Creating a path from school to work: Reconceptualising economic participation for young Australians with intellectual disability

A thesis in fulfilment of the requirements for the degree of
Doctor of Philosophy

Jennifer Crosbie
Bachelor of Arts (Disability Studies), Graduate Diploma of Industrial Relations and Human Resource Management

Centre for Social Impact, School of Business, Law and Entrepreneurship,
Swinburne University of Technology
Victoria, Australia
2023

Declaration

DECLARATION BY CANDIDATE

This declaration confirms that:

- The thesis contains no material that has been accepted for the award to the candidate of any other degree or diploma.
- To the best of the candidate's knowledge the thesis contains no material previously published or written by another person except where due reference is made in the text of the examinable outcome, and with permission received to republish the work in the thesis.
- Where the work is based on joint research or publications, discloses the relative contributions of the respective creators or authors using the authorship declaration form.

Jennifer Crosbie

October 2022

Table of contents

List of tables

List of figures

Acknowledgments

Many thanks to my supervisors Professor Erin Wilson and Dr Perri Campbell for your guidance and support, and in particular your unwavering belief that I could do this. I have learnt so much and I'm very grateful you were my supervision team.

I would like to acknowledge Emeritus Professor Joe Graffam, Professor Keith McVilly and Professor Jane McGillivray for encouraging me to take this journey and for supporting me in all sorts of ways over the last 30 years. Thank you to Dr Kevin Murfitt and Dr Jo Watson, who stepped up when I needed them.

I acknowledge the financial support received from Swinburne University of Technology, in the form of a scholarship. Thank you also to Kerrie Le Lievre for editing and formatting the thesis.

I couldn't have completed this thesis without an enormous amount of support from my family and friends. Thanks to my father Richard for instilling in me a lifelong love of learning and to my mother Rona for being an enormous support, and particularly helping me to juggle my work and family responsibilities over the last 20 years. Thanks to everyone who kept me afloat throughout the journey in a myriad of ways.

A huge thank you to my daughters and fellow students Eloise and Zali, who have joined me on the higher education journey. Thank you for all the cups of tea and snacks, for cooking endless dinners and for just being there when I needed you.

I could not have completed this thesis without the support of my husband Craig. I am lucky to have you as my partner in life.

Finally, a very big thank you to the young people with intellectual disability, family members and key informants who participated in this study and who shared their experience and their knowledge with me and allowed me to share their stories. I admire you for the tenacity you show every day in trying to forge a different path and I hope this study goes some way to making that path smoother.

Abstract

In recent years there has been a shift in expectations about the roles young people with intellectual disability can and should undertake post-school, however very few people with intellectual disability hold jobs in the community. The Australian Government recognises that more needs to be done to include Australians with disability in the economic and social life of the community, and the implementation of the National Disability Insurance Scheme (NDIS) is considered a key mechanism to drive change.

This thesis utilises qualitative methods to examine the expectations of post-school economic participation held by nine young people with intellectual disability and ten family members in Victoria, Australia, along with their experiences transitioning from school and entering the adult service system. The data identifies expectations about creating an ‘ordinary life’ post-school – that is, one that includes community-based work. However, school-based transition practices continue to focus on transfer from school to disability services, a pathway that closes off opportunities for community-based employment in the long term.

This thesis triangulates data from 13 key informants with the lived-experience data from young people and family members and analyses it utilising an ecological framework to make the barriers to young people’s economic participation visible. It identifies significant policy and attitudinal barriers, including widely held beliefs about this cohort’s need for and capacity to engage in community-based work. The study identifies how unclear transition timeframes result in poor planning and a failure to understand how economic participation unfolds throughout the transition to adulthood. Individualised funding adds further complexity to systems and fails to address key policy and attitudinal barriers to economic participation. In addition, the study identifies how the service provider market remains wedded to institutionalised practices and has failed to adopt evidence-informed practice that supports economic participation outcomes for this cohort. Together these failures have reduced the opportunities available to individual young people.

The thesis highlights ways to address these challenges and mitigate the barriers that lead to young people with intellectual disability experiencing marginalisation from the community-based labour market. It adds to the evidence on barriers to community-based employment, focusing particularly on young people with significant intellectual disability, a cohort who have received little research attention. In the context of shifting attitudes about economic participation for this cohort and the introduction of individualised funding, it identifies practical strategies to improve transitions to work for young people with intellectual disability.

Keywords

Young people with significant intellectual disability, transition from school, economic participation, ecosystem

Glossary

Term	Definition
Australian Disability Enterprise (ADE)	The Australian title for a segregated disability employment provider
Community-based work	Work performed in the community alongside people without disability
Customised employment	A job or self-employment opportunity that fits an individual's skills, interests, strengths, and support needs as well as the needs of businesses and the community
Disability day program	Activities organised or provided directly by community service organisations for people with a disability aged 16 years and over
Disability Employment Network (DEN)	Government-funded employment service system for people with disabilities operating in Australia between 1991 and 2010
Disability Employment Services (DES)	Government-funded employment service system for people with disabilities operating in Australia from 2010 to the present
Disability Services Provider	A business, organisation, or person providing funded disability support services
Disability Support Pension (DSP)	The Disability Support Pension provides income support for people who are unable to work due to a physical, intellectual, or psychiatric impairment. DSP is granted if a medical assessor determines that an individual is unable to work at least 15 hours per week for at least the next 2 years or if the person is deemed to have a manifest medical entitlement
Discovery	A process that assists job seekers in identifying employment that would be a good fit for both them and an employer
Economic participation	Activities undertaken that are primarily oriented towards paid employment, including work, study and training and volunteer work

Integrated Practical Placement Program (IPP)	A Victoria-based demonstration project based on Project SEARCH principles
Manifest medical entitlement to DSP	Disability Support Pension (DSP) medical rules are one set of rules used to assess if a person is eligible for the DSP. Having an intellectual disability with an IQ of less than 70 is a condition that meets the manifest medical rules for DSP, meaning that it is granted without the need for further assessment
National Disability Insurance Agency (NDIA)	The statutory authority responsible for the implementation of the National Disability Insurance Scheme
National Disability Insurance Scheme (NDIS)	A scheme of the Australian Government that funds costs associated with disability
Post-school provider	A provider of services to young people who have completed their compulsory schooling
Quasi-market	A public-sector institutional structure that is designed to reap the supposed efficiency gains of free markets without losing the equity benefits of traditional systems of public administration and financing
Registered Training Organisation (RTO)	A provider registered by the Australian Skills Quality Authority (or a state regulator) to deliver nationally recognised Vocational Education and Training (VET) and qualifications
School Based Apprenticeship or Traineeship (SBAT)	A program that offers students the option of combining their senior secondary education with part-time employment and skills training
School Leaver Employment Support (SLES)	NDIS funding to help participants move from school to work, which is available in the final years of school and directly after leaving school
Social enterprise	A business with social objectives that serve its primary purpose

Supported employment	Refers to competitive employment in an integrated setting, with ongoing support services for individuals with the most severe disabilities
Supported wage	Special workplace arrangements that enable employers to pay wages to people with disability based on how productive they are in their jobs
TAFE	Technical and Further Education colleges: government-owned providers of VET courses
Ticket to Work (TTW)	Ticket to Work is an Australian transition model for young people with disability
Work experience	Unpaid short-term placement that enables a person to gain experience of work in a mainstream employment setting
Work Integrated Learning (WIL)	An arrangement in which students undertake learning at a workplace outside of their school or higher education provider

Chapter 1: Introduction

This thesis explores the experiences of young people with intellectual disability as they transition away from school in order to understand the barriers to and enablers of their economic participation. The economic participation of young people with intellectual disability is of interest because this cohort continues to be underrepresented in economic participation activities post-school, putting them at increased risk of social exclusion and poverty (Kavanagh et al., 2013; Lysaght et al., 2017). In 2013 the National Disability Insurance Scheme (NDIS) was introduced to provide Australians with disability with individualised funding to purchase the supports they need to reach their potential. Despite this – and increased expectations both internationally and in Australia about the capacity of young people with intellectual disabilities to work in the mainstream labour market – their rates of labour market participation remain low (Australian Institute of Health and Welfare [AIHW], 2020). By drawing on the perspectives of young people, family members and key informants, this study seeks to understand how and why these young people continue to be excluded from economic participation activities post-school. This thesis will also develop a rich understanding of how inclusion in economic participation activities can become the norm for them in late secondary school, the years post-school and throughout their adult lives.

1.1 Who is this study about?

This thesis focuses on young people who have been diagnosed as having an intellectual disability at birth or in early childhood, and specifically those considered to have a moderate to severe intellectual disability who have been educated in special schools (National Disability Insurance Agency [NDIA], 2019b). People with moderate to severe intellectual disability typically require daily assistance with a range of everyday activities (Schalock et al., 2021; World Health Organisation [WHO], 2011), and young people in this cohort are at increased risk of being relegated to sheltered workshops or non-work programs, where they have fewer opportunities to develop normative valued roles, post-school (AIHW, 2015; Bell, 2019; Davies & Beamish, 2009; Shogren et al., 2019). This cohort has poorer outcomes on a range of measures related to health and wellbeing (AIHW, 2008, 2017b; Australian Social Inclusion Board, 2010; Kavanagh et al., 2013; Stokes et al., 2013), and its labour force rates remain persistently low (AIHW, 2020).

Intellectual disability is the contemporary label used to describe people who experience 'significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills' (Tassé et al., 2016, p. 381). Likewise, The World Health Organisation (WHO) defines intellectual disability as

> a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood and has a lasting effect on development. (2018, para. 1)

This contemporary biopsychosocial model of disability recognises that disability is the result of intersections between an impairment in body function and structure, such as a cognitive impairment, and a limitation in activities or restriction in participation, such as in work (AIHW, 2008; WHO, 2011). These understandings of intellectual disability sit within contemporary notions of disability defined by human rights conventions, including The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD adheres to the social model of disability, understanding that 'disability results from interaction between impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others' (United Nations, 2006). In other words, a lack of accessible facilities, poor access to education and information, and discrimination impact upon opportunities for people with disabilities to reach their potential and become fully valued citizens. The UNCRPD definition recognises that rather than focusing on how impaired individuals can fit into society, society must become more able to accommodate a wide range of people who experience the human condition differently.

In Australia, approximately 2.9% of the population, or 668,100 people, has an intellectual disability (Australian Bureau of Statistics [ABS], 2012), with approximately 88,000, or 12.8%, of these aged 15-24 (ABS, 2016). It is estimated that approximately 85% of people with intellectual disability worldwide have a mild disability and 13.5% a moderate or severe intellectual disability (American Psychiatric Association [APA], 2013). The Australian Bureau of Statistics (ABS) defines severe limitation as a person having difficulty or sometimes requiring help with a 'core activity' – self-care, mobility or communication – of daily living (ABS, 2019). Unlike people in other major disability groups, where severe limitations are more likely to be related to self-care and mobility, almost 60% of people with intellectual disability have severe communication limitations. In addition, people with intellectual disability are more likely to have severe limitations in all three core activities (AIHW, 2008).

In a functional sense, intellectual disability causes unique challenges, and people with intellectual disability experience difficulty with a range of cognitive tasks including learning and applying knowledge (Foley et al., 2012), decision-making, and adjusting to changes in circumstances and unfamiliar environments (AIHW, 2008). In addition, they may experience difficulty following instructions, solving day-to-day problems, understanding others, expressing themselves, and having a concept or firm understanding of time and time management (Crawford, 2011; Tassé et al., 2016). Deficits in adaptive behaviour such as travelling to and from work and having the necessary independent living skills for the workplace can also impact on their ability to work in the mainstream labour market (AIHW, 2008). For example, lack of travel training or additional support to obtain a driver's licence can impact on an individual's capacity to get to a worksite. Significant support is therefore required during times of change, and there is a need to carefully plan how the environments people with intellectual disability operate in are structured, how tasks are taught, and which strategies best enable this cohort to communicate with a wide range of others (AIHW, 2008; Schalock et al., 2021).

People with intellectual disability are not homogenous; impairments impact each individual differently (Schalock et al., 2021). In contemporary society, the environment – particularly the family environment – also impacts functioning, resulting in people with intellectual disability having different strengths, support needs, available supports and interests (Wong et al., 2021). It is therefore incorrect to assume that all people labelled 'intellectually disabled' are similar and treat them as such.

1.2 Statement of the problem: Exclusion from economic participation

Young people with intellectual disability are among the most marginalised in Australian society (Bigby & Fyffe, 2010; Commonwealth of Australia, 2009; Gooding et al., 2017). By any measure, they fare poorly compared to their non-disabled peers, and are less likely to achieve important markers of adulthood such as working in community-based jobs and having their own homes (Wood et al., 2018). Therefore, special attention needs to be paid to their economic participation.

Internationally it is widely acknowledged that transition from secondary school is a particularly challenging time for young people with intellectual disability (Bouck, 2014; Jacobs et al., 2018). Despite extensive research and the introduction of legislative and human rights instruments, they continue to lag behind their peers in terms of post-school outcomes, with data consistently indicating high unemployment rates post-school (Kohler et al., 2017; Richardson et al., 2017; Shogren & Wehmeyer, 2020; Siperstein et al., 2013) and fewer students transitioning from school to post-school education (AIHW, 2008; Baer et al., 2011;

Bouck, 2012; Davies & Beamish, 2009; Grigal et al., 2011; Newman et al., 2009; Stanwick et al., 2017). Australian data indicates that young people with intellectual disability experience unemployment rates more than four times those of their non-disabled peers (ABS, 2012; Cheng et al., 2018).

In Australia, many young people with intellectual disability continue to be educated in segregated settings and are considered a cohort at risk of transitioning to non-vocational or segregated settings (Blacher, 2001; Cox, 2017; Davies & Beamish, 2009; Meadows, 2009; NDIA, 2019b, 2020; Winn & Hay, 2009). For example, over half of the young people with intellectual disability involved in a Queensland study (Davies & Beamish, 2009) transitioned from high school to disability day programs focused on recreation activities and life skills development rather than economic participation. This results in their exclusion from the labour market throughout their lifetime (Arvidsson et al., 2016; Australian Government, 2006; Cocks & Harvey, 2008; Dempsey & Ford, 2009; Organization for Economic Co-operation and Development [OECD], 2010). Research from the United States also suggests that young people with intellectual disability are more likely to stay in special schools until they age out, and less likely to complete high school with a recognised diploma (Papay & Bambara, 2014). Historically, undertaking some or all of their compulsory education in special schools has led to these young people having less access to early economic participation-focused activities such as career education and technical skills training (Baer et al., 2011), and work experience. This acts to reduce expectations about later work (Carter et al., 2011a) and increases the likelihood that the young people will never participate in the mainstream labour market (Baer et al., 2011). In the United States, Wagner et al. (2005) reported that students with intellectual disability had lower expectations about post-school outcomes than other students and were more often planning to transition to sheltered employment rather than competitive employment. In addition, students with intellectual disability thought they were unlikely to enrol in or graduate from post-secondary education (Baer et al., 2011). Consequently, by their mid-20s very few have a community-based job: that is, a job alongside non-disabled community members (Health and Social Care Alliance Scotland & Scottish Government Directorate for Children and Families, 2017; NDIA, 2019b, 2020).

People with intellectual disability are particularly impacted by being excluded from the labour market, because this closes off a pathway to inclusion in broader community life (Kavanagh et al., 2013; Saunders et al., 2007). In Australia, it remains optional for the significant proportion who are in receipt of the Disability Support Pension (DSP) to engage in economic participation activities post-school, and there continues to be little awareness of the important role economic participation can play in the lives of young people with intellectual disability in the broader community.

Increasing the economic participation of people with disability benefits both them and the broader community (Australian Human Rights Commission [AHRC], 2016; Murfitt et al., 2018; Sundar et al., 2018). Despite these benefits, Australia’s obligations under the UNCRPD, and the introduction of individualised funding via the NDIS, employment rates have remained stagnant (Cheng et al., 2018; NDIA, 2020). Australian governments recognise both that more needs to be done to include young people with disability in economic participation activities and work post-school, and that existing policy settings have not brought about significant change (AHRC, 2016; NDIA, 2019a). Recent government strategies, statements and inquiries, such as the NDIA’s *Participant Employment Strategy (NDIA, 2019a)*, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Australia’s Disability Strategy* (Australian Government Department of Social Services [DSS], 2021a) and the *National Disability Employment Strategy* (DSS, 2021b) provide significant evidence and personal stories about how low economic participation results in a raft of negative outcomes for young people with intellectual disability, including social exclusion and poverty. Individualistic disability policy settings and supply side-focused labour market policies have failed to address entrenched structures and deeply held negative beliefs about people with intellectual disability's capacity. These conditions have resulted in economic participation-focused institutions and structures failing to support people with intellectual disability to achieve their economic participation goals (DSS, 2021d; Barnes, 2000). It is therefore important to examine the barriers to economic participation experienced by young people with intellectual disability, including where they exist in the broader systems individuals intersect with and how they can be addressed to improve economic participation opportunities for these young people across their lifespan.

1.3 Transition

This study is focused on the period termed 'transition', which is widely understood 'to describe the task of moving from the protected life of a child to the autonomous and independent life of an adult' (Foley, 2014, p. 20). It is recognised as a particularly risky time for young people because of the impact decisions made about post-school options can have on later economic participation (Schoon & Heckhausen, 2019).

In the literature and in practice, the term transition is used interchangeably to mean 'transition from school', 'transition to adulthood' and 'transition to work'. In addition, young people are often described as being of 'transition age' (Kohler et al., 2016). Kohler (1996) refers to 'transition focused education', a period that encompasses the final years of schooling, while Children and Young People with Disability Australia [CYDA] (2015, p. 6) uses 'post-school transition', which refers to 'a time period and/or a process where a young person is able to access information and make choices about their future after leaving school'. Foley et al. (2012), on the other hand, draw attention to the longer period of transition to adulthood.

Schoon and Heckhausen (2019, p. 135) focus on the outcomes of transition rather than a period of time, defining the transition period as spanning 'the phase between completion of full-time education or training, the entry into continuous full-time employment, and establishing oneself in a career'.

Both in the disability and special education literature and in practice, the term 'transition' is often used narrowly to describe the period in which a young person completes their compulsory schooling and moves to the adult service system. Historically, for young people with intellectual disability this was a relatively straightforward process in which young people who aged out of school, particularly those with moderate to severe intellectual disability, typically transitioned from school to a post-school disability setting (Papay & Bambara, 2014). This system, described as 'operational' or 'practical' transition (Kaehne, 2013; McMahon et al., 2020), comprised schools and disability service providers, and the role of school-based transition coordinators was practical and short-term in nature. Transition success was understood to be a smooth transition to an appropriate adult service with the young person settled or happy in their post-school placement (Dyke et al., 2013; McMahon et al., 2020), instead of the post-school education, employment and independent living that are considered normative markers of post-school success (Luecking & Luecking, 2013).

Finishing school, coinciding as it does with turning 18, the age at which adulthood legally commences, signals that the period of childhood has ended and a new life phase full of opportunity and hope is commencing (Schoon & Heckhausen, 2019). Finishing school is a significant transition for young people, a 'key developmental task in the lives of adolescents' (Schoon & Heckhausen, 2019, p. 135) and an important phase in the life course because of the critical role it plays in later 'adult social status attainment and developmental prospects throughout adulthood' (Schoon & Heckhausen, 2019, p. 135). It is the period in which most young people leave school behind to focus on building their capacity for employment, begin to undertake adult roles and responsibilities, and assert their independence (Arnett, 2000). Young people make important decisions in the transition period, for example about whether they will undertake further study and what type of career they will pursue, and these can have important long-term implications across the young person's lifespan (Schoon & Heckhausen, 2019).

Normative thinking about transition from school began to shift during the 1980s, driven by the increasing complexity of the labour market and numbers of young people engaging in post-school education, and changes in economic and social conditions that resulted in young people reaching the common markers of adulthood far later than their parents (Arnett, 2000). Levinson (1986) referred to this period as 'early adulthood'; Arnett (2000) reconceptualised it as 'emerging adulthood', a period spanning the end of adolescence and the beginning of full adulthood. Emerging adulthood, which can last up to 10 years, is conceptualised as a time for young people to develop their skills and identity and to understand their place in the world (Arnett, 2000). Despite recognition of the importance of this period, transition supports for people with intellectual disability are not currently framed within an emerging adulthood understanding, and therefore opportunities to plan for the longer adulthood period are missed.

In this context, the late secondary school years and the period after leaving school can be seen to be a critical time in the development of important life skills, work skills and identity that prepares young people for later adult life, including long-term employment (Arnett, 2000; Stokes, 2012). Education, training and exposure to work lead to the development of an employment skillset along with recognised qualifications that increase later employment opportunities. It is therefore imperative that young people with intellectual disability are not excluded at this important time. Like all young people, they require access to education, training and work opportunities to improve their later employment outcomes (Carter et al., 2017; Molfenter et al., 2017), as well as access to opportunities to explore who they are and can be (Midjo & Aune, 2018; Stokes et al., 2013). Yet they are often denied those opportunities, instead spending their early adulthood in segregated disability settings, which create additional disadvantage during the period when their peers and contemporaries are building capacity and learning new skills and ultimately reduces their later economic participation (Cocks & Harvey, 2008). The segregated nature of these programs acts to limit their opportunities for inclusion and exploration of vocational and further education opportunities. In addition, segregated programs fail to recognise the importance of the post-school period for the development of identity, exploration of possibilities and acquisition of important capacities that support the achievement of valued adult roles (Cocks & Harvey, 2008).

1.4 Economic participation

In this study, the term ‘economic participation’ is used broadly to describe activities that are primarily oriented towards paid employment, and includes work, study and training, and volunteer work (Saunders et al., 2003). While in Australia there is a strong policy focus on economic participation for people with disability, the term is not well understood among stakeholders, who thus have many different interpretations of it. According to Saunders et al. (2003), economic participation is primarily related to employment and includes ‘all activities that either represent increased paid work or raise the probability of achieving an outcome that involves a degree of paid work’ (p. 5). In contrast, the Victorian Department of Health and Human Services (2018) includes paid employment, study or training, business ownership and innovation in its economic participation plan for people with disabilities, *Every Opportunity.* Likewise, the NDIS considers economic participation to include ‘work or study’ (NDIA, 2019a), and the scheme can fund a range of activities related to these, such as support to transition from school to further study, training or work and help to build basic work skills. However, in describing the concept of ‘economic exclusion’, Saunders et al. (2007) expanded the notion to focus on ‘restricted access to economic resources and low economic capacity’ (p. 9), and in this context, the idea of economic participation, while primarily linked to employment, has the potential for wider conceptualisation.

Economic participation is widely regarded as the cornerstone of an ordinary life, as it provides access to valued roles and financial resources and helps shape identity (Independent Advisory Council of the NDIS, 2015; Weld-Blundell et al., 2021; Xu & Stancliffe, 2019). Undertaking economic participation activities is normalised in Western culture, and is important for individuals both in terms of their identity and because it provides purpose and meaning in life. In the 1990s, disability employment programs therefore operated under the assumption that ‘the employment of people with disabilities in open labour market jobs promotes their integration into the mainstream community’ (Anderson & Wisener, 1996, p. 5).

Neoliberal discourse, apparent in nations such as Australia and the United Kingdom, emphasise independent labour market participation as the ‘essence of adult citizenship’ (Parker et al., as cited in Van Aswegen, 2020, p. 435), and there is an expectation that people will lead productive lives (Shogren & Wehmeyer, 2020). Economic participation in Western neoliberal democracies is centred around paid work, and having a job is regarded as ‘a central pillar of personal identity in American society’ (Wehman et al., 2018, p. 3). Inclusion in economic participation activities is therefore important to and for people with disabilities for a range of reasons. Labour market participation continues to be the primary determinant of life chances (Anderson, 1990, as cited in Kavanagh et al., 2013), and Dempsey and Ford (2009) assert that ‘participation in the labour force is the surest road out of social marginalization and economic disadvantage' (p. 234). An extensive literature demonstrates the relationship between unemployment and poor health (Emerson et al., 2018; Kavanagh et al., 2013). For people with intellectual disabilities already experiencing impairments and associated health issues, being employed in a good quality job may moderate these, particularly in relation to mental health (Dean, Shogren, Hagiwara et al., 2018; Emerson et al., 2018). There is also increasing evidence that young people with intellectual disability prefer community-based employment over sheltered employment or segregated day centres (Wehman et al., 2018), as it enables them to participate in the community, learn new skills and contribute to society, and provides structure, routine and rhythm in their days (Ineland et al., 2015), as well as meaning (Holwerda et al., 2013; Honey et al., 2014; WHO, 2011). Studying and having a job also provide valued social roles (Lysaght et al., 2017; Voermans et al., 2021) and enables the development of social networks, friendships and relationships in the community (Blick et al., 2016), which are protective factors for young people with intellectual disability (Lysaght et al., 2017). Finally, economic participation supports people to grow and develop, builds confidence and is a platform for the development of an ordinary life (Clifford Simplican et al., 2014). For people at high risk of marginalisation, participation in the labour force is especially important because whereas carrying the low-status label 'unemployed' adds to marginalisation (Lysaght et al., 2017), work provides the means to live as a citizen. People with intellectual disability who have jobs in the community also have significantly higher levels of quality of life (Kraemer et al., 2003), and generally experience higher rates of job satisfaction than those in sheltered employment settings (Akkerman et al., 2016; Kocman & Weber, 2018; Voermans et al., 2021).

Finally, like all Western economies, Australia has an ageing population, is experiencing labour shortages and has high welfare expenditure. There are currently over 780,000 Australians in receipt of the DSP (AIHW, 2017a), many of whom have capacity to work under the right conditions. Price Waterhouse Coopers (2011) estimates that Australia's Gross

Domestic Product would be boosted by up to $50 billion if a further 320,000 Australians with disability were supported to participate in the economy. In addition, based on NSW data, there are potential savings of $54.2 million available on NDIS packages with a stronger focus on open employment for people with intellectual disability (Pearce, 2017).

1.4.1 Economic participation data

As outlined above, economic participation rates for people with intellectual disability are consistently lower across the Western world (AHRC, 2016; Bell, 2019; Crawford, 2011; Dempsey & Ford, 2009). The impact on young people with intellectual disability in Australia is spelled out in the NDIA's own reports. Nearly 80,000 (23%) NDIS participants have a primary intellectual disability (NDIA, 2019b), of whom 36.7% are aged 15-24 and 12.3% are under 14. Only 18% of those aged 15-24 are in paid work, and only 15% of these are in full award-wage employment in the mainstream labour market; the remainder are in segregated Australian Disability Enterprises (ADEs) (NDIA, 2019b). The NDIA's own data demonstrates that participants with intellectual disability aged 25 and over are more likely to be in 'paid jobs' than other disability cohorts; however, that includes working in ADEs. While 39% of young people with disability overall transition to community-based employment post-school, the rate drops to 15% for people with intellectual disability aged 25 and over (NDIA, 2019b). Further, while ADE employment has slightly decreased for participants with intellectual disability aged 15-24, it has increased by 8% for participants aged 25 and over (NDIA, 2019b), indicating that as young people with intellectual disability move into their mid-20s, options for community-based work decrease and they move to work in ADEs instead.

Contemporary Australian disability policy settings such as the NDIS are based on biopsychosocial (WHO, 2011) and human rights (United Nations, 2006) models of disability. The 'root causes of disability' are therefore considered to be the physical, psychological and social environments (Ton et al., 2021), and ‘exclusion or restriction of work participation is ... the result of multiple interacting and interdependent factors, all of which require intervention for employment to be achieved’ (Productivity Commission, 2021a, p. 15). Labour market factors, including at the level of the employer, business, industry or workplace, therefore require intervention. This view of work capacity views it as changeable across different contexts, with different supports and in the presence or absence of barriers, rather than static.

Human rights models, underpinned by the UNCRPD, emphasise the interaction between impairment, personal factors and environment on the capacity of people with disability (K. Moore et al., 2018; Schalock et al., 2018; Wong et al., 2021), while also emphasising that people with disabilities are entitled to the adaptations and supports they need to live their lives in the community (Buntinx & Schalock, 2010; Schalock et al., 2021; Wehmeyer & Craig, 2013) and that the onus is on ‘duty bearers’ such as governments and services to enact change. In relation to employment, the UNCRPD states that people with disability, regardless of type and severity, have the right to reasonable accommodations in the workplace, as well as supports to find and maintain employment, and that types and scale of supports, along with environmental adaptations and broader interventions, should differ based on their individual needs. In the case of young people with intellectual disability, their heterogeneity means there is a need to focus on their youth, their strengths and the individual adaptations and supports they need to harness their potential and build capacity for work. This shifts the focus to identifying and unlocking different types of potential work opportunities with different supports across a lifespan of changing needs, and to the capacity of education and training providers and employers to support people with diverse characteristics including disability, illness and injury. These policy settings have increased expectations that young people with intellectual disability have the right to work and that redesigning society by changing attitudes about disability and the physical environment will afford them opportunities to do so.

1.4.2 Why are economic participation rates so low for young people with intellectual disabilities?

The causes of low economic participation rates for young people with intellectual disabilities are complex and multi-faceted (Clifford Simplican et al., 2014). They include low expectations about people with disabilities, discrimination and stigma, the shift to a knowledge-based labour market, the neoliberal underpinnings of the labour market and human services policy settings, and the barriers individuals face due to low levels of education, skills, literacy and numeracy (Dempsey & Ford, 2009; Dowse, 2009; Hart, 2006; Quinlan et al., 2001; Woden, 2017). Severity, type and duration of disability are also barriers to paid employment (Lindsay, 2011; K. Moore et al., 2018); given the lifelong nature of intellectual disability and the severity of its impact on individuals, people with intellectual disability are disproportionally impacted.

As discussed above, in Western countries work – and therefore capacity to work – is constructed through a neoliberal lens (Beer et al., 2016). In neoliberal economies a person’s inclusion in society is ‘framed in terms of productivity and contribution rather than self-fulfilment or quality of life’ (Dowse, 2009, p. 573). Neoliberal attitudes ‘place responsibility for human flourishing in the bodies and minds of individual citizens rather than in the state’ (Goodley, 2018, p. 18). Because globalisation and neoliberal policies privilege narrowly defined concepts of competency, capacity and individual independence people with intellectual disability are disproportionally impacted by them (Dowse, 2009; Soldatic, 2019).

There is an extensive literature base that details the stigma and discrimination people with disability face in the labour market (AHRC, 2016). Widely held negative views about people with intellectual disability result in judgements about their capacity to work in the mainstream labour market (AHRC, 2016; Brown, 2012; National People with Disability and

Carer Council, 2009) which impact the real opportunities available to them. Furthermore, the neoliberalist underpinnings of the labour market in Western economies focus on narrow views of productivity which disadvantage those who cannot compete equally with more productive workers (Dowse, 2009). This view of productivity as individualised and competitive shapes perceptions that young people with intellectual disability have a low capacity to contribute, especially in an increasingly complex labour market environment, and ultimately results in less suitable work being available for people with cognitive impairment (Dowse, 2009; Foley et al., 2014; K. Moore et al., 2018).

Negative employer attitudes about capacity to work are often related to concerns about individual workers and their disabilities, such as their job and workplace capability (Ju et al., 2013; Kocman et al., 2018; Zappella, 2015), their work performance in terms of efficiency and accuracy, and their ability to learn a job (Baker et al, 2018). In addition, people with disability are perceived as lacking employability skills such as interpersonal and communication skills, and are regarded as being less reliable, having fewer problem-solving skills and having fewer professional skills to contribute overall (Riesen et al., 2014). Furthermore, despite findings that employees with intellectual disability require less support than expected and perform their role at a better standard than expected (Baer et al., 2021), employers hold more negative views of people with intellectual disability than people with other types of disability, for example, physical disability (Kocman et al., 2018; K. Moore et al., 2018). Finally, employing organisations and businesses face barriers to understanding the supports available to them in relation to employing a person with intellectual disability, such as the government-funded services available to assist Australian employers in employing a person with a disability (Business Council of Australia, 2015).

Individual ‘capacity’ and ‘disability’ are assessed in various contexts, including the context of ‘work readiness’ – a poorly defined concept, particularly for young people with intellectual disability who learn in-situ (Schalock et al., 2021; Spicker, 2003). Noel et al. (2017) have identified that employment barriers for people with developmental disability are frequently environmental, and include lack of work experience and transport and program engagement issues, rather than just the cognitive problems and social skills associated with intellectual disability. However, the shift to biopsychosocial and human rights models of disability has not led to the use of contextually based assessment tools focused on these environmental dimensions (Cronin et al., 2013; Dyson et al., 2016). A biomedical focus on measuring capacity to work continues to predominate, resulting in an understanding of cognitive impairment as the sole cause of work-related incapacity (Schalock et al., 2021). In the Australian context, for example, Intelligence Quotient (IQ) is a primary measure used to determine work capacity during the income support (DSP) assessment process, which is undertaken at age 16, well before a young person has had the opportunity to engage in work preparation activities. The DSP assessment process constructs young people with an IQ below 70 as incapable of work throughout their lifetime. It does not undertake any broader range of vocational, workplace, job capacity or career pathway assessments, and does not require consideration of how environmental and social factors will impact on the individual’s work capacity over their lifetime. This process further impacts expectations about both young people’s capacity to work and their need to work, and when it is overlaid with paternalistic service delivery models that promote safety and security above other factors such as independence and decision-making, work is deemed risky (Wehmeyer & Craig, 2013).

Broad legislative and policy frameworks such as labour market policy have the potential to impact on the economic participation of people with intellectual disability (Holland et al., 2011). Trends towards labour market flexibility, privatisation, deindustrialisation and the decline of formal workplace structures such as unions have left vulnerable and marginalised people, including those with disability, on the fringes of the labour market, where they are more likely to experience unemployment, underemployment or precarious employment than their non-disabled peers. In addition, the shift to centralised recruitment processes has reduced their ability to negotiate opportunities at the local level within large national businesses (K. Moore et al., 2018). The changing nature of work has also impacted heavily on people with intellectual disability in terms of the employment opportunities available to them (Kocman et al., 2018): reduced availability of manual work, increased emphasis on flexible working arrangements, the gig economy, increases in required skill levels and increases in automation have all reduced their opportunities in many parts of the labour market (Jarhag et al., 2009; K. Moore et al., 2018; OECD, 2010) as have the outsourcing of low skilled jobs (Kocman et al., 2018) and reduction in available entry-level jobs. Labour market changes such as the growth in jobs that require university qualifications (Noonan, 2016) and the increase in jobs in the services sector (Productivity Commission, 2021b) have also reduced opportunities for people with intellectual disability. Finally, structural labour market reforms and the rise of the 'new economies' such as micro-businesses and the gig economy have led to increasingly precarious working arrangements that lack the certainty and predictability (Furlong, 2017) that people with intellectual disability require.

Government policy settings, including the decision to locate education, training and employment services and supports for people with disability predominately outside the NDIS, impact on the availability of appropriate services. NDIA data indicates that only 17% of participants with intellectual disability reported that their involvement with NDIS had helped them find a job that was right for them (NDIA, 2020).

The complexity of Australia’s industrial relations systems also disincentivises businesses and organisations from taking risks such as hiring a person with a disability. Small- to medium-sized businesses lack the human resources infrastructure needed to accommodate the complex processes involved in employing a person with a disability (Murfitt et al., 2018). In addition, closed job markets, in which employers hire people known to them, create barriers for people who have low social capital, such as people with intellectual disability (Australian Council of Social Services [ACOSS], 2018).

In combination, the factors outlined above impact on the availability of opportunities for young people with intellectual disability to develop necessary skills, particularly at critical points in the lifespan (Hart, 2006). In addition, these young people commonly spend their teenage years in segregated education settings, have smaller social networks and are less likely to be involved in community-based activities (AIHW, 2008). Their Year 12 completion rates are lower (ABS, 2008) and they are less likely to have part-time jobs while at school and undertake work experience (Carter et al., 2011) or other school-based, structured work readiness programs. While a transitional period without employment or study is fairly common for young people, a prolonged period without either is a predictor of long-term poor employment outcomes, and unemployment (Stanwick et al., 2017). Therefore, the streaming of young people with intellectual disability into non-vocational programs and segregated programs that do not constitute work ‘as it is ordinarily conceptualised and valued in society’ (Engeset et al., 2015, p. 193) increases their reliance on government pensions or benefits, rather than paid employment, as their main source of income early in life (AIHW, 2008).

1.5 Study purpose

This study aims to examine and extend good practice which supports young people with intellectual disability to transition from school to economic participation activities, and ultimately to community-based employment. It examines the barriers these young people experience and the opportunities to build capacity for economic inclusion that are available to them in late secondary school and early adulthood. It draws on the insights of young people with intellectual disability and their family members and the expertise of key informants – individuals who have experience in the design or delivery of economic participation-focused services and supports to young people with intellectual disability – to examine how the theoretical underpinnings that support good practice intersect with the policy and practice environment in which they operate.

1.5.1 Research questions

RQ1: How do young people with intellectual disability and their families describe their transition experiences? How do these experiences influence their decision-making related to pursuing economic participation-related activities?

RQ2: What are the barriers to economic participation for young people with an intellectual disability as they leave school, and how can these be addressed?

RQ3: What are the resources and supports young people with intellectual disability and their families value in relation to economic participation as they transition from adolescence to adulthood? How should these resources and supports be provided, by whom and when?

1.6 Thesis overview

Chapter 1 outlines the topic of the thesis and provides background to the problem as it relates to young people with intellectual disability.

Chapter 2 details the policy and practice contexts within the Australian environment, focusing particularly on the construction of intellectual disability in contemporary Australia and the way policy settings and practices are influenced by negative perceptions about the capacity of people who carry the label. In addition, it explores the influence of broad macro-level settings on the provision of economic participation services in the Australian context, and describes Australia’s disability, transition and economic participation policy and practice frameworks.

Chapter 3 reviews the literature related to the transition from school experiences of young people with intellectual disability and their family members, and of the evidence about ‘best practice’ in supporting young people with intellectual disability’s transition from school to post-school economic participation.

Chapter 4 sets out the theoretical frameworks within which the study was undertaken, including social constructivism and critical disability theory, ecological models and emerging adulthood.

Chapter 5 outlines the method and methodology utilised in the study and provides information about the research participants, including recruitment methods. It also details the data analysis procedures used.

Chapter 6 is the first of three data presentation chapters. It presents data, beginning with the views of young people with intellectual disability and their family members about their experience of transition from school. These are deliberately presented first to privilege their lived reality of transition.

Chapter 7 presents the data related to barriers to economic participation experienced by young people with intellectual disability, utilising Clifford Simplican et al.’s (2014) ecological model of social inclusion and participation as a framework. Data derived from young people with intellectual disability, their family members and key informants are presented.

Chapter 8 presents data on the resources and supports valuable to young people with intellectual disability and family members during the transition period, and on strategies to address the barriers identified in Chapter 7. It uses Clifford Simplican et al.'s (2014) ecological model of social inclusion and participation to organise the data, which is derived from young people with intellectual disability, family members and key informants.

Chapter 9 discusses the study's key findings in light of existing literature and theory. It draws from social constructivism, ecological theory and emerging adulthood to propose a multi-level shift in the conceptualisation of young people with intellectual disability, their economic participation and the role their families play in supporting this. The chapter concludes by outlining the need for multi-level, multi-factor responses to the barriers that exist for young people with intellectual disability in relation to economic participation.

Chapter 10 summarises the study's key findings and identifies its contribution to the field. It also notes the study's limitations and presents recommendations for future research.

1.7 Terminology

This thesis uses multiple terms that have various meanings in the Australian and international contexts. Key terminology is defined as follows.

Young people is used where possible to describe young people with intellectual disability. This is to position them as young people first.

Family member is used to describe the primary person who makes decisions with or on behalf of a young person. All family members in this study were parents.

Special School is used to identify a segregated school for students with disability.

Transition from school is used to describe the period in which young people prepare to finish school and the period immediately after doing so.

Transition to adulthood is used to describe the period between adolescence and adulthood, generally understood to be ages 18-25.

Economic participation is used to describe the activities young people undertake, including those which prepare them for work. This is used in preference to 'work' because 'work' has a narrower meaning. The expected outcome of economic participation activities is generally understood to be paid employment in the labour market.

Various terms are used to describe employment in policy and in practice. Terms such as 'open employment', 'competitive employment', 'supported employment', 'community-based employment' and 'integrated employment' are used interchangeably in the literature and in practice, while 'open employment' is used in Australia to describe employment open to all members of the community in which people with intellectual disability and without work together in the same workplaces (Everyone can work, n.d.). This thesis uses the term **community-based employment** to describe employment that is undertaken in a community-based setting rather than a segregated one.

In Australia the term '**supported employment'** refers to employment within a business that primarily employs people with disability and supports them in their jobs (JobAccess, n.d.). These segregated settings are known as ADEs. It should also be noted that 'supports in employment' is a term used by the NDIS to denote an individualised funding category whereby funding to purchase a range of 'supports' to utilise in an employment setting is provided. In the United States, however, the term 'supported employment' refers to competitive employment in an integrated setting, with ongoing support services for individuals with the most severe disabilities, including those for whom competitive employment has not traditionally occurred (Wehman & Targett, 2013).

This thesis uses the term in line with the US definition. That is, community-based employment with appropriate support.

1.8 Author's position

I became interested in the inclusion of people with intellectual disability after spending time with a young woman my age with Down syndrome during my adolescence. That experience led me to work in one of Victoria's last remaining residential institutions. This was an eye-opening experience for a young adult but one that ultimately started me on a journey to advocating for better opportunities for people with intellectual disability in our society.

Following completion of a Disability Studies degree in 1991, I became interested in the transition from school to employment for people with intellectual disability. I was lucky enough to be part of an amazing group of people who pioneered open employment services in Australia and to personally support people in finding community-based work. Eventually, I shifted to advocacy at the national level, as the Executive Officer of the Disability Employment Peak Body. Now, as a researcher, I continue to be interested in supporting the economic participation of people with intellectual disability.

This thesis topic emerged from my observation that while expectations about economic participation for young people with intellectual disability have shifted, there has been a reduction in the employment and training supports available to help them realise those goals. In order to understand the barriers facing them, I deliberately chose a 'worm's-eye view', interviewing young people with intellectual disability and their family members to understand both their aspirations and the challenges they face in achieving them. Having worked at the system level, I understand that barriers to economic participation exist for this cohort across systems, and strategies to address them therefore need to be system-wide. In addition, my experience parenting my own daughters in transition from school made me reflect on the way low expectations about young people with intellectual disability lead to separate pathways for them, and a subsequent reduction in opportunities. Therefore, I saw a need to examine the period of early adulthood more broadly, to understand its impact on the economic participation of people with intellectual disability.

1.9 A note on thesis chronology

I began work on this thesis at Deakin University, and first obtained ethics approval via the Deakin University Human Research Ethics Committee in 2019. I transferred to Swinburne University of Technology in May 2019, when my primary supervisor transferred there. Ethics approval and all research management were then undertaken by Swinburne University of Technology.

Chapter 2: Disability, transition and economic participation policy and practice frameworks in Australia

2.1 Introduction

Young Australians with moderate to severe intellectual disability predominately grow up in their family homes alongside their parents and siblings (AIHW, 2008) and are involved in their local communities to varying degrees (AIHW, 2017b). They are predominately educated in special school settings (NDIA, 2019b), qualify for income support in the form of the DSP and are in receipt of funding via the NDIS. They are thus operating within a complex policy environment impacted by Commonwealth and State or Territory government policies and practices. Disability supports, particularly post-school supports, are largely the domain of the Commonwealth, whereas education policy, which impacts school leavers, is shared between the Australian and State and Territory governments. Of particular concern is the fractured accountability related to transition from school, post-school training and education, and employment (CYDA, 2015), which means no one agency or level of government has accountability for improving economic participation outcomes for young people with intellectual disability. This creates a risk that the issue will slip through the gaps (Malbon et al., 2017). In addition, highly siloed programs result in eligibility criteria that fail to understand the multiple identities young people with intellectual disability carry, such as: a person with intellectual disability; a young person; a school leaver; a DSP recipient; an NDIS participant; a jobseeker; and a student. These identities directly influence access to economic participation opportunities, in many cases by determining the spaces, programs and supports young people can access.

Arguably, it is the label ‘intellectual disability’ that underpins policy assumptions and most strongly influences young people with intellectual disability’s life chances. It is therefore important to explore and critique the concept of intellectual disability.

2.2 The construction of intellectual disability

The young people in this study carry the label ‘intellectual disability’. While the concept of intellectual disability was recognised as early as the Middle Ages, its construction has not been stable. It was considered to be ‘possession by the devil’ in early times and a set of scientifically identified syndromes in the nineteenth and twentieth centuries, and now a culturally situated social phenomenon (Odom et al., 2009). The advent of psychometric testing, in the form of IQ testing, during the 1900s also enabled a statistical definition of intellectual disability to develop through the comparison of an individual’s IQ test performance against that of a standardised normative group (Wehmeyer & Craig, 2013); as a result, an IQ below 70 came to be considered deficient. The dominance of biomedical model settings enabled intellectual disability to be constructed as a ‘biologically anchored diagnosis of lacking intellectual capacities’ (Altermark, 2018, p. 6). Psychometric testing provided the opportunity to pinpoint people with ‘mental deficits’, categorise them and label them, ‘sifting and sorting individuals on the basis of dis/ability’ (Goodley, 2018, p. 2). According to Becker (1963), however, the social construction of labels has more than just practical implications. A label associated with stigma, such as the label ‘intellectual disability’, can dictate the life paths of those it is applied to (Cluley, 2016; Green et al., 2005). In addition, the use of the term ‘special’, as in ‘special education’, further impacts on opportunities, including employment opportunities (Algraigray & Boyle, 2017).

During the 1900s, dual logics of ameliorating disability and protecting society from the disabled (L. Carlson, 2010; Walmsley, 2005) resulted in government policies such as eugenics and institutionalisation which had enormous ramifications on the lives of people with intellectual disability, including their widespread segregation from the community and treatment as lesser beings right up until the end of the twentieth century. Consequently, people with intellectual disability remain among the most stigmatised of any group, and until recently have been assumed to lack the necessary capacities for citizenship (Altermark, 2018). Widespread contemporary views about people who carry the label intellectual disability are the result of what Senge (1996) calls mental models – ‘deeply ingrained assumptions, generalizations and images people use to understand the world’ (p. 8). As they relate to people with intellectual disability, mental models predominately focus on deficit, and this has influenced both the policies and practices that apply to them and the wider community’s understanding of who they are.

Jordan (2014) argues that the focus of disability discourse, which he describes as ‘a series of statements and writings that accrue over time and imbue a physical or mental difference with social meaning and value’ (p. 2), needs to shift to ‘open up critical space to theorize the gap between representations of disability and their physical manifestations’ (p. 3). He argues that cultural attitudes associated with disability impact far more heavily on the lived experience of disability than the impairment itself:

> Discourses are not simply representations, but representations that have achieved a general sense of approbation, to the point where they appear to articulate the world as it really is. Focusing on discourses of disability rather than disabilities themselves does not aim to deny the material reality of physical and mental difference, but only to suggest that physical and mental differences do not carry an innate value. In other words, disability only becomes a problem, a limit, or a disadvantage within a specific social context. (Jordan, 2014, p. 2)

Although the operational definition of intellectual disability has not changed considerably since the 1950s, its construction has, in line with shifts in contemporary understanding of disability more broadly (Buntinx & Schalock, 2010). For example, the *Diagnostic and statistical manual of mental disorders* (*DSM-5*) recently updated its definition of intellectual disability, conceptualising it as deficits in conceptual, social and practical adaptive skills (APA, 2013). Likewise, Schalock et al. (2021) recently shifted the focus from IQ to the supports people with cognitive impairment require to function well in society. The constitutive definition of intellectual disability proposed by Wehmeyer and Craig (2013) recognises it as a 'multidimensional state of human functioning in relation to environmental demands' (p. 9). This definition shifts the construct of intellectual disability from something residing within the person (i.e., mental retardation) to 'the fit between the individual's capacities and the context within which the individual is to function' (Wehmeyer & Craig, 2013, p. 9). It also recognises that intellectual disability is biologically and socially complex and that individualised supports have a role in improving functioning, and situates the person within an ecological framework of supports. This aligns with Odom et al.'s (2009) and Tassé et al.'s (2016) conceptualisations of intellectual disability as a culturally situated social phenomenon.

Despite states legislating about rights and inclusion (Hall, 2017; United Nations, 2006), changes in attitudes to people with intellectual disability have occurred gradually and over an extended period (Hall, 2017). The federal Disability Services Act (1986) was the first piece of Australian legislation to enshrine the right of people with disability to receive services that enable community inclusion. The human rights-focused UNCRPD was enacted in 2006, and the *National Disability Insurance Scheme Act 2013 (Cth)*, enabling people with disability to have choice and control over the services they receive, was legislated in 2013. These recent changes to policy settings create new ways of thinking about intellectual disability, focusing on humanity, rights and citizenship (Schalock et al., 2018). However, while state policies have shifted to focus on 'citizen inclusion', with its accompanying mantra of self-determination and independence, the service system remains wedded to paternalism, coercion and restraints. People with intellectual disability are still not equal and fully integrated citizens (Hall, 2017). According to Bach (2017):

> Claims for full inclusion and citizenship for the growing number of people with significant intellectual, cognitive, and psycho-social disabilities are unrealised because

> of a cognitive ableism embedded in law, policy, and social practice that construes people as 'cognitive foreigners', excluded from belonging on this basis. (p. 4)

Goodley (2018) argues that the role of supporters of people with intellectual disability is therefore to 'focus on the enhancement of humanity', 'who we value and why' and 'whether everyone is invited into the human category' (p. 316).

In contemporary Australia, people with intellectual disability continue to be 'held back in their everyday lives in ways that would be deemed unacceptable if they belonged to any other group' (Altermark, 2018, p. 8). Altermark (2018) refers to the current period as 'post-institutionalisation' – a period where formal state policies have shifted to human rights and social model settings but many of the instruments of institutionalisation continue to exist. According to Jordan (2014), segregated facilities including special schools, sheltered workshops and segregated day activity centres continue to separate able-bodied and disabled people, existing in place of mainstream education facilities and workplaces:

> Even as the old walls of the institution begin to crumble, the group home, the nursing home, the special education classroom, and the government-funded facility continue to mark a point of separation between the able-bodied and the disabled. (p. 7)

In the post-institutionalisation period, it is argued, there is a need to reframe the construct of intellectual disability within the broader diversity movement which is growing worldwide (Odom et al., 2009). The most recent literature related to intellectual disability shifts the focus to the role of the environment, adaptive behaviour and functioning (Schalock et al., 2021), highlighting the presence of strengths as well as limitations, and the necessity of developing a system of supports for the individual that is based on their age, peers and culture as well as their differences in communication, sensory, motor and behavioural function (Wehmeyer & Craig, 2013). Further, the research and change agenda needs to be placed within the social contexts of society, rejecting the old biological/medical definition of deficient intelligence and replacing it with a view that intellectual disability is a socially constructed phenomenon constituted by certain discourses and mental models (Cluley, 2018; Watson, 2004). According to Barnes (2003), the social model of disability must be actively implemented in order to close off the old institutionalised approaches and fully include people with intellectual disability in the life of the community. Ferri and Connor (2005), drawing on civil rights movements, argue that a period of 'desegregation' is required, in which there is a deliberate effort to desegregate people with intellectual disability by closing down segregated spaces or making them into integrated ones. This is evidenced by American states such as Vermont and Iowa, which have legislated to close down sheltered workshops, with a subsequent increase in community-based outcomes (Iowa Department of Human Rights, n.d.). US states that have adopted progressive Employment First style policies (i.e., Vermont, Connecticut, Michigan, Oregon, Nebraska, Idaho and Nevada) have higher integrated employment outcomes than states with supported employment alone (Winsor et al., 2019), indicating that it is policy and practice that reduce employment opportunities rather than the capacity or incapacity of people with intellectual disability (Wehman et al., 2018).

In recent times, stakeholders including people with disability, family members, service providers and researchers have mobilised to focus attention on the issue of integrated employment for people with disabilities (Association of People Supporting Employment First (APSE), n.d.; Giordono, 2020). In the United States, Employment First policy settings have supported efforts to desegregate, espousing that 'employment in the general workforce should be the first and preferred option for individuals with disabilities receiving assistance from publicly-funded systems' (APSE, n.d.). Underpinned by human rights settings, Employment First focuses attention on the alignment of policies, regulation, and payment systems, committing to community-based employment as the priority for young people and adults with disabilities, including significant disabilities (U.S. Department of Labour: Office of

Disability Employment Policy, n.d.). Employment First provides a national systems-change framework which has resulted in state-wide policy and systems change projects, which are described in 3.4.5. Such policy approaches are not currently reflected in Australian policy.

2.3 Disability policy settings

Macro-level policies such as the UNCRPD, to which Australia is a signatory, and the Australian NDIS emphasise the need to improve the economic and social inclusion of people with disability. Article 27 of the UNCRPD (United Nations, 2006) recognises 'the right of persons with disabilities to work, on an equal basis with others' (p. 19), and Article 26 details States' responsibility to

> organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
>
> (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
>
> (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas. (p. 19)

Articles 23, 24, 27, 28, and 29 also refer to education and transition from school. In 2021 the Commonwealth released *Australia's Disability Strategy* (DSS, 2021a) and *Employ My Ability: A Disability Employment Strategy* (DSS, 2021b), which lay out the government's plan to meet its obligations under the UNCRPD in relation to the economic participation of people with disability. Policy Priority 1 of *Australia's Disability Strategy* is to 'Increase employment of people with disability' and Policy Priority 2 is to 'improve the transition of young people with disability from education to employment' (p. 9). While there is hope that the strategies will result in improved outcomes for people with disability, the failure to date to set and monitor targets and lack of coordination at the macro level, which the strategies have not addressed, have negatively impacted on employment outcomes for people with disability (AHRC, 2016).

The NDIS, introduced in 2013, provides new opportunities for young people with intellectual disability to use their own individual funding to purchase the supports they need to achieve their goals (Dew et al., 2019; Laragy & Fisher, 2020; *NDIS Act 2013* (Cth); Productivity Commission, 2011). It is built on inclusion rather than exclusion. General Principle 2 of the *National Disability Insurance Scheme Act 2013 (Cth)* states that 'People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability' (p. 4), and that 'People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports' (p. 4) through individualised funding to purchase a range of supports from both outside of and within traditional disability service systems. A primary aim of the NDIS is to increase opportunities for people with disability to participate in the ordinary, everyday life of their communities (*NDIS Act 2013* (Cth)), and improving employment outcomes is another specified goal (NDIA, 2019a). In December 2019, there were $10.5 billion of annualised committed supports in approved plans for people with intellectual disability – nearly half of the NDIS's total committed expenditure (NDIA, 2019b). The average annualised cost per participant with intellectual disability is over $97,000. At 2020, 32.3% of NDIS participants aged 15 or over had a work-related goal in their plan: the average was higher for younger participants (45.2% for 15-24-year-olds) and then declined to 27.9% for participants aged 25 and over (NDIA, 2020). It should be noted, however, that people with intellectual disability who work in ADEs and have no goal to move to community-based employment also have work-related goals in their plans.

The introduction of the NDIS, with its focus on economic participation, was expected to increase the labour market participation rates of people with disability. It has resulted in service providers, including disability providers, no longer receiving government funding directly and instead operating within a quasi-market, receiving payments directly from people with disability via NDIS funding. Eligible school leavers receive an annualised amount of School Leaver Employment Supports (SLES) funding (currently $22,750 in total over two years), via the NDIS, to support their preparation for employment. Despite the new funding structures, however, service offerings have largely remained unchanged, with segregated employment and day centre settings continuing to comprise a large share of the market (NDIA, 2019b). Since 2017, there has been a noticeable shift whereby disability providers, in response to the availability of SLES funding, have established transition-to-work-style programs for school leavers to focus more heavily on preparation for employment (NDIA, 2020). However, data about the outcomes of SLES programs is still emerging. Recent data from the NDIA indicates that less than 20% of SLES participants achieve an open employment outcome, while a further 10% exit into an ADE (NDIA, 2020).

2.3.1 Australian transition policy and practice

The principal Commonwealth legislation for school education and school reforms is the *Australian Education Act 2013*, which outlines both the provision of Australian Government education funding and responsibilities related to the provision of education. There is formal recognition in policy statements at Commonwealth level that a core outcome of education is for students to gain the skills they need to transition to further study and/or work and life success (Council of Australian Governments, 2013, p. 7).

There are no Commonwealth or state laws that require individualised transition planning for young people with intellectual disability; nor are there any specific references to post-school transition in the legislation (CYDA, 2015; O'Neill et al., 2016). Responsibility for transition is shared, with 'young people and their families, service programs, schools, tertiary education institutions, employment services and government departments having key responsibilities' (CYDA, 2015, p. 8), but key responsibilities are poorly defined. The Australian Government Department of the Prime Minister and Cabinet (2014) notes that within each State and Territory, young people receive early economic participation-focused activities and supports, including work experience and career education, within a range of school settings including government and non-government schools, which further adds to the lack of structure. In addition, each State and Territory has a different policy and program and these change regularly (CYDA, 2015).

Increasing recognition that transition from school is an important and high-risk period for young people has led to the development of strategies to improve it, including the National Career Education Strategy *Future ready* (Australian Government Department of Employment and Workplace Relations [DEWR] and Department of Education, n.d.), which was endorsed by federal, State and Territory governments in February 2019. *Future ready* mandates career education for every Australian high school student. Within the labour market program arena, the Commonwealth funds 'Transition to Work' to provide additional support to young people aged 15-24 who are deemed at risk during transition. The program has eligibility requirements that exclude some young people with intellectual disability who are in receipt of the DSP.

As early as 2011, the Australian Government committed to addressing poor transition outcomes for young people with disability through the development of specific actions within the National Disability Strategy implementation plan *Laying the groundwork 2011-2014* (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012). This includes Action 5.5, to 'identify and establish best practice for transition planning and support through all stages of learning and from education to employment' (p. 131), and Sub-action 5.5.1, to 'improve school transitions' (p. 131). The recent *Australia's Disability Strategy* (2021) also refers to transition from school in Policy Priority 2: 'Improve the transition of young people with disability from education to employment' (p. 9). However, there is no specific discussion of young people with intellectual disability.

Victoria, where this study was undertaken, has policy related to young people generally and young people with disability. In addition, the Victorian Government provides funding to 'Victorian government secondary schools, including specialist schools, to provide career education activities to all students in Years 7 to 12' (Victorian Government, n.d.-a). This includes students with disabilities who attend specialist and special schools: 'Schools in receipt of this funding must ensure students in Years 7 to 12 participate in planned career education activities and have access to appropriate support services' (Victorian Government, n.d.-a). In addition, while it is not compulsory for Victorian schools to offer work experience – defined as the short-term placement of secondary school students with employers, usually in Year 9 or 10 – or for students to undertake it, a set of resources is available to support students with intellectual disability undertaking work experience (Victorian Government, n.d.-d). The Victorian Government also provides a range of resources including guidelines to support the inclusion of parents of students with disability in career planning, acknowledging the role parents play in influencing their children's education and career decisions (Victorian Government, n.d.-b).

In addition, the Victorian Government has a separate policy for students with disability, titled *Transitions and Pathways* (Victorian Government, n.d.-c). It acknowledges that students with disability may have additional needs during the transition period. Strengthened career planning provides students with disability with extra supports to identify their goals, aspirations and strengths and provide a snapshot of a student's work-related skills and employability in order to enable conversations about their capabilities, strengths and readiness for work (Victorian Government, n.d.-b).

At the school level, funding of $750 per student is available to provide transition supports for students attending special schools. For students with higher support needs, such as intellectual disability, the language shifts from career planning to supporting young adults and their families to access a post-school placement or option. This includes a set of procedures to be completed prior to the student finishing school, such as organising site visits and organising a service provider expo (Victorian Government, n.d.-c).

In NSW, the Transition to Work program (now a Commonwealth program) operated between 2005 and 2015 to support young people with disability in transitioning from school to work. Xu and Stancliffe (2019) found that less than 50% of young people with disabilities who entered the program achieved an employment outcome. There was also huge variation in the employment outcomes providers were achieving, with a few very high-performing agencies accounting for a high proportion of the outcomes. They noted that lack of regulation resulted in low performing Transition to Work providers continuing to receive funding. In addition, the failure to collect high-quality data on outcomes, including longitudinal data, impacted on the capacity of funders, including the NDIS, to implement evidence-informed approaches, assess the effectiveness of the program and provide information to consumers about which providers were effective and what outcomes they achieved (Xu & Stancliffe, 2019). Riches's (2014) evaluation of one Transition to Work provider supported Xu and Stancliffe's finding that policy-related factors impacted on the employment outcomes achieved through the program. Riches (2014) found that one provider was particularly high-performing, with 95% of young people exiting that provider with an open employment outcome.

Poor transition outcomes for young people with disability can also be partially attributed to poor collaboration between schools and the post-school system that young people and their families interact with (ARTD Consultants, 2019; Carter, McMillan, & Willis, 2017). The service systems that exist for young people transitioning from school are fragmented and siloed (Antonelli et al., 2018; ARTD Consultants, 2019; CYDA, 2015; Redgrove et al., 2016; Foley, 2013), which makes these complex and ever-changing systems difficult to navigate. Young people therefore fail to utilise important services (AHRC, 2016). In the case of people with intellectual disability, this also extends to family members who navigate systems on their behalf (Brooks et al., 2016). Funding systems also create barriers to collaboration, for example by failing to fund the important collaborative work required at the service and system level (ARTD Consultants, 2019b; Davies & Beamish, 2009; Green, 2018; Hummell et al., 2021; Meadows, 2019). Finally, fragmentation also results from the intersection of Commonwealth and State systems such as employment services and schools (CYDA, 2015).

People with intellectual disability are eligible to apply for the DSP from the age of 16. Young people who have an intellectual disability and an IQ of less than 70 are considered to be manifestly eligible for the DSP – currently $987.60 per fortnight – and therefore do not have any requirement to seek employment over the course of their lifetime (Australian Government Services Australia, n.d.). DSP recipients can work for up to 29 hours per week without losing their entitlement to DSP although wages earnt from paid income in excess of $178 per fortnight reduce the amount of DSP payable to an individual by 50 cents in the dollar. The DSP cuts out completely once a person is earning $2115 per fortnight, however the individual can restart their DSP payment if their earnings drop below the threshold within a 2 year period (Australian Government Services Australia, n.d.). DSP recipients are required to report any income earned from paid work to Services Australia each fortnight. Complex income support systems can act as barriers to employment for people with disability in several ways, and people with disability who are in receipt of income support report that the complexity of these systems, coupled with fear of losing their benefits, acts as a deterrent to employment, as do the low wages people with disability are paid (Campbell et al., 2022; DSS, 2015).

2.4 Post-school education and training and employment services

As with compulsory education, the policy environment related to post-school education, training and employment is complex. The Commonwealth government has legislative oversight of the higher education sector via the *Higher Education Support Act 2003*, which includes funding for improving outcomes and supporting students with disability. Courses are available to a broad range of students, including school leavers. Post-school education and training are provided by public and private universities, public Technical and Further Education (TAFE) colleges and private Registered Training Organisations (RTOs) at low or no cost to people in receipt of income support, such as people with intellectual disability, or through FEE-HELP. Universities are regulated at the Commonwealth level, while TAFEs and RTOs are regulated at the State/Territory level.

Education and training providers are regulated via the Australian Skills Quality Authority and provide qualifications from Certificate I through to postgraduate level. Young people with intellectual disability commonly access Certificate I in Transition and Certificate I in Work Education when they complete their compulsory schooling (DEWR, n.d.).

The Commonwealth government provides labour market programs to support unemployed Australians in entering or returning to the labour force. The primary programmatic response to Article 27 of the UNCRPD continues to be the Disability Employment Service (DES) program, which comprises two streams, DES-ESS for permanent or long-term disabilities or health conditions, including intellectual disability, and DES-DMS for non-permanent injuries, health conditions or disabilities (Australian Government Department of Social Services, 2020). DES-ESS has capacity to provide long term support to people with disabilities in employment if required.

Originally born out of the *Disability Services Act (1986),* an act which enshrined the right of people with disability to have access to services that supported their inclusion in mainstream society (Cheng et al., 2018), the Act created the concept of open and supported employment services. Open employment services were established to create integrated employment opportunities for people with significant disability (Anderson & Wisener, 1996), while supported employment services primarily encompassed sheltered workshops, now called ADEs (Cheng et al., 2018). ADEs are a significant component of the disability service system, offering 'supported employment', and are a post-school destination for young people with intellectual disability, particularly those who attend special schools (Hemphill & Kulik, 2017; NDIA, 2020). However, they rarely provide a pathway to community-based employment: in 2014, less than 1% of those employed in ADEs transitioned to community-based employment (Commonwealth of Australia, 2017), indicating that ADEs are not a pathway to these outcomes.

Government-funded employment services in Australia have low rates of employment outcomes and sustainability overall (DSS, 2016). The neoliberal and Active Labour Market policy settings introduced throughout the 1990s and 2000s have resulted in supply side-focused economic participation programs, increased privatisation of employment service providers and a reduction in appropriate employment and training supports for people with intellectual disability (Dempsey & Ford, 2009; Devine et al., 2021). There is also poor alignment between DES and 'adjacent' programs, including poor integration with the NDIS, which results in confusion for participants. Inconsistencies in the incentive structures of DES and the mainstream 'jobactive' program have resulted in people who have a long-term health condition or disability shifting to DES. Over 80% of DES participants have a physical or psychiatric disability, and more than half are over 45 (DSS, 2020).

The DES Eligible School Leavers (ESL) program has specific provision to support young people with disabilities into employment, governed by the ESL Guidelines. These guidelines specify that eligibility is restricted to students under the age of 22 and that the program supports a transition pathway straight from secondary school to open employment. In addition, they focus on severity of impairment and related barriers to employment, rather than ‘multiple structural and social barriers and the intersection of these barriers with a person’s impairment causing disablement’ (Stafford et al., 2017, p. 639). This narrow view of transition supports fails to align with contemporary approaches, in which school-to-work transition occurs over an extended period and is impacted by environmental as well as individual factors.

These policy settings have resulted in DES having a poor record of successfully creating sustainable employment opportunities for people with intellectual disability (DSS, 2021c). In 2017-18, 30.2% of DES users were employed for three months following assistance (Australian Government, 2018). Following significant reforms to DES in 2018, there was a decline in employment outcomes, with 24% of DES participants achieving a 13-week outcome after 18 months on the program in 2020 (DSS, 2020). In addition, in May 2022 just over 3% of the DES caseload was people with intellectual disability (DSS, 2022). DES has complex rules regarding work capacity of at least eight hours (Waghorn & Hielscher, 2015), which impacts the availability of supports for people with intellectual disability who cannot demonstrate their capacity to work for that number of hours. In addition, Devine et al. (2021) reported that DES participants wanted both more and more highly tailored support to find employment, and once in employment wanted appropriate support to maintain their roles.

Strategies have been implemented to improve employment outcomes for people with intellectual disability. The precursor to the current Australian DES system, the Disability Employment Network (DEN), was predominately focused on people with lifelong disabilities who required significant ongoing supports (Cheng et al., 2018). Consequently, highly specialised intellectual disability organisations delivered employment supports, obtaining good employment outcomes (Anderson & Wisener, 1997). Since 2011, however, policy shifts have resulted in DES being underpinned by an Active Labour Market approach in which jobseekers are matched to available vacancies (Fredriksson, 2021). Active Labour Market approaches do not typically result in jobs for people with significant labour market disadvantage, including people with intellectual disability, because when required to compete against applicants without disability for job openings, or when their skills and abilities are compared against an existing job description, people with a more significant disability simply do not measure up (Condon & Callahan, 2008). In addition, DES fails to offer the highly individualised supports people with disability need to secure and maintain employment in the open labour market (Dempsey & Ford, 2009; Stafford et al., 2017), and few DES providers have the highly specialised skills needed for supporting people with intellectual disability to be included in the community-based labour market, such as using customised employment approaches.

The need for specialisation is supported by data from the previous DEN model, which show that a small number (5) of highly specialised providers accounted for 75% of intellectual disability employment outcomes (Pearce, 2017). However, the introduction of a significant extra payment for DES providers in 2011 in the form of a moderate intellectual disability allowance failed to incentivise DES providers to improve their supports for this cohort, resulting in no significant shift in outcome rates for people with intellectual disability (Pearce, 2017). Nor did the financial incentive address DES providers’ lack of skills to support people with complex needs, which may have contributed to its failure to shift outcome rates (DEWR, 2012; Pearce, 2017).

Active Labour Market approaches do not address structural issues such as community attitudes towards groups that are over-represented in unemployment, including people with disability (Bennett et al., 2018; Stafford et al., 2017). They also lack structured demand-side-focused strategies that provide awareness-raising, information and advice, despite employers stating that doing so would address low awareness about the issue (AHRC, 2016).

The privatisation and contracting-out of DES has also resulted in providers, including not-for-profit providers, orienting their services towards individuals who can provide the financial outcomes required (Devine et al., 2021). Privatisation has reversed much of the progress made throughout the 1990s, when the highly specialised DEN, underpinned by rights-based values, provided employment support primarily to people with intellectual and other lifelong disabilities in receipt of the DSP (Anderson & Wisener, 1996; Pearce, 2017). Given the extensive ongoing support people with intellectual disability require, privatisation and contracting out also reduced the ability of highly specialised DES providers to compete. Over time, most closed or merged with other providers, and their specialisation was lost (Considine et al., 2011; Pearce, 2017).

The compliance role Australian employment services undertake for government in relation to mutual obligations for people receiving income support has also shifted their focus away from the provision of evidence-based employment supports (ACOSS, 2018; Lantz & Marston, 2012). For example, despite the strong evidence base for providing Individual Placement and Support (IPS) for people with persistent mental illness, and the high number of people accessing DES who have mental health issues (DSS, 2020), IPS is not widely available in Australia (Lockett et al., 2018; Waghorn & Hielscher, 2015). Likewise, evidence-based specialised employment services such as customised employment are not uniformly available for people with intellectual disability (Pearce, 2017). Because evidence-based practice requires providers to employ more highly skilled and trained staff and provide support within the workplace (Dew & Boydell, 2017; Diallo et al., 2014), privatised models have reduced the incentive for employment services to implement it. There is also early evidence that individualised funding systems such as the NDIS further erode implementation of good practice due to their focus on individualised service delivery, which takes precedence over reflective practice and information sharing (Green, 2018). This results in few young people achieving their preferred post-school outcomes, particularly paid employment (Pearce, 2017; Xu & Stancliffe, 2019).

2.5 De-differentiation

The increasing shift to de-differentiated service delivery has particularly negatively impacted young people with intellectual disability (Clegg & Bigby, 2017). De-differentiation 'describes the merging of intellectual disability and other disability groups into the broader disability category, losing the specialisation of particular impairments or challenges' (King, 2020, p. 320). De-differentiated policies are characterised by the 'dismantling of special arrangements for vulnerable groups, dissolution of categories and growing individualism' (Sandvin & Soder, 1996, p. 117). De-differentiation has several perceived advantages, including drawing attention away from devalued differences and stigmatising labels such as 'intellectual disability'. It also supports inclusion in mainstream, rather than specialist or segregated services, and potentially strengthens collective advocacy, increasing opportunities to bring about rights-based and structural changes to society (Clegg & Bigby, 2017). However, de-differentiated models also 'devalue specialised training and expertise, and provide general services and staff' (Clegg & Bigby, 2017 p. 3), resulting in individual providers and staff supporting people who have cognitive impairment, physical impairment, are Deaf or Blind, or have mental health issues. De-differentiated services emphasise shifting attitudes and providing appropriate accommodations and technology in order to create opportunities for people with disabilities to be included in all aspects of the community (Bigby, 2020a; King, 2020). Driven by the shift towards understanding disability through the social model lens, this approach has resulted in the real differences contained in the experiences of some disabilities being dismissed (King, 2020).

People with intellectual disability fare poorly within de-differentiated systems because the barriers they experience are complex and lifelong and require ‘nuanced and often complex adjustments to facilitate participation’ (Clegg & Bigby, 2017, p. 83). Rather than adaptations to the environment or changing attitudes alone, people with intellectual disability require ongoing support to navigate the complex world they live in, including community spaces such as education facilities and workplaces (Wilson et al., 2017). This reflects the *embedded difference* inherent to intellectual disability. The realities of difference for people with intellectual disability, such as lower levels of literacy and numeracy, difficulty learning new tasks, and cognitive and communication issues, result in their exclusion from the mainstream labour market, in which these characteristics are highly valued. De-differentiated services seek to ‘fit’ them into existing offerings, instead of recognising the need to consider the realities of difference and tailor the offering accordingly. De-differentiated approaches to tackling the broader issue of low economic participation for people with disability generally result in the specific support needs of people with intellectual disability being lost (DSS, 2021d), and heighten the risk that they will fall through the cracks due to the intensity and length of support often required. The shift to de-differentiated policy settings also results in young people with intellectual disability and family members reporting a limited range of economic participation options available to them when they complete school (Davies & Beamish, 2009), with the options available tending to be segregated (e.g., day programs and ADEs) or programs that fail to provide effective bridges to employment (e.g., short-term TAFE courses). In addition, highly specialised, evidence-informed practice is not uniformly available (Waghorn & Hielscher, 2015). The raft of strategies outlined in *Australia's Disability Strategy* (2021) lacks any detailed plan to address the poor economic participation of people with intellectual disability specifically.

Differentiation, in contrast, recognises that differentiated policies may be beneficial to people with intellectual disabilities because different impairments mean they need services and supports that are highly specialised (Clegg & Bigby, 2017). The Australasian Society for Intellectual Disability has developed a position on de-differentiation which states: 'treat people with intellectual disability as members of the broad disability group wherever possible, and protect and develop differentiated opportunities, services and research whenever necessary' (Australasian Society for Intellectual Disability, 2017, as cited in Bigby, 2020, p. 310). Differentiated policy supports the planning of new services specific to people with intellectual disability (Smith, 2013, as cited in Clegg & Bigby, 2017) and will provide people with intellectual disability with increased access to resources and opportunities (Clegg & Bigby, 2017). In addition, it ensures that resources and opportunities intended for people with intellectual disabilities are reserved for their use (Smith, 2013, as cited in Clegg & Bigby, 2017).

The complex communication, cognitive and behavioural barriers experienced by people with intellectual disability mean that they need services and individual staff with specialist expertise and skills to support their community inclusion (Clegg & Bigby, 2017). The delivery of such specialised services within segregated settings such as ADEs has come to be considered exclusionary, and there is now a preference for people with intellectual disability to have opportunities to be in the same spaces as other citizens (Clegg & Bigby, 2017), such as through employment in the community-based labour market. Rather than being delivered within segregated or institutionalised settings, differentiated services can recognise that ‘true inclusion supports realities of difference; and is not simply striving to negate them altogether’ (King, 2020, p. 324). Moreover, *s*ervices that are ‘tailored for the unique talents of people with intellectual disabilities in the same way as specialist arts and sport facilities are tailored for artists and sportspeople’ (Clegg & Bigby, 2017 p.89) can be delivered within community-based settings. There is therefore tension between the roles of community-based, segregated, differentiated and de-differentiated models of service delivery for people with intellectual disability.

2.6 Conclusion

This chapter has described the complex set of policy settings that impacts on young people with intellectual disability in Australia. Technically, human rights-focused policy grounded in the social model of disability predominates through the NDIS. However, people with intellectual disability intersect with several separate policy environments underpinned by neoliberalism, in which their right to services and the provision of appropriate services are compromised due to historical conceptualisations of intellectual disability that function to remove them from effective policy design.

Chapter 3: Literature review

3.1 Introduction

This literature review focuses on two key areas of interest: the experiences of young people with intellectual disability and their family members during their transition from school and how those experiences influenced decisions about their post-school economic participation; and what is known about the factors and practices that shape economic participation for young people with intellectual disability and how these have been described and evaluated in the literature.

The bulk of research related to economic participation of young people with intellectual disability has been undertaken in high-income countries such as the United States and the United Kingdom (Weld-Blundell et al., 2021). Australian studies, including both published literature and unpublished reports, are included where relevant to understand transition to economic participation in the Australian context.

3.2 The good, the bad and the unknown: Transition from school experiences of young people with intellectual disability and their family members

It is widely acknowledged that young people with intellectual disability face particular challenges during the period of transition from school (Davies & Beamish, 2009; Foley et al., 2012; Leonard et al., 2016), and that the experience of transition differs significantly for them and their family members compared to that of their peers without intellectual disability (Jacobs et al., 2018). Transition has been described as a challenging time for individuals, families and the service system, one of ‘heightened opportunities and new risks’ (Blacher, 2001, p.173). Understandings of youth transitions, and youth citizenship, have historically been underpinned by the notion of successful attainment of normative markers for the young person who moves through a ‘series of steps and pathways into economically-independent adulthood and full citizenship’ (Wood, 2017, p. 4). This normative idea of transition draws our attention to how young people will spend their time post-school, the type of activities they will undertake, the spaces they will spend time in, and – sometimes for the first time – what their longer-term adult life might look like (Jacobs et al., 2018). As Halpern (1994), a pioneering transition researcher, argues:

> Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services, and natural supports within the community. The foundations for transition should be laid during the elementary and middle school years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning. (p. 117)

However, understandings of transition for young people in general have changed drastically over the past two decades. Understandings in the tradition of Halpern, which cover both transition from school and transition to adulthood, ‘capture the hopeful promise of a future which unfolds with forward momentum, generating progress (as education, training or career development), knowledge (as psychological development), security, and personal development’ (Kelly et al., 2019, p. 100). However, recent theorisations suggest that this gives a false impression of the life path following schooling years as ‘linear’ and certain, when today, transitions are anything but (Kelly et al., 2019).

Despite the heterogeneity of young people with intellectual disability, much of the transition from school literature is focused on those with mild to moderate intellectual disability – including in the literature on young people with disability more generally, and to some extent the literature on typically developing young people (Bouck, 2014; Bouck & Joshi, 2016; Salt et al., 2019). A second set of literature focuses on transition from school for young people considered to have severe or profound intellectual disability – e.g., those who attend special schools and typically transition to disability centres post-school (Carter et al., 2011a; Carter et al., 2012; Jacobs et al., 2020; Wehman et al., 2018). This literature has also focused on the experiences of family members during this period (Codd & Hewitt, 2021; Dyke et al., 2013; Leonard et al., 2016). In 2012, in Australia, Foley et al. (2012) reported a 'paucity of data' in relation to transition for people with intellectual disability, and little in the way of high-quality studies. This has not changed with the advent of the NDIS.

In the 1980s, changing societal responses to intellectual disability, such as deinstitutionalisation and human rights-based approaches, began to focus attention on the post-school lives of young people with intellectual disability. Recognising the different and more complex needs of young people with intellectual disability, researchers began to investigate transition practice as it related to this cohort, particularly those educated in special education settings (Baer et al., 2011; Beamish et al., 2012; Bouck & Joshi, 2016; Carter et al., 2012; Gilson et al., 2017; Grigal, Dukes, et al., 2021; Papay & Bambara, 2014; Park & Bouck, 2018; Wehman et al., 2014). However, even these studies have tended to show bias towards people with mild intellectual disability (Foley et al., 2013) over those with moderate, severe and profound intellectual disability who are more likely to be educated in special school settings (Baer et al., 2011). Further research is required to understand how to support young people with moderate to severe intellectual disability (Bouck & Joshi, 2016). Given that this study is focused on young people with moderate to severe intellectual disability, the literature review will focus primarily on the experiences of that cohort.

3.2.1 Experiences of transition from school for young people with moderate and severe intellectual disability

As noted above, the lack of focus on transition for people with moderate, severe, and profound intellectual disability may be due to lower expectations about post-school work and study for this cohort, as well as the fact that fewer young people are classified as having moderate to profound intellectual disability compared to those classified as having mild disability (APA, 2013). Much of the literature related to moderate, severe, and profound intellectual disability has focused on the experience of parents as they adjust to post-school life with their young people and make decisions about post-school services. Numerous studies (see Brown & Smith, 1989; Codd & Hewitt, 2021; Dyke et al., 2013; Leonard et al., 2016; McKenzie et al., 2017; Pallisera et al., 2016) have identified school completion as a particularly difficult time for young people with intellectual disability and their families. For example, parents report 're-experiencing' their children's disability and experiencing a new range of issues, emotions and fears for their children (Dyke et al., 2013; Redgrove et al., 2016). It has also been described as a time of redefinition, conflict and tension (Schneider et al., 2006; Smith & Routel, 2010), and sadness as families strive to create a 'good life' for their young people and consider whether they will reach their full potential (Blacher, 2001; Davies & Beamish, 2009). Societal norms about adulthood (e.g., attaining a job) also begin to impact on young people with intellectual disability during transition, and are heightened by the need to step out of the relative safety of the school system (Jacobs et al., 2018).

The important role families play in supporting young people with disabilities through transition is well established in the literature (Kohler et al., 2016; Landmark et al., 2010; Leonard et al., 2016; Smith & Routel, 2010), as is the fact that post-school outcomes for young adults with intellectual disability are better where there has been significant parental involvement in the transition process (Kohler & Field, 2003; Kraemer et al., 2003). Families are commonly the main and central support systems for young people (Dyke et al., 2013; Giri et al., 2022; Jacobs et al., 2018; McMahon et al., 2020), and are well placed to provide them with practical and emotional support, to create a vision of their adult lives and to advocate for the services and supports needed to bring that vision to reality (Davies & Beamish, 2009; Jacobs et al., 2018). Indeed, Jacobs et al. (2018), recognising the interdependence of the needs of the young people and the needs of the family overall, suggest that for the moderate to severe cohort, the 'family system' is central to transition planning.

In order to understand transition from school for young people with severe and profound intellectual disability and their families, Jacobs et al. (2018) undertook a systematic review of the international literature, finding that their experience of transition was in stark contrast to that of typically developing young people – and that it was this difference that defined the transition period. It was also apparent that this experience of difference was more pronounced for this cohort than for young people with milder intellectual disability. The literature on young people with intellectual disability's transition from school and its impacts on individuals and their families should therefore be more narrowly understood within the context of specific cohorts of people with intellectual disability.

Jacobs et al. (2018) differentiated between the terminology used in health care, such as 'transfer', which describes a short one-off event, and 'transition', which occurs over a longer period of time. However, there is a lack of clarity in the literature about models and timeframes of transition, and family members describe transition programs that are 'operational' (Kaehne, 2013) or practical (McMahon et al., 2020), starting in the final year of compulsory education and being completed when a suitable post-school placement is found (Beamish et al., 2012). In other words, they focus attention on the short period of time in which a young person transitions from school. However, transition supports that start too late and are not collaborative lead to poor-quality provision of the information required to support effective decision-making. Codd and Hewitt (2021) therefore describe this period as ‘The Good, the Bad and Unknown’ (p. 43).

The operational nature of transition supports, and a lack of shared understanding can result in young people with intellectual disability, family members and the service system all working within different transition timeframes (Jacobs et al., 2018; Redgrove et al., 2016). Hudson (2006) recognises what he calls ‘visible’ and ‘invisible’ transitions, the first of which is associated with formality and support and the second of which occurs later, often in an unstructured and unsupported manner. Jacobs et al. (2018) identified a misalignment between the life course perspectives in transition planning that family members were focused on, which centred around the complex barriers young people with intellectual disability face, and their greater need for ongoing support after leaving school than students with other disabilities (Schalock et al., 2021; Shogren & Plotner, 2012). This is due in part to concepts of adulthood for young people with intellectual disability being contested (Hudson, 2006; Redgrove et al., 2016) and often viewed through biological and socially constructed lenses, with the first relating to the biological changes happening to the young person and the second to the roles they are expected to take up in adulthood. The parents in McMahon et al.’s (2020) study reflected on their children as young adults, seeking an initial young adult placement before considering ‘settling their children’. However, such placements were often not available.

The lack of clarity about transition, including its purpose and timeframe, leaves young people, their family members and the various institutions they interact with unclear regarding what is commonly referred to as ‘transition’ (Redgrove et al., 2016). The lack of shared understanding about transition timeframes also results in stress for families that continues into the longer transition to adulthood period. This is caused by uncertainty related to the family’s role (Codd & Hewitt, 2021), the challenge of navigating complex systems (Codd & Hewitt, 2021; Leonard et al., 2016; Pallisera et al., 2016), the more difficult pathways to attaining stability in adult roles for young people with intellectual disability, limited choice, and ongoing struggles to secure suitable employment, vocational and day recreation programs for their young people, regardless of the length of time since leaving school (Dyke et al., 2013; McMahon et al., 2020). Additional significant factors during the transition period include changing social networks, the impact of school ending and the need for new services and supports to be introduced into a young person’s life (Jacobs et al., 2018). This aligns with Shogren and Wehmeyer’s (2020) description of transition as a major change that encompasses changing roles, responsibilities and support systems. Families report the transition period impacting on them broadly due to disruption to routine and the loss of informal supports, which can impact on their own employment, for example, due to the increased pressure of balancing safety and autonomy as their young people navigate the adult world (Davies & Beamish, 2009; Dyke et al., 2013; Schneider et al., 2006). Transition was also associated with a sudden decrease in formal supports (Dyke et al., 2013; Schneider et al., 2006), with the perception that support was abruptly ‘cut off’ after schooling (Meadows et al., 2006) – something Schneider et al. (2006) refer to as service discontinuity. Having left behind the safe and well-known school environment, families attempt to create new daily routines that are ‘sustainable, meaningful and congruent with the individual needs of all family members’ (Gallimore et al., 2003, as cited in Schneider, 2006 p. 927), and take into account practical issues such as transport (Dyke et al., 2013).

Young people with disability and their families report experiencing difficulty finding the information they need about post-school options (Carter et al., 2017; Davies & Beamish, 2009; Gauthier-Boudrealt et al., 2017; Jacobs et al., 2018; Leonard et al., 2016). While there are plenty of resources available, they frequently fail to reach families of young people at the crucial time they need it (Dyke et al., 2013). Australian families have described a short timeframe for the provision of information from which they could choose the most appropriate post-school options (Dyke et al., 2013; Kaehne, 2013; Leonard et al., 2016; McMahon et al., 2020). Information provision was also narrowly focused on identifying and connecting with appropriate post-school providers such as disability programs, rather than on preparation for work and for later adult life (Beamish et al., 2012; Dyke et al., 2013).

Choice of post-school services also emerged as an issue for family members of young people with intellectual disability during transition (Jacobs et al., 2018). Family adjustment issues coupled with narrowly defined transition programs (Leonard et al., 2016) caused increased stress and worry, and put families under pressure to make quick decisions about their children’s post-school services before they had had time to explore and assess a range of options (Leonard et al., 2016; McKenzie et al., 2017; Schneider et al., 2006). This stress was compounded when the young person had limited independence, emphasising the need for a safe space (Codd & Hewitt, 2021), and this resulted in the selection of options that offered security and safety for both the young person and their family, such as a supported workplace with other adults with disability (Dyke et al., 2013; Meadows et al., 2006; Redgrove et al., 2016) at the expense of exploring community-based work, education and training possibilities.

Service discontinuity also results in stress and frustration for families, many of whom report that they themselves require access to support, which is often not readily available (Codd & Hewitt, 2021). Family members have reported low involvement in transition planning (Davies & Beamish, 2009; Leonard et al., 2016), despite family support being a practice identified as occurring within Australian schools (Beamish et al., 2012). Leonard et al. (2016) found that attendance at meetings and other planning activities did not automatically result in families leading the process, or in genuine collaboration between schools and family members.

In addition, there was little evidence of interagency collaboration between schools, post-school education and employment services, despite teachers and others identifying this as important (Beamish et al., 2012). This may be due to a lack of funding to enable post-school agencies to collaborate, and to school staff having little understanding of the post-school service sector or how to work within it (Beamish et al., 2012).

In addition, transition leads to changes to roles and relationships, particularly between parents and other actors (Jacobs et al., 2018). Parents find themselves mediating on behalf of their young people, trying to locate suitable services and funding for them while also maintaining the family routine (Codd & Hewitt, 2021; Schneider et al., 2006). Coordinating services and managing budgets and funding processes are particularly complex for families (Jacobs et al., 2018). This may be exacerbated by the increased complexity in transition planning for people with intellectual disability, including the need to navigate complex adult service systems comprising disparate and fragmented service providers that offer a broad range of options (Foley et al., 2012). External factors such as what funding and services are available, also greatly influence the options available to families (Jacobs et al., 2020) and therefore the decisions they make. The need to source funding for the post-school adult services their young people require and uncertainty about whether that funding would be secured were sources of stress (Dyke et al., 2013). Delays in employment opportunities being available, along with part-time and insecure employment, also resulted in a need to ‘fill up the rest of the week’ (Dyke et al., 2013, p. 153).

Finally, research has consistently found that students with disabilities are less likely to take leadership roles in their transition planning (Shogren & Plotner, 2012), or to be involved in any meaningful way at all (Jacobs et al., 2018). In one Australian study, less than two thirds of young people with intellectual disability were involved in planning their transition process

(Leonard et al., 2016). Instead, school-based personnel planned their transitions, often with little involvement of external agencies.

Increasingly, expectations for young people with moderate and severe intellectual disability are changing, with higher expectations about their involvement in community-based economic participation activities post-school. This has resulted in a recognition of the need to expand the framework for transition because of its increasing complexity and the way in which it occurs over time and across settings and domains (Trainor et al., 2019). It is increasingly recognised that normative contemporary transition represents both processes and results, and has been influenced by the complexity of the postmodern world, which has challenged the usefulness of stage-based, age-linked theories of career development (Ashton & Ashton, 2016; Walsh et al., 2019; Wehmeyer et al., 2019). Transition for young people, including people with intellectual disability, is increasingly fluid, with multiple transitions that occur over a longer period of time, including a higher propensity to undertake post-school education, to travel and to change course throughout young adulthood (Arnett, 2000; Walsh et al., 2019). There is thus an increasing need to understand the practices that support post-school success for young people with intellectual disability and to ensure that they are widely available.

3.3 Evidence-based transition predictors and practices

As described in Chapter 2, operational transition models historically transferred young people with intellectual disability from school to a post-school adult service when they aged out of school (Kaehne, 2013; McMahon et al., 2020; Papay & Bambara, 2014). At the time, this process met the need of ensuring an appropriate post-school placement. In contemporary society, however, post-school goals and expectations for young people with intellectual disability are increasingly aligned with those of typically developing young people (Bouck et al., 2020). Transition to paid work post-school has been a focus in the Australian context, given its normative role in young people's lives and the benefits it provides. Transition to post-school education has also been a focus in the United States, especially for underrepresented groups such as young people with intellectual disability, as it is a normative pathway to paid employment (Grigal & Dwyre, 2010; Moore & Schelling, 2015). According to Mazzotti et al. (2009),

> The primary purpose of transition planning is to clearly define the student's postsecondary goals by addressing and defining student strengths, needs, and desires to develop an appropriate curricular plan, including academic and functional coursework and community-based instruction necessary to meet postsecondary goals. (p. 45)

Shogren and Wehmeyer (2020) focus attention on the importance of transition planning for young people with disability, stating that '21st century academic and work skills coupled with self-determination and family involvement are imperative for all youth to live as productive citizens and are inherently embedded in the field of transition' (p. 21).

Coinciding with the introduction of human rights-based policy settings, the *Individuals with Disabilities Education Act 1990* in the United States and increased awareness of the importance of quality of life for people with disability, a large body of research has emerged. This literature is primarily from the United States and the United Kingdom and focuses on both desired post-school outcomes and the practices that promote their achievement since the 1980s (Carter et al., 2011b; Haber et al., 2016; Halpern, 1985; Hudson, 2006; Kohler, 1996; Kohler et al., 2016; Mazzotti et al., 2021; Meadows et al., 2006; Sheppard et al., 2017; Test et al., 2009; Wehmeyer & Webb, 2011). The majority of this research has been correlational and quasi-experimental studies, often drawing from the *National Longitudinal Transition Study (NLTS)*, with very few randomised controlled studies (Haber et al., 2016; Mazzotti et al., 2021; Test et al., 2009). Synthesised research has used the National Technical Assistance Center on

Transition's quality indicators for correlational and qualitative research, assessing practice as evidence-based, research-based or promising based on peer-reviewed research that meets the criteria to be considered scientifically-based and peer-reviewed research in secondary special education and transition (National Technical Assistance Center on Transition, 2019). High-quality correlational research is considered Tier 3 for promising evidence (*Every Student Succeeds Act 2015*). Predictors of post-school success should therefore be treated with caution when used as interventions, because the Institute of Education Sciences does not consider Tier 3 as providing evidence of effectiveness (Institute of Education Sciences: What Works Clearing House, 2020).

The following discussion explores 'best practices' for young people with disability broadly, as these predict post-school success. Research has focused on identifying 'in-school predictors' of post-school success to enable the design, evaluation, and improvement of transition programs (Mazzotti et al., 2021). Over time, combinations of in-school predictors have become known as best practices. The impact of best practices on the post-school outcomes of students with disability, including employment, post-school education and quality of life, have been studied utilising data from the NLTS (Wagner et al., 2005).

The earliest lists of best practices in transition from school for people with disability generally began to be published in the 1980s and 1990s. They were developed by analysing exemplary programs, surveying teachers and reviewing the literature (Test et al., 2009). This early body of research resulted in the development of Kohler's Taxonomy for Transition Programming (Kohler, 1996), a system of classification to organise and guide delivery of transition practice for students with disability, including intellectual disability, in school settings (Haber et al., 2016; Kohler, 1996; Kohler & Field, 2003). Originally developed based on four research and evaluation studies, the Taxonomy was re-evaluated in 2003 and again in

2016 (Kohler & Field, 2003; Kohler et al., 2016), when the second version was released. It is divided into five practice areas: student-focused planning; student development; family engagement; collaboration; and program structure. The practices contained within each area focus on what Kohler and Field (2003) refer to as 'transition focused education': that is, an education program in the later years of high school that supports the attainment of appropriate post-school outcomes. In summarising what is known, Kohler et al. (2017) state:

> Over more than three decades, transition practices research has demonstrated that post-school outcomes of students with disabilities improve when educators, families, students, and community members and organizations work together to implement a broad perspective of transition planning, more appropriately referred to as transition-focused education. (p. 2)

There continues to be wide agreement in the literature that Kohler's Taxonomy for Transition Programming comprehensively describes substantiated good practice as it relates to transition for students with disability. For example, Haber et al. (2016) undertook a meta-analysis that found evidence for the descriptiveness of taxonomy categories, with student-focused planning, collaboration and family involvement being of particular interest. Test et al. (2009) used the Taxonomy to organise the 16 best practices identified from their review of the literature. The Taxonomy has been used extensively in the US to develop transition-related tools and benchmarks, including the national post-school dataset (National Center for Special Education Research, n.d.). The revised Taxonomy for Transition Programming (Kohler et al., 2016) has maintained the five primary practice categories while adapting each to reflect new transition research and practice that has demonstrated efficacy. Within each primary practice area, it identifies specific practices that support effective transition education (Kohler et al., 2016).

Since 2009, research has focused on understanding which practices are more effective based on the evidence, for which cohorts, and in which contexts, as well as how effective practice can be made available to young people with disability, particularly in school settings (Haber et al., 2016). Much of it has focused on identifying predictors of post-school success (Haber et al., 2016; Kohler et al., 2016; Mazzotti et al., 2021; Test et al., 2009) as well as effective practices in transition planning (Foley et al., 2013; Kohler et al., 2017; Landmark et al., 2010; Luecking & Luecking, 2013). Reviews of the literature (Baer et al., 2011; Cobb et al., 2013; Kohler et al., 2016; Mazzotti et al., 2021; Test et al., 2009) and one meta-analysis (Haber et al., 2016) have identified 23 in-school practices that are considered evidence-based, research-based or promising in terms of predicting post-school outcomes for young people with disability generally. Mazzotti et al. (2021) recently reviewed and updated the evidence for youth with disability broadly, which is summarised in Table 3.1 below. Each practice is aligned with the level of evidence supporting it, using the National Technical Assistance Centre on Transition's rating criteria.

Table 3.1

In-school predictors of post-school success

(from Mazzotti et al., 2021)

In-school practices that predict post-school success for people with disability (pan-disability)	**Evidence level for item as a predictor of outcome** *** Evidence-based; ** Research-based, * Promising		
	Outcome		
	Post-school employment	**Post-school education**	**Independent living**
Career and technical education (previously vocational education)	***	**	
Career awareness	*	*	
Community experiences	*		
Exit exam/high school diploma status	*		
Goal-setting		**	
Inclusion in general education	**	**	**
Interagency collaboration	*	*	
Occupational courses	*	*	
Paid employment/work experience	**	**	*
Parent expectations	**	*	
Parent involvement	*		*
Program of study	**	**	
Psychological empowerment	*	*	
Self-care independent living skills	*	*	**
Self-determination/self-advocacy	**	**	*
Self-realisation	*	*	
Social skills	*	*	
Student support	**	*	*
Technology skills	*		
Transition program	**	**	*
Travel skills		*	
Work study	**		
Youth autonomy/decision-making	**	**	*

Additional characteristics such as functional academic skills, high school completion, family income, ethnicity and whether the school setting was urban or rural were also found to be significant predictors of at least one outcome (Papay & Bambara, 2014). In addition, policies at state or district level, recommendations for systemic change, and post-school services and supports were found to be predictors of post-school outcomes for students with disability (Certo et al., 2003; Rusch et al., 2009).

In describing ‘best practices’ in transition, Papay and Bambara (2014) focus on essential components both in planning and support provision. They note that ‘these practices represent alterable variables that schools can implement to increase the chances of success of youth with intellectual disabilities over and above unalterable variables, such as the characteristics of youth or their families’ (Papay & Bambara, 2014, p. 136). This distinction between alterable and unalterable variables is important, as characteristics that are considered unalterable, such as socioeconomic status, parents’ level of education and parent expectations, were considered the most important predictors of post-school outcomes by early researchers such as Heal and Rusch (1995).

Despite extensive research into understanding the barriers and facilitators of economic participation for people with intellectual disability, concern about translating research to practice remains (Stoneman, 2009). In particular, a lack of uniformity in the application of evidence-based practice for supporting young people with disability who are transitioning from school reduces economic participation outcomes for young people with intellectual disability (Department for Work and Pensions, 2011; Diallo et al., 2014; Inge et al., 2016; Sherman et al., 2018). Transition planning is often treated as an add-on, or a tick-box exercise designed to meet the requirements of the law (Herbert et al., 2010), with a ‘lack of focus on integrated employment options during the transition from school to adult life and in adult service systems’ (Shogren et al., 2019, p. 22). Miller-Warren (2015), in her analysis of the quality of transition plans prepared for 39 American students with disabilities, found that plans were not well-written, with sections left blank or completed in a pro forma way – that is, they were not written for the particular student. Students with intellectual disability also had less contact with external professionals such as vocational rehabilitation providers during their transition planning and in developing their Individual Employment Plans (IEP), despite interagency collaboration being a predictor of post-school success (Grigal et al., 2011; Shogren & Plotner, 2012).

The Australian transition research base is small (Beamish et al., 2012; Foley et al., 2012; Meadows, 2009; Meadows et al., 2006), with very few peer-reviewed studies specifically addressing transition to economic participation for young people with intellectual disability. Xu and Stancliffe (2019) published peer-reviewed data about the NSW-based Transition to Work program, and the NDIA has released employment outcome data for the NDIS cohort, including for the SLES program (NDIA, 2020). Recent evaluation research data from the Australian Ticket to Work (TTW) model, which has drawn strongly on the international peer-reviewed literature, has shown efficacy for the model, but is yet to be peer reviewed itself (ARTD Consultants, 2019b). In addition, an evaluation of one Transition to Work provider predominately focused on intellectual disability has been undertaken, though this was also not peer reviewed (Riches, 2014).

3.4 Best practice in transition for young people with intellectual disability

While higher expectations about post-school economic participation for young people with intellectual disability are still relatively new (Martinez et al., 2012), they have created a shift in thinking about the role transition planning plays in supporting their post-school economic participation, along with the factors that result in post-school success. Shogren et al. (2019) noted the critical need for ‘the implementation and evaluation of evidence-based transition practices to enhance the postschool employment outcomes of youth with intellectual disability’ (p. 3). However, despite the large body of research regarding young people with disability generally, there remains a lack of clarity in relation to whether recommended school-based best practices for transition do predict post-school outcomes for people with intellectual disability (Papay & Bambara, 2014), and the question of which practices best prepare young people for post-school economic participation remains unanswered (Bigby & De Losa, 2021). This is in part due to the reliance on correlational studies rather than experimental studies, and the low number of studies that focus attention on highly influential factors such as interagency collaboration (Haber et al., 2016). In addition, models of transition have tended to focus on evidence-based practices that improve transition outcomes for all students. However, as Flexer et al. (2011) identified, characteristics such as gender, minority status and disability level strongly influence the effectiveness of the evidence-based predictors identified by the NSTTAC meta-analysis. This suggests that there is a need to develop theoretical transition models that take these factors into account, for example for young people with intellectual disability.

The literature reviewed in Part 3.3 focused on understanding which transition planning practices were supported by research evidence and how to ensure that good practice was widely available to students within school settings (Kohler, 1996; Mazzotti et al., 2021; Test et al., 2009). However, it was broadly-based, and tended toward positioning students with mild to moderate intellectual disability as a component of the broader cohort of students with disability. Recently, a number of authors have focused attention on students with intellectual disability specifically, including students in special education settings (Bouck, 2012; Carter et al., 2012; Papay & Bambara, 2014; Park & Bouck, 2018). Correlational studies utilising NLTS data have identified a number of practices that are predictive of improved post-school outcomes, including employment, independent living and quality of life, for young people with intellectual disability (Baer et al., 2011; Carter et al., 2012; Kraemer et al., 2003; Papay & Bambara, 2014).

Papay and Bambara (2014) focused attention on the evidence identifying predictors of positive post-school outcomes for young people with intellectual disability using NTLS outcome data. They initially identified seven common best practices that support transition success for students with disability generally. These are:

- youth involvement in transition planning and other strategies to develop self-determination;
- family involvement in transition planning;
- individualised planning for transition;
- instruction and experiences that prepare youth for employment, including vocational education and work experiences;
- instruction and experiences that prepare youth for independent living, including a functional life skills curriculum and community-based instruction;
- general education participation and age appropriate inclusion with peers without disabilities; and
- interagency involvement and collaboration (Papay & Bambara, 2014).

Notably, these practices support the five primary practice categories of Kohler's Taxonomy. For youth with intellectual disabilities, four practices in particular were found to be predictive of post-school outcomes including employment, independent living, and quality of life. These were:

- work experiences;
- inclusion in general education;
- family involvement; and
- preparation for independent living through life skills instruction or community-based instruction (Papay & Bambara, 2014).

Papay and Bambara (2014) clustered predictive activities or components into five sets of 'best practice' which each comprise of a number of components. While they note the lack of consistent use of the 'best practice' term, they emphasise the need to focus attention on making practice that is associated with successful post-school outcomes available to young people. They examined whether the use of the five best practices predicted successful post-school outcomes for young people with intellectual disabilities beyond what would have been achieved via the effect of 'unalterable' individual, family and school characteristics such as IQ, school completion, family income and education levels, and expectations about post-school education and training. The five best practices draw from the seven best practices identified in the previous literature. They are:

- youth involvement;
- family involvement;
- work experience;
- life skills instruction; and
- interagency collaboration.

Papay and Bambara (2014) chose to exclude 'inclusion in general education' and 'transition planning' from their analysis due to the poor quality of the data available.

Papay and Bambara (2014) undertook regression analysis using US national data from the *National Longitudinal Transition Study-2 (NLTS2)* to examine two- and four-year employment, education, enjoyment of life and social inclusion outcomes for a cohort of students with intellectual disability. They found that characteristics and best practice school program variables predicted the outcomes in combination. Characteristics including high school completion, family income, parent expectations for employment, parent expectations for post-secondary education, and living in an urban area were found to be significant predictors of at least one outcome. The addition of the five best-practice school program variables (youth involvement, family involvement, work experience, life skills instruction and interagency collaboration) contributed to a significant improvement in the prediction of two-year and four-year employment, post-secondary education, and enjoyment of life outcomes. Their findings are discussed in detail in the summary of evidence for best practice in transition for young people with intellectual disability below.

3.4.1 Youth involvement in transition planning and self-determination strategies

Youth involvement in transition planning has been identified as a significant predictor of successful post-school outcomes for students with intellectual disability. Papay and Bambara (2014) found that youth with intellectual disability who were involved in their transition planning were five times more likely to be employed two years post-school. This aligns with previous research findings that effective early transition planning which involves students, particularly in their Individual Education Plan (IEP) meetings, is a key strategy (Kohler et al., 2016; Mazzotti et al., 2012; Test et al., 2009; Winn & Hay, 2009). Youth involvement is particularly important when it occurs before the students are in the last stages of their education, commencing at age 14 (Kohler et al., 2017). One key strategy is enabling young people, specifically vulnerable people such as those with intellectual disabilities, to explore the conditions that foster healthy development and functioning and support them to decide what they want, rather than having external providers plan for them (Foley et al., 2012).

Self-determination is defined as ‘acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference’ (Wehmeyer, 2003, p. 177). Promoting self-determination is an emerging area of interest, particularly with young people with intellectual disability, which has been highlighted as a critical element in optimising outcomes in their process of transition from secondary school to adulthood, particularly in the United States (Foley et al., 2012; Hagiwara et al., 2019; Laragy, 2004; Stancliffe et al., 2020). For example, Benitez et al. (2005) found that teaching self-determination skills in high school was positively correlated with improved post-school outcomes for students with disability, and Wehmeyer and Palmer (2003) found that self-determination skills in high school were significant predictors of post-school education and independent living success.

More recently, there has been increasing interest in the use of the Self-Determined Learning Model of Instruction (SDLMI), an evidence-based practice for teachers with a focus on setting and attaining educationally relevant goals (Shogren et al., 2019). There is evidence of the SDLMI's efficacy for young people with intellectual disability, including a recent large study which found that self-determination status at school exit predicts more positive adult employment and community participation outcomes both one and two years post-school (Shogren et al., 2019).

Self-determination strategies, particularly in regard to career planning and employment, are evolving for young people in general and more specifically for those with intellectual disability. The modern job market is unsettled and fluid, and young people are expected to have multiple jobs across their lifespan, essentially selling their services and skills within a competitive labour market (Savickas, 2012). Therefore, people with intellectual disability must be prepared for this new landscape. There is growing interest in the US in career design based around career construction theory, which has a central premise that careers are constructed – 'that individuals build careers through personal constructivism and social constructionism' (Savickas, 2005, p. 147). This focuses attention on career adaptability and person-environment fit, and emphasises the need for approaches that enable young people to construct their work narrative and work towards the achievement of goals. Dean, Shogren, Wehmeyer et al. (2018) used the Self-Determined Career Design Model (SDCDM) and job development activities in a community service agency to promote integrated employment for 12 people with intellectual disabilities. There was a strong focus on fully involving these individuals in the career design process, focusing on strengths and identifying environmental supports. The program drew from best practice to support the participants' self-determination, job development and career design. On completion of the program, all but three were employed in a community-based job, working an average of ten hours per week. According to researchers, the model, when used in conjunction with employment supports, enables full involvement of the person with intellectual disability in the career design process (Dean et al., 2018; Hagiwara et al., 2019).

Building on career design, 'life designing' (Nota & Rossier, 2015; Savickas et al., 2009) has emerged as a new model for career development and guidance that widens the focus from work to life. Life designing shifts the focus from development to the more active notion of designing one's life, promoting skills and competencies in life planning and considering the role of work within the broader life (Wehmeyer et al., 2019). Shogren and Wehmeyer (2020) state that

> Planning for a job can no longer be the target; instead, designing a career (and life) characterized by the ability to adapt to changes that will continue to emerge both in the work sector as well as in the communities within which we live is a necessity. (p. 1)

Life designing recognises that in modern society, different life domains are interconnected (Savickas et al., 2009). It draws strongly from a constructivist perspective, recognising that most people no longer continuously work within one specific industry, and goes beyond career construction by attending to self-construction through all life roles, because for some people work may not be the salient role (Savickas et al., 2009). Rather, people need to 'develop a work-related identity through engagement in many employment and life-related activities, to design, in essence, one's work life and other life areas' (Savickas et al., 2009, p. 244). Life design models are therefore lifelong, holistic, contextual and preventative (Dean et al., 2018). Life designing enables the focus to be on the young person's life themes, vocational personality, positive resources and subjective identity as well as their career and life goals (Wehmeyer et al., 2019).

3.4.2 Family involvement in transition planning

Family involvement in transition planning is a significant predictor of post-school success (Gilson et al., 2018; Kohler et al., 2016; Pleet-Odle et al., 2016), particularly in relation to post-school education (Papay & Bambara, 2014). Family involvement generally refers to family members' involvement in developing individual education plans and post-school goal-setting (Papay & Bambara, 2014), although there is increasing recognition of the role they play in supporting economic participation post-school (Hirano & Rowe, 2015). Family-centred transition planning particularly impacts on expectations for the future among both parents and young people, and improves self-determination and employment-related decision-making (Kohler et al., 2016; Meadows, 2009).

Hagner et al. (2012) delivered structured training, individualised planning sessions and follow-up support to families of young people with Autism in the United States. Involvement in the intervention resulted in significant increases in student and family expectations for the future, as well as improved student self-determination and career decision-making. Hirano and Rowe (2015) developed a model focused on the role of families both in high school and beyond. Parents were found to have significant roles as decision-makers and collaborators, as well as in advocating for their child, supporting self-determination and supporting young people to develop independent living and social skills. Increased family involvement resulted in increased access to information about the options and programs young people could engage in, such as vocational programs. In addition, family members developing advocacy skills was identified as helpful in navigating complex adult systems.

Pleet-Odle et al. (2016) likewise found that strategies to involve parents in transition planning improved outcomes. For example, providing training and information sessions linking families to family support groups that could support the development of a strong vision was important, as was partnering with families to identify positive role models, including people with disability who are employed. Ensuring that interactions are culturally appropriate and respectful, and that planning starts early and involves families in all its aspects, including supporting them to create networks in the community and build independence in the community, were important factors.

3.4.3 Work experience

Numerous studies (Test et al., 2009; Test et al., 2014; Wehman et al., 2014) have associated work experience with positive employment outcomes for students with disability, particularly intellectual disability. Work experience includes short on-the-job tasters, internships, work sampling, paid work and unpaid work. Papay and Bambara (2014) found it to be statistically significant for three post-school outcomes for youth with intellectual disability and practically significant for another three; however, these tended to be non-employment outcomes, such as life satisfaction. However, it was also a predictor of employment two to four years post-school (Papay & Bambara, 2014). Jun et al. (2015) found that for students with cognitive disability, participation in school transition programs including Project SEARCH (a structured school-based internship program) positively predicted employment outcomes. Project SEARCH reports that over two thirds of its participants have a paid employment outcome on completion of the program (Project SEARCH, n.d.). In addition, longitudinal data indicates an overall outcome rate of 83% among program participants with intellectual and developmental disabilities (Christensen & Richardson, 2017).

Unpaid work experience can also be a pathway to paid work experience. Carter et al. (2011a) found that students with intellectual disability who participated in internships and other work preparation programs gained more paid work experience. This is important because paid work experience more strongly predicts later paid employment: multiple studies (Carter et al., 2011a; Carter et al., 2012; Wehman et al., 2014) have analysed US national data (*NLTS-2*) which strongly suggested that youth with intellectual and developmental disability who had paid work experience during their schooling were more likely to have a paid job after graduation. Likewise, Luecking and Luecking (2013) found that while work experience was the single most important predictor of later work for students with intellectual disability, the impact doubled if they had paid work. Carter et al. (2012) also found paid work, either school-sponsored or in community employment, was associated with employment post-school.

Work experience has a range of benefits for young people with intellectual disability that may support later employment, including influencing parental expectations (Blustein et al., 2016; Carter et al., 2017; Luecking & Luecking, 2013; Lysaght et al., 2017). Blustein et al. (2016) found that early hands-on work experience in the community predicted higher parental expectations of full-time employment for their children post-school. A number of state-based strategies in the US, such as Tennessee Works (Carter et al., 2017) and The Let's Get to Work Wisconsin program (Molfenter et al., 2017), have focused on early work experience as a way to change attitudes about students with intellectual disability's post-school outcomes. Lindstrom et al. (2014) reported that structured and well-supported work experience helped young people learn about work, develop soft skills and task skills and become more independent in the workplace. Work experience has also been identified as a strategy to promote self-determination. When linked to IEP and goals it can be used as an assessment tool. It also builds confidence and helps to identify young people with intellectual disability's strengths and interests as well as supporting understanding of the accommodations they need (Dean et al., 2018).

Not all studies support work experience as a predictor of later employment for young people with intellectual disability specifically, potentially due to the quality of the work experience provided. Baer et al. (2011) found that school-arranged work was not significantly related to post-school employment for students with significant disability. Likewise, Daviso et al. (2016), who investigated the impact of school-arranged work and work experience for students in the USA with different disabilities, found that neither significantly predicted employment outcomes for students with intellectual disability. This could be due to unpaid work experience being poorly structured or poorly supported. For example, Jun et al. (2015) and Molfenter et al. (2017) found that participating in more highly structured school-sponsored work and unpaid internships positively predicted employment outcomes for students with intellectual disability.

3.4.4 Preparation for independent living through life skills instruction or community-based instruction

Life skills instruction, including learning banking, food preparation and cooking, grocery shopping, home maintenance and laundry skills, was a strong predictor for post-school education for students with intellectual disability (Papay & Bambara, 2014) and also predictive of post-school outcomes more generally (Baer et al., 2011; Carter et al., 2012; Gilson et al., 2017; Kraemer et al., 2003). In contemporary society, information technology skills were also found to be important for young people with intellectual disability (Szidon et al., 2015). Students' communication and self-care skills, and their ability to independently travel outside the home, significantly increased their odds of getting paid work experience (Carter et al., 2011b), which is a predictor of post-school paid employment.

3.4.5 Interagency involvement and collaboration

There is increasing interest in the role interagency collaboration plays in supporting post-school success for young people with intellectual disability and increasing evidence that additional focus on the role of collaborative structures is needed (Haber et al., 2016; Kohler et al., 2016; Meadows, 2019; Papay & Bambara, 2014; Sheppard et al., 2017). Interagency collaboration describes coordination between education agencies and adult services, including employment-related service providers (Plotner et al., 2018). Haber et al.'s (2016) meta-analysis found that student development and program structure were weak predictors of post-school success for students with intellectual disability, recommending a shift in focus from these to multi-stakeholder collaboration. In the United Kingdom, there has been a shift away from practical/operational transition to multi-agency/multi-stakeholder transition, because of the improved outcomes young people achieve (Hudson, 2006; Kaehne, 2013). Papay and Bambara (2014) found that interagency collaboration was a statistically significant predictor of one non-employment-related outcome for young people with intellectual disability and an important predictor of four employment-related outcomes, including four-year employment and post-school education. Kohler et al. (2016) strengthened the focus on interagency collaboration in their 2016 update to the Taxonomy for Transition Programming. Importantly, collaboration was found to increase when key roles were undertaken by dedicated transition support coordinators rather than school teachers, due in part to the transition support focus of their role (Plotner et al., 2018).

Recently there has been a focus on state-wide, collaborative system change models to increase competitive employment outcomes for young people with intellectual disability in the

US. For example, the Mississippi Partnerships for Employment (Hughes Jr, 2017), Tennessee Works (Carter et al., 2017) and Let's Get to Work Wisconsin (Molfenter et al., 2017) have achieved higher rates of competitive employment for young people with disability, including intellectual disability, than states without them. The projects have a system-wide focus, are collaborative and have the goal of increasing the number of people with intellectual and developmental disabilities who are employed. Let's Get to Work Wisconsin addressed low rates of employment for this cohort using four interconnected strategies. Firstly, it built a consortium of key stakeholders whose role was to identify policy issues, including a specific 'youth track' to identify issues from a young person's perspective. Secondly, a policy team developed strategies to implement identified policy changes. Thirdly, school pilot sites implemented evidence-based practices and identified barriers to employment. Lastly, coaches provided intense, on-site technical assistance to the school sites. State-wide targets were set and an annual 'expect work' report was presented to the government (Molfenter et al., 2017). Let's Get to Work Wisconsin increased students with disability's participation in paid employment during school from 11.5% to 73% over three years (Molfenter et al., 2017).

In addition, post-school models such as the rural community change model have brought together young people, families, service providers and employers to deliver evidence-based practice and create integrated employment opportunities for young people with intellectual disabilities (Shogren et al., 2017). In alignment with Let's Get to Work Wisconsin, this collaborative model used multiple integrated strategies to bring about change, including implementing customised employment, the Discovery process, and the SDCDM. In addition, the model addressed environmental barriers through capacity building, including delivering training and ongoing support in implementing customised employment, and the SDCDM within both support-provider organisations and the community more broadly. Employers were engaged through an Active Employer Council, and the model utilised flexible funding strategies. Overall 88 support providers and community members were trained in the model (Shogren et al., 2017).

In Australia, local collaborative structures such as Ticket to Work (TTW) and the Integrated Practical Placement (IPP) program are emerging (Wakeford & Waugh, 2014; White et al., 2019). Both models have drawn on the international literature to create bespoke models for the Australian context. TTW is focused on supporting young people with disability as they transition from school, creating networks in 31 local areas across Australia. Its collaborative structures support students with disability, approximately half of whom attend special schools (ARTD Consultants, 2019b), when transitioning from school. Each place-based TTW network involves young people, family members, schools, employers, employment agencies and training providers in planning for post-school economic participation. In addition, TTW builds the capacity of service providers and the broader community by delivering training, resources and support (Wakeford & Waugh, 2014). Data from TTW networks indicates that involvement in the network leads to increased paid employment and enrolment in post-school education, and a reduction in transition to ADEs and day centres (ARTD Consultants, 2016, 2019b). A 2019 evaluation using comparison data derived from the Household, Income and Labour Dynamics in Australia (HILDA) Survey, found program participants were more than twice as likely to be employed and significantly less likely to not be either working, studying or training post-school. Participants also had higher rates of high school completion and post-school education. Importantly, TTW participants were twice as likely to obtain further qualifications as the comparison group (ARTD Consultants, 2019b); however, the TTW data was drawn from a small sample. In addition, TTW has been found to be effective at supporting collaborative approaches at the system level in order to improve economic participation outcomes for young people involved in its networks (ARTD Consultants, 2019a). For example, employment services and TAFE colleges have supported young people with disability to undertake school-based apprenticeships and traineeships.

In Victoria (Australia), the pilot IPP program created a collaboration between a major hospital, a training provider and an employment agency. Based on the Project SEARCH model, ten young people undertook a one-year internship program that combined classroom-based instruction and on-the-job work experience. Aligned with Project SEARCH outcome data, 80% of participants were in paid employment at the end of the program (White et al., 2019).

3.4.6 Parental expectations

Parent expectations can be described as the broad ideas parents have about what is realistic for their child's future (Martinez et al., 2012). Parents play a key role in shaping visions for young people with intellectual disability, for example by modelling of work roles (Hall et al. 2018), and their expectations are influenced by a range of factors including access to information and involvement in transition planning (Martinez et al., 2012). In addition, inclusion in mainstream education positively impacts parents' expectations about and desire for post-school education for their children with intellectual disability (Martinez et al., 2012).

There is a large literature on the direct impact of parent expectations on young people with intellectual disability's later economic participation (Carter et al., 2017; Kirby et al., 2019; Southward & Kyzar, 2017). Several studies (Carter et al., 2017; A. Hall et al., 2018; Papay & Bambara, 2014) report that parental expectation is the greatest predictor of paid work for people with intellectual disability. For example, Papay and Bambara (2014) found parental expectations for post-secondary education and employment to be the most significant predictor of employment and post-school education outcomes, and Carter et al. (2012) compared employment rates for young people with intellectual disability whose parents expected them to be employed and those who didn't and found that parental expectations of post-school employment resulted in employment rates 58 times greater two years post-high school, a figure that was largely maintained between two and four years post-school.

Supporting families in developing high expectations about work for young people with intellectual disability is most effective when the support is provided early, and the high expectations are continually reinforced (Blustein et al., 2016; Francis et al., 2018). For example, providing families with structured training and support to develop advocacy skills and learn how to navigate systems has been effective in raising expectations (Francis et al., 2013; Roy, n.d.). In addition, providing access to mentors and others with shared experience raises expectations (Carter et al., 2017; Francis et al., 2013).

High expectations lead to young people with intellectual disability having access to more opportunities, such as undertaking work experience and particularly paid work experience (Carter et al., 2011a). In addition, parents who hold high expectations about their young people's self-sufficiency actively tend to work towards that goal, for example by ensuring that they develop independent living skills (Francis et al., 2018).

3.5 Evidence about post-school pathways to community-based employment

An extensive research base has emerged, particularly from the United States, that identifies evidence-informed post-school pathways to community-based integrated employment for people with intellectual disability. In particular, the provision of employment supports, customised employment, internship experiences and post-secondary education, including at college level, have been identified as supporting economic participation for this cohort (Wehman et al., 2018). The literature review will now focus on the evidence that relates to each of these.

3.5.1 Post-school education

Increasingly, post-school education is recognised as a normative pathway to higher employment outcomes for young people post-school (Grigal & Hart, 2010). It therefore represents a potential pathway to employment for people with disabilities (Grigal, Dukes, et al., 2021; Migliore & Butterworth, 2009; Wehman et al., 2018). Despite this, research on post-school education for young people with intellectual disability is currently lacking (Wehman et al., 2018). The overwhelming majority of the available literature is descriptive in nature (Moore & Schelling, 2015), and provides little understanding of how post-school education specifically impacts on employment rates, or how the various practices used in post-school education programs impact employment outcomes (Grigal et al., 2012). More recently, however, Dukes et al. (2017) developed The Postsecondary Access and Student Services Taxonomy in order to provide a 'tool for organizing the extant and future literature base on postsecondary level students with disabilities' (p. 114). Whirley et al.'s (2020) review of the literature specifically related to young people with intellectual disability found support for elements of the Taxonomy such as Student-Focused Support, which they reported included academic skills, independent living, behavioural, social and vocational domains.

Early interest in improving inclusive post-school education opportunities began in Canada, driven by notions of normative pathways and life avenues that are ordinarily pursued by individuals without disability (Uditsky & Hughson, 2012). Research into improving post-school education opportunities for people with intellectual disability began to gain momentum in 2004, when a number of demonstration projects commenced across the United States (Grigal, Dukes, et al., 2021). It was further strengthened following the passing of the *Higher Education Opportunity Act* in the US in 2008 (Whirley et al., 2020), and in 2010 a model demonstration program was developed in order to expand inclusive higher education options for people with intellectual disability. The Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID) was subsequently piloted, and funding was also made available to provide technical support to families and colleges (Grigal, Hart, et al., 2021). Several authors have subsequently focused on post-school education for students with intellectual disability (Grigal, Dukes, et al., 2021; Grigal & Dwyre, 2010; Moore & Schelling, 2015).

One strategy to increase young people with intellectual disability's involvement in post-school education is college-based transition programs, in which transition-aged students are enrolled in school and at college simultaneously (Grigal & Papay, 2018). The in-school predictors of post-school success outlined previously (see Table 3.1), including interagency collaboration, career awareness and occupational readiness courses, have been found to be more prevalent in college-based transition services than in conventional school-based ones (Grigal, Dukes, et al., 2021). In addition, evaluations demonstrate substantial gains in employment outcomes for students undertaking these programs (Moore & Schelling, 2015).

In the US, 305 colleges provide post-secondary education programs to approximately 6440 students with intellectual disability (Think College National Coordinating Center Accreditation Workgroup, 2021). Students are enrolled in fully inclusive programs alongside students without disability, in hybrid programs that combine inclusive and segregated activities, and in segregated programs that are taught on college campuses (Grigal et al., 2012; Hart, 2006). Moore and Schelling (2015) examined college programs for young people with intellectual disability and found that almost all of their students were enrolled in community-based vocational training or college-based education rather than non-vocational community access programs. A later follow-up study suggested that students with intellectual disability attended college campuses primarily for the purpose of accessing opportunities for vocational training and employment. Participation in post-secondary education significantly increases the odds of students with intellectual disability successfully gaining employment (Grigal et al., 2011), and although the data is recent and not sizeable, college experiences seem to provide a viable and unique pathway to community-based integrated employment (Grigal et al., 2015; Moore & Schelling, 2015; Ross et al., 2015). Moore and Schelling (2015) used US national data *(NLTS-2)* to compare outcomes, finding that post-school education programs achieved integrated employment rates for people with intellectual disability of between 73% and 91% (Moore & Schelling, 2015). This aligned with findings from Migliore and Butterworth (2009) of 58%, and Grigal and Dwyre (2010) of between 83% and 73%. In addition, once in the workforce, college graduates with intellectual disability worked more hours and earned higher wages across a wider range of occupations than those without college experience (Cimera et al., 2018). Young people's sustained involvement in social activities on campus combined with inclusive academic coursework enabled them to develop skills needed for employment success (Prohn et al., 2018).

There have been few studies on post-school education for young people with intellectual disabilities in Australia, with two notable exceptions: the 'Up the Hill Project' delivered at Flinders University (Rillotta et al., 2020), and the 'Uni 2 beyond' program developed by Sydney University to include young people with intellectual disability in university life as a means of increasing social inclusion and employment (O'Brien et al., 2019). While individual participants reported positive experiences, including increased learning, independence, self-determination, social networks and preparation for employment, both programs have remained small (Gadow & MacDonald, 2018; Rillotta et al., 2020).

Although it is still an emerging practice within Australia, strong evidence is emerging that increasing young people with intellectual disability's opportunities for post-school education benefits them in terms of economic participation, which suggests that such opportunities should be more widely available.

3.5.2 Employment supports

There continues to be little in the way of evidence-based practice for providing employment supports that lead to integrated work outcomes for people with intellectual disability (Kavanagh et al., 2021). Instead, there are employment support practices which show stronger evidence of effectiveness for community-based integrated employment outcomes, including supported employment and customised employment.

Increasingly there is a shift to a strengths-based approach which recognises that people with disabilities have personal competencies that need to be understood and leveraged to guide the planning of supports (Buntinx & Schalock, 2010; Wehmeyer, 2020). This aligns with research that increasingly demonstrates that work capacity increases with the provision of appropriate supports, such as Project SEARCH (see below). As discussed in Chapter 2, In Australia, the provision of highly individualised employment services in the early 1990s via the DEN resulted in a halving of the number of school leavers transitioning from school to an ADE, and the rate of open employment increasing by nearly five times (Pearce, 2017).

Supported employment

Supported employment is an evidence-based practice widely used in the United States to support individuals with significant disabilities in achieving inclusion in integrated work (Drake et al., 2012; Verdugo et al., 2006; Wehman, et al., 2014). Underpinning supported employment is the understanding that the majority of people can work competitively if provided with appropriate workplace and family supports (Wehman et al., 2018). Supported employment therefore emphasises capacity and capabilities, and an individual’s positive attributes rather than their deficits (Wehman et al., 2003). Over time, it has become an accepted best practice in the employment of people with intellectual and other disabilities (Lysaght et al., 2017). It has four phases: getting to know the jobseeker; job development and matching; training and support; and job retention services (Schall et al., 2015; Wehman, 2012).

Supported employment has also been found to be more cost-effective than sheltered employment (Cimera et al., 2011; Wehman et al., 2018), and is related to improvements in social inclusion and quality of life (Akkerman et al., 2016; Dague, 2012; Voermans et al., 2021). Wehman et al. (2014) found that provision of supported employment increased employment rates for youth with all types of disability, but especially for youth who were Social Security beneficiaries, special education students, and individuals with intellectual disabilities or Autism who were high school graduates. In the US, where supported employment is widely used, between 20% and 25% of people with intellectual and developmental disability are employed in a community-based job (Wehmeyer et al., 2019).

Customised employment is a highly personalised supported employment approach for people with significant disability, including intellectual disability (Riesen et al., 2015). As with supported employment, this approach is fundamentally underpinned by the belief that everyone can work in an open environment if well supported (Griffin et al., 2012). In particular, it targets individuals who require customisation of job responsibilities beyond those that naturally occur within the labour market, reducing competition with other job seekers by engaging in direct negotiation with an employer to customise a role so that it is suitable for a specific individual (Inge et al., 2018). Customised employment commences with a Discovery process in which the individual’s strengths, interests and preferences are identified, resulting in a clear understanding of available employment opportunities that meet both an employer’s and the young person’s needs and interests (Wehman et al., 2018). It develops job roles through job carving, negotiation and creation, and through the use of microenterprises (Riesen et al., 2015). It also recognises the need for long-term follow-up with both employee and employer (Wehman et al., 2018). Customising the approach and providing on-site training show promise in terms of supporting young people with intellectual disability, particularly those who are unlikely to fill an advertised job vacancy, to achieve transition to work (Xu & Stancliffe, 2019).

The evidence base for customised employment has been developing since the early 2000’s. In the US, Inge et al. (2018) reported that using customised employment led to high employment rates for people with intellectual disability, as did Wehman et al. (2014) in a randomised controlled trial with young people with Autism. In addition, customised employment has been used as a component of other successful programs, including college-based post-school education, Project SEARCH and TTW (Moore & Schelling, 2015; Persch et al., 2015; Wakeford & Waugh, 2014). Despite strong anecdotal evidence about its effectiveness, however, there is still a lack of experimental studies to support understanding of how it impacts on integrated employment outcomes for this cohort (Wehman et al., 2018).

IPS is an evidence-informed approach to supported employment that is predominately used to support people with mental illness (Drake et al., 2012; Noel et al., 2017). There is growing interest in using it to support people with other disability types, including intellectual disability (Noel et al., 2017; Wehman et al., 2020). However, due to the different employment support needs of people with intellectual disability, Noel et al. (2017) suggest that it would need to be modified to provide additional on-site support and social skills training, and fully involve young people and their family members in order to ensure high expectations about employment are maintained (Noel et al., 2017).

In Australia, the US style supported employment has not been widely implemented for people with intellectual disability. There is little in the way of recent research regarding the provision of employment supports for young people with intellectual disability in Australia (Bennett et al., 2018; Buys et al., 2014; Cheng et al., 2018; Dimov et al., 2021; Hall et al., 2020; Kavanagh et al., 2021; Meltzer et al., 2020; Stafford et al., 2017). Ellenkamp et al. (2016) undertook a systematic review of the literature for people with intellectual disability and identified a need to address barriers related to job content and workplace culture and a need for job coaches to support young people with intellectual disability to find and maintain employment.

3.5.3 Work Integrated Learning (WIL)

One model shown to facilitate successful post-school employment outcomes including employment for students with disability is participation in internships prior to finishing high school. Internships involve a student working within a host organisation to learn skills that benefit both the business and the intern (Daston et al., 2012; Wehman et al., 2018). Aligned with the evidence related to factors that promote economic participation more broadly, correlational studies indicate that internship models are effective, although whether that effectiveness is related to particular employment settings, and which factors contribute to the success are not clear. In addition, it remains unclear whether the model is effective for people with significant disabilities (Wehman et al., 2018).

As discussed above, one internship model – Project SEARCH, an employment training program for high school students with disability – has documented success in the literature (Christensen & Richardson, 2017; Kaehne, 2016; Project SEARCH, n.d.). Project SEARCH programs are available to young people with significant intellectual and developmental disability – generally high school students who have a recognised disability and are in their last year of high school. The program can also be adapted for young people who have completed their formal schooling. The most important criterion for acceptance into Project SEARCH is a desire to achieve competitive employment. The model involves intensive job-site training and minimal time spent in the classroom, with students primarily spending their time in real settings where they learn and practice work and social skills (Schall et al., 2015). The model includes short, daily classroom-based training sessions in employability skills such as workplace safety and self-advocacy. Students then rotate through three different 10- to 12-week internships in a supportive workplace, receiving support to acquire job skills from teachers and post-school employment specialists. Towards the end of the program, they focus on individualised job development to enable them to move into integrated employment (Persch et al., 2015).

Initial studies on the Project SEARCH model have shown that the model is successful in supporting students to obtain paid employment post-school. Wehman et al. (2016), in a randomised controlled trial, showed that students with significant needs who participated in Project SEARCH internships with job and behavioural supports were more likely to gain employment than students who did not receive these services. The UK-based Project SEARCH program achieved employment rates of 50% for participants with intellectual disability (Kaehne, 2016).

In the Australian context, ADEs have the potential to offer WIL opportunities to young people with intellectual disability, for example by implementing the Work Integrated Social Enterprise (WISE) model (Campbell et al., 2022). This model focuses on providing appropriate support structures for on-the-job learning and training, and professional development towards employment goals. Hands-on learning is supported by skilled staff/trainers, accessible tools, equipment and work spaces. Matching individuals to tasks they are interested in creates the right conditions for learning and meaningful work. WISEs that are able to do this in real workplace conditions offer broader learning options and help individuals to build personal and social skills.

Various research related to employment has demonstrated that working on the job with coaches and trainers has enabled individuals to be supported in discovering different interests and employment pathways. These interests and skills can then be aligned to a customised or carved role in which skills and learning options are further developed and refined.

3.6 Conclusion

This literature review has focused on the experiences of young people with intellectual disability and their family members during transition from school, and on the factors that promote their post-school economic participation. While expectations about the post-school lives of people with intellectual disability have begun to shift, the literature reports that current transition practices do not meet the needs of families as their young people transition from school, and there is a need to implement early family-centred transition practice to promote this cohort's economic participation. However, the bulk of the research focuses on transition from school, and there has been little research in the context of the longer emerging adulthood period as it relates to people with intellectual disability.

This literature review has identified evidence-informed practices that promote economic participation of young people with disability during their transition to adulthood, including several that significantly predict employment, post-secondary education and enjoyment of life outcomes for those with intellectual disability (Papay & Bambara, 2014). However, implementation of this evidence in the Australian setting appears minimal. Beamish et al. (2012) investigated whether the evidence-based components of Kohler's (1996) Taxonomy were in use in schools in one Australian state and found that while there was strong support for a significant number of practices, very few were being used. People with intellectual disability are also less likely to receive economic participation-focused supports such as career education and work experience during their secondary education (ARTD Consultants, 2019b; New South Wales Legislative Council Standing Committee on Social Issues, 2012; Smith et al., 2016). Barriers to work-based learning at school include limited availability of resources and transportation, and a lack of employers willing to host students (Bromley et al., 2022).

Nevertheless, researchers and professionals in the field agree that particular best practices are beneficial and lead students on the path to success. Future research should therefore shift its focus to implementing these practices within school settings (Papay & Bambara, 2014). In addition, there is a need to undertake qualitative research regarding transition for youth with intellectual disability, to gain the perspectives of multiple individuals about what constitutes good practice.

Chapter 4 will describe the theoretical framework used in this thesis.

Chapter 4: Theoretical frameworks

This study is guided by several key theories to understand the complex nature of economic participation for young people with intellectual disability, including how intersecting factors across the environment impact on the provision of the supports that enable them to be included in economic participation. Its overarching methodological position is social constructivism, which is based on an acknowledgment that individuals subjectively interpret their environment and that environments are constructed within specific contexts and through human interactions (Holstein & Gubrium, 2007). Alongside this, the social model of disability (Oliver & Barnes, 2012; Shakespeare & Watson, 2001; Watson, 2004) explores the construction of 'disability' in the interactive and variable contexts of environment, personal factors and impairment. The study also utilises critical disability theory (Devlin & Pothier, 2006; Goodley, 2013; Hosking, 2008; Porpora, 2015) to understand the roles language, power and dis-citizenship play in excluding people with disabilities from economic participation. Ecological models of inclusion, drawing on the work of Bronfenbrenner, (1994) and Clifford Simplican et al., (2014), provide a lens through which to explore both barriers and enablers at various levels of the ecosystem, and how they interact to create both exclusionary and inclusive environments. Finally, the concept of emerging adulthood (Arnett, 2000) is utilised to explore the role the early adulthood period can play in improving economic participation outcomes for young people with intellectual disability.

4.1 Social constructivism and critical disability theory

Social constructivism, first introduced by Berger and Luckmann in 1966, is the theory that knowledge and people's understanding of what reality is, are deeply embedded in the institutions which comprise the society in which they live. It seeks to describe how individuals assemble meanings and subjective understandings of everyday realities through language use and social interaction, and proposes that meaning is not inherent in phenomena but rather assigned to them (Holstein & Gubrium, 2007). Reality is therefore said to be socially constructed (Berger & Luckmann, 1966). Social constructivism not only considers knowledge construction to be contextual, it emphasises the importance of collaboration, negotiation, iterative methodologies, reflexivity and the construction of shared meanings (Ernest, 1995).

The social model of disability, which came to prominence in the 1970s, has strong social constructivist underpinnings. Social model theory makes a distinction between impairment, which is an attribute of the individual body or mind, and disability, which is a construction of society (Shakespeare & Watson, 2001). Oliver (1992) promotes a social constructivism approach toward disability, stating ‘Disability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located’ (p. 101). Disability is socially constructed, determined by the social meanings attached to particular physical and mental impairments (Albrecht & Levy, 1981, as cited in Oliver, 1990). Public policy further acts to define disability as an individual, rather than a societal, problem which requires compensatory action without specifying its location (Hahn, 1985, as cited in Oliver, 1990).

Critical disability theory interrogates the way in which disability is constructed, with a particular interest in the ‘socio-cultural conceptions of disablism’ (Goodley, 2013, p. 632). Disablism, much like racism and hetero/sexism, is defined as a form of social oppression (Goodley, 2013). Devlin and Pothier (2006) use critical disability theory to explore how disability can lead to ‘dis-citizenship’ for people with disabilities. Dis-citizenship can be defined as ‘a form of citizenship minus, a disabling citizenship’ (Devlin & Pothier, 2006, p. 2). While neoliberal frameworks espouse values of liberty, equality and inclusion, traditional responses to meeting the needs of people with disability, such as charity and welfarism, have not only failed to meet these needs but also compounded the exclusion many disabled people face. Devlin and Pothier (2006) argue that this has led to 'a system of deep structural, economic, social, political, legal and cultural inequality in which persons with disabilities experience unequal citizenship, a regime of dis-citizenship' (p. 1).

The goal of critical disability theory is to challenge the dominant liberalist ideology which, according to Devlin and Pothier (2006), 'has a hard time dealing with disability' (p. 11). Devlin and Pothier (2006) argue that liberalist ideology's core assumptions that disability is misfortune and that productivity is essential to personhood, and the structuring of society based on able-bodied norms, need to be challenged to enable people with disabilities to participate more fully in society. Critical disability theory questions narrow notions of productivity based on neoliberalist and post-industrial views. It questions whether disabled people's perceived lack of productivity is in fact their fault, or whether social barriers are to blame. It also challenges the efficiency/productivity paradigm in which decisions about who is productive and who is not are made by the powerful few based on criteria that are potentially not legitimate (Devlin & Pothier, 2006), labelling it an 'ablest' ideal that condemns some persons with disabilities to a presumptive inferior status. This theoretical lens thus opens up the relationship between the construction of economic participation and disability for exploration, as well as providing a lens through which to critically analyse policy underpinnings.

4.2 Ecological models

Uri Bronfenbrenner was the first to study child development within the context of the social environments in which children grow and develop. Bronfenbrenner's (1994) ecological model suggests that humans simultaneously occupy multiple social ecosystems that maintain dynamic interactions and that human development must therefore be understood through a holistic lens of these hierarchical ecosystems. He identified five interrelated social systems, noting that the influence of one system on a child's development depends on its relationship with the others (Bronfenbrenner, 1994). Bronfenbrenner identified four ecological levels: 1. the **microsystem**, 'a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics' (Moore & Schelling, 2015, p. 22); 2. the **mesosystem**, 'the interrelations among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighborhood peer group; for an adult, among family, work, and social life)' (Moore & Schelling, 2015, p. 25); 3. the **exosystem**, 'one or more settings that do not involve the developing person as an active participant, but in which events occur that affect or are affected by, what happens in the setting containing the developing person' (Moore & Schelling, 2015, p. 25), such as a parent's workplace, as although the child does not interact with the workplace environment, positive or negative aspects of a parent's workplace may affect the child's home microsystem; and 4. the **macrosystem**, or larger cultural world or society surrounding the developing person (Moore & Schelling, 2015).

While Bronfenbrenner (1994) revised his ecological theory several times and it has since been further (re) interpreted by others, it offers a way to consider spheres of activity and influence around an individual's experience. Specifically, ecological frameworks enable the analysis of barriers and enablers within complex systems (Lindsay et al., 2018) and fit within the broader understanding that disability is a product of individual, environmental and social factors (Clifford Simplican et al., 2014). Young people with intellectual disability are part of a larger social network comprising several components including micro-, meso-, exo- and macrosystems, and their transition from adolescence to adult life is a complex process dependent on individual and environmental factors that can be considered within an ecological framework (Bronfenbrenner, 1994). The ecological perspective is also useful because it incorporates the complexity of environmental influences, individual characteristics and other mediating factors, expanding the frame of view from the individual alone to the multi-layered context they inhabit and are influenced by (Lindsay et al., 2018; Small et al., 2013). In the disability and inclusion literature, ecological theory has been used by several scholars. For example, Clifford Simplican et al. (2014) used it to define social inclusion of people with intellectual disability, noting that broadly held attitudes and cultures impact on not only the opportunities made available for this cohort to be included, but also the availability of appropriate services and the way they are organised. Ecological models can also identify strengths and weaknesses in an individual's social network, enabling the development of strategies to build social connection opportunities (Small et al., 2013).

Ecological theory has primarily been utilised to understand the various factors and contexts influencing human development. More recently it has also been used to make visible the way facets of human development, are shaped and evolve (Clifford Simplican et al., 2014). It is thus an appropriate theory with which to analyse the complex barriers and solutions to what can be regarded as a social inclusion problem: i.e., economic participation (Clifford Simplican et al., 2014; Lindsay et al., 2018). When the environment is understood as an ecosystem shaped by attitudes, market forces, policy frameworks, service delivery practice and cultural norms, which interact to create barriers to economic participation for young people with intellectual disability, and aligned with an understanding of economic participation as a complex social problem, both barriers and enablers can be mapped to this ecosystem, as can strategies and interventions that target barriers.

Ecological readings of the complex and challenging period of transition from school (Leonard et al., 2016; Stewart, 2009) have enabled the identification of the dynamic relationships that exist between individuals and their immediate environments, and how peripheral systems and forces shape those relationships (Jacobs et al., 2018; Small et al., 2013). When considering transition from a developmental perspective, ecological approaches also help in considering the influence of context on the individual's development during the transition period (Moore & Schelling, 2015). Finally, mapping facilitators and barriers across systems makes visible the involvement of multiple 'actors' such as government services, schools, funding bodies, adult disability services and families, and therefore draws attention to the relationships between these actors and how they impact on young people's transition from school (Jacobs et al., 2018; Small et al., 2013). Small et al. (2013) recognise the need to look beyond the individual and map individual ecosystems in order to create post-school opportunities. As the barriers that young people experience at the individual level are the result of the intersection of factors from across the ecosystem, including how policy intersects with practice and delivery of services, Snell et al. (2013) argue that individualised planning does not address these systemic issue, especially in the absence of methods to collate and analyse individual-level goals, outcomes and experiences.

Recently, disability employment researchers have utilised ecological framing to draw attention to the complex policy and social environment in order to understand how to improve employment outcomes for people with disability (Khayatzadeh-Mahani et al., 2020; Lindsay, 2011). Moore and Schelling (2015) utilised ecological systems thinking in order to understand how offering different contexts in which young people with intellectual disability can grow and develop through post-school education programs influences employment outcomes. In addition, utilising an ecological lens recognises that the biological, material, social and cultural aspects of individual's social environments cannot be compartmentalised. An employment ecosystem recognises that barriers exist at different levels, from micro to macro, and that diverse strategies are required, including but not limited to, the level of the individual (Nicholas et al., 2018).

This thesis uses Clifford Simplican et al.’s (2014) ecological model of social networks and community participation, which draws from Bronfenbrenner’s (1994) model, to understand and describe the ecosystems of young people with intellectual disability. This ecosystem is comprised of individual, interpersonal, organisational, community and sociopolitical level factors, which influence their ability to engage in economic participation activities. Each level is described below aligning the Clifford Simplican et al. (2014) definition with literature relevant to the context of transition for young people with intellectual disability.

Individual level

Personal characteristics including age, gender, ethnicity, disability type and severity, health, educational attainment, employment-related skills, lack of work experience, access to transport, and socioeconomic factors such as poverty influence the likelihood of social inclusion (Clifford Simplican et al., 2014; Lindsay et al., 2015; Papay & Bambara, 2014; Sundar et al., 2018). Young people with intellectual disability are impacted by individual-level factors, which must be considered within the broader ecosystem context.

Interpersonal/micro level

Bronfenbrenner’s micro level is referred to as the interpersonal level in Clifford Simplican et al.’s (2014) ecological model of social networks and community participation. This level comprises factors related to the young person and the environments they spend time in (e.g., school, family, disability services and community-based organisations), which are important to consider in the context of expectations of future economic participation. Personal relationships such as those with family, friends, teachers and peers influence the likelihood of people with disability’s economic participation. For example, having access to trusted transition advisers, and appropriate role models, and whether influential people have low expectations about individuals' future economic participation, all impact on young people as they transition from school (Lindsay et al., 2015).

Organisational/meso level

Bronfenbrenner's (1994) meso level is described as the organisational level by Clifford Simplican et al. (2014). It focuses on the contexts in which the social relationships that act to influence transition outcomes and economic participation of people with disability occur. It acts as an intermediate space in which various microsystems (e.g., family members and school) interact with each other and in turn influence the individual. In relation to transition from school, key influences include information with which to make decisions and choices, as well as involvement of the young person in transition decisions (Jacobs et al., 2020). According to Clifford Simplican et al. (2014), the individual's or family's social capital and family culture, as well as the culture of groups within the community such as schools and disability providers, influence outcomes. Improved outcomes are achieved when various microsystem actors have similar cultures and perspectives, which enable individuals to move seamlessly between them (Bronfenbrenner, 1981).

Community factors/exo level

Bronfenbrenner (1994) describes the exosystem as distal systems, e.g., the structure of programs to support economic participation, that impact on the individual indirectly. Clifford Simplican et al.'s (2014) community level includes both characteristics of the broader community, such as attitudes towards people with disability and community discourse in relation to economic participation, availability of and access to appropriate services.

Sociopolitical/macro level

Macro-level factors such as norms and values influence the overall ecosystem. Clifford Simplican et al. (2014) refer to this level as sociopolitical, noting the role of state perspectives, market forces and historical aspects of service delivery in influencing the opportunities for economic participation available to people with intellectual disability. Economic, labour market and social policy settings, neoliberal economic structures (including the structures of income and support systems), and social and cultural norms about the capacity of people with disability all impact on the opportunities available.

Chronosystem level

The chronosystem incorporates time and events that occur across the lifespan (Bronfenbrenner, 1994; Lindsay et al., 2018). For young people in transition, this can include the timeframe in which important economic participation activities occur, such as understanding how a longer period of emerging adulthood can impact on the opportunities young people have access to and how those opportunities build capacity for later work.

4.3 Emerging adulthood

The period from the late teens to the twenties, termed ‘emerging adulthood’ (Arnett, 2000), is one of profound change and growth. Now regarded as a distinct period in the life course, this extended period is used by young people to prepare for the longer lifespan period of adulthood, which is said to commence from about age 25, when key adult milestones such as full-time employment and living independently of parents are reached (Arnett, 2000). Described as the time between adolescence and adulthood, according to Arnett (2000), it is neither; while the dependency of childhood and adolescence is left behind, the full responsibilities of adulthood, such as establishing a home and family and holding a full-time job, are yet to emerge. The period therefore provides opportunities to young people to explore possibilities, make choices and emerge with a sense of self, as well as build capacity, including gaining education and skills, and explore who they are, who they want to become and how they will get there (Arnett, 2000). The timeframe for completing transition – that is, commencing full-time work in their chosen career – can therefore take up to 10 years post-school (Arnett, 2000).

In late modernity, young people are experiencing a more complex and uncertain world as they move from the relative safety of the school environment to post-school study and work (Midjo & Aune, 2018; Stokes, 2012). Globalisation, individualism and the changing nature of work mean the period of transition to adulthood is less predictable and linear. Many of the ordinary markers that define adulthood, such as employment, moving out of the parental home and creating a family, are occurring later and with less certainty, while part-time and casual work and the gig economy predominate (Kelly et al., 2019). Young people are also more likely to undertake post-school education and training than previous generations, and this is often punctuated by periods of work and non-attendance, resulting in longer periods of family interdependence (Arnett, 2004). Rather than transition failure, Arnett (2004) regards nonlinear transitions, including periods of unemployment and returning to study from time in employment, as a natural part of the important identity work a young person must undertake in the emerging adulthood period.

Multiple factors can influence the life course during the emerging adulthood period. For example, societal influences such as attitudes towards women or minority groups impact on the opportunities available to these cohorts (Arnett, 2004). At the meso level, relationships between young people and their family, and at the micro level, individual factors such as cognitive ability can impact on the types of further education opportunities young people can take up (Wood et al., 2018).

The concept of emerging adulthood adds another layer to 'transition': that of a longer 'transition to adulthood', in which 'transition from school' is one component. Young people with intellectual disability also enter a period of emerging adulthood when they finish school;

however, factors from across the ecosystem limit the opportunities they can access to build necessary capability in this important time, particularly in relation to concomitant opportunities to explore economic participation options and build skills and capacities for adult life. For example, few young people with intellectual disability have the opportunity to attend TAFE or university to gain an accredited qualification. In particular, their disability influences expectations about the adult roles they will be able to achieve. Rather than reducing opportunities in the emerging adulthood period, it can be argued that this cohort requires additional supports to be exposed to the same opportunities as other young people, and that the full emerging adulthood life course should be made available to them (Redgrove et al., 2016).

4.3.1 People with intellectual disability and development of self in the emerging adulthood period

The typical emerging adult enjoys a period of exploration in which they clarify their identity and learn who they are and what they value. This period of identity development can take place in multiple environments, including work, family and social settings (Stokes, 2012). In contrast, the period of transition from adolescence to adulthood for people with intellectual disability is more complex and challenging (Leonard et al., 2016), characterised by reduced opportunities to explore possibilities for their adult selves (Davies & Beamish, 2009). The low expectations families and teachers often hold in relation to their economic participation (Chambers et al., 2004), the complexity of disability services systems and the impact of the end of formal schooling on the whole family (McKenzie et al., 2017; Pallisera et al., 2016) compound the need for decisions about placement to be made quickly, and prior to the important period of emerging adulthood as described by Arnett (2000). The primary focus of transition thus becomes transferring from school and children’s services to adult services (Leonard et al., 2016), with the needs of the individual one of a range of factors including family adjustment (Davies & Beamish, 2009). Adult services focused on independent living and recreation programs instead of economic participation fail to consider that this important developmental phase continues until the young person is 25. Decisions about service types made early in the emerging adult period therefore lead to a reduction in opportunities to explore identity and a stagnation in skill development, and become difficult to change (Cocks & Harvey, 2008). Redgrove et al. (2016) believe concerns about people with intellectual disability remaining in a state of 'eternal childhood' have led to important developmental and support processes being overlooked in the rush to adulthood. Existing transition literature focusing on this cohort has failed to adequately define the concept of adulthood, and has largely ignored emerging adulthood altogether, resulting in a *rushed process* from school to adulthood that misses vital developmental processes that occur in the emerging adulthood period. Redgrove et al. (2016) argue that emerging adulthood should instead be an extended life stage for people with disabilities, enabling a range of rich experiences aligned with those experienced by their peers without disability. Greater alignment of the definitions of adolescence, emerging adulthood and adulthood between families, service providers and policy-makers may support better understanding of the normative processes and practices that occur in each period.

There has also been little exploration of the perspectives of young people with intellectual disability in relation to their identity narrative (Foley et al., 2012; Midjo & Aune, 2018). Shakespeare (2006) asserts that 'the experience of disability as a negative identity arises out of a process of socialization or in the context of social relations, in which impairment is the sole focus of analysis' (p. 99). Stigmatising labels such as 'intellectual disability' applied at a young age tend to overrule the formation of other identities as young people grow and develop. According to Morris (1991, as cited in Shakespeare, 1996), people with disabilities are therefore socialised to understand themselves as inferior, and strong messages of physical difference and personal deficit are reinforced; self-image is 'dominated by the non-disabled world's reaction to us' (p. 103). However, Midjo and Aune (2018) report that many young people with disability do not use the label of 'intellectual disability' to describe themselves: 'They seem more interested in producing alternative identities in accordance with their presentation of living an ordinary life' (p. 44). Gustavsson and Nyberg (2015, as cited in Midjo & Aune, 2018) propose that family involvement supports the development of alternative and positive identifications as competent and ordinary persons.

As the primary influences on young people, parents and teachers shape their development of self and visions for the future. Parents and professionals also contribute to both enabling and disabling processes, particularly through attitudes and identity constructions about who young people are and can be (Midjo & Aune, 2018). Parents, in particular, take on the roles of advocate and decision-maker, and professionals such as teachers provide access to, or limit, opportunities for young people to develop the confidence, skills and abilities that help to define self (Midjo & Aune, 2018).

As Stokes (2012) has noted, identity development occurs in multiple sites, allowing young people with intellectual disability to draw from a range of resources and roles. Low expectations stemming from labels and placement in segregated settings limit their opportunities to fully explore a sense of self, instead trapping them in the disability identity. Given that for many, transition involves moving to adult services such as day centres and sheltered workshops at a young age, further reinforcing the disabled identity, they have fewer opportunities to explore what and who they want to be (Midjo & Aune, 2018), and access to fewer environments in which to do the necessary exploring. More optimistically, however, opposition to the dominant label of intellectual disability, sociopolitical reforms and the growth of the self-advocacy movement have the potential to create expectations of an 'ordinary life' for young people (King's Fund Centre, 1980).

Overall, the literature leads to the conclusion that how young people are positioned allows them to explore different versions of 'self' in different roles and is vitally important for young people with intellectual disability as they move into adult roles beyond the disability label. The concept of emerging adulthood offers a valuable lens for this thesis, as there is little understanding in the wider community about the importance of this period in terms of the development of capacity for later, long-term adult roles. Widely held beliefs that people with intellectual disability are not capable of the same growth and development as their non-disabled peers, potentially results in a reduction in opportunities that lead to the development of capabilities.

4.4 Conclusion

This chapter has described the theoretical frameworks of the study; social constructivism and critical disability theory, ecological models and emerging adulthood. In chapter 5, the method and methodology will be described along with information about the study participants.

Chapter 5: Method and methodology

This chapter outlines the research methodology utilised in this thesis including the use of constructivist research methods, such as semi-structured interviews, and inclusive methods such as photo elicitation to engage young people with intellectual disability in the research process.

As discussed in Chapter 4, this thesis draws on critical disability theory and social constructivism to frame an inclusive research methodology. This approach enables a critical engagement with the liberalist underpinnings within society that influence how difference is viewed. It also enables the lived experiences of young people with intellectual disability and the family members who support them to be captured. Drawing on the key theories explained in Chapter 4 provides different lenses for data analysis. Clifford Simplican et al.'s (2014) ecological model of social networks and community participation is used to draw attention to the complex barriers that inhibit economic participation for young people with intellectual disability and identify the strategies required to address those barriers. Overlaying this is the concept of emerging adulthood, which is particularly pertinent due to the lifespan stage the young people occupy.

5.1 Design of the study

5.1.1 Research aims

The purpose of this study is to examine and extend good practice in the area of supporting young people with intellectual disability to increase their opportunities to engage in community-based economic participation in young adulthood. Its aim is to gain insight into the lived experiences of young people with intellectual disability and the family members supporting them in relation to transition from school and the availability of early economic participation opportunities. The knowledge gained from these lived experiences, overlaid with that of key informants working in the system, will enable an examination of how the theoretical underpinnings that support good practice intersect with the policy and practice environment in which they operate.

5.1.2 Research questions

Objective 1: To identify the expectations young people with intellectual disability and their family members have about economic participation post-school.

Objective 2: To explore the extent to which opportunities for economic participation are available to young people with intellectual disability post-school.

> RQ1: How do young people with intellectual disability and their families describe their transition from school experiences? How do these experiences influence their decision-making related to pursuing economic participation-related activities?

Objective 3: To identify where in the system/environment barriers to economic participation exist.

> RQ2: What are the barriers to economic participation for young people with an intellectual disability as they leave school and how can these be addressed?

Objective 4: Identify the resources and supports that would enable increased economic participation opportunities for young people with intellectual disability.

Objective 5: Explore how these supports can be provided and in what context.

> RQ3: What are the resources and supports young people with intellectual disability and their family members value in relation to economic participation as they transition from adolescence to adulthood? How should these resources and supports be provided, by whom and when?

5.2 Methodology

5.2.1 Constructivist research methods: The making of meaning

The overarching methodological position guiding this study is social constructivism. This approach acknowledges the roles that subjective interpretation and context-specific human interaction play in our understandings of our environments or reality. Social constructivist perspectives focus on the roles of individual and social experiences in generating knowledge, or meaning making and ‘personal models of the world’ (Fosnot, 2005, p. 9). This chapter sets out a methodological approach for understanding the subjective experiences of young people with intellectual disability and their family members during transition from school, and how those and the broader experience of growing up with an intellectual disability shape decision-making about economic participation. Disability, as experience and as discursive terrain, is a product of individual, environmental and social factors. Ecological models of social inclusion help to distinguish the different ways in which experiences of disability are shaped and provide a conceptual framework for understanding the responses of young people, family members and key informants. In particular, the commonality of lived experiences makes systemic barriers and enablers to economic participation visible. The ecological and constructivist approach used in this chapter therefore allows for insights into how the subjective experiences of young people are shaped by social rules and contexts, policy and practice, people and institutions.

5.2.2 Inclusive research methodology

As discussed, this study is positioned within a broad social constructivist methodology, which in turn sits within an interpretive paradigm. Such methodologies utilise a range of, usually qualitative, processes such as discourse analysis, interactional analysis, interview analysis and document analysis to explore the ordinary and the everyday, interpret meaning and examine the what and the how of the social world. These approaches are relevant to exploring the lived experiences of people with intellectual disability as they enable the amplification of voices within this population (Beail & Williams, 2014; Milen & Nicholas, 2017). Historically, people with intellectual disabilities have had little opportunity to participate in research about their lives (Jurkowvski, 2008), with the opinions of family members and professionals taking precedence over their own views (Cluley, 2016). However, the social model of disability has given rise to more inclusive research approaches that value their lived experience. Within this broad approach, a focus on collaborative research – research in which people with intellectual disability are viewed as experts and the researcher as someone who learns from them – is developing (Knox et al., 2000), and including people with intellectual disabilities in research projects that address their lives via inclusive research processes is now regarded as best practice (Cluley, 2016). These methodological imperatives require a set of research methods that privilege stakeholder views, including those of young people with disability, and seek to offer opportunities for collaborative meaning-making. This thesis thus used photo elicitation to support data collection from young people with intellectual disability (see Part 5.6.2).

5.3 Research participants

To answer the research questions, the researcher sought the views of a range of people located in Melbourne, Victoria, including young people with intellectual disability, family members of young people with intellectual disability and key informants – that is, people with a professional involvement in transition or economic participation for people with intellectual disability.

5.3.1 Young people with intellectual disability

People with intellectual disability are often disempowered, with decisions being made for them by others including family members, teachers and service provider staff. However, they have their own unique insights into their life experiences, including their transition from school, their aspirations and what can support them in undertaking economic participation activities after they finish school. Nevertheless, there have been very few studies exploring their economic participation aspirations, particularly in the context of individualised funding and increased choice and control.

Nine young people with intellectual disability aged between the ages of 19 and 25, who had finished school and were undertaking post-school activities, participated in the study. Five participants were aged 19-20 and four were aged 21-25. All had attended a special school for at least part of their schooling and would be described as having a moderate or severe intellectual disability. Only one was currently in paid employment; however, two had been employed previously. Five of the young people had a family member participate in the study.

Information about the young people with intellectual disability is presented in Table 5.1 below.

Table 5.1

Young people with intellectual disability

Pseudonym	**Age**	**Gender**	**Type of schooling**	**Current activity**	**Previous post-school activities**	**Parent in study**
Brandon	25	M	Special school	Looking for work	Paid employment Day service TAFE	Yes – Janice
Corey	20	M	Special school	SLES program	Nil	Yes – Brian
James	19	M	Specialist unit within mainstream school	SLES Program	Nil	No
Amy	20	F	Mainstream Primary Specialist unit within mainstream school	SLES Program	Nil	Yes – Rhonda
Leanne	23	F	Special school	Work Experience program provided by disability provider	Paid employment TAFE	No
Melissa	19	F	Special school	SLES Program combined with training	Nil	No
Rohan	25	M	Mainstream primary and secondary education. Special school secondary education	Pilot employment program	Paid employment Day service TAFE	Yes – Anne
Penny	19	F	Special school	Transition program provided by	Nil	Yes – Clare

				disability provider		
Bobby	25	M	Special school	Paid employment and employment focused program provided by disability provider	Nil	No

5.3.2 Family members of young people with intellectual disability

Family members are an important source of support for people with intellectual disability during the transition process. They have decision-making authority and often make decisions on their young people's behalf. These decisions directly impact on the opportunities their young people have access to. It is therefore important to also understand family members' experience of transition and early adulthood for the young people they support, and to understand what factors influence their decision-making and how those decisions are made. It is also important to understand their aspirations for their young people, how they experience the transition period, the barriers they experience and their support and information needs.

Ten family members of young people with intellectual disability aged between 18 and 26, who had left school and were undertaking post-school activities, participated in in-depth interviews. Nine were female and one was male. All were parents of a young person with intellectual disability and had significant involvement in decisions related to their post-school activities. Information about the family members is presented in Table 5.2 below.

Table 5.2

Family members of young people with intellectual disability

Pseudonym	**Gender**	**Relationship to young person with intellectual disability**	**Type of Schooling young person attended**	**Current activity young person is undertaking**	**Previous post-school activities of young person**	**Young person in study**
Rhonda	F	Mother	Mainstream primary Specialist unit within mainstream school	SLES Program	Nil	Yes – Amy
Mary	F	Mother	Special school	SLES Program	Nil	No
Brian	M	Father	Special school	SLES Program	Nil	Yes – Corey
Vera	F	Mother	Special school	SLES Program	Nil	No
Francine	F	Mother	Special school	Training	Disability day program	No
Anne	F	Mother	Mainstream primary and secondary school. Special secondary school	Pilot employment program	Paid employment Disability day program TAFE	Yes – Rohan
Clare	F	Mother	Special school	Transition program with disability provider	Nil	Yes – Penny
Jane	F	Mother	Mainstream primary school Mainstream non-government secondary school	Disability day program	Nil	No

Janice	F	Mother	Special school	Looking for work	Paid employment Disability day program TAFE	Yes – Brandon
Carol	F	Mother	Special primary school Mainstream non-government secondary school	Awaiting acceptance to employment program	Part-time after-school job	No

5.3.3 Key informants

Key informants are individuals who have information or expertise about transition from school or the post-school service system for people with intellectual disability. They were selected for this study because of their involvement in the design and delivery of transition and economic participation services and supports for this cohort, or their direct involvement in supporting a young person with intellectual disability. Key informants have a broad range of experiences and insights to draw from, and can therefore provide useful information about the barriers and enablers to economic participation that young people face, particularly at the sociopolitical and community levels, and how these intersect and influence each other.

Thirteen key informants participated in in-depth interviews, including individuals involved in direct service delivery, school staff, an employer, and individuals involved in program design, policy and advocacy. They were recruited from a range of organisations. Further information about key informants is given in Table 5.3.

Table 5.3

Key informants

Pseudonym	**Gender**	**Role**
Mandy	F	Manager of a pilot program supporting transition to work for young people with intellectual disability
Sharyn	F	Chief Executive Officer of an organisation supporting large businesses in creating economic participation opportunities for people with disability
Laurelle	F	State government employee working in a strategic policy role related to economic participation of people with disability
Donna	F	Executive Officer of a family-led organisation supporting families of people with intellectual disability to create ordinary, included lives
Paul	M	Senior government bureaucrat
Lawrie	M	Manager of a disability-specific transition program
Kate	F	Careers counsellor working within a specialist disability program in a secondary school
George	M	Manager of a disability-specific transition program
Susan	F	Senior employee at a disability service provider
Bianca	F	Manager of a careers education-focused organisation
Lisa	F	Small business owner who has employed a person with a disability
Joanne	F	Chief Executive Officer of a training organisation focused on delivering post-school training to people with disability
Kylie	F	Staff member at a large DES provider

5.4 Ethical considerations

There is growing interest in the research and disability communities in the inclusion of people with an intellectual disability in research. However, there are also concerns about the capacity of people with intellectual disability to provide informed consent (Carey & Griffiths, 2017; Knox et al., 2000). Dalton and McVilly (2004) acknowledge that this cohort is vulnerable to exploitation when involved in research, highlighting the need for 'rigorous ethical safeguards to be in place prior to the commencement of research to protect the health, safety and rights of participants and to prevent their exploitation' (p. 59). There are thus a number of ethical considerations related to undertaking research that involves people with intellectual disability, including explaining the research to participants and gaining informed consent, using inclusive practices, safeguarding participants, protecting their privacy and confidentiality and ensuring that, where possible, they benefit from their involvement in the research (Dalton & McVilly, 2004).

However, it is also important to respect the right of people with intellectual disability to participate in research, as documented in the UNCRPD (2006). In this case, young people with intellectual disability were already engaged in post-school activities requiring similar levels of decision-making to this research. In this context, a high-risk ethics application addressing these issues was submitted to the Deakin University Human Research Ethics Committee (DUHREC) in early 2019. This ethics application was endorsed by DUHREC in 2019 and later also endorsed by Swinburne University following the transfer of the study (Approval number 20220381-11004 in Appendix A).

5.4.1 Informed consent

Participation in the study was voluntary. All participants were provided with a Plain Language Statement (PLS), (Appendices B, C, D) in Easy English if required, and a written consent form, and were encouraged to ask questions and clarify concerns prior to providing consent. Participants were also informed of their right to withdraw from the study at any time. Where required, the researcher read information to the participants before checking their understanding of what they were consenting to.

At the start of each stage of data collection, the researcher reminded the young people with intellectual disability about the purpose of the study and confirmed that they were still willing to be involved. Each participant's family member or other trusted person was also provided with information about the study, and could be included in the consent process to support the young person's decision-making if requested. The design and implementation of the research project ensured that participants did not experience any discomfort or harm.

5.4.2 Confidentiality and security

Several measures were put in place to ensure participant confidentiality was maintained. All information was stored as non-identifiable data during the analysis process, with codes replacing the names of the participants. All data was securely stored at Swinburne University according to university protocols. The data was password-protected. Consent forms were scanned, and the originals stored in a locked filing cabinet. In all written documentation produced as part of the research, including this thesis, participants were given pseudonyms.

5.4.3 Rigour and trustworthiness

Qualitative research has been criticised for its potential to become a collection of anecdotes subject to researcher bias (Mays & Pope, 1995). Concerns about its lack of replicability and generalisability result in perceptions that qualitative research lacks the rigour of quantitative methods (Braun & Clarke, 2006). These concerns can be addressed through 'systematic and self-conscious research design, data collection, interpretation, and communication' (Mays & Pope, 1995, p. 110), which increase the credibility, transferability, dependability and confirmability of the data (Nowell et al., 2017). It is therefore imperative that the account of the methods used, and the data collected produce 'plausible and coherent explanations of the phenomenon under scrutiny' (Mays & Pope, 1995, p. 110).

Credible qualitative research results in a report in which the experience is recognisable by others. There is currently a great deal of interest in the economic participation of young people with intellectual disability. Recent reports on the topic that have included the lived experience of both young people with intellectual disability and their family members (e.g., Kavanagh et al., 2021; SVA Consulting, n.d.) and the views of sector key informants (e.g., DSS, 2021d) have produced findings aligned with those of this thesis.

Triangulation was used to reinforce the validity of the findings. This term refers to the practice of ‘using multiple sources of data or multiple approaches to analysing data to enhance the credibility of a research study’ (Hastings, 2010, p. 1538). Triangulation of the data drawn from young people themselves, their family members and the key informants meant the researcher was able to confirm that the experience or knowledge of one group was aligned with that of the other groups, which supported the credibility of the data. During this process, the researcher drew on her significant experience working with young people with intellectual disability and their family members to ensure that they were comfortable and at ease during conversational interviews. Her knowledge of the topic under study resulted in high levels of trust from participants, which in turn produced high-quality data.

Transferability relates to how generalisable the research is to another setting. It is intended that the themes derived from this research will be broad enough to be transferable to a range of settings (i.e., policy and practice), particularly as they relate to young people with intellectual disability as they transition from school, the delivery of economic participation supports from a policy and practice perspective, and supporting families to navigate complex systems. Data collected in the Australian context is interpreted and compared to other Australian and international data.

5.4.4 Reflexivity

Qualitative research is an inherently subjective endeavour which entails the interpretation of assumptions, values, interests, emotions and theories, or ‘preconceptions’, within and across the research project (Tufford & Newman, 2010). These preconceptions influence how data are gathered, interpreted and represented. Constructivist approaches regard the interpretation of data as a single representation of multiple realities co-constructed among participants and researchers (Charmaz, 2014). The goal is therefore to represent and interpret responses faithfully, paying attention to the experiences the researcher brings with them and how these shape the interpretation of participants' voices.

Reflexivity involves the realisation that researchers are part of the social world that they study (Frank, 1997, as cited in Ahern, 1999). The researcher recognises her significant professional experience, including working within the disability services and employment services sectors, and a viewpoint related to the topic. The researcher's viewpoint is strongly aligned with integration of people with intellectual disability into all aspects of the life of the community and, based on her prior experience, the belief that people with intellectual disability can engage in community-based economic participation activities if adequately and appropriately supported to do so.

In order to address potential bias, Ahern's (1999) process of 'reflexive bracketing' was utilised throughout the research, including the use of a reflexive journal in which the researcher documented day-to-day thinking about the research, the methodological decisions made and the rationales for data analysis decisions. This was underpinned by reflections about values and interests, particularly given the strong alignment of the researcher towards inclusion in community-based settings as opposed to segregated ones for people with intellectual disability. Rather than the researcher trying to eliminate the effects of her subjective position and experiences, she used the iterative and reflexive process of bracketing to understand how they influenced the project design and analysis process. Potential biases and reflections were documented prior to the study commencing and were used to maintain awareness throughout the project. One subjective position that was challenged by the data was the role of payment of wages for work. The data from family members highlighted the importance of social inclusion rather than the financial aspects of economic participation, which resulted in new thinking about the relationship between income support and paid employment for people who are likely to be excluded from work in the way that work is normally conceptualised.

5.5 Sampling and recruitment

This study used purposive sampling, which aims to identify and include information-rich cases who can provide a ‘full and sophisticated understanding of the phenomena under study’ (Hansen, 2006, p. 52). Purposive sampling is concerned with the quality of the information obtained from each ‘sampling unit’ rather than the number of units (Barbour, 2001, as cited in Hansen, 2006). It was considered appropriate due to the study’s highly specific focus on young people with intellectual disability during transition and early adulthood, and the need for participants to have experience related to that. The initial sampling frame aimed to recruit ten young people with intellectual disability, ten family members of young people with intellectual disability and ten key informants.

5.5.1 Recruitment of young people and family members

Young people and family members were recruited via a range of organisations in Melbourne. This ensured that the study participants had a sufficiently broad range of experiences. Young people and family members were recruited separately; that is, they were not matched purposively, though some participants from the same families were included. Each participant was given a $50 store voucher to compensate them for travel costs and lost wages involved in attending the interview.

Eight organisations in total were contacted and provided with information about the study’s purpose and its inclusion criteria for young people and family members. The inclusion criteria were:

a) a young person with intellectual disability aged 18-25 who has finished school;

b) a family member of a young person aged 18-25 who was involved in making decisions about their post-school activities.

All eight organisations agreed to recruit for the study. The researcher held a face-to-face meeting with senior managers from six organisations, at which information was provided about the study, including its inclusion criteria. Staff from the remaining two organisations were contacted by phone and provided with the same information. The managers were asked to identify young people and family members who met the inclusion criteria. The organisations then contacted the young people and family members to advise them of the opportunity to participate in the study and to ascertain their initial interest. The organisations are described below.

Organisation 1

Organisation 1 is a large disability services provider with which the researcher has a personal connection. It offers a range of services and supports to people with disability, including a transition program. The transition manager identified ten young people in the transition program who met the inclusion criteria and sent each young person and their family member a copy of the plain language statements for young people and for family members, inviting them to participate in the study. The young people were encouraged to discuss their involvement with a trusted person and then, if interested, to meet with the researcher at a face-to-face meeting to learn more about the study, including participation requirements. Interested family members were invited to contact the researcher directly by telephone or email. A suitable time to meet face-to-face was then arranged. One family member preferred to meet by telephone.

Five young people and five family members were recruited from Organisation 1. Two young people met with the researcher and subsequently declined to be involved. One young person became unwell and was unable to participate. One young person's involvement was cancelled due to COVID-19.

Organisation 2

Organisation 2 is a disability service provider that offers a transition program. The process outlined above for Organisation 1 was also followed with Organisation 2. Two young people and one family member were recruited from Organisation 2.

Organisation 3

Organisation 3 is a disability service provider. The process outlined above for Organisation 1 was also followed for Organisation 3. One young person was initially engaged, but then chose not to become a participant.

Organisation 4

Organisation 4 is a social enterprise. It did not identify anyone who met the eligibility criteria.

Organisation 5

Organisation 5 is a school for young people at risk of disengagement from education. The researcher met with the principal and a teacher, who reported that many of their students had undiagnosed mild intellectual disability, so staff were unsure whether they would respond positively. There was no further follow-up.

Organisation 6

Organisation 6 is a national initiative to improve the school-to-work transition for young people with intellectual disability. The organisation did not have direct contact information for young people with intellectual disability or family members who met the inclusion criteria.

Organisation 7

Organisation 7 is a pilot Work Integrated Learning (WIL) program for people with intellectual disability. The program director was contacted and identified one student who met the inclusion criteria. That person and their family member agreed to participate.

Organisation 8

Organisation 8 is a family-led capacity building organisation. One young person with intellectual disability and three family members were recruited via Organisation 8.

5.5.2 Recruitment of key informants

An initial list of individuals with suitable expertise in the area of economic participation and young people with intellectual disability was created. A number were known to the researcher via her professional networks; others were suggested by participants. These individuals were initially invited to take part in the study by email. They received a copy of the PLS and were invited to contact the researcher by phone or email if they were interested in participating.

5.6 Data collection methods

The data for this study were collected between August 2019 and February 2020.

5.6.1 Use of semi-structured interview procedure

An exploratory qualitative design using individual interviews, aligned with constructivist perspectives (Charmaz, 2008), was used to generate data. An interview schedule was developed containing 23 questions for the young people, 17 for family members and 14 for the key informants (see Appendices E, F, G). All interviews were recorded and professionally transcribed to enable the researcher to fully engage with the participant during the interview and follow the interview schedule. Where possible, interviews were conducted face-to-face. One family member was interviewed by phone.

Young people with intellectual disability were supported to engage using the participatory methods Photovoice and photo elicitation (see Part 5.6.2). As part of this process, they were asked to show the researcher any photos they had taken at the beginning of the interview. In all cases, photos were stored digitally on a phone or laptop. The participants were asked to describe these photos and why they took them, and each photo was then discussed. The participants were also invited to look through the set of photos provided. This enabled them to both discuss photos they had taken themselves and choose photos from the pack that had personal meaning.

Following the photo elicitation process, the young people were asked to provide responses according to the interview schedule (Appendix E).

5.6.2 Photovoice and photo elicitation

To ensure the equal participation of the young people, the researcher employed several practices to support their inclusion, including using visual images in semi-structured interviews. Traditional qualitative research methods often used in inclusive research, such as interviews and focus groups, implicitly favour cognitive ability (Klotz, 2014, as cited in Cluley, 2016) such as the ability to recall information or relate a story. To overcome this, the researcher used an adapted version of Photovoice, a visual method focusing on participant-led photography that was originally developed by Wang and Burris (1997).

Photovoice is a creative form of community-based participatory research (Schleien et al., 2013) that is grounded in both qualitative and action research. Its theoretical underpinnings include the critical education approach (Freire, 1973), feminist theory, and documentary photography (Wang & Burris, 1994). According to Wang and Burris (1994), Friere's approach enables identification of important issues in people's lives: critical reflection through conversation supports the identification of causes and solutions in real-life contexts.

Feminist theory recognises that the dominant culture can result in research that is biased. There is therefore a need for individuals from underrepresented groups to be provided with opportunities to assert authority on their own lives using methods that value their experiences (Jenkins et al., 2019). Photovoice also draws on the critical consciousness raised through the powerful visual images generated via the practice of documentary photography (E. D. Carlson et al., 2012), which allows others to see the world from the viewpoint of people who are leading different lives (Wang & Burris, 1994). The provision of cameras to members of an underrepresented group, enables the creation of a 'voice' through the photographs that are taken (Wang & Burris, 1994).

Photovoice is explicitly useful for vulnerable populations because it does not presume the ability to read or write (Overmars-Marx et al., 2017). Booth and Booth (2003) emphasise its suitability for people with intellectual disabilities because it helps to include people who have difficulties with communication or cognitive function in research. By supporting people with intellectual disabilities to communicate, it can be used to answer research questions.

Photovoice uses photographs to facilitate the expression and documentation of the views and needs of people with intellectual disability (Jurkowvski, 2008). It involves individuals taking photographs to illustrate the research problem or question and/or their social roles and identities (Dorozenko et al., 2015). Dorozenko et al. (2015) used Photovoice and conversational interviewing in their study with young people with intellectual disability, in which photos taken by the participants acted as a stimulus for the interviews. The photos themselves were not analysed; rather, the descriptions of the photos provided the interviewer with points of engagement. Conversational interviewing can accompany Photovoice, allowing the researcher to provide participants with additional information, for example by clarifying a question, to ensure that they can participate (Folkestad, 2000).

This study used an adapted version of Photovoice in conjunction with conversational interviewing to enable the young people to participate in the study. Participants were provided with information about Photovoice, and with verbal and written instructions in Plain English about taking photos to use in the conversational interview. This was done using a 3-phase meeting process.

Meeting 1

Once an organisation identified a young person with intellectual disability who met the eligibility criteria and wanted to be involved in the study, the organisational contact arranged for the young person and the researcher to meet at a suitable time and location (e.g., the organisation's premises). The young person was introduced to the researcher by a member of the organisation's staff who was known to them, and who asked the young person if they would like them to stay in the meeting. None of the young people asked the organisational contact to stay. The researcher then introduced herself to the young person and engaged in conversation to break the ice, then explained what would be involved in the study, and the researcher and young person read through the PLS together. The researcher checked whether the young person had any questions, and asked them to take the PLS home with them and check with someone they trusted, such as their mum and dad, about being involved in the study. The researcher's contact details were provided on the PLS so that parents or other significant support persons could contact them with any questions.

At this point three potential participants declined to be involved.

Meeting 2

The researcher met with each interested young person again approximately one week after Meeting 1. The researcher checked with the young person that they remembered what the study was about and what they were being asked to do, and then read over the PLS with them again. The researcher confirmed whether the young person had spoken with a significant support person about the study and confirmed again that they wanted to be involved. The young person then signed the consent form. At this point one potential participant declined to be involved. Another young person became unwell between Meetings 1 and 2 and did not participate.

At Meeting 2, the researcher asked each young person some background questions (see Appendix E). This was done to collect relevant data, such as age and type of schooling, and to build rapport. The researcher explained that the study was about work, study and training, and that she was interested in talking to them about the work, study and training they do now, have done before and want to do in the future. The researcher and the young person also discussed work, study and training in general, to ensure the young person understood the subject clearly.

The researcher then explained Photovoice in simple language, providing a copy of the Photovoice Easy English instructions (see Appendix H) explaining each step. The researcher then showed the young person photos from the ‘Picture My Future’ photo kit (Ottmann et al., 2013) as examples of photos that other people had taken. The researcher then checked that the person had a camera, which all the young people did on their mobile phones, and that they knew how to use it. A short conversation about some of the young people’s current work, study and training activities was held, during which the researcher asked the young person to suggest some things about work, study and training that they could take photos of for the project to reinforce the task. The researcher reminded the young person that they had two weeks to take the photos, and that they would meet again in two weeks to look at them. The researcher finished the meeting by telling the young person that she would call them or meet with them one week later to check their progress with taking the photos, and made a time with them. Finally, she checked that the young person was clear about everything and did not have any questions.

Meeting 3

Meeting 3 was held face-to-face, or by phone if face-to-face could not be arranged. The researcher asked each young person if they remembered what they were being asked to do for the project, and once they confirmed this, checked whether they had been able to take any photos. The researcher asked if the young person was experiencing any difficulties and reminded them that they had been asked to take photos about work, training and study. They then confirmed the date and time for Meeting 4, to conduct the semi-structured interview.

The young people were asked to take photos about things that were important to them about work, study and training (see Appendix H). Despite having easy access to cameras on their mobile phones and being in work, study and training spaces, the young people were not able to use Photovoice in its pure form outlined earlier, as the Photovoice method imposed a level of abstraction that did not allow participants to capture their activities. Only one participant brought her own photos to the conversational interview, having been provided with significant support by her father to do so. One participant demonstrated the inaccessibility of the method by bringing a personal item that was representative of her strong work interest in a particular field to the interview instead.

The use of photos in conversational interviewing, known as photo elicitation (Folkestad, 2000; Glaw et al., 2017), was substituted for Photovoice where the young person did not provide photos of their own. In this situation, the young person was provided with 64 loose photos covering a range of topics based on the UNCRPD Articles (see Appendix I for examples). The young people enjoyed looking through the photos, which acted as a concrete anchor enabling them to talk about work, study and training (e.g., a picture of a person gardening prompted recollection of their own experience gardening). The eight specifically work-related photos elicited highly specific information, such as the young people expressing preferences for or dislike of a particular type of work. The broader photos also elicited important information about the young people's lives more generally, particularly their hobbies and interests, and provided an opportunity for the young people to identify the strengths and barriers they perceive they experience in relation to economic participation. The young people were assertive, particularly when they had a strong dislike for something. It was also clear that their exposure to economic participation options was limited, as they often stated that they had not tried something or did not know about it. The photos therefore helped expose the young people to a broader range of options than they had previously known about.

The photos were particularly important for the young people who had impaired speech or experienced difficulty organising and expressing their thoughts. For example, a football image sparked a detailed conversation about work preferences with one young person. Using the photos enabled them to convey their thoughts more effectively, which was particularly important when talking to the researcher, whom they did not know very well. The photo also acted as a communication aid, enabling the researcher to better understand what the young person was trying to convey. All the interviews produced useful data.

5.7 Data analysis methods

The data collected from the young people, family members and key informants was thematically analysed using inductive data analysis. The themes derived from the data collected from young people and family members related to RQ1 are reported in Chapter 6.

Deductive analysis of the themes was undertaken using Clifford Simplican et al.'s (2014) ecological model of social networks and community participation. Themes derived from the data collected from young people, family members and key informants relating to RQ2 and RQ3 are reported in Chapters 7 and 8.

5.7.1 Inductive data analysis

Thematic analysis is ‘a method for identifying, analysing and reporting patterns (themes) within data’ (Braun & Clarke, 2006, p. 79). The flexibility of this approach means that it can be used in a wide range of studies to provide a ‘rich and detailed, yet complex account of data’ (Nowell et al., 2017, p. 2). It is also a useful way to manage large datasets, supporting the summarising of key features by forcing the researcher to ‘take a well-structured approach to handling data’ and thus helping to produce a clear and organised final report (Nowell et al., 2017, p. 2). It was chosen for this study because it is useful for examining the perspectives of different research participants (Nowell et al., 2017), in this case young people with intellectual disability, family members and key informants. Thematically analysing the data using a systematic line-by-line approach made similarities and differences in the data apparent and assisted in generating unanticipated insights.

The data was initially analysed using inductive thematic analysis, which was informed by existing theoretical ideas about transition from school and the economic participation of young people with intellectual disability (King, 2020). Inductive thematic analysis stems from a tradition of qualitative research in which the researcher is guided by data rather than a pre-established hypothesis (Hansen, 2006; Saldana, 2016). This analysis occurred concurrently with the semi-structured interviews. The process involved ‘systematic examination and re-examination of the data line by line in order to obtain meaningful categories that can be grouped to form a theme or a series of themes’ (Minichiello et al., 2008, p. 280). The data from each participant group were analysed separately before being compared and contrasted

(Lindsay et al., 2018). Axial coding was used to make connections between the various themes in order to organise and understand the data (Minichiello et al., 2008).

The five phases of analysis (based on Braun and Clarke, 2006) used to undertake the analysis were:

1. **Familiarisation with the data**: The researcher conducted all interviews, which were recorded and transcribed. Each interview was read and reread several times, and uploaded to NVivo. Initial ideas were noted down in a series of notebooks.
2. **Generation of initial codes**: NVivo was used to undertake coding. Inductive analysis, in which the researcher read through each transcript systematically and generated initial codes based on the data, was used initially. Interesting features of the data were then coded systematically across the entire dataset. This allowed the collation of data relevant to each code.
3. **Search for themes**: The initial codes were collated into potential themes using the research questions as a guide. All data relevant to each potential theme were collated under that theme. A map of themes is provided at figure 5.1.
4. **Review of themes**: Themes were reviewed throughout the write-up phase, with an emphasis on whether they worked in relation to the coded extracts (Level 1) and the entire data set (Level 2). The final themes are presented in Chapters 6–8.
5. **Definition and naming of themes**: As the themes were further refined, their names evolved. Ongoing analysis also refined the specifics of each theme and the overall story the analysis told, generating clear definitions and names for each theme.

Themes

A thematic map is provided below in figure 5.1.

5.7.2 Deductive data analysis

In the second stage of data analysis, Clifford Simplican et al.'s (2014) ecological model of social networks and community participation outlined in Part 4.2 was used as a coding framework to explore the data derived from young people, family members and key informants that was related to the barriers the young people experienced to economic participation and the strategies used to address them. The data derived from key informants was triangulated with the data provided by young people and family members (reported in Chapter 6). This enabled the barriers to be identified across the ecosystem and from differing perspectives. Data from young people and family members about the resources and supports they valued during the transition period was then triangulated with data from key informants to identify resources, supports and strategies to address the barriers identified (see Chapter 8).

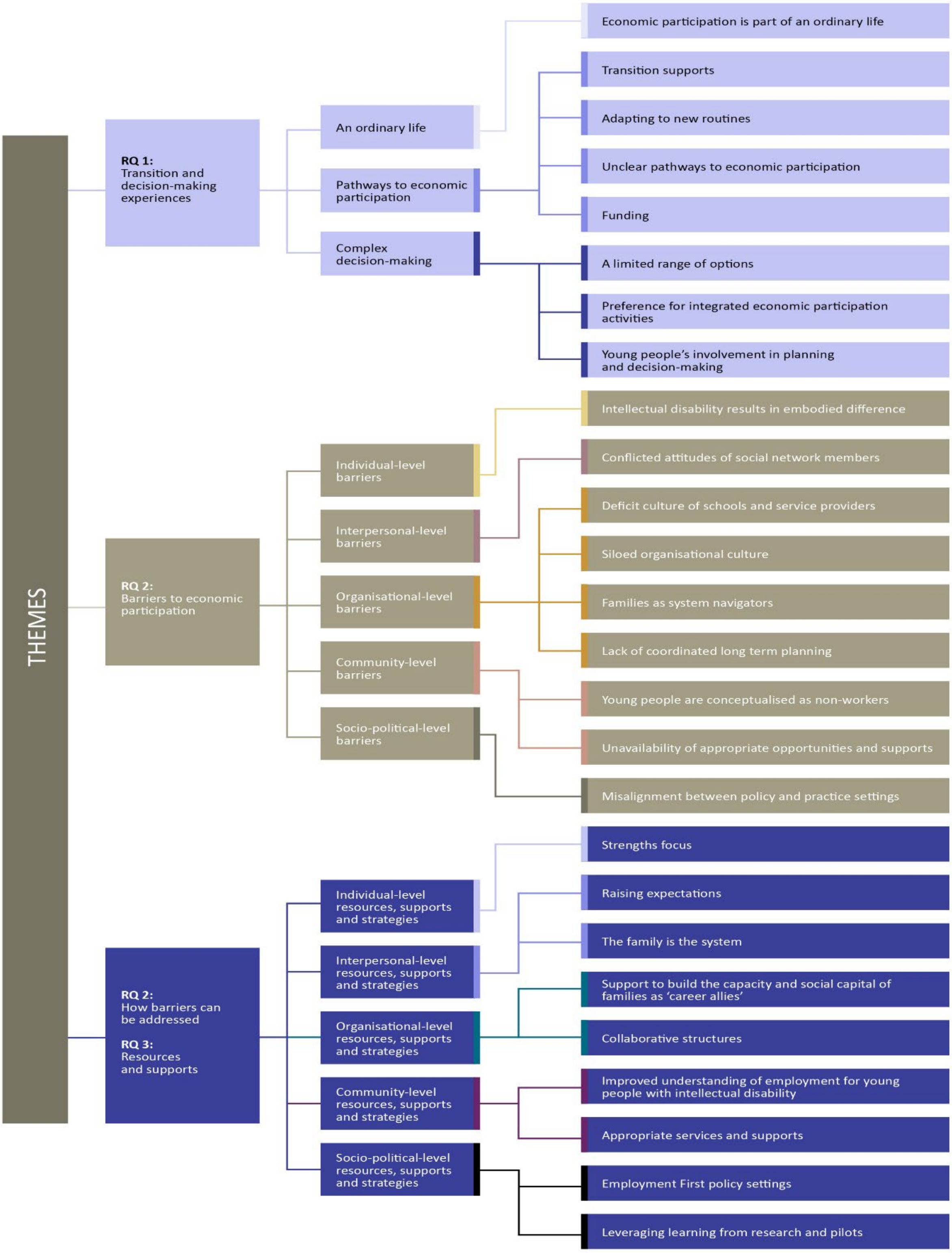
Using a deductive approach, the data was categorised at the individual, interpersonal, organisational, community and sociopolitical levels (Clifford Simplican et al., 2014) to enable analysis of the barriers and enablers to economic participation for young people with intellectual disability and how they intersect with one another. The deductive analysis started from the premise that the lack of economic participation opportunities available to young people with intellectual disability is the result of a complex set of factors that operates across the ecosystem, that the barriers described by the participants would therefore be apparent across the ecosystem and that it was important to illuminate those in order to avoid simplistic solutions and enable complex responses to address the barriers. The deductive data analysis process made those barriers visible, demonstrated how they interacted across systems and helped to identify where in the ecosystem strategies would need to be implemented to address them. This enabled a determination of whether the factors that promote economic participation (e.g., attitudes, funding, support models and individual factors related to intellectual disability) were missing or present, and at what level of the ecological system.

Themes related to RQ2 and RQ3

The organisation of data into the categories of the ecosystem (using the Clifford Simplican model) was accompanied by further inductive analysis, as described above, where sub themes within each ecological level were derived from the data (see figure 5.1).

Figure 5.1

Themes



5.8 Conclusion

This chapter detailed the method and methodology adopted for the study and provided information about the research participants. In chapter 6, the data related to RQ1 is presented.

Chapter 6: Transition experiences of young people with intellectual disability and family members

6.1 Introduction

This chapter examines young people's and family members' expectations about economic participation, and how their experiences of transition from school impact on the decisions they make regarding economic participation-related activities.

The chapter addresses RQ1: *How do young people with intellectual disability and their families describe their transition experiences? How do these experiences influence their decision-making related to pursuing economic participation-related activities?* Three main themes structure the discussion of transition experiences: an ordinary life; pathways to economic participation; and complex decision-making factors.

6.2 An ordinary life

Expectations and aspirations about paid work and young people's futures shaped young people's transition experiences and those of family members. The young people clearly articulated the importance of family relationships to them, detailing their reliance on family members for a range of informal supports. Family members were positioned as crucial to opening up opportunities for them, including economic participation opportunities. Young people identified mums or dads as the people who would teach them new skills or help them find a job: for example, Clare's daughter Penny thought it would be her mother who would 'book her in to get a job'. Across the cohort of family members, it was clear that visions for young people's futures were created and held with their families, and family members saw themselves as being responsible for holding and realising those visions, teaching their young people a range of life skills and working towards realising desired outcomes.

Expectations about young people's future roles were firmly grounded in expectations about them being included, having something valued and meaningful to do, feeling like they belonged and being part of the community. Family members recognised the role community-based employment would play in this. Both young people and family members had a strong desire for the young people to have 'ordinary life' goals. Here the idea of 'ordinary' is informed by normative standards for life pathways, which involve having work opportunities and a range of relationships, and moving out of the family home. This vision was grounded in ideas related to life in the broader community, including employment in a community-based job.

Seven family members involved in the study – Rhonda, Francine, Anne, Clare, Carol, Janice and Jane – had strong visions for their young people and were actively managing access to services and supports to bring about this vision of an ordinary life. Clare has a 19-year-old daughter, Penny – her youngest child – who has Down syndrome. She described her vision for Penny's future:

> Eventually I would like to think that she has an independent life that has structure and meaning, that she has relationships that are meaningful to her. There is no reason why she can't eventually be independent with her travel and work and living, she can be taught to do those things. I think that … eventually when she lives independently she will always need to have someone regularly coming in and making sure that things are still on track. (Clare, family member)

Clare clearly articulated her expectation that Penny would become independent and lead a meaningful life. However, neither she nor the other family members had formally documented their visions; nor were they explicitly using them to drive the post-school activities their young people were engaged in. Penny had recently finished school, and it was clear Clare had thought very deeply about her future. For her, this was a responsibility that fell to Penny's parents, not her service providers. When asked if service providers had given any advice about future planning, Clare replied:

> No. No, no. Not at all. Certainly not from [provider]. It’s really up to yourself as the parent. You know, if the person with a disability doesn’t have a family that will do this then they will stay at [service provider] full time forever. (Clare, family member)

Parents play a key role in engaging with ideas of what an ordinary life is and shaping ideas of what an ordinary life could be for their young people. The concept of ‘ordinary’ here describes modes of social inclusion that parents feel their young people are marginalised from. It holds in tension the lived experience of marginalisation, the practical opportunities that young people and parents aspire to and the skill sets of the young people and families.

6.2.1 Economic participation is part of an ordinary life

The young people in this study aligned their thinking about their futures with that of other young adults in their lives, expecting that they would get jobs. They valued being employed, and spoke about learning new skills for work, expecting that service providers and family members would help them to find jobs. Having a job featured particularly heavily in their thinking when their individual values were negotiated in relation to those of siblings.

For James, having a job was part of having a life: ‘I had to obviously get a job. … I can’t just live, with no life and have no job. … I don’t want to live without a job… [It’s] very important [to me]’. Work was an important goal for him and other young people because of the perceived benefits a paid role would bring, including social benefits such as new friends, improved independence, responsibilities and commitments to look forward to and something to do. As James said,

> Actually, it’s not about the money. I want to have more experience in myself and teach myself more about these different kinds of jobs. Learning new things is more important than money to me. I care about meeting more people, new people, more than money. (James, young person)

Not all of the young people were as verbally articulate as James. Many used the photos provided by the researcher or photos they took as part of the study to talk about what was important in their life. They engaged with ideas about their own futures, discussing what they thought the future held and the types of activities and roles they had access to. Those who had recently finished school were full of expectation and hope about the future, including holding dreams of getting married one day, having homes of their own and working. Conversations about work focused on the types of work they would like to do.

The young people recognised their limitations, yet none spoke specifically about having an intellectual disability. Instead, their conversations focused on their work preferences and how they thought their goal of working would be realised. Having finished school, the young people were involved in activities including unpaid work experience, classroom-based activities and travel training. They thought these activities were valuable, and described the skills they had learned since finishing school.

Family members thought having a job in the community would provide their young people with valued roles, meaning and opportunities to grow and develop. Janice, who has a son in his mid-20s, held an expectation of work for him and strongly believed that ‘everyone is employable if you just find the right fit’. Clare’s daughter Penny was the youngest in a large family in which everyone worked. Having a job was regarded as a component of adulthood, and as important to Penny’s identity and self- esteem:

> …she knows, when you're an adult you move out, you have a job. I think it’s probably more about how she feels about herself, her identity, and that’s probably the most important part of that. She’s quite task-oriented so if she knows these are the jobs that have to be done and she’s able to do those in an orderly way then that makes her feel really good about herself too. (Clare, family member)

Mary’s son had left school two years ago and was undertaking a transition program. When asked about his future roles, employment was the first thing she discussed:

> I hope that he's in some sort of steady employment … paid work. I don't think what he's doing at the moment is something that you can have for many, many, many years. It's nice perhaps for five years or so, but eventually we'd like to see him in employment of some sort. (Mary, family member)

Francine explained that a small amount of paid work would provide her son with the independence he sought:

> I would like to see him in what he’s doing now at the local pizza place or some type of establishment like that where he can actually go to be employed. And he wouldn’t be able to do full-time. It’s more like maybe two afternoons or two sessions or whatever you want to call it, three sessions. But just enough to give him – he wants independence. (Francine, family member)

For Anne, work would bring her son a range of benefits:

> I’ve always wanted him to work. I’ve always pushed for that. I’ve always pushed for him to be as independent as possible ... give him something to look forward to every day. It’d also give him access to the community, it’ll give him a different social aspect, it’ll get him to mix with regular people in the workforce. It’ll broaden his horizons. I can see a lot of positives for him. It’ll also show him how he needs to behave in the workplace. (Anne, family member)

Her son’s previous paid job had led to a range of valuable social opportunities: ‘When he was at [name of employer] he went to the Christmas party. They had a cricket day and he went to that. He loved it and they loved him’. Similarly, Jane saw work as providing an opportunity for her daughter to feel valued, something that activities alone could not provide:

> Working – especially if it’s a valued role, makes you feel valued, and I think that’s important … work provides – gives you something to do. Gives you socialisation as well. Otherwise … if you’re just floating along doing all these activities but you’re just

> doing stuff. Even though it’s stuff you enjoy – oh, I don’t know. It’s a really hard question. (Jane, family member)

She spoke about being able to ‘fill up’ her daughter’s time with non-work activities if necessary, but did not think this was a good option:

> I don’t know that I really want this model of her being part of a [disability] organisation … where they just do this and this and – the week’s planned out accordingly. There are so many things I think she would enjoy doing. (Jane, family member)

The concept of occupying a young person’s time resonated with Carol, whose son had just finished school. She described her planning for the next year:

> … we expect him to be busy nine to five and have a social life. But it will be this mixture of work, which I really hope in the long term will increase, some explicit self-advocacy stuff where you talk about speaking up for yourself, and being in charge of your own life and learning. (Carol, family member)

For Clare the financial aspect of work was not the critical factor:

> The advantages of [Penny] having a job, it’s not about the money, it really isn’t. Because the reality is that if she’s working eight hours a week it’s offset with [the DSP] ... but it will then equalise out, you know. It’s not really about the money. Penny sees her siblings getting jobs and going to work and in her mind you're an adult when you go to work, and you have jobs and then you manage your own life. She said, ‘Eventually I’ll have my own house’. (Clare, family member)

For Francine, the benefits of work were expressed in terms of how it helped shape her son’s identity, giving him a sense of pride and contributing to his wellbeing:

> Yeah … it’s who he is and what he can do. And of course, have pride in himself. He really glows when he’s going to work, and he takes pride in what he does. (Francine, family member)

Carol had worked hard to have her son included in the basketball club their family was part of, including negotiating a casual role for him at the stadium. Similarly, family member Brian’s son Corey loved football, and his involvement in a local club as a player was a source of great pride to Brian. He thought it provided a range of opportunities for Corey to be part of the local community and could lead to employment opportunities for him.

The expectation that work would be a component of the young people’s future life was very clear, and family members and young people both used that goal to anchor their thinking about ‘what next’ now school had finished.

6.3 Pathways to economic participation

6.3.1 Transition supports

Family members described how the range of supports available to them and their young people were dependent on the schools the young people attended. Special schools provided process-oriented transition supports that were driven by school staff over a short period of time in the last year of school. Family members were expected to attend activities and information sessions about options, and received support when preparing reports and deciding about the programs or services their young people would attend post-school. In contrast, family members of young people attending non-government mainstream schools described a poorly mapped-out transition process which resulted in the school failing to provide all the supports promised.

Within special schools, it was typical for transition planning to commence at the beginning of a young person’s final year of school, although several schools provided activities earlier. Family members received information from the schools about the activities they should attend. Rhonda described in detail the transition process developed by her daughter Amy’s special school:

> It started early in the year … it was compulsory for parents to attend a Careers Expo. I think I went to a meeting after that at school as well … It was probably like a one-on-one, you know when they would do their parent-teacher interviews they probably said a bit more about it then, just to let me know the timeline. Then a timeline was presented for me to come to a decision, what I would like Amy to do the following year when she left school. Then there was some testing (such as IQ testing) involved as well, because things needed to be up-to-date. (Rhonda, family member)

The planning was heavily focussed on locating suitable options for students to transition to post-school. Family members and young people described activities such as regional careers expos, information sessions held at schools, one to one meetings and assistance with preparing reports and applications. The process culminated with a post-school option being selected for the young person and the school liaising with the provider if required. Family members were expected to choose before the end of the school year so assistance with handover could be provided if necessary. However, there was no evidence that the process included any detailed or long-term planning about the young person's future.

The regionally organised 'careers expo', at which local organisations – predominantly disability service providers – provided information about the post-school services they offer to young people with intellectual disability, was the first transition event several families attended. Some described it as the first chance for them and their young people to see what was available. Rhonda found it valuable:

> At this careers expo there were providers for all different types of services, things for us to think about for the following year; what we planned with our child, what we thought – just to give us ideas for the next step. Because it's – like myself and other parents – completely new to me. I didn't know what was out there and it was just food for thought. That was really good that expo, because I was quite surprised – the services that were able to be provided for the following year. (Rhonda, family member)

The expo was designed to help young people and family members narrow down their preferred options rather than make a final decision. They spoke to service providers and collected information about what each provider offered and followed up with their preferred providers later.

School staff guided the decision-making process by giving parents recommendations about the suitability of the various options available, including whether a young person was suitable for economic participation activities. In some cases, they also made recommendations about particular service providers families should speak to at the expo. For instance, school staff suggested the SLES program as suitable for Mary's son, which she agreed was a good choice. Rhonda followed up with a DES after the expo, describing a tour she took with other parents and students from the school to see the workplaces people with intellectual disability had been placed in:

> I went with Amy for an information day. I went with the school, with a few other parents and it was a presentation, then a bus tour visiting some of the students they'd found jobs for. That was one of the places at the Careers Expo. If you were interested there was another step to that as well. The school helped organise that, the lady who did all the transitions, she came along. That was interesting … I found it valuable but at the same time I found that it wasn't the right thing for Amy as well. (Rhonda, family member)

Jane's daughter and Carol's son transitioned from non-government mainstream schools, where the highly structured transition processes outlined above were unavailable. They therefore took on a more proactive role in planning for their young people's transition, leading the process themselves and relying less on school staff to plan and guide the transition.

Regardless of which schools they attended, all of the young people exited school with a transition outcome; that is, they were linked to a post-school provider, most often a disability service provider. Several recent school leavers had chosen a SLES provider, one a day service and another a DES. Young people who exited school prior to the establishment of the SLES transitioned to day activity centres and specialist disability programs at TAFE.

Families whose young people had attended special schools were largely satisfied with the transition supports they received. Staff were described as helpful and knowledgeable about their young people, and they received necessary information:

> I felt the school was pretty good. Once you had a better idea what you were drawn to through the Careers Expo – and there were lots of options there – I found Amy's school really, really helpful actually. They were really good. [Q: They seemed to know what the options were? It wasn't like you found out a year later that there were all these other options that you didn't know about?] No, I was really happy with the school. They were terrific, every step of the way actually, they were really good. (Rhonda, family member)

Despite receiving support to plan for post-school life, none of the young people or family members could remember being provided with a written plan during their transition process. In addition, once school finished, the resources families had relied upon for so long were unavailable, leaving some family members with gaps in information and support. Some later realised they had made the wrong choice about their young people's post-school options. For example, Brandon's special school only provided his mother Janice with information about segregated disability programs, and she was expected to make decisions before Brandon had had the opportunity to engage in any work-related activities. Janice described a laid-out pathway in which no thought was given to non-disability options:

> The school and the services, there was a kind of coordinated approach. There was nothing about stepping off that pathway and looking somewhere else or doing your own thing at all. It was just basically, 'Here are the options; A, B, C, D.' We were just comparing what we thought was an innovative service to a more traditional service … There was a pretty laid-out pathway, it seemed to me. [Q: Laid out by the school you mean?] Yeah. They did some tours at school and him and I went, and we just went on

> a feel and it was really what he thought which was great. He went to this particular day service and said ‘Okay, well this seems quite innovative,’ and we got a good feel for it. (Janice, family member)

Two years later, Janice removed Brandon from the day program he had transitioned to, and he was supported into a paid job. Likewise, Francine followed the school’s process, which resulted in her son moving from a special school to a disability day service without any opportunity to experience economic participation activities. She regretted this decision when his behaviour became problematic and eventually moved him out.

The non-government independent schools Carol’s son and Jane’s daughter attended were focused on moving students from school to university and other mainstream post-school options, and this meant there were no supports available during the transition period for students with intellectual disability. Instead, families undertook the necessary work, searching for the right post-school options for their young people. For Jane’s daughter, the school year finished in mid-October when the senior students started their exam period. Jane had not yet finalised post-school arrangements for her, thus this early finish to the school year resulted in a gap.

6.3.2 Adapting to new routines

For young people and their families, finishing school was a time of upheaval that required a period of adjustment. The initial focus was on establishing new routines and learning new skills, and on work preparation, including undertaking courses and work experience and learning to travel on public transport. It was hoped these activities would eventually result in paid employment outcomes for the young people. However, after a period of relative stability at school, family members recalled this time as being particularly stressful, as they took on the bulk of the responsibility for sourcing information about options for their young people, weighing them up and making decisions regarding post-school programs. They also shouldered much of the responsibility for the day-to-day management of funding and service access under the NDIS. Some family members reported feeling overwhelmed by the decisions they needed to make and the complexity of the system they were required to navigate. Some felt unsure about whether they had made the right decisions, often doubting themselves when things did not go to plan.

Attendance at school had provided routine, and arrangements had been structured around the young people being occupied and supervised during school hours. The work of transitioning the young people into their new post-school activities only began once school finished. Families needed to plan new routines for both their young people and the family as a whole and recognised that that might take a while. For many, disability services programs provided structure due to the young people being engaged in activities during school hours and school terms. For Clare, the disability transition program she chose for Penny provided a stepping stone from school to the adult world:

> Our decision-making on what we were going to do after that was heavily based on coming out of 14 years in one supported structure and trying to make that transition a little bit easier. We opted to look at [disability service] because it was a program that was already close to us and she could go there five days a week initially and then we could work it out from there. If we could get her going to one place that was supportive for that first year [it] would make it easier for her. (Clare, family member)

Rhonda had a clear goal around paid work for her daughter, but was using a transition-type disability service as an initial, interim approach. She hoped it would be a stepping stone on the pathway to work. Rhonda’s daughter and not been out of school long, and having her at home doing nothing was not the outcome Rhonda wanted:

> I don't want Amy just at home doing nothing. I don't want that at all. So even if she is doing a few hours here and a few hours there of different things and there's a combination of social things as well. (Rhonda, family member)

Clare couldn’t imagine Penny being stuck at home without structured activities:

> You know, you leave school, it’s structured and you're told ‘This is the program,’ and then, I think if she wasn’t at [disability provider] and she was at home, there would be absolutely no structured program, gosh what would you do? Just imagine leaving school, not going into a program and then just staying at home. For those families, then what happens? I think five days a week there needs to be structure because I see what happens over the holidays, and she doesn’t like it either, where you get a bit lazy and you watch movies and it’s not ideal. She would need to have structured activities where she goes out of the home, whether that be music, art, physical activity or something like that. (Clare, family member)

James was involved in a transition program with a disability service where he primarily undertook unpaid work experience. He clearly valued the routine and busyness the program provided, and agreed that without structure he could get lazy:

> [Q: Okay. If you ended up and you didn’t have a job, what would you do with your time?] I would be upset probably. Probably sleep all day. Won’t get up and play video games. (James, young person)

Carol, whose son was about to finish school, wanted him to be ‘busy nine to five and have a social life’. Mary outlined how she had blended together a range of activities including work experience, a TAFE course and sports participation for her son to keep him busy:

> I just couldn't imagine the thought of my son just sitting at home not doing anything. No, no. And that scares me too. That really scares me. Because ideally – I couldn't even imagine the thought of having a 25-year-old just lounging around at home, sitting at the television or his phone or his games. No. (Mary, family member)

Learning how to move around the community independently was a skill the young people needed to learn to support their new activities and routines. Penny proudly talked about the travel training her family had been helping her with, focused on using local buses. Rohan travelled all over the city independently, including to his city-based training course, something he was very proud of. However, travelling around in the community created stress for several family members. Family member Brian's son Corey had only just started to travel on public transport with a group, learning how to use the ticketing system. For Brian, stepping up to travelling alone was 'petrifying'. Jane's daughter was learning to travel to her day program, as was Clare's daughter Penny. They described in detail the effort they had gone to create a safe, almost foolproof, route for their young people, putting in the supports they needed while the young people built their confidence and skills.

6.3.3 Unclear pathways to economic participation

The period of transition from school foregrounded feelings of uncertainty about what the future held for both the young people and their family members. The completion of the relatively stable period of schooling forced young people to think, sometimes for the first time, about what their adult life might look like. While the family members in this study overwhelmingly had high expectations about their young people being able to obtain paid community-based work, they expected it to be difficult and recognised that intellectual disability would result in a need for additional support. Rhonda summed up those feelings by saying:

> People say, 'Will Amy get a job?' Yeah, well hopefully! I do want that, and I hope that and I'm going to be positive that it will happen one day. I'm not being negative, but I can't imagine it at this stage. (Rhonda, family member)

This expectation was shaped by experiences of negotiating the barriers and pitfalls of the economic participation landscape. Family members were very aware that unlike other activities undertaken by their young people, gaining paid employment required buy-in from an employer willing to make a significant commitment to supporting a young person. They expressed concerns about finding employers who were willing to engage young people with intellectual disability in paid roles, due in part to the stigma that exists about the capabilities of this cohort. Clare, for example, recognised that people would judge Penny, who has Down syndrome, based on how she looks and behaves:

> I know when we've had almost 20 years of 'Don't do that in public,' 'Pull your trousers up higher,' you know, 'That's not a good look,' 'Make sure you wash your face'. I'm aware that things that other people can get away with someone with a disability can't get away with. And that the standard for her behaviour and look is much higher than other people's. When you're different you can't afford to stand out. (Clare, family member)

Anne thought that work was achievable for her son despite his challenges. She recognised that to be employed her son would need to be productive, and that managing his disability was one way to ensure that he was:

> … provided we can control the Obsessive-Compulsive Disorder (OCD) and the Oppositional Defiance Disorder (ODD), I cannot see why he can't hold down a job, whether it's five days a week or whether it's seven or whatever … Even if it's only 10:00 until 3:00 every day … if they want to work, they've got to be able to produce something. They can't just go there and expect to sit on their backside and do nothing. It's important that they contribute if they go to work. (Anne, family member)

Family members were unsure whether employers would be willing to provide paid work and whether there were jobs available that their young people could do after they finished their training. Francine's son, who was 24, had been involved in a range of training programs since finishing school, none of which had led to a paid job:

> You can do all the training, which he's doing, right. And you can do training on the job, that's fine, but then once the training on the job is finished you're back to square one. You don't have a job to go to. (Francine, family member)

The young people themselves recognised that gaining employment might be difficult. For example, they stated that not being good with money could be an issue for retail roles. Others thought that their physical limitations would impact on their ability to work in particular industries. For example, Brandon recognised he might not be fast enough to work in hospitality, and he and Leanne were concerned that they would be unable to complete the necessary minimum training to work in childcare and the fitness industry.

Some participants were unsure about how paid work opportunities would become available to young people, and felt a lack of clarity about how the activities they were undertaking were building towards the goal. The short-term transition-focused planning discussed in Part 6.3.1 ensured that each young person was connected to a post-school provider, commonly a SLES provider. However, a number of family members were concerned about ongoing planning and feedback about progress towards employment goals. Families relying on providers described a lack of formal planning and felt left in the dark about what was happening, sometimes being unsure if funding would continue post the two-year program period. No one had documented agreed, outcome-based goals, and there was little in the way of feedback about progress or next steps. Family members also reported not receiving regular information or updates about activities their young people were undertaking beyond basic information about problems or issues, or funding coming to an end. Due to the highly individualised nature of the programs and services the young people were engaged in, they rarely saw agency staff. As Mary commented,

> I love the guys at [program] … but what I find is, I don't get feedback enough. I get feedback when I'm alerted to the problems, the incidents that crop up, and we've had a few doozies with [son]. [Q: But you're not getting any ongoing stuff?] No, and if I don't initiate: ‘Look, I'd like to meet with you, I'd like to have an update – I think six monthly as he is moving [towards the end]. Okay, [he] started here, six months [ago], how is he doing?’ [Q: You didn’t get anything?] Never, no. Unless I say, ‘Look I'd like to meet with [you].’ (Mary, family member)

The lack of a written plan left Vera unsure about her daughter’s pathway. She had little contact with the staff from her daughter’s program, and the contact she did have was informal. She thus did not know if her daughter would be able to continue in the program once her funding ran out. ‘I don’t know what’s going to happen’, she replied when asked about her daughter’s activities post-SLES.

Additionally, while the young people were engaged in a range of activities, there was no coordination between the various providers, and no clear long-term goals around employment. Some family members had taken on a quasi-support coordination role, but many were struggling to find services that would lead to employment. The poor communication between family members, young people and service providers resulted in a lack of collaboration, with family members working autonomously to move their young people along when they thought the service provider was not delivering what was promised. For instance, family member Brian said:

> I don’t know if this is a copout or not, but if you don’t do it, no one will tell you ... I just thought we would have got a little bit more. (Brian, family member)

Family member Rhonda noted, ‘It's me digging for things’. For example, Rhonda was trying to organise volunteering for her daughter to help build her work skills:

> Volunteering is one of the things I want to get happening in the next year or so, at an animal shelter just for a few hours. To get to that stage (being independent), she would need someone to show her what to do and work with her. (Rhonda, family member)

Young people were unsure about next steps towards community-based work. Leanne had been in the same unpaid work experience program for nearly a year and was very keen to get back into a paid role, but as staff from her SLES program hadn’t undertaken any detailed planning with her, she was unsure what would happen next and who would help her. Similarly, James was unsure about the process for moving from group to individual work experience. Although some young people had undertaken unpaid work experience in the same business for several years, there were no clear pathways for them to convert an unpaid role into a paid one. For example, Francine's son had been working in an unpaid role since undertaking a placement at a local business. For her, jeopardising the arrangement by asking for it to become a paid role was too risky, and she preferred it to continue unpaid because of the benefits it provided for her son:

> I don't want to shatter that for him. If they say, 'No we don't want to go down that pathway, if you want to go down that pathway we're not interested.' At the moment I'm happy for him to just go there and volunteer, learn some skills. And for him to have that confidence and he goes somewhere he feels like he's making a contribution. (Francine, family member)

Nevertheless, the young people often continued to place their trust in staff members from the agencies they were involved with.

Despite the lack of structured planning, families were initially optimistic about the future, hopeful that paid work opportunities would become available. They held a firm belief that with the right supports their young people were capable of working in community-based jobs, and that was the focus of their thinking. Some young people had transitioned to programs that had an employment focus or purported to offer pathways to employment, while others were undertaking a mix of activities that families hoped were building skills that would eventually enable them to transition out of disability services and into community-based employment. Clare's daughter Penny was typical of this approach:

> So, the thing with the five days of [disability provider], it's not a long-term aim for her to be there five days at all ... she was at [disability program] five days and she does some work experience programs with them at the library. Then she was offered the commercial cooking over at the [name of] campus on Thursdays and then a place come up on Wednesdays to go out in the coffee trailer. So, she does that as well. It's a good mix of work experience and then there's some sport and rec. Then Tuesday, which is not her favourite day, is classroom work. She says, 'I like hard work but it's

> hard work.’ The last few weeks they've been working on movie reviews which involves them working with someone else and writing things down and presenting. It’s all a bit of fun. (Clare, family member)

Several family members reported experiencing significant stress and worry about whether the decisions they made were the right ones for their young people. Negotiating economic participation opportunities was particularly complex for them. They expressed concern that their young people were missing out on things that could help them, and sometimes felt overwhelmed by information from a range of sources including school staff, service providers, other parents and their own research. The individualised nature of the system meant that the activities on offer for their young people also kept changing, which caused confusion. Mary eventually sought counselling to help her manage the difficulties she experienced during the transition period:

> I actually got some counselling because I was struggling in that first year because it was really hard transitioning [son], his mindset of school and then in this new environment and that's where he was really being a little bit difficult. (Mary, family member)

For others, there was the frustration of coming up against bureaucratic systems that prevented them from connecting their young people to the supports they thought would assist them in finding a community-based work opportunity. For example, families were given conflicting information about funding and available services and supports, while NDIS Local Area Coordinators were not up-to-date with relevant programs and did not provide consistent advice. Clare described the conflicting information she had received about funding:

> This discussion we’ve had about SLES funding and DES funding, I keep asking people and they're like, ‘Oh, yeah no, you don’t need that.’ Then someone else, ‘You know you can use it for two years and you should use it.’ I don’t know. I don’t think the Local Area Coordinator with her NDIS knows what she’s done… I just have to tell her ‘This is

> what we want' … I think really understanding what's available and what's the best way to head forward is a good idea. (Clare, family member)

Vera has an intellectual disability herself, and although she had received information about programs and supports for her daughter, she found it difficult to understand and the NDIS confusing.

Given this complex environment, some family members felt they had insufficient knowledge. As Brian said, 'There's no book you can read on this'. Mary also found the information overload overwhelming, and Clare reported that a year into her daughter Penny's post-school life she was starting to doubt herself, wondering if she was doing the right things for her:

> Something that we've touched on before is we don't know what's there and we don't know how… so once you leave the school system and, as I said, we were quite well supported to leave school and get somewhere … once we've done that, we talked about SLES funding and DES funding, well how the hell do you know what that is if no one tells you? And now we're at a DES provider and she's going to find a job. What else is out there that I don't know that we should be doing? I wish we knew what we were meant to be doing. (Clare, family member)

Failing to achieve economic participation outcomes led to families beginning to lose hope over time. Several family members recognised the significant barriers their young people faced in gaining and maintaining employment, which they had been unable to overcome. Despite experiencing a range of programs and activities, inability to secure ongoing community-based work had dented their optimism, and they had begun to seek segregated work opportunities instead, despite knowing it was against their young people's wishes.

6.3.4 Funding

Despite the young people's seemingly similar goals relating to economic participation and their, on the face of it, similar support needs, the funding available to each varied enormously, and this in turn impacted on the supports available to them and the post-school activities they engaged in. The process of obtaining funding for economic participation-focused supports from the NDIS – the primary funder of supports to the young people – was not straightforward. Funding available depended on a range of factors including: age, goals and level of functioning, and the capacity of their advocate (usually a family member) to make a case for why the funding was necessary. Some family members found the planning processes frustrating, confusing and inequitable, and they did not receive the funding they needed. Others were able to advocate successfully to gain economic participation-related funding. For example, Rhonda had located a program she thought would be suitable for Amy, and organised funding so Amy could attend:

> I looked up something on the Internet to do with animals – it's a farm in [suburb]. I rang the lady – she was lovely – she said that things have changed and there is a really big waiting list. She told me what particular funding was needed so I brought that up at the NDIS meeting and Amy actually did get funding to attend one day a week. I'm looking at when a vacancy does become available and that probably won't be until early next year. I wanted her to do something different and this is probably more of the social side of things. But it would team nicely with the environment; they've got chooks, they've got garden nurseries and they have a café. I spoke with Amy about it. She seems really, really keen. (Rhonda, family member)

Some family members also had help from service providers to get funding in place. Carol described how her preferred provider was undertaking a range of preparatory work for her son as he got ready to leave school, despite having no guarantee he would get the SLES funding required to access their program:

> … in fact, they're going to come and assess him. They're going to talk to the school. They're doing all the assessment preparation work now. So, this is the thing that I've realised for providers. It's not great. But they're doing all their preparation and setup now without the guarantee that he has it in his [NDIS] plan. But I cannot believe that

> he won’t get it. He’s got ‘Finding and Keeping a Job’ in his plan. So, he only gets $2,500 the last two years. But because he’s actually got a part-time job – I cannot believe that he wouldn’t get SLES. (Carol, family member)

Likewise, Clare had support from Penny’s preferred provider to develop her plan:

> At [provider] there’s a woman who is absolutely fantastic with NDIS plans. Prior to [Penny's] first NDIS plan I went to her and she made up recommendations. She was really, really good. Then when I went to the Local Area Coordinator and – it was all over the shop. She said, ‘Well, we need to think about this and we need to look at that.’ I just whipped out this plan and said, ‘Will this help?’ She saw who’d done it and she said, ‘That’ll do.’ (Clare, family member)

Jane also had an advocate attend her daughter’s NDIS planning meeting, which helped her to get the funding she needed. Anne’s son was involved in a WIL demonstration project, and staff from the program had provided her with a detailed document to give to the NDIS planner to ensure that her son received the right funding items to enable his involvement in the program.

Accessing SLES funding was important for young people with economic participation goals, particularly in the critical period straight after school. Corey, James, Amy and Melissa had access to SLES funding through the NDIS which enabled them to attend what they referred to as a ‘SLES program’. This funding, of approximately $20,000 available over a two-year period, was being used primarily to fund work experience and travel training. However, Clare’s daughter Penny, who had recently finished school, did not receive SLES funding and Clare was unsure why. While Penny was still able to access the transition program, Clare was not sure how it was being paid for. The time-limited nature of the SLES funding was also a concern for some family members, such as Brian, as his son was approaching the two-year mark:

> So next year, they’re trying a job ready thing, still through [disability provider], which hopefully, they’ll get funding for that. [Q: So that’s a different type of funding than SLES though?] Yeah. SLES only lasts for two years, so they’re trying to get him a third

> year of funding under a different umbrella. We don't know whether that's going to happen or not. (Brian, family member)

Some of the young people had NDIS funding for 'Finding and Keeping a Job', as well as for speech therapy, occupational therapy, independent living skills support and attending social and leisure activities. Some also had funding via state government training programs, and others were using DES providers funded by the Australian Government. Each family was juggling their young people's funding in an attempt to purchase the right supports for them. Receiving funding also did not guarantee access to a service or program: Rhonda had the right funding for Amy to attend the volunteer program, but was waiting for a space to become available, and Clare was negotiating with a DES provider about a new training opportunity that had become available, which she described as perfect for Penny. However, Penny needed to be eligible for DES before she could access it.

While it might be expected that planning processes would alleviate some of this sense of confusion and overload, the young people in the study were involved in formal planning processes at several levels, including at school, via the NDIS and with their service providers. This plethora of planning generally did nothing to alleviate the issues described above. Family members still managed these processes in an attempt to create the 'ordinary life' described earlier in this chapter.

Overall, the data within the 'pathways to economic participation' theme revealed family members and young people grappling with the complex reality of matching aspirations to lack of opportunities and the need for flexible and supportive workplaces. Inevitably this dependence on factors they could not control resulted in uncertainty about what would eventuate. This sense of uncertainty acknowledged the paucity of pathways into meaningful employment for the young people, and the unknown nature of the work required from all to carve out new economic participation pathways. However, their visions remained grounded in their young people having access to ordinary life opportunities.

6.4 Complex decision-making

Family members chose post-school services based on a range of factors, including gut feel, proximity to home and whether suitable activities were available for their young people. Activities the young people would enjoy, and that would result in them feeling valued and able to contribute, were important. Family members also expressed concerns about safety, boredom and lack of opportunities to grow and develop, and many felt they were making 'compromised decisions' because the services they wanted were not available.

Most young people in this study transitioned, at least initially, to a disability service provider or disability-specific program. Family members reported choosing service providers after meeting program staff at the careers expo. The initial focus was on locating what were considered 'connecting' services and supports for the young person, rather than typical economic participation activities, which family members thought would be overwhelming so early in the young person's transition to adult life.

6.4.1 A limited range of options

Rather than a coordinated, planned, collaborative approach, family members described being steered towards disability service providers from which they could choose the most suitable option via the careers expo. Disability day services, transition programs referred to as 'SLES', supported employment via an ADE, community-based employment via DES, and disability programs offered by TAFE were the primary options available. Families were not provided with information about traineeships or apprenticeships, despite their availability to people with intellectual disabilities. Rhonda had concerns about Amy working in open employment straight from school:

> It just gave me the feeling that she would end up being isolated. It's great that they find you a job, but then when I saw what they were doing; they weren't working as a team with anyone. They were by themselves … I'm open to anything. I think she would work well as a team member, being able to do to things independently still but as a part of a team. (Rhonda, family member)

For some family members the services available were not a good fit for their young people due to transport or other logistical issues, especially if a young person was not able to travel independently. Francine described the significant frustration she experienced finding services that were right for her son in her geographic region, and Janice reported choosing her son's initial service provider 'because it was close to home'. Likewise, Clare chose Penny's provider because of the transport options. Jane's daughter's original plans changed when she became unwell toward the end of her final year of school:

> We had great plans she would – that we'd jump straight on to … the disability employment agency. We had spoken to them and I thought that we would jump straight in there. Because all the research that I had done – I've been to lots of workshops and so forth – said the sooner you can get these kids going into employment, the more likely you are to have success. But then [daughter] had a stroke in early September, and although she's had an amazing recovery -I just thought I'm probably – it's pushing her in the deep end. She just needs to have a bit of routine. We went to see [disability provider] for their – supposedly it's a transition to employment thing for three days a week, using SLES funding from NDIS. (Jane, family member)

When Anne's son Rohan finished school prior to the SLES program commencing, she was told that the local day centre wouldn't take him, because he was 'not day centre material' and would be bored.

While family members sometimes knew about programs, these were not necessarily available in their area, or might not have capacity. Francine was frustrated that she couldn't find the supports she thought her son needed, including a person to find a work opportunity for him and negotiate with the employer. Janice, who self-managed her son Brandon's NDIS funding, also experienced frustration in finding the right supports for him, particularly someone to work with him using a customised employment approach.

6.4.2 Preference for integrated economic participation activities

The expectations family members and young people held about community-based employment (see Part 6.2.1) led them to favour post-school services they believed had a focus on economic participation, including TAFE courses and transition-style SLES programs offered by disability providers. None of the young people had chosen an ADE straight from school. SLES programs had a focus on unpaid work experience in the first-year post-school, with young people working in mainstream workplaces supervised by disability provider staff, which was particularly attractive to family members. Brian's 19-year-old son had virtually no work experience when he finished school. He thought the opportunity to be in a workplace was beneficial for him:

> Because it was work, we thought the idea of him working at [supermarket] packing shelves or something, would suit him. He enjoys it – they were doing [sports store] one day a week and he loves it because he's so sports – such a footy head. (Brian, family member)

The young people also valued learning in real workplaces over spending time in classrooms. James, for example, had a strong opinion about what he wanted to do, which included getting out into the workplace:

> It was more placements, no studying. [Q: You didn't want to do the studying?] No. I didn't. I wanted to work at different places. (James, young person)

The unpaid work experience was based in large shopping centres, and sometimes undertaken in small groups. This enabled young people to develop their travel skills while getting to and from work, and to use the facilities, for example to buy lunch. Family members and young people felt they were important skills to learn, and it was a safe and supervised environment, which appealed to the family members. Clare's daughter Penny was attending a transition-style program. Both were pleased that the program was work focused and that Penny was learning new skills, including travelling independently to the centre and doing unpaid work experience. Penny spoke proudly about the skills she was learning in the program, including preparing food to sell in a coffee van, working in the coffee van and working in a library. Corey and James were also very keen to talk about the new skills they were learning at their work experience program. It was clear they valued the opportunity to learn in real workplaces.

Neither the young people nor their family members preferred traditional post-school options for people with disabilities such as day centres; families expressed concern that they would not support their young people to grow, develop and transition to suitable work. Francine's son was placed in a disability day service when he finished school; his behaviour deteriorated, and the placement ultimately ended. Francine attributed this to boredom:

> He doesn't do really well. He's either causing trouble or trouble's finding him. [Q: Do you have a theory on that?] He's bored, I think he's bored and he's not interested in what's going around. I know what he wants to do. He wants to go out and work. (Francine, family member)

Bobby's teachers recommended a local day service to him when he finished school, which he did attend. He described his reason for changing services:

> And, they [school staff] also talked about after school finished, they told me to go to [day service] … I didn't like it … I reckon it's too boring. (Bobby, young person)

6.4.3 Young people's involvement in planning and decision-making

Family members ultimately had decision-making authority in relation to the services and supports the young people accessed post-school. The degree to which the young people were involved in planning their transitions and making choices and decisions varied, and there was little evidence that they were systematically involved in planning for their futures in any meaningful way, or that inclusive planning processes had been implemented. Nor was there evidence of involvement in a structured planning process to support the creation of longer-term visions for their future.

Young people reported that teachers and family members helped them make decisions. Some perceived that their parents had largely made those decisions:

> [Q: Did anybody talk to you about work? Did someone sit down with you and talk to you about the types of jobs you might like to do? Or what you're good at? Or what you liked?] Not really. (Brandon, young person)
>
> [Q: When you finished school, who helped you decide whether you would come to (disability service) or go somewhere else?] My mum booked me in. [Ok. And when you were at school did the teachers or your mum ask you what you would like to do?] My mum told me what to do. (Penny, young person)

These decisions made by others sometimes went against the young people's wishes. For example, despite expressing their views, Leanne and Bobby went to post-school services they didn't like. Leanne was living with her grandparents when she finished school, and her grandmother influenced decisions about her post-school destination:

> I went to a meeting with [DES provider] but my nan didn't like it, so she said, 'Go to TAFE,' so I did. I didn't really want to go there because there was a lot of drama with a lot of girls, and I didn't like that. (Leanne, young person)

Bobby felt that his mum was stopping him from pursuing his goal of studying to be an accountant by telling him, 'Do not study yet until you're ready', preferring him to undertake social activities instead.

Families included elements of 'good fit' in their decision-making. In addition to the ingredients discussed above, a service or program was considered a 'good fit' if it had activities that tapped into a young person's strengths and interests, was logistically suitable and had a culture that supported the inclusion of people with disabilities in the community. In this way, despite a lack of formal engagement in selecting specific options or developing plans, young people were involved by expressing preferences and having these built into family decision-making. Family members were clearly cognisant of the interests and preferences of their young people and actively sought opportunities aligned to them, using a range of informal methods to ascertain 'good fit'. Bringing young people to meetings, expos and information days with them was one mechanism family members used to understand their preferences. Many family members also had a deep understanding of what was important to their young people, and made considerable efforts to find activities suited to their individual needs. For example, Clare reported she was able to make decisions on Penny's behalf because she knew her daughter well and therefore knew what would suit her:

> I probably am guilty of not having talked to her too much about it. But I feel I know her pretty well. So, I figured out what really suits her. (Clare, family member)

Similarly, Jane explained how finding a program that catered to her daughter's interest in the performing arts was important:

> I keep thinking I've got to look at what her passion is. And it's in the performing arts. She's not so much of a drawer or anything like that… I've also been to workshops that have been run by [capacity building organisation], where they talk about 'think outside the square'. So even – she could even have a position in a theatre where she's an usher. Could she learn how to show people to their seats, if she could learn that alphabet. (Jane, family member)

Rhonda spoke throughout her interview about finding opportunities she thought would suit Amy and how she would check in with her about them:

> First, I'll always ask, 'Is this something you want to do?' Like volunteering at the school. I wanted something for another day and spoke to her about what volunteering is.

> ‘Would you like to work with animals?’ She was the one who came up with the idea of working with children! … and it's something I know she's passionate about and she seems to have a certain aura around animals, she's very calming. (Rhonda, family member)

Amy also demonstrated how she had input into her mother’s thinking, describing an idea she had for work experience:

> In [Airport] – because I said to my mum, it was a good idea. You know those newsagents – I said to mum, ‘Can I work there? Like work experience or the shops.’ She said, ‘Oh nice, that’s a good idea.’ [Q: When was that, when you were at school or recently?] No that was like a few weeks ago. [Q: Was mum able to talk to someone about organising that?] She’s going to ask [service provider]. (Amy, young person)

Family members were also cognisant of ‘poor fit’ for their young people. Clare described how Penny’s reaction to a segregated day service they visited influenced her decision-making:

> We went and did a tour at [disability service] and Penny came with me and we went around there. There are some areas there that are high need, high care. We walked into the area where they actually have hospital beds and Penny stepped back and went, ‘Why is this like a hospital?’ She was really taken aback and was surprised. I said, ‘Because some people, you know, need some extra care and that’s why they come here.’ So if that was our option ... she wouldn’t have gone there. (Clare, family member)

Likewise, Anne described taking her son Rohan to visit an ADE:

> He didn’t come in the door, didn’t come past the office. He didn’t even know what we were going there for. He sat in the office. In fact, he went out of the office and sat in the gutter while [husband] and I went through it. [Q: And you weren’t impressed, it wasn’t what you were looking for?] I thought it was good and the people there were doing good things, but it wouldn’t have been for Rohan. (Anne, family member)

Exposure to real work was one mechanism that helped young people express their views about economic participation. Brandon, James, Amy, Bobby and Rohan had had multiple opportunities to undertake work experiences, including work experience and paid work prior to finishing school, and this supported their decision-making about later work. They drew on that experience to express clear preferences related to their future economic participation, including which study and jobs they preferred, and which were not of interest to them. For example, Brandon stated, ‘I don’t want to study at [TAFE] but I want to pursue becoming a [personal trainer] maybe’; Bobby said, ‘I want to be an accountant. I want to work five days a week as an accountant. But I’ve got to study first’; and James said, ‘I did horticultural actually at school. [Q: Did you like that?] No. Didn’t like it. [Q: So, why did you pick that?] The teachers had to choose’.

Interests and hobbies also provided mechanisms for thinking about work preferences. Melissa’s strong interest in horses had resulted in her undertaking equine studies at TAFE. Subsequently, all of her job interests were centred around horses, including this example:

> I will get a certificate and then I can work with mare horses, stallions I really want to get. Because I really want to train stallions, I really want to get a stallion and train it. (Melissa, young person)

Similarly, Amy had a strong interest in dancing, and her work interests centred around the entertainment industry, such as working in a theme park. Corey and James both had a strong interest in sport, which was reflected in their work preferences:

> I really like [sports store]. That’s one of them. My other one would be [supermarket]. [Q: Doing what? Go back to [sports store], why would you like to work at [sports store]?] I love my sports equipment, shoes, all the different brands there. Would like to sort it all out, have a look at it while working … Just stocking up, yes and cleaning up. Pumping the footballs and soccer balls up, basketballs. (James, young person)

While there were no formal processes in place to engage young people in planning, it was nevertheless clear that in some cases, family members and teachers were tapping into the preferences of their young people when making decisions. There was some evidence that the young people had directly influenced decisions made about them.

6.5 Conclusion

Ordinary life goals, including community-based work, drove the thinking of both the young people and their family members. They saw a range of benefits from paid community-based work that extended beyond financial benefits. Their focus was on social inclusion and the young people having valued roles and a mechanism for feeling useful. Their thinking was strengths-based; the young person was considered capable and competent, requiring opportunities that were a ‘good fit’. However, the family members were unsure whether the opportunities they sought would be available.

School staff supported young people and family members by providing information about post-school options, making recommendations about suitable services and providing reports and other supports within a structured, time-limited process. The vision of paid community-based employment drove decision-making, with young people and family members choosing the service providers and supports they believed were economic participation-focused and offered pathways to community-based employment. However, a broader range of factors, including the need to adjust to post-school life and limitations related to intellectual disability such as transport, supervision and vulnerability in the community also factored into their decision-making.

Post-school, young people required time to adjust to changes in their routine and learn new skills to navigate the adult world. Family members navigated a complex system that lacks clear pathways to employment for their young people, and reported feeling overwhelmed and unsure about what they should be doing to help their young people realise their economic participation goals. While family members moved around the service system and tried out a range of supports and services, for many young people this did not ultimately lead to the desired outcome of paid community-based work.

Family members felt unsure about the choices they had made, and about the opportunities that would be available to their young people. Many felt overwhelmed by the service system and frustrated by the barriers they faced in relation to accessing funding and supports. Chapter 7 presents data about the barriers identified by young people and family members. This is overlaid with data provided by key informants to make visible the full set of barriers to economic participation across the ecosystem.

Chapter 7: Barriers to economic participation for young people with intellectual disability

7.1 Introduction

Young people with intellectual disability must negotiate a range of barriers that inhibit transitions and career trajectories into the mainstream labour market. This chapter reports the data regarding RQ2: *What are the barriers to economic participation for young people with an intellectual disability as they leave school, and how can these be addressed?* The data from young people, family members and key informants is presented using the Clifford Simplican et al. (2014) ecological model of social networks and community participation outlined in Chapter 4, focusing on 1) where in the ecosystem barriers exist, and 2) how the interactions of barriers influence economic participation outcomes for young people with intellectual disability. The use of Clifford Simplican et al.'s (2014) ecological model also aligns with the social inclusion outcomes described by young people and family members in Chapter 6.

Research participants described significant and complex barriers to engagement in economic participation-related activities both in school settings and in post-school supports and services. While these were primarily encountered at the service level, Clifford Simplican et al.'s organisational level, the interactions of policy, funding, attitudes and practices created barriers that could become insurmountable even for those with significant and committed support. While several of these barriers could be addressed at the individual and interpersonal level, others at the organisational, community and sociopolitical levels – where young people and their families can exert less influence – were more complex, and resulted in significant stress for family members who, particularly within the context of individualised funding, were required to navigate complex systems.

Table 7.1 below outlines the key barriers identified by participants and how they align with different 'ecosystem' levels. The table is used to structure this chapter's discussion of individual, interpersonal, organisational, community and sociopolitical barriers and how these barriers intersect.

Table 7.1

Barriers to economic participation for young people with intellectual disability

BARRIERS				
Individual	**Interpersonal**	**Organisational**	**Community**	**Sociopolitical**
Intellectual disability results in embodied difference	Conflicted attitudes of social network members	Deficit culture of schools and service providers	Young people are conceptualised as non-workers	Misalignment between policy and practice settings
		Organisational culture of working in silos	Unavailability of appropriate opportunities and supports	
		Families as system navigators		
		Lack of coordinated long-term planning		

7.2 Individual-level barriers

Barriers at the individual level include factors directly related to the young person, including the impacts of their intellectual disability. This section argues that an overemphasis on individual characteristics and lack of attention to environmental and contextual factors results in minimal effort to adapt environments to capitalise on young people's individual strengths. It identifies barriers to economic participation and makes visible the intersection between the conceptualisations of economic participation and intellectual disability which results in the widespread belief that young people with intellectual disability are not suitable to engage in community-based economic participation.

7.2.1 Intellectual disability results in embodied difference

The embodied nature of intellectual disability creates barriers to economic participation. For all the young people participating in this study, intellectual disability impacted on functioning to some extent. Reduced cognitive functioning combined with behavioural and communication difficulties resulted in significant reductions in their capacity to undertake day-to-day activities without support, including in a range of key areas associated with economic participation, such as literacy and numeracy, problem-solving, learning new things and moving around the community. Many of the young people had difficulty communicating with others, had health- and stamina-related constraints and, in some cases, had behaviours that impacted on others' perceptions of their suitability for economic participation activities. Intellectual disability created a perception of them as being unsuited to a range of post-school economic participation activities such as higher education and training. Reduced literacy and numeracy skills also resulted in TAFE and other structured training being dismissed as a post-school option for them by some family members. For example, when Mary reflected on her son's experiences at school when considering his post-school options, she said, 'he's not a book person, so he wouldn't be suitable to go and do a TAFE course where he's required to read and write'. Likewise, James dismissed TAFE as an option for himself because of the reading required: 'Probably not, because there's way too much reading and stuff as well'. Penny, James and Leanne were not confident in their numeracy skills, which meant that they found using money challenging. They thought this would reduce their opportunities to work in retail. Health and mental health issues and restrictions also impacted on some young people. For example, Vera's daughter had a long-term health issue associated with her intellectual disability: 'It's just her health. The stoma, that's my concern, even picking up big heavy boxes. She can't lift them. And that's what I worry about for her'. Finally, family members acknowledged that their young people learned differently and were sometimes slower to learn. Rhonda recognised that for her daughter Amy, learning new things took longer: 'It's just a longer road; it takes a long time'. Family members also thought employers would assume that the young people could not perform jobs to the required standard.

Bobby was working for Lisa, a small business owner. She acknowledged that his interpersonal and communication skills were markedly different from those of other employees at the company – for instance, he was more direct in his communication and less willing to be flexible in the way work was undertaken – resulting in other staff needing to learn to communicate differently with him.

7.3 Interpersonal-level barriers

The focus at the interpersonal level is on the attitudes of individuals who interact with young people with intellectual disability and those who interact with family members. At this level of the ecosystem, young people interact directly with a social network, including family members and school and service provider staff, who directly open up or close off economic participation opportunities for them. In addition, it was evident that the attitudes of individual social network members can influence the social network more broadly.

7.3.1 Conflicted attitudes of social network members

Attitudes of social network members about economic participation for the young people in this study could be described as conflicted – while they believed in the ability of their child, they were worried about the limitations identified by others. Family members, while strengths-focused individually, were cognisant of social stigma toward intellectual disability and therefore influenced by it. Their beliefs about their young people’s potential were thus mediated by the beliefs of others within their young people’s social networks, particularly school and disability service staff. Family members, having raised their children from birth, were working within a context of being told to have realistic expectations for them, and of awareness of the difficulty of locating suitable economic participation opportunities for them. Carol (parent) and Mandy (key informant) felt that special school staff were trying to encourage the parents not to get their hopes up:

> The special school gives you a whole ‘You’ve got to be realistic.’ The thing about low expectations in special schools sounds like, ‘You’ve got to be realistic. They’re probably really not going to get an open employment job, so you wouldn’t want to … that’s not fair to them to make them think that they’re going to get a job like that when they’re not really.’ (Carol, family member)
>
> And one of the things we talk about is the authority of the parent, that they know their child, but they’ve often been told by so many professionals, ‘Don’t get your hopes up.’ (Mandy, key informant)

Key informants noted a wide variation in attitudes and expectations about post-school activities among the families they interacted with:

> As much as things change, they stay the same. There’s a few parents who want more, you know, and it's those parents who come to us. Expectations of the family influence. Some families are very clever and very clear about their needs. Some families aren’t. Because if your expectations are low, it's going to reflect in your plan. (Joanne, key informant)

Pursuit of community-based economic participation is therefore not a priority for staff in schools, disability services and broader economic participation providers, and a narrower range of options are made available at transition.

Post-school, the vulnerability created by the young people's age and their intellectual disability, combined with family adjustment issues, led to family members making decisions that minimised risk and prioritised predictability, safety and protection. In some cases, family members left decision-making to school staff or service providers, as was the case for Lawrie, Mandy and Joanne. They described their experiences:

> [Some families], you'll just hear from them once and they're happy and you just do the paperwork closer to the end of the year and you just go from there, … [some] will just go along with whatever you're telling them. (Lawrie, key informant)
>
> … it's kind of like, 'It's all too hard, you tell me what to do,' or 'I don't know.' It's not like when you've got a young person without a disability you go to a barbeque and family friends, and 'Oh, what is your son doing?' 'Oh, we did this and then we did this,' so you learn about pathways from school through some of those conversations, where often for parents of young people with disability you might not have that, and the school's not showing you clear pathways or road maps, so it's like, 'Just tell me what I have to do.' (Mandy, key informant)
>
> I'm not supposed to guide families, but it's really sad when they have information night at the end of Year 12, families don't turn up. They expect the school to put them into – and they don't really care where it is because the expectations are so low. They just want five days a week, and they don't care where it is. I think that's really, really sad. (Joanne, key informant)

The extent to which these decisions had been influenced by years of being told by all parts of the system to lower their expectations was unclear; however, family members transitioning their young people to disability services appeared to be a response to longstanding deficit messages. Kylie, for example, felt that disability programs at TAFE were considered a safe option by family members, with little expectation that they would deliver an employment outcome:

> To be honest, they're just happy. The other students back at TAFE are going back to study. They're doing Cert II. [Q: So, it's another year and still no industry placement] No. [Q: They'll do their Cert II and then?] Work experience at Coles then back to TAFE. Because it's a safe space. They never move on and no one's pushing them. [Q: They're choosing TAFE because it's a safe space?] Yes. Yes. Absolutely. (Kylie, key informant)

Outwardly, some school and service provider staff showed belief in economic participation for young people with intellectual disability, recommending them for economic participation-focused programs for example. However, these activities did not draw on the individual young people's strengths, resulting in a failure to align those strengths with early economic participation opportunities. Mandy saw staff responding to broad stereotypes about intellectual disability rather than the strengths of individual young people:

> This preconceived idea of what someone's capabilities are ... has got nothing to do with them as an individual. And we know one of the key things to improve good work transition is high expectations, and particularly from parents; there's very clear research that that's there. Also, opportunities like work experience. But we know young people with disabilities often don't get work experience, and often their parents are told not to have high expectations. It's a range of professionals and, I guess, a focus on safety and what is safe, which is a weird thing in itself. How do we keep this person wrapped up? (Mandy, key informant)

Susan, a service provider, has regular contact with special schools and young people transition from school to her disability service. In her experience, special school staff did not work with young people to develop their work readiness: 'work is not a priority in a special school environment' (Susan). Joanne, a post-school training provider, was particularly concerned about the role of school staff in setting expectations:

> I don't think they realise how damaging what they're doing is for people, because they’ve usually got the trust of the parents and then the families have got the low expectations. (Joanne, key informant)

Bianca, a career educator, recounted a conversation with a school staff member that evidenced strong deficit readings of the economic participation capability of young people with intellectual disability: the staff member stated ‘needing to improve how she managed the unrealistic expectations of parents and students’ as her reason for attending a careers education training session.

School staff had a significant role in directing young people to vocational or non-vocational post-school options by providing advice to families about which services they should consider. Young people and family members had high trust in school staff, and relied on them for guidance about the most appropriate options for the young people. Mandy described seeing a deficit focus impact on the opportunities available to some young people in the collaborative transition network she is involved in:

> We still have networks that say, ‘that person shouldn’t do [transition program] because they won’t succeed’. So, we’re nowhere near perfect. (Mandy, key informant)

Likewise, Lawrie, the coordinator of a SLES program, has seen a practice among some school staff of sorting young people into two groups, ‘work suitable’ and not, before they have had the opportunity to explore work:

> Potentially, they’re more ‘day service’. The way it works with the expos, because I’ve got a really good relationship with [special schools], is the teachers, prior to the expo, will highlight to the families which service providers they should go and approach … ‘You should go and see [name] over there at the [disability provider] stand, I think Billy and Jackson will be really suitable for that.’ Whereas other students aren’t directed my way, presumably are being directed to day services and [TAFE] and things like that. (Lawrie, key informant)

Although staff in mainstream schools held very high economic participation expectations for their students generally, their attitudes towards students with intellectual disability differed. Rather than providing additional supports for these young people to undertake economic participation activities, or to adapt them to meet their needs, they expected family members to arrange the activities. In the case of parents Carol, Jane and Anne, their strong networks enabled them to locate suitable work experience placement for their young people, and they arranged the supports themselves.

Once young people were in the adult service system, the supports offered did not always align with family members' positive expectations about their economic participation. Clare felt that the plans put in place when her daughter Penny started with a transition-focused disability service had not been delivered on, because promised opportunities, such as a range of work experiences, had not materialised for her. She was concerned that the low expectations staff held about Penny's capacity to work were steering her towards non-vocational activities, as evidenced by their failure to communicate with her about registering with a DES:

> I suspect they had in their head, "She's only just out of school and, you know, we don't think she's ready for work and so we're not going to talk to the parents about that. (Clare, family member)

Several disability providers operated day-service-type models where young people undertook work-focused activities such as unpaid work experience, travel training, practical skill development and literacy and numeracy classes from a separate facility. Being in separate spaces sent a strong message that people with intellectual disability were not 'part of our world' – a world which includes employment – as described by Mandy:

> These are people within our community, so why do we have this segregated system that these young people have a special pathway? There's a whole systemic system

> that keeps people with disabilities – particularly intellectual disabilities – that ‘You’re not part of our world.’ You can have your little special work over there. (Mandy, key informant)

Conflicted attitudes about young people’s economic participation resulted in staff developing post-school activities that failed to build their capacity to the full extent possible. Although young people spent considerable time in unpaid work experience, it was often in enclave-style environments under the supervision of a disability support worker, rather than undertaking the real tasks of the workplace. Corey, Leanne and Melissa said that the work they did was predominately related to tidying the store, for example, rather than serving customers, and they had little interaction with other staff in the workplace. Some young people were excluded from being involved in some or all components of the activity they were undertaking, which were done instead by the disability support staff. This resulted in the young people lacking the full range of skills they needed to take up paid roles within their workplaces if they became available. James, for example, undertook unpaid work experience in a large supermarket, but had not yet had the opportunity to learn the skills required to be employed there such as operating the registers or working in the delicatessen. He had not been offered a paid role, despite the supermarket regularly recruiting new and sometimes unskilled staff. Likewise, Penny worked in an unpaid capacity at a coffee cart managed by a disability service provider, but a staff member made the coffee. Penny had also not been taught a broader range of skills despite working at the library for nearly a year, instead returning books and other items to the shelves under the supervision of a paid disability support worker. Similarly, Rhonda’s daughter Amy was involved in an unpaid work experience program, primarily in retail environments, and Rhonda expressed concern about the type of work Amy was doing:

> Even though she's working at these retail outlets, they're not actually on the floor – I think she's more out the back … And they should be. I would like that to transition so

> they're actually on the floor in the shops … if they're going to be in [name of store] or [name of store], just doing things in the shop as well. (Rhonda, family member)

Key informant Mandy felt that the deficit-focused DSP application process, occurring as it does concurrently with planning for transition, contributed to conflicted attitudes about economic participation:

> We know that when teenagers’ brains are developing there’s an optimum kind of thing around career development. Looking at ‘who am I, what am I, what do I like?’ -those kind of things – Year 9/10, 15/16 [years old]. And often parents thought the DSP process was some sort of scientific thing, that this government agency’s determining what your child could do work-wise, that ‘Oh, they can only work 0-8 hours.’ It was schools ‘Well, we can’t focus on employment for them because the government said that they can’t.’ [Q: Right, so the DSP was almost seen as a confirmation that the person can’t [work]?] Yeah. And I guess it was at that stage where young people are looking at what their futures are. It’s bad timing. And look, it’s just ridiculous that – it’s not a scientific mechanism; often it’s a 10-minute chat with someone that might have a preconceived idea of what people with certain disabilities can do or can’t do. (Mandy, key informant)

Family members’ expectations about the amount of income their young people would earn through paid work, and the low likelihood that it would replace the DSP, meant that earning money was not a high priority for them. Rather, they and others in the social network viewed DSP as their young people’s primary income source and were cognisant of the need to protect it when planning economic participation supports:

> Often the schools would tell us that they’re [family members] so worried about DSP and things like that and keeping DSP. I think it was just a fear, and particularly because now DSP is so hard to get, and you do have to kind of give the worst-case scenario. [Q: As in that they’ll lose it and they won’t be able to get back on?] Well, that ‘my child can’t do anything’. The victim narrative. (Mandy, key informant)

The fact that the financial aspects of working were unimportant meant family members, including Brian and Anne, believed their young people could be paid less than other employees if they were less productive, and this did not concern them. A lower wage may also help to protect the DSP payment, which begins to reduce once $178 in wages has been received in a fortnight. For example, Francine's son was paid in tips for working at a local pizza restaurant, which both she and he were happy with.

7.4 Organisational-level barriers

This level of Clifford Simplican et al.'s (2014) ecosystem model focuses on the organisations in which young people spend their time, and the impact of their cultures. In the context of intellectual disability, single organisations can hold a primacy in the lives of individuals as they spend large portions of time at those organisations. However, families also remain in focus at this level, as they hold key responsibility for selecting organisations and mediating their effects on young people's lives.

7.4.1 Deficit culture of schools and service providers

Decisions made and supports provided at the level of institutions such as schools were directly shaped by broadly held deficit-focused perceptions of the capabilities of young people with intellectual disability, and this resulted in a lack of normative economic participation opportunities for many. Individual school culture, rather than overarching policy settings, determined what early economic participation activities and supports were available to students, resulting in a wide variation of available opportunities. However, the deficit focus in many school settings in particular resulted in reduced access to early economic participation preparation activities: interviewees reported that appropriate early career development activities such as career education and work experience were rarely available to their young people because their schools did not prioritise work readiness for their students.

Two key informants provided examples:

> From a government point of view, you can implement things and have funding for things, but the funding goes to the school and then the school can determine what they do **…** So some schools won't do any work experience, or all the work experience would be in an ADE, so it's where they want to put their resources. (Mandy, key informant)
>
> **…**it's optional to take it [education department produced materials] up, so they're just materials that are there for the schools to take. Because you can't tell schools what to do, so the government can't mandate anything. (Laurelle, key informant)

Bianca was concerned about the impact of poor-quality career education in special schools, which was not provided by trained Career Practitioners:

> They're working outside the standards, and this is where the problem is. If they worked to the standards, which is what we expect them to be doing, the word is Career Practitioner. [Q: Even if you're in [a special school]?] Correct. Any touchpoint. [Q: Do many special development schools have a Career Practitioner? Is that your experience?] No. They've got people that are very well-meaning that might be social workers, and I don't think they're necessarily qualified. Certainly, the people in that room were not qualified, the vast majority of them, because I asked. (Bianca, key informant)

Schools often failed to provide young people with opportunities for work experience in real workplaces, and were considered to 'tick off' work experience rather than use it as an opportunity to support young people in exploring work. Lawrie thought that because schools did not prioritise work experience, they did not have the resources to provide on-site support to young people doing work experience: 'The teachers have classes to run and things to do'. Young people worked in groups and in 'safe' workplaces such as retail stores, libraries and op shops where there were protections in place, and were supervised. The stigma surrounding the capability, goals and future employability of young people with intellectual disability is indeed so entrenched in special schools that students often do work experience is ADEs:

> We often don't listen to the cues because we see the disability instead of the person, and that's really, really evident in the way that teachers approach these children. Their work experience at Year 10 is an ADE. You should not be taking people to an ADE as part of their Life Skills program, because it's basically lowering everyone’s expectations. That sets up a very dangerous precedent. (Joanne, key informant)

Mandy provided an example from her experience:

> I went to one mainstream school and a kid was doing his work experience in the library, at the school. He had a disability and I said, ‘Oh, does he want to be a librarian?’ and they looked at me like, *What a stupid question*. ‘We don’t know; he’s doing work experience, we’ve ticked.’ (Mandy, key informant)

Mary’s son had only been involved in group work experience, including at a fundraising sausage sizzle at a large retailer and at an ADE. Likewise, Leanne and Corey had been involved in group-based work experience, and Penny’s work experience at a large retailer was also in a group. When the young person was not supported well in work experience and it was not successful, this had the potential to reinforce low expectations. Mandy reported seeing this in special schools, for example:

> If you haven’t prepped the employer properly it’s going to be a disaster. And then that kid will come back, and they go, “Oh we knew it wouldn’t work, it’s the kid’s fault. (Mandy, key informant)

Despite some schools offering their students recognised Certificate-level qualifications, few of the young people had successfully completed them. Instead they undertook specific units, such as hospitality and horticulture, without the relevant workplace-based experience. This meant they missed out on practical work experience and the beginning of an accredited qualification pathway which was available to their peers.

7.4.2 Siloed organisational culture

Key informants identified barriers to organisations working collaboratively to support young people with disability holistically. One was the way in which individualised and competitive funding systems have resulted in organisations being disincentivised to engage in collaborative approaches. Lawrie's disability organisation, for example, is a registered training provider; the local TAFE would no longer work collaboratively with them because they were considered a competitor. These siloed organisational cultures are also driven by policy settings (discussed in 7.6).

The interface between the NDIS and other parts of the system, particularly the education system and DES, has also created barriers to people with intellectual disability receiving seamless services because they can't be registered with two service providers, such as a SLES provider and a DES provider concurrently. Lawrie provided an example:

> I actually have my first two participants who were at [DES] who are just not getting anywhere. They need work experience, they just can't get a job yet, so we're, in a sense, doing the opposite process and taking them back to NDIS. They're in their early 20s … we can't use Capacity Building [funding], Finding and Keeping a Job funding, and they're registered at the DES. You can't do that – that's double dipping … the government says, 'That's two buckets of funding doing the same thing.' (Lawrie, key informant)

Susan agreed that the interface between the NDIS-funded SLES program and the DES program, particularly related to individuals receiving services concurrently, was problematic, reinforcing siloed or isolationist organisational cultures and operating environments:

> There's questions about the overlap [between SLES and DES]. I said, 'I think he's pretty DES ready'. The problem is if it takes DES six months to find him a job, he's sitting at home for six months, and he's going backwards. The cohort we are working with are not in that DES specific category. They're in the zero to eight hours [work] capacity, where 'Let's just pop them in things, give them something to do'. And they've been

> told, ‘No, no, no, you can't work. No, you can't do that’. They've been told the sort of things they're not capable of doing. Right down to having that zero to seven [hours per week] working capacity says they don't have a capacity to work. Therefore, ‘You don't have to go there’. If they were to go to a DES, the DES would say, ‘You don't really have to come here, I can exit you’. I know it happens. (Susan, key informant)

Support to obtain a first after-school job is also unlikely. While it is technically possible to receive support from a DES while at school, doing so was described by key informants as complex, and therefore it rarely happened. In addition, DES providers are unable to support young people on school-based work experience, and NDIS funding for employment supports is not supposed to be used within education settings. Mandy described the interface issue, saying:

> We often get ‘what you’re doing is double dipping’, and so even the language; there’s not the language within government of collaboration. Because how do you access this bit, that bit, if they’re all working together? Or that’s federal money and that’s state money and we can’t have them crossing paths. Life doesn’t work with this compartmental [thinking] – it’s not like anyone’s success is [due to only] one thing. (Mandy, key informant)

There is a failure to recognise the significant support young people with intellectual disability require to undertake work experience or obtain their first job, and at the organisational level, interface issues therefore inadvertently reduce opportunities to engage in early work experience. Mandy described the complexity:

> [Q: They can use (Finding and Keeping a Job funding) for work experience?] Well, it depends. So, what is the responsibility of the school, and what is the responsibility of the NDIS? That old interface. We argue that people with disabilities need more than your couple of days work experience in Year 10, and those additional work experiences should be the responsibility of the NDIS, if that’s their choice. We know that people with disability, we’ve got the research that says that, they need multiple work experiences and activities, more than people without disability, so it’s the

> disability that's the difference, and how we deal with that. But it's often hard, when you're working with Local Area Coordinators who conduct the NDIS planning to get that through. (Mandy, key informant)

The difficulty Mandy experienced made her conscious of how much more difficult it must be for family members and people with intellectual disability to navigate such complex systems:

> If I have trouble and I'm living and breathing it, how the hell is anyone else supposed to do this, and how the hell are young people, a person with an intellectual disability, and their parents supposed to do it?

Mandy described families as 'exhausted' and having endured a 'hard slog'.

7.4.3 Families as system navigators (an informal service)

As detailed in Chapter 6 and Part 7.3.1 above, family members participating in this study bore the brunt of responsibility for obtaining economic participation opportunities for their young people. The introduction of the NDIS had added complexity to an already complex and siloed economic participation ecosystem, inadvertently leading to family members becoming de facto service coordinators. Although they felt capable of using NDIS funding to arrange services and supports for their young people, including therapies, social support, recreation activities and independent living skills training, the complexity of the economic participation system left them feeling that they lack the confidence and skills to do so in this area. Several described their frustration at the lack of collaboration or connection between disparate parts of the system, such as disability providers and employers. Vera, who has an intellectual disability herself, described how complex it was for her to arrange for her daughter to attend TAFE on some days and use NDIS funding to purchase supports from a disability provider on the others:

> I rang [disability provider] and asked them [for paperwork related to her daughter]. 'Oh, we can't give you that.' I told TAFE, I said, 'I'll give you their number and you can ring them up.' Because they won't give me anything. On that plan that I gave [disability

> provider], it said it’s supposed to give her a Certificate when she’s done her literacy. [Q: You couldn’t get the two services to work out a way that they could come together and work for [daughter]?] No. So I said, ‘Well, don’t worry about it. I’ll just keep her home.’ I just couldn’t be bothered with them. [Q: That’s a shame for [daughter] isn’t it?] Yes. And they wonder why people with disabilities – it’s hard for them. (Vera, family member)

The reliance on family members to support young people during the transition period, particularly within an individualised funding system, resulted in wide variations in what was available to individuals. In the absence of connected and collaborative organisational models, family members needed to be highly skilled and confident to navigate the route to economic participation support. Several, driven by a strong vision, were committed to achieving their young people’s economic participation goals and were therefore actively working towards them. In Chapter 6 they described their roles in planning and coordination, which were built partly on luck and partly on the resources and supports they had access to. Despite adopting ‘consumer’ thinking, and expecting to be able to ‘shop around’ as necessary to purchase the necessary services and supports across various life areas, they found that disability and mainstream services failed to deliver what was promised, particularly in relation to economic participation. They therefore had to fill the gaps themselves. In addition, their preference for avoiding segregated services meant there were few options available to them, despite having adequate funding for post-school supports.

The barriers family members reported at the organisational level were common and systemic: poor experiences with service providers; battles with NDIS planners about funding; confusing systems; and a lack of support to engage with employers and training providers. The formal service system’s failure to provide the opportunities young people and family members were seeking resulted in an impression among family members that they would only achieve economic participation outcomes via their own efforts, and that they could not rely completely on services to do what they needed:

> I think a lot of parents that I know through the footy club [felt] the same thing – if we don't chase it up, which is the world we live in now, if you don't chase it up, it ain't going to happen. (Brian, family member)

Family member Carol's expectation that she would organise and support individualised work experience for her son was an example, as was the significant effort she made to secure him a part-time job and put the necessary supports in place. Without her efforts, in the absence of formal organisational supports, neither the work placement nor the part-time job would have eventuated.

The variation in families' capacity to support young people directly, for example by facilitating community-based opportunities and supports, resulted in inequity in the provision of opportunities for the various young people involved in this study. Family members with strong networks, social capital and advocacy and system navigation skills were able to create a greater range and volume of opportunities for their young people, as a direct result of their access to a wider range of information and supports. Vera's own intellectual disability impacted on the support she could provide to her daughter and the opportunities that were available to her. While her strong beliefs about her daughter working meant she was trying her best to find the right options, with little support and a confusing system, she was experiencing significant barriers to managing her daughter's NDIS plan and instead had to rely on service providers to do it for her:

> [Re managing NDIS funding] I couldn't do that. My brain will just go. 'No. I can't do that.' [Q: Has anybody talked to you about using NDIS money to support [daughter] at work, has that come up? Or has anyone told you about the DES?] They have, but that has gone over me. It's very complicated because I'm no good at things like that. Too much information. (Vera, family member)

System barriers such as the NDIS interface issues outlined above meant that even the most highly skilled advocates were unable to make the various parts of the system join up as required.

In addition to this, lack of knowledge about employment, including industrial arrangements and wages, resulted in family members lacking the confidence to broker economic participation opportunities themselves. In particular, they knew little about labour market regulation, how regulations differ for young people with intellectual disability, and what economic participation services and supports were available. Rather than being supported in developing these skills, family member Brian described a service provider 'glossing over it' during one of their short informal meetings, leaving him lacking the confidence to source economic participation opportunities for his son from within his own networks.

Overall, despite an emerging evidence base describing the supports that achieve economic participation outcomes for young people with intellectual disability, there were insufficient services available within the community to support their economic participation, and some that were available were inappropriately designed. This resulted in families moving around the service system, seeking out appropriate supports.

7.4.4 Lack of coordinated long-term planning

Siloed systems led to fragmented planning for economic participation for young people with intellectual disability. Given the role schools assume in preparing young people for transition, it would be reasonable to expect them to play a significant role in supporting or facilitating longer-term thinking and planning about post-school economic participation. However, at the point of leaving school none of the young people had a documented vision or formal plan that included the actions required to achieve their economic participation goals. Mandy thought that despite a purported focus on family engagement, different schools involved family members in planning to varying degrees, and this was dependent on individual personnel within each school rather than a systematised approach. There was no formal, structured method for including young people in decision-making about their economic participation in any meaningful way. Instead, the young people had only limited information about the types of programs, services and supports available to them, often gleaned from attending the careers expo.

There was also a lack of crucial long-term planning and coordination to help young people with intellectual disability understand and interconnect the various parts of their ecosystem, including family members, school, disability service providers, and training and employment providers, to achieve economic participation outcomes. Instead, several separate, disjointed planning processes were undertaken by various system actors, including schools, service providers and the NDIS. Mandy noted the complex planning processes she had seen firsthand while working with families in transition over the past eight years:

> We counted, there's about five different planning processes that they've been involved with. You're going through NDIS planning and then Centrelink, and if you're accessing a DES, and schooling often has two planning processes; it might be pathway planning and then individual learning planning ... not integrated. So ideally, I would like to see one plan, so the poor people don't have to try to coordinate all those different relationships – and then having all these resources to implement a plan. (Mandy, key informant)

The fractured nature of individualised service delivery exacerbated the disjointed planning according to Mandy, particularly where multiple providers were involved with a young person:

> If you're getting a range of NDIS providers and they all want you to do another kind of process, it's just like 'oh my God, enough already'. You know, more action, less planning. (Mandy, key informant)

Often there was limited involvement by young people and family members, and siloed systems meant that plans were not always documented or shared among young people, family members and other service providers. There was also no clear mechanism for the various service providers to communicate regularly with the young people and their family members about goals or progress towards achieving them, despite their reliance on providers to create the pathway to work. For example, Mary's son had been with a disability provider since finishing school two years previously. Her experience was typical of the disjointed planning process:

> [Q: Was there a plan or something written for [son] at the start?] Probably, but I've never actually seen whether he's obtained or surpassed any of the goals they've set for him. [Q: You weren't involved in setting those goals?] I don't think so. I don't recall. No one's come out and discussed his strengths, his weaknesses, his passions, his interests … 'Hey, how about we could go down this avenue because he's showing great potential', you know something like that. (Mary, key informant)

Clare felt service providers were uninterested in collaborating with families: 'I think they think they're the experts on it and they know what they're doing and they're going to do it'.

Service provider staff decided what activities the young people would undertake, primarily using informal methods. The conversation below with James demonstrates his lack of involvement in the planning of his work experience.

> [Q: So, you went to [sports store] and how come you don't go there anymore?] Because there's not enough spaces lately. [Staff members name], she chooses where I go. [Q: Does she know that you really love [sports store]?] Yes, she does. [Q: But she hasn't been able to organise for you to go there?] Yes. (James, young person)

In the absence of a plan from the provider, James had written his own plan, detailing the jobs he would like to try, although he had not shared this with his service provider:

> [Q: So, [provider] didn't write a plan for you?] No, I did it myself. [Q: And so, what did you put on the plan?] Well. My jobs. Personal training, my shops that I want to work at. Things like that. (James, young person)

Despite all of the young people being NDIS participants, NDIS planning processes also lacked a collaborative or longer-term focus, being geared instead towards allocating the short-term funding the young person needed to purchase necessary services over the next 12 months. Family members described processes that were complex and stressful, and difficulty communicating with NDIS planners about their young people's needs. Rather than being collaborative, the planning meetings involved power imbalances, and decisions being made without adequate knowledge of the young people's circumstances, resulting in inequity in the allocation of funding. Clare, for example, remains unclear about why Penny did not receive SLES funding despite seemingly being eligible.

The lack of coordinated planning led to young people moving around the system without any plan, instead focusing on being in a program to fill time: 'Often with a young person it'll be, "Oh you do this program" or "You do that program"' (Mandy, key informant). It also resulted in agencies failing to take responsibility when outcomes were not reached, preferring to shift the blame to other parts of the system:

> Often there's this blame game, that everyone blames each other for things not working; schools blame the post-school world and these providers, and vice versa. DES providers say 'It's just the schools haven't prepared these kids.' [Q: And when you're in silos I guess it's easy to do that, isn't it?] It's very easy to do that, and you don't want to blame yourself, so it is very easy to lay blame. (Mandy, key informant)

7.5 Community-level barriers

Clifford Simplican et al. (2014) describe the community-level of the ecosystem as focusing on the availability of services and broader community discourses that have influence. This section explores community attitudes, culture and discourse about economic participation for young people with intellectual disability, along with the availability of appropriate services to support them in achieving economic participation outcomes.

7.5.1 Young people are conceptualised as non-workers

Family members and key informants outlined a broad set of attitudes that exist across the community about young people with intellectual disability's capacity to engage in economic participation. A complex policy environment underpinned by disparate education and labour market policies and income support at the sociopolitical level (7.6) drives attitudes, which in turn become reinterpreted as assumed facts that are relayed across all ecosystem levels. The community discourses around DSP, work capacity and the nature of 'work' are thus reinscribed by parties at various levels, especially in parts of the service system (e.g., schools, service providers) and among employers and others at the community level.

Underpinning much of the service delivery system at community level are pervasive attitudes that conceptualise young people with intellectual disability as non-workers. Manifest entitlement to DSP – that is, lifetime income support – and the availability of segregated specialist services correlates with the assumption that people with intellectual disability are essentially exempted from economic participation:

> We've got a government system that quashes expectations, so normally young people without disabilities, they can't just do nothing. There's an expectation that you'll be doing something. From that policy level, people are exempt if you've got a disability, there is this general 'Okay, well, all young people should be active and doing things, unless you've got a disability and then it doesn't matter'. (Mandy, key informant)

Family members thought that the wider community was unaware that community-based economic participation is an aspiration for this cohort because so few people with intellectual disability are in community-based spaces. In addition, the widespread perception that people with intellectual disability could be kept occupied with work-like or leisure activities rather than paid work, which resulted in young people being in devalued roles such as disability centres or sheltered workshops, reinforced widely held views about their capacity:

> People particularly with intellectual disabilities, or people with disabilities in general, have been stigmatised by society and marginalised, and one of the reasons is because they don't have access to valued roles, so people see people in devalued roles, like going to a day service. Most of the community just cannot relate to what happens in a day service. (Donna, key informant)

Lisa, an employer, agreed that there was ignorance in the wider community about the employment aspirations of people with intellectual disability, which restricted their opportunities:

> I would say that the first thing would be ignorance. That we're not aware that there's a need for these people to be employed, as a culture. [Q: So, before the DES contacted you, you wouldn't have known?] No idea. Never even considered it. And yet I've been going for nine years, I would have considered it right from the beginning. So, ignorance is the first thing, we don't know. (Lisa, key informant)

Clare and Anne thought employers believed that young people with intellectual disability had less capacity to work in mainstream roles:

> [Q: What do you think, if I said to this café, 'Let's think about hiring a person with Down syndrome,' what would their assumptions be about a person?] I think they would assume that that person is never going to work to capacity. Which is a shame because in some aspects they'll work beyond the capacity, that once you show them how to do something it will be done exactly right every time. Same with a lot of people with intellectual disabilities, especially if they're on the spectrum, it'll be done exactly the way you want it. (Clare, family member)
>
> I think most people think that people with disability can't keep a job, they're always sick, they can't work, they can't do anything because they've got a disability. Well, that's a load of baloney because they can do what you and I can do. They might take 10 times as long or they might do it different, but they can still do it. (Anne, family member)

Donna, a key informant, felt that assumptions about capacity to work were based on outdated models of employment:

> People often think that work is nine until five. And if we really look at society, it's not nine to five anymore. It might have been 30 years ago, but it's not like that now. So, the notion that people could not work that many hours a week [is outdated]. The other thing is that some of our employment processes [are too rigid], like you get a PD [position description] for a whole job, and someone with an intellectual disability may not be able to fill that PD. (Donna, key informant)

Joanne, another key informant, believed that thinking about work opportunities was limited by a perception that people needed to be independent:

> They expect that you need be totally independent to work. They can't imagine – they don't see the examples, so they can't imagine the examples. Examples are not out there. They don't see it. And that's why things really get turned around when people come and see us, they can see people doing all sorts of different roles they never expected. (Joanne, key informant)

Young people with intellectual disability are frequently judged against a concept of 'work readiness' despite this never being formally measured. The need to have an eight-hour minimum work capacity to access DES acts to exclude people who are not ready to work eight hours per week, which impacts on school leavers profoundly. For example, Janice was told her son was not 'work ready':

> … it was only a couple of months before that we'd had the final meeting with [disability provider] and they'd said to us, 'He's a long way from being work ready. A long way.' Well three months later he was working. (Janice, family member)

7.5.2 Unavailability of appropriate opportunities and supports

Clifford Simplican et al.'s (2014) ecological model focuses on the availability of and access to appropriate services at the community level. Lack of access to appropriate economic participation services for young people with intellectual disability was a key barrier, family members and key informants agreed. Participants in this study reported that very few of the specialist services and evidence-informed economic participation activities described in Chapter 3 are widely or systematically available in Australia, and mainstream services fail to adapt their offerings to include these young people.

Mandy felt that young people with intellectual disability having less access to economic participation-related capacity building opportunities widened the gap between them and their peers without disability, leaving them with fewer skills:

> Young people with disabilities are already disadvantaged, and then they leave school and all their peers without disabilities have done vocational education, they've done work experience, they've done an after-school job. And they [young people with disabilities] come out with nothing. (Mandy, key informant)

Few had a casual job while at school, despite their siblings being expected to do so. For example, family member Brian had a strong opinion about the need for his son without disability to have a casual job once he turned 15. I asked him if anybody thought it would be a good idea for Corey to have a casual job too and he replied, 'No, we didn't think it was necessary'. While Rohan had worked for a short time in a milk bar and Carol's son had worked in a canteen at a sports stadium on Saturday mornings, both jobs were organised and supported by family members, rather than by paid services.

Evidence-informed transition approaches were not widely or systematically available. Key informant Mandy's transition program, contextually developed based on research evidence, was only available to young people if their schools were members of a locally based network, and none of the young people in the study had access to such a network. In addition, typical post-school economic participation activities such as studying for a degree, diploma or certificate or undertaking a traineeship or apprenticeship were not readily available to the young people, and were difficult to complete. They were typically offered in a narrow range of occupations such as hospitality. Carol’s son and Brandon were both unable to complete their TAFE courses successfully because TAFE was unable to adapt its offerings or provide the specialised supports needed for them to successfully undertake the course requirements. This was despite significant involvement from external supports and family members:

> [Brandon’s] passed quite a number of the units and I believe he probably would (pass them all) – it was technicalities really. We had a lot of difficulties. Both TAFE settings, there was all sorts of problems. It was very difficult to coordinate. We put supports in place, a person to be there and we tried different ways of doing that, either being in the class with him or meeting up afterwards as more of a tutor to help with assignments. We were trying to be less intrusive on his experience as a student. (Janice, family member)

Carol outlined a long list of failings in communication, the provision of supports and the skillset of the staff involved in the program her son attended:

> We set up this system where I thought we had the school on board, we had the extra teacher on board, we used our NDIS plan. And the TAFE did nothing – the TAFE has been a disaster… the TAFE … didn’t do any reasonable adjustment. They didn’t change any of the materials …. I don’t want to have anything to do with these people anymore. (Carol, family member)

Sharon reported that the increasing privatisation of TAFE meant its ability to support people with additional needs has reduced, as has its connections to industry that lead to jobs. Rather than creating real pathways to work, Kylie and Joanne felt there was no expectation among TAFE students with intellectual disability of a paid employment outcome. Instead, they attended specific TAFE courses such as disability-specific ‘work education’ and ‘transition’ courses to keep them busy:

> If you ask someone who’s gone through TAFE, we know the work placement officer at [name of TAFE], and he’s open about it: ‘We put people through the same thing. We’ve got no expectations of getting anyone a job’. [Q: Because they haven’t got the

> resources, or they haven’t –] They just don't believe people can work. So now they're doing Certificate IV. Why are you doing Certificate IV in work education? Certificate II in work education, there’s going to be Certificate III in work education, there’s – they just need to get a job … it's just giving them the experience of work. And in fact, there’s no expectation of doing work education to get a job. (Joanne, key informant)

SLES programs were a popular post-school choice for families with economic participation goals. However, SLES provider staff members interviewed, including Lawrie, George and Susan, were unable to articulate a clear model or pathway to work for the young people involved in their programs and acknowledged the low employment outcomes their programs achieved. Susan, an ADE staff member, was in the early stages of implementing a new SLES program for school leavers. It was unclear how the service model had been developed or whether the organisation had drawn from the research evidence to create it. Despite this, it was fully subscribed in its first year.

SLES programs were considered a ‘stepping stone’ post-school. Family members and young people were initially satisfied that the economic participation needs of the young people were being met. However, the activities provided – including unpaid work experience and ‘job readiness’ courses – had not led to the employment outcomes they sought and there were no obvious links between the programs and employers. There was also confusion among the young people and family members about the role of the SLES provider: James and Leanne both thought their SLES providers would help them find a paid job once they were considered ‘work ready’, despite that being the role of a DES provider. Referral to DES for job placement was also required despite the barriers people with intellectual disability face accessing DES (see Part 7.6.1).

Key informant Mandy was concerned that SLES had created another disability pathway:

> We’re trying to create normal pathways. Employers don’t say ‘Oh, you’ve done SLES for two years’ – it’s not a normal pathway, it’s a disability pathway. We talk about it should be a normal pathway with additional supports, rather than trying to create new, different ways and pathways. (Mandy, key informant)

Several key informants believed the lack of widespread customised employment in Australia created a significant barrier for young people with intellectual disability:

> In Australia, we just do not have a good understanding of customised employment, which is really what’s needed for people with intellectual disability, and those types of processes, and sticking with it. (Donna, key informant)

Despite families instinctively knowing that their young people needed jobs tailored specifically for them in a highly supportive workplace, they were not able to locate suitably skilled providers who could support them in brokering an arrangement. While some family members were aware of specialist DES providers with deep skills supporting people with intellectual disability into work, these services were only available to young people in certain regions. Customised employment and the Discovery process were not available to any of the young people, resulting in vital information about their strengths and aptitudes, including the social networks they could draw from, not being documented and thus not informing the delivery of their supports.

The government-funded DES program, the primary service-level mechanism for young people with intellectual disability seeking employment, came in for heavy criticism. The program is underpinned by Active Labour Market approaches rather than working to any mandated evidence-informed model. Paul, a key informant, had seen examples of good practice in the system, but said these were not embedded:

> Look, there's a couple of little organisations that I see do quite well in this space, but they do it in spite of, rather than because of, the program. (Paul, key informant)

Several young people and family members had engaged with DES providers with very poor outcomes. Francine had had a particularly negative experience when she signed her son up with a DES provider on the advice of his disability provider:

> I know there are a few agencies out there who say they can find you employment. But DES was one of them and they let me down. And I haven't gone down to try and find someone else. (Francine, family member)

Anne's son Rohan was supported by a DES when he worked in a community-based job with a not-for-profit organisation:

> The DES program was absolutely hopeless because that person from DES was supposed to be there, supervising and never was there. Even if they just went and just checked that he was doing whatever once a week because he was there five days a week, three or four hours a day. Even if they did that. (Anne, family member)

There was an overwhelming feeling that DES providers had the wrong model, the wrong culture and complex rules, and over time had lost their specialisation, so were no longer suitable for people with intellectual disability. Key informants were of the strong opinion that most lacked the necessary expertise to place people with intellectual disability into work. Paul, who had a long history working in roles related to employment for young people with intellectual disability, explained how he felt the culture had shifted:

> What we know from the 80s, there was a belief around that everybody could work. That's what we believed, and we'll do what it takes to get someone a job, and yes, they need support, and it's not time-limited. We're talking about helping people with complex needs to get employment and keep it. For most people with intellectual disability, it's not like an eight-week job support model, it's the wrong model. It's a much more values-based, commitment-based, visionary type of model that has some flexibility, good, solid understanding of process, good understanding of relationship, how to build relationship with business, all of those types of things. [Q: Which are not characteristics we would say are in a current DES?] You might see some workers with those characteristics spasmodically. It's not to say every DES organisation does.

> Spasmodically we see some glimmers. [Q: But having a case load of 70 clients is not going to be conducive] That’s not going to work. It’s just not going to work. We're at a time where probably the skill level of DES for people with intellectual disability or on the spectrum is at an all-time low. It's at an all-time low. (Paul, key informant)

A key role of DES is to manage the compliance of people with disability who have mutual obligation requirements because they are in receipt of income support. This has resulted in DES’s staffing shifting to the administrative skill sets needed to manage high caseloads of unemployed clients. For Susan, this was the key factor in DES’s inability to support people with intellectual disability:

> Ultimately, that's why DES doesn't work. It is a compliance-driven contract that we are trying to place people into. They don't necessarily fit that compliance model. [Q: You can't do the individualisation that people need?] No. It's black and white. People are grey. Really. And ultimately, that's what's letting people down. (Susan, key informant)

The complex rules associated with DES also created barriers for people with intellectual disability. One common example was the requirement for young people to have capacity to work eight hours per week, as previously identified. Laurelle, a key informant, illustrated how this rule could impact on young people with intellectual disability who were trying to get a foothold in the system:

> The other big issue is that you’re only eligible for DES if you can demonstrate eight hours work capacity. There is a whole group of people who can’t, so it’s the call of the DES to say ‘We will take you on anyway and we will help you build up the hours,’ because that is what you’re going to need. (Laurelle, key informant)

In addition to the poor service DES provides, there is a lack of alternative employment service providers in the system. SLES programs rely on DESs to undertake employment placement at the completion of their programs rather than delivering customised employment approaches themselves, leaving young people with intellectual disability without ‘fit-for-purpose’ employment supports. WIL programs are only at demonstration stage in Australia, and are supported primarily by philanthropy. Very few young people therefore have access to the in-situ training opportunities available within these programs: For example, Rohan only obtained a place in a one-year WIL demonstration project after his mother received information about it from someone in her social network, though they were hopeful it would lead to a paid job with one of the employer partners at the completion of the year. Kylie's involvement in a demonstration WIL program as a job coach had resulted in good outcomes for a very small number of young people. She felt that the model was appropriate for young people but unsustainable in the current market due to the high cost of delivery and the need for collaborative approaches, which were not funded.

Access to appropriate supports for employers was an additional issue raised by family members, who thought employers were unlikely to know that young people with intellectual disability were seeking community-based employment opportunities or how they could support such opportunities. The non-worker expectation outlined previously meant that specific employer-focused initiatives targeting other underemployed groups were not available to people with intellectual disability. Sharyn, the CEO of a national employer-focused organisation, described how government supported the employment of other priority groups using what she called 'enterprise solutions':

> The Department of Prime Minister and Cabinet runs the employment parity program, and so they'll say to a large business, 'We'll give you $16.5 million if you commit to taking on 200 Indigenous employees over the next two years.' [Q: Great. Do we have anything similar?] Nothing. No. [Department of] Jobs and Small Business have it for young people, they have it for single mums, they have it for old people. The DES program is the only program that there's no enterprise solution. (Sharyn, key informant)

This was particularly problematic for large businesses which were identified as difficult to navigate:

> You've got to get through the reception gatekeeper to get the HR person's name. Then they've got to speak to the department. It’s a 12-month process just trying to speak to the right person half the time. (Susan, key informant)

George’s organisation was using individualised processes to locate employment opportunities. He described this as difficult.

> It’s not like there’s a job coming along every week. It’s about finding that right employer, that right workplace, that is supportive of our person, that is going to be able to meet their needs, that can take some time. When you do find that, you celebrate it because it’s hard and even harder than that is not just finding the job it’s then keeping the job. (George, key informant)

7.6 Sociopolitical-level barriers

This section focuses on the impact policy settings and funding mechanisms have on the real economic participation opportunities young people have access to. However, it is important to note that as levels are interdependent, sociopolitical settings influence other ecological levels too.

7.6.1 Misalignment between policy and practice settings

> Yeah, the system never gets blamed, it’s always the young person. (Mandy, key informant)

The barriers described throughout this chapter are largely the result of disparate policy and funding structures within the ecosystem. Young people with intellectual disability experience a complicated and confused policy agenda, driven by a mixture of welfare and rights-based policies that at once encourage them to have economic participation goals and disincentivise the service system from providing the supports they need to achieve them. Disability-focused policy such as the NDIS, education policy, income support policy and labour market policy all impact on this cohort, in a sense due to the different identities its members carry. For example, education department policy impacts the early economic participation opportunities young people have access to via the school system as students. Paul described the economic participation policy and practice landscape for people with intellectual disability as a ‘market mess’:

> So, there's this market mess that’s been created through a policy setting that really mixes up entitlement with welfare with economy with sort of jobs, and because the four are sort of in a mixing machine, people find it very hard, particularly people with permanent impairments, find it very hard to engage. (Paul, key informant)

Disability policy settings, despite becoming more human rights-based, continue to perpetuate an image of people with intellectual disability as needing care and protection, as incapable and as benefiting from being in segregated settings with others with intellectual disability. Ideas of an ordinary life and improved economic and community participation underpin the NDIS, but key informants reported that new policy and funding settings have not changed how economic participation supports are delivered to young people with intellectual disability:

> The biggest enabler to people having as ordinary life as possible is employment. We should really put lots of focus and emphasis on employment, and we should be demanding the policy positions that we want of the Commonwealth government in this space. (Paul, key informant)

Paul thought that the ideals of the NDIS had not been realised in its implementation:

> I always liked to think of it in a very simple way, that there are pushing sorts of mechanisms for people with disability to work and there's pulling mechanisms. Without saying this is the full list of them, at the macro level, I think the policy settings are all wrong. Disability is still viewed as welfare, so as long as people remain the objects of the lawmakers' pity, we will always have a mismatch with policy versus intent. The NDIS is a fantastic piece of legislation: rights-based, humanistic insurance principles that should collude together to change the world, but I'm looking at Australia really struggling to implement it in any meaningful way. That doesn't mean that there haven’t been good news stories. That doesn't mean some good things

> haven't happened, but the NDIS Act is more than about just giving some people money. (Paul, key informant)

Paul described the policy settings as perpetuating welfare approaches for some people with disability, as they allow people to

> opt in if you want to, but we're happy for you to go and take welfare for the rest of your life and go on the DSP and we'll put you in this special program where you can weave baskets for a month or whatever it may be. (Paul, key informant)

Rather than simplifying service access for young people with intellectual disability and their family members, individualised funding has added complexity. The NDIS was described as overly bureaucratic and difficult to deal with. In addition, securing funding didn’t guarantee that the economic participation supports young people needed were available to purchase. As Paul noted:

> We've moved to a world of consumer-directed supports. Disability has gone down this path as well, and the other aspect of that consumer-directed supports is there is a market response and maybe that's just a little bit too premature to think that the market can respond to the individual needs of every person through the current construct of human services in Australia. [Q: So, you're saying that the market is still too immature within the disability landscape? The market has got a long way to go?] A long way to go. (Paul, key informant)

Paul saw the separation of non-work supports (provided by the NDIS) and employment supports (provided by another arm of government) as problematic, because for a person with intellectual disability they need to be seamless to create a successful work outcome:

> This interface issue between the [NDIS] and the DES is probably one of the biggest barriers, so if we could rethink what works within intellectual disability in relation to the journey to work, we probably wouldn't have DES on the landscape. Not because it mightn't have a role to play, but it's just an option of a number of mechanisms you might have to do that final step into work, right into a job, into some sort of economic participation. To me that means there is a massive opportunity for a market to form

> around this very personalised, very individualised, customised employment. The NDIS needs to get its head around the fact that those activities are not all predictable. There is this freedom that needs to come back in. Now, we've got the major building block, the NDIS, which is individually funded, but then we've got to get the individual motivated and their significant others motivated to go on the journey, and it is a journey, isn't it? It's not, ‘I want my son to work.’ But some special mums and dads do find their own way and you do say, ‘Wow, wow, look at them go.’ But if we systematise that, you've got to start and meet the person where they're at. You've got to have the resources and decision-making as close to the individual as you can, and you've got to have a properly oriented professional around them who is doing that. (Paul, key informant)

Economic participation policy responsibility for young people with intellectual disability rests partially with the NDIS and partially with the DSS, which manages and oversees the DES program. SLESs and ADEs are purchased using individualised NDIS funding, as are day centre style programs, the alternative to economic participation for this cohort. In the absence of community-based economic participation goals, this creates an easy default pathway for young people to move from school to segregated options. In addition, working within an ADE is considered an employment outcome by the NDIS and by service providers, despite young people and their family members seeking community-based outcomes. When young people want to pursue non-traditional options such as community-based employment, however, policy setting are more complex. They and their family members must navigate mainstream economic participation systems such as DES, or advocate for small amounts of NDIS employment-related funding such as Finding and Keeping a Job funding. Carol explained why this is hard to get:

> I’ve heard other people didn’t get Finding and Keeping a Job [funding]. It seemed to be because we already had [the job] – it seemed like you had to have the gig before you get the money. Whereas, really, people need the money before they get the gig.

> Because they need the gig – they need the money to find the gig – you know. (Carol, family member)

The policy settings fail to incentivise providers, within both the NDIS marketplace and the mainstream economic participation system, to deliver the evidence-based supports that lead to improved economic participation outcomes. Key informants explained that there are few incentives for mainstream contracted DESs to make the often complex adjustments required to deliver evidence-based practice to young people with intellectual disability, and no penalties for not doing so. The contracted funding mechanism results in providers being able to achieve their contracted outcomes despite failing to provide adequate supports to people with intellectual disability. Outcome measures and payments are not linked in any way to the achievement of individual outcomes, or to outcomes for specific cohorts such as people with intellectual disability, who are the most highly disadvantaged in terms of economic participation. In addition, being in receipt of DSP manifestly results in an absence of mutual obligation requirements for this cohort, and mutual obligations are a key driver of eligibility for government-funded employment-related programs. This creates a disincentive for DES to provide the necessary support. Key informants described DES providers as ‘parking’ people with intellectual disability – that is, providing them with minimal levels of service – in order to receive government payments, then exiting them at the completion of the 18-month program period.

Laurelle, a long-time policy adviser, agreed that over time the emphasis of the employment services system had changed:

> There used to be a whole lot of capacity in the DES program to do this work and it’s just gone over the years because it just wasn’t attractive, it didn’t work, it didn’t fit in the model, in the framework. Especially when the DES program moved out of FaHCSIA [Department of Families, Housing, Community Services and Indigenous Affairs] into Department of Jobs, it became a labour market program. It wasn’t being informed by

> the Disability Services Act or the principles of normalisation, it was a labour market program. People who work in labour market programs call unemployed people stock. It's the stock of unemployed people. That includes a lot of people with intellectual disability that wouldn't be considered in that way because they would just be considered people you have to look after. And if they can do a few hours a week that's really nice but it's not going to make an impact on the bottom-line of the welfare bill. (Laurelle, key informant)

DES and NDIS policy and program guidelines are poorly aligned, which creates interface barriers, particularly related to individuals receiving services from two funding streams concurrently. When Francine followed the advice of her son's disability provider and registered him with a DES to help look for work, it inadvertently resulted in the loss of his critical NDIS funding:

> DES stuffed up, right up with everything. We, through [disability provider] were told to register with DES, because they had a connection there … but we were told they would help [son] prepare a resume, they'd work with him to do a resume. Maybe go to a few job interviews. But that never happened. And because we did sign up, NDIS saw it that we were double dipping and that he was capable of going to work and didn't need his day services. [Q: So that's where you lost the funding?] Yes. So we're no longer registered with DES. (Francine, family member)

Young people and family members described their own poor experiences of DES not as anomalies at the service provider level but as systemic policy failings that locked people with intellectual disability out of one of the few programmatic responses designed to support their employment aspirations. The system itself, rather than individual providers, was described as deeply flawed and unable to cater to the needs of young people with intellectual disability who want to work in the community-based labour market.

Overlaying evidence-based practice such as customised employment onto the existing funding models has been problematic. One DES's attempt to introduce customised employment ultimately failed because the funding model did not support the intense work required. Donna thought that rather than this being an individual provider-level problem, it would be difficult to deliver customised employment within the existing DES framework:

> To say DES is going to do customised employment is a bit like what we are really seeing with the NDIS. Big vision, but practical implementation doesn't happen like that. It's got to be built from the ground up with people who know, who can build their knowledge and understand it and really get their head around and find people jobs, know what's involved in that … there's a couple of little organisations that do quite well in this space [customised employment], but they do it in spite of, rather than because of the [DES] program. (Donna, key informant)

Paul was also unsure how customised employment could be delivered by DESs under the current funding arrangements:

> I'm going to be quite blunt and say to you the DES program is about numbers. It's about the government focusing on efficiency, a false efficiency that says there's an amount of time that we'll allow for a DES provider to find and place a person in work [i.e. two years] … And if you get that right, we'll reward you at the maximum. If you don't get that quite right, you won't do as well. And if you get that wrong, you'll probably lose money on it. But if you think about a person with intellectual disability, if the evidence shows that you work with them in a journey of discovery and in a strengths-based way, and you go at their pace, they may not necessarily fit that programmatic structure. **…** So, people with permanent disability, particularly intellectual disability, and indeed many people on the [Autism] spectrum, don't fit that structure and, therefore, the DES market won't respond to them [because they are not rewarded for doing so]. (Paul, key informant)

Donna had attempted to skill up a local DES provider in customised employment, albeit informally:

> It's informal support, and coaching, and resources and, getting people to training. I could count on one hand significant people in Australia who have a very good understanding of customised employment, so the leadership is lacking. In the United

> States, we see such a good understanding of customised employment, really strong efforts of individuals and organisations who find people with very complex disability employment. (Donna, key informant)

Kylie, a DES employee, was utilising customised employment approaches within a WIL demonstration program, including providing significant on-site support to 10 young people undertaking training within a large hospital. This was possible because the DES she is employed by agreed to make extra funding available during the demonstration phase of the project, due to funding being sourced through other means.

The misalignment between policy and practice impacted more broadly than employment supports. Several participants provided examples of how collaborative training models such as WIL models were being trialled in the Australian context. Despite these achieving a high rate of economic participation outcomes for the young people involved, there was no overarching strategy for external evaluation, sharing of knowledge or replication to ensure their wide availability. Such activities were also not described as clearly linked to and supported by government policy. Kylie’s non-profit DES committed significant additional project funds due to their commitment to developing innovative economic participation approaches. Likewise, George had time-limited funding for a ‘steps to employment’ style program for young people attending a special school, which he thought would have to finish when the funding ran out.

Current policy settings also disincentivise TAFE and other post-school providers from supporting young people with intellectual disability. A reduction in secure funding and the privatisation of the sector have resulted in providers stripping out additional supports, as both Carol and Janice experienced when their sons enrolled in mainstream courses.

The lack of specific targets for the employment of people with intellectual disability was identified as a barrier by key informants. Laurelle, who worked in state government, was not aware of any targets or nationally consistent data collection related to employment outcomes for young people with intellectual disability, or any state-based transition data about their post-school destinations. Sharyn, who had worked in employment services since the 1980s, reflected on the lack of data in the highly individualised system in which young people with intellectual disability currently operate. Paul strongly believed that what gets measured gets prioritised, and explained the focus of the NDIS outcomes framework:

> We have an agency (NDIA) that is driven by the outcomes data that the actuary wishes to collect. You probably haven't got it quite right, have you? [Q: And employment is not critical enough] It's a very low level. ‘I've got the amount of work I want. I want more work’ [as indicators]. [Q: There's not enough strong employment indicators?] Yeah. We are quite happy to wallow in mediocrity, because there's no consequences, you see? There are no consequences. (Paul, key informant)

There is little policy focus on working with employers to create opportunities, and little focus on creating the customised roles young people with intellectual disability require. In particular, there are few structured opportunities for businesses and organisations to meet young people and see if there is a ‘good fit’. Paul thought that employers lacked awareness of the issue and had no leadership incentivising action or change that would create much-needed employment opportunities. Sharyn agreed that lack of demand and leadership were a major challenge that inhibited pathways between training and education and employment:

> It’s an interesting dilemma because you can’t just have people going to TAFE without it being connected to something. So that’s been a challenge. That’s where trying to get a more demand led approach, where there’s a linkage to employers from the get-go, would be, of course, more expensive, but would get better outcomes. (Sharyn, key informant)

Providing individualised funding would not by itself address this complex issue. For Sharyn, the challenge was the lack of a systems ‘framework’ to generate pathways into employment that would support both employee and employer:

> At the moment, you could use the $10,000 to do lots of courses, but at the point where you're looking for a job, who would help you, and how would you know how much money you need for support, or would you just take the money, and then take it to [employment services] and say, 'I've got this money'? No, you wouldn't say, 'I've got this money and I'll give you 50 bucks now, and I'll give you $5,000 when you get me a job.' No, you wouldn't, because it's complex. Also implied is the legal relationships between the employee and the employer, and the boundaries around those legal relationships. Getting a job is a contract, and you can't sell out your rights under that contract. We didn't know how that would work. (Sharyn, key informant)

The absence of a structured option for supporting a young person with intellectual disability potentially left the employer exposed to risk, and therefore reluctant to engage. Mandy argued that because the collaborative network she managed provided risk mitigation to local employers, this encouraged them to engage:

> They [employers] were willing to take a risk. And a lot of them had some connection with disability, but it was, 'We'll give this a go, we think everyone should have a go,' but they didn't want to be left, because it was a risk for them. They wanted to know that they could mitigate that risk. (Mandy, key informant)

Without explicit policy focus on the human rights underpinning of economic participation for young people with intellectual disability, significant barriers will continue to exist within a complex policy environment predominately driven by economic settings.

7.7 Conclusion

This chapter presented data related to barriers drawn from young people, family members and key informants, mapped against the ecological model of social networks and community participation proposed by Clifford Simplican et al. (2014). Barriers to economic participation within each level of the ecosystem were made visible, along with system interface barriers emanating primarily from the complex policy, funding and practice settings. Intersecting ecosystem barriers shape the experiences, pathways and challenges faced by young people and family members, and are framed by short term pathway thinking.

Chapter 8 will present data about strategies to address these barriers, including the resources and supports young people and family members value, how these are provided, by whom and when.

Chapter 8: Resources, supports and strategies to address barriers

8.1 Introduction

With the right forms of support and strategies in place the opportunities and pathways to employment for young people with a disability can be significantly expanded. This chapter reports the data regarding the second part of RQ2, *How can barriers to economic participation for young people with intellectual disability as they leave school be addressed?* and RQ3, *What are the resources and supports young people with intellectual disability and their families value in relation to economic participation as they transition from adolescence to adulthood? How should these resources be provided and by whom?* The themes identified below are categorised according to Clifford Simplican et al.'s (2014) ecological model and reflect the data provided by young people with intellectual disability, family members and key informants. They identify strategies to address the barriers identified in Chapter 7.

8.2 Individual-level resources, supports and strategies

8.2.1 Strengths focus

There was a strong belief among participants that all young people have skills and attributes suitable for work and that these need to be deliberately highlighted due to widely held negative perceptions about intellectual disability. Respondents thought a greater focus on the strengths of the young people and their positive attributes would lead to the identification of economic participation opportunities. Attributes such as interests or passions, reliability, a caring nature, friendliness, a sense of humour and pride in their work were identified as positive characteristics that shifted the focus from young people's deficits, productivity or work skills and enabled them to be viewed more holistically. Family members were strengths-focused, but required support to recognise strengths and share them with others. For example, Carol expected her son's school to identify his competencies and provide her with a competency statement at the end of his schooling. Janice would have liked something similar, given that her son had developed a range of competencies in the TAFE courses he had undertaken despite not completing the units. In her mind, documentation of her son's competencies would enable her to communicate those to potential employers.

A strengths focus underpins career development. Bianca believed that supporting young people to explore their own place in the world was an important first step in understanding their strengths:

> The self-awareness component – self-actualisation, who am I, what do I value, where do I come from, where's my place in this world – has to be worked on first before you even think about whether or not they're suitable for being an astronaut. (Bianca, key informant)

Strengths-focused approaches recognise that young people have the capacity to learn and develop, and the post-school period is critical in terms of developing skills for work. Mandy noted that access to high-quality training and support for learning new skills, such as school-based apprenticeships and traineeships in the workplace, resulted in employment outcomes for the young people concerned:

> They're [people with disabilities] finishing [School Based Apprenticeships and Traineeships (SBATs)] at a higher rate than people without disabilities. All they needed was an opportunity that was supported, and scaffolded. It's not that we did anything, it was just we created an opportunity they should have had anyway. (Mandy, key informant)

Strengths-focused approaches recognise the longer timeframes in which young people with intellectual disability learn new skills, and their need for specialised approaches or additional supports. Paul thought the focus needed to move to highly personalised approaches, which is what the evidence says is effective. For example, Rohan's strengths-focused WIL program enabled him to develop skills in the classroom and the workplace simultaneously. In addition, by providing a broad range of opportunities to experience different roles and work environments it allowed him to identify his strengths and preferences. A key component of Kylie's WIL program was therefore to support young people in exploring a range of job roles in vastly different settings so that they could develop strengths and preferences.

Mandy believed that parents have a critical role to play in developing a strengths-focused perspective, by supporting their young person in having 'role models, opportunities, and by accepting that failure and being nervous is okay, that it's normal'. Bianca referred to the need to engage with young people and families using what she called 'hope-centred engagement':

> Hope-centred is where you start where the person is at and you allow the story to come out and you listen. You listen to the cues to see what they've experienced, what they're really interested in. (Bianca, key informant)

Recognising the ages of their young people at school leaving time, their limited life skills and vulnerability, families were seeking developmental approaches focused on opportunities to safely build skills and confidence, particularly in the period immediately post-school. Mandy thought of this as providing 'the same pathway as other young people, with scaffolding'. Family members recognised the need to customise a work role based on their young person's strengths and preferences, with part-time hours and suitable job tasks. Brian thought customising a role should not necessitate complex changes:

> Where he [son] does his thing at [store] and some of the bigger companies stacking shelves and that sort of thing, I couldn't see that being a problem for them [employers]. They don't have to do anything different, they don't have to tool up, they don't have to change anything, really. (Brian, family member)

All of the young people had particular interests that could be used as platforms to develop economic participation opportunities and were able to talk about these during the interview.

Family members often referred to them as ‘passions’. As Donna noted, drawing on those interests and hobbies was another way to be strengths-based and create opportunities:

> It’s much easier to ask when you know what someone does. ‘My son would love to do that job, or is passionate about this’, not become something about disability, but about the person’s interests. (Donna, key informant)

For example, Melissa’s equestrian passion led to a paid role teaching young children how to ride horses, and she was studying to further her opportunities in that field.

Strengths- and outcome-focused approaches enabled the young people to have access to a broader range of opportunities to develop and understand their strengths. For example, Kate’s school used career education, work experience and accredited curriculum as strengths-based approaches, with work experience opportunities providing family members and school staff with important information about the students’ strengths and preferences as well as their support needs as they prepared to move out of the school system. TTW schools, as key informant Mandy reported, likewise supported young people to develop and recognise their strengths through work experience opportunities.

8.3 Interpersonal-level resources, supports and strategies

8.3.1 Raising expectations

There was widespread agreement that economic participation, particularly in the form of a paid job in the community, was an important mechanism for promoting community inclusion of people with intellectual disability. Participants felt that changing economic participation outcomes for young people with intellectual disability would require a shift in understanding of the purpose and value of community-based work, and the various ways in which it is achievable, in order to build expectations. Joanne, a training provider, sees a multitude of benefits from young people with intellectual disability having a job:

> I say to families, ‘Recreation’s good, but on the weekend or at night. People need to work. They need to have meaningful engagement. You need quality of life, you need to have unpaid people in your life, you need to have money, and you need to be connected. And you can hit all three of those buttons if you get a job.’ (Joanne, key informant)

In Paul’s experience, conversations about work needed to start when a young person is about fifteen. Joanne felt that it started with the language used, noting that Employment First was powerful language to change attitudes:

> Employment First. Try it first before you go to an ADE. Use the language, the language reflects the expectations. Even if they're wrong, they’ve got the right to try it. (Joanne, key informant)

Susan saw it as a human rights issue for the young people, who were often told they could not work before being given the chance to try:

> Belief is the hugest thing. You and I have a right and a pathway through employment and to follow what it is we're passionate about. Young people with a disability are told that they can't, when they actually can. Given the right environment and the right support, they absolutely can. (Susan, key informant)

Key informants noted that while pockets of raised expectations exist, the norm of young people with intellectual disability having the opportunity to try work before transitioning to non-work or segregated service types needed to be embedded. Donna thought that the change was occurring among younger people who had been raised within a more integrated community culture: ‘What we’re seeing is younger families actually expecting their son or daughter to leave school and work’.

Young people and family members also benefited from seeing other young people’s success, a strategy used by the collaborative network Mandy manages:

> When you have [collaborative network] working in the school, the Year 7 kids can see the older kids going out to work, the parents can see kids that look like their kid [going out to work] and newsletters, and just that element of knowing what is possible. [Q: Is that what builds expectations the most, from what you've seen, is other kids doing it?] Yeah, and then the school's changing their expectations. One of the schools was saying, 'We used to talk about skills for life, now we talk about career skills' ... One parent … said '[collaborative network] was the first time someone had said that employment was possible… 'if that wasn't there, she would have gone through and just reinforced the thoughts that she'd been told. [Q: Straight to another option.] Yep. (Mandy, key informant)

One strategy to change expectations was the use of ambassadors:

> [Collaborative network] used school ambassadors, young people who had left school and got into work. I was working with some of our partners and gave them public speaking skills, and they would go back into the school and do presentations, to parents and young people. For the parents and for the young person, they could see a real person. (Mandy, key informant)

Donna felt that creating an expectation of community inclusion was critical, as was working one person at a time with both families and young people to integrate young people into community settings, including economic participation settings:

> I'm not one for ripping the rug out from people. Often, our approach when people have been in a day program full-time is to work with the person and their family to just do one day in the community, and then two days, and then three days, so they build their confidence and they work backwards. But the vision is up front that the person will be included in that community. (Donna, key informant)

Recognising that intellectual disability created barriers to employment, the family members participating in this study valued information about what was possible; therefore, supporting them in exploring options was an effective strategy to raise expectations. Rhonda valued attending a formal information session at her daughter's school where previous parents spoke about what helped them, because it opened her eyes to what her daughter might be able to do post-school:

> I remember going, maybe when Amy was in Year 10, they had an information evening at her school, where they had parents, previous parents coming in and speaking about their experiences and what their children have done now. So, that was really lovely too. Just to think, ‘Oh wow! They can do that!’ [Q: So, that really did help you in terms of thinking about what was possible?] Yeah, yeah definitely. It was a real positive and they're the sorts of things you do – it's not so much about what they can't do, it's what they can do and you build on that. (Rhonda, family member)

Laurelle provided an example of a pilot project aimed at raising expectations that she thought had been well received by families:

> I’m aware of workshops talking about raising expectations, and then you can draw on the tools, the online tools to reinforce that. I think the power of meeting other parents who are going through the same thing, and raising those expectations with parents around yes, ‘you can expect this for your child’. (Laurelle, key informant)

Bianca’s organisation ran training:

> We got funding and we ran ‘Building Ability Through Career Management’. That was the program, and it started with the parents and we ran five workshops for parents. The first group we had 12 or 13 parents, then the second group we had 30. They just rocked up. They'd heard about it. We got 12 registrations and 30 showed up. Mums and dads. Kids with them. Young adults with them. Then we had one where grandparents came. (Bianca, key informant)

Lisa, an employer, agreed that young people who were working could act as influencers, raising the expectations of other young people with intellectual disability:

> If Bobby was able to talk about his job to other people who didn’t have a job, it might motivate them to want to get a job. I think from the inside there could be more energy going towards getting a job. I don’t think where he goes there’s any real, ‘Oh, great, Bobby you’ve got a job’. They’re quite happy for them to just keep cycling through,

> going to the same things throughout their lives. Learning skills that never get applied in the workforce. I think people who do succeed in getting a job could be given opportunities to share that. (Lisa, key informant)

Interacting with people with intellectual disability working in community-based workplaces was another way family members learned what might be possible. Family member Brian's involvement with a local football club gave him hope about what his son Corey might be able to achieve when he was older, as other club members with intellectual disability worked, held driver's licences and lived in their own homes. Likewise, Clare shopped at a local supermarket where a man with intellectual disability was employed, and seeing him maintain that role over time helped her to think about Penny's future work.

8.3.2 The family is the system

As is typical for young people in early adulthood, family support was critical during transition. As discussed previously, young people recognised family members as an important and long-term source of support and relied on them to undertake a range of tasks during transition and early adulthood. When asked who would help them find a job or a course, they typically stated that their mother or father would, not a service provider, which matched Mandy's experience with the young people in her collaborative network, who stated that their greatest support was from family. For example, Melissa's mother was helping her find information about a life skills course she wanted to do and had organised enrolment in a Certificate-level course, and Melissa thought it would also be her mum who would help organise the work experience she was hoping to undertake. Family members also helped with learning new life skills, such as using public transport and cooking, and drove young people to activities.

Young people also drew on their siblings for support and to frame normative expectations in early adulthood. James described his brother as 'really good at technology' and said that his brother taught him computer skills. Melissa's brother had taught her a range of skills, including how to use public transport and top up her travel card. Siblings were also a source of ideas about the types of work young people might be able to do:

> I like working – like fast food. [Q: In fast food?] Yeah, I like working at Macca's. [Q: Okay, have you ever done that?] No. My sister's boyfriend does. (Amy, young person).

They therefore both provide positive role models and have a key role to play in building important skills that young people need in order to engage in economic participation activities.

As discussed, family members regarded themselves as the primary supports of their young people, and actively sought opportunities for them to thrive in their adult lives. They took on a wide variety of roles supporting their young people, including developing and holding onto their vision, sourcing courses and programs, and seeking employment opportunities. For instance, James' mother was looking for work for him using mainstream avenues:

> [Q: has mum helped you at all with looking for a job?] Yes, she has. [Q: What sort of things has mum helped you with?] She thinks I'm perfect for Coles. She would actually go on the Internet on her phone and search up job placements sometimes. (James, young person)

Brandon also spoke about a work opportunity his mother organised with his uncle.

> When I went there last, I did work experience with my uncle, when I was 22, I went and did sheep shearing, helped them with sheep shearing. [Q: Were you actually shearing the sheep?] No, I was running the sheep up and like whacking them with a stick [Q: To get them moving?] Yeah. But running them up. (Brandon, young person)

And George's service was building family and community connections into its employment planning:

> I guess we saw a few gaps in that we needed the family to be involved more. Because we would come out with all these great pathways that the people were involved in and had buy-in. 'My mum said no. It's too far away. Mum doesn't think I can get

> there.’ Those sorts of challenges started to come up. So in comes the family. Part of what we do is a networking piece [for each young person] on getting to know that community – you know, ‘what does your uncle do?’ All those sorts of things. And we start exploring their wider network and around who they know and those sorts of things [as a precursor to searching for employment]. (George, key informant)

Much of the young people’s community access was organised via activities they were involved in with their families rather than through disability services. Being a member of a community-based club or association supported young people in being included in community-based activities from an early age, which both enabled the development of soft skills required for work and helped them build connections to community members who might offer economic participation opportunities later. Sporting clubs and community organisations such as Scouts were examples of places where young people spent time. Brandon’s involvement in a local church also provided him with a valued role and a network of friends and supports.

Carol used community connections to support her son’s economic participation. Not only did he go back to his own childcare provider to undertake work experience, it was Carol’s networks within the sports club her family was involved in that led to the opportunity for him to work casually in the stadium’s café. Similarly, Jane was trying to utilise her daughter’s networks to increase the opportunities available to her:

> It’s not what you know, it’s who you know. If you have a big network of friends and people and do whatever, you’re spreading your possibilities more broadly. And hopefully some opportunities will come out of them. (Jane, family member)

8.4 Organisational-level resources, supports and strategies

8.4.1 Support to build the capacity and social capital of families as ‘career allies’

Mandy, Bianca and Joanne felt that given their importance, the roles families play in the transitions of young people with intellectual disability needed to be formally acknowledged and supported within the complex post-school systems they navigate. For Bianca, parents’ aspirations for their children were critically important, and the role of services was not to take over from them, but to skill up families and support their journey so that they could become 'career allies'.

Access to information was a critical support families needed, particularly because they had little experience in navigating the adult disability and employment systems. They reported needing a wide range of information to support their decision-making about economic participation, including information about what was possible, practical support including how to locate supports and services, and advice on 'what works'. They needed different information at different times and from different sources. The careers expo was an example of a systemic support that was valued by young people and family members because it provided information about multiple services in one place, giving them a way to sort through what interested them so that they could follow up and get more detailed information later. For example, several family members stated that they visited a service provider after the expo to assess whether it was a good fit for their young person. Rhonda also attended a tour organised by her child's school where she saw people with intellectual disability working in open employment. Brandon has undertaken paid roles talking to families about his experience of moving into his own home and having paid work. He thinks it helps to inspire people.

Practical information such as knowing who to contact to ask, 'How do I do X, Y or Z?' was also important to the family members. Brian was looking for a 'guide'. He felt that he had one shot at it, so he wanted to be clear about what he should be doing to support his son's work goals. Information about activities that young people should be undertaking was also seen as important. For example, information about the importance of casual after-school employment for people with disabilities that Carol received during a formal training session provided by a capacity building organisation, set her on a path toward identifying a suitable opportunity for her son when he turned fifteen. Similarly, Janice had the support of a formal parent group when she started self-managing, which she found invaluable.

Information about what funding a young person was eligible for and support in navigating the NDIS planning process were important. Anne had the support of an experienced person, who was both a parent of a person with intellectual disability and a service provider, to help her negotiate with the NDIS for funds for her son to be involved in a demonstration project. Clare and Jane had help from an advocate to prepare their NDIS plans and reported that they got exactly what they needed from the NDIS as a result. Likewise, Carol was getting advice from a service provider to ensure that her son had access to the funding he needed to undertake the transition program they offered.

Brian was seeking information about employers in his area who might be willing to employ his son and was willing to do whatever was needed to help his son find a paid work opportunity, but needed support to talk to employers about how he would be paid. Jane had connections which she thought might have work opportunities for her daughter but felt nervous about approaching them. Other family members also had connections with local businesses that they thought might offer opportunities to their young people but needed support and information in order to approach them. Information about the legal aspects of employment – in particular, information about how a young person would be paid – was critical to support families in utilising their own networks to create opportunities. Mary needed information about employment specifically, and thought that ‘a guide’ to talking to employers about employing your child would be helpful. Francine thought that access to a skilled ‘broker’ – someone who knew the young person well and could talk to employers on their behalf – would be helpful, particularly for navigating complex systems and negotiating within their existing networks:

> They're missing that middle person, you've got the educators and then you've got the employers. But that middle person who can actually connect both of them [is needed]. (Francine, family member)

Other parents of young people with intellectual disabilities were a valuable source of both information and support to the family members. They were available via formal means such as information sessions, and through informal networks such as schools and sporting clubs. Mary and Brian valued the informal information they received from other parents at their sons' sporting clubs, Brian thought the club could host formal information sessions about various topics related to disability, as it would be easy for the families and young people to engage with the information in a familiar and comfortable environment. He also felt that the natural leaders in the club – in his case the coach – should be supported to take on a more formal role supporting other families:

> You feel more comfortable. For Corey to come along, he would know that his teammates are going to be there. It would certainly be a friendlier environment. I actually believe our coach [and his wife] they've got a lot of time on their hands, and their son's 31 now. They've been doing it longer than [wife] and I, they've got 10 years on us. I said to him if we had an NDIS night, he could get up there – because everybody listens to him, and he's got that natural [leadership] and he's the head coach. (Brian, family member)

Family members of young people with Down syndrome had been connected to formal support networks since their children's birth. They relied heavily on the advice and information they received from other members of these networks, particularly those whose children were older than theirs. Jane looked up to another woman in the group who she saw as a natural leader, a person who could be relied upon for information and advice, and Anne received information about a new employment initiative her son was suitable for through the network.

Family-led capacity building organisations supported families seeking to create valuable and valued lives for their young people. However, seven of the ten family members had not heard of the Victorian-based family capacity building organisation, despite the resources they could access through it. For Jane, Janice and Carol, who were connected to it, the organisation's key role was to open their minds to possibilities related to ordinary life goals and help create typical pathways for young people with intellectual disability:

> Typical pathways for people post-school is to have work, go overseas, volunteer maybe, do some things, hang out with their mates. Life is not just one thing, it's a holistic thing. A model that could help people to build a good life, what does that look like at your age, and for you to control supports and direct, one person at a time. Those themes could be developed into an employment approach. (Donna, key informant)

The organisation had strong roots in Social Role Valorisation, which is based on the notion that the good things any society has to offer are more easily accessible to people who have valued social roles (Wolfensberger, 2000). Donna described why the concept is important:

> Valued roles are really important because our whole identity is tied up in our roles, and our valued roles. Everyone wants to be valued. No one wants to be devalued in what we do. That's an important concept. (Donna, key informant)

Janice believed all families should be exposed to this theory, to help them understand how to build communities around their young people.

The organisation provided Janice and others with a broad range of information and resources to support families, including a website, videos, tools, workshops and webinars, mentors and paid supports. Janice was also a member of a smaller formal network of parents established to support the ordinary life goals of young people with intellectual disability. This network offered capacity building activities as well as individualised supports that could be paid for using NDIS funding:

> One of the most powerful things that has helped me are the family stories, being exposed to that. I was really fortunate to be part of [name of network] where I had mentors who'd been down the track 10 years on. I remember the first meetings, I'd be like 'So how do you employ someone? If I want to get this funding, what do I have to do exactly?' [Q: And other families gave you that?] Yeah, 'Ring up and say you want to do this.' 'Oh okay, as simple as that?' (Janice, family member)

Janice was involved in the network as both a parent and a resource for other families. Her involvement in a pilot program helped her learn how to self-manage her son's NDIS funding, establish a circle of support and employ her own support workers. She considered it important to be taught how to do things, rather than having a service do it for you. Mary relied on other parents from her son's school for information. Brian had done likewise for 13 years, but then suddenly lost contact with them. He felt there should be a link to a formal parents' network post-school:

> That would be really good, because you learn a lot through parents don't you, good or bad… We've all got the same dramas, we all sook about the same things come Friday. (Brian, family member)

Vera also wanted a support group of other parents:

> A support group would be better. If you've got any problems, you can talk around to people and see what they think. Give me some ideas about what to do. (Vera, family member)

School staff were a trusted source of information for family members as they planned their young people's transitions due to the long connections they had to the schools. The structured approach to transition these family members experienced was valuable and one of the few systemic structures in place.

Disability providers were another important source of information, particularly during the transition period. Rhonda and Vera recalled feeling a strong sense of trust for one particular staff member, which influenced their decision to choose that provider. Joanne, a service provider, believed that a trusting relationship with families was critical and took time to build. Aligned with a ‘Just Three’ (i.e., just three hours employment per week) approach to creating small first jobs, Joanne’s organisation used family connections to try to broker employment opportunities:

> Tell us your network and if you want us to contact them we’ll contact. If you've been shopping in your local supermarket for 20 years, I’ll talk to the person. We’ve got a lot of outcomes like that. And you know, half of these Just Three outcomes will come through people who know families. They don't come out of the woodwork. (Joanne, key informant)

The two-year structure of her post-school program resulted in high levels of trust and for her that made all the difference.

Circles of support were another mechanism for increasing access to economic participation opportunities. Donna explained the value of a circle:

> We found often mum gets stuck with the implementation in individualised support. That doesn’t mean it doesn’t progress. We have seen some amazing results, or it’s just mum and dad. The idea of bringing more people into the conversation, gathering a group of people who know and care about the person, is they’ve got more ideas, more contacts, more links with the community. It creates a ground swell of connection and knowledge, but also can offer some support. Not always, but it certainly does that, and people holding the vision into the future. (Donna, key informant)

Carol felt strongly that a circle of support needed a purpose, so setting one up around employment was a goal for her now that her son had finished school. Janice’s son Brandon had a circle of support comprising people from his community to help him to be involved in planning his life. Janice said it was helpful to both Brandon and her, because the community members saw things through a different lens. Brandon thought Circle members gave him ‘ideas as well as connections’, and Janice provided an example of how the circle had provided practical support to Brandon:

> And practical things, like for example when he was going on his first job interview, we did a Circle session where we did mock interviews and people threw questions at him, which was great. And we had a Circle member who is a year younger than Brandon who was also looking at getting her first part-time job and was having trouble with getting that work. So the brainstorms in the circle were relevant to her so it was very rich. (Janice, family member)

Janice purchased the supports needed to establish and manage Brandon’s Circle via her NDIS funding, something she thought other families could do if they were provided with the information.

8.4.2 Collaborative structures

Collaborative structures and cultures were identified as critical for addressing the fragmented service system the young people and families needed to navigate. Rather than linking into one service provider, collaborative structures improved system navigation and brought a range of actors to the table, which promoted problem-solving and helped to build the ‘basket’ of services and supports available to young people. Mandy’s collaborative network provided an example:

> We talk about blending and braiding, so we’re looking at in this local community – because there’s state funding, and federal funding, and local funding, philanthropic funding … It’s like, ‘Where do you want to go? We can use a bit of this and a bit of that, and do this; oh that didn’t work, so we’ll try that, that individualised pathway,’ and having a range of different organisations involved. (Mandy, key informant)

Collaborative place-based practice also brought businesses to the table, something key informant Sharyn thought helped solve local problems:

> Coming back to that idea of having a local place-based approach where there are some employers, linking that to either your local Chamber [of Commerce] or something, and then you ask the employers to solve the problem. Because everyone likes to think that they can solve a problem. You then ask them to help, and then to be part of that solution for your community. (Sharyn, key informant)

The WIL collaboration between a large hospital, a training provider and Kylie's employment service utilised a collaborative framework to provide accredited work-based training to young people with disability where, individually, none of the actors would have been able to provide the support required. The project resulted in paid employment outcomes for nearly all of its participants. Similarly, George's disability service was working collaboratively with a DES to build employment opportunities for the young people in his transition program. This blending of specialist knowledge and skills in supporting people with intellectual disability with employment sector contacts and knowledge resulted in the creation of several paid roles, including Bobby's job with an organic food company.

As Donna noted, using the right structures and models leads to better outcomes:

> [Disability advocate] Michael Kendrick would say "You can't grow oranges from a lemon tree," you know. Like, the model needs to be right, right from the start. (Donna, key informant)

Mandy felt that collaborative structures supported sharing the workload among different actors, thereby increasing the opportunities available to young people:

> We ran information nights, and we often went to careers nights or post-school transition nights, so that group of people, rather than having a stall of their own, they could present as a collective. (Mandy, key informant)

Critically, such approaches become replicable and a source of knowledge for others wanting to address a similar issue:

> We have all the research, so we can say ‘What do you want to do?’ and we can just pull it, ‘Here you go,’ it just makes it easier… Because we had an evidence base on what was happening overseas, and quite a structured model in the sense of taking all the resources from the pilot, people didn’t have to re-create it. It was ‘Here’s your little formula, here you go, we’ll be in support’ ... we’d get all the players round the table and we’d go and present and then they’d decide if that’s something they wanted to do in their communities. (Mandy, key informant)

Another approach to bring about collaboration was via an intermediary; this role was critical within Mandy’s network, but it was unclear whose responsibility it was:

> With our networks there’s someone there to pull everything together, navigate the system. We think that the LAC [Local Area Coordinator] could take on that role and they talk about between the mainstream and the disability world, so they’ve got that element. There would have to be a directive or an expectation that they would do that role from the NDIA. (Mandy, key informant)

Paul referred to the need for a ‘system wrangler’:

> It was a person who could work with multiple environments and sometimes it was the job coach to get everyone on the same page about what you wanted to achieve. Don't argue the rights space, don't argue the advocacy stuff. Do the ‘Can we help this young person? Are you in or are you not in?’ Giving people options rather than painting them into the corner, because as soon as you get into an adversarial role, you'll never win with a TAFE. You'll never win with any institution. (Paul, key informant)

In addition, Mandy argues that specific training, mentoring and coaching within schools and disability services supports the raising of expectations, which helps to embed long-term change. In Amy’s and James’ school there were deliberate, successful integrated strategies that had been implemented to build a ‘work first’ culture and orient young people toward post-school economic participation. In 2019, only one student from a cohort of over 50 transitioned to a non-vocational service provider post-school. The strategies were not difficult or costly. There was a strong focus on students spending time in spaces where other senior students spent time, including the senior campus being located within a mainstream secondary school, as this enabled the students access to a broader range of networks and opportunities and supported the shaping of their identity. The campus focused on students undertaking a recognised school leaving certificate, and supported that by employing a curriculum coordinator to work collaboratively and in a strengths-based way with students to design a suitable curriculum, which set up pathways to further training post-school. Additionally, the school employed a trained careers adviser to provide advice and guidance to students and family members. The use of the title ‘Careers Advisor’, particularly on her name badge, continually reinforced the word ‘career’ for students and family members. Being accredited also required her to deliver services to the students within standards and a code of conduct. Finally, a work experience coordinator established connections with local organisations to create work experience opportunities for students in host workplaces where staff were trained and supported in supervising the students rather than staff from the school doing so. The use of a ‘graded’ system resulted in students experiencing a much broader range of workplaces as they became increasingly independent and built expectations about their capacity to work in a range of community-based settings.

8.5 Community-level resources, supports and strategies

8.5.1 Improved understanding of employment for young people with intellectual disability

Addressing the mismatched discourse and lack of clarity about the forms economic participation can take requires an improved understanding of and focus on the value of paid employment. Raising this awareness in the wider community, particularly in relation to the human rights aspects and broad benefits of economic participation, was considered critical to creating opportunities by study participants. Family members felt that personalised information and support for businesses would help create real jobs for young people with disability, as while businesses might be willing, family members thought they needed support to make it happen. Clare thought in particular that employers/businesses were not aware of the supports available:

> Government needs to make all employers know that it’s a possibility. [Q: Like a campaign?] Yes, I think so. They don’t understand, they think it’s going to cost them money to have someone there who needs more training. They're like, ‘I need someone to do this job and I don’t have the time and money to train them, someone with a disability.’ They don’t understand that there is support and funding to get that person up to capacity. (Clare, family member)

Laurelle agreed that employers were not aware of the benefits employing a person with intellectual disability, particularly in a customised job role, could bring to a workplace:

> Well the way that we construct work means there is little room to do anything a little bit altruistic. Also, the real benefit of a customised job, in terms of co-workers, is taking tasks off other people. There hasn’t been enough exposure to it. Whenever you hear about it, and whenever you meet employers who have done it, they love it. (Laurelle, key informant)

Lawrie felt that programmatic structures were a mechanism for engaging employers willing to employ young people with intellectual disability:

> I would say, encourage employers to engage in and work with programs like ours. When they first start to work with people and through work experience our staff are there and they can start to see … it’s sort of easing their way into it. And also, those – I can’t think of the exact term and I know that some businesses have them – but those obligations to hire a certain [Q: Like corporate social responsibility?] That’s it – exactly, that sort of thing. And to have more of that and actively use it ... and we work with them and they can say ‘These are the jobs that someone with an intellectual disability can do,’ as opposed to us going to that business and sussing it out – they can say that ‘We have lots of this and that to do, can you provide some participants?’ (Lawrie, key informant)

Lisa explained how she came to meet Bobby:

> A DES sent me an email asking if I would be interested in employing someone. [Q: Just a cold email? Did you have any connection to anyone?] No, I had no connection to them at all. And it offered a wage rebate so long as the person stayed for the full six months. And I just really liked the initiative. That was probably where it was successful, it struck a chord. I went and met Bobby and we gave him a trial and we went from there. It was quite smooth from the practical side of it. (Lisa, key informant)

Laurelle thought that a sustained campaign was required:

> I would love to have a big campaign. We need to shift and have maybe at different levels, but we haven't really had a serious national campaign around disability. There's been little efforts but there's not been anything sustained that people could call to mind. And I guess we're not talking about TV anymore, we're talking about social media and all the different segments. It might be that you really only want to focus on employers and you just do a really sustained effort there. (Laurelle, key informant)

George felt the right employer had to be supportive of the person as well as providing real opportunities, and such employers were difficult to locate:

> [Q: What is it about those workplaces that works? What is it? What are you looking for?] They've got people in charge, whether it's a CEO or a manager or a business owner or supervisor they really have got a heart for our guys and they really want to offer that opportunity. They've got a workplace that has a need, that they feel that one of our guys – [Q: It's not a charity model, is it?] No, no. We don't want it to be either. We wouldn't want it to be tokenistic. We want our guys to go to work and work is about making a contribution. That should be the expectation of everyone whether you've got a disability or not. Some might need more support. (George, key informant)

Paul agreed that the match went beyond the tasks performed, and that supportive employers were critical:

> The evidence out of the US shows the importance of matching with the employer is more than just the tasks you perform. It's about the employer really feeling very comfortable with the skills and talents you bring. Not 'This person has got a disability; this person has got an intellectual disability. I'll do the right thing by community and

> give them a bit of a go.' It's about actually saying, 'You're a valued employee.' (Paul, key informant)

Lisa, Bobby's employer, explained how she had customised a role for Bobby, noting that it could be beneficial for both employer and employee:

> He's really good at [deliveries]. That's been the key to it working, has been to find something he's really good at and give him that. Unlike the rest of us, he doesn't get bored of it, doesn't require a lot of change or stimulation or challenge, just give him what he's good at and let him go. And he's good at driving … the two runs he's taken over I've been doing for eight years, I was well over it. [Q: That's freed up you to do other things?] Yes, and [other employee] not doing the last run has freed her up to do the run in the van, which Bobby can't drive. You just move things around. (Lisa, key informant)

Small to medium businesses were considered more likely to come on board than larger ones:

> I feel that it – [long pause] they're a higher chance to believe in the purpose of what we're doing. Lived experience or a shared experience with somebody, whether it's a family member, a son, daughter, something like that. (George, key informant)

Drawing on businesses' connections to their local community was a successful strategy Mandy's program used to drive opportunities:

> Some of the work with employers is around why they got involved. We've got quite specific employers that are involved because they're small to medium, they're part of the community. (Mandy, key informant)

Lisa thought organisations also needed to be encouraged to be more creative: 'People need to create [a good job match]. But you can get creative, you know'. Certain employers or industries were seen as having the right culture to support the economic participation of young people with intellectual disability. For example, Lisa employed Bobby partly through a sense of providing a community service:

> There might be the type of businesses where you have more success – businesses where there’s a bigger goal than a profit. Those types of businesses may be more open because they’re already in service in the way they operate. They’re already operating in a bigger domain than just all about the money … (For Bobby), what I pay him actually is about what I would pay to put them on a courier. But I wanted to give him a start because I think employment is key. It’s key to feeling useful and having money and the freedom of having your own money and earning your own money and all that. (Lisa, key informant)

Laurelle knew about a project that had targeted a particular industry:

> [Project] was done by [DES]. One of their clients got a job in an advertising agency and this agency loved it. They said we don’t know why more people aren’t doing this. Then they took it on themselves to launch a campaign for every creative agency in New South Wales to employ a person with intellectual disability in a customised role. (Laurelle, key informant)

As an employer, Lisa felt strongly that financially incentivising employers, particularly at the commencement of a job, was helpful in mitigating risk:

> Bobby, he’s not that different to anyone who gets a first job. That’s why we pay teenagers really low money, because they’re not worth more. Training wages for a first job for someone with a disability should be given, they’re just not worth 100% of a wage. Review it every three months, whatever. And if small business is going to be your main employers, they need to feel like they’re not taking a financial risk. There might even be some financial benefit to encourage them to try it. If I had been paying Bobby a full wage, there’s no way we would have made it. They [DES] subsidised his wages – everything I paid him for the first six months, they paid me back. It has to work financially. Small businesses getting a financial kickback, it really means something. It wouldn’t mean something to [large employer], they don’t care, but it meant something to me. [Q: And did it mitigate the risk for you?] Exactly, yeah. It meant I could take him on and if it didn’t work, it didn’t matter. It wasn’t going to cost me. (Lisa, key informant)

The young people and families were able to clearly articulate the economic participation outcomes they were seeking, framed through a human rights lens rather than a labour market one. The reframed human rights perspective enabled thinking about a broader range of economic participation opportunities. Given the highly heterogenous nature of the young people, these could range from full competitive employment through to small part-time customised roles and micro-businesses.

The varying financial circumstances of the young people, which included being in receipt of the DSP, meant that in some cases they had more scope to explore volunteer and unpaid opportunities. Likewise, subsidies and reduced wages could be palatable to the young people and family members if a role itself was valuable. Rohan’s volunteer role with the Parks service and Francine’s son’s unpaid role at a local restaurant provided them with meaningful roles and the lack of payment did not concern them or their family members:

> I’m talking on behalf of [son]. Because he has an intellectual disability he wouldn’t be able to perform the same job as what a normal person can. And maybe you’d have to – I know the award wage and you have to pay everyone the same amount of money, but would it be okay to – you don’t pay them the award wage. (Francine, family member)

> There should be more opportunities for them out there. Whether they get paid or don’t get paid, to some people that’s important, to me, it’s not. It’s making them feel needed and wanted. Rohan loves going to [volunteer job]. (Anne, family member)

Joanne focused on identifying work that was valuable to a business in order to negotiate opportunities. She approached businesses from a value-for-money mindset, trying to turn that into opportunities for young people based on them being paid what the work was worth:

> Some people work at different rates. But what would you pay to get that done? That's worth about three hours, this person takes about four hours, so he gets paid three

> hours of work. And he’s getting a bit faster now, he’s working for about three and a half hours. (Joanne, key informant)

Paul felt that there needed to be open discourse about the hours of work people with intellectual disability were seeking:

> I've done enough work with people with intellectual disability to say quite comfortably that most people with an intellectual disability won't work full-time. Why are we kidding ourselves? Why are we kidding ourselves? (Paul, key informant)

George’s new employment program was focusing on small numbers of work hours for young people:

> We're looking at it differently. The work option could just be a couple of hours a week. It's still work. (George, key informant)

For some businesses, offering a small opportunity to start with is an effective strategy to build their confidence. Joanne, a service provider, was using a strategy called ‘Just Three’ to find three-hour first jobs for her students with intellectual disability:

> Just Three. Anybody who’s out there who really wants to give someone a go, because ‘Oh, three hours, we can do three hours.’ Once they’ve busted three hours, once they’ve got that little bite, it’ll be more than three hours. It always ends up more. (Joanne, key informant)

In addition, a small amount of community-based work combined with other activities could be suitable. Carol could see that her son could combine work with a broader range of activities, including some segregated activities:

> If they [service providers] worked out if people weren’t going to work full time, well, there’s all the stuff, cooking and other life skills, self-advocacy skills, fitness. Some social is okay … mixed in with work. I’ve got no problems doing one after the other. He [son] has talked more recently about doing a drama club. Well, okay. On the one hand, I could go and find a local drama club and that’s a thing about in your local community and all the rest of it. But also, if he’s also doing a whole lot of other mainstream things,

> I don’t really hate that he would go to a drama club for half a day with other people with intellectual disabilities. (Carol, family member)

While ADEs were widely rejected, there was recognition that segregated work opportunities, for example within social enterprises and WIL programs, could deliver benefits to young people, especially in the period immediately post-school. Both of the WIL programs described in this study’s data involved segregated classes and integrated work placements.

Reconceptualising economic participation, and particularly by focusing on the human rights and inclusionary aspects of work for individuals and their family members, enables employers to engage from that perspective and potentially opens a whole raft of new opportunities to young people with intellectual disability.

8.5.2 Appropriate services and supports

Addressing lack of access to appropriate services and supports was particularly important to family members and key informants. They believed that real change could result from the right supports being available to young people and family members at the right time. In particular, they sought widely available programs, services and supports that could achieve employment outcomes, and identified a range of ingredients that characterised appropriate services:

> Research and evidence is coming out of the US regarding what works and what doesn't work. What works is when you take a very person – a-family-community-centred approach. You build trusting relationships; you go on that journey of discovery and you work to the person's strengths. (Paul, key informant)

Family members reflected that a broader range of easily accessible transition resources and supports bridging the school/post-school divide, that were available to all young people and their families, would be helpful. Structured programs, such as TTW, draw together a range of services and supports to help young people and families plan for economic participation post-school. Mandy suggested that making this more widely available through a place-based approach could result in greater equity of access.

In terms of transition from school, Paul thought the first six to twelve months were critical:

> The best providers I saw understood that post-school to about six months post-school was very much about building the young person's individual life skills, but also building systems of support around them that meant if they didn't find work in that six months that they wouldn’t fall back on mum and dad. Transport, train – all of that sort of stuff. They would then really start what I call the discovery process. They’d start to work with the individual, start them on volunteering and job tasters and those sorts of things. By the end of the first year, 75 per cent of the hard-lifting had been done and then you could start to enjoy the successes for that young person. Some of them found jobs within nine months and others it took them the full two years. (Paul, key informant)

Joanne’s transition program emphasised the need for young people to be exposed to a range of opportunities, with a focus on work placements:

> With the SLES program, we do one day. We call it the [name] program, where they do one day of classroom-based, then they do SLES, and they try stuff. It’s one-on-one for people finding a job. And the next year they’ll do the training, work placement. They're going to get more intensive work placements. More goes on with them if they want to do that. (Joanne, key informant)

Access to appropriate early work experience was considered critically important to improving economic participation opportunities for young people with intellectual disability. However, creating a positive experience for the young person, their family and the host employer was crucial. For Janice, work experience was critical because people with intellectual disability learn best in real environments:

> The idea that you have to get the skills first before you do the thing, that's backwards. I know it's the other way around because Brandon has proved it to me. You don't get life skills and then move out of home and live independently. You live with a dirty toilet or unwashed sheets for three months and then you realise, 'Oh wow, it's more pleasant to wash my sheets!' That's how it happens. That's the same for everybody else. There's a mindset shift that's actually at the heart of it that isn't working. That's why the system itself is reflected in that. It's got it backwards (Janice, family member).

Access to highly individualised and skilled supports to undertake work experience was also crucial to ensuring that early work experience was meaningful.

Improving access to school-based resources and support – for example, having 'a trained, skilled person in that careers/work experience role' and schools 'linked in to a collaborative network' (Mandy, key informant) – was seen as having the potential to improve school-based opportunities. Kate outlined the approach her school uses, which has resulted in good outcomes for students:

> Some students have undertaken school-based apprenticeships, in warehousing and food processing, so they're walking out with that qualification and that's paid employment. Cert II in Warehousing Operations and Cert II in Food Processing. [Name of business] have been fantastic to our students. Our students end up trained by the school to independently travel there too on their work days. And Warehousing Operations, Cert II in Food Processing, the work and the study is all done there at [name of business]. They do a lot of food for disadvantaged people and the homeless and foodbanks. The students are involved with the machinery, the preparation of food, packaging. They get a Cert II. Their study is actually here at campus on a Friday. The RTO comes to us. We have one student who did the food processing, loves it so much, she will go into hospitality. She's doing the SLES program and combining TAFE, but she's not doing the Work Education or Transition to Education one [ie courses targeting people with disability], she's going into a Cert II in Hospitality. (Kate, key informant)

Family members recognised that a customised role within a supportive workplace that capitalised on a young person’s strengths and interests would lead to a better outcome. The customisation required could involve not only the tasks undertaken, but also the hours worked and the way the role was supported. Several family members knew about one intellectual disability-specific DES provider with over 30 years of experience in supporting people to obtain and maintain community-based jobs using customised employment approaches, and were hoping to use its services. The collaborative network Mandy was involved in had also used customised approaches successfully in its work: ‘We talk about one jobseeker and one employer. It’s trying to find the right fit’ (Mandy, key informant).

Rohan appreciated the effort staff and other volunteers from the Parks department put into preparing his schedule of jobs each week and ensuring he was fully included and valued. The staff from the WIL host workplaces also arranged specific, suitable tasks for him and he was supported by a paid support worker. The co-workers at Bobby’s workplace, an organic food supplier, had adapted the work environment to ensure he was undertaking tasks that suited him. His boss was also teaching him new skills to expand the number of job roles he could undertake, despite not having any experience in supporting people with disability prior to employing Bobby.

Paid supports in the form of coordinators, teachers and brokers were important. Rohan’s WIL program coordinator had helped him learn new skills and brokered meetings with potential employers. Staff from a DES provider had helped Bobby find his job and Penny described her ‘boss’, a disability provider staff member, as the person who helped her to learn about working in the coffee cart. The coordinator from James’ SLES program also organised his work experience schedule each week. James thought having a support worker to help him on his first day in a job was important:

> For the start, yes, I would [want a support worker], because I wouldn’t know what to do. I don’t want to fail or break anything. (James, young person)

Structured post-school training was valued by both the young people and family members in the first-year post-school, including programs provided by disability services and training providers. Services provided at set times that mirrored school hours were particularly valued, as were a range of supports available within the same environment. For example, travel training that was provided alongside work-type activities was a good fit. Family members recognised the young people’s vulnerability in community settings due to their age, their limited life experience and their intellectual disability; therefore, environments offering security and protection were important as the young people undertook their new activities and learned new skills.

Disability-specific RTOs providing post-school transition courses structured to account for the learning needs of students with intellectual disability are emerging to compete with TAFE. Joanne’s RTO had smaller class sizes than TAFE, which means it could include people with higher support needs:

> Some of the local TAFEs have minimum class sizes of 13. That just wouldn't work. We’re able to take on people who want to work and want to learn who’ve got higher than usual support needs. (Joanne, key informant)

Disability-specific WIL demonstration programs based on the Project SEARCH model achieved employment outcomes for the small number of young people involved. One model involved students undertaking training within a university setting combined with placements within a range of businesses. The other involved students undertaking training on-site at a large hospital, including doing three placements in various parts of the hospital. Students chose from a wide variety of settings, including childcare, catering, administration and cleaning.

Being on-site and involved with a young person over an extended period of time was beneficial, according to their job coach Kylie:

> They [students] had a relationship with me all year and I knew them. I knew where they'd come from. I knew their challenges. To work with someone everyday like that you pretty much know how they work and what they need. (Kylie, key informant)

This also enabled Kylie to work closely with staff from the host organisation and teach them strategies for supporting the young person, and to solve any issues that arose:

> [Teacher] and I negotiate with supervisors, the employer, all day every day. It's like chess. We're moving, we're on the job with students as well. We're talking them through and breaking down their process. There's a lot happening. Then we're negotiating which students go where, understanding their strengths and where their career path is likely to be looking, based on their interest and what they showed in the rotations. I stay in contact with them [host organisation staff] too: 'How are you going?' Because often those moments – and that's the beauty of working at the organisation, you can be having that corridor meeting: 'Oh, hi, how's things? Oh, good. But how are things really going?' And that's when they let you know, 'Oh, this happened.' (Kylie, key informant)

Over time, Kylie saw these learnings become more embedded across the organisation:

> They take it on board and they own it. And then they go, 'Actually, well I could do this differently.' And in fact, departments like the Equipment Distribution Centre have now modified their induction program to teach the staff the way they taught the student. It made them think, 'Oh, well, actually that would be confusing if we taught them that.' It's changed the whole way that they do their induction for their program. (Kylie, key informant)

The program supported the young people who had gained employment or a traineeship to transition into a longer-term support system providing ongoing support:

> At the end we do pathway interviews – [teacher], myself and the parents and the student. We talk about where they've come from and what they want to do and what

> the parents want for their child as well, which is really important. And then we talk about our DES service and give them the option to sign up, and then they go into employment assistance. (Kylie, key informant)

As suggested by Francine and Anne, there was a need for a broker – a person who knew the young person well and could approach employers to negotiate or create a suitable position on their behalf. Mary thought wage subsidies would also be attractive to employers, and that would need specialist expertise to arrange. Brandon's family employed their own broker, a person who had experience in the industry Brandon was looking to work in, and paid him using individualised NDIS community participation funding. The broker was able to identify suitable roles and workplaces for Brandon and used his connections to negotiate a role for him and then provide the support he needed when he commenced work.

Bobby's job with Lisa came about when she was approached by a DES that brokered the role for him by clearly articulating his suitability and offering a wage subsidy. She felt that using a broker was appropriate because there needed to be some separation between the family and the workplace:

> If I had had calls from [Bobby's] family that I felt were intrusive or controlling in any way, I wouldn't have taken that too kindly, if I felt like they were interfering, or they were overly involved. I feel like I have employed an adult and I have an adult relationship with him. Yes, he has a disability. Having the one-on-one relationship with professional support [DES] has been excellent. (Lisa, key informant)

Low awareness of the possibility of customising a role for a young person with intellectual disability, and the benefits of doing so, meant that businesses needed access to skilled brokers to support customisation. Joanne provided an example of how her organisation brokered customised roles for students:

> One of the questions that we'd ask businesses is 'what do you do, who are your customers?' It's like any appreciative inquiry approach, and then just saying 'what

> never gets done?' and then you may be able to carve or scope a job around the stuff that never gets done in a workplace that needs to get done. It's important that work is not a token. It needs to be a real contribution, good match, all of those sorts of things. (Joanne, key informant)

Broadening the pool of people available to provide economic participation supports to young people beyond just disability support workers also opens opportunities. Brandon's barista-trained support worker, who worked alongside him in a hospitality workplace, had previously not had disability or employment support experience prior to working with Brandon. His skills and connections in the occupation Brandon was seeking to be employed in were invaluable, and he was eventually employed to train other staff in the workplace, which meant that Brandon's support experience was normalised. Donna also described a broker employed by a family she supported who had no prior disability experience, but was 'known and trusted by the local community. She held the vision for inclusion'. Likewise, Joanne employed some staff from outside the disability sector in her RTO because they had specific training skills, and higher expectations of the students.

There was also a need to draw from the supports available in the workplace, as Joanne noted:

> [The employer] employed someone who was really high support needs and he put his grandson buddying up with him because they're from the same age group. It makes sense. It's fantastic. He's going to be employing quite a few people in a whole range [of roles]. He thinks it really adds value, particularly with some of the young people who are doing their first job. (Joanne, key informant)

8.6 Sociopolitical-level resources, supports and strategies

The sociopolitical level of the ecological model is concerned with laws, market forces, state perspectives and histories of service delivery. Research informants identified a need to align policy, funding and practice with the ordinary life expectations of young people with intellectual disability and family members in order to create the market of appropriate services and supports required to increase their economic participation opportunities.

8.6.1 Employment First policy settings

The barriers created by the confused and confusing policy framework, outlined in Chapter 7, require new cross-sector policy settings that recognise both the paid and voluntary nature of economic participation for people with intellectual disability. Shifting the focus of policy to inclusion, with economic participation framed as part of an included life, requires a service system underpinned by human rights policy settings and outcomes rather than economic ones.

An asset-focused Employment First strategy was seen as one way of bringing about broad system change. Donna had seen Employment First policies implemented overseas, resulting in the closure of segregated services and a shift to increased community-based outcomes for young people with intellectual disability. She argued that actively supporting young people with intellectual disability in community-based employment was necessary to change attitudes about their capacity to be included:

> If we want attitudes in society to change, one of the most powerful ways to do that is to assist people with intellectual disability to get work and participate. (Donna, key informant).

Employment First policy frameworks shift attention to the provision of the supports – to young people, family members, school staff and the broader community – necessary to create economic participation. Mandy explained how the collaborative network she managed, which had a strong Employment First underpinning, had influenced expectations within schools and families, and specific targeted strategies had changed the culture within schools and other settings.

Specific, targeted policy settings are required to address the interface issues between the human rights-focused NDIS and other service systems that were outlined in chapter 7. Lawrie provided an example of how policy interface issues, in this case the interface regarding NDIS-funded SLES participants using DES, could be overcome, indicating how other problematic interface issues could also be addressed:

> With the SLES participants, there's six months where they can do both – it's called 'concurrency'. They [SLES participants] can be registered with DES and job search and also continue using their SLES, only for six months' (Lawrie, key informant).

However, Lawrie's example does highlight that issues of concurrency or 'double dipping' are interpretive and can be removed when policy makers decide to do so. It remains unclear, however, whether concurrency has led to improved employment outcomes for people with intellectual disability.

The reconceptualisation of economic participation would also require a rethink about the intersection of paid work and income support, and how that information was made available to young people and family members:

> To not have the disability support pension and only have a few hours work, if you lose it, it's a fear, it's a fear-based thing. If there was more flexibility around that, more information about 'you can work, and this is what happens'. (Donna, key informant)

Government, in particular the NDIA, was identified as a key source of leadership given the NDIS' focus on social and economic participation and the policy, funding and practice levers it could use to drive change. Anne thought that government should lead by example, by 'putting their money where their mouth is'. Mary agreed that governments should be employing people with disabilities themselves, and Sharyn identified procurement and enterprise initiatives as two levers government have to drive change – levers which have been used effectively with other disadvantaged groups.

8.6.2 Leveraging learning from research and pilots

Key informants recognised the importance of pilot projects in driving change, but also identified the need for strategies to develop good practice and make it widely available via evaluation, replication and scaling within a coordinated framework. Pilot projects, many funded by philanthropy, provided leadership by undertaking research, building models and collecting data about what works. However, while philanthropy had supported the pilot phases of Rohan's WIL program and the WIL program Kylie worked in, these could only continue if they had secure ongoing funding. Key informants also provided examples of a range of small-scale projects that had demonstrated good outcomes. Bianca's 'Building Ability Through Career Management' was one:

> It was two days. The first day, we looked at employment readiness and how ready they were to actually enter the workforce, and then they all got one-on-one [careers] counselling for an hour plus a career plan plus a workshop around preparing for employment. We ended up with 60 young people in the end. (Bianca, key informant)

Donna knew about effective evidence-based programs such as customised employment operating overseas, which were suitable to be adapted to the Australian context given the right environment in which to scale and replicate them. Donna thought there was a need to engage with established leaders, particularly in relation to customised employment, in order to support the adoption of evidence-informed practice in Australia. For example, Laurelle knew of one DES provider implementing customised employment, having organised training for its staff via an American university, that could potentially take on a leadership role. Mandy's innovative transition project was another example of a model that would benefit from a structured strategy to implement it widely. Mandy was conscious of the need for policy change, and for access to the learnings from her pilot to bring about system-wide change so that all young people had access to its supports:

> We've got all this stuff, and now we have to look at how we ensure that we get learnings and policies that actually support effective school-to-work transition, because currently it doesn't happen. (Mandy, key informant)

Likewise, Sharyn's organisation had created innovative programs for businesses that were very successful in creating economic participation opportunities for young people with disability, but its growth was organic rather than structured:

> We have an internship program, we've got our mentoring program, but for our internship program, for example, the demand just keeps growing and growing [from businesses] (Sharyn, key informant).

Finally, there was also wide agreement that targets, data collection and reporting drive change. Better data supports decision-making, and programmatic structures enable data to be collected at individual and cohort levels:

> The point is it's about the data. When people participate in programs you get really good data, and then you've got a chance to go back and do some analysis and review, and then create a step change (Sharyn, key informant).

Kylie's education partner organisation was therefore considering establishing a Centre of Excellence to share knowledge about the WIL model they had established. Likewise, Mandy thought that capacity building was a critical aspect in bringing about change in transition practice at the system level. Her organisation was focusing on developing training, resources and practical tools that could be made widely available.

8.7 Conclusion

This chapter has explored the strategies, supports and resources that research participants identified as valuable for increasing the economic participation of young people with intellectual disability, which are situated across all levels of the ecosystem. Broadly, many rely on changed thinking and attitudes about the employment potential of young people with intellectual disability, and about what sorts of activities constitute economic participation. However, without a well-funded, structurally supported array of appropriate economic participation supports and services, even motivated families and employers cannot achieve the change required.

In Chapter 9, the findings of the thesis are explored by drawing on the existing literature and theory.

Chapter 9: Discussion

9.1 Introduction

This chapter returns to the aims of this thesis, to understand how economic participation of young people with intellectual disability can be enhanced and encouraged. It uses constructivism, a key theoretical underpinning of this thesis, to consider how the system broadly constructs intellectual disability and economic participation and therefore how these concepts can be reconstructed. The use of ecosystem theory focuses attention on multi-level strategies to reconstruct economic participation for this cohort, drawing attention to the barriers that exist across all layers of the systems that young people with intellectual disability intersect with.

9.2 Reconceptualise young people with intellectual disability

Since the shift from institutionalised residential settings to community settings began, young people and families have begun to reconceptualise intellectual disability. Although they had diverse goals, overwhelmingly the young people and families in this study were shifting towards alignment of their everyday experiences and employment opportunities with 'ordinary life' and human rights ideas, in which economic participation is contextualised as an important part of an ordinary life. However, wider community discourse remains wedded to deficit-focused thinking about intellectual disability, resulting in a disconnect between the expectations of families and young people and the opportunities available. It is this deficit lens and the deeply ingrained assumptions, images and generalisations about the capacity of people with intellectual disability (Senge, 1996), that form a core barrier to realising their aspirations and potential.

Despite a formal shift at the level of the state to understanding disability through a human rights and biopsychosocial lens, as evidenced by Australia becoming a signatory to the

UNCRPD, the introduction of the NDIS and the newly released *Australia's Disability Strategy* (Australian Government Department of Social Services, 2021a), young people with intellectual disability experience a continued emphasis on medical diagnosis and are labelled based on their IQ from early childhood. This categorisation disproportionately dictates their life path (Altermark, 2018; Cluley, 2016). In particular, the use of standardised tests, results in them being categorised based on deficiencies in cognition and adaptive behaviour, which leads to separate and segregated spaces, particularly for learning and working.

Authors such as Odom et al. (2009) have described the conceptualisation of people with intellectual disability throughout history, as based on the prevailing characteristics of society more broadly. The widespread dis-citizenship of people with intellectual disability, including their removal from society throughout the nineteenth and twentieth centuries, occurred because their worth was viewed in the context of their ability to be productive (Dowse, 2009). Altermark (2018) describes the current period as 'post-institutionalisation' – a period in which formal policy settings have shifted away from segregation of people with intellectual disability yet the structures and mechanisms of segregation, such as special schools and ADEs, continue to exist. This has served to reinforce deficits, difference and separateness, and set up a trajectory into separate and segregated spaces across the lifespan (Grigal et al., 2011).

Despite formal shifts, including the policy-level emphasis on inclusion in the ordinary life of the community, as evidenced by the NDIS, the data collected for this study has made visible the continuing deficit lens through which young people with intellectual disability are viewed by the institutions and structures which form Australian society. Shifts in attitudes towards disability and recognition of diversity and difference in broader society have not translated to changes for people with intellectual disability. The lack of opportunities experienced by young people with disability within special schools, day centres and ADEs impacts far more on their economic participation capacity than their impairment does (Jordan, 2014).

Widespread deficit practice is visible in the data for this cohort. High numbers of young people with intellectual disability continue to attend special schools for some or all of their schooling, and these schools are viewed as lacking a culture of preparing young people for work. Rather, according to Janice, they create an easy pathway to disability services post-school. Typical opportunities that are available to other young people are absent in the later years of school, including career development activities. Work experience, normatively a first step towards later economic participation, is mostly a tick-box exercise undertaken in groups, within segregated ADE settings or not at all. Information about post-school options is provided primarily via a careers expo, which in reality is an expo providing information about the adult disability services available for them to choose from. However, non-specialist schools do not fare any better in supporting young people with intellectual disability during transition, given their emphasis on high academic achievement and pathways to university.

Post-school, programs are segregated, rarely offering normative activities such as the structured and accredited training other young people without disability receive. This lack of opportunity resulted from prevailing attitudes that young people with intellectual disability are ‘non-workers’, linked to an overemphasis on cohort deficits and a failure to actively uncover and document individual strengths.

Reconceptualising intellectual disability requires a shift in focus from the impairment to the role of the environment, adaptive behaviour and functioning in supporting the inclusion of people with intellectual disability in community settings (Schalock et al., 2021). Bringing about change that addresses exclusion and facilitates community participation requires recognition of the complex interactions between impairment and social context (Bigby, 2020b). It requires a twofold strategy that simultaneously draws out and addresses disabling social structures and recognises the real-world implications and limitations that people with intellectual disability experience (Bigby, 2020b). It also requires an understanding of each individual's difficulties, including how these relate to an impairment and how social contexts, like negative attitudes about intellectual disability, exacerbate the difficulties they experience. This leads to a dual strategy to both alter the social contexts that have created barriers and support the individual in overcoming personal barriers in order to participate.

The provision of highly specialised supports and environmental adaptations within community-based settings is critical to opening up economic participation opportunities, as described by Wehmeyer and Craig (2013). In the Australian context, the drift from highly specialised employment supports during the 1990s to the de-differentiated DES program available now has reduced the availability of the highly specialised supports necessary for people with intellectual disability (Tuckerman et al., 2012). This has acted to reinforce community attitudes that people with intellectual disability do not belong in community-based economic participation settings. In addition, failing to provide the specialised services within the context of transition to adulthood results in missed opportunities for young people with intellectual disability to develop skills and competencies that support later economic participation.

Placing increased emphasis on the role of environmental adaptation and supports means individually mapping these for each young person as they transition from school, identifying the strengths and weaknesses of their 'individual ecosystem', and the resources and supports available to them (Small et al., 2013). The Discovery process is one mechanism that enables a young person to be viewed within an 'ecosystem' in which paid and natural supports and environmental adaptations influence thinking about economic participation broadly, as well as within a strengths-based framework (S. R. Hall et al., 2018). Its dual focus on individual and environmental strengths results in important understandings of the factors that promote economic participation for a particular person, which is critical given the heterogeneity among people with intellectual disability. However, none of the young people in this study had access to a Discovery process or any formal assessment of their strengths or preferences in relation to economic participation. In addition, none of the young people had been specifically taught self-determination skills, been formally involved in their transition planning, or been offered structured choice-making activities related to economic participation, despite increasing evidence of the important role these play (Hagiwara et al., 2019; Stancliffe et al., 2020). This resulted in little understanding of their specific strengths and interests beyond what family members knew and tried to 'tap into', and little knowledge of the type and volume of supports and the environmental settings that would enable each individual young person to engage in community-based economic participation.

A reconceptualisation of young people with intellectual disability must formally recognise both their right and their capacity to be self-determining in relation to their adult lives. The ecosystem must therefore centre structured support and training in the development of self-determination, starting early (Stancliffe et al., 2020) and linking to diverse opportunities for identity development. This means intervening from an early age in order for different outcomes to be possible later in life. The opportunities to be actively involved in planning transition afforded by programs such as TTW enabled young people with intellectual disability to construct their identities in different spaces, using multiple lenses (Midjo & Aune, 2018; Stokes, 2012; Stokes et al., 2013). While family remains the strongest influence on identity for young people with intellectual disability, the data in this study indicated that enabling young people's inclusion in spaces in which they could undertake important identity work in adolescence and early adulthood influenced family members' expectations and their visions for their young people. Successfully undertaking work experience in community-based settings, paid or unpaid, had a particularly strong impact on young people's expectations for themselves and their family members' expectations for them. Making good quality work experience within community-based settings available to all young people with intellectual disability is therefore a critical step in expectation-setting within the family environment, and the development of self-determination skills. These diverse early experiences recognise and reinforce the normative opportunities of development for young people with intellectual disability. In this context, a first job is seen as a stepping-stone, rather than a lifelong job that predetermines the economic participation pathway of the individual.

Strengths-based approaches are a key mechanism that drives the reconceptualisation of young people with intellectual disability (Shogren et al., 2018; Wehmeyer, 2020; Wehmeyer et al., 2017). In this study, family members' holistic focus on their young people resulted in a far stronger emphasis on the personal characteristics they regarded as strengths. Family members described their young people as funny, kind and passionate about an interest. The young people themselves drew on their families' strengths focus in framing their own identities, particularly aligning themselves with their siblings in terms of preparing for adult life. However, while the family setting was strengths-based, family members recognised that in broader society the deficit lens is widespread. This set up an identity 'battle' in which young people and family members sought out valued, normative strengths-based opportunities post-school within a deficit based, segregated system in which they had to constantly advocate for the services and supports the young people needed. Carol and Clare were early in their journeys and were hopeful about being able to achieve their goals for their children. Anne and Francine were seven years post-school and worn out. Despite their considerable efforts to carve out community-based economic participation opportunities, they felt the deficit-focused service system had let their young people down. In particular, the focus on her son being kept 'busy' rather than engaging in meaningful roles was a concern for Francine, who felt that it underestimated his capacity to be bored and his need to experience the reciprocation that comes from being engaged in a valued role.

Similarly, in this study, young people did not see themselves via the lens of intellectual disability, although they did acknowledge specific barriers such as an inability to handle money. Instead, their identities were more closely aligned to those of 'young person' or 'school leaver', as ready to try new things and carve out a future. They drew on what their siblings of the same age and friends were doing post-school, emphasising intellectual disability as only one aspect of their identity. Being in real workplaces, even in unpaid roles, helped to shape their identities not just as a worker but as people who could learn new things and be responsible for getting important work done, which is how they drew value from their work.

In order to reconceptualise young people with intellectual disability, we must validate the period of emerging adulthood (Arnett, 2000) as it relates to them. Young people with intellectual disability require the same opportunity to discover who they are and who they can be, begin to realise their adult potential, and ready themselves for adult life (Arnett, 2007; Redgrove et al., 2016; Stokes, 2012) as their non-disabled peers. The unstructured and fragmented planning experienced by young people with intellectual disability and family members fails to understand the importance of an extended post-school development period and to incorporate important activities that support development and growth. Given the expectation among family members that 'things take time' for young people with intellectual disability, the emerging adulthood framework offers a structured developmental approach in which a young person, their family members and the service system more broadly can align their 'efforts', focusing on the attainment of valuable roles, including community-based economic participation, across the adult lifespan. Reconceptualising young people with intellectual disability as emerging adults reframes them as having potential to learn and develop, and to build their identity outside of the intellectual disability identity assigned to them. Policy settings and service delivery within an emerging adulthood framework would create the stepping stones and bridges the young people and family are seeking, fostering increased independence, skills and confidence as a young person moves towards adulthood. Additionally, an emerging adulthood approach would address the adjustment issues family members experience, giving them the time and support necessary to cultivate the ordinary and valued life they aspire to for their young people.

In this context, reconceptualising young people with intellectual disability emphasises them as individuals with normative human rights but differentiated needs and supports. They are first and foremost young adults in a period of significant identity growth and exploration, informed by diverse community-based opportunities.

9.3 Reconceptualise economic participation

Within Westernised countries such as Australia, economic participation continues to be viewed through a neoliberal lens, which predicates a narrow and individualised view of productivity (Dowse, 2009). The increasingly complex labour market has resulted in fewer of the routine and manual jobs people with intellectual disability traditionally undertook, reinforcing the broad view that they are unsuitable for work. This exclusion from the labour market has been based on attitudes and discourse about their capacity and the perception of significant barriers to employment (Kocman et al., 2018). The continuing existence of segregated spaces for people with intellectual disability also perpetuates their absence from mainstream workplaces and reinforces community expectations. Negative views of intellectual disability are therefore particularly prominent within the context of economic participation, resulting in a clear path or ‘sealed highway’ to segregated settings.

In a formal sense, Australian economic participation support systems use the concept of work ‘capacity’ to determine eligibility for services and supports within the Active Labour Market. This includes mutual obligation to engage in economic participation-related activities in return for income support. Expectations about work ‘capacity’ for young people with intellectual disability remain wedded to biomedical views of disability. The deficit-focused income support assessment requires the individual to demonstrate that disability has resulted in an incapacity to work. The granting of DSP ‘manifestly’, based on IQ, formally exempts a young person from work, effectively labelling them a ‘non-worker’ in the broader ecosystem. This process occurs simultaneously with preparation for the completion of formal schooling and transition to the adult world. The process itself, and the language associated with the payment – in particular, the use of the word ‘pension’ – sends a strong message to the broader community about both the person’s capacity to work and the lack of necessity for them to do so. In a formal sense, DSP also reduces entitlement to many employment supports provided through Commonwealth government-funded labour market programs. Accordingly, the system orients resources toward non-work or segregated work settings for DSP recipients. This is particularly problematic in terms of future economic participation, as the young person misses out on vital early development opportunities. There is therefore a need to include a range of community-based economic participation options for young people with intellectual disability within the parameters of NDIS funding and, more broadly, by redesigning eligibility for Active Labour Market supports such as DES-ESS.

Aligning the concept of work capacity with biopsychosocial and human rights conceptualisations of disability would result in work capacity assessments being conducted within an environmental framework, with particular emphasis on the role of supports that give rise to capacity in the community-based labour market. However, flipping to notions of supported capacity rather than manifest incapacity destabilises young people with intellectual disability's automatic and permanent entitlement to income support as it is currently framed. Given the uncertainty their young people face in achieving economic participation outcomes, families rightly protect their young person's DSP income support payments, setting up a tension between maintaining income support and economic participation. The fears held by family members about loss of income support (Kramer et al., 2020) and their reticence to engage in complex income reporting systems (DSS, 2015), must therefore be addressed by delinking income support from economic participation supports. For this cohort specifically, formally framing income support as a Universal Basic Income (UBI) payment, rather than an incapacity payment, would enable a broader scope for conversations about a young person's strengths, their potential for economic participation (including very minimal hours of work activity), the supports necessary to realise an economic participation outcome and the timeframe in which it occurs. The data indicates that family members were already informally treating the DSP as a UBI as they focused on economic participation in light of the social inclusion aspects it brings rather than income as a prime driver. Given the range of issues and barriers experienced by people with intellectual disability and the low likelihood that paid employment will replace the DSP entirely, the young people's manifest eligibility for income support held value for them and their family members as an economic safety-net from which they could explore economic participation activities.

A reconceptualisation of economic participation for this cohort also extends to formal recognition of the role it plays in the 'ordinary life' aspirations of young people with an intellectual disability. Drawing from human rights perspectives, work for these young people is considered a natural pathway post-school – an ordinary part of adult life. In the United States, shifts in thinking about economic participation for this cohort have been driven by Employment First policy settings, which are underpinned by human rights frameworks in which young people with intellectual disability have the right to be, are expected to be, and are supported to be in community-based work settings (Association of People Supporting Employment First [APSE], n.d.; Giordono, 2020).

In addition, place-based, system-wide change programs involving young people with disability, families, schools, employers, service providers, policy-makers and the broader community address cultural attitudes, align policy and practice, interrupt deficit-focused pathways and provide structured support to engage in economic participation activities (Carter et al., 2017; Giordono, 2020; Molfenter et al., 2017). Critically, the 'attitude change' approach is coupled with the provision of strengths-based supports that enable community-based employment to be realised. The result is a shift in expectations about economic participation for this cohort, and improved economic participation outcomes (APSE, n.d.; Giordono, 2020; U.S. Department of Labor: Office of Disability Employment Policy, n.d.). The data from this study indicated that the capacity of young people has been redefined by an increasing shift to Employment First thinking among young people, their family members and key informants. The Australian TTW model, drawing on Employment First approaches, has demonstrated capacity to reconceptualise young people with intellectual disability in the Australian context at the local community level (ARTD Consultants, 2019b). For example, Mandy, a key informant, reported that improved economic participation outcomes achieved by older students lead to changed attitudes among younger students and their family members and staff within TTW schools. In addition, TTW's collaborative approaches, specifically bringing together previously deficit-focused key service providers and employers to create solutions, resulted in a shift to supports provided within a strengths-based, environmental focus. Its additional focus on capacity building, supporting young people, family members, school staff and the wider service system and community to build knowledge and skills, resulted in successful outcomes for individual young people. These activities acted as catalysts for a reconceptualisation of economic participation for young people with intellectual disability both at the individual level and within the community more broadly. Such examples made visible what the families referred to as 'what's possible'.

Family members in this study had a flexible approach to economic participation for their young people. As noted above, rather than being aligned to generating income, they saw economic participation primarily as a vehicle for social inclusion. Working for only a small number of hours, particularly for young people with stamina and health barriers, was considered sufficient to contribute to the valuable social inclusion outcomes they sought. Family members thus described seeking a good fit for the young people, while the young people themselves focused their thinking about work around their interests and hobbies such as sport, horses and dancing. The challenge, from their perspective, was to locate an employer prepared to act altruistically as Lisa did, recognising that while limitations exist, adapting the environment – for example, by customising a range of suitable tasks – enables a young person to contribute within a workplace where this is aligned with their interests and strengths.

In a social inclusion context, community-based economic participation has two primary components: 'social interaction and community participation' (McConkey & Collins, 2010, p. 692). Drawing on societal expectations about work and its role in perceptions of citizenship, family members sought opportunities they described as valuable in terms of enabling their young people to be present in community spaces, to expand their social networks – particularly beyond others associated with disability agencies, also identified by Forrester-Jones et al. (2004) – and to have meaningful, reciprocated roles alongside a broader range of people, as discussed in Akkerman et al. (2018). Segregated options, the alternatives to community-based economic participation, represented social exclusion and limited opportunities for young people to feel valued and develop a broad range of relationships.

Young people and family members in this study recognised the need for customisation of community-based economic participation settings and ongoing supports to create the structured environment which lead to success. There was, however, flexibility about the settings in which economic participation can occur, which was not necessarily aligned with binary ‘integrated or segregated, paid or unpaid’ thinking. While community-based economic participation was ultimately the goal, family members were also seeking to shift the focus to whether the roles available to their young people would provide value and improve their quality of life (see Akkerman et al., 2018; Rustad & Kassah, 2021). Volunteering was considered a suitable economic participation option if the role held value; for example, if it was within a valued organisation and was individualised, and the work was carried out alongside volunteers without disability. In addition, value came from a young person being appropriately supported and undertaking meaningful tasks that tapped into their strengths and interests despite being unpaid. Both Rohan and Francine’s son had highly valued unpaid roles in which they worked among non-disabled co-workers, wore uniforms and undertook important tasks such as greeting customers and maintaining equipment. Recognising the complexity of intellectual disability, family members considered a small number of hours, such as two to three hours for two to three days per week, suitable to meet their young people’s needs when balanced out with other activities across the week. Broader options such as micro-businesses (Thoresen et al., 2017) and being employed within social enterprises would also potentially meet the needs of young people and families if they had the valued aspects described.

The data indicated that young people and families are open to blending and braiding a range of activities across their week, engaging in a combination of community-based and disability-specific settings. However, there is a strong preference for community-based economic participation, and for economic participation to act as the ‘anchor’ activity for the person, as it does normatively. Hybrid models in which young people are in community-based work for part of their week and non-work activities for the other part potentially open up opportunities for people with intellectual disability to be included in community-based economic participation facilitated by a disability service provider (Murphy et al., 2014).

Economic participation is fundamentally about valued work, either paid or unpaid, where the criteria for value are the alignment with the interests of the young person, the nature of the tasks having wider workplace or social meaning, and the opportunity to engage with diverse co-workers. In the main, the opportunities for such economic participation is in community-based employment, but other settings can also deliver these. Notions of work capacity are replaced by strengths-based assessments of supports needed, to address personal and environmental barriers to economic participation.

9.4 Reconceptualise the role of families

Interpersonal relationships have a direct impact on improving attitudes and behaviours towards people with disability and enabling others to take on a role that Idle et al. (2021) refer to as that of an ally. Families as allies help young people with intellectual disability to realise their economic participation goals over the long term (Carter et al., 2011b; Kramer et al., 2020; Park & Park, 2019; Roy, n.d.; Southward & Kyzar, 2017), maintaining their vision, advocating on their behalf, providing supports over the lifespan and holding ‘a more complete grasp of the whole picture’ than the service system or individual service providers do (Kramer et al., 2020,

p. 315). Families must be supported in this role as their young people transition from school into adult life.

Transition from school is a particularly difficult time for families of young people with intellectual disability, as they experience significant adjustment issues (Dyke et al., 2013; McMahon et al., 2020). The data from this study support previous findings (Codd & Hewitt, 2021) that family members have unmet support needs in the post-school period, which here have been exacerbated by the complicated roles they were required to undertake in an individualised funding system. While the family members felt that school-based transition support was adequate at the time, it was only later that they realised how unprepared they were to navigate complex post-school systems. This was compounded by the failure to link family members and young people with intellectual disability to the post-school support networks they needed.

The family members and young people in this study were signalling and driving shifts in the conceptualisation of both intellectual disability and economic participation, although it is not clear if they were outliers, or representative of family members more broadly. A number of key informants reported family members of young people with intellectual disability as being prepared to accept the laid-out pathway from school to disability services rather than challenging limiting community expectations. The extent to which family members engaged in supporting economic participation outcomes depended on their own expectations, their advocacy skills and their support networks.

Parental involvement in transition planning improves post-school outcomes (Kohler et al., 2016; Papay & Bambara, 2014), and families are critical for realising the economic participation goals of young people with intellectual disability over the long term (Carter et al., 2011b; Francis et al., 2013; Kohler et al., 2016; Papay & Bambara, 2014; Roy, n.d.). The data made visible their critical role, and also made visible the manner in which their role has changed within the new individualised funding environment (Tracey et al., 2018). Rather than being only interpersonal-level supports, family members span the interpersonal and organisational levels of the ecosystem, performing an important function that connects the two. Families take on significant quasi-formal roles managing funding, coordinating services and seeking out the supports required to realise their young people's community-based economic participation roles. In particular, families were required to develop specialised/professional knowledge, managing significant workloads, 'interfacing' with services, employers and training providers and coordinating the various services and supports their young people received across the week. In the absence of adequate employment support services, family members were attempting to 'fill the gap' by providing the types of supports that would normally be the domain of vocational rehabilitation or employment services staff, along with other roles such as support co-ordination. The role of families must therefore be formally acknowledged within systems.

The issue of support to families is critical, as the quality of the support they receive influences their decision-making regarding pursuit of economic participation (Kramer et al., 2020). Like the families in Kramer et al. (2020), interactions with the service system left families in this study feeling frustrated and hopeless due to poor service, confusing information and an inability to locate suitable supports for their young person in the complex service system. This was heightened by the lack of evidence-informed, person-centred economic participation supports available, particularly within the individually funded NDIS marketplace. Family members' experiences of significant and long-term frustration due to poor services and supports caused them to reconsider their economic participation goals and, for some, ultimately to give up. The highly individualised and unstructured nature of support systems risks producing a two-tiered system due to the wide variation in families' ability to navigate complex systems and available social capital (Carey et al., 2019). Family members in this study with system navigation skills, advocacy skills and social capital, such as Carol and Janice, were able to carve out opportunities for their young people, utilising significant support from their networks, including a parent-led capacity building organisation they were connected to. However, other families had less capacity to ‘fill the gaps’ in the system, and thus relied more heavily on formal services, which resulted in their young people having fewer opportunities. There is therefore a need to assess a family’s need for support holistically, recognising that different families require different supports to ensure equality of access to economic participation opportunities.

Reframing families as allies who are resourceful, committed and knowledgeable about the strengths of their young people but in need of support from the formal system would support their capacity to seek out supports and opportunities, including beyond the service system where required (Petner-Arrey et al., 2016; Sanderson et al., 2017). The literature supports the need to reorient service provision so that young people and families are supported holistically, as a single unit, through transition and emerging adulthood (Francis et al., 2013; Jacobs et al., 2018; Kramer et al., 2020). In the United Kingdom, for example, individualised funding processes assess the whole family for support needs (Brooks et al., 2016). If family members are formally recognised as a significant component of the economic participation ecosystem, their needs must be considered alongside a young person’s needs as they transition to adulthood. The diverse needs of families will mean they require different amounts and types of support, and that all families require more support at particular times.

Families are operating within a longer life course perspective, that is not currently supported by the broader system (Redgrove et al., 2016). The transition support family members received from school staff ended suddenly when school finished. Yet that was the point at which their role shifted from ‘parenting a school-aged child’, with all the inbuilt supports that come with that, to having quasi-formal responsibility to create a life for their young person post-school. Extra support was required as they began navigating the complex adult services system, trying to locate services to support the realisation of their visions. Families require the period of ‘transition’ to be extended to align with emerging adulthood, so that formal transition supports are extended to cover a seven to ten-year period and support the development of a longer-term ‘life’ vision drawing on life designing principles (Wehmeyer et al., 2019). The families were seeking support to realise their visions through the provision of information about ‘what they should be doing’, along with capacity building supports to enable them to ‘properly’ take on the quasi-formal role outlined above. Rather than locating transition supports solely within school settings, locating them within and across a broader range of ‘systems’ including the education system, disability systems and mainstream employment would enable families to ‘dip in and out’ as required, with the supports acting as building-blocks as they moved through the emerging adulthood period. The role of parts of the system would be to formally signpost families to the range of supports available, acknowledging their different individual needs.

Alongside support from services, families are seeking peer support from other families. Disabled Persons and Family Organisations (DPFOs) have emerged in the Australian context to support young people and families in realising their individual aspirations/visions for an ordinary life. Several family members had received significant support from a DPFO, including in building capacity for providing advocacy and informal support over the lifetime of their young people. Families can also benefit from specific training and support to build their capacity to support economic participation aspirations (Francis et al., 2013; Roy, n.d.). Several family members in this study reported lacking knowledge about the employment system, and so being unable to seek out work opportunities directly for their young people. Bianca’s career development workshops demonstrated a willingness to help families engage in capacity building and a recognition that the service system alone could not be relied upon. Families have emerged as leaders in developing novel approaches to economic participation for young people with intellectual disability, particularly through DPFOs. The importance of peer support suggests governments and service providers must be willing to co-design solutions at the system level with young people and their families.

Overall, families have emerged as the most important factor in attaining economic participation for young people with intellectual disability in Australia, and this quasi formal role requires greater attention and support across the ecosystem.

9.5 The construction of the service system

If the Australian Government's goal to include people with disability in society is to be realised, then more needs to be done than becoming a signatory to the UNCRPD and implementing the NDIS. The UNCRPD and NDIS must become catalysts to transform the systems that deliver– or fail to deliver – the real supports that people with intellectual disability need for economic participation. So far, left to their own devices, the NDIS provider market and mainstream providers have not responded to the needs of this cohort. To bring about substantial change in their lives, government must use the levers it has available to intervene and shepherd the service delivery market toward reflecting the values of its broad policy settings and those of young people with intellectual disability and their families.

In the context of transitioning from school to work, the data identified multiple systems that influence this cohort's economic participation outcomes, including the government and non-government secondary education systems, the post-school education system (tertiary and vocational), government-funded Active Labour Market programs such as DES-ESS, the income support system such as DSP, the individualised funding system (NDIS), the disability service system (including ADEs and day services), and industry and employers. In addition, there are emerging place-based actors introducing innovative approaches and programs, such as TTW and WIL, often using philanthropic funding. Despite new expectations and understandings about intellectual disability, particularly within families, the complexity of the systems described in this study increases the likelihood that families will give up on their economic participation goals over time – especially families with lower social capital and fewer system navigation skills. While it is not impossible, using NDIS funding to operate outside the disability service system currently requires families to have significant skillsets or supports in their own networks. The data show that many do not have these, and that even those with these skillsets and networks struggled. Reflecting this, NDIS data shows that by age 25, the proportion of people with intellectual disability in community-based employment or with work goals in their plan has reduced compared to those aged 18 (NDIA, 2020).

Buntinx and Schalock (2010) describe the need for service system alignment: that is, for the service system to reflect the formal policy perspective of state parties, for organisational-level structures to deliver supports and for those supports to be directed toward facilitating the individual functioning of persons with intellectual disability. As a signatory to the UNCRPD, Australia has aligned its ambitions with human rights perspectives, with the NDIS being its key policy driver. However, this study identified a significant gap in organisational-level structures and an absence of evidence-informed supports and services, which restricted access to the interventions that create economic participation opportunities for young people with intellectual disability. There is therefore a need to purposefully align the drivers of policy as they relate to people with intellectual disability with the arrangement of a system of supports and interventions in order to deliver highly personalised supports to young people with intellectual disability and their families that support the achievement of their individual goals. Some major areas of change are discussed below.

9.5.1 Policy clarity

Policy settings impact both the broad composition of the service system and the delivery of supports to individuals who utilise the services. This study's data made visible widespread misalignment across and within policy and service systems. In particular, the broader systems young people with intellectual disability interact with are underpinned by a range of perspectives, policy settings and funding models which do not necessarily support their human rights-focused aspirations and that of the rights-based policy settings within disability policy more broadly. For example, despite the human rights underpinnings of Australia's disability policy, economic participation policy is driven by neoliberal settings (embedded in labour market policy) which fail to serve young people with intellectual disability well (Australian Government Department of Social Services, 2020).

The introduction of the NDIS has created a raft of policy and funding interface issues that impact on transition from school specifically because of the interface between school and post-school economic participation systems. This in-between space - where we find transition practice - is shaped by the state-funded TAFE sector, the Commonwealth-funded university sector, Commonwealth labour market programs including DES-ESS, and NDIS-funded service providers (e.g., SLES providers) used by many participants. Policy interface issues mean that these systems, including DES-ESS, could not be 'topped up' by specialised intellectual disability supports funded by the NDIS. For example, a support worker can easily be purchased to undertake an activity of daily living (using NDIS funding), but individualised funding cannot be used to top up the minimal supports available within the DES-ESS system by purchasing specialised intellectual disability supports. Essentially, the individualised funding of people with intellectual disability is of little use in existing government labour market programs. Overall, the available individualised funding cannot be used to mediate these systems and customise them to suit young people with intellectual disability.

Given the social inclusion underpinning of economic participation for this cohort, the policy decision to leave community-based economic participation supports, including training and employment supports, outside the human rights underpinned NDIS, while incorporating segregated economic participation (e.g. ADEs) and non-economic participation activities within it, has exacerbated existing barriers for young people with intellectual disability who seek economic participation. The confused policy and practice interface this has created also means that while social and economic participation are the desired outcomes of the NDIS, there are very few community-based economic participation supports within it. This has resulted in a two-tier system, whereby young people and families can stay within the NDIS system to access mainly segregated economic participation services or move outside of it and attempt to access employment support systems that are designed to exclude them. However, despite the NDIS' ambition for mainstream services to become more accessible to people with disability, the neoliberal policy settings driving those systems and the small number of young people in this cohort have resulted in little attention being paid to their goals and aspirations.

There is emerging evidence to suggest that individualised funding is not an appropriate lever to shift complex barriers in complex systems (Carey et al., 2017; Green, 2018). The marketisation of supports for people with intellectual disability, via the NDIS, has resulted in an atomised funding system in which the parts of the system are separate rather than joined up. The individualised funding system makes it difficult for families to join up necessary supports at the individual level to build the support network their young people require. No single agency is supporting young people and their families to develop overarching economic participation plans that draw on supports across systems, either during or post-school. For example, families wanted more information and support about transition and economic participation options while their young people were at school. Currently this must either be provided by schools, or young people must use their individualised funding to source it from a limited market. Support for families is also problematic within individualised funding systems in which the young person with intellectual disability is the focus of support. This conflicts with the literature, in which actively supporting families to build capacity to support the economic participation of young people leads to improved outcomes (Francis et al., 2013; Kramer et al., 2020; Roy, n.d.).

Current policy settings result in individualised funding for economic participation supports typically not being available until school completion, resulting in young people missing out on important early economic participation activities such as after-school jobs. The result is young people and family members experiencing frustration because the structured pathways – the ‘sealed highways’ in which the appropriate supports are joined up at the system level and readily available – are absent. There is also evidence of funding inequity, with some young people receiving funding for a specific support while others do not. In countries seeing improved economic participation outcomes, such as the US, individualised funding is not used. There is thus a need to consider whether individualised funding – while being a possibly important resource if it could be activated – is the right model for economic participation for this cohort. Individualised funding is not used in the economic participation ecosystem more broadly, therefore it creates further difference for young people with intellectual disability, reinforcing their separateness from the mainstream post-school pathways.

There is also growing evidence that individualised funding disincentivises collaborative practice (Green, 2018), which is problematic because the literature is increasingly pointing toward the importance of interagency collaboration, defined as schools and post-school services working together (Haber et al., 2016; Kohler et al., 2016; Magee & Plotner, 2022). For young people with intellectual disability, this has demonstrated efficacy in improving post-school outcomes (Papay & Bambara, 2014). Individualised funding was reported by key informants as reducing interagency collaboration and increasing the siloing of service systems, especially in relation to economic participation. Vera's example of being unable to arrange for her daughter to be provided with blended supports by two different organisations – a disability service provider and a TAFE – illustrates the issue. Collaborative practice must be incentivised at the policy level by connecting atomised systems using models that draw system actors together to build pathways to economic participation, such as by 'blending and braiding' funding streams into a structured pathway. Examples from the data include post-school education providers, employment services and employers collaborating to create an in-situ learning opportunity that led to employment for 80% of participants in one program, and 100% in another.

The experience of the young people and family members was that individualised funding did not provide the choice and control it promised, particularly in relation to economic participation. In particular, the market-based approach of the NDIS has not resulted in highly specialised supports such as customised employment being available in the market nor the delivery of other evidence-based practice. Uniquely in the Australian context, the NDIA has the responsibility to intervene where there are market gaps or thin markets by 'stewarding': making 'efforts to address market deficiencies, such as thin markets, market gaps or other market failures' (Carey et al., 2018; p. 1). The NDIA has policy levers available with which it can address the absence of suitable supports in the market, particularly as they relate to scheme participants. For example, the introduction of SLES by the NDIS, and particularly its 'programmatic' structure, made it appealing to families as a post-school choice, and they chose SLES 'programs' over traditional day centres or ADEs. This demonstrates that policy decisions can have an immediate effect on the market and, thereby, on the opportunities available to young people with intellectual disability.

As an independent statutory agency, the NDIA is supported by legislation and an outcomes framework to drive change for people with disability – both those within the NDIS and more broadly. The significant number of people with intellectual disability in the NDIS means that the NDIA has the authority and 'impetus' to drive changes in expectations and in the composition of the NDIS market/service system that young people with intellectual disability primarily utilise. In particular, the NDIA has policy levers such as planning directives and funding mechanisms that mean it can lead the high-level policy work required to reduce the policy interface issues that are widely known to cause barriers for young people. For example, policy settings related to utilising NDIS funding within school settings, including for work experience supports, have the potential to impact on the availability of appropriate work experience for this cohort.

While governments have a range of policy and intervention levers available to them, multi-level and multi-factor interventions are needed to effect change (Idle et al., 2021). The experience of the US lifts the viewpoint to overarching economic participation policy, above the mechanism of individualised funding. Employment First policy has been shown to support collaboration, influence practice and achieve outcomes. Employment First policy settings bring a focus on capacity building, provider transformation, school-to-work transition, employer engagement, and policy/funding alignment (Giordono, 2020). Employment First policy is both a suitable framework to drive the system-wide change required in the Australian context and a suitable lens through which to align policy, structure and practice. Part of a shift to Employment First policy settings is a reconceptualisation of 'supported employment' in the Australian context, one which aligns it with the terminology in the literature (Wehman, Taylor, Brooke, Avellone, Whittenburg, Ham, Brooke, et al., 2018). Rather than binary notions of open or sheltered employment (confusingly called 'supported employment' in Australia), supported employment – as is internationally evidenced – recognises the need for ongoing supports to enable people with intellectual disability to work in community-based settings. Conceptually, supported employment is derived from human rights standpoints as they relate to people with intellectual disability. According to Wehman (2012), it is a movement that directly challenges the system, in terms of entitlement to both be included in the community and have access to appropriate supports. Supported employment is underpinned by strengths-based approaches, and acknowledges the embodiment of intellectual disability and the need for personalised, structured and ongoing (rather than one-off) supports and adaptations. In addition, it fundamentally shifts the engagement of employers to a human rights lens, which aligns with inclusive workplace approaches (Mor-Barak, 2014) in which employers engage in strategies to improve employment for disadvantaged groups aligned with corporate social responsibility. In this context, Employment First policy focuses all economic participation activities across the plethora of systems delivering it.

Finally, the shift to de-differentiated economic participation policy settings has resulted in poor economic participation outcomes for this cohort. The evolution of DES, as described by key informants, is indicative of the powerful influence of policy settings on both the composition of the service system and the direct supports service users have access to. The drift from early human rights settings to today’s neoliberal model, has resulted in people with intellectual disability being almost entirely shut out of DES, making up just 3% of the caseload (Australian Government Department of Social Services, 2022). This thesis argues that a shift to differentiated economic participation policy settings could rapidly result in suitable employment services becoming available for people with intellectual disability, by ensuring access to appropriate resources.

9.5.2 Service systems and transition structures

At the implementation level, services that potentially support economic participation for young people with intellectual disability sit within multiple systems. Because of this plethora of service systems, there is no clear marketplace of economic participation providers delivering the desired forms of economic participation support for this cohort and their families.

Despite high-level policy changes, including the introduction of the NDIS, there has been a failure to ensure that operational-level policy settings reflect those changes. Organisational-level policy settings are those that connect broad-level policy to practice. It is these policy settings, for example within DES-ESS and the NDIS, that profoundly influence both the construction of the service system and the way supports are delivered to individuals. The data demonstrates that the organisational structures, such as ADEs and day centres, have barely shifted their practice since the introduction of the NDIS, leading to what could be described as market failure (Malbon et al., 2017). The choice-of-provider model within the NDIS results in meaningful choice and control for participants actually being dependent on local ‘market structure’: that is, the availability of multiple, competing providers (Carey et al., 2017). However, in reality there is no existing 'market' of service providers to deliver evidence-informed economic participation supports to young people with intellectual disability post-school, regardless of whether they have economic participation goals and funding. In other words, there is a market gap. Within the quasi-market system, these market gaps result in young people and families not having choice and control, and therefore choosing supports that align most closely with their goals regardless of whether they produce real outcomes.

Disability system

The data made visible the continued existence of a primary ‘disability service system’ within which young people and family members operate, and that at the completion of school, the primary task of the education system is to direct young people and families into that system utilising operational transition practices (Kaehne, 2013). Families not seeking community-based economic participation stay comfortably within this system, with their young people transitioning from school to day services and ADEs. However, where economic participation is a goal, the supports required to achieve it are scattered across several systems, including disability, education, NDIS, post-school training, and employment and labour market programs. In these settings, the human rights underpinnings of economic participation are not recognised and there is a lack of knowledge and skills to support young people's economic participation aspirations.

Despite being in a period of post-institutionalisation, and the ongoing debate about the future of segregated settings in Australia, the post-school experiences of young people and family members were the continuation of a largely segregated system, particularly for economic participation. The data supports Kramer et al.'s (2020) findings that disability systems, including those established specifically to support people with intellectual disability, remain wedded to institutionalised thinking, with low expectations about what people with intellectual disability can achieve (Altermark, 2018; Griffin et al., 2012). Young people and family members acknowledge difference and the need for specialised responses, but reject segregation, especially in the context of economic participation. In their minds, this is a rejection of the institutional era system which contemporary human rights focused policy has replaced. Disability services are regarded as a pathway to exclusion rather than inclusion, and so they lack value for the young people, particularly when the goal is to create an ordinary life. Given the inability of alternative systems, including Commonwealth labour market programs such as DES-ESS, to provide the necessary supports, the responsibility for delivering post-school supports falls primarily to the disability service system. The fact that young people and family members did not reject disability organisations in their entirety, however, indicates that the structure they offer is valuable to them, particularly immediately post-school. However, the continuing emphasis on institutionalised service models clearly does not meet their need in the contemporary context, meaning that families must continually push back against a deficit-focused system and the individual organisations operating within it.

Reconceptualised understandings of intellectual disability and economic participation provide opportunities for the construction of the disability service system to shift and realise the state's human rights perspective. States in the US that actively 'desegregated' by shifting the delivery of supports away from segregated settings saw improved community-based economic participation outcomes (Winsor et al., 2019). In the Australian context, there is a need for disability service systems to actively de-institutionalise to meet the needs of young people and family members, and to act as change agents in further reconceptualising intellectual disability in the broader community. As Barnes (2003) described, a deliberate shift away from deficit models and segregation to supported, integrated, community-based models is a powerful lever for reconceptualising intellectual disability across the broader community.

In addition, there is a need to shift organisational cultures toward strengths-based approaches, person/environment fit and supported models of community inclusion, all within the developmentally focused context of emerging adulthood. Adaptation of community-based environments, including provision of supports for adapting environments, must therefore become the focus of service delivery.

Transition structure

A key area requiring improved operational structure is transition from school. According to Trainor et al. (2019), 'contemporary transition policies and practices are grounded in the belief that students with disabilities are far more likely to achieve their aspirations for life after high school if provided the right combination of opportunities, instruction, services, and supports'

(p. 5). Kohler et al. (2016) identifies key elements of transition practice – family involvement, student-focused planning, interagency collaboration, student development and program structure – within the structure of a taxonomy. ‘Best practices’ that support post-school outcomes like employment, further education and independent living, include a combination of: high expectations, early exposure to work experience, family involvement in transition planning, preparation for independent living through life skills or community-based instruction, and youth self-determination (Papay & Bambara, 2014).

The data indicates that educational settings are the primary providers of early economic participation activities and transition supports in Australia. Changing transition practice must therefore occur and be supported in education settings by aligning their practice to best practice within the literature. The family members in this study described operational transition practice (Kaehne, 2013) as being focused on transfer from school to the disability service system. The extent to which the evidence-informed best practices described previously are available to young people and families is therefore dependent on the cultures of individual schools rather than on structured transition support being available across the education system. Although some young people and families did have access to particular elements of transition support, these supports were not delivered within the ’taxonomy’ approach (Beamish et al., 2012): in other words, while some elements were available, they were not delivered within a structured ‘transition program’ starting at age 15. The lack of a transition model left many young people with intellectual disability with little in the way of transition-focused education. Family members filled gaps, for example by setting up work experience. Schools that did align their practice with elements of best practice, such as Kate’s school and TTW schools, had high numbers of students transition from school to economic participation activities instead of disability services.

Despite its lack of structure, the process of transfer from school was described as appropriate by families at the time. SLES, perceived as a disability program by young people and families, was the preferred post-school option for many because it is community-based and economic participation-focused, and delivered by organisations that have shifted the focus of their supports in line with human rights principles. However, for the families that transitioned to SLES, a second, invisible transition, as described by Hudson (2006), later occurred. This was neither formally acknowledged nor well supported, and it was at this point that family members began to doubt whether economic participation could be a reality for their young people.

The data indicates that funded collaborative, structured partnerships, such as TTW and the WIL programs Rohan and Kylie were involved with, were successful in supporting young people's economic participation goals, thereby avoiding the invisible transition point. Such collaborative models not only achieved outcomes for this cohort but also facilitated bringing 'on board' a range of actors, such as training organisations and businesses, which is known to be critical to opening up opportunities for young people (ARTD Consultants, 2016; Shogren et al., 2017). Several examples show that collaborative structures bring a broader range of resources to young people, and that cooperation between various system actors leads to improved service delivery due to the increased breadth of opportunities and skills they make available, which aligns with the results Project SEARCH-type models achieve (Butterworth et al., 2017; Christensen & Richardson, 2017; Kaehne, 2016; Persch et al., 2015). These collaborative structures create 'sealed highways' to economic participation in a similar vein to those normatively in place for young people, which is critical to changing the trajectory of young people with intellectual disability away from segregated disability services. Dual enrolment school/college programs, for example, provide a pathway to a normative post-school spaces focused on training, skills development and employment (Grigal & Hart, 2010;

Grigal et al., 2012; Moore & Schelling, 2015). Collaborative structures can also work alongside individualised funding if they are structured so that individuals maintain choice and control, and can utilise their individualised funding to purchase appropriate supports. Rohan's WIL program demonstrated the efficacy of this approach; however, its reliance on philanthropy meant that its reach was limited.

By enabling 'buy in' to a structured program that supports risk management, collaborative structures also enable employers to be engaged in creating solutions (Shogren et al., 2017). According to key informant Sharyn, 'you can't use individualised funding to buy a job'. The data highlighted employers' willingness to engage in economic participation initiatives for disadvantaged people where there was a program of support. Employment initiatives for people with intellectual disability must therefore offer the structured approaches that incentivise employers to engage. Employer engagement is particularly critical because employers bring innovative solutions to creating opportunities for young people with intellectual disability in the community. The absence of structured demand-side programs or supports in the Australian context must be addressed, through funding of both structured models such as TTW and WIL and employer capacity building models such as the Diversity Field Officer approach that was successful in engaging small-to medium-sized employers (Murfitt et al., 2018; Murfitt et al., 2016).

Technical Assistance has been widely used in the US to embed evidence-based practice, including the 'Think College' approach, which has resulted in changed attitudes about college for young people with intellectual disability, the development of an evidence base, and strategies and resources to support colleges to implement best practice approaches so that young people with intellectual disability can be included in college settings. A Technical Assistance approach within the Australian context could support capacity building across systems by gathering evidence about what works, providing training and coaching to support system change and measuring progress. Technical Assistance therefore has a key function in brokering inclusion opportunities for young people with intellectual disability within community-based settings.

The introduction of new models and structures across the service systems also needs to be based on shared expertise. The data has made visible the specialist skills disability providers hold, particularly in relation to understanding intellectual disability. However, there is a need to extend the concept of collaboration to include the resources and knowledge of the young people and their family members, along with those of differentiated intellectual disability specialists and economic participation specialists. This will create highly personalised economic participation supports within collaborative service systems.

9.5.3 Supports that facilitate the economic participation of young people with intellectual disability

The role of supports in mediating the impacts of intellectual disability, improving the fit between a person's strengths and the demands of their context, and enhancing community inclusion is increasingly being recognised (Bigby, 2020b; Buntinx & Schalock, 2010; Wehmeyer, 2020). Via the NDIS, Australians with intellectual disability have access to funding for supports related to their goals and, in a general sense, they commonly require similar types of supports – for example, support with decision-making, organising information and learning new things. Shifting away from providing such supports in segregated settings requires skilling-up professionals and service deliverers. There is a need to transform how supports are provided to young people with intellectual disability so that they align with biopsychosocial models, human rights principles and the state's broad policy settings. In this context, economic participation supports will be focused on using adaptation and support to create environments within the community in which young people with intellectual disability can exercise their right to engage in economic participation alongside their peers.

Delivered within ecological context

Applying an ecological lens recognises that ‘supports’ must be viewed from a much broader perspective – that of the person and the environment – with a dual focus on addressing barriers within social structures (including workplaces and training settings) and directly supporting young people’s skill development. Rather than focusing on individualised services, this requires a stronger focus on capacity building to support communities in becoming inclusive and facilitate the individual functioning of young people with intellectual disability. The data demonstrates that currently, the provision of supports is heavily weighted towards individuals, with little emphasis placed on supporting the *environments* young people want to be included in. There is thus an overreliance on the delivery of supports within segregated settings. One strategy for addressing this is to enable NDIS funding to be more easily utilised to purchase supports that add on to external systems such as TAFE colleges – for example, the brokers family members described a need for, who could act as conduits between young people and workplaces.

Employers are under no obligation to include people with intellectual disability in workplaces, and the absence of structured support to do so is a barrier to this cohort’s inclusion in the labour market (D. Moore et al., 2018; Murfitt et al., 2018). There is a need to purposefully support employers in engaging and building inclusive opportunities, for example by ensuring that the young person is productive and safe through the provision of an on-site support worker (K. Moore et al., 2018). Supporting employers within structured economic participation models such as customised employment, TTW and Project SEARCH-based WIL models has been shown to open up economic participation opportunities for people with intellectual disability, because these are in fact employer-engagement approaches. Making them more widely and systemically available therefore has the potential to expand opportunities for people with intellectual disability.

Family-centred practice

Despite the newly conceptualised role of families and the clear leadership role they hold in shifting the conceptualisation of people with intellectual disability, formal services have failed to shift their support models to work collaboratively with families, leverage their skills, or support them as their young people transition from school. The data showed that families felt the lack of collaboration with services and education providers to be a major barrier to realising their young people’s economic participation goals. Of particular concern was poor planning and communication, and service providers failing to deliver the supports or opportunities family members expected. Given the important role families play in transition, supports must actively collaborative with them and their young people to broker economic participation arrangements. Framing the delivery of supports around a ‘family-led’ model would help to skill up families and build their capacity to be ‘career allies’ over the long-term.

In addition, supports for young people and families must be provided with the context of realising their individual aspirations and visions for the young people’s adult lives. Young people and their families must have access to supports which work in a highly personalised way to build on the young people’s strengths and preferences as they progress toward community-based economic participation. Despite Australia’s individualised funding model, the highly person-centred approaches that support community-based economic participation for this cohort were not apparent, and supports were instead provided within segregated settings or in groups.

Rather than individualisation, then, there is a need to shift to the personalisation of supports, where the focus is on leveraging and building on young people's individual strengths within structured support systems that empower them and their family members to achieve their individual 'ordinary life' goals (Bigby, 2020b). The uptake of SLES demonstrates how a programmatic structure can meet the needs of young people and family members immediately post-school. The challenge in utilising SLES more effectively is empowering young people and their families through the provision of information and support for planning highly personalised strategies that incorporate the longer 'emerging adulthood' period. Incorporating a Discovery process within SLES is one example of how evidence-informed practice can 'set up' supports within the context of transition to adulthood.

Differentiated supports

The shift to de-differentiated policy settings and the subsequent 'dismantling of special arrangements for vulnerable groups, dissolution of categories and growing individualism' (Sandvin & Soder, 1996, p. 117) has reduced the availability of economic participation supports for young people with intellectual disability – most significantly, access to employment supports through the DES-ESS system. Differentiated models deliver highly specialised supports to people with intellectual disability that account for the embeddedness of intellectual disability and the need to adapt environments for this cohort (Bigby, 2020b; Buntinx & Schalock, 2010). Importantly, differentiation recognises the dynamic nature of environments, and thus how people with intellectual disability need to be supported to engage in community settings via ongoing and tailored supports. The use of differentiated supports, including customised employment and WIL, would enable young people with intellectual disability to achieve community-based economic participation outcomes. The data demonstrates how adapting the environment to support the specific needs of an individual with intellectual disability, while also providing supports within the workplace can result in successful work placements that meet the needs of both employers and young people. Differentiated in-situ learning opportunities also support skill development, expectations and choice-making (Persch et al., 2015). WIL programs such as Project SEARCH provide highly specialised, tailored support and environmental adaptation for both young people and workplaces, and thus enhance learning. The use of specialised techniques such as repetition, task analysis and shadowing have been proven effective in supporting young people with intellectual disability to learn work-related skills (Gilson et al., 2017). Two differentiated in-situ economic participation support models in which young people were taught work skills and soft skills via in-situ work experience opportunities were described in the data, and Rohan detailed how his involvement in a WIL program supported choice-making in relation to which jobs he preferred and which companies provided a good fit for him. Both models produced excellent outcomes, in line with those achieved by Project SEARCH (Kaehne, 2016; Persch et al., 2015; Project SEARCH, n.d.).

Best practice supports

Despite a substantial, and growing, evidence base of practices that result in community-based economic participation for young people with intellectual disability (Dean et al., 2018; Moore & Schelling, 2015; Papay & Bambara, 2014; Persch et al., 2015; Shogren et al., 2017; Wehman et al., 2018), the data made visible the fact that in Australia, supports were not being delivered in the context of evidence-informed 'best practice'. In particular, the young people participating in the study had not been supported to undertake early work experience, despite strong evidence that this is an important predictor of economic participation and an 'indispensable transition tool' (Luecking et al., 2020, p. 1). While the young people in the study did have access to school-based work experience, this was poorly 'integrated' into broader transition planning, and in some cases was used as a 'stepping stone' into the segregated disability system. Work experience was not utilised as a strategy for building self-determination, undertaking assessment, or building expectations among young people and family members about community-based economic participation (Luecking et al., 2020). Post-school, the young people's unpaid work experience did not take place within an evidence-informed framework, and young people were not provided with supports to move from unpaid to paid employment, creating a risk that they would remain unpaid over the long-term. Work experience within both school and post-school settings therefore requires reframing as an economic participation development opportunity. This would enable young people with intellectual disability to develop an understanding of work, develop work skills and make choices and decisions, and act as a mechanism for developing an understanding of the young person's strengths, interests and support needs within a biopsychosocial context (Luecking et al., 2020).

Positive interactions are a key mechanism for breaking down stereotypes and changing attitudes about people with intellectual disability (Brown & Moncrieff, 2018; McManus et al., 2010). Well supported work experience is thus a tool for engaging employers and enabling them to see firsthand how a person with intellectual disability can be supported within their workplace (D. Moore et al., 2018). In addition, work experience, particularly when it is structured within a WIL program, is an important step toward long-term paid work (Moore & Schelling, 2015).

Post-school, the data made visible a lack of evidence-informed supports such as customised employment, WIL, integrated post-school education and place-based collaborative approaches. Despite the strong evidence that 'supported employment' models, (i.e. customised employment), lead to the economic participation outcomes the young people and families in this study aspired to, this practice is largely absent from the Australian environment. Customised employment, although not labelled as such by some family members, was considered by key informants to be critical to driving change in economic participation for young people with intellectual disability. The use of the word ‘broker’ by family members indicates their recognition of a need for a conduit between young people and employers – a role that is a key component of a customised employment strategy. Customised employment could become more widely available if the right organisational structures were in place to support its delivery, and the policy settings related to employment supports were aligned.

Delivery of such highly specialised supports requires trained and skilled staff whose work is underpinned by social inclusion theories. However, within a quasi-market environment such as the NDIS, service providers are less incentivised to provide training to or upskill staff (Ryan & Stanford, 2018). Therefore, a workforce development strategy must be developed and implemented in order to increase young people with intellectual disability’s access to evidence-informed supports such as customised employment. Evidence-informed employment support for young people with mental health issues, in the form of Individualised Placement and Support, has been supported in Australia by a nationally funded rollout of training for staff in mental health support services (DSS, 2019). A similar approach should be considered to support the development of an appropriate workforce to support the economic participation of young people with intellectual disability.

Timeframe

Economic participation-related supports need to be delivered within a developmental context for young people with intellectual disability (Redgrove et al., 2016). The emerging adulthood period, as described by Arnett (2004), offers a normative framework within which young people with intellectual disability have an extended period of time to prepare for the longer adulthood period. Naming the period ‘emerging adulthood’ enables improved long-term planning and increased access to the normative activities of the emerging adulthood period, in contrast to the hurried transition processes the young people and families in this study experienced. Rather than an intense period of activity immediately post-school, which for some families acted to reinforce views about the lack of suitability of young people with intellectual disability for community-based economic participation, a stepped approach over a 7- to 10-year period would align with the young people's and their families' developmental perspective, and their need for a period of adjustment post-school. In addition, the longer-term perspective has the potential to reduce 'dropout' into segregated disability systems, by providing a structured approach to the delivery of economic participation in which young people and their families could build capacity and readiness over time.

In order for the emerging adulthood period to become available to young people with intellectual disability, the role of schools needs to shift so that they become in essence a 'pre-emerging adulthood' space and a period of developing readiness for post-school life in the way that it is normatively framed. Aligned with Kohler's (2016) Taxonomy for Transition Planning, the role of the school centres on family and student-centred planning, and student development, keeping post-school pathways open and providing key information about young people's strengths, interests and support needs. In addition, the use of multi-agency planning structures creates bridges to post-school supports – the 'stepping stones' the families are seeking – resulting in bridges to post-school life rather than the 'cliff' described in the literature (Pallisera et al., 2016).

9.6 Conclusion

There is currently a groundswell of interest in improving economic participation for young people with intellectual disability in Australia (DSS, 2021a; NDIA, 2019a). However, the data clearly demonstrates that little will change without a reconceptualisation of both intellectual disability and economic participation in the context of intellectual disability, as well as improved access to evidence-based best practice supports.

The use of a policy framework to drive system change, such as Employment First, would support the necessary shifts in conceptualisation and enable systems to align their practice to its human rights-informed underpinnings. Employment First can also address a key challenge, which is to embed evidence-informed practice widely. The increased inclusion of young people with intellectual disability in workplaces is necessary to drive the ongoing reconceptualisation of people with intellectual disability and increase awareness of their right and capacity to be included in the communities in which they live. Critically, service systems need to align with policy and put in place structures that can drive and support best practice. According to Stoneman (2009), three issues warrant attention in relation to changing support systems: adoption (translation of research into practice); sustainability (ensuring that interventions are not discontinued); and implementation drift (a gradual deterioration of good practice over time). Employment First policy settings must therefore ensure that progress towards achieving the state’s objectives of economic and social inclusion of people with intellectual disability is measured and monitored, and that the delivery of supports leads to the kind of economic participation young people with intellectual disability and their families are seeking.

Chapter 10: Conclusion

10.1 Introduction

This chapter returns to the problem identified at the outset of this thesis: the lack of inclusion in economic participation of young people with intellectual disability. The thesis explored the experience of young people and their family members as they transition from school to adult life, focusing on their expectations for economic participation and the barriers they face in realising their goals. The views of key informants supported the mapping of barriers to economic participation, and the identification of strategies to address them using an ecological framework.

A major aim in writing this thesis was to hear from young people with intellectual disability and their family members regarding their expectations and aspirations for adult life, and to make visible both the factors that impede the realisation of their goals, and those that support them. In particular, the thesis aimed to highlight the discourse and attitudes about economic participation of young people with intellectual disability across the various systems that together comprise the economic participation ecosystem, and how they create barriers, particularly in those parts of the system that offer normative economic participation supports and opportunities.

10.2 Key findings

This thesis has made visible the new expectations young people with intellectual disability and their families hold about carving out an ordinary life in the community – expectations that include working in an ordinary job. However, it has also demonstrated the increasingly challenging pathway to economic participation this cohort faces, shaped by complex funding and service systems that take sophisticated in-depth knowledge, advocacy skills, and often luck to navigate. The barriers young people and their families face are the result of entrenched societal norms that dictate the economic participation roles people with intellectual disability can assume in their adult lives. The data made it apparent that despite significant shifts in perspectives about disability overall, societal norms about people with intellectual disability have barely shifted in the period since de-institutionalisation, and those norms operate at systemic levels, leaving young people who aspire to community-based economic participation and their families facing significant, often insurmountable barriers, to achieving their goals.

10.2.1 Designing an included life

The data highlights the need for a widespread and fundamental paradigm shift in the conceptualisation of young people with intellectual disability, their economic participation and the systems that support them. Citizenship in neoliberal Western democracies is dependent on the individual making a productive contribution to society. Given the benefits good quality work can provide in terms of social inclusion and valued roles, economic participation for already marginalised groups such as young people with intellectual disability should therefore be framed within a human rights paradigm rather than an economic one. A key finding of the study is the importance of meaningful and ordinary life roles to people with intellectual disability. The cohort of young people with moderate intellectual disability aged 15-24 is small, and its members have highly specialised support needs in relation to economic participation – needs which are easily overlooked given that within broader society they are considered non-workers. Government should therefore prioritise early investment in creating expectations of economic participation for this cohort, framed within the broad range of ways in which it can occur and the provision of resources to support the deliberate design and maintenance of an included life across the lifespan.

The findings of this thesis demonstrate the conceptualisation of economic participation for this cohort as a means to social inclusion. It could therefore be termed ‘economic inclusion’. Chapter 6 provides a rich picture of the ordinary life aspirations held by young people and their family members, providing an insight into the importance of economic inclusion to citizenship and feelings of being valued. The notion of an ‘ordinary life’ anchors economic inclusion, and paid community-based employment is considered to underpin an ordinary life. As James put it, ‘What else would you do?’ Drawing from Clifford Simplican et al.’s (2014) theory of social inclusion enables economic inclusion to be considered a critical component of an included life. For young people and families, it is a vehicle for a young person’s acceptance as an individual beyond their disability; it enables them to develop significant and reciprocal relationships; and it results in them engaging in normative activities in the community (Clifford Simplican et al., 2014). Like social inclusion, however, it requires the provision of both informal and formal supports, and it requires those supports to be oriented toward person-environment fit.

The barriers that exist in society broadly and in economic participation spaces such as colleges and workplaces must be deliberately addressed to enable the economic inclusion of people with intellectual disability. Rather than creating separate spaces, the provision of supports must shift towards the goal of creating inclusive environments, shifting attention away from the perceived deficits of intellectual disability to create strengths-based environments in which young people with intellectual disability can thrive.

Chapter 7 identified a lack of clarity about the purpose of economic participation for this cohort. While they and their families were seeking economic inclusion, the systems themselves viewed them within a welfare paradigm, narrowly focused on assessing their suitability for work as it is normatively constructed. As a result, the discourse surrounding community-based work for young people with intellectual disability fails to pay explicit attention to the non-monetary value work provides. This has resulted in conflicting views across the ecosystem about this cohort's suitability for community-based work – and a system that has failed to respond to the aspirations of young people and families or provide the information, opportunities and supports they require. In essence, there is an identity battle, in which both young people themselves and their family members, who were strengths-based and focused on economic inclusion, were required to navigate systems that viewed the economic participation potential of young people with intellectual disability negatively.

The thesis highlights both the breadth of mechanisms available for building economic inclusion for young people with intellectual disability, and the need for highly personalised pathways for each young person and family. Young people and their families are not necessarily 'binary' about integrated and segregated services and supports, and each frame their expectations differently. Integrated and segregated options can therefore be combined in a 'hybrid approach' which recognises that disability supports have value and that young people require a range of relationships, including with others who have an intellectual disability. However, the strong preference for economic participation activities in community-based settings was apparent among young people and families.

This notion of economic inclusion, and the need for significant effort to sustain an included life, can be best framed as 'life designing' (Wehman, et al., 2018): that is, designing a good life in the community and taking action to make it happen. The role of formal systems must therefore be to support the development of a vision and its realisation based on the individual needs and circumstances of a young person and their family. This recognises the family's critical role in sustaining economic participation across the lifespan. Through this new lens, the trajectories of young people with intellectual disability are framed as a sustained and supported journey from preparation through to participation. The concept of emerging adulthood enables planning for economic inclusion which explicitly recognises the importance of this period. replacing short-term placement with longer-term, developmentally focused planning creates sustainable economic inclusion across the lifespan. Sustaining economic inclusion across the lifespan requires the creation of a support system (Lindstrom, 2014; Taubner, 2021), and efforts to create that support system begin in adolescence. This includes ongoing training and supervision, an inclusive workplace with flexible employers and supportive co-workers (Lindstrom, 2014), and natural supports, including the family as a critical element. Schools have a key role to play in providing the early support system and building normative expectations (Wehman et al., 2018), enabling the full period of emerging adulthood to be available to young people and families. Understanding economic inclusion as part of the unfolding and changing life course significantly impacts the way services should be made available to young people and families, putting the focus on providing flexible life-course supports that align with their conceptualisations of economic participation. However, these are not currently available within the system.

10.2.2 Market mess, employment barriers and changing expectations

A major aim of this thesis was to take an ecological approach to make visible the complex and intersecting barriers that prevent the economic participation aspirations of young people and their family members from being realised. The thesis has described a complex range of factors that result in the exclusion of young people with intellectual disability from normative pathways to economic participation as experienced by their peers. Strategies to address low economic participation must therefore be multi-level, both recognising the interconnectedness and embeddedness of barriers and addressing them across the system.

This thesis highlights the ‘market mess’ that exists, including the significant barriers it creates at the community and organisational levels of the ecosystem for young people and family members seeking economic inclusion post-school. This market mess has been exacerbated by the way the human rights-driven individualised funding scheme has been overlaid across a neoliberal styled economic participation system in Australia. Family members attempting to navigate both the multiple systems that normatively support young people’s economic participation and additional, specialised disability systems felt that, overall, systems were fundamentally unfit for purpose for this particular cohort. Key informants working within the various systems agreed that pushing young people and family members into multiple complex systems, each with its own set of complex policy settings and rules, is unfair and unsustainable, and ultimately leads to drop-out back into the segregated settings they wanted to avoid.

The incremental development of policy without an ecological lens has resulted in a myriad of interface issues that reduce service access, particularly for this cohort. The thesis has laid bare the problem of incompatible systems and identified how ineffective individualised funding is within them. The most evident incompatibility is in the interface between the NDIS and the Commonwealth employment services system, within which DES-ESS sits. The policy decision to send people with intellectual disability who have economic participation goals into the complex, Active Labour Market-underpinned DES-ESS system is fundamentally flawed, especially when ADEs and day centres have remained within the NDIS. While the NDIS and DES-ESS have broadly aligned goals to increase the economic participation of people with disability, the mechanisms that drive their operations, including their funding systems, are poorly aligned. DES-ESS funding mechanisms disincentivise providers from supporting people with intellectual disability due to the intensity of the supports that are often required.

The data demonstrates that for people with intellectual disability, market failure has resulted in contemporary evidence-based supports such as customised employment being largely unavailable to them, in the NDIS marketplace or in any other system. The lack of innovation apparent in the marketplace adds to concern about the impact of highly individualised funding and subsequent marketisation on innovation and risk-taking within the provider market. Perhaps due to the immaturity of the NDIS and its early focus on transitioning people with disability into the scheme, the primary disability service system has barely shifted in terms of the services and supports available. Within traditional day centre and ADE settings, for example, young people and families reported that there has been little innovation.

Employment First approaches to system change offer insight into the ingredients required to drive that change (Giordono, 2020; Molfenter et al., 2017) and to deliver services and supports based on the latest available evidence of what works. The implementation of Employment First in Australia can be facilitated both by drawing on existing good practice, such as TTW, and the international literature, and by undertaking research and development, to produce appropriate models. Bringing about change will require replacing existing employment services policy as it relates to young people with intellectual disability with human rights policy settings that recognise the significant and sustained effort required to build economic inclusion for them, and the deliberate creation of a highly specialised, differentiated, evidence-informed employment support program. Locating this within the NDIS system in direct competition with day centres and ADEs will result in ease of access for NDIS participants and increase the options available to young people and families with economic participation goals.

The rejection of segregated spaces by young people and family members highlights a critical need for organisational structures to align with new conceptualisations of economic participation. Overreliance on segregated structures is an issue of particular concern to young people and families who are seeking community-based opportunities. Deinstitutionalising systems to close off default pathways to segregated settings for young people finishing school must become a priority.

Key informants reported that the shift to individualised funding has reduced collaboration. In many cases, the resources needed to create pathways to economic inclusion were unavailable, or the pathways were blocked by systemic barriers. To drive system change, a range of flexible funding solutions must be made available, with a stronger focus on *personalisation* rather than individualisation. Incentivising young people, families, support providers, training providers and employers to work together to build economic inclusion can increase choice and control by bringing additional opportunities into the market. In addition, collaborative structures such as TTW have demonstrated capacity to address the significant attitudinal barriers young people with intellectual disability face, particularly within the wider community.

The thesis therefore draws attention to the difference between highly *individualised* and highly *personalised* supports. Young people and their families were focused on personalisation: rather than carving out entirely new paths, they sought accessible pathways – ‘sealed highways’ which they could personalise, drawing on the young people’s strengths, interests and preferences to shape economic inclusion opportunities.

The data made visible the shift in the previously informal role played by families since the introduction of individualised funding, and in particular their quasi-formal role in realising economic participation goals. This new ‘dual’ role must be understood and supported by formal recognition of family members as the primary support system for young people with intellectual disability who live in community-based family settings. Given the critical and profound influence of families on this cohort’s life outcomes, their needs should be treated holistically in terms of the planning and provision of supports. Specific training and support to equip families for the role of long-term career ally is also critical, and must start early. Given the increased range of opportunities available to the young people in this study who were supported by family members operating as career allies, improving the support available to families has the potential to unlock significant support for young people as they transition to adulthood.

Research has identified five best practices in the area of transition as critical to supporting employment outcomes for young people with intellectual disability. These include: work experience, involvement of young people in transition planning, family support, interagency collaboration and preparation for independent living. However, these are not systematically available to young people and families. Shifting from operational to multi-agency transition planning and focusing on the availability of the five best practices within schools has the potential to shift both the culture of special schools and the life trajectories of young people who attend them. In addition, they bring a broader range of transition support resources to the table, and have demonstrated their ability to change broader attitudes about economic participation for young people with intellectual disability.

Underpinning system change is the need to set targets for the economic inclusion of people with intellectual disability, collect data to monitor change and continually drive best practice through an ongoing program of research and evaluation. Currently, segregated and community-based employment are both considered employment outcomes within NDIS reporting frameworks, despite the differences in life outcomes between them. A more nuanced and sophisticated definition of economic inclusion for this cohort is therefore necessary to drive change.

10.3 The role of government and key levers for change

This thesis has identified several levers available to government and has outlined how those levers could be used to significantly improve access to economic participation supports for young people with intellectual disability within a short timeframe. The NDIA could play a key role in the implementation of Employment First practice for this cohort, given its role in planning and the availability of several funding items, including SLES funding, within the NDIS. Mandating discussion of economic participation within the planning process for young people in this cohort and inclusion of economic participation-focused funding from the age of 15 would encourage early exploration of the world of work. The NDIA could also play a role in directing families to supports such as DPFOs for developing their role as 'career allies'.

The NDIA has legislative responsibility to monitor the NDIS market, and in particular to address 'thin markets'. These have typically related to geographic regions rather than support types, but as the scheme matures, it must have flexibility to address service gaps such as the economic participation support gaps identified in this thesis. Since 2017, the NDIA has iteratively introduced new economic participation funding and has increased the flexibility of funding items to provide individual scheme participants with the funding they need to purchase individualised economic participation supports. However, the market has been slow to respond, except in relation to SLES. The data suggest that because it offered providers security of funding, the 'packaging up' of SLES funding resulted in providers quickly bringing post-school employment supports into the marketplace. Similarly, the recent implementation of IPS within Headspace has resulted in the implementation of a best practice model for young people with mental health issues. Likewise, the widespread availability of the DEN model in the 1990s points to the need for government intervention to bring best practice to the market. The NDIA therefore has a role to play in shepherding the economic participation marketplace for its own scheme participants by implementing strategies to incentivise best practice within the NDIS market. This could involve providing incentives to train staff and build capacity to deliver best practice, particularly in the form of funding security.

Increasing the flexibility of NDIS funding, for example by enabling the funding of collaborative models, is critical to supporting the economic inclusion of young people with intellectual disability. The NDIA provides funding for existing programmatic structures such as ADEs and day programs; this needs to be extended beyond segregated settings. The NDIA can do this by creating funding structures to enable the introduction of best practice community-based models, such as WIL. As a result, the NDIS will need to both give careful attention to funding design and description, and recognise the limitations of individualised funding, particularly as it relates to community-based economic participation within the emerging adulthood timeframe.

Given the complexity of economic participation systems, the NDIA must also work collaboratively with other arms of government, including the DSS, which has policy responsibility for Commonwealth DES and carriage of *Australia's Disability Strategy*, and delivers the Information Linkages and Capacity Building program. One strength of Employment First policy settings is their ability to identify and address barriers across systems. Therefore, framing a change strategy within an Employment First framework has the capacity to drive the multi-level and inter-governmental change required to make a real difference to young people with intellectual disability.

DES-ESS remains a potentially important component of the employment support system for young people with intellectual disability. However, the data and literature highlight the need for a highly specialised model of employment support for this unique cohort. Given its origin as a human rights-underpinned employment support model, the government has the capacity to reinstate those settings within the DES-ESS system, offering a differentiated employment support model for young people with intellectual disability in receipt of DSP.

10.4 Critical evaluation of the research

10.4.1 Strengths

This study has added to the otherwise limited literature on the experiences of young people with significant intellectual disability and their family members during the period of transition from school, in the context of the changing landscape that has resulted from the introduction of the NDIS in Australia.

A significant strength of this study was its qualitative design and use of Photovoice and photo elicitation methodology in order to hear the voices of young people with intellectual disability themselves. The voices of key informants and family members can dominate in studies that involve complex information; this study adds to the evidence that people with intellectual disability can contribute to research about their lives when appropriately supported to do so. The challenges of using Photovoice meant that few of the young people were able to take photos, as work, study and training are abstract concepts that are difficult to photograph. However, the use of a pack of photos based on the UNCRPD Articles, which was provided by the researcher, supported the young people to be included in interviews even if they were unable to participate in Photovoice in its strictest interpretation. Providing a broader range of economic participation-focused photographs would have potentially further improved discussion.

The use of different data sources, including those with lived experience of the problem under study, and triangulation of the data enabled the problem to be looked at from different angles (Jacobs, 2018). In addition, it enabled the individual experiences of young people and families to be examined from policy and structural perspectives in order to understand how poorly constructed systems impact on individuals at the interpersonal and individual levels of the ecosystem. The use of ecological analysis highlighted the influence of distal ‘forces’ on the economic participation opportunities available to young people with intellectual disability, emphasising the limited power that individualised funding has to alter and ultimately adapt complex systems such as economic participation systems.

The theoretical and practical implications of this study have application beyond young people with intellectual disability, including other disability cohorts who experience significant barriers to employment, such as Autistic people. The highly applied nature of the study has resulted in strong interest from families and the sector, in terms of the practical applications of its findings. In particular, its identification of barriers unique to the Australian context increases the likelihood that policy-makers, service providers and advocates will be able to address those barriers.

10.4.2 Limitations and challenges

As a qualitative study, this thesis has a number of limitations. The study is highly contextual in that the data was collected in Victoria, Australia. The participants had all experienced transition from school within the context of Victorian and Australian Government policies and programs. While there was a strong Victorian context, the funding and post-school service systems the young people, family members and key informants discussed were primarily national ones, and their lived experiences echo similar lived experience studies from other countries (i.e. Akkerman, et al. 2018; Jacobs, et al., 2018;), and other Australian states (i.e. Davies & Beamish, 2009; Foley et al., 2012). This indicates that the data reflect the experiences of young people with intellectual disability and families more broadly. In addition, several key informants worked in organisations that operate across Australia, which enabled a national perspective in terms of the key informants’ data. The findings of the study, particularly in relation to barriers and enablers to economic participation for this cohort, were therefore consistent with Australian and international research.

In addition, the young people and family members in this study are not necessarily representative of young people with intellectual disability and their family members more broadly. They were recruited from organisations that support economic participation for young people with intellectual disability specifically in order to discuss economic participation, and no interviews were conducted with young people or family members who did not hold expectations about economic participation. Therefore, their expectations might not be shared by the broader cohort. Nevertheless, focusing attention on young people and families with high expectations about economic participation enabled the data collection process to uncover a broad range of barriers to economic participation.

10.5 Suggestions for future research

Several areas for potential future research have emerged from this thesis.

10.5.1 A research framework

According to Trainor et al. (2019), 'moving forward as a field will require continued investment in strong scholarship and careful consideration of new areas of inquiry' (p. 5). Australian transition-related research, and particularly research focused on economic participation, is lacking. While families and providers are beginning to look to the US, in particular, for guidance about improving economic participation outcomes for young people with intellectual disability, there is a need to contextualise evidence for the unique ecosystem that exists in Australia and focus on ensuring that evidence-informed practice is available to young people and families.

There would be benefits to the development of a comprehensive and interactional framework to steer future research such as the one developed by Trainor et al. (2019), which is available at https://journals.sagepub.com/doi/full/10.1177/2165143419864551(Figure 1).

Trainor et al.’s (2019) framework recognises that transition is a dynamic process and utilising an ecological framework places individuals with disabilities at the core of the ecosystem, impacted by the culture of a range of groups and the provision of both disability-specific and generally available services and supports. It also recognises the critical impact of a range of levers, including policy and funding levers, for realising the outcomes young people aspire to and ultimately improving their quality of life throughout their lifespan. In addition, it identifies the need to consider the longer timeframe of transition, from school years through young adulthood and into later adulthood.

The role of NDIS in promoting economic participation for this cohort

As the NDIS is in its infancy, there is an absence of empirical research regarding the impact of its individualised funding scheme on the economic inclusion of young people with intellectual disability (Dyke et al., 2013; Kavanagh et al., 2021). This thesis has identified levers available to the NDIA and has outlined, based on the literature, how those levers could result in improvement in the availability of supports for young people with intellectual disability. It is critically important to understand the role of the NDIA in shepherding the economic participation marketplace for its own scheme participants.

Involving young people with intellectual disability in creating solutions

Researchers are increasingly including people with intellectual disability in research (see Giri et al., 2022; Hall, 2017; Rustad & Kassah, 2021) by employing inclusive research methods. People with intellectual disability are demonstrating their capacity to contribute to the literature and policy and program design via their lived experiences. The young people involved in this study would normally be excluded from research because of their significant communication barriers and capacity to engage in discussion of abstract concepts. However, the use of photos proved to be a valuable method of supporting them in talking about their economic participation experiences and aspirations.

Little research specifically examines young people with intellectual disability's preferences for economic inclusion, including which pathway best suits their goals (Wehman et al., 2018). There is thus a need to work collaboratively with these young people, using co-design methods to create economic participation pathways at the individual and system levels and to produce resources that enable them to have input into the development of economic participation programs and supports they value.

Promoting self-determination

Self-determination strategies for young people with intellectual disability as they relate to economic inclusion are under-researched in the Australian context. There is emerging evidence from overseas about the importance of self-determination to long-term economic participation outcomes (Shogren et al., 2019; Stancliffe et al., 2020). While specific self-determination tools, such as the SDCDM (Dean et al., 2018; Hagiwara et al., 2019), have become available, they need to be contextualised for the Australian environment. Employment circles of support are another mechanism that warrants further exploration, given the interest in them among families and the lack of evidence regarding their efficacy in the economic participation context.

Develop, evaluate and expand the concept of economic inclusion

Young people and their families are open to community-based economic inclusion in a range of forms, recognising the role the existing disability system can play in supporting their aspirations. However, there is a need to align service delivery models and the supports and expertise available within disability service systems with the concept of economic inclusion they hold. Emerging research about hybrid models to support economic inclusion (Campbell, 2022; Murphy et al., 2014) offers opportunities to expand the role of disability services within an Employment First framework.

In addition, the lack of an outcome framework to measure the economic inclusion of young people with intellectual disability in the way they and their families conceptualise it in the Australian context must be addressed. Further research is required to define economic inclusion and to develop an outcome framework to measure progress toward shifting outcomes. In particular, cost-benefit analyses of customised employment strategies and a broader focus on social inclusion outcome measures, including outcomes related to the businesses and organisations engaged in customised employment, may be useful to drive change.

Reducing inequity

The data supports emerging evidence that the introduction of the NDIS has resulted in inequities (Carey & Griffiths, 2017; Malbon, 2019), and that economic inclusion and exclusion are influenced by the capacity of social networks to navigate complex systems. Further research is required to understand (a) the conditions in which economic participation expectations develop in the Australian context and how families choose to pursue economic participation or not; and (b) the structures and supports that enable access to economic participation opportunities for all young people with intellectual disability.

10.6 Concluding comments

The overall purpose of this qualitative study was to examine young people with intellectual disability's transition to adulthood and extend support to them to enable them to realise their economic participation goals. This study relates to a small, unique cohort of young people with intellectual disability, for whom there is no societal expectation of economic participation but who nevertheless seek to work in the community-based labour market primarily for the social inclusion benefits it offers. Like others, I was hopeful that the introduction of the NDIS would shift the paradigm for this cohort, empowering family members and others to work one person at a time to create meaningful opportunities. However, experience told me that widely held attitudes about intellectual disability, combined with the complex economic participation systems operating in Australia, meant that unless barriers were addressed at the sociopolitical level, very little would change at the individual and interpersonal levels.

Undertaking the study has caused me to rethink how economic participation can be conceptualised and realised for this cohort. However, without a significant shift in organisational practice, the delivery of evidence-informed supports, a modification of systems, and empowerment of young people and families to expect an ordinary life, a full reconceptualisation of people with intellectual disability in the context of economic participation is unlikely to occur.

I am hopeful that these findings will result in change for young people and families, and that families will be supported to realise economic inclusion for their young people as a component of a valued life lived in the community. Only when young people with intellectual disability are supported to be included in community-based employment will expectations change more broadly among families, service system actors and the wider community. The goal is that economic inclusion will be the norm for young people with intellectual disability just as it is for other members of society.

References

Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, *9*(3), 407-411. https://doi.org/10.1177/104973239900900309

Akkerman, A., Janssen, C., Kef, S., & Meininger, H. (2016). Job satisfaction of people with intellectual disabilities in integrated and sheltered employment: An exploration of the literature. *Journal of Policy and Practice in Intellectual Disabilities*, *13*(3), 205-216. https://doi.org/10.1111/jppi.12168

Akkerman, A., Kef, S., & Meininger, H. P. (2018). Job satisfaction of people with intellectual disabilities: the role of basic psychological need fulfillment and workplace participation. *Disability & Rehabilitation*, *40*(10), 1192-1199. https://doi.org/10.1080/09638288.2017.1294205

Algraigray, H., & Boyle, C. (2017). The SEN label and its effect on special education. *Educational and Child Psychology*, *34*.

Altermark, N. (2018). *Citizenship inclusion and intellectual disability: Biopolitics post-institutionalisation*. Routledge.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Anderson, P., & Wisener, K. (1996). *Open employment services for people with disabilities 1995: The first year of NIMS data*. Australian Institute of Health and Welfare. https://www.aihw.gov.au/getmedia/df4852be-c44e-4ebe-95c9-aa0339efff5e/oespd95.pdf.aspx?inline=true

Arnett, J. (2000). Emerging adulthood: A Theory Of Development From The Late Teens Through The Twenties. *American Psychologist*, *55*(5), 469-480. https://doi.org/10.1037//0003-066X.55.5.469

Arnett, J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. Oxford University Press.

Arnett, J. (2007). Emerging adulthood: What is it, and what is it good For? *Society for Research in Child Development*, *1*(2), 68-73.

ARTD Consultants. (2016). *Ticket to Work Pilot outcomes study: A quasi-experimental analysis of pathways from school to economic and social inclusion*. *Report for National Disability Services*. https://tickettowork.org.au/media/research_submissions_files/Ticket-to-work-outcome-report-ARTD-final.pdf

ARTD Consultants. (2019a). *Ticket to Work network analysis: A report for NDS*. https://tickettowork.org.au/media/download_resources/pdf/Ticket_To_Work_network_anaylsis_survey.pdf

ARTD Consultants. (2019b). *Ticket to Work Post school outcomes: Report for National Disability Services. Final report*. https://tickettowork.org.au/media/submissions_researches_buttons/Ticket_to_Work_Post_School_Outcomes_final_2019.pdf

Arvidsson, J., Widén, S., Staland-Nyman, C., & Tideman, M. (2016). Post-school destination – A study of women and men with intellectual disability and the gender-segregated

Swedish labor market. *Journal of Policy and Practice in Intellectual Disabilities*, *13*(3), 217-226. https://doi.org/https://doi.org/10.1111/jppi.12157

Ashton, H. S., & Ashton, D. N. (2016). 'Bring on the dancers': Reconceptualising the transition from school to work. *Journal of Education and Work*, *29*(7), 747-766. https://doi.org/10.1080/13639080.2015.1051520

Association of People Supporting Employment First (APSE). (n.d.). *APSE Fact Sheet: Employment First*. https://www.apse.org/wp-content/uploads/2019/08/What-is-E1-UPDATED.pdf

Australian Bureau of Statistics. (2012). *Intellectual disability, Australia*. http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4433.0.55.003Main+Features12012

Australian Bureau of Statistics. (2016). *Census*. http://www.abs.gov.au/census

Australian Bureau of Statistics. (2019). *Disability, ageing and carers, Australia: Summary of findings*. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

Australian Council of Social Services. (2018). *Submission on future employment services*. https://www.acoss.org.au/wp-content/uploads/2018/08/ACOSS_submission-on-future-employment-services_FINAL.pdf

Australian Education Act 2013. (Cth). https://www.legislation.gov.au/Details/C2013A00067

Australian Government Department of Employment and Workplace Relations. (2006). *OECD Thematic review: Reforming sickness and disability policies to improve work incentives*. http://www.oecd.org/social/soc/39149583.pdf

Australian Government Department of Employment and Workplace Relations. (2012). *Evaluation of the moderate intellectual disability loading*. https://jobsupport.org.au/wp-content/uploads/2019/03/Evaluation-of-Moderate-Intellectual-Disability-Loading-2010-to-2012.pdf

Australian Government Department of Employment and Workplace Relations. (n.d.). *Accredited Course Details: 22566VIC – Certificate I in Work Education*. https://training.gov.au/Training/Details/22566VIC#

Australian Government Department of Employment and Workplace Relations and Department of Education. (n.d.). *Future ready*. https://www.dewr.gov.au/future-ready

Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. (2012). *Report to the Council of Australian Governments 2012: Laying the groundwork 2011-2014*. https://www.dss.gov.au/sites/default/files/documents/01_2013/nds_first_year_final_-_20_12_12_2.pdf

Australian Government Department of Social Services. (2015). *A new system for better employment and social outcomes – Report of the Reference Group on Welfare Reform to the Minister for Social Services*. https://www.dss.gov.au/sites/default/files/documents/02_2015/dss001_14_final_report_access_2.pdf

Australian Government Department of Social Services. (2016). *New disability employment services from 2018: Discussion paper*. https://engage.dss.gov.au/wp-content/uploads/2016/11/DES-Reform-Discussion-Paper-November-2016.pdf

Australian Government Department of Social Services. (2019). *Final report for the evaluation of the Individual Placement and Support trial.* https://www.dss.gov.au/sites/default/files/documents/08_2019/individual-placement-and-support-trial-evaluation-report-june-2019.pdf

Australian Government Department of Social Services. (2020). *Mid-term review of the Disability Employment Services (DES) program*. https://www.dss.gov.au/disability-and-carers-programs-services-disability-employment-services/mid-term-review-of-the-disability-employment-services-des-program#:~:text=The%20mid-term%20review%20informed%20improvements%20to%20the%20DES,2023.%20Last%20updated%3A%2021%20May%202021%20-%205%3A00pm

Australian Government Department of Social Services. (2021a). *Australia's disability strategy*. https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf

Australian Government Department of Social Services. (2021b). *Employ my ability: Disability employment strategy*. https://www.dss.gov.au/disability-and-carers/disability-employment-strategy

Australian Government Department of Social Services. (2021c). *Inclusive. Accessible. Diverse. Shaping your new disability employment support program. Consultation paper*. https://engage.dss.gov.au/wp-content/uploads/2021/11/New-Disability-Employment-Support-Model-Consultation-Paper.pdf

Australian Government Department of Social Services. (2021d). *National disability employment strategy consultation report*. https://engage.dss.gov.au/wp-content/uploads/2021/10/dss-consultation-report.pdf

Australian Government Department of Social Services. (2022). *DES monthly report 31 May 2022*. https://data.gov.au/dataset/ds-dga-e258b678-eb6b-4ebb-92d8-0fe7c1122c42/distribution/dist-dga-2a42d01a-01a3-49ad-82a5-9033ac7c0f04/details?q=disability%20employment

Australian Government Department of the Prime Minister and Cabinet. (2014). *Roles and responsibilities in education part B: Reform of the Federation White Paper issues paper 4* . Department of the Prime Minister and Cabinet (Australia). https://apo.org.au/node/56124

Australian Government Services Australia. (n.d.). *Manifest medical rules*. https://www.servicesaustralia.gov.au/manifest-medical-rules-for-disability-support-pension?context=22276#whatmanifestrulesare

Australian Government Services Australia. (n.d.) *Disability Support Pension.* www.servicesaustralia.gov.au/disability-support-pension

Australian Human Rights Commission. (2016). *Willing to work: National inquiry into employment discrimination against older Australians and Australians with disability*. https://humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination

Australian Institute of Health and Welfare. (2008). *Disability in Australia: Intellectual disability*. https://www.aihw.gov.au/reports/disability/disability-in-australia-intellectual-disability/contents/summary

Australian Institute of Health and Welfare (Ed.). (2015). *Australia's welfare 2015*. https://www.aihw.gov.au/getmedia/692fd1d4-0e81-41da-82af-be623a4e00ae/18960-aw15.pdf.aspx?inline=true.

Australian Institute of Health and Welfare. (2017a). *Australia's Welfare 2017*. https://www.aihw.gov.au/getmedia/df93d37c-aa21-446b-a183-2e5e70fe9309/aihw-australias-welfare-2017-chapter8-1.pdf.aspx

Australian Institute of Health and Welfare. (2017b). *Disability in Australia: Changes over time in inclusion and participation in education*. https://www.aihw.gov.au/getmedia/34f09557-0acf-4adf-837d-eada7b74d466/Education-20905.pdf.aspx

Australian Institute of Health and Welfare. (2020). *People with disability in Australia*. https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/unemployment

Australian Social Inclusion Board. (2010). *Social inclusion in Australia: How Australia is faring*. https://melbourneinstitute.unimelb.edu.au/assets/documents/hilda-bibliography/other-publications/2012/Social_Inclusion_how-australia-is-faring-report.pdf

Bach, M. (2017). Inclusive citizenship: Refusing the construction of ‘cognitive foreigners’ in neo-liberal times. *Research and Practice in Intellectual and Developmental Disabilities*, *4*, 4-25. https://doi.org/10.1080/23297018.2017.1306794

Baer, H., Welker, K., & Cox, C. (2021). Work performance and support needs analysis of students with intellectual disabilities. *Journal of Vocational Rehabilitation*, *55*, 335-344. https://doi.org/10.3233/JVR-211167

Baer, R. M., Daviso III, A. W., Flexer, R. W., McMahon Queen, R., & Meindl, R. S. (2011). Students with intellectual disabilities: Predictors of transition outcomes. *Career Development for Exceptional Individuals*, *34*(3), 132-141. https://doi.org/10.1177/0885728811399090

Barnes, C. (2000). A working social model? Disability, work and disability politics in the 21st century. *Critical Social Policy*, *20*(4), 441-457. https://doi.org/10.1177/026101830002000402

Barnes, C. (2003). What a difference a decade makes: Reflections on doing ‘emancipatory’ disability research. *Disability & Society*, *18*(1), 3-17. https://doi.org/10.1080/713662197

Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *27*, 85-96. https://doi.org/10.1111/jar.12088

Beamish, W., Meadows, D., & Davies, M. (2012). Benchmarking teacher practice in Queensland transition programs for youth with intellectual disability and autism. *The Journal of Special Education*, *45*(4), 227-241. https://doi.org/10.1177/0022466910366602

Becker, H. S. (1963). *Outsiders: Studies in the sociology of deviance*. Free Press Glencoe.

Beer, A., Bentley, R., Baker, E., Mason, K., Mallett, S., Kavanagh, A., & LaMontagne, T. (2016). Neoliberalism, economic restructuring and policy change: Precarious housing and precarious employment in Australia. *Urban studies (Edinburgh, Scotland)*, *53*(8), 1542-1558. https://doi.org/10.1177/0042098015596922

Bell, M. (2019). People with intellectual disabilities and labour market inclusion: What role for EU labour law? *European Labour Law Journal*, *11*(1), 3-25. https://doi.org/10.1177/2031952519882953

Bennett, O., Dawson, E., Lewis, A., O'Halloran, D., & Smith, W. (2018). *Working it out: Employment services in Australia*. Per Capita. https://percapita.org.au/wp-content/uploads/2018/09/Working-It-Out-FINAL.pdf

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality*. Penguin. http://perflensburg.se/Berger%20social-construction-of-reality.pdf

Bigby, C. (2020a). Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together. *Journal of Intellectual & Developmental Disability*, *45*(4), 309-319. https://doi.org/10.3109/13668250.2020.1776852

Bigby, C. (2020b). Programs and practices to support community participation of people with intellectual disabilities. In P. Liamputtong (Ed.), *Handbook of Social Inclusion: Research and Practices in Health and Social Sciences* (pp. 1-34). Springer International Publishing. https://doi.org/10.1007/978-3-030-48277-0_36-1

Bigby, C., & De Losa, L. (2021). *After school jobs for students with intellectual disabilities.* Living with Disability Research Centre, La Trobe University. https://tickettowork.org.au/media/download_resources/word/Final_After_School_Jobs_Report_27_April_2021_003.pdf?msclkid=02040636a5ad11ecbd50dc08f1374671

Bigby, C., & Fyffe, C. (2010). *More than community presence: Social inclusion for people with intellectual disability. Proceedings of the Fourth Annual Roundtable on Intellectual Disability Policy*. La Trobe University. http://docshare.tips/-social-inclusion-for-people-with-intellectual-disability_584ff6c5b6d87f6d358b554f.html

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Association on Mental Retardation*, *106*(2), 173-188.

Blick, R., Litz, K., Thornhill, M., & Goreczny, A. (2016). Do inclusive work environments matter? Effects of community-integrated employment on quality of life for individuals with intellectual disabilities. *Research in Developmental Disabilities*, *53-54*, 358-366. https://doi.org/10.1016/j.ridd.2016.02.015

Blustein, C. L., Carter, E. W., & McMillan, E. D. (2016). The voices of parents: Post-high school expectations, priorities, and concerns for children with intellectual and developmental disabilities. *The Journal of Special Education*, *50*(3), 164-177. https://doi.org/doi: 10.1177/0022466916641381

Bouck, E. C. (2012). Secondary students with moderate/severe intellectual disability: considerations of curriculum and post-school outcomes from the National Longitudinal Transition Study-2. *Journal of Intellectectual Disability Research*, *56*(12), 1175-1186. https://doi.org/10.1111/j.1365-2788.2011.01517.x

Bouck, E. C. (2014). The postschool outcomes of students with mild intellectual disability: does it get better with time? *Journal of Intellectual Disability Research*, *58*(6), 534-548. https://doi.org/10.1111/jir.12051

Bouck, E. C., & Joshi, G. S. (2016). Transition and students with mild intellectual disability: Findings from the National Longitudinal Transition Study–2. *Career Development and Transition for Exceptional Individuals*, *39*(3), 154-163. https://doi.org/https://doi.org/10.1177/2165143414551408

Bouck, E. C., Long, H. M., & Costello, M. P. (2020). Parent and youth post-school expectations: Students with intellectual disability in rural schools. *Rural Special Education Quarterly*, *40*(1), 14-23. https://doi.org/10.1177/8756870520945572

Boyland, J. (2019). A social constructivist approach to the gathering of empirical data. *Australian Counselling Research Journal*.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Bromley, K. W., Hirano, K., Kittelman, A., Mazzotti, V. L., & McCroskey, C. (2022). Barriers to work-based learning experiences: A mixed methods study of perceptions from the field. *Journal of Vocational Rehabilitation*, *56*, 17-27. https://doi.org/10.3233/JVR-211169

Bronfenbrenner, U. (1981). *The ecology of human development: Experiments by nature and design*. Harvard University Press. http://ebookcentral.proquest.com/lib/swin/detail.action?docID=3300702

Bronfenbrenner, U. (1994). *Ecological models of human development* (Vol. 3). Pergamon Press.

Brooks, J., Mitchell, W., & Glendinning, C. (2016). Personalisation, personal budgets and family carers. Whose assessment? Whose budget? *Journal of Social Work*, *17*(2), 147-166. https://doi.org/10.1177/1468017316638554

Brown, G., & Moncrieff, J. (2018). *On course to inclusion: Changing attitudes towards disability, from the waves to the workplace*. Hult Research. https://www.hult.edu/blog/media/uploads/2019/01/Hult_Research_Report_Braclays_JST_Inclusive_Training.pdf

Brown, H., & Smith, H. (1989). Whose 'ordinary life' is it anyway? *Disability, Handicap & Society*, *4*(2), 105-119. https://doi.org/10.1080/02674648966780131

Buntinx, W., & Schalock, R. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of policy and practice in intellectual disabilities*, *7*, 283–294.

Business Council of Australia. (2015). Recognising Ability: *Business and Employment of People with Disability.* https//d3n8a8pro7vhmx.cloudfront.net/ bca/pages/4095/attachments/original/1527659601/Recognising_Ability_Business_and_the_Employment_of_People_with_Disability_FINAL_Nov.pdf?1527659601)

Butterworth, J., Christensen, J., & Flippo, K. (2017). Partnerships in employment: Building strong coalitions to faciliate systems change for youth and young adults. *Journal of Vocational Rehabilitation*, *47*, 265-276. https://doi.org/doi:10.3233/

Buys, N., Matthews, L. R., & Randall, C. (2014). Contemporary vocational rehabilitation in Australia. *Disability and Rehabilitation*, 37(9),820–824. https://doi.org/10.3109/09638288.2014.942001

Campbell, P., Wilson, E., Crosbie, J., & Eversole, R. (2022). *Connecting pathways to employment with the Work Integration Social Enterprise (WISE) model*. Centre for Social Impact, Swinburne University. https://www.csi.edu.au/media/Report_-_Connecting_Pathways_to_Employment_with_the_Work_Integration_Social_Enterprise_WISE_model.pdf

Carey, E., & Griffiths, C. (2017). Recruitment and consent of adults with intellectual disabilities in a classic grounded theory research study: Ethical and methodological considerations. *Disability & Society*, *32*(2), 193-212. https://doi.org/10.1080/09687599.2017.1281793

Carey, G., Crammond, B., & Malbon, E. (2019). Personalisation schemes in social care and inequality: review of the evidence and early theorising. *International Journal for Equity in Health*, *18*(1), 170. https://doi.org/10.1186/s12939-019-1075-2

Carey, G., Malbon, E., Marjolin, A., & Reeders, D. (2018). *National disability markets: Market stewardship actions for the NDIS*. Centre for Social Impact. https://www.csi.edu.au/media/What_are_market_stewardship_actions_for_the_NDIS_Final.pdf

Carey, G., Malbon, E., Reeders, D., Kavanagh, A., & Llewellyn, G. (2017). Redressing or entrenching social and health inequities through policy implementation? Examining personalised budgets through the Australian National Disability Insurance Scheme. *International Journal for Equity in Health*, *16*(1), 192. https://doi.org/10.1186/s12939-017-0682-z

Carlson, L. (2010). *The faces of intellectual disability: Philosophical reflections.* Indiana University Press.

Carlson, E. D., Engebretson, J., & Chamberlain, R. M. (2012). Photovoice as a Social Process of Critical Consciousness. *Qualitative Health Research*, 16(6) 836-852. https://doi.org/10.1177/1049732306287525

Campbell, P., Barraket, P., Suchowerska, R., McNeill, J., & Moussa, B. (2020). *Improving health equity for young people? The role of social enterprise*. WorkVentures case study. Swinburne University of Technology Centre for Social Impact. https://researchbank.swinburne.edu.au/file/8b2b6f17-5ab9-4e9e-b2e5-43811b79a5ee/1/2020-campbell-workventures_case_study.pdf

Campbell, P., Wilson, E., Crosbie, J. & Eversole, R. (2022). *Connecting Pathways to Employment with the Work Integration Social Enterprise (WISE) model.* Centre for Social Impact, Swinburne University.

Carter, E. W., Austin, D., & Trainor, A. A. (2011a). Factors associated with the early work experiences of adolescents with severe disabilities. *Intellectual and Devlopmental Disabilities*, *49*(4), 233-247. https://doi.org/10.1352/1934-9556-49.4.233

Carter, E. W., Austin, D., & Trainor, A. A. (2011b). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*, *23*(1), 50-63. https://doi.org/10.1177/1044207311414680

Carter, E. W., Brock, M. E., & Trainor, A. A. (2012). Transition assessment and planning for youth with severe intellectual and developmental disabilities. *The Journal of Special Education*, *47*(4), 245-255. https://doi.org/10.1177/0022466912456241

Carter, E. W., McMillan, E., & Willis, W. (2017). The TennesseeWorks Partnership: Elevating employment outcomes for people with intellectual and developmental disabilities. *Journal of Vocational Rehabilitation*, *47*(3), 365-378. https://doi.org/10.3233/JVR-170909

Certo, J. L., Cauley, K. M., & Chafin, C. (2003). Students' perspectives on their high school experience. *Adolescence*, *38*(152), 705-724.

Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, *39*(2), 79-94. https://www.jstor.org/stable/pdf/23880058.pdf?refreqid=excelsior%3Acf440747f214839348cddd662c3a4a6c

Charmaz, K. (2014). *Constructing grounded theory: A practical guide through qualitiative analysis*. Sage.

Cheng, C., Oakman, J., Bigby, C., Fossey, E., Cavanagh, J., Meacham, H., & Bartram, T. (2018). What constitutes effective support in obtaining and maintaining employment for individuals with intellectual disability? A scoping review. *Journal of Intellectual & Developmental Disability*, *43*(3), 317-327. https://doi.org/10.3109/13668250.2017.1327040

Children and Young People with Disability Australia. (2015). *Post school transition: The experiences of students with disability*. https://www.cyda.org.au/images/pdf/post_school_transition.pdf

Christensen, J., & Richardson, K. (2017). Project SEARCH workshop to work: Participant reflections on the journey through career discovery. *Journal of Vocational Rehabilitation*, *46*, 341-354. https://doi.org/10.3233/JVR-170871

Cimera, R. E., Thoma, C. A., Whittenburg, H. N., & Ruhl, A. N. (2018). Is getting a postsecondary education a good investment for supported employees with intellectual disability and taxpayers? *Inclusion*, *6*(2), 97-109. https://doi.org/10.1352/2326-6988-6.2.97

Cimera, R. E., Wehman, P., West, M., & Burgess, S. (2011). Do sheltered workshops enhance employment outcomes for adults with autism spectrum disorder? *Autism*, *16*(1), 87-94. https://doi.org/10.1177/1362361311408129

Clegg, J., & Bigby, C. (2017). Debates about dedifferentiation: Twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities*, *4*(1), 80-97. https://doi.org/10.1080/23297018.2017.1309987

Clifford Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2014). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, *38*, 18-29. https://doi.org/10.1016/j.ridd.2014.10.008

Cluley, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, *45*, 39-46. https://doi.org/10.1111/bld.12174

Cluley, V. (2018). From 'Learning disability to intellectual disability'—Perceptions of the increasing use of the term 'intellectual disability' in learning disability policy, research and practice. *British Journal of Learning Disabilities*, *46*(1), 24-32. https://doi.org/https://doi.org/10.1111/bld.12209

Cobb, R. B., Lipscomb, S., Wolgemuth, J., & Schulte, T. (2013). *Improving post-high school outcomes for transition-age students with disabilities: An evidence review (NCEE 2013-4011)*. National Center for Education Evaluation and Regional Assistance, Institute of Education Sciences, U.S. https://ies.ed.gov/pubsearch/pubsinfo.asp?pubid=NCEE20134011

Cocks, E., & Harvey, T. (2008). *Employment/day options interface research project*. https://espace.curtin.edu.au/bitstream/handle/20.500.11937/43977/135257_18935_Employment%20Day%20Options%20Final%20Report.pdf?sequence=2

Codd, J., & Hewitt, O. (2021). Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective. *British Journal of Learning Disabilities*, *49*(1), 39-51. https://doi.org/https://doi.org/10.1111/bld.12327

Commonwealth of Australia. (2009). *Shut out: The experience of people with disabilities and their families in Australia*. https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf

Commonwealth of Australia. (2017). *Ensuring a strong future for supported employment*. https://engage.dss.gov.au/the-future-of-supported-employment/a-strong-future-for-supported-employment-discussion-paper/

Considine, M., Lewis, J., & O'Sullivan, S. (2011). Quasi-Markets and Service Delivery Flexibility Following a Decade of Employment Assistance Reform in Australia. *Journal of Social Policy*, *40(4)*, 811-833. https//doi.org/10.1017/S0047279411000213

Council of Australian Governments. (2013). *National school reform agreement*. https://federalfinancialrelations.gov.au/sites/federalfinancialrelations.gov.au/files/2021-07/national_school_reform_agreement_8.pdf

Crawford, C. (2011). *The employment of people with intellectual disabilities in Canada: A statistical profile.* Institute for Research and Development on Inclusion and Society (IRIS). https://irisinstitute.ca/wp-content/uploads/sites/2/2016/07/Intellectual-disability-and-employment_iris_cr.pdf

Cronin, S., Curran, J., Iantorno, J., Murphy, K., Shaw, L., Boutcher, N., & Knott, M. (2013). Work capacity assessment and return to work: A scoping review. *Work*, *44*(1), 37-55. https://doi.org/10.3233/wor-2012-01560

Dague, B. (2012). Sheltered employment, sheltered lives: Family perspectives of conversion to community-based employment. *Journal of Vocational Rehabilitation*, *37*(1).

Dalton, A. J., & McVilly, K. R. (2004). Ethics guidelines for international, multicenter research involving people with intellectual disabilities. *Journal of policy and practice in intellectual disabilities*, *1*(2), 57-70. https://doi.org/10.1111/j.1741-1130.2004.04010.x

Daston, M., Riehle, J. E., & Rutkowski, S. (2012). *High school transition that works! Lessons learned from Project SEARCH.* Paul H. Brookes Publishing Company.

Davies, M. D., & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on 'life as an adjustment'. *Journal of Intellectual and*

Developmental Disability, *34*(3), 248-257. https://doi.org/10.1080/13668250903103676

Daviso, A. W., Baer, R. M., Flexer, R. W., & Meindl, R. (2016). Career and technical education, work study, & school supervised work: How do they impact employment/or students with disabilities? *Journal of Applied Rehabilitation Counselling* , *47*(2), 10-19. https://doi.org/10.1891/0047-2220.47.2.10

Dean, E. E., Shogren, K. A., Hagiwara, M., & Wehmeyer, M. L. (2018). How does employment influence health outcomes? A systematic review of the intellectual disability literature. *Journal of Vocational Rehabilitation*, *49*, 1-13. https://doi.org/10.3233/JVR-180950

Dean, E. E., Shogren, K. A., Wehmeyer, M. L., Almire, B., & Mellenbruch, R. (2018). Career design and development for adults with intellectual disability: A program evaluation. *Advances in Neurodevelopmental Disorders* (Preprints), 1-8.

Dempsey, I., & Ford, J. (2009). Employment for people with intellectual disability in Australia and the United Kingdom. *Journal of Disability Policy Studies*, *19*(4), 233-243. https://doi.org/10.1177/1044207308314946

Devine, A., Shields, M., Dimov, S., Dickinson, H., Vaughan, C., Bentley, R., LaMontagne, A. D., & Kavanagh, A. (2021). Australia's Disability Employment Services program: Participant perspectives on factors influencing access to work. *International Journal of Environmental Research and Public Health*, *18*(21), 11485. https://doi.org/10.3390/ijerph182111485

Devlin, R., & Pothier, D. (2006). *Critical disability theory: Essays in philosophy, politics, policy and law*. UBC Press.

Dew, A., & Boydell, K. M. (2017). Knowledge translation: Bridging the disability research-to-practice gap. *Research and Practice in Intellectual and Developmental Disabilities*, *4*(2), 142-157. https://doi.org/10.1080/23297018.2017.1315610

Dew, A., Collings, S., Dillon Savage, I., Gentle, E., & Dowse, L. (2019). 'Living the life I want': A framework for planning engagement with people with intellectual disability and complex support needs. *Journal of Applied Research in Intellectual Disabilities*, *32*(2), 401-412. https://doi.org/10.1111/jar.12538

Diallo, A., Roy, K. C., & Barrera, M. M. (2014). Barriers to using evidence-based practice among supported employment staff serving individuals with intellectual disabilities. *Journal of Rehabilitation Administration*, *38*(1), 35-44.

Dimov, S., Kavanagh, A., Shields, M., Badij, S., Lamontagne, A., Vaughan, C., Petrie, D., King, T., & Dickinson, H. (2021). *The Youth Employment Study (YES): Findings from the first survey.* University of Melbourne. https://doi.org/10.26188/14747361.v2

Dorozenko, K. P., Roberts, L. D., & Bishop, B. (2015). The identities and social roles of people with an intellectual disability: Challenging dominant cultural worldviews, values and mythologies. *Disability & Society*, *30*(9), 1345-1364. https://doi.org/10.1080/09687599.2015.1093461

Dowse, L. (2009). 'Some people are never going to be able to do that': Challenges for people with intellectual disability in the 21st century. *Disability & Society*, *24*(5), 571-584. https://doi.org/10.1080/09687590903010933

Drake, R. E., Bond, G. R., & Becker, D. R. (2012). *Individual placement and support an evidence-based approach to supported employment*. Oxford University Press.

Dukes, L. L., Madaus, J. W., Faggella-Luby, M., Lombardi, A., & Gelbar, N. (2017). PASSing college: A taxonomy for students with disabilities in postsecondary education. *Journal of Postsecondary Education and Disability*, *30*, 111–122.

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual and Developmental Disabilities*, *38*(2), 149-162. https://doi.org/10.3109/13668250.2013.789099

Dyson, M., Brown, M., & Canobi, S. (2016). *Critical literature review: Instruments assessing work capacity*. Dyson Consulting Group for Department of Social Services.

Ellenkamp, J., Brouwers, E., Embregts, P., Joosen, M., & Weeghel, J. (2016). Work environment-related factors in obtaining and maintaining work in a competitive employment setting for employees with intellectual disabilities: A systematic review. *Journal of Occupational Rehabilitation*, *26*(1), 56-69. https://ezproxy.deakin.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=s3h&AN=112903019&authtype=sso&custid=deakin&site=eds-live&scope=site

Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2018). The association between employment status and health among British adults with and without intellectual impairments: Cross-sectional analyses of a cohort study. *BMC Public Health*, *18*. https://doi.org/10.1186/s12889-018-5337-5

Engeset, A., Söderströmb, S., & Vik, K. (2015). Day activity centres – work for people with intellectual disabilities: A Norwegian perspective. *Work*, *50*, 193-203. https://doi.org/10.3233/WOR-131734

Ernest, P. (1995). The one and the many. In S. L. P. & G. Jerry (Eds.), *Constructivism in education* (pp. 459-486). Lawrence Erlbaum Associates Inc.

Everyone Can Work. (n.d.). https//www.everyonecanwork.org.au/thinking-about-work/what-is-open-employment/

Farmer, J., De Cotta, J., Kilpatrick, S., Barraket, J., Roy, M. J., & Munoz, S. A. (2019). How work integration social enterprises help to realize capability: A comparison of three Australian settings. *Journal of Social Entrepreneurship*. https://doi.org/10.1080/19420676.2019.1671481

Ferri, B. A., & Connor, D. J. (2005). Tools of exclusion: Race, disability, and (re)segregated education. *Teachers College Record Volume*, *107*(3), 453-474. https://teachingisintellectual.com/wp-content/uploads/2020/12/ToolsofExclusion.pdf?msclkid=395c5755b71011eca239160cf1e70573

Flexer, R. W., Daviso, A. W., Baer, R. M., McMahan Queen, R., & Meindl, R. S. (2011). An epidemiological model of transition and postschool outcomes. *Career Development for Exceptional Individuals*, *34*(2), 83-94. https://doi.org/10.1177/0885728810387922

Foley, K. R. (2014). *Post-school adult life for young people with Down syndrome*. https://ro.ecu.edu.au/theses/1396

Foley, K. R., 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.-R., Girdler, S., Bourke, J., Jacoby, P., Llewellyn, G., Einfeld, S., Tonge, B., Parmenter, T. R., & Leonard, H. (2014). Influence of the environment on participation in social roles for young adults with down syndrome. *PloS one*, *9*(9), e108413. https://doi.org/10.1371/journal.pone.0108413

Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., . . . 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

Folkestad, H. (2000). Getting the picture: Photo-assisted conversations as interviews. *Scandinavian Journal of Disability Research*, *2*(2), 3-21. https://doi.org/http://doi.org/10.1080/15017410009510757

Forrester-Jones, R., Jones, S., Heason, S., & Di'Terlizzi, M. (2004). Supported employment: A route to social networks. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 199-208. https://doi.org/https://doi.org/10.1111/j.1468-3148.2004.00199.x

Fosnot, C. (2005). *Constructivism: Theory, perspectives, and practice* (2nd ed.). Teachers College Press.

Francis, G., Gross, J., Turnbull, R., & Parent-Johnson, W. (2013). Evaluating the effectiveness of the Family Employment Awareness Training in Kansas. *Research & Practice for Persons with Severe Disabilities*, *38*(1), 44-57.

Francis, G., Stride, A., & Reed, S. (2018). Transition strategies and recommendations: Perspectives of parents of young adults with disabilities. *British Journal of Special Education*, *45*, 277.

Fredriksson, D. (2021). Reducing unemployment? Examining the interplay between active labour market policies. *Social Policy & Administration*, *55*(1), 1-17. https://doi.org/https://doi.org/10.1111/spol.12606

Freire, P. (1973). *Education for critical consciousness*. Seabury Press. https://books.google.com.au/books?id=0QfZAAAAIAAJ

Furlong, A. (2017). The changing landscape of youth and young adulthood. In A. Furlong (Ed.), *Routledge Handbook of Youth and Young Adulthood* (2nd ed.) (pp. 3-11). Routledge.

Gadow, F., & MacDonald, J. (2018). Scope, challenges and outcomes of an inclusive tertiary university initiative in Australia. In M. L. Bonati, F. Gadow, R. Slee, & P. O'Brien (Eds.), *People with intellectual disability experiencing university life: Theoretical underpinnings, evidence and lived experience*. Brill.

Gauthier-Boudrealt, Gallagher, F., & Couture, M. (2017). Specifc needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in Developmental Disabilities*, *66*, 16-26. https://doi.org/10.1016/j.ridd.2017.05.001

Gilson, C., Carter, E., Bumble, J., & Mcmillan, E. (2018). Family perspectives on integrated employment for adults with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities*, *43*(1), 20-37.

Gilson, C. B., Carter, E. W., & Biggs, E. E. (2017). Systematic review of instructional methods to teach employment skills to secondary students with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities*, *42*(2), 89-107. http://journals.sagepub.com/doi/10.1177/1540796917698831

Giordono, L. S. (2020). From employment optional to 'Employment First': Explaining two cases of state-level disability policy change. *Public Policy and Administration*, *37*(3), 283-316. https://doi.org/10.1177/0952076720942822

Giri, A., Aylott, J., Giri, P., Ferguson-Wormley, S., & Evans, J. (2022). Lived experience and the social model of disability: Conflicted and inter-dependent ambitions for employment of people with a learning disability and their family carers. *British Journal of Learning Disabilities*, *50*(1), 98-106. https://doi.org/https://doi.org/10.1111/bld.12378

Glaw, X., Inder, K., Kable, A., & Hazelton, M. (2017). Visual methodologies in qualitative research: Autophotography and photo elicitation applied to mental health research. *International Journal of Qualitative Methods*, *16*, 1-8. https://doi.org/https://doi.org/10.1177/1609406917748215

Gooding, P., Anderson, J., & McVilly, K. (2017). Disability and social inclusion 'Down Under': A systematic literature review. *Journal of Social Inclusion*, *8*(2). https://josi.journals.griffith.edu.au/index.php/inclusion/article/view/964

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, *28*(5), 631-644. https://doi.org/10.1080/09687599.2012.717884

Goodley, D. (2018). Understanding disability: Biopsychology, biopolitics, and an in-between-all politics. *Adapted physical activity quarterly : APAQ*, *35*(3), 308-319. https://doi.org/10.1123/apaq.2017-0092

Green, C., Malbon, E., Carey, G., Dickinson, H., & Reeders, D. (2018). *Competition and collaboration between service providers in the NDIS*. Centre for Social Impact. https://www.csi.edu.au/media/Report_-_Competition__Collaboration_in_the_NDIS.pdf

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry*, *75*(2), 197-215. https://doi.org/https://doi.org/10.1111/j.1475-682X.2005.00119.x

Griffin, C., Niemiec, B., & Zeilinger, M. (2012). *Customizing job development: Un-occupying the workshop, one person at a time*. https://publications.ici.umn.edu/impact/25-1/customizing-job-development-un-occupying-the-workshop-one-person-at-a-time

Grigal, M., Dukes, L. L., & Walker, Z. (2021). Advancing access to higher education for students with intellectual disability in the United States. *Disabilities*, *1*(4), 438-449. https://www.mdpi.com/2673-7272/1/4/30

Grigal, M., & Dwyre, A. (2010). Employment activities and outcomes of college-based transition programs for students with intellectual disabilities.*Think College*, *3*. https://thinkcollege.net/sites/default/files/files/resources/209_employ%20activities%20and%20outcomes%20of%20transition%20programs.pdf

Grigal, M., & Hart, D. (2010). What's the point? A reflection about the purpose and outcomes of college for students with intellectual disabilities.*Think College*, *2*. https://thinkcollege.net/sites/default/files/files/resources/INSIGHT_2_F2.pdf#:~:text=

The%20employment%20experiences%20of%20students%20with%20intellectual%20disabilities,continue%20to%20access%20learning%20throughout%20their%20adult%20lives.

Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career Development for Exceptional Individuals*, *34*(1), 4-17. https://doi.org/10.1177/0885728811399091

Grigal, M., Hart, D., Papay, C., Wu, X., Lazo, R., Smith, F., & Domin, D. (2021). *Annual Report of the Cohort 2 TPSID Model Demonstration Projects (year 5, 2019–2020)*. Think College. https://thinkcollege.net/sites/default/files/files/TCReports_Year5_TPSID.pdf

Grigal, M., Hart, D., Smith, F., Domin, D., Sulewski, J., & Weir, C. (2015). *Think College National Coordinating Center: Annual report on the transition and postsecondary programs for students with intellectual disabilities (2013–2014)*. University of Massachusetts Boston, Institute for Community Inclusion. https://scholarworks.umb.edu/ici_pubs/156/

Grigal, M., Hart, D., & Weir, C. (2012). A survey of postsecondary education programs for students with intellectual disabilities in the United States. *Practice in Intellectual Disabilities*, *9*(4), 223-233.

Grigal, M., & Papay, C. (2018). New directions for adult and continuing education. *New Directions for Adult and Continuing Education*, *160*, 77-88. https://doi.org/10.1002/ace.20301

Haber, M. G., Mazzotti, V. L., Mustian, A. L., Rowe, D. A., Bartholomew, A. L., Test, D. W., & Fowler, C. H. (2016). What works, when, for whom, and with whom: A meta-analytic review of predictors of postsecondary success for students with disabilities. *Review of Educational Research*, *86*(1), 123-162. https://doi.org/10.3102/0034654315583135

Hagiwara, M., Dean, E., & Shogren, K. A. (2019). The self-determined career design model: Supporting young people with developmental disabilities and their families in home and community settings. *Journal of Intellectual Disability Research*, *63*(7), 862-862. https://search.ebscohost.com/login.aspx?direct=true&db=edswss&AN=000474486305049&authtype=sso&custid=deakin&site=eds-live&scope=site

Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *27*(1), 43-50.

Hall, A., Butterworth, J., Winsor, J., Kramer, J., Nye-Lengerman, K., & Timmons, J. (2018). Building an evidence-based, holistic approach to advancing integrated employment. *Research and Practice for Persons with Severe Disabilities*, *43*(3), 207–218.

Hall, S., Fildes, J., Liyanarachchi, D., Plummer, J., & Reynolds, M. (2020). *Young, Willing and Able – Youth Survey Disability Report 2019.* Mission Australia. file:///C:/Users/jcrosbie/Downloads/Youth%20disability%20Report%20-%20web.pdf

Hall, S. A. (2017). Community involvement of young adults with intellectual disabilities: Their experiences and perspectives on inclusion. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), 859-871. https://doi.org/10.1111/jar.12276

Hall, S. R., Keeton, B., Cassidy, P., Iovannone, R., & Griffin, C. (2018). *Discovery Fidelity Scale*. https://www.griffinhammis.com/wp-content/uploads/2019/11/DFS-Dec-2018.pdf

Halpern, A. S. (1985). Transition: A look at the foundations. *Exceptional Children*, *51*(6), 479-486. https://doi.org/10.1177/001440298505100604

Hansen, E. C. (2006). *Successful qualitative health research*. Allen & Unwin.

Hart, D. (2006). *Research to practice: Postsecondary education options for students with intellectual disabilities*. Institute for Community Inclusion. https://scholarworks.umb.edu/cgi/viewcontent.cgi?article=1005&context=ici_researchtopractice

Hastings, S. L. (2010). Encyclopedia of Research Design. In (pp. 1538-1540). SAGE Publications, Inc. https://sk.sagepub.com/researchdesign

Heal, L. W., & Rusch, F. R. (1995). Predicting employment for students who leave special education high school programs. *Exceptional Children*, *61*(5), 472-487. https://doi.org/10.1177/001440299506100506

Health and Social Care Alliance Scotland & Scottish Government Directorate for Chidren and Families. (2017). Experiences of transitions to adult years and adult services. https://www.alliance-scotland.org.uk/wp-content/uploads/2017/11/ALLIANCE-GIRFEC-Experiences-of-Transitions-to-Adult-Years-and-Adult-Services-2017-1.pdf

Hemphill, E., & Kulik, C. T. (2017). The tyranny of fit: Yet another barrier to mainstream employment for disabled people in sheltered employment. *Social Policy Administration*, *51*(7), 1119-1134.

Higher Education Support Act 2003 (Cth). https://www.legislation.gov.au/Details/C2022C00005

Hirano, K. A., & Rowe, D. A. (2015). A conceptual model for parent involvement in secondary special education. *Journal of Disability Policy Studies*, *27*(1), 43-53. https://doi.org/10.1177/1044207315583901

Holstein, J. A., & Gubrium, J. F. (2007). Constructionist perspectives on the life course. *Sociology Compass*, *1*(1), 335-352. https://doi.org/10.1111/j.1751-9020.2007.00004.x

Holwerda, A., van der Klink, J. J. L., de Boer, M. R., Groothoff, J. W., & Brouwer, S. (2013). Predictors of sustainable work particpation of young adults with developmental disorders. *Research in Developmental Disabilities*, *34*, 2753-2763. https://doi.org/10.1016/j.ridd.2013.05.032

Honey, A., Kariuki, M., Emerson, E., & Llewellyn, G. (2014). Employment status transitions among young adults, with and without disability. *Australian Journal of Social Issues*, *49*(2), 151-170. https://doi.org/10.1002/j.1839-4655.2014.tb00306.x

Hosking, D. L. (2008, 2-4 September, 2008). Critical disability theory [Conference presentation]. *4th Biennial Disability Studies Conference*, Lancaster University. http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2008/papers/hosking2008.pdf

Hudson, B. (2006). Making and missing connections: Learning disability services and the transition from adolescence to adulthood. *Disability & Society*, *21*(1), 47-60. https://doi.org/10.1080/09687590500375366

Hughes Jr, C. (2017). Mississippi Partnerships for Employment: Collaborating for systems change. *Journal of Vocational Rehabilitation*, *47*(3), 327-335. https://doi.org/10.3233/JVR-170906

Hummell, E., Venning, A., Foster, M., Fisher, K. R., & Kuipers, P. (2021). A rapid review of barriers and enablers of organisational collaboration: Identifying challenges in disability reform in Australia. *Australian Journal of Social Issues (John Wiley & Sons, Inc.)*, 1. https://doi.org/10.1002/ajs4.188

Idle, J., Giuntoli, G., Fisher, K., Robinson, S., Purcal, C., Newman, C., & Reedy, K. (2021). *Changing community attitudes to improve inclusion of people with disability*. UNSW Social Policy Research Centre. https://apo.org.au/sites/default/files/resource-files/2022-05/apo-nid317650.pdf

Independent Advisory Council of the NDIS. (2015). *Capacity building for people with disability, their families and carers*. https://www.ndis.gov.au/medias/IAC-advice-on-Capacity-Building-PDF-?context=bWFzdGVyfHJvb3R8NTg5MDU2fGFwcGxpY2F0aW9uL3BkZnxoZWYvaGFlLzg3OTc4NjQ1MjU4NTQucGRmfDE3NDEzNWIwZDM5ODUxNjRkNTA5M2FhMjQ3ZGY4YzI2MDg3OWQ4MGVjOGI2NWYwYjNjMDc2MTEzZDllOTViNjA

Ineland, J., Molin, M., & Sauer, L. (2015). Discursive tensions in late modern society: on education and work for people with intellectual disabilities in Sweden. *European Journal of Social Education*(26-27), 118.

Inge, K., Graham, C., Brooks-Lane, N., Wehman, P., & Griffin, C. (2018). Defining customized employment as an evidence-based practice: The results of a focus group study. *Journal of Vocational Rehabilitation*, *48*(2), 155-166. https://doi.org/doi: 10.3233/JVR-180928

Institute of Education Sciences: What Works Clearing House. (2020). *Standards handbook version 4.1*. https://ies.ed.gov/ncee/wwc/Docs/referenceresources/WWC-Standards-Handbook-v4-1-508.pdf

Iowa Department of Human Rights. (n.d.). *The great debate: The shift from sheltered workshops to competitive integrated employment*. https://humanrights.iowa.gov/sites/default/files/media/The%20Great%20Debate_%20The%20Shift%20from%20Sheltered%20Workshops%20to%20Competitive%20Integrated%20Employment_1.pdf

Jacobs, P., MacMahon, K., & Quayle, E. (2018). Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 962-982. https://doi.org/10.1111/jar.12466

Jacobs, P., MacMahon, K., & Quayle, E. (2020). Who decides? – Transitions from school to adult services for and with young people with severe intellectual disabilities. *Disability & Society*, *35*(7), 1058-1084. https://doi.org/10.1080/09687599.2019.1669435

Jarhag, S., Nilsson, G., & Werning, M. (2009). Disabled persons and the labor market in Sweden. *Social Work in Public Health*, *24*(3), 255-272. https://doi.org/10.1080/19371910802595315

Jenkins, K., Narayanaswamy, L., & Sweetman, C. (2019). Introduction: Feminist values in research, Gender & Development, 27:3, 415-425, DOI: 10.1080/13552074.2019.1682311

JobAccess. (n.d.). https://www.jobaccess.gov.au/ people-with-disability/australian-government-support-work

Jordan, T. (2014). Disability, able-bodiedness, and the biopolitical imagination. *The Review of Disability Studies: An International Journal*, *9*(1).

Ju, S., Roberts, E., & Zhang, D. (2013). Employer attitudes toward workers with disabilities: A review of research in the past decade. *Journal of Vocational Rehabilitation*, *38*(2), 113-123. https://doi.org/10.3233/JVR-130625

Jun, S., Kortering, L. J., Osmanir, K., & Zhang, D. (2015). Vocational rehabilitation transition outcomes: A look at one state's evidence. *Journal of Rehabilitation*, *81*(2), 47-53.

Jurkowvski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, *46*(1), 1-11. https://doi.org/10.1352/0047-6765(2008)46[1:PAPART]2.0.CO;2

Kaehne, A. (2013). Partnerships in local government: The case of transition support services for young people with learning disabilities. *Public Management Review*, *15*(5), 611-632. https://doi.org/10.1080/14719037.2012.698855

Kaehne, A. (2016). Project SEARCH UK – Evaluating its employment outcomes. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 519-530. https://doi.org/10.1111/jar.12207

Kavanagh, A., Brown, D., Dickinson, H., Mallett, S., Marck, C., & Weld-Blundell, I. (2021). *Evidence review: Strategies to increase employment and economic participation for people with a cognitive disability*. University of Melbourne. https://mspgh.unimelb.edu.au/research-groups/centre-for-health-equity/disability-and-health-unit/strategies-to-increase-employment-and-economic-participation-for-people-with-a-cognitive-disability

Kavanagh, A., Krnjacki, L., Beer, A., La Montagne, A., & Bentley, R. (2013). Time trends in socio-economic inequalities for women and men with disabilities in Australia: Evidence of persisting inequalities. *International Journal for Equity in Health*, *12*(73), 2-10. https://doi.org/10.1186/1475-9276-12-73

Kelly, P., Campbell, P., & Howie, L. (2019). *Rethinking young people's marginalisation: Beyond neoliberal futures?* Routledge.

Khayatzadeh-Mahani, A., Wittevrongel, K., Nicholas, D. B., & Zwicker, J. D. (2020). Prioritizing barriers and solutions to improve employment for persons with developmental disabilities. *Disability and Rehabilitation*, *42*(19), 2696-2706. https://doi.org/10.1080/09638288.2019.1570356

King's Fund Centre. (1980). *An ordinary life: Comprehensive locally-based residential services for mentally handicapped people*. King's Fund Centre.

King, M. (2020). Dedifferentiation and difference: People with profound intellectual and multiple disabilities and the National Disability Insurance Scheme (NDIS) . *Journal of Intellectual and Developmental Disability*, *45*(4), 320-325. https://doi.org/10.3109/13668250.2020.1759246

Kirby, A. V., Dell'armo, K., & Persch, A. C. (2019). Differences in youth and parent postsecondary expectations for youth with disabilities. *Journal of Vocational Rehabilitation*, *51*(1), 77-86. https://doi.org/10.3233/jvr-191027

Knox, M., Mok, M., & Parmenter, T. R. (2000). Working with the experts: Collaborative research with people with an intellectual disability. *Disability & Society*, *15*(1), 49-61. https://doi.org/10.1080/09687590025766

Kocman, A., Fischer, L., & Weber, G. (2018). The employers' perspective on barriers and facilitators to employment of people with intellectual disability: A differential mixed-method approach. *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 120-131. https://doi.org/10.1111/jar.12375

Kocman, A., & Weber, G. (2018). Job satisfaction, quality of work life and work motivation in employees with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 1-22. https://doi.org/10.1111/jar.12319

Kohler, P. D. (1996). *Taxonomy for transition programming.* University of Illinois.

Kohler, P. D., & Field, S. (2003). Transition-Focused Education: Foundation for the Future. *The Journal of Special Education*, *37*(3), 174–183.

Kohler, P. D., Gothberg, J., & Coyle, J. (2017). Using the taxonomy for transition programming 2.0 to guide transition education. In E. A. L. (eds) (Ed.), *Transitioning children with Disabilities: Studies in inclusive education.* SensePublishers. https://doi.org/https://doi.org/10.1007/978-94-6351-134-6_11

Kohler, P. D., Gothberg, J. E., Fowler, C., & Coyle, J. (2016). *Taxonomy for transition programming 2.0: A model for planning, organizing, and evaluating transition education, services, and programs*.

Kraemer, B. R., McIntyre, L. L., & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation*, *41*(4), 250-262. https://doi.org/10.1352/0047-6765(2003)41<250:Qolfya>2.0.Co;2

Kramer, J., Bose, J., Shepard, J., & Winsor, J. (2020). Engaging families in employment: Individuals and families' retrospective transition experiences with employment services. *Intellectual and Developmental Disabilities*, *58*(4), 314-327. https://doi.org/10.1352/1934-9556-58.4.314

Landmark, L. J., Song, J., & Dalun, Z. (2010). Substantiated best practices in transition: Fifteen plus years later. *Career Development for Exceptional Individuals*, *33*(3), 165-176. https://doi.org/10.1177/0885728810376410

Lantz, S., & Marston, G. (2012). Policy, citizenship and governance: the case of disability and employment policy in Australia. *Disability & Society*, *27*(6), 853-867. https://doi.org/10.1080/09687599.2012.686881

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

Laragy, C., Fisher, K.R., (2020). Choice, Control and Individual Funding: The Australian National Disability Insurance Scheme. In R.J. Stancliffe, M.L. Wehmeyer, K. A. Shogren & B. H. Abery (Eds.), Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan (pp. 133-143). Springer. https://doi.org/10.1007/978-3-030-35683-5

Leonard, H., Foley, K.-R., 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 and Adolescent Psychiatry*, *25*, 1369-1381. https://doi.org/10.1007/s00787-016-0853-2

Levinson, D. J. (1986). A conception of adult development. *American Psychologist*, *41*(1), 3-13. https://doi.org/10.1037/0003-066X.41.1.3

Lindsay, S. (2011). Discrimination and other barriers to employment for teens and young adults with disabilities. *Disability and Rehabilitation*, *33*(15-16), 1340-1350. https://doi.org/10.3109/09638288.2010.531372

Lindsay, S., Duncanson, M., Niles-Campbell, N., McDougall, C., Diederichs, S., & Menna-Dack, D. (2018). Applying an ecological framework to understand transition pathways to post-secondary education for youth with physical disabilities. *Disability and Rehabilitation*, *40*(3), 277-286. https://doi.org/http://dx.doi.org/10.1080/09638288.2016.1250171

Lindsay, S., McDougall, C., Menna-Dack, D., Sanford, R., & Adams, T. (2015). An ecological approach to understanding barriers to employment for youth with disabilities compared to their typically developing peers: views of youth, employers, and job counselors. *Disability and Rehabilitation*, *37*(8), 701-711. https://doi.org/10.3109/09638288.2014.939775

Lindstrom, L., Hirano, K. A., McCarthy, C., & Alverson, C. Y. (2014). 'Just having a job': Career advancement for low-wage workers with intellectual and developmental disabilities. *Career Development and Transition for Exceptional Individuals*, *37*(1), 40-49. https://doi.org/10.1177/2165143414522092

Lockett, H., Waghorn, G., & Kydd, R. (2018). A framework for improving the effectiveness of evidence-based practices in vocational rehabilitation. *Journal of Vocational Rehabilitation*, *49*(1), 15-31. https://doi.org/10.3233/JVR-180951

Luecking, D., & Luecking, R. (2013). Translating research into a seamless transition model. *Career Development and Transition for Exceptional Individuals*, *38*(1), 4-13. https://doi.org/10.1177/2165143413508978

Luecking, R., Morningstar, M. E., & Will, M. (2020). *The way to work: How to facilitate work experiences for youth in transition.* Brookes Publishing.

Lysaght, R., Petner-Arrey, J., Howell-Moneta, A., & Cobigo, V. (2017). Inclusion through work and productivity for persons with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), 922-935. https://doi.org/10.1111/jar.12284

Magee, E., & Plotner, A. (2022). Examining barriers and strategies for effective professional or interagency collaboration in secondary transition. *Journal of Vocational Rehabilitation*, *56*, 29-42. https://doi.org/10.3233/JVR-211170

Malbon, E., Carey, G., & Dickinson, H. (2017). Accountability in public service quasi-markets: The case of the Australian National Disability Insurance Scheme. *Australian Journal of Public Administration*, *77*, 468 – 481. https://doi.org/http://dx.doi.org/10.1111/1467-8500.12246

Malbon, E., Carey, G., & Meltzer, A. (2019). Personalisation schemes in social care: are they growing social and health inequalities? BMC Public Health, 19, 805. https://doi.org/10.1186/s12889-019-7168-4

Martinez, D. C., Conroy, J. W., & Cerreto, M. C. (2012). Parent Involvement in the Transition Process of Children With Intellectual Disabilities: The Influence of Inclusion on Parent

Desires and Expectations for Postsecondary Education. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 279-288.

Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ*, *311*, 109-112. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2550154/pdf/bmj00600-0043.pdf

Mazzotti, V., Test, D., & Mustian, A. (2012). Secondary transition evidence-based practices and predictors: Implications for policymakers. *Journal of Disability Policy Studies*, *25*, 5-18. https://doi.org/10.1177/1044207312460888

Mazzotti, V. L., Rowe, D. A., Kelley, K. R., Test, D. W., Fowler, C. H., Kohler, P. D., & Kortering, L. J. (2009). Linking transition assessment and postsecondary goals: Key elements in the secondary transition planning process. *Teaching exceptional children*, *42*(2), 44-51. https://doi.org/10.1177/004005990904200205

Mazzotti, V. L., Rowe, D. A., Kwiatek, S., Voggt, A., Chang, W.-H., Fowler, C. H., Poppen, M., Sinclari, J., & Test, D. W. (2021). Secondary transition predictors of postschool success: An update to the research base. *Career Development and Transition for Exceptional Individuals*, *44*(1), 47-64. https://doi.org/10.1177/2165143420959793

McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, *54*(8), 691-700. https://doi.org/10.1111/j.1365-2788.2010.01295.x

McKenzie, K., Ouellette-Kuntz, H., Blinkhorn, A., & Demore, A. (2017). Out of school and into distress: Families of young adults with intellectual and developmental disabilities in transition. *Journal of Applied Research in Intellectual Disabilities*, *30*, 774-781. https://doi.org/10.1111/jar.12264

McMahon, M., Moni, K., Cuskelly, M., Lloyd, J., & Jobling, A. (2020). Aspirations held by young adults with intellectual disabilities and their mothers. *Australian Journal of Career Development*, *29*(2), 107-116. https://doi.org/10.1177/1038416220916813

McManus, J. L., Feyes, K. J., & Saucier, D. A. (2010). Contact and knowledge as predictors of attitudes toward individuals with intellectual disabilities. *Journal of Social and Personal Relationships*, *28*(5), 579–590. https://doi.org/10.1177/0265407510385494

Meadows, D. (2009). Where have all our students gone? School to post-school transition in Australia. *Australasian Journal of Special Education*, *33*(02), 87-108. https://doi.org/10.1375/ajse.33.2.87

Meadows, D. (2019). *Collaboration – The key to unlocking a successful future for young people with disability*. National Disability Services. https://tickettowork.org.au/media/download_resources/pdf/Collaboration-the-key-to-unlocking-a-successful-future-for.pdf

Meadows, D., Alcorn, I., Beamish, W., Davies, M., Elias, G., Grimbeek, P., & Punch, R. (2006). *Quality outcomes for students with a disability: School to post-school transition.* Griffith University. www.education.qld.gov.au/studentservices/learning/docs/qualityoutcomes.pdf.

Meltzer, A., Robinson, S., & Fisher, K. R. (2020). Barriers to finding and maintaining open employment for people with intellectual disability in Australia. *Social Policy & Administration*, *54*(1), 88-101. https://doi.org/https://doi.org/10.1111/spol.12523

Midjo, T., & Aune, K. (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities. *Journal of Intellectual Disabilities*, *22*(1), 33-48. https://doi.org/10.1177/1744629516674066

Migliore, A., & Butterworth, J. (2009). Data note: postsecondary education and employment outcomes for youth with intellectual disabilities. *Data Note Series, Institute for Community Inclusion*, *16*. https://scholarworks.umb.edu/ici_datanote/16/

Milen, M. T., & Nicholas, D. B. (2017). Examining transitions from youth to adult services for young persons with autism. *Social Work in Health Care*, *56*(7), 636-648. https://doi.org/10.1080/00981389.2017.1318800

Miller-Warren, V. (2015). Examining the quality of secondary transition plans against research-based criteria in preparing students with disabilities for postsecondary success. *The Journal of Special Education Apprenticeship*, *4*(1), 1-14. https://files.eric.ed.gov/fulltext/EJ1127761.pdf#:~:text=According%20to%20federal%20law%2C%20transition%20services%20must%20be,and%20needs%20in%20order%20to%20maximize%20postsecondary%20success.

Minichiello, V., Aroni, R., & Hays, T. (2008). *In-depth interviewing: Principles, techniques, analysis* (3rd ed.). Pearson Education.

Molfenter, N. F., Hartman, E., Neugart, J., & Web, S. (2017). Let's Get to Work Wisconsin: Launching youth with intellectual and developmental disabilities into the workforce. *Journal of Vocational Rehabilitation*, *47*(3), 379-390. https://doi.org/10.3233/JVR-170910

Moore, D., Haines, K., Bradshaw, H., Porter, A., Smith, J., & Foley, S. (2018). Development of the Progressive Employment dual customer model for vocational rehabilitation. *Journal of Vocational Rehabilitation*, *49*, 149-160. https://doi.org/10.3233/JVR-180961

Moore, E. J., & Schelling, A. (2015). Postsecondary inclusion for individuals with an intellectual disability and its effects on employment. *Journal of Intellectual Disabilities*, *19*(2), 130-148. https://doi.org/10.1177/1744629514564448

Moore, K., McDonald, P., & Bartlett, J. (2018). Emerging trends affecting future employment opportunities for people with intellectual disability: The case of a large retail organisation. *Journal of Intellectual & Developmental Disability*, *43*(3), 328-338. https://doi.org/10.3109/13668250.2017.1379250

Mor-Barak, M. E. (2014). Managing diversity: Toward a globally inclusive workplace (3rd ed.). Sage.

Murfitt, K., Crosbie, J., Zammit, J., & Williams, G. (2018). Employer engagement in disability employment: A missing link for small to medium organizations – A review of the literature. *Journal of Vocational Rehabilitation*, *48*(3), 417-431.

Murfitt, K., Zammit, J., Bryant, R., Strachan, V., & Williams, G. (2016). *Diversity Field Officer service pilot project evaluation*. https://dro.deakin.edu.au/view/DU:30107655

Murphy, S., Easterbrook, E., Bendetson, S., & Lieberman, S. (2014). TransCen, Inc.'s WorkLink program: A new day for day services. *Journal of Vocational Rehabilitation*, *40* 125-130. https://doi.org/DOI:10.3233/JVR-130678

National Center for Special Education Research. (n.d.). *National Longitudinal Transition Study-2 (NLTS2)*. https://ies.ed.gov/ncser/projects/nlts2/

National Disability Insurance Agency. (2019a). *NDIS Participant Employment Strategy 2019 – 2022*. https://www.ndis.gov.au/about-us/strategies/participant-employment-strategy#strategy

National Disability Insurance Agency. (2019b). *People with an intellectual disability in the NDIS*. https://data.ndis.gov.au/reports-and-analyses/participant-groups/people-intellectual-disability-ndis#:~:text=The%20People%20with%20an%20intellectual%20disability%20in%20the,understand%20participant%20characteristics%2C%20participant%20outcomes%20and%20market%20trends.

National Disability Insurance Agency. (2020). *Employment outcomes for NDIS participants as at 31 November 2020*. https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/employment-outcomes-participants-their-families-and-carers

National Disability Insurance Scheme Act 2013 (Cth), https://www.legislation.gov.au/Details/C2013A00020

National People with Disabilities and Carer Council. (2009). *Shut Out.* https://www.dss.gov.au/sites/default/files/documents/03_2022/shut-out-standard.pdf

National Technical Assistance Center on Transition. (2019). *Effective Practices in Secondary Transition: Operational Definitions*. https://transitionta.org/wp-content/uploads/docs/Description-of-EBPs_2020_02-02.pdf

New South Wales Legislative Council Standing Committee on Social Issues. (2012). *Transition support for students with additional or complex needs and their families*. https://www.parliament.nsw.gov.au/lcdocs/inquiries/2165/120306%20Final%20report.pdf

Newman, L., Wagner, M., Cameto, R., & Knokey, A.-M. (2009). *The post-high school outcomes of youth with disabilities up to 4 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)*. https://thinkcollege.net/resource/student-outcomes/post-high-school-outcomes-youth-disabilities-4-years-after-high-school

Nicholas, D. B., Mitchell, W., Dudley, C., Clarke, M., & Zulla, R. (2018). An ecosystem approach to employment and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(1), 264-275. https://doi.org/10.1007/s10803-017-3351-6

Noel, V., Oulvey, E., Drake, R., & Bond, G. (2017). Barriers to employment for transition-age youth with developmental and psychiatric disabilities. *Administration and Policy in Mental Health and Mental Health Services Research*, *44*, 354–358.

Noonan, P. (2016). *Participation in tertiary education in Australia: Policy imperatives and scenarios*. Mitchell Institute at Victoria University. https://www.vu.edu.au/sites/default/files/participation-in-tertiary-education-in-australia-mitchell-institute.pdf

Nota, L., & Rossier, J. (2015). *Handbook of life design: From practice to theory and from theory to practice*. Hogrefe.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*, 1-13. https://doi.org/10.1177/1609406917733847

O'Brien, P., Bonati, M. L., Gadow, F., & Slee, R. (2019). People with intellectual disability experiencing university life: Theoretical *underpinnings, evidence and lived experience*. Brill.

O'Neill, S. C., Strnadová, I., & Cumming, T. M. (2016). Evidence-based transition planning practices for secondary students with disabilities: What has Australia signed up for? *Australasian Journal of Special Education*, *40*(1), 39-58. https://doi.org/10.1017/jse.2015.15

Odom, S., Horner, R., Snell, M., & Blacher, J. (2009). The construct of developmental disabilities. In S. Odom, R. Horner, M. Snell, & J. Blacher (Eds.), *Handbook of Developmental Disabilities* (pp. 3-14). Guildford Press.

U.S. Department of Labor: Office of Disability Employment Policy. (n.d.). *Employment First*. https://www.dol.gov/agencies/odep/initiatives/employment-first

Organization for Economic Co-operation and Development. (2010). *Sickness, disability and work: Breaking the barriers*. https://www.oecd.org/publications/sickness-disability-and-work-breaking-the-barriers-9789264088856-en.htm

Oliver, M. (1990). *The politics of disablement*. Palgrave.

Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, *7*(2), 101-114. https://doi.org/10.1080/02674649266780141

Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. Palgrave Macmillan.

Ottmann, G., McVilly, K., Wilson, E., Prain, M., Crosbie, J., Anderson, J., & Curtis, A. (2013). Picture my future: Image-assisted goal exploration. *Intellectual Disability Australasia*, *34*(3), 15-16.

Overmars-Marx, T., Thomése, F., & Moonen, X. (2017). Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative. *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 92-104. https://doi.org/10.1111/jar.12329

Pallisera, M., Fullana, J., Puyalto, C., & Vila, M. (2016). Changes and challenges in the transition to adulthood: Views and experiences of young people with learning disabilities and their families. *European Journal of Special Needs Education*, *31*(3), 391-406. https://doi.org/10.1080/08856257.2016.1163014

Papay, C. K., & Bambara, L. M. (2014). Best practices in transition to adult life for youth with intellectual disabilities. *Career Development and Transition for Exceptional Individuals*, *37*(3), 136-148. https://doi.org/10.1177/2165143413486693

Park, J., & Bouck, E. (2018). In-school service predictors of employment for individuals with intellectual disability. *Research in Developmental Disabilities*, *77*, 68-75. https://doi.org/10.1016/j.ridd.2018.03.014

Park, J. Y., & Park, E. Y. (2019). Factors affecting the acquisition and retention of employment among individuals with intellectual disabilities. *International Journal of Developmental Disabililities*, *67*(3), 188-201. https://doi.org/10.1080/20473869.2019.1633166

Pearce, D. (2017). *Securing savings from open employment: The case of persons with moderate intellectual disability*. Centre for International Economics.

Persch, A. C., Cleary, D. S., Rutkowski, S., Malone, H. I., Darragh, A. R., & Case-Smith, J. D. (2015). Current practices in job matching: A Project SEARCH perspective on transition.

Journal of Vocational Rehabilitation, *43*(3), 259-273. https://doi.org/10.3233/JVR-150774

Petner-Arrey, J., Howell-Moneta, A., & Lysaght, R. (2016). Facilitating employment opportunities for adults with intellectual and developmental disability through parents and social networks. *Disability and Rehabilitation*, *38*(8), 789-795. https://doi.org/10.3109/09638288.2015.1061605

Pleet-Odle, A., Aspel, N., Leuchovius, D., Roy, S., Hawkins, C., Jennings, D., Turnbull, A., & Test, D. W. (2016). Promoting high expectations for postschool success by family members: A 'to-do' list for professionals. *Career Development and Transition for Exceptional Individuals*, *39*(4), 249-255. https://doi.org/10.1177/2165143416665574

Plotner, A. J., Mazzotti, V. L., Rose, C. A., & Teasley, K. (2018). Perceptions of interagency collaboration: Relationships between secondary transition roles, communication, and collaboration. *Remedial and Special Education*, *41*(1), 28-39. https://doi.org/10.1177/0741932518778029

Porpora, D. (2015). *Reconstructing sociology: The critical realist approach*. Cambridge University Press. https://doi.org/10.1017/CBO9781316227657

Priestly, M. (1998). Constructions and creations: Idealism, materialism and disability theory. *Disability & Society*, *13*(1), 75-94. https://doi.org/10.1080/09687599826920

Productivity Commission. (2011). *Disability care and support: Productivity commission inquiry*. http://www.pc.gov.au/inquiries/completed/disability-support/report

Productivity Commission. (2021a). *Chapter 15. Services for People with Disability, Report on Government Services.* https://www.pc.gov.au/research/ongoing/report-on-government-services/2021/community-services/services-for-people-with-disability/rogs-2021-partf-section15-services-for-people-with-disability.pdf

Productivity Commission. (2021b). *Things you can't drop on your feet: An overview of Australia's services sector productivity*. https://www.pc.gov.au/ongoing/productivity-insights/services/productivity-insights-2021-services.pdf

Prohn, S. M., Kelley, K. R., & Westling, D. L. (2018). Students with intellectual disability going to college: What are the outcomes? A pilot study. *Journal of Vocational Rehabilitation*, *48*, 127-132. https://doi.org/10.3233/JVR-170920

Project SEARCH. (n.d.). https://www.projectsearch.us/

Quinlan, M., Mayhew, C., & Bohle, P. (2001). The global expansion of precarious employment, work disorganization, and consequences for occupational health: A review of recent research. *International Journal of Health Services*, *31*(2), 335-414. https://doi.org/10.2190/607H-TTV0-QCN6-YLT4

Redgrove, F. J., Jewell, P., & Ellison, C. (2016). Mind the gap between school and adulthood for people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, *3*(2), 182-190. https://doi.org/10.1080/23297018.2016.1188671

Richardson, T. D., Jindal-Snape, D., & Hannah, E. F. S. (2017). Impact of legislation on post-school transition practice for young people with additional support needs in Scotland. *British Journal of Special Education*, *44*(3), 239-256. https://doi.org/10.1111/1467-8578.12178

Riches, V. (2014). *Nova Transition To Work (TTW) program evaluation report 2014*. https://www.cds.org.au/wp-content/uploads/2017/06/Final-Nova-TTW-2014-Evaluation-report.pdf

Riesen, T., Morgan, R. L., & Griffin, C. (2015). Customized employment: A review of the literature. *Journal of Vocational Rehabilitation*, *43*(3), 183-193. https://doi.org/doi: 10.3233/JVR-150768

Riesen, T., Schulte, T., Morgan, R. L., & Kupferman, S. (2014). School-to-work barriers as identified by special educators, vocational rehabilitation counselors, and community rehabilitation professionals. *Journal of Rehabilitation*, *80*(1), 33-44. file:///C:/Users/jcrosbie/Downloads/TransitionBarriers.pdf

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.

Ross, J., Marcell, J., Williams, P., & Carlson, D. (2015). Postsecondary education employment and independent living outcomes of persons with autism and intellectual disability. *Journal of Postsecondary Education and Disability,*, *26*(4), 337 – 351. https://files.eric.ed.gov/fulltext/EJ1026890.pdf

Roy, S. (n.d.). *Engaging families in employment system change: Lessons from partnerships in employment states*. The Lewin Group/TASH. https://yestoemployment.org/wp-content/uploads/2021/08/FamilyEngagementBrief-FINAL.pdf

Rusch, F. R., Hughes, C., Agran, M., Martin, J. E., & Johnson, J. R. (2009). Toward self-directed learning, post-high school placement, and coordinated support constructing new transition bridges to adult life. *Career Development for Exceptional Individuals*, *32*(1), 53-59. https://doi.org/10.1177/0885728809332628

Rustad, M., & Kassah, K. A. (2021). Learning disability and work inclusion: on the experiences, aspirations and empowerment of sheltered employment workers in Norway. *Disability & Society*, *36*(3), 399-419. https://doi.org/10.1080/09687599.2020.1749564

Ryan, R., & Stanford, J. (2018). A Portable Training Entitlement System for the Disability Support Services Sector. The Centre for Future Work at the Australia Institute. https://d3n8a8pro7vhmx.cloudfront.net/theausinstitute/pages/2746/attachments/original/1523429118/ASU_Training_Report_Formatted.pdf?1523429118

Saldana, J. (2016). *The coding manual for qualitative researchers*. Sage.

Salt, E., Melville, C., & Jahoda, A. (2019). Transitioning to adulthood with a mild intellectual disability – Young people's experiences, expectations and aspirations [Article]. *Journal of Applied Research in Intellectual Disabilities*, *32*(4), 901-912. https://doi.org/10.1111/jar.12582

Sanderson, K. A., Burke, M. M., Urbano, R. C., Arnold, C. K., & Hodapp, R. M. (2017). Who helps? Characteristics and correlates of informal supporters to adults with disabilities. *American Journal on Intellectual and Developmental Disabilities*, *122*(6), 492-510. https://doi.org/10.1352/1944-7558-122.6.492

Sandvin, J., & Soder, M. (1996). Welfare state reconstruction. In J. Tossebro, A. Gustavsson, & D. G (Eds.), *Intellectual disabilities in the Nordic welfare states: Policies and everyday life* (pp. 167-177). Hoyskole Forlage.

Saunders, P., Brown, J., & Eardley, T. (2003). *Patterns of economic and social participation among FaCS customers*. https://www.dss.gov.au/sites/default/files/documents/05_2012/prp_no_19.pdf

Saunders, P., Naidoo, Y., & Griffiths, M. (2007). *Towards new indicators of disadvantage: Deprivation and social exclusion in Australia*. https://www.sprc.unsw.edu.au/media/SPRCFile/Report12_07_Deprivation_and_exclusion_in_Australia.pdf

Savickas, M. L. (2005). The theory and practice of career construction. In S. D. Brown & R. W. Lent (Eds.), *Career development and counseling: Putting theory and research to work* (pp. 42–70). John Wiley & Sons, Inc.

Savickas, M. L., Nota, L., Soresi, S., Rossier, J., Dauwalder, J. P., Duarte, M. E., Guichard, J., Soresi, S., Van Esbroek, R., & van Vianen, A. E. M. (2009). Life designing: A paradigm for career construction in the 21st century. *Journal of Vocational Behavior*, *75*(3), 239-250. https://doi.org/10.1016/j.jvb.2009.04.004

Schall, C. M., Wehman, P., Brooke, V., Graham, C., McDonough, J., Brooke, A., Ham, W., Rounds, R., Lau, S., & Allen, J. (2015). Employment interventions for individuals with ASD: The relative efficacy of supported employment with or without prior Project SEARCH training. *Journal of Autism and Developmental Disorders*, *45*(12), 3990-4001. https://doi.org/10.1007/s10803-015-2426-5

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). *Intellectual disability: Definition, classification, and systems of supports*. AAIDD.

Schalock, R. L., Luckasson, R., Tassé, M. J., & Verdugo, M. A. (2018). A holistic theoretical approach to intellectual disability: Going beyond the four current perspectives. *Intellectual and Developmental Disabilities*, *56*(2), 79-89. https://doi.org/10.1352/1934-9556-56.2.79

Schleien, S. J., Brake, L., Miller, K. D., & Walton, G. (2013). Using Photovoice to listen to adults with intellectual disabilities on being part of the community. *Annals of Leisure Research*, *16*(3), 212-229. https://doi.org/10.1080/11745398.2013.828364

Schneider, J., Wedgewood, N., Llewellyn, G., & McConnell, D. (2006). Families challenged by and accommodating to the adolescent years. *Journal of Intellectual Disability Research*, *50*(12), 926-936. https://doi.org/https://doi.org/10.1111/j.1365-2788.2006.00925.x

Schoon, I., & Heckhausen, J. (2019). Conceptualizing individual agency in the transition from school to work: A social-ecological developmental perspective. *Adolescent Research Review*, *4*(2), 135-148. https://doi.org/10.1007/s40894-019-00111-3

Senge, P. M. (1996). *The fifth discipline: The art and practice of the learning organization*. Doubleday.

Shakespeare, T. (1996). Disability, identity and difference. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 94-113). The Disability Press.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, *2*, 9-28. https://doi.org/10.1016/S1479-3547(01)80018-X

Sheppard, L., Harrington, R., & Howard, K. (2017). *Leaving school and getting a job: Research to action guide. A guide for young people with disability who want to work*. https://tickettowork.org.au/media/uploads/2020/03/02/empserviceusers.pdf

Shogren, K. A., Burke, K. M., Antosh, A., Wehmeyer, M. L., LaPlante, T., Shaw, L. A., & Raley, S. (2019). Impact of the self-determined learning model of instruction on self-determination and goal attainment in adolescents with intellectual disability. *Journal of Disability Policy Studies*, *30*(1), 22-34. https://doi.org/10.1177/1044207318792178

Shogren, K. A., Dean, E., Griffin, C., Steveley, J., Sickles, R., Wehmeyer, M. L., & Palmer, S. B. (2017). Promoting change in employment supports: Impacts of a community-based change model. *Journal of Vocational Rehabilitation*, *47*(1), 19-24. https://doi.org/10.3233/JVR-170880

Shogren, K. A., Luckasson, R., & Schalock, R. L. (2018). The responsibility to build contexts that enhance human functioning and promote valued outcomes for people with intellectual disability: strengthening system responsiveness. *Intellectual and Developmental Disabilities*, *56*(4), 287-300. https://doi.org/10.1352/1934-9556-56.5.287

Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, *50*(1), 16-30. https://doi.org/10.1352/1934-9556-50.1.16

Shogren, K. A., & Wehmeyer, M. L. (2020). *Handbook of adolescent transition education for youth with disabilities* (2nd ed.). Routledge. https://doi.org/https://doi.org/10.4324/9780429198342

Siperstein, G. N., Parker, R. C., & Drascher, M. (2013). National snapshot of adults with intellectual disabilities in the labor force. *Journal of Vocational Rehabilitation*, *39*(3), 157-165. https://doi.org/10.3233/JVR-130658

Small, N., Raghavan, R., & Pawson, N. (2013). An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning. *Journal of Intellectual Disabilities*, *17*(4), 283-300. https://doi.org/10.1177/1744629513500779

Smith, D. L., Atmatzidis, K., Capogreco, M., Lloyd-Randolfi, D., & Seman, V. (2016). Evidence-based interventions for increasing work participation for persons with various disabilities: A systematic review. *OTJR: Occupation, Participation and Health*, *37*(2_suppl), 3S-13S. https://doi.org/10.1177/1539449216681276

Smith, P., & Routel, C. (2010). Transition failure: The cultural bias of self-determination and the journey to adulthood for people with disabilities. *Disability Studies Quarterly*, *30*(1). https://doi.org/10.18061/dsq.v30i1.1012

Soldatic, K. (2019). *Disability and neoliberal state formations*. Routledge.

Southward, J., & Kyzar, K. (2017). Predictors of competitive employment for students with intellectual and/or developmental disabilities. *Education and Training in Autism and Developmental Disabilities*, *52*(1), 26-37.

Spicker, P. (2003). Distinguishing disability and incapacity. *International Social Security Review*, *56*(2), 31-43. https://doi.org/https://doi.org/10.1111/1468-246X.00156

Stafford, L., Marston, G., Chamorro-Koc, M., Beatson, A., & Drennan, J. (2017). Why one size fits all approach to transition in Disability Employment Services hinders employability of young people with physical and neurological disabilities in Australia. *Journal of Industrial Relations*, *59*(5), 631. https://ezproxy.deakin.edu.au/login?url=https://search.ebscohost.com/login.aspx?dir ect=true&db=edb&AN=126317488&authtype=sso&custid=deakin&site=eds-live&scope=site

Stancliffe, R. G., Wehmeyer, M. L., Shogren, K. A., & Abery, B. H. (2020). *Choice, preference, and disability: Promoting self-determination across the lifespan*. Springer Nature. https://doi.org/https://doi.org/10.1007/978-3-030-35683-5

Stanwick, J., Forrest, C., & Skujins, P. (2017). *Who are the persistently NEET young people?* NCVER. https://www.ncver.edu.au/research-and-statistics/publications/all-publications/who-are-the-persistently-neet-young-people

State of Victoria Department of Health and Human Services. (2018). *Every opportunity: Victorian economic participation plan for people with disability 2018-2020*. http://www.statedisabilityplan.vic.gov.au/application/files/7815/3740/3384/Every_opportunity_-_Web.pdf

Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental Medicine & Child Neurology*, *51*(s4), 169-173. https://doi.org/https://doi.org/10.1111/j.1469-8749.2009.03419.x

Stokes, H. (2012). *Imagining futures: Identity narratives and the role of work, education, community and family*. Melbourne University Press.

Stokes, H., Turnbull, M., & Wyn, J. (2013). *Young people with a disability: Independence and opportunity. A literature review*. Youth Research Centre, Melbourne Graduate School of Education. http://web.education.unimelb.edu.au/yrc/linked_documents/research_report39.pdf

Stoneman, Z. (2009). Disability research methodology: Current issues and future challenges. In S. Odom, R. Horner, M. Snell, & J. Blacher (Eds.), *Handbook of Developmental Disabilities* (pp. 35-54). The Guildford Press. https://books.google.com.au/books?hl=en&lr=&id=U4VpCKVomHkC&oi=fnd&pg=PA1&ots=Nr7v73pCxp&sig=ZjQpfEnGIegntjzbvEqrL1QS3SI&redir_esc=y#v=onepage&q&f=false

Sundar, V., O'Neill, J., Houtenville, A., J, Phillips, K., G, Keirns, T., Smith, A., & Katz, E., E. (2018). Striving to work and overcoming barriers: Employment strategies and successes of people with disabilities. *Journal of Vocational Rehabilitation*, *48*(1), 93-109. https://doi.org/10.3233/JVR-170918

SVA Consulting. (n.d.). *Reaching potential: Experiences of young people with significant intellectual disability*. https://www.socialventures.com.au/assets/Reaching-Potential-Full-Report-web.pdf?mc_cid=8f01a7b02f&mc_eid=7dae59d7b4

Szidon, K., Ruppar, A., & Smith, L. (2015). Five steps for developing effective transition plans for high school students with Autism Spectrum Disorder. *Teaching Exceptional Children*, *47*(3), 147-152. https://doi.org/10.1177/0040059914559780

Tassé, M. J., Luckasson, R., & Schalock, R. L. (2016). The relation between intellectual functioning and adaptive behavior in the diagnosis of intellectual disability. *Intellectual and Developmental Disabilities*, *54*(6), 381-390. https://doi.org/10.1352/1934-9556-54.6.381

Taubner, H., Tideman, M., & Staland Nyman, C. (2021). Employment Sustainability for People with Intellectual Disability: A Systematic Review. *Journal of Occupational Rehabilitation, 2021.* https://doi.org/10.1007/s10926-021-10020-9

Test, D. W., Mazzotti, V. L., Mustian, A. L., Fowler, C. H., Kortering, L., & Kohler, P. D. (2009). Evidence-based secondary transition predictors for improving postschool outcomes for students with disabilities. *Career Development for Exceptional Individuals*, *32*(3), 160-181. https://doi.org/10.1177/0885728809346960

Test, D. W., Smith, L. E., & Carter, E. W. (2014). Equipping youth with Autism Spectrum Disorders for adulthood:promoting rigor, relevance, and relationships. *Remedial and Special Education*, *35*(2), 80-90. https://doi.org/10.1177/0741932513514857

Think College National Coordinating Center Accreditation Workgroup. (2021). *Report on model accreditation standards for higher education programs for students with intellectual disability: Progress on the path to education, employment, and community living*. University of Massachusetts Boston, Institute for Community Inclusion. https://thinkcollege.net/sites/default/files/files/TCreport_Accreditation-full_2021.pdf

Thoresen, S. H., Thomson, A., Jackson, R., & Cocks, E. (2017). Meaningful social and economic inclusion through small business enterprise models of employment for adults with intellectual disability. *Journal of Vocational Rehabilitation*, *49*(2), 161-172. https://doi.org/10.3233/JVR-180962

Ton, K. T., Gaillard, J. C., Adamson, C., & Akgungor, C. (2021). Researching the capabilities of people with disabilities: would a critical realist methodology help? *Journal of Critical Realism*, *20*(2), 181-200. https://doi.org/10.1080/14767430.2021.1885907

Tracey, D., Johnston, C., Papps, F. A., & Mahmic, S. (2018). How do parents acquire information to support their child with a disability and navigate individualised funding schemes?. *Journal of Research in Special Educational Needs*, *18*(1), 25-35. https://doi.org/10.1111/1471-3802.12390

Trainor, A. A., Carter, E. W., Karpur, A., Martin, J. E., Mazzotti, V. L., Morningstar, M. E., Newmann, L., & Rojewski, J. W. (2019). A framework for research in transition: Identifying important areas and intersections for future study. *Career Development and Transition for Exceptional Individuals*, *43*(1), 5-17. https://doi.org/10.1177/2165143419864551

Tuckerman, P., Cain, P., Long, B., & Klarkowski, J. (2012). An exploration of trends in open employment in Australia since 1986. *Journal of Vocational Rehabilitation*, *37*, 173-183. https://doi.org/10.3233/JVR-2012-0612

Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work*, *0*, 1-17. https://doi.org/10.1177/1473325010368316

U.S. Department of Labor: Office of Disability Employment Policy. (n.d.). *Employment First*. https://www.dol.gov/agencies/odep/initiatives/employment-first

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/doi:10.1111/jppi.12005

United Nations. (2006). *Convention on the rights of persons with disabilities* (CRPD). https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Van Aswegen, J. (2020). Disabling discourses and charitable model of disability: labour market activation for people with disabilities, Ireland – A critical policy analysis. *Disability & Society*, *35*(3), 435-459. https://doi.org/10.1080/09687599.2019.1634519

Verdugo, M. A., Jordán de Urríes, F. B., Jenaro, C., Caballo, C., & Crespo, M. (2006). Quality of life of workers with an intellectual disability in supported employment. *Journal of Applied Research in Intellectual Disabilities*, *19*(4), 309-316. https://doi.org/https://doi.org/10.1111/j.1468-3148.2006.00277.x

Victorian Government Department of Education (n.d.-a). *Career education funding — Accountability and reporting requirements*. https://www2.education.vic.gov.au/pal/career-education-funding-accountability-and-reporting-requirements/policy

Victorian Government, Department of Education. (n.d.-b). *Strengthened career planning*. https://www.education.vic.gov.au/school/teachers/teachingresources/careers/Pages/disabilitypathways.aspx

Victorian Government, Department of Education. (n.d.-c). *Students with disability*. https://www2.education.vic.gov.au/pal/students-disability/resources

Victorian Government, Department of Education. (n.d.-d). *Work experience*. https://www2.education.vic.gov.au/pal/work-experience/policy?Redirect=1

Voermans, M. A. C., Taminiau-Bloem, E. F., Giesbers, S. A. H., & Embregts, P. J. C. M. (2021). The value of competitive employment: In-depth accounts of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 239-249. https://doi.org/10.1111/jar.12802

Waghorn, G., & Hielscher, E. (2015). The availability of evidence-based practices in supported employment for Australians with severe and persistent mental illness. *Australian Occupational Therapy Journal*, *62*(2), 141-144. https://doi.org/https://doi.org/10.1111/1440-1630.12162

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: A first look at the postschool experiences of youth with disabilities. A Report from the National Longitudinal Transition Study-2 (NLTS2)*. Office of Special Education, US Department of Education. https://files.eric.ed.gov/fulltext/ED494935.pdf

Wakeford, M., & Waugh, F. (2014). *Transitions to employment of Australian young people with disability and the Ticket to Work initiative*. http://www.tickettowork.org.au/wp-content/uploads/2016/03/Transitions-to-Employment-of-Australian-Young-People-with-Disability-Full-Report.pdf

Walmsley, J. (2005). Institutionalization: A historical perspective. In K. Johnson & R. Traustadóttir (Eds.), *Deinstitutionalization and people with intellectual disabilities* (pp. 50–65). Jessica Kingsley Publishers.

Walsh, L., Keary, A., & Gleeson, J. (2019). Non-linear transitions: An intergenerational longitudinal study of today's young women in education and work. *YOUNG*, *27*(5), 468-485. https://doi.org/10.1177/1103308818817632

Wang, C. C., & Burris, M. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, *21*, 171-186.

Watson, N. (2004). The dialectics of disability: A social model for the 21st Century? In C. Barnes & G. Mercer (Eds.), *Implementing the social model of disability: Theory and research* (pp. 101-117). The Disability Press.

Wehman, P. (2012). Supported employment: What is it? *Journal of Vocational Rehabilitation*, *37*, 139-142. https://doi.org/10.3233/JVR-2012-0607

Wehman, P., Chan, F., Ditchman, N., & Kang, H. (2014). Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: A case control study. *Intellectual and Developmental Disabilities*, *52*(4), 296-310. https://doi.org/10.1352/1934-9556-52.4.296

Wehman, P., Revell, W. G., & Brooke, V. (2003). Competitive employment: Has it become the 'first choice' yet? *Journal of Disability Policy Studies*, *14*(3), 163-173. https://doi.org/10.1177/10442073030140030601

Wehman, P., Schall, C., McDonough, J., Kregel, J., Brooke, V., Molinelli, A., & Thiss, W. (2014). Competitive emploment for youth with autism spectrum disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders*, *44*, 487-500. https://doi.org/10.1007/s10803-013-1892-x

Wehman, P., Schall, C., McDonough, J., Sima, A., Brooke, A., Ham, W., Whittenberg, H., Brooke, V., Avellone, L., & Riehle, E. (2020). Competitive employment for transition-aged youth with significant impact from autism: A multi-site randomized clinical trial. *Journal of Autism and Developmental Disorders*, *50*(6), 1882-1897. https://doi.org/10.1007/s10803-019-03940-2

Wehman, P., & Targett, P. (2013). Supported employment. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders* (pp. 3041-3047). Springer New York. https://doi.org/10.1007/978-1-4419-1698-3_1807

Wehman, P., Taylor, J., Brooke, V., Avellone, L., Whittenburg, H., Ham, W., Brooke, A. M., & Carr, S. (2018). Toward competitive employment for persons with intellectual and developmental disabilities: What progress have we made and where do we need to go. *Research and Practice for Persons with Severe Disabilities*, *43*(3), 131-144. https://doi.org/10.1177/1540796918777730

Wehmeyer, M. L. (2003). 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). New York, NY: Charles C. Thomas.

Wehmeyer, M. (2020). Strengths-based approaches to disability, the supports paradigm, and the importance of the supports intensity scales. *Revista Educação Especial*, *33*. https://doi.org/10.5902/1984686X48249

Wehmeyer, M., & Palmer, S. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education & Training in Developmental Disabilities*, *38*(2), 131-144.

Wehmeyer, M., & Webb, K. (2011). *Handbook of adolescent transition education for youth with disabilities*. Routledge.

Wehmeyer, M. L., & Craig, E. M. (2013). *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Paul H. Brookes Publishing Co.

Wehmeyer, M. L., Nota, L., Soresi, S., Shogren, K. A., Morningstar, M. E., Ferrari, L., Sgaramella, T. M., & DiMaggio, I. (2019). A crisis in career development: Life designing and implications for transition. *Career Development and Transition for Exceptional Individuals*, *42*(3), 179-187. https://doi.org/doi.org/10.1177/216514341775009

Wehmeyer, M. L., Shogren, K. A., Singh, N. N., & Uyanik, H. (2017). Strengths-based approaches to intellectual and developmental disabilities. In K. A. Shogren, M. L.

Wehmeyer, & N. N. Singh (Eds.), *Handbook of Positive Psychology in Intellectual and Developmental Disabilities: Translating Research into Practice* (pp. 13-21). Springer International Publishing. https://doi.org/10.1007/978-3-319-59066-0_2

Weld-Blundell, I., Shields, M., Devine, A., Dickinson, H., Kavanagh, A., & Marck, C. (2021). Vocational interventions to improve employment participation of people with psychosocial disability, autism and/or intellectual disability: A systematic review. *International Journal of Environmental Research and Public Health*, *18*(22), 12083. https://doi.org/10.3390/ijerph182212083

Whirley, M. L., Gilson, C. B., & Gushanas, C. M. (2020). Postsecondary education programs on college campuses supporting adults with intellectual and developmental disabilities in the literature: A scoping review. *Career Development and Transition for Exceptional Individuals*, *43*(4), 195-208. https://doi.org/10.1177/2165143420929655

White, G., Kiegaldie, D., & Hunter, S. (2019). *The integrated practical placement program: A program of social inclusion in the workplace for people with disability*. Holmsglen and the Royal Children’s Hospital.

Wilson, N. J., Jaques, H., Johnson, A., & Brotherton, M. L. (2017). From social exclusion to supported inclusion: Adults with intellectual disability discuss their lived experiences of a structured social group. *Journal of Applied Research in Intellectual Disabilities*, *30*(5). https://doi.org/https://doi.org/10.1111/jar.12275

Winn, S., & Hay, I. (2009). Transition from school for youths with a disability: Issues and challenges. *Disability & Society*, *24*(1), 103-115. https://doi.org/10.1080/09687590802535725

Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2019). *StateData: The national report on employment services and outcomes.* University of Massachusetts Boston, Institute for Community Inclusion. https://www.thinkwork.org/sites/default/files/files/bluebook2019_Final.pdf

Woden, M. (2017). *The changing nature of work and worker wellbeing*. Australian Institute of Health and Welfare. https://www.aihw.gov.au/getmedia/ac1e8df0-4f19-4c59-9df8-3211c395bd3f/aihw-australias-welfare-2017-chapter4-1.pdf.aspx

Wolfensberger W. (2000). A brief overview of Social Role Valorization. *Mental retardation*, *38*(2), 105–123. https://doi.org/10.1352/0047-6765(2000)038<0105:ABOOSR>2.0.CO;2

Wong, S. S., Ong, K. R., Teo, C. H. X., Ng, J. Y., Gwee, A. J., & Toh, A. Y. (2021). Development and validation of an instrument to assess work support needs of adults with intellectual disabilities in sheltered employment. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 295-306. https://doi.org/https://doi.org/10.1111/jar.12807

Wood, D., Crapnell, T., Lau, L., Bennett, A., Lotstein, D., Ferris, M., & Kuo, A. (2018). Emerging adulthood as a critical stage in the life course. In N. Halfon, C. F. Forrest, R. M. Lerner, & E. M. Faustman (Eds.), *Handbook of life course health development* (pp. 123-143). Springer. https://doi.org/https://doi.org/10.1007/978-3-319-47143-3_7

World Health Organisation. (2002). *World health report: 2002. Reducing risks, promoting healthy life*. https://www.who.int/publications/i/item/9241562072

World Health Organisation. (2011). *World report on disability*. https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

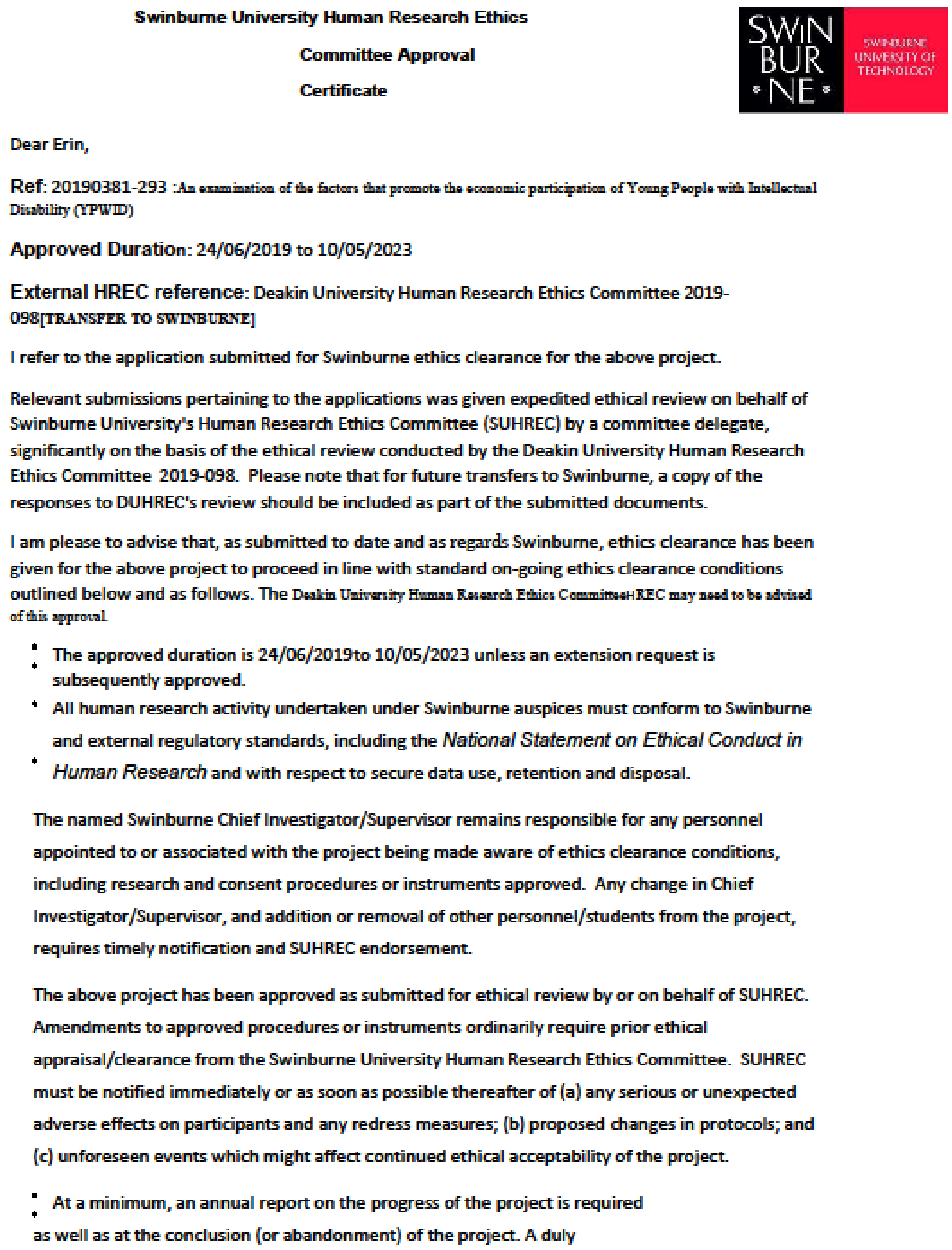
World Health Organisation. (2018). *Definition: Intellectual disability*. WHO Regional Office for South East Asia. http:// www.who.int/southeastasia/health-topics/mental-health/key-terms-and-definitions-in-mental-health#intellectual

Xu, T., & Stancliffe, R. J. (2019). An evaluation of employment outcomes achieved by transition to work service providers in Sydney, Australia. *Journal of Intellectual & Developmental Disability*, *44*(1), 51-63. https://doi.org/10.3109/13668250.2017.1310809

Zappella, E. (2015). Employers' attitudes on hiring workers with intellectual disabilities in small and medium enterprises: An Italian research. *Journal of Intellecual Disabilities*, *19*(4), 381-392. https://doi.org/10.1177/1744629515580883

Appendices

Appendix A: Ethics Approval



Swinburne University Human Research Ethics

Committee Approval

Certificate

Dear Erin,

Ref: 20190381-293 :An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Approved Duration: 24/06/2019 to 10/05/2023

External HREC reference: Deakin University Human Research Ethics Committee 2019-098[TRANSFER TO SWINBURNE]

I refer to the application submitted for Swinburne ethics clearance for the above project.

Relevant submissions pertaining to the applications was given expedited ethical review on behalf of Swinburne University's Human Research Ethics Committee (SUHREC) by a committee delegate, significantly on the basis of the ethical review conducted by the Deakin University Human Research Ethics Committee 2019-098. Please note that for future transfers to Swinburne, a copy of the responses to DUHREC's review should be included as part of the submitted documents.

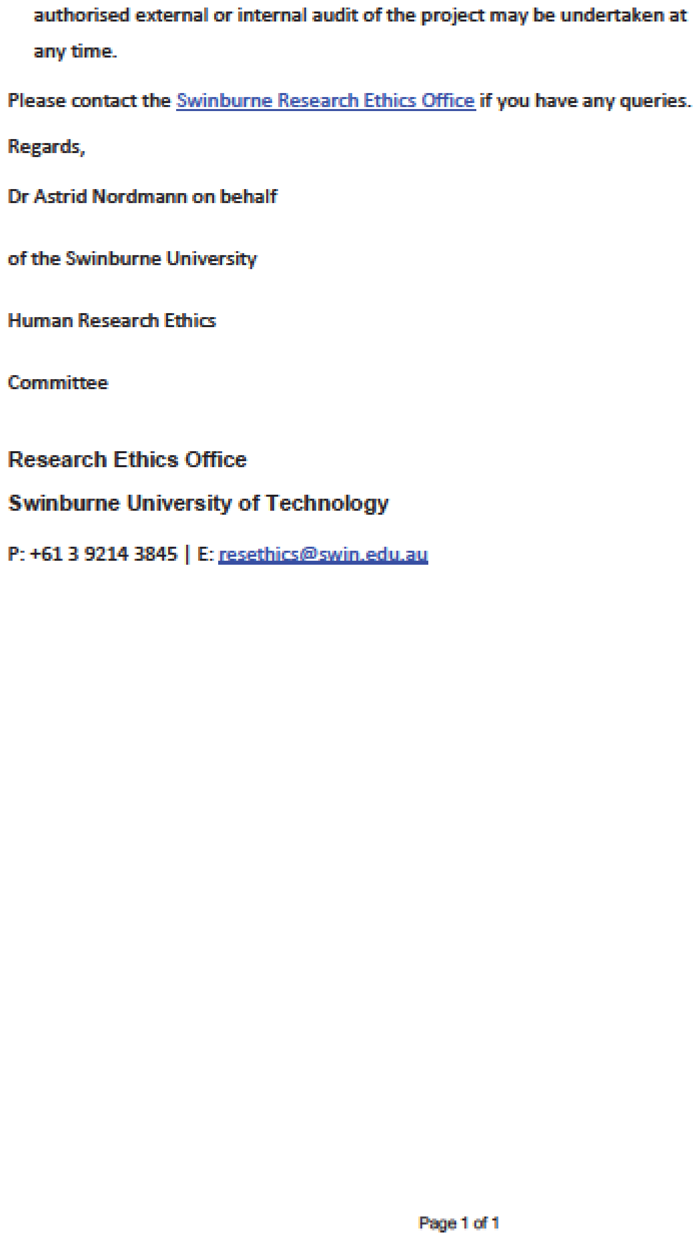
I am please to advise that, as submitted to date and as regards Swinburne, ethics clearance has been given for the above project to proceed in line with standard on-going ethics clearance conditions outlined below and as follows. The Deakin University Human Research Ethics CommitteeHREC may need to be advised of this approval.

- The approved duration is 24/06/2019to 10/05/2023 unless an extension request is subsequently approved.
- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the *National Statement on Ethical Conduct in Human Research* and with respect to secure data use, retention and disposal.

The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in Chief Investigator/Supervisor, and addition or removal of other personnel/students from the project, requires timely notification and SUHREC endorsement.

The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/clearance from the Swinburne University Human Research Ethics Committee. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project. A duly



authorised external or internal audit of the project may be undertaken at any time.

Please contact the Swinburne Research Ethics Office if you have any queries.

Regards,

Dr Astrid Nordmann on behalf

of the Swinburne University

Human Research Ethics

Committee

Research Ethics Office
Swinburne University of Technology
P: +61 3 9214 3845 | E: resethics@swin.edu.au

Appendix B: Plain Language Statement for young people with intellectual disability

Plain Language Statement for Young People with Intellectual Disability

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Hello,

My name is Jenny Crosbie. I am a student researcher from Swinburne University. I am researching how young people with intellectual disability can learn more about getting training and work after they finish school.

Who is doing this research?

I am a student researcher. That means I am learning to be a researcher. I will have some very experienced researchers helping me with this project. They are

1) Professor Erin Wilson, Swinburne University
2) Dr Perri Campbell, Swinburne University
3) Dr Kevin Murfitt from Deakin University
4) Professor Keith McVilly, University of Melbourne

What is the aim of the study?

At the moment some people with intellectual disability don't get the opportunity to try work and study when they finish school. The aim of this study is to find out what helps people learn about training and work opportunities after school and what makes it hard for young people with intellectual disability to find training and work opportunities after they finish school.

To do this I will talk to young people with intellectual disability, family members of young people with disability and workers who help young people with intellectual disability when they finish school.

At the end of the study the information will be made available to young people with intellectual disability, their families and workers to help them learn more about training and work opportunities once they finish school.

What will I need to do?

A researcher from Swinburne University will meet with you three times over 2 months. Each meeting will take about 1 hour.
The researcher will meet you somewhere you usually go such as where you attend training or work, and at a time that is good for you.

In the first meeting the researcher will tell you all about the project including what you would need to do and give you some written/printed information about the project to keep. You can ask questions at the meeting as well.

If you decide to be part of the study the researcher will organise a second meeting. At the second meeting the researcher will ask you some questions to get to know you. Questions about how old you are, where you went to school, who you live with and what you like to do will be asked. You will also be given information and instructions about taking some photos about work and training. This is called "Photovoice".

You will have 2 weeks to take the photos.

At the end of the first week the researcher will visit you to check that you have started to take photos and answer any questions you have.

For the third meeting, you will be asked to bring the photos you have taken with you. The researcher will ask you questions about the photos and about training and work.

All of the interviews will be recorded.

At the end of the Photovoice part of the project, you will be asked whether you would like to attend a discussion group with other people who have an intellectual disability. It will be held at a disability organisation. The discussion group will go for about 2 hours. You don't have to be involved in the discussion group if you don't want to.

At the discussion group I will tell the group about what people who were in the study told me. I will not tell the group the name of the person who gave me the information. It will be a summary of what everyone told me.

I will ask the group members whether they agree with what people said. I will then ask the group to tell me their ideas about how to make it easier for people with intellectual disabilities to know about training and work after they finish school.

What are the benefits for me?

It is important to hear from young people with intellectual disability themselves about what helps them to know about training and work opportunities after school. By being involved in this study you might learn about training and work options available to you and you will be helping other young people with intellectual disability and their families in the future.

You will also receive a $50 gift card for participating to help cover your travel or parking costs.

Are there any risks in participating?

We don't think being involved in the research project will upset you. However, you can stop the interview at any time, take a break or do it another time if you do feel upset. You can decide not to answer certain questions, or you can decide not to take part anymore. If you don't want to be part of the research anymore, you can tell us not to use the information you gave us in the research.

If you feel upset after the interview and would like to speak to someone, we will assist you in getting the help you need. If you need to speak to someone, we recommend you call your case manager, doctor or regular support workers. Please let us know if you would like to bring someone to the interview with you. We will also give you details about mental health support services you can access for assistance in case you need this information.'

If you decide to join the discussion group, we will make sure it is a safe space and that everyone treats others with respect.

How will my identity be protected?

Your name and all the information you tell us will be kept private. That means we will not tell anybody else what you tell us.

We will not tell anyone what you have said and will not identify you in any written or spoken materials about the research. This means that there are not likely to be risks of being involved. However, if you choose to come to the discussion group then other people will know you are taking part in the research and will hear what you say. You and all the participants will be asked not to tell anyone outside the group what was said by others in the discussion group.

You can decide not to take part any more at any time. However, the information you have provided in the discussion group will still be used in the research as we don't have a way to identify what you have said and delete it.

Do I have to be involved in this research?

No, you don’t have to be involved in this research. If you decide not to be involved it will not affect the services you receive from ______________________.

If you change your mind you can stop at any time and you won’t get into trouble with anyone. If you stop, we won’t keep any notes about you unless we have used them in a report already but no one will know that you helped us.

What will happen with the results?

When we finish this work we will write a report and tell people about what we have found. We will also write up some reports called “Promising Practice Profiles” that help people understand about training and work for people with intellectual disabilities after they have finished school.

We will write the reports in Plain English to make it easy for people to read them. We will also record some of the information into a podcast so people can listen to it.

Who do I contact to be part of the study?

You can email Jenny Crosbie at jcrosbie@swin.edu.au or call her on (03) 9214 8477

What if I have a complaint?

This project has been approved by or on behalf of Swinburne’s Human Research Ethics Committee (SUHREC) in line with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68),
Swinburne University of Technology,
PO Box 218, HAWTHORN VIC 3122.
Tel (03) 9214 3845 or +61 3 9214 3845 or resethics@swin.edu.au

Please quote project number 20190381-293
If you experience any distress you can contact a staff member from or Lifeline on 13114

Participant Consent Form for Young People with Intellectual Disability

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date:

Reference Number: 20190381-293

Please tick each of the following:

- ☐ I understand the attached Plain Language Statement.
- ☐ I have been given a copy of the Plain Language Statement and Consent Form to keep.
- ☐ I freely agree to participate in this project according to the conditions in the Plain Language Statement.
- ☐ I give permission for the researcher to audio-tape the interviews. The recordings will be destroyed once they have been transcribed.
- ☐ Everything about me will be stored safely and only the researchers will be able to see it. Everything will be destroyed 5 years after the end of the project.
- ☐ The researcher will not tell anyone that I was in this project.
- ☐ I would like to hear about what happens in this project.
- ☐ I know I can leave the project any time and I won't get into any trouble

Participant's Name (printed) ……………………………………………………………………………………

Signature of participant ……………..……………………………………………………

Date ……………………………

Phone number and/or email to contact you on: …………………………………………………………

Please mail this form to:

Ms Jenny Crosbie

Centre for Social Impact

Faculty of Business and Law

Swinburne University of Technology

PO Box 218, Mail H23,

Hawthorn 3122

Withdrawal of consent

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date:

Reference Number: 20190381-293

I hereby wish to WITHDRAW my consent to participate in the above research project. I don't want to do it any longer. I understand that I WILL NOT get into trouble with Swinburne University or my staff or ____________________

Participant's Name (printed) ……………………………………………………………………………………

Signature of participant ………………………………………………………………….……

Date ………………………….…

Please mail this form to:

Ms Jenny Crosbie

Centre for Social Impact

Faculty of Business and Law

Swinburne University of Technology

PO Box 218, Mail H23, Hawthorn 3122

Appendix C: Plain Language Statement for family members of young people with intellectual disability

Plain Language Statement for Family Members of Young People with Intellectual Disability

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Hello,

My name is Jenny Crosbie. I am a PhD candidate from Swinburne University. I am researching the factors that promote the economic participation of young people with intellectual disability in the emerging adulthood period.

Who is doing this research?

I am a PhD candidate and this research is part of my candidature. I am being supervised by:

1) Professor Erin Wilson, Swinburne University
2) Dr Perri Campbell, Swinburne University
3) Dr Kevin Murfitt from Deakin University
4) Professor Keith McVilly, University of Melbourne

What is the aim of the study?

The broad aim of this research is to examine the experience of young people with intellectual disabilities and their families related to economic participation in the emerging adulthood period, and to identify barriers and enablers to increase opportunities.

What is involved?

Family members of people with an intellectual disability will be asked to participate in a semi-structured interview that will take approximately 1 hour. The interview will be scheduled at a time and venue that suits you. During the interview you will be asked about your experience of supporting a family member who has an intellectual disability during their transition from school to post school options. You will also be asked about the training, study and work programs your family member is currently involved in and how the transition from school to post school options can be more effective for families. For example we will ask you to describe the transition support you and your family member received when leaving school and tell us what supports and resources you would have valued.

You may also be invited to be part of a discussion group comprised of family members of young people with a disability and key informants to discuss the findings of the project and develop a set of promising practice profiles which will tell others about how to support young people with intellectual disabilities increase opportunities for economic participation. The discussion group will meet twice for approximately 2 hours each time. The group will be provided with key barriers and enablers to economic participation identified by the researcher and asked to provide feedback about improving opportunities for economic participation for YPWID.

What are the benefits for me?

This project will not benefit you directly, but we hope that by hearing about the experience of family members of young people who have an intellectual disability we can learn about how to make the transition from school to post school options easier. You will also receive a $50 voucher to cover your travel costs.

Are there any risks in participating?

The risks associated with participating in this research are minimal. The content of the interview is not anticipated to cause distress. You can take a break from the interview at any time and you do not have to answer a question if you don't want to. You can also withdraw from the study at any time.

In the unlikely event that being involved in the study causes distress you can contact Lifeline on 13 11 14 and they can provide you with free counselling.

How will my identity be protected?

Your identity will be kept confidential, however, if you participate in discussion groups, you should be aware that others present (family members of young people with intellectual disability and other key informants) will hear your views. Once your interview is transcribed the recording will be destroyed. Data will be de-identified by replacing your name with a code or pseudonym. Data will be aggregated and any reporting of your comments will take care to ensure you cannot be identified via contextual details. The transcript of your interview and consent forms will be kept in a locked filing cabinet or stored on a password protected computer at Swinburne University. The data will be kept for five years after the project ends.

Do I have to participate?
No. You can choose not to participate in this study or to participate in the interview component only. If you do participate, you can choose to withdraw at any time.
You can also stop the interview at any time to have a break or you can ask us to come back another day. Saying no or withdrawing from this study will not harm your relationship with the researchers, Swinburne University, or __. If you withdraw from the study, we will remove all of your data from our findings except discussion group data. It will also not harm any relationship that your family member has with these different groups of people. Please note that we cannot remove data or quotes once they have been de-identified and analysed.

What will happen with the results?
The findings from this project will assist Jenny Crosbie to meet the requirements for her PhD studies.

Findings from this research will be available to young people with intellectual disabilities, family members of people with intellectual disabilities, policy makers, service providers and others via a series of promising practice profiles. These profiles will be prepared in conjunction with research participants.

A plain English summary of the project results will be made available to participants. The results will also be presented in a PhD thesis, conferences and published in academic journals. Results will also be used to inform other products such as practice guides or policy briefs.

Who do I contact to be part of the study?
You can email Ms Jenny Crosbie at jcrosbie@swin.edu.au or contact her on (03) 9214 8477

What if I have a complaint?
This project has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68),

Swinburne University of Technology,

PO Box 218, HAWTHORN VIC 3122.

Tel (03) 9214 3845 or +61 3 9214 3845 or resethics@swin.edu.au

Please quote project number 20190381-293

If you experience any distress you can contact Lifeline on 131114

Participant Consent Form for family members of Young People with Intellectual Disability

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date:

Reference Number: 20190381-293

I have read and I understand the attached Plain Language Statement.

I freely agree to participate in this research and understand that I can change my mind not to take part at any time during the interview or later. If I later change my mind and no longer want my information used in the research I will contact the researchers to tell them.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to keep my identity and person details confidential and I won't be named in any reports or presentations about the research.

I agree to take part in (tick as many as you agree to)

☐ A one-hour interview

☐ Two discussion groups (two hours each)

☐ I would like to receive information about the findings of this research

☐ I understand that both the interview and discussion groups will be audio recorded.

Participant’s Name (printed) ……………………………………………………

Signature ……………………………………………………

Date…………………………

Phone number and/or email: ……………………………………………………………………….

Please mail this form to:

Ms Jenny Crosbie

Centre for Social Impact

Faculty of Business and Law

Swinburne University of Technology

PO Box 218, Mail H23, Hawthorn 3122

Participant withdrawal of consent

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date:

Reference Number: 20190381-293

I hereby wish to WITHDRAW my consent to participate in the above research project.

Participant's Name (printed) ……………………………………………………………………….

Signature of participant ……………………………………………………………………………….

Date ……………………………

Please mail this form to:

Ms Jenny Crosbie

Centre for Social Impact

Faculty of Business and Law

Swinburne University of Technology

PO Box 218, Mail H23, Hawthorn 3122

Appendix D: Plain Language Statement for key informants

Plain Language Statement for Key Informants

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Hello,

My name is Jenny Crosbie. I am a PhD candidate from Swinburne University. I am researching the factors that promote the economic participation of young people with intellectual disability in the emerging adulthood period.

Who is doing this research?

I am a PhD candidate and this research is part of my candidature. I am being supervised by:

1) Professor Erin Wilson, Swinburne University
2) Dr Perri Campbell, Swinburne University
3) Dr Kevin Murfitt from Deakin University
4) Professor Keith McVilly, University of Melbourne

What is the aim of the study?

The broad aim of this research is to examine the experience of young people with intellectual disabilities and their family members related to economic participation in the emerging adulthood period, and to identify barriers and enablers to increase opportunities.

What is involved?

Key informants are people who have knowledge or expertise related to economic participation of young people with intellectual disabilities. Key informants will participate in a semi-structured interview that will take approximately 1 hour. The interview will be scheduled at a time and venue that suits you.

During the interview you will be asked about the individual and structural barriers to economic participation for young people with intellectual disabilities as well as the training, study and work programs available to young people and how the transition from school to post school options can be more effective for young people with intellectual disability and their families. For example you will be asked to describe the programs and supports that enable young people with intellectual disability to access economic participation opportunities when they finish school.

You may also be invited to be part of a discussion group comprised of family members of young people with a disability and key informants to discuss the findings of the project and develop a set of promising practice profiles which will tell others about how to support young people with intellectual disabilities increase opportunities for economic participation.

The discussion group will meet twice for approximately 2 hours each time. It is likely that the discussion groups will occur approximately 6-9 months after your interview.

In total, your participation involves:

1. One X one hour interview
2. Two discussion group meetings X 2 hours each.

You can choose to only be involved in the interview and not the discussion groups.

Interviews and discussion group will be audio recorded and transcribed.

What are the benefits for me?
This project will not benefit you directly, but we hope that by hearing about the experience of young people with intellectual disability, their family members and key informants we can learn about how to make the transition from school to post school options easier and improve economic participation of young people with intellectual disability.

Are there any risks in participating?
The risks associated with participating in this research are minimal. The content of the interview is not anticipated to cause distress. You can take a break from the interview at any time and you do not have to answer a question if you don't want to. You can also withdraw from the study at any time.

In the unlikely event that being involved in the study causes distress you can contact Lifeline on 13 11 14 and they can provide you with free counselling.

How will my identity be protected?
Your identity will be kept confidential, however, if you participate in discussion groups, you should be aware that others present (family members of young people with intellectual disability and other key informants) will hear your views. Once your interview is transcribed the recording will be destroyed. Data will be de-identified by replacing your name with a code or pseudonym. Data will be aggregated and any reporting of your comments will take care to ensure you cannot be identified via contextual details. The transcript of your interview and consent forms will be kept in a locked filing cabinet or stored on a password protected computer at Swinburne University. The data will be kept for five years after the project ends.

Do I have to participate?
No. You can choose not to participate in this study or to participate in the interview component only. If you do participate, you can choose to withdraw at any time.
You can also stop the interview at any time to have a break or you can ask us to come back another day. Saying no or withdrawing from this study will not harm your relationship with the researchers or Swinburne University.

If you withdraw from the study, we will remove all of your interview data, except discussion group data, from our findings. Please note that we cannot remove data or quotes once they have been de-identified and analysed. We also cannot remove your information from discussion group data as we cannot separately identify your information from that provided by others.

What will happen with the results?
This findings from this project will assist Jenny Crosbie to meet the requirements for her PhD studies.

Findings from this research will be available to young people with intellectual disabilities, family members of people with intellectual disabilities, policy makers, service providers and others via a series of promising practice profiles. These profiles will be prepared in conjunction with research participants.

A plain English summary of the project results will be made available to participants. The results will also be presented in a PhD thesis, conferences and published in academic journals. Results will also be used to inform other products such as practice guides or policy briefs.

Who do I contact to be part of the study?
You can email Ms Jennifer Crosbie at jcrosbie@swin.edu.au or contact her on (03) 9214 8477

What if I have a complaint?
This project has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68),
Swinburne University of Technology, P O Box 218, HAWTHORN VIC 3122.
Tel (03) 9214 3845 or +61 3 9214 3845 or resethics@swin.edu.au

Please quote project number 20190381-293

Participant Consent Form for Key Informants

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date: ______________________ **Reference Number:** 20190381-293

I have read and I understand the attached Plain Language Statement.

I freely agree to participate in this research and understand that I can change my mind not to take part at any time during the interview or later. If I later change my mind and no longer want my information used in the research I will contact the researchers to tell them.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to keep my identity and person details confidential and I won't be named in any reports or presentations about the research.

I agree to take part in (tick as many as you agree to)

☐ A one hour interview

☐ Two discussion groups (two hours each)

☐ I would like to receive information about the findings of this research

☐ I understand that both the interview and discussion groups will be audio recorded.

Participant's Name (printed) ....

Signature .... Date.................................

Participant withdrawal of consent

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Date: ________________________

Reference Number: 20190381-293

I hereby wish to WITHDRAW my consent to participate in the above research project.

Participant's Name (printed) ....

Signature of participant ....Date ....

Please mail this form to:
Ms Jenny Crosbie
Centre for Social Impact
Faculty of Business and Law
Swinburne University of Technology
PO Box 218, Mail H23,
Hawthorn 3122

Appendix E: Semi-structured interview schedule for young people with intellectual disability

Attachment E: Semi-Structured Interview Schedule for YPWID

Recruitment and consent meeting

In the recruitment and consent meeting the researcher will meet with the participant to explain the project, check the participant's understanding of the project and participation in it, confirm consent and make a time for meeting 1.

Meeting 1

In meeting 1 the researcher will re-confirm consent, collect background information and introduce Photovoice.

Specific Questions

Introduction/warm up (background information)	Please tell me a bit about yourself. • How old are you? • Where do you live? • Who do you live with? • What school did you go to? • What are you doing now that you have left school? • What are some things you like to do? • Who are the people who help you to do things?

Before explaining the Photovoice process the researcher will introduce the following concepts to help the person to think about training and work opportunities after school. The researcher may use visual supports to illustrate the concepts below.

- Think about the training and work you would like to do now that you have finished school.
- Think about the things that you like.
- Think about the things that you don't like.

- Think about your hopes and dreams.
- Think about things you want to do.
- Think about people, places and things that are important to you.

Introduce Photovoice

Provide Plain English Instruction Sheet about photovoice (attachment F) and read through it together. Explain the process and check whether the participant has any questions. They will be asked to take photos for two weeks with the following instructions;

- Take photos of the work you do or want to do

- Take photos of the training you do or want to do.

The participant can utilise a trusted person to assist them if required.

Meeting 2 will be held 1 week after meeting 1.

The purpose of the meeting is to check that the participant understands the Photovoice instructions and has commenced taking photos.

Meeting 3

Meeting 3 will be held 2 weeks after meeting 1.

In this meeting the researcher will discuss each picture that the person has collected to identify what it represents to that person.

Specific questions will include

- What is this picture about?
- What is going on in this picture?
- Why do you like that picture?
- Why is that picture important to you?

Once the pictures have been discussed and notated, the researcher will use the pictures to prompt discussion related to the research objectives.

Objective 1: To identify the expectations YPWID and their family have about economic participation post school.	What do you like doing? Where do you do it? When do you do it?

	Do you want to do it more? • Would you like to do more of/less of...? Are there any things that you don't like doing? Are there other people you would like to meet or spend time with? Are there other things you would like to try out or do? What would you like to do in the future? How might you do that? What are your hopes and dreams for the future? What would you like to do when you are an adult?
Objective 2: To explore the extent to which opportunities for economic participation are available to YPWID post school.	Who helped you decide what you would do when you finished school? What programs have you done at school and at XX that are about study/training and work? Tell me what you do in the program/s?
Objective 3: To identify where in the system/environment barriers to economic participation exist	Has anything stopped you from doing study/training or work since you left school? If yes, tell me about that?
Objective 4: Identify the resources and supports that would enable increased economic participation opportunities for YPWID	Who has helped you with study/training and work since you left school? How did they help you? What programs/courses have you done that have helped you? How did they help you?

Objective 5: Explore how these supports can be provided and in what context.	What will help you achieve your dreams? What might stop you or make it difficult? What will help you to do this? Who are the best people to help you learn more about study/training and work when you finish school? Is it better if you learn about study/training and work while you are at school or when you finish?

Appendix F: Semi-structured interview schedule for family members of young people with intellectual disability

Attachment G: Semi-Structured Interview Schedule for Family Members of YPWID.

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Research Objective	Questions
Introduction/warm up	Introduce project. Background information. - Tell me a bit about X. Name, age - What is your relationship to X? - What school did X attend? - Does X receive NDIS funding? - Describe their involvement in post school planning - What sort of work or study related activities is X involved in (now, during their teenage years, in the past)?

Objective 1: To identify the expectations YPWID and their family have about economic participation post school.	Thinking about X's future, what sort of roles do you see him/her undertaking in 5-10 years time? Thinking about X's future, how important do you think him/her undertaking study/training and paid work is? Probe: Why is study/training work important/not important? Have your expectations or aspirations changed over time (what influenced that)? If X doesn't undertake study/training or work in the future, what sort of activities will they undertake? What are some of the benefits for X if he/she undertakes paid work in the future? Are you aware of many young people who have an intellectual disability who are undertaking study/training or work since leaving school?

Objective 2: To explore the extent to which opportunities for economic participation are available to YPWID post school.	Please describe how you and X were involved in planning for study/training after school. - What activities related to work and future study/training did X participate in while he/she was at school? - What sort of planning were you and X involved in prior to him/her finishing school related to post-school study/training and work? Please describe some of the specific programs and supports that you were made aware of related to study/training and work post school. - How would you rate the effectiveness or adequacy of these in supporting/preparing X for economic participation? - What would improve them or what are the ingredients of other supports/activities/ programs that could be implemented?

Objective 3: To identify where in the system/environment barriers to economic participation exist	What do you think are the barriers to young people with intellectual disability accessing study/training and work opportunities when they leave school? Probe: Personal barriers Systemic barriers (ie transition from school) Structural barriers (ie programs, funding) Other barriers Have barriers increased or decreased since the NDIS commenced? How would you address the barriers that you identified? Probe: Policy change Practice change Capacity building for YPWID Capacity building for families
Objective 4: Identify the resources and supports that would enable increased economic participation opportunities for YPWID	Please describe resources and supports that you know about, or would like to see made available, that have led/could lead to increased study/training and work opportunities for YPWID. How would they help? What are the ingredients that make them work? Are they currently available? If not, why not? How could these resources and supports be provided to families? Who should provide them? Probe – School staff? Disability workers? Family members of YPWID? YPWID themselves? Other?
Wrap up	Is there anything else you would like to tell me that relates to opportunities for study/training and work opportunities for YPWID when they leave school? Thank participant and provide voucher. Advise participant that will make contact again regarding involvement in discussion groups.

Appendix G: Semi-structured interview schedule for key informants

Attachment H: Semi-Structured Interview Schedule for Key Informants

An examination of the factors that promote the economic participation of Young People with Intellectual Disability (YPWID)

Research Objective	**Questions**
Introduction/warm up	Introduce project. Background information. - How long involved in work related to economic participation for YPWID - Employment information - Role
Objective 1: To identify the expectations YPWID and their family have about economic participation post school.	In your experience what are the expectations of YPWID and their families in relation to training and work once they finish school?
Objective 2: To explore the extent to which opportunities for economic participation are available to YPWID post school.	Please describe how YPWID and their families are involved in planning / preparation for economic participation after school. Please describe some of the specific programs and supports that are available to support the economic participation of YPWID when they finish school.

Objective 3: To identify where in the system/environment barriers to economic participation exist.	What are the barriers to young people with intellectual disability accessing study/training and employment opportunities when they leave school? Probe: Personal barriers Family barriers Systemic barriers (ie transition from school) Structural barriers (ie programs, funding) Have barriers increased or decreased since the NDIS commenced? How would you address the barriers that you identified? Probe: Policy change Practice change Capacity building for YPWID Capacity building for families Other
Objective 4: Identify the resources and supports that would enable increased economic participation opportunities for YPWID.	Please describe resources and supports that you have seen/would like to see in your work that have led/could lead to increased economic participation opportunities for YPWID. - How would you rate the effectiveness or adequacy of these in supporting/preparing YPWID for economic participation? - What would improve them or what are the ingredients of other supports/activities/ programs that could be implemented? How would new/proposed/programs from elsewhere help? - What are the ingredients that make them work? Are they currently available? If not, why not? How could these resources and supports be provided in the Australian context? Who should provide them?
Wrap up	Is there anything else you would like to tell me that relates to opportunities for study/training and work opportunities for YPWID when they leave school? Thank participant Advise participant that will make contact again regarding involvement in discussion groups.

Appendix H: Photovoice Instructions

SWINBURNE UNIVERSITY OF TECHNOLOGY

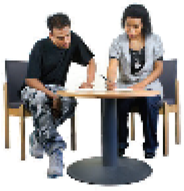
Attachment F– Photovoice instruction sheet for YPWID

Photovoice Instructions in Easy English

Sometimes it's hard for people to find the words to tell others all the things they like and want.

Using pictures can help show other people what study, training and work you want to do. It can help start a conversation about the things you want.

How to do Photovoice

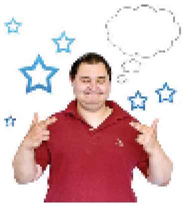


The researcher will come to talk about you and the training and work you want to do now you have finished school.

Think about ALL the training and work you want to do now you have finished school.

Think about the things that you like.

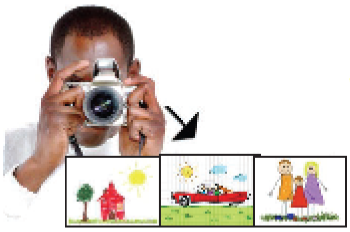
Think about the things that you don't like.



Think about your hopes and dreams.

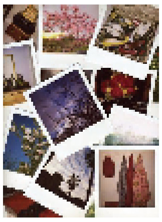
Think about things you want to do.

Think about people, places and things that are important to you.



Think about how you would take photos or collect pictures of these things.

Over the next 2 weeks, take photos and collect pictures of things that you like about study, training and work. This can be things you are doing now or things you would like to do.



Bring all the photos and pictures to show the researcher who comes to talk to you about the training and work you would like to do.

The person will help you sort the pictures into order to find out the things that are important to you.

The person will ask you to explain what each photo means to you.

The collection of pictures will be used to help the researchers to understand what study, training and work you would like to do in the future and what will help you to do it.

Appendix I: Examples from photo pack

Hawthorn v Geelong at the G. Neil Roach

Appendix J: Description of young people

Pseudonym	Description
Brandon	Brandon is a 25-year old man who lives in his own unit with a housemate. He attended a special school. Post-school Brandon attended a disability day program before seeking employment opportunities. He has been in a number of paid roles since. Brandon is not currently employed. He would like to work in the fitness industry.
Corey	Corey lives with his mum and dad and his brother. He attended a special school until 18 months ago. He loves watching and playing football and would like to work in the sports industry. Corey is attending a SLES program where he undertakes work experience in a retail outlet. Corey is learning to travel and build his independence. He has difficulty communicating verbally.
James	James lives with his mum and his brother. He attended a vocational program for students with disability based in a mainstream school setting. He is very outgoing and personable and has excellent communication skills. James attends a SLES program where he undertakes work experience in a retail outlet. James would like to work in the sports industry or a retail store.
Amy	Amy lives with her mum and sister. She attended a mainstream primary school and then a special school. She finished school 18 months ago. Amy is very outgoing and friendly. She attends a SLES program where she undertakes work experience in a retail outlet and is undertaking a Certificate course in Hospitality. Amy loves dancing and would like to work in that industry.
Leanne	Leanne lives with her grandfather. She enjoys spending time with her boyfriend. She attended a special school, finishing 4 years ago. Immediately post-school Leanne

	attended TAFE to undertake a Certificate 1 in Transition and Work Education. She was employed during that period. She is now involved in an unpaid work experience program run by a disability organisation. She is unclear about her preferred job.
Melissa	Melissa lives with her mum and dad and brother. She attended a special school finishing 18 months ago. She loves horses and is a champion equestrian rider. Melissa is currently attending a SLES program where she undertakes work experience in a retail outlet and is undertaking a Certificate course in Hospitality. Melissa would like to work with horses.
Rohan	Rohan is a 25-year old man who lives with his mum and dad. He is very personable and outgoing, and travels independently. Rohan attended a number of special and mainstream schools. Post-school he has engaged in a range of activities including paid work, volunteer work and is currently attending a pilot WIL program. Rohan is hopeful that the WIL program will lead to a paid job within one of the partner companies.
Penny	Penny is 19 and lives at home with her mum and dad and sister. She attended a special school, leaving 18 months ago. Penny is currently attending a transition program run by a disability organisation where she attends classes and activities and undertakes work experience. Penny's speech can be difficult to understand at times.
Bobby	Bobby is an outgoing 25-year old man who lives with his mum. He attended a special school. Since leaving school Bobby has been engaged with a disability service undertaking work experience and other work preparation activities. Bobby has his license and a car. He is now employed one day per week in an organic food business which he loves. He would like to study to be an accountant.