Exploring the outcomes of participation in the SSAYiT transition program

for youth with cognitive difficulties

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December 2018

A Dissertation Presented to The College of Nursing and Health Sciences Flinders University Adelaide

In Partial Fulfilment of the Requirements for the Degree Master of Disability Policy and Practice

Declaration of Authenticity

I certify that this dissertation does not contain any material previously published or written by another person except where due acknowledgement is made in the text.

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Acknowledgement

I would like to thank my supervisors, Dr Michelle Bellon and Elizabeth Goble. Thank you for your invaluable support, encouragement, and guidance to develop this dissertation. I learned a great deal from your expertise. I believe the knowledge and experiences that I gained from you will be of help in my further studies. I also extend my thanks to Pawel for helping to clear up doubtful areas in statistical analysis of this study.

Special thanks also to Melissa Ramsey and Navar Keelan from Brain Injury SA for collecting the data and providing further details on the SSYiT transition program.

I am indebted to the Australian Government Department of Foreign Affairs and Trade for granting me an Australia Awards Scholarship to enable this opportunity for me to study the Master of Disability, Policy and Practices at Flinders University.

Additional acknowledgements are due to my friend Florence De Silva, and my mother; thank you for your support for my mental well-being throughout this study period.

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List of Abbreviations

ABI: Acquired Brain Injury

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

BOOST-ATM: Better Outcomes & Successful Transition for Autism

CRC: Convention on the Rights of the Child

CRPD: Convention on the Rights of Persons with Disabilities

DASS 21: Depression Anxiety Stress Scales 21

FS: Flourishing scale

ICF: The International Classification of Functioning, Disability and Health

ID: Intellectual Disability

IDEA: Individuals with Disabilities Education Act

LGTW: Let's Get to Work project

PATHS: Postschool Achievement Through Higher Skills

SSAYiT: Support SA Youth initiative Transition program

SPSS: Statistical Package for the Social Sciences

TAFE: Technical and Further Education

TBI: Traumatic Brain Injury

VET: Vocational Education and Training

WHO: World Health Organisation

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Abstract

Introduction

Transition from school to adult life is a challenging period for most young adults as many will make choices on their employment, further education and housing. This is particularly critical for youth with cognitive disabilities who should be supported during this period to achieve successful post-school transition outcomes. Although many transition programs exist in Australia, transition outcomes for youth with disabilities remain poor. The current study evaluated the effectiveness of the novel Support SA Youth initiative Transition (SSAYiT) program on transition to adult life for youth with cognitive difficulties. The aims were to identify the outcomes of participation in the SSAYiT program, and the factors which may influence these outcomes.

Method

Data were collected by an interviewer-administered survey at baseline and repeated after the program's 10-week group sessions, after the 16-week individualised sessions and at three-month follow-up. A combination of repeated measure ANOVA, Freidman tests and Wilcoxon sign tests were used to compare changes in the Depression, Anxiety and Stress Scale (DASS-21), the Flourishing Scale (FS), and levels of perception of disability, confidence in gaining employment and negotiating reasonable adjustments in the work place. Descriptive statistics were used to report changes in education, employment and community activities over time.

Results

One hundred and ten youth commenced in the program, with 79 participants included in final data analysis. The sample consisted of youth aged 15-25 years (median 18.2 years, IQR = 2.27) with a wide range of cognitive disabilities, the majority of whom had a primary intellectual disability (67.1%). Stress levels significantly improved over the study period from moderate down to mild (p=0.01); however, there were no significant changes in depression or anxiety. Similarly, no significant changes were recorded in psychological wellbeing as measured by the FS, or perception of disability, confidence in gaining employment, and negotiating reasonable adjustments in work place. A small positive activity trend was noted at 16-weeks, with 13 participants (16.4%) engaged in new activities: 5 in employment, 5 volunteering, 1 in work experience placement, 1 studying at TAFE, and 1 seeking employment.

Conclusion

The results suggest that participation in a 16-week program can improve stress levels in preparing for the transition to employment for some youth with cognitive difficulties and support the introduction of new vocational and educational activities. A range of study limitations are identified, which have limited the quality and scope of the data collected. Future transition programs should consider employing rigorous evaluation design and consider ways in which emotional distress and psychological wellbeing can be best supported through this difficult transition period.

Chapter 1: Introduction

Transition from school to adult life is a challenging period for most young adults as many will make choices on their employment, further education and housing. This is particularly critical for youth with cognitive disabilities who should be supported during this period to achieve successful post-school transition outcomes. During the past two decades, there has been an increase in targeted programs aimed at helping youth with cognitive disabilities and their families to tackle the obstacles to engaging with the workforce, achieving their aspirations, and leading full lives in the community. This study sets out to examine one of these novel programs to gauge its effectiveness and supportiveness for transition to adult life.

Transition from school is "a coordinated set of activities for a child with a disability, that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post school activities" (Wehman, 2012, p. 4). Transition from school to adult life is a process where a young adult is able to access information and make decisions about their future after leaving school. This processing period is a challenging time for most young adults, as they must make choices concerning their employment, further education, social relationships, and housing during this phase of their lives. These challenges are widely recognised as being more complex for youth with disabilities than for typically developing adolescents, because they may be exposed to a range of negative experiences in school and the broader community. In particular, youth with disabilities face stigma, prejudice, discrimination, and exclusion, which may

lead to low self-esteem, anxiety, depression, and distress (Austin, Hunter, Gallagher, & Campbell, 2018; Forte, Jahoda, & Dagnan, 2011; Winn & Hay, 2009).

There is an abundance of research and published literature on the transition from school to adult life for young people with disabilities, which has demonstrated the importance of support during this period to achieve better post-school transition outcomes. Successful transition improves the long-term economic status, well-being, and social inclusion of youth with disabilities, as well as benefiting the wider community through their gainful employment and contributions, integration with society, and fulfilment of aspirations to live a productive and meaningful life (Wakeford & Waugh, 2014). However, many young adults with disability have poor transition experiences and achieve limited success in adjusting to conventional living as an adult (Baer, Daviso, Flexer, Queen, & Meindl, 2011; Bouck, 2012; Kieling & Rohde, 2010).

1.1 Statement of the Problem

Transition to adult life is a subject of study that has been widely discussed since the 1980s and continues to draw the attention of researchers. Even though this topic has received much more attention in recent times from policy makers, health professionals, social workers, and disability advocates, transition outcomes for some disability groups still remain poor (Cai & Richdale, 2016; Mcconkey & Haddock, 2012; Taylor & Seltzer, 2011). Youth with cognitive difficulties are the most disadvantaged and vulnerable group within the disability spectrum, because they need more support to transition to adult life (Gauthier-Boudreault, Gallagher & Couture, 2017; Parsi & Elster, 2015). Consequently, they are lagging behind their peers with other disabilities in achieving transition outcomes, such as employment, post-school education, independent living, interpersonal relationships, and community participation (Neary, Gilmore, & Ashburner, 2015; Paniccia, Colquhoun, Kirsh, & Lindsay, 2018; Ros & Graziano, 2018).

In response to the acknowledged special needs of youth with disability, governments, public health agencies, clinical experts, and disability service providers have undertaken to develop programs aimed at enabling youth to successfully navigate this time of transition. These programs are often publicly funded, short-term initiatives designed primarily to increase the prospects of further education and employment for this population. However, a number of Australian and international studies have investigated post-school transition programs and found that organisations and programs dedicated to helping young people and their families do not always serve them wisely or fulfil their needs effectively (Christensen, Hetherington, Daston, & Riehle, 2015; Daston, 2012; Farnon, Ellie, Jennifer, & Shannon, 2017; Hatfield, Falkmer, Falkmer, & Ciccarelli, 2018b; 2016; Wehman et al., 2013). The transition outcomes for Australian youth with disabilities are low in comparison to the results in some other developed, member countries of the Organisation for Economic Co-operation and Development (OECD). Of particular concern is that employability of youth with disability in Australia is only 50% and it sits at 21st out of 29 OECD countries (Barnett, 2015). Poor post-school transition and preparation has been identified as the primary reason for the low rates of employment sustainability and post-school education achievements of people with disability in Australia (Barnett, 2015). Australia's poor record suggests that existing transition programs are not meeting the needs of youth with disability, including those with cognitive impairment (Australian Bureau of Statistics, 2012; Neary et al., 2015).

Although transition programs differ in content and the method of delivery, their aims are similar. Transition programs are focused on one or more of the following goals: employment, post-school education, community participation, social network, and quality of life. However, preparing young adults with disability for employment has remained a dominant theme in postschool transition programs (Wehmeyer & Webb, 2012).

1.2 Statement of Purpose

Although many transition programs exist, their results are varied in short term and long-term effectiveness. The purpose of this study was to evaluate the effectiveness of the Support SA Youth Initiative Transition (SSAYIT) Program in supporting transition to adult life for youth with cognitive difficulties (Brain Injury SA, 2018). The SSAYIT Program is a newly developed initiative of Brain Injury SA, focusing on improving the psychological well-being, reducing emotional distress, enhancing perception of disability, increasing confidence in gaining and maintaining employment, and increasing participation in employment, education, and community activities for participants in the program. Thus, the success of this program and others in Australia to support youth with disability is vital to their welfare. The aims of the current study were to identify the outcomes of participation in the SSAYIT program, and the factors which may influence these outcomes.

This dissertation is structured into five chapters. Chapter 2 will review the literature on post-school transition of youth with cognitive impairment, Chapter 3 will describe the methodology of the evaluation of outcomes of the SSAYiT Program, Chapter 4 will reveal the results of the quantitative analysis, and Chapter 5 will discuss the results, and provide the conclusion and recommendations.

Chapter 2: Literature Review

2.1 Introduction

This chapter critically reviews the literature on transition from school to adult life for young people with cognitive difficulties. To begin, definitions of disability and cognitive function are presented, followed by descriptions of cognitive difficulties following acquired brain injury, developmental disabilities, and mental health conditions. Literature examining factors influencing post-school transition, transition planning, transition programs and transition outcomes for this population are also reviewed.

2.2 Disability and Cognitive Function

The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on human functioning which defines disability as "an umbrella term for impairments, activity limitations and participation restrictions" (World Health Organization & World Bank, 2011, p. 5). In recognition of the special nature of disabilities affecting young people, ICF developed a companion classification for children and youth (ICF-CY) in 2007. According to the world report on disability, disability interacts with an individual's health condition, environment and personal factors. Around 15% of the global human population live with some form of a disability (World Health Organization & World Bank, 2011). The Australian Bureau of Statistics (2012b) found that 18.3% of Australians live with a disability and this rate is 7.8% in young adults aged between 15-24 years.

Cognition is a broad term which refers to the fundamental brain function enabling a person to think, understand, remember, and process information (Ashcraf & Radvansky, 2010). There are different domains in human cognition, such as perception, attention,

memory, language, executive functioning and Visuospatial ability (Riva, 2015). Some of the main cognitive functions and associated skills are summarised in Table 2.1. Cognitive difficulties commonly present as a result of, or together with, an acquired brain injury (ABI), developmental disabilities, or mental health conditions (Simonoff, Pickles, Wood, Gringras, & Chadwick, 2007; Lambregts et al., 2018).

Cognitive Function	Skills involved			
Perception	The process of recognition and interpretation of information received			
	through sensory modalities (visual, auditory, haptic, olfactory, and			
	gustatory perceptions) (Ashcraf & Radvansky, 2010).			
	Example: identifying a photograph.			
Attention	The ability to concentrate on a task and manage competing demands in			
	the environment (Ashcraf & Radvansky, 2010). Attention also depend on			
	the situation and the state of the individual (Cohen, 2013).			
	Example: focus attention on reading a book, not on other's conversation			
	in the class room.			
Memory	The process of retaining information over time (Ashcraf & Radvansky,			
	2010. There are three types of memory: Short term memory retains			
	information for a few seconds (for example, retaining a phone number			
	long enough to dial it), working memory manipulates and prioritises the			
	sensory information and retains it for a short period (for example,			
	remembering directions), and the long-term memory enables learning of			
	new information and recalling it at a later point in time. There are two			
	major sub divisions of long-term memory: implicit and explicit (Amato &			
	Goretti, 2016). Implicit memory refers to learning and remembering			
	things from tasks and activities without conscious awareness (example,			
	riding a bicycle). Explicit memory consciously recollects the information			
	(example, writing in an exam)			
Language	A shared symbolic system for communication. Language may be verbal			
	or non-verbal (Ashcraf & Radvansky, 2010)			

Table 2.1: Description of some of the main cognitive functions

Executive Function	Executive functions are complex set of higher order process, includes			
	abilities, such as planning, initiating, directing, monitoring, focusing,			
	problem solving, and inhibitory control. Executive function is important in			
	every aspect of life, for example, success in education and employment			
	(Zillmer, V.Spiers, & Culbertson, 2008).			
Visuospatial ability	The capacity to accurately perceive a person's surrounding world in its			
	completeness (Zillmer et al., 2008).			
	Example: estimating the distance between two objects.			

2.2.1 Cognitive Difficulties in Developmental Disability.

Developmental disabilities are based on neurological function, with onset before birth or during childhood, and are associated with significant long-term impairment (Roger, 2012). The most common developmental disabilities associated with cognitive difficulties include Autism Spectrum Disorder (ASD) (Matson, 2016; Sachse et al., 2013), Attention Deficit Hyperactivity Disorder (ADHD) (Sjowall, Roth, Lindqvist, & Thorell, 2013), and Intellectual Disability (ID), including Down's syndrome (Simonoff et al., 2007), and Fragile X syndrome, (Huddleston, Visootsak, & Sherman, 2014). Several causative factors for ID have been identified, such as chromosomal abnormalities, infections, birth trauma, and environmental factors (Goodman & Scott, 2012). However, despite much research on the subject, ASD and ADHD have no known, single cause, and possible influences of genetic and environmental factors are being explored (Kieling & Rohde, 2010; Lubetsky, Handen, & McGonigle, 2011).

Autism Spectrum Disorder (ASD) is characterized by difficulties in social interactions, social communication, and restricted and repetitive interests and behaviours (Lubetsky et al., 2011). The word 'spectrum' is used as there is a wide range and severity of the difficulties people with ASD experience. Some people may be able to live relatively normal lives, while others may have accompanying learning challenges and require continued specialist support (Smith & Noble, 2014). The pathophysiology of ASD is still not well understood. However, individuals with ASD may show levels of difficulty in some areas in cognitive function, such as processing speed, attention (Matson, 2016), working memory (Lind & Bowler, 2009), executive functions (Sachse et al., 2013), and language (Happe & Frith, 2006).

Attention-deficit hyperactivity disorder (ADHD) is a neuropsychiatric disorder characterized by inattention, hyperactivity and impulsivity (Kieling & Rohde, 2010). In about 15% of children with ADHD the disorder persists into adulthood (Faraone, Biederman, & Mick, 2006). Impairment in executive functions, working memory, inhibition, and reaction time are often observed in individuals with ADHD (Sjowall et al., 2013). Moreover, ADHD may be associated with ASD (Karalunas et al., 2018) and several comorbid mental health issues, such as schizophrenia, anxiety disorder, and substance abuse (Kieling & Rohde, 2010).

Individuals with intellectual disabilities are characterized by mild-to-profound impairment in cognitive functioning which determine how well an individual copes with everyday tasks. DSM V describes the difficulties can be seen in communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. Difficulties in memory, attention, language, and learning are frequently reported in Down's syndrome (Simonoff et al., 2007). However, their visuospatial short-term memory, associative learning, and implicit long-term memory functions are preserved (Lott & Dierssen, 2010). Children with Fragile X syndrome demonstrate the range of neurocognitive strengths and weaknesses (Huddleston et al., 2014). Relative limitations have been demonstrated in visual–motor coordination, visual memory, short-term memory, and executive function. In contrast, relative strengths have been shown in language, acquired knowledge and long-term memory of verbal information (Huddleston

et al., 2014).

2.2.2 Cognitive Difficulties in Acquired Brain Injury

Acquired Brain Injury (ABI) is a broad term, which describes all types of injuries to the brain that have occurred since birth (Ciuffreda & Kapoor, 2012). It can be the result of a traumatic or non-traumatic event. Traumatic event include motor vehicles accidents, falls, assault, war injuries, and sport injuries, where as non-traumatic injuries include, stroke, aneurysm, brain tumors, infections, autoimmune diseases, neurodegenerative diseases, and post-surgical complications resulting from anoxia or hypoxia (Ciuffreda & Kapoor, 2012; De Kloet, 2013). Most prevalent events for acquired brain injury are Traumatic Brain Injury (TBI) and stroke (Ciuffreda & Kapoor, 2012).

Incident rates and mechanisms of injury of TBI are varied across age groups (Faul & Coronado, 2015; Ponsford, 2013). Motor vehicle accidents and falls are the most common causes for TBI, followed by assault, war injuries, and sport injuries. Motor vehicle accident related TBI is higher in age 15-24 years, whereas fall related TBI is higher in age 0-4 years and above 75 years (Faul & Coronado, 2015; Ponsford, 2013).

Stroke is a major public health issue and leading to long term disability in developed countries. There are two types, ischemic stroke result in narrowing or blocking blood vessel in the brain, and haemorrhagic stroke caused by a bleeding from a blood vessel in the brain (Hennerici, 2012). A number of modifiable and non-modifiable risk factors for stroke are identified in the literature (Kjerpeseth et al., 2018). Age, gender, family history, and genetic diseases are the non-modifiable factors, while hypertension, diabetes, high cholesterol level, lack of physical activity, and unhealthy dietary habits are identified modifiable factors.

However, the elders are more susceptible to stroke, as most of the above risk factors are developing with age (Minnerup, et al., 2010).

People with ABI may experience changes across a range of areas, including physical functioning (Walker & Pickett, 2007), cognition (de Vries et al., 2018; Lambregts et al., 2018), (Turkstra, Visscher & Vandenheuvel, 2014) and behaviour (Doser, Poulsen, emotion Wuensch, & Norup, 2018). However, cognitive difficulties are more commonly reported and persist long term (Cattelani, Zettin, & Zoccolotti, 2011; de Vries et al., 2018; Douiri, Rudd, & Wolfe, 2013). A systematic review concludes that although most symptoms of mild TBI such as headache, fatigue, depression, anxiety and irritability, are resolved within 3 months postinjury, cognitive difficulties persist over the long term (McInnes, Friesen, MacKenzie, Westwood, & Boe., 2017). In contrast, cognitive functioning in people with autoimmune diseases such as in Multiple Sclerosis (MS) can be dependent on the progression of the disease. For instance, a study by Matias-Guiu (2017) revealed that cognitive difficulties were more frequent among patients with primary and secondary progressive MS than patients with relapses. Thus, the effects of ABI may differ according to causal factors and individual circumstances. However, stroke (Ovbiagele & Nguyen-Huynh, 2011) and multiple sclerosis Simpson et al., 2011) are not common in young age.

Following ABI, cognitive difficulties are commonly experienced in attention, working memory, processing speed, learning, and executive functions (de Vries et al., 2018; Zasler, Katz, & Zafonte, 2012). The nature and extent of cognitive difficulties relate to the location and severity of the injury (Ponsford, 2013). More severe brain injuries and damage to the area of the brain which contains myelinated axons (white matter) have been found to lead to poor cognitive function recovery (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012; Hulkower et

al., 2013). Furthermore, cognitive recovery from ABI not only depends on injury factors but also on pre-injury characteristics, such as level of education and existence of pre-injury cognitive difficulties (Lambregts et al. 2018). In their recent study of children and youth with mild TBI, Lambregts et al. (2018) found that a lower level of pre-injury education is associated with poor adjustment in responding to received information, low visuospatial ability, reduced visuospatial memory, and reduced working memory. Lambregts et al.'s (2018) research strongly suggests that having pre-injury cognitive problems and less education is associated with slower and fluctuating reaction times (processing speed) and also less cognitive flexibility (flexibility speed) in adjusting responses to received information.

2.2.3 Cognitive Difficulties in Mental Health Conditions

Many mental health conditions, including depression, anxiety, stress, schizophrenia and bipolar, are associated with varying degree of decline in cognitive functions (Lynham et al., 2018; Rock, Roiser, Riedel, & Blackwell, 2014; Yang et al., 2015). The deficits are commonly observed in executive function, learning, memory and attention domains (Reppermund, Ising, Lucae, & Zihl, 2009; Rock et al., 2014; Yang et al., 2015). Further, in a study of youth populations, researchers have found that cognitive decline occurs in acute mental health episodes as well as after remission of mental health symptoms (Reppermund et al., 2009).

A systematic review and meta-analysis reveals that cognitive impairment is associated with poor psychosocial functioning in people with depression (Rock et al., 2014). People with depression and cognitive difficulty may have associated social difficulties, including inability to respond appropriately in a work or social environment (Saperstein et al., 2014). The findings of these studies demonstrate how cognitive difficulties have such a devastating effect on the welfare and functioning of people with cognitive difficulties in society. Moreover, results reveal that young people are particularly affected, which emphasises the importance of supporting youth with cognitive difficulties through their post education transition to a productive and healthy adulthood.

Generalized anxiety disorder and schizophrenia also contribute to impaired cognitive function, particularly in selective attention and working memory ((Cirillo & Seidman, 2003; Eysenck, Derakshan, Santos, & Calvo, 2007; Yang et al., 2015). A study done among 73 homeless youth shows a high rate of mental health disorders, including anxiety, mood disorders, and substance abuse. The majority of people diagnosed with mental health disorders reported cognitive difficulties (Saperstein et al., 2014). Austin et al. (2018), assessed the protective and risk factors for anxiety and depression symptoms in 55 young adults with ID and a sample of age-matched controls. Findings suggest that youth with ID had less insight (ability to evaluate personal internal states) compared to the control group, and the study asserts that having poor insight and maladaptive coping style are risk factors for the depression among youth with ID.

Association of the severity of the mental health issue and cognitive disability is not clearly found in literature. Lynham et al. (2018) found that cognitive difficulties can increase with the severity of these mental health issues. However, Reppermund et al. (2009) found that there was no association between severity of depression and cognitive difficulties. Further, much of the recent research literature suggests that there is a reciprocal interaction between mental health issues and cognitive functions. People with mental health issues report cognitive difficulties (Lynham et al., 2018; Rock et al., 2014; Yang et al., 2015), whereas people with disability together with cognitive difficulties also report mental health problems

(Albicini, Eggleston, & McKinlay, 2017; Austin et al., 2018; Neary et al., 2015). Studies show that around 45% of people with ASD (Neary et al., 2015) and 28% of individuals with TBI (Albicini et al., 2017) have mental health disorders.

2.3 Post School Transition

Young people face many transitions throughout their school life. Transition from school to adulthood is a most difficult, confusing, and anxious period for many youth as they try to develop their own identity and make decisions about their future (Snee & Devine, 2015). The *Individuals with Disabilities Education Act (IDEA)* (1990) in United States was the first school related legal mandate to recognise transition services for students with a disability. According to the IDEA, transition services are a coordinated set of activities for a child with a disability that are designed within a results-oriented process, focused on improving the academic and functional achievement of the child to facilitate movement from school to postschool activities. Kohler and Field (2003) recommended that a transitional focused curriculum and education experiences should begin no later than 14 years and should continue for a few years after leaving the school. According to the authors, many youths with disabilities leave the school without a future plan.

Transition to adult life is more challenging for youth with cognitive difficulties compared to their peers without disabilities (Austin et al., 2018; Forte et al., 2011; Winn & Hay, 2009). Youth with cognitive difficulties may be exposed to a range of negative experiences in school and the broader community, such as stigma and exclusion, which may lead to low self-esteem, anxiety, depression, and distress in transitioning towards adult life (Dagnan & Sandhu, 1999; Shier, Graham, & Jones, 2009). Consequently, support, encouragement, resources, and practical facilitation are needed for youth with cognitive difficulties to gain the self-

confidence, training, and capability to achieve employment and productive adult lives as members of the community.

2.3.1 Post-school Transition in Australia

Australia is a signatory of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006 and the Convention on the Rights of the Child (CRC) 1989 (Australian Human Rights Commission, 2018). These two conventions (Article 23,28,29 in CRC and Article 24, 27 in CRPD) along with the Disability Discrimination Act 1992 ensure the rights of children and people with disability to equal participation in education and employment in Australia (Federal Register of Legislation, 2018). The Australian Government has identified that post school transition is an important component of ensuring the equal participation in education and employment for young people with disabilities. Therefore, one of the outcome areas of the National Disability Strategy in Australia, "learning and skills", focuses the post school transition to "improve pathways for students with disability from school to further education, employment and lifelong learning"(Department of Social Services, Australian Government, 2017).

There is a range of post school options for youth with disability in Australia (Wakeford & Waugh, 2014). Youth with disabilities can obtain academic degrees from tertiary education units such as universities, and vocational skills and training in particular job from Technical and Further Education (TAFE) institutes and Vocational Education and Training (VET). Moreover, youth can start apprenticeships or traineeships while in high school. The literature supports that having work experiences in a real work setting while in school is a predictive factor for the successful post school transition to employment for youth with cognitive difficulties (Carter, Austin, & Trainor, 2011; Test et al., 2009).

Two types of employment options available for youth with disability are open employment and supported employment (Wakeford & Waugh, 2014). Open employment means that people regardless of disability can work in a job that can be done by any person and be paid the same wages (Autism Spectrum Australia, 2018). Supported employment provides the individual with the assistance of a support worker (Wakeford & Waugh, 2014). Supported employment opportunities are mainly provided by Australian Disability Enterprises (Department of Social Services Australia, 2018). However, supported employments are characterized by low wages compare to open employments (Wakeford & Waugh, 2014; Wehman et al., 2018). Open employment provides many benefits compared to supported employment, such as increasing independence, enhancing choice, financial improvements, and better quality of life (Beyer et al., 2010). Disadvantages of open employment can include work-related stress and anxiety (Banks et al., 2010; Jahoda, Kemp, Riddell & Banks, 2008). Further, there are volunteering opportunities in non-profit organizations as well as recreation focus, day programs, and community day centres.

A number of government and non-government organisations provide support and services for post school transition of youth with disability in Australia (Department of Child Protection, South Australia, 2018). These programs are managed and facilitated by a number of key government departments and agencies, such as Disability Employment Services, Disability SA, Barkuma Employment, Community Bridging Services (CBS), and Autism SA.

2.3.2 Transition Planning

Transition planning is a process that guides the individuals to achieve their desired future goals. Wehman et al. (1985), suggested that the transition process should be initiated several years prior to a student's graduation and continue for one or two years after school

exit. Luecking and Certo (2003), also emphasise the need of integrated transition servicesbased transition plan implements before the final year of school. Further, they recommended that the maintainance of post-school transition should be planned during the last year of school. In Australia, the transition process for most young people starts at 15 years (National Centre for Vocational Education Research, 2013). However, youth with disability may have more complex transition requirements than their non-disabled peers. Therefore, they need more support and a specialized, detailed transition plan to make a successful transition to adult life. Transition planning is a long process with a set of coordinated activities that involve a number of stakeholders, including the individual with disability, their family, and outside service agencies, to ensure the youth receives adequate support, services and information to plan their future (Wehmeyer & Webb, 2012).

Best practice in transition planning is characterized by the participation of both the student and their family in the process, which helps in developing student skills linked with their preferred life outcomes and coordination with service agencies (Cobb, 2006). Involvement of young adults in their own transition planning has been reported as an important factor for their desired achievements and better quality of life (Foley et al., 2013). However, these ideals are not always experienced in reality. For example, a study done from Western Australia reported that 87% of parents of students with intellectual disability had been involved in decision-making about transition planning, but less than two-thirds (59.5%) of the students were involved in this same process that affected their futures (Leonard et al., 2016).

2.3.3 Transition Outcomes

Transition outcomes have been assessed in a number of studies, and across several

settings (Leonard et al., 2016; Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008; Meiring, Seabi, Amod, Vorster, & Kern, 2016). Assessing transition outcomes is important as it helps in understanding the individual's challenges, achievements, and experiences in the transitioning process. For the society, assessment of transition outcomes helps to identify weaknesses and strengths in community practices that are required to enable these young people to take their role in society (Krishnasamy, Li, & Chen, 2016).

Even though the topic of transition for youth with disability has received much more attention from policy makers and researchers during the last two decades, transition outcomes for youth with disability remain poor (Cai & Richdale, 2016; Mcconkey & Haddock, 2012; Taylor & Seltzer, 2011). Many transition programs and services for people with disability predominantly target employment outcomes (Bouck, 2012; McDonough & Revell, 2010), post-secondary education (Taylor & Seltzer, 2011; West, Cifu, Wehman, & Chen, 2014), opportunity for living independently and experiencing social and personal relationships (Alwell & Cobb, 2006).

Employment.

Employment is the cornerstone of social inclusion, and therefore plays a major role in transition to adult life. Several studies have showed that labour participation by individuals with cognitive difficulties is significantly lower than people with other disabilities (Australian Bureau of Statistics, 2012; Carter et al.,2012; Neary et al., 2015). In Australia, the employment rate for individuals with mild to moderate ID is very low, being 34.9% in comparison to 52.8% for all individuals with disability (Australian Bureau of Statistics, 2012). Furthermore, Neary et al. (2015) reports that only 49% of youth with ASD in Queensland are employed. Moreover, mental health conditions also play a role in lowering employment outcomes in the transition process. Mental health conditions can disrupt the development of employment skills of individuals and limit future attainment of more skilled jobs (Lloyd & Waghorn, 2005). For example, a study done using secondary data on Australian youth with mental health issues showed that only 26.5% of young people with depression had the experience of any employment (Caruana et al., 2018).

Accumulating evidence shows that youth with cognitive difficulties have many more obstacles to obtaining and retaining paid employment that are appropriate to their skills when compared to their non-disabled peers (Carter et al., 2011; Neary et al., 2015). Barriers can include social, family, or individual factors. Work place discrimination, stereotypes and stigma are significant social barriers to maintaining and securing employment of youth with disability (Shier et al., 2009). Shier and others (2009) found that people with intellectual disability experienced workplace discrimination and stigma, which resulted in resignation or termination of their employment more frequently than people with other forms of disabilities. A comprehensive literature review on employers' attitudes toward disability, identified that negative attitudes of employers were a major barrier to engaging and retaining of people with disabilities in competitive employment situations (Burke et al., 2013). In addition, lack of quality transition programs also contribute to the poor transition outcomes (Xu et al., 2014).

Family related factors also play an influential role in successful employment outcomes of individuals with disability (Carter et al., 2011; Trainor, 2008). Trainor (2008) identified that parental education and income level have a significant impact on post school paid employment outcomes. In contrast, Carter et al. (2011) has argued that neither parental education nor income level is significantly associated with children's paid employment

outcome. A number of studies have reported that parents who had high expectations for their children and assigned household responsibilities for their children with severe disability, such as ASD, ID, and multiple disabilities, helped them to achieve better paid work outcomes (Carter et al., 2011; Lindstrom, Doren, Metheny, Johnson & Zane, 2007; Wehman et al., 2015). These results may indicate that parents with higher expectations provide more support and motivate their children to be more independent, which in turn leads to improved employment prospects for them (Lindstrom et al., 2007).

Gender, education level, psychological factors, priority of future goals, and work related experiences while in school have been found to be individual factors that influence employment outcome of youth with cognitive difficulties (Baer at al., 2011; Carter et al., 2011; Jung et al., 2018 & Wehman et al., 2015). Most studies have reported young females with ID are half as likely to enter employment, are less likely to be successful in securing a job, and have lower earnings per hour than their male counterparts (Baer et al., 2011, Dong et al., 2016; Gold Fabian & Luecking, 2013). This gender discrepancy is also noted in attending postsecondary education where males show greater success. However, a study by Wehman et al. (2015) did not show a significant gender difference in employment outcomes. Wehman's study was based on secondary data from National Longitudinal Transition Study– 2 (NLTS2) in USA.

Work-related experiences during secondary school provide a strong base for postschool employment (Carter et al., 2012; Test et al., 2009). However, most of the students with disability did not have opportunities to access paid work during their secondary school (Carter et al., 2011)

Fundamental to the poor post school transition outcomes for youth with disability is

a school education system that is inadequate to meet the requirements of students with disability (Bouck, 2012). Bouck (2012) shows the relationship between post school outcomes and secondary school curriculum for the student with ID in the USA. He reported that, overall, the secondary school curriculum is not related to the outcomes of employment or to postsecondary education and independent living. Similar findings have been reported in a South African study, where responses from parents of students with ASD, and transition professionals, highlighted that the secondary school curriculum basically focuses on the literacy skills rather than on daily living skills (Meiring et al., 2016; Pallisera et al., 2014). Moreover, lack of collaboration among transition stakeholders has been found to be a prime reason for the poor transitional outcomes in many countries (Meiring et al., 2016; Pallisera et al., 2014). Further, an individual's skill level is also strongly associated with access to paid employment. For example, Carter et al. (2011), states that individuals who have difficulties in communication and self-care skills are facing more difficulties to acquiring paid employment. Complex work environments require these skills for applicants to successfully interview for positions with employers.

Irrespective of cognitive difficulties, many youth with disability show poor selfdetermination due to difficulties with self-awareness, decision-making, problem solving, selfmanagement, leadership, and goal setting (Carter et al., 2011). Self-determination relates to having the skills, attitudes, and support to make their own life decisions that enhance valued outcomes (Lee & Carter, 2012). Self-determination is strongly associated with positive employment outcomes (Australian Bureau of Statistics, 2017). Therefore, several intervention studies have been conducted to develop self-determination for youth with disability in transition age (Held, Thoma, & Thomas, 2004; Powers et al., 2012). Major component skills of self- determination used were self-advocacy and choice making while others have used goal attainment, self-regulation, self-evaluation, and problem solving skills (Wood, Fowler, Uphold, & Test, 2005).

Post-Secondary Education.

There have been a growing number of young people with disability engaged in postsecondary education. With the 'guarantee' of equality and protection from discrimination in education afforded by UN Conventions on the Rights of the Disabled, the number of students with a disability entering university and further education students has been steadily increasing over the past few years (Pillay & Bhat, 2012). A recent international report, *A Summary of the Evidence on Inclusive Education* (Hehir et al., 2017), presents the results of a systematic review of 280 studies on inclusive education from 25 countries. According to the report, students with disabilities who have been in an inclusive education system are more likely to be enrolled in higher education, and to be employed or living independently (Hehir et al., 2017). In Australia, the *Disability Discrimination Act* and *Higher Education Equity Plan* have had a positive impact on policies for access to post-secondary education for people with disabilities. For example, in 1996, 1.9% of students with disability had enrolled in Australian university education, but by 2000, it had increased up to 2.7%. (Parliament of Australia, 2002).

However, students with cognitive difficulties also face many difficulties in postsecondary education. Students with ASD report difficulties in adjusting to new settings, facing unexpected changes, social relationships, slow information processing, and time management, and had doubts about disclosure of their disability (Van Hees, Moyson, & Roeyers, 2015). Individuals with ADHD in higher education have been shown to experience poor academic performance, poor social relationships, and early substance experimentation and abuse (Kieling & Rohde, 2010).

Summarizing findings from 22 studies, Test and others (2009) identified 16 predictors for post school transition outcomes of youth with disabilities. This study focused on employment, education and independent living outcomes. Career awareness, inclusive education, interagency collaboration in transition process, self-determination, independent living skills, having supportive friends and family, and participation in the transition programs are identified most important predictors for successful post school education outcomes (Test et al., 2009).

Thus, there are increased opportunities, advantages, and support for young people with a disability to gain a tertiary qualification. There is also greater incentive in the form of improved employment prospects, more financial independence, and a more secure future. Research has shown that post-secondary education experiences of youth with disability have a correlation with higher salaries and better job opportunities for the graduate student with disability (Marcotte, Bailey, Borkoski, & Kienzl, 2005).

Social Participation.

Social participation consists of the achievement of regular activities and social roles valued by the person or their sociocultural context, according to personal characteristics (Sirois et al., 2017). The impact of cognitive function on social participation is well documented in the research literature (Lambregts et al., 2018; Neary et al., 2015; Rosema, Crowe, & Anderson, 2012). For example, Lambregts et al. (2018) states that slower information processing, impaired visuospatial and working memory are associated with an individual's reduced participation in social activities. Moreover, findings of a study of youth with TBI shows that social participation is significantly reduced after TBI, and that an individual's problem solving ability significantly correlates with their social participation

(Sirois et al., 2017)

Research has found that individuals with ASD are usually more socially isolated and have difficulties in building friendships. For example, a study done in the UK reported that none of the youth with ASD in the sample had "close friends", whereas all typically developing peers reported having close friends (Whitehouse, Watt, Line, & Bishop, 2009). Further, youth with ASD spent more time in solitary leisure activities, especially technology-based activities, rather than socializing. An average Australian youth aged 18-24 years spends around nine hours per week in internet-based leisure activities (Australian Bureau of Statistics, 2017). In contrast, a Queensland survey showed that a youth with ASD in the same age bracket spent an average of 37 hours per week playing computer games and other online, noncommunicative activities (Neary et al., 2015).

These findings strongly suggest that schools need to adjust education programs for youth with ASD to improve their social participation skills. School curriculum for students with disability should have a greater focus on the post-school outcomes. However, the major components of school curriculum have been found to mainly focus on the literacy skills rather than social and life skills which are needed by these students for the independent living and social participation in adulthood (Bouck, 2012). It is clear from the research that schools with policies on inclusion of students with ASD in classrooms need to ensure that there is more emphasis placed on preparing these special students for post-school employment and social environments, and activities of daily living.

2.4 Transition Programs.

Several local and international programs have been conducted to support the postschool transition of youth with cognitive difficulties. Published studies of these programs have led to better understanding of the issues and methods. A search of four databases (CINAHL, PubMed, ERIC, and Scope) was conducted using the following key words: "disability" OR "cognitive impairment" OR "cognitive disability" OR "cognitive deficit" OR "cognitive difficulties" AND "transition" OR "post-school transition". This search identified six studies which described outcomes of transition programs for this population. Each are presented in Table 2.2 and described in further detail below.

		[
Author(year)	Aim	Methodology	Participants	Findings
country				
Ashburner,	Impact of Studio	Qualitative	11 individuals	Positive psychological
Bobir, & van	G program on		with ASD aged	outcomes in the levels of
Dooren	mentees' social	Face to face	17–21 years, 12	motivation and
(2018).	participation and	interview,	family	enjoyment, social
	friendships,		members, and	participation, emotional
Australia	emotional well-	Telephone	seven Studio G	well-being and skill
	being, project	interview and	mentors	development.
	skills, and	secondary		
	awareness of and	data from		Some participants show
	transition to	mentors'		awareness of future
	further education	records.		employment and
	and/or			education options, while
	employment.			others show difficulties
	. ,			in developing future
				goals.
				5
				Two participants
				entered further
				education.
Hatfield,	Examine the	Quasi-	94 adolescents	BOOST-A can improve
Falkmer,	effectiveness of	randomised	with ASD and	some career-readiness
Falkmer, &	BOOST-A [™]	control trial	their parents.	out-comes, but it did not
	program in			

Ciccarelli (2018).	enhancing self- determination			show impact on Self- determination.
Australia				57% of parents and 49% of adolescents reported that they felt the program helped them to prepare for leaving school.
Schall et al. (2015). USA	Compare outcomes in implementation of support employment with and without project SEARCH with ASD support	retrospective observational records review study	45 individuals with ASD, who was referred to support employments from 2009- 2013	Higher wages and higher work retention rates by participants.
Christensen, Hetherington, Daston, & Riehle (2015). USA	Long-term employment outcomes of SEARCH project	Longitudinal study	124 students with Intellectual and Development Disability (IDD)	SEARCH project successfully preparing youth with IDDD with the skills necessary to both gain and retain employment in integrated work settings.
Farnon, Ellie, Jennifer, & Shannon (2017). USA	Evaluate the LGTW project		72 students with ID at age 14-17	Improvement in self- determination and increased community integrated job experiences while in school.
Walsh, Holloway, & Lydon (2018). Ireland	Evaluate the effectiveness of the ACCESS program and video modelling on increasing social communication skills	Pre-test post- test study	Seven youth (19y-22y) with both ASD and ID	Significant increases in target social skills and a significant decrease in problem behaviours following intervention.

"Studio G" program is a mentoring program developed by Autism Queensland, to support young people with autism in transition to employment, training or further education (Autism Queensland, 2018). The aims of the program are to enhance social participation, emotional well-being, develop project, work and communication skills, and improve awareness of future study and employment options. However, this program is available to individuals who have ability to independently manage basic self-care, self-regulate emotions and behaviours, understand instructions, and express needs. The program consists of onehour sessions for three times weekly for 10 weeks. Mentors keep records of mentee attendance and progression every fortnight. Participants are assisted by mentors to build up a computer base project according to their self-selected goal, facilitate the transition process by exploring their future educational and vocational goals, and facilitate the pathways to achieve their goals.

Ashburner et al. (2018) evaluated the impact on participation in the Studio G program. Interested youth age between 17-24 years who had been diagnosed with ASD were invited to participate in the study. They were offered a two weeks period to familiarise themselves with the program aims and consider their participation. This evaluation study had collected comprehensive data through face-to-face mentee interviews from 11 participants (aged between 17-21 years), telephone interviews with 12 family members, and from their mentors' records. These data were analysed qualitatively.

Findings from research on the Studio G program reveal that positive outcomes were achieved on subjective emotional well-being, happiness, social participation and friendship. This program shows some key features of successful transition programs. First, allowing participants to choose a project based on their skills and interest improved engagement.

Second, involving family members in choosing a project helped improve confidence. Third, follow-up assessment of the participants after the program, and coordination with an established network of education institutes, employment support services, and work places enabled participants to gain maximum benefit (Wehmeyer & Webb, 2012). However, interviewer bias cannot be excluded as this evaluation study was done by the staff members of the organisation who developed the program, which could in turn affect the reliability of the findings (Smith & Noble, 2014).

The Better Outcomes & Successful Transition for Autism (BOOST-A[™]) is a web-based program that is developed to improve self-determination of Australian adolescents (aged 14-25 years) with autism spectrum disorder (Hatfield et al., 2018). It was a self-directed by the participants. It included four modules guided by structured cartoon animations and visuals for participants to plan their post-school transition with collaboration of the family. Additionally, these modules assist participants to identify people who would support them in transition planning. They are facilitated to arrange meetings with those selected people to discuss their strengths, work interests, and potential job pathways. Interested adolescence who were enrolled in year 8-11 were invited to participate. However, participants had to have formally diagnosed ASD, and capability to write at a year 5 reading level and basic computer skills. Individuals with ID were excluded from this study. Quasi-randomised control trial was conducted and participants were randomly allocated to intervention group (n=49) and control group (n=45). Intervention group had received 12 months to complete BOOST-A program while control group participated regular practice at school. Participation details were obtained by login details. Pre and post program data from participants and their parents were collected by self-administered online questionnaire. However, this evaluation study had used

number of scales to measure outcomes; Self-Determination Scale, Career Development Inventory—Australia—Short Form, Personal Wellbeing Index- School Children and Learning Climate Questionnaire.

Findings revealed that no significant difference in self-determination between two groups, but it showed enhancing career awareness by the participants. Around half of the participants rated BOOST-ATM highly in preparing them for post-school transition. However, self-directed technology-based programs are found to be less effective when compared to program delivery by specialists (Grynszpan, Perez-Diaz, Weiss, & Gal, 2014).

Research studies have noted that access to work experiences in a real work setting while in school is a predicting factor for the successful post-school transition to employment for youth with cognitive difficulties (Carter et al., 2011; Test et al., 2009). Burgstahler (2001) argues that many students with significant cognitive difficulties are more likely to be unemployed, as most of the school-to-work programs do not support on-the-job experiences in a real work setting. The Project SEARCH is an intensive secondary school job training program that originates in the United States and aims to support school-to-work transition for young people with significant developmental disabilities (Daston, 2012). This program is a combination of classroom instruction at a work place coupled with workplace internship rotation over 10-12 weeks. Important key features of this project include collaboration with several partners, such as students with developmental disabilities and their family members, a local education agency, a local community rehabilitation program, the state vocational rehabilitation program, and a host business (Daston, 2012). This program provides intensive job opportunities for students with developmental disabilities to gain experiences in actual work environments with other employees without disabilities.

The effectiveness of SEARCH has been assessed in several studies (Christensen et al., 2015; Schall et al., 2015; Wehman et al., 2013). Schall et al. (2015) conducted a retrospective study using secondary data on 45 individuals with ASD who were referred to Support Employment (SE). Schall et al. (2015) compared the outcomes of SE with and without prior project of SEARCH with ASD support. Observational records prior to referral to SE of 25 youth who had participated in the SEARCH project and 20 who had not been included to the study. Results showed that individuals who participated in the SEARCH project achieved higher wages and higher retention rates compared with their peers who had not participated in the SEARCH project. Youth who participated in the SEARCH project earned average \$9.89 per hour while another group earned \$8.82 per hour.

A longitudinal study over four years revealed even higher employment outcomes from the SEARCH project than in Schall et al.'s study (Christensen et al., 2015). In Christensen et al.'s study conducted in Monroe County, New York, data was collected from each cohort in every year (2009-2014) of participation in the SEARCH project. Details of the engaged employment, working hours and wages had been collected from 125 students with IDD every six months, for up to 48 months after program completion. The reported average employment rate was 84%. Moreover, they showed increased wages up to \$11.24/hr. as well as increased working hours 35/week at 48 months period. Christensen et al. (2015) suggested that a collaborative approach in transition-to-work training for high school students in the SEARCH project might increase the likelihood of obtaining and maintaining employment over time. Kaehne (2016) evaluated the employment outcomes of the SEARCH project in the UK with a sample of 315 youth with ID from 2009-2013. This study reported approximately 50% employment rate among participants of the project. By examining the results of these studies, it can be seen that there are some successful aspects of the SEARCH program which can be used as benchmarks for future projects. The benefits of collaboration with several partners (Wehmeyer & Webb, 2012), and the importance of internship in integrated work settings in the community, rather than within educational settings, such as college or school, are highlighted. Experiences in real work environments have been demonstrated to develop better self-confidence, self-esteem, and employability of young people with developmental disability (Beyer & Kaehne, 2008).

The Let's Get to Work (LGTW) project was a four-year pilot project aimed to increase the participation of youth with ID to integrated competitive jobs (Farnon et al., 2017). This project was conducted in a selection of nine schools in Wisconsin state, USA. The project group consisted of 72 students with ID who were aged 14-17 years. A core team from each school was responsible for collaborating on a work plan to support selected students from their school to gain employment within three years. The core team consisted of teachers, students with and without disabilities, parents, vocational rehabilitation staff, and community members. The interventions in this project were conducted by schools and every participating school was coached in implementation methods. The interventions were based on coordination of transition services (Wehmeyer & Webb, 2012), integration of classes and extra-curricular activities, developing individualized career goals based on strengths and interests, integrated community work experiences, and facilitating collaboration between teachers and vocational rehabilitation partners. An evaluation study at the end of this project showed that there was significant improvement in self-determination of the participants and increases in their community-integrated job experiences while in school (Farnon et al., 2017). Out of participants 73% of students had one or more paid job experience while in school.

Social communication skills are identified as an important factor for obtaining employment for people with cognitive difficulties (Baldwin, Costley, & Warren, 2014; Meulenbroek & Cherney, 2017). Adolescent Curriculum for Communication and Effective Social Skills (ACCESS) is a program designed to teach social skills for the young adults with learning disabilities in Ireland (Walker, 1988). This program teaches 31 social communication skills in peer-related social skills, adult related social skills, and self-related social skills (Shukla-Mehta, Miller, & Callahan, 2010). Video modelling is also effective for improving general social and communication skills of students with ASD (Shukla-Mehta, Miller, & Callahan, 2010).

A recent study by Walsh et al. (2018) evaluated the effectiveness of combining these two programs on social communication skills of youth with both ASD and ID. Seven young adults aged between 19-22 years were recruited from a vocational training centre. Social communication skills training sessions were conducted additional to the vocational training. In this study, two sessions of 1.5 hours per week were conducted over 20 weeks, according to the individual's training plan, which targeted their employment and education. The researcher, teachers, and parents have rated the pre, post and three-month follow-up outcomes using ACCESS Placement Test, Social Skills Improvement System Rating Scale (SSISR), and Social Responsiveness Scale (SRS). Results showed increased SSISR scores from baseline (M = 85.14, SD = 10.61), to post program (M = 93.14, SD = 13.23), t (6) = -2.90, p < 0.05.) with large effect size (0.58). The social skills were measured in a naturalistic vocational setting. Finding could be more generalisable if this study conducted in a work place.

2.5 Summary of the Literature Review

Transition from school to adult life is a challenging period for youth with cognitive disabilities. Post-school transition programs focus on enhancing employment, post-secondary

education, well-being, and social participation of youth with disabilities. This literature review identified several factors which can influence the transition outcomes of this group. Work place discrimination, stigma, lack of interagency collaboration, literacy skills focused school curriculum (instead of employment skills), and poor-quality transition programs can negatively affect transition outcomes. In contrast, work related experiences while in school coupled with individual and family involvement in transition planning have demonstrated improved transition outcomes. Poor self-determination, underdeveloped social skills, low level of functioning, and mental health disorders have been identified as individual factors that make post-school transition of youth with cognitive disability more difficult. However, the recent literature includes studies of several local and international transition programs that have demonstrated progress in addressing those factors and improving transition outcomes. Therefore, recently published research is of significant value in providing guidance for schools, government, and non-government agencies in developing effective transition programs for these students. Although a number of evaluation studies have been published highlighting transition outcomes for this population, they have mainly focused on employment outcomes for selected populations. Studies that focus on social participation, social communication skills, and self-determination are lacking. The current study evaluates the SSAYiT Program by focusing on well-being, in addition to vocational and educational changes, and community participation for individuals with cognitive difficulties. This approach will expand our understanding of transition program design by identifying the key factors that would contribute to successful participation and improved outcomes.

Chapter 3: Research Methodology

3.1 Introduction

This chapter begins by identifying the aim and research questions for the current study. This is followed by an overview of the intervention: The Support SA Youth Initiative Transition (SSAYIT) program, including information on the conduct and delivery of the training sessions, and a description of the participants in the study. It will then present the research methodology and study design, including data collection, data analysis, ethical considerations, and the reliability and validity of the results.

3.2 Aim and Research Questions

The aims of this study were to:

- Identify the outcomes of participation in the SSAYiT program
- Identify factors which may influence successful outcomes for participants in the SSAYiT program

The following research questions were developed:

Research Questions.

- 1 Does participation in the SSAYiT program positively impact on (a) depression, anxiety and stress, (b) psychological wellbeing over time?
- 2 Does participation in SSAYiT program change the participants' or family's perceptions of disability, confidence in gaining employment and negotiating reasonable adjustments in work place over time?
- 3 Does participation in the SSAYiT program change the number and range of education, employment and community activities participants engaged in over time?
- 4 What factors influence outcomes from participation in the SSAYiT program?

3.3 Overview of the Support SA Youth initiative Transition (SSAYiT) Program.

The SSAYiT program was developed by Brain Injury SA (Brain Injury SA, 2018) to support youth affected by ABI or by a disability that impacts their cognitive functioning to achieve successful employment, education and community outcomes. This was an 18-month program, run between December 2016 to June 2018, funded by the Department of Employment's Empowering Youth Initiatives in South Australia. Once the funding had been secured and the program was about to commence, Brain Injury SA approached Flinders University to conduct the evaluation of this program.

The objectives of the SSAYiT program were to:

- Explore the employment goals of participants and support them to achieve these by providing training and employment pathways.
- Prepare participants with a solid understanding of how their disability can impact on the vocational success and support them to develop strategies to overcome their barriers.
- Support for the smooth transition to employment by connecting participants with disability services and employers.
- Build participants' support networks along with training these individuals and groups with the knowledge and approaches to increase positive employment results for participants.
- Improve the participant's mental health and develop their confidence, resilience and coping skills to continue employment or studies.
- Capacity building of the participants and real-world functioning aligned with their personal goals.

- Promote participants' community integration and healthy social relationships.
- Strengthen support network of the participants (Brain Injury SA, 2018).

The program was designed and delivered to youth who met the following criteria:

- 15-24 years of age
- lived in Adelaide
- diagnosed as having ABI or a disability that impacts on cognitive functioning
- had finished or nearly finished post-acute rehabilitation

SSAYiT Recruitment.

Information on the SSAYiT program was disseminated time to time by Brain Injury SA to potential participants and interested parties in several ways, including:

- advertisements in several disability related websites and magazines
- individual information sessions, email and post to disability service organisations, health professionals, employment providers, schools, justice agencies and family members
- email to all Brain Injury SA stakeholders.

One hundred and ten eligible participants joined the SSAYiT program. This program consisted of two stages: a ten-week group training program followed by a sixteen-week block of individual sessions.

Ten-week group training program.

Ten training sessions were delivered in group format in eight centres across Adelaide (See Table 3.1). Selected groups started the program on different dates and in different locations.

Group	Location	Program Started date	Number of
			participants
Group 1	Central (Brain Injury Office)	16 August 2016	17
Group 2	Northern (Hypa Office Elizabeth)	18 November 2016	10
Group 3	Northern (Craigmore High School)	01 February 2017	10
Group 4	Southern (Christies Down Community House)	25 July 2017	9
Group 5	Southern (Christies Beach High School)	28 July 2017	11
Group 6	Southern (Christies Beach High School)	20 October 2017	9
Group 7	Western (Brocas Community House)	20 November 2017	6
Group 8	Regional (Mount Barker High School)	31 January 2018	9
Group 9	Northern (Craigmore High School)	02 February 2018	10
Group 10	Southern (Hamilton Secondary College)	08 February 2018	19
	Total		110

Table 3.1.	Training	delivery	centre	locations
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All centers had a room equipped with tables, chairs and technology to deliver power point presentations, videos, films and other audio-visual education equipment, and had enough space to comfortably accommodate 15-20 people. There were 10 groups ranging from 6-19 participants. The training consisted of 20 hours of 'health and well-being' modules and 30 hours of 'vocational skill' modules. Health and wellbeing sessions were conducted by a youth counsellor, who holds a Bachelor's degree in psychology, while vocational skills sessions were conducted by a vocational consultant, who holds a Certificate III in Community Services.

Each session was scheduled for five hours on a fixed day of the week. Each group received one training session per week for a total of ten weeks. If a participant was unable to attend a training session, they were invited to attend the same training session with another group when possible. During this period participants were offered individual counselling sessions as required. The program outline is presented in Table 3.2.

	Health and well-being	Vocational skills
Week1	Welcome-Participant introduction and sharing and	Vocational Aspiration- Getting to know the group and
	relating experiences	sharing and focusing goals and aspiration
Week 2	Increasing connection with others	Communication Tool- Building and developing skills to use
		in the workplace

Week 3	Understanding Self	Workplace Laws, Regulations and industrial process, workplace safety and protecting self
Week 4	Relationship with self	Introduction to workplace providers
Week 5	Optimal Functioning	A guide to apply for employment
Week 6	Adapting and challenges of change	Mock interviews and workplace scenarios
Week 7	Values and growth	Mock interviews and workplace scenarios
Week 8	Challenges of mental health	Life skills
Week 9	Summary and feedback	Life skills: personal relationships with others and yourself
Week 10	Graduation	

Sixteen-week individual sessions

Sixteen-weeks of individual sessions on health and wellbeing, and vocational skills were offered by the youth counsellor and vocational consultant. These sessions were conducted at a location of the participant's choice. Some were in Brain Injury SA central office and some sessions were in a convenient place for the participants such as in a café, in a park, workplace or school etc. Health and well-being sessions involved individual counselling and referrals to other health services where appropriate. Vocational sessions focused on enhancing individuals' vocational skills and linking them to their vocational goals and developing pathways.

3.4 Methodology

3.4.1 Study Design

A quantitative, pretest–posttest study design was used to evaluate the effect of participation in this program (Creswell, 2014; Neuman, 2006). According to Creswell, pretest–posttest designs allow a researcher to assess the changes within a group in response to an interventional manipulation (Roberts & Ilardi, 2008). Furthermore, a researcher can detect interventional effects more readily in the posttest phase, as they are able to statistically control for subjects' initial responses prior to manipulation in the pretest stage (Roberts & Ilardi, 2008). However, this was an evaluation of a funded support program delivered by a

non-profit organisation. Resources did not allow for the including of a control group, which would have strengthened the design (Newman, 2006).

3.4.2 Participants

One hundred and ten youth commenced in the program, with 79 participants included in final data analysis, as they had engaged in at least in two "group" or "individual" sessions in the SSAYIT program. Participants were from central, southern, northern, western, and regional Adelaide (see Table 3.1).

3.4.3 Data Collection

Pre and post-program surveys were developed by the researcher's primary supervisor in conjunction with Brain Injury SA's psychologist. Data was collected by Brain injury SA, using the interviewer-administered pre and post-course surveys (Appendices A & B).

Face to face interview is considered as the gold standard method of data collection in surveys, as it shows higher response rates compared to self-administered questionnaires (Christensen, Ekholm, Glümer, & Juel, 2014) and it helps to get more accurate responses (Abbott & Mckinney, 2013). Furthermore, it is suitable for participants with cognitive deficits which can affect their understanding and reading abilities (Nishiyama & Ozaki, 2010).

A pre- course survey was administered at week one of the ten-week training program to collect baseline data, with three post-course surveys repeated at the end of the ten-weeks training program, at the end of the sixteen-weeks support period, and at three months after completion of the support period. The data collection process is outlined in Figure 3.1

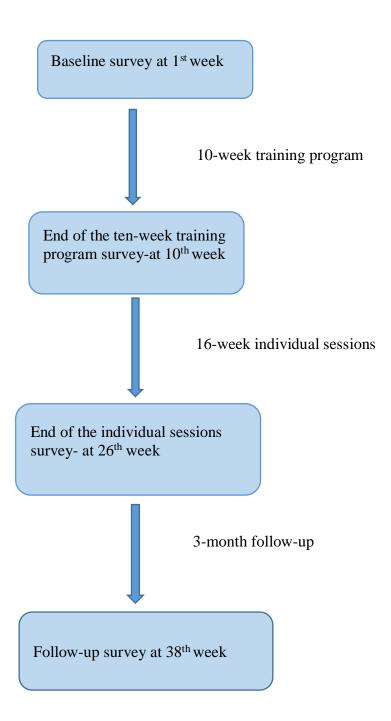


Figure 3.1. Outline of the data collection process

3.4.4 Surveys

Pre-course survey.

This survey was administered during the first week of the ten-week training program, consisting of 50 items covering the following areas (See Appendix A).

Sociodemographic data.

Thirteen items sought socio-demographic information including gender, age, language spoken at home, ancestry, living arrangements, type of disability, and current involvement in educational, vocational and community activities.

Perception of disability, confidence in gaining employment and negotiating reasonable adjustments in work place.

Six items sought information on each participant's understanding of their own disability, by family and those around them, confidence to apply for work, the perception of whether they feel their disability has or will have a negative impact on getting a job, confidence to approach an employer for accommodations, and confidence to ask for help in the work place. A five-point Likert scale (1= strongly disagree, 5= strongly agree) was used to indicate responders' agreement with those six statements. Except item 4; "I feel my disability has or will have a negative impact on getting a job" all other items are phrased in positive direction.

Flourishing scale (FS).

The Flourishing Scale (FS) is a brief eight-item tool to subjectively measure the main aspects of the human psychological well-being (Diener et al., 2009). Psychological well-being captures both the hedonic and eudaimonic perspective on well-being. Hedonic perspective denotes to the 'feeling good' dimension of well-being (Belzak, Thrash, Sim, Wadsworth, 2017) while eudaimonic perspective denotes 'living well' dimension of well-being (Hirata, 2016). This self-reported scale assessed how respondents perceived there: relationships, commitment, competence, self-esteem, purpose in life, life satisfaction, optimism and contribution to others' well-being (Diener et al., 2009). A seven-point Likert scale (1= strongly disagree, 7= strongly agree) is used to indicate responders' agreement with eight statements. All items are phrased in positive direction. Total scores can range from 8 (Strong Disagreement with all items) to 56 (Strong Agreement with all items). A high score signifies a respondent with many psychological resources and strengths (Diener et al., 2009).

The FS has good psychometric properties; good internal reliability (\propto =.87), as well as good convergent validity (r = 0.43–0.70) (De la Fuente, Parra, & Sánchez-Queija, 2017). FS is widely used in well-being intervention studies and clinical practice, because it is brief, simple and comprehensive. It has been translated into several languages (Schotanus-Dijkstra et al., 2016) and has been validated in a number of different settings and different populations, such as university students in China (Tang, Duan, Wang, & Liu, 2016), and adults in USA (Chen, Lee, Pethtel, Gutowitz, & Kirk, 2012). It also has been used to measure the psychological wellbeing of people with cognitive difficulties such as individuals with Multiple Sclerosis (Strober, 2017).

Depression Anxiety Stress Scales 21 (DASS-21).

The DASS-21 was developed by Lovibond & Lovibond (1995), to measure emotional distress in three subcategories; depression, anxiety and stress. It is a short version of DASS, which has 42 items. DASS-21 version has several advantages relative to DASS 42 item version including less items, a cleaner factor structure, and smaller inter-factor correlations. This scale is widely used in western countries to screen distress in individuals (Oei, Sawang, Goh, & Mukhtar, 2013). DASS-21 consists of the seven questions per subcategory for a total of 21 questions. Each item is based on a 4-point rating scale ranging from 0-3. Each rate is multiplied by two and added to calculate the final score (Lovibond & Lovibond, 1995). DASS severity is rated according to the Table 3.3. (Lovibond & Lovibond, 1995).

Literature shows that DASS- 21 has good internal consistency (α = 0.84–0.94) and construct validity (r= 0.65 and 0.75) as DASS 42 (Antony, Bieling, Cox, Enns, & Swinson, 1998; Oei et al., 2013). As it is a shorter version it saves time in data collection. Further, it shows smaller inter-factor correlation (Antony et al., 1998; Clara, Cox & Enns, 2001). It can be used in both clinical and non-clinical settings (Ownsworth et al., 2008). Clinical potential for assess emotional status following brain injury was studied using DASS in individuals with traumatic brain injury and brain tumors (Ownsworth et al., 2008). The findings generally support the clinical application of the DASS following ABI. It has also been validated in western and Asian countries (Crawford et al., 2009; Norton, 2007; Oei et al., 2013) and has been used in more diverse populations than the DASS–42, such as in young adolescent samples (Szabo, 2010) and the elderly sample (Del Brutto et al., 2015). Further, DASS 21, has been used in women with intellectual disabilities. Mcconnell, Mayes and Llewellyn (2008), has used DASS 21 scale to measure pre-partum distress level of pregnant women with intellectual and learning disabilities.

Both studies had not found difficulties in use DASS 21 scale in women with intellectual disabilities, however, both studies had not assessed the degree of the ID of the participants.

	Depression total score	Anxiety total score	Stress total score
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

Table 3.3. DASS Severity Table

Post-course survey.

This survey was administered after the 10-week group session, at the end of the 16-week individual sessions, and at 3-month follow-up (Appendix B). Repeated questions included:

- Current involvement in educational, vocational and community activities (1 item)
- Perception of disability and confidence in gaining employment and negotiating reasonable adjustments in work place (6 items).
- FS (8 items)
- DASS-21 (21 items)

3.4.5 Ethical Considerations

As Flinders University researchers were approached and commissioned to analyse the de-identified data collected by Brain Injury SA, low risk ethical approval was sought from the Flinders University Social and Behavioural Research Ethics Committee (Project No 7524 – see Appendix D). Brain Injury SA sent de-identified Excel spread sheets to the researcher's primary supervisor. Respect for the privacy and confidentiality of participants was paramount and was fully protected by this approach, with no individual identifiable information included in the data files provided to the researcher. The research study did not present any risks of harm or

discomfort to participants, as the methodology involved secondary analysis of data only. The results of the research will be available to Brain Injury SA and could have implications and benefits for the participants and the broader community, in that it will enhance our understanding of the outcomes of such a program and provide recommendations for future development. All research data will be stored on the secured Flinders University computer server for a minimum of 5 years following publication.

3.4.6 Data Analysis

An excel spread sheet containing final de-identified data was send to the researcher's primary supervisor in July 2018. This file only included data from nine of the ten groups. Surveys for group six were not conducted by the organisation due to their concern of the severity of cognitive difficulties in this group. Prior to the analysis, a process of 'cleaning' of the data was undertaken to remove any invalid data points from the data set. The cleaning included checking for duplicates in the data, identifying any probable errors or logical inconsistencies, such as values out of the expected range, and scanning for any missing values (Hurley, 2014). A total of 79 participants were included in the final analysis. The data analysis was conducted using Statistical Package for the Social Sciences (SPSS) software version 25 (IBM Corp., 2017; Pallant, 2016).

Descriptive statistics were used to summarize the general characteristics of the sample. It included means, standard deviations, percentages, frequencies and range for all dependent and independent variables (Creswell, 2014). A dependent variable is the variable being examined and measured in the research, while an independent variable is hypothesized to lead to changes in dependent variables being tested (O'Dwyer, 2014). The participation in

activities across the time point were analysed using descriptive statistics. The independent

and dependent variables are presented in Table 3.3.

Research questions	Independent variables	Dependent variables		
RQ: 1	Participation in the SSAYiT program	Depression, anxiety & stress scores		
RQ: 2	(pre, post 10 weeks group sessions, post	Flourishing Scale		
RQ: 3	16 weeks individualized sessions and	Perception of disability, confidence in		
	three months follow-up)	gaining employment and negotiating		
		reasonable adjustments in work place.		
		Number and range of engaged activities.		
RQ:4	Sociodemographic characteristics	Depression, anxiety & stress score		
	(gender and being a school student	Flourishing Scale score		
		Perception of disability, confidence in		
		gaining employment and negotiating		
		reasonable adjustments in work place.		

 Table 3.4. Summary of the variables

The distribution of the data was assessed by visual method as well as Shapiro-Wilk test. It is preferable that normality be assessed both visually and through normality tests (Ghasemi & Zahediasl, 2012). The Shapiro-Wilk test is based on the correlation between the data and the corresponding normal scores (Peat & Barton, 2014) and it provides better power than other normality tests (Steinskog, 2007). Parametric tests were used to analyse dependent variables which fulfilled the normality assessment, and non-parametric tests were used for dependent variables which did not fulfill the normality assessment (Pallant, 2016).

Parametric tests are more powerful than non-parametric tests (Sahu, 2015). The power of the test denotes the likelihood of detecting differences between the groups being compared when such differences exist (Kinnear & Gray, 2010). In contrast, using nonparametric tests typically make fewer assumptions about the data and are very simple and easy to apply (Pallant, 2016). A variety of non-parametric tests and a parametric test; repeated measure Analysis of Variance (ANOVA) were employed in analysis of the data.

Repeated Measure ANOVA.

Repeated measure ANOVA is a parametric test, which compares means of variables that are based on repeated observations (Kinnear & Gray, 2010). However, there are few assumptions to fulfill the use of this test (Pallant, 2016).

- Independence of observations
- Normal distribution
- Sphericity. Sphericity is the condition where the variances of the differences between all combinations of related groups (levels) are equal. It is tested by Mauchly's test.

Repeated measure ANOVA was used in the current study to analyse the difference in stress levels over the four time points: base line; after 10 weeks post program; 16 weeks post individualized sessions; and at three months follow-up.

If the results showed a significant difference, post hoc test with Bonferroni adjustment was performed in pairwise comparison of stress levels at each time point (Pallant, 2016).

Friedman Test.

The Friedman test is the non-parametric equivalent of one-way repeated measures analysis of variance (Pallant, 2016). It is used to analyse ordinal or continuous data from a dependent group in more than two different time points. The Friedman test was used in the current study to determine differences over time in:

- FS score
- depression and anxiety scores

 scores for perception of disability, confidence in gaining employment and negotiating reasonable adjustments in work place

If the Friedman test showed a statistically significant difference, the Wilcoxon Signed rank test was used to compare both time points (Pallant, 2016; Peat & Barton, 2014).

Wilcoxon Sign Rank Test.

The Wilcoxon signed-rank test is the nonparametric test equivalent to the dependent t-test and it compares two dependent samples. When the Friedman test result showed a significant difference, the Wilcoxon sign test was run to compare both time points separately to identify which time point changes were the cause of the significant difference. Similar to the Friedman test, Wilcoxon converts ordinal or continuous data to mean ranks and compares them. However, repeated pairwise analysis introduces Type I error (Kinnear & Gray, 2016; Pallant, 2010). Type I errors lead to false positive findings. Therefore, Bonferroni adjustment alpha value was applied to the Wilcoxon Sign Rank Test to control Type I error (Pallant, 2016). Bonferroni adjustment helps keep the alpha (0.05) at a reasonable level across all the tests.

For all tests, a p value less than or equal to 0.05 was required to indicate statistical significance (Pallant, 2016). A statistically significant level is used to refer to a pre-chosen probability of falsely rejecting the null hypothesis. The null hypothesis is an assumption that there is no statistical significance in given observations (O'Dwyer, 2014). It does not indicate the size of the effect. Effect size is the magnitude of the difference between groups (Sullivan & Feinn, 2012). In reporting and interpreting studies, both effect size and p value are essential results to be reported. It gives a comprehensive idea to the reader and is useful to further quantitatively compare results from different studies. Therefore, both effect size and p value were reported in the statistical analysis.

SPSS provides effect sizes (partial eta squared) for the repeated measures ANOVA,

but not for the Freidman and Wilcoxon tests. Cohen's (1988) guidelines were used to

interpret the partial eta squared (.01=small, .06=moderate, .14=large effect size).

Flowing equations were used to measure effect sizes for Friedman and Wilcoxon tests (Kinnear & Gray, 2010, p.332). Cohen's (1988) guidelines were used to interpret the effect sizes of Friedman and Wilcoxon tests (.1= small, .3= medium, .5=large effect size).

Table 3.5. Effect size measure for Freidman and Wilcoxon sign test

Test	equation	Explanation
Friedman test	$W = X^2 / N (k-1)$	W= coefficient of concordance
		X ² = Friedman test statistic
		<i>N</i> = number of subjects
		<i>k</i> = number of conditions
Wilcoxon Signed test	r =Z/√N	R= correlation coefficient
		N= number of observations
		Z= Wilcoxon test statistic

3.5 Reliability and Validity

Reliability and validity demonstrate the rigour of research processes and the trustworthiness of research findings (Claydon, 2015).

3.5.1 Reliability

Creswell (2012) defined reliability as the stability and consistency of an instrument or procedure. A basic premise for reliability of research is that it should be repeatable and the results, when conducted by another researcher within the same conditions, should be at least similar. However, in the social sciences, there are likely to be variations resulting from differences between observers, and differences among the behaviours and responses of human participants. In this research, two scales (FS & DASS 21) used in the surveys have good psychometric properties, Cronbach's alpha 0.84–0.94 for DASS 21, and 0.87 for FS. Therefore,

these instruments enhance the reliability of the findings (De la Fuente et al., 2017; Donnelly & Carswell, 2002; Oei et al., 2013).

3.5.2 Validity

Validity refers to the degree of the credibility or believability of the research (Creswell,

2014). There are two aspects of validity in research: external validity and internal validity.

External validity refers the degree to which results of a study can be generalized to the population from which the sample is taken (O'Dwyer, 2014). The research methods for this study did not ensure the external validity due to non-random sampling method.

Internal validity determines whether the effects observed in a study are due to the manipulation of the independent variable or by some other factors (O'Dwyer, 2014). There were a number of threats identified for the internal validity in this study, which could not be eliminated. These were:

- The external events (for example, stressful event, participation in programs that focus the similar outcome in school or education institutions) that happened during an intervention period may have an influence on outcome measures. The effect, if any, was difficult to measure as there was no control group in this study. Torgerson (2008), states that a control or comparison group is usually needed to account for this possible effect on research outcomes.
- Participants were selected through referrals, not randomly selected. Therefore, selection bias may have occurred (Creswell, 2014).
- The last two surveys were not conducted in group 6-9 due to the organisaiton's staff resourcing issues. Therefore, outcomes of participants who did not receive these last two surveys were not included in the results. As this proportion was very high and the

recruited sample size was not large enough to compensate for non- completers, this potential influence could not be eliminated from the study (Creswell, 2014).

- Data was collected by interviewer-administered survey and these interviews were done by the personnel who delivered the SSAYiT program. Therefore, it is possible that interviewer bias may have an impact on the credibility of the outcomes (Creswell, 2014; Neuman, 2006).
- Maturation and history related to the single group pretest- posttest design could affect the post test scores. Participants' biological and psychological changes could have occurred over the period of intervention, affecting their post test scores (Dimitrov & Rumrill, 2003). In addition, exposure to the baseline survey could have influenced how they responded in subsequent repeated surveys (Dimitrov & Rumrill, 2003).

Chapter 4: Results

4.1 Introduction

This chapter presents the results of the study, including the demographic characteristics of participants, levels of participation in the SSAYiT program, outcomes over time, and the factors which may influence outcome scores.

4.2 Participant Demographics

A total of 110 youth was involved in the SSAYiT program. Of this number, 79 youth (72%) attended at least two sessions (either group or individual) and were included in the analysis. Demographic characteristics of the sample are summarised in Table 4.1. Participants were aged between 15 and 25 years, with a median age of 18.2 years (IQR=2.27) (see Figure 4.1). Of these, 45 (57%) were male. Participants had a wide range of cognitive disabilities, with more than half (67.1%) diagnosed with an intellectual disability, ABI (n=8, 10.1%), ASD (n=8, 10.1%) or other mental health disorders (n=4, 5.1%). Mental health disorders, such as bipolar, anxiety, and depression, were commonly reported in participants who had multiple disabilities (n=9, 11.4%).

Characteristics	Ν	Percentage
		%
Gender		
Male	45	57.5
Female	34	42.5
Primary disability		
Intellectual disability	52	65.8
Acquired Brain Injury	8	10.1
Autism Spectrum Disorder	8	10.1
Mental health disorder	4	5.1
Learning disability	3	3.8
Attention Deficit Hyperactivity Disorders	1	1.3
Sensory/Physical disability	3	3.8

Table 4.1. Socio-demographic characteristics and diagnoses of the sample

Continued

Characteristics	Ν	Percentage %	
Additional disability			
Attention deficit hyperactivity disorders	2	2.5	
Mental health disorder	6	7.6	
Sensory/Physical disability	1	1.3	
Residency			
Major city area	67	84.8	
Inner regional area	11	13.9	
Current living			
With family	78	98.7	
Independent with support	1	1.3	
Country born			
Australia	77	97.5	
Other	2	2.5	
Language spoken			
English only	75	93.8	
Other language and English	4	5.1	
English speaking ability			
Very well	55	69.6	
Well	19	24.1	
Not well	5	6.3	
Currently in high school			
Yes	57	72.2	
No	22	27.8	
Post-school education			
None	12	54.5	
TAFE/Trade qualification	9	40.9	
Undergraduate qualification	1	4.5	
Current/completed highest school year level			
Year 9	1	1.3	
Year 10	23	29.1	
Year 11	17	21.5	
Year 12	29	36.7	
Current living			
With family	78	98.7	
Independent with support	1	1.3	

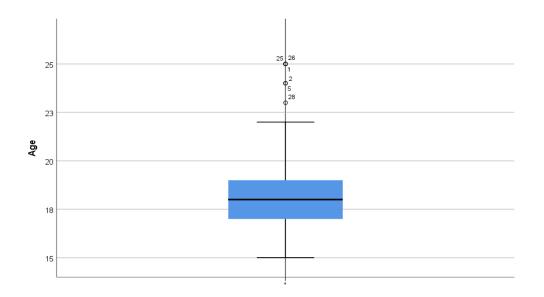


Figure 4.1. Age distribution of the sample

Apart from two participants who migrated from Indonesia and Sudan, all were born in Australia (n=77, 97.5%). The majority lived in the Adelaide major metropolitan area (n=67, 84.8%) with their family members (n=78, 98.7%). More than half of the participants (n=46, 58.2%) were in senior secondary school (Year 11 and 12) or had completed secondary school education. Around 46% (n=10) of school leavers had engaged in post school education, with certificate courses at TAFE being the most common further education activity.

4.3 Participation in the SSAYiT Program

Participant attendance over the course of the SSAYiT program varied. In the first 10week phase, an average of nine group sessions were attended with an average of six individual sessions. Average participation in the 16-week post-program phase was one individual session.

Members of group 6 were not surveyed due to concern by the program facilitators regarding the severity of their cognitive difficulties. Groups were re-numbered after excluding Group 6. The number of participants who completed the survey in each of the nine groups is presented in Table 4.2. The program was conducted by the same youth counsellor and vocational consultant for all nine groups; therefore, the nesting effect was not consequential (Moerbeek, 2004; Van Breukelen & Holling, 2013). Due to the organisation's staffing changes, the last five groups (6-9) were given only the first two surveys. Participation decreased at each data collection point, starting at 88.6% after the 10-week program, and reducing to 40.5% after 16-week individual sessions then 25.3% by three month-follow-up. The attrition rate by the end of the study was approximately 75%. It is noted that this was predominantly due to data collection ceasing as the funded program had ended, and staff had left the organisation.

Group	Baseline	10-week	16-week	3 months follow-up
1	9	9	9	9
2	5	5	5	5
3	10	9	6	2
4	4	4	4	4
5	10	10	8	0
6	6	4	0	0
7	9	6	0	0
8	10	10	0	0
9	16	13	0	0
Total	79	70	32	20

Table 4.2. Number of participants at each time point

4.4 Outcomes Over Time

This section addresses the following research questions:

- 1 Does participation in the SSAYiT program has positive impact on (a) depression, anxiety and stress, (b) psychological wellbeing over time?
- 2 Does participation in SSAYiT program change the participant's or family's perceptions of disability, confidence in gaining employment and negotiating reasonable adjustments in work place over time?
- 3 Does participation in the SSAYiT program change the number and range of education, employment and community activities participants engaged in over time?
- 4 What factors influence outcomes from participation in the SSAYiT program?

Distribution of depression, anxiety, stress, and FS scores were assessed by normality tests. A Shapiro-Wilk test (p<0.05) and visual inspection of histogram and normal Q-Q plots demonstrated that there was skewed distribution for depression, anxiety and FS scores at all four time points (Ghasemi & Zahediasl, 2012; Pallant, 2016). However, stress scores were normally distributed (Shapiro-Wilk test, p> 0.05) at all-time points, except 10-weeks. To evaluate the significance of changes over time, non-parametric tests were therefore applied, with parametric tests utilised to evaluate stress (Ghasemi & Zahediasl, 2012; Pallant, 2016).

4.4.1 Depression, Anxiety, and Stress Levels

Depression, anxiety, and stress scores represent the emotional distress of the person (Lovibond & Lovibond, 1995). The pre-program depression, anxiety, and stress levels of the sample were moderate (Lovibond & Lovibond, 1995), increased after the group sessions, and then decreased after 16-weeks individual sessions.

The repeated measures analysis of variance (ANOVA) was used to assess stress level changes over the study period, as it fulfilled the assumptions of parametric tests. Freidman test was used for depression and anxiety level changes, as both scores were not normally distributed. The changes are shown in Table 4.3.

Table 4.3.	Changes in a	depression,	anxiety, al	nd stress	over time
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	Depression ^a	Anxiety ^a	Stress ^b
	Median (IQR)	Median (IQR)	Mean (SD)
Baseline (N=70)	<mark>12 (6.0-18.5)</mark>	<mark>10 (6.0-16.5)</mark>	<mark>20.0 (8.6)</mark>
10-weeks (N=67)	<mark>14 (8.0-20.0)</mark>	<mark>12 (6.0-20.0)</mark>	<mark>23.2 (12.5)</mark>
16-weeks (N=32)	10 (4.0-17.5)	<mark>8 (4.0-14.0)</mark>	15.2 (7.9)
3 months follow-up (N=20)	<mark>11 (6.5-22.50)</mark>	<mark>11 (4.0-14.0)</mark>	<mark>15.6 (8.5)</mark>
χ ²	0.24	4.20	3.88°
p	0.08	0.24	0.03*
Effect size	0.15	0.09	0.21 ^d

a= Freidman test applied therefore median (IQR) presented b= repeated measure ANOVA applied, therefore mean (SD) presented c= F value for repeated measure ANOVA. d= partial eta square. * Significant (p<0.05) Mild – Moderate-

The results showed that there were no significant differences in either depression or anxiety levels over the study period. As the assumption of sphericity was violated for the stress level (Mauchly's test p=.042), the Greenhouse-Geisser correction was applied in repeated measures analysis of variance (ANOVA) (Kinnear & Gray, 2010).

The ANOVA test results indicated that there was a significant difference in stress levels (F _(2.268, 31.749) =3.88, p= 0.03, η_p^2 = 0.21) over the study period. This difference corresponded with a medium size effect (Cohen, 1988). A post hoc test with Bonferroni adjustment was performed in pairwise comparison of stress levels at each time point (Pallant, 2016). The comparisons are shown in Table 4.4.

Time	Mean	SE	p value	95% CI for
	difference			difference
Baseline and 10-week survey	-3.20	3.16	1.00	-12.91-6.51
Baseline and 16-week survey	4.80	2.30	0.33	-2.25-11.86
Baseline and 3 months follow-up	4.40	3.13	1.00	-5.21-14.01
10 week and 16-week survey	8.00	2.11	0.01*	1.52-14.48
10 week and 3 months follow-up	7.60	3.36	0.24	-2.726-17.93
16 weeks and 3 months follow-up	-0.40	2.01	1.00	-6.57-5.78
SE= standard error CI= confidence interval		* sig	nificant (n< ()5)

SE= standard error, CI= confidence interval * significant (p<.05)

A post hoc test revealed that there was a significant reduction in stress levels (p= 0.01) from 23.2 (moderate stress) to 15.2 (mild stress) from the 10-week to 16-week time points. This improvement was maintained by 3-month follow-up (15.6, mild stress), however did not reach statistical significance.

4.4.1 Psychological Well-Being

Psychological well-being was evaluated using the Flourishing Scale (FS). As the FS scores did not follow the normal distribution, non-parametric Friedman test was used to analyse the scores for the following labelled items as well as the total FS score. Results are presented in Table 4.5.

Item 1: I lead a purposeful and meaningful life
Item 2: My social relationships are supportive and rewarding
Item 3: I am engaged and interested in my daily activities
Item 4: I actively contribute to the happiness and well-being of others
Item 5: I am competent and capable in the activities that are important to me
Item 6: I am a good person and live a good life
Item 7: I am optimistic about my future
Item 8: People respect me

At baseline, the median FS score was 46.00 (39.75-50.25) out of a maximum possible score of 56. Post- 10-week group sessions, this level increased to 47.00 (40.75-50.00), indicating a slight improvement in wellbeing. However, after the 16-week time period, it decreased to 44.50 (36.75-49.75) and then 44.00 (36.50-48.50) by 3-month follow-up. However, the Friedman test results showed these changes were not significant (p= 0.22).

The median scores of individual FS items range from 2–6. The scores for all individual items were 6 at baseline and this was not changed after the 10-week group sessions. After the 16-week individual sessions, median scores for items seven and eight decreased while others remained unchanged. However, by 3-month follow-up, all scores had decreased below the baseline scores except items one and two (see the Table 4.5).

		Baseline Median (IQR)	10-weeks Median (IQR)	16-weeks Median (IQR)	3-months follow-up	χ^2	р	Effect size
		(N=70)	(N=66)	(N=32)	Median (IQR) (N=20)			5120
ltem 1		6.00	6.00	6.00	6.00	4.69	0.19	0.70
		(4.75-7.00)	(4.75-7.00)	(4.00-6.00)	(4.00-6.75)			
Item 2		6.00	6.00	6.00	6.00	2.13	0.55	0.32
		(5.007.00)	(5.00-6.00)	(5.00-6.75)	(5.00-6.00)			
Item 3		6.00	6.00	6.00	2.00	4.21	0.24	0.63
		(4.75-7.00)	(5.00-6.00)	(5.00-6.00)	(5.00-6.00)			
Item 4		6.00	6.00	6.00	5.00	1.60	0.68	0.38
		(5.00-7.00)	5.00-6.00	(4.25-7.00)	(5.00-6.75)			
Item 5		6.00	6.00	6.00	5.00	2.52	0.47	0.54
		(5.00-7.00)	(5.00-7.00)	(5.00-6.75)	(5.00-6.75)			
ltem 6		6.00	6.00	6.00	5.00	3.62	0.30	0.42
		(4.00-7.00)	(5.00-7.00)	(4.25 -7.00)	(4.25-7.00)			
ltem 7		6.00	6.00	5.00	5.00	2.81	0.42	0.42
		(4.00-7.00)	(5.00-7.00)	(4.00-6.00)	(4.00-6.00)			
Item 8		6.00	6.00	5.00	5.00	1.12	0.77	0.17
		(4.00-7.00)	(4.75-6.25)	(4.00-6.00)	(4.00-6.00)			
Total	FS	46.00	47.00	44.50	44.00	4.40	0.22	0.66
score		(39.75-50.25)	(40.75-50.00)	(36.75-49.75)	(36.50-48.50)			

Table 4.5. Individual median item scores in the FS

4.4.2 Perceptions of Disability, Confidence in Gaining Employment and Negotiating Reasonable Adjustments in Workplace.

The following six questions were analysed to compare each individual's perception of disability, confidence in gaining employment, and negotiating reasonable adjustments in work place over the study period (see Table 4.6).

Perception of the disability

- I believe I have a good understanding of my disability and how it impacts on my life
- I believe my family and those around me have a good understanding of my disability

Confidence in gaining employment

- I feel confident enough to apply for work right now
- I feel my disability has or will have a negative impact on me getting a job

Negotiating reasonable adjustments

• I feel confident enough to approach or speak with an employer about changes that

might be needed in the workplace to assist me to work at my best

• I feel confident enough to ask someone for help if I am struggling

	Baseline Md (IQR) N=68	After10 w Md (IQR) N=65	After 16 w Md (IQR) N=32	After 3 months Md (IQR) N=10	χ^2	p	Effect size
My understanding of disability.	4.00 (4.00-4.50)	4.00 (4.00-5.00)	4.00 (4.00-5.00)	4.00 (3.00-4.75)	1.17	0.76	0.04
Family understanding of disability.	4.00 (4.00-5.00)	4.00 (3.00-5.00)	4.00 (4.00-5.00)	4.00 (4.00-4.75)	0.77	0.85	0.03
Confident to apply work.	4.00 (2.50-4.00)	4.00 (3.00-5.00)	4.00 (3.00-4.00)	3.00 (3.00-4.00)	7.28	0.06	0.24
Disability has negative impact.	3.00 (3.00-4.00)	3.00 (2.00-4.00)	3.00 (2.00-4.00)	3.00 (3.00-4.00)	3.20	0.57	0.11
Confident ask changes at work place.	4.00 (3.00-4.00)	4.00 (3.00-4.00)	4.00 (3.00-4.00)	4.00 (3.00-4.00)	1.20	0.75	0.04
Confident to ask help.	4.00 (4.00-4.00)	4.00 (4.00-4.00)	4.00 (3.25-4.00)	4.00 (3.00-4.00)	1.87	0.60	0.06

Table 4.6. *Perception of their disability, confidence in gaining employment and negotiating reasonable adjustments in the workplace*

Md= Median

IQR= Inter Quartile Range

Baseline median scores were four out of five (indicating agreement) for all items except for the "my disability has a negative impact". However, as this statement was negatively worded, a score of three indicated a neutral response. Thus, scores for all the statements were more towards the positive at baseline. Baseline scores were unchanged throughout the study with the exception of confidence to apply for work which decreased by 3-month follow-up. However, this change was not statistically significant.

4.4.3 Participation in Employment, Education, and Community Activities

Engagement in employment, education, and community activities over time is shown in Table 4.7. At baseline, the majority of participants were attending high school (n=49, 62%) and most were still doing so by 10-week post program (n= 42, 53.2%). As indicated in section 4.3 above, surveys were not collected at the final two data collection points for the last 4 groups, 3 of which were conducted in high schools.

None of the participants changed the baseline activities by 10-week time point. However, small positive trend is noted at 16-weeks with 13 (43.3%) participants, of whom five were now in employment (38.75%) and five were volunteering (38.75%). One was engaged in a work experience placement, another was studying a course at TAFE, and a final participant was seeking employment.

By 3-month follow-up, two of the 13 had change activities again, and were now actively seeking employment. In addition, two new participants had now secured employment. The majority were male (n=8, 61.5%), from group one and three (n=10, 77.0%), completed year 12 (n=9, 69.2%), and were engaged in work experience at baseline.

However, due to lack of information on participants' activity involvement within the complete surveys, further analysis was restricted.

Activity	Baseline N (%)	10 weeks N (%)	16 weeks N (%)	3 months N (%)
Studying at high school	49 (62%)	42 (60.0%)	7 (23.3%)	0
Work experience placement	11(13.9%)	10 (14.3%)	2 (6.6%)	2 (11.7%)
Studying a course/TAFE/trade	11(13.9%)	11 (15.7%)	9 (30.0%)	6 (35.3%)
Volunteering	4 (5.1%)	4 (5.7%)	6 (20.0%)	3 (17.6%)
Participating in community/recreation	1 (1.3%)	1 (1.4%)	0	0
program or service	(0-7%)	0	0	0
Employed part-time/full-time	0	-0	5 (16.7%)	4 (23.6%)
other	2 (2.6%)	2 (2.9%)	1 (3.3%)	2 (11.8)

Table 4.7. Participants' activities

Total	78	70	30	17	
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4.4.4 Factors Influencing Outcomes from Participation in the SSAYiT Program

The influence of gender and student status on depression, anxiety, stress and FS were assessed using Friedman test. However, as there was a considerable reduction in data collected from high school students at 3-month follow-up, analysis of student status was explored over the first three time points. These results are shown in Table 4.8 and Table 4.9.

Significant differences were found in anxiety and stress levels in participants who were no longer in school (termed 'school-leavers') over the period. The Wilcoxon sign test was used to analyse these differences further (See Appendix C). Results found a statistically significant increase in stress levels in school-leavers from baseline (Md= 16) to 10-week time point (Md=20, *Z*= -2.04, p=0.04), with medium effect size (r=0.42). Moreover, the reduction in stress from 10-week (Md=20) to 16-week (Md= 16) time point was also statistically significant (Z=-3.587, p=<0.001). The effect size of this reduction was large (r=0.87). Similarly, the anxiety level of school-leavers significantly reduced from moderate to mild between the 10-week (Md=14) and 16-week time points (Md=9, Z=-3.18, p=0.01).

Even though results indicate that depression, anxiety, stress, and FS levels were higher in females compared to males, the outcomes did not differ according to gender. However, results showed that school leavers reported significant reductions in anxiety and stress between the 10-week and 16-week sessions, but this was not the case for participants who were still in school.

		Baseline <i>Md (IQR)</i> n=70 [♦]	10-weeks <i>Md (IQR)</i> n=66 [♦]	16-weeks <i>Md (IQR)</i> n=32 [◆]	3-months follow-up <i>Md (IQR)</i> n=20 [●]	χ ²	р	Effect size
Depress	sion							
	Male	<mark>8.00</mark>	<mark>13.00</mark>	<mark>10.00</mark>	<mark>14.00</mark>	5.40	0.14	0.18
		(6.00-16.0)	(7.50-18.50)	(5.00-17.0)	(8.00-26.00)			
	Female	<mark>14.00</mark>	<mark>16.00</mark>	<mark>10.00</mark>	<mark>8.00</mark>	3.00	0.39	0.20
		(10.00-20.00)	(7.00-22.00)	(4.00-22.00)	(6.00-18.00)			
Anxiety								
	Male	<mark>8.00</mark>	<mark>10.00</mark>	<mark>8.00</mark>	<mark>8.00</mark>	1.82	0.61	0.06
		(4.00-14.0)	(3.50-17.00)	(4.00-13.00)	(2.00-16.00)			
	Female	<mark>16.00</mark>	<mark>14.00</mark>	<mark>8.00</mark>	<mark>14.00</mark>	4.10	0.27	027
		(8.00-20.00)	(6.00-21.00)	(4.00-16.00)	(12.00-18.00)			
Stress								
	Male	<mark>12.00</mark>	<mark>14.00</mark>	<mark>14.00</mark>	<mark>16.00</mark>	3.78	0.29	0.03
		(6.00-20.00)	(9.50-24.50)	(14.00-18.00)	(6.00-26.00)			
	Female	18.00	18.00	14.00	14.00	7.24	0.65	0.24
		(12.00-24.00)	(12.00-26.00)	(8.00-24.00)	(12.00-24.00)			
FS score	5							
	Male	44.50	48.00	44.00	40.00	2.74	0.43	0.09
		(38.75-50.00)	(40.50-50.00)	(38.00-50.00)	(32.50-45.00)			
	Female	46.50	47.00	46.00	54.00	6.91	0.07	0.46
		(41.25-50.75)	(40.50-48.50)	(46.00-50.00)	(45.00-54.00)			

Table 4.8. Gender impact on outcomes in psychological well-being and emotional distress

* n denotes full sample size, however Friedman test analysis performed on n=20



		Baseline	10-weeks	16-weeks	χ²	р	Effect
		Md (IQR)	Md (IQR)	Md (IQR)			size
		n=70 [♦]	n=66 [♦]	n=32 [♦]			
Depress	sion						
	Student	<mark>12.00</mark> (6.00-16.00)	<mark>12.00</mark> (12.00-16.00)	<mark>9.00</mark> (3.00-13.00)	1.682	0.43	0.03
	School-leaver	<mark>16.00</mark> (9.00-29.00)	<mark>17.00 (</mark> 12.50-28.00)	<mark>15.00</mark> (7.00-24.50)	3.846	0.15	0.06
Anxiety		<mark>10.00</mark> (6.00-16.00)	<mark>10.00 (</mark> 4.00-20.00)	<mark>5.00</mark> (3.50-11.00)	1.000	0.61	0.01
	Student						
	School-leaver	<mark>14.00</mark> (4.00-20.00)	<mark>14.00</mark> (8.50-22.00)	<mark>9.00</mark> (4.00-14.50)	7.686	0.02*	0.12
Stress		<mark>12.00</mark> (10.00-20.00)	<mark>14.00</mark> (8.00-22.00)	<mark>14.00</mark> (6.00-19.00)	0.440	0.98	0.01
	Student						
	School-leaver	<mark>16.00</mark> (11.00-23.00)	<mark>20.00</mark> (12.50-31.50)	<mark>16.00</mark> (11.50-24.00)	11.81	0.003*	0.18
FS score		46.00 (41.00-50.25)	48.00(43.00-50.00)	48.50 (43.50-53.50)	3.040	0.22	0.05
	Student						
	School-leaver	44.00 (36.50-50.25)	42.00 (37.00-47.00)	41.50 (31.75-47.25)	4.000	0.13	0.06

Table 4.9. Impact of student status on outcomes in psychological well-being and emotional distress

* significance= (p<0.05) * n denotes full sample size, however Friedman test analysis performed on n=20



4.5 Summary

The research sample consisted of youth with a wide range of cognitive disabilities. Due to staffing changes, the last two surveys were not conducted in groups 6 – 9 and this led to vast reduction (75%) of survey data by three-month follow-up. As skewness and ketosis of the data did not meet the requirement of normal distribution, non-parametric tests were used to analyse all outcomes of interest other than stress.

Significant reductions in stress levels from 10-week to 16-week time periods were recorded. It was noted that no significant changes were made across other outcome measures over time, however some activity changes occurred, with an increase in participation in employment. When the data were analysed according to demographic factors, participants who were no longer in high school were found to report significant reductions in anxiety and stress levels by the end of the program.

Chapter 5: Discussion

The purpose of this chapter is to critically discuss the study findings, the implications for future research and application to the transition to adult life for youth with cognitive difficulties. In addition, the limitations of the study, recommendations for future research and conclusions are presented.

5.1 Impact of the Support SA Youth Initiative Transition (SSAYiT) Program

This study sought to evaluate the impact of the SSAYiT program on: depression, anxiety, and stress levels; psychological wellbeing; perception of disability, confidence in gaining employment, and negotiating reasonable adjustments in the workplace; and participation in employment, education and community activities. The SSAYiT program was designed and delivered by Brain Injury SA. The data was collected by this organization, by a youth counsellor and a vocational consultant. The overall goal of the program was to support the transition into adulthood for youth with cognitive difficulties. Due to a number of methodological challenges, the breadth and quality of the data available limited the ability to draw solid conclusions on the effectiveness of the program. However, some preliminary findings, discussed below, shine a light on areas which may warrant future exploration.

5.1.1 Emotional distress and psychological well-being

The first research question sought to identify and measure the impact of the SSAYiT program on emotional distress and psychological well-being.

At baseline, three subscales of Depression, Anxiety and Stress (DASS-21), varied from mild to moderate (Lovibond & Lovibond, 1995). Previous studies have documented higher levels of depression and anxiety among youth with cognitive difficulties compared to their

non-disabled peers at transition age (Austin et al., 2018; Gau et al., 2010; Santomauro, Sheffield, & Sofronoff, 2016; Vasa et al., 2014). However, a potential limitation in comparing the results across past studies is that different tools were used in these studies, such as the Glasgow anxiety scale and Glasgow depression scale.

Transition to adult life is a challenging period for youth as they make decisions on their housing, employment and further education in a tight timeframe. Therefore, mental health conditions, such as anxiety, stress and depression can be amplified during this period (Hatfield et al., 2018a; Vasa & Mazurek, 2015), and this risk is higher in youth with cognitive difficulties in transitional age (Vasa & Mazurek, 2015; Volkmar, Jackson, & Hart, 2017). Anxiety, depression and stress can make the transition to adult life more difficult as the conditions exacerbate difficulties in communication, decision-making, social integration, and work performance (Hartley, & Phelps, 2012; Leykin et al., 2011). Thus, these difficulties may reduce opportunities for employment and community participation (Eapen, 2014).

Further, Austin et al. (2018) state that anxiety and depression in the young adult with ID are interrelated with low insight (ability to evaluate one's own thoughts) and maladaptive coping behaviour. People with ID who have low insight and high maladaptive coping behaviours have been reported to have a higher level of anxiety and depression (Austin et al., 2018). The issues of insight and coping abilities of the participants were addressed by "the understanding self" and "adapting to changes" topics in health and well-being modules of the SSAYIT program. It was expected that there would be a significant reduction in emotional distress after the SSAYIT program. In contrast, results by the 10-week time point indicated that all emotional distress levels had increased from baseline. However, this increase was not significant. The increase in distress levels might be due to discussion by participants regarding their future plans and expectations during this period and becoming concerned about their

ability to achieve what was expected of them. However, to prove this assumption, further research with qualitative data will be needed. Research evidence shows that discrepancy between aspiration and expectation leads to depression of undergraduate students (Greenaway, Frye, Cruwys, & Eapen, 2015). Greenaway et al. (2015) revealed that when undergraduate students are encouraged to aspire higher, circumstances can be harmful to their psychological well-being. Further research suggests that mere positive thinking is not enough to overcome the barriers to success and, therefore, intervention is needed to address this gap. A similar type of unforeseen change was reported in another evaluation study in a different setting and a different population. In that study, cardiac patients reported an increased anxiety level unexpectedly after a motivational interviewing intervention (Chair et al., 2012).

Following the 16-week individual sessions, emotional distress scores had reduced. Of note, the reduction in stress levels at this time was statistically significant (p=0.03). Improvements in emotional distress levels might be due to the strengths and weaknesses based individual sessions, which had focused on each individual's issues in health, well-being, development of vocational skills, and vocational pathways which may have played a role in reducing the emotional distress of participants (Lee & Carter, 2012). Lee and Carter, highlight that the strength and weaknesses based individual support is an important element of successful post school transition.

Psychological well-being was measured using the Flourishing scale (FS). An expected outcome of the SSAYiT program was an increased Flourishing scale score. After the 10-week group sessions, scores had increased (although this did not reach statistical significance), which reflected the improvement of psychological well-being in participants. However, after the 16-week and 3-month follow-up, FS levels unexpectedly decreased. As above, these

changes were also not statistically significant. These findings might indicate that either the program had little impact on psychological wellbeing, or the sensitivity of the outcome measure was not adequate. Another intervention study to promote well-being in a nonclinical sample used both FS and Mental Health Continuum-Short Form (MHC-SF) to measure psychological well-being (Schotanus-Dijkstra et al., 2017). In their study, the MHC-SF scale indicated significant positive improvements in psychological well-being, while FS did not achieve significance. The authors of that study point out that when compared to the MHC-SF, the FS does not measure emotional well-being and only one item in the scale measures social well-being. It is acknowledged that there are a number of other studies which have demonstrated the reliability of this scale with similar populations (De la Fuente et al., 2017; Duan et al., 2016; Strober, 2017).

Psychological well-being is associated with several successful outcomes in human life (Lyubomirsky, King, & Diener, 2005). People who have higher psychological well-being and happiness are more likely to achieve success in many life domains, such as vocation, education, and relationships. The results of this study showed a significant positive improvement in stress levels overtime. Unfortunately, similar statistically significant improvements were not recorded against other emotional and psychological outcome variables.

5.1.2 Perception of disability, confidence in gaining employment, and negotiating reasonable adjustments in the workplace

The second research question explored the impact of the SSAYiT program on perceptions of disability, confidence in gaining employment and negotiating reasonable adjustments in workplace.

Perceptions of disability, confidence in gaining employment, and negotiating reasonable adjustments by participants remained stable from baseline to 3-month follow-up in almost all items. There was a small decrease in median confidence levels from the 16-week time period to 3-month follow-up on the item "I feel confident enough to apply for work right now". However, this decrease was not significant.

There are several possible reasons for this finding. Firstly, at baseline, participants' levels of perception and confidence was initially high on all items. It is acknowledged that these questions might not be sensitive to change. The current study used two items per outcome in the perception of the disability, confidence in gaining employment, and negotiating reasonable adjustments in the workplace. However, Dong, Fabian, & Xu (2016), used a two item scale in their study with a five points Likert scale, "readiness in requesting job accommodations" and "commitment in requesting job accommodations", to measure the intention to request workplace accommodations. Their findings showed that internal consistency of the scale was 0.75 and reliability of the two items scale was 0.94. Therefore, this suggests that using two item scale is an effective method of assess perception of disability and confidence level in gaining employment and requesting reasonable adjustments of participants.

Perception of their own disability and understanding of the impact of disability are important factors in the event of requesting reasonable adjustments in the workplace. Even though the current survey results indicated baseline scores for confidence in gaining employment and negotiating reasonable adjustments were high, the literature shows that disclosing disability and requesting reasonable adjustments in the workplace or further studying is a very challenging task for youth with disabilities (Georgiou, Espahbodi, & de Souza, 2012; Lindsay, 2011; Van et.al., 2015). Lindsay, Cagliostro and Carafa (2017), identified

the poor perception of own disability and the severity of the disability are great barriers to disclose the disability in the workplace. The SSAYiT program included lessons and activities to improve understanding of own disability, communication skills in workplace and work place rights, which are supported to disclose the disability and asking reasonable adjustments. A similar 18-week intervention the Postschool Achievement Through Higher Skills (PATHS) for female high school students with disability showed an increased awareness of disability issues in carreer planing (Lindstrom, Doren, Post, & Lombardi, 2013). Similar to the SSAYiT program, PATHS also delivered modules focussing the career development for young women with disabilities in transition from school to adult life, include self-awareness, disability issues, gender identity and career and college. Lindstrom and group had included 65 female high school students with a disability and 32 typically developing female students in a control group. Further, they had used mixed methods to analyse the effectiveness of the PATHS program.

Although the current study did not show a significant improvement in perception of disability, confidence in gaining employment, and negotiating reasonable adjustments in the workplace, similar types of interventions in other studies have shown improvements in self-awareness of disability.

5.1.3 Participation in employment, education, and community activities

The third research question focused on participation in education, employment and community activities.

More than half of the sample consisted of secondary school students. Therefore, the predominant activity of participants at baseline was studying at high school. Three out of the last four groups which did not receive the 16-week survey and 3-month follow-up were high school student groups. Thus, a large proportion of high school students were no longer participating at the end of the study. By 3-month follow-up, none of the participants were in high school. No changes were recorded in their baseline activities by the 10-week survey. This finding could be because of the short time period which might not be long enough to expect a change, such as being employed or entering into post-school education. However, a total of 15 participants had commenced new activities by the three-month follow-up. The majority who changed activities were in work experience (placement) at baseline and then changed to employment or volunteering by the 16-week time point and 3-month follow-up. Successful engagement with a job placement or paid employment is one of the central aims of the SSAYiT program, and participation in the program for those 15 youth who commenced new employment and volunteer works afterward may have been assisted or encouraged through their involvement with the program.

5.1.4 Factors which may influence outcomes

Even though gender did not show significant difference in outcomes of emotional distress and psychological well-being, participants who were no longer in high school had significantly reduced anxiety and stress levels over time.

School-leavers had higher levels of emotional distress in comparison to high school students over the period of study. Of interest, school-leavers also reported significant reductions in stress and anxiety between 10 and 16-week points. However, further assessment of influencing factors was restricted due to the significant reduction of survey completers at the end of the study.

5.2 Limitations

As with all research, this study has some noteworthy limitations. Foremost is the important limitation that the survey was not given to participants in groups 6-9 at the 16-week and 3-month follow-up time points as staffing levels had changed at the end of the funding period. Consequently, these data were unavailable for analysis.

In addition, issues such as missing data compromise and limit the analysis. The final sample size following data cleaning was smaller than anticipated. The final sample size was not large enough to compensate for the influence of "non-completers", and compromises the ability to generalise the results, affecting the external validity of the study (O'Dwyer, 2014).

Another limiting factor is that due to limited funding and resources the study did not employ a control group. Thus, it could not eliminate the influence of external events during the study period, such as stressful events, school assessments or participation in other programs that also focus on supporting transition (Torgerson, 2008).

Further, participants were self-selected rather than randomly selected. Data was collected by the program facilitators through interviewer administered surveys. Therefore, selection bias and interviewer bias could not be eliminated (Creswell, 2014), which can impact on the validity of the findings.

The short time-frame available for data collection represents a limitation, which restricted the capture of large-scale changes such as "going to university" or "being

employed". The most useful research done to evaluate interventions on post school transition to employment are prospective longitudinal studies (Farnon et al., 2017; Schall et al., 2015) or retrospective studies (Schall et al., 2015) which follow participants for 1-4 years.

The heterogeneity of the group may also have been a limitation in this study. The sample consisted of youth with a wide range of disabilities and cognitive difficulties which were self-reported only. It is acknowledged that type of disability and level of cognitive functioning can impact participation in a range of activities such as employment, education and community roles (Lindsay, 2011; Payne et al., 2018). Payne et al. (2018), found that people with TBI who had slow processing speed and memory difficulties were not engaged in productive activities, such as employment, education, or community activities, compared to people with other types of cognitive difficulties.

Further, most questions in the survey are Likert scale type. However, understanding of the Likert scale type questions for individuals with ID is doubtful. Hartley and McLean, (2006), found that Likert scale type questions causes response bias. They highlight the value of providing pictorial representations of response alternatives to assist people with ID in distinguishing the subtle differences among responses.

In the current study, activity involvement had been assessed by a single question with ten choices. Even though the question mentioned "tick all that apply", all except two selected only one activity. In the excel spreadsheet received, multiple responses were recorded as 'no change', flagging some concerns regarding the integrity of the survey completion process. Multiple choice questions (MCQs) are subject to chance "success," especially when the number of choices is less (Dehnad, Nasser, & Hosseini, 2014; Rodriguez, 2005). A meta-analysis of the empirical literature on the number of options per MCQ found that the optimal response can be achieved by three options per question (Rodriguez, 2005). Asking one

question on involved activities in this study did not provide enough information on participants' engagement in employment, education and community activities. If open-ended questions were included in this section, more informative and reliable responses could have been achieved (Knapp, 2018). Therefore, lack of more extensive information on involved activities restricted the deep analysis of activity involvement and range of participants' activities.

5.3 Recommendations

A randomized controlled trial is the ideal methodology for intervention research since it eliminates possible selection bias and provides a control group against which to assess the outcomes (Walliman, 2018). Even though the researcher in this study had the intention to assess the impact of the SSAYiT program on employment, education and community participation, results were limited due to incomplete data sets, and a short time period of follow-up. A longitudinal, case-control research with minimum one-year follow-up is recommended to overcome these weaknesses in the future research (Creswell, 2014).

In the original study design, it was intended that data on individual goal setting be collected by staff not directly involved in the delivery of the program through the use of repeated the Goal Attainment Scale (GAS). This scale has been used in evaluating programs and services such as rehabilitation (Eftekhar, Mochizuki, Dutta, Richardson, & Brooks, 2016), education (Fronczek, Rouhana, & Kitchin, 2017), and life-skills (Keenan, King, Curran, & McPherson, 2014). Unfortunately, this data was not routinely collected for analysis, however would make a valuable addition for future studies on the effectiveness of transition programs.

To elevate the response bias in Likert scale questionnaires and difficulties in explain in face to face interview, some adjustment to the visual presentation of the response alternatives could be considered in future research of this nature (Hartley & McLean, 2006).

The results of this evaluation study suggested that emotional distress measures (i.e. depression, anxiety, and stress) increased (although findings were not significant). This is a previously documented response to interventions which target major life changes (such as transition), and should be anticipated by service providers who may need to accommodate this tendency and ensure appropriate counseling and support during this period.

5.4 Conclusion

The findings suggest that participation by the 16-week time-point in the SSYiT program may improve stress levels in youth with cognitive difficulties. Moreover, significant reduction in stress and anxiety levels were identified after the 16-week individualized session time period in school-leavers rather than higher school students. In addition, there were cases of participants engaging in new activities in employment, study and work experience at the end of the program. Although the data available for analysis was not complete, these are interesting preliminary findings for future exploration, and could be targeted in future evaluation studies of transition programs for youth with cognitive difficulties.

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Appendix A

Baseline Survey

Part	ticipant Name:						
Part	ticipant Number:						
Date	e:						
	·						
1.	What is your postco	ode?		-			
2	What is your goods	*2					
۷.	2. What is your gender?						
3.	3. What is your date of birth?						
4.	In which country were you born?						
	Australia						
	Other – please speci	fy					
Do you speak a language other than English at home? (If more than one lan indicate the one that is spoken most often)							
		it is spoken in	iost oiteil)				
	No, English only						
	Yes, other – please s	specify					
£	How well do you sp	oak English?					
0.		ear English?					
	Very well						
	Well						

Not well
Not at all

7.	Are	you c	of Aborigina	al or	Torres	Strait	Islander	origin?

No 🗖

Yes, Aboriginal

- Yes, Torres Strait Islander
- **8. What is your ancestry?** (for example: English, Scottish, South African, Italian, Malaysian, Vietnamese etc). Provide more than one ancestry if necessary.

Ancestry: _____

9. Do you currently go to High School? Yes 🗆 No 🗖

If yes, what year level are you now in?

If no, what was the highest year level you completed?

10. If you are no longer at school, what study have you done since school?

None	
TAFE/Trade qualification	□
Undergraduate qualification	□
Postgraduate qualification	□
Other (please indicate)	□

11. Where do you currently live?

At home with family	
Independently without support	
Independently with support	
Supported accommodation	

Other comments:

12. What educational, community and vocational activities are you <u>currently</u> involved in? (please tick all that apply)

Studying at High School	o
Studying a course/TAFE/trade	□
Studying at University	□
Work experience placement	□
Employed part-time (hrs p/week)	٥
Employed full-time (hrs p/week)	
Volunteering (hrs p/week)	□
Participating in community/recreation program/service	n □
Family/Home duties	□
Other (please indicate)	□

13. Diagnosis: How would you best describe your disability? (please tick all that apply)

Acquired brain injury (ABI)	□
How long ago was the injury?	
Autism spectrum disorder (ASD)	□
Attention Deficit Hyperactivity Disorder (ADHD)	□
Mental health difficulties	□
Other	o

14. Please circle a response for each of the following questions: Questions in red not included in research analysis

	Questions in red not included in re	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
1.	I believe I have a good understanding of my disability and how it impacts on my life	1	2	3	4	5
2.	I believe my family and those around me have a good understanding of my disability	1	2	3	4	5
3.	I believe that overall the community has a good understanding of my disability	1	2	3	4	5
4.	I feel confident enough to apply for work right now	1	2	3	4	5
5.	I feel I need some support to gain employment or keep employment	1	2	3	4	5
6.	I feel that I have been well supported to gain employment in the past	1	2	3	4	5
7.	I feel my disability has or will have a negative impact on me getting a job	1	2	3	4	5
8.	I feel my disability has or will have a positive impact on me getting a job	1	2	3	4	5
9.	I feel that there might be a need to make some changes in a workplace to assist me to work to at my best	1	2	3	4	5
10.	I feel confident enough to approach or speak with an employer about changes that might be needed in the workplace to assist me to work at my best	1	2	3	4	5
11.	I feel confident enough to ask someone for help if I am struggling	1	2	3	4	5
12.	I tend to hide or not disclose my disability if I feel it will disadvantage me	1	2	3	4	5
13.	I feel that telling people that I have a disability will make it harder for me to get employment	1	2	3	4	5
14.	I feel that understanding disability is very important for employers and staff in workplaces	1	2	3	4	5

15. Rosenberg's Self-esteem Scale- deleted Please circle a response for each of the following questions:

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	I feel that I am a person of worth, at least on an equal plane with others.	4	3	2	1
2.	I feel that I have a number of good qualities.	4	3	2	1
3.	All in all, I am inclined to feel that I am a failure.	4	3	2	1
4.	I am able to do things as well as most other people.	4	3	2	1
5.	I feel I do not have much to be proud of.	4	3	2	1
6.	I take a positive attitude toward myself.	4	3	2	1
7.	On the whole, I am satisfied with myself.	4	3	2	1
8.	I wish I could have more respect for myself.	4	3	2	1
9.	I certainly feel useless at times.	4	3	2	1
10.	At times I think I am no good at all.	4	3	2	1

16. Flourishing Scale © Diener & Biswas-Diener (2009)

Below are 8 statements with which you may agree or disagree. Please indicate your agreement with each item by circling a response for each statement.

		Strongly agree	Agree	Slightly agree	Neither agree nor disagree	Slightly disagree	Disagree	Strongly disagree
1.	I lead a purposeful and meaningful life	7	6	5	4	3	2	1
2.	My social relationships are supportive and rewarding	7	6	5	4	3	2	1
3.	I am engaged and interested in my daily activities	7	6	5	4	3	2	1
4.	I actively contribute to the happiness and well- being of others	7	6	5	4	3	2	1
5.	I am competent and capable in the activities that are important to me	7	6	5	4	3	2	1
6.	I am a good person and live a good life	7	6	5	4	3	2	1
7.	I am optimistic about my future	7	6	5	4	3	2	1
8.	People respect me	7	6	5	4	3	2	1

17. DASS-21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

0 – Did not apply to me at all – NEVER

- 1 Applied to me to some degree, or some of the time SOMETIMES
- 2 Applied to me a considerable degree, or a good part of time OFTEN
- 3 Applied to me very much, or most of the time ALMOST ALWAYS

		for office				lice	e <u>use</u>				
		Ν	S	0	AA		D	Α	S		
1	I found it hard to wind down	0	1	2	3						
2	I was aware of dryness of my mouth		1	2	3						
3	I couldn't seem to experience any positive feeling at all	0	1	2	3						
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3						
5	I found it difficult to work up the initiative to do things	0	1	2	3						
6	I tended to over-react to situations	0	1	2	3						
7	I experienced trembling (eg, in the hands)	0	1	2	3						
8	I felt that I was using a lot of nervous energy	0	1	2	3						
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3						
10	I felt that I had nothing to look forward to	0	1	2	3						
11	I found myself getting agitated	0	1	2	3						
12	I found it difficult to relax	0	1	2	3						
13	I felt down-hearted and blue	0	1	2	3						
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3						
15	I felt I was close to panic	0	1	2	3						
16	I was unable to become enthusiastic about anything	0	1	2	3						
17	I felt I wasn't worth much as a person	0	1	2	3						
18	I felt that I was rather touchy	0	1	2	3						
19	I was aware of the action of my heart in the absence of physical exertion (eg sense of heart rate increase, heart missing a beat)	0	1	2	3						
20	I felt scared without any good reason	0	1	2	3						
21	I felt that life was meaningless	0	1	2	3						
L			1	То	tals	J					

	Goal Attainment Scaling Goals					
	<u>Goal 1:</u>	<u>Goal 2:</u>	<u>Goal 3:</u>			
Time Line						
Level of Attainment						
Much less -2 than expected						
Somewhat less -1 than expected						
Expected level 0 of outcome						
Somewhat more +1 than expected						
Much more +2 than expected						
Level achieved & comments:						



Appendix B

Post-Program Survey

Participant Name:					
Participant Number:					
Date:					
Circle data collection poir	nt:				
post 10-week group ses	ssion /	post 16-	week support	1	3 month follow-up

1. What educational, community and vocational activities are you <u>currently</u> involved in? (please tick all that apply)

Studying at High School	□
Studying a course/TAFE/trade	□
Studying at University	
Work experience placement	
Employed part-time (hrs p/week)	
Employed full-time (hrs p/week)	□
Volunteering (hrs p/week)	□
Participating in community/recreatio program/service	n □
Family/Home duties	□
Other (please indicate)	□

2. Please circle a response for each of the following questions:

_		Strongly disagree	Disagree	Unsure	Agree	Strongly agree
1.	I believe I have a good understanding of my disability and how it impacts on my life	1	2	3	4	5
2.	I believe my family and those around me have a good understanding of my disability	1	2	3	4	5
3.	I feel confident enough to apply for work right now	1	2	3	4	5
4.	I feel my disability has or will have a negative impact on me getting a job	1	2	3	4	5
5.	I feel confident enough to approach or speak with an employer about changes that might be needed in the workplace to assist me to work at my best	1	2	3	4	5
6.	I feel confident enough to ask someone for help if I am struggling	1	2	3	4	5

3. Rosenberg's Self-esteem Scale Please circle a response for each of the following questions:

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	I feel that I am a person of worth, at least on an equal plane with others.	4	3	2	1
2.	I feel that I have a number of good qualities.	4	3	2	1
3.	All in all, I am inclined to feel that I am a failure.	4	3	2	1
4.	I am able to do things as well as most other people.	4	3	2	1
5.	I feel I do not have much to be proud of.	4	3	2	1
6.	I take a positive attitude toward myself.	4	3	2	1
7.	On the whole, I am satisfied with myself.	4	3	2	1
8.	I wish I could have more respect for myself.	4	3	2	1
9.	I certainly feel useless at times.	4	3	2	1
10.	At times I think I am no good at all.	4	3	2	1

4. Flourishing Scale © Diener & Biswas-Diener (2009)

Below are 8 statements with which you may agree or disagree. Please indicate your agreement with each item by circling a response for each statement.

		Strongly agree	Agree	Slightly agree	Neither agree nor disagree	Slightly disagree	Disagree	Strongly disagree
1.	I lead a purposeful and meaningful life	7	6	5	4	3	2	1
2.	My social relationships are supportive and rewarding	7	6	5	4	3	2	1
3.	I am engaged and interested in my daily activities	7	6	5	4	3	2	1
4.	I actively contribute to the happiness and well- being of others	7	6	5	4	3	2	1
5.	I am competent and capable in the activities that are important to me	7	6	5	4	3	2	1
6.	I am a good person and live a good life	7	6	5	4	3	2	1
7.	I am optimistic about my future	7	6	5	4	3	2	1
8.	People respect me	7	6	5	4	3	2	1

5. DASS-21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <u>over the past week</u>. There are no right or wrong answers. Do not spend too much time on any statement.

0 – Did not apply to me at all – NEVER

- 1 Applied to me to some degree, or some of the time SOMETIMES
- 2 Applied to me a considerable degree, or a good part of time OFTEN
- 3 Applied to me very much, or most of the time ALMOST ALWAYS

						for	offic	e us	е
		Ν	S	0	AA		D	Α	S
1	I found it hard to wind down	0	1	2	3				
2	I was aware of dryness of my mouth	0	1	2	3				
3	I couldn't seem to experience any positive feeling at all	0	1	2	3				
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3				
5	I found it difficult to work up the initiative to do things	0	1	2	3				
6	I tended to over-react to situations	0	1	2	3				
7	I experienced trembling (eg, in the hands)	0	1	2	3				
8	I felt that I was using a lot of nervous energy	0	1	2	3				
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3				
10	I felt that I had nothing to look forward to	0	1	2	3				
11	I found myself getting agitated	0	1	2	3				
12	I found it difficult to relax	0	1	2	3				
13	I felt down-hearted and blue	0	1	2	3				
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3				
15	I felt I was close to panic	0	1	2	3				
16	I was unable to become enthusiastic about anything	0	1	2	3				
17	I felt I wasn't worth much as a person	0	1	2	3				
18	I felt that I was rather touchy	0	1	2	3				
19	I was aware of the action of my heart in the absence of physical exertion (eg sense of heart rate increase, heart missing a beat)	0	1	2	3				
20	I felt scared without any good reason	0	1	2	3				
21	I felt that life was meaningless	0	1	2	3				
		•		To	tals				

Goal Attainment Scaling Goals								
	<u>Goal 1:</u>	Goal 2:	Goal 3:					
Times Line								
Time Line								
Much less -2								
than expected								
Somewhat less -1								
than expected								
Expected level								
0 of outcome								
Somewhat more								
+1 than expected								
Much more								
+2 than expected								
Level achieved &								
comments:								

Subject: 7524 SBREC - Approval Notice (9 December 2016)

Date: Friday, 9 December 2016 at 11:58:58 AM Australian Central Daylight Time

From: Human Research Ethics

To: Michelle Bellon

Priority: High

Dear Michelle,

Your ethics application was considered by the Low Risk Sub-Committee of the <u>Social and</u> <u>Behavioural Research Ethics Committee (SBREC)</u> at Flinders University and was granted approval. Your ethics approval notice can be found below.

APPROVAL NOTICE

Project No.:	75	524			
Project Title:				ive Transition Program (SS n in a South Australian you	, 0
Principal Researcher:		Dr Miche	elle Bello	n	
Email:		michelle.	bellon@	flinders.edu.au	
Approval Date:	9 Dece	mber 201	6	Ethics Approval Expiry Date:	31 December 2019

The above proposed project has been **approved** on the basis of the information contained in the application and its attachments.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

 the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email <u>human.researchethics@flinders.edu.au</u>.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **9 December** (approval anniversary date) for the duration of the ethics approval using the report template available from the <u>Managing Your Ethics Approval</u> SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request <u>and</u> an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **9 December 2017** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

change of project title;

• change to research team (e.g., additions, removals, principal researcher or supervisor change);

- changes to research objectives;
- changes to research protocol;
- · changes to participant recruitment methods;
- · changes / additions to source(s) of participants;
- · changes of procedures used to seek informed consent;
- · changes to reimbursements provided to participants;

- changes / additions to information and/or documentation to be provided to potential participants;

- changes to research tools (e.g., questionnaire, interview questions, focus group questions);

• extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the <u>Managing Your Ethics Approval</u> SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted <u>prior</u> to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or <u>human.researchethics@flinders.edu.au</u> immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards Rae

Mrs Andrea Fiegert and Ms Rae Tyler Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley Telephone: +61 8 8201-5466 | email: <u>peter.wigley@flinders.edu.au</u> <u>Research Services Office</u> |Union Building Basement Flinders University Sturt Road, Bedford Park | South Australia | 5042 GPO Box 2100 | Adelaide SA 5001

CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A This email and attachments may be confidential. If you are not the intended recipient, please inform the sender by reply email and delete all copies of this message.

Appendix D

Pairwise comparison of anxiety and stress levels on participants were no longer in school

Table 4.10. Pairwise comparison of stress level in school leavers

	Md (IQR)	Ζ	р	ES
Stress baseline(n=20)	16.00 (11.00-23.00)	-2.036	0.04*	0.48
10-week stress (n=18)	20.00 (12.50-31.50			
Baseline Stress (n=20)	16.00 (11.00-23.00	-1.740	0.08	4.12
16-week stress (n=17)	16.00 (11.50-24.00)			
10-week stress (n=18)	20.00 (12.50-31.50	-3.587	0.001*	0.87
16-week stress (n=17)	16.00 (11.50-24.00)			

Table 4.11. Pairwise comparison of anxiety level in school leavers

	Md (IQR)	Ζ	p	ES
anxiety baseline(n=20)	14.00 (4.00-20.00)	-1.518	0.13	0.36
10-week anxiety (n=18)	14.00 (8.50-22.00			
Baseline anxiety (n=20)	14.00 (4.00-20.00)	-0.563	0.57	0.136
16-week anxiety (n=17)	9.00 (4.00-14.50			
10-week anxiety (n=18)	14.00 (8.50-22.00	-3.180	0.01*	0.77
16-week anxiety (n=17)	9.00 (4.00-14.50			