughter and I were having difficulties with our communication. This mother later explained that she wanted me to experience the challenge of

trying to understand her daughter's thoughts which, as a parent, she often needed to do to facilitate her daughter's decision making: "She was just going on, one sentence after another. I thought it's good for you to see – having to make decisions for someone… She just kept on waffling. [laughter] And, I thought, it had to be exhausting for you."

In contrast, two other parents played more active roles in supporting their respective children (aged 19 and 22) to respond to the interview questions. A couple of participants deferred to their parents, using the words "Mum?" or "Dad?", when they found the interviewing challenging. Some parents also prompted their children with particular responses to the interview questions:

Interviewer:	So, why do you want to study at TAFE?
Melissa:	Because it is fun.
Peter:	Why did you choose the Animal Studies course, Melissa?
Melissa:	Well, I love dogs.
Peter:	What sort of a job did you want?
Melissa:	A job?
Peter:	Would you want to work with animals?
Melissa:	Maybe.
Peter:	What was the inspiration? Remember the small animal hospital?
Melissa:	Ah, the vet. Yeah. Dad, I need some help.
Peter:	You need some help.

Parents often played a vital role, therefore, in the construction of meaning that occurred throughout the interviewing process. Nonetheless, it was always the voices and lived experiences of their child with Down syndrome which were foregrounded by the parents. In no way was it perceived that the participants with Down syndrome were coerced by their parents into giving a response.

Support documents

The participants with Down syndrome were also encouraged to use support documents during the interviews. Since the participants had received the questions beforehand, they could use their written notes to follow along with the questions. Around half of the participants with Down syndrome first read out their pre-written responses and then responded to follow-up questions. Whilst this may seem to be a rigid procedure, it was important for making the research more accessible:

Interviewer:	Let's talk a little bit about your experience of finishing high school.
Helen:	Oh yeah.
Interviewer:	You found it?
Helen:	Yep.
Interviewer:	What choices did you have after finishing high school? How was your transition out of high school?
Helen:	Okay. While I was still in school, I went to TAFE to do a baking course. And that made it easy for me to go to TAFE after I graduated from Year 12.

In summary, this research has applied insights from the field of inclusive disability research to enhance the accessibility of the study. Consultation

with participants and stakeholders from Down syndrome communities has shaped the research. The use of Easy Read, visual research methods, inclusive communication and interpersonal skills, support people, and support documents have strengthened the inclusivity and accessibility of the research. Supported by these measures, people with Down syndrome were able to engage more fully and meaningfully with the study.

Doing the interviews

This section discusses the interviewing process that occurred in this research. Reflexivity is practised throughout the discussion to highlight the complexities that emerged during the interviewing process.

Online interviewing

This research was conducted against the backdrop of the COVID-19 pandemic. People with Down syndrome were typically more at risk of COVID-related medical complications (Callea et al., 2020; Hüls et al., 2021). This health risk affected the research in that people with Down syndrome and their families were likely to have been more hesitant to meet people face-to-face, especially during the heightened periods of the pandemic. The ethics approval and recruitment occurred during late-2021 to early-2022, during which there was still great uncertainty in Australia towards COVID-19.

The global crisis presented unique challenges and opportunities to doing research. The benefits of conducting interviews on Zoom included enabling the research to engage families across Australia and allowing participants to be in a comfortable environment from which they could share their experiences (Oliffe et al., 2021). Another advantage of using Zoom was the ability to use screen sharing to improve communication and engagement (Archibald et al., 2019). Visual supports facilitate communication and learning for people with Down syndrome (Bray, 2017; Faragher et al., 2020). By seeing

the Easy Read questions during the interviews, the participants with Down syndrome were able to follow the conversation more easily and to share their responses more effectively.

Concurrently, a shortcoming of online interviewing is that the personal connection between the researcher and the participant is more difficult to establish (Oliffe et al., 2021). Paralinguistic features of communication, such as body language, facial expression, and eye contact, which are important for effective communication with and by people with Down syndrome (Bray, 2017), were harder to express through Zoom conversations.

Pre-interview meetings

Prior to the formal interviews, I organised an informal meeting with each family. These conversations occurred on Zoom and were roughly 30 minutes long. The meetings were helpful for preparing both me and the participants to engage in the interviews proper. One significant reason for doing the pre-interview meetings was to ensure that people understood the research and what their participation would involve. Each participant had the opportunity to ask questions about the research.

Another purpose of the pre-interview meetings was to establish rapport with the participants. From the perspective of ethical and inclusive research, it is important for people to have a degree of trust in the researcher/s, so that they feel more comfortable to give informed consent to participate. In general, rapport building is vital to gathering useful and credible interview data (Patton, 2015). In building rapport, I sought to engage with people firstly as people rather than as interviewees. The participants and I engaged in conversations over general topics, as would be expected in small talk. As both the parent and the person with Down syndrome were present (in all but one meeting), it was necessary to give attention to both people. If the person with Down syndrome appeared to be quiet or reserved, I would address them specifically

to engage them in conversation. In some instances, the person with Down syndrome showed much initiation, which meant I had to actively include their parent in the conversation as well.

Self-disclosure by the researcher is one way of establishing rapport by lessening the power distance between the interviewer and interviewees (Lichtman, 2014). During the informal meetings, my positionality was made clear, as I shared photos of my own family, especially of Micah, my child with Down syndrome. I spoke about Micah's interests and achievements to highlight my positive and hopeful sentiments towards people with Down syndrome.

Finally, the pre-interview meetings helped to establish communication between me and the participants. Individuals with Down syndrome have particular communication strengths and challenges (Bray, 2017). By meeting with the participants informally, I was able to gain some insight into each individual's communication style. These pre-interview meetings also provided opportunities for me to develop inclusive communication skills (Williams, 2011).

The interviews

A total of 15 interviews were conducted with the participants (n=15). The interviews with people with Down syndrome were 45 to 60 minutes long, whereas the interviews with parents were 60 to 90 minutes in duration.

The structuredness of each interview depended on the participants' responses. The interviews with participants with Down syndrome tended to be more structured and standardised. In a structured interview, each interview question is carefully worded beforehand, and the questions are ordered in a specific way (Patton, 2015). Although the "objectivity" of the interviews might apparently be enhanced (since every participant is asked the same questions in the same way), standardised interviews can restrict the interviewer's ability

to ask probing questions to gain deeper insights (Lichtman, 2014). Structured interviews can also limit the participants from speaking on topics and issues that are of relevance to them.

For the interviews with people with Down syndrome, the wording and order of the questions were the same as what the participants had received in the week/s prior. Having a clear and pre-planned structure was a strength of these interviews. This is because people with Down syndrome tend to benefit from having clear structures and routines in learning contexts (Faragher, 2023). A few participants had prepared written responses and used them as notes during the interviews. This process was beneficial because it helped to overcome difficulties and anxieties relating to communication. The “rigidity” and predictability of the interviews enhanced, therefore, the accessibility of the research. Furthermore, the structuredness of the interviews did not prevent me from asking follow-up questions. By showing interest, asking questions, and giving remarks, I encouraged the participants to go on seeming tangents on topics that they were interested in sharing about (e.g. Adam and his video games):

Interviewer:	Can I just ask you a couple more questions before we finish?
Adam:	Sure, I’m going off topic! [laughter]
Interviewer:	[laughter] That's OK! I mean you're very, very passionate about it, obviously…

Meanwhile, the interviews with parents were semi-structured in nature. In semi-structured interviews, the researcher uses an interview guide, which outlines the main themes to be explored, along with some suggested questions (Brinkmann & Kvale, 2018). This provides the flexibility to phrase and order questions spontaneously, as well as the opportunity to investigate themes further as they are shared by the participants (Patton, 2015). Although

the parents in this study received a list of interview questions beforehand, the wording and order of the questions in the actual interviews did not necessarily follow that guide. Importantly, the parent participants expressed perceptions towards post-secondary education by making links to and/or initiating questions that they had received prior: “Yeah, so he doesn't love reading and writing… You asked the question about TAFE. I could not see him attending TAFE right now.”

In semi-structured interviews like this, it was necessary to pay close attention to the participants’ responses to notice which pre-planned questions had already been addressed and to decide whether follow-up questions were needed. I also had to tactfully guide the conversation to ensure that the most important themes were given sufficient attention, whilst also giving the participants time and space to express their thoughts on topics of relevance to them.

The reflections above highlight, also, that what a researcher plans for their interviews may or may not eventuate, depending on the participants’ responses. It is important, therefore, that researchers hold their carefully designed methods somewhat flexibly. This is especially so when the participants (like those with disability) might have had and/or still have their voices marginalised.

Regardless of how structured or unstructured the interviews are aimed to be, researchers need to be thoroughly prepared prior to conducting the interviews (Lichtman, 2014). In my case, I thought carefully about the topics to be asked, as well as how and in what sequence they would be asked. The interviews followed a general structure consisting of three phases, as outlined by Hatch (2023): the introductory phase, the body, and the concluding phase. The body of my interviews focused on post-secondary education, which was introduced by a general background question and was concluded with questions surrounding Down syndrome.

Following Patton's (2015) analysis of question types, the interview questions can also be categorised into the following: Firstly, background and demographic questions were useful for building rapport and encouraging participants to speak freely. Each participant had the opportunity to construct identities that were of importance to them as they responded to the statement, "Please tell me a little bit about yourself." Secondly, experience and behaviour questions were asked with a focus on further education. Such questions included **"**What did you / your child do at TAFE or university?", "What was the process of getting into TAFE or university?" and "What was enjoyable / difficult about studying there?" Thirdly, feeling questions were used to explore the participants' emotions in relation to post-secondary education. Feeling questions included: **"**How did you feel when you finished high school?" and "How did you feel when you started TAFE or university?" Finally, opinions and values questions engaged the participants' perceptions towards deeper issues concerning VET and higher education. Such questions were predominantly addressed to the parents/carers: "How important do you think it is for people with Down syndrome to have access to TAFE or university?" and "What opportunities and barriers are there to accessing and participating in further education?" Appendices 8 and 9 provide the interview guides with all of the interview questions.

In summary, the interviews were conducted online because of the COVID-19 pandemic. Online interviewing afforded the opportunity to engage participants across Australia, as well as the use of technology to strengthen the accessibility of the research. To build rapport, a pre-interview meeting was held with each family. The nature of the interviews varied in terms of structuredness, though common sets of questions guided the interviews.

Interpreting the interviews

This study has adopted critical-reflexive thematic analysis (Braun & Clarke, 2006, 2019) as its approach to analysing the interview data. The process of interpreting the interviews was two-staged, involving both transcription and analysis. From the viewpoint of critical-constructivist research, the act of transcribing an interview is itself an interpretive act rather than a mere writing down of what was spoken.

Transcribing the interviews

Compared to other facets of research methodology, transcription often does not receive adequate discussion (Bucholtz, 2000). While interview transcripts provide researchers with access to interviews "frozen in time" (p. 321), they are not unbiased representations of the interviews (Edwards, 2001). Fundamentally, transcription is a socio-political act because there is essentially "no natural or objective way in which talk can be written" (Roberts, 1997, p. 168). Every transcript is, inevitably, shaped by factors such as the purpose/s of the research, the conceptualisation of the research topic, and transcription conventions, all of which are determined by the researcher (Green et al., 1997). It is crucial, then, to conduct transcription reflexively by explaining my transcription decisions, as well as acknowledging the biases and limitations of my transcription practices (Bucholtz, 2000).

A significant transcription decision relates to the form or style of transcripts. This issue arises because there is a fundamental difference between written text and oral communication (Brinkmann & Kvale, 2018). A researcher, therefore, must choose between two broad transcript styles: a "naturalised" transcript, which follows written discourse conventions, or a "denaturalised" transcript, which closely reproduces oral discourse forms (Bucholtz, 2000). In making this decision, the researcher must grapple with the apparent tension between the accuracy and readability of transcripts (Roberts, 1997).

Essentially, a written transcript that is a verbatim record of the spoken interaction is likely to be more difficult to read as a written text. Conversely, a more readable, naturalised transcript typically does not contain the same level of detail and "accuracy" as in a denaturalised transcript.

While both styles of transcription have their use, I have adopted a naturalised approach to improve readability and to focus on meaning. The main reason is that my research is primarily interested in what themes and ideas are spoken about by the participants regarding the topic of further education. This kind of thematic analysis usually does not require transcripts to be as detailed as those in conversation analysis or discourse analysis (Braun & Clarke, 2006). In practice, this meant that details such as pauses, filler words (e.g. "ums" and "ahs"), overlapping speech, and intonation have not been transcribed. Furthermore, words were occasionally added or edited to improve readability and clarity, while recognising that such editing is also an interpretive act by the researcher (Gibson & Brown, 2009).

The intended readers of the transcripts are another factor that determines whether naturalised or denaturalised transcription is undertaken (Bucholtz, 2000). It was decided that highly detailed and technical transcripts were not necessary, because the research was not conducted for the purposes of conversation analysis. Rather, the stakeholders who are likely to benefit from the research include researchers in disability and/or post-secondary education research, people with Down syndrome and their families, disability peak organisations, educators and education institutions, and education policymakers.

Although the transcription choices seem justified, it is also essential to acknowledge their shortcomings. One limitation of not transcribing the interviews verbatim is that the communication difficulties I encountered during the interviews become somewhat hidden. As the readability of the transcripts was prioritised, the texts may give the impression that the

interviews proceeded entirely smoothly. There were, however, communication challenges which occurred between me and the participants with Down syndrome. These barriers were, in large part, due to me not having prior relationships with the participants nor knowledge of their personal experiences and communication styles. At other times, the participants with Down syndrome appeared to face difficulty in verbally expressing themselves within the context of a formal interview.

For instance, Elise, a 17-year-old with Down syndrome, used many filler words, false starts, and "just waffled on" (her mother's words). Irene explained that the communication difficulties were due to an apparent gap between the interview questions and Elise's level of understanding: "I think you're probably still aiming too high for them. You think they have more insight than they actually have." While transcribing Elise's interview, I needed to listen to her speech closely and repeatedly and made many more editorial decisions compared to other interviews. Below is a short excerpt from the interview as Elise responded to the question, "What choices did you have when you left school?" The first text is a relatively denaturalised transcript, whilst the second is a naturalised transcript. It can be noted that the second transcript preserves the overall meaning of Elise's words (i.e. that she did not entirely like her mother's decision to stop her schooling early), though her words have been editorialised.

A denaturalised transcription:

> Okay, so. Okay, if I – . So, my mum – my mum actually – I wanted to go to school. I wanted to go to school when I was in Year 12, but – Actually, yes, I would say that, but my mum actually did not. My mum actually wanted me to kick out of school. I don't really like it. Well, anyways, about that one. Okay, when I finished school, I wanted to go to TAFE with my friends… Okay, so when I finished school, I really want

> – not really want. Okay, if I finish school, I – I forget. I usually – I usually go on my, like. So, I usually go to TAFE, when I'm not at school.

A naturalised transcription:

> I wanted to go to school when I was in Year 12. Actually, yes. I would say that, but my mum actually did not. My mum actually wanted me to kick out of school. I don't really like it. Well, anyways, about that one. Okay, when I finished school, I wanted to go to TAFE with my friends… So, I usually go to TAFE, when I'm not at school.

Analysing the interviews

As discussed earlier, the interview transcripts have been analysed using principles of critical-reflexive thematic analysis (Braun & Clarke, 2006, 2019). Thematic analysis involves identifying, analysing, and interpreting themes (patterns of meaning) within qualitative research data (Clarke & Braun, 2017). A "theme" is an idea that captures something significant about the data in relation to the research question (Braun & Clarke, 2006). In reflexive thematic analysis, themes are not simply "discovered" in the data, but are constructed and interpreted by the researcher (Braun & Clarke, 2019). In critical thematic analysis, issues of power and ideology that underpin the data are uncovered (Lawless & Chen, 2019). In applying thematic analysis, some of the steps outlined by Braun and Clarke (2006) were adopted.

The first step was familiarisation with the data, which involved thorough reading and re-reading of the data (Braun & Clarke, 2006). Since I was the sole researcher in this study, I approached the data analysis with a prior understanding and experience of the data. Not only did I conduct the participant interviews, but I also personally transcribed the majority of the transcripts. (A few manuscripts were transcribed by Pacific Transcription, a reputable transcription service used by academics and industry stakeholders

alike.) The transcription process allowed me to become more familiar with the interview data.

The second step in the analysis was the generation of codes to identify features in the data that were of interest to the research questions (Braun & Clarke, 2006). My approach to coding could be perceived to be more theory-driven than data-driven (Braun & Clarke, 2006). That is, I approached the transcripts with particular interests (the topic of post-secondary education), as well as theoretical concepts (self-determination and capital), in mind. Whilst every ideational unit (paragraph) in each transcript was coded, the coding was much more extensive when the utterances were directly related to the research questions. Moreover, some particular "domains", defined by Braun and Clarke (2019) as broad topics or areas of focus, had more codes than other domains. For instance, the domain of "Further education" had considerably more codes than "High school" and "Primary School". Codes within the domain of "Further education" included "Interests", "Access", "Parent support", "Independence", and "Employment". Practically, the coding was done using Microsoft Excel. Functions such as conditional formatting can help qualitative researchers to navigate large amounts of data (Meyer & Avery, 2009; Ose, 2016). An example of coding in this research can be found in Appendix 10.

The third step in the analysis was the construction of themes, which involved working with the list of codes to form overarching themes (Braun & Clarke, 2006). Since the big-Q qualitative researcher has interpretative and storytelling roles, these themes were constructed by the researcher and not simply "discovered" in the data (Braun & Clarke, 2019). In my research, the process of constructing themes was guided by the theoretical ideas of "field", "self-determination", and "capital". Having identified the themes, I produced theme names that clearly and comprehensively captured what is significant and meaningful about the data in relation to the research questions (Braun et

al., 2019). Ideally, theme names should be interesting and punchy to engage the reader (Braun & Clarke, 2006). In this research, the themes have been named using participant quotes. Some themes foregrounded the self-determination of people with Down syndrome in further education contexts ("My decision was that I wanted to go to TAFE"). Other themes emphasised the family capital of parents which enabled further education journeys for people with Down syndrome ("We were professional people").

Conclusion

The research design and methodology of the study have been outlined with a level of detail that is, arguably, not often found in other research studies. The complexities of doing qualitative disability research have been highlighted in transparent detail. The research has been intentionally designed by me as the researcher, but it has also been contingent upon the moment-by-moment interactions with the participants with Down syndrome and their parents.

The most important aspect of the research has been its priority on strengthening its inclusivity and accessibility so that people with Down syndrome and their parents might be empowered to participate meaningfully in it. While the study has been researcher-led, it has applied principles of inclusive research to ensure that the interests of people with Down syndrome and their families might be attended to. Consultations with stakeholders within the Down syndrome community in Australia and with the participants themselves have given shape to the research. Several strategies have been used to make the research more accessible. Easy Read was used to produce the research participant information sheet and the interview guide. Participants with Down syndrome were invited to share photographs and artefacts to complement and enrich their spoken responses to the interview questions. Visual research methods and Easy Read were both able to capitalise on the visual learning strengths of people with Down syndrome.

Meanwhile, approaching communication more inclusively by allowing time for responses and providing positive feedback to responses helped me to align my communication with the participants' communication needs. Moreover, people with Down syndrome were encouraged to have their written notes and/or their parent to support them during the interviews, if they wanted that assistance.

As a result of these research practices, rich insights into the further education journeys of people with Down syndrome were generated. These findings are explored in the following three chapters.

Chapter 7: “No way could a university drop its bar”

Findings on “field”

Introduction

This thesis explores the further education journeys of people with Down syndrome. The present chapter is the first of the three findings chapters. It aligns with the first sub-question of the thesis: How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?

There are important connections between this chapter and the preceding ones, particularly through the ideas of “field” and “capital”. Chapter 2 has discussed several issues related to the post-secondary education fields in Australia, particularly as relevant to people with disability. Using Bourdieu’s idea of “field” (Bourdieu & Passeron, 1977; Wacquant, 1989) and with reference to further education reports (e.g. Department of Education, 2024b; Parliament of Victoria, 2021), it has been argued that vocational education and training (VET) and university fields in Australia are sites of inequality where people with disability have persistently encountered barriers to access, participation, and completion. In Chapters 2 and 4 alike, the issues surrounding the inclusion of people with disability and people with Down syndrome specifically in mainstream education fields have been primary concerns.

The idea of “capital” is an important link between this chapter and the previous ones. Chapter 4 has presented a literature review on the lived experiences of people with Down syndrome in further education fields in

Australia and around the world. The reasons for which people with Down syndrome undertake post-secondary education (i.e. to acquire forms of capital), the nature of their participation, and the supports and accommodations they receive have been explored. Meanwhile, from the theoretical perspective outlined in Chapter 5, further education fields provide its graduates with "institutionalised cultural capital" (Bourdieu, 1986). A post-secondary qualification is a valuable form of "capital" because it represents a "certificate of cultural competence" (p. 248) on the part of its holder (Bourdieu, 1984), even though there are no guarantees that it will be converted to "economic capital" (Ronnie, 2023). The economic perspective is often what is foregrounded by reports on the VET (Joyce, 2019; Productivity Commission, 2020) and higher education (Department of Education, 2024b) sectors in Australia, as Chapter 2 has argued.

This present chapter continues with the focus on "field". The chapter presents the findings on how the VET and university fields in Australia are perceived by people with Down syndrome and their parents and carers. The findings indicate that there are complex and, sometimes, competing attitudes towards further education systems among people with Down syndrome and their families. The chapter also makes use of the concept of "capital", especially "institutionalised cultural capital" and "economic capital". The findings highlight that there is a range of reasons for which people with Down syndrome wish to acquire post-secondary qualifications, and that the returns provided by these certifications also differ from person to person. The chapter now explores three key themes in turn, with the first two themes being primarily "field" related and the third being mostly "capital" related.

"Just like everybody else"

The interviews with people with Down syndrome and their parents uncovered somewhat divergent perceptions on the VET and higher education fields in

Australia. Notions such as “meritocracy” and “equity” were constructed in complex ways by the participants. There were differing views on the extent to which post-secondary education systems can be considered meritocracies. Some parents highlighted that their family member with Down syndrome was able to earn their academic achievements “just like everybody else”, whilst other parents more keenly argued that further education systems need to be transformed according to principles of inclusion and social justice.

It is, perhaps, not surprising that the family of Renee, a participant with Down syndrome who has completed university, somewhat reproduced the belief that further education systems are meritocracies. Renee’s father, James, emphasised that personal effort and achievement were keys to Renee’s academic success at university: “Renee had to pass the same entry bar as everybody else. She did the foundation course… At the end of that, …their marks… sort of generated an ATAR… [Renee] comfortably exceeded the entry requirement for a Bachelor of Arts.”

In a seemingly meritocratic system, Renee was treated just like “everybody else”. It was her academic performance in the foundation course that gained her the right to enrol in a Bachelor of Arts. Furthermore, throughout her entire university journey, Rachel was a consistently hardworking and successful student, as James explained:

> If there was an essay of 2,000 words or 5,000 words or whatever, she had to produce that and submit it the same as everybody else… And right through her university, she got really very good remarks… Renee would have had 16 or 18 different tutors, different lecturers, all marking and putting their marks in.

Throughout her degree, Renee was expected to fulfil the same assessment requirements “as everybody else”. Significantly, her work across many different units were assessed by multiple university staff members to be of a high standard, reflecting the consistency of standards expected of a

meritocratic system. At one stage, Renee's parents doubted her capability to achieve the high grades that she was receiving. They thought, perhaps, that the university was being generous to Renee because of her disability:

> Melanie [her mother] was saying to this tutor, "Was it really good enough to be a Distinction?" because we always had that fear that perhaps they might be kind. She said, "Mrs Hughes, you ought to read some of the other essays I have to mark."

Renee's experience gives support to the view that higher education is a meritocratic field that rewards "quality work". Higher education is perceived to be a field of "excellence", meaning that universities need to uphold a high standard of academic rigour: "The university would not – you couldn't have it downgraded. You couldn't have an easy option. That's really counter to everything the university would be standing for in quality." Operating in this manner means that universities apparently have a fair and equal standard for all learners regardless of their personal and social backgrounds. In particular, both students with a disability and students without a disability are assessed equally on the basis of merit, according to James:

> So, in a way, the disability or non-disability doesn't come in at that point because… what was being applied was what was applied to all the general public and in no way, I think, could one expect a university to somehow drop its bar because the person's got a disability.

Throughout the interviews, Renee's parents foregrounded the notion of "capability" in Renee's journey. Her academic capability and potential gained her entry into the elite field of higher education, as well as academic success in that field. Significantly, Renee's parents seemed hesitant to generalise Renee's story to other people with Down syndrome. Melanie did not draw the conclusion that every individual with Down syndrome should necessarily enter higher education or vocational training: "I can't say I really think it's important for people to go to TAFE or to uni. But I can say, if they've got the

will, the ability, the goals, then we should make that journey possible for them." So, while inclusion in further education is vital ("we should make that journey possible for them"), it seems that that inclusion is predicated, at least partly, on the capability of those who seek to be included. This finding suggests that there are tensions between ideas such as "excellence" and "equity" in post-secondary learning fields, particularly in higher education.

The issues surrounding concepts such as "capability" and "inclusion" were more keenly contested by other parent participants. One mother, Jessica, argued that "it is important" for everyone with Down syndrome to have access to further education. Additionally, she argued that there should not be any restrictions on accessing post-secondary education. Entry should not be based on student merit or capability alone. The main criterion for participation, in Jessica's view, should be a person's desire to learn:

> I think it is important for everyone to have access to that further education, if they want it. Even if they need some sort of assistance with the entry exams and things like that… I don't think there should be any limits on who can enter programs… I know a lot of adults with Down syndrome who would be fantastic at TAFE.

Although the perspectives of Jessica and Melanie are not necessarily conflicting, there are clearly distinct emphases within each view. Jessica foregrounded the issue of access, stating that no academic barriers should hinder people with Down syndrome from accessing further education. On the other hand, Melanie foregrounded the idea of capability, arguing that people with Down syndrome who show potential for further education should be given access to that learning.

Leanne was another parent who expressed similar views to Jessica, advocating the "access for all" stance. According to Leanne, people with Down syndrome need to have the opportunity to access further education just

like everybody else, because they perceive it to be a “natural” part of growing up and transitioning into adulthood:

> Oh, I think it's really important. Because they've got an intellectual disability, they do tend to be a little bit more immature than other people… I think it's this whole lifelong learning… I can see how much Helen has grown since she left school. And it really is a natural progression, isn't it, to go on to further education when you leave school? I really believe that it's something that they all should have access to.

The distinct point in Leanne’s response is that further education is itself a field in which people with Down syndrome can develop in their learning and capabilities. Instead of requiring people with Down syndrome to reach a certain level of “capability” or “maturity” before admitting them into further study, improved access into VET and university can be provided to people with Down syndrome precisely so that they can grow in their potential.

In addition, Leanne raised issues with the ways in which university teaching and learning operate, whereby student success is predominantly dependent upon learner effort and responsibility. Leanne implied that university students generally do not receive adequate face-to-face classroom learning support. During the online-learning period of the COVID-19 pandemic, some of the potential shortcomings of the university system were especially brought to light:

> A big thing is that the onus is totally on you to be on top of everything and be doing what you have to with uni. Particularly at the moment [with the pandemic], there's a lot of online learning. There's not a lot of face-to-face, is there, with uni?

Leanne also noted that opportunities to participate in higher education are particularly difficult to come by for people with Down syndrome: “And I love

seeing these little programs coming up in some of the unis, but I'd love to see it in every university." In Australia, the opportunities to access university are especially scarce for people with Down syndrome. It is still very uncommon for people with Down syndrome to be enrolled as university students in a degree, though the example of Renee shows that it is possible. While it is more common for people with Down syndrome to experience university as audit students, there are only few such opportunities in Australia. The "little programs" referred to by Leanne are most likely uni 2 beyond at the University of Sydney and the Up the Hill Project at Flinders University. Leanne expressed the hope that the higher education field would establish more of these inclusion opportunities.

To summarise, the parent participants expressed varied attitudes towards the further education systems in Australia. Some parents reproduced the understanding that post-secondary education, particularly university, is for "capable" students. In contrast, other parents foregrounded issues surrounding "equity" and "inclusion", arguing that there should be no barriers to accessing further education for people with Down syndrome.

"The course really wasn't appropriate for her"

The theme of accommodating and supporting people with Down syndrome in further education contexts was another significant topic throughout the interviews. People with Down syndrome have experienced varying levels of support and accommodation within and across university and VET. Accordingly, the learning success (or otherwise) of the participants with Down syndrome have also varied.

On a positive note, the higher education field was noted to have undergone some changes to accommodate learners with disability. A parent participant, Peter, explained that universities are now "expected" to make reasonable adjustments for learners with disability. In referring to higher education

accommodating for vision-impaired learners, Peter was perhaps implying that the system can go further to accommodate for learners with Down syndrome and other intellectual disabilities. Historically, universities operated as elite institutions in which ableist assumptions prevented people with disability from participating therein:

> I've got a friend who works in learning support at the [university]. And they've spent a lot of time getting people's heads around the idea that people who are blind can actually do higher education. And so, they've got technological solutions to that... That stuff started off pretty gingerly about 20 years ago now, but it's just mainstream. Everyone is expected to do it now.

Notwithstanding some of the positive developments within the sector, the university field was largely criticised by parents as being lacking in their accommodation of learners with Down syndrome. Leanne argued that, instead of foregrounding student merit and responsibility, more attention ought to be directed towards inclusion and accessibility within the higher education sector. When asked about potential deficiencies in the field, Leanne explained:

> Well, it's that there aren't the courses so much that are geared to what might be of interest and what might be a possibility for [people with Down syndrome] to study... Particularly at university, I think that they would have to tailor courses a little bit to what would be appropriate, what would suit their individual learning needs. And I don't know see that they're anywhere near really achieving that in the near future.

So, Leanne identified the problem of the "under-representation" of people with Down syndrome in higher education as being structurally caused. From her perspective, university courses are not designed with people with disability in mind. Although social fields such as higher education can change

to become more inclusive and accessible, Leanne believed that universities would be slow to embrace such change.

Another parent, Philippa, spoke of specific challenges that her daughter with Down syndrome, Sherry, encountered in higher education. There were marked differences between Sherry's and Renee's university experiences. Although they both enrolled in foundation courses, their outcomes were starkly different. Philippa made the argument that it was not so much Sherry's "capability" that led Sherry to discontinue the foundation course but the non-inclusive pedagogies she experienced at university:

> There wasn't really any problem at all in terms of her getting into [the foundation course], because they had a special education support unit. They gave her the support in terms of filling in the application and everything else. But what was set up as the course really wasn't appropriate for her. Not that she didn't handle any of it. She couldn't keep awake for an hour and a half, sitting there listening to something boring. I remember going to sleep in university lectures, anyway.

Although Sherry received support from the university to access the foundation course, she was not well served by the teaching and learning practices of the university. In Philippa's response above, it is implied that there are traditional, privileged ways of using language (i.e. lecturing) to deliver academic content in university fields. Moreover, it is implied that changes in the operation of such an elite field are slow to come about, since Philippa herself used to sleep through lectures. Thus, higher education practices can be seen to be resistant to change, even when those practices do not necessarily serve the needs of students. Philippa argued that the foundation course "wasn't a course that was designed for people with special needs or certainly people with short attention spans, because the lecture would go for an hour and a half…"

It is necessary to further explore what might have contributed to the different experiences that Sherry and Renee had in their university foundation courses. As mentioned, Sherry did not complete her foundation course, whereas Renee did and progressed further to complete a Bachelor of Arts. As quoted earlier, the account of Renee's story was centred around the notion of "capability", stating that Renee earnt her academic success throughout university "just like everybody else".

There were, however, environmental and structural factors that contributed to Renee's outcomes. Melanie spoke of the support that Renee received from her family and the university staff throughout the foundation course. In contrast to other parents in the research, Melanie portrayed the university system as being overwhelmingly accommodating and supportive: "We had the support of all these other people who were saying, 'Yes, let's do that. Let's go ahead with that, and let's make that happen.'" One specific way in which the university allowed for Renee's learning needs to be met was to agree to her parents attending the lectures: "So, we went to... the lecturers in the foundation course and said, "Can we sit in on the lectures, so that we have got the information that we can share with Renee and help her to get through this...?" Arguably, then, it was not solely Renee's individual effort and capability that earnt her academic success but also the widespread support she received, including from those within the university structure. Melanie effectively theorised learning as a social activity, not an individualistic one: "We became her learning community, and so did these other tutors who were at uni. They were always there by her side and helping her to learn."

In marked contrast, this was precisely the kind of support that was lacking in Sherry's university experience. According to her mother, the period of time during which Sherry attempted the foundation course was less than ideal, in terms of how much support and accommodation were given by the university: "[Sherry] was very keen to enrol in university. I think she was a bit ahead of her

time, from the point of view that she didn't have the support that she needed to get through even the foundation course." From what Philippa understood, the university field has since become more accommodating to learners with disability: "I know that kids get more support now when they're doing things like foundation courses, but I think [Sherry] certainly tried it before the supports were in place." Philippa recounted how she had to encourage Sherry by explaining that it was the university that had failed her: "[Sherry] said, 'Mum, I failed.' I said, 'No, you didn't fail, honey. The university failed to accommodate your needs. And that is a different thing.'"

The difference in time between when Sherry and Renee participated in the foundation courses is important. It was difficult to determine from the interview data when exactly Sherry and Renee began the foundation courses. Sherry likely attempted it when she was about 20 years old in the early-2000s, whereas Renee enrolled when she was roughly aged 32 in the early-2010s. So, not only was there a time difference of approximately one decade, but there was a considerable age difference between Sherry and Renee when they began their foundation courses. That difference in age, furthermore, would have meant differences in life experiences, personalities, and skills with which the two learners entered university. Such individual differences would have impacted on how well equipped the two students were to navigate higher education fields.

The specific university fields in which Renee and Sherry accessed the foundation courses were also vastly dissimilar. Prior to commencing the foundation course, Renee had been involved with the same university for five years. She had participated in an inclusive program for three years, during which she experienced university life as an audit student. Subsequently, Renee spent another two years working closely with university staff and students to write and produce a film. This was the catalyst to Renee undertaking formal university study: "By the end of that time, which took

about two years, other people in the university had seen Renee working. It was them who then suggested she did the foundation course." The parts of the university system that Renee experienced, therefore, were very supportive of her disability. Key stakeholders continually prompted Renee towards the next steps in her university journey. Compared to what Sherry experienced at university, there was already a history and culture of inclusion that marked the environment of Renee's university. The primary barriers that hinder people with Down syndrome from participating in further education are, to a large extent, structural in nature. This argument was made by Melanie:

> We should be able to break down the barriers to make it possible for them to follow those journeys. Yes. TAFE, I think, should be – and university should be open to adjusting their curriculum or whatever they do to match the needs of those people, because we know that they can learn. And it's only the structure of the organisation that often inhibits people learning.

Likewise, Peter contended that there are systemic issues within education fields that disadvantage people with Down syndrome. According to Peter, accommodating learners with Down syndrome should not be seen as a burden: "And the only challenges to that, really, are the inability of the school system and TAFE and uni to recognise these kids as deserving as everybody else and to make the appropriate accommodations. And the accommodations aren't that difficult." In addition, Peter argued against a deficit approach to learners with disability. The learning potential of people with disability are to be foregrounded, as well as the role that post-secondary learning contexts ought to play in supporting these learners' needs:

> They will learn at a different rate, and they will retain in different ways. But it seems to me that it should be entirely possible. And it may be happening now. I've not gone there. I just don't know what's happening

> in the university sector. But I know that TAFE has been very, very responsive.

It can be seen from Peter's response that the university sector is more rigid and less accommodating than VET towards learners with disability. From the interview data, it was nonetheless difficult to compare in great detail how university and VET were experienced differently by people with Down syndrome. One reason is that very few people with Down syndrome have studied at university. Regardless, the participants indicated that people with Down syndrome experienced the VET field as largely supportive and accommodating. With statements such as "they just were really supportive" and "they've all been pulling together", parents spoke highly of the VET staff who were involved in their children's further education journey.

In summary, the participants with Down syndrome received varying degrees of support from their post-secondary education institutions. Broadly speaking, the VET field was perceived to be more accessible and accommodating than the university field to learners with Down syndrome. Regardless, parents expressed hope that further education systems would become more inclusive of learners with Down syndrome.

"They're the only avenues for me"

In addition to exploring the perceptions of people with Down syndrome and their parents and carers towards VET and higher education as "fields", the interviews also investigated the reasons that people with Down syndrome have for undertaking further study. The findings show that there is a range of reasons, including economic and non-economic ones, for which people with Down syndrome engage in further study. Furthermore, the further education outcomes attained by people with Down syndrome also varied.

Some people with Down syndrome and their families expressed the view that post-secondary education is highly valuable for economic reasons. Post-secondary qualifications were spoken of in terms of being "a ticket" and "a stamp of approval" that enables a person to gain employment. It was particularly common for participants to speak of further education in terms of the employment and economic benefits it affords. One participant with Down syndrome, Gina, said of post-secondary qualifications, "They're the only avenues for me", regarding them as being essential for her livelihood.

The instrumental view towards further education was clearly brought out by one parent's response. In particular, Irene spoke of university participation as the means for attaining "better jobs". Although she did not envisage her 17-year-old daughter participating in university in the near future, Irene believed that having university experience leads to having "better paid jobs": "I borrowed a book from Canada about children with Down syndrome attending university… And what they found was that these students would have better jobs afterwards. They would have better connections. They would have better paid jobs." It is unclear whether Irene was referring to people with Down syndrome auditing university subjects or studying subjects for credit. Regardless, her main point was that university leads to "better" employment outcomes.

Family expectations that further study leads to better employment opportunities applied not only to university education but also to VET. Given this perception, post-secondary learning for people with Down syndrome "just makes sense", as Peter shared: "[I]t just makes so much sense. It offers great opportunities for kids to learn new skills, to have that ticket that says, 'I can do this job', opens up opportunities in employment…" A post-school qualification is perceived to be "a ticket" proving that one's knowledge and competencies are institutionally and culturally recognised. Peter also linked independent living to having certifications and being employed: "All the

evidence suggests that that will propel them into greater success in independent living and greater success in employment generally, if they've actually been able to achieve something through higher education…" There are perceived to be wide-ranging benefits of attaining further education, including enhancing one's confidence ("but also just in terms of massive self-satisfaction of having achieved that. And all the kudos that comes with that.")

Not only do people with Down syndrome reap benefits from post-secondary education but so does society at large. Peter argued that "the economics do add up", as he explained the widespread advantages of having people with Down syndrome being "more skilled up" through further study:

> The more skilled up somebody is the more ready for employment they're going to be. And once people are employed and earning money and paying tax, that's a massive burden off the disability support system and off the social security bill… And if someone is able to work, they're not needing to be cared for…

Peter's argument supports the view that post-secondary qualifications function as a form of capital for individuals with Down syndrome who acquire them but also for the economy as more people with Down syndrome become active in the labour market.

The story of Helen, a 22-year-old with Down syndrome, illustrates how some people with Down syndrome might gain economic capital by completing further education qualifications. When Helen was asked why she wanted to study at TAFE and whether she would want to study there again, she shared, "Okay, because it will help me to get work" and "Okay, if I needed to, I would be happy to go back to TAFE to learn skills for my current job." Helen saw further education in quite instrumental terms. For Helen, gaining cultural capital in the form of training qualifications was motivated by the potential outcome of getting a job and keeping a job.

At the time of graduating from high school and transitioning into adulthood, one of Helen's main goals was to find employment. Her mother, Leanne, recalled: "When she left school, it was really the getting-a-job. Well, she wanted to study, which was the TAFE, because that's what all her friends were doing. They were mostly continuing education. The getting-a-job was a big one."

Helen's mother shared in detail the reason behind Helen's decision to go to TAFE. From the perspective of gaining employment, it was perceived that obtaining a TAFE qualification was preferable to accessing an employment agency:

> Because she'd already decided that she wanted to work in a cafe. So, it was a natural thing. She needed to do TAFE. There were other avenues where she could have gone to an employment agency or something. But yeah, TAFE was what she wanted. That's what she had in her mind.

Helen's interest in hospitality began in high school, with her favourite subject being food technology. In Year 10, a café offered her paid employment, after she had completed work experience there. So, Helen had quite clear goals for her training and employment post-school. Prior to studying at TAFE, Helen had begun attending work experience at another café. This helped to make her vocational training even more beneficial for employment purposes:

> And the TAFE was really good, because they would go out to where she was doing work experience… And they'd let her practise… how to [make coffee] on their machine and talk to the staff there about what she knew and how they could get her doing different things.

After she completed her Certificate III in Hospitality, Helen was employed as a barista at a medical centre. Her journey in education and employment has been relatively straightforward, as she has been able to convert her cultural capital of a hospitality qualification into financial gains in the same field.

Not only so, but her employment has created additional skills and opportunities for herself. Over the course of time, her workplace discovered that she also had skills in tasks such as data entry and filling out forms, such that she then became employed as an administration assistant at the medical centre. Working in a healthcare environment has further fostered Helen's career interests, to the extent that she wishes to study at university "to become a nurse".

Another participant agreed strongly that post-school qualifications are essential economic assets. Gina is a 37-year-old with Down syndrome who has trained in fashion design at TAFE. Gina shared that she does not qualify for the Disability Support Pension (DSP) nor the National Disability Insurance Scheme (NDIS), though she did not explain why this was the case. This meant that her need to work was even greater than most people with Down syndrome. According to Gina, the only way to secure employment and make a living is through further education:

> Because they're the only avenues for me, in the land of void. I don't qualify for DSP or NDIS. So, I've got to pay everything out of my own pocket, so that means I have to work, and I have to work hard. For that, that's qualifications.

Speaking more broadly, Gina argued that post-secondary education is essential for all people with Down syndrome for employment and economic reasons: "Further education is important for people with Down syndrome. Like the NDIS and Disability Support Pension... Yes, they've increased the rate up a bit, but it's not enough to live on." At the same time, Gina highlighted a major issue associated with the strong link between qualifications and employment. That is, the need for qualifications to find employment can disadvantage some people with Down syndrome. According to Gina, people with Down syndrome might be suitable for particular jobs because of their

existing skills and knowledge, but they are unable to gain employment in those jobs because of their lack of formal qualifications:

> The fact that the university tertiary system is what it is, and the mindset of “You have to have a certificate and a stamp of approval to go do what you've studied”... There's plenty of people with intellectual disability who... know what they want to do but, because the system is the way it is, they can't. They can't get recognised to work in that field where they know it more because of personal and previous experience. But you've got to have that stamp of approval and that certificate completed. It's a bit backwards, you know?

Degrees and certifications are “stamps of approval”, meaning they are culturally recognised forms of capital. In most cases, qualifications are valued more highly than qualities such as personal experience.

Another significant issue that deserves attention is that having post-secondary qualifications does not necessarily lead to employment and economic outcomes for people with Down syndrome. The case of Sherry, an adult aged 41, exemplifies this matter. Her mother joked about how Sherry is “a professional TAFE student”, as Sherry has completed a diverse range of VET courses including hospitality, coffee making, car detailing, computing, and social media. The challenge, however, has been finding meaningful employment that makes use of her skills and interests:

> She's just started going through an employment agency again, so I don't know what they're going to come up with... She certainly worked in the local politician's office for quite a while, but most of the job really just was put down to shredding and cleaning up and so forth. It didn't use her computer skills or any of the abilities she had.

It was implied that employers and workplaces could invest more time and effort into discovering and developing the capabilities that workers with Down

syndrome have: “And I think that was one of the things that was disappointing to me, that she did have all these skills. I suppose it's expecting a bit much of a workforce to actually spend time developing them.”

Apart from the apparent lack of meaningful employment opportunities, people with Down syndrome also face physiological challenges that can affect their work life. Sherry’s disability impacts on how much she can work and also the type of work she can do:

> As she's gotten older, she's not going to be able to do a job that requires her to stand up for eight hours… I'm saying [to her], “Really, three hours of work a day for you is a full-time job… because that's all your body's going to take at the moment.”

Although the findings discussed thus far have focused on the instrumental value of further education as a form of capital, it should be acknowledged that some participants also regarded post-secondary education in non-instrumental terms. That is, the learning itself was perceived to be intrinsically valuable. People with Down syndrome tend to find that engaging in further learning is a good way of spending their time. As Adam shared, it is a way of being productive in life: “It's less boring. It's something to do, instead of being bored.” Additionally, it provides opportunities to develop one’s social life, as Sherry pointed out: “Bit of development, studying new things, meet people. Socialise and eventually find a boyfriend.” Post-secondary education can, therefore, enable people with Down syndrome to fulfil various life goals and to achieve overall quality of life.

A non-instrumental view on further education was brought out by Melissa, a 19-year-old who was completing a Certificate II in Animal Studies. Her love for dogs was foregrounded as the primary reason for studying at TAFE. During the interview, it was her father who tried to steer the conversation towards the topic of employment:

Interviewer:	So, why do you want to study at TAFE?
Melissa:	Because it is fun.
Peter:	Why did you choose the Animal Studies course, Melissa?
Melissa:	Well, I love dogs.
Peter:	What sort of a job did you want?
Melissa:	A job?
Peter:	Would you want to work with animals?
Melissa:	Maybe.
Peter:	What was the inspiration? Remember the small animal hospital?
Melissa:	Ah, the vet.

Melissa was quite content with studying for the enjoyment of studying. Peter, on the other hand, tried to remind her of the employment prospects that come with studying at TAFE. At the same time, Peter also stressed that he was not overly concerned, at this stage, whether or not Melissa would find a job after completing her training: “I don't know whether she's there yet. I think she would like to, but in terms of looking around and seeing what's available, we've not spotted anything that might fit that bill just yet…” From his perspective, employment itself is not solely about money but also about engaging in workplace relationships: “As I say, she's a busy girl… She doesn't need the money, but employment would be a good thing, just in terms of the socialisation and what have you.”

Another parent, Irene, was also not worried about what employment outcomes would come of her daughter’s training. The current period of

learning at TAFE was perceived to be a time for Elise to “find herself” and to enjoy the learning itself: “It's about learning skills and finding your interest… It's just not about having that money coming…”

A similar sentiment was shared by Melanie, reflecting on the fact that “I don’t think [Renee] had any reasons to go into university”. Studying a Bachelor of Arts provided many opportunities for Renee to explore subjects that were of interest to her, without concern for the instrumental or economic value of the content: “[S]he didn't study at university to get a degree. She studied at university because there was another interesting thing to learn.” In the end, however, employment did become a concern for Renee, as she faced a challenging transition after graduating from university. Renee felt a sense of loss when she completed university, because a significant chapter in her life had ended and a new phase had not immediately commenced. It was only after she recommenced paid employment that she felt grounded: “Once she left uni, she felt a bit of a loss. But now, her work is re-established… She’s got something in her life now, so that’s very good… [S]he was very flat, …and she’s now quite bubbly…”

In summary, the participants with Down syndrome and their parents valued post-secondary education for a range of reasons. Employment was perceived to be a major reason for studying at university and VET, regardless of whether the participants had an actual financial need to work.

Conclusion

The field of further education in Australia is a complex one, and it is one that people with Down syndrome have diverse and wide-ranging experiences of. The idea of post-secondary education being an entirely meritocratic field was challenged by some parents of people with Down syndrome. Whilst student capability and responsibility were identified as important for academic success, it was also argued that further education needs to be more

accommodating to provide greater access, as well as more tailored instruction, to people with Down syndrome. The university sector, in particular, was judged by some parents to be less responsive than the VET sector to the needs of learners with Down syndrome. Despite their highlighting of the potential flaws in further education systems, the parents held the belief that positive structural change is possible and worth advocating. Indeed, there appears to be evidence of some positive transformation in the two sectors in recent decades.

In addition, people with Down syndrome and their parents often regarded further education as a form of capital. As institutionalised forms of cultural capital, post-secondary qualifications tend to be highly valued because of the instrumental and economic benefits associated with them. While some people with Down syndrome have had the opportunity to participate in meaningful employment, others have encountered challenges in converting their cultural capital into economic capital. Furthermore, despite its importance for quality of life for people with Down syndrome, employment was not the sole driving factor for accessing further education. For some people with Down syndrome, enjoying the learning, having fun, socialising, and spending time meaningful were all significant non-instrumental reasons for participating in post-secondary learning.

Now that the participants' perceptions towards further education fields have been explored, the following two chapters analyse how the participants' self-determination (Chapter 8) and capital (Chapter 9) operated within these social fields.

Chapter 8: “My decision was that I wanted to go to TAFE”

Findings on “self-determination”

Introduction

This chapter is the second of the three findings chapters. It focuses on the idea of “self-determination” and aligns with the second sub-question of the thesis: How do people with Down syndrome exercise and develop self-determination throughout their further education journeys?

“Self-determination” has been discussed in numerous ways in the preceding chapters, chiefly in the theoretical framework explained in Chapter 5. Within disability studies, self-determination is said to be a “disposition” (p. 179), meaning that self-determined people have a propensity to think and behave in self-determined way (Wehmeyer, 2003a). Being a dispositional characteristic, it is shaped by one’s physiological body, meaning that self-determination is always influenced in some way by one’s “capacity” (Wehmeyer, 2003a, p. 179). At its core, self-determined behaviour consists of “volitional actions that enable one to act as the primary causal agent… to maintain or improve one's quality of life” (Wehmeyer, 2005, p. 117).

Self-determination has been theorised by disability scholars in three distinct but non-conflicting ways. The functional theory emphasises self-determined actions performed by people with disability, such as goal setting, choice making, decision making, and problem solving (Wehmeyer, 2003a, 2003b). The ecological theory places more emphasis on the individual’s numerous social ecologies, that ultimately shape the individual’s self-determination (Abery & Stancliffe, 2003a). The tripartite ecological theory explains that self-

determination lies at the intersection between three circles of "control": a person's desired degree of personal control; that individual's actual degree of personal control; and the degree of importance ascribed to the areas of life in which the individual with disability exercises control (Abery & Stancliffe, 2003b).

For people with Down syndrome, self-determined behaviours such as choice making have been found to impact quality of life in areas such as employment (Bush & Tassé, 2017) and housing (McGinley, 2002), as mentioned in Chapter 1. Young people with Down syndrome who are more involved in decision making throughout the transition process are also more likely to attain positive post-school outcomes, including participating in vocational training (Foley et al., 2013), as discussed in Chapter 4. Self-determination in people with Down syndrome is related to their cognitive development, such as their executive functioning (Landuran et al., 2022; Tomaszewski et al., 2018) and adaptive behaviours (Onnivello et al., 2022), as explained in Chapter 3. At the same time, people with intellectual impairment are not precluded from thinking and acting in self-determined ways (Wehmeyer & Palmer, 2003). Rather, people with intellectual disability can develop skills in self-determination through explicit teaching (Agran et al., 2000). Moreover, since self-determination is the product of the individual and their social environments (Wehmeyer & Abery, 2013), people with Down syndrome who express self-determination towards post-secondary education usually require the support of their family to fulfil that self-determination (Taylor et al., 2019). Supporting self-determination is, however, a complex task. Parents and carers may need to act as "gatekeepers" and/or "facilitators" in the post-school transitions their children with Down syndrome (Docherty & Reid, 2009).

This present chapter explores the interviews with people with Down syndrome and their parents through the lens of "self-determination". It presents three

key themes: firstly, people with Down syndrome made choices and decisions towards further education ("My decision was that I wanted to go to TAFE"); secondly, those choices and decisions were supported and/or redirected by parents ("I'll have to ask mum for that opinion"); thirdly, people with Down syndrome were presented with opportunities to grow in their self-determination throughout their post-secondary education journeys ("I was a bit nervous to go up to the teachers"). The chapter highlights that self-determination functioned in varied and complex ways for people with Down syndrome.

"My decision was that I wanted to go to TAFE"

The findings in this first theme have been mainly informed by the functional model of self-determination, highlighting self-determined behaviours such as choice making and decision making. The interviews with people with Down syndrome and their parents revealed that people with Down syndrome made choices and decisions to participate in post-secondary education. The choices and decisions made are often shaped by one's interests, strengths, and circumstances. It was, however, also found that the perceived levels of self-determination in people with Down syndrome towards vocational education and training (VET) and higher education were varied and complex.

Choosing further education based on interests and circumstances

The importance of choosing post-secondary courses that align with one's interests and strengths was a central theme of the participant interviews. For instance, Melissa, a 19-year-old with Down syndrome, chose to study a Certificate II in Animal Studies because "it is fun" and because of her love for dogs ("Well, I love dogs").

Helen, a 22-year-old with Down syndrome, studied a Certificate III in Hospitality at TAFE. Choosing the hospitality course was an act of building

upon the interests and strengths she had developed in high school: “While I was still in school, I went to TAFE to do a baking course. And that made it easy for me to go to TAFE after I graduated from Year 12.” Helen’s interest and past experiences formed the basis of her choice to do hospitality and also facilitated her transition into post-secondary education. Leanne, her mother, explained in detail that hospitality was something Helen “really liked” and that was why Helen “chose hospitality”:

> She really liked the hospitality. She'd done food technology at school… And she wanted to work in a cafe. She had a job; she did work experience at a cafe when she was in Year 10. And they actually offered her a Saturday morning job. So, she had a paid job in Year 10… So, that's why she chose hospitality.

It is interesting to note that Helen’s experiences were shared in greater detail by her mother than by herself in the interviews. Nonetheless, Helen’s self-determination in choosing post-secondary education was made clear. When asked the question of whether Helen had employment goals for her TAFE education, Leanne foregrounded that studying hospitality was Helen’s decision. Significantly, there was a sense of finality in how Helen’s decision was described:

> [S]he'd already decided that she wanted to work in a cafe. So, it was a natural thing. She needed to do TAFE. There were other avenues where she could have gone to an employment agency… But yeah, TAFE was what she wanted. That's what she had in her mind. So yeah, that was it.

The choice-making and decision-making aspects of Helen’s self-determination can both be noted here. Importantly, Helen’s decision to go into TAFE was made as a preferred choice over other post-school options, namely employment services. Going into further education was seen to be a “natural” progression from high school. As Leanne explained, “So, to her, it

was just that's what everyone else was doing. So, that's what she wanted to do. She wanted to continue learning."

Furthermore, because of the influence of others around her at school and in the family environment, Helen also had the goal of entering higher education. "Her second sister... went off to Brisbane and went to uni. So, she did have that example of 'This is what they did and that's what I'm going to do.'" Although it remained a not-yet-fulfilled dream, Helen had taken steps to explore pathways towards university study: "Oh, yes, she would love to... [S]he has this idea that she'd like to be a nurse, which... she's already researched... So, she knows that, if she wanted to be a nurse, she would have to go to uni."

Adam, a 39-year-old with Down syndrome, was another participant who exercised self-determination in his choice making and decision making. Adam articulated specific goals towards further education, according to his interests, strengths, and circumstances. Throughout his education journey, Adam had completed several TAFE certificates, including a Certificate II in Media Studies and a Certificate III in Multimedia. The importance of discovering his learning interests and strengths was highlighted by Kate, his mother: "He never liked the literacy and numeracy courses. There was no motivation there. But once he got into drama or music or artwork, he was very regimented." For Adam, motivation in learning depended on whether he had the opportunity to study courses that fit his interests and abilities.

Adam's interest in gaming and graphic design played a central role in guiding his learning goals. When asked the question "What choices and plans do you have for further education?", Adam said, "Well, hopefully jumping into university is one, instead of going... to TAFE in that process again... Yeah, my main goal is to get into university and do all those PlayStation modelling stuff that I like doing." In terms of employment, he expressed his hope for the future as "designing open world RPG [role-playing games] games for

PlayStation". It can be seen, therefore, that goals for further education and employment were closely linked in both Adam's and Helen's accounts.

Having set these education and employment goals, Adam identified the necessary steps to reaching them (i.e. he would need to "go to university, get the Diploma level, complete all the units that need to be done, and work on those modules.") In other words, he expressed self-determination in both his choice making and decision making. Based on his interests, Adam named a specific creative media institute in which he preferred to study. He also understood that there were alternative pathways towards achieving his goals, as well as the potential advantages and disadvantages of each pathway: "I've done all the stuff in TAFE. University is better than TAFE. It's one step further. But I want to jump straight into university, instead of going into TAFE and doing that again... Otherwise, it's too long, too difficult."

In evaluating the different pathways, Adam clearly preferred the first option of going straight into university rather than going through VET into university. His judgment that the second option would be "too long, too difficult" showed his insight into the effort and commitment that would be required to achieving his goals. University was also perceived to be a better option than TAFE because of the more advanced facilities that are offered for game design: "Because their tools there for open world games are much more advanced than Blender and things like that." TAFE had provided invaluable experience in using game development software such as Blender, but university was perceived to enable Adam to progress further towards his dream of designing PlayStation games.

Additionally, Adam perceived that it was his personal responsibility to gain access into university. He explained that he wanted to study a Diploma at a specific creative media institute and had taken concrete actions by speaking to the college. There was a clear sense of agency in his words: "That's the level [Diploma] that I was requesting." He had also taken a tour of the campus

and perceived it to be much more advanced than what he had experienced at TAFE, concluding that “besides, their campus is not that bad”.

Adam’s agency and self-determination were also highlighted by Kate, his mother. She likened Adam’s initiative in contacting universities to how he had contacted real estate agents about buying a house. With the latter, Adam’s actions did eventually cause the outcome he desired:

> With bigger decisions, like when he bought this house, he, again, like with the multimedia that he was trying to find a course for – he went online and started making appointments with the salespeople… Anyway, so that went on for a couple of years. And eventually, he found a house that he liked. And we agreed… So, he ended up getting his house. So, he forced us into making the decision. [laughter]

By acknowledging that his dream of studying at university is yet to be fulfilled, Adam also demonstrated self-awareness and self-knowledge. These two aspects of self-determination enabled him to understand his strengths and weaknesses, and how these might affect his further education opportunities. Being self-aware meant that he was able to identify the barriers to fulfilling his dream of studying at university and becoming a games developer. Adam had insight into his own learning abilities, and agreed with his mother, Kate, that the Diploma would be academically challenging: “Yes, she was right on that. My mum was right.” Although he was aware of the barriers to accessing university, Adam expressed a sense of hope and determination towards getting into his desired Diploma one day: “But I still want to get into that anyway.”

Gina, a 37-year-old with Down syndrome, was another participant who demonstrated self-awareness when making the decision to not pursue higher education: “I got the opportunity to go to university, but I thought, ‘Nah, I can't do it. It's too much work.’” The decision to decline university was in spite of her interest in the subject area: “I wanted to do an arts degree, because I was

very, very good at art and still am." That interest, however, eventually led Gina into a VET course: "And then, I got offered this fashion course, and I thought, 'That's more me.'" Her knowledge of herself enabled her to decide that VET was the more suitable option.

To summarise, people with Down syndrome exercised self-determination in their post-secondary education journeys by making choices and decisions in relation to VET and higher education. The choices and decisions were predominantly shaped by their personal interests and abilities.

Choice making was varied and complex

The interviews have shown that self-determination operated in complex ways in the post-secondary education journeys of people with Down syndrome.

One family shared that opportunities for further education are not always the product of personal choice. Renee's journey into higher education was not due to her nor her family's planning: "It was just the chance. No plans. It just happened." The journey was, instead, initiated by a key stakeholder within the university field: "There wasn't even a question of choice… It was that one person who said, 'Have you thought about this?' So, it was just chance." This finding suggests that, as important as self-determination is, self-determination is not always necessary for further education opportunities to eventuate. In such circumstances, self-determination can nonetheless grow in the learner with Down syndrome, as it did throughout Renee's university studies. Although she did not initiate her entry into university, it became clear that it was a suitable option for her because of her abilities and interests:

> What I did at university as a subject were drama and film studies. I became very much involved in both subjects because they're both hands-on… I learned some history on the two topics, which I found interesting, fun to learn and research about. This became the best part

> of my studies. I even did some performing as part of my research, fascinating.

In another family's account, self-determination was not possible to examine in straightforward terms. Elise was a 17-year-old with Down syndrome who had left high school before graduation because of ongoing health issues. The years leading up to leaving school were difficult, a period during which "everything was out of balance, and… nothing worked", as her mother, Irene, explained. Based on what would be in Elise's best interests, Irene explained the decision to leave school as "I took her out of school". The decision was largely made for Elise rather than by or with her. Elise shared that she "didn't really like it", framing the experience as "being kicked out of school":

> I wanted to go to school when I was in Year 12. Actually, yes, I would say that. But my mum actually did not. My mum actually wanted me to kick out of school. I didn't really like it. Well, anyways, about that one. Okay, when I finished school, I wanted to go to TAFE with my friends.

On the one hand, Elise seemingly had little opportunity to exercise self-determination in the decision of becoming an early school leaver. Yet, it appeared that Elise exercised a degree of self-determination in her transition into further education. She expressed a desire to enter VET to be with her friends from school. Significantly, in response to the question, "What advice do other people give you about your life decisions?", Elise shared, "Okay, so my decision was that I wanted to go to TAFE and see my friends. I love being there." She viewed herself as taking ownership of the decision. What was initially a decision that she "didn't like" eventually led to an outcome which she "loves".

At the same time, there were indications that the transition into VET was not as straightforward nor self-determined as Elise portrayed it to be. Her mother's account was different in that it was the mother's agency that was foregrounded:

> I wanted to find something before I took her out of school. And it was very close to not having anything at all… Once we had a conversation with TAFE, and they said, 'Yep, this is an option.' That was just a week before school started. And that's when I cancelled school…

Elise's journey into VET was, therefore, shaped by several complex factors, including her health issues and her mother's decision for her to leave school. Elise, nonetheless, perceived that it was also her decision to enter TAFE. Importantly, she has grown to "love TAFE", which her mother was pleased about: "[S]he said about TAFE, 'I love it', which she hasn't said before. Before, she would say, 'Well, I don't really like it. I don't want to go.'"

In the story of another young person with Down syndrome, self-determination towards post-secondary education was perceived by the parent to be somewhat under-developed. In the case of David, a 16-year-old, whose mother was interviewed, it appeared that David's seeming unawareness of post-school options would be a reason for not choosing further education. Jessica shared, "He doesn't know what TAFE is." At the time of the interview, David was still in high school and did not seem to have any specific post-school goals, according to his mother. In Jessica's words, "I don't think he has a concept of finishing school yet… As far as finishing school, I don't think that's on his radar at the moment." As a result, Jessica felt that she had to take more ownership of the planning and decision making regarding David's post-school transition: "I know what he likes to do. So, I probably do a lot of decision making… [I]f I said, 'What do you want to do when you've finished school?' I think he'd probably just look at me." Although Jessica does have some ideas for David post-school, further education was not currently on the agenda: "I could not see him attending TAFE right now."

Despite the uncertainties surrounding David's post-secondary options, Jessica did not rule out the possibility of David participating in TAFE. Speaking about the future, she highlighted that David might become self-determined to

choose post-secondary education one day. That choice, Jessica envisaged, would be based on David's interests and employment goals:

> Never say 'never'... David might decide he wants to do a trade, and you're never too old for TAFE... Who knows? Maybe one day, he may wish to go to TAFE to get some sort of formal qualification in some areas.

Nonetheless, it must be acknowledged that not every individual with Down syndrome aspires to access further education. It would appear that a lack of awareness of post-secondary education opportunities can hinder some from choosing further education. Peter, a father, argued that people with Down syndrome should be shown examples of others who have participated in further study:

> You just need for kids to have the desire. And to have the desire, they need to know that it's possible... They need to have the example... And so, there needs to be a bit more conversation about what's possible. And for kids coming up through school to be exposed to kids who've done well in TAFE or at uni...

According to Peter, therefore, schools play a vital role in raising the aspirations of students with Down syndrome towards further education and employment: "[If you] see that you can also go on to do higher learning, which might help you do a job that you might like..., those things are possible for you when you start aspiring to them."

In summary, the research has found that some people with Down syndrome exercised self-determination in choosing to study in post-secondary education. Such individuals made choices and decisions regarding their learning based on their strengths, interests, and circumstances. Self-awareness and self-understanding of one's learning opportunities and limitations were also important elements of self-determination in people with

Down syndrome, as the functional theory of self-determination would explain. At the same time, the research has also found that self-determination in people with Down syndrome towards further education was varied. Self-determination itself operated in complex ways, especially within the family unit.

"I'll have to ask mum for that opinion"

The previous theme has focused on the functional model of self-determination, showing how actions such as decision making impact on further education journeys. Although the agency of people with Down syndrome has been foregrounded, there have also been hints that parents and carers played a vital role in facilitating the decision making of people with Down syndrome. Throughout the interviews, the parents often provided greater insight into post-secondary education decisions than their children did. In this second section of the findings, the ecological theory and the tripartite ecological theory of self-determination are used to interpret the interview data. The ecological perspectives are helpful for exploring how the self-determination of people with Down syndrome was shaped, fulfilled, and/or redirected by their parents.

Facilitating decisions towards post-secondary education

The participants with Down syndrome generally perceived that some of their life decisions were made interdependently by themselves and their parents. Reflecting on the question, "How do you make decisions in life?", the participants shared responses such as "I think about my family" and "I talk to my friends and my family and my psychologist". Melissa, for instance, felt that it was a positive experience to have her parents' input and advice when making decisions, since "[t]hey are proud of me and support me".

Adam was aware that he needed his mother's advice regarding his dream of entering university. When he was asked whether he could enter university directly rather than going through TAFE, he said, "I'll have to ask mum for that opinion." His mother, Kate, agreed that seeking family advice was part of Adam's decision-making process generally: "With bigger decisions, we discuss it, and he will often say, 'I have to talk to my mum about that.' He knows that there are some decisions that need another person."

So, while they might be framed as "causal agents" acting volitionally in their decision making (as per the functional theory), people with Down syndrome also turned to their parents for advice, support, and the execution of their decisions (as per the ecological theory). Being causal agents, therefore, did not preclude people with Down syndrome from giving control to their families to help make and enact decisions on their behalf (as per the tripartite ecological theory).

Being supportive families, parents shared that developing the decision-making skills of their children with Down syndrome was one of their priorities. Leanne spoke of needing to be cautious to not relate to Helen in an overbearing manner but to encourage Helen's independence: "Because we don't want to always be just there going, 'Well, this is what you should do' or whatever. We want her to be able to make those decisions." As a father, Peter, would encourage Melissa to become more independent in exercising agency in her decision making:

> [I]n terms of decision making, she tends to defer to Lauren or myself. 'What's my decision? What have I decided to do?' And you have to push back a bit and say, 'It's your decision. What do you want to do?' She will get there… She does know that she can make the decisions.

Nonetheless, parents also expressed that they felt the tension between enabling their child with Down syndrome to become more independent and safeguarding them from making decisions that might have negative

outcomes: “And that's not always easy as a parent. It can be really hard to kind of let her make choices that you know are not going to really be the right one.” This was shared in the context of Leanne feeling the need to ensure that Helen’s everyday decisions would not impact Helen’s daily routines in a negative way. Leanne perceived herself to have insight into Helen’s needs that Helen herself might sometimes neglect: “[A] lot of her friends stay up till midnight, texting and stuff. And we couldn't have her being awake till midnight and then trying to get up and go to work the next morning.”

Leanne also expressed that she would have a level of control over Helen’s decisions towards further education. Helen has studied hospitality at TAFE and would like to become a nurse, which would require her to study at university. Leanne, however, is uncertain as to whether this goal would be fulfilled. She would, nonetheless, “let” Helen pursue the goal, indicating that she exercised some control over Helen’s decisions:

> And I would let her attempt it, to try and see where she could fit in that goal. She's actually just done her first aid course, so now she can be a first aid officer at work… So, we kind of let her work towards these goals that she has.

Likewise, Renee’s family needed to play a protective role in the decision-making process in relation to university studies. As mentioned earlier, Renee’s entry into higher education was not initiated by herself nor her family but by a stakeholder within the education field. Renee’s parents were initially surprised by the stakeholder’s suggestion, indicating that they did not believe it would be the right option for Renee:

> It was them who then suggested she did the foundation course. We were saying, ‘Whoa, whoa, come on. What are you talking about?’ But because they were so insistent, we said, ‘Okay, we'll go along with it, but we're not setting her up to fail… The moment she looks as if she's

> going to have a mental breakdown, she's out.' We were not going to allow her to do that.

So, while Renee's family "went along" with the stakeholder's prompting and decided that Renee would attempt the foundation course, they were also aware that they would need to intervene if Renee's participation in the course was not positive. Renee's mother, Melanie, perceived that it was ultimately her responsibility to ensure that the decision would not be harmful for Renee's mental health. Melanie would "not allow" Renee to be put into a situation within higher education where Renee would potentially feel like a "failure".

The research has, therefore, found that facilitating decisions towards post-secondary education can be a complex task for parents. This was particularly evident throughout the interview with Irene. On the one hand, Irene's guiding principle in helping her daughter with post-school decisions was clear: "I'm not focused or attached to anything... It's not about me... It's about me helping Elise to get the life that fits with her." It was clear that Irene wished to make decisions together with Elise that would be in Elise's best interests. To some extent, Irene had some clarity as to what Elise might like to do post-school: "So, she wanted to do hospitality, which she already did in high school."

Yet, although Irene's overall principle of supporting Elise's life decisions was clear, it was a complex process in practice. There were many different factors which Irene needed to take into account to facilitate Elise's choices and decisions. Due to issues relating to Elise's health and interests, Irene described the decision-making process as a "puzzle": "I have to help her to see what the right fit in the difficult puzzle is. It's so complicated with the health issues, with all her interests." Since ongoing health issues had led to Elise leaving secondary school before completion, it was vital to Irene that Elise's post-secondary learning be manageable for Elise. In addition, Elise had diverse interests in hospitality, drama, dance, and hairdressing, which Irene

needed to consider during the decision-making process. At times, Irene perceived that her daughter's interests were unpredictable and constantly evolving:

> [I ask] about her interest – 'What do you want to do?' And then, she'll say she loves to dance, so she loves to become a dancer, to become a dance teacher. Every time she has a conversation with someone else, …she says, 'I'm going to work at a hairdresser.' And it's like, 'Oh, you never told me that.'

On several occasions, Irene portrayed her role as a kind of "balancing act", as she tried to manage the complexities surrounding Elise's life: "So, it's all a matter of balancing and finding the right way. I just want her to perform to what she can do with a life that suits her… It's a balancing act… And it's trial and error." The post-school futures of people with Down syndrome can, therefore, be marked with uncertainty.

In Elise's case, communication issues also affected how Irene was able to support her self-determination. Part of the challenge was due to Elise being a 17-year-old: "They are the teenager, and they don't want to do anything. But they are also almost an adult, so you have to start listening to… how they want to lead their lives…" Irene expressed difficulty in understanding Elise's thoughts and desires: "For me, it's also very hard to make the difference between what she really means and what is caused by other things". There was often a degree of interpretation required on Irene's part: "So, I look at what Elise says, what that means…" Despite these communication challenges, Irene shared that the family was usually able to arrive at a shared decision, as was the case with deciding which TAFE course to pursue:

> I'm having lots of little conversations, like long conversations don't really go, so a lot of little check-ins like 'How do you think about this? What do you think about that?' And usually, she'll roll her eyes, and she'll give me a short answer. But all these little, short answers do, in

the end, come up with something that becomes a plan. And that's kind of how we found TAFE.

In summary, parents shared that facilitating decisions towards further study (and other life decisions more broadly) for their children with Down syndrome was a challenging and complex process. Parents played the role of "supporters" in encouraging independence but also the role of "protectors" in safeguarding their family member with Down syndrome from potential harms of a given decision.

Acting upon decisions towards post-secondary education

The research has also found that families supported self-determination in the participants with Down syndrome by acting upon their decisions towards further education. For people with Down syndrome, getting into and through post-secondary required facilitation and coordination by their parents/carers.

This was a reality that the participants with Down syndrome were perceptive of, when they were asked "How did you get into TAFE/university? What was the process like?". Elise shared about how her mother made numerous enquiries to TAFE: "So, my mum spoke to TAFE people… So, my mum talked to many people at TAFE, saying if I can go to TAFE." Likewise, Helen spoke about her mother's help throughout the enrolment process: "My mum helped me with the paperwork and told me what to do." A similar experience was shared by Melissa: "My teachers and parents helped me complete my application." While they all expressed self-determination in framing the decision to study in further education as their decision, these participants were also aware of their parents' support in gaining access to VET. Their decision to study in further education needed to be carried out by their parents.

From a parent's perspective, Peter portrayed his role as a facilitator and supporter, making it possible for Melissa to transition into further study.

Melissa needed her parents' help to "set up" TAFE. Self-determination and parental support played complementary roles in Melissa's experience:

> She tends to rely on us to give effect to her decision. If she wants to go to TAFE, she relies upon us to set up the mechanisms to make sure she gets there and comes back… But once she's got the pattern going, she will remind me when it's time to go. She texts me…, "I'm almost finished now. You can come and collect me." So, she manages the process well, once it's set up.

Irene shared a similar perspective, noting that her supportive actions were in response to her daughter's wishes: "First, I look at what Elise wants to do. And then, I look at: How are we going to organise this, and what's fitting best? And if it doesn't exist, then I'll organise it myself." Throughout the interview with Irene, the role of parents in supporting and facilitating post-secondary education decisions of people with Down syndrome was a key theme. Irene was a very involved parent and, at times, it appeared that she had more control over the post-school transition than Elise did: "I wanted to find something before I took her out of school."

A significant theme in Irene's account was the need for parents and carers to exercise their own self-determination in contexts that presented barriers to accessing further education for their children. Firstly, Irene had to resist the deficit discourse that was produced by the disability specialist at Elise's Catholic secondary school: "Yeah, well, if I would have listened to the specialist at [Elise's] college – he said, 'Yeah, no. No, TAFE – it wouldn't work' – that was the answer." Irene described the meeting in very discouraging terms: "The so-called 'support' that we had from someone specialised in disability… It was just completely the wrong information, like totally not supportive." From the specialist's perspective, post-secondary education was not perceived to be an appropriate choice for Elise, probably because of her health issues and learning and communication difficulties. So, the

family's decision to enrol Elise into TAFE could be seen as a form of resistance against deficit discourses. Irene generalised her negative experience to what people in the broader Down syndrome community might face. Referring to this research project, she explained that "You will only speak to the people who are pushing through and having thoughts and having expectations. Otherwise, it's not happening."

Apart from the school-based deficit discourse, Irene also faced structural barriers within the VET system, which she needed to overcome to facilitate Elise's entry into further education. These obstacles included limited course availability and inadequacies of institutional structures, which were exacerbated by the COVID-19 pandemic. Irene spoke of how she had to persist in seeking opportunities for Elise to participate in post-secondary education: "And everything that was on offer at TAFE – I picked one course after another and then, in the end, it was like, 'Oh yeah, it's not on next year' or 'No, that's not on next year.'" This was a frustrating experience for Irene, because the information provided on the TAFE website did not seem to be accurate: "You look online... and then you think, 'Oh, maybe this one. Let's call about that.' And then, everything is like, 'Oh, no. That's not happening this year...'"

Irene expressed that the TAFE system needed to be better organised: "I felt like there was no coordination... If there's anything TAFE needs to improve – It was just really not doable, just not doable." Irene felt that she was "bounced around" from one person to another during her phone enquiries to TAFE regarding courses:

> Yeah, unbelievable. I think I spoke to at least six people. If I would say, "Oh, she wants to do cooking or something", [the response would be] "Oh, there's a different person for that in Ultimo."
>
> And then I said, "Oh, maybe hospitality." "Oh, that's in Randwick. Yeah, we have another person for that."

> And then I said, “Oh, maybe if nothing’s on, we might do online.” “Oh, well, we've got another person for that.” It just kept going on…

Reflecting on this experience of “turning around in circles” and feeling that she “couldn’t decide what to do”, Irene highlighted that some families would probably have ceased pursuing further education opportunities in the face of these barriers: “Now, as a parent, yeah, you would have given up 10 times before.” Her implication, therefore, was that parents and carers themselves needed to be determined and persistent in seeking post-secondary learning opportunities for their child with Down syndrome.

Another parent, Kate, had to take risks and even defy certain rules so that Adam could study a TAFE course that matched his interests. She explained that, when Adam finished school roughly 20 years ago in the early 2000s, there were limited choices in TAFE courses for people with disability: “So, with TAFE, when he left school, it was very rigid… He could only enrol in courses for people with a disability. And they were always incredibly boring and not anything he wanted to do, like literacy and numeracy.” Within this restrictive context, Kate decided to exercise her agency in a defiant manner to enrol Adam in his preferred course: “But he always talked about wanting to do a media course. They wouldn't let me enrol him in media. So, one year, I just enrolled him anyway and I didn't put that he had a disability.”

Additionally, Kate approached the TAFE teacher to advocate Adam’s inclusion and to offer her support towards that inclusion. She, thus, understood the need for collaboration between families and learning institutions to foster the inclusion of post-secondary learners with Down syndrome: “So, I turned up at the class with him, and spoke to the lecturer and said, ‘Look, he wants to do this. Is it OK if he stays? Contact me if there's a problem.’”

In summary, parents and carers performed a vital role in carrying out the choices and decisions that people with Down syndrome had made towards

post-secondary education. The self-determination of the family unit as a whole was needed to enable further education journeys.

Redirecting post-secondary education goals

The roles that parents played in the post-secondary education journeys of people with Down syndrome were multiple. At times, families fulfilled the self-determined decisions that people with Down syndrome made towards further study (as found above). In other instances, parents redirected the further education goals that people with Down syndrome had. Such redirection occurred when families perceived the goals to be unsuitable for their child with Down syndrome. Specifically, parents were often found to redirect their child's goal of studying higher education.

For Irene, diverting Elise from entering university took place in a jovial conversation. Because she had just heard about university at school one day, Elise did not have a serious intention to enter university:

> One day, she came home, and she said, "Oh, I'm going to go to university. I'm going to do real estate, because that's what my friend's doing."
>
> [laughter] And I said, "So, do you know what real estate is?"
>
> And she goes, "No."
>
> I said, "Look, it's when you sell houses."
>
> She said, "Oh, I don't want to do that!"

In contrast to this one-off conversation with apparently little significance, conversations between Adam and Kate on the topic of university had been much more serious and frequent: "Oh gosh. We talk about it all the time." Kate acknowledged Adam's strong desire to enter university, highlighting that it was one of the few unfulfilled dreams that Adam had: "I think, most of the

things he's wanted he's got, except for the going to university. He desperately wanted to go to university… [H]e spoke of going to university as soon as he left school." Kate, however, also perceived that it would be unlikely that Adam would enter university. From her perspective, Adam did not fully understand the implications of studying in higher education. Furthermore, she did not seem to encourage Adam's enduring optimism in contacting universities regarding his study goals:

> I'm not sure he really understood what it meant to be at university. But since he's been about 30, 35, he's gone online and applied for things. And often, I'll get a call from somebody in Queensland saying, "Your son's inquiring about a course at university." And I'll say, "Oh, yes, that's nice." Yes, he's still doing that.

As a parent, Kate assessed the goals that Adam had for his life according to their likelihood of being fulfilled. Adam's dream of studying at university to become a game designer was as improbable as the goal of joining the army, according to Kate. Although she did not completely discount Adam's university dream, Kate's overall tone was not optimistic ("I just go along with it"):

> Well, there's… the real goals for Adam, and then there's the fantasy goals. So, Adam would like to be designing games… I can't see it really happening…
>
> He would like to be playing AFL. He'd like to be in the army or the air force. But those sorts of things he talks about a lot. But I don't know if he understands that it's unlikely… But I just go along with it.

Kate referred to the academic demands of university study as the reason for the unlikelihood of Adam fulfilling his dream. In response to the question, "What sort of barriers or challenges might hinder him from getting into university?" she responded:

> [H]e would need to do the Certificate IV, which the lecturers [at TAFE] say is intellectually beyond him. And then, he would have to do a Diploma at TAFE, that will involve two more years of study. And then, he would be eligible to go to [university]...

Kate perceived that the journey into and through university would be too long and too academically challenging for Adam. Significantly, Kate based her assessment of Adam's learning ability on the opinion of the TAFE lecturers: "'[A]t the end of Certificate III, one of the lecturers said, 'He's not going to be able to cope with higher levels. And it's not really fair on him or the lecturers to enrol him in Certificate IV.'" Based on her knowledge of Adam, Kate also perceived that the academic workload at university would also be difficult for Adam to manage: "[At university], they said they have 8 hours of lectures. And for every 8 hours of lectures, they expect you to do 16 hours of self-study... I could see that that was going to be a problem as well."

In light of these challenges to participating in higher education, Kate tried to redirect Adam's dream. She did this by encouraging him to focus on his current responsibilities and achievements. By diverting his attention away from his wishes, Kate felt that she was playing the role of "the doomsday person". Nonetheless, her emphasis was on encouraging Adam to see value and meaning in his current employment:

> TAFE is the option – to go back to TAFE and start doing a few units at TAFE again. But as I said to Adam, "At the moment, you are so busy... Do you want to give up something?" And I think, he's kind of quite happy to be going on as he is... I guess I'm the doomsday person...

This redirecting role was adopted in a similar way by Leanne in how she approached Helen's dream of studying at university and becoming a nurse. Leanne assessed Helen's higher education goal as being somewhat "unrealistic":

> She's been through a thing of where she'd really liked to be a nurse. And I'm sure she could quite easily pass the TAFE course to be an aged care nurse. But I don't think she could realistically get full nurses' qualifications.

Given the challenges to achieving her goal, Helen was encouraged by Leanne to concentrate on how meaningful her current employment was. Since Helen was working as an administrative assistant in a medical centre, Leanne pointed out how she was, in a way, already performing some nurse-like duties:

> [W]e sort of give her little things like, "You're working in a medical centre. And you're being part of the team that's helping people, especially with COVID." She's been very involved in doing the vaccines and everything for COVID... so she's happy with that at the moment.

In short, the family context is a central ecology in which self-determination in people with Down syndrome was developed, as the ecological perspectives on self-determination would explain. The research has found that parents and carers facilitated and enacted the decisions of people with Down syndrome towards post-secondary education. Supporting self-determination was a complex process for families, because it entailed enabling decisions towards further study but also redirecting some decisions away from further education, particularly higher education. Regardless, parents and carers were found to exercise their knowledge of their child with Down syndrome in decision making for their child's best interests.

"I was a bit nervous to go up to the teachers"

The previous findings have emphasised that self-determination played an important role for both people with Down syndrome and their parents in

making choices and decisions towards post-secondary education and in enacting those choices and decisions to access further education.

The findings in this current section, meanwhile, highlight that self-determination was vital throughout post-secondary education journeys. It has been found that further education presented opportunities and challenges for people with Down syndrome to further develop their self-determination. This third theme draws upon the functional understanding of self-determination to show how the post-secondary learners with Down syndrome progressed in aspects of their self-determination, namely their independence, decision making, and problem solving. The ecological perspective on self-determination is also used to highlight how the support of families, peers, and post-secondary education practitioners was vital for enabling the participants with Down syndrome to grow in their self-determination.

Developing independence

The participants with Down syndrome viewed participating in further education as an important part of developing their independence as adults. Families perceived that transitioning into further study was the "natural" pathway for high school graduates: "It really is a natural progression, isn't it, to go on to further education when you leave school?" For people with Down syndrome, engaging in post-secondary education was both an experience of gaining independence and an opportunity for growing in independence. A couple of activities surrounding the post-secondary education experience were particularly identified as opportunities for expressing independence.

Transitioning out of high school and into adulthood can be a challenging time for people with Down syndrome and their families. Leanne shared that, at times, she felt sad for her daughter, because Helen's post-school transition was different to that of her peers without disability. Most of Helen's high school friends had moved away from their small city to study at university in

major cities like Sydney, making Helen feel left behind: “This journey into adulthood and everything – initially, you do go through a bit of ‘Oh, it's so sad. Her friends are going off to uni. They've moved away, and her life is here.’”

Leanne, however, also reflected on how studying at TAFE enabled Helen to feel grown up like her peers. This was one of the things that Helen most liked about further education: “She felt quite grown up, in the fact that she was there, and she was negotiating this new area of study.” Furthermore, Helen’s TAFE campus is unique in that it shares a site with a university. Some of her schoolmates attended this university, so seeing familiar peers on campus also gave Helen the sense that she was growing as a young adult like everybody else around her.

Going into further education also increased the independence of the participants with Down syndrome. It was seen to be a different experience to attending secondary school, because it felt more “away from home” and “away from the family”. Peter observed how Melissa’s quality of life was enhanced as she gained independence through post-secondary education: “Yeah, she very much thinks of it as her TAFE. And I think she's quite buoyed by the fact that it's given her a degree of independence. She loves being there by herself…” After receiving some initial support from her father, Melissa eventually navigated her time on campus independently: “I used to hang around campus all day Monday… But now, I just drop her in the morning. Pick her up half past four, five o’clock in the evening. And she runs the show herself.”

Similarly, Kate explained that Andrew enjoyed the independence that came with studying at TAFE. Interestingly, it was not only the being at TAFE itself that helped Adam to feel independent, but also the other everyday activities that surrounded the TAFE experience:

> Well, he loved the freedom. Get away from his family, yes. And he liked to make friends. And he liked to wander around town. Most of the

> TAFEs were in town, like in the city. And so, he could wander around, go into shops and look at things. And lord only knows what he got up to.

The opportunity for Adam to "wander around" independently was related to the opportunity to commute to and from his TAFE campus. As Kate shared, travelling by himself provided greater freedom to Adam, to the extent that he would sometimes miss what he was supposed to be doing. Adam recognised that one of the challenges he faced during his TAFE studies was punctuality: "Being on time. I'm usually late sometimes and not getting there at the right time." It was his mother, however, who pointed to his independence as the reason for this issue:

> [H]e's capable to take the bus and do all that. But he's not necessarily going to go where he's meant to go. So, if he sees people having coffee, he might decide he'll go have a coffee instead. He might not get to the place.

The theme of travelling independently was, indeed, an important one for several participants. For Helen, the transition into post-secondary education required her to strengthen her ability to commute using public transport. Living in a small city, as well as having prior experience in commuting, meant that Helen's transition was relatively smooth and simple, as Leanne explained:

> We had to organise how she was going to get there… But that was fairly easy. We've got the bus stop out the front… The TAFE is not far from where her school was, anyway. So, it was kind of the same bus during that journey.

Leanne believed, however, that living in a major city would require greater independence on the part of people with Down syndrome, as she observed when she visited Sydney: "[T]here were some of the young adults with Down

Syndrome, and off they go to catch the bus or the train… [T]hat would be such a daunting thing to send her off in busy Sydney."

This was, indeed, the case for another participant family, who lived in Sydney. In Elise's experience, commuting between home and TAFE was much more complex, so it presented her with a significant opportunity to develop her independence. Elise needed to use multiple modes of transport to commute to TAFE from her home in the Eastern Suburbs. Importantly, the ability to travel independently was foregrounded in Elise's self-identity. At the beginning of her interview when she was asked to introduce herself, Elise spoke a little about her interests but outlined in detail her routine of commuting to TAFE:

> Well, I love to do some dancing. I love doing that by myself.
>
> I usually travel to TAFE and go somewhere. So, I go with my friend. My friend is Janet. She goes to TAFE as well. We travel there. So, I go by bus to Bondi Junction. And then, I wait for Janet, or she waits for me. And together, we catch the train together. And then after that, we hop out at Central. And then, we walk to [TAFE].

The challenge of commuting by oneself and/or with a friend on public transport was not to be under-estimated. Irene wondered whether Elise found the whole TAFE experience too difficult, "because she's got to get up early, she's got to do that difficult travelling with the train and the bus and then be there all day". With this struggle, however, came positive outcomes for Elise, as she became more independent and competent: "It's now getting exciting. She can do more complicated stuff. And in the end, she will be able to just look up on an app, 'What time is which bus going? And how am I going to catch it?'"

In addition to travelling independently, learners in post-secondary education also developed their independence in self-care, specifically with regards to

their meals on campus. Elise shared that having the freedom to choose her own food at TAFE was one of the highlights of further education: “Okay, so why TAFE? So, I do… typing. So, I usually talk to my friends at TAFE. I really like it. Oh yeah, I love buying stuff. [laughter] I love buying food, snacks…” Elise portrayed buying food as part of her routine at TAFE: “I usually buy a chicken wrap at the canteen. I usually go to the cafeteria.” This aspect of campus life at TAFE was perceived by Elise’s mother to be a distinguishing feature of post-secondary education compared to secondary school:

> So, being always having lunch from me, now she's buying her own lunch sometimes. So, she has to go to the canteen, and then choose what she wants to eat, and then buy a drink… And so, that freedom of being away from home and buying your own stuff and being with people that you like.

Similarly, Peter framed the act of buying food on campus as an act of independence for Melissa. He described Melissa’s actions with a strong sense of agency:

> [TAFE] has given her a degree of independence. She loves being there by herself, and going to the café, buying her own lunch, using her debit card, and choosing her own lunch. [laughter] It's usually a sausage roll with tomato sauce. She's got the café tray, and she walks in, and they know what she's looking for.

Importantly, going to the café was a way in which Melissa experienced inclusion at TAFE. Melissa’s presence at TAFE was recognised by others, as were her meal-time routines and preferences (“they know what she’s looking for”). This recognition was likely made stronger by the fact that Melissa’s TAFE was in a small town in New South Wales.

To review, for people with Down syndrome, developing independence was an important part of growing in self-determination, which was afforded by participating in further education.

Developing decision-making skills

Decision-making skills were another aspect of self-determination that was developed in post-secondary learning contexts. Having independence in one's life also entailed the need to develop one's decision-making skills. Specifically, not only was buying food and drink a means of exercising independence for people with Down syndrome, but it was also an area in which they developed the decision-making aspect of self-determination. Some participants had to evaluate their food and drink choices. Often, parents provided input into these choices to guide their children's decision making.

While discussing a photo of Melissa eating a vanilla slice at TAFE, Peter hinted that the freedom to choose one's own food and drink also comes with certain responsibilities and implications. Peter jokingly suggested that he would have chosen something healthier for Melissa, if it were his decision to make: "That's what happens when you get to buy your own lunch."

The topic of choosing the "right" food and drink was discussed much more explicitly by Elise and Irene. Elise herself shared how her mother did not like her buying certain drinks at TAFE. She, thus, experienced a tension between exercising her independence and following her mother's advice: "Okay, so why TAFE? …I love buying food, snacks, but not drinks, because mum hates me [buying drinks] – I do buy some drinks, but usually I buy food and other stuff." Irene explained in detail that she wanted Elise to make healthier and wiser choices regarding her diet. Irene exercised a degree of control over Elise's choices, stating that "I've gotten her off the drink". Significantly, this

point was introduced while Irene was speaking about the freedom and independence that Elise enjoyed at TAFE:

> So, she has to go to the canteen, and then choose what she wants to eat, and then buy a drink – but I've gotten her off the drink because she loves Coca-Cola. And we can't have it that she's drinking Coca-Cola all the time.

When Elise shared her perspective, there was an indication that she had been influenced by her mother to "not like drinks". She stated, "I usually buy a chicken wrap at the canteen. I usually go to the cafeteria. I usually buy food but not drinks. I don't like drinks when I'm at the cafeteria…"

Elise also spoke of how the commute to and from TAFE also presented her with an opportunity to choose drinks that she "loved": "I like, actually, drinks when I'm in Bondi Junction after TAFE. I love to buy Boost." On this point, however, Elise did not share the whole story, which included how she developed her decision making on when to buy or not buy Boost Juice. Irene explained how Elise also learnt to set boundaries and to assess how wise it was to spend her money on Boost Juice. Again, it was emphasised that having freedom and independence required Elise to develop her decision-making skills surrounding finances and drinks:

> [S]he used to buy a Boost very often… So, it's $8.10 for drink. But then, her friend started saying, "I'm going to save my money, so I'm not going to buy it…" So now, she says, "I'm not buying Boost anymore. I'm going to save my money."

A similar concern regarding making wise decisions on food was shared by Leanne. It was interesting that Leanne recounted an incident involving food choices, when she was asked the question, "Was there anything that Helen found hard about studying at TAFE?". The tension between intervening to

influence Helen's choices and allowing Helen to make her own decisions as an adult was discussed by Leanne:

> Oh, there was one little thing... [laughter] I got a phone call from Cassie, the friend who is a student support officer... [Helen] was using the vending machines and buying chocolate and stuff all the time. And we always have to watch Helen's weight... And [Cassie] goes, "I know she's an adult... But I thought you really would like to know that she's doing that." [laughter]

Significantly, Leanne perceived that this specific issue regarding food choices would not have arisen with her other children who do not live with Down syndrome: "We had to have a little talk about that... I wouldn't have imagined ever doing that to my other girls going, 'Oh, you know, it's not really a good idea to go using those vending machines.'"

In summary, people with Down syndrome developed their decision-making skills within further education contexts, particularly with regards to their dietary choices and use of money.

Developing problem-solving skills

During their time in post-secondary education, the participants with Down syndrome also grew in their problem-solving skills. The challenges that the learners navigated in further education included adjusting to a new environment, shyness, health issues, and learning difficulties. It was noteworthy that these issues were predominately talked about by the parents rather than by the people with Down syndrome themselves. The reasons could relate to their unwillingness to share about these challenges or their awareness of these challenges. Regardless, it was evident that people with Down syndrome developed their problem-solving competencies to handle these struggles.

The challenge of adjusting to a new environment when entering further education was faced by two participants. Although Helen lived in a small city on the North Coast of New South Wales, starting TAFE was still a very different experience compared to attending high school. Since her TAFE campus shares the site with a university and a senior secondary college, entering the campus was quite overwhelming initially: “She got off that bus, and there's all these people around. It would be a bit overwhelming for her.” With the support of a TAFE worker, however, Helen soon developed the confidence and ability to navigate the campus independently:

> The TAFE organised that the aide would be there to get her off the bus... but she only had to do that for a few times. Because the TAFE is quite a big campus... compared to what she'd had in high school. So yeah, it was just negotiating that. Helen can be quite shy in a new environment... But once she'd done it a couple of times with the aide, she was fine to do that herself.

Melissa, likewise, encountered the challenge of settling into a new learning environment. She experienced being lost on her TAFE campus, but this was also only during the early stages of her study. Not only did she learn to find her way around independently, but Peter also implied that she would be able to transfer those navigation skills to another learning context in the future:

> She got lost early in the piece at the campus. It's not that complex of a campus, but it's got lots of buildings with little laneways and things. But now, she knows her way around... And so, she's really feeling at home there. But hopefully, if she does do some further study, it'll be closer to home. She can get used to finding her way around another campus.

Another challenge that Melissa faced in further education related to shyness. On Melissa’s first day at TAFE, she was initially nervous to speak to the TAFE teachers: “I was a bit nervous to go up to the teachers.” She, however, soon

overcame this feeling, with the help of her father: “She hid behind me for a while, and then she started talking.” Despite experiencing shyness, Melissa’s overall perception of her first day was positive, reporting that she felt “Happy… to be in TAFE.”

Peeter explained that, generally, Melissa required time to get comfortable with people:
“There's always that little hesitancy. It takes a while to thaw, but once she's there – she's loving TAFE now.” At the same time, Melissa was described as having strong social skills, which were used to her advantage at TAFE “to win people over”:

> She's always having a chat with the woman who's in the classroom helping her and the teachers. She just seems to have an immense capacity to win people over. People will go out of their way to help Melissa. So, that's the magic she's got there.

Some participants, meanwhile, faced health challenges during their time in post-secondary education. As explained earlier, Elise had experienced ongoing health issues which resulted in her leaving high school before completion. These health problems remained a concern when Irene was investigating different post-school options for Elise. Discussing the question, “What is hard about studying at TAFE?”, Elise shared that her health challenges resurfaced, though she did not talk about them in great detail: “I sit still and listen… So, when my teacher says, ‘Stay at TAFE’ – So, if I don't feel good, I don't always do that at TAFE. So, I used to do that at school.” Irene explained the situation more clearly, adding that Elise was managing the challenges more successfully at TAFE than when she was in high school. With the social support of her TAFE teachers and friends, Elise developed a greater sense of resilience as a self-determined learner:

> So, one of the things was that, because she was so used to going to school – stay there for two hours, and then go to the office and say,

> “Look, I'm not feeling well” – that when she went to TAFE, she did the same… And then somehow, the teacher did a fist bump. “Have a fist bump” – solves all problems, apparently. [laughter]

With regards to health issues affecting the learning experiences of people with Down syndrome, it was found that a holistic approach needs to be adopted to address these issues adequately. Irene described the complex health needs that Elise had and how they have affected Elise’s learning: “So, zinc too low, iron too low, vitamin D way too low… And then, she was dehydrated. So, the fainting that she did was probably because she was dehydrated. And then, all the stress at school made her faint.” Significantly, self-determination on Elise’s part was required to address these health concerns. Self-awareness and communication skills were necessary for Elise to communicate her health challenges: “[S]he would keep saying to me, ‘Mum, my bones hurt…’ And I said, ‘No, Elise, it’s not your bones. It's your muscles.’ But it was her bones, because there was no zinc…”

Another participant, Adam, also shared how his TAFE experience was impacted by health issues: “Concentration. I tend to lose my concentration occasionally. Constantly falling asleep at odd times. That's when I found out I had sleep apnoea.” Adam also needed to act in a self-determined way, namely to recognise his learning problems and to take responsibility, to address the health issues causing those learning difficulties: “I didn't even realise, until I was tested, that I have sleep apnoea. Yeah… I didn't want to do [the test]. But, in the end, I ended up doing it. And I got over it.”

Finally, some participants with Down syndrome faced difficulties with the learning itself throughout their further education journeys. Although some learners shared struggles they experienced with their studies in further education, it was primarily the parents who explained the challenges with greater clarity. For instance, Helen initially shared that she did not experience any challenges at TAFE, but her mother intervened to explain that there was

one part of the learning which was “very hard” for Helen: “The till and the EFTPOS was the one thing that Helen failed in the first semester, and she had to redo in the second semester. So, it was very hard for her.” Through persistence and practice, as well as with support from a TAFE worker, Helen was successful in the second semester.

During her interview, Leanne shared that persistence and perseverance were qualities that Helen exhibited in other areas of life and learning: “When Helen's determined on something, she'll usually stick to it till she gets it.” Leanne recalled an experience in which Helen expressed her agency in taking responsibility for her learning by using effective learning strategies to navigate her TAFE studies: “[B]ecause it was hospitality, that's a very practical kind of thing. But like with the barista things, she did up little laminated cards with each of the different coffees: ‘This is how you make a latte.’”

In summary, people with Down syndrome developed their problem-solving skills within further education journeys with the support of their teachers and peers.

Conclusion

Self-determination featured in multiple ways in people with Down syndrome throughout their post-secondary education journeys. Acting in a self-determined manner, people with Down syndrome made choices and decisions towards VET and higher education. Owing to their unique interests and strengths, the participants had diverse goals for further study. By participating in further education, people with Down syndrome also grew in their self-determination, particularly in their independence, decision making, and problem solving.

Self-determination in the participants with Down syndrome, however, did not operate as an individualistic construct. Rather, the support of parents was

needed for further education choices to be enacted and fulfilled. Parents themselves needed to act with persistence and determination to overcome barriers that would have prevented their child with Down syndrome from accessing post-secondary education. In supporting self-determination, parents also played a redirecting role when they perceived the goals of their child with Down syndrome to be currently unsuitable. The self-determination of people with Down syndrome was also supported by stakeholders, such as teachers and peers, within further education fields.

To conclude, self-determination was found to be associated with an individual's dispositions and behaviours (as per the functional theory) and to be shaped by an individual's social contexts (as per the ecological and tripartite ecological theories). If it is understood as an individual construct, self-determination in itself on the part of people with Down syndrome was not sufficient for enabling further education journeys. The next chapter builds upon this conclusion by exploring how family and individual capital functioned to facilitate VET and higher education opportunities for people with Down syndrome.

Chapter 9: “It’s a bit of whom-you-know”

Findings on “capital”

Introduction

This chapter is the final findings chapter. It is divided into two main sections, with the first addressing the role of family capital in the further education journeys of people with Down syndrome and the second addressing the role of personal embodied cultural capital of people with Down syndrome in these journeys.

“Capital” has been discussed in several ways in the preceding chapters, particularly in the theoretical framework explained in Chapter 5. In this thesis, the idea of “capital” is derived from Bourdieu, the French sociologist. According to Bourdieu, social fields are sites of inequality, where different players possess different levels of capital to use to their advantage to acquire more capital (Wacquant, 1989). Fundamentally, Bourdieu (1986) uses capital as an explanatory tool to argue that some people have advantages to succeed in education fields, because they possess from their family backgrounds the norms and values (i.e. cultural capital) upon which education fields are established. Education systems are, therefore, not the meritocracies that they proclaim themselves to be, but are themselves sites for the reproduction of social inequalities (Bourdieu & Passeron, 1977). Chapter 2 of this thesis has drawn attention to some of the inequities that disadvantaged learners, such as those with disability, encounter in vocational education and training (VET) and higher education fields in Australia (e.g. Department of Education, 2024b; Parliament of Victoria, 2021).

There are three main forms of capital, namely economic, cultural, and social capital, which are all interrelated, as Bourdieu (1986) explains. Importantly, these forms of capital are transmitted, first and foremost, within the family context (Bourdieu, 1986). As the literature review has highlighted, people with Down syndrome whose family backgrounds are well resourced (financially, culturally, and/or socially) experience better quality of life and developmental outcomes (Alrayes et al., 2024; Channell et al., 2021). Importantly, having such family backgrounds also facilitates post-secondary education opportunities for people with Down syndrome (Casale-Giannola & Kamens, 2006; Hamill, 2003; Taylor et al., 2019).

Bourdieu's emphasis on biological bodies within his discussions on capital is useful for disability-related research (Edwards & Imrie, 2003; Gibson et al., 2007). Drawing from Bourdieu's (1986) concept of "embodied cultural capital", the theoretical framework in Chapter 5 has conceptualised "physical capital" (Bourdieu, 1978; Shilling, 1991, 2004), "behavioural capital" (Bourdieu, 1977b), and "linguistic capital" (Bourdieu, 1977a) as significant forms of cultural capital that can be used for disability studies.

This present chapter explores the interviews with people with Down syndrome and their parents through the lens of "capital". Two major themes are presented. The first theme examines the role of family capital in terms of economic, social, and cultural capital in facilitating further education for people with Down syndrome. The second theme analyses the role of personal embodied cultural capital in people with Down syndrome with respect to their physical, behavioural, and linguistic capital in VET and higher education journeys. The chapter emphasises that forms of capital operated in multifaceted ways in the further education experiences of people with Down syndrome.

Family capital

The findings in this first theme address the third sub-question in this thesis: How do different forms of capital (i.e. economic, social, and cultural) interrelate to enable post-secondary education journeys for people with Down syndrome?

The research has found that families' economic capital ("Certainly, we're not a wealthy family"), social capital ("We already had the contacts"), and cultural capital ("We were professional people") all played significant roles in enabling the participation of their children with Down syndrome in further education. Of the three forms of capital, however, it was cultural capital that was found to have the most effect on post-secondary learning.

"Certainly, we're not a wealthy family"

The research found that economic capital facilitated further education for people with Down syndrome in several ways. On the one hand, the families who were interviewed did not perceive themselves to be "wealthy". One mother, Melanie, stated emphatically that it was the family's cultural capital ("background knowledge") and not economic capital that shaped their child's (Renee's) success in university: "I think it was our background knowledge. We have not got lots of money, so it was certainly nothing to do with wealth." Similarly, Leanne considered that money had not played a significant role in her daughter's TAFE journey. Interestingly, whilst describing her family as being "not wealthy", Leanne was also aware that they would have the means to invest in higher education for Helen, should such an option arise:

> [C]ertainly we're not a wealthy family or anything. If she wanted to go away somewhere, it probably would have had a financial impact. [laughter] But it was just locally here. And I mean, the TAFE course was free, because she's always had a disability pension… University would have been more expensive, but it certainly wouldn't have been out of

> our ability to have been able to do it, if she had an opportunity for university.

The families who participated in this study did possess financial resources that were advantageous to their children with Down syndrome. The purpose of the findings is not to argue whether or not the participant families were "wealthy", but to show that economic capital may have operated in ways that were not immediately obvious to the families themselves.

Firstly, the family context in which the participants were brought up was not one of deprivation. The participants with Down syndrome did not have financial concerns that would have negatively impacted on their post-secondary studies. As Gina noted, her family's economic resources made it possible for her to devote the capacity she had towards her TAFE studies. Her family's financial support helped to mitigate challenging mental and physical health issues she experienced through further study: "They covered the finances and everything… They knew the struggles that I had. So, just getting a job and holding a job just to be able to have a phone and a car was hard enough."

The ability to lean upon the family's economic capital was explicitly identified by James, the father of Renee, as an "advantage" that Renee had over many other university students. As she did not have the financial pressure to focus on paid employment, Renee could complete her Bachelor of Arts over an extended period of time:

> She had, of course, an advantage over most other students in that she was only doing a quarter load… There's a heck of a difference [for] people who are doing four [subjects] and trying to earn money to keep a roof over their head and food on the table…"

Moreover, economic capital affected not only the duration of time that Renee could devote to her university studies but also the quality of those studies.

Having more time for each subject meant that she could study the content in depth: “So, Renee has had a distinct advantage of only doing one subject, which she could then explore at great length.” This advantage was crucial to her academic success.

Secondly, financial capital was found to directly facilitate the further education experiences of people with Down syndrome. For both Gina and Renee, being financially secure meant that there was money available to obtain much-needed supports that were not provided by their TAFE and university respectively. Importantly, Gina had not disclosed her disability to TAFE because she felt that she would have been “pigeonholed” rather than be supported by the system. (Gina has “mosaic Down syndrome”, which is where not every cell of the body has three copies of chromosome 21, meaning that her disability was perhaps not immediately noticeable to others.) Instead of accessing additional support through TAFE, Gina chose to pay an external tutor to assist with some of the practical and numeracy components of her course. Notably, Gina had already possessed a level of competency, but the paid tutor enabled her to maximise that competency:

> Outside of TAFE, I got a tutor to help me with some of the sewing components… There's a bit of maths in that. And she helped me out with a bit of pattern making as well and just fine-tuning my technique.

Similarly, Renee’s family used their financial resources to pay for mentors and tutors to assist with Renee’s learning. Throughout the university inclusion program, Renee had been supported by peer mentors who journeyed with her in both the academic and social aspects of university life. Once she commenced the foundation course, however, the university no longer provided such mentors. In response, Renee’s parents employed a mentor who sat with Renee in class and provided additional learning support in the library. Renee also received academic aid in the comfort of her home. Studying the course material at home allowed her to learn at her own pace

and, importantly, with the help of a paid tutor: “Most of the learning that took place was probably after she came home from uni, because then we would plug into the uni online session and we’d have… a tutor, who worked with her, who helped with the readings…” So, whilst her own cultural capital as a learner was essential to her academic achievements, Renee’s learning potential needed to be unlocked using economic capital. For both Renee and Gina, economic capital could be seen to act as a “multiplier” to their cultural capital.

Thus far, the findings have foregrounded the economic capital that the families possessed to support further education journeys. One family, however, indicated that the financial cost of further education can be prohibitive. After completing a Certificate III, Adam was not able to progress further in his formal learning, partly because it was perceived by his TAFE lecturer that the Certificate IV would be “intellectually beyond him” (a perceived lack of cultural capital). At the same time, there was also a financial barrier that limited Adam’s opportunity to study further. Kate explained that going beyond the Certificate III would come with a considerable financial cost:

> It was hundreds of dollars, when he was doing Certificate III… But in those multimedia classes, it went up to, like, $3000 to do a semester. Well, I couldn't afford to pay $3000 for something that I wasn't sure if he was going to use or cope with… I saw it as a valid way to spend money, because it was something he was interested in. But when it got to thousands for each unit – well, I couldn't [afford it].

It was not strictly the financial cost that was the primary issue, but the efficacy of spending the money on the higher-level courses. Kate strongly believed in the value of investing economic capital into Adam’s further education, but there was also a limit as to how much she could spend, given the uncertainty of whether Adam would have been successful in those higher courses.

Finally, families perceived that possessing economic capital within the family does not automatically guarantee that people with Down syndrome will reap benefits from that capital. This was the observation made by Irene, as she reflected on the many different families she had met through her work in a Down syndrome organisation. Drawing a contrast between herself and some other families, Irene explained that the fundamental issue is whether parents are willing to invest financial capital into the lives of their children with Down syndrome:

> Yeah, and before the NDIS [National Disability Insurance Scheme], it cost a fortune to get children to speech therapy and occupational therapy and stuff. But it's an investment, so we've always done that too. But I've seen parents with very high incomes not spend a cent on their child with a disability. It's not guaranteed, because you also see that parents go for their career. They work full-time, and they just get babysitters for their child with disability, and nothing comes from the child.

In summary, the families who participated in the research perceived themselves to be “not wealthy”, but they had access to financial resources that enabled their family member with Down syndrome to invest the necessary time and effort into further education. The participants with Down syndrome did not “buy” their post-secondary qualifications, but their economic capital enabled them to capitalise on their learning potential.

“We already had the contacts”

The research found that social capital enabled post-secondary learning journeys for people with Down syndrome, often in unexpected ways. The families in this research were well-connected members of society. The relationships that they had within fields such as education, work, and the general community all played key roles in the further education experiences of

the participants with Down syndrome. Compared to their perceptions on their economic capital, the families seemed much more aware of how their social capital was instrumental in their children's post-secondary learning journeys.

Some participants had prior relationships with relevant stakeholders within further education fields, which made their transition into further study easier. In Helen's story, social capital was accumulated through her VET experiences during high school: "I was first introduced to TAFE through school, which made it easy when I left school, because we already had the contacts." Her mother explained that the planning and decision-making process prior to commencing further study was facilitated by Helen's prior relationship with an important stakeholder: "[Helen's] best friend's mum is the Disability Support at the TAFE. So, she was quite comfortable to sit down with Cathy and talk about... what options there were." Helen's social capital gave her the advantage of receiving person-centred guidance from the disability support officer, who happened to be her school friend's mother. After she completed her hospitality qualification, Helen gained employment as a barista in a medical centre. This positive employment outcome was also made possible through social capital:

> One of the owners... he'd been Helen's doctor for years, since she was a baby... [T]hat's not how she got the job. It was through another friend who was doing a little bit of work there who said, "Have you ever thought of putting somebody on with a disability?" And that's how it all started.

Importantly, the research found that social capital did not operate on the basis of favouritism, pity, nor any other questionable motive. Rather, it could be said that the participants with Down syndrome "earnt" their social capital by way of their knowledge and competencies (i.e. their cultural capital). This was a prominent theme in Renee's story. Throughout her extended journey into and through higher education, each major milestone was initiated by a

significant player in the education field. Each of these stakeholders prompted Renee towards the next step of the university journey, because they identified in her the potential to progress higher in her formal learning: “That’s where the journey started, and it started by chance… Somebody saying something that we didn’t know anything about. Unexpected.”

Renee and her family themselves had not set goals nor make plans towards higher education. In other words, they did not act with self-determination in that regard: “It was never our intention that she learned at university. We never had that dream for her because we never thought it was possible. But it was what other people discovered about her…” It was, therefore, Renee’s cultural capital in the form of her academic potential and ability that prompted other people to suggest that she pursue higher education. Social capital did not operate in isolation from cultural capital in enabling Renee’s further education journey. Instead, social capital “multiplied” Renee’s cultural capital by providing her with more learning opportunities.

The interview with Peter, the father of Melissa, also brought out the significance of social capital. Melissa has a friend, Heidi, who is a year older and who also lives with Down syndrome. The two have known each other for over ten years. Being a slightly older friend, Heidi is also a role model to Melissa, and it was partly Heidi’s example that encouraged Melissa to pursue further education. The story of how Heidi herself accessed TAFE is important for understanding the role of social capital, as Peter recounted:

> Heidi… completed a Certificate II or a Certificate III in Admin at TAFE. And she got there via – it's one of those whom-you-know type things.
>
> So, Heidi's mum is involved with netball… And there's a woman involved with the netball who also works in the administration at [the Hunter Company]. She actually was working near me… And she also drinks at the local pub. So, we've got a bit of a connection there. But this woman, who was basically running the mail department… – she

> pushed her boss to provide for a traineeship for Heidi. And so, Heidi's been working [there]... So, in the process, she was also doing this TAFE Certificate in Admin...
>
> But it was an encouragement for us to encourage Melissa to go on with this as well... So again, it's a bit of whom-you-know.

There were two “whom-you-know” mechanisms at work, one being Melissa getting inspired by Heidi to pursue VET and the other being Heidi being supported by a lady from netball to gain the opportunity to have a traineeship, which led to her studying at TAFE. Significantly, the netball lady held a prominent position within the Hunter Company in that she was “basically running the mail department”. This lady made use of her professional identity by “pushing” her boss to offer a traineeship for Heidi. Incidentally, Peter also had some professional and social connections to the netball lady.

This highlighting of social capital was not an isolated occurrence in Peter’s interview. In fact, throughout Melissa’s whole life, the social connections her family has had in many different spheres have profoundly shaped who Melissa is today. It may be impossible to determine how each connection has affected her post-secondary learning journey specifically but they, undoubtedly, have had a cumulative effect.

Before Melissa was born, her family had already established important social connections through their own schooling and employment. These networks unexpectedly gained new value when Peter and Lauren found out that Melissa would be born with Down syndrome. The fact that the family went against other people’s expectations to terminate the pregnancy could largely be credited to the conversations they had with people in several networks:

> So, we found out quite early in the pregnancy that Melissa had Down syndrome... But we were lucky to be able to take advice from some friends. One of Lauren's schoolmates was working as a genetics

> counsellor at that stage. I was [previously] working in… the College of Advanced Education… with their special education unit… so I was able to talk to them about things.

The family's social capital became valuable again when Melissa started primary school. Many members of the primary school staff were previously known to Lauren and Peter from their prior education and work. Peter attributed Melissa's schooling success partly to these prior connections: "And so, all the way through school, she did very well." Firstly, Peter had a prior relationship with the school principal, who himself had had experience of including learners with disability prior to Melissa attending:

> The school had been very good. It was actually an acquaintance of mine who was the principal… He previously made some accommodations for a child who was in a wheelchair… So, by the time Melissa got there, there had already been a couple of kids with Down syndrome…

The school environment in which Melissa entered was, therefore, a supportive one. She also had the advantage that her parents had had some prior relationships with her teachers. Another advantage was that the field in which her schooling occurred was small and close-knit. Being in a smaller city in New South Wales meant that "everybody knew everybody". Her parents' professional backgrounds further broadened and strengthened the family's social connections within the education field. Knowing Melissa's teachers was particularly advantageous because the teachers themselves possessed cultural capital in that they were good teachers: "[A]s I say, we were lucky. We had teachers whom we knew whom we knew also were very good at their job."

The importance of having social capital continued into Melissa's post-secondary journey. Melissa's entry into TAFE was facilitated by her family's social capital. Again, by "chance" and "luck", her father happened to know some key personnel within the Hunter TAFE system: "As it turns out, the

woman who heads up the disability unit in TAFE used to previously work in the university when I was there…" Peter perceived that it was this personal connection that made Melissia's transition into TAFE straightforward:

> I had made phone calls before I knew this woman was there. And they had registered Melissa's interest, so they knew that she was in the pipeline… [I]n terms of going forward, I think it was the people we knew who got us there rather than the system itself.

Melissa may have been able to access disability support more quickly because of Peter's initial connection to the disability unit: "And because TAFE Disability Services came on board quite early in the piece and had provided an in-room support for Melissa at every lecture…" It should, however, be acknowledged that many participants spoke of TAFE as being a supportive learning environment, so Melissa presumably would have received support regardless of her father's prior connection to the TAFE disability services staff member. Nonetheless, her family's social capital likely enhanced the efficacy of the support provided.

Although Peter often credited many of his family's personal connections to "luck" or "chance", it was evident that his family had invested time and effort into cultivating those relationships. Social capital was accumulated and maintained by Melissa and her family through a range of social practices. The existing relationships with Melissa's teachers needed to be continually nurtured: "We had teachers whom we knew… [W]e nurtured and encouraged that all the way through. We always made sure that people got positive feedback…" Working to establish positive social connections to stakeholders within education fields had been a lifelong labour: "That's the game we've been playing since preschool… Always writing that letter and congratulations to the teacher who's done well…"

In addition, Melissa herself was described as being capable of accruing her own social capital. By being an amiable learner, which is a type of cultural

capital, Melissa nurtured positive relationships with teachers who became more inclined to support her: “Melissa developed a bit of a reputation going through school as being someone lovely to work with, so people weren't afraid to work with her. I think that was very much to her benefit.” Furthermore, Melissa was portrayed to have a kind of “magic” in being able to build rapport to gain support: “She just seems to have an immense capacity to win people over. People will go out of their way to help Melissa. So, that's the magic she's got there.”

In summary, the families in this research were well-connected members of society. People with Down syndrome who had access to social capital because of their family backgrounds were at an advantage in that they were able to access and participate in post-secondary education more easily. Families’ social networks within education and employment fields greatly facilitated post-secondary learning for the participants with Down syndrome. Furthermore, social capital provided greater advantages when the people within one’s social network had forms of capital which were relevant and valuable within education fields. Notably, social capital was found to operate not on the basis of favouritism towards people with Down syndrome but on account of the cultural capital that people with Down syndrome themselves possessed. That is, important players within further education fields believed that people with Down syndrome demonstrated the potential for further study and so facilitated them to access those learning opportunities.

“We were professional people”

The research found that cultural capital was the most important form of capital in facilitating the post-secondary education journeys of people with Down syndrome. Although economic and social capital both enhanced cultural capital, they alone did not secure access to further education opportunities. Cultural capital on the part of individuals with Down syndrome themselves and from their families were both required for post-secondary

learning journeys. Families perceived that being well educated and having a professional background were vital resources that enabled their children to be included in mainstream education fields, including that of post-secondary education. As Melanie explained, parents need both knowledge and confidence to advocate for their children:

> The other advantage we had… was that we were not afraid of authority… Because if you are in any way afraid of authority, you can't make those overtures. You can't challenge people… One of the major assets that we had was our security as people… We were professional people. We knew what we were talking about.

The importance of cultural capital has already been noted in relation to economic and cultural capital. Melanie emphasised that it was her family's cultural capital and not economic capital that enabled Renee's university experiences: "I think it was our background knowledge… [I]t was certainly nothing to do with wealth." The financial resources that the family used to support Renee's learning were effective only because Renee herself possessed potential for academic study. Economic capital did not operate in place of cultural capital, but it maximised the cultural capital that already existed. The social networks that were established within higher education fields also came about because of Renee's cultural capital. That is, key stakeholders prompted Renee to pursue university because they had identified her potential for such study.

The centrality of cultural capital has also been identified in Melissa's story, which was analysed earlier. Melissa was noted to possess cultural capital in that she had a pleasant disposition, which helped her to gain the support of TAFE teachers and other stakeholders (i.e. social capital). Moreover, Melissa's parents both had prior connections to many of her school teachers, as well as a TAFE disability support worker, which were derived from their own education and professional backgrounds.

Families' cultural capital has been found to shape the development of the participants with Down syndrome in several ways. Renee's parents noted that their professional backgrounds facilitated Renee's learning from a young age: "Both James and I were trained youth and community workers, so we were in the mindset of teaching… So, when Renee was born, we had that asset." Reflecting on her learning strengths and interests, Renee positioned herself as a "researcher". Melanie believed that Renee's desire to learn and conduct research was borne out of her childhood experiences in being regularly exposed to the world around her: "Where that [interest in research] came from, I don't know. Clearly, it comes from when she was very tiny… Somebody had said to me, 'You need to show her a new thing every day.' So, that was my task." The academic practices that Renee later used to steer her to success in higher education were, therefore, shaped by her childhood learning experiences.

The parents in this research also placed importance on developing the self-determination and independence in their children with Down syndrome. The families intentionally raised their children in ways that might help them develop self-determined dispositions. As Irene shared, this involved building up their independence and not treating them as passive care-receivers: "I am different from most parents. I find that most parents… are very much focused on 'Who can look after my child?' I'm more like: First, I look at what Elise wants to do." Jessica spoke of developing self-determination in David by teaching them self-regulation: "[H]e's had consequences like his brothers did if he was misbehaving or whatever – just teaching him to do the right thing." Such approaches to parenting were attributed to the parents themselves being informed on issues to do with raising children with Down syndrome: "[O]ur background had a great deal of influence on where Renee is today. [W]e knew we had to put that effort into her if she was going to have any sort of life that was meaningful for her."

The post-school aspirations that families had for their children with Down syndrome were also shaped by families' cultural capital. Because they themselves were well educated, parents expected that their children would participate in further education. Kate shared that Adam's desire to study in higher education had been shaped by their family background: "The fact that his three siblings all went to university, that my husband and I studied at university. It was just a normal thing. We expected the children to go to university."

Yet, it was also found that even with their "high expectations", parents did not perceive that their family member with Down syndrome could participate in higher education. Although Renee completed a bachelor's degree, her parents initially did not think that it would be possible: "It was never our intention that she learned at university. We never had that dream for her because we never thought it was possible..." It could be said that, even for parents with high expectations, there was still a prevailing belief that there are limitations on what people with Down syndrome might be able to achieve, namely that university would be too out of reach ("a big leap, really"). This sentiment was shared by other parents, including Kate ("I can't see it really happening") and Leanne ("I don't think she could realistically get full nurses' qualifications.")

Nevertheless, the parent participants held positive aspirations towards their children's post-secondary learning. On the one hand, people with Down syndrome were perceived to make self-determined decisions to pursue further education. Significantly, on the other hand, those choices had been strongly influenced by their family ecology. As Philippa shared concerning Sherry, "Because her brother and sister had been to uni, so it was just natural for her that she should go. It was entirely her, 'Well, that's what I'll do next.'" The decisions were self-determined ("it was entirely her") but also socialised

to the extent that the participants with Down syndrome thought of them as being the “normal” or “natural” post-school transitions.

Families’ cultural capital directly facilitated the post-secondary learning journeys of their children in important ways. Firstly, their education and professional backgrounds made it possible to navigate further education systems so that their family member could access learning opportunities. Speaking of Adam’s entry into VET, Kate shared, “it was lucky for him that I was in that field”. Adam had an advantage in that Kate was a TAFE teacher herself, meaning that she possessed both knowledge of and connections within the TAFE system:

> [B]ecause I was in TAFE, I could find the courses. It was almost impossible to find them. The TAFE system… is very complicated. And unless you know what you want to study and you type in the right words, you can't find the course. But because I was behind the scenes, I could ring up somebody over in another TAFE and say, “Look, what do you have there for people with a disability?”

Being a VET trainer herself also provided Kate with the ability and confidence to advocate for Adam’s inclusion within TAFE. Recall that Kate had to defy the rules of the system to enrol Adam in a course that was not normally open to people with disability many years ago: “I just enrolled him anyway and I didn't put that he had a disability.” Additionally, her professional background made it easier to speak with Adam’s TAFE teacher about his inclusion: “So, I turned up at the class with him, and spoke to the lecturer and said, “Look, he wants to do this… Contact me if there's a problem.’”

Other parents also reported that “not being afraid of the system” was a key asset that enabled them to advocate for their child with Down syndrome. As Peter explained, “Melissa’s just fortunate in one respect… [I]if parents know a bit about higher education and bureaucracy, and we're not daunted by the spectre of all of that.” Peter himself had had experience working in further

education systems, which provided him with relevant knowledge to navigate those fields to Melissa's benefit. Similarly, Irene reported that her background as a legal auditor equipped her with the confidence to navigate the barriers she encountered when exploring VET options for Elise: "[T]he things that happen and the way organisations work – it's unbelievable. People who do not know the system – they would be so overwhelmed with everything that's going on." As explained in the previous findings chapter, Irene needed to exercise her own self-determination in the face of structural barriers to find a suitable VET course for Elise.

The second way by which families' cultural capital facilitated post-secondary learning in people with Down syndrome was by supporting their learning in the home environment. Well-educated parents held not only an optimism towards the post-school learning potential of people with Down syndrome, but they also invested time into reinforcing their children's learning in the home setting. For instance, Renee's parents were thoroughly involved in her university studies. Firstly, they approached her lecturers to ask for permission to attend the lectures so that they could revise the content with her at home: "[Us] stepping in as her parents created that learning at home… We talked about it together, and so we were able to help her go deeper into those topics." There was synergy between Renee's learning ability and her parents' learning support. Renee had the potential to develop a deep understanding of the content in her university foundation course, but that potential could only be realised through her parents' hands-on support. Along with her peer mentors and home tutors, Renee's parents became part of her "learning community".

The research also found, however, that parents differed in the degree to which they were involved in their child's learning. Families seemed to be less involved when the person with Down syndrome was studying in VET compared to if they were studying in university. Parents have reported that, when asking

about VET homework and assignments, their children with Down syndrome said that this work is completed at their college (“‘Oh, I do those in the class.’”) It has also been heard that TAFE colleges usually provided adequate support to learners with Down syndrome in relation to their assessment tasks (“That's plenty of time for the teacher, the tutor, to give her what she needs for whatever assessment task…”) This might explain why families did not appear to be intimately involved in their child’s VET studies. Moreover, because of communication issues with their child or other barriers, parents may have had little insight into the specific details on their child’s VET studies: “I'm not getting a lot of information. Because when I say, ‘So, do you like it at TAFE?’ She goes, ‘Not really.’” These statements contrasted to those of Renee’s parents, who were intricately involved in her university learning.

Summary of family capital

The parents who participated in this research were well educated and had professional backgrounds. Families’ cultural capital facilitated the post-secondary education journeys of people with Down syndrome in multiple ways. Parents were found to hold expectations that their children would participate in further study. They navigated complex further education systems so that their children could access post-secondary learning. Additionally, they supported their children by reinforcing their learning in the home context. The cultural resources that families had access to were in addition to the financial and social resources that they also possessed. Although economic, social, and cultural capital all operated in unison to enable further education opportunities, cultural capital was found to be the most important capital. Whilst economic and social capital did not in themselves activate post-secondary learning journeys, they did enable people with Down syndrome to multiply and capitalise on the cultural capital that were already possessed.

Given that cultural capital is indispensable for post-secondary learning, it is afforded specific attention in the next section of the findings. In particular, the role of personal embodied cultural capital in people with Down syndrome in enabling further education is examined.

Personal embodied cultural capital

The findings in this section focus on the idea of "personal embodied cultural capital" to address the fourth sub-question in the thesis: How does embodied cultural capital in people with Down syndrome facilitate further education opportunities?

The research has found that the physical capital ("Every part of me hurt"), behavioural capital ("She's ready for the real world"), and linguistic capital ("You need a comma there, mum") of the participants with Down syndrome shaped post-secondary learning in complex ways.

"Every part of me hurt"

The research found that the physical capital of people with Down syndrome influenced further education journeys in several ways. Engaging in post-secondary education as an embodied activity differed between the participants with Down syndrome. These differences were due to the reality that living with Down syndrome is unique to each individual. As one participant with Down syndrome explained, "It's different for everyone". Whilst physiological impairments related to Down syndrome were found to impact on further education experiences, they also provided opportunities to the participants to develop their perseverance as post-secondary learners. Their physiological bodies acted, therefore, as forms of physical capital.

Health issues related to having Down syndrome impacted specifically on Elise's education experiences. As discussed in the self-determination

findings, Elise had had ongoing health issues that eventually led to her mother taking her out of high school before completion. Irene described that period of Elise's life as one where "everything was out of balance" and "nothing worked". Elise faced numerous physiological challenges: "So, zinc too low, iron too low, vitamin D way too low… And then, she was dehydrated… And then, all the stress at school made her faint." Elise's health conditions, including hypothyroidism, affected her engagement with school and everyday life: "[S]he would do always school and something after school. But then when she got very tired… and her thyroid was no good, she could only do school, and that was it."

As the transition to post-school was being planned, Elise's physical needs had to be considered: "It's so complicated with the health issues…" Elise began her TAFE Certificate I soon after she left school, but some of her health difficulties persisted. She did, however, explain that she was managing them better than at school, and she was not missing days at TAFE: "So, when my teacher says, 'Stay at TAFE' – So, if I don't feel good, I don't always do that at TAFE. So, I used to do that at school." Irene, nevertheless, pointed out that Elise's health and well-being needed to be continually monitored: "She's never 100% that she can go for something. She's been pretty good lately. She can go to TAFE and do something after TAFE… She's got the energy, but how much energy?"

Several other participants described how issues of embodiment and impairment impacted on their post-secondary education and employment. General tiredness and fatigue associated with Down syndrome were notable in the experiences of Melissa and Adam. The transition from high school to TAFE meant new and longer daily routines for Melissa. Her father explained, "[It was] a bit of a shock… TAFE runs from 9 till 5 or 5:30, whereas with school you're home and hosed by 3:30. Melissa did tire in the afternoons. Sometimes, she had to go out for a walk…" In an assessment support class

for people with additional needs, Melissa's mental and physical energy were also tested: "Melissa really tires after about an hour and a half. That's plenty of time for the teacher, the tutor, to give her what she needs for whatever assessment task…" In Melissa's case, tiredness at TAFE was managed by going for walks and being accommodated to by TAFE teachers.

Tiredness was, likewise, a factor in Adam's TAFE experience. In his case, however, the fatigue was compounded by having sleep apnoea, a common condition in Down syndrome. Adam shared what he found difficult during his TAFE learning: "Concentration. I tend to lose my concentration occasionally, constantly falling asleep at odd times. That's when I found out I had sleep apnoea." The issue was not limited to his time at TAFE, but it also occurred at work, where his colleagues were often saying to him, "'Stop falling asleep, stop falling asleep' all the time."

The topic of health was a major theme in the interview with Gina. Not only had she "fought through" various health issues of her own, but Gina also worked as a health ambassador within a Down syndrome organisation. Her role involved supporting people with Down syndrome to understand health issues, as well as raising awareness of such issues to people outside of Down syndrome communities. In this, Gina's impairment functioned as physical capital in helping her to gain this employment on the basis that she "can articulate that lived experience so well". She shared what living with Down syndrome meant in her lived experience: "I definitely know how it feels to live with thyroid conditions and gut issues and intellectual disability."

Gina experienced serious health issues that affected her secondary and post-secondary learning: "Looking back, I know I was in severe depression and had anxiety even in high school and then going into TAFE… I don't how I fought through it." Gina perceived that her learning "capability" had been impacted by physical and mental health issues: "I would love to see my capability now, as opposed to where I was after I finished high school, with tertiary, because I

was extremely sick at the time with undiagnosed health concerns with Down syndrome…" While she persisted through these challenges and completed a TAFE Diploma, health difficulties caused her to cease studying an Advanced Diploma when she was two subjects short of completion:

> I got really sick… And like it was the worst point in my life. I don't know how I got through my tertiary studies, to be honest… Every part of me hurt. And I was going through undiagnosed celiac… So, I had the terrible brain fog…

In summary, the embodied lived experiences of people with Down syndrome in further education and other areas of life were varied. Health issues had complex effects on post-secondary learning experiences, ranging from less severe to more severe. Regardless, the participants with Down syndrome developed ways of managing these effects and were not necessarily prevented from participating in further education because of these impacts. Therefore, people with Down syndrome have been found to be "fighters" in that they persevered through their physiological challenges to participate in post-secondary education. Their bodies functioned, therefore, as physical capital in that they provided opportunities to grow in resilience and self-determination.

"She's ready for the real world"

The research found that behavioural capital in people with Down syndrome was a significant enabler of post-secondary education journeys. Behavioural capital entailed the ability to conduct oneself within "real-world" education fields. This cultural capital was framed around qualities of a "good student". Mainstream education settings were perceived by parents to be the primary field in which people with Down syndrome acquired this embodied capital.

Families strongly expressed that mainstream education was the ideal form of schooling for people with Down syndrome. Parents, such as Melanie,

advocated their children's inclusion in mainstream education fields: "We had many, many battles to ensure that she stayed in the mainstream, because the mainstream was where her most valuable education was. It wasn't off in the special school, which is what people all insisted…" Mainstream education was perceived to be "more valuable" than specialist schooling, because it affords opportunities for learners of all backgrounds and abilities to engage in life together. Peter argued that inclusive schooling benefits all learners, not just those with disability: "It's bloody logical, you'd think. If you separate kids out during their education process, they will never know what it's like to be among society, and society generally won't know what it's like [to include people with disability]."

Specifically, parents reflected that mainstream schooling enabled people with Down syndrome to acquire a form of cultural capital that is vital for participating in further education. A particular way of being was believed to be required for VET and higher education. The interview with Leanne especially brought out the importance of mainstream education for developing behavioural capital. Helen, her daughter, had attended a mainstream Catholic high school. Leanne was a strong advocate of mainstream schooling, and she would often advocate for other families to have their children with disability included in mainstream schools. According to Leanne, people with disability attain different developmental outcomes depending on whether they attended mainstream or specialist schools: "I can certainly see the difference in the other people with disabilities who've gone to the [special education] units."

Leanne recounted a time when she had accompanied a friend to a workplace that offered supported employment, as her friend's son was seeking employment there. The son had attended a support unit in school, as opposed to a more mainstream inclusive context. During the workplace visit, the employer asked Leanne about Helen's schooling and post-school plans.

Since Helen had attended a mainstream school, the employer said, “she’s ready for the real world”:

> And the guy there asked me, “So, you've got a daughter leaving school too? …So, where is she at school?” I go, “St Peter’s College.”
>
> He goes, “Oh, so mainstream? …This isn't the place for her. If she's managed to negotiate a mainstream high school, then she's ready for the real world.

The employer explained how, in his opinion, the supported employment environment differed to “the real world”:

> The biggest obstacle we have – We train these guys up to put them into paid employment, in open employment. And they can't cope, because they're not used to the real world. They're not used to their workmates, and the jokes, and how to negotiate real life.”

The employer perceived that people with Down syndrome who have navigated mainstream education develop the necessary cultural capital for negotiating other real-life contexts. Being resilient and coping with real-world challenges were thought to be benefits gained from mainstream schooling. Leanne herself gave the example of managing difficult relationships within mainstream schools: “They have to learn to negotiate the fact that not everybody's nice and not everybody wants to be your best friend… It's the real world.”

Another example she highlighted was related to Helen’s resilience and self-determination as a learner: “Helen's always been very determined in that she will stick with something until she's got it. At school, she never gave up on things.” The determination and resilience which Helen had gained from her mainstream schooling became a key resource throughout her TAFE studies. Helen did not allow the discouragement of failing a subject to cause her to give up: “Yeah, the till and the EFTPOS was the one thing that Helen failed in

the first semester, and she had to redo in the second semester. It was very hard for her." Leanne explained that it was through "lots and lots of practice" with the support of TAFE teachers that Helen eventually completed the unit.

Importantly, Leanne implied that acquiring behavioural capital in mainstream education was potentially more important than acquiring academic capital (if one had to choose). Leanne has another daughter with Down syndrome, Tara, who was adopted from a South Asian country. An interesting comparison between Helen and Tara was made by Leanne concerning their learning profiles. Tara was perceived to have less developed academic and linguistic skills than Helen at the same age:

> [Mainstream education] was a no-brainer with Helen, because Helen just fitted into school so well. She had a level of capability. For Tara, she went to high school with very limited language, very basic reading ability, and barely able to even write her name. So, we really struggled with that, whether a mainstream high school was the right place for her...

Although there was initially some concern that mainstreaming secondary schooling would not be the right fit for Tara, the family reflected on it as being "the best decision". This was because mainstream schooling enabled Tara to develop skills for thriving in "the real world":

> And two and a half years into Tara's schooling, it was still the best decision. She's well loved. She loves to go to school. And it really isn't so much about the academics for her, but it's really about being able to cope in a real-world situation.

Significantly, Leanne valued different aspects of schooling in contrasting ways. Whilst behavioural capital and linguistic capital are both important, Leanne implied that, at least in Tara's case, acquiring the former was of greater importance. Tara's linguistic capital was somewhat limited, but this

did not seem to impact negatively on her mainstream schooling experience. Linguistic capital was, therefore, not the only form of cultural capital that was valued in mainstream education, nor was it the only capital to be developed through mainstream schooling. Cultural capital in the form of a resilient way of being appeared to hold greater "real-world" currency than the linguistic capital commonly tied to schooling and academic learning.

In addition to determination and resilience, another closely associated form of cultural capital that was emphasised in the interviews related to "good behaviour". It was perceived that a particular way of being and behaving was required of people with Down syndrome who wished to participate in mainstream post-secondary education. Knowing how to behave in a socially and culturally appropriate way facilitated access to further education.

Adam was one individual for whom being a "good" learner enabled him to participate in post-secondary learning. Interestingly, Adam had portrayed himself as a kind of troublemaker, saying that "apparently, trouble follows me around, really, such a heat seeker". Within his TAFE classes, however, Adam caused no such trouble for his teachers and peers. In fact, his classroom behaviour surpassed what was probably expected of learners with disability some two decades ago. Kate described the time when she enrolled Adam in a TAFE course that was normally closed to people with disability. Adam's conduct functioned as the ticket that allowed him to stay within his preferred course: "The lecturer said he was no more difficult than the other kids in the class. And they just were really supportive."

Another parent, Irene, similarly spoke of the value of "good behaviour" when she described what was expected of Elise as a learner at TAFE. In order for Elise to enrol in TAFE after she left school early, TAFE wanted her to complete a Statement of Attainment to demonstrate that she could behave as a "good student" in class: "[TAFE] want to see if they can be in a group, if they can listen to the teacher, if they behave properly." Irene responded to TAFE by

arguing that, since Elise had attended a mainstream high school, Elise would not display any "behavioural issues" in class:

> I said to [TAFE], "Well, I can get it from school… She's been through mainstream school, so there's not going to be any issues at TAFE. She knows how to behave, and how to fit in, and not to make trouble." So, [TAFE] did skip that part, and they put her straight in the course…

Irene further explained that, without the cultural capital associated with being a "good learner", people with Down syndrome would likely face being excluded from further education contexts:

> And that's why [TAFE] had the Statement of Attainment, so that they must be at the level where they can sit through the day. They can learn at that level. So, I think you wouldn't get in, if you have behavioural issues or something. So, they're really being assessed for that.

With regards to acquiring behavioural capital during schooling, a comparison between mainstream and specialist education was drawn by another parent. Jessica's son, David, had had experiences in both mainstream and specialist schools. Jessica observed how classroom behaviour was one of the key differences between the two settings:

> It was good for [David] to be in [a mainstream school] in a bigger classroom and experience that different sort of thing. Because I find that at his specialist school, if the kids don't want to do something, they're not going to do it. They don't care who they're pleasing or anything whereas, at the mainstream school, the kids always want to please the teacher… So, first on the mat, sitting up straight, all that sort of stuff. So, he learnt about that as well.

Jessica, nonetheless, also stressed that the home environment has played a key role in shaping David's conduct: "[H]e's had consequences like his brothers did, if he was misbehaving or whatever… So, Down syndrome is an

extra chromosome. That doesn't mean he's silly. He understands.” Importantly, having Down syndrome was not to be taken as a reason for not following social norms around behaviour. Jessica reflected on how David knows how to behave in socially appropriate ways: “I'm proud of how he conducts himself out in the community. He's very respectful of others… He behaves a lot better than some other people.”

To summarise, parents viewed appropriate conduct and behaviour as forms of cultural capital that are essential for people with Down syndrome to participate in mainstream post-secondary learning contexts. The acquisition of behavioural capital occurred, in large part, within mainstream education in primary and secondary schooling. In mainstream contexts, learners with Down syndrome developed skills and behaviours for coping in other real-world environments, like those of VET and university. Being a “good student” was perceived to be a key asset that shaped further education opportunities for people with Down syndrome.

“You need a comma there, mum”

The research found that linguistic capital had varied effects on the post-secondary learning journeys of people with Down syndrome. Broadly speaking, traditional literacy and numeracy learning were found to be a potential barrier to participating in further education, especially university. It was, however, also found that people with Down syndrome have forms of linguistic capital which are sometimes not immediately recognised within further education fields.

From a traditional understanding, literacy and numeracy posed challenges to people with Down syndrome studying in further education. A traditional understanding of literacy and numeracy as school-based cognitive skills often featured in the interviews. Literacy was commonly understood to be a skill that needed to be “mastered”. As Leanne explained, some parents want their

children with Down syndrome “to continue learning those skills that they hadn't quite mastered when they were in the school system”. Jessica perceived that having less developed skills and interests in traditional literacy would be barrier to participating in further education:

> [David] doesn't love reading and writing. He's never loved that. It's always been quite difficult. He engages a little, but then he turns off after a little while. You asked the question about TAFE. I could not see him attending TAFE right now…

Although she thought that it would be unlikely for David to enter VET immediately after finishing high school because of his perceived disinterest in reading and writing, Jessica was also hopeful that he would acquire this form of linguistic capital: “We're gonna still keep trying with reading and writing… I can see him learning it properly eventually. As I said before, I never say ‘never’, and [you’re] never too old to learn.” The refrain “Never say ‘never’” echoed several times when Jessica spoke of a range of different areas of David’s life.

The issue of not being able to progress further in one’s formal education because of a perceived lack in linguistic capital was also shared by another participant. Being 39 years of age, Adam had already attained several TAFE certificates, including a Certificate II in Media Studies and a Certificate III in Multimedia. Having gained these VET qualifications, Adam wished to go further by gaining a university degree. His goal was to develop video games for PlayStation. He was aware, however, that his academic literacy was not at the level required for university. This issue of not having a particular type of linguistic capital for higher education was elaborated on by Kate, his mother: “[A]t the end of Certificate III, one of the lecturers said, ‘He's not going to be able to cope with higher levels. And it’s not really fair on him or the lecturers to enrol him in a Certificate IV.’” Essentially, the TAFE lecturer had adopted a traditional understanding of literacy and numeracy as cognitive skills that are

acquired within academic contexts. From their perspective, literacy becomes more and more tied to intellect and cognition as one goes higher in their formal education. Not only did Kate agree with the lecturer on this point, but she also perceived that the teaching and learning practices privileged within higher education fields would pose challenges to Adam's participation:

> And also, at [university], they said they have eight hours of lectures. And for every eight hours of lectures, they expect you to do 16 hours of self-study. Well, there's no way Adam… I could see that that was going to be a problem as well.

Although it was common for people with Down syndrome to find difficulty in traditional literacy and numeracy learning, the research also found that at least one participant with Down syndrome displayed "excellence" in their academic literacies. Throughout her journey through higher education, Renee had many opportunities to develop her academic skills. Although her primary interest was in drama and the arts, Renee was successful in a university foundation course that targeted conventional academic literacies. As her father explained, the contents of the course were more aligned to traditional literacy and numeracy skills: "They covered… two categories. One was… the sort of English and writing and comprehension… The other was in terms of more scientific mathematics…" Throughout her university journey, Renee developed her academic literacy by learning to read academic texts and "translating from the academic to languages she can understand". Furthermore, she produced academic texts that were thousands of words in length to fulfil assessment requirements, which were all consistently graded highly by university staff.

As explained earlier, Renee's disposition towards learning and research had been shaped by her family's cultural capital while growing up. When she was asked in the interview how she felt about learning, Renee positioned herself as an enthusiastic learner. Specifically, she thought of herself as a

researcher: “Okay. I like to learn, yes. But mostly, I like to research. I choose the research way to get me information that I need and want, sometimes out of interest or because I am instructed to.” Her academic skills, especially in research and writing, enabled her to succeed in her university degree.

Moreover, Renee’s success at university could be credited to the fact that she was able to study university subjects that she had prior knowledge and interests in. The two areas of knowledge that especially excited Renee throughout schooling and university were related to the arts and Indigenous Australians. Her knowledge formed part of her cultural capital, which she capitalised upon by choosing related subjects within her Bachelor of Arts. As her mother explained, “She never ever was saying, ‘I'm going to get a degree.’ She was saying, ‘What am I going to study next? …I think I'll look at Stanislavski this term, mum. That looks interesting.’”

Since graduating from university, Renee has still been engaged with literacy learning and development. In her work with a theatre company, Renee attends a weekly writing program where she produces poetry, stories, and other texts. From all her post-secondary learning experiences, both formal and informal, Renee has accumulated linguistic capital to the extent that she is able to correct her mother’s writing. Melanie shared with much joy one example of being instructed by Renee in the use of punctuation: “When she’s reading something that I’ve written, she’ll say things like ‘Oh, you need a comma there, mum.’ Which is lovely… because she’s got the pattern of it.” In other words, Renee had acquired particular social norms around using language (“the pattern of it”) because of her opportunity to access higher education. Renee’s parents perceived that not everyone with Down syndrome has the opportunity nor potential to complete higher education (“part of her is a bit of an oddity”).

Unlike Renee, it could be said that the participants with Down syndrome generally faced difficulty with traditional literacy and numeracy learning but

had strengths in multiliteracies. Moreover, their skills in multiliteracies enabled them to engage in a myriad of post-secondary learning opportunities. People with Down syndrome were found to have studied diverse courses, including hospitality and animal studies, across TAFE contexts. Post-secondary learners with Down syndrome experienced increased motivation when given the opportunity to engage their strengths in multiliteracies.

For instance, Adam's initial experience of further education was a challenging one. At the completion of high school, Adam had little interest in and struggled with traditional literacy and numeracy learning:

> So, with TAFE, when he left school, the system was very rigid... [T]his was like 20 years ago. He could only enrol in courses for people with a disability. And they were always incredibly boring and not anything he wanted to do, like literacy and numeracy. Well, he had no idea about numeracy, anyway. A thousand, to him, is the same as ten... So, he wasn't very successful at those...

Several factors made Adam's initial TAFE experience unsuccessful. One was the lack of choice due to structural issues of the TAFE system at that time. Another factor was that Adam was not motivated to continue with conventional literacy and numeracy learning. Additionally, his learning ability was not aligned with those traditional TAFE courses, with numeracy singled out as being especially difficult.

The turning point in Adam's post-secondary learning journey came when he enrolled in TAFE courses aligned to his interests and strengths. As Kate explained, "He never liked the literacy and numeracy courses. There was no motivation there. But once he got into drama or music or artwork, he was very regimented." Once his interests in multiliteracies were engaged, Adam went from being a seemingly "disengaged learner" to successfully acquiring Certificates II and III in media studies. Adam spoke with excitement about learning games design at TAFE: "They also showed me how to use a tool that

you can get on a Mac called Blender... You can design the world, the cities, buildings. If it's open world, pretty much like the entire world has opened up..."

Although he had not yet fulfilled his goal of studying at university and becoming a game developer, Adam was still using some of his multiliteracy skills in his current employment. Adam works as a business administrator in a health insurance company. In this role, he is able to do graphics design and continue building on the multiliteracy skills acquired at TAFE. As Kate shared, Adam is finding some sense of fulfilment in this role: "The organisation's fabulous, because they support him and what he wants to do... He is following a sort of pathway that he's interested in, just not the gaming."

Notwithstanding the above emphasis that people with Down syndrome were able to broaden their linguistic capital through post-secondary learning, the research also found that further education fields privilege particular linguistic codes and practices, which can hinder the participation of people with Down syndrome in further education. As discussed in the findings on "field", universities favour the act of lecturing as a primary way of teaching and learning. Parents questioned whether lecturing was an effective pedagogical practice for university learners, particularly those with disability. Philippa spoke of how the university foundation course which Sherry had attended did not accommodate learners with disability. According to Philippa, the problem was not in the learners themselves but in the linguistic practices that universities privilege: "Not that [Sherry] didn't handle any of it. She couldn't keep awake for an hour and a half, sitting there listening to something boring. I remember going to sleep in university lectures, anyway."

The VET system was also said to privilege certain linguistic codes and practices to the detriment of learners with Down syndrome. For instance, it was suggested by Peter that bureaucratic processes dictated some linguistic practices within the TAFE system, which hindered the learning of people with

Down syndrome. Specifically, the written course materials that Melissa received used language that was reflective of organisational concerns rather than being pedagogically focused. The linguistic practice privileged within the TAFE structure was that of official authoritative discourses:

> One of the issues that we've had with the Cert II is the written material that's provided. They give you these two big folders of material... [but] the language that they're written in, I think, is designed more to impress the curriculum review committee or a course supervisor... They could have taught the concepts and competencies that the kids need to have in simpler language.

Peter noted, nevertheless, that the written material was not relied upon in the actual teaching and learning practices. The actual teaching was more multiliteracies-based: “And most of the teaching is actually done just on slideshows in the classroom or practical outings and things...” In contrast to the formal structure of TAFE, the teachers were seen to be responsive to the needs of learners like Melissa and were able to adapt their pedagogies according to those needs. There was also, however, a suggestion that TAFE teachers themselves needed to be more cognisant of the literacy strengths of learners with Down syndrome. The linguistic capital that Melissa possessed was initially not recognised by her TAFE teacher:

> With the first couple of assignments she did, her handwriting was quite big... Her lecturer at TAFE, initially, was a bit concerned, because she took a while to be able to read it. But once she started to read, she recognised that Melissa had put down the right answers... So, from then on, the lecturer was very connected with her, because she realised that Melissa was retaining the information.

In summary, people with Down syndrome had forms of linguistic capital that enabled them to participate meaningfully and successfully in further education. This was notwithstanding the reality that some aspects of literacy

and numeracy learning presented as barriers to post-secondary learning. People with Down syndrome were best positioned to make gains in their linguistic capital when they had opportunities to engage with learning that was aligned to their multiliteracy interests and strengths.

Summary of embodied cultural capital

People with Down syndrome were found to have physical capital, behavioural capital, and linguistic capital that facilitated their participation in further education. For the participants in this study, having impairments associated with Down syndrome was a form of physical capital in that it provided opportunities to grow in resilience and self-determination. (This is notwithstanding the reality that health issues and impairments can pose significant difficulties for accessing further education.) Meanwhile, following appropriate classroom conduct formed the behavioural capital that enabled people with Down syndrome to participate in mainstream further education. Finally, having some level of traditional literacy and numeracy and multiliteracy skills also facilitated VET and higher education journeys.

Conclusion

Capital operated in varied ways to facilitate the post-secondary education journeys of people with Down syndrome. Both personal and family capital were seen to enable post-secondary learning.

Embodied cultural capital acquired by people with Down syndrome was fundamental for further education journeys. Knowing how to conduct oneself as a “good”, resilient learner was a highly regarded form of behavioural capital for participating in further education contexts. These culturally shaped ways of being in the world were particularly acquired in mainstream schools. As important as academic literacy skills were for success in post-secondary learning, linguistic capital could be seen to take lower precedence compared

to behavioural capital. Nonetheless, the role of linguistic capital was important in that, despite facing challenges with traditional literacy and numeracy learning, the participants with Down syndrome continued to expand their linguistic capital especially when their learning needs and strengths were considered from a multiliteracies perspective in further education fields. Physical capital was also relevant in that lived experiences in post-secondary education are embodied experiences. Living with Down syndrome was a varied experience, with some participants being impacted by health and impairment-related issues in their learning journeys. People with Down syndrome were portrayed as "fighters" in that they persevered through their physiological challenges as they engaged in post-secondary education.

Family capital in all its economic, social, and cultural forms was found to be the most significant enabler of further education journeys for people with Down syndrome. The parents in this research had acquired significant cultural capital in that they were well educated and had professional backgrounds. Having cultural capital meant that they held expectations that their child would enter further education. Since they were well informed and confident, parents were able to navigate complex further education systems to ensure that their child could access post-secondary learning, as well as to reinforce their child's learning in home settings. Families' cultural capital, therefore, both shaped the dispositions of the participants with Down syndrome towards further education and enabled success in further learning. In addition, parents' financial and social resources also assisted post-secondary education for their child with Down syndrome. Whilst economic and social capital did not in themselves activate further education opportunities, they made it possible for people with Down syndrome to capitalise on their cultural capital.

To conclude, the families in the study were well resourced to navigate further education systems for their family members with Down syndrome. Due to

their family and personal backgrounds, the participants with Down syndrome had important advantages that ultimately enabled them to participate and flourish in VET and higher education fields.

Chapter 10: Navigating post-secondary education fields

Discussion on key findings

Introduction

This penultimate chapter presents the key findings of the thesis in relation to the four sub-questions that have guided the study. The main research question, meanwhile, is addressed in the final chapter of the thesis. In the present discussion chapter, the key findings are situated in relation to the existing literature on post-secondary learners with Down syndrome and other relevant topics within Down syndrome research. The key findings are also discussed through the theoretical lenses of "self-determination" and "capital". The chapter argues that people with Down syndrome exercise self-determination towards and within further education contexts but, for it to be fulfilled, that self-determination must be supported by multiple forms of capital, particularly from within the family context.

Review of research aims

This thesis explores the lived experiences of people with Down syndrome within the fields of post-secondary education in Australia. While people with disabilities such as Down syndrome seem to be increasingly participating in vocational education and training (VET) and higher education in Australia, they continue to experience disadvantages and inequities within these fields (Cavallaro et al., 2005; Department of Education, 2024b; Parliament of Victoria, 2021). The barriers encountered by people with disability relate to accessing and participating in further education (Griffin, 2014; Griffin &

Nechvoglod, 2008), as well as completing and gaining positive outcomes from further study (National Centre for Student Equity in Higher Education, 2017; Pitman, 2022). The barriers can be related to learner characteristics and/or structural issues within the field. Literacy and numeracy challenges (Bruniges et al., 2023, 2024; Karmel & Nguyen, 2008) and issues with making choices towards further study (Brown, 2017; Productivity Commission, 2020) are common challenges for disadvantaged learners. Importantly, people with disability attain the most success in VET and higher education when they exhibit learner agency and self-determination (Coyle et al., 2018; Ganguly et al., 2015), but also when they are holistically supported by their home environments and learning contexts (Cocks & Thoresen, 2013a; Kilpatrick et al., 2016; Rooney, 2019). The findings cited in this paragraph highlight the need for a whole-of-life approach to researching disability-related issues in further education (Griffin & Beddie, 2011).

To address this need, a critical disability studies approach has been adopted in this thesis because it enables the exploration of "disability" as a complex, multifaceted phenomenon (Meekosha & Shuttleworth, 2009). This kind of research is undertaken by drawing upon a range of theoretical perspectives to shed light on the complexities and contingencies of living with disability (Goodley, 2018; Shildrick, 2020). In this thesis, a step towards interdisciplinarity has involved adopting the concepts of "self-determination" from psychology (Wehmeyer et al., 2003) and "capital" from sociology (Bourdieu, 1986). The two ideas have featured (whether explicitly or implicitly) in existing research on post-secondary learners with Down syndrome and research on living with Down syndrome more broadly. Quality of life and learning and enhanced developmental outcomes in people with Down syndrome have been positively linked to self-determination in people with Down syndrome (Faragher et al., 2020; Jevne et al., 2022; Landuran et al., 2022). Concurrently, such positive outcomes are attained through a range of resources and capital, particularly from within the family context (Evans &

Uljarević, 2018; Hilvert et al., 2023; Krueger et al., 2019). People with Down syndrome need personal, family, and other resources to fulfil their self-determination towards participating in post-secondary education (e.g. Casale-Giannola & Kamens, 2006; Hamill, 2003; Taylor et al., 2019).

In view of these issues, this thesis has aimed to analyse the interrelationships between self-determination and capital. The principal research question addressed is:

- How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?

The main research question is supported by several sub-questions surrounding self-determination, capital, and the fields of further education in Australia:

1. How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?
2. How do people with Down syndrome exercise and develop self-determination throughout their further education journeys?
3. How do different forms of capital (i.e. economic, cultural, and social) interrelate to enable post-secondary education journeys for people with Down syndrome?
4. How does embodied cultural capital in people with Down syndrome facilitate further education opportunities?

Key findings

The sub-questions are now addressed in turn, whereas the main research question is addressed in the concluding chapter.

But first, it needs to be stressed that every person with Down syndrome is unique, as are their family backgrounds. Individuals with Down syndrome vary greatly in their self-determination and their access to forms of capital that can support self-determination. They also have varied experiences of further education fields. The findings discussed in this chapter represent the experiences of those who have participated in this research.

1. The perceptions toward further education fields

The first sub-question in this thesis concerns the notion of "field": How do people with Down syndrome and their families perceive the fields of post-secondary education in Australia?

The interviews with people with Down syndrome and their parents have uncovered somewhat competing attitudes among the participants regarding further education fields in Australia. Specifically, the findings indicate that the concept of "meritocracy" stands in opposition to notions of "inclusion" and "equity" in post-secondary learning fields. Ideological issues in the field are in addition to the general barriers that participants have faced in their access of post-secondary learning. Despite the challenges to participating in them, VET and higher education fields are perceived to provide people with Down syndrome with important resources to attain positive personal, economic, and other outcomes.

Barriers within further education fields

In this study, barriers to accessing VET have been reported by families of people with Down syndrome. One such barrier is the difficulty of navigating VET information sources. The TAFE system has been experienced as being extremely difficult to navigate via telephone enquiries. The experience of enquiring about courses has been described as being "bounced around" on the phone from one staff member to another. Furthermore, families have

stated that there is sometimes uncertainty as to which courses would be offered at a particular college. The uncertainty surrounding course offerings was exacerbated by the COVID-19 pandemic. Notably, these barriers that have been reported by parents in this research are similar to those that have been identified by recent reports on the Australian VET sector (Bruniges et al., 2023; Productivity Commission, 2020). This thesis confirms, therefore, that changes within the field are needed to improve the accessibility of further education. In this study, the support and resources provided by families have been essential for navigating further education barriers for people with Down syndrome.

Contested values within further education fields

Apart from the general barriers to participating in further education, competing values and beliefs have been found by this study to operate within VET and university fields. The taken-for-granted belief that further education fields operate on the principle of meritocracy (Bourdieu & Passeron, 1977; Thomson, 2012) was reproduced to some extent by a few research participants. When speaking about the further education journey of Renee, a university graduate with Down syndrome, the notion of "capability" was foregrounded by her parents. Being able to access higher education was perceived to be due to one's academic ability. Likewise, academic success has been understood to be credited to student capability and effort. Further education fields were thought by Renee's family to be built upon principles of fairness and excellence.

These perceptions uncovered in this study relate to broader discourses on further education. In Chapter 2 of this thesis, several reports on higher education and VET in Australia have been analysed. In one such discourse, "widening participation" in higher education has been defined as "[p]roviding opportunities for all capable students to participate" (Bradley et al., 2008, p. 27). Although the Bradley Review problematically omits people with disability

from its discourse on “capable students”, university graduates like Renee show that some people with Down syndrome might fulfil the “capability” requirement to access higher education. The findings in this research, therefore, contest deficit-based ableist framings that underpin some discourses within post-secondary education fields in Australia.

Significantly, the framing of Renee’s further education journey around the notion of “capability” both resists and reinforces dominant discourses on people with disability. On the positive side, Renee serves as an example of how higher education is now “increasingly possible” (p. 36) for people with Down syndrome around the world (Faragher et al., 2020). The possibility of entering university is founded partly on the field having become more inclusive and accessible, but also on people with Down syndrome themselves reaching greater potential in recent decades (Carr, 2011; Gothard, 2011). In Renee’s story, the deficit-based assumption that the learning and development of people with Down syndrome reach a plateau in adolescence is strongly countered (Moni & Jobling, 2001).

At the same time, the construction of Renee as “a capable student” only challenges the “capability” discourse insofar as advocating for people with Down syndrome to have a place within the discourse rather than disrupting the logic of the discourse itself. While Renee’s family expressed that further education journeys should be made possible for people with Down syndrome, their argument was still centred around notions of learner capability and agency. The potential danger in this thinking is that it can reinforce the neoliberal underpinnings of “widening participation” discourses, which ultimately place the responsibility on the individual to prove themselves capable and worthy of higher education opportunities (O'Shea, 2020).

Arguably, Renee’s story provides hope that one can access university only to those with Down syndrome who are able to assimilate to the norms and values of the higher education system, as Bourdieu would argue (Bourdieu &

Passeron, 1977). The same could be said regarding the accounts of other university graduates with Down syndrome around the world (e.g. Calderón-Almendros & Calderón-Almendros, 2016; Woodward, 2022). As important as these academic achievements are for Down syndrome communities, they might not sufficiently disrupt the fundamental ways by which post-secondary fields operate. As Bourdieu's notion of "controlled mobility" (p. 54) argues, structural inequalities ultimately persist when only few members of dominated classes experience mobility by attaining the norms and behaviours of the dominant class (Bourdieu & Passeron, 1977). Globally, there are still very few people with Down syndrome who have participated in university education.

Other families in this research expressed more critical views towards post-secondary education systems as sites of inequality. Deficiencies have been identified in further education fields as the primary barriers to accessing further study. In line with the "widening participation" ideals of the VET (Department of Employment and Workplace Relations, 2024) and university (Department of Education, 2024b) sectors in Australia, families have expressed that people with Down syndrome should be provided greater access to further study. Yet, post-secondary learning fields are perceived to be somewhat closed systems, since people with Down syndrome are disadvantaged in meeting the requirements to enter further education. The participants in this research have stated that alternative pathways, especially into higher education, need to be promoted and provided to people with Down syndrome and other disabilities. This finding concurs with that of Jackson et al. (2023).

The tensions between "equity" and "excellence" within Australia higher education discourses, which Rizvi and Lingard (2011) have discussed, are significant when considering people with Down syndrome. The belief that higher education is "quality education" was held to some extent by some

participants. The research has confirmed that, when “excellence” is foregrounded in higher education discourses, “equity” is at risk of being overlooked. As Butler and Ferrier (2022) argue, “[w]here 'equity' can be found, it is most often framed within deficit discourses” (p. 7). In summary, the above findings show that issues surrounding “access” and “capability” are constructed in somewhat divergent ways by different families within Down syndrome communities.

The research in this thesis finds that universities can still do much more in their accommodation of people with Down syndrome. Families have expressed that barriers to accessing higher education are predominantly structural rather than individual. Instead of requiring learners with Down syndrome to reach a certain level of “capability” before granting them entry into higher education, there is room to consider how universities might work with the existing capabilities of individuals with Down syndrome to provide them with study options. Families in this study have echoed the view that each learner with Down syndrome is unique (Faragher et al., 2020), as the literature review in Chapters 3 and 4 has argued. According to the research participants, post-secondary education fields still need to become more accessible to people with all abilities, rather than placing the onus on people with disability to “earn” their right to enter these fields.

Whilst social fields are always open to change (Bourdieu & Wacquant, 1992), there is still much to be done within further education fields to include learners with Down syndrome. Families in this study have expressed that universities still need to become much more accommodating towards people with Down syndrome. Academic success for students with Down syndrome is dependent on the level of support and accommodation to which they are afforded. This argument is supported by a comparison of two participants with Down syndrome, namely Renee (who received wide-ranging support from numerous stakeholders within higher education) and Sherry (who was unable

to complete her foundation course because of a lack of institutional support and accommodation). These findings suggest that some education providers, particularly within the higher education sector, could make a greater effort to ensure that their practices meet their legislative obligations under the *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005*. Moreover, the findings align with those made in the Disability Royal Commission, namely that education institutions whether deliberately or inadvertently exclude students with disability "by not providing appropriate adjustments and supports" (Commonwealth of Australia, 2023b, p. 10). The research in this thesis has heard that universities, in particular, need to consider whether their established pedagogies are serving the needs of their students and fostering participation. Overall, the field of VET has be seen by the participants to be more open to inclusion and accommodation than higher education.

Attaining capital through post-secondary education fields

The research has also found that people with Down syndrome and their families perceive further education to be valuable for one's quality of life. Post-secondary qualifications are valued as "institutionalised cultural capital" (Bourdieu, 1986) by people with Down syndrome and their families. This study has found that post-secondary certifications provide people with Down syndrome with institutional recognition and "external validation" (Polidano & Mavromaras, 2010, p. 21) of their knowledge and competence for employment. People with Down syndrome have been found by this research to undertake further study for employment purposes. This is reflective of what existing studies have found in people with disability in Australia generally (Nechvoglod & Griffin, 2011).

Yet, not all post-secondary graduates with Down syndrome have the opportunity to convert their institutionalised cultural capital into economic capital, an issue that Bourdieu (1986) has identified in society more broadly.

Nevertheless, this study has confirmed that gaining a post-secondary qualification generally enhances the employment prospects of people with Down syndrome (Buckland et al., 2024; Polidano & Mavromaras, 2010). As argued in the "Living with Down syndrome" chapter of this thesis, employment is a key aspect of quality of life for people with Down syndrome (Faragher et al., 2020; Scott et al., 2014).

Summary

The findings indicate that people with Down syndrome and their families have complex perceptions towards VET and higher education in Australia. By and large, however, they believe it is valuable for people with Down syndrome to participate in these fields. Furthermore, families express hope in the potential for further education fields to become more inclusive of and accommodating towards people with Down syndrome.

2. The exercise and development of self-determination

The second sub-question revolves around the concept of "self-determination": How do people with Down syndrome exercise and develop self-determination throughout their further education journeys?

The interviews have found that self-determination functions in complex ways. While people with Down syndrome exhibit self-determination towards and within further education, their self-determination is influenced by a range of stakeholders (particularly family) and other factors. The findings, therefore, support the argument that self-determination on the part of people with disability alone is not sufficient for attaining positive post-school transition outcomes for young people with disability (Trainor, 2008).

Self-determination is not always essential

The research has found that not all post-secondary education opportunities come about through self-determination. As Faragher (2023) has observed, further study can come about by chance or opportunity without intentional planning. Renee's whole university journey can be understood in this way. Similar to Kerri-Ann Messenger (Messenger et al., 2018), Renee and her family did not initiate joining a university inclusion program but were, instead, introduced to it by a relevant stakeholder in the field. In this research, it has been found that "chance" or, more precisely, social capital can operate in the absence of self-determination to produce university and VET opportunities.

Self-determination towards further education

Nevertheless, as the title of this thesis ("My main goal is to get into university") suggests, people with Down syndrome exercise self-determination by making goals towards post-secondary education. Individuals with Down syndrome have unique interests and strengths that shape their learning goals. This finding attests to the functional theory of self-determination (Wehmeyer, 2003a, 2003b). People with Down syndrome express positive attitudes towards vocational training, indicating that gaining work skills and finding employment are primary goals for entering training. Expressing self-determination towards further education can involve choosing to study a particular course because of employment goals. In this regard, the participants in this study have made further education decisions in ways that are similar to the broader population of people with disability in Australia (Nechvoglod & Griffin, 2011).

People with Down syndrome have, therefore, been found in this research to act as the "primary causal agent" (Wehmeyer, 1992, p. 305) to bring about opportunities for post-secondary education. This confirms the finding of Foley et al. (2013), which is that young people with Down syndrome who are

involved in decision making are more likely to have “better” post-school outcomes, namely to be in VET and/or open employment.

The study has found that prior experiences of VET in school shape the employment goals of people with Down syndrome and also facilitate their transition into post-secondary education. Secondary schools have been observed to play a vital role in providing VET-related information and guidance to young people with Down syndrome. Teenagers with Down syndrome who engaged with VET while at school were facilitated in their decision making regarding post-school transitions. Participating in VET and work placements during schooling enabled successful transitions into further study and/or employment for the participants. Thus, the research findings underscore the need to promote VET experiences to secondary learners with Down syndrome, as identified in existing literature (Cocks & Thoresen, 2013b; Faragher, 2023; Joyce, 2019).

Having both the ambition and the opportunity to work is crucial for the further education journeys of people with Down syndrome. Unlike many VET learners with disability who are unable to attain work experience during their training, (Parliament of Victoria, 2021), one participant in this study was well supported by employers who provided her with work experience opportunities and paid employment. Since completing TAFE, Helen has worked as a barista in a medical centre and also as an administration assistant in the same workplace. Moreover, a readiness to return to further education to upskill was expressed. In contrast to what has been found in many people with disability (Australian Institute of Health and Welfare, 2024; Cavallaro et al., 2005), the VET graduates with Down syndrome in this study have largely attained desirable employment outcomes.

Irrespective of the post-secondary qualifications they might have already attained, people with Down syndrome might still have unfulfilled goals and wishes towards further study. Higher education has been observed in this

study to be a common yet-to-be-accomplished goal. Since going to university is thought to be a major post-school milestone, people with Down syndrome might experience a sense of loss when their school friends and peers without disability enter university without them. Compared to other important aspects of adulthood, such as open employment and independent living, higher education remains a particularly difficult milestone for people with Down syndrome to attain.

At the same time, this research has found that having unfulfilled goals can be seen as an opportunity for people with Down syndrome to exercise self-determination rather than as an absence of self-determination. As Wehmeyer (2005) points out, self-determination is not to be equated with the success of achieving one's goal. Even if a person with Down syndrome is afforded the opportunity to enter higher education, they may decide not to for any given reason. The participants in this research have been found to engage in decision making by identifying and evaluating various options before implementing a plan of action, as per the functional theory of self-determination (Wehmeyer, 2003a, 2003b). In reflecting on their unfulfilled goals towards further education, people with Down syndrome in this study have displayed self-awareness and self-knowledge. For instance, they have reflected on their own strengths and limitations and possibly agreed with others who perceive university to be too difficult. This finding confirms that having self-awareness is an important component of self-determination (Wehmeyer, 2003a, 2003b), specifically within post-secondary contexts.

Self-determination within further education contexts

People with Down syndrome not only exercise self-determination towards further education, but they also develop self-determination within further education. As the ecological theory of self-determination states, self-determination is not static but develops along one's lifespan (Abery & Stancliffe, 2003a). This research has found that post-secondary learning

contexts are important life settings in which people with Down syndrome grow in their self-determination. This growth is supported by both peers and teaching staff within further education contexts. Independence, decision making, and problem solving are all enhanced through post-secondary education. By participating in further education, people with Down syndrome develop skills such as commuting on public transport, navigating learning campuses, making decisions regarding food and drink, budgeting, socialising and, of course, academic learning itself. In other words, self-determination begets self-determination. Therefore, the findings confirm that participating in further study enables people with disability to develop their independence which, in turn, contributes to enhancing their well-being and quality of life (Parliament of Victoria, 2021).

Self-determination from a family perspective

While the above findings have foregrounded the self-determination of people with Down syndrome themselves, it is also necessary to acknowledge that their self-determination does not operate as an individualistic construct. The present study has attested that self-determination is the product of the individual and their environment, as the ecological theory of self-determination states (Wehmeyer & Abery, 2013). This research has also verified that the family setting is the first and primary microsystem which influences self-determination in people with disability (Abery & Stancliffe, 2003a). People with Down syndrome have been found to require a range of supporting resources from their parents and carers to fulfil their self-determined goals and decisions towards further education, as Taylor et al. (2019) have also found.

Correspondingly, this thesis has found that people with Down syndrome are quite aware of the support given by their parents towards their life decisions. Parent support has often been keenly recognised and framed in positive terms. People with Down syndrome themselves have perceived family

support as being necessary for fulfilling their further education goals. They have spoken of how their parents organised their course of study and assisted with the enrolment process. The participants' sentiments are similar to those, in existing literature, of people with disability who have spoken of their parents' practical help with accessing college (Pascall & Hendey, 2004). Adults with Down syndrome in this study have largely reported positive feelings towards their parents and carers for supporting their growth in independence, in agreement with Scott et al. (2014). This study also concurs with Loveall et al. (2022), finding that parent involvement is fundamental to positive post-school transition outcomes for young people with Down syndrome. Furthermore, the findings in this research highlight that people with Down syndrome often share control over further education decisions with trusted family members. Such sharing of control is the central tenet in the tripartite ecological theory of self-determination (Abery & Stancliffe, 2003b), a view of self-determination that has been supported by the findings in this research.

Notably, the research has found that parents and carers play multiple roles in relation to the self-determination of people with Down syndrome. The parents in the study were well aware that people with Down syndrome wish to make agentic choices in relation to further study. Families were also aware that those decisions would not come to fruition without their hands-on support. Sometimes, parents and carers have needed to resist deficit-based discourses to ensure that their children have access to a particular further education opportunity. Given that there are persistent barriers to accessing further education (Bruniges et al., 2023; Productivity Commission, 2020) as discussed in the previous key finding, parents and carers have been required to actively support their family member with Down syndrome to make further study possible. In fact, parents and carers themselves have been noted to act with self-determination to navigate those barriers.

Although a large part of their role is to fulfil their child's self-determination, parents and carers may sometimes redirect the goals and wishes of their child with Down syndrome. This can occur when parents and carers consider those goals to be (currently) unattainable and/or unrealistic. Consequently, parents and carers have been found to play a redirecting role to guide their family member towards more suitable options in life. Whilst parents and carers might perceive this role in negative terms, they also redirect their child by emphasising the positive and meaningful experiences that their child is currently engaging in. These findings are in agreement with Faragher (2023) and Docherty and Reid (2009).

Parents and carers have been noted to perform multiple, complex roles in relation to their children's post-school transitions. Some parents are required to assume more control of the decision-making process for whatever reason. This might be the case for school-aged children with Down syndrome, who might experience difficult decisions being made for them by parents. Such decision making, however, occurs while keeping the interests of the person with Down syndrome in mind. At times, parents and carers might feel the need to make difficult decisions that their children dislike. These findings suggest that some school-aged children with Down syndrome might occupy a relatively low position on the "self-determination continuum" (Abery & Stancliffe, 2003a, p. 29). Families can, however, be reassured that the decisions they make for their child with Down syndrome might later be taken on board as the child's own decision.

The research has observed that facilitating self-determination is not a straightforward task, since families need to consider multiple factors in their decision making. Living with Down syndrome is a complex, multifaceted experience, as discussed in Chapter 3 of this thesis. Health issues and medical conditions can impact significantly on quality of life for people with Down syndrome (Haddad et al., 2018). It has, therefore, been one of the

complex factors that families considered when deciding on post-school options with and for people with Down syndrome.

Summary

People with Down syndrome can display functional aspects of self-determination, such as goal setting and decision making, in relation to post-secondary education. They tend to choose further education options that suit their interests, needs, and abilities. Self-determination cannot, however, be viewed in purely functional and individualistic terms. Rather, it is shaped by one's ecological environments, particularly one's family context. People with Down syndrome require the support of their parents and carers to make post-secondary education journeys possible. Self-determination in and of itself is, therefore, not adequate for enabling further education journeys. It is from this perspective that the third sub-question is raised.

3. The interrelationships between economic, social, and cultural capital

The third sub-question relates to the idea of "capital": How do different forms of capital (i.e. economic, social, and cultural) interrelate to enable post-secondary education journeys for people with Down syndrome?

The interviews have found that cultural capital plays a primary role in shaping further education journeys, while the effect of cultural capital itself is supported by both economic and social capital (especially the latter). People with Down syndrome themselves hold various forms of capital, though these are usually derived from their family background. (The latter point concerning family capital is given much more emphasis in the concluding chapter.) Analysing the post-secondary education experiences of people with Down syndrome from the perspective of Bourdieu's (1986) "capital" uncovers the reality that some people with Down syndrome have relative advantages over

others with the same disability within education fields. These advantages help to explain how some people with Down syndrome have been able to navigate barriers to further education.

Economic capital

Economic capital is an important enabler of further education for people with Down syndrome. As Bourdieu (1986) states, financial resources facilitate the accumulation of cultural capital, particularly within education fields. In the interviews with parent participants, the importance of financial capital was somewhat backgrounded compared to cultural capital. The phrase “we’re not wealthy” was a common sentiment among families when speaking of the family factors that contributed to further education opportunities. The findings have, however, suggested that economic capital played a greater role in facilitating post-secondary education journeys than the families may have realised.

From what was perceived in the interviews, the families of people with Down syndrome were not of low socioeconomic status. As Bourdieu (1986) argues, members of families with financial resources are afforded more “free time” (p. 246) to pursue post-compulsory education. Accordingly, the research has found that family economic resources facilitate further education opportunities for people with Down syndrome. The advantage of being able to devote time to further study without financial stress is a significant one. People with Down syndrome have been found to generally require more time than people without disability to complete their studies. This finding reflects what the existing literature has found in VET students with disability more broadly (Australian National Training Authority, 2000). Without a well-resourced family unit and the time that it affords, people with Down syndrome might not be successful in completing their further study.

Families have been found to possess adequate finances to access additional supports for their child with Down syndrome beyond what is provided by formal learning institutions. Paid supports might include peer mentors within university contexts and external tutors who can reinforce learning outside of the classroom. People with Down syndrome who have mobilised personal and/or family finances to access external supports have been observed to be at an advantage. This is because learners with disability are at risk of not completing their further education due to a lack of support from learning institutions (Cocks & Thoresen, 2013a).

Economic capital has been found, therefore, to "multiply" (Bourdieu, 1986) cultural capital in people with Down syndrome. When people with Down syndrome have shown potential for further education, economic capital has facilitated the realisation of that potential.

Social capital

Social capital is another important facilitator of VET and university journeys for people with Down syndrome. The research has found that social capital performs a more obvious and, arguably, a more significant role than economic capital in enabling further education opportunities. Bourdieu's (1986) notion of "social capital" has been defined as "valued relations with significant others" (Jenkins, 1992, p. 53). The families who participated in this research study were well-connected and socially established members of society. The connections that they have had with others within social fields such as education, work, and the general community all played significant roles in enabling the further education experiences of the participants with Down syndrome. The families often possessed insider knowledge and relationships that vulnerable, disadvantaged families do not possess. This finding echoes that of Yoon (2020).

Parents and carers have been aware of the importance of social capital for higher education and VET journeys. Having social capital has enabled families to navigate the structural barriers that hinder people with Down syndrome from accessing further education. The planning and decision-making process prior to commencing further study has also been facilitated by social capital. The findings support Bourdieu's (1986) argument that social capital depends not only on "whom you know" but, more importantly, the amount and nature of capital possessed by those known people. In this research, social capital has been found to consist of relationships within the broader education field with teachers who are competent and knowledgeable. These latter connections are significant because they have prepared students with Down syndrome for a lifetime of learning.

Although families in the study credit many of their personal connections to chance, it is also evident that families devote time and effort into cultivating these relationships. As Bourdieu (1986) states, accumulating social capital requires labour of a social nature. For some families in the study, working to establish positive social connections to stakeholders has been a lifelong pursuit. Clearly, parents and carers play a vital role in building up the interpersonal networks of people with Down syndrome, which can become invaluable resources in times of need. Personal connections with relevant stakeholders can lead to post-secondary learning opportunities. These findings agree with those of Roll and Koehly (2020) and Roll and Bowers (2019).

People with Down syndrome can accumulate social capital in education fields from a young age, as they encounter stakeholders who are able to support and include them in mainstream learning contexts. This finding differs somewhat from that of Polidano and Mavromaras (2010), who state that an early onset of disability can prevent the accumulation of social capital.

Cultural capital

Cultural capital has been found to be the most significant enabler of post-secondary education. For starters, social capital does not operate in isolation from cultural capital but is derived from the cultural capital of the individual with Down syndrome. Bourdieu's (1986) idea of "cultural capital" refers primarily to knowledge and competencies that are deemed to be valuable according to the dominant norms of society (Jenkins, 1992). The research in this thesis has found that people with Down syndrome can acquire social capital on account of their cultural capital when other people notice their knowledge and abilities. Gaining social capital in this manner can lead to further education opportunities that are not the product of self-determined goals and decisions. For people with Down syndrome, social capital has been found by this study to act, therefore, as a "multiplier" to cultural capital, as Bourdieu (1986) states. Moreover, some people with Down syndrome might have dispositions that enable them to be particularly effective in acquiring social capital. This finding echoes existing studies which have found that strong social skills are assets that people with Down syndrome often have (Fidler & Daunhauer, 2011; Grieco et al., 2015).

This research has found that families' cultural capital plays a fundamental role in facilitating their children's further education journeys. Parents and carers who are well educated and/or have professional backgrounds provide their child with Down syndrome with important advantages in participating in VET and higher education. Such parents and carers have expectations that their child will access further study which, in turn, shape their child's dispositions and aspirations towards the same. People with Down syndrome in culturally resourced families receive from their parents' concrete support with accessing further education, as well as support with the actual learning process. Furthermore, many personal connections to stakeholders within further education fields (i.e. social capital) are derived from the education and

professional backgrounds of parents and carers (i.e. cultural capital). This point is given much more emphasis in the concluding chapter.

Cultural capital is, therefore, the most powerful enabler of VET and university education for people with Down syndrome. Although economic and social capital both operate to enhance cultural capital, these two forms of capital alone cannot secure access to further education opportunities. Cultural capital on the part of individuals with Down syndrome themselves and from their families are both required for post-secondary learning journeys. Given its significance within further education fields, (embodied) cultural capital is afforded specific attention in the next sub-question.

Summary

People with Down syndrome require all forms of capital to fulfil their self-determination towards and within further education fields. Self-determined learners are not simply self-determined but well-resourced and well-supported learners. Cultural capital is the basis upon which people with Down syndrome can participate in further education, but economic and social capital contribute to facilitating that participation. Cultural capital in people with Down syndrome is, therefore, multiplied and capitalised upon by their and their families' economic and social capital.

4. The role of embodied cultural capital

The final sub-question focuses specifically on "embodied cultural capital": How does embodied cultural capital in people with Down syndrome facilitate further education opportunities?

This research has found that embodied cultural capital is vital for enabling further education journeys. Physical capital, behavioural capital, and linguistic capital are all forms of embodied cultural capital that impact on people with Down syndrome and their participation in post-secondary

education. This finding is focused on the individual with Down syndrome, whereas the importance of family cultural capital is discussed in the concluding chapter. As a whole, the participants with Down syndrome in this study had bodily advantages for studying in further education. In this regard, they were largely similar to the participants in an existing study: “The young adults with [intellectual disability] in these families are high functioning, verbal and physically healthy.” (Taylor et al., 2019, p. 1125)

Physical capital

In this research, the bodies of people with Down syndrome have been found to be a form of physical capital. This finding attests to the reality that there is “value placed upon the size, shape and appearance of the flesh” (Shilling, 2004, p. 474). The interview findings also confirm a key topic discussed in the literature review in Chapter 3, namely that the learning development and quality of life for people with Down syndrome are shaped by bodily concerns, such as one’s health conditions.

This study has demonstrated how health issues like hypothyroidism can impact on the learning journeys of people with Down syndrome (Donaldson & Leyland, 2015). Importantly, school attendance can be impacted by hypothyroidism and other health issues to the extent that families might decide for their young person with Down syndrome to leave secondary school before completion. Health issues can persist into adulthood, thereby affecting post-secondary education also. With the support of further education staff and peers, however, people with Down syndrome can manage to navigate their physiological challenges.

This research has found that some learners with Down syndrome perceive issues such as tiredness and concentration to be the main challenges faced within further education contexts. Tiredness can be due to the changes in daily routines that come with post-school transitions. It has also been found

to be due to sleep-disturbed breathing, which can be a common concern for people with Down syndrome (Evans et al., 2015). Nonetheless, people with Down syndrome have been found to seek strategies and supports that can help them to manage their tiredness within further education settings. The findings made by this thesis contribute much-needed knowledge on how impairments associated with Down syndrome can shape post-secondary education experiences.

Considering these physiological and other challenges throughout their post-school journeys, people with Down syndrome in this research have been found to position themselves as "fighters". Perseverance in people with Down syndrome can also be seen in how they navigate learning challenges throughout their further study. This finding supports the understanding that students with Down syndrome tend to have dedication to tasks as one of their learning strengths (Faragher, 2023). Therefore, far from being entirely constrained by their bodily impairments, people with Down syndrome can persist through physiological and other barriers to achieve their goals towards further education. By doing so, they also disrupt normative ableist discourses that stigmatise their bodies as forms of "deviance" and "tragedy" (Gabel & Kotel, 2018; Johnson & West, 2021). In this study, the research participants with Down syndrome have shown that their bodies are valuable, despite society judging them to be the "other" (Edwards & Imrie, 2003; Shilling, 2004).

Behavioural capital

Another form of embodied cultural capital that impacts on living with Down syndrome has been theorised as "behavioural capital" in this thesis. This study has found that knowing how to conduct oneself in mainstream settings is fundamental for people with Down syndrome to be able to access further education. Exhibiting behavioural capital provides people with Down syndrome with the advantage that they receive the support to which they are entitled in VET and university fields. This suggests that so-called "problem

behaviours" in people with Down syndrome might affect the level of learning support they receive. Importantly, externalising maladaptive behaviours such as aggression and delinquency (Channell et al., 2021; Dykens et al., 2002), which can affect education outcomes, have not been reported in the participants with Down syndrome in this research.

Behavioural capital has been perceived by families in this research to be more important than linguistic and academic capital for people with Down syndrome to participate in "the real world". This view shapes how the purpose of formal schooling is perceived by parents and carers. This finding suggests that low prior educational attainment might not be the primary factor that hinders people with disability from participating in post-compulsory education, contrary to existing literature (cf. Cavallaro et al., 2005; Griffin, 2014; Karmel & Nguyen, 2008; Polidano & Vu, 2011). Rather, knowing how to conduct oneself in mainstream education contexts might, at least to an extent, be more "valuable" than having strong academic capabilities. This finding confirms the importance for all students with Down syndrome to be expected to learn and exhibit behaviours that are socially appropriate within classrooms (Faragher, 2023). Acquiring these ways of being throughout early childhood learning and formal schooling can facilitate further education journeys.

Significantly, mainstream education contexts are a central social context in which behavioural capital is acquired by young people with Down syndrome. Without this form of cultural capital, people with Down syndrome face disadvantage in relation to accessing further study. The findings provide further evidence that inclusive mainstream education significantly enhances the post-school outcomes of people with Down syndrome (Buckley et al., 2006; Faragher et al., 2020; Faragher, 2023).

In contrast to learners in mainstream education, it might be the case that students with Down syndrome in specialist schools do not acquire the same

kinds of socially valued behaviours. Social environments, therefore, noticeably impact on people with Down syndrome. This finding seems to support the idea that "imitation", as Down (1866) argues, is a key strength in people with Down syndrome. This aptitude can be harnessed within mainstream classrooms "where learners with Down syndrome are surrounded by students on whom they can model learning behaviour" (Faragher et al., 2020, p. 8). Although it expresses caution towards Down's (1866) claims, this thesis acknowledges that people with Down syndrome can be advantageously positioned to access further education, if they have the means to adopt the ways of being that are considered normative in such fields.

The above findings support Bourdieu's (1977b) notion of "bodily hexis", which refers to ways of behaving and using one's body as deemed appropriate by culture and society. In education fields, some particular ways of being and behaving (i.e. the dominant, middle- and upper-class ways) are considered more legitimate and, thus, more valuable than other ways of using one's body (Bourdieu & Passeron, 1977). By analysing further education journeys from this perspective, this thesis contributes much-needed sociological insights to Down syndrome research.

Linguistic capital

The third form of embodied cultural capital that facilitates post-secondary education is "linguistic capital". This study has found that people with Down syndrome have a range of literacy practices and needs, which can shape their VET and university participation. The findings support several aspects of Bourdieu's understanding. Being literate is a form of "cultural competence" (Bourdieu, 1986, p. 245). Yet, not all forms of literacy and linguistic practices are equally valued in social fields such as education systems (Bourdieu, 1991).

On the surface, it appears that people with Down syndrome experience disinterest in and challenges with traditional literacy and numeracy learning. The traditional framing of literacy as a cognitive, school-based practice impacts on their participation in further study. In the past, people with Down syndrome had few options for further study because of their perceived limitations in academic literacy. Such deficit-based views result in people with Down syndrome being deprived of genuine choice in post-secondary education contexts, since their courses of study might be decided for them instead of by or with them. These findings attest to the need for person-centred information and guidance regarding training options to be provided to foster genuine choice making by prospective learners (Brown, 2017; Bruniges et al., 2023; Productivity Commission, 2020). The people with Down syndrome who participated in this research have largely received such individualised support and guidance. This is one significant factor that accounts for their success in the field.

Post-secondary studies become more engaging and successful when they are aligned with learner needs and interests, particularly in multiliteracies. People with Down syndrome can be found studying diverse courses, including hospitality and animal studies, across VET contexts. Learners with Down syndrome experience enhanced motivation when given the opportunity to engage their strengths in multiliteracies. This research has found that learners with Down syndrome should not be presumed to have low motivation but, rather, their motivation is strengthened when provided with appropriate learning challenges that match their interests. This point has also been argued by Li et al. (2006) and Gilmore and Cuskelly (2014). Additionally, this research has found that developing multiliteracies has positive effects on post-training employment satisfaction. Although people with Down syndrome generally experience difficulties with language and literacy development from a cognitive perspective on language, they have strengths in multiliteracies that

can be capitalised upon in further education contexts. This finding supports what has been argued by Abbeduto et al. (2023) and Moni and Jobling (2014).

Concurrently, it should be noted that some people with Down syndrome can excel in their traditional literacy and academic skills. This can be seen to be particularly true of university graduates with Down syndrome, like Renee. Academic writing and research skills are valuable competencies that enable people with Down syndrome to engage in higher education. As discussed in the findings on "field", it is perceived that learner "capability" is vital for accessing and succeeding in the elite field of higher education.

Nonetheless, the research has found that participation in university remains a rare occurrence for people with Down syndrome. This concurs with recent figures showing that people with intellectual disability remain severely under-represented in higher education in Australia (Cadby et al., 2024). In this study, higher education fields have been noted by parents to privilege particular linguistic and academic practices that ultimately disadvantage learners with Down syndrome. The nature of teaching and learning within university contexts poses a barrier to participation. For example, the expectations that students stay seated for extended periods of learning and that students learn independently with minimal support both place people with Down syndrome at a disadvantage. Other studies have noted similar barriers to learning for students with Down syndrome (Esbensen et al., 2021; Sabat et al., 2020).

Discourses that foreground "capability" also hinder people with Down syndrome from going higher in their further education. People with Down syndrome have been found to be under-represented in higher levels of further education. This concurs with existing literature on disadvantaged learners (Bruniges et al., 2023; Cavallaro et al., 2005; Griffin, 2014; Joyce, 2019; Karmel & Nguyen, 2008), suggesting that it is a longstanding inequity. The research has found that the perceived lack of academic and linguistic capital in people

with Down syndrome is a primary factor for their under-participation in higher education and higher levels of VET.

At the same time, it has been found that opportunities for higher-level study need to be made available to people with Down syndrome if they are to increase their levels of academic and linguistic capital. As Kliewer (1998) has argued in relation to children with Down syndrome in schools, people with Down syndrome who do not conform to nor perform socially accepted literacy practices are not to be marginalised and excluded from literacy-developing activities. In other words, people with Down syndrome need not be excluded from higher-level study simply because they do not currently possess the privileged forms of literacy on which higher-level courses are built. In addition to this, as was noted by one parent participant, one issue in Australia is that there are currently only two inclusion programs that enable people with intellectual disability to experience university study as audit participants (National Disability Services, 2021). Yet, these are the very programs that can enable people with Down syndrome, such as Renee, to build up their academic skills to eventually be enrolled in higher education.

Summary

Embodied cultural capital is essential for participating in post-secondary education. People with Down syndrome who can navigate their physiological impairments, have a resilient disposition, can act and behave in socioculturally accepted ways, and/or possess a particular level of literacy, numeracy, and multiliteracy skills are better positioned to attaining further education opportunities. Having these forms of physical, behavioural, and linguistic capital provides some people with Down syndrome with advantages in VET and university fields. In particular, linguistic and academic capital play a distinct role in that they enable people with Down syndrome to progress further into university and/or higher levels of VET. Physical capital and behavioural capital, on the other hand, are seemingly not able to facilitate

such higher-level opportunities. Although the findings in this section have framed cultural capital in rather individualistic terms, the research has also found that many forms of capital are derived from the family (see concluding chapter).

These findings shed light on the idea that embodied cultural capital is intricately connected to one's "biological capacity" (p. 245), which affects one's potentialities in accumulating cultural capital in education fields (Bourdieu, 1986). Importantly, the findings contribute to addressing the need to research how issues of embodiment and impairment impact on further education journeys for people with disability. This has been identified as a gap in the existing literature on VET (Ferrier & Selby Smith, 2010) and higher education (National Centre for Student Equity in Higher Education, 2017).

Conclusion

The key findings in relation to the four sub-questions of this thesis have been discussed in this penultimate chapter. The fields of post-secondary education in Australia are perceived and experienced by people with Down syndrome and their families in varied ways. Barriers within VET and higher education fields, along with ideological contestations on values such as "excellence" and "equity", can hinder people with Down syndrome from successfully accessing and participating in further study. To navigate these fields effectively, people with Down syndrome and their parents and carers must exercise self-determination whilst also utilising a range of capital to their advantage.

People with Down syndrome often make self-determined decisions towards further education based on their personal interests, abilities, and goals for learning and employment. Their self-determination is exercised and developed primarily within the family context, where parents and carers play vital roles in both fulfilling and redirecting that self-determination. Self-

determination throughout further education journeys is, therefore, an individual and a social construct. Most importantly, self-determination requires family capital and personal capital for it to be realised. Parents and carers who are well resourced with relevant forms of economic, social, and cultural capital are well positioned to support the post-secondary learning of their children with Down syndrome. The forms of embodied cultural capital that people with Down syndrome themselves might possess are also advantageous for further education journeys. As a whole, the participants with Down syndrome and their parents in this research have been found to hold numerous resources that have made it possible for them to navigate significant barriers within VET and higher education fields.

Chapter 11: Self-determination and capital in further education journeys

Conclusion

Wrapping up the thesis

In this final chapter, the key findings of this research are synthesised to address the main research question: How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome? The chapter theorises five ways by which capital and self-determination have been found to interrelate. It is necessary to provide a novel theorising of further education experiences of people with Down syndrome, because the existing literature on this topic is rather under-theorised. In this chapter, the contributions of this research are also highlighted to stress the significance of this study, as well as the implications of the research for several stakeholder groups. Recommendations for future research are also suggested, before concluding remarks are offered.

Relating capital and self-determination

Overall, this thesis argues that people with Down syndrome require access to various socially valued forms of capital to fulfil their self-determination towards and in post-secondary education. Whilst people with Down syndrome express self-determination in their choice making and decision making towards further education, the execution of these choices and decisions require a range of family and personal capital. Similarly, as much as people with Down syndrome develop their self-determination by participating in post-secondary education contexts, this personal growth is enabled by a

variety of resources. This research advances the literature which finds that the self-determination of people with disability, in and of itself, is not sufficient for enabling positive post-school transitions such as participation in further education.

Before discussing this main finding further, it should be emphasised that all individuals with Down syndrome, as well as their families, are unique in many ways, including in their perceived levels of self-determination and capital. Moreover, not all people with Down syndrome have access to relevant forms of capital that can enable them to fulfil their self-determination in further education. This means, inevitably, there are inequalities within Down syndrome communities with respect to post-school outcomes and other quality of life issues more broadly.

The following discussion theorises five main ways by which capital and self-determination are found to be related in the post-secondary learning journeys of people with Down syndrome.

1. Family capital supports self-determination

This thesis has shown that the first and most important relationship between self-determination and capital is that self-determination requires family capital for it to be fulfilled. Parents and carers of people with Down syndrome may have access to significant forms of capital that can enable their family member with Down syndrome to fulfil their self-determination in post-secondary education. As Bourdieu (1986) explains, capital is transmitted within the family unit. In this study, individuals with Down syndrome have been found to benefit significantly from their family capital. Being well educated and/or having a professional background have been found in this research to provide parents and carers with relevant economic, social, and cultural capital to enable further education journeys for their children.

The families who participated in this study were largely well equipped in this regard. Although they encountered barriers within further education fields, the families were able to draw upon a range of resources to overcome those barriers. On the one hand, because they have a "disability", the participants with Down syndrome in this study fit the category of "disadvantaged learners", the term often used within VET and higher education discourses (e.g. Department of Education, 2024b; Lamb et al., 2018). On the other hand, the participants in this study could be seen as being among the more "advantaged" or "privileged" members of the "disadvantaged cohorts".

This is because, according to the interview data, the participants did not appear to experience overlapping disadvantages, unlike many other people among equity cohorts (Bruniges et al., 2023; Butler & Ferrier, 2022). That is, the families' socioeconomic, ethnic, cultural, and linguistic backgrounds were not ones of disadvantage. Instead, their social backgrounds can be likened to those of the families in Taylor et al.'s (2019) study: "They belong to racial and linguistic majorities, benefit from formal and informal support networks and have high socioeconomic statuses. Their resources… proved essential to successful [post-school] transitions" (p. 1125). From a Bourdieusian perspective, the families had cultural, social, and economic capital to fulfil their children's self-determination towards post-secondary education. As Goodley (2014) states, disability intersects with other social identity markers in complex ways. In the case of the families in this research, these interactions were for the better.

Economic capital has been found by this research to support self-determination. Like many other families who have participated in Down syndrome research more widely (e.g. Channell et al., 2023; Gabel & Kotel, 2018; Lalvani, 2011), the socioeconomic backgrounds of the families in this study were not ones of disadvantage. Instead, the families have been able to provide a financially stable home environment in which people with Down

syndrome were brought up and, ultimately, supported throughout their further education. With this kind of family background, people with Down syndrome have been free of financial pressures to invest time and effort into university and/or VET studies. This finding confirms that economic capital affords time for post-compulsory education (Bourdieu, 1986). For people with Down syndrome in this study, additional supports outside of their learning institutions have also been accessed by use of family income. Although people with Down syndrome have been found in this study to generally be self-determined and resilient, like the learner in Hamill's (2003) research, their perseverance in learning has been reinforced by paid supports such as external tutors and peer mentors. It is uncertain to what extent their further education journeys would have been successful without their family's financial resources.

Social capital has been found in this research to be accumulated by parents and carers from their education and professional backgrounds. Family connections to further education stakeholders facilitate the transition into VET and university for people with Down syndrome. This finding is consistent with that of Casale-Giannola and Kamens (2006). Accessing post-secondary education is observed to be made easier with prior personal connections to relevant stakeholders in the field. This study attests that social capital acts, therefore, as a "multiplier" (p. 249) of cultural capital (Bourdieu, 1986).

In further education fields in Australia, there are structural barriers that hinder people from accessing further study (Bruniges et al., 2023; Productivity Commission, 2020). Barriers such as the difficulty of accessing information to aid students' choice making often hinder already-disadvantaged cohorts more than the general population (Productivity Commission, 2020). It may have been anticipated, therefore, that all people with Down syndrome would be obstructed from engaging in further education. This, however, has not been found to be the case among the participants in this research. The reason is

that families who have social capital are well positioned to overcome those barriers. People with Down syndrome in socially connected families can more readily access tailored information supports and guidance, as the participants in this study have.

This research has found cultural capital to be an invaluable asset gained by families' education and professional backgrounds and one that can significantly shape post-school journeys. It is the most significant form of capital in this regard. This finding parallels that of Albright et al. (2018). People with Down syndrome who are born into well-educated families have advantages in their learning and development while growing up. The findings support existing studies reporting that parent education levels influence the cognitive functioning of people with Down syndrome (Evans & Uljarević, 2018; Golden & Pashayan, 1976; Wasant et al., 2008) which, in turn, shapes self-determination in people with Down syndrome (Landuran et al., 2022).

The link between family background and self-determination in people with Down syndrome has been shown in this research to be related to how people with Down syndrome are brought up in the home environment. The families in this research have placed importance on helping their family member with Down syndrome to attain a self-determined sense of quality of life. Additionally, the families have intentionally raised their children in ways that might develop self-determined dispositions. This involves building up their independence and not treating them as passive care-receivers. The finding supports existing research showing that parenting practices can shape the executive functioning and goal-oriented behaviours of infants with Down syndrome (Schworer et al., 2020). Developing self-determination in children with Down syndrome also involves teaching them self-regulation and "good behaviour". The findings indicate that people with Down syndrome in well-educated families are intentionally given opportunities to grow in their self-determination. Furthermore, the self-determination that leads into and

develops throughout post-secondary education is a product of lifelong and lifewide experiences initiated by family capital.

Another advantage that families with strong education and professional backgrounds have is the knowledge and confidence to advocate for their children with Down syndrome to be included in mainstream schools. This study has confirmed that such advocacy is also fundamental in post-secondary education fields. Parents and carers who are intentional and assured can create opportunities for further education that their child with Down syndrome expresses interest in but would not ordinarily be available to them. These findings attest that well-educated parents and carers with professional backgrounds are strongly positioned to advocate the inclusion of their children with Down syndrome in mainstream education (Gabel & Kotel, 2018). This thesis provides insight into how advocacy occurs within VET and university fields.

Additionally, this research has demonstrated that families with cultural capital have the means and knowledge to help people with Down syndrome to succeed in further study. Such families provide not only an optimism towards the post-school learning potential of people with Down syndrome, but also the time and knowledge to reinforce the content learning in the home setting. This further strengthens the disposition and self-determination to learn for people with Down syndrome. Self-determined learners are not simply self-motivated and self-reliant but are well-supported and well-resourced learners. These findings confirm that post-secondary learners with Down syndrome attain greater success in their learning when their parents and carers are involved in reinforcing that learning (Casale-Giannola & Kamens, 2006; Hamill, 2003).

This study, however, has also found that parent support in the learning process varies from family to family. Families appear to be less involved when the person with Down syndrome is studying in VET compared to if they are

studying in university. Parents have reported that, when asking about VET homework and assignments, their children with Down syndrome say that this work is completed at their college. It has been found that TAFE colleges usually provide adequate support to learners with Down syndrome in relation to their assessment tasks. Moreover, because of communication issues with their children or other barriers, parents and carers might have little insight into the specific details on their child's VET studies. In contrast, families have positioned themselves as the "learning community" when their child is in higher education. These findings suggest that families' hands-on engagement in the learning process is especially vital for post-secondary learners with Down syndrome who are studying higher-level qualifications. This is related to the finding that higher education fields are perceived to be less supportive and less accommodating than VET contexts.

To summarise, the central way in which self-determination and capital relate is that family capital supports the individual self-determination of people with Down syndrome in further education contexts. Without the economic, social, and cultural resources afforded by parents and carers, it is uncertain to what extent people with Down syndrome might access and participate meaningfully and successfully in VET and higher education.

2. Personal capital shapes self-determination

A second way in which capital and self-determination interrelate is that people with Down syndrome themselves possess various forms of capital which impact on their self-determination in further education contexts. Although individual capital is largely inherited from family (Bourdieu, 1986), it is helpful to analyse the personal knowledge and competencies that people with Down syndrome bring on their post-school learning journeys.

The research findings concur with Wehmeyer's (2003a) functional model, which states that one's "capacity" (p. 179) is a major factor that shapes self-

determination. Concurrently, this research has found that self-determination can be theorised along sociological lines by using the concept of "embodied cultural capital" (Bourdieu, 1986). That is, it has been observed by this study that one's "capacity" to be self-determined depends, in part, on their possession of embodied cultural capital. The nature of the physical, behavioural, and linguistic capital that a person with Down syndrome has influences their self-determination in post-secondary education and other contexts.

The present study has confirmed the understanding that self-determination is linked to communication and social skills (Abery & Stancliffe, 2003b). Existing research has found some connection between communication skills and post-school transition outcomes, including post-secondary learning, for young people with Down syndrome (Foley et al., 2013). The present study has found that the ability to express self-determination in choice making and decision making depends, in large part, on the communication skills of the person with Down syndrome. The research has also found that the communication skills and styles of people with Down syndrome varied considerably. This finding concurs with existing literature (Fidler & Daunhauer, 2011; Martin et al., 2009),

This research has found that one's self-determination is perceived to be greater when one is perceived to have better communication skills (i.e. linguistic capital). Through communication, people with Down syndrome can demonstrate aspects of self-determination such as decision making. Having higher levels of communication enables people with Down syndrome to invite family members to collaborate in decision making. People with Down syndrome who are perceived to have lower communication skills might have difficulty in helping others to understand the goals and decisions they have towards further education. This finding has implications for how a person with Down syndrome might engage in joint decision making and sharing control

with trusted family members. These are important aspects of self-determination according to the tripartite ecological theory (Abery & Stancliffe, 2003b). The research, therefore, provides insight into the complexities with understanding self-determination from the tripartite perspective.

Self-determined learning in people with Down syndrome has been found to be dependent on their linguistic capital. Literacy, in the traditional sense of reading and writing, has been found to be one important form of linguistic capital, confirming Bourdieu's (1986) theory. Having literacy skills enables people with Down syndrome to persist in their reading and writing development. The findings confirm that literacy and numeracy skills are essential for participating in VET and higher education fields, as reported by Joyce (2019) and the Department of Education (2024b). As academic challenges are faced by learners with Down syndrome, having relevant literacy and numeracy skills can make it possible for these obstacles to be overcome. It is necessary for people with Down syndrome to have field-specific literacy skills, particularly within higher education contexts.

At the same time, the linguistic capital that people with Down syndrome possess needs to be valued by others in the field. The research has found that people with Down syndrome experience education fields to privilege certain linguistic codes and practices, such as particular styles of writing, as being more legitimate and valuable. This finding confirms the critical view towards education systems which Bourdieu and Passeron (1977) hold. It is important that people with Down syndrome are not disadvantaged in higher education and VET fields because of their "non-normative" linguistic practices. Additionally, the multiliteracy strengths that people with Down syndrome have can enhance their self-determined learning. The study has found that motivation, as a central aspect of self-determined behaviour (Wehmeyer, 2003d), can be strengthened in learners with Down syndrome by providing them with learning challenges that suit their multiliterate interests and needs.

These findings concur with the existing studies by Kliewer (1998), Gilmore and Cuskelly (2014), and Moni and Jobling (2014).

As people with Down syndrome participate in further education contexts, their self-determination is presented with opportunities for development on account of their physical capital. Post-secondary education is a bodily experience, meaning that one's lived experiences of it are shaped by issues of embodiment and impairment. For post-secondary students with Down syndrome, health issues and general tiredness have been found to affect their bodies' capacity to acquire cultural capital in university and VET, as Bourdieu (1986) would say. At the same time, physiological barriers present opportunities to act in self-determined ways (i.e. to be resilient in navigating the challenges of having impairments). Instead of judging impairments in Down syndrome as "weaknesses" and "deficiencies" as some ableist discourses do (e.g. Powell-Hamilton, 2023), the research has found that impairments can be conceptualised as "double-edged swords" of sorts. That is, impairments have the potential to produce self-determination or to hinder it. In this research, people with Down syndrome have been found to persist in their further study through their bodily struggles. By doing so, they also strengthen their disposition to act in self-determined ways, thereby increasing their embodied cultural capital.

Finally, behavioural capital has been found to also impact on self-determination throughout further education journeys. People with Down syndrome who have the benefit of knowing how to conduct oneself in further education settings are more likely to experience inclusion and support in such contexts. In principle, all VET and university learners with Down syndrome have the right to be supported by their learning institutions. Yet, it might also be the case that those who do not exhibit "problem behaviours" might gain that support more readily.

In short, people with Down syndrome themselves can possess forms of embodied cultural capital that enable them to fulfil their goals in further education. Despite family capital being a greater facilitator of self-determination, one's own personal capital is also a key player in post-secondary learning journeys.

3. Capital operates in the absence of self-determination

A third way in which self-determination and capital interrelate is that forms of capital can enable further education journeys even when self-determination is seemingly absent. Whilst many of the previous findings have foregrounded the self-determination of people with Down syndrome, the research has also found that self-determination is not always necessary for post-secondary education opportunities to come about.

Family cultural capital can offset a perceived under-development of self-determination in an individual with Down syndrome. For example, parents and carers might exercise more control than their child with Down syndrome in making decisions regarding post-school transitions when they perceive a relative under-development of self-determination in their child. The research has found that, within well-informed and supportive families (i.e. those with cultural capital), such decisions are made in the perceived best interests of the person with Down syndrome. Communication difficulties, an apparent lack of awareness towards post-school transitions, and/or other issues experienced by a person with Down syndrome have been found to indicate to families that they do not (yet) have specific goals or plans towards further education. This can prompt parents and carers to employ their knowledge of their child and of social fields to consider post-secondary options.

As pointed out by Faragher (2023), VET and higher education can come about without intentional planning. The study has found that even parents and carers themselves might not identify a particular further education

opportunity as a possible option, but that this does not preclude that option from eventuating. That is because family and individual capital can act in place of self-determination in both people with Down syndrome and their parents or carers. Social capital has been observed to facilitate further education opportunities that were not originally chosen by people with Down syndrome nor their families.

In short, these findings show that self-determination is not always required in the first instance to initiate post-secondary education journeys. Importantly, family and individual capital can operate in lieu of self-determination to create such journeys.

4. Self-determination is determined by capital

A fourth way that self-determination and capital are related is that one's capital determines, to some extent, the nature of one's self-determination. The thesis argues in favour of the view that one's choices and decisions are never entirely free, conscious choices and decisions (Bourdieu, 1998). The research findings attest that choice making and decision making are constrained by one's capital.

People with Down syndrome have their self-determined dispositions towards post-school education shaped by their home environment. Therefore, even when the decision to study in post-secondary education is framed as being owned by the person with Down syndrome, that decision is also the product of that individual's family ecology. The school environment also shapes the plans for further education that people with Down syndrome adopt for themselves. A "natural" or taken-for-granted pathway after secondary school is only so because it is the post-school transition that a person has observed most other people to undertake. Social capital, therefore, determines post-secondary choices and decisions (to a large extent).

People with Down syndrome look to role-models to make plans and decisions regarding further study. The findings in this research are significant in light of how people with Down syndrome have been said to have strengths in "imitation" (Down, 1866; Faragher et al., 2020). While some reservation has been expressed in Chapter 4 towards the idea that people with Down syndrome should "conform" to societal expectations and ways of being, it is important to observe that individuals with Down syndrome do, indeed, have their post-secondary goals and aspirations strongly moulded by their social networks and society at large.

Contrary to Elster's (1986) rational choice theory, the findings in this study support the view that choices and decisions towards further education are not unconditioned by one's environment and one's access to capital (Bourdieu, 1998; Bourdieu & Wacquant, 1992). The decisions that people with Down syndrome make towards post-secondary learning are not entirely "self-determined", but are always constrained in some way by their capital within social fields. This constraint is present even when those decisions are seen to be positive and empowering ones, such as the decision to go higher in one's further education. As Albright et al. (2018) have pointed out, education research on student aspirations has been predominantly undertaken using rational choice theory, so there is a need to adopt a critical Bourdieusian sociology to inform future research. This thesis contributes to such research.

5. Self-determination itself is a form of capital

A final way in which self-determination and capital interrelate is that self-determination itself can be theorised as a form of embodied cultural capital. People with Down syndrome have been found to have dispositions towards VET and higher education. Such dispositions of the body and mind, as Bourdieu (1986) would argue, are forms of embodied cultural capital that determine how people with Down syndrome aspire to participate in further education. As Albright et al. (2018) would state, the post-school aspirations of

people with Down syndrome towards education and employment are a form of cultural capital in themselves.

The present study finds numerous ways in which self-determination has acted as a form of capital for the participants. Self-determination in people with Down syndrome has been found to contribute to enabling participation and success in post-secondary education. People with Down syndrome who make self-determined choices and decisions can "cause" further education opportunities to eventuate. Learners with Down syndrome who are self-determined can navigate various challenges within VET and higher education fields to ensure that they complete and/or benefit from their further study.

In short, this thesis contributes a novel way of theorising the post-secondary education journeys of people with Down syndrome. Specifically, self-determination and capital have been theorised as being interrelated in five distinct ways in these journeys: Firstly, family capital supports self-determination in people with Down syndrome. Secondly, the personal capital of people with Down syndrome shapes their self-determination. Thirdly, family and personal capital operate in the absence of self-determination. Fourthly, self-determination in people with Down syndrome is determined by their personal and family capital. Finally, self-determination itself can be conceptualised as a form of embodied cultural capital. Understanding the VET and higher education journeys of people with Down syndrome in these ways contributes to the much-needed theorising of this important topic.

Summary of main argument

This thesis has generated insight into the question: How do self-determination and capital interrelate to facilitate the post-secondary education journeys of people with Down syndrome?

The thesis has argued that self-determination in people with Down syndrome within further education fields requires the support of family and personal capital for it to be fulfilled. The economic, social, and cultural resources to which families have access can enable post-secondary learning opportunities to come about and be successful for people with Down syndrome. Family cultural capital is the most important form of capital in fulfilling self-determination in people with Down syndrome on their further education journeys. People with Down syndrome who are self-determined and have access to socially valued forms of capital are better positioned to navigate the complex barriers and challenges encountered in vocational education and training (VET) and higher education fields in Australia. Engaging in Down syndrome research in a critical sociological manner, as this thesis has done, is vital because it has the potential to uncover inequalities that might exist within Down syndrome communities.

Contributions of the research

The significance of the thesis relates to four major contributions.

The first major contribution is towards knowledge about people with Down syndrome and their post-secondary education journeys. The literature on this important topic is scarce, particularly with respect to learners with Down syndrome in mainstream VET contexts. This study has engaged people with Down syndrome from both VET and higher education contexts, with an emphasis on the former. Moreover, several distinct findings have been made by this study. The complex decision-making processes in people with Down syndrome towards further education have been elucidated. It has been argued that decisions toward further study are profoundly shaped by family backgrounds, classmates and peers, prior experiences of VET in school, as well as broader ideological discourses on VET and higher education as means to economic success. In addition, new knowledge has been generated on the

intricate roles that parents and carers perform when they perceive that their family member with Down syndrome either seemingly does not have further education goals or has further education goals that are seemingly unrealistic. Another distinct finding relates to areas of growth that people with Down syndrome attain by participating in further education. Whilst academic learning and vocational skills development have both been enhanced in post-secondary learners with Down syndrome, it has been found that families also place a strong emphasis on non-academic areas in which learners have developed. By engaging in further study, people with Down syndrome develop their independence as adults, as well as their everyday decision-making and problem-solving skills.

The second major contribution of the thesis is towards theory building. Not only is the existing literature on further education for people with Down syndrome scarce, but it is arguably also somewhat under-theorised. This thesis, in contrast, has been firmly grounded in theories on self-determination and capital. It, therefore, proposes a novel way of understanding the post-secondary education journeys of people with Down syndrome. The thesis has shown how both self-determination and capital operate in complex, varied ways in further education learners with Down syndrome. Notably, the research has integrated knowledge from two academic fields, namely psychology and sociology, which historically have been relatively divergent. The thesis represents, therefore, a significant step towards the interdisciplinarity and postconventionalism that critical disability scholars have called for (Shildrick, 2020).

This thesis contributes to informing and expanding theories on self-determination and capital alike. On the psychological side, the current study has generated insights on how the self-determination of a person with disability is shaped by their “capacity” (Wehmeyer, 2003a) and “competencies” (Abery & Stancliffe, 2003b). It has been argued that

communication skills (i.e. forms of linguistic capital) influence how people with Down syndrome express their choices and decisions to their parents and carers. This, in turn, influences how families support self-determination and enable collaborative decision making with the interests of the person with Down syndrome at heart. The thesis, therefore, contributes to understanding how "control" is shared within families of people with Down syndrome (Abery & Stancliffe, 2003b). At the same time, the thesis has identified some of the potential limitations of self-determination theory. For instance, when self-determination is theorised along the lines of Elster's (1986) rational choice theory (Mithaug et al., 2002), it potentially minimises the roles that family background and capital play in moulding self-determined dispositions (Bourdieu, 1998; Bourdieu & Wacquant, 1992).

The thesis contributes to the conceptualisation of "self-determination" as a form of "capital". This has been done by foregrounding the notion of "embodied dispositions" as an important bridge between theories on "self-determination" and "capital". Self-determination is a disposition in that it describes the tendency that self-determined people possess to think and behave in self-determined ways (Wehmeyer, 2003a). Dispositions, meanwhile, are forms of cultural capital in that how a person tends to think and behave can be a valuable resource for acquiring capital within social fields (Bourdieu, 1986; Edgerton & Roberts, 2014). It is possible, therefore, to conceptualise self-determined dispositions as cultural capital. Furthermore, self-determination is embodied cultural capital, because it is the product of "the organization of cognitive, psychological, and physiological elements" (p. 179) of people's bodies and minds (Wehmeyer, 2003a). The implication is that self-determination is formed according to one's "capacity" (Wehmeyer, 2003a, p. 179), just as embodied cultural capital is accumulated according to one's "biological capacity" (Bourdieu, 1986, p. 245). While their emphases differ, both self-determination and capital are perceived to be essential for human agents to attain gains in their lives within social fields. Approaching

both “self-determination” and “capital” with the above emphasises contributes to the theorising of both concepts, as well as moving “self-determination” in the direction of critical sociology.

Meanwhile, on the sociological side, the thesis has proven the ongoing relevance of Bourdieusian thinking for disability research in the field of education. The research has demonstrated how cultural capital in people with Down syndrome and their families is the most significant enabler of post-secondary education for people with Down syndrome (Bourdieu, 1986; Bourdieu & Passeron, 1977). In addition, it has determined the ways by which cultural capital is “multiplied” (Bourdieu, 1986) and “accelerated” (Grenfell, 2009) by economic and social capital for VET and higher education learners with Down syndrome. Moreover, the thesis has argued that this multiplication and acceleration process is effective only insofar as people with Down syndrome already possess potential and capabilities for further education. Significantly, it has been argued that, while they are generally “disadvantaged” and “marginalised” members of society, some people with Down syndrome possess and have access to valuable resources that facilitate their further education journeys. Such individuals have, therefore, advantages over others with the same disability. This argument is exceptionally significant, because the issue of inequality within Down syndrome communities is something of an “elephant in the room”. The thesis has brought a much-needed sociological emphasis to Down syndrome research, a field which is predominantly informed by psychological-developmental research (Burack et al., 2023).

The third major contribution of the thesis is towards the higher education and VET fields in Australia. The research has uncovered a range of barriers that people with Down syndrome face within further education fields. Even more importantly, it has generated insight into how those barriers are navigated by individuals with Down syndrome and their families. For some time, further

education reports have stated that future research should explore not only the barriers encountered by people with disability, but how people with disability might overcome those barriers (Griffin & Nechvoglod, 2008). Additionally, the research has highlighted how issues of impairment shape the further education journeys of people with Down syndrome. This has been identified by VET and higher education reports as an area in need of research for people with disability more broadly (Ferrier & Selby Smith, 2010; National Centre for Student Equity in Higher Education, 2017). Existing research on post-secondary students with Down syndrome has tended to speak generally of "challenges" faced by these learners without exploring these "challenges" in relation to physiological conditions associated with Down syndrome. In contrast, the present research has, without falling into a deficit-based view, analysed how Down syndrome as a disability impacts on one's participation in VET and university. Moreover, the thesis has argued that further education fields are perceived in varied ways among people with Down syndrome and their families. It has not only confirmed that notions such as "equity" and "excellence" are contested within further education fields (Butler & Ferrier, 2022; Rizvi & Lingard, 2011) but, more significantly, how these taken-for-granted values shape the lived experiences of people with Down syndrome in these learning fields.

Finally, the fourth major contribution of the thesis relates to its critical, reflexive research methodology. The discussions on how decisions on the study were made and how the research unfolded have been both detailed and candid. A significant strength of the thesis is its transparent account on the difficulties encountered despite the researcher's best intentions to undertake the research in an inclusive and sensitive manner. Down syndrome research is of utmost importance for people with Down syndrome, their families, and society at large, but it must not be idealised by concealing or minimising its challenges. By reading and reflecting on this thesis, researchers can be better informed on how research with people with Down syndrome might be

undertaken. For instance, the methodological decision on whether research interviews should be more or less structured needs to be made with the actual participants in mind, given that individuals with Down syndrome have a range of communicative strengths and challenges.

Implications of the research

This thesis has argued that the self-determination and capital of people with Down syndrome and their families interrelate in complex ways to enable and facilitate the post-secondary education journeys of people with Down syndrome. In light of this central argument, there are several important implications for the varied stakeholders with whom this research concerns.

People with Down syndrome have the right to exercise and develop their self-determination to enhance their personal outcomes and quality of life in further education and other life domains. An awareness of the possibilities of and options for participating in VET and higher education is to be raised among people with Down syndrome. Additionally, people with Down syndrome are to be supported as they develop a self-understanding of their personal strengths, limitations, interests, and needs, and how these factors might impact on their post-secondary learning. People with Down syndrome can develop and perform a positive sense of self in relation to further study, disrupting deficit-based, ableist attitudes towards them. Importantly, the voices and lived experiences of people with Down syndrome should be given central attention in all stages of their further education journeys. Individuals with Down syndrome are, in their own unique ways, capable and resourced to participate in mainstream VET and university fields. Like everybody else in society, people with Down syndrome have a fundamental right to access further education, should they choose to do so. At the same time, it is necessary to recognise that aspirations towards post-secondary education are inevitability socially and ideologically produced. This means that the

expectation that people with Down syndrome should participate in VET and/or higher education should, to some extent, be problematised. People with Down syndrome must also be supported to be self-determined to find quality of life in many other life domains apart from further education. What matters most is that quality of life is defined by people with Down syndrome themselves.

For communities of people with Down syndrome at local, national, and international levels, there is a need to raise awareness of further education opportunities. The stories of people with Down syndrome who have participated in post-secondary learning contexts should be intentionally shared within Down syndrome communities. In Australia and around the world, there are well-established communication channels such as newsletters, social media posts, webinars and seminars, and conferences and events within Down syndrome communities and organisations through which further education experiences can be promoted. Given that social capital is crucial for facilitating university and VET participation, Down syndrome communities must be well connected internally and externally. The mutual sharing of information, knowledge, personal connections to further education stakeholders and institutions, and other resources can help to address the reality that not every person with Down syndrome has access to forms of capital that enable further study. There is a need for Down syndrome communities and associations to attend to reducing the inequalities that might exist within their folds.

Families of people with Down syndrome play a fundamental role in developing both the self-determination and capital of people with Down syndrome for post-secondary education and other life contexts. Parents and carers should be encouraged to consider how their personal backgrounds and social networks might be utilised to support their children's engagement with further education. University and VET journeys are inevitably shaped by lifelong and

lifewide experiences, which the family unit is usually a constant participator of and contributor to, alongside the individual with Down syndrome. This means not only that parents and carers can be actively promoting learning and self-determination throughout all life stages in the person with Down syndrome, but also that they must take an active role in collaborating with important stakeholders within further education and other social fields. At the same time, since families are not equally resourced (economically, culturally, and/or socially) to support and advocate for people with Down syndrome, they themselves must be assisted by a range of stakeholders.

Schools and other learning contexts are primary ecologies in which people with Down syndrome grow in their self-determination, capital, and overall development. Fundamentally, inclusive mainstream schooling must continually be improved for and available to people with Down syndrome and other disabilities. Early childhood and primary and secondary school teachers and staff members can adopt inclusive pedagogies and practices, which can ultimately prepare children and young people with Down syndrome to engage in further study. Skills for independence and learning can be targeted throughout all stages of childhood and schooling. Stakeholders within schools and learning contexts adopting a strengths-based perspective on learners with Down syndrome can promote growth and learning in this cohort. At the same time, educators must be assisted with appropriate training and support to include learners with Down syndrome in their classes. Furthermore, partnering with families of people with Down syndrome, external services and organisations, and other stakeholders is an important role that players in education fields can perform to prepare children and young people with Down syndrome for post-secondary education. In particular, schools can facilitate work experience programs and VET experiences because these opportunities significantly shape the post-school transitions of this learner group.

A range of stakeholders within VET and higher education fields can support people with Down syndrome in their access of and participation in these spaces. Reports from policymakers and other experts on further education systems need to reflect greater awareness of how people with disability are positioned and portrayed within their discourses. Contested ideas such as "equity", "capability", and "excellence" must be critically examined to ensure that people with disability (and other disadvantaged cohorts) are not inadvertently marginalised within the "widening participation" discourses that promote their inclusion. Teaching staff in VET and higher education fields are closely and personally involved in the further education experiences of people with Down syndrome. These important players can promote success in learning for this student population by accommodating their diverse needs, strengths, and challenges in further study. Educators within universities and VET colleges are likely to benefit from greater support and training to include students with Down syndrome. As a whole, the two sectors can collaborate to reach prospective learners with Down syndrome, without positioning either field above the other.

In all this, it should be stressed again that the voices of people with Down syndrome must be listened to by those who are involved in their post-secondary education journeys.

Recommendations for future research

Notwithstanding the significant contributions and implications of this research, the study has several limitations that can be addressed by future research.

One limitation is that the participants do not adequately represent the diversity of people within Down syndrome communities in Australia. The families who participated in the research could be seen as representing only "success stories". All the participants with Down syndrome had already

engaged in further education or were doing so. The parents were, likewise, "successes" in their own right, as they were strong advocates for their children. From a sociological perspective, moreover, the participants represented the "dominant" groups in Australian society, due to their ethnic, cultural, linguistic, and socioeconomic backgrounds. The issue of sampling bias appears to be a relatively common issue that persists in Down syndrome research (e.g. Channell et al., 2023; Krueger et al., 2019; Onnivello et al., 2023; Skotko et al., 2016). It is crucial for future research to address this issue to analyse inequalities that might exist along socioeconomic, ethnic, cultural, and/or other lines within Down syndrome communities. Participants from more diverse backgrounds might be engaged through connections with a broader range of Down syndrome and disability organisations, services, and stakeholders.

Another possibility for future research is to undertake a more inclusive research project. As Nind (2014) points out, inclusive research exists as a continuum. Although this research applied several practices to enhance its accessibility, it remained largely researcher led. People with Down syndrome are increasingly taking ownership of research concerning their lives (Faragher et al., 2024; White & Morgan, 2012). There is potential, then, for future research on post-secondary education to be undertaken in collaboration with people with Down syndrome. The benefits of doing inclusive research would include the framing of the research in ways that people with Down syndrome consider to be important and relevant, as well as mitigating the power imbalances between researchers and participants. Undertaking inclusive research would require investing time and effort into establishing relationships with people with Down syndrome, as well as with families, organisations, and other relevant stakeholders.

Other possibilities for future research relate to methodological issues. In the present study, one difficulty encountered was that the participants with Down

syndrome sometimes did not know, could not remember, or were unable to express some of the details regarding their education journeys. Future research on this topic could, therefore, be conducted as an ethnography. Doing fieldwork would enable researchers to observe the intricate events that occur when people with Down syndrome participate in VET and/or higher education settings. The observations would generate rich data and can also give shape to the interviews with the participants. Moreover, an ethnography would provide opportunities to explore the views of a broader range of stakeholders, including peers and classmates of people with Down syndrome. The present study has highlighted that post-secondary pathways are shaped by numerous players within the social networks of people with Down syndrome. Another methodological possibility is to incorporate some quantitative research methods. The current study has been greatly informed by existing quantitative studies on issues related to living with Down syndrome. For future studies, a quantitative tool could be cautiously used to further explore self-determination in people with Down syndrome, specifically toward further education. Doing so could enable researchers to contribute to quantitative self-determination literature in disability studies.

The topic of post-secondary education journeys of people with Down syndrome is one in need of further exploration. Diversity in research design for this topic is to be encouraged.

Closing remarks

People with Down syndrome and their families can be highly self-determined and well-resourced members of society. The personal outcomes and quality of life of people with Down syndrome have been increasing in recent decades. Many barriers in social fields such as post-secondary education have been or are being dismantled for and by people with Down syndrome and their families. When university and vocational education and training (VET) fields

are further reformed according to principles of equity and inclusion, people with Down syndrome will attain greater participation and outcomes in these fields.

It is hoped that this thesis might contribute to equitable changes in further education policies and practices. Fundamentally, it is hoped that this research might encourage people with Down syndrome, along with their families and communities, to exercise their self-determination towards post-secondary education and to bring together their wide-ranging capital and resources to enable successful journeys through VET and university. Concurrently, it is also recognised that people with Down syndrome should be supported, according to their interests and needs, towards attaining quality of life in a range of post-secondary domains.

For a thesis that has foregrounded the voices and lived experiences of people with Down syndrome, it is fitting for the final word to be from Charlotte Woodward, a person with Down syndrome:

> Thirty-two years ago, on December 18, 1989, in Miami, Florida doctors told my mom that–because I was diagnosed with Down syndrome–I would not be able to read or write… My mom–who had been a teacher before I was born–ignored the doctors' dire predictions and… read to me nonstop. I learned to read, myself, by the time I was 3 and a half years old and went on to graduate, summa cum laude, from Northern Virginia Community College. I then transferred to George Mason University… [T]he Honors Committee of the Sociology Program… selected me to receive the 2022 Outstanding Sociology Undergraduate Award. So, as you can see, what the doctors predicted for me when I was born was absolutely wrong. (Woodward, 2022, p. 732)

References

Abbeduto, L., Arias-Trejo, N., Thurman, A. J., Ramos-Sanchez, J., & del Hoyo Soriano, L. (2023). Language development in Down syndrome. In J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford handbook of Down syndrome and development* (pp. 332–366). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.18

Abbeduto, L., Warren, S. F., & Conners, F. A. (2007). Language development in Down syndrome: From the prelinguistic period to the acquisition of literacy. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(3), 247-261. https://doi.org/10.1002/mrdd.20158

Abery, B. H., & Stancliffe, R. J. (1996). The ecology of self-determination. In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 111-145). Paul H. Brookes Publishing Co.

Abery, B. H., & Stancliffe, R. J. (2003a). An ecological theory of self-determination: Theoretical foundations. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 25-42). Charles C Thomas Publisher, Ltd.

Abery, B. H., & Stancliffe, R. J. (2003b). A tripartite-ecological theory of self-determination. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 43-78). Charles C Thomas Publisher, Ltd.

Adorno, E. T., Dos Santos, D. C., DeJesus, B. M., Passos, A. A., & Teixeira-Machado, L. (2022). Dance, functioning and quality of life in children with Down syndrome and autism spectrum disorder dance, functioning and quality of life in Down syndrome and autism spectrum disorder. *Clinical Child Psychology and Psychiatry*, *27*(4), 967-977. https://doi.org/10.1177/13591045211061795

Agran, M., Blanchard, C., & Wehmeyer, M. L. (2000). Promoting transition goals and self-determination through student self-directed learning: The self-determined learning model of instruction. *Education & Training in Mental Retardation & Developmental Disabilities*, *35*(4), 351-364.

Al Otaiba, S., Lewis, S., Whalon, K., Dyrlund, A., & McKenzie, A. R. (2009). Home literacy environments of young children with Down syndrome: Findings from a web-based survey. *Remedial and Special Education*, *30*(2), 96-107. https://doi.org/10.1177/0741932508315050

Albright, J., Gore, J., Smith, M., & Holmes, K. (2018). Operationalizing Bourdieu for the study of student aspirations: Conceptual and methodological challenges. In G. Stahl, D. Wallace, C. Burke, & S. Threadgold (Eds.), *International perspectives on theorizing aspirations: Applying Bourdieu's tools* (pp. 83-97). Bloomsbury Academic. https://doi.org/10.5040/9781350040359.0015

Aldridge, J. (2015). *Participatory research: Working with vulnerable groups in research and practice*. Policy Press.

Alecu, A., Helland, H., Hjellbrekke, J., & Jarness, V. (2022, 2022/06/01). Who you know: The classed structure of social capital. *The British Journal of Sociology*, *73*(3), 505-535. https://doi.org/10.1111/1468-4446.12945

Allen, G., Benda, C. E., Böök, J. A., Carter, C. O., Ford, C. E., Chu, E. H. Y., Hanhart, E., Jervis, G., Langdon-Down, W., Lejeune, J., Nishimura, H., Oster, J., Penrose, L. S., Polani, P. E., Potter, E., Stern, C., Turpin, R., Warkany, J., & Yannet, H. (1961). "Mongolism". *The Lancet*, *277*(7180), 775-775.

Alrayes, N., Issa, N. M., Alghubayshi, O. Y., Al-Amaa, J. Y., Alsabban, A. H., Al Shaer, D. S., Alyoubi, R. A., Nasser, K. K., & Alkhiary, Y. M. (2024). Quality of life in children with Down syndrome and its association with parent and child demographic characteristics: Parent-reported measures. *Molecular Genetics & Genomic Medicine*, *12*(1), e2337. https://doi.org/10.1002/mgg3.2337

Andrewartha, L., & Harvey, A. (2017). Employability and student equity in higher education: The role of university careers services. *Australian Journal of Career Development*, *26*(2), 71-80. https://doi.org/10.1177/1038416217718365

Angyal, A. (1941). *Foundations for a science of personality*. The Commonwealth Fund.

Arango, P., Aparicio, A., Strasser, K., Rosas, R., & Tenorio, M. (2023). Analysis of home literacy environment in Chilean families of children with Down syndrome. *International Journal of Disability, Development, and Education*, *70*(6), 1008-1023. https://doi.org/10.1080/1034912X.2021.1950650

Arango, P. S., Aparicio, A., & Tenorio, M. (2018). Developmental trajectories of children with Down syndrome by socio-economic status: The case of Latin America. *Journal of Intellectual Disability Research*, *62*(9), 759-774. https://doi.org/10.1111/jir.12516

Archer, L. (2007). Diversity, equality and higher education: A critical reflection on the ab/uses of equity discourse within widening participation. *Teaching in Higher Education*, *12*(5-6), 635-653. https://doi.org/10.1080/13562510701595325

Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, *18*, 1-8. https://doi.org/10.1177/1609406919874596

Disability standards for education 2005, (2005). https://www.legislation.gov.au/Details/F2005L00767

Australian Government. (2019). *Standards for Registered Training Organisations (RTOs) 2015*.

Australian Government. (2020). *Final Report of the 2020 Review of the Disability Standards for Education 2005*.

Australian Government. (2024). *Disability Discrimination Act 1992*.

Australian Institute of Health and Welfare. (2024). *People with disability in Australia 2024*. Australian Institute of Health and Welfare.

Australian National Training Authority. (1998). *Vocational education and training issues for people with a disability*. Australian National Training Authority.

Australian National Training Authority. (2000). *Bridging Pathways: The national strategy for increasing opportunities for people with a disability in vocational education and training from 2000 to 2005*. Australian National Training Authority.

Baksh, R. A., Pape, S. E., Chan, L. F., Aslam, A. A., Gulliford, M. C., & Strydom, A. (2023). Multiple morbidity across the lifespan in people with Down syndrome or intellectual disabilities: A population-based cohort study using electronic health records. *The Lancet. Public health*, *8*(6), e453-e462. https://doi.org/10.1016/S2468-2667(23)00057-9

Barnett, K. (2004). VET-ability: The capacity of the Australian VET system to be inclusive for people with a disability. In K. Bowman (Ed.), *Equity in*

vocational education and training: Research readings (pp. 90-107). National Centre for Vocational Education Research.

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research: QR*, *15*(2), 219-234. https://doi.org/10.1177/1468794112468475

Bird, G., & Buckley, S. (1999). Meeting the educational needs of pupils with Down syndrome in mainstream secondary schools. *Down Syndrome News and Update*, *1*(4), 159-174. https://www.down-syndrome.org/en-au/library/news-update/01/4/meeting-educational-needs-pupils-down-syndrome-mainstream-secondary-schools/

Birrell, B., & Edwards, D. (2009). The Bradley Review and access to higher education in Australia. *Australian Universities' Review*, *51*(1), 4-13.

Borthwick, C. (1996). Racism, IQ and Down's syndrome. *Disability & Society*, *11*(3), 403-410. https://doi.org/10.1080/09687599627688

Bottroff, V., Brown, R., Bullitis, E., Duffield, V., Grantley, J., Kyrkou, M., & Thornley, J. (Eds.). (2001). *Some studies involving individuals with Down syndrome and their relevance to a quality of life model*. Whurr Publishers.

Bourdieu, P. (1977a). The economics of linguistic exchanges. *Social Science Information*, *16*(6), 645-668. https://doi.org/10.1177/053901847701600601

Bourdieu, P. (1977b). *Outline of a theory of practice*. Cambridge University Press. https://doi.org/10.1017/CBO9780511812507

Bourdieu, P. (1978). Sport and social class. *Social Science Information*, *17*(6), 819-840. https://doi.org/10.1177/053901847801700603

Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Routledge & Kegan Paul.

Bourdieu, P. (1985). The market of symbolic goods. *Poetics*, *14*(1), 13-44. https://doi.org/10.1016/0304-422X(85)90003-8

Bourdieu, P. (1986). The forms of capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241-258). Greenwood Press.

Bourdieu, P. (1990). *In other words: Essays toward a reflexive sociology*. Stanford University Press. https://doi.org/10.1515/9781503621558

Bourdieu, P. (1991). *Language and symbolic power*. Polity Press.

Bourdieu, P. (1998). *Practical reason: On the theory of action*. Stanford University Press.

Bourdieu, P., & Passeron, J. C. (1977). *Reproduction in education, society and culture*. Sage Publications.

Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology*. University of Chicago Press.

Bowman, K., & McKenna, S. (2016). *The development of Australia's national training system: A dynamic tension between consistency and flexibility*. National Centre for Vocational Education Research.

Bradley, D., Noonan, P., Nugent, H., & Scales, B. (2008). *Review of Australian higher education: Final report*. Department of Education, Employment and Workplace Relations.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37-47. https://doi.org/10.1002/capr.12360

Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences* (pp. 843-860). Springer.

Bray, M. (2017). *Exploring fluency in Down syndrome: A discussion of speech dysfluencies for professionals and parents*. J & R Press Limited.

Brinkmann, S. (2018). The interview. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (5th ed., pp. 576-599). SAGE Publications Inc.

Brinkmann, S., & Kvale, S. (2018). *Doing interviews* (2nd ed.). SAGE Publications Ltd. https://doi.org/10.4135/9781529716665

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *The American Psychologist*, *32*(7), 513-531. https://doi.org/10.1037/0003-066X.32.7.513

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Brossard, B., & Sallée, N. (2019). Sociology and psychology: What intersections? *European Journal of Social Theory*, *23*(1), 3-14. https://doi.org/10.1177/1368431019844869

Brown, I., Wehmeyer, M. L., Webb, K. W., & Seabrooks-Blackmore, J. (2017). The transition from school to adult life. In M. L. Wehmeyer, I. Brown, M. Percy, K. A. Shogren, & W. L. A. Fung (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 541-555). Paul H. Brookes Publishing, Company.

Brown, J. (2017). *In their words: Student choice in training markets - Victorian examples*. National Centre for Vocational Education Research.

Brown, R. I. (2014). A lifespan approach to learning in the context of quality of life. In R. Faragher & B. K. Clarke (Eds.), *Educating learners with Down syndrome: Research, theory and practice with children and adolescents* (pp. 19-39). Routledge.

Brown, R. I., Kyrkou, M. R., Watchman, K., & Hodapp, R. M. (2020). A brief history of Down syndrome: Key moments and reflections. In J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford handbook of Down syndrome and development* (pp. 3-18). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.1

Bruniges, M., Ardler, J., & Firth, V. (2023). *NSW VET Review: Interim Report | December 2023*.

Bruniges, M., Ardler, J., & Firth, V. (2024). *NSW VET Review: Final Report | June 2024*.

Bucholtz, M. (2000). The politics of transcription. *Journal of Pragmatics*, *32*(10), 1439-1465. https://doi.org/10.1016/S0378-2166(99)00094-6

Buckland, A., Dockery, M., Duncan, A., Sanchez Arenas, V., Sotirakopoulos, P., Twomey, C., & Vu, L. (2024). *Employment and disability in Australia: Improving employment outcomes for people with disability*. Bankwest Curtin Economics Centre.

Buckley, S., & Bird, G. (1998). Including children with Down syndrome (part 1). *Down Syndrome News and Update*, *1*(1), 5-13. https://www.down-syndrome.org/en-au/library/news-update/01/1/including-down-syndrome-part/

Buckley, S., Bird, G., & Sacks, B. (2006). Evidence that we can change the profile from a study of inclusive education. *Down Syndrome Research and Practice*, *9*(3), 51-53. https://doi.org/10.3104/essays.294

Burack, J. A., Lai, J., Stewart, J., & Landry, O. (2023). Developmental traditions in the study of persons with Down syndrome. In J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford handbook of Down syndrome and development* (pp. 19-30). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.2

Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual disability, autism, and Down syndrome. *Research in Developmental Disabilities*, *65*, 23-34. https://doi.org/10.1016/j.ridd.2017.04.004

Butler, E., & Ferrier, F. (2022). *A fair go for all? Equity frameworks and landmark documents in Australian vocational education and training [full-length review]*. VET Knowledge Bank, National Centre for Vocational Education Research.

Byun, S., Schofer, E., & Kim, K.-k. (2012). Revisiting the role of cultural capital in East Asian educational systems: The case of South Korea. *Sociology of Education*, *85*(3), 219-239. https://doi.org/10.1177/0038040712447180

Cadby, G., Pitman, T., & Koshy, P. (2024). *Students with disability in Australian higher education: An overview*. Australian Centre for Student Equity and Success, Curtin University.

Calderón-Almendros, I., & Calderón-Almendros, R. (2016). 'I open the coffin and here I am': Disability as oppression and education as liberation in the construction of personal identity. *Disability & Society*, *31*(1), 100-115. https://doi.org/10.1080/09687599.2015.1133400

Calderón-Almendros, I., & Habegger-Lardoeyt, S. (2017). *Education, disability and inclusion: A family struggle against an excluding school*. Sense Publishers. https://doi.org/10.1007/978-94-6300-890-7

Calderón Gómez, D. (2020). The third digital divide and Bourdieu: Bidirectional conversion of economic, cultural, and social capital to (and from) digital capital among young people in Madrid. *New Media & Society*, *23*(9), 2534-2553. https://doi.org/10.1177/1461444820933252

Callea, M., Cammarata-Scalisi, F., Galeotti, A., Villani, A., & Valentini, D. (2020). COVID-19 and Down syndrome. *Acta Paediatrica*, *109*(9), 1901-1902. https://doi.org/10.1111/apa.15409

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: The issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, *35*(2), 113-120. https://doi.org/10.1111/j.1468-3156.2006.00404.x

Capone, G., Goyal, P., Ares, W., & Lannigan, E. (2006). Neurobehavioral disorders in children, adolescents, and young adults with Down syndrome. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *142C*(3), 158-172. https://doi.org/10.1002/ajmg.c.30097

Carr, J. (2008). The everyday life of adults with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, *21*(5), 389-397. https://doi.org/10.1111/j.1468-3148.2007.00418.x

Carr, J. (2011). Down syndrome: Lifetime course and strategies for intervention. In P. Howlin, T. Charman, & M. Ghaziuddin (Eds.), *The SAGE handbook of developmental disorders* (pp. 28-42). SAGE Publications Ltd. https://doi.org/10.4135/9781446201107.n3

Casale-Giannola, D., & Kamens, M. W. (2006). Inclusion at a university: Experiences of a young woman with Down syndrome. *Mental Retardation*, *44*(5), 344-352. https://doi.org/10.1352/0047-6765(2006)44[344:IAAUEO]2.0.CO;2

Cavallaro, T., Foley, P., Saunders, J., & Bowman, K. (2005). *People with a disability in vocational education and training: A statistical compendium*. National Centre for Vocational Education Research.

Centre for Disability Studies. (2025). *uni 2 beyond*. Retrieved 5th of February, 2025, from https://cds.org.au/education-training/u2b/

Channell, M. M., Loveall, S. J., & Burke, M. M. (2023). Exploring caregiver perceptions of post-high school employment experiences among young adults with Down syndrome. *Intellectual and Developmental Disabilities*, *61*(2), 158-171. https://doi.org/10.1352/1934-9556-61.2.158

Channell, M. M., Mattie, L. J., Hamilton, D. R., Capone, G. T., Mahone, E. M., Sherman, S. L., Rosser, T. C., Reeves, R. H., & Kalb, L. G. (2021). Capturing cognitive and behavioral variability among individuals with Down syndrome: A latent profile analysis. *Journal of Neurodevelopmental Disorders*, *13*(1), 16. https://doi.org/10.1186/s11689-021-09365-2

Charleton, P., & Woodhouse, M. (2015). Vision and eye disorders. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome: Current perspectives* (pp. 77-87). Mac Keith Press.

Choi, E. K., & Yoo, I. Y. (2015). Resilience in families of children with Down syndrome in Korea. *International Journal of Nursing Practice*, *21*(5), 532-541. https://doi.org/10.1111/ijn.12321

Cicchetti, D., & Beeghly, M. (Eds.). (1990). *Children with Down syndrome: A developmental perspective*. Cambridge University. https://doi.org/10.1017/CBO9780511581786

Circelli, M., & Siekmann, G. (2022). *VET for secondary school students: A research synthesis*. National Centre for Vocational Education Research.

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297-298. https://doi.org/10.1080/17439760.2016.1262613

Cocks, E., & Thoresen, S. (2013a). *Barriers and facilitators affecting course completions by apprentices and trainees with disabilities*. National Centre for Vocational Education Research.

Cocks, E., & Thoresen, S. (2013b). *Social and economic outcomes from VET in schools for people with disabilities: Initial findings from an Australian national longitudinal study*. AVETRA 16th Annual Conference, Apr 3-5 2013, Fremantle, WA.

Cologon, K. (2013). Debunking myths: Reading development in children with Down syndrome. *The Australian Journal of Teacher Education*, *38*(3), 142-163. https://doi.org/10.14221/ajte.2013v38n3.10

Commonwealth of Australia. (2023a). *Final Report - Executive Summary, our vision for an inclusive Australia and recommendations*.

Commonwealth of Australia. (2023b). *Final Report - Volume 7, inclusive education, employment and housing*. https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%207%2C%20Inclusive%20education%2C%20employment%20and%20housing%20-%20Summary%20and%20recommendations.pdf

Commonwealth of Australia. (2025). *Easy Read*. Retrieved 5th of February, 2025, from https://www.stylemanual.gov.au/content-types/easy-read

Coster, W., Deeney, T., Haltiwanger, J., & Haley, S. (1998). *School Function Assessment: User's Manual*. Psychological Corporation.

Coyle, J., Freire, K., Wood, D., Wilding, C., Taylor, D., Ganguly, R., Burke, J., Downing, L., & Siliézar, L. (2018). *The influence of disability, socioeconomic status and regionality on higher education access and participation*.

Crawford, L. A., & Novak, K. B. (2018). *Individual and society: Sociological social psychology* (2nd ed.). Routledge.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, *1989*(1), 139–167.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). SAGE Publications.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). SAGE Publications.

Cunningham, C. C., Glenn, S., Lorenz, S., Cuckle, P., & Shepperdson, B. (1998). Trends and outcomes in educational placements for children with Down syndrome. *European Journal of Special Needs Education*, *13*(3), 225-237. https://doi.org/10.1080/0885625980130301

Curryer, B., Stancliffe, R. J., Dew, A., & Wiese, M. Y. (2018). Choice and control within family relationships: The lived experience of adults with intellectual disability. *Intellectual and Developmental Disabilities*, *56*(3), 188-201. https://doi.org/10.1352/1934-9556-56.3.188

Cuskelly, M., & Faragher, R. (2019). Developmental dyscalculia and Down syndrome: Indicative evidence. *International Journal of Disability, Development, and Education*, *66*(2), 151-161. https://doi.org/10.1080/1034912X.2019.1569209

Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2008). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice*, *10*(2), 105-113. https://www.down-syndrome.org/en-au/library/research-practice/online/2008/families-down-syndrome-what-need/

Cuskelly, M., Jobling, A., Chant, D., Bower, A., & Hayes, A. (2001). Multiple perspectives of family life. In M. Cuskelly, A. Jobling, & S. Buckley (Eds.), *Down syndrome across the life span* (pp. 159-173). Whurr Publishers.

Dalprà, M., Chiogna, M., Frattari, A., & Primon, G. (2018). Casa satellite: Pilot study for a smart home for people with Down syndrome. *Journal of Architectural Engineering*, *24*(1), 1-10. https://doi.org/10.1061/(ASCE)AE.1943-5568.0000279

Davies, M., & Beamish, W. (2009). Transitions from school for young adults with intelletual disability: Parental perspectives on "life as an adjustment". *Journal of Intellectual & Developmental Disability*, *34*(3), 248. https://doi.org/10.1080/13668250903103676

Day, S. (2012). A reflexive lens: Exploring dilemmas of qualitative methodology through the concept of reflexivity. *Qualitative Sociology Review: QSR*, *8*(1), 60-85. https://doi.org/10.18778/1733-8077.8.1.04

Deci, E. L., & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*. Plenum.

Deckers, S. R. J. M., Van Zaalen, Y., Van Balkom, H., & Verhoeven, L. (2019). Predictors of receptive and expressive vocabulary development in children with Down syndrome. *International Journal of Speech Language Pathology*, *21*(1), 10-22. https://doi.org/10.1080/17549507.2017.1363290

del Hoyo Soriano, L., Thurman, A. J., Harvey, D., Kover, S. T., & Abbeduto, L. (2020). Expressive language development in adolescents with Down syndrome and fragile X syndrome: Change over time and the role of family-related factors. *Journal of Neurodevelopmental Disorders*, *12*(1), 18. https://doi.org/10.1186/s11689-020-09320-7

Department of Education. (2024a). *AQF qualifications*. Retrieved 16th of February, 2025, from https://www.aqf.edu.au/framework/aqf-qualifications

Department of Education. (2024b). *Australian Universities Accord Final Report*.

Department of Education, Skills and Employment. (2020). *Factors affecting higher education completions – disability*. https://www.education.gov.au/integrated-data-research/resources/disability

Department of Employment and Workplace Relations. (2024). *Overview of the new National Skills Agreement: Reforming the national VET system*.

Department of Social Services. (2025). *Inclusive Employment Australia*. Retrieved 27th of June, 2025, from https://www.dss.gov.au/disability-employment-reforms/inclusive-employment-australia

Docherty, J., & Reid, K. (2009). ‘What’s the next stage?’ mothers of young adults with Down syndrome explore the path to independence: A qualitative investigation. *Journal of Applied Research in Intellectual Disabilities*, *22*(5), 458-467. https://doi.org/10.1111/j.1468-3148.2009.00492.x

Doll, B., Sands, D. J., Wehmeyer, M. L., & Palmer, S. (1996). Promoting the development and acquisition of self-determined behavior. In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 65-90). Paul H. Brookes Publishing Co.

Dolva, A. S., Kollstad, M., & Kleiven, J. (2019). Friendships and patterns of social leisure participation among Norwegian adolescents with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1184-1193. https://doi.org/10.1111/jar.12609

Donaldson, M., & Leyland, K. (2015). Endocrine disorders. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome: Current perspectives* (pp. 137-147). Mac Keith Press.

Down's Syndrome Association. (2021). *Including pupils with Down's syndrome: Information for teachers and support staff - early years*. https://downsyndromedevelopment.org.uk/wp-content/uploads/2021/01/Including_pupils_Early_Years.pdf

Down's Syndrome Association. (2023). *Transition to secondary school*. https://www.downs-syndrome.org.uk/wp-content/uploads/2023/12/Transition-to-secondary-school.pdf

Down's Syndrome Association and Down's Syndrome Scotland. (2013). *Including pupils with Down's syndrome: Information for teachers and learning support assistants - primary*. https://upsanddowns.net/wp-content/uploads/2013/11/including_pupils_primary.pdf

Down, J. L. H. (1866). Observations on an ethnic classification of idiots. *London Hospital Reports*, *3*, 259-262.

Down Syndrome Australia. (2018). Early years. Retrieved 25th of June, 2024, from https://www.downsyndrome.org.au/wp-content/uploads/2020/04/DSA_EarlyYears_Resource_May19.pdf

Down Syndrome Australia. (2022). *What is Down syndrome?* https://www.downsyndrome.org.au/about-down-syndrome/what-is-down-syndrome/

Down Syndrome Australia. (2025). *Right to work: Employment explainer*. Retrieved 27th of June, 2025, from https://www.downsyndrome.org.au/right-to-work/wp-content/uploads/sites/14/2025/03/Right-To-Work-Employment-Explainer.pdf

Down Syndrome New South Wales. (2023). Anne and Andrew's story. Retrieved 27th of June, 2024, from https://dk6f8ezfgkj58.cloudfront.net/bfcf56ea02aadffbb84adeb89ac5be15.pdf

Down Syndrome New South Wales. (2024). *NDIS services & supports*. Retrieved 16th of February, 2025, from https://www.downsyndromensw.org.au/programs/ndis-services-and-support

Down Syndrome Western Australia. (2015). *The really useful leaving school book: 15-18 years*. https://www.downsyndrome.org.au/wp-content/uploads/2020/04/DSAWA-Booklet-15-18yrs-Leaving-School.pdf

Dykens, E. M. (2007). Psychiatric and behavioral disorders in persons with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(3), 272-278. https://doi.org/10.1002/mrdd.20159

Dykens, E. M., Shah, B., Sagun, J., Beck, T., & King, B. H. (2002). Maladaptive behaviour in children and adolescents with Down's syndrome. *Journal of Intellectual Disability Research*, *46*(6), 484-492. https://doi.org/10.1046/j.1365-2788.2002.00431.x

Edgerton, J. D., & Roberts, L. W. (2014). Cultural capital or habitus? Bourdieu and beyond in the explanation of enduring educational inequality. *Theory and Research in Education*, *12*(2), 193-220. https://doi.org/10.1177/1477878514530231

Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology (Oxford)*, *37*(2), 239-256. https://doi.org/10.1177/0038038503037002002

Edwards, J. A. (2001). The transcription of discourse. In D. Schiffrin, D. Tannen, & H. E. Hamilton (Eds.), *The handbook of discourse analysis* (pp. 321-348). Blackwell Publishers Ltd.

Eloff, I., & Kriel, T. (2003). Construction of their role in inclusive education by parents of a child with Down's syndrome. *South African Journal of Education*, *23*(4), 328-337.

Eloire, F. (2018). The Bourdieusian conception of social capital: A methodological reflection and application. *The Forum for Social Economics*, *47*(3-4), 322-341. https://doi.org/10.1080/07360932.2015.1028084

Elster, J. (Ed.). (1986). *Rational choice*. New York University Press.

Erevelles, N. (2006). Postcolonialism. In G. L. Albrecht (Ed.), *Encyclopedia of disability* (Vol. 1, pp. 1277-1284). SAGE Publications, Inc.

Esbensen, A. J., Hoffman, E. K., Shaffer, R., Chen, E., Patel, L., & Jacola, L. (2018). Reliability of parent report measures of behaviour in children with Down syndrome. *Journal of Intellectual Disability Research*, *62*(9), 785-797. https://doi.org/10.1111/jir.12533

Esbensen, A. J., Hoffman, E. K., Shaffer, R. C., Patel, L. R., & Jacola, L. M. (2021). Relationship between parent and teacher reported executive functioning and maladaptive behaviors in children with Down syndrome. *American Journal on Intellectual and Developmental Disabilities*, *126*(4), 324-323. https://doi.org/10.1352/1944-7558-126.4.307

Evans, D. W., & Uljarević, M. (2018). Parental education accounts for variability in the IQs of probands with Down syndrome: A longitudinal study. *American Journal of Medical Genetics. Part A*, *176*(1), 29-33. https://doi.org/10.1002/ajmg.a.38519

Evans, H., Pike, K., McGowan, M., & Shott, S. (2015). Respiratory disease. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome: Current perspectives* (pp. 111-126). Mac Keith Press.

Faragher, R. (2014). Learning mathematics in the secondary school. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome* (pp. 174-191). Routledge.

Faragher, R., & Brown, R. I. (2005). Numeracy for adults with Down syndrome: It's a matter of quality of life. *Journal of Intellectual Disability Research*, *49*(10), 761-765. https://doi.org/10.1111/j.1365-2788.2005.00747.x

Faragher, R., Cooke, E., & Lloyd, J. (2024). Gen Zest: The lived experiences of adult Gen Zs with Down syndrome. *Disability & Society*, 1-20. https://doi.org/10.1080/09687599.2024.2438123

Faragher, R., Robertson, P., & Bird, G. (2020). *International guidelines for the education of learners with Down syndrome*. Down Syndrome International.

Faragher, R. M. (2023). *A practical guide to educating learners with Down syndrome: Supporting lifelong learning*. Routledge. https://doi.org/10.4324/9780429262739

Faucher, K. X. (2018). *Social capital online: Alienation and accumulation*. University of Westminster Press.

Ferrier, F., & Selby Smith, C. (2010). Persons with a disability and vocational education and training. In P. Peterson, E. Baker, & B. McGaw (Eds.), *International encyclopedia of education: Volume 8* (3rd ed., pp. 294-299). Elsevier.

Fidler, D. J., & Daunhauer, L. A. (2011). Down syndrome: General overview. In P. Howlin, T. Charman, & M. Ghaziuddin (Eds.), *The SAGE handbook of developmental disorders* (pp. 9-27). SAGE Publications Ltd. https://doi.org/10.4135/9781446201107.n2

Fidler, D. J., Daunhauer, L. A., Schworer, E., & Patel, L. (2023). Executive function in Down syndrome: Links to adaptation and treatment implications. In J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford handbook of Down syndrome and development* (pp. 305–331). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.17

Fidler, D. J., Schworer, E., Prince, M. A., Will, E. A., Needham, A. W., & Daunhauer, L. A. (2019). Exploratory behavior and developmental skill acquisition in infants with Down syndrome. *Infant Behavior & Development*, *54*, 140-150. https://doi.org/10.1016/j.infbeh.2019.02.002

Field, J. (2017). *Social capital* (3rd ed.). Taylor and Francis. https://doi.org/10.4324/9780203794623

Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*(2), 209-230. https://doi.org/10.1177/146879410200200205

Fleming, V., Piro-Gambetti, B., Handen, B., Christian, B. T., Cohen, A., Tudorascu, D., Plante, D. T., Okonkwo, O., & Hartley, S. L. (2022). Physical activity and physical and mental health in middle-aged adults with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(4), 408-418. https://doi.org/10.1111/jppi.12434

Flick, U. (2014). Mapping the field. In U. Flick (Ed.), *The SAGE handbook of qualitative data analysis* (pp. 3-18). SAGE Publications Ltd.

Flinders University. (2023). *The Up the Hill project*. https://www.flinders.edu.au/content/dam/documents/engage/community/up-the-hill-project/up-the-hill-brochure.pdf

Foley, K., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation*, *34*(20), 1747-1764. https://doi.org/10.3109/09638288.2012.660603

Foley, K., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., Einfeld, S., Llewellyn, G., Parmenter, T. R., & Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health and Development*, *39*(6), 789-800. https://doi.org/10.1111/cch.12019

Franco, F., & Wishart, J. (1994). Pre-verbal communication in young Down's syndrome children: The use of pointing and other gestures. *First Language*, *14*(42-43), 322-323. https://doi.org/10.1177/014272379401404227

Furlong, M. A. (2003). Self-determination and a critical perspective in casework: Promoting a balance between interdependence and autonomy. *Qualitative Social Work*, *2*(2), 177-196. https://doi.org/10.1177/1473325003002002004

Gabel, S., & Kotel, K. (2018). Motherhood in the context of normative discourse: Birth stories of mothers of children with Down syndrome. *Journal of Medical Humanities*, *39*(2), 179-193. https://doi.org/10.1007/s10912-015-9367-z

Gadow, F., & MacDonald, J. (2018). 8. Scope, challenges and outcomes of an inclusive tertiary university initiative in Australia. In P. O'Brien, M. L. Bonati, F. Gadow, & R. Slee (Eds.), *People with intellectual disability experiencing university life* (pp. 129-140). Brill Sense. https://doi.org/10.1163/9789004394551_008

Gale, T., & Tranter, D. (2011). Social justice in Australian higher education policy: An historical and conceptual account of student participation. *Critical Studies in Education*, *52*(1), 29-46. https://doi.org/10.1080/17508487.2011.536511

Ganguly, R., Brownlow, C., Du Preez, J., & Graham, C. (2015). *Resilience/thriving in post-secondary students with disabilities: An exploratory study*. National Centre for Student Equity in Higher Education, Curtin University.

Gao, Q. (2015). Bourdieu and body. In lisahunter, W. Smith, & e. emerald (Eds.), *Pierre Bourdieu and physical culture* (pp. 143-148). Routledge. https://doi.org/10.4324/9780203628744

Garvan Institute of Medical Research. (n.d.). *Genomics explainer: Genotype and phenotype*. Retrieved 11th of June, 2024, from https://www.garvan.org.au/news-resources/science-explained/genotype-phenotype

George Mason University. (2022). *Charlotte Woodward*. Retrieved 12th of July, 2024, from https://chss.gmu.edu/spring-2022-outstanding-students/overview?profile_id=1630

Gibson, B. E., Young, N. L., Upshur, R. E., & McKeever, P. (2007). Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. *Social Science & Medicine*, *65*(3), 505-517. https://doi.org/10.1016/j.socscimed.2007.03.043

Gibson, W., & Brown, A. (2009). *Working with qualitative data*. SAGE Publications, Ltd. https://doi.org/10.4135/9780857029041.d96

Gilmore, L., & Cuskelly, M. (2014). Mastery motivation in children with Down syndrome: Promoting and sustaining interest in learning. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome: Research, theory, and practice with children and adolescents* (pp. 60-82). Routledge. https://doi.org/10.4324/9781315883588

Golden, W., & Pashayan, H. M. (1976). The effect of parental education on the eventual mental development of noninstitutionalized children with Down syndrome. *The Journal of Pediatrics*, *89*(4), 603-605. https://doi.org/10.1016/S0022-3476(76)80398-8

Goldstein, S., & Naglieri, J. A. (2012). Preface. In S. Goldstein & J. A. Naglieri (Eds.), *Handbook of executive functioning* (pp. ix-xi). Springer.

Goldstein, S., Naglieri, J. A., Princiotta, D., & Otero, T. M. (2012). Introduction: A history of executive functioning as a theoretical and clinical construct. In S. Goldstein & J. A. Naglieri (Eds.), *Handbook of executive functioning* (pp. 3-12). Springer.

Gonski, D., & Shergold, P. (2021). *In the same sentence: Bringing higher and vocational education together*. Department of Premier and Cabinet.

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. SAGE Publications.

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, *28*(5), 631-644. https://doi.org/10.1080/09687599.2012.717884

Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism*. Routledge. https://doi.org/10.4324/9780203366974

Goodley, D. (2018). Understanding disability: Biopsychology, biopolitics, and an in-between-all politics. *Adapted Physical Activity Quarterly*, *35*(3), 308-319. https://doi.org/10.1123/apaq.2017-0092

Goodley, D. (2020). The psychology of disability. In N. Watson & S. Vehmas (Eds.), *Routledge handbook of disability studies* (2nd ed., pp. 362-376). Routledge. https://doi.org/10.4324/9780429430817-26

Goodley, D., Lawthom, R., Liddiard, K., & Cole, K. R. (2017). Critical disability studies. In B. Gough (Ed.), *The Palgrave handbook of critical social psychology* (pp. 491-505). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-51018-1_24

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, *34*(6), 972-997. https://doi.org/10.1080/09687599.2019.1566889

Goodwin, J., Mason, V., Williams, V., & Townsley, R. (2015). Easy information about research: Getting the message out to people with learning disabilities. *British Journal of Learning Disabilities*, *43*(2), 93-99. https://doi.org/10.1111/bld.12128

Gothard, J. (2001). Beyond the myths: Representing people with Down syndrome. In M. Cuskelly, A. Jobling, & S. Buckley (Eds.), *Down syndrome across the life span* (pp. 2-15). https://doi.org/10.1002/9780470777886.ch1

Gothard, J. (2011). *Greater expectations: Living with Down syndrome in the 21st century*. Fremantle Press.

Green, J., Franquiz, M., & Dixon, C. (1997). The myth of the objective transcript: Transcribing as a situated act. *TESOL Quarterly*, *31*(1), 172-176. https://doi.org/10.2307/3587984

Green, W., Gannaway, D., Sheppard, K., & Jamarani, M. (2015). What's in their baggage? The cultural and social capital of Australian students preparing to study abroad. *Higher Education Research and Development*, *34*(3), 513-526. https://doi.org/10.1080/07294360.2014.973381

Grenfell, M. (2009). Applying Bourdieu's field theory: The case of social capital and education. *Education, Knowledge & Economy*, *3*(1), 17-34. https://doi.org/10.1080/17496890902786812

Grenfell, M. (2012a). Biography. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 11-25). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/biography/15A3ECC7DD5A2EF766F8326D0DAA9460

Grenfell, M. (2012b). Introduction. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 1-6). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/introduction/5BF65F9CB288C405F2331D356E3EA68E

Grieco, J., Pulsifer, M., Seligsohn, K., Skotko, B., & Schwartz, A. (2015). Down syndrome: Cognitive and behavioral functioning across the lifespan. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *169*(2), 135-149. https://doi.org/10.1002/ajmg.c.31439

Griffin, M. M., Fisher, M. H., Dykens, E. M., & Hodapp, R. M. (2013). Adolescents with intellectual disabilities. In W. T. O'Donohue, L. T. Benuto, & L. Woodward Tolle (Eds.), *Handbook of adolescent health psychology* (pp. 537-548). Springer New York. https://doi.org/10.1007/978-1-4614-6633-8_34

Griffin, T. (2014). *Disadvantaged learners and VET to higher education transitions*. National Centre for Vocational Education Research.

Griffin, T. (2016). *Costs and benefits of education and training for the economy, business and individuals*. National Centre for Vocational Education Research.

Griffin, T., & Beddie, F. (2011). *Researching VET and disability: At a glance*. National Centre for Vocational Education Research.

Griffin, T., & Nechvoglod, L. (2008). *Vocational education and training and people with a disability: A review of the research*. National Centre for Vocational Education Research.

Grigal, M., & Papay, C. (2018). The promise of postsecondary education for students with intellectual disability. *New Directions for Adult and Continuing Education*, *2018*(160), 77-88. https://doi.org/10.1002/ace.20301

Haddad, F., Bourke, J., Wong, K., & Leonard, H. (2018). An investigation of the determinants of quality of life in adolescents and young adults with

Down syndrome. *PLOS One*, *13*(6), e0197394. https://doi.org/10.1371/journal.pone.0197394

Hamill, L. B. (2003). Going to college: The experiences of a young woman with Down syndrome. *Mental Retardation*, *41*(5), 340-353. https://doi.org/10.1352/0047-6765(2003)41<340:GTCTEO>2.0.CO;2

Hardy, C. (2013). New Literacy Studies and Bourdieu: Working at the intersections of theory and practice. In M. Grenfell, D. Bloome, C. Hardy, K. Pahl, J. Rowsell, & B. V. Street (Eds.), *Language, ethnography, and education: Bridging New Literacy Studies and Bourdieu* (pp. 151-173). Routledge.

Harlak, H. (2022). Psychology, sociology, and social psychology. In D. Gursoy & S. Çelik (Eds.), *Routledge handbook of social psychology of tourism* (pp. 1-20). Routledge. https://doi.org/10.4324/9781003161868-1

Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, *25*(3), 134-150. https://doi.org/10.1177/1088357610373759

Hatch, J. A. (2023). *Doing qualitative research in education settings* (2nd ed.). State University of New York Press.

Head, L. S., & Abbeduto, L. (2007). Recognizing the role of parents in developmental outcomes: A systems approach to evaluating the child with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 293-301. https://doi.org/10.1002/mrdd.20169

Healthdirect Australia Limited. (2024). *Down syndrome*. Retrieved 16th of April, from https://www.healthdirect.gov.au/down-syndrome

Heffernan, T. (2021). Academic networks and career trajectory: 'There's no career in academia without networks'. *Higher Education Research and Development*, *40*(5), 981-994. https://doi.org/10.1080/07294360.2020.1799948

High, R., & Robinson, S. (2021). Graduating university as a woman with Down syndrome: Reflecting on my education. *Social sciences*, *10*(11), 444. https://doi.org/10.3390/socsci10110444

Hilvert, E., Lorang, E., Maltman, N., & Sterling, A. (2023). Assessing the quantity and quality of language used by mothers and fathers of children with Down syndrome during shared book reading. *Journal of*

Child Language, *50*(3), 778-790. https://doi.org/10.1017/S0305000922000046

Hodge, S., Billett, S., & Choy, S. (2022). Influences on post-school decision-making: Perspectives of school students, parents, teachers (phase 1). In S. Billett, B. E. Stalder, V. Aarkrog, S. Choy, S. Hodge, & A. H. Le (Eds.), *The standing of vocational education and the occupations it serves: Current concerns and strategies for enhancing that standing* (pp. 325-351). Springer International Publishing. https://doi.org/10.1007/978-3-030-96237-1_16

Houston, S. (2017). Towards a critical ecology of child development in social work: Aligning the theories of Bronfenbrenner and Bourdieu. *Families, Relationships and Societies*, *6*(1), 53-69. https://doi.org/10.1332/204674315X14281321359847

How, B., Smidt, A., Wilson, N. J., Barton, R., & Valentin, C. (2019). 'We would have missed out so much had we terminated': What fathers of a child with Down syndrome think about current non-invasive prenatal testing for Down syndrome. *Journal of Intellectual Disabilities*, *23*(3), 290-309. https://doi.org/10.1177/1744629518787606

Hüls, A., Costa, A. C. S., Dierssen, M., Baksh, R. A., Bargagna, S., Baumer, N. T., Brandão, A. C., Carfi, A., Carmona-Iragui, M., Chicoine, B. A., Ghosh, S., Lakhanpaul, M., Manso, C., Mayer, M., Ortega, M., de Asua, D. R., Rebillat, A., Russell, L. A., Sgandurra, G., Valentini, D., Sherman, S. L., & Strydom, A. (2021). Medical vulnerability of individuals with Down syndrome to severe COVID-19–data from the Trisomy 21 Research Society and the UK ISARIC4C survey. *eClinicalMedicine*, *33*. https://doi.org/10.1016/j.eclinm.2021.100769

Illarramendi, J. P., Mattson, J., & Peterson, M. (2002). Having a life. In W. I. Cohen, L. Nadel, & M. E. Madnick (Eds.), *Down syndrome: Visions for the 21st century* (pp. 105-111). Wiley-Liss.

Jackson, D., Li, I., & Carroll, D. (2023). Student access to higher education through alternative pathways and differences by equity group and discipline. *Journal of Higher Education Policy and Management*, *45*(6), 593-625. https://doi.org/10.1080/1360080X.2023.2212850

Jenkins, R. (1992). *Pierre Bourdieu*. Routledge.

Jevne, K. W., Kollstad, M., & Dolva, A. (2022). The perspective of emerging adults with Down syndrome – on quality of life and well-being. *Journal of Intellectual Disabilities*, *26*(4), 839-852. https://doi.org/10.1177/17446295211030097

Jobling, A. (2001). Life be in it: Lifestyle choices for active leisure. *Down Syndrome Research and Practice*, *6*(3), 117-122. https://doi.org/10.3104/perspectives.102

Johnson, B., & West, R. (2021). Ableist contours of Down syndrome in Australia: Facebook attitudes towards existence and parenting of people with Down syndrome. *Journal of Sociology*, *57*(2), 286-304. https://doi.org/10.1177/1440783319893474

Jones, E. A., Neil, N., & Feeley, K. M. (2014). Enhancing learning for children with Down syndrome. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome: Research, theory, and practice with children and adolescents* (pp. 83-115). Routledge. https://doi.org/10.4324/9781315883588

Joyce, S. (2019). *Strengthening skills: Expert review of Australia's vocational education and training system*. Department of the Prime Minister and Cabinet.

Karmel, T., & Nguyen, N. (2008). *Disability and learning outcomes: How much does the disability really matter?* National Centre for Vocational Education Research.

Kendall, L. (2019). Supporting children with Down syndrome within mainstream education settings: Parental reflections. *Education 3-13*, *47*(2), 135-147. https://doi.org/10.1080/03004279.2017.1412488

Kilpatrick, S., Johns, S., Barnes, R., McLennan, D., Fischer, S., & Magnussen, K. (2016). *Exploring the retention and success of students with disability*. National Centre for Student Equity in Higher Education.

Kliewer, C. (1995). *The social representation of children with Down syndrome: An interpretivist analysis* [Doctoral dissertation, Syracuse University]. ProQuest Dissertations Publishing.

Kliewer, C. (1998). Citizenship in the literate community: An ethnography of children with Down syndrome and the written word. *Exceptional Children*, *64*(2), 167-180. https://doi.org/10.1177/001440299806400202

Kliewer, C., Biklen, D., & Kasa-Hendrickson, C. (2006). Who may be literate? Disability and resistance to the cultural denial of competence. *American Educational Research Journal*, *43*(2), 163-192. https://doi.org/10.3102/00028312043002163

Koustourakis, G., Asimaki, A., & Spiliopoulou, G. (2018). Cultural activities and the family's 'institutionalised' cultural capital: The case of native

and immigrant primary school pupils. *Pedagogy, Culture & Society*, *26*(3), 397-415. https://doi.org/10.1080/14681366.2017.1412340

Kraaykamp, G., & van Eijck, K. (2010). The intergenerational reproduction of cultural capital: A threefold perspective. *Social Forces*, *89*(1), 209-231. https://doi.org/10.1353/sof.2010.0087

Krell, K., Pless, A., Michael, C., Torres, A., Chung, J., Baker, S., Blake, J. M., Caughman, K., Cullen, S., Gallagher, M., Hoke-Chandler, R., Maina, J., McLuckie, D., O'Neill, K., Peña, A., Royal, D., Slape, M., Spinazzi, N. A., Torres, C. G., & Skotko, B. G. (2023). Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, or of mixed race. *American Journal of Medical Genetics. Part A*, *191*(3), 742-752. https://doi.org/10.1002/ajmg.a.63069

Krueger, K., Cless, J. D., Dyster, M., Steele, R., & Nelson Goff, B. S. (2019). Understanding the systems, contexts, behaviors, and strategies of parents advocating for their children with Down syndrome. *Intellectual and Developmental Disabilities*, *57*(2), 146-157. https://doi.org/10.1352/1934-9556-57.2.146

Kutchel, D. (2016, May 13). Work and further study remain a huge challenge for students with an intellectual disability. *The Sydney Morning Herald*. https://www.smh.com.au/education/work-and-further-study-remain-a-huge-challenge-for-students-with-an-intellectual-disability-20160509-goq4aq.html

Kutzsche, S. (2018). John Langdon Down (1828–1896) – a pioneer in caring for mentally disabled patients. *Acta Paediatrica*, *107*(11), 1851-1854. https://doi.org/10.1111/apa.14505

Lahire, B. (2019). Sociology at the individual level, psychologies and neurosciences. *European Journal of Social Theory*, *23*(1), 52-71. https://doi.org/10.1177/1368431018809548

Lalvani, P. (2011). Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome. *Narrative Inquiry*, *21*(2), 276-293. https://doi.org/10.1075/ni.21.2.06lal

Lalvani, P. (2013). Land of misfit toys: Mothers' perceptions of educational environments for their children with Down syndrome. *International Journal of Inclusive Education*, *17*(5), 435-448. https://doi.org/10.1080/13603116.2012.683047

Lamb, S., Maire, Q., Walstab, A., Newman, G., Doecke, E., & Davies, M. (2018). *Improving participation and success in VET for disadvantaged learners*. National Centre for Vocational Education Research.

Landuran, A., Raynaud, C., & N'kaoua, B. (2022). Cognitive and motor skills of people with Down syndrome according to their perceived self-determination. *Journal of Developmental and Physical Disabilities*, *34*(1), 89-111. https://doi.org/10.1007/s10882-021-09791-z

Laragy, C. (2004). Self-determination within Australian school transition programmes for students with a disability. *Disability & Society*, *19*(5), 519-530. https://doi.org/10.1080/0968759042000235343

Latch-On. (2018). *Latch-On research group and related publications*. Retrieved 26th of June 2025, from https://www.latch-on.net/wp-content/uploads/2018/09/Latch-On-Publications2018.pdf

Latch-On. (2021a). *About us*. Retrieved 23rd of June 2021, from https://www.latch-on.net/about-us/

Latch-On. (2021b). *Special features*. Retrieved 23rd of June 2021, from https://www.latch-on.net/special-features/

Lawless, B., & Chen, Y. (2019). Developing a method of critical thematic analysis for qualitative communication inquiry. *The Howard Journal of Communications*, *30*(1), 92-106. https://doi.org/10.1080/10646175.2018.1439423

Lee, A., Knafl, K., & Van Riper, M. (2021). Family variables and quality of life in children with Down syndrome: A scoping review. *International Journal of Environmental Research and Public Health*, *18*(2), 419. https://doi.org/10.3390/ijerph18020419

Leonard, H., Foley, K., Pikora, T., Bourke, J., Wong, K., McPherson, L., Lennox, N., & Downs, J. (2016). Transition to adulthood for young people with intellectual disability: The experiences of their families. *European Child & Adolescent Psychiatry*, *25*(12), 1369-1381. https://doi.org/10.1007/s00787-016-0853-2

Leshin, L. (2002). Pediatric health update on Down syndrome. In W. I. Cohen, L. Nadel, & M. E. Madnick (Eds.), *Down syndrome: Visions for the 21st century* (pp. 187-201). Wiley-Liss.

Levy, J. C. (2025). *Introductory psychology and the human condition: Cultural adaptation in pursuit of self-actualization*. Routledge. https://doi.org/10.4324/9781003293040

Li, E., Liu, Y., Lok, N., & Lee, V. (2006). Successful experience of people with Down syndrome. *Journal of Intellectual Disabilities*, *10*(2), 143-154. https://doi.org/10.1177/1744629506064010

Li, I., Mahuteau, S., Dockery, M., Junankar, P., & Mavromaras, K. (2016). *Labour market outcomes of Australian university graduates from equity groups*. National Centre for Student Equity in Higher Education, Curtin University.

Lichtman, M. (2014). *Qualitative research for the social sciences*. SAGE Publications Ltd. https://doi.org/10.4135/9781544307756

Lightbown, P., & Spada, N. (2013). *How languages are learned* (4th ed.). Oxofrd University Press.

Lightfoot, L., & Bond, C. (2013). An exploration of primary to secondary school transition planning for children with Down's syndrome. *Educational Psychology in Practice*, *29*(2), 163-179. https://doi.org/10.1080/02667363.2013.800024

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2017). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 213-263). SAGE Publications, Inc.

lisahunter, Smith, W., & emerald, e. (2015). Pierre Bourdieu and his conceptual tools. In lisahunter, W. Smith, & e. emerald (Eds.), *Pierre Bourdieu and physical culture* (pp. 3-23). Routledge. https://doi.org/10.4324/9780203628744

Loveall, S. J., Channell, M. M., Burke, M. M., & Rodgers, D. B. (2022). Post-high school transition outcomes for young adults with Down syndrome. *American Journal on Intellectual and Developmental Disabilities*, *127*(2), 135-148. https://doi.org/10.1352/1944-7558-127.2.135

Ma, G., & Wu, Q. (2020). Cultural capital in migration: Academic achievements of Chinese migrant children in urban public schools. *Children and Youth Services Review*, *116*, 105196. https://doi.org/10.1016/j.childyouth.2020.105196

Mannay, D. (2020). Artefacts, third objects, sandboxing and figurines in the doll's house. In L. Pauwels & D. Mannay (Eds.), *The SAGE handbook of visual research methods* (pp. 322-332). SAGE Publications, Inc. https://doi.org/10.4135/9781526417015.n20

Martin, G. E., Klusek, J., Estigarribia, B., & Roberts, J. E. (2009). Language characteristics of individuals with Down syndrome. *Topics in Language*

Disorders, *29*(2), 112-132. https://doi.org/10.1097/TLD.0b013e3181a71fe1

Mavropoulou, S., Mann, G., & Carrington, S. (2021). The divide between inclusive education policy and practice in Australia and the way forward. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(1), 44-52. https://doi.org/10.1111/jppi.12373

McCormick, L., Wong, M., & Yogi, L. (2003). Individualization in the inclusive preschool: A planning process. *Childhood Education*, *79*(4), 212-217. https://doi.org/10.1080/00094056.2003.10521195

McGinley, K. H. (2002). Playing the housing "game": People with Down syndrome and their families can have more control when it comes to housing. In W. I. Cohen, L. Nadel, & M. E. Madnick (Eds.), *Down syndrome: Visions for the 21st century* (pp. 83-103). Wiley-Liss.

Mcneilage, A. (2014, October 26). HSC 2014: Two determined girls on a road less travelled. *The Sydney Morning Herald*. https://www.smh.com.au/education/hsc-2014-two-determined-girls-on-a-road-less-travelled-20141024-11b5v8.html

McNeill, E., Sheehan, P., & Marder, L. (2015). Hearing issues. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome: Current perspectives* (pp. 70-76). Mac Keith Press.

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47-75. https://doi.org/10.1080/1323238X.2009.11910861

Meral, B. F., Wehmeyer, M. L., Palmer, S. B., Ruh, A. B., & Yilmaz, E. (2022). Parental habitus in promoting self-determination of children with/without intellectual and developmental disabilities in Türkiye. *Research in Developmental Disabilities*, *131*, 104347. https://doi.org/10.1016/j.ridd.2022.104347

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation* (4th ed.). Wiley.

Messenger, K., Lindsay, L., & Rillotta, F. (2018). 11. Journey "Up the Hill" to my hopes and dreams. In P. O'Brien, M. L. Bonati, F. Gadow, & R. Slee (Eds.), *People with intellectual disability experiencing university life* (pp. 173-178). Brill Sense. https://doi.org/10.1163/9789004394551_011

Meyer, D. Z., & Avery, L. M. (2009). Excel as a qualitative data analysis tool. *Field Methods*, *21*(1), 91-112. https://doi.org/10.1177/1525822X08323985

Mihaila, I., Handen, B. L., Christian, B. T., Lao, P. J., Cody, K. A., Klunk, W. E., Tudorascu, D. L., Cohen, A. D., Okonkwo, O. C., & Hartley, S. L. (2019). Leisure activity, brain β-amyloid, and episodic memory in adults with Down syndrome. *Developmental Neurobiology*, *79*(7), 738-749. https://doi.org/10.1002/dneu.22677

Miller, C., & Nguyen, N. (2008). *Who's supporting us?: TAFE staff perspectives on supporting students with mental illnesses*. National Centre for Vocational Education Research.

Mills, S., Bird, G., Black, L., Ridley, V., Heslam, S., Marsden, L., McCall, C., & Straw, F. (2015). Life with and for a person with Down syndrome. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome: Current perspectives* (pp. 23-69). Mac Keith Press.

Milne, E., & Muir, R. (2020). Photovoice: A critical introduction. In L. Pauwels & D. Mannay (Eds.), *The SAGE handbook of visual research methods* (2nd ed., pp. 282-296). SAGE Publications, Inc. https://doi.org/10.4135/9781526417015.n17

Mithaug, D. E., Mithaug, D. K., Agran, M., Martin, J. E., & Wehmeyer, M. L. (2002). The credibility and worth of self-determined learning theory. In D. E. Mithaug, D. K. Mithaug, M. Agran, J. E. Martin, & M. L. Wehmeyer (Eds.), *Self-determined learning theory: Construction*, *verification*, *and evaluation* (pp. 223-246). Routledge. https://doi.org/10.4324/9781410606235

Mohseni, A. (2022). The idea of capital in Bourdieu and Marx. *Philosophical Papers*, *51*(2), 265-293. https://doi.org/10.1080/05568641.2022.2077230

Monari Martinez, E., & Benedetti, N. (2011). Learning mathematics in mainstream secondary schools: Experiences of students with Down's syndrome. *European Journal of Special Needs Education*, *26*(4), 531-540. https://doi.org/10.1080/08856257.2011.597179

Moni, K., Jobling, A., & Baffour, B. (2018). Literacy learning outcomes in a longitudinal study of a postschool literacy education program for young adults with intellectual disabilities: Literacy outcomes in post-school education. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(2), 155-165. https://doi.org/10.1111/jppi.12247

Moni, K. B., & Jobling, A. (2001). Reading-related literacy learning of young adults with Down syndrome: Findings from a three year teaching and research program. *International Journal of Disability, Development and Education*, *48*(4), 377-394. https://doi.org/10.1080/10349120120094275

Moni, K. B., & Jobling, A. (2008). A case for including popular culture in literacy education for young adults with Down syndrome. *The Australian Journal of Language and Literacy*, *31*(3), 260-277.

Moni, K. B., & Jobling, A. (2014). Challenging literate invisibility: Continuing literacy education for young adults and adults with Down syndrome. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome: Research, theory and practice with children and adolescents* (pp. 235-251). Routledge. https://doi.org/10.4324/9781315883588

Moore, R. (2012). Capital. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 98-113). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/capital/E8B5975FC6F26975FA65AF7D16A3D9AF

Morgan, G. A., Harmon, R. J., & Maslin-Cole, C. A. (1990). Mastery motivation: Definition and measurement. *Early Education and Development*, *1*(5), 318-339. https://doi.org/10.1207/s15566935eed0105_1

Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, *29*(8), 1305-1318. https://doi.org/10.1080/09687599.2014.934440

Morgan, M. F., Moni, K. B., & Cuskelly, M. (2015). The development of research skills in young adults with intellectual disability in participatory research. *International Journal of Disability, Development, and Education*, *62*(4), 438-457. https://doi.org/10.1080/1034912X.2015.1028905

Mullan, P., Prendeville, P., & Kinsella, W. (2018). Factors influencing the successful transition of young people with Down syndrome. *British Journal of Special Education*, *45*(4), 371-391. https://doi.org/10.1111/1467-8578.12237

Murray, S. (2007). Families' care work during the transition from school to post-school for children with severe disabilities. *Family Matters*, (76), 24-29.

National Centre for Student Equity in Higher Education. (2017). *Successful outcomes for students with disability in Australian higher education*. National Centre for Student Equity in Higher Education.

National Centre for Vocational Education Research. (2023). *Student equity in VET 2021: Participation, achievement and outcomes*. National Centre for Vocational Education Research.

National Disability Insurance Agency. (2025). *Higher education and vocational education and training*. Retrieved 16th of February, 2025, from https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports/who-responsible-supports-you-need/higher-education-and-vocational-education-and-training

National Disability Insurance Scheme. (n.d.). Leaving school. Retrieved 27th of June, 2025, from https://easyread.ndis.gov.au/leaving-school/

National Disability Services. (2021). *Inclusive higher education for young people with intellectual disability: An overview of the literature and outcomes*. Ticket to Work.

National Health and Medical Research Council. (2023). *National Statement on ethical conduct in human research 2023*.

National VET Equity Advisory Council. (2011). *Equity Blueprint 2011–2016: Creating futures: Achieving potential through VET*. National VET Advisory Council.

Nechvoglod, L., & Griffin, T. (2011). *The attitudes of people with a disability to undertaking VET training*. National Centre for Vocational Education Research.

Nilholm, C. (1999). The zone of proximal development: A comparison of children with Down syndrome and typical children. *Journal of Intellectual & Developmental Disability*, *24*(3), 265-279. https://doi.org/10.1080/13668259900034031

Nind, M. (2014). *What is inclusive research?* Bloomsbury Academic. https://doi.org/10.5040/9781849668149

Nirje, B. (1972). The right to self-determination. In W. Wolfensberger (Ed.), *Normalization: The principle of normalization* (pp. 176-200). National Institute on Mental Retardation.

NSW Education Standards Authority. (2024a). *Life Skills in Stage 6*. Retrieved 27th of June, 2024, from https://curriculum.nsw.edu.au/ace-rules/ace11/life-skills-s6

NSW Education Standards Authority. (2024b). *Vocational education and training (VET) Stage 6*. Retrieved 27th of June, 2024, from https://educationstandards.nsw.edu.au/wps/portal/nesa/11-12/stage-6-learning-areas/vet

O'Rourke, J. (2011). Inclusion at university: Can we do more than open the door? *Journal of Social Inclusion*, *2*(2), 19-33. https://doi.org/10.36251/josi31

O'Shea, S. (2020). Rethinking 'widening participation' in higher education. In P. Burke, M. Bunn, & L. M. (Eds.), *An invitation to reconceptualise widening participation through praxis*. Centre of Excellence for Equity in Higher Education Resource.

Oates, A., Bebbington, A., Bourke, J., Girdler, S., & Leonard, H. (2011). Leisure participation for school-aged children with Down syndrome. *Disability and Rehabilitation*, *33*(19-20), 1880-1889. https://doi.org/10.3109/09638288.2011.553701

Oliffe, J. L., Kelly, M. T., Gonzalez Montaner, G., & Yu Ko Wellam, F. (2021). Zoom interviews: Benefits and concessions. *International Journal of Qualitative Methods*, *20*. https://doi.org/10.1177/16094069211053522

Oliver, M. (1996). *Understanding disability: From theory to practice*. Macmillan.

Ollerton, J., & Horsfall, D. (2013). Rights to research: Utilising the Convention on the Rights of Persons with Disabilities as an inclusive participatory action research tool. *Disability & Society*, *28*(5), 616-630. https://doi.org/10.1080/09687599.2012.717881

Onnivello, S., Colaianni, S., Pulina, F., Locatelli, C., Marcolin, C., Ramacieri, G., Antonaros, F., Vione, B., Piovesan, A., & Lanfranchi, S. (2022). Executive functions and adaptive behaviour in individuals with Down syndrome. *Journal of Intellectual Disability Research*, *66*(1-2), 32-49. https://doi.org/10.1111/jir.12897

Onnivello, S., Schworer, E. K., Prince, M. A., Daunhauer, L. A., & Fidler, D. J. (2023). Early developmental profiles among infants with Down syndrome. *Journal of Intellectual Disability Research*, *67*(3), 228-238. https://doi.org/10.1111/jir.12997

Ordem, O. A. (2018). Families of children with Down syndrome in Turkey: A sociocultural approach. *International Journal of Social Science Studies*, *6*(10), 67-73. https://doi.org/10.11114/ijsss.v6i10.3579

Ose, S. O. (2016). Using Excel and Word to structure qualitative data. *Journal of Applied Social Science*, *10*(2), 147-162. https://doi.org/10.1177/1936724416664948

Parliament of Victoria. (2021). *Inquiry into access to TAFE for learners with disability*. Parliament of Victoria.

Pascall, G., & Hendey, N. (2004). Disability and transition to adulthood: The politics of parenting. *Critical Social Policy*, *24*(2), 165-186. https://doi.org/10.1177/0261018304041949

Paterson, K. (2020). It's about time! Understanding the experience of speech impairment. In N. Watson & S. Vehmas (Eds.), *Routledge handbook of disability studies* (2nd ed., pp. 206-218). Routledge. https://doi.org/10.4324/9780429430817-15

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice*. SAGE Publications Inc.

Pena-López, A., Rungo, P., & Sánchez-Santos, J. M. (2021). Inequality and individuals' social networks: The other face of social capital. *Cambridge Journal of Economics*, *45*(4), 675-694. https://doi.org/10.1093/cje/beab016

Piro-Gambetti, B., Schworer, E. K., Handen, B., Glukhovskaya, M., & Hartley, S. L. (2023). Does employment complexity promote healthy cognitive aging in Down syndrome? *Journal of Intellectual Disabilities*, *28*(2), 499-513. https://doi.org/10.1177/17446295231169379

Pitman, T. (2022). *Supporting persons with disabilities to succeed in higher education*. National Centre for Student Equity in Higher Education, Curtin University.

Polidano, C., & Mavromaras, K. (2010). *The role of vocational education and training in the labour market outcomes of people with disabilities*. National Centre for Vocational Education Research.

Polidano, C., & Mavromaras, K. (2011). Participation in and completion of vocational education and training for people with a disability. *Australian Economic Review*, *44*(2), 137-152. https://doi.org/10.1111/j.1467-8462.2011.00632.x

Polidano, C., & Vu, H. (2011). *To gain, retain and retrain: The role of post-school education for people with a disability*. National Centre for Vocational Education Research.

Powell-Hamilton, N. N. (2023). *Down syndrome (trisomy 21)*. MSD Manuals. Retrieved 26th of May, 2024, from https://www.msdmanuals.com/professional/pediatrics/chromosome-and-gene-abnormalities/down-syndrome-trisomy-21?query=down%20syndrome

Priest, S. (2008). What is "social capital" and how can vocational education and training help develop it? Australian Learning Communities Network.

Productivity Commission. (2020). *National Agreement for Skills and Workforce Development review, study report*.

Queensland Government. (2018). *Reasonable adjustment in teaching, learning and assessment for learners with disability: A guide for VET practitioners*. Queensland Government.

Raffaele, G., Blout Zawatsky, C. L., Cottrell, C., & Santoro, S. L. (2022). Assessing co-occurring mental health conditions in a multidisciplinary Down syndrome clinic and the role of family history. *American Journal of Medical Genetics. Part A*, *188*(11), 3162-3171. https://doi.org/10.1002/ajmg.a.62948

Rasmussen, S. A., Wong, L., Correa, A., Gambrell, D., & Friedman, J. M. (2006). Survival in infants with Down syndrome, metropolitan Atlanta, 1979-1998. *The Journal of Pediatrics*, *148*(6), 806-812.e1. https://doi.org/10.1016/j.jpeds.2006.01.010

Riches, V., Gadow, F., & MacDonald, J. (2018). 20. Transition from university to employment. In P. O'Brien, M. L. Bonati, F. Gadow, & R. Slee (Eds.), *People with intellectual disability experiencing university life: Theoretical underpinnings, evidence and lived experience* (pp. 255-266). Brill Sense. https://doi.org/10.1163/9789004394551_020

Rillotta, F., Arthur, J., Hutchinson, C., & Raghavendra, P. (2020). Inclusive university experience in Australia: Perspectives of students with intellectual disability and their mentors. *Journal of Intellectual Disabilities*, *24*(1), 102-117. https://doi.org/10.1177/1744629518769421

Rillotta, F., Gobec, C., & Adam, T. (2020). *Up the Hill project: Accessible research summaries*.

Rillotta, F., Lindsay, L., & Raghavendra, P. (2018). 10. Journey “Up the Hill” through inclusive higher education for people with intellectual disability at a South Australian university: Scope, challenges and outcomes to date and into the future. In P. O’Brien, M. L. Bonati, F. Gadow, & R. Slee (Eds.), *People with intellectual disability experiencing university life* (pp. 155-169). Brill Sense. https://doi.org/10.1163/9789004394551_010

Rizvi, F., & Lingard, B. (2011). Social equity and the assemblage of values in Australian higher education. *Cambridge Journal of Education*, *41*(1), 5-22. https://doi.org/10.1080/0305764X.2010.549459

Robbins, D. (2012). Theory of practice. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 26-40). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/theory-of-practice/933FFBE27CD820E6361FA86EBF6A0A5D

Roberts, C. (1997). The politics of transcription: Transcribing talk: Issues of representation. *TESOL Quarterly*, *31*(1), 167-172. https://doi.org/10.2307/3587983

Robertson, R., Sclanders, M., Zed, J., & Donaldson, H. (2004). *Working with diversity: Quality training for people with a disability*. Australian National Training Authority.

Rogošić, S., & Baranović, B. (2016). Social capital and educational achievements: Coleman vs. Bourdieu. *CEPS Journal*, *6*(2), 81-100. https://doi.org/10.26529/cepsj.89

Roll, A. E., & Bowers, B. J. (2019). Building and connecting: Family strategies for developing social support networks for adults with Down syndrome. *Journal of Family Nursing*, *25*(1), 128-151. https://doi.org/10.1177/1074840718823578

Roll, A. E., & Koehly, L. M. (2020). One social network, two perspectives: Social networks of people with Down syndrome based on self-reports and proxy reports. *Journal of Applied Research in Intellectual Disabilities*, *33*(6), 1188-1198. https://doi.org/10.1111/jar.12736

Ronnie, L. (2023). The South African TVET sector: A Bourdieusian perspective. *Diaspora, Indigenous and Minority Education*, *17*(3), 182-197. https://doi.org/10.1080/15595692.2022.2164270

Rooney, C. (2019). *Listening to other voices: Building inclusion of higher education students with disability from the ground up*. English Language and Foundation Studies Centre and the Centre of Excellence for Equity in Higher Education, University of Newcastle.

Rose, D. (2003). Collaborative research between users and professionals: Peaks and pitfalls. *Psychiatric Bulletin*, *27*(11), 404-406. https://doi.org/10.1192/pb.27.11.404

Rudick, K. C., Quiñones Valdivia, F. I., Hudachek, L., Specker, J., & Goodboy, A. K. (2019). A communication and instruction approach to embodied cultural and social capital at a public, 4-year university. *Communication Education*, *68*(4), 438-459. https://doi.org/10.1080/03634523.2019.1642501

Runswick-Cole, K. (2008). Between a rock and a hard place: Parents' attitudes to the inclusion of children with special educational needs in mainstream and special schools. *British Journal of Special Education*, *35*(3), 173-180. https://doi.org/10.1111/j.1467-8578.2008.00390.x

Runswick-Cole, K., & Goodley, D. (2013). Resilience: A disability studies and community psychology approach. *Social and Personality Psychology Compass*, *7*(2), 67-78. https://doi.org/10.1111/spc3.12012

Ryan, J. (2011). Access and participation in higher education of students with disabilities: Access to what? *Australian Educational Researcher*, *38*(1), 73-93. https://doi.org/10.1007/s13384-010-0002-8

Sabat, C., Arango, P., Tassé, M. J., & Tenorio, M. (2020). Different abilities needed at home and school: The relation between executive function and adaptive behaviour in adolescents with Down syndrome. *Scientific Reports*, *10*(1), 1683. https://doi.org/10.1038/s41598-020-58409-5

Schubert, J. D. (2012). Suffering/symbolic violence. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 179-194). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/sufferingsymbolic-violence/E7A23471D9136B86482CC9807362CF3E

Schworer, E. K., Fidler, D. J., Kaur, M., Needham, A. W., Prince, M. A., & Daunhauer, L. A. (2020). Goal-directed action planning in infants with Down syndrome. *Journal of Intellectual Disability Research*, *64*(9), 713-724. https://doi.org/10.1111/jir.12763

Scott, M., Foley, K., Bourke, J., Leonard, H., & Girdler, S. (2014). "I have a good life": The meaning of well-being from the perspective of young adults with Down syndrome. *Disability and Rehabilitation*, *36*(15), 1290-1298. https://doi.org/10.3109/09638288.2013.854843

Sheldon, J. P., Oliver, M., & Yashar, B. M. (2021). Rewards and challenges of parenting a child with Down syndrome: A qualitative study of fathers'

perceptions. *Disability and Rehabilitation*, *43*(24), 3562-3573. https://doi.org/10.1080/09638288.2020.1745907

Shergold, P., Calma, T., Russo, S., Walton, P., Westacott, J., Zoellner, D., & O'Reilly, P. (2020). *Looking to the future: Report of the review of senior secondary pathways into work*, *further education and training*. Education Council.

Shildrick, M. (2020). Critical disability studies: Rethinking the conventions for the age of postmodernity. In N. Watson & S. Vehmas (Eds.), *Routledge handbook of disability studies* (2nd ed., pp. 32-44). Routledge. https://doi.org/10.4324/9780429430817-3

Shilling, C. (1991). Educating the body: Physical capital and the production of social inequalities. *Sociology*, *25*(4), 653-672. https://doi.org/10.1177/0038038591025004006

Shilling, C. (2004). Physical capital and situated action: A new direction for corporeal sociology. *British Journal of Sociology of Education*, *25*(4), 473-487. https://doi.org/10.1080/0142569042000236961

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education*, *48*(4), 256-267. https://doi.org/10.1177/0022466913489733

Shuttleworth, R., & Meekosha, H. (2012). The sociological imaginary and disability enquiry in late modernity. *Critical Sociology*, *39*(3), 349-367. https://doi.org/10.1177/0896920511435709

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011a). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics. Part A*, *155A*(10), 2348-2359. https://doi.org/10.1002/ajmg.a.34228

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011b). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics. Part A*, *155A*(10), 2335-2347. https://doi.org/10.1002/ajmg.a.34293

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011c). Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics. Part A*, *155A*(10), 2360-2369. https://doi.org/10.1002/ajmg.a.34235

Skotko, B. G., Levine, S. P., Macklin, E. A., & Goldstein, R. D. (2016). Family perspectives about Down syndrome. *American Journal of Medical*

Genetics Part A, *170*(4), 930-941. https://doi.org/10.1002/ajmg.a.37520

Smith-Merry, J. (2017). Inclusive disability research. In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences* (pp. 1935-1952). Springer. https://doi.org/10.1007/978-981-10-5251-4_129

Soldatic, K., & Meekosha, H. (2012). Disability and neoliberal state formations. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (1st ed., pp. 195-210). Routledge. https://doi.org/10.4324/9780203144114

State of NSW. (2024). *Choosing HSC subjects*. Retrieved 27th of June, 2024, from https://www.nsw.gov.au/education-and-training/nesa/hsc/subject-selection

Strunk, K. K. (2024). Critical approaches to quantitative research: Review, critique, and applications. In M. D. Young & S. Diem (Eds.), *Handbook of critical education research: Qualitative, quantitative, and emerging approaches* (pp. 56-74). Routledge. https://doi.org/10.4324/9781003141464

Tabron, L. A., & Thomas, A. K. (2024). (un)learning white supremacy ideologies to advance critical approaches to quantitative inquiry. In M. D. Young & S. Diem (Eds.), *Handbook of critical education research: Qualitative, quantitative, and emerging approaches* (pp. 401-413). Routledge. https://doi.org/10.4324/9781003141464

Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1116-1128. https://doi.org/10.1111/jar.12601

Thomson, G. O. B., Ward, K. M., & Wishart, J. G. (1995). The transition to adulthood for children with Down's syndrome. *Disability & Society*, *10*(3), 325-340. https://doi.org/10.1080/09687599550023561

Thomson, P. (2012). Field. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts* (2nd ed., pp. 65-80). Acumen Publishing. https://www.cambridge.org/core/books/pierre-bourdieu/field/598F9B7BEBF21AAA64832754A86AFA5A

Thorpe, C. (2018). *Social theory for social work: Ideas and applications*. Routledge. https://doi.org/10.4324/9780203529638

Tilly, L., & Walmsley, J. (Eds.). (2024). *Rights in practice for people with a learning disability: Stories of citizenship*. Springer Singapore Pte. Limited.

Tomaszewski, B., Fidler, D., Talapatra, D., & Riley, K. (2018). Adaptive behaviour, executive function and employment in adults with Down syndrome. *Journal of Intellectual Disability Research*, *62*(1), 41-52. https://doi.org/10.1111/jir.12450

Tong, F. (2022). Breaking Down: A critical discourse analysis of John Langdon Down's (1866) classification of people with trisomy 21 (Down syndrome). *Critical Discourse Studies*, *19*(6), 648-666. https://doi.org/10.1080/17405904.2021.1933117

Trainor, A. A. (2008). Using cultural and social capital to improve postsecondary outcomes and expand transition models for youth with disabilities. *The Journal of Special Education*, *42*(3), 148-162. https://doi.org/10.1177/0022466907313346

Uditsky, B., & Hughson, E. (2012). Inclusive postsecondary education-an evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 298-302. https://doi.org/10.1111/jppi.12005

UNICEF. (2017). Inclusive education: Understanding Article 24 of the Convention on the Rights of Persons with Disabilities. Retrieved 23rd of June, 2024, from https://www.unicef.org/eca/sites/unicef.org.eca/files/IE_summary_accessible_220917_0.pdf

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved 27th of May, 2021, from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-24-education.html

Van Riper, M., Ryff, C., & Pridham, K. (1992). Parental and family well-being in families of children with Down syndrome: A comparative study. *Research in Nursing & Health*, *15*(3), 227-235. https://doi.org/10.1002/nur.4770150309

Wacquant, L. J. D. (1989). Towards a reflexive sociology: A workshop with Pierre Bourdieu. *Sociological Theory*, *7*(1), 26-63. https://doi.org/10.2307/202061

Wagner, B., & McLaughlin, K. (2015). Politicising the psychology of social class: The relevance of Pierre Bourdieu's habitus for psychological

research. *Theory & Psychology*, *25*(2), 202-221. https://doi.org/10.1177/0959354315580606

Walker, S., & MacDonald, J. (2018). 12. My life as a university student. In P. O'Brien, M. L. Bonati, F. Gadow, & R. Slee (Eds.), *People with intellectual disability experiencing university life: Theoretical underpinnings, evidence and lived experience* (pp. 179-184). https://doi.org/10.1163/9789004394551_012

Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, *32*(2), 65-71. https://doi.org/10.1111/j.1468-3156.2004.00281.x

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present, and futures*. J. Kingsley Publishers.

Ward, K., Thomson, G. O. B., & Riddell, S. (1994). Transition, adulthood and special educational needs: An unresolved paradox. *European Journal of Special Needs Education*, *9*(2), 125-144. https://doi.org/10.1080/0885625940090202

Ward, O. C. (1999). John Langdon Down: The man and the message. *Down's Syndrome, Research and Practice*, *6*(1), 19-24. https://doi.org/10.3104/perspectives.94

Wasant, P., Boonyawat, B., Tritilanunt, S., Vatanavicharn, N., Sathienkijakanchai, A., Ratanarak, P., Malilum, O., & Liammongkolkul, S. (2008, Jul). Factors influencing development of Down syndrome children in the first three years of life: Siriraj experience. *J Med Assoc Thai*, *91*(7), 1030-1037.

Waterhouse, P., Kimberley, H., Jonas, P., & Glover, J. (2010). *What would it take? Employer perspectives on employing people with a disability*. National Centre for Vocational Education Research.

Webb, S. (2022). Higher vocational education and the matter of equity. In E. Knight, A.-M. Bathmaker, G. Moodie, K. Orr, S. Webb, & L. Wheelahan (Eds.), *Equity and access to high skills through higher vocational education* (pp. 9-35). Springer International Publishing. https://doi.org/10.1007/978-3-030-84502-5_2

Webb, S., Burke, P. J., Nichols, S., Roberts, S., Stahl, G., Threadgold, S., & Wilkinson, J. (2017). Thinking with and beyond Bourdieu in widening higher education participation. *Studies in Continuing Education*, *39*(2), 138-160. https://doi.org/10.1080/0158037X.2017.1302926

Wehmeyer, M. L. (1992). Self-determination and the education of students with mental retardation. *Education and Training in Mental Retardation*, *27*(4), 302-314.

Wehmeyer, M. L. (1995). The Arc's Self-Determination Scale: Procedural guidelines.

Wehmeyer, M. L. (1996). Self-determination in youth with severe cognitive disabilities: From theory to practice. In L. Powers, G. H. S. Singer, & J. Sowers (Eds.), *On the road to autonomy: Promoting self-competence in children and youth with disabilities* (pp. 115-133). Paul H. Brookes Publishing Co.

Wehmeyer, M. L. (2003a). A functional theory of self-determination: Definition and categorization. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 174-181). Charles C Thomas Publisher, Ltd.

Wehmeyer, M. L. (2003b). A functional theory of self-determination: Model overview. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 182-201). Charles C Thomas Publisher, Ltd.

Wehmeyer, M. L. (2003c). Research using the functional model of self-determination. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 202-220). Charles C Thomas Publisher, Ltd.

Wehmeyer, M. L. (2003d). Self-determination: A review of the construct. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 5-24). Charles C Thomas Publisher, Ltd.

Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, *30*(3), 113-120. https://doi.org/10.2511/rpsd.30.3.113

Wehmeyer, M. L. (2007). *Promoting self-determination in students with developmental disabilities*. Guilford Press.

Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities*, *51*(5), 399-411. https://doi.org/10.1352/1934-9556-51.5.399

Wehmeyer, M. L., Abery, B. H., Mithaug, D. E., & Stancliffe, R. J. (Eds.). (2003). *Theory in self-determination: Foundations for educational practice*. Charles C Thomas.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities*, *38*(2), 131-144.

Whitaker, S. (2013). *Intellectual disability: An inability to cope with an intellectually demanding world*. Palgrave Macmillan UK. https://doi.org/10.1057/9781137025586

White, E. L., & Morgan, M. F. (2012). Yes! I am a researcher. The research story of a young adult with Down syndrome. *British Journal of Learning Disabilities*, *40*(2), 101-108. https://doi.org/10.1111/j.1468-3156.2012.00745.x

Whitten, M. S. (2018). *The story of two syndromes*. Global Down Syndrome Foundation. Retrieved 23rd of May 2021, from https://www.globaldownsyndrome.org/about-down-syndrome/the-story-of-two-syndromes/

Will, E. A., Gerlach-McDonald, B., Fidler, D. J., & Daunhauer, L. A. (2016). Impact of maladaptive behavior on school function in Down syndrome. *Research in Developmental Disabilities*, *59*, 328-337. https://doi.org/10.1016/j.ridd.2016.08.018

Williams, V. (2011). *Disability and discourse: Analysing inclusive conversation with people with intellectual disabilities*. Wiley-Blackwell. https://doi.org/10.1002/9780470977934

Wong, S. I. (2002). At home with Down syndrome and gender. *Hypatia*, *17*(3), 89-117. https://doi.org/10.1111/j.1527-2001.2002.tb00943.x

Woodward, C. (2022). Adults with intellectual disabilities: Get to know Charlotte. *PM&R*, *14*(6), 731-733. https://doi.org/10.1002/pmrj.12812

Woolcott Research. (2017). *Drivers of participation and completion of VET*. Woolcott Research.

Yamamoto, Y., & Brinton, M. C. (2010). Cultural capital in East Asian educational systems: The case of Japan. *Sociology of Education*, *83*(1), 67-83. https://doi.org/10.1177/0038040709356567

Yang, Y. (2014). Bourdieu, practice and change: Beyond the criticism of determinism. *Educational Philosophy and Theory*, *46*(14), 1522-1540. https://doi.org/10.1080/00131857.2013.839375

Yoon, E. (2020). School choice research and politics with Pierre Bourdieu: New possibilities. *Educational Policy*, *34*(1), 193-210. https://doi.org/10.1177/0895904819881153

Appendices

List of appendices

1. Research flyer
2. Participant information sheet and consent form (People with Down syndrome) in Easy Read
3. Participant information sheet and consent form (People with Down syndrome)
4. Participant information sheet and consent form (Children with Down syndrome)
5. Participant information sheet and consent form (Parents and Carers)
6. Distress and referral protocol
7. Participant backgrounds
8. Interview guide (People with Down syndrome) in Easy Read
9. Interview guide (Parents and Carers)
10. Sample interview coding

Appendix 1: Research flyer

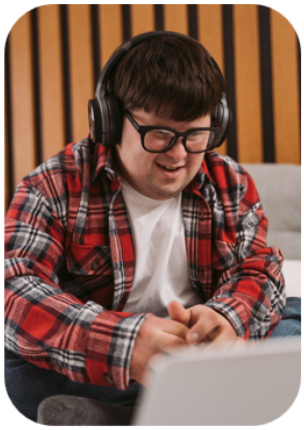
made with photosymbols

UTS

The University of Technology Sydney Human Research Ethics Committee has approved this research study (UTS HREC REF NO. ETH21-6453)

RESEARCH STUDY

Going further: Continuing learning and education for people with Down syndrome



Many people with Down syndrome want to keep learning after finishing high school. Some wish to go to university or TAFE.

We would like people with Down syndrome to share their voice on:

- What are your dreams for the future?
- Would you like to study further?
- How do you make choices about your life?



Who can take part?

People with Down syndrome aged 16-45

Parents & Carers

Australia wide



What is involved?

- 1-hour interview using questions, photos and objects for person with DS
- 1-hour interview for parents & carers



Who are we?

My name is Fievel Tong. I am a research student. My child also lives with DS. My research supervisor is Dr Keiko Yasukawa.



For more information (Easy Read): https://tinyurl.com/going-further-ds
fievel.tong@student.uts.edu.au or keiko.yasukawa@uts.edu.au

Appendix 2: Participant information sheet and consent form (People with Down syndrome) in Easy Read

Participant Information Sheet

Going further: Continuing learning and education for people with Down syndrome



My name is Fievel Tong. I am a research student at the University of Technology Sydney (UTS). My child also lives with Down syndrome.

My research supervisor is Dr Keiko Yasukawa.



This sheet has information about my **research**.

Research means finding out what people think about something.



My research is funded by an Australian Government Research Training Program Scholarship.



My research is about **further education**.

Many people with Down syndrome want to keep learning after finishing high school.



Some people with Down syndrome wish to study in **university or TAFE**.



I invite you to take part in my research because you are a person with Down syndrome aged 16 to 45.



I would like to **interview** you.

This means I would ask you questions about your life and your learning.



I would like to ask you questions like:

- What are your dreams for your future?
- How do you make choices about your life?
- Would you like to go to university or TAFE? Why or why not?



You will also use photos and personal objects to share your story.

You might show a photo of your dream life in the future, or something that you are proud of.



I will take photos of these photos and objects that you share with me.



I will also audio record our interview.

There will be no video recordings. I will not take any photos of you.



The interview will take about 1 hour.



You can decide where to do the interview.

It should be a place where you feel comfortable.



If you are not in Sydney, we can meet online on Zoom. If COVID-19 is really bad, we can meet online.



You can bring someone with you to the interview.

If you are under 18, your parent, carer or another adult must be with you.



I will also interview your parents or carers in a separate interview. They will help me to understand your experiences even more.



You will get the questions in Easy Read before the interview. You can prepare your answers beforehand. You can also ask someone for help.



There are some inconveniences and risks, if you take part in this research.

You will need to give time for the interview.



You might get nervous or tired during the interview.

You might feel sad or angry, if your life story has things that you do not like.

You might worry when you talk about your future.



You can stop the interview at any time. Then you can take a break or leave the interview.

You can decide if you want to do the interview again at another time.



If the interview gives you bad feelings, ask for help. Talk to your family, or someone you trust, like a doctor, counsellor or support worker.



You can also contact these organisations for support:

- Lifeline (13 11 14)
- Down Syndrome Australia (1300 881 935)
- People with Disability Australia (1800 843 929)
- Council for Intellectual Disability (1800 424 065)



Some people who read or look at my research might recognise you from the information you give. This is because the Down syndrome community is a little bit small in Australia.



To try to stop this from happening, I will not use your name in the research. You can also look at your interview transcript to change or delete any information you like.



You can decide if you want to participate in this research.

If you **consent**, that means you say **Yes** and you want to do this research.



If you say **No**, no one will be upset. Nothing will happen.

It will not affect your relationship with the researchers or with UTS.



Even if you say Yes, you can change your mind later. You can withdraw your participation.



If you withdraw, I will destroy the audio recording, transcript and photos. I will not use your information in the research.



If you say Yes, I will keep your information safely on my computer. No one else will see your information, because it will be protected by a password.



I will use the information for research purposes only.

I might publish the research or talk about it at a conference.



No one else will know that the information is about you. I will use a fake name.

I will blur out anything in the photos that can be traced back to you. I will not use faces of people, names, or specific place names in the research.



You can ask me or my supervisor any questions about the research.

Please email us at fievel.tong@student.uts.edu.au or keiko.yasukawa@uts.edu.au.

The University of Technology Sydney Human Research Ethics Committee has approved this research study (HREC Ref. No. ETH21-6453).

You can contact the Ethics Secretariat on (02) 9514 2478 or Research.Ethics@uts.edu.au.

made with photosymbols®

Participant Consent Form

Going further: Continuing learning and education for people with Down syndrome



If you would like to participate in this research, please fill out this **consent form**.

Consent means saying Yes.



I _____
(your name) agree to participate in the research project by Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au).



I know that an Australian Government Research Training Program Scholarship has funded this research.



I have read the Participant Information Sheet or someone has read it to me in a language I understand.



I know and understand:

- what the research is about
- what will happen in the research
- what the risks are in the research



I have had a chance to ask questions. I am happy with the answers I have received.



I want to take part in this research.

I know that I can change my mind at any time. This will not affect my relationship with the researchers or with UTS.



I know that I will get a signed copy of this document to keep.



I know that I can contact Fievel Tong and Keiko Yasukawa if I have any questions or concerns about the research.

_____ ____/____/____

Name and Signature (participant) Date

_____ ____/____/____

Name and Signature (researcher) Date

made with photosymbols®

Appendix 3: Participant information sheet and consent form (People with Down syndrome)

PARTICIPANT INFORMATION SHEET:
PEOPLE WITH DOWN SYNDROME AGED 16–45

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

WHO IS CONDUCTING THIS RESEARCH?

My name is Fievel Tong, and I am a research student at UTS (fievel.tong@student.uts.edu.au). My child also lives with Down syndrome.

My research supervisor is Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au).

WHAT IS THE RESEARCH ABOUT?

Many people with Down syndrome want to continue learning after they finish high school. They have the ability and potential to keep learning throughout their lives. Some people with Down syndrome may wish to study in university or vocational education and training (VET).

The purpose of this research is to find out what hopes and goals people with Down syndrome (aged 16-45) have towards further education.

I would like to find out what experiences people with Down syndrome have had in relation to post-secondary education. These experiences can include hopes and goals, decision-making processes, consultation and application processes, and actual experiences in university and VET.

This research will include people with Down syndrome (aged 16-45) and their parents/carers.

This research hopes to contribute to increasing the participation of people with Down syndrome in post-secondary education.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you are a person living with Down syndrome aged 16-45.

You might have goals and dreams about your future. You might be making decisions about your life independently or with support from others. You might be interested in going to university or VET. You might have some experience of learning and studying in university or VET. Your thoughts and feelings on further study are very important to this research.

Your parents/carers have also been invited to participate in this research to share their unique voice on this topic. They have received a separate participant information sheet and consent form. They will be interviewed separately, not during your interview.

FUNDING

Funding for this project has been received from an Australian Government Research Training Program Scholarship. This scholarship supports students completing a higher degree by research.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, I will invite you to take part in a 1-hour interview.

I will ask you questions such as: What are your dreams for your future? Do you wish to go to university or vocational education and training? How do you make choices about your life?

You will also use photographs and personal objects to share your story. This might be easier and more interesting than just answering questions. For example, you might show a photo or an object of your dream life in the future, or something that you are proud of.

The interviews will be audio recorded. The photographs and personal objects you share will also be photographed. The audio recordings and photographs will be used for research purposes only. No video recordings will be made. No photographs of you will be taken during the interview.

You will receive the interview questions in Easy Read before the interview. You can think about and prepare your responses. You can also ask someone to support you.

You will decide where we should do the interview. It should be a place where you feel comfortable and relaxed. If you are not in Sydney, we can meet online on Zoom. If the COVID-19 situation is a major issue, we can meet online.

You can bring someone you trust to support you in the interview. If you are under 18, your parent, carer or another adult you trust must be with you in the interview.

ARE THERE ANY RISKS/INCONVENIENCES?

Yes, there are some risks/inconveniences.

You will need to give 1 hour of your time to do the interview. You will also need to do some preparation before the interview.

During the interview, you might feel nervous or tired. You may feel sad, angry or embarrassed, if your life story has things that you do not like. You might feel worried when you talk about your future.

You can stop the interview at any time. Then you can take a break or leave the interview. You can decide if you want to do the interview again at another time.

If you get very strong feelings because of the interview, you can get support. You should contact a doctor, counsellor, psychologist or support worker after the interview. The following organisations can be contacted, if support is required:

Lifeline (13 11 14)

Down Syndrome Australia (1300 881 935)

People with Disability Australia (1800 843 929)

Council for Intellectual Disability (1800 424 065)

Since the Down syndrome community in Australia is relatively small, there is also the risk that you might be identifiable by people who will read the research outputs. If your lived experiences are particularly unique and well-known in the Down syndrome community or broader community, then you could be identified by those who already know of your particular lived experiences.

To mitigate this risk, the research data will be de-identified (please see details below in 'What will happen to information about me?'). You can also review the interview transcript to edit or withdraw any information which could lead to you being identified.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not to take part. If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers or the University of Technology Sydney. If you say No, no one will be upset. Nothing will happen.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

Even if you say Yes to participating in the research, you can change your mind later. You can withdraw your participation. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Fievel Tong (fievel.tong@student.uts.edu.au) or Keiko Yasukawa (keiko.yasukawa@uts.edu.au). If you withdraw from the study, the interview transcript, audio recording and photos from the interview will be destroyed. Your personal details will also be destroyed. I will not use any of your information in the research, if you withdraw.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form, you consent to me collecting and using personal information about you for the research project. All this information will be treated confidentially. I will keep your personal details, the transcript and audio recording of the interview, and the photographs of your photographs and personal objects safely on my computer. No one else will see this information, because it will be protected by a password. Your real name will not be used in the transcript.

I will use the information for my research purposes only. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. No one else will know that the information is about you. I will not use your name. I will blur out anything in the photos that can be traced back to you. For example, faces of people, names, and specific place names will not be used in my research.

Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the research that I or my supervisor can help you with, please feel free to contact us on fievel.tong@student.uts.edu.au or keiko.yasukawa@uts.edu.au.

You will be given a copy of this form to keep.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

CONSENT FORM

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

I _____ *[participant's name]* agree to participate in the research project being conducted by Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au). I understand that funding for this research has been provided by an Australian Government Research Training Program Scholarship.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I am aware that I can contact Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au) if I have any concerns about the research.

_____ ____/____/____

Name and Signature [participant] Date

_____ ____/____/____

Name and Signature [researcher] Date

Appendix 4: Participant information sheet and consent form (Children with Down syndrome)

PARTICIPANT INFORMATION SHEET:
PARENTS AND GUARDIANS CONSENT FORM

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

WHO IS CONDUCTING THIS RESEARCH?

My name is Fievel Tong, and I am a research student at UTS (fievel.tong@student.uts.edu.au). My child also lives with Down syndrome.

My research supervisor is Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au).

WHAT IS THE RESEARCH ABOUT?

Many people with Down syndrome want to continue learning after they finish high school. They have the ability and potential to keep learning throughout their lives. Some people with Down syndrome may wish to study in university or vocational education and training (VET).

The purpose of this research is to find out what hopes and goals people with Down syndrome (aged 16-45) have towards further education.

I would like to find out what experiences people with Down syndrome have had in relation to post-secondary education. These experiences can include hopes and goals, decision-making processes, consultation and application processes, and actual experiences in university and VET.

This research will include people with Down syndrome (aged 16-45) and their parents/carers.

The family plays an important role in the life choices of people with Down syndrome. So, it is important to give voice to families on the topic of post-secondary education.

To highlight each person's unique voice, people with Down syndrome and their parents/carers will be interviewed separately. A separate information sheet and consent form is available for parents/carers to participate.

This research hopes to contribute to increasing the participation of people with Down syndrome in post-secondary education.

WHY HAS MY CHILD BEEN INVITED?

Your child has been invited to participate because they are a person living with Down syndrome aged 16-17.

Your child might have goals and dreams about their future. They might be making decisions about their life with support from others, and taking part in transition programs. They might be interested in going to university or VET. Their thoughts and feelings on further study are very important to this research.

FUNDING

Funding for this project has been received from an Australian Government Research Training Program Scholarship. This scholarship supports students completing a higher degree by research.

WHAT DOES MY CHILD'S PARTICIPATION INVOLVE?

If you decide to allow your child to participate, they will be invited to take part in a 1-hour interview.

I will ask your child questions such as: What are your dreams for your future? Do you wish to go to university or vocational education and training? How do you make choices about your life?

Your child will also use photographs and personal objects to share their story. This might be easier and more interesting for them than just answering questions. For example, they might show a photo or an object of their dream life in the future, or something that they are proud of.

The interviews will be audio recorded. The photographs and personal objects your child shares will also be photographed. The audio recordings and photographs will be used for research purposes only. No video recordings will be made. No photographs of your child will be taken during the interview.

You and your child will receive the interview questions in Easy Read before the interview. This will give your child time and space to think about and prepare their responses. You can also support your child in this preparation, particularly to ensure that their chosen photographs and personal objects are appropriate for sharing.

You and your child will decide where we should do the interview. It should be a place where you and your child feel comfortable and relaxed. If you are not in Sydney, we can meet online on Zoom. If the COVID-19 situation is a major issue, we can meet online.

Since your child is under 18, a parent, carer or another trusted adult must be with your child in the interview.

ARE THERE ANY RISKS/INCONVENIENCES?

Yes, there are some risks/inconveniences.

Your child and you (or another trusted adult) will need to give 1 hour to do the interview. Your child and you will also need to do some preparation before the interview.

During the interview, your child might feel nervous or tired. They may feel sad, angry or embarrassed, if their life story has things that they do not like. They might feel worried when they talk about their future.

You or your child can stop the interview at any time. Then your child can take a break or leave the interview. You and your child can decide whether to do the interview again at another time.

If your child experiences very strong feelings because of the interview, they can get support. You should contact a doctor, counsellor, psychologist or support worker after the interview. The following organisations can be contacted, if support is required:

Lifeline (13 11 14)

Down Syndrome Australia (1300 881 935)

People with Disability Australia (1800 843 929)

Council for Intellectual Disability (1800 424 065)

Since the Down syndrome community in Australia is relatively small, there is also the risk that your child might be identifiable by people who will read the research outputs. If your child's lived experiences are particularly unique and well-known in the Down syndrome community or broader community, then your child could be identified by those who already know of your child's particular lived experiences.

To mitigate this risk, the research data will be de-identified (please see details below in 'What will happen to information about my child?'). You and your child can also review the interview transcript to edit or withdraw any information which could lead to your child being identified.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not you agree to allow your child to take part. If you decide not to allow your child to participate, it will not affect your relationship with the researchers or the University of Technology Sydney.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw your child from the study once it has started, you can do so at any time without having to give a reason, by contacting Fievel Tong (fievel.tong@student.uts.edu.au) or Keiko Yasukawa (keiko.yasukawa@uts.edu.au). If you withdraw your child from the study, the interview transcript, audio recording and photos from the interview will be destroyed. Your child's personal details will also be destroyed. I will not use any of your child's information in the research, if you withdraw them from the research.

WHAT WILL HAPPEN TO INFORMATION ABOUT MY CHILD?

By signing the consent form you consent to me collecting and using personal information about your child for the research project. All this information will be treated confidentially. I will keep your child's details, the transcript and audio recording of the interview, and the photographs of your child's photographs and personal objects safely on my computer. No one else will see or access this information, because it will be protected by a password. Your child's real name will not be used in the interview transcript.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that your child cannot be identified, except with your permission. I will not use your child's name in any publication or presentation. I will also blur out anything in the photos that can be traced back to your child. For example, faces of people, names, and specific place names will not be used in my research.

Your child's information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the research that I or my supervisor can help you with, please feel free to contact us on fievel.tong@student.uts.edu.au or keiko.yasukawa@uts.edu.au.

You will be given a copy of this form to keep.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

CONSENT FORM

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

I _____ *[name of Parent/Guardian]* give permission for my child _____ *[name of child]* to participate in the research project being conducted by Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au). I understand that funding for this research has been provided by an Australian Government Research Training Program Scholarship.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to allow my child to participate in this research project as described and understand that I am free to withdraw my child at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I am aware that I can contact Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au) if I have any concerns about the research.

_____

Name of child [please print]

_____ ____/____/____

Signature or mark of child Date

_____

Name Parent/Guardian [please print]

_____ ____/____/____

Signature of Parent/Guardian Date

Appendix 5: Participant information sheet and consent form (Parents and Carers)

PARTICIPANT INFORMATION SHEET:

PARENTS AND CARERS

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

WHO IS CONDUCTING THIS RESEARCH?

My name is Fievel Tong, and I am a research student at UTS (fievel.tong@student.uts.edu.au). My child also lives with Down syndrome.

My research supervisor is Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au).

WHAT IS THE RESEARCH ABOUT?

Many people with Down syndrome want to continue learning after they finish high school. They have the ability and potential to keep learning throughout their lives. Some people with Down syndrome may wish to study in university or vocational education and training (VET).

The purpose of this research is to find out what hopes and goals people with Down syndrome (aged 16-45) have towards further education.

I would like to find out what experiences people with Down syndrome have had in relation to post-secondary education. These experiences can include hopes and goals, decision-making processes, consultation and application processes, and actual experiences in university and VET.

This research will include people with Down syndrome (aged 16-45) and their parents/carers.

This research hopes to contribute to increasing the participation of people with Down syndrome in post-secondary education.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you are a parent or carer of a person living with Down syndrome aged 16-45.

Your adolescent/adult child might be interested in going to university or VET, or they may have had some experience of learning and studying in these contexts.

As a parent/carer, you likely play a vital role in shaping the life goals of your child. Families are often also involved in the decision-making processes of the individual with Down syndrome. Additionally, family background might affect the individual's opportunities for post-secondary education. Your perspective on this important topic of further education for people with Down syndrome is valuable and unique.

Your adolescent/adult child has also been invited to participate in this research to share their unique voice. They have received a separate participant information sheet and consent form, including an Easy Read version. They will be interviewed separately, not during the interview with you.

FUNDING

Funding for this project has been received from an Australian Government Research Training Program Scholarship. This scholarship supports students completing a higher degree by research.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, I will invite you to take part in a 1-hour interview.

I will ask you questions such as: What dreams and aspirations does your adolescent/adult child have? How are you involved in their decision-making processes? What opportunities and barriers do you see for their participation in university and/or VET?

The interviews will be audio recorded for research purposes only. No video recordings will be made. No photographs of you will be taken during the interview.

You will decide where we should do the interview. It should be a place where you feel comfortable and relaxed. If you are not in Sydney, we can meet online on Zoom. If the COVID-19 situation is a major issue, we can meet online.

ARE THERE ANY RISKS/INCONVENIENCES?

Yes, there are some risks/inconveniences.

You will need to give 1 hour of your time to do the interview. You will also need to do some preparation before the interview, to consider your responses to the interview questions.

During the interview, you might feel nervous or tired. You might experience complex feelings (positive and negative), as you share about your experiences of parenting/caring for your adolescent/adult child with Down syndrome. You might feel embarrassed or ashamed to share certain thoughts or feelings you may have had towards your child. You might also feel burdened by worry and responsibility, as you discuss your child's future, especially their prospects for accessing post-secondary education opportunities.

You can stop the interview at any time, should any distress or strong emotions arise. Then you can take a break or leave the interview. You can decide if you want to do the interview again at another time.

If you experience very strong feelings because of the interview, you can get support. You should contact a doctor, counsellor, psychologist or support worker after the interview. The following organisations can be contacted, if support is required:

Lifeline (13 11 14)

Down Syndrome Australia (1300 881 935)

People with Disability Australia (1800 843 929)

Council for Intellectual Disability (1800 424 065)

Since the Down syndrome community in Australia is relatively small, there is also the risk that you might be identifiable by people who will read the research outputs. If your (and your child's) lived experiences are particularly unique and well-known in the Down syndrome community or broader community, then you could be identified by those who already know of your particular lived experiences.

To mitigate this risk, the research data will be de-identified (please see details below in 'What will happen to information about me?'). You can also review the interview transcript to edit or withdraw any information which could lead to you being identified.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not to take part. If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers or the University of Technology Sydney.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Fievel Tong (fievel.tong@student.uts.edu.au) or Keiko Yasukawa (keiko.yasukawa@uts.edu.au). If you withdraw from the study, the interview transcript and audio recording will be destroyed. Your personal details will also be destroyed. I will not use any of your information in the research, if you withdraw.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form, you consent to me collecting and using personal information about you for the research project. All this information will be treated confidentially. I will keep your personal details, and the transcript and audio recording of the interview safely on my computer. No one else will see or access this information, because it will be protected by a password. Your real name will not be used in the transcript.

I will use the information for my research purposes only. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. No one else will know that the information is about you, as I will not use your name.

Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the research that I or my supervisor can help you with, please feel free to contact us on fievel.tong@student.uts.edu.au or keiko.yasukawa@uts.edu.au.

You will be given a copy of this form to keep.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

CONSENT FORM

UTS HREC REF NO. ETH21-6453

Going further:
Continuing learning and education for people with Down syndrome

I _____ *[participant's name]* agree to participate in the research project being conducted by Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au). I understand that funding for this research has been provided by an Australian Government Research Training Program Scholarship.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I am aware that I can contact Fievel Tong (fievel.tong@student.uts.edu.au) and Dr Keiko Yasukawa (keiko.yasukawa@uts.edu.au) if I have any concerns about the research.

_____ ____/____/____

Name and Signature [participant] Date

_____ ____/____/____

Name and Signature [researcher] Date

Appendix 6: Distress and referral protocol

UTS HREC REF NO. ETH21-6453

Going further: Continuing learning and education for people with Down syndrome

Distress and Referral Protocol

The following protocol will be put in place should a participant become distressed and require either additional or ongoing assistance. This protocol applies to both types of participants: people with Down syndrome aged 16-45 and their parents/carers.

Prior to the commencement of any interview, individuals will receive detailed information regarding the risks and benefits of the research, so that each individual may freely accept or decline participation. This information will be communicated on the participant information sheets and consent forms (including the Easy Read version), as well as the parents' and guardians' information sheet and consent form for the participants aged 16-17. The participants will also receive the interview questions (including the Easy Read version) before the interview, to allow them to process their responses in their own time and space.

Approximately one week prior to each interview, the researcher will also speak or meet with each participating family (in person or online) to ensure that they have understood and accepted the risks of participation. The information in this distress protocol will also be communicated to the participants.

At the commencement of the interview, the researcher will remind each participant of the information in this protocol, namely what will happen should they experience emotional and/or psychological distress at any time during the interview.

Strategies to mitigate the risk of distress before/during interview:

- Provide participants with information sheets, consent forms and interview questions prior to the interview
- Meet or speak with each participating family approximately one week before the interview
- Inform participants with Down syndrome that they can bring a support person to the interview
- Allow adequate time for participants to process and share their experiences and perspectives
- Reassure participants that they can pause and/or leave the interview at any time
- Ask participants intermittently during the interview how they are feeling
- Reassure participants that if they feel sad or need to talk to someone after the interview that support organisations can be contacted

Strategies to assist those distressed during an interview:

Should a participant become uncomfortable or distressed while discussing any topic during an interview, the following actions will be taken by the researcher:

1. Suggest to the participant to pause the interview and take a break. If the discomfort appears transient and non-severe, and if the participant's condition improves after the break, then ask the participant whether they wish to resume the interview. The participant's decision will be respected by the researcher.

2. Suggest to the participant to leave the interview. This action will be taken especially if their distress appears acute and/or their condition does not improve after the break.

3. Refer the participant to support services. In addition to the participant's GP and/or other existing services used, the follow support services will be recommended:

   Lifeline (13 11 14)

   Down Syndrome Australia (1300 881 935)

   People with Disability Australia (1800 843 929)

Council for Intellectual Disability (1800 424 065)

4. Follow up with participant within 1-3 days of the interview to offer further support. Ask if the participant has contacted any support services, and encourage them to (if they have not done so already).

5. Ask participant whether they wish to participate in the interview at another time. This question will not be asked, if the participant has previously expressed a wish to withdraw from the research, unless they now initiate this discussion.

6. Remove participant from research study. As outlined in the participant information sheet, if a participant withdraws, any data that has been collected will be destroyed and not be used in the research.

Summary:

In line with the researcher's duty of care, the researcher has outlined specific strategies for mitigating the risk of participant distress and also for assisting participants who experience discomfort and/or distress. The participants will be informed of these support mechanisms before, during, and after the interviews.

Appendix 7: Participant backgrounds

Person with Down syndrome	Age	Post-secondary education experience/s	Parent / Carer	Location	Recruitment
Renee	44	TAFE, University	Melanie James	Adelaide, SA	Direct (journal article)
Helen	22	TAFE	Leanne	North Coast, NSW	Celebrate T21
Elise	17	TAFE	Irene	Sydney, NSW	Down Syndrome Australia, Council for Intellectual Disability
Adam	39	TAFE	Kate	Perth, WA	Down Syndrome Australia
(David)	*(16)*	*(None)*	Jessica	Melbourne, VIC	Direct (Facebook)
Melissa	19	TAFE	Peter	Hunter Region, NSW	Direct (business)
Sherry	41	TAFE, University	Philippa	North Coast, NSW	Down Syndrome Queensland
Gina	37	TAFE		Brisbane, QLD	Down Syndrome Queensland

Note: David was not interviewed, but his mother, Jessica, was interviewed

Appendix 8: Interview guide (People with Down syndrome) in Easy Read

Going further: Continuing learning and education for people with Down syndrome

Interview Questions

(Easy Read)







My name is Fievel Tong.

I am a research student at the University of Technology Sydney (UTS).

My child lives with Down syndrome. He is the inspiration for my research.





Please tell me a little bit about yourself.



What are your hopes and dreams for your future?

Share a photo or an object to talk about your dream life in the future.



How do you make decisions about your life?



What advice do other people give you about your life decisions?



What choices did / do you have after finishing high school? How was your transition out of school?





What do you enjoy learning about? How do you learn about it?

Share a photo or an object of something you like learning about.



Do you like learning and studying?

Why or why not?



Why did / do you want to study at university or TAFE?



How did you get into university or TAFE? What was the process?





What did / do you do at university or TAFE?

Show a photo or an object of something you did / do at university or TAFE.



What did / do you like about studying at university or TAFE?

Show a photo or an object of something you liked at university or TAFE.



What was / is hard about studying in university or TAFE?



What choices and plans do you have for further learning and education?



What does Down syndrome mean to you?



What is good about living with Down syndrome?

Is there anything hard about it?





What are you good at? What are you proud of yourself for?

Share a photo or an object of something you are good at or proud of.



Thanks for sharing your voice in this research!

made with photosymbols®

Appendix 9: Interview guide (Parents and Carers)

Going further: Continuing learning and education for people with Down syndrome

Interview Questions

(Parents / Carers)





Introduction:

1. Please tell me a little bit about yourself.

2. How would you describe your child?

3. What does Down syndrome mean to you?
    a. What has living with Down syndrome looked like in your child's life?

Life goals and decision-making:

4. What are your child's hopes and goals in life?
    a. How are these similar or different to your hopes and goals for their life?

5. How does your child make decisions about their life?
    a. How are you involved in these decisions?
    b. Who else is involved in the decision-making process?

6. What did / will your child do after finishing high school?
    a. What choices did / do they have?
    b. How was their transition out of high school?

Further education:

7. How would you describe your child as a learner?
    a. What might be some strengths and challenges your child has for studying at university or TAFE?

8. Why did / does your child study at university or TAFE?
9. How did they get into university or TAFE? What was the process?

10. What did / does your child do at university or TAFE?

11. What did / do they like about studying at university or TAFE?

12. What was / is hard about studying in university or TAFE?

13. How important is it to you that your child has access to university or TAFE?
    a. How important do you think it is for people with Down syndrome in general?

14. Do you think your family background could affect your child's opportunities for university or TAFE? If so, how?

15. What opportunities and barriers are there to accessing and participating in university or TAFE for people with Down syndrome?

Conclusion:

16. What are you proud of your child for?

Thank you for sharing your voice in this research!

Appendix 10: Sample interview coding

Line	Speaker	Utterance	Domains	Codes
476	Irene	Yeah, so, the thing is that I'm not getting a lot of information. Because when I say, 'So, do you like it at TAFE?', she goes, 'Not really.' So, and then, it's kind of the question: What is it that is 'not really'? But, so one of the things was that, because she was so used to going to school – stay there for two hours, and then go to the office, and say, 'Look, I'm not feeling well' – that when she went to TAFE, she did the same. So, she would – after a few days of being there, she went there as well, 'I'm not feeling so well.' And then somehow, the teacher did a fist bump. 'Have a fist bump' – solves all problems, apparently. [laughter]	Further education High school Down syndrome	Likes; Challenges; Support; Family support; Teachers and staff Challenges Health