

Adults with Autism Spectrum Disorder: Experiences Related to Post-secondary Education,
Employment, and Supports

Anastasia H. Anderson

Master of Research

Master of Special Education

Bachelor of Laws

Graduate Diploma in Legal Practice

Bachelor of Economics

Macquarie University

Faculty of Arts

Department of Educational Studies

August 2020

This thesis is presented for the degree of Doctor of Philosophy

TABLE OF CONTENTS

REQUIREMENTS AND FORMAT OF A THESIS BY PUBLICATION FOR THE DOCTOR OF PHILOSOPHY 2020.....	iii
SYNOPSIS.....	iv
STATEMENT OF ORIGINALITY AND CANDIDATURE	vii
STATEMENT OF CONTRIBUTION.....	viii
ACKNOWLEDGEMENTS.....	x
 Chapter 1: Introduction	 1
Chapter 2: An On-Line Survey of University Students with Autism Spectrum Disorder in Australia and New Zealand: Characteristics, Support Satisfaction, and Advocacy	 53
Appendix 1: Survey: The Experiences of University Students with ASD	72
Chapter 3: Perspectives of Former Students with ASD from Australia and New Zealand on Their University Experience.....	 94
Chapter 4: A Systematic Literature Review of Empirical Research on Post-Secondary Students with Autism Spectrum Disorder	 113
Chapter 5: A Qualitative Study of the Employment Experiences of Former University Students on the Autism Spectrum from Australia and New Zealand.....	 143
Chapter 6: Conclusion.....	185
 APPENDICES	 195
Appendix A: Ethics Approval for Chapter 2.....	196
Appendix B: Ethics Approval for Chapters 3 and 5.....	199
Appendix C: Survey of University Students	201
Appendix D: Perspectives of University Students with Autism Spectrum Disorder ...	223
Appendix E: Interview Questions for Former University Students with ASD from Australia and New Zealand	 239
Appendix F: Codebook for Qualitative Study of Former University Students on the Autism Spectrum.....	 248

REQUIREMENTS AND FORMAT OF A THESIS BY PUBLICATION FOR THE DOCTOR OF PHILOSOPHY 2020

Doctor of Philosophy – Thesis by Publication Model

A thesis must form a distinct contribution to knowledge either by the discovery of new facts or by the exercise of independent critical power. The thesis should be focused on a single project or set of related questions and should present an integrated body of work, reflecting a coherent program of research.

A thesis by publication would typically include:

- An introductory chapter providing a coherent overview of the background to the thesis, the research questions, and the structure and organisation of the remaining chapters. The distinct contribution of the thesis should be clearly identified.
- Several chapters each written in the format of self-contained journal articles. These chapters can be published, in press or in submission ready format. Where articles are published, they do not need to be reformatted for inclusion in the thesis. Each chapter should be prefaced by a brief introduction outlining how the chapter fits into the program of research and, in the case of jointly authored chapters, the student's contribution should be clearly specified.
- A final chapter providing an integrative summary and conclusion, drawing together all the work described in the other parts of the thesis, and relating this back to the issues raised in the introduction.

For further details see information refer to the Higher Degree Research website:

<https://students.mq.edu.au/study/my-research-program/before-submission-and-prep>

SYNOPSIS

Autism spectrum disorder (ASD) is a neurological condition characterised by poor communication and social interaction skills, and restricted interests and behaviours. These characteristics may impact the university and post-university experiences of students with ASD. Indeed, university completion rates in this group remain low despite ability and strengths, and rates of unemployment and underemployment are much higher than the general population of workers. Though research has since increased, at the time this thesis began research on the university and employment experiences of students with ASD was very limited, especially from Australia and New Zealand.

To address the need for more research that might identify possible reasons for the poor outcomes, and ways of addressing their concerns, four related studies were conducted. The first study was an on-line survey of 102 current undergraduate and post-graduate Australian and New Zealand university students with ASD (chapter 2). It confirmed several key findings revealed in prior smaller studies. Namely, that students with ASD study a broad range of disciplines and have diverse strengths and challenges. It was found that despite high satisfaction ratings, most participants used only a few supports, possibly suggesting a mismatch of needs and supports. They further indicated that their greatest concerns were academic requirements and mental health, and the rate of self-reported suicidal ideation and self-harm was very high. This study was the largest survey of current university students with ASD at the time it was published, and the participants were drawn nationwide from Australia and New Zealand.

Qualitative methods were used to investigate the university and employment experiences of 11 Australian and New Zealand former university students and their significant others. The university experiences are reported in chapter 3 and the employment experiences in chapter 5. Issues that were analysed included reasons for completion and non-

completion, perceptions of strengths, difficulties and supports, coping strategies, and university structural and organisational issues. The participants' suggestions for future students and their recommendations for making universities more autism friendly were a key contribution of the research. In addition, it was noted that most participants had made slow progress due to having changed their study discipline and/or because they switched to part-time study to manage poor mental health and/or executive function. The possible need for transition and structured study supports at university was also identified. Factors that may facilitate student achievement were highlighted, including the need to identify student strengths, interests, weaknesses, and an appropriate discipline choice. This study contributed to the then limited research on the university experiences of students with ASD by presenting the retrospective perspectives of Australian and New Zealand university students and their significant others. Further, it illuminated several participant suggestions for improving supports and services.

The findings from a systematic literature review of 24 empirical studies of interventions used in post-secondary contexts with students with ASD are reported in chapter 4. Preliminary evidence for a range of interventions was noted but the findings are tentative. Most studies were pre-experimental, and few examined academic interventions though many students with ASD indicate academic supports are their most preferred. At the time of the research, the review was the most extensive and it included a comprehensive examination of article quality. Furthermore, the need for more studies beyond the US and UK, and for researchers to consider participant preferences when planning projects were identified.

Chapter 5 includes a report about the employment experiences of the 11 former university student participants that were described in chapter 3. While some former student participants had positive working experiences, despite many strengths and high academic

achievement, most had extensive periods of under-employment and/or unemployment, and all but one had poor mental health. Facilitators, barriers, and suggestions for improving employment prospects were provided. All former students reported that while their autism-related problems reduced over time, they nevertheless continued to some extent throughout their life, yet few had support after leaving university other than that provided by their family. The study contributed to the research by providing retrospective insights into employment experiences from a diverse range of former university students that included graduates and those who did not complete a qualification. Moreover, their very broad age range provided a cross-section of experiences across the lifespan.

STATEMENT OF ORIGINALITY AND CANDIDATURE

I certify that this thesis entitled “The Experiences of Post-Secondary Students with Autism Spectrum Disorder in Australia and New Zealand” is an original piece of research and my own work. All assistance from others in conducting the research and preparing this thesis has been appropriately acknowledged. I also certify that the work in this thesis has not been submitted for a higher degree to any university or institution other than Macquarie University. In addition, I certify that all sources of information and literature used are indicated in the thesis. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

The research presented in this thesis was approved by the Macquarie University Faculty of Human Sciences and Humanities Human Research Ethics Committee on 17 May 2018 (Reference no: 5201800294; Appendix A) and 21 August 2018 (Reference no: 5201831063862; Appendix B).

Anastasia Anderson

Date: 1 August 2020

STATEMENT OF CONTRIBUTION

This is a statement of contribution to this thesis and the co-authored papers that comprise it. The following is a list of papers written in conjunction with my academic supervisors Associate Professor Mark Carter, Associate Professor Jennifer Stephenson, and Dr. Sarah Carlon.

1. Anderson, A.H., Carter, M., & Stephenson, J. (2020). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand: Characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders*, 50, 440-454. <https://doi.org/10.1007/s10803-019-04259-8>

I am the principal author of this on-line survey study and took primary responsibility for conception, survey development, research design, data analysis and writing the manuscript, with advice from my supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

2. Anderson, A., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886-2901. <https://doi.org/10.1007/s10803-020-04386-7>

I am the principal author of this qualitative study and took primary responsibility for conception, research design, development of the interview schedules, the interviewing of all participants, conducting data analysis, and writing the manuscript, with advice from my supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

3. Anderson, A.H., Stephenson, J., Carter, M., & Carlon, S. (2019). A systematic literature review of empirical research on post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49, 1531-1558.
<https://doi.org/10.1007/s10803-018-3840-2>

I am the principal author of this systematic literature review and took primary responsibility for conception, research design, data analysis, and writing the manuscript, with advice from my supervisors Associate Professor Mark Carter, Associate Professor Jennifer Stephenson, and Dr. Sarah Carlon.

4. Anderson, A.H. Stephenson, J., & Carter, M. (under review). Anderson, A.H., Stephenson, J., & Carter, M. (under review). A qualitative study of the employment experiences of former university students on the autism spectrum from Australia and New Zealand.

I am the principal author of this qualitative study and took primary responsibility for conception, research design, development of interview schedules, the interviewing of all participants, conducting data analysis, and writing the manuscript, with advice from my supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

ACKNOWLEDGEMENTS

I am very grateful to my supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson. This thesis would not have been possible without their generosity of time, guidance, wisdom, constructive feedback, ideas, and constant encouragement. Their respectful approach made the research enjoyable, and the knowledge and skills I gained from them are invaluable.

In addition, I would like to thank the disability support officers and autism support group conveners who distributed the invitations to participate in our research. Without their input our research data could not have been collected. I also appreciate the time and care the participants took completing the surveys or participating in an interview, and their willingness to share their insights with candour. Dr Sarah Carlon also provided very helpful feedback on the survey, interview questions, and manuscripts that are presented in chapters 2 and 4. I am also grateful for the financial support provided by the Australian Government Research Training Program (RTP) Scholarship which allowed me to spend more time on my research projects.

Finally, the love and support I received from Tony, Josh, and Nick while researching and writing this thesis encouraged and sustained me.

CHAPTER 1: INTRODUCTION

Chapter Overview

The experiences of current and former post-secondary students with autism spectrum disorder (ASD) are explored in this thesis. Chapter 1 presents the background information and an overview. Definitions, an explanation of autism terminology, prevalence estimates, and a description of the models of disability that provided the theoretical framework for the research are provided. Also, the characteristics of adults and current and former post-secondary students with ASD are described. With a view to highlighting the research gaps that prompted the research questions, the extant literature on post-secondary education, interventions, and employment experiences for individuals with ASD are reviewed. Finally, the survey and qualitative research methodology, thesis structure, and chapter summaries are presented.

Purpose of the Research

The aim of this thesis is to extend understanding and knowledge about the experiences of current and former post-secondary students with autism spectrum disorder (ASD). It is anticipated that the findings may inform policy development, and staff and other stakeholders, about the strengths and needs of current and former post-secondary students with ASD. Furthermore, it is hoped that this research may provide direction for future research that may help improve educational and post-educational outcomes.

Background to the Research

Definitions

Autism spectrum disorder. Autism spectrum disorder is a lifelong neurodevelopmental condition. The cause has not been identified so a diagnosis is made with reference to the Diagnostic Statistical Manual of Mental Disorders (DSM; American Psychiatric Association [APA], 2013) or the World Health Organization International

Classification of Diseases (ICD-11, 2018). Earlier versions of the DSM and the ICD specified four separate disorders (autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified) but the lack of diagnostic consistency over time and between clinicians (Lord & Bishop, 2015) led to the current systems (DSM-5, ICD-11) which have reduced the classifications into one broad continuum, autism spectrum disorder (ASD).

There are two core features, namely: (a) difficulties with social interaction and verbal and non-verbal social communication, across multiple contexts, and (b) restricted, repetitive patterns of behaviour, interests, or activities. Sensory dysfunction was specifically recognized as an example of the restricted interest or activity criteria, and intellectual and language impairment were distinguished as possible co-occurring conditions. The DSM also highlighted the possibility of other co-occurring medical, genetic, neurodevelopmental, mental, or behavioural conditions. Finally, there is a requirement that autism symptoms be exhibited from early childhood and cause clinically significant difficulties in functioning.

Post-secondary education. Post-secondary education in this thesis refers to courses presented at nationally recognised universities, Technical and Further Education (TAFE; nationally recognised post-secondary vocational education and training in Australia), two, and four-year colleges, and further education institutes. Private short courses which do not provide a state or nationally recognised qualification were excluded.

Terminology

There are differing opinions regarding autism terminology (Kenny et al., 2016; Vivanti, 2020). Many self-advocates and researchers prefer identity-first language (e.g., autistic person; Kenny et al., 2016; <https://www.identityfirstautistic.org/>). They argue that autism is both positive and central to identity, and that person-first language (e.g., person with autism) may increase stigma as positive attributes generally precede a noun while those

that follow are typically undesirable (Gernsbacher, 2017). Further, they point out that identity-first language is a positive endorsement of autism as a difference and that it celebrates cultural neurodiversity (Robertson & Ne’eman, 2008). In contrast, those who promote person-first language point out that disability is only one component of a person’s identity, and that person-first terminology highlights the unique strengths and weaknesses of an individual that are unrelated to any diagnosis (Vivanti, 2020). In this thesis, only the participants described in the qualitative studies (chapters 3 & 5) were asked their view on this issue. There were two who preferred identity first terminology, while the remainder preferred person-first, were ambivalent, or unsure. Thus, the DSM (APA, 2013) and ICD (ICD-11, 2018) terminology “autism spectrum disorder” (ASD) and the phrase “person on the autism spectrum” are used throughout this thesis.

Prevalence Estimates

The Centers for Disease and Prevention (CDC, 2020) biennially report estimates of autism among children aged 8 years old in the US (Autism and Developmental Disabilities Monitoring [ADDM] Network). In 2020 the CDC reported a prevalence estimate of 18.5 per 1,000 (one in 54 or 1.85%), which was a significant increase from their 2002 estimate of 6.7 per 1,000 (one in 150 or 0.67%; CDC, 2020). Most commentators attribute the increase to several factors. These include greater recognition of ASD by practitioners and the community, and increased incentives for parents to seek a diagnosis due to more funding and intervention options. In addition, different versions of the DSM, better recognition of those with lower support needs (CDC, 2020; May et al., 2017; Myers et al., 2019), and diagnostic reclassification from other co-occurring diagnoses (Polyak, Kubina, & Girirajan, 2015) may also explain some of the increase. Recent estimates of co-occurring intellectual disability (IQ<70) vary greatly (30-68%; Polyak et al., 2015; Rogge & Janssen, 2019), and the CDC (2020) reported that approximately a third have co-occurring intellectual disability, but the

proportion of those with a diagnosed co-occurring intellectual disability has significantly reduced over time (Polyak et al., 2015), arguably due to the greater recognition of those with lower support needs (May et al., 2017).

The prevalence of adults with ASD in the US was recently estimated to be approximately 2.21%, or 1 in 45 (Dietz, Rose, McArthur, & Maenner, 2020), and males (3.62%) were found 4.2 times more likely to have a diagnosis than females (0.86%). Some commentators argue that the number of females with ASD may be underreported due to a possible diagnostic gender bias toward males, and Loomes, Hull, and Mandy (2017) estimated that the ratio may be closer to three males to one female.

The prevalence of ASD has also been estimated in Australia. The Australian Bureau of Statistics reported 205,200 Australians with autism in 2018. This represented a 25.1% increase above their 2015 estimate (Australian Bureau of Statistics, 2018). More specifically, out of the total national Australian population of approximately 25 million, 1.3% of males had an autism diagnosis compared with only 0.4% of females. A much smaller longitudinal study of Australian children (May, Sciberras, Brignell, & Williams, 2017) found parents and teachers reported a higher ASD prevalence rate of between 1.9% and 3.9%.

White, Ollendick, and Bray (2011) estimated the prevalence of university students with ASD. They sampled 667 students from one college in the U.S. and estimated that approximately 1% of college students may have ASD (range 0.7% - 1.9% depending on diagnostic criteria used). No similar study has been reported in Australia. However, the Australian Bureau of Statistics (ABS, 2018) reported that the percentage of people with autism who have a bachelor's degree or higher was only 8.1%, which is lower than the rate for individuals with any disability (16.1%) or those without disability (31.2%).

The number of students with ASD (and other disabilities) in post-secondary education has consistently increased (Van Bergeijk, Klin, & Volkmar, 2008) and Taylor and Seltzer

(2011) reported that nearly half of youths on the spectrum without intellectual disability attempt a post-secondary qualification. Suggested reasons for the increase include: (a) better diagnostic procedures and detection, especially for those without intellectual disability (Gobbo & Shmulsky, 2014), (b) early intervention services that enable students with ASD to matriculate (Barnhill, 2016; Pillay & Bhat, 2012; Van Bergeijk et al., 2008), (c) anti-discrimination legislation (e.g., *Americans with Disabilities Act, 1990*; *Disability Discrimination Act, 1992* [Austl.]; *Equality Act, 2010*, [UK]; VanBergeijk, Klin, & Volkmar, 2008) that mandates the availability of appropriate supports for students with disabilities at post-secondary education, and (d) increased services for post-secondary students that may have encouraged more to enrol and disclose to disability services (Gobbo & Shmulsky, 2014).

Models of Disability

This thesis was informed by the social model of disability and the autism acceptance movement. In addition, a social/advocacy framework was used. These concepts will now be described.

Social v medical model of disability. The medical and social models of disability have opposing theoretical positions. The medical model views an impairment as the source of the problem, and people with disability, their families, and the medical profession, as being responsible for managing or eliminating this problem (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). In contrast, proponents of the social model argue that disability is caused by economic, cultural, physical, or social environmental barriers (Barnes, 2003), and that society is obliged to provide accommodations that would enable people with disability to participate in all aspects of life (Oliver, 2013). The social model underpins many of the conclusions in this thesis. For example, it will be suggested that post-secondary institutions are responsible for providing teaching environments, practices, and supports that can facilitate the inclusion

of all students, including those with ASD.

Neurodiversity and the autism acceptance movement. Neurodiversity is a concept that has similarities with the social model of disability, but it focuses on neurological differences (Kapp et al., 2013). It holds that neurological differences are natural variations of humanity and that disability is the product of social and political deficiencies that fail to provide the necessary supports for inclusion (den Houting, 2019; Kapp et al., 2013; Robertson & Ne’eman, 2008). The autism acceptance movement promotes neurodiversity, self-advocacy, and the right of all individuals to access needed supports (Gobbo & Shmulsky, 2016). It emphasises the positive aspects of autism, and advocates for better supports rather than a cure. It promotes acceptance of differences and seeks recognition and respect from society for the contributions made by people with ASD (Gobbo & Shmulsky, 2016; Owren & Stenhammer, 2013; Runswick-Cole, 2014). While some commentators note there may be circumstances where adapting to a neurotypical world may have practical advantages, especially for those with co-occurring intellectual disability (Kapp et al., 2013), others argue that given appropriate physical, social, and environmental accommodations and support, all can contribute and be included in all aspects of life (den Houting, 2019).

Acceptance and understanding of ASD by the wider community have increased but are still emerging (Gobbo & Shmulsky, 2016). Thus, a pragmatic approach has been adopted in this thesis. For example, it is recognised that supports may facilitate the social pragmatic skills necessary for classroom participation or other interactions in the wider student community (and more generally), and thereby may improve the post-secondary experience (Gobbo & Shmulsky, 2016). However, it is noted that camouflaging (“monitoring and modifying behaviour to conform to conventions of non-autistic social behaviour”; Mandy, 2019, p. 1879) has risks associated with poor mental health and identity confusion (Cage & Troxell-Whitman, 2019). The complex issues around neurodiversity are thus acknowledged

in this thesis by drawing attention to the unique strengths of students with ASD and how these can greatly contribute to academic and employment success, while also noting that students with ASD may have diverse challenges. Moreover, it is argued that while society needs to provide the diverse range of supports that may be needed, it should also be more accepting of differences.

Social/advocacy framework. Creswell (2007) argued that research should include an agenda for reform that benefits the participants being studied and other stakeholders. In addition, Pelicano, Dinsmore, and Charman (2014) argued that researchers should include and prioritise research in areas that are important to the cohort being studied. In a large UK study, most adults with ASD, immediate family members, professionals, and researchers indicated that they would prefer research to focus on improving supports and services that might enhance the daily lives of people with ASD and their families (Pelicano, Dinsmore, & Charman, 2014). The research in this thesis upholds those ideals by exposing the strengths and contributions of post-secondary students with ASD with a view to increasing their recognition and the need to provide more appropriate educational and employment opportunities. In addition, diverse needs are highlighted in the hope that it may lead to improved and more individualised supports and intervention programs. Better supports and interventions may improve educational, post-educational, and other quality of life experiences of current, former, and future post-secondary students with ASD.

Characteristics of Adults with ASD without Co-occurring Intellectual Disability

Characteristics of ASD can be variable and categorising strengths or challenges may be somewhat arbitrary as functioning (positive or negative) may be dependent on context (Grove, Hoekstra, Wierda, & Begeer, 2018). Thus, the following information on strengths and challenges only seeks to highlights some characteristics that have been reported to impact the post-secondary educational and employment experiences of individuals with ASD.

Self-reported strengths. Kirchner, Ruch, and Dziobek (2016) compared the self-reported character strengths of 32 adults with ASD without intellectual disability with 32 neurotypical controls. They found that the “signature” character strengths as ranked by the participants with ASD were open-mindedness, authenticity, creativity, love of learning, and fairness. The self-reported strengths of post-secondary students with ASD that have been identified as facilitating educational outcomes are also broad and include attention to detail, strong memory, good technological skills, an intense interest in the subject they are studying, and consistency (Jansen, Petry, Ceulemans, Noens, & Baeyens, 2018).

Characteristic challenges of adults and post-secondary students with ASD.

Difficulties with social communication and interaction, and a preference for restricted interests and activities (APA, 2013) are the core characteristics of ASD. In addition, many adults with ASD, including current and former post-secondary students, have co-occurring conditions, limited independence and daily living skills (Lei, Ashwin, Brosnan, & Russell, 2020; McMorris et al., 2019), poor executive function (Jansen et al., 2018), reduced theory of mind, and weak central coherence (Bolourian, Zeedyk, & Blacher, 2018; Brewer, Young, & Barnett, 2017). There is a spectrum of ability (APA, 2013), however, and the complexity of these characteristics will now be discussed in turn.

Difficulties with verbal and non-verbal social communication and interaction. The spectrum of ability with respect to social communication and interaction is very apparent among post-secondary students with ASD (Colclough, 2016; Gurbuz, Hanley, & Riby, 2019). For example, some post-secondary students with ASD have indicated that they view their preference for aloneness as an advantage, as it affords them more study time (Colclough, 2016). Moreover, 19% of the participants in Gurbuz et al. (2019) stated that “having friends [did] not bring much to [their] life”, and 28% indicated that they had the “social skills to succeed at [their] institution”. However, other studies have revealed that many students with

ASD state that they are lonely and that they have poor mental health due to having few friends and feeling isolated on campus (Ashbaugh, Koegel & Koegel, 2017; Jackson, Hart, Brown, & Volkmar, 2018).

Class presentations and group work can be difficult for many students with ASD due to poor communication skills (MacLeod & Green, 2009; McLeod, Meanwell, & Hawbaker, 2019). Lack of friends on campus may also limit opportunities for acquiring catch-up notes from missed lectures, discussing difficult concepts outside class, and receiving reminders about upcoming assignments and exams. As many students with ASD indicate that they have poor executive function, support from friends may have been especially helpful (Dijkhuis, Sonnevile, Zermans, Staal, & Swaab, 2020; MacLeod & Green, 2009; Sarrett, 2018). Moreover, Ashbaugh et al. (2017) found that a social integration intervention for college students with ASD led to improved academic performance and college satisfaction, suggesting more research may be needed to assess the impact of social communication and interaction difficulties on academic performance.

Poor social and communication skills can also be a significant barrier to finding and maintaining employment (Anderson, Moore et al., 2017; Chen, Leader, Sung, & Leahy, 2015). Indeed, Muller, Schuler, Burton, and Yates (2003) found that social difficulties were the most common obstacle to employment success. Social communication skills are needed for preparing resumes, contacting potential employers, attending interviews, communicating with co-workers, following instructions, integrating into work culture, and using appropriate social etiquette and work language (Gal, Landes, & Katz, 2015; Muller et al., 2003; Scott et al., 2019). Further, difficulty with social communication can lead to poor relationships with work colleagues and employers (Hurlbutt & Chalmers, 2004), disappointing work appraisals (Muller et al., 2003), and feelings of social isolation (Gal et al., 2015). Evidence is emerging that interventions and supports can improve interview skills (e.g., Strickland, Coles, &

Southern, 2013), social problem-solving, and socialisation in the workplace (e.g., Bonete, Calero, & Fernández-Parra, 2015). Few adults with ASD have access to employment supports and services, however, so more may be needed, especially ones that help employers implement autism workplace accommodations (Scott et al., 2019).

Restricted interests and activities, sensory sensitivities, and other environmental issues. Although restricted interests and repetitive behaviours for most individuals with ASD tend to reduce over time, outcomes can be variable (Farley & McMahon, 2014), and sensory sensitivity and a preference for sameness and routine tends to persist into adulthood (Jansen et al., 2018). Restricted interests can be an advantage (Grove et al., 2018; Jordan & Caldwell-Harris, 2012; Ward & Webster, 2017). Strong interests can increase motivation to acquire knowledge and skills (Drake, 2014), reduce anxiety, and increase opportunities and satisfaction with leisure and socialisation (Grove et al., 2018; Jordan & Caldwell-Harris, 2012; Ward & Webster, 2017). Moreover, many post-secondary students with ASD report that having an intense interest in the topic they studied led to high academic achievement (Gurbuz et al., 2019; Van Hees, Moyson, & Roeyers, 2015). Restricted interests can also increase motivation and attention in the workplace when jobs are well matched with interests (Lorenz & Heinitz, 2014). The need to adjust to a new environment and cope with unexpected changes in routine can be a concern for both students (Knott & Taylor, 2013; Van Hees et al., 2015) and workers (Muller et al., 2003), however, and restricted interests may reduce motivation outside areas of intense interest (Koegel, Singh, & Koegel, 2010; Tops, Van Den Bergh, Noens, & Baeyens, 2017). In addition, noisy and crowded campuses (Gobbo & Shmulsky, 2012; Jackson et al., 2018) and workplaces (Black et al., 2019; Hedley et al., 2018; Hurlbutt & Chalmers, 2004) can disturb sensory sensitivities, causing a distraction, anxiety, and reduced quality of life (Madriaga, 2010). Relatively simple environmental accommodations such as dimmed lighting, quiet areas, and permitting students

and workers to wear sound cancelling headphones appear helpful (Hedley et al., 2018; Owen et al., 2016), suggesting more research on this issue may be helpful.

Co-occurring mental health conditions. Students with ASD have high rates of co-occurring conditions (e.g., anxiety, attention deficit, bipolar disorder, depression, obsessive compulsive disorder; Chandrasekhar, 2019; Pinder-Amaker, 2014). Moreover, rates of stress, anxiety, loneliness, low-mood, and life-long suicidal behaviours are much higher for students with ASD when compared to post-secondary peers without disabilities (Jackson et al., 2018). Poor mental health has been found to be correlated with academic, social, and everyday living difficulties (VanBergeijk, Klin, & Volkmar, 2008). Indeed, it is associated with lower academic achievement and college retention for the general population of students (Eisenberg, Golberstein, & Hunt, 2009) and those with ASD (McMorris et al., 2019). In addition, poor mental health can negatively impact the ability to find and maintain employment (Lizotte, 2016). Moreover, employment can contribute to stress, anxiety, anger, depression, and low self-esteem (Gillott & Standen, 2007; Hurlbutt & Chalmers, 2004). Factors which may contribute to poor mental health include difficulties with understanding social etiquette and work-related communication requirements, coping with change, and unwanted sensory stimuli. Thus, there is an apparent interrelationship between mental health and achievement (Ward & Webster, 2016). That is, the demands of university and employment can cause poor mental health, and poor mental health can reduce achievement in post-secondary education and employment (Hurlbutt & Chalmers, 2004; Ward & Webster, 2016).

Limited independence skills. Many post-secondary students with ASD report low independence and daily living skills (Fleischer, 2012). Indeed, everyday tasks (e.g., buying food, meeting appointments, living in student accommodation, cleaning, paying bills) have been reported to be a considerable burden and distraction from studying in many published

articles (e.g., Fleischer, 2012; Van Hees et al., 2015). Further, poor independence skills can reduce self-advocacy skills and the ability to find employment (Hedley et al., 2018) or ask for support when needed (Van Hees et al., 2018). This can be a concern as preliminary evidence suggests transition supports are more effective when accessed early (Chen et al., 2015).

Executive function. Johnston, Murray, Spain, Walker, and Russell (2019) found clinically impaired executive function (EF) was a co-occurring condition of a majority (64.2%) of adults with ASD, though a third may not be affected. EF controls a range of higher order thought processes and behaviours such as working memory, mental flexibility, attention, impulse control, planning, organisational skills, task initiation, and monitoring (Dijkhuis et al., 2020; Hill, 2004). These abilities are necessary for decision making, goal directed and self-regulated behaviours (Dijkhuis et al., 2020; Hill, 2004), capacity to cope with change, regulate emotions, and manage everyday living tasks (Dijkhuis et al., 2020; Robertson & Ne'eman, 2008; Shmulsky et al., 2017). There may be educational implications as poor ability to manage time or switch between tasks can reduce capability to manage multiple courses (Jansen et al., 2018; Tops et al., 2017) or to cope with large volumes of coursework (Bolourian et al., 2018; Bucaille et al., 2016; Shmulsky & Gobbo, 2013; Tops et al., 2017). Also, rigid thinking may cause difficulty with critical or abstract thinking, and with comparing competing and inconsistent viewpoints which are hallmarks of post-secondary education (Gobbo & Shmulsky, 2012; Tops et al., 2017). Tellingly, Dijkhuis et al. (2020) and Shmulsky, Gobbo, Donahue, and Banerjee (2017) both found a significant negative relationship between self-reported weak EF and academic achievement.

Vincent (2019) described the struggles of students with ASD as they transitioned out of post-secondary education and he attributed this to poor goal directed behaviours and a lack of identity achievement. In addition, EF has been implicated in poor employment outcomes due to reduced time management and task engagement, and low productivity (Anderson,

Moore et al., 2017; Chen et al., 2015; Gal et al., 2015). Thus, for a majority of current and former students with ASD, EF can have a pervasive negative impact on student and working life.

Theory of mind. Theory of mind refers to the ability to recognise that people have beliefs, desires, imagination, and emotions, and that this knowledge can be used to make inferences about our own and others' mental states (Crehan, Althoff, Riehl, Prelock, & Hutchins, 2020). Lack of theory of mind can impact capacity to understand irony, metaphors, sarcasm, and social cues (Baker-Ericzén et al., 2018). Gernsbacher and Yergeau (2019) argue that there is little empirical support for Baron-Cohen et al.'s (1988) proposition that theory of mind is an autism-specific deficit or that all people with ASD have reduced theory of mind. Some studies have found that the perspective taking ability of adults with ASD is variable, however (Crehan et al., 2020). While many individuals with ASD do *not* exhibit reduced theory of mind (Gillespie-Lynch, Riccio, Zajic, & DeNigris, 2020), and *most* adults with ASD without co-occurring intellectual disability can make simple inferences about their own mental state and that of others, *some* individuals with ASD can struggle with more complex social situations where social cues are less obvious (Ben-David, Ben-Itzhak, Zukerman, Yahav, & Icht, 2020; Mathersul, McDonald, & Rushby, 2013; Spek, Scholte, & Van Berckelaer-Onnes, 2010). Also, poor theory of mind has been reported to impact *some* post-secondary students with ASD during group work (Brewer et al., 2018), when analysing competing viewpoints, and when applying learnt strategies and processes (Tops et al., 2017). Moreover, poor theory of mind has been reported to impact employment experiences for some workers on the spectrum. For example, some studies have reported that poor theory of mind may cause difficulty with interpreting the meaning of verbal instructions, understanding work culture and relationships with management and peers, and to negatively impact work performance (Baker et al., 2018; Muller et al., 2003).

Weak central coherence. Central coherence refers to the ability to contextualise detail within a broader global processing framework (Berger, Aerts, van Spaendonck, Cools, & Teunisse, 2003; Tops et al., 2017). Some researchers dispute that weak central coherence is a commonly occurring characteristic of people with ASD (e.g., Koldewyn, Jiang, Weigelt, & Kanwisher, 2013; Ozonoff, Strayer, McMahon, & Filloux, 1994), and alternative theoretical propositions have been put forward. These include enhanced perceptual functioning (Mottron, Dawson, Soulières, Hubert, & Burack, 2006), superior ‘systemising’ in the ‘extreme male brain’ (Baron-Cohen, 2002), featured processing bias and unimpaired global processing (Hadad & Ziv, 2015), and superior contour integration (Almeida, Dickinson, Maybery, Badcock, & Badcock, 2014). These theories variously suggest that individuals with ASD may have superior local processing or a processing bias without weak global processing. However, there are many studies, including some specifically related to higher education students with ASD, that have found some individuals with ASD score more poorly on global processing assessments than their neurotypical peers (e.g., Tops et al., 2017). While weak central coherence can be an advantage, especially in the workforce where strong attention to detail can be required (Booth & Happé, 2018), it may also impose limitations. For example, weak central coherence may impede comprehension and ability to generalise information to new contexts, ignore irrelevant information, identify the main idea, separate minor and major issues, and conceptualise the context of assignment questions (Jansen et al., 2018; Tops et al., 2017).

Post-secondary Education

A university qualification predicts improved quality of life, employment, and wage prospects for the general population (Rast, Roux, & Shattuck, 2020), and many studies have found it similarly assists those with ASD (Aspect, 2013; Australian Bureau of Statistics, 2015; Baldwin, Costley, & Warren, 2014; Jackson et al., 2018; Newman et al., 2011).

However, the post-secondary completion rates of students on the autism spectrum (approximately 40%; Newman et al., 2011) are much lower than that of the general population of students (approximately 60%; Newman et al., 2011). When commencing this thesis (2017), there was very little research on current and former post-secondary students with ASD. While research has greatly increased in the intervening years, more may be needed (Accardo et al., 2019; Bakker, Krabbendam, Bhulai, & Begeer, 2020; Cage & Howes, 2020; Cage, De Andres, & Mahoney, 2020; Fabri, Fenton, Andrews, & Beaton, 2020; Jackson et al., 2018), as students with ASD are very diverse and many reported studies have very small sample sizes (e.g., Adams, Simpson, Davies, Campbell, & Macdonald, 2019; Gelbar, Shefyck, & Reichow, 2015; Kuder & Accardo, 2018).

There is very little research from Australia or New Zealand (Anderson, Stephenson, & Carter, 2017, Appendix C; Cai & Richdale, 2016; Siew, Mazzucchelli, Rooney, & Girdler, 2017). Although the Australian and New Zealand post-secondary educational sectors have much in common with those of the US and UK where most of the research in this area has been conducted, there are structural differences (see <https://www.tafecourses.com.au/>; <https://www.universitiesaustralia.edu.au/>; <https://www.universitiesnz.ac.nz/>; New Zealand Education, 2020). Furthermore, most students in Australia attend a local campus and live at home while studying (Australian Bureau of Statistics, 2013). Thus, given the apparent differences between countries, specific knowledge about the Australian and New Zealand post-secondary educational context is needed to better inform support staff and academics in those countries about the particular needs, supports, environmental conditions, and teaching practices that may be most appropriate for students with ASD in Australia and New Zealand. The information may also inform future research that includes cross-cultural analysis.

Thus, the research in this thesis seeks to contribute to the research base by exploring the experiences of university students with ASD from Australia and New Zealand and the

interventions used to support them. In addition, the employment experiences and outcomes of former students will be studied. The background information to those research projects will now be briefly summarised.

Prior Research on the Experiences of University Students with ASD

At the commencement of the research presented in this thesis there were only a limited number of surveys of current university students with ASD (Anderson, Carter, & Stephenson, 2018 [Australia], Appendix D; Cai & Richdale, 2016 [Australia]; Gelbar et al., 2015 [US]; White et al., 2011 [US]). White et al. (2011) estimated the prevalence of university students with ASD at one US college (described above) and they also pointed out a correlation between those who met the criteria for ASD and those who indicated they had social anxiety, depression, and aggression. Gelbar et al. (2015) and Cai and Richdale (2016) revealed that while post-secondary students with ASD have diverse academic, social, and emotional needs, most supports provided at post-secondary education were only academic in nature. More recent studies have also reported very high rates of poor mental health, including lifetime suicidal behaviours, and significantly worse academic, social, and physical outcomes compared to students without disabilities (Jackson et al., 2018 [US]; McLeod et al., 2019 [US]; Sarrett, 2018 [US]). Sarrett (2018), recommended that autism awareness training be available for staff, academics, and peers, and that more neurodiverse spaces and social supports on campus be provided. Finally, Sarrett (2018) highlighted the need to improve access to disability services due to many institutions having long and complicated registration processes that may dissuade some students from registering and using supports.

There were only two Australian surveys at the time the research in this thesis began. Cai and Richdale (2016) interviewed and surveyed both current post-secondary students with ASD and their parents in the state of Victoria. The student participants indicated that only their academic needs were well supported while the parent participants reported that neither

academic nor non-academic needs were adequately met. Furthermore, Cai and Richdale (2016) noted that few student participants had support to transition to university and that many had only registered with disability services after a significant problem arose. Anderson et al. (2018) conducted an online survey in New South Wales and the Australian Capital Territory and identified that a broad range of both academic and non-academic supports (e.g., alternative assessments, exam accommodations, counsellors, mentors, support groups) were available to university students with ASD. Most participants indicated that they used only a few supports occasionally, however, even though most supports were rated as helpful. They found that many students with ASD delayed registration with disability services and that a delay was associated with a slightly poorer overall self-reported rating of satisfaction with their university experience and available supports and services. The two Australian surveys were limited by small sample sizes and geographic focus. No prior studies were found from New Zealand.

Thus, a need for a larger survey with a broader geographic focus across Australia and New Zealand that might increase knowledge about demographic characteristics, strengths, weaknesses, and student satisfaction with supports, was detected. Further, more information regarding gender differences, reasons for not using or delaying support use, mental health issues, advocacy, and support access experiences was required. Finally, there was a case for identifying possible future research priorities and student perspectives on their greatest concerns.

Qualitative methods provide a framework to collect detailed descriptions of participant settings, experiences, feelings, and opinions that can be examined and analysed in-depth and for meaning (Brantlinger, Jimenez, Klingerner, Pugach, & Richardson, 2005; Creswell, 2007). Qualitative analysis can be nuanced, acknowledging diverse cultural and social contexts, and this can be particularly useful when exploring the reasons some students

do better than others in variable educational (and post-educational) contexts (Kozleski, 2017). Further, qualitative research enables participants to highlight the issues which are important to them and it can illuminate individual barriers to education and employment, as well as their diverse range of personal support needs (Kozleski, 2017).

Several qualitative studies have investigated the experience of university students with ASD (e.g., Bolourian et al., 2018; Cullen, 2015; MacLeod, 2016; Van Hees et al., 2018; Ward & Webster, 2017), but prior to the research presented in this thesis only two Australian studies had a qualitative component (Cai & Richdale, 2016; Owen et al., 2016), and no qualitative study had been conducted in New Zealand. The findings of Cai and Richdale (2016) are noted above. Owen et al. (2016) found that the built environment could have a significant impact on student social inclusion, academic performance, and health and wellbeing. Their participants revealed difficulties with sensory sensitivities to classroom acoustics, visual stimuli, and crowded and noisy spaces, and the authors suggested that the student with ASD experience could be improved greatly with modest changes to campus facilities.

As most post-secondary students with ASD do not complete their university qualifications (Newman et al., 2011) their perspective may be particularly important as they may highlight different issues from those of graduates. Importantly, the hindsight of former students may allow an overall perspective not coloured by immediate concerns. An analysis of the university experience from the perspective of former students had been conducted by Anderson and Butt (2017), Cox et al. (2017), Drake (2014), and Lee (2010). The direct recommendations of former students with ASD to future students was only reported by Van Hees et al. (2018), however. Further, only Anderson and Butt (2017) and Cox et al. (2017) included both former student participants who had completed and those who did not complete a qualification. Finally, the perspective of students with ASD and their significant other can

differ, and they can emphasise different things (Ward & Webster, 2017), yet few studies include both perspectives (Heasman & Gillespie, 2018).

In summary, when beginning the thesis there was an apparent need for more survey and qualitative research from the perspective of current and former university students with ASD from Australia and New Zealand and their significant others. Studies from the perspective of students who had withdrawn without completing a university qualification, and research that examined the employment experiences of former students were also found wanting. The findings from such research could be used to better inform staff, academics, employment agencies, and other stakeholders about student and employment strengths and support needs. This may lead to better opportunities and support development that may improve educational and employment outcomes.

Interventions Used to Support Post-secondary Students with ASD

Post-secondary institutions have increasingly recognised the need to provide supports to students, including those with and without disabilities, and most post-secondary educational institutions offer both academic and non-academic supports and services such as examination accommodations, tutors, peer mentors, and counselling (Jansen et al., 2018; Sarrett, 2018). Moreover, some campuses offer specialised services for students with ASD (Barnhill, 2016; Collegechoice ranking 2020; Sarrett, 2018). However, there is little empirical research to evaluate the effectiveness of those services (Ashbaugh et al., 2017; Jansen et al., 2018). When beginning the research reported in this thesis only one prior systematic literature review had focused on the empirical findings of interventions used to support students with ASD (Kuder & Accardo, 2018). While that study highlighted important research directions and concluded that specialist autism support programs were more likely to meet the diverse needs of students with ASD, the report was based on only eight studies and they did not analyse article quality or conduct interrater reliability on article

selection. Further, as noted above, there has been an increasing amount of new research on post-secondary students with ASD. As Kuder and Accardo's (2018) search was limited, it appeared possible that they may have missed some relevant studies. Thus, an updated review was justified to allow an assessment of the strength of evidence supporting intervention practices and to make recommendations for future research directions.

The Employment Experiences of Former University Students with ASD

A satisfying job can have a significant positive impact on quality of life, health, and well-being (Anderson, Moore, et al., 2017; Faragher, Cass, & Cooper, 2003). Specifically, employment provides financial independence, increased status and self-esteem, and opportunities to contribute to the community and interact with others (Chen et al., 2015; Fleming, Fairweather, & Leahy, 2013). However, poor employment outcomes for adults with ASD have been reported in many countries (e.g., Black et al., 2019; Australia, US, Sweden; Roux et al., 2013, US; Scott et al., 2019, scoping review of studies from Australia, Sweden, UK, & US), including Australia, where only 38% of working age adults with ASD are employed full or part time, compared with 53.4% for those with any disability, and 84.1% for those without disability (Australian Bureau of Statistics, 2018). In addition, many adults with ASD indicate that they have trouble finding a job (Muller et al., 2003), have poor mental health, feel isolated at work (Smith, Ollendick, & White, 2019), and that their individual employment outcomes decline over time (Taylor, Henninger, & Mailick, 2015). Further, outcomes for females with ASD are notably worse (Baldwin & Costley, 2016; Taylor et al., 2015).

Despite ASD being a life-long condition, and preliminary findings indicating that supports can be helpful for a range of adult issues, including mental health (Russell et al., 2019; Spek, Van Ham, & Nyklíček, 2013), executive function, social skills development (e.g., Baker-Ericzen et al., 2018; Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015;

Sung et al., 2018), and finding and maintaining employment (e.g., Anderson, Moore, et al., 2017; Hedley et al., 2017; Nicholas, Mitchell, Dudley, Clarke, & Zulla, 2018), far less support is available for adults with ASD compared to children on the autism spectrum (Anderson, Moore, et al., 2017; Flower, Sadka, Richdale, & Haschek, 2019; Hurley-Hanson, Giannantonio, & Griffiths, 2020; Wright, Wright, D'Astous, & Wadsworth, 2019). While some researchers have found a post-secondary qualification improves employment prospects (Migliore, Timmons, Butterworth, & Lugas, 2012; Rast et al., 2020; Whittenburg, Cimera, & Thoma, 2020), other studies have found that many former university students are underemployed in jobs that do not require their experience, skills, or qualifications (e.g., Baldwin et al., 2014; Chen et al., 2015), and that some are not employed at all (Taylor, Henninger, & Mailick, 2015).

When beginning the research on post-university experiences, there was only one qualitative study whose primary focus was the employment experiences of former university students with ASD (Lizotte, 2016; US). Most of the seven graduates with ASD (26-37 years) in Lizotte's (2016) study revealed that they worked in low skilled and low paying jobs in a different field to their qualification. Their social difficulties were reported to have negatively impacted their ability to find and maintain employment. Vincent (2019; UK) also examined the transition from university but he did not focus on the employment experiences. Thus, there was a clear case for a qualitative study on the employment experiences of former university students with ASD.

In summary, it was revealed that more research from a broader perspective of current and former post-secondary students with ASD was needed to provide a better understanding of the characteristics, strengths, and support needs of Australian and New Zealand post-secondary students with ASD. The requirement for an updated systematic literature review of interventions and supports that may better inform students and staff about the effectiveness

of supports and services was also identified. Finally, more research was found warranted on the employment experiences of Australian and New Zealand former university students and their significant others.

The broad research questions that guided this thesis were:

1. What are the experiences of current and former university students with ASD in Australia and New Zealand?
2. What does the extant literature reveal about interventions used to support post-secondary students with ASD?
3. What are the employment experiences of former university students with ASD in Australia and New Zealand?

Methodological Approaches

The research conducted for this thesis draws on three methodological approaches. These include a systematic literature review, an on-line survey, and a qualitative study. A brief overview of these approaches will now be presented.

Systematic Literature Review

To provide an overview and understanding of current knowledge about the supports and services used by university students with ASD, a systematic literature review on empirical research of interventions used with post-secondary students with ASD was conducted. A systematic literature review is a scientific method that seeks to minimise bias when collecting, appraising, aggregating, and interpreting data from relevant studies to answer pre-determined research questions (Schlosser, Wendt, & Sigafoos, 2007). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocol was used to guide the methodology and reporting of the literature review. The PRISMA protocol includes a statement, a 27-item checklist, and a four-phase flow diagram that aims to improve the consistency and quality of systematic reviews (Moher et al., 2009). PRISMA

also provide an explanation and elaboration document, with examples for each checklist item, that explains the meaning and rationale of their system.

Though the PRISMA protocol provides protections, there may be limitations. For example, it can be difficult to locate unpublished studies or studies not found on academic search engines, and there may be a risk of publication bias (the tendency to report “positive” findings; Gopalakrishnan & Ganeshkumar, 2013) from the published studies. A systematic literature review may also be limited by the quality of the studies reviewed, including any methodological flaws or other biases (Gopalakrishnan & Ganeshkumar, 2013; Schlosser et al., 2007). For this reason, the quality of all studies that had an experimental design were assessed. (The quality of the pre-experimental studies was not assessed for quality because the cause of their outcomes cannot be determined; Campbell and Stanley 1963). Despite these possible shortcomings, systematic literature reviews may improve reliability and they provide a summary of the extant literature that can be useful for identifying future research directions (Gopalakrishnan & Ganeshkumar, 2013; Schlosser et al., 2007).

Survey Research

Survey research can facilitate the collection and analysis of a large sample of individualised cross-sectional quantitative or qualitative data (Jones, Baxter, & Khanduja, 2013). The findings from large surveys can potentially be generalised and compared with other similar populations. For example, a survey of students with ASD could be compared to students with other disabilities or students with no disability (McLeod et al., 2019). While survey data does not directly provide information on causation, possible causal inferences may become apparent by examining patterns of association or variations in participant behaviour across the data (Bryman, 2016).

Another benefit of on-line surveys is that they can be easily distributed to a larger geographical area than paper surveys and thus may attract a larger sample size. Larger

sample sizes may enable inferential testing that can help interpret the significance of the results (Bryman, 2016). Moreover, on-line surveys can be relatively quick to conduct, and they may generate fewer data entry errors (Jones et al., 2013). Finally, on-line surveys can include prompts to ensure respondents do not miss questions, including open-ended questions. Also, as with paper surveys, respondents may be more truthful if the on-line survey is made anonymous (Bryman, 2016).

There may be limitations of surveys (postal or online), however. For example, a low response rate may reduce external validity. Drafting on-line (or postal) survey questions requires more care as neither respondents nor researchers can seek clarification. Moreover, pilot studies and the involvement of people from the target population may be necessary to test and evaluate the survey for clarity and appropriateness which can be very time consuming (Jones et al., 2013).

Qualitative Research and the Descriptive Approach

Qualitative research is a scientific approach that can be used to study a phenomenon from the perspective of those living it (Vaismoradi, Turunen, & Bondas, 2013). It can provide “rich descriptions” that instil greater depth of understanding. This can be useful during the early stages of research when existing data is too scant to suggest a hypothesis that is needed with other forms of research (Palinkas, 2015). A qualitative descriptive approach may be useful when the purpose of the research is to inform policy or intervention development with a precise description of the complex experiences and issues at stake, and to provide direction for future research (Palinkas, 2015). Qualitative descriptive reports rely on a more literal interpretation of the participants’ comments, and the analysis is presented from the participants’ point of view, with less focus on developing theory or high-level interpretations that are a feature of other qualitative methods (Sullivan-Bolyai, Bova, & Harper, 2005). The specific assumptions that apply to qualitative descriptive research will

now be described.

Philosophical assumptions. Qualitative description is a naturalistic enquiry. When using a qualitative descriptive approach, data is collected directly on the phenomenon being studied and the participant's comments are accepted at face value (Bradshaw, Atkinson, & Doody, 2017). It holds that meaning is subjective and that both the interviewer and interviewee may be influenced by their own preconceptions and experiences. My acceptance of participatory research principles and the concept of neurodiversity are acknowledged as having influenced my analysis in this thesis.

Ontological assumptions. Qualitative description assumes that individuals may have differing subjective perspectives about their "reality" due to having had varying influences from diverse prior experiences (Bradshaw et al., 2017). Reality is construed as having been constructed through language and a literal interpretation of the participants' statements (Bradshaw et al., 2017; Sandelowski, 2010).

Epistemological assumptions. Qualitative description is a naturalistic approach. It relies on verbatim participant quotes and assumes that the views of participants and researchers are subjective (subjectivism). Specifically, it acknowledges that there may be divergent interpretations from different participants about a phenomenon (Bradshaw et al., 2017). In this regards I acknowledge that being a parent of an adult with ASD may have influenced my interpretation and analysis of the findings of the research.

Methodological assumptions. Qualitative description seeks to interpret a phenomenon based on a literal and accurate description as provided by the participants. The research questions for a qualitative descriptive study are designed to explore the meaning of the participants' experiences in their environment, with the aim of informing policy and intervention development (Bradshaw et al., 2017). In this thesis, to ensure the analysis provided a faithful description of the university experience of current and former students, the

participants were asked to comment on the accuracy of their transcripts and a summary of the key findings.

Structure of the Thesis

This thesis has six chapters and four self-contained manuscripts. There are three manuscripts in journal article format and the fourth is in a format ready for journal submission. Chapters 1 and 6 are introductory and concluding chapters, respectively. Chapter overviews, which include the article publication reference or status, precede the self-contained manuscripts.

Chapter Summaries

Chapter 2

The results of an on-line survey of 102 current undergraduate and post-graduate university students with ASD from Australia and New Zealand are presented in chapter 2. The survey was the largest survey of current university students with ASD at the time of publication. Although the participants reported a broad range of strengths, they indicated far more weaknesses, which may suggest some do not recognise all their strengths, which may have implications for academic achievement. Most participants stated that they had weak executive function, sensory sensitivities, poor sleeping habits, few friends, and that they struggled with the lack of structure at university. However, mental health and academics were identified as their most significant concerns. Further, no significant differences were noted in the number of supports used by males and females. Some participant behaviours appeared problematic, however. For example, many started or switched to part-time study, an enrolment practice associated with lower completion rates for the general population of students (Norton, Cherastidham, & Mackey, 2018). Also, most only used a few supports (other than exam accommodations) despite many saying they needed them and most participants who used supports rated them as helpful. Finally, implications and suggestions

for future research were identified.

Chapter 3

A qualitative study that focused on the university experience of 11 former students with ASD from Australia and New Zealand is presented in chapter 3. A qualitative descriptive approach was used as the aim of the study was to provide an emic perspective that could be used to inform policy and intervention development. A notable feature of the study was the diversity of participants. They provided a broad range of perspectives, including high achievers and those who did not complete, recent graduates through to those close to retirement age, and significant others. All former student participants indicated that they had made slow progress as all started or switched to part-time study to manage mental health issues and/or poor executive function. Furthermore, the participants nominated factors that contributed to their completion or non-completion, coping strategies, and perceptions about supports. Finally, participant suggestions for future students and recommendations for creating more autism friendly campuses were provided, a feature found in only one prior study (Van Hees et al., 2018).

Chapter 4

Chapter 4 presents the findings from a systematic literature review of 24 empirical articles that analysed a variety of interventions that were used with post-secondary students with ASD. This review was much larger than the only other prior review by Kuder and Accardo (2018) which included only eight studies. Most of the studies reviewed were of low quality as only seven had an experimental or quasi-experimental design and this limited conclusions about intervention effectiveness. Most interventions (notably specialist mentoring and transition programs) were found to be feasible and promising, warranting future experimental research. Moreover, a need for more research on academic supports was identified, as only two studies focused on this, despite prior research finding students with

ASD prefer academic supports and rate them as their most helpful support.

Chapter 5

Chapter 5 reports the employment experiences of the participants described in chapter 3. There are very few studies on the employment outcomes of former university students with ASD and no qualitative studies on this topic from Australia or New Zealand. The broad age range of participants allowed a preliminary examination of experiences across the lifespan, which is unique to research on former university students. The findings were mixed. While some had employment success, it was notable that despite high intelligence, qualifications and/or non-work-related achievements, most former students indicated that they were unemployed or under-employed and that they struggled with poor mental health. Few indicated that they had support since leaving university apart from that provided by family members. Facilitators and barriers to employment were highlighted and implications discussed. For example, it was suggested that non-vocationally specific courses may pose more difficulties when looking for a job. It was suggested that university courses may need to include content that could increase employability skills and help students with ASD to conceptualise how a qualification could be used in the workforce. Finally, the need for university and non-university supports to help former university students find and maintain employment throughout life was discussed.

Chapter 6

Chapter 6 is a concluding chapter. The findings and analyses of all the chapters were considered to draw the conclusions. In addition, the contributions made to the research on post-secondary students with ASD, and the recommendations and suggestions for future research offered throughout the thesis, were summarised.

Summary

The purpose, rationale, and background information to the research were provided in this chapter. In addition, the broad research questions which guided the research were delineated. Finally, the thesis structure was outlined, and a summary of the chapters presented.

References

- Accardo, A. L., Bean, K., Cook, B., Gillies, A., Edgington, R., Kuder, S. J., & Bomgardner, W.M. (2019). College access, success and equity for students on the autism spectrum. *Journal of Autism and Developmental Disorders*, 49, 4877-4890.
<https://doi.org/10.1007/210803-019-04205-8>
- Adams, D., Simpson, K., Davies, L., Campbell, C., & MacDonald, L. (2019). Online learning for university students on the autism spectrum: A systematic review and questionnaire study. *Australasian Journal of Educational Technology*, 35, 111-131.
<https://doi.org/10.14742/ajet.5483>
- Almeida, R. A., Dickinson, J. E., Maybery, M. T., Badcock, J. C., & Badcock, D. R. (2014). Enhanced global integration of closed contours in individuals with high levels of autistic-like traits. *Vision Research*, 103, 109–115.
<https://doi.org/10.1016/j.visres.2014.08.015>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Americans with Disabilities Act 1990 (as amended 2008)*. 42 U.S.C § 12101 et seq. Retrieved 2 May, 2018 from <https://www.ada.gov/pubs/adastatute08.htm>
- Anderson, C., & Butt, C. (2017). Young adults on the autism spectrum at college: Successes and stumbling blocks. *Journal of Autism and Developmental Disorders*, 47, 3029–3039. <https://doi.org/10.1007/s10803-017-3218-x>
- Anderson, A.H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651-665. <https://doi.org/10.1007/s10803-017-3257-3>
- Anderson, A.H., Carter, M., & Stephenson, J. (2020). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand:

- Characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders*, 50, 440-454. <https://doi.org/10.1007/s10803-019-04259-8>
- Anderson, A.H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33–53. <https://doi.org/10.1016/j.rasd.2017.04.002>
- Anderson, A.H., Stephenson, J., Carter, M., & Carlon, S. (2019). A systematic literature review of empirical research on postsecondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49, 1531-1558. <https://doi.org/10.1007/s10803-018-3840-2>
- Anderson, A.H., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886-2901. <https://doi.org/10.1007/s10803-020-04386-7>
- Anderson, A.H., Stephenson, J., & Carter, M. (under review). A qualitative study of the employment experiences of former university students on the autism spectrum from Australia and New Zealand.
- Anderson, A., Moore, D., Rausa, V.C., Finkelstein, S., Pearl, S., & Stevenson, M. (2017). A systematic review of interventions for adults with autism spectrum disorder to promote employment. *Review Journal of Autism and Developmental Disorders*, 4, 26-38. <https://doi.org/10.1007/s40489-016-0094-9>
- Ashbaugh, K., Koegel, R.L., & Koegel, L.K. (2017). Increasing social integration for college students with autism spectrum disorder. *Behavioral Development Bulletin*, 22, 183-196. <https://doi.org/10.1037/bdb0000057>

- Autism Spectrum Australia (Aspect). (2013). *We belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism*. Retrieved from https://www.autismspectrum.org.au/uploads/documents/Research/Autism_Spectrum_WE_BELONG_Research_Report-FINAL_LR_R.pdf
- Australian Bureau of Statistics. (2013). *Australian Social Trends, 2013. Hitting the books: Characteristics of higher education students*. Retrieved 15 April 2020 from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20July+2013>
- Australian Bureau of Statistics. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings, 2018. Autism in Australia*. Retrieved 13 April 2020 from <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>
- Australian Bureau of Statistics. (2015). *Qualifications and Work, Australia, 2015. Summary of Findings. Qualifications and the Labour Market*. Retrieved 18 April 2020 from <https://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4235.0?OpenDocument>
- Baker-Ericzén, M.J., Fitch, M.A., Kinnear, M., Jenkins, M.M., Twamley, E.W., Smith, L., ... Leon, J. (2018). Development of the Supported Employment, Comprehensive Cognitive Enhancement, and Social Skills program for adults on the autism spectrum: Results of initial study. *Autism*, 22, 6-19. <https://doi.org/10.1177/1362361317724294>
- Bakker, T., Krabbendam, L., Bhulai, S., & Berger, S. (2020). First-year progression and retention of autistic students in higher education: A propensity score-weighted population study. *Autism in Adulthood*. Advance online publication. <https://doi.org/10.1089/aut.2019.0053>

- Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, 44, 2440–2449.
<https://doi.org/10.1007/s10803-014-2112-z>
- Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses: current practices. *Focus on Autism and Other Developmental Disabilities*, 31, 3-15.
<https://doi.org/10.1177/1088357614523121>
- Barnes, C. (2003). What a difference a decade makes: Reflections on doing 'emancipatory' disability research. *Disability & Society*, 18, 3-17. <https://doi.org/10.1080/713662197>
- Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences*, 6, 248-25. [https://doi.org/10.1016/S1364-6613\(02\)01904-6](https://doi.org/10.1016/S1364-6613(02)01904-6)
- Ben-David, B., Ben-Itzhak, E., Zukerman, G., Yahav, G., & Icht, M. (2020). The perception of emotions in spoken language in undergraduates with high functioning autism spectrum disorder: A preserved social skill. *Journal of Autism and Developmental Disorders*, 50, 741–756. <https://doi.org/10.1007/s10803-019-04297-2>
- Berger, H.J., Aerts, F.H., van Spaendonck, K. P., Cools, A.R., & Teunisse, J. (2003). Central coherence and cognitive shifting in relation to social improvement in high-functioning young adults with autism. *Journal of Clinical and Experimental Neuropsychology*, 24, 502–511. <https://doi.org/10.1076/jcen.25.4.502.13870>
- Black, M.H., Mahdi, S., Milbourn, B., Thompson, C., D'Angelo, A., Ström, E., ... Bölte, S. (2019). Perspectives of key stakeholders on employment of autistic adults across the United States, Australia, and Sweden. *Autism Research*, 12, 1648–1662.
<https://doi.org/10.1002/aur.2167>
- Bolourian, Y., Zeedyk, S. M., & Blacher, J. (2018). Autism and the university experience: Narratives from students with neurodevelopmental disorders. *Journal of Autism and*

Developmental Disorders, 48, 3330–3343.

<https://doi.org/10.1007/s10803-018-3599-5>

Bonete, S., Calero, M., & Fernández-Parra, A. (2015). Group training in interpersonal problem-solving skills for workplace adaptation of adolescents and adults with Asperger syndrome: A preliminary study. *Autism*, 19, 409-420.

<https://doi.org/10.1177%2F1362361314522354>

Booth, R.D., & Happé, F.G. (2018). Evidence of reduced global processing in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48, 1397–1408.

<https://doi.org/10.1007/s10803-016-2724-6>

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 1-8.

<https://doi.org/10.1177/2333393617742282>

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, 71, 195–207.

<https://doi.org/10.1177/001440290507100205>

Brewer, N., Young, R.L., & Barnett, E. (2017). Measuring theory of mind in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47, 1927–1941. <https://doi.org/10.1007/s10803-017-3080-x>

Bryman, A., (2016). *Social research methods* (5th ed). Oxford, UK: Oxford University Press.

Bucaille, A., Grandgeorge, M., Degrez, C., Mallegol, C., Cam, P., Botbol, M., & Planche, P.

(2016). Cognitive profile in adults with Asperger syndrome using WAIS-IV:

Comparison to typical adults. *Research in Autism Spectrum Disorders*, 21, 1-9.

<https://doi.org/10.1016/j.rasd.2015.09.001>

- Cage, E., De Andres, M., & Mahoney, P. (2020). Understanding the factors that affect university completion for autistic people. *Research in Autism Spectrum Disorders*, 72. Advance online publication. <https://doi.org/10.1016/j.rasd.2020.101519>
- Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, 24, 1664-1675. <https://doi.org/11.1177/1362361320918750>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49, 1899–1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher educational students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Centers for Disease Control and Prevention. (2020). *Prevalence of autism spectrum disorder among children aged 8 years. Autism and developmental disabilities monitoring network, 11 Sites, United States, 2016. Morbidity and Mortality Weekly Report (MMWR) Surveillance Summary 2020*, 69(4), 1–12. https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w
- Chandrasekhar, T. (2019): Supporting the needs of college students with autism spectrum disorder. *Journal of American College Health*, 1-4. <https://doi.org/10.1080/07448481.2019.1686003>
- Chen, J.L., Leader, G., Sung, C., & Leahy, J. (2015). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders*, 2, 115–127. <https://doi.org/10.1007/s40489-014-0041-6>

- Crehan, E., Althoff, R.R., Riehl, H., Prelock, P. A., & Hutchins, T. (2020). Brief report: Me, reporting on myself: Preliminary evaluation of the criterion-related validity of the theory of mind inventory-2 when completed by autistic young adults. *Journal of Autism and Developmental Disorders*, 50, 659–664.
<https://doi.org/10.1007/s10803-019-04278-5>
- Colclough, N. (2016). Exploring the social experiences of college students who have autism spectrum disorders. *Journal of Student Affairs*, 26, 21-32. Retrieved from
https://www.academia.edu/33063329/Exploring_the_Social_Experiences_of_College_Students_Who_Have_Autism_Spectrum_Disorders
- Collegechoice ranking (2020). Best colleges for autistic students. Retrieved April 2020 from
<https://www.collegechoice.net/rankings/best-colleges-for-students-with-autism>
- Cox, B.E., Thompson, K., Anderson, A., & Taylor, A.M., Locks, T., Morgan, L., Edelstein, J., & Wolz, A. (2017). College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, 58, 71-87. <https://doi.org/10.1353/csd.2017.0004>
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Cullen, J.A. (2015). The needs of college students with autism spectrum disorders and Asperger's syndrome. *Journal of Postsecondary Education and Disability*, 28, 89 – 101. Retrieved from <https://eric.ed.gov/?id=EJ1066322>
- Dietz, P.M., Rose, C.E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Advance online publication. <https://doi.org/10.1007/s10803-020-04494-4>
- Dijkhuis, R., de Sonnevile, L., Ziermans, T., Staal, W., & Swaab, H. (2020). Autism symptoms, executive functioning and academic progress in higher education students.

Journal of Autism and Developmental Disorders. Advance online publication.

<https://doi.org/10.1007/s10803-019-04267-8>

Disability Discrimination Act 1992 (Cth) s. 22. (Austl.)

Drake, S. (2014). College experience of academically successful students with autism.

Journal of Autism, 1, 1–4. <https://doi.org/10.7243/2054-992x1-5>

Eisenberg, D., Golberstein, E., & Hunt, J.B. (2009). Mental health and academic success in

college. *The B.E. Journal of Economic Analysis & Policy*, 9(1, article 40).

<https://doi.org/10.2202/1935-1682.2191>

Den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23, 271-273.

<https://doi.org/10.1177/1362361318820762>

Fabri, M., Fenton, G., Andrews, P., & Beaton, M. (2020). Experiences of higher education students on the autism spectrum: Stories of low mood and high resilience.

International Journal of Disability, Development and Education. Advance online publication. <https://doi.org/10.1080/1034912X.2020.1767764>

Faragher, E.B., Cass, M., & Cooper, C.L. (2003). The relationship between job satisfaction and health: A meta-analysis. *Occupational and Environmental Medicine*, 62, 105–

112. <https://doi.org/10.1136/oem.2002.006734>

Farley, M., & McMahon, B. (2014). Range of outcomes and challenges in middle and later

life. In F.R. Volkmar, B. Reichow, J. C. McPartland (Eds). *Adolescents and adults with autism spectrum disorders*. (1st ed., 211-238).

https://doi.org/10.1007/978-1-4939-0506-5_11

Fleischer, A.S. (2012). Alienation and struggle: Everyday student-life of three male students with Asperger syndrome. *Scandinavian Journal of Disability Research*, 14, 177-194.

<https://doi.org/10.1080/15017419.2011.558236>

- Fleming, A., Fairweather, J., & Leahy, M. (2013). Quality of life as a potential rehabilitation service outcome: The relationship between employment, quality of life, and other life areas. *Rehabilitation Counseling Bulletin*, 57(1), 9-22.
<https://doi.org/10.1177%2F0034355213485992>
- Flower, R., Sadka, N., Richdale, A., & Haschek, A. (2019). The Australian context: Commentary on “Mothers’ experiences of the transition of young people with autism spectrum disorder to adult care” (McMinn, Schulz, & Ludlow, 2019) and “Challenging the status quo” (Beadle-Brown & Roberts, 2019). *Research and Practice in Intellectual and Developmental Disabilities*, 6, 147-153.
<https://doi.org/10.1080/23297018.2019.1652928>
- Gal, E., Landes, E., & Katz, N. (2015). Work performance skills in adults with and without high functioning autism spectrum disorders (HFASD). *Research in Autism Spectrum Disorders*, 10, 71-77. <https://doi.org/10.1016/j.rasd.2014.10.011>
- Gelbar, N. W., Shefyck, A., & Reichow, B. (2015). A comprehensive survey of current and former college students with autism spectrum disorders. *The Yale Journal of Biology and Medicine*, 88, 45–68.
- Gernsbacher, M.A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry* 58, 859–861. <https://doi.org/10.1111/jcpp.12706>
- Gillespie-Lynch, K., Hotez, E., Zajic, M., Riccio, A., DeNigris, D., Kofner, B., ... Luca, K. (2020). Comparing the writing skills of autistic and non-autistic university students: A collaboration with autistic university students. *Autism*. Advance online publication.
<https://doi-org.simsrad.net.ocs.mq.edu.au/10.1177%2F1362361320929453>

- Gillott, A., & Standen, P. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities, 11*, 359-370.
<https://doi.org/10.1177/1744629507083585>
- Gobbo, K., & Shmulsky, S. (2012). Classroom needs of community college students with Asperger's disorder and autism spectrum disorders. *Community College Journal of Research and Practice, 36*, 40-46. <https://doi.org/10.1080/10668920903381813>
- Gobbo, K., & Shmulsky, S. (2014). Faculty experience with college students with autism spectrum disorders: A qualitative study of challenges and solutions. *Focus on Autism and Other Developmental Disabilities, 29*, 13–22.
<https://doi.org/10.1177/1088357613504989>
- Gobbo, K., & Shmulsky, S. (2016). Autistic identity development and postsecondary education. *Disability Studies Quarterly, 36*(3).
<https://doi.org/10.18061/dsq.v36i3.5053>
- Gopalakrishnan, S., & Ganeshkumar, P. (2013). Systematic reviews and meta-analysis: Understanding the best evidence in primary healthcare. *Journal of Family Medicine and Primary Care, 2*, 9-14. <https://doi.org/10.4103/2249-4863.109934>
- Grove, R., Hoekstra, R., Wierda, M., & Begeer, S. (2018). Special interests and subjective wellbeing in autistic adults. *Autism Research, 11*, 766-775.
<https://doi.org/10.1002/aur.1931>
- Gurbuz, E., Hanley, M., & Riby, D. (2019). University students with autism: The social and academic experiences of university in the UK. *Journal of Autism and Developmental Disorders, 49*, 617–631. <https://doi.org/10.1007/s10803-018-3741-4>
- Hadad, B.S., & Ziv, Y. (2015). Strong bias towards analytic perception in ASD does not necessarily come at the price of impaired integration skills. *Journal of Autism and*

Developmental Disorders, 45, 1499–1512.

<https://doi.org/10.1007/s10803-014-2293-5>

Händel, M., & Dresel, M. (2018). Confidence in performance judgment accuracy: The unskilled and unaware effect revisited. *Metacognition and Learning*, 13, 265–285.

<https://doi.org/10.1007/s11409-018-9185-6>

Heasman, B., & Gillespie, A. (2018). Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*, 22, 740-750. <https://doi.org/10.1177/1362361317708287>

Hedley, D., Cai, R., Uljarevic, M., Wilmot, M., Spoor, J.R., Richdale, A., & Dissanayake, C. (2018). Transition to work: Perspectives from the autism spectrum. *Autism*, 22, 528-541. <https://doi.org/10.1177/1362361316687697>

Hedley, D., Uljarevic, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, 21, 929-941.

<https://doi.org/10.1177/1362361316661855>

Hill, E. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences*, 8, 26-32. <https://doi.org/10.1016/j.tics.2003.11.003>

Hurley-Hanson, A. E., Giannantonio, C. M., & Griffiths, A. J. (2020). *Autism in the workplace: Creating positive employment and career outcomes for generation A*. Palgrave Macmillan. <https://doi.org/10.1007/978-3-030-29049-8>

Hurlbutt, K., & Chalmers, L. (2004). Employment and adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 19, 215-222. <https://doi.org/10.1177/10883576040190040301>

Jackson, S.L.J., Hart, L., Brown, J.T., & Volkmar, F.R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with

- autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 643-650. <https://doi.org/10.1007/s10803-017-3315-x>
- Jansen, D., Petry, K., Ceulemans, E., Noens, I., & Baeyens, D. (2018). Functioning and participation problems of students with ASD in higher education: Which reasonable accommodations are effective? *European Journal of Special Needs Education*, 32, 71-88. <https://doi.org/10.1080/08856257.2016.1254962>
- Johnston, K., Murray, K., Spain, D., Walker, I., & Russell, A. (2019). Executive function: Cognition and behaviour in adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 49, 4181–4192. <https://doi.org/10.1007/s10803-19-04133-7>
- Jones, T.L., Baxter, M.A.J., & Khanduja, V. (2013). A quick guide to survey research. *Annals of the Royal College of Surgeons of England*, 95, 5-7. <https://doi.org/10.1308/003588413X13511609956372>
- Jordan, C., & Caldwell-Harris, C. L. (2012). Understanding differences in neurotypical and autism spectrum special interests through Internet forums. *Intellectual and Developmental Disabilities*, 50, 391-402. <https://doi.org/10.1352/1934-9556-50.5.391>
- Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E., & Hutman, T. (2013). Deficit, difference or both? Autism and neurodiversity. *Developmental Psychology*, 49, 59-71. <https://doi.org/10.1037/a0028353>
- Kenny, L., Hattersley, C., Mollins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20, 442-462. <https://doi.org/10.1177/1362361315588200>
- Kirchner, J., Ruch, W., & Dziobek, I. (2016). Brief report: Character strengths in adults with autism spectrum disorder without intellectual impairment. *Journal of Autism and*

Developmental Disorders, 46, 3330–3337.

<https://doi.org/10.1007/s10803-016-2865-7>

Koegel, L.K., Singh, A.K., & Koegel, R.L. (2010). Improving motivation for academics in children with autism. *Journal of Autism and Developmental Disorders*, 40, 1057–1066. <https://doi.org/10.1007/s10803-010-0962-6>

Koldewyn, K., Jiang, Y.V., Weigelt, S., & Kanwisher, N. (2013). Global/local processing in autism: Not a disability, but a disinclination. *Journal of Autism and Developmental Disorders*, 43, 2329–2340. <https://doi.org/10.1007/s10803-013-1777-z>

Kozleski, E.B. (2017). The uses of qualitative research: Powerful methods to inform evidence-based practice in education. *Research and Practice for Persons with Severe Disabilities*, 42, 19–32. <https://doi.org/10.1177/1540796916683710>

Knott, F., & Taylor, A. (2013). Life at university with Asperger syndrome: A comparison of student and staff perspectives. *International Journal of Inclusive Education*, 18 411–426. <https://doi.org/10.1080/13603116.2013.781236>

Kuder, S.J., & Accardo, A. (2018). What works for college students with autism spectrum disorder? *Journal of Autism and Developmental Disorders*, 48, 722–731. <https://doi.org/10.1007/s10803-017-3434-4>

Laugeson, E.A., Gantman, A., Kapp, S.K., Orenski, K., & Ellingsen, R. (2015). A randomised controlled trial to improve social skills in young adults with autism spectrum disorder: The UCLA PEERS program. *Journal of Autism and Developmental Disorders*, 45, 3978–3989. <https://doi.org/10.1007/s10803-015-2504-8>

Lee, K. B. (2010). *Understanding the friendship processes of individuals with Asperger's syndrome: A phenomenological study of reflective college experiences*. (Doctoral dissertation). Retrieved from

<https://eric.ed.gov/?q=Asperger+AND+Syndrome+AND+Higher+AND+Education&pg=2&id=ED517591>

Lei, J., Ashwin, C., Brosnan, M., & Russell, A. (2020). Differences in anxieties and social networks in a group-matched sample of autistic and typically developing students transitioning to university. *Autism, 24*, 1138-1151.

<https://doi.org/10.1177/1362361319894830>

Lizotte, M. (2016). *A phenomenological study of vocational experiences in adult college graduates with autism spectrum disorders* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. Retrieved from

<https://search.proquest.com/docview/1806124714>

Loomes, R., Hull, L., & Mandy, W.P. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 56*, 466-474.

<https://doi.org/10.1016/j.jaac.2017.03.013>

Lord, C., & Bishop, S.L. (2015). Recent advances in autism research as reflected in DSM-5 criteria for autism spectrum disorder. *The Annual Review of Clinical Psychology, 11*, 53-70. <https://doi.org/10.1146/annurev-clinpsy-032814-112745>

Lorenz, T., & Heinitz, K. (2014). Aspergers – different, not less: Occupational strengths and job interests of individuals with Asperger's syndrome. *PLoS ONE 9*(6): e100358.

<https://doi.org/10.1371/journal.pone.0100358>

Macaskill, A., & Denovan, A. (2013). Developing autonomous learning in first year university students using perspectives from positive psychology. *Studies in Higher Education, 38*, 124-142. <https://doi.org/10.1080/03075079.2011.566325>

- MacLeod, A.G. (2016). *“Determined to succeed”: Perceptions of success from autistic adults*. (Doctoral dissertation). Retrieved from <https://etheses.bham.ac.uk/id/eprint/6798/>
- MacLeod, A., & Green, S. (2009). Beyond the books: Case study of a collaborative and holistic support model for university students with Asperger syndrome. *Studies in Higher Education*, 34, 631-646. <https://doi.org/10.1080/03075070802590643>
- McLeod, J., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*, 49, 2320-2336. <https://doi.org/10.1007/s10803-019-03910-8>
- Madriaga, M. (2010). ‘I avoid pubs and the student union like the plague’: Students with Asperger syndrome and their negotiation of university spaces. *Children's Geographies*, 8, 39-50. <https://doi.org/10.1080/14733280903500166>
- Mandy, W. (2019). Social camouflaging in autism: Is it time to lose the mask? *Autism*, 23, 1878-1881. <https://doi.org/10.1177/1362361319878559>
- Mathersul, D., McDonald, S., & Rushby, J.A. (2013). Understanding advanced theory of mind and empathy in high-functioning adults with autism spectrum disorder. *Journal of Clinical and Experimental Neuropsychology*, 35, 655–668. <https://dx.doi.org/10.1080/13803395.2013.809700>
- May, T., Sciberras, E., Brignell, A., & Williams, K. (2017, March). Autism spectrum disorder: Updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample. *BMJ Open* 2017;7:e015549. <https://doi.org/10.1136/bmjopen-2016-015549>
- McLeod, J.D., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and*

Developmental Disorders, 49, 2320-2336.

<https://doi.org/10.1007/s10803-019-03910-8>

- McMorris, C.A., Baraskewich, J., Ames, M.A., Shaikh, K.T., Ncube, B.L., & Bebeko, J. (2019). Mental health issues in post-secondary students with autism spectrum disorder: Experiences in accessing services. *International Journal of Mental Health and Addiction*, 17, 585-595. <https://doi.org/10.1007/s11469-018-9988-3>
- Migliore, A., Butterworth, J., & Zalewska, A. (2014). Trends in vocational rehabilitation services and outcomes of youth with autism: 2006–2010. *Rehabilitation Counseling Bulletin* 2014, 57, 80–89. <https://doi.org/10.1177/0034355213493930>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G., The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS Medicine* 6(7): e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
- Mottron, L., Dawson, M., Soulières, I., Hubert, B., & Burack, J. (2006). Enhanced perceptual functioning in autism: An update, and eight principles of autistic perception. *Journal of Autism and Developmental Disorders*, 36, 27–43. <https://doi.org/10.1007/s10803-005-0040-7>
- Muller, E., Schuler, A., Burton, B.A., & Yates, G.B. (2003). Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*, 18, 163-175.
- Myers, S.M., Voigt, R.G., Colligan, R.C., Weaver, A.L., Storlie, C.B., Stoeckel, R.E., ... Katusic, S.K. (2019). Autism spectrum disorder: Incidence and time trends over two decades in a population-based birth cohort. *Journal of Autism and Developmental Disorders*, 49, 1455–1474. <https://doi.org/10.1007/s10803-018-3834-0>
- New Zealand Education. (2020). Education system, 2020. Retrieved 15 April 2020 from <https://www.studyinnewzealand.govt.nz/why-nz/education-system/#>

- Newman, L., Wagner, M., Knokey, A.M., Marder, C., Nagle, K., Shaver, D., ... Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005)*. Menlo Park, CA: SRI International. Retrieved from https://nlts2.sri.com/reports/2011_09_02/
- Nicholas, D.B., Mitchell, W., Dudley, C., Clarke, M., & Zulla. (2018). An ecosystem approach to employment and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 264–275. <https://doi.org/10.1007/s10803-017-3351-6>
- Norton, A., Cherastidtham, I., & Mackey, W. (2018). *Dropping out: the benefits and costs of trying university*. Grattan Institute. ISBN: 978-0-6482307-7-9. Retrieved from <https://grattan.edu.au/report/dropping-out/>
- Ohl, A., Sheff, M.G., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work*, 56, 345-355. <https://doi.org/10.3233/WOR-172492>
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28, 1024-1026. <https://doi.org/10.1080/09687599.2013.818773>
- Owen, C., McCann, D., Rayner, C., Devereaux, C., Sheehan, F., & Quarmby, L. (2016). *Supporting students with autism spectrum disorder in higher education*. National Centre for Student Equity in Higher Education. Hobart, TAS. Retrieved from <https://ecite.utas.edu.au/108977>
- Owren, T., & Stenhammer, T. (2013). Neurodiversity: Accepting autistic difference. *Learning Disability Practice*, 16, 32-37. <https://doi.org/10.7748/ldp2013.05.16.4.32.e681>
- Ozonoff, S., Strayer, D. L., McMahon, W. M., & Filloux, F. (1994). Executive function abilities in autism and Tourette syndrome: An information processing approach.

Journal of Child Psychology and Psychiatry and Allied Disciplines, 35, 1015–1032.

<https://doi.org/10.1111/j.1469-7610.1994.tb01807.x>

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N., & Hoagwood, K.

(2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administrative Policy and Mental Health*, 42, 533–544. <https://doi.org/10.1007/s10488-013-0528-y>

Pelicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon?

Community views and priorities from the United Kingdom. *Autism*, 18, 756-770.

<https://doi.org/10.1177/1362361314529627>

Pillay, Y., & Bhat, C. S. (2012). Facilitating support for students with Asperger's syndrome.

Journal of College Student Psychotherapy, 26, 140-154.

<https://doi.org/10.1080/87568225.2012.659161>

Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22, 125-137.

<https://doi.org/10.1097/hrp.0000000000000032>

Polyak A., Kubina R.M., & Girirajan S. (2015). Comorbidity of intellectual disability

confounds ascertainment of autism: Implications for genetic diagnosis. *American Journal of Medical Genetics. Neuropsychiatric Genetics, Part B*, 168B, 600-608.

<https://doi.org/10.1002/ajmg.b.32338>

Rast, J.E., Roux, A.M., & Shattuck, P.T. (2020). Use of vocational rehabilitation supports for postsecondary education among transition-age youth on the autism spectrum. *Journal of Autism and Developmental Disorders*, 50, 2164-2173.

<https://doi.org/10.1007/s10803-019-03972-8>

- Robertson, S.M., & Ne'eman, A.E. (2008). Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly*, 28(4). <https://dx.doi.org/10.18061/dsq.v28i4.146>
- Rogge, N., & Janssen, J. (2019). The economic costs of autism spectrum disorder: A literature review. *Journal of Autism and Developmental Disorders*, 49, 2873–2900. <https://doi.org/10.1007/s10803-019-04014-z>
- Runswick-Cole, K. (2014). ‘Us’ and ‘them’: the limits and possibilities of a ‘politics of neurodiversity’ in neoliberal times. *Disability & Society*, 29, 1117-1129. <https://doi.org/10.1080/09687599.2014.910107>
- Russell, A., Gaunt, D.M., Cooper, K., Barton, S., Horwood, J., KesslerD., ... Wiles, N. (2019). The feasibility of low-intensity psychological therapy for depression co-occurring with autism in adults: The Autism Depression Trial (ADEPT) – A pilot randomised controlled trial. *Autism*. Advance online publication. <https://doi.org/10.1177/1362361319889272>
- Sandelowski, M. (2010). What’s in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77-84. <https://doi.org/10.1002/nur.20362>
- Sarrett, C. (2018). Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders*, 48, 679-693. <https://doi.org/10.1007/s10803-017-3353-4>
- Schlosser, R. W., Wendt, O., & Sigafos, J. (2007). Not all systematic reviews are created equal: Considerations for appraisal. *Evidence-Based Communication Assessment and Intervention*, 1, 138-150. <https://doi.org/10.1080/17489530701560831>
- Scott, M., Milbourn, B., Falkmer, M., Black, M., Bolte, S., Halladay, A., ... Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism*, 23, 869-901. <https://doi.org/10.1177/1362361318787789>

- Shmulsky, S., & Gobbo, K. (2013). Autism spectrum in the college classroom: Strategies for instructors. *Community College Journal of Research and Practice*, 37, 490-495.
<https://doi.org/10.1080/10668926.2012.716753>
- Shmulsky, S., Gobbo, K., Donahue, A.T., & Banerjee, M. (2017). College students who have ASD: Factors related to first year performance. *Journal of Postsecondary Education and Disability*, 30, 373-382.
- Siew, C. T., Mazzucchelli, T.G., Rooney, R., & Girdler, S. (2017). A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PLoS ONE*, 12(7), e0180854. <https://doi.org/10.1371/journal.pone.0180854>.
- Smith, I.C., Ollendick, T.H., & White, S.W. (2019). Anxiety moderates the influence of ASD severity on quality of life in adults with ASD. *Research in Autism Spectrum Disorders*, 62, 39-47. <https://doi.org/10.1016/j.rasd.2019.03.001>
- Spek, A.A., Scholte, E.M., & Van Berckelaer-Onnes, V. (2010). Theory of mind in adults with HFA and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 40, 280-289. <https://doi.org/10.1007/s10803-009-0860-y>
- Spek, A.A., Van Ham, N.C., & Nyklíček, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: A randomised controlled trial. *Research in Developmental Disabilities*, 34, 246-253. <https://doi.org/10.1016/j.ridd.2012.08.009>
- Strickland, D.C., Coles, C.D., & Southern, L.B. (2013). JobTIPS: A transition to employment program for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 2472–2483. <https://doi.org/10.1007/s10803-013-1800-4>
- Strum, A., & Kasari, C. (2019). Academic and psychosocial characteristics of incoming college freshmen with autism spectrum disorder: The role of comorbidity and gender. *Autism Research*, 12, 931-940. <https://doi.org/10.1002/aur.2099>

- Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nurse Outlook*, 53, 127-133. <https://doi.org/10.1016/j.outlook.2005.03.005>
- Sung, C., Connor, A., Chen, J., Lin, C., Kuo, H., & Chun, J. (2018). Development, feasibility, and preliminary efficacy of an employment-related social skills intervention for young adults with high-functioning autism. *Autism*, 23, 1542-1553. <https://doi.org/10.1177/1362361318801345>
- Taylor, J.L., & Henninger, N.A., & Mailick, M.R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, 19, 785–793. <https://doi.org/10.1177/1362361315585643>
- Taylor, J.L., & Seltzer, M.M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41, 566-574. <https://doi.org/10.1007/s10803-010-1070-3>
- Tops, W., Van Den Bergh, A., Noens, I., & Baeyens, D. (2017). A multi-method assessment of study strategies in higher education students with an autism spectrum disorder. *Learning and Individual Differences*, 59, 141–148. <https://doi.org/10.1016/j.lindif.2017.09.003>
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15, 398-405. <https://doi.org/10.1111/nhs.12048>
- Van Bergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38, 1359-1370. <https://doi.org/10.1007/s10803-007-0524-8>

- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45, 1673–1688.
<https://doi.org/10.1007/s10803-014-2324-2>
- Van Hees, V., Roeyers, H., & De Mol, J. (2018). Students with autism spectrum disorder and their parents in the transition into higher education: Impact on dynamics in the parent–child relationship. *Journal of Autism and Developmental Disorders*, 48, 3296–3310. <https://doi.org/10.1007/s10803-018-3593-y>
- Van Heijst, B.F., & Geurts, H.M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, 19, 158-167. <https://doi.org/10.1177/1362361313517053>
- Vincent, J. (2019). It's the fear of the unknown: Transition from higher education for young autistic adults. *Autism*, 23, 1575-1585. <https://doi.org/10.1177/1362361318822498>
- Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, 50, 691-693. <https://doi.org/10.1007/s10803-019-04280-x>
- Ward, D., & Webster, A. (2017). Understanding the lived experiences of university students with autism spectrum disorder (ASD): A phenomenological study. *International Journal of Disability, Development and Education*. 65, 373-392.
<https://doi.org/10.1080/1034912X.2017.1403573>
- White, S. W., Ollendick, T., & Bray, B. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism*, 15, 683-701.
<https://doi.org/10.1177/1362361310393363>
- Whittenburg, H. N., Cimera, R. E., & Thoma, C. A. (2019). Comparing employment outcomes of young adults with autism: Does postsecondary educational experience matter? *Journal of Postsecondary Education & Disability*, 32(2), 159–172.

World Health Organization. (2018). *International classification of diseases for mortality and morbidity statistics* (11th Revision). Retrieved from <https://icd.who.int/browse11/l-m/en>. Accessed 15 April 2020.

Wright, S.D., Wright, C.A., D'Astous, V., & Wadsworth, A.M. (2019). Autism aging. *Gerontology & Geriatrics Education*, 40,3, 322-338.
<https://doi.org/10.1080/02701960.2016.1247073>

CHAPTER 2: AN ON-LINE SURVEY OF UNIVERSITY STUDENTS WITH AUTISM SPECTRUM DISORDER IN AUSTRALIA AND NEW ZEALAND: CHARACTERISTICS, SUPPORT SATISFACTION, AND ADVOCACY

Chapter 2 Overview

Chapter 2 includes a journal article that has been published in the *Journal of Autism and Developmental Disorders*. The chapter describes a survey whose findings address the first thesis research question, “What are the experiences of current and former university students with ASD in Australia and New Zealand?”

Prior to conducting the nationwide survey described in this chapter, there were only two prior small Australian surveys on post-secondary students with ASD (Anderson, Carter, & Stephenson, 2018, Appendix D; Cai & Richdale, 2016). As little was known an exploratory approach was used. Also, while the prior studies identified interesting findings about demographic student characteristics, gender outcome differences, student strengths and weakness, supports and advocacy, and mental health, the studies were very small preventing statistical inferential analysis that may have identified any significance of the findings. Moreover, the participants in the prior surveys had not directly asked the participants to identify their greatest concerns at university, information which could highlight research and support priorities. Thus, the research questions reflected the purpose of the study, which was to explore further the findings of a prior smaller survey of university students with ASD (Anderson, Carter, & Stephenson, 2018) with more in depth survey questions and a larger sample of current undergraduate and post-graduate students with ASD from a broader geographic area (Australia and New Zealand).

Inferential testing of four a priori questions revealed no significant difference in support use by gender. In addition, no significant relationship was found between the percentage of students passing all their courses and the number of supports used, or student

satisfaction with the university experience and the time of student registration with disability services. The respondents indicated that their greatest concerns were academic requirements and mental health, and suicidal ideation rates were much higher than comparative rates for the general population of students. Moreover, many respondents stated that there was a lack of mental health supports and that they found it difficult to ask for support.

Implications arising from the results include the need for more transition programs to help students identify any weaknesses that may hinder their university experience (Lei, Calley, Brosnan, Ashwin, & Russell, 2020). In addition, some may need advocacy skills training prior to or while at university to enable them to apply for and use supports when needed. Finally, there is an apparent need for more mental health supports and a possible role for parents to assist with advocacy.

This study contributed to the research on post-secondary students with ASD. It was the largest survey of current undergraduate and post-graduate university students with ASD at the time the research was published, and it was only the third survey from Australia and the first from New Zealand. The participants greatest concerns were identified, highlighting possible future research priorities, and the urgent need to provide more mental health supports and to encourage students to use them was illuminated.

References

- Anderson, A.H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651-665. <https://doi.org/10.1007/s10803-017-3257-3>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher educational students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Lei, J., Calley, S., Brosnan, M., Ashwin, C., & Russell, A. (2020). Evaluation of a transition to university programme for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 50, 2397–2411. <https://doi.org/10.1007/s10803-018-3776-6>

Publication Status

Anderson, A.H., Carter, M., & Stephenson, J. (2020). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand: Characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders*, 50, 440-454. <https://doi.org/10.1007/s10803-019-04259-8>

The findings of this study were also presented at the Asia Pacific Autism Conference Singapore (APAC, 2019), and at CANVAS College Autism Network Virtual Association of Scholars, July 2019 (<https://collegeautismnetwork.org/research/canvas/>).

Pages 57-71 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Anderson, A. H., Carter, M., & Stephenson, J. (2020). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand: characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders*, 50, 440-454.

DOI: [10.1007/s10803-019-04259-8](https://doi.org/10.1007/s10803-019-04259-8)

Appendix 1: Survey: The Experiences of University Students with ASD

Faculty of Human Sciences



MACQUARIE
University

Information and Consent

Participant Information and Informed Consent

HREC Project Number: 5201800294

Name of Project: The experiences of University Students with ASD

Chief Investigator's/Supervisor's Name & Title: Assoc. Prof. Mark Carter

You are invited to participate in a study that will examine the experiences of university students with autism spectrum disorder (ASD). When students with ASD commence university, they may experience challenges that impact their success and enjoyment. The purpose of this study is to better understand your experience of being a university student with ASD and to discover your opinion about available supports and services. We hope that your responses may help in better supporting students with ASD at university.

Who can take part in this study?

All current university students who are 18 years or older and who have a formal diagnosis of ASD may participate in this study. You have been contacted because you are registered with the office of disability services and they have sent out this email invitation at the request of the researchers.

What must I do if I want to participate in this study?

If you want to participate in this study please follow the link below or copy and paste the URL below into your internet browser and complete the survey about your experiences and the services and supports provided to you at university. It should take approximately 20-25 minutes, and you are free to discuss the survey with your family or a friend if you need any assistance completing it.

Survey Link: https://mqedu.qualtrics.com/SE/?SID=SV_cAx29a1SfsXB07H&Q_JFE=0

Remuneration

You will not be paid, however, those who complete the survey may choose to enter a draw to win one of three gift vouchers from JB Hi Fi or Myer worth \$100 each.

Do I have to participate in this study?

Participation in this study is entirely voluntary and you are not obliged to participate. Refusing to participate will not affect your current or future enrolment.

Can I withdraw from this study?

Responses will be stored anonymously so once you have submitted your responses you cannot withdraw from the survey and your survey responses cannot be removed. Submission of the survey will be regarded as consent to use the information for research purposes only, however, participants may close the browser at any time prior to submission. If you have any questions about the research, please contact Anastasia Anderson at [REDACTED]

Who is conducting this research?

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Anastasia Anderson ([REDACTED]) under the supervision of A/Prof Mark Carter (Tel: [02]9850 7880, email: Mark.carter@mq.edu.au); A/Prof Jennifer Stephenson (Tel: [02]9850 8694, email: jennifer.stephenson@mq.edu.au); and Dr Sarah Carlon ([02]9850 9699, email: sarah.carlon@mq.edu.au).

How can I be sure the information about me is kept confidential?

Any information or personal details gathered during the study are confidential, except as required by law. The survey is anonymous so your name will not appear on the survey, and participants will not be identifiable to the researchers. Also, no teaching staff or staff at disability services will know whether you completed the survey or not, or how you answered any of the questions.

No individual will be identified in any publication or talk about the results. Access to the data is limited to the researchers only, namely, Assoc. Prof. Mark Carter, Assoc. Prof. Jennifer Stephenson, Dr Sarah Carlon, and Anastasia Anderson, and the information may be kept for at least 5 years following publication arising from the research. It is intended that the results of this study will be published in a peer reviewed journal, and may also be presented at talks about the study. A summary of the results of the data can be made available to you by emailing Anastasia Anderson: [REDACTED]

Data relating to the entry into the prize draw will be stored in a separate survey so that information regarding participation cannot be cross-referenced.

Commercial funding.

There have been no commercial or other sponsored funding for this project and the researchers will not receive any financial gain from this research.

Are there any risks?

Ther It is unlikely that you will experience any distress, however, if you do experience any concerns when answering any of the questions and you want support, you can contact the 24-hour Lifeline Counselling

Service on Ph. 131114 or Beyondblue on Ph. 1300224636, or your usual source of support.

What can I do if I want to make a complaint about this survey?

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Many thanks.

A/Prof Mark Carter; Anastasia Anderson; A/Prof Jennifer Stephenson; Dr Sarah Carlon

Eligibility 1 - Diagnosis

Eligibility and instructions

You are eligible to participate in this survey if you are 18 years or older and have a formal diagnosis of autism spectrum disorder. Eligible participants who complete the survey will have the opportunity to enter the prize draw for one of three \$100 gift vouchers from JB Hi Fi or Myer. However, if you answer no to either of the next two questions you will be taken to the end of the survey.

Have you been formally diagnosed by a medical doctor or psychologist as having an autism spectrum disorder (ASD)?

Yes

No

Are you 18 years or older?

Yes

No

Default Question Block

Which autism condition were you formally diagnosed with? If you have been given more than one diagnosis choose the one that you consider is most relevant to you.

I would prefer not to say
autism spectrum disorder (ASD) or high functioning autism spectrum disorder
asperger syndrome (AS)
autistic disorder (AD)
pervasive developmental disorder not otherwise specified (PDD-NOS)

Other (please specify)

At what age were you formally diagnosed with an autism spectrum disorder?

Have you been formally diagnosed with any other conditions? Select as many as apply.

I would prefer not to answer
I do not have any other conditions
Attention deficit hyperactive disorder (ADHD) or attention deficit disorder (ADD)
Anxiety
Depression
Epilepsy
Other. Please specify

What is your gender?

Male
Female
Other

What is your age?

I would prefer not to answer
17-24
25 or above

What is your highest qualification?

Year 12 certificate/NCEA

TAFE certificate or diploma
Bachelor degree or higher

Where are you currently studying?

Select Country/State

Select University

At what level are you currently studying?

Undergraduate

Postgraduate. Please indicate what level

When did you start your current enrolment at university?

the year immediately after high school

1-2 year break after high school

3-4 year break after high school

5 or more year break after high school

What did you do before you started university? Select any that apply.

A TAFE or non-university course

Social skills training course

Transition to post-secondary education course

I worked part-time (less than 25 hours per week)

I worked full-time (more than 25 hours per week)

I pursued my hobbies

Other. Please describe

What skills did you acquire while attending TAFE or other non-university course ? Select any that apply.

My non-university course did not help me prepare for university

I acquired knowledge in the area I am currently studying

I improved my time management skills

I improved my organisational skills

I became more independent

I became more confident to start university

I would recommend completing a non-university course before starting university

Would you recommend studying at TAFE or other non-degree institution as a pathway to university?

Yes

Neutral

No. Please say why

How many semesters have you completed at university?

Less than 1

1

2

3

4

5

6

7

8

9

10 or more

If you have ever withdrawn from university before completing your course please indicate why. Select any that apply.

I have never withdrawn from university

I would prefer not to answer

Financial reasons

Family matters

Mental health issues

I wanted to pursue other interests (e.g., job, travel)

Difficulty coping with academic demands

Other. Please explain

Why did you choose to go to university? Select all that apply.

I want to work in field I am studying

I am interested in the field I am studying

I could not get a job and hoped a higher qualification would help

Parent suggestion

School counsellor suggestion

Other. Please explain

What degree (or major) are you studying towards? Select any that apply.

Maths/Engineering/Science/Information Technology/Computing

Business/Finance/Commerce/Marketing

Law

Education

Medicine and health sciences

Social work, psychology, community services, sociology

Media, creative arts, English and communication

Anthropology, History, society, linguistics, and languages

Agriculture, vet science

Architecture, town planning

Other

Which of the following best describes your enrollment status?

Always full-time

Always part-time

I started full-time student but switched to part-time

I started part-time student but switched to full-time

Other - please describe

Have you studied any modules on-line?

Yes

No

Please indicate your preference for studying on-line or studying a traditional contact course on campus.

I prefer on-line courses. Please briefly state why.

I prefer traditional contact courses. Please briefly state why.

I have no preference.

When did you disclose your diagnosis of autism spectrum disorder to the Disability Support Unit?

Prior to enrollment

When I enrolled

After classes started

I have not disclosed

Why did you delay your disclosure? You may select as many as apply.

I was not diagnosed with ASD till after enrollment

I did not think it was necessary

I was worried about being stigmatised

I did not know how to disclose

I wanted to try on my own

My condition deteriorated after enrollment

Poor self-advocacy skills

Other

Please indicate if the following attributes are a personal strength or if they cause you difficulty.

This is one of my strengths

I find this difficult

Ability to use technology

☐☐

Memory

☐☐

Consistency e.g. sticking to a study routine

☐☐

This is one of my strengths

I find this difficult

Original and creative thoughts	<input type="radio"/>	<input type="radio"/>
Attention to detail	<input type="radio"/>	<input type="radio"/>
An intense interest in the subject I am studying	<input type="radio"/>	<input type="radio"/>
Staying on-task	<input type="radio"/>	<input type="radio"/>
Organisational skills	<input type="radio"/>	<input type="radio"/>
Time management	<input type="radio"/>	<input type="radio"/>
Expressing myself verbally in class	<input type="radio"/>	<input type="radio"/>
Expressing myself in writing	<input type="radio"/>	<input type="radio"/>
A strong motivation to complete my work	<input type="radio"/>	<input type="radio"/>
Ability to solve problems independently	<input type="radio"/>	<input type="radio"/>
Ability to work in a team	<input type="radio"/>	<input type="radio"/>
Public speaking	<input type="radio"/>	<input type="radio"/>

Please indicate any other personal strengths or difficulties that impact your success at university.

To what extent have the following issues concerned you? Only consider the time when you have been a university student.

	It does not bother me	A moderate concern for me	A big concern for me
Loneliness at uni	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of friends at uni	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socialising with peers at uni	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling isolated at uni	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Romance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bullying at uni	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of structure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please state any other concerns you have about your university experience.

To what extent do you agree or disagree with the following statements. Only consider the time you have been a university student.

	Disagree	Neutral	Agree
People are more accepting of me at university compared with school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family are very supportive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can follow what is going on in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel comfortable asking questions in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lecturers/tutors have a good understanding of ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My sensitivity to noise, light or smells on campus sometimes interferes with my ability to study or cope on campus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes avoid places because of sensitivities (e.g. noise or crowds)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty navigating the campus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty with daily living tasks such as cooking, paying bills or doing laundry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Congratulations! You are more than half way through the survey. Your contribution is very important and much appreciated. The next section asks your opinion about the supports and services you have received at University. Do not consider any supports or services received prior to university or those you obtain privately.

Please indicate if the following academic supports provided by your university were helpful, not helpful, or if you did not use that support.

	The support was helpful	The support was not helpful	I did not use support for that
Assistance with group work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to do a presentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to ask questions in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with time management of academic work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to stay on-task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to understand course work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	The support was helpful	The support was not helpful	I did not use support for that
Assistance to organise my study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to understand lectures and tutorials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with assignments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mentor to assist with academic work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to approach teachers out of class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tutoring centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	The support was helpful	The support was not helpful	I did not use support for that
Note-taker/scribe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recorded lectures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lecture transcription	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On-line discussion board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reduced course load	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate why you did not use the supports listed. Select all that apply.

	Why didn't you use this support? Select all that apply.				
	This support was not available	I don't need support for this	I didn't know how to ask for support for this	I was refused support for this	Other
» Assistance with group work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Why didn't you use this support? Select all that apply.

	This support was not available	I don't need support for this	I didn't know how to ask for support for this	I was refused support for this	Other
» Assistance to do a presentation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to ask questions in class	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance with time management of academic work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to stay on-task	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to understand course work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to organise my study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to understand lectures and tutorials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance with assignments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	This support was not available	I don't need support for this	I didn't know how to ask for support for this	I was refused support for this	Other
» Mentor to assist with academic work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to approach teachers out of class	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Tutoring centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Note-taker/scribe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Recorded lectures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Lecture transcription	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» On-line discussion board	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Reduced course load	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate any other academic support(s) you may have used and state how helpful it was.

Please indicate if the following non-academic supports provided by your university were helpful, not helpful, or if you did not use that support.

	This support was helpful	This support was not helpful	I did not use that support
Peer mentor/buddy/life coach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relaxation techniques (e.g., mindfulness)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress or anxiety management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling for depression or low mood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other counseling support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consultation with a disability support officer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	This support was helpful	This support was not helpful	I did not use that support
Training to improve self-advocacy skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orientation week activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ASD support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Campus social/sports clubs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support to transition to university provided by the university	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support to transition to university provided by your high school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	This support was helpful	This support was not helpful	I did not use that support
On-line well-being course	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance to live on-campus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Career planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with everyday living activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate why you didn't use the non-academic supports listed. Select all that apply.

Why didn't you use this support? Select all that apply.

<input type="checkbox"/> This support was not available	<input type="checkbox"/> I don't need this support	<input type="checkbox"/> I didn't know how to ask for this support	<input type="checkbox"/> I was refused this support	<input type="checkbox"/> Other
---	--	--	---	--------------------------------

	Why didn't you use this support? Select all that apply.				
	This support was not available	I don't need this support	I didn't know how to ask for this support	I was refused this support	Other
» Peer mentor/buddy/life coach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Relaxation techniques (e.g., mindfulness)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Stress or anxiety management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Counselling for depression or low mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Other counseling support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Consultation with a disability support officer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Training to improve self-advocacy skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Orientation week activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» ASD support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	This support was not available	I don't need this support	I didn't know how to ask for this support	I was refused this support	Other
» Campus social/sports clubs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Support to transition to university provided by the university	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Support to transition to university provided by your high school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» On-line well-being course	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance to live on-campus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Career planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Social skills training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Assistance with everyday living activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify any other non-academic support or service you have received and state whether it was helpful or not helpful.

Please indicate the number of times you have used the following supports for exams and/or assignments per semester.

	Never	Once or Twice	Three	Four or more
Alternate room for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reader for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
One exam per day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extended time for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extended time for assignments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alternative assessment to replace group work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alternative assessment to replace class presentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of a computer in an exam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How helpful was the support you received for exams and assignments?

	Not helpful	Somewhat helpful	Very helpful
» Alternate room for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Reader for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» One exam per day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Extended time for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Extended time for assignments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Alternative assessment to replace group work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Alternative assessment to replace class presentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
» Use of a computer in an exam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate why you did not use this support. Select all that apply.

	Why didn't you use this support? Select all that apply.				
	This support was not available	I don't need this support	I didn't know how to ask for this support	I was refused this support	Other
» Alternate room for exams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Why didn't you use this support? Select all that apply.					
	This support was not available	I don't need this support	I didn't know how to ask for this support	I was refused this support	Other
» Reader for exams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» One exam per day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Extended time for exams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Extended time for assignments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Alternative assessment to replace group work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Alternative assessment to replace class presentation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
» Use of a computer in an exam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you used a mentor while at university?

Yes. For how long have you used a mentor.

No.

What sorts of things did your mentor assist you with? Select all that apply.

Organisation and time management of academic demands

In class activities such as note-taking, asking questions

Group assignments

Socialising with peers

Orientation of the campus

Social skills training

Tutoring in coursework

Other. Please specify

Overall, how helpful was your mentor in improving your university experience?

Extremely helpful

Very helpful

Helpful

Neutral

Not helpful

They worsened my university experience

Have you ever withdrawn from a unit due to lack of support?

Yes. Please indicate why support was not provided.

No

Do you think the range of academic supports and non-academic supports offered at university adequately match your needs?

Yes

No. More academic supports are needed

No. More non-academic supports are needed

No. More academic and non-academic supports are needed

How many different supports or services have you used at university?

None

One

Two

Three

Four or more

Were any approved supports or services you requested NOT provided?

Yes. Please state why

No

How long did you have to wait to receive support after you registered with disability services?

Less than one month

One to two months

More than two months. Please specify

What is your most significant concern at university?

Academic requirements

Sensory sensitivities

Mental health issues, e.g., anxiety, depression

Social requirements at uni

Other

Do you think the supports offered meet your needs at university?

Yes

No

This question asks about your academic achievement.

I would prefer not to answer

I passed all my courses this year

I did not pass all my courses this year

Privacy laws restrict the rights of parents to advocate for their adult children. Do you think it should be easier for parents to advocate for their children at university?

Yes. Briefly explain why

No. Briefly explain why

Neutral

The next six questions concern self-harm, suicidal thoughts, anxiety and depression. If you find these topics upsetting and would prefer not to read or answer any of them then you may skip to the next section. If you would like to talk to someone you can contact the 24 hour Lifeline Counselling Service on Ph. 131114 or Beyondblue on Ph. 1300 224 636, or your usual source of support.

Would you like to skip the questions on suicidal thoughts, self-harm, anxiety or depression?

Yes

No

Please indicate if you identify with any of the following statements about self-harm. If you would like to talk to someone you can contact the 24 hour Lifeline Counselling Service on Ph. 131114 or Beyondblue on Ph. 1300 224 636, or your usual source of support.

During the time I have been a university student I have never thought about self harm

During the time I have been a university student I have thought about self-harm but I would not act on those thoughts

During the time I have been a university student I have made plans to self-harm but I did not act on those plans

During the time I have been a university student I have self-harmed myself

Please indicate if you identify with any of the following statements about suicide. If you would like to talk to someone you can contact the 24 hour Lifeline Counselling Service on Ph. 13114 or Beyondblue on Ph. 1300 224 636, or your usual source of support.

During the time I have been a university student I have never thought about suicide

During the time I have been a university student I have thought about suicide but I would not act on those thoughts

During the time I have been a university student I have made plans to suicide but I did not act on those plans

During the time I have been a university student I have attempted suicide

Have you ever received support for depression since you have been a university student?

Yes

No

Why have you not received support for depression? If you would like to talk to someone you can contact the 24 hour Lifeline Counselling Service on Ph. 13114 or Beyondblue on Ph. 1300 224 636, or your usual source of support.

I don't need support for this

I asked for help but none was available

I have not asked for support because I don't know how or who to ask

I have not asked for support because I did not think support would help

I have not asked for support because I think I can manage on my own

I have not asked for support because I was worried about the stigma of disclosing mental health problems

I have not asked for support because I was worried about any potential cost of treatment

Other

Have you received support for anxiety since you have been a university student?

Yes

No

Why have you not received support for anxiety? If you would like to talk to someone you can contact the 24 hour Lifeline Counselling Service on Ph. 13114 or Beyondblue on 1300 224 636, or your usual source of support.

I don't need support for this

I have not asked for support because I did not think support would help

I have not asked for support because I don't know how or who to ask

I did not ask for help because I think I can manage on my own

I have not asked for support because I was worried about the stigma of disclosing mental health problems

I have not asked for support because I was worried about any potential cost of treatment

I asked for help but none was available

Other

Only 5 short questions remaining.

For the remaining questions your response can include any supports and services you have experienced at university, including any which have not been mentioned in this survey. If you wish to review the list of supports and services, click on the back arrow below.

What is the most helpful support or service you have received at university?

What is the least helpful support or service you have received at university?

What is your overall rating of your university experience?

	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
Overall rating of the supports and services at university?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
Overall rating of your university experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I enjoy university

True

Neither true nor false

False

Please state any further comments you may have with regard to the experiences or supports you have received at university. Also, please state any further suggestions you may have as to supports or services you think should be provided.

Thank you for your time and your important contribution to this research.

If you have experienced any psychological issues when answering any of the questions and you want support, you can contact the **24 hour Lifeline Counselling Service on ph. 131114 or Beyondblue on ph. 1300 22 4636, or your usual source of support.**

Would you like to enter the prize draw?

Yes

No

Going to Prize Draw

Great! Please click the next arrow to be taken to the Prize Draw.

Please note, the responses you have made are anonymous. We cannot link these answers with your entry in the prize draw.

Powered by Qualtrics

CHAPTER 3: PERSPECTIVES OF FORMER STUDENTS WITH ASD FROM AUSTRALIA AND NEW ZEALAND ON THEIR UNIVERSITY EXPERIENCE

Chapter 3 Overview

This chapter presents the perspectives of 11 former students with ASD and six significant others from Australia and New Zealand on their university experience. The study has been reported in the *Journal of Autism and Developmental Disorders* (Anderson, Stephenson, & Carter, 2020) and it addresses the first thesis research question, “What are the experiences of current and former university students with ASD in Australia and New Zealand?”. The semi-structured interview questions used for the study were partially informed by the findings from the systematic literature review presented in Chapter 4, and as the purpose was to provide data that could be used to inform policy and intervention development, a qualitative descriptive approach was used.

Barriers and facilitators to post-secondary education were identified. The barriers included poor mental health and executive function which caused most of the participants to switch to part-time study and thus make slow rates of progress. In addition, some former student participants had difficulty recognising their strengths and weaknesses and some indicated that this may have contributed to their poor initial discipline choice.

Facilitators to academic achievement identified in the study include having a strong motivation to study, studying a discipline in an area of high interest, and available supports and the skills to access them. In addition, it was suggested that individualised and more structured study supports, autism specific social support groups, autism friendly spaces, and transition supports that help students identify their strengths and weaknesses and an appropriate discipline to study may be helpful.

There were several notable contributions to the research on post-secondary students with ASD. The participants provided a retrospective perspective from both graduates and those who did not complete a university qualification. There was a diverse range of participant ages and abilities that spanned recent graduates to those of retirement age, and the participants provided helpful suggestions for future students. They also contributed interesting recommendations for universities on ways to make campuses and courses more autism friendly.

Publication Status

Anderson, A.H., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886-2901.
<https://doi.org/10.1007/s10803-020-04386-7>

The findings of this study were also presented at the Asia Pacific Autism Conference, Singapore (APAC, 2019).

Pages 97-112 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Anderson, A. H., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886-2901.

DOI: [10.1007/s10803-020-04386-7](https://doi.org/10.1007/s10803-020-04386-7)

CHAPTER 4: A SYSTEMATIC LITERATURE REVIEW OF EMPIRICAL RESEARCH ON POST-SECONDARY STUDENTS WITH AUTISM SPECTRUM DISORDER

Chapter 4 Overview

Chapter 4 presents a systematic literature review that was published in the *Journal of Autism and Developmental Disorders* (Anderson, Stephenson, Carter, & Carlon, 2019). The second thesis research question, “What does the extant literature reveal about interventions used to support post-secondary students with ASD?” is addressed in this chapter. The purpose of the review was to identify and analyse published articles that reported empirical findings from interventions used to support post-secondary students with ASD. It was hoped that the results may help identify evidence-based practices. Interrater reliability of article inclusion, data coding and data analysis, were recorded, and the experimental studies were assessed for quality. There were 24 studies with 291 participants located. While most of the studies demonstrated high social validity and participant satisfaction, many were of poor quality and only seven studies used an experimental or quasi-experimental design, limiting conclusions. It was found that few interventions had targeted academic concerns despite prior research indicating post-secondary students predominantly access academic supports and often view them as their most helpful support. The findings suggest that more high-quality experimental research is needed, particularly concerning academic supports.

There were several contributions to the research on post-secondary students with ASD. The study updated the only prior review with a much larger sample of studies and participants, and the true-experimental and quasi-experimental studies were assessed for quality. It was revealed that more high-quality experimental research was needed, and that researchers may need to consider more participant research priorities when planning research projects.

Publication Status

Anderson, A.H., Stephenson, J., Carter, M., & Carlon, S. (2019). A systematic literature review of empirical research on postsecondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49, 1531-1558.
<https://doi.org/10.1007/s10803-018-3840-2>

The findings of this study were presented at the Macquarie University Department of Educational Studies Conference, 2018.

Pages 115-142 of this thesis have been removed as they contain published material.
Please refer to the following citation for details of the article contained in these pages.

Anderson, A. H., Stephenson, J., Carter, M., & Carlon, S. (2019). A systematic literature review of empirical research on postsecondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49, 1531-1558.

DOI: [10.1007/s10803-018-3840-2](https://doi.org/10.1007/s10803-018-3840-2)

CHAPTER 5: A QUALITATIVE STUDY OF THE EMPLOYMENT EXPERIENCES OF FORMER UNIVERSITY STUDENTS ON THE AUTISM SPECTRUM FROM AUSTRALIA AND NEW ZEALAND

Chapter 5 Overview

Chapter 5 includes a manuscript in journal ready form that addresses the third thesis research question: “What are the employment experiences of former university students with ASD in Australia and New Zealand?”. The investigation formed part of the larger qualitative study that was described in Chapter 3 and the manuscript is currently under review with a journal.

While there are many studies that have addressed the employment experiences of adults with ASD, there are few studies that solely focused on employment from the perspective of former university students with ASD. Given, university qualifications generally enhance employment and income prospects, this group is of particular interest. The participants featured in this chapter were very diverse. They had a very wide age range, studied divergent disciplines, and had variable employment outcomes. While most participants had some employment successes, despite high intelligence, post-secondary qualifications, and other non-employment related achievements, most also had extended periods of under-employment or unemployment, and all but one struggled with poor mental health. Those who studied non-vocationally specific degrees had more difficulty finding employment, and few had access to employment supports other than that provided by family members. The findings draw attention to the need for supports to be available for former university students with ASD at all ability and employment levels, and throughout working life. In addition, the importance of providing transition supports that help students select an appropriate discipline and for university courses to include components that increase employability, was illuminated. The value in transition supports that help students

conceptualise how their degree could be used in the workplace was also identified. Finally, the benefit of promoting the strengths of former university students among the community, career advisers, disability support agencies, employers, and work peers, to increase employment opportunities more aligned to skills and talents was also highlighted. Other strengths of the study included the diverse range of participants and perspectives from graduates, former students who did not complete a qualification, and significant others. Indeed, the participants' very broad age range enabled a preliminary examination of the employment experience of former students with ASD across the lifespan. The study also added to the discussion over possible underlying theoretical reasons for difficulty with transition to employment, and the specific difficulties associated with courses that do not have a clear vocational trajectory. In addition, the participants were predominantly female, adding to the research of that less reported demographic. Finally, suggestions for improving outcomes and future research directions on the employment of adults with a university experience were made.

Publication Status

Anderson, A.H., Stephenson, J., & Carter, M. (under review). A qualitative study of the employment experiences of former university students on the autism spectrum from Australia and New Zealand.

The findings of this study were presented at the Asia Pacific Autism Conference, Singapore (APAC, 2019).

A Qualitative Study of the Employment Experiences of Former University Students on the
Autism Spectrum from Australia and New Zealand

Abstract

Background: Individuals on the autism spectrum with a post-secondary educational experience have poor employment outcomes despite employment strengths, qualifications, and ability, so research is required to better understand the factors that may improve their working careers. The purpose of the current study was to examine the employment experience from the perspective of former Australian and New Zealand university students and their significant others. In addition, as many university students on the autism spectrum do not complete their qualification, we included both graduates and those who did not complete.

Method: A qualitative study that included semi-structured interviews with 11 former university students with ASD and five significant others from Australia and New Zealand was conducted and analysed thematically.

Results: Most participants described difficulties with transitioning to employment, especially those who studied non-vocationally specific courses. While most former students described some employment successes, most had careers characterised by interruptions, poor mental health, and long periods of underemployment and/or unemployment. Also, all had lifelong minimal access to employment supports.

Conclusions: Increasing employability skill components within university courses and early access to specialist university autism careers advisors and employment agencies may facilitate the transition to employment. Many former university students on the spectrum may need support to find and maintain employment throughout their working life and at all employment levels. Also, supports should be available for both graduates and those who do not complete.

Keywords: adult supports; ASD; autistic, employment; university students; autism spectrum

A Qualitative Study of the Employment Experiences of Former University Students on the Autism Spectrum from Australia and New Zealand

The prevalence of autism (clinically significant impairment in social communication and interaction, and restricted interests or behaviours; American Psychiatric Association, 2013) among adults has been estimated at approximately 2.21% or 1 in 45 (US, Dietz, Rose, McArthur, & Maenner, 2020), and approximately two thirds have been found to have no co-occurring intellectual disability (IQ<70; Centers for Disease Control and Prevention, 2020). In addition, individuals with autism show a spectrum of abilities. Their strengths can include good attention to detail, logical reasoning, consistency, creativity, retentiveness (Gal, Landes, & Katz, 2015; Lorenz & Heinitz, 2014), open-mindedness, and authenticity (Kirchner, Ruch, & Dziobek, 2016), and up to half of youths on the spectrum without intellectual disability attempt a post-secondary degree (Taylor & Seltzer, 2011).

Employment can improve quality of life by improving independence, health, self-esteem, and general wellbeing (Anderson, Moore, et al., 2017; Ayres et al., 2018), and many individuals on the spectrum have employment success (e.g., Grandin, 2014; Shore, 2003). However, studies across the globe (e.g., Australia, Canada, Sweden, UK, US) indicate that most adults on the spectrum have long periods of unemployment or underemployment (Baldwin, Costley, & Warren, 2014; Black et al., 2019; Roux, Rast, Anderson, & Shattuck, 2017; Scott et al., 2019; Taylor & Seltzer, 2011). In addition, individual employment outcomes often worsen over time (Taylor, Henninger, & Mailick, 2015) and female outcomes are particularly poor (Baldwin & Costley, 2016; Hayward, McVilly, & Stokes, 2018; Taylor et al., 2015).

As a post-secondary qualification improves employment and income prospects for the general population of workers (Rast, Roux, & Shattuck, 2020), outcomes for those on the spectrum with a university experience may be of particular interest. However, findings for

graduates on the spectrum have been mixed (Chen, Leader, Sung, & Leahy, 2015). In Australia, Aspect (2013) surveyed 267 adults on the spectrum without co-occurring intellectual disability about their educational and post-educational experiences. They found as the participants' education level rose, their unemployment rate fell. Thus, while 69% of their participants who finished schooling after year 10 were unemployed, only 40% of those who finished after year 12 did not have a job, and only 34% of those with a bachelor's degree or higher were unemployed. Also, Migliore, Timmons, Butterworth, and Lugas (2012) found those with a post-secondary qualification worked longer hours and had higher wages and employment rates. However, a number of other studies have reported that a post-secondary qualification may not lead to employment for those on the spectrum (Taylor et al., 2015) and that many on the spectrum are overqualified for their jobs and work in a field unrelated to their qualification (Baldwin et al., 2014; Chen et al., 2015).

The skills required to obtain and maintain employment (complete job applications, attend interviews, interact with staff, cope with changing routines and new environments) can be challenging for those on the spectrum (Muller, Schuler, Burton, & Yates, 2003). Many studies have reported experiences of poor mental health and feelings of being isolated at work and this can also negatively impact the ability to find and maintain work (e.g., Ohl et al., 2017, Smith, Ollendick, & White, 2019). It has also been revealed that few workers on the spectrum have access to employment supports (Rast et al., 2020; Roux et al., 2015).

While studies about the university experience of students with ASD are growing rapidly (McLeod, Meanwell, & Hawbacker, 2019), there remain few studies that have specifically focused on post-university employment experiences (Cashin, 2018; Lizotte, 2016). Prior research on employment experiences has more generally focused on mixed ability populations (e.g., Hayward, McVilly, & Stokes, 2019; Hayward, McVilly, & Stokes, 2020). In addition, there are few qualitative studies that have studied the impact of an

incomplete university qualification on employability.

The participants in Lizotte's (2016) study, which included seven graduates on the spectrum (26-37 years), revealed that social difficulties could negatively impact both finding and maintaining a job. In addition, she found most graduates were underemployed in low skilled and low paid jobs that were in a different field to their qualification. Vincent (2019) interviewed 10 final year university students and 11 recent graduates on the spectrum and focused on the transition out of higher education. He pointed out that there was a need for more research on the post-university experience across a more diverse range of universities, fields of study, and individual outcomes. Vincent (2020) extended his prior study by including the perspectives of an additional 58 community stakeholders (across 16 focus groups), and he provided more in-depth descriptions of the difficulties experienced during the recruitment process (e.g., applications, interviews, employer discrimination). He also discussed participant concerns about disclosing and a perceived need to camouflage their autism. In addition, Vincent (2020) revealed that while university careers services and disability support services were helpful, they were less effective when resources were low, and staff lacked knowledge about higher education students and graduates with autism.

Qualitative methods allow an in-depth and nuanced analysis of individual participant experiences, feelings, and opinions (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Creswell, 2007) and they can be particularly useful when exploring the reasons some students do better than others across variable educational and post-educational contexts (Kozleski, 2017). Qualitative methods also enable participants to highlight issues which are important to them, including illuminating individual barriers and support needs (Kozleski, 2017). In addition, significant others sometimes express a different perspective (Cai & Richdale, 2016; Heasman & Gillespie, 2018) or emphasise different things compared to individuals on the spectrum (Ward & Webster, 2017). Finally, most students on the spectrum

do not complete their university course (Newman et al., 2011), so the perspectives of both graduates and those who did not complete their qualification may be needed.

In summary, while a university qualification typically leads to better outcomes for the general population, there is very little qualitative research, including from Australia or New Zealand, that has focused solely on the employment experiences of former university students on the spectrum. Such research may clarify the factors that may lead to better employment outcomes. Thus, the purpose of this study was to explore the employment experiences from the perspective of former Australian and New Zealand university students and their significant others, including both graduates and those who withdrew before completion. The broad research question that guided this study was:

What are the perceptions of former Australian and New Zealand university students on the spectrum (and their significant others) about their employment experiences?

Methods

This research is part of a larger study that explored the university and post-university experiences of individuals on the spectrum. The university experience was analysed with 18 transcripts and is described in Anderson, Stephenson, and Carter (2020). The current paper focusses on the post-university employment experiences. There were two interviews from the main study that were not used in this study as the significant other for participants 4 and 7 was unable to provide any details on employment experiences.

Ethics

The Macquarie University Research Ethics Committee granted approval for this study before the participants were approached. Also, prior to each interview, informed written consent was obtained.

Theoretical Approach

A qualitative descriptive approach was used. Qualitative descriptive reports can be

used to inform policy and/or intervention development (Bradshaw, Atkinson, & Doody, 2017; Sullivan-Bolyai, Bova, & Harper, 2005). They are particularly useful when an emic stance that describes the participants' viewpoint is sought (Bradshaw et al., 2017; Sullivan-Bolyai et al., 2005). As researchers from the discipline of special education our interest lay in highlighting the strengths, difficulties, barriers, facilitators and support needs of students with ASD and with identifying the participants' views on the most beneficial approaches and support practices that enabled them to succeed at university. We hoped that the information obtained could be used to inform and thereby improve transition to post-secondary education programs and support practices used by staff, teachers, and career and employment services.

Author Positionality

Author positionality should be acknowledged in qualitative research (Braun & Clarke, 2019). The first author is a parent of an adult son with autism. She has completed a Master of Special Education and a PhD at Macquarie University in the Department of Educational Studies. The second and third authors are associate professors in higher education, also at Macquarie University in the Department of Education. All authors have worked and researched extensively in the field of autism and acknowledge participatory research principles and the concept of neurodiversity.

Participant Recruitment and Remuneration

A total of 17 autism specific organisations, support groups, and networks in Australia and New Zealand, forwarded, at our request, a recruitment notice through their websites or listservs that invited former university students on the spectrum to participate in a qualitative study. The recruitment notice provided details about the study, and potential candidates completed an on-line expression of interest form. The form provided details of the selection criteria, the purpose of the research, and information concerning a \$25 incentive gift voucher. The eligibility criteria were that the former student had previously studied at an Australian or

New Zealand university, that they were 18 years or older, and that they had a formal diagnosis of ASD. Current post-graduate students with ASD were included if they had had a break of more than a year between courses. The participants were also asked to nominate a significant other (e.g., parent, spouse, partner, close friend) who had knowledge of their university and post-university experience who was willing to be interviewed. All participants who met criteria were accepted.

Interview Question Development and Format

Due to the limited research on former university students, the development of the questions was informed by prior research on the employment experiences of adults on the spectrum (e.g., Aspect, 2013; Baldwin et al., 2014; Cashin, 2018; Farley & McMahon, 2014; Gal et al., 2015; Hedley et al., 2017). Also, prior to the interviews, possible topics were discussed with a former university student on the spectrum. Participants were given an opportunity to request a copy of the questions before their interview and they were also invited to introduce new topics at the start of the interview. The questions were emailed in advance to the three former students and two significant others who requested them. One made rephrasing suggestions which were accepted.

The interview schedule (Appendix E) had mostly open-ended questions that covered university and post-university experiences. The topics that were related to the post-university experience included transition supports from university and/or other organisations, positive employment experiences, challenges at work, the impact of a university experience on employment, and employment suggestions for future students and universities. Other issues indirectly related to employment discussed included general quality of life, family, other non-employment supports since leaving university, achievements, and social and community life experiences. The location of the interviews was chosen by the participants, including three via the internet, and a hand-held recorder was used to record all interviews.

Data Extraction and Codebook Development

There were 16 interviews that were transcribed verbatim that provided the data for this article. NVivo 12 software was used to categorise and sort the data into codes and themes. The codes constantly changed as new insights were identified and they were later collapsed by a consensus of all three authors to form a codebook. Of the 15 final parent codes, eight related directly and/or indirectly (e.g., strengths, weaknesses, and mental health) to post-university experiences (Appendix F).

Data Analysis

Themes were identified from the codes. Counting was used to confirm identification of the themes rather than as a quasi-quantitative analysis, so that codes with few endorsements as well as those with many, that were important to the participants, were included in the analysis (Sandelowski, 2000). Further, when developing the themes, the transcripts were read and re-read in an inductive, iterative, and circular process (Bradshaw et al., 2017). The aim was to produce an accurate description of the reported employment experiences of former university students on the spectrum, and to analyse the participants descriptions for meaning.

Steps Taken to Increase the Credibility of the Data

To limit researcher bias, a reflexive journal and an audit trail were maintained. Also, the data was triangulated (transcripts with field notes, former students with significant others, independent coding of two investigators compared). Finally, the participants were given an opportunity to comment on the accuracy of their transcript and to provide feedback on a summary of the findings and key issues.

Interrater reliability was assessed for the overall project (by using four of the 16 transcripts: 22%) as the percent agreement (Campbell, Quincy, Osserman, & Pedersen, 2013). The total number of sentences where both coders agreed on the code(s) was divided

by the total number of sentences coded and multiplied by 100 (Campbell et al., 2013; Lombard, Snyder-Duch, & Bracken, 2002). This was found to average 80%.

Results

Participant Demographics

There were ten former students on the spectrum from Australia and one from New Zealand. In addition, seven of the former students were female, two were non-binary (biologically female), and two were male (Table 1). All were Caucasian, but specific data on socio-economic status was not recorded due to privacy concerns. Both male and one former female student had an autism diagnosis (ASD, Asperger Syndrome, high functioning ASD) before they started university while the remainder were diagnosed while at university or after leaving it. There were eight former students completed a qualification and six of these completed two or more degrees, while three withdrew before completing a university qualification. Most former students (10) indicated that they had co-occurring conditions, including ten who had anxiety, and four depression. Also, at the time of interview, just over half had been married (6), and four had children. There were also five significant others, all of whom were Australian. They included two mothers and three husbands.

Only one former student (former student 3), who was self-employed, was currently working full-time, and two were working part-time (former students 6 & 11). A further three who were older than 65 years (former students 5, 8, & 10) had previously worked in a field in which they had studied, but at the time of interview were working as volunteers for non-profits in a field related to their most recent qualification. None identified as retired, and former student 10 was a current part-time post-graduate student. There were three former students who had briefly worked in their family's business (former students 6, 7 & 9), and six who had worked casually before or during university, including four who had been employed (3, 6, 10 & 11) and two who had never been employed (7 and 9) since leaving university.

Finally, former student 2 had extensive prior work experience in the field she was qualified in but was currently studying part-time and caring for her children, while former students 1 and 4 had no work experience.

Strengths, Volunteering, and Special Interest Achievements

The former students all reported diverse employment related strengths. These included high intelligence, good attention to detail, resilience, determination, and a unique perspective. Former student 11, who previously worked in IT, stated, “So probably my strengths are that I’m logical, analytical”, and former student 6, a researcher, stated, “I would say that my attention to detail and my ability to focus are strengths. And my ability to ask questions that other people don’t ask.”

Many former students had a diverse range of talents that enabled them to achieve in non-employment related activities. This included exhibiting artwork (former student 5) and playing national and international level sport (former student 10). Also, a number of former students were involved in leadership positions in community groups, including a music group for people with disabilities (former student 7), public health, children’s sport and music (former student 10), and autism advocacy (former students 3, 5, & 8). In addition, former student 6 worked as a volunteer in a heritage centre which led to a paid job in the field she studied. Finally, former students 2 and 5 worked and travelled overseas.

Themes

The participants’ employment experiences were categorized into two broad themes. First, difficulties transitioning to work, and second, career interruptions and difficulties coping at work. There were also many subthemes which are depicted in Figure 1. The three subthemes of difficulty recognising strengths and weaknesses, limited use of supports, and mental health and other co-occurring conditions, were sub-themes that interrelated to both broad themes. Though interconnected these themes and sub-themes will be discussed in turn.

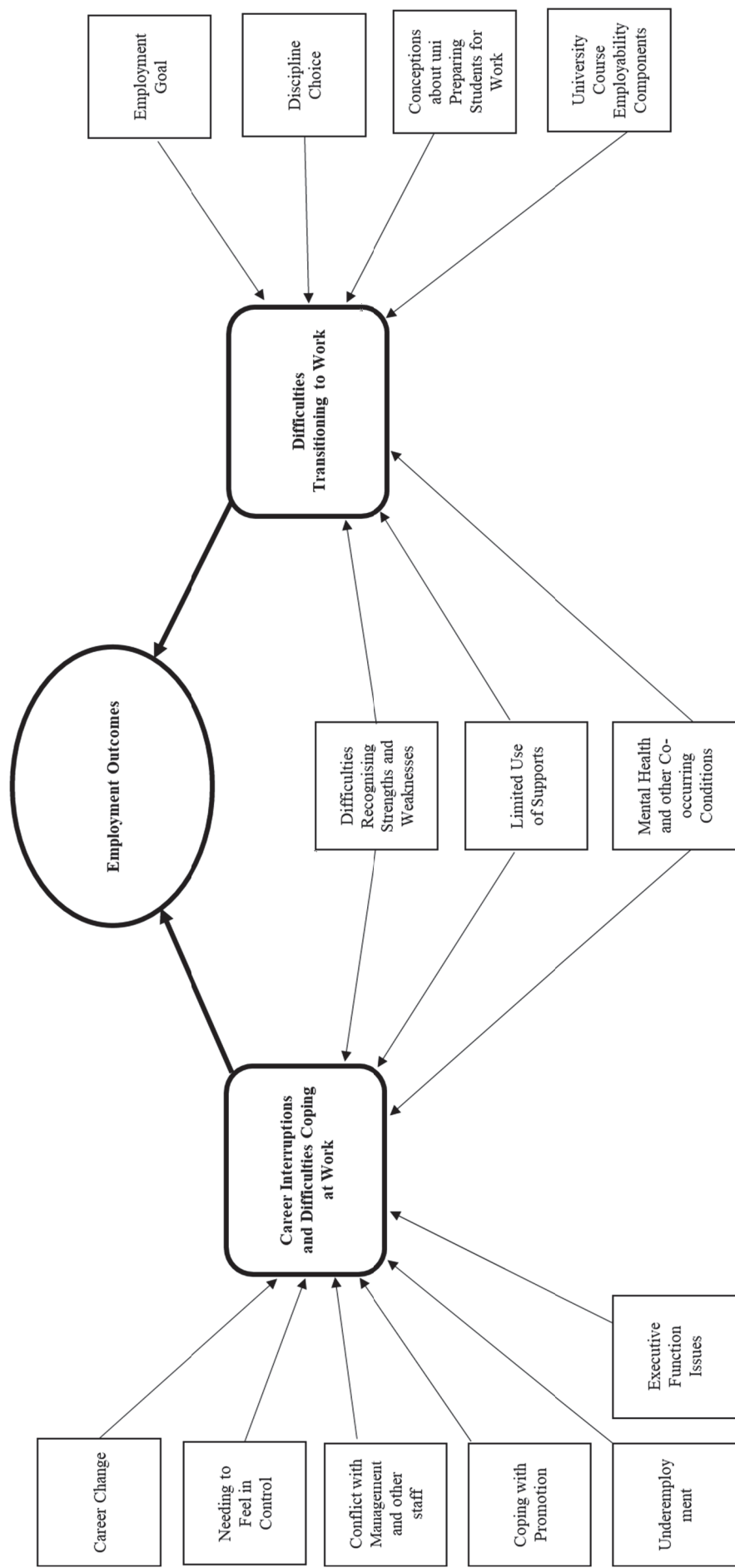


Figure. 1. Thematic map of factors that may impact employment outcomes. Themes are indicated by rectangles and sub-themes by squares.

Difficulties Transitioning to Work

The participants indicated several factors that impacted their transition to work. These included having a clear employment goal, discipline choice, conceptions about the role of universities in preparing students for work, university course employability components, and difficulty recognising strengths and weaknesses.

Employment goal. Many of the former students stated that they chose their discipline without any expectation of obtaining employment in that field (former students 1, 4, 5, 6, 7, 9, & 11). Former student 9 for example said, “Well, I’m actually not doing it for work’s sake ... No, I’m not really settled on anything ... I’d say mainly something that fulfils my interests”. Similarly, former student 1 stated: “Yeah, unfortunately I haven’t really come up with any clear ideas for a career path.” Furthermore, five former students (1, 4, 6, 7, & 9) were unaware how they could use their qualification for work. Former student 6 for example stated, “I don’t even know what I am qualified for. I don’t understand what my qualifications could get me.” In contrast, there were two former graduates (8 and 11) who found work after they subsequently completed a non-university qualification with the specific goal of getting a job. The significant other for former student 11 explained: “[After completing her degree] she was unemployed for a couple of years. ... [so], she did a TAFE [technical education] course which then led to a trainee job.”

Discipline choice. Some of the former students indicated that studying in a field that had a demand for workers made it easy to find a job. Former student 8 stated, “They needed more social workers. We were a bit like hen’s teeth so that wasn’t difficult.” In contrast, most of the former students who studied non-vocationally specific courses had trouble finding a job. The significant other of former student 1 said, “You may specialise in something, but it doesn’t open doors at the end of it.” Also, after completing a history degree participant 6 said:

I don't know how I could earn money ... I think I have a lot to offer but I don't know where to offer it. And I don't think most people are able to see what I have to offer - to use it to its best advantage. And I'm sick of being paid shit for doing – you know – it's that integrity thing. I can't do less than my best. So, they get their money's worth out of me and there is no loyalty or respect in return which is frustrating.

Conceptions about the role of universities in preparing students for work. Most former students and some of the significant others expressed the perception, at least to some extent, that it was not the role of university education to prepare students for employment. Former student 2 stated, “They don't really have much to do with each other realistically. It depends on the course you do I guess, but I don't see that university and work life really have much to do with each other.” Further, former student 6 stated, “No. I don't think so. It's pretty narrow in that it has a subject base, and they work on the subject but that is as far as it goes.” Further, participant 11 said, “it's always a bit of a surprise which knowledge you end up using”. Also, the significant other of participant 6 said, “It does to a degree in the fact that on your resume you've got a degree in this and a diploma in that. It teaches you how to write, how to write your resume and that all helps. But it is probably as good as you can have for getting a job. Once you get a job, as to whether you can do it or not depends on yourself.”

Some expressed the view that only vocationally oriented courses should prepare students for work. Former student 9 said, “I think that depends on the course. In arts degrees, generally not. In science education and vocationally oriented degrees like medicine or law, yes.” Also, the significant other for participant 1 said, “Unless it's a specific thing that leads to like law Not all the degrees that you do at uni involve that, especially arts degrees. They're a bit more loose.” Only one participant, the significant other to participant 11, definitively expressed the view that universities should prepare students for work when he responded, “definitely yes”.

University course employability components. Former students 2 and 8 specifically indicated that the university work placements that were part of their course had been helpful in finding a job. Former student 8 explained: “Most of us upon graduation got a job somewhere with the agencies that already knew us from when we were students there.”

Career Interruptions and Difficulties Coping with Work

There were several factors that caused difficulties at work and/or an interruption to the participants’ career. These included changing career due to a poor initial choice, struggling with a sense of lack of control at work, conflicts with staff and/or management, difficulty coping with a promotion, underemployment, and executive function difficulties.

Career change due to poor initial discipline choice. There were six participants (2, 5, 6, 8, 10, 11) who returned to university to study a new degree after deciding they no longer wanted to work in the field they initially studied. Participant 6 said, “Whereas with the technical writing it was sort of a means to an end. I think I will be really good at this, but I don’t have a passion for it. ... So, it was more of a head decision. The history that I study is more of a - that’s where I lose time.” However, at the time of interview only two (participants 6 and 11) had found a part-time job and none a full-time job in the new discipline (Table 1).

Needing to feel in control. Former students 3, 10, and 11 stated that they needed to feel in control of how they did their job. Former student 10, who had a very long teaching career said, “The best situations are where I am actually meant to be in control, and I can control it. And if I’m not, it doesn’t work as well.” Former student 3 similarly indicated that a main benefit of having her own business was being able to “control a lot more”. Some former students indicated that they preferred working environments with few staff. For example, former student 10 indicated that working in a very small regional school of 13 students was more suitable for her. In addition, former student 3 indicated that while she

could have earned more as an employee elsewhere or by expanding her business, she had resisted this to keep staff numbers low.

Conflict with management and/or other staff. Some participants indicated that they did not respect their supervisors or other staff. The significant other of participant 6 commented, “She seemed to be forever changing jobs and it was always the bosses that were hopeless, and they were never any good. Incompetent. That was always the issue. She struck very few people that she was comfortable working for”.

There were three participants who reported being bullied at work and they noted the lack of support related to this issue. Participant 5 stated, “I taught at primary school. ... teachers were pretty nasty – even one which would get her class to gang up against me.” In addition, participant 2 explained, “Bullying is a difficult one to work out. ... so, it would’ve been good to have somebody at least notice it.”

Difficulty coping with a promotion. Former student 2 described her difficulty after being promoted to management. She said, “I was so good at that job that they put me in a management role and that was the end of it. I’m not a manager, it was hideous ... that’s when I completely melted down and quit.” In addition, former student 11 who also left her job after a promotion said, “When you had to deal with the upper management, logic wasn’t a factor anymore and I didn’t know what they wanted.”

Underemployment. Many participants were underemployed, though in different ways. Some worked part-time when they would have preferred full-time while others (reluctantly) worked in jobs which did not require their qualification(s). For example, after working a few years in a job that was related to her degree, participant 8 had many jobs that did not require tertiary qualifications such as receptionist and taxi driver. Finally, participant 6 who only very briefly worked as a teacher, reported that she was frustrated by her persistent underemployment. She stated, “I can’t face starting a new one. ... it is breaking my soul.”

Executive function difficulties. Many participants described difficulties with time management and coping with change. Participant 9 stated, “My punctuality isn't that good ... and coping with changes especially is quite difficult. So, if an unexpected situation emerges, how to adjust to that. I find that incredibly difficult.”

Factors that Impacted Both Transitioning to Work and Coping with Work

Difficulty recognising strengths and weaknesses. Some participants did not recognise their strengths. For example, participant 2 (in relation to her university course) said, “I actually gave my first speech and everybody laughed at it and it was a great success, so I thought awesome, I can do this.” Some participants had trouble recognising their weaknesses. For example, participant 11 explained that though academically very strong, participating in work placements had helped her identify that she was weaker on the practical side. She stated:

That’s when I also discovered that compared to other people, learning movement patterns is really, really hard for me. And I went, aww, bugger! But I didn’t know that at the time, and so I couldn’t work out why I couldn’t do these things.

Some of the participants indicated that they did recognise their weaknesses and that they used this knowledge to help rule out some career options. For example, participant 8 said, “I probably wouldn’t have coped with nursing, I wouldn’t have coped with being in an office with a typewriter. I certainly wouldn’t have coped with being a teacher.” Also, participant 5 said “I knew I couldn’t cope at [teaching] secondary school. At high school I knew I could cope subject wise, but I knew I would be a dead duck to [teach] secondary school kids.”

Limited use of Transition and Employment Supports

No former student reported having used a university careers service to help choose a career or find a job, and the few who used a non-university employment service indicated that

the service was variable. Former student 6 said, “The [non-university] disability employment services ... were completely useless. ... They don’t know what to do with anybody who doesn’t want to stand on a production line or work in hospitality or something.” The significant other of former student 1 said, “[The non-university career advisor] hasn’t really been terrific. So, we’ve gone through two different mentors, a little bit of money, and now they’ve recommended that he do another course.” In addition, participant 8 stated, “No. I did go to one ... which was an outgrowth of mental health services and it was supposed to aid me into work but they were worse than useless and they still bloody are.” Moreover, former student 7 reported that due to her extensive co-occurring conditions, “my [non-university] employment agency quit on my behalf without asking me”.

Mental Health and Other Co-occurring Conditions

All but one former student had co-occurring conditions, the most prevalent being poor mental health, including 10 participants who had anxiety and four who had attempted suicide. Former students 2, 3, 5, and 11 described specific work-related stress. Former student 2 stated: “[you feel] like everything is against you, it’s not your safe place. ... I’d work for two years, be completely and utterly burnt out, have to take three to six months off, and then I’d get another job.” Former student 3 described the stress of running a successful business. “Earlier this year I had to take three weeks off, that was sort of forced leave as well because I wasn’t managing things particularly well. So, it is an ongoing issue, I guess”.

Former student 6 stated she intentionally looked for low status jobs, even though she did not enjoy them. She said, “But mostly I *don’t* go for jobs that I’m qualified for. I go for jobs that are much lower”. Participant 6, who stated she did not have any co-occurring conditions, also indicated that she may have difficulty recognising her anxiety and that this may have had implications for her support and career choices. She explained:

I haven't been diagnosed with any comorbid anxiety/depression, but I think there is a degree of anxiety that I don't recognise because that is what I live with, and I don't like to be a bother to people. ... I am not very good at self-identifying what's helpful. I just have always made do.

Her significant other also explained:

I think she's - I think she's anxious when she is stressed. ... If she's got too much happening. If she has too many things going on at once. She is good at managing everything, but it does take it out of her. And the fact that she can't concentrate on – on complexity - she needs to have things simply sorted out and organised. ... We would try, we are in the position where we can prevent that.

Some significant others did not recognise the mental health concerns of their partner.

For example, a significant other was perplexed when his partner (former student 11)

“*suddenly* just couldn't cope with her manager and just walked out.” Also, when asked what supports she needed since leaving university, participant 3 indicated more support for others to understand the issues faced by people with autism. She stated:

It's more just having people around you aware. ... [My husband] will get frustrated and upset with me sometimes [if I don't want to go out after work] ... And I will say: You know I never go out after a day of work. So, it's like sometimes he gets it and sometimes he doesn't. So, I guess [we need] more support groups and awareness groups for families of people on the spectrum.

Discussion

This study is one of only a few studies and the first from Australia or New Zealand that solely focused on the employment experiences of former university students with ASD. As there are differences within the Australian and New Zealand higher education sectors, outcomes found from other jurisdictions cannot be assumed to apply to Australia. Moreover,

if findings are similar across countries, this may highlight the possibility of multinational collaborative research on this issue. This could facilitate greater participant sample sizes and increase external validity.

A compelling finding was that most former student participants in this study had some employment successes, but in line with prior research of adults with ASD with average or above intellectual ability (e.g., Baldwin et al., 2014; Taylor et al., 2015), most worked in a field unrelated to their qualification and had considerable periods of unemployment or underemployment. Unemployment and underemployment (and low economic standing) are associated with low self-esteem, frustration, depression, and poor quality of life (Baldwin et al., 2014; Muller et al., 2003; Ohl et al., 2017). This study identified several personal and environmental themes and sub-themes that point to some of the factors that may impact on the employment outcomes of former students on the autism spectrum.

Difficulties Transitioning to Work

The participants in this study who worked in the field they studied mostly completed vocationally oriented degrees (e.g., teaching, social work) in a field that had a strong demand for workers at the time they studied. Also, most of the participants who found work, completed work placements as part of their course, and they had a clear idea of what they wanted to do with their qualification. There were four working graduates who did not enjoy their jobs, however, and they subsequently studied a course in an area of greater interest that was not vocationally specific. Only one found employment (part-time) in that new field, however. While this is disappointing, there may be problems with choosing a discipline primarily because of its employment prospects. Apart from the increased difficulty of completing a degree in a field that is not of special interest (Anderson et al., 2020), there can be significant negative health and quality of life implications from working in an unsatisfying job (Faragher, Cass, & Cooper, 2005) and the demand for workers in particular fields can be

variable (Frey & Osborne, 2017; Marx, 2015). So, understanding how to help students on the spectrum find work in an area of interest rather than encouraging them to move to an area in higher demand, may be the imperative.

Conceptualising the transition to employment may be more difficult for students on the spectrum (Vincent, 2019), and possibly more so for those with a non-vocationally specific qualification. While prior research suggests most university students without disabilities who graduate with non-vocationally specific qualifications find work (Roksa & Levey, 2010), students on the spectrum may have more difficulty (Taylor et al., 2015), possibly due to more limited generalisation ability (Sapey-Triomphe, Sonie, Henaff, Mattout, & Schmitz, 2018). In the current study, for example, several former students indicated that they were unclear how their qualification could be used in the workforce. Thus, transition support and course curricula that aims to increase employability skills and conception of how a qualification could be used for employment may be needed for *some* students with ASD.

Work placements tailored to individual needs have been found helpful with some university students (Hurley-Hanson, Giannantonio, & Griffiths, 2020) and high school graduates on the spectrum (Wehman et al., 2020), and all but one of the former students in the current study who were employed in the field they studied directly after university, participated in placements. However, Grant-Smith and McDonald's (2018) literature review of unpaid work experiences of students *without* disabilities (volunteering, internships, educational vocational training) warned of possible risks, including student exploitation and poorly supervised and inappropriate placements. They also found that placements may be less beneficial for those studying arts, humanities, and social sciences degrees, and that there is little objective evidence that placements lead to higher rates of employment (Grant-Smith & McDonald, 2018). This is interesting as the former students in the current study who participated in placements also studied vocationally specific courses in fields that were in

high demand at the time they graduated. Further, Grant-Smith and McDonald (2018) noted that the rising prevalence of internships may be creating an ever-increasing expectation for longer and longer periods of unpaid work as a necessary precursor to paid employment. Work placements have intuitive appeal, and there is strong favourable evidence from interventions with high-school graduates on the spectrum (e.g., Wehman et al., 2020), and preliminary evidence from interventions conducted with post-secondary students (Hurley-Hanson et al., 2020). However, placements and other non-paid positions need to be monitored to avoid internships which only benefit the employer, and more objective evidence on effectiveness, particularly from those who studied non-vocationally specific qualifications, is needed. In addition, as some students with ASD find placements very stressful, more supports for this may be required.

Many former students and a few significant others did not link university courses with the preparation of students for employment which suggests a misunderstanding of the relationship between higher education and employment. This is surprising as student employability is an indicator of higher education quality in many countries (Harvey, Andrewartha, Edwards, Clarke, & Reyes, 2017) including Australia where graduate employability ratings are used to access funding growth (Australian Government Department of Education, 2019). As this is a fundamental issue that may have a significant impact on students' discipline choices, and a greater understanding of the connection may encourage students to seek more opportunities that increase their employability whilst a student, there may be a need to explain this connection explicitly before they start university. Moreover, research on this topic may be a priority.

Difficulties Coping at Work

The work related difficulties reported by the former university students were consistent with the findings of research about the working experience of adults on the

spectrum (having to follow others instructions, understanding management objectives and directions, time management, coping with change and work demands, and struggles with mental health and sensory issues). Also, as with prior research (e.g., Anderson, Moore, et al., 2017; Aspect, 2013; Flower, Sadka, Richdale, & Haschek, 2019; Wright, Wright, D'Astous, & Wadsworth, 2019), the current participants indicated that their needs were often not recognised by others, and that their employment difficulties did not improve over time (Taylor et al., 2015). Significantly, all but one of the current participants who worked, had career interruptions. Some due to changing careers after a poor initial choice, which emphasises the critical need to provide early career guidance. In addition, all but one had career interruptions due to poor mental health. As the reasons for their poor mental health were very varied (peer and management bullying, frustration from under-employment, lack of respect for management, difficulties understanding management demands, and stress coping with a promotion to management) supports clearly need to be individualised. Only one of the former students in the current study had access to minimal support at work, however. While there are many studies providing preliminary evidence for support for entry level positions for adults on the spectrum with no intellectual disability (e.g., Flower et al., 2019; Hedley et al., 2018; Nicholas et al., 2018), we could find no research on supports for those with more senior or managerial roles. As individuals with university qualifications have the intellectual ability to work at more senior levels, and the participants who were under-employed were deeply frustrated and saddened by this, research specifically aimed at helping workers with ASD to transition into more senior employment roles, and to maintain them, is needed.

Limited Use of University and Non-university Careers and Employment Services.

A few former participants did not use supports because they did not recognise their own difficulties and need for support. Although this issue only related to a minority of

participants, there may be merit in including instruction on recognising strengths, weaknesses, and support needs in transition programs, as it may have an impact on career choices and lack of awareness prevented some from seeking needed supports. Also, to enable significant others to provide more effective supports, some significant others may need help to understand and recognise the difficulties their partners on the spectrum experience.

Most participants indicated that they did not use supports because they believed they would not be helpful and the few who used a non-university employment service stated that the service had been ineffective, a finding similar to that reported by Flower et al. (2019). University careers services typically include a range of supports such as interview and resume preparation, and help to locate job opportunities (Andrewartha & Harvey, 2017), but no participant in the current study approached a university career adviser, and other studies have similarly found that students with disabilities are reluctant to use these services (e.g., Andrewartha & Harvey, 2017). Some US universities, with comprehensive autism specific transition to employment programs have reported encouraging results that warrant further investigation (e.g., Ball State University, Landmark College, Marshall University, Sam Houston State University, Texas Tech University; Hurley-Hanson et al., 2020). Also, a recent qualitative study by Vincent (2020) suggests that university career services can be helpful when staff are knowledgeable about the needs of students on the spectrum. Moreover, early use of careers services can encourage students with disabilities to develop an employment goal and it may lead to increased rates of course completion (Andrewartha & Harvey, 2017). Thus, while more research is needed, preliminary evidence suggests that university careers services might be helpful where staff have knowledge about autism and ideally, an autism specialist and that students should be encouraged to use them. In addition, as many former students with autism do not finish their degree, and many graduates experience difficulty in finding employment (Andrewartha & Harvey, 2017; Lizotte, 2016),

career service should be available for both graduates and those who withdraw before completion for a while after exiting university.

Future Research Directions

Many former students indicated that they participated in interest groups and/or had volunteered for non-profit organisations. While there may be non-employment related benefits from volunteering (Tabassum, Mohan, & Smith, 2016), its impact on obtaining employment may be more tenuous (Paine, McKay, & Moro, 2013) so research may be needed to examine possible optimal levels and types of volunteering that may increase employability and quality of life for post-secondary students on the spectrum. In addition, as only a few studies have directly compared outcomes based on graduate discipline (Ohl et al., 2017), and a university course is a significant financial investment, more research is needed to better inform future students about the employment prospects of vocational versus non-specific vocational university courses. Finally, a larger study with more diverse participants is needed to explore the student with autism understanding about the role of universities to prepare students for employment and the connection between education and employment.

Limitations

Although all former students stated that they had a formal diagnosis, proof of diagnosis was not requested. Further, the sample had several specific features that limit generalisability of the findings. While some participants studied more recently, others studied during a time when university services for students with disabilities were far less developed. Those earlier experiences may have less relevance to current students. Also, only two former students were male, and there were only three former students who did not complete. Finally, many of our former students were diagnosed later in life, and their experiences may not be relevant to those diagnosed as children or those who received support most of their life (Farley & McMahon, 2014).

Implications

There are several implications arising from this study that may help former students on the spectrum improve employment outcomes. Students should be encouraged to consider many factors when choosing a discipline to study. This includes their interests and talents and the possible vocational trajectory and demand for workers in possible fields of interest. Also, ways a generic course might be used when seeking employment should be considered. The caveat that work demand can change should be noted. University courses may need to include employability skills components, (with appropriate supports since some may find them challenging), such as work placements, team building, and communication skills development. This may develop needed skills and help students conceptualise how a qualification could be used in the workplace. Safeguards should be put in place to ensure placements are meaningful and that students are not exploited. In addition, students should have early access to university careers advisors and/or specialist autism employment agencies to help students prepare for the transition to employment. These supports should be available for an extended period after university exit and for both graduates and those who withdraw before completion. Pointing out strengths may increase graduate's confidence to apply for roles in line with their qualifications and enable skills and talents to be better acknowledged and used by others, benefitting companies, and reducing underemployment. Also, analysing personal working preferences such as smaller companies with fewer staff and jobs that allowed them to have more control over how they did their job may help participants to thrive in the workforce. Further, mental health supports may be critical for many workers on the spectrum, especially those in more senior employment rolls. Finally, employment supports should be available at all levels and throughout working life.

Conclusion

There is little research on employment that solely focuses on the experiences of former university students on the spectrum. This qualitative study suggested that university courses may need to include more employability components and that students should be encouraged to make greater use of university careers services. Also, the study highlighted how some students with ASD may need help in conceptualising how their qualification could be used in the workforce, especially those who are considering studying non-vocationally specific courses. The study revealed that employment supports need to be tailored to individual needs and may be required throughout life and at all employment levels. Moreover, there remains a need to increase recognition and use in the workforce of the strengths and talents of former university students on the autism spectrum.

Acknowledgements: We would like to acknowledge the important contribution of Dr. Sarah Carlon to this research. We also appreciate the effort of the autism support groups and associations who helped distribute the invitations to participate. Finally, the participants' insights were invaluable.

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Author contribution: AA developed the study aims and research questions, liaised with participating autism associations and participants, prepared the semi-structured questions, conducted all interviews, prepared and/or checked the written transcripts, extracted and analysed the data, prepared the table, and drafted the manuscript. JS independently extracted and analysed the data. JS and MC participated in the development of the study aims and research questions, the analysis of the data, and provided feedback on the semi-structured questions and the manuscript. All authors read and approved the final version of the manuscript and agreed to submit the article for publication.

Disclosure of potential conflicts of interest: The Authors declare that there is no conflict of interest.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Anderson, A., Moore, D., Rausa, V.C., Finkelstein, S., Pearl, S., & Stevenson, M. (2017). A systematic review of interventions for adults with autism spectrum disorder to promote employment. *Review Journal of Autism and Developmental Disorders*, 4, 26-38. <https://doi.org/10.1007/s40489-016-0094-9>
- Anderson, A.H., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886-2901. <https://doi.org/10.1007/s10803-020-04386-7>
- Andrewartha, L., & Harvey, A. (2017). Employability and student equity in higher education: The role of university careers services. *Australian Journal of Career Development*, 26, 71-80. <https://doi.org/10.1177/1038416217718365>
- Australian Government Department of Education. (2019). *Higher education policy changes – provider FAQs*. Retrieved from <https://www.education.gov.au/higher-education-policy-changes-provider-faqs>
- Autism Spectrum Australia (Aspect). (2013). *We belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism*. Retrieved from https://www.autismspectrum.org.au/sites/default/files/Autism_Spectrum_WE_BELOING_Research_Report-FINAL_LR_R.pdf
- Ayres, M., Parr, J.R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism*, 22, 774-783. <https://doi.org/10.1177/1362361317714988>

- Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism, 20*, 483–495.
<https://doi.org/10.1177/1362361315590805>
- Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 44*, 2440–2449. <https://doi.org/10.1007/s10803-014-2112-z>
- Black, M.H., Mahdi, S., Milbourn, B., Thompson, C., D'Angelo, A., Ström, E., ... Sven Bölte (2019). Perspectives of key stakeholders on employment of autistic adults across the United States, Australia, and Sweden. *Autism Research 12*, 1648–1662.
<https://doi.org/10.1002/aur.2167>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research, 4*, 1–8.
<https://doi.org/10.1177/2333393617742282>
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*, 195–207.
<https://doi.org/10.1177/001440290507100205>
- Cai, R.Y., & Richdale, A.L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*, 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Campbell, J.L., Quincy, C., Osserman, J., & Pedersen, O.K. (2013). Coding in-depth semi structured interviews: Problems of unitisation and intercoder reliability and agreement. *Sociological Methods & Research, 42*, 294–320.
<https://doi.org/10.1177/0049124113500475>

- Cashin, A. (2018). The transition from university completion to employment for students with autism spectrum disorder. *Issues in Mental Health Nursing*, 39, 1043-1046.
<https://doi.org/10.1080/01612840.2017.1401188>
- Centers for Disease Control and Prevention. (2020). *Prevalence of autism spectrum disorder among children aged 8 years. Autism and developmental disabilities monitoring network, 11 Sites, United States, 2016. Morbidity and Mortality Weekly Report (MMWR) Surveillance Summary 2020*, 69(4), 1–12.
https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w
- Chen, J.L., Leader, G., Sung, C., & Leahy, M. (2015). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders*, 2, 115-127.
<https://doi.org/10.1007/s40489-014-0041-6>
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Dietz, P.M., Rose, C.E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Advance online publication. <https://doi.org/10.1007/s10803-020-04494-4>
- Faragher, E.B., Cass, M., & Cooper, C.L. (2005). The relationship between job satisfaction and health: A meta-analysis. *Occupational and Environmental Medicine*, 62, 105–112. <https://doi.org/10.1136/oem.2002.006734>
- Farley, M., & McMahon, B. (2014). Range of outcomes and challenges in middle and later life. In F.R. Volkmar, B. Reichow., & J.C. McPartland. *Adolescents and adults with autism spectrum disorders* (pp. 211-238).
https://doi.org/10.1007/978-1-4939-0506-5_11

- Flower, R., Sadka, N., Richdale, A., & Haschek, A. (2019). The Australian context: Commentary on “Mothers’ experiences of the transition of young people with autism spectrum disorder to adult care” (McMinn, Schulz, & Ludlow, 2019) and “Challenging the status quo” (Beadle-Brown & Roberts, 2019). *Research and Practice in Intellectual and Developmental Disabilities*, 6, 147-153.
<https://doi.org/10.1080/23297018.2019.1652928>
- Frey, C.B., & Osborne, M.A. (2017). The future of employment: How susceptible are jobs to computerisation? *Technological Forecasting & Social Change*, 114, 254-280.
<https://doi.org/10.1016/j.techfore.2016.08.019>
- Gal, E., Landes, E., & Katz, N. (2015). Work performance skills in adults with and without high functioning autism spectrum disorders (HFASD). *Research in Autism Spectrum Disorders*, 10, 71-77. <https://doi.org/10.1016/j.rasd.2014.10.011>
- Grandin, T. (2014). *The autistic brain: Exploring the strength of a different kind of mind*. London: Rider Books.
- Grant-Smith, D., & McDonald, P. (2018). Ubiquitous yet ambiguous: An integrative review of unpaid work. *International Journal of Management Reviews*, 20, 559–578.
<https://doi.org/10.1111/ijmr.12153>
- Harvey, A., Andrewartha, L., Edwards, D., Clarke, J., & Reyes, K. (2017). *Student equity and employability in higher education. Report for the Australian Government Department of Education and Training. Melbourne: Centre for Higher Education Equity and Diversity Research, La Trobe University*. Retrieved from https://www.latrobe.edu.au/__data/assets/pdf_file/0006/792222/La-Trobe-NPP-Employability-Research-Report-1-February-2017.pdf

- Hayward, S., McVilly, K., & Stokes, M. (2018). "Always a glass ceiling." Gender or autism; the barrier to occupational inclusion. *Research in Autism Spectrum Disorder*, 50, 50-60. <https://doi.org/10.1016/j.rasd.2018.09.001>
- Hayward, S., McVilly, K., & Stokes, M. (2019). Autism and employment: What works? *Research in Autism Spectrum Disorder*, 60, 48-58. <https://doi.org/10.1016/j.rasd.2019.01.006>
- Hayward, S., McVilly, K., & Stokes, M. (2020). Sources and impact of occupational demands for autistic employees. *Research in Autism Spectrum Disorder*, 76. Advance on-line publication. <https://doi.org/10.1016/j.rasd.2020.101571>
- Heasman, B., & Gillespie, A. (2018). Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*, 22, 740-750. <https://doi.org/10.1177/1362361317708287>
- Hedley, D., Cai, R., Uljarevic, M., Wilmot, M., Spoor, J.R., Richdale, A., & Dissanayake, C. (2018). Transition to work: Perspectives from the autism spectrum. *Autism*, 22, 528-541. <https://doi.org/10.1177/1362361316687697>
- Hedley, D., Uljarevic, M., Cameron, L., Halder, S., Richdale, A., & Dissnayake, C. (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, 21, 929-941. <https://doi.org/10.1177/1362361316661855>
- Hurley-Hanson, A. E., Giannantonio, C. M., & Griffiths, A. J. (2020). *Autism in the workplace: Creating positive employment and career outcomes for generation A*. Palgrave Macmillan. https://doi.org/10.1007/978-3-030-29049-8_1
- Kirchner, J., Ruch, W., & Dziobek, I. (2016). Brief report: Character strengths in adults with autism spectrum disorder without intellectual impairment. *Journal of Autism and Developmental Disorders*, 46, 3330-3337. <https://doi.org/10.1007/s10803-016-2865-7>

- Kozleski, E.B. (2017). The uses of qualitative research: Powerful methods to inform evidence-based practice in education. *Research and Practice for Persons with Severe Disabilities*, 42, 19–32. <https://doi.org/10.1177/1540796916683710>
- Lizotte, M. (2016). *A phenomenological study of vocational experiences in adult college graduates with autism spectrum disorders* (Doctoral dissertation). Retrieved from <https://search.proquest.com/docview/1806124714>
- Lombard, M., Snyder-Duch, H., & Bracken, C. (2002). Content analysis in mass communication. Assessment and reporting of intercoder reliability. *Human Communication Research*, 28, 587-604. <https://doi.org/10.1111/j.1468-2958.2002.tb00826.x>
- Lorenz, T., & Heinitz, K. (2014). Asperger's – different, not less: Occupational strengths and job interests of individual with Asperger's Syndrome. *PLoS ONE*, 9(6): e100358. <https://doi.org/10.1371/journal.pone.0100358>
- Marx, G. (2015). Jobs and careers on the front line of the future. *Career Planning & Adult Development Journal*, 31(2), 20–27. <https://www.careernetwork.org/Journals/Vol%2031,%20Nr%202,%20Sum%202015.%20OUR%20FUTURE%20.pdf>
- McLeod, J., Meanswell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*, 49, 2320–2336. <https://doi.org/10.1007/s10803-019-03910-8>
- Migliore, A., Butterworth, J., & Zalewska, A. (2014). Trends in vocational rehabilitation services and outcomes of youth with autism: 2006–2010. *Rehabilitation Counseling Bulletin*, 57, 80–89. <https://doi.org/10.1177/0034355213493930>

- Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin* 55, 176-184. <https://doi.org/10.1177/0034355212438943>
- Muller, E., Schuler, A., Burton, B.A., & Yates, G.B. (2003). Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*, 18(3), 163-175.
- Newman, L., Wagner, M., Knokey, A.M., Marder, C., Nagle, K., Shaver, D., ... Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005)*. Menlo Park, CA: SRI International. Retrieved from https://nlts2.sri.com/reports/2011_09_02/
- Nicholas, D.B., Zwaigenbaum, L., Zwicker, J., Clarke, M., Lamsal, R., Stoddart, K.P., ... Lowe, K. (2018). Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*, 22, 693-702. <https://doi.org/10.1177/1362361317702507>
- Ohl, A., Sheff, M.G., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work*, 56, 345-355. <https://doi.org/10.3233/WOR-172492>
- Paine, A.E., McKay, S., & Moro, D. (2013). Does volunteering improve employability? Insights from the British Household Panel Survey and beyond. *Voluntary Sector Review*, 4, 355–376. <https://doi.org/10.1332/204080513X13807974909>
- Rast, J.E., Roux, A.M., & Shattuck, P.T. (2020). Use of vocational rehabilitation supports for postsecondary education among transition-age youth on the autism spectrum. *Journal of Autism and Developmental Disorders*, 50, 2164–2173. <https://doi.org/10.1007/s10803-019-03972-8>

- Roksa, J., & Levey, T. (2010). What can you do with that degree? College major and occupational status of college graduates over time. *Social Forces*, 89, 389-415.
<https://doi.org/10.1353/sof.2010.0085>
- Roux, A.M., Rast, J.E., Anderson, K.A., & Shattuck, P.T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood. Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University*. Retrieved from https://www.familyvoicesofca.org/wp-content/uploads/2017/06/Natl-Autism-Indicators-Report-2017_Final.pdf
- Roux, A.M., Shattuck, P.T., Rast, J.E., Rava, J.A., Edwards, A.D., Wei, X., ... Yu, J.W. (2015, November). Characteristics of two-year college students on the autism spectrum and their support services experiences. *Autism Research and Treatment*, 391693. <https://doi.org/10.1155/2015/391693>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Focus on Research Methods*, 23, 334-340.
[https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Sapey-Triomphe, L., Sonié, S., Hénaff, M., Mattout, J., & Schmitz, C. (2018). Adults with autism tend to undermine the hidden environmental structure: Evidence from a visual associative learning task. *Journal of Autism and Developmental Disorders*, 48, 3061-3074. <https://doi.org/10.1007/s10803-018-3574-1>
- Scott, M., Milbourn, B., Falkmer, M., Black, M., Bolte, S., Halladay, A., ... Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism*, 23, 869-901. <https://doi.org/10.1177/1362361318787789>
- Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome* (2nd. ed). Shawnee Mission, KS: Autism Asperger Publishing Company.

- Smith, I.C., Ollendick, T.H., & White, S.W. (2019). Anxiety moderates the influence of ASD severity on quality of life in adults with ASD. *Research in Autism Spectrum Disorders*, 62, 39-47. <https://doi.org/10.1016/j.rasd.2019.03.001>
- Sullivant-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nursing Outlook*, 53, 127-133. <https://doi.org/10.1016/j.outlook.2005.03.005>
- Tabassum, F., Mohan, J., & Smith, P. (2016). Association of volunteering with mental well-being: A lifecourse analysis of a national population-based longitudinal study in the UK. *BMJ Open*, 6:e011327. <https://doi.org/10.1136/bmjopen-2016011327>
- Taylor, J.L., Henninger, N.A., & Mailick, M.R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, 19, 785–793. <https://doi.org/10.1177/1362361315585643>
- Taylor, J.L., & Seltzer, M.M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41, 566-574. <https://doi.org/10.1007/s10803-010-1070-3>
- Vincent, J. (2019). It's the fear of the unknown: Transition from higher education for young autistic adults. *Autism*, 23, 1575-1585. <https://doi.org/10.1177/1362361318822498>
- Vincent, J. (2020). Employability for UK University Students and Graduates on the Autism Spectrum: Mobilities and Materialities. *Scandinavian Journal of Disability Research*, 22, 12–24. <https://doi.org/10.16993/sjdr.656>
- Ward, D., & Webster, A. (2017). Understanding the lived experiences of university students with autism spectrum disorder (ASD): A phenomenological study. *International Journal of Disability, Development and Education*, 65, 373-392. <https://doi.org/10.1080/1034912X.2017.1403573>

- Wehman, P., Schall, C., McDonough, J., Sima, A., Brooke, A., Ham, W., ... Riehle, E. (2020). Competitive employment for transition-aged youth with significant impact from autism: A multi-site randomized clinical trial. *Journal of Autism and Developmental Disorders*, 50, 1882-1897.
<https://doi.org/10.1007/s10803-019-03940-2>
- Wright, S.D., Wright, C.A., D'Astous, V., & Wadsworth, A.M. (2019). Autism aging. *Gerontology & Geriatrics Education*, 40, 322-338.
<https://doi.org/10.1080/02701960.2016.1247073>

Table 1*Demographic and Employment Characteristics*

Participant number and significant other	Age/Gender	When Diagnosed before/during/after uni	Field studied	Degrees	Non-degree qual	Time since uni	Worked in field studied	Current job	Employment history	Living arrangement/ marital status/ (Children)
1 SO mother	30-40 Male	Before	Languages	B		3 years	N	U	nil	With parents Single (0)
2 No SO	40-50 Female	During	IT	B, 3PGD	2	current M	Y	U, PTPG, carer	Several large companies (IT)	With parents Divorced (2)
3 SO husband	30-40 Female	During	Education	B, M		2 years	Y	FTJ – own business	Teacher, Own business	Married (0)
4 No SO	18-30 Other	After	Humanities	I		6 months	N	U	nil	Independent Single (0)
5 No SO	50+ Other	After	Education Fine arts Humanities	2B, M(I)	1	10 years	Y	U PTV	Teacher; overseas work	Married (0)
6. SO husband	50+ Female	During	Education Arts Tech writing	B, PGD(I)		current M	Y	PTJ PTPG	Teacher; Office work, Researcher	Married (3)
7 No SO	18-30 Female	Before	Music Humanities	I		6 months	Y	U	Casual retail (before uni), casual private music tutor	Independent S (0)
8 No SO	50+ Female	After	Arts Humanities	B, PGD	1	> 10 years	Y	U FTV	Social worker, ESL teacher	Independent Divorced (2)
9 SO mother	18-30 Male	Before	Languages	I	1	1 year	N	U	Casual tutor for family business	Independent S (0)
10 No SO	50+ Female	During	Education Health	B		current M	Y	PTV, PTPG, carer	Teacher	Independent Divorced (2)
11 SO husband	40-50 Female	During	Science Health	2B, 2M	1	1 month	Y	PTJ	Science (casual PT), IT (FT), Allied health (PT)	Married (0)

Note: B bachelor; D divorced; ESL English as a second language; F female; FTJ full-time job; FTV full time volunteer; I incomplete, IT information technology; M master; PGD post graduate diploma; PTV part-time job; PTJ part-time volunteer; PTPG part-time post graduate student, S single; SO significant other; U unemployed

CHAPTER 6: CONCLUSION

Chapter Overview

Chapter 6 includes a summary of the research, an explanation of how the broad thesis research questions were addressed, and a delineation of implications and major contributions to the research on post-secondary students with ASD that were derived from the research.

Summary of the Research

The purpose of the research presented in this thesis was to discover greater knowledge and understanding of the educational and employment experiences of current and former post-secondary students with ASD in Australia and New Zealand. To this end, an exploration of the strengths, weaknesses, barriers, and facilitators that might impact the university and employment experience was provided. It was hoped that the research may better inform decision making about post-secondary education and employment, and that this may ultimately improve the provision, use, and development of supports and thereby outcomes.

To provide an overview and context for the research, definitions, prevalence rates, and characteristics of post-secondary students and workers with ASD were detailed in the first chapter. Also, the theoretical concepts that guided the research, including the social model of disability, neurodiversity, and the autism acceptance movement, that oblige the community to provide the supports necessary for students with ASD to participate in all levels of education and employment were described. Further, several measures were taken that endorsed participatory research principles (den Houting, 2019). Firstly, the issues were examined from the student perspective. In addition, prior to their use, a former student with ASD trialled the survey (Chapter 2) and reviewed the semi-structured interview questions for the qualitative studies (Chapters 3 and 5), and he provided useful suggestions that were adopted. During their interview, the qualitative study participants (Chapters 3 & 5) were encouraged to introduce new topics. They were also given an opportunity to comment and provide feedback on the

accuracy of their transcript and a prepared summary of the key findings and themes.

There were three overarching thesis research questions that guided the research and four studies that informed the response.

The first thesis research question, “What are the experiences of current and former university students with ASD in Australia and New Zealand?” was addressed in chapters 2 and 3. Chapter 2 included a report of a primarily quantitative on-line survey of 102 current university students from Australia and New Zealand while chapter three explored the experiences of former students. The survey included questions about student strengths and difficulties, disclosure to disability services, support use, student satisfaction with available supports and services, and student assessment of their overall university experience. It was revealed that the respondents studied a diverse range of disciplines, and that their greatest concerns were academic requirements and mental health. An urgent need for more mental health supports was identified as many of the participants in both chapters 2 and 3 indicated suicidal ideation and a lack of available mental health services. In addition, many respondents in both studies stated that they found it difficult to ask for support, suggesting a need for both advocacy support and training. These findings were in line with prior research by Gelbar, Shefcyk, and Reichow (2015) and White et al., (2016). The similar findings and issues found among post-secondary students with ASD across countries and cultures suggest that these issues are universal and that researchers could collaborate internationally. This may enable larger samples of participants to be recruited and possibly improve efficiency and study quality. At the time the article was published, the survey was the largest on this topic and there were only two small prior surveys from Australia (including my own, Anderson et al., 2018), and none from New Zealand.

The third chapter, a qualitative study of eight university graduates and three ex-university students who did not complete their university qualification, and six of their

significant others, provided a diverse range of retrospective perspectives that addressed the first research question. It was found that most of the former university students had switched to part-time study and/or taken extended leave to manage mental health and/or poor executive function which resulted in slow progress. A need for more executive function supports to help students manage a full-time load, such as supervised study tables, was highlighted. In addition, it was noted that most former students had difficulty identifying their strengths and many revealed that they had made poor initial discipline choices. It was suggested that more transition supports were needed to help students recognise their strengths and to choose an appropriate discipline. Cage and Howes (2020), who also studied former university student with ASD, similarly highlighted the need for improved advocacy support and for universities to be more proactive in providing supports for executive function, mental health, and sensory issues. Further, they also concluded that increased course and other structures may help students meet their academic requirements and that transition courses are needed to better prepare students for post-secondary education.

Many former students indicated an interrelationship between academic requirements and mental health, and it was noted that those who did not complete their qualification also did not have a definitive employment goal. In addition, very divergent views about the importance of friendships at university were indicated. This study contributed to the research as it was one of the first to qualitatively analyse the university experience from the former student with ASD perspective and it provided specific details about Australian and New Zealand practices. It further included a very diverse range of participants whose ages ranged from their twenties to over 65 years, and both graduates and those who did not complete a university qualification. The heterogeneity of post-secondary students with ASD and their need for individualised supports was thus highlighted. Finally, as most participants were female, the study added knowledge about that less frequently reported demographic.

The second thesis research question, “What does the extant literature reveal about interventions used to support post-secondary students with ASD?” was addressed in Chapter 4. That chapter included the findings of a systematic literature review of empirical research on interventions used to support post-secondary students with ASD. There was a limited number of studies and most had low methodological quality. Nevertheless, many of the interventions appeared promising given the predominance of high participant satisfaction ratings, indicating a need for more research. It was revealed that there were few studies that focused on academic issues, however. This contrasts with the survey findings presented in chapter 2 where most of the respondents indicated that their most pressing concern was academic requirements and that academic supports are their most helpful support (Anderson et al., 2018). Numerous researchers working in the field of autism and other stakeholders have stated that issues of importance to individuals with ASD should be prioritised (Pelicano, Dinsmore, & Charman, 2014), and there thus appears to be a need for more research guided by this principle. Moreover, additional high quality and larger scale empirical research may be warranted to enable evidence-based practices to be identified. This study contributed to the research as it included many more studies than the only previous review and it included an analysis of study quality.

The third thesis research question: “What are the employment experiences of former university students with ASD in Australia and New Zealand?” was addressed in Chapter 5. Most former student participants reported many strengths, improvements in autism related issues, non-employment achievements, and some employment successes. However, most revealed extensive periods of unemployment and/or under-employment, and few had access to support other than that provided by their family. Difficulties with non-vocationally oriented qualifications were noted. It was suggested that there was a need for universities to include more employability components within courses, and transition supports that help students

conceptualise how their qualification could be applied in differing jobs. Also, in chapter 3 it was also revealed that a strong motivation to achieve a specific employment goal helped students complete their qualifications highlighting an interrelationship between the topics. In addition, it was revealed that more university and non-university supports that assist former students to find and maintain employment were required. The study contributed to the research as it was the first from Australia and New Zealand and only the second qualitative study to investigate the employment experiences of former university students. Further, it provided a broad and retrospective perspective from both graduates and those who did not complete, and their significant others. Finally, it provided a preliminary cross-sectional analysis of employment outcomes across the working lifespan.

Implications of the Research

There are several potentially important implications for policy and practice arising from the research in this thesis. The conclusions in this thesis are in line with prior research (e.g., Lei, Calley, Brosnan, Ashwin, & Russell, 2020; Toor, Hanley & Hebron, 2016) that transition courses from both high school and university are needed to better prepare students for university. Transition courses should inform future students about the benefits of registering with disability services prior to starting university (chapters 2, 3, 4; Cage & Howes, 2020; Cai & Richdale, 2016), namely, to enable early access to available supports, which if needed may prevent problems from developing. Also, there is a need for transition supports to help students identify an employment goal and an appropriate discipline to study that is in line with their employment goal, interests, and skills (chapter 3; Van Hees et al., 2018). It may be necessary to help students identify their strengths and learning weaknesses (chapter 3; Accardo et al., 2019), and to provide supports for them to develop any missing skills needed to succeed at post-secondary education. In addition, advocacy skills training may be required to equip students with the ability to request support (chapters 2, 3, 4; Cai & Richdale, 2016). Moreover,

the importance of considering the university's available supports, size, environment, location, and inclusive approaches towards students with differences should be pointed out (chapters 2, 3, & 4; Owen et al., 2016).

Universities may want to consider any changes to their courses and campuses that could make them more autism friendly (chapters 2 & 3; Cage & Howes, 2020). For example, quiet areas and adjustments to lighting and acoustics may help students with sensory sensitivities (Owen et al., 2016). Academic accommodations such as study tables supported by trained staff may help students manage their academic load (Edgington, 2019), and alternative assessments for groupwork and assistance with managing in-class social and communication requirements (Hillier et al., 2018) may enable students to demonstrate their knowledge more easily and thereby improve their overall university experience (chapters 2 & 3). In addition, specialist autism support groups and mentors may be helpful for non-academic issues such as mental health and socialisation (chapters 2 & 4; Siew et al., 2017). As many participants indicated that they had suicidal ideation and that access to mental health support was limited, an apparent urgent need for more support in this area is warranted (Chapter 2; Jackson et al., 2018; McLeod et al., 2019; Sarrett, 2018).

The need for more supports to help former post-secondary students find and maintain employment was also identified (Chapter 5; Taylor, Henninger, & Mailick, 2015; Vincent, 2020). Increasing employability components within university courses and providing transition to employment supports, including early access to university and non-university-based career services (Vincent, 2020), and helping students conceptualise how their qualification could be used for employment, may be helpful. Finally, supports may be needed for both graduates and those who do not complete a university qualification, at all employment levels, and throughout working life.

Conclusion

At the time this research began, little was known about post-secondary students with ASD, and this research added to the rapidly growing knowledge. Issues relating to the strengths, difficulties, barriers, facilitators, and support needs of current and former post-secondary students with ASD were analysed and highlighted. The thesis includes a theoretical discussion about disability and reasons why the responsibility of providing supports rests with the community. Also, care was taken to provide a balanced view that recognised the strengths and contributions of students with ASD, as well as possible difficulties and support needs. Finally, implications, recommendations and future research directions were provided which could be used to inform policy, teaching practices, intervention development, and campus design and facilities. Together these contributions may lead to better educational and employment outcomes for post-secondary students on the autism spectrum.

References

- Accardo, A. L., Bean, K., Cook, B., Gillies, A., Edgington, R., Kuder, S. J., & Bomgardner, W.M. (2019). College access, success, and equity for students on the autism spectrum. *Journal of Autism and Developmental Disorders*, 49, 4877-4890.
<https://doi.org/10.1007/210803-019-04205-8>
- Anderson, A.H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651-665. <https://doi.org/10.1007/s10803-017-3257-3>
- Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, 24, 1664-1675.
<https://doi.org/11.1177/1362361320918750>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher educational students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23, 271-273.
<https://doi.org/10.1177/1362361318820762>
- Gelbar, N. W., Shefyck, A., & Reichow, B. (2015). A comprehensive survey of current and former college students with autism spectrum disorders. *The Yale Journal of Biology and Medicine*, 88, 45–68.
- Hillier, A., Goldstein, J., Murphy, D., Trietsch, R., Keeves, J., Mendes, E., & Queenan, A. (2018). Supporting university students with autism spectrum disorder. *Autism*, 22, 20-28. <https://doi.org/10.1177/1362361317699584>.
- Jackson, S.L.J., Hart, L., Brown, J.T., & Volkmar, F.R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism

- spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 643-650.
<https://doi.org/10.1007/s10803-017-3315-x>
- Lei, J., Calley, S., Brosnan, M., Ashwin, C., & Russell, A. Evaluation of a transition to university programme for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 50, 2397–2411. <https://doi.org/10.1007/s10803-018-3776-6>
- McLeod, J.D., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*, 49, 2320-2336. <https://doi.org/10.1007/s10803-019-03910-8>
- Owen, C., McCann, D., Rayner, C., Devereaux, C., Sheehan, F., & Quarmby, L. (2016). Supporting students with autism spectrum disorder in higher education. National Centre for Student Equity in Higher Education. Hobart, TAS. Retrieved from <https://ecite.utas.edu.au/108977>
- Pelicano, E. Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18, 756-770.
<https://doi.org/10.1177/1362361314529627>
- Sarrett, C. (2018). Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders*, 48, 679-693.
<https://doi.org/10.1007/s10803-017-3353-4>
- Siew, C. T., Mazzucchelli, T.G., Rooney, R., & Girdler, S. (2017). A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PLoS ONE*, 12(7), e0180854. <https://doi.org/10.1371/journal.pone.0180854>.
- Taylor, J.L., & Henninger, N.A., & Mailick, M.R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, 19, 785–793. <https://doi.org/10.1177/1362361315585643>

- Toor, N., Hanley, T., & Hebron, J. (2016). The facilitators, obstacles and needs of individuals with autism spectrum conditions accessing further and higher education: A systematic review. *Journal of Psychologists and Counsellors in Schools*, 26, 166–190.
<https://doi.org/10.1017/jgc.2016.21>
- Van Hees, V., Roeyers, H., & De Mol, J. (2018). Students with autism spectrum disorder and their parents in the transition into higher education: Impact on dynamics in the parent–child relationship. *Journal of Autism and Developmental Disorders*, 48, 3296–3310.
<https://doi.org/10.1007/s10803-018-3593-y>
- Vincent, J. (2020). Employability for UK University Students and Graduates on the Autism Spectrum: Mobilities and Materialities. *Scandinavian Journal of Disability Research*, 22, 12–24. <https://doi.org/10.16993/sjdr.656>
- White, S. W., Richey, J. A., Gracanin, D., Coffman, M., & Elias, R. (2016). Psychosocial and computer-assisted intervention for college students with autism spectrum disorder: Preliminary support for feasibility. *Education and Training in Autism and Developmental Disabilities*, 51, 307–317.

APPENDICES

Appendix A: Ethics Approval for Chapter 2

The survey research presented in Chapter 2 was approved by the Macquarie University Faculty of Human Sciences and Humanities Human Research Ethics Committee, on 17 May 2018, Reference no: 5201800294.

Office of the Deputy Vice-Chancellor
(Research)

Research Services
Research Hub, Building C5C East
Macquarie University
NSW 2109 Australia
T: +61 (2) 9850 4459
<http://www.research.mq.edu.au/>
ABN 90 952 801 237



MACQUARIE
University
SYDNEY • AUSTRALIA

17 May 2018

Dear Associate Professor Carter

Reference No: 5201800294

Title: *The experiences of university students with autism spectrum disorder in Australia and New Zealand*

Thank you for submitting the above application for ethical and scientific review. Macquarie University Human Research Ethics Committee (HREC) (Human Sciences & Humanities) considered your application.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by Mrs Anastasia Anderson under the supervision of Associate Professor Mark Carter, Associate Professor Jennifer Stephenson and Dr Sarah Carlon.

Approval Date: 17 May 2018

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

<https://www.mq.edu.au/research/ethics-integrity-and-policies/ethics/human-ethics>

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely

Dr Karolyn White

Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Appendix B: Ethics Approval for Chapters 3 and 5

The qualitative research presented in chapters 3 and 5 were approved by the Macquarie University Faculty of Human Sciences and Humanities Human Research Ethics Committee, on 21 August 2018, Reference No:5201831063862

21/08/2018

Dear Associate Professor Mark Carter,

Reference No:5201831063862

Title: 3106 Exploring the experiences of former university students with autism spectrum disorder.

Thank you for submitting the above application for ethical and scientific review. Macquarie University Human Research Ethics Committee HREC EXEC Humanities & Social Sciences Committee considered your application.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by Associate Professor Mark Carter and other personnel: Associate Professor Jennifer Stephenson, Mrs Anastasia Anderson, Dr Sarah Carlon.

Approval Date: 21/08/2018

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007, updated July 2018) (the *National Statement*).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:
<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>
2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.
3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.
4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC EXEC Humanities & Social Sciences Committee Terms of Reference and Standard Operating Procedures are available from the Research Office website at: <https://www.mq.edu.au/research/ethics-integrity-and-policies/ethics/human-ethics>

The HREC EXEC Humanities & Social Sciences Committee wishes you every success in your research.

Yours sincerely,

Dr Karolyn White
 Chair, HREC EXEC Humanities & Social Sciences

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007, updated July 2018) and the CPMP/ICH Note for Guidance on Good Clinical Practice

Appendix C: Survey of University Students

Please note:

The article included in Appendix C was written for a prior qualification. It does NOT contribute to the examinable portion of the thesis and is included for reference purposes only.

Anderson, A.H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33–53.
<https://doi.org/10.1016/j.rasd.2017.04.002>

Pages 202-222 of this thesis have been removed as they contain published material.
Please refer to the following citation for details of the article contained in these pages.

Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33–53.

DOI: [10.1016/j.rasd.2017.04.002](https://doi.org/10.1016/j.rasd.2017.04.002)

Appendix D: Perspectives of University Students with Autism Spectrum Disorder

Please note:

The article included in Appendix D was written for a prior qualification. It does NOT contribute to the examinable portion of the thesis and is included for reference purposes only.

Anderson, A.H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651-665. <https://doi.org/10.1007/s10803-017-3257-3>

Pages 224-238 of this thesis have been removed as they contain published material.
Please refer to the following citation for details of the article contained in these pages.

Anderson, A.H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651-665.

DOI: [10.1007/s10803-017-3257-3](https://doi.org/10.1007/s10803-017-3257-3)

Appendix E: Interview Questions for Former University Students with ASD from Australia and New Zealand

Demographic Survey Questions

- i. Name:
- ii. Diagnosis:
- iii. How old were you when you were diagnosed?
- iv. Age range:

18-30
<hr style="width: 100%; border: 0.5px solid blue;"/>
31-40
41-50
50+
- v. Gender?
- vi. University attended?
- vii. Discipline studied?
- viii. Why did you choose that field?
- ix. How many years did you study at uni?:
- x. How long since you finished university?
- xi. Enrolment status: full/part time?
- xii. Highest qualification?
- xiii. Do you have a job?
- xiv. If so, are you working in the area you studied?

University Experiences

1. Support to transition to university:

Tell me about the period when you were starting your university studies.

Sample of probe questions:

- i. Can you tell me about any support you got from school or from the university to transition to university?
- ii. How were you involved in the transition program and how confident did you feel advocating for yourself?
- iii. What advice did the transition staff give you with respect to transitioning out of school?

2. University experience:

Tell me about your experience with studying.

Sample of probe questions:

- i. What did you find helpful at university? (e.g., people, certain spaces, technology, library, supports)
- ii. What did you find unhelpful at university? (e.g., people, certain spaces, technology, library, supports)
- iii. What were the most important factors that you think contributed to you completing/not completing your studies?
- iv. Tell me what you liked about university.
 - a. What was the easiest part of being a uni student?
 - b. Highlight on the map, and then describe the areas where you felt most comfortable at uni (e.g., library etc.).
- v. Tell me what did you disliked about university?
 - a. What was the hardest part about being a uni student?
 - b. Highlight on the map, and then describe the areas where you felt most uncomfortable at uni (e.g, cafeteria).

3. Supports outside uni:

What support did you get from outside uni?

Sample of probe questions:

- i. Were there people in your life (e.g., parents, friends) who helped you get through uni? Tell me about that.
- ii. How did they help you?

4. Personal characteristics:

Tell me about your personal characteristics and how they influenced your university experience.

Strengths: Can you tell me about your strengths and how you think they may have helped you at university?

Weaknesses: What things about yourself do you think may have made university difficult for you?

Sample of probe questions:

- i. How did those issues make things more difficult?
- ii. Were there any other skills you wished you had?

5. Academic problems/strengths:

- i. What are some of your academic strengths that helped your university experience?
- ii. What are some of the academic problems you experienced at university?
- iii. Did you have any academic weaknesses? For example;
 - a. poor/good organisational and time management skills;
 - b. easily distracted/not easily distracted;
 - c. poor/good attention.
- iv. How did you feel about the workload (manageable/too hard)?

6. Non-academic problems/positives:

Tell me about your experiences at university that were not related to academics.

- i. What are some of the non-academic positives you experienced at university?
(e.g., interesting activities for students, meeting a diverse range of people, enjoyed being on campus).
- ii. Tell me about your social activities while at uni.
- iii. University clubs: Did you join any other social groups or clubs or get involved in any university activities while at university?
- iv. If they joined a club:
 - a. Can you tell me about your experience with clubs or groups joined ?
 - b. Were they helpful or not helpful?
 - c. How did they help/not help?
- v. Did you form any friendships at these clubs? If no, did you identify that as a problem?
- vi. What are some of the non-academic problems you experienced at university?
(e.g., bullying, loneliness, sensory, managing everyday activities, orientation around the campus, managing change).
- vii. How did you try to manage those problems?

Sample of probe questions:

- i. Did you use any university support services for this?
- ii. If so, how helpful were they?

7. Teaching style:

Tell me about the teaching styles you experienced.

- i. What teaching style worked best for you?

- ii. What did not work well for you? (E.g. group work, tests, presentations, lab work, etc.)
- iii. Is there something your university teachers could have done that would have been more helpful?
- iv. What is your experience with on-line learning?

8. Registration with Disability Services:

Tell me about your experience with disability services?

- i. Did you register with disability services?
- ii. If so, did you register as soon as you started uni?
- iii. Why/why not?
- iv. Can you please describe the experience of registering?

Sample of probe questions:

- i. Did you register to access services or a particular service?
- ii. Did you disclose your diagnosis to anyone else (e.g., a teacher)?
- iii. Was it worth registering/disclosing?

Supports

9. Academic support:

Can you tell me about any academic supports you used while at university?

- i. Why did you apply for those supports?
- ii. How did you apply for those supports?
- iii. Was it difficult applying and how did you feel applying?

Sample of probe questions:

- i. What was the most/least helpful academic support?
- ii. What academic supports do you wish you had? e.g., alternative assessments.

10. Non-academic supports:

Can you tell me about any non-academic supports you used while at university - for example, a social support group organised by disability services; counselling?

- i. What was the most helpful non-academic support?
- ii. What was the least helpful non-academic support?
- iii. What non-academic supports do you wish you had? e.g., a support group, social supports.

11. Transition support:

Can you tell me about any support you may have received to transition beyond university?

Sample of probe questions:

- i. If so, were you satisfied with that support?

Experiences since leaving university

1. Demographic questions.

e.g., When did you leave university?

2. Quality of life:

Tell me about your life since leaving university.

- i. How do you think your university experience has impacted your life (positive and negative)? (suggestions: - made me more independent, helped get a job/frustrated that I can't get a job that matched my qualifications, not impacted).
- ii. How has going to university benefitted your life?
- iii. What life skills did you gain from studying at university? (Probes: managing finances, advocacy skills, organisational skills, communication skills, planning skills).

- iv. Did going to university worsen your life in any way? — why do you think that happened?

3. Advice to future students:

What advice would you give to someone with ASD who was thinking of attending uni in terms of how you think it may impact their life after uni?

4. Support since leaving uni:

Tell me about the support you have received since leaving uni.

Sample of probe questions:

- i. what supports have you received?
- ii. what is your most valued support?
- iii. what supports do you think were not helpful?
- iv. were any supports detrimental?
- v. do you feel supported?
- vi. are there any supports you would like to receive?
- vii. why have you not received that support?

5. Achievements:

Tell me about your achievements since leaving uni.

Sample of probe questions:

- i. What were the factors that contributed to your achievements since leaving uni?
 - a. university experience or qualification - if so how?
 - b. personal skills
 - c. family
 - d. Is there anything else (probe: support group, other supports/mentors)?

6. Employment:

- i. Do you have a job?
- ii. What was your experience in looking for a job after leaving university?
- iii. If you don't have a job, what do you think may be the reasons?
- iv. How has this impacted you?
- v. Tell me about your job.

Sample of probe questions:

- i. Are you happy at work?
- ii. What aspects are enjoyable?
- iii. What challenges do you face at work? (probes: bullying, advocacy, communication, relationships, coping with anxiety, organisational and time management skills, coping with changes, sensory issues)
- iv. Did your university experience equip you for work and life after uni generally?
- v. Could the university have done something to better equip you for employment?

7. Social life experiences:

Tell me about your social experiences since leaving uni.

- i. Has your university experience impacted your social experiences in any way?
- ii. Tell me your experience with volunteering or other community activities.
- iii. Has your university experience enabled you to be more involved in the community?

Sample of probe questions:

- i. Social anxiety,
- ii. Loneliness,

- iii. would you like more friends,
- iv. are you content with your friendships?.

Concluding questions

- i. What advice would you give to a person with ASD who was about to start uni?
- ii. What changes to university could be made to make it more autism friendly?
- iii. Would you like to make any final suggestions or comments about how the university experience could be improved for students with ASD or anything else?

Appendix F: Codebook for Qualitative Study of Former University Students on the

Autism Spectrum

Codes	Nodes
1. Life experiences post university	Achievements and positives after uni Other experiences post university Problems after uni Should university prepare students for life after uni
2. Employment	Difficulties experienced working Employment - different jobs Finding a job Positives Unemployed
3. Degree completion or benefits from studying at uni	Benefits and improvements Factors contributing to completion Unsatisfactory aspects
4. Degree incomplete	
5. Personal characteristics	Strengths Weaknesses and mental health
6. Masking	
7. Supports	Disability services Other and outside supports Support access difficulties Support after university Support before university (e.g. transition) Supports used Helpful supports Not used or not provided Support not helpful
8. Campus experiences and university lifestyle	Difficulties Helpful
9. Family	After uni family support Family support during uni Pre university family support
10. Academic issues	Academic barriers or difficulties Academic facilitators (e.g., computer in library, online lectures)

Codes	Nodes
11. Non-academic issues	Non-academic barriers or difficulties Disconfirming evidence Non-academic facilitators Outside non-academic facilitators
12. Pre university experiences	
13. Advice and suggestions	Advice for future students Suggestions to make uni more autism friendly
14. Peers or friends	
15. Miscellaneous	Achievements during uni Benefits of a diagnosis Comparing courses Conflicting statements from significant other Demographics Easiest part of uni Enjoys uni General comments about autism Hardest part of uni Living arrangement during uni