

The Experiences of Students with Autism Spectrum Disorder
in Post-Secondary Education

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Bachelor of Laws

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October 2016

This thesis is presented for the degree of Master of Research.

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REQUIREMENTS AND FORMAT OF THE MASTER OF RESEARCH 2015-2016

Master of Research - 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 as a whole 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.

The Master of Research degree provides the standard mode of entry to Doctoral programs at Macquarie University and offers the opportunity to evaluate the capacity of candidates for doctoral study. Students achieving a Distinction grade or above in their Master of Research program may be offered admission to a Doctoral program.

The Macquarie University Special Education Centre (MUSEC) adopts the thesis by publication model. The basic structure of a thesis by publication for the Master of Research at MUSEC would normally be as follows:

- A brief introduction providing a coherent overview of the background of the thesis, the research questions and the structure and organisation of the remaining chapters. The distinct contribution of the thesis should be clearly identified.
- Two chapters, each written in the format of a self-contained submission ready journal article. These chapters do not necessarily need to be published or submitted for publication. The first chapter would normally consist of a literature review and the second a pilot study, with the potential to lead into doctoral research. 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. If articles are published, they do not need to be reformatted for inclusion in the thesis.

- A brief final chapter providing an integrative 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.

The maximum length is 20,000 words.

For further details, please refer to the Higher Degree Research website

<http://www.mq.edu.au/research/phd-and-research-degrees>.

SYNOPSIS

The purpose of this thesis was to investigate, from the student perspective, the experiences of post-secondary students with ASD. The benefits and barriers, and the supports made available to students, were analysed, as were the student satisfaction with those supports. A systematic literature review of 23 studies examined the perspectives of 378 post-secondary students with ASD, representing the most comprehensive review conducted to date. The quality of the studies were assessed and interrater reliability conducted at all stages of data collection and coding, increasing confidence in the findings. Most of the studies were qualitative with small sample sizes, and originated from either the UK or USA, limiting generalisation. Nevertheless, the studies highlighted the diverse problems experienced by students with ASD, and how supports were often inadequate or inappropriate, providing differing benefit to students and illuminating the need for supports to be individualised. Also, the strengths of students, and the benefits they obtained from attending post-secondary education were described. Finally, the theoretical concepts that informed the studies were presented.

In response to identified limited survey research, and none from New South Wales (NSW) or the Australian Capital Territory (ACT), a report of an on-line survey of 48 university students with ASD from eight universities across NSW and the ACT was conducted. The respondents revealed a range of personal strengths and weaknesses, as well as their difficulties coping with loneliness, anxiety, depression, sensory sensitivities, and the lack of structure at university. In contrast to prior research (e.g., Cai & Richdale, 2016), only a minority of respondents reported a delay in disclosing to disability services. In spite of this, many respondents declared that they had not used many of the available supports, even though the majority of those who did stated that the supports were helpful. Respondents provided more positive appraisals for academic supports than non-academic supports, and

rarely reported that supports were refused. These findings reveal that in addition to individualised supports, there is also a need for transition planning and novel solutions for some students.

Thus, this thesis extended the research by updating the only prior review of post-secondary students with ASD. Also, the survey is the largest to date, and the only study from the student perspective of university students with ASD from NSW and the ACT. Moreover, the survey provided a unique perspective from a cohort that had predominantly disclosed their disability to disability services at or prior to enrolment in university courses. It highlighted the possible need to educate students with ASD about the supports that are available, and to encourage them to make greater use of them. In addition, it was noted that new approaches may be needed for those who find existing supports inappropriate.

STATEMENT OF CANDIDATURE

I certify this thesis entitled “The Experiences of Students with Autism Spectrum Disorder in Post-Secondary Education” 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.

The research presented in this thesis was approved by the Macquarie University Faculty of Human Sciences and Humanities Human Research Ethics Committee, on 18 November 2015 (Reference no: 5201500819; see Appendix A).

STATEMENT OF CONTRIBUTION

This is a statement of my contribution to this thesis and the papers included in it.

The following is a list of papers written in conjunction with my Co-Supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

1. A Systematic Literature Review of the Experiences of Students with Autism Spectrum Disorder in Post-Secondary Education was written by me with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.
2. Perspectives of University Students with Autism Spectrum Disorder is a report from an on-line survey of university students with ASD that was conducted and written by me with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

ACKNOWLEDGEMENTS

I would like to thank my supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson for their clear and expert guidance in preparing this thesis. Thank you for your rapid responses, generosity of time, and insightful comments.

Thank you Genevieve Godwin for conducting reliability checks in a thorough, diligent, and professional manner, and Nick Anderson for proof reading this thesis.

Also, I would like to thank my family, Tony, Josh and Nick for their encouragement to complete this project.

CHAPTER 1: INTRODUCTION

Chapter Overview

Chapter 1 is an introduction that outlines the purpose and structure of the thesis. It provides the background to the research, including relevant definitions, current prevalence rate estimates, key characteristics and difficulties experienced by post-secondary students with autism spectrum disorder (ASD), and a theoretical perspective. The significance of the research and the research questions are outlined, and summaries of the literature review and pilot project are presented.

Purpose of the Research

The purpose of this thesis is to better understand, from the student perspective, the needs of post-secondary students with ASD and their perspectives on the supports used to assist them. Ultimately, it is hoped that this research will inform best practice for assisting post-secondary students with ASD.

Structure of the Thesis

This thesis has four chapters. Chapter 1 is an introduction. Chapters 2 and 3 are manuscripts in journal submission ready format, and Chapter 4 provides a conclusion.

Background to the Research

Definitions

Autism spectrum disorder (ASD). Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition whose core criteria are delineated in *The Diagnostic Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, [APA], 2013). While earlier versions specified four separate disorders (autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified), the *DSM-5* collapsed the categorisations into one broad continuum of core symptoms. These symptoms are present from early childhood but may vary in intensity over time, and the heterogeneity of persons with ASD is recognised across a continuum. In

addition, the core symptoms were reduced from three to two categories, namely: “(a) persistent deficits in social communication and social interaction across multiple contexts”; and (b) “restricted repetitive patterns of behaviour, interests, or activities” (s299.00; APA, 2013). Sensory sensitivities were also recognised as a core feature of ASD and it was noted that comorbid conditions such as intellectual disability, language disorder, and attention deficit hyperactivity disorder frequently co-occur.

Post-secondary education and post-secondary institutions. Post-secondary education describes education beyond secondary school. For the purposes of this study it refers to education conducted at universities, colleges (two and four year), further education, and technical colleges, that provide nationally or state recognised qualifications. Private short courses that do not provide nationally or state recognised qualifications were excluded.

Prevalence Rates

The prevalence rate of ASD has continued to rise (Rice et al., 2012). In the early 1970s, European studies estimated the prevalence of autism at one in 2,500 children (Centers for Disease Control and Prevention [CDC], 2014), but by 2010 that estimate had risen to approximately one in 68 (CDC, 2014; Rice et al., 2012) with the most significant increases occurring for those with no intellectual disability (Lord & Bishop, 2015; White et al., 2016). In Australia, the prevalence rate is similarly high and was estimated by Randall et al. (2016) at between 1.5% and 2.5%. Approximately 46% of students with ASD have average or above intellectual ability (CDC, 2014) and White, Ollendick, and Bray (2011) estimated that there were between 0.7 and 1.9% of college students with ASD.

Characteristics of Post-Secondary Students with ASD and the Challenges of Post-Secondary Education

Post-secondary education may cause difficulties for students with ASD. It is less structured than school, and has a greater volume of more demanding and multi-dimensional content compared with school, and class sizes are larger with less student-teacher contact (Glennon, 2001; Gobbo & Shmulsky, 2012; Pinder-Amaker, 2014; White et al., 2016). These

factors may cause difficulties given their preference for routine and aversion to change (Robertson & Ne’eman, 2008). Although many students with ASD have academic strengths such as good attention to detail, a hardworking nature, and intense interest in narrow subject areas (Blamires & Gee, 2002; Gobbo & Shmulsky, 2012), the benefits gained from those strengths may be diminished by other academic and non-academic concerns. For example, they may have difficulty with socialising and listening to peers and interpreting or using verbal and non-verbal communication (Glennon, 2001; Pinder-Amaker, 2014; White et al., 2016). Many may have difficulty with understanding concepts that require critical evaluation due to a tendency for more literal thinking, and they may also have trouble coping with group work, planning, and time management (Gobbo & Shmulsky, 2012; Gobbo & Shmulsky, 2014; Longtin, 2014; White et al., 2016). Van Hees, Moyson, and Roeyers (2015) argued that many of these difficulties stem from core deficits of ASD, including weak central coherence (inability to process global information), lack of “theory of mind” (understanding the mental state of others and using this information to predict their responses), and poor executive function (ability to plan, working memory, and flexibility of attention; Drake, 2014). In addition, many suffer loneliness and may have sensory sensitivities to sounds, smells, touch or light (Pinder-Amaker, 2014; Robertson & Ne’eman, 2008). They may also have comorbid conditions such as anxiety and/or depression (Mazurek, 2014; Pinder-Amaker, 2014), and remain dependent on their parents (Cai & Richdale, 2016; White et al., 2016).

Theoretical Considerations

The social model of disability, neurodiversity, and the medical model of disability, are theoretical concepts that inform much of the discussion in this thesis and provide relevant background. The medical model views autism as environmentally and genetically caused, and contends that disability, measured by reference to the community average (in the absence of biological markers), is an impairment that should ideally be eliminated or ameliorated, and is a concern for the person with the disability (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Madriaga, 2010; Maxam, 2012). People with disabilities are seen as dependent on the

benevolence of society and at risk of segregation or discrimination (The Michigan Disability Rights Coalition, <http://www.copower.org/leadership/models-of-disability>). Kapp et al. (2013) argued that the medical model contrives and deems what is “appropriate behavior” and disregards the strengths of people with disability.

In contrast, the social model of disability contends that disability is caused by societal, environmental, and attitudinal barriers (Maxam, 2012). Rather than a medical issue in need of rehabilitation or a cure, disability is viewed as a human condition, and society is regarded as having the responsibility to provide the necessary modifications that would enable people with disabilities to participate in all aspects of life (Maxam, 2012). Adopting the social model, Madriaga and Goodley (2010) argued that educational institutions need to consider how their environments and teaching practices cause barriers for students with ASD, and how they can better facilitate inclusion.

The concept of neurodiversity extends the social model of disability to include difficulties caused by the brain. The neurodiversity model similarly holds that autism is biologically caused and part of the spectrum of human diversity with disability created by inadequate social and political infrastructures that cause barriers to participation (Kapp et al., 2013). The neurodiversity movement views autism as a difference, and while they recognise possible weaknesses of people with ASD, they encourage a focus on strengths and positive contributions rather than pursuing normality (Drake, 2014; Robertson & Ne’eman, 2008). Some proponents oppose the search for a cure (e.g., Kapp et al., 2013; Runswick-Cole, 2014), preferring to seek “adaptive” functioning and quality of life rather than typical functioning (e.g., Kapp et al., 2013, p. 60).

Goodley (2001) argued that many traditional supports such as alternative assessments or separate quiet areas isolate students, and that a strengths-based approach to assisting students was preferred. An example of the latter is Universal Design for Learning (CAST, 2011; Dalton & Berquist, 2016), a teaching framework that uses a flexible curriculum design

to provide students with a range of learning and assessment options that potentially reduce their need for additional supports.

Maxam (2012) contended that the theoretical models should not be viewed as exclusive options but that positives can be taken from each and applied simultaneously. This view was endorsed by Kapp et al. (2013) who found that 223 formally diagnosed respondents celebrated their ASD identity while acknowledging the practical benefits of interventions that helped them adapt to a 'neurotypical' world (p. 67). Furthermore, Kapp et al. concluded that the "spectrum nature of disability [supported] the legitimacy of multiple agendas" (p. 68). In particular, the social and neurodiversity models directly inform the approach taken in this thesis with regard to examination of environmental barriers to participation and the strengths of individuals with ASD.

Research Questions

There is an increase in the number of post-secondary students with ASD and many disability units and faculties feel unprepared to meet their needs (McKeon, Alpern, & Zager, 2013; Pillay & Bhat, 2012; Taylor, 2005); there is also limited research to guide and assist them (Anderson, Stephenson, & Carter, 2016; Gelbar, Smith, & Reichow, 2014; White et al., 2016). Indeed, Gelbar et al. (2014), who examined only 18 studies with 68 participants, has conducted the only systematic review of the experiences of post-secondary students with ASD. Gelbar et al.'s review, however, had a number of methodological limitations. In addition, they neglected a number of relevant studies as they did not search educational databases. There was thus a need for a more comprehensive and updated review. Further, there is limited quantitative or survey research, which limits the ability to make generalisations from the current extant literature. In Australia, research is also limited, with only one published Victorian study that had a survey component within its focus group study design (Cai & Richdale, 2016). There is thus a particular need for more survey research within an Australian context.

The broad research questions used to guide this thesis were:

1. What does the extant literature reveal about the student perspective of the benefits, barriers, and support experiences of post-secondary students with ASD?
2. What supports and services were used by university students with ASD in New South Wales and the Australian Capital Territory, and how satisfied were the students with those supports and services?

Chapter Summaries

Chapter 2 presents a systematic literature review that provided analysis of 23 studies that reported on the student perspective of 378 post-secondary students with ASD. The only other prior review conducted by Gelbar et al. (2014) provided valuable insights, but also had methodological shortcomings. Their search was restricted to non-educational databases (Medline, Embase, PsychINFO) causing them to miss some relevant studies and there were other problems with study selection. For example, studies were included that did not provide a description of the methodology (Brazier, 2013; Glennon, 2001; Jurecic, 2007; Langford-Von Glahn et al., 2008; Oda, 2010; VanBergeijk, Klin, & Volkmar, 2008) or whose purpose was not to describe the experiences or supports provided to students with ASD in post-secondary education (Jones, Huws, & Beck, 2013; Lee, Duggan, & Schuntermann, 1999; MacLeod, Lewis, & Robertson, 2013). Moreover, Gelbar et al. did not examine the strengths of students with ASD, nor the potential benefits attained from post-secondary education. Thus, their review was limited, and some of the analysis was based on studies with methodological and content limitations. Hence, there was a case for a re-examination of the research on the experiences of students with ASD in post-secondary education. In contrast, the review described in Chapter 2 was based on a search that included educational databases and addressed several of the methodological issues of the previous review. The specific research questions were:

1. What are the post-secondary barriers and/or benefits experienced by students with ASD, and how do they impact both academic and non-academic aspects of post-secondary education?

2. What supports and services were offered to assist students with ASD to complete their post-secondary education?
3. How satisfied were post-secondary students with ASD with the supports and services offered to them?

A diverse range of student characteristics, and the benefits and barriers they experienced at post-secondary education were described. In addition, a scarcity of studies and a particular need for more survey research that investigated the experiences of students with ASD from countries outside the UK and USA (Gelbar et al., 2014) was revealed. A mismatch of supports was identified in that more academic supports were provided when non-academic issues were more often a greater concern (e.g., Connor, 2012; Gelbar, Shefcyk, & Reichow, 2015; Knott & Taylor, 2014), indicating that the needs of students with ASD remain poorly understood. Furthermore, students often reported that unresolved non-academic difficulties rendered academic supports ineffective (e.g., MacLeod & Green, 2009). Thus, the diverse characteristics of students with ASD, and their idiosyncratic responses to supports, indicated that supports need to be individualised, ubiquitous, and continually monitored to be effective. Finally, the need for transition planning was highlighted, as many students revealed they felt unprepared for post-secondary education but were still reluctant to disclose to disability services or to use available supports.

The review presented was the most comprehensive systematic literature review of studies from the student perspective to date. It included an assessment of the quality of the studies plus interrater reliability of the findings, strengthening the trustworthiness of the results. The need for more quantitative and survey research from countries outside the USA and the UK was found. In addition, a more balanced perspective was presented with the inclusion of both the challenges, and the strengths and benefits obtained by students from attending post-secondary education. Important issues were highlighted, including the mismatch of supports (predominantly academic) compared with needs (predominantly non-

academic), how unresolved non-academic issues (e.g., anxiety) often rendered supports ineffective, and the student need for transition support.

Chapter 3 is a report from an on-line survey of students with ASD from six universities in New South Wales (NSW), and two universities in the Australian Capital Territory (ACT). It was revealed that respondents made only infrequent use of a limited number of available supports, and that they were more satisfied with academic supports than non-academic supports. Females, and those who delayed their disclosure, reported that they accessed fewer supports and they also provided poorer ratings of their overall university experiences. Finally, many students identified sensory sensitivities that they claimed impacted their ability to cope and enjoy their time at university.

This study was the only survey study of university students with ASD that has been conducted in NSW and the ACT. The strengths of students with ASD were highlighted, and a suggestion of how those strengths may be better used to assist students was suggested (Universal Design for Learning). Also, the description of both the strengths and weaknesses of students provided a clearer understanding of the needs of students with ASD. It was identified that students were more satisfied with academic than non-academic supports, and gender anomalies were noted, thereby contributing to the shortage of this research. Finally, the possible need for universities to provide their own transition programs and to consider the sensory sensitivities of students with ASD was highlighted.

Summary

The purpose of the introduction was to provide an overview of the background of the thesis, delineate the research questions, and describe the structure and organisation of the thesis. The theoretical positions that informed much of the research presented in this thesis was described. In addition, the strengths and the challenging characteristics of students with ASD and post-secondary education were outlined. Finally, summaries of each chapter and their contributions to the research were provided.

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CHAPTER 2: A SYSTEMATIC LITERATURE REVIEW OF THE EXPERIENCES OF STUDENTS WITH AUTISM SPECTRUM DISORDER IN POST-SECONDARY EDUCATION

Chapter Overview

The purpose of Chapter 2 is to present a systematic literature review of the research that analysed the experiences of post-secondary students with autism spectrum disorder (ASD). This chapter supports the program of research by updating and extending the only prior review by Gelbar, Smith, and Reichow (2014) with additional new studies published since that review, and relevant studies not located by Gelbar et al. Also, checklists were used to conduct a more thorough assessment of article quality, and interrater reliability was assessed on all data collection and coding.

The chapter is formatted as appropriate for submission to a relevant journal. The review revealed a number of issues. First, although many students struggled, some students gained benefit from attending post-secondary education. Second, a mismatch of supports and needs was noted in several studies and this highlighted the need to individualise academic and non-academic supports. Third, many students were reluctant to disclose or use supports. Finally, the extant literature was mostly small scale, and geographically circumscribed, thus identifying the need for more research from different jurisdictions.

A Systematic Literature Review of the Experiences of Students with Autism Spectrum
Disorder in Post-Secondary Education

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Abstract

Background

Post-secondary students with ASD experience a range of academic and non-academic difficulties and represent approximately one percent of the post-secondary cohort. The purpose of this review is to conduct a systematic literature review of articles that examined the barriers and benefits experienced by post-secondary students with ASD, and the supports and services provided to them, and also to analyse student satisfaction with those supports.

Method

Three databases were searched and articles were screened against eligibility criteria. The twenty-three studies (reported in twenty-nine articles) that met criteria were also assessed for quality. Data pertaining to the benefits and barriers experienced, and student satisfaction with supports and services provided, were extracted and analysed.

Results

The studies highlighted the diverse range of social, emotional and sensory difficulties experienced by students with ASD, and how those difficulties negatively impacted all aspects of their post-secondary education. In addition, the supports provided were often incongruous with need and produced idiosyncratic benefits, demonstrating the need for individualised supports and novel solutions to be identified. Suggestions for future research were made.

Conclusions

Prior research on the experiences of post-secondary students with ASD is limited and geographically circumscribed. More academic supports were provided although addressing non-academic issues was the imperative, and non-academic problems often rendered academic supports ineffective. The diverse characteristics of students with ASD, who experience idiosyncratic responses to accessed supports, demonstrated that ideally supports need to be individualised, ubiquitous, and continually monitored.

Keywords: autism spectrum disorder, ASD, higher education, post-secondary education, experiences, educational supports.

CHAPTER 2:

A Systematic Literature Review of the Experiences of Students with Autism Spectrum

Disorder in Post-Secondary Education

The prevalence of autism spectrum disorder (ASD) in Australia was estimated by Randall et al. (2016) at between 1.5% and 2.5%, which is similar to the one in 68 prevalence reported by the Centers for Disease Control and Prevention in 2010 (CDC, 2014). The CDC also established that almost half of students with ASD (46%) have average through to gifted intelligence (CDC, 2014). Moreover, Camarena and Sarigiani (2009) found that adolescent students with ASD have a strong desire to attend post-secondary education, and that this goal is increasingly being realised. Indeed, White, Ollendick, and Bray (2011) found that between 0.7 and 1.9 percent of college students (at a single USA university) met the criteria for ASD.

The characteristics of post-secondary students with ASD can be diverse and paradoxical (Chown & Beavan, 2014). They may possess significant strengths such as a strong memory, original and creative thought patterns with good attention to detail, and a single minded and determined nature, coupled with intense narrow interests (Drake, 2014a; Gobbo & Shmulsky, 2012). However, co-occurring atypical communication and social behaviours, an aversion to change and restricted interests (*The Diagnostic and Statistical Manual of Mental Disorders*, 5th ed.; DSM-5; American Psychiatric Association [APA], 2013) may negatively impact these strengths. Further, post-secondary students with ASD may be prone to loneliness, anxiety and depression (Mazurek, 2014), have difficulty interpreting or using verbal and non-verbal communication (Glennon, 2001; Pinder-Amaker, 2014), and struggle with group work, presentations, time management, and sensory sensitivities (Gobbo & Shmulsky, 2014; Pinder-Amaker, 2014).

Although many countries have legal obligations to assist post-secondary students with ASD (e.g., s 22 of the *Disability Discrimination Act 1992* [Cth; Australia]; s. 42 U.S.C. 12101

et seq of the *Americans with Disabilities Act* 2008 [U.S.]), there are also practical advantages in providing supports. For example, the very low graduation rates of students with ASD (Gobbo & Shmulsky, 2014; Universities Australia, 2015) are significantly improved with support (White et al., 2011). Further, graduates with ASD have substantially better long-term income and employment prospects compared to non-graduates with ASD (Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013).

The possibility of creating inclusive environments in school education has been demonstrated in research (Blamires & Gee, 2002), but there is limited research into the post-secondary educational experiences and needs of students with ASD. Indeed, only 6% of the extant literature on ASD examined participants older than 19 years (Jang et al., 2014), and research from the post-secondary student perspective is particularly scant (Gelbar, Shefcyk, & Reichow, 2015; Hastwell, Martin, Baron-Cohen, & Harding, 2012). Thus, there is little research guidance for academics and disability support personnel in post-secondary settings to inform best practice when providing support for students with ASD.

Gelbar, Smith, and Reichow (2014) provided the only systematic review of studies reporting on the experiences and supports available to students with ASD in post-secondary settings from the student perspective. They reviewed 18 studies (reported in 20 articles) with 68 unique participants who described the first-hand experiences and supports of students with ASD at college and university. Their review provided some interesting insights and had several strengths, but it also had a number of methodological weaknesses. They restricted their search to Medline, Embase (a biomedical and pharmacological database), and PsychINFO databases, missing some relevant studies, which were far more likely to be indexed in educational databases. Further, they used very broad inclusion criteria that allowed articles without description of methodology or of data analysis, impeding interpretation of the relevant research and making replication impossible. Gelbar et al.

acknowledged using a “liberal” definition of a case study that permitted studies with scant detail whose primary purpose was to support the author’s theoretical position (p. 2599). They did not strictly apply their own inclusion criteria and included articles where the participants did not have a diagnosis of ASD (Jurecic, 2007), or where first-hand accounts were not provided (Langford-Von Glahn, Zakrajsek, & Pletcher-Rood, 2008). In addition, they included studies that did not enable data on students with ASD to be separated from other participants (Griffin & Pollak, 2009), and their review was limited to studies in peer reviewed journals, with the attendant risk of findings being affected by publication bias (Schlosser, Wendt, & Sigafoos, 2007). Moreover, Gelbar et al. did not study the strengths of students with ASD, nor the potential benefits attained from post-secondary education. Thus, the existing review had methodological and content limitations and may have resulted in an incomplete view of the experiences of post-secondary students with ASD. Given these issues, there is a case for re-examination of research on the experiences of individuals with ASD in post-secondary education.

The present review examined research that analysed first-hand accounts of post-secondary students with ASD and addressed several of the methodological issues noted above. Specifically, the studies included in this review reported on descriptions provided by post-secondary students with ASD of their academic and non-academic experiences, and/or their satisfaction with the supports provided or used. The research questions were:

1. What are the post-secondary barriers and/or benefits experienced by students with ASD and how do they impact both academic and non-academic aspects of post-secondary education?
2. What supports and services were offered to assist students with ASD to complete their post-secondary education?

3. How satisfied were post-secondary students with ASD with the supports and services offered to them?

Method

The PRISMA statement protocol, which includes a 27-item checklist and four phase flow diagram, was used to guide the methodology and reporting of this review (see *figure 1*). The PRISMA statement was devised to improve the quality and consistency of systematic review reporting (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) and includes an explanation and elaboration document that provides the meaning and rationale (with examples) for each checklist item.

A search for articles addressing the post-secondary educational experiences of students with ASD was made using three educational electronic databases, namely ERIC (Educational Resources Information Center), Education Research Complete, and A+, on 2 April 2015 using the following search terms: (autis* OR asperge* OR pervasive development disorder OR high functioning autism OR PDD OR HFASD OR ASD) AND (college OR university OR higher education OR tertiary OR post-secondary OR postsecondary OR post secondary OR further education OR TAFE). A total of 561 records were identified (517 records after excluding duplicates). In addition, ten articles were found following a hand search of five autism specific journals between January 1995 and July 2015 (Autism, Journal of Autism and Developmental Disorders, Research in Autism Spectrum Disorders, Focus on Autism and Other Developmental Disabilities, and Good Autism Practice), and six studies were located from the reference list of Gelbar et al. (2014), bringing the total to 533 articles.

The abstract and titles of the 533 articles identified were then screened by the first author as to whether: (a) the participants in the study were post-secondary students with a diagnosis of autism spectrum disorder; (b) the study was conducted in a postsecondary educational setting, including university, college, further education, or technical colleges; (c)

the article described a research study; (d) the study examined the experience of being a student with ASD and/or the supports provided to post-secondary students with ASD; and (e) the study was informed by first-hand accounts.

After the initial screening of abstracts and titles 27 articles remained. The articles were then read in entirety and screened against more detailed eligibility criteria.

1. The aim of the study was to examine the experiences and/or supports or services provided to students with ASD in a post-secondary educational setting.
2. The study described the methodology used for data collection and analysis.
3. The participants within each study had a diagnosis of ASD.
4. The study included first-hand accounts by participants with ASD of their post-secondary experiences and/or use of educational supports and services.

Studies were excluded if:

1. They were not published in English.
2. The study used an experimental design to test a specific intervention.
(Experimental studies are typically highly focussed and interest in this review was on broader university experiences).
3. More than 20% of participants did not have a formal diagnosis of ASD. Studies with up to 20% of participants with no formal diagnosis were accepted due to the paucity of studies and in recognition of the difficulty and expense in obtaining a formal diagnosis. Also, the perceived stigma of an ASD label reduces the likelihood of a false declaration.

To reduce the risk of publication bias, no restrictions were placed on publication source, date, or type of article (Schlosser et al., 2007), and this allowed the inclusion of journal articles, dissertations, and reports. In addition, articles studying multiple disability

groups were included if the results concerning students with ASD could be extracted. A total of 15 articles matched the eligibility criteria.

An ancestral search of the reference lists of the 15 selected articles was conducted by the first author, who identified a further 26 articles that met the inclusion criteria. The full texts of these 26 articles were screened against the eligibility criteria, and 14 articles met these standards, bringing the total to 29 articles that reported on 23 studies.

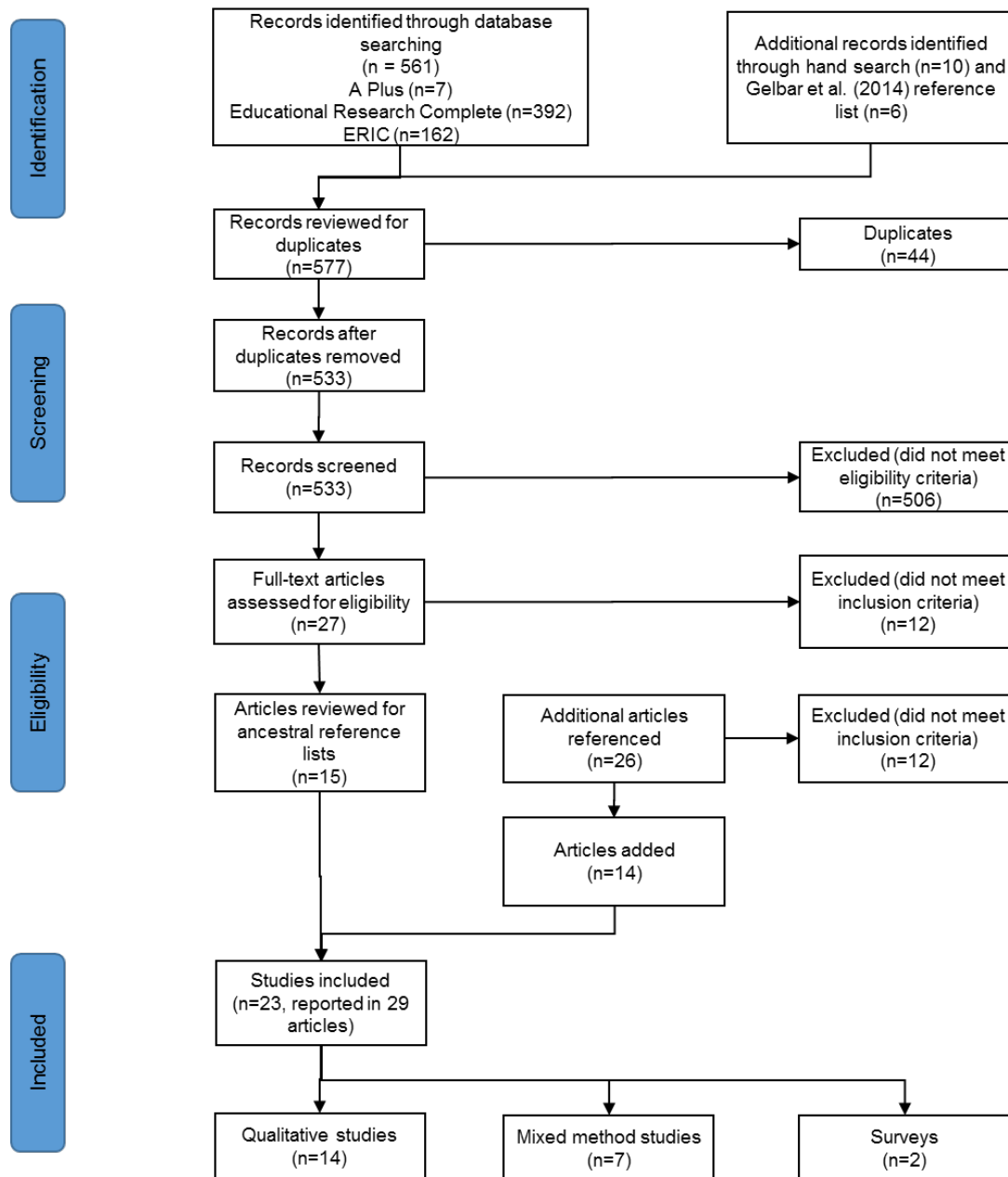


Figure 1. PRISMA flowchart of study selection process.

Data Extraction

Data was extracted onto separate coding sheets for survey studies and qualitative studies. The data extracted included: sample size, participant characteristics (age, gender, country where study was carried out), course studied, grade point average, graduate/undergraduate status, type of institution (university, college, TAFE, further education, other), student accommodation (home, on-campus, other), diagnosis (formal diagnosis verified by researcher, formal diagnosis not verified by researcher, not specified), research design (longitudinal, cross-sectional, case study, qualitative, quantitative, mixed method, other), recruitment method (disability services, on-campus poster, E-mail invitation, incentives provided, other, not stated), participant retention rate, length of study/interview, and the method used to assess participants (interview, observation, on-line, focus group, questionnaire).

Study Quality Assessment

The quality of the studies was assessed using checklists devised by the authors from various quality frameworks, addressing some basic but key methodological characteristics. The checklist criteria for qualitative research were presence or absence of: a clear statement of aims, participant recruitment and selection method, justification of setting, ethics approval, appropriate data collection methods (Centre for Evidence-Based Management [CEBMA]; CASP, 2015), disconfirming evidence considered, triangulation of data, researcher reflexivity, member checks, concurred conclusion, interrater reliability checks (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005), and description of thematic data analysis (Greenhalgh & Taylor, 1997). For surveys and the survey component of mixed method studies, the checklist criteria used were presence or absence of: research questions, population and sampling frame specified, method of item generation, pretesting of questions, content and inter-rater reliability, response rate, sample size justified, report addressed survey questions,

demographic data, clear analytical methods (Burns & Kho, 2015), description of survey design and recruitment method (Eysenbach, 2012), definitions of inclusion and exclusion criteria, description of methodology adequate to allow replication, description of data collection, and conflict of interest (Glynn, 2006). Tables 2.6 and 2.7 summarise the key indicators of the quality checklists, and the full versions are available by contacting the first author.

Reliability

An experienced and trained research assistant independently carried out initial screening and screening of full texts to establish interrater reliability. Reliability was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100. In all instances, records or articles used for training and reliability were selected using a random number generator. For the initial screen, the research assistant was trained with 20 records. She then independently screened 25% of the abstracts and headings of the initial 533 records (133 records) and agreement was 93% with disagreements resolved by consensus. (Reliability above 80% is acceptable; Alberto & Troutman, 2013).

For the second round of full text screening the research assistant was trained with one article and she then independently scanned the full text of six articles. Seven articles were also screened from the ancestral search. Interrater reliability for full text screening was 92% with differences resolved by consensus.

The research assistant was trained to extract and code data by providing explicit definitions for coding criteria and jointly coding one article with the first author. The research assistant then independently extracted information from seven (24%) additional articles. Interrater reliability for data extraction averaged 86%.

Results

Research Design

The studies were reported in 19 peer reviewed journals, four reports, and six dissertations, and research designs included nine mixed-method and 14 qualitative studies. Only two studies were surveys (Table 2.1). Data collection methods included four case studies, three focus groups, seven interviews, seven quantitative surveys, eight qualitative surveys, an email dialogue, and a chart review. (Note: mixed method studies appear in more than one category).

Participant Characteristics and Contexts

There were 23 studies reported in 29 articles and a total of 378 participants (Table 2.1). In the studies that classified gender, 138 were males (71%) and 56 were females (29%). In eight studies (35%), at least one participant was diagnosed during post-secondary education, and in three studies (13%) at least one participant was diagnosed after completing post-secondary education. The diagnoses of the participants were verified by the authors in three studies (13%), and the eligibility criteria were explicitly extended to include students with no formal ASD diagnosis in five studies (22%). In the remaining 13 studies (57%), the formal diagnoses of the participants were not verified by their authors. Finally, the participants studied at a range of institutions (including two and four year colleges, universities, and further education), a variety of courses (including arts, medicine, zoology, and computer technology), and towards different awards (certificates, diplomas, undergraduate degrees, and post-graduate degrees).

The average sample size was 16, and there was a range of one through to 135 participants per study. Only one study had more than 35 participants, and 14 studies (61%) had fewer than 10 participants. Study location was predominantly from the USA (10) and UK (7) but also included studies from five other nations (Table 2.1).

Academic and Non-Academic Challenges

Table 2.2 summarises both academic and non-academic challenges experienced by some students within each of the identified studies. Specifically, Table 2.2 shows that at least one academic and one non-academic challenge was identified by at least some of the students in each study. Frequently reported challenges included difficulty understanding abstract or ambiguous concepts (16 studies; 70%), poor planning skills with a tendency towards procrastination (20 studies; 87%), poor concentration while studying (9 studies; 39%), and difficulty with group work, presentations, and the social demands in class (13 studies; 57%).

Similarly, some students in each of the identified studies in Table 2.2 reported a range of non-academic challenges, including difficulties with social interaction (23 studies; 100%), mental health (21 studies; 91%), sensory sensitivities (14 studies; 61%), and daily living skills (13 studies; 57%). Moreover, communication skills (17 studies; 74%), and organizational and time management skills (20 studies; 87%), were found to affect both academic and non-academic experiences.

Benefits of Attending Post-Secondary Education

Table 2.3 summarises the benefits obtained from attending post-secondary education, as expressed by some of the students in each mentioned study. Benefits included improved socialisation, independence, life skills, or self-awareness (16 studies; 70%); high academic achievement (14 studies; 61%), enjoyment from academic learning (12 studies; 52%); and improved self-advocacy skills (10 studies; 43%).

Strengths of Students with ASD

Some students with ASD described personal strengths that contributed to their academic success, including strong technological (Van Hees et al., 2015) and self-advocacy skills (e.g., Lee, 2010; Maxam, 2012), persistence (Drake, 2014a), and an intense interest in the subject they were studying (e.g., Tarallo, 2012). In addition, some were diligent and had a

determination to complete their degree and gain employment in their chosen area of study (e.g., Szentmiklosi, 2009; Tarallo, 2012).

Disclosure and/or Refusal of Supports

Table 2.4 summarises the reasons why some students in each of the mentioned studies failed to disclose their ASD diagnosis to disability services. The most common reason was fear of being stigmatised (8 studies; 35%), followed by wanting to try on their own (5 studies; 22%), a belief that supports would not help (3 studies; 13%), being too traumatised to accept support (two studies, 9%), and preferring to be alone (Blamires & Gee, 2002).

Supports and Services

A range of different supports was described in all but one study (Table 2.5). Academic and non-academic mentoring was the most common support and featured in 15 studies (65%). Supports were also provided for mental health (15 studies; 65%), exam accommodations (13 studies; 57%), scribes or the provision of notes (12 studies; 52%), social clubs (13 studies; 57%), alternative assessments (10 studies; 43%), and assistance with time management (11 studies; 48%). The most commonly used supports for mental health issues were mentors and social support groups (e.g., MacLeod & Green, 2009), parents and friends (e.g., Lee, 2010), counselling (Ames et al., 2016), and behavioural therapy (Taylor et al., 2008). Although not a support provided by post-secondary institutions, it was notable that many students took medication for mental health issues.

Study Quality

The quality of the qualitative studies was summarised in Table 2.6. A clear description of data collection was provided in 17 studies (95%), and triangulation of data was described in 16 studies (89%). Additional quality indicators included a description of participant selection (14 studies; 78%), details of the analysis process (12 studies; 67%), member checks (12 studies; 67%), and outliers or negative case analysis (six studies; 33%).

The quality of survey research was summarised in Table 2.7. A description of the population studied and recruitment method was provided in all studies. Other quality indicators for survey studies included a description of the survey design (eight studies; 89%), data collection procedures (six studies; 67%), and a description of how the response rate was calculated (five studies; 56%). Also, the questionnaire was provided in full in three studies (30%).

Discussion

The current review included 29 articles that reported on 23 studies and 378 participants. This considerably extended the earlier review of Gelbar et al. (2014) that included only 18 studies (reported in 20 articles) and 68 unique participants. Of the 18 studies analysed by Gelbar et al., only five (eight articles and 15 participants) were included in the present review. Some studies were excluded because they did not include a description of methodology (i.e., Brazier, 2013; Glennon, 2001; Jurecic, 2007; Langford-Von Glahn et al., 2008; Oda, 2010; VanBergeijk, Klin, & Volkmar, 2008). The authors view a description of methodology as a fundamental prerequisite of research, because its omission prevents an understanding of data collection and analysis, and it also precludes replication. A further three studies included by Gelbar et al., but not in the present review, had a purpose other than to describe the experiences or supports provided to students with ASD in post-secondary education (i.e., Jones, Huws, & Beck, 2013; Lee, Duggan, & Schuntermann, 1999; MacLeod, Lewis, & Robertson, 2013). The study by Griffin and Pollak (2009) did not allow for the extraction of data pertaining only to students with ASD, and Mason, Rispoli, Ganz, Boles, and Orr (2012) and Pugliese and White (2014) both used an experimental design that was outside the scope of the current review. Finally, the participant in Jurecic (2007) had no diagnosis (due to parent refusal to allow an assessment or diagnostic label), and was only suspected of being on the autism spectrum by the author (who was an assistant professor of

English). Thus, there is only limited overlap between the studies included in this review and that of Gelbar et al.

The studies in the current review had methodological strengths. There were 11 longitudinal studies (Table 2.1) that allowed an analysis over time of the impacts of autism and supports upon academic and non-academic demands. In addition, the report by Beardon and Edmonds (2007), with its 135 respondents, provided extensive data. These longitudinal and large scale studies contributed important insights into the experiences of individuals with ASD in post-secondary education. For example, Ames et al. (2016) identified that support usage increased in the final years, highlighting the need to promote and encourage both early disclosure and prompt access to supports, a view endorsed by Cai and Richdale (2016). Connor (2012) illuminated the impact of latent disclosure and the development of self-advocacy skills that proved crucial to the participant's ability to access supports, form friendships, and complete his degree. Moreover, Connor identified the readiness skills that may need to be included in transition training.

Study Quality

The key quality indicators used to evaluate the studies in this review offered mixed results (Tables 2.6 and 2.7). In the majority of qualitative studies, techniques were used to increase their trustworthiness, such as data source triangulation or member checks. Also, in the majority of survey studies, clear descriptions were provided of the survey design, and recruitment and data collection procedures. Some qualitative studies, however, did not provide a negative case analysis, consider contradictory data, or conduct methodological triangulation which reduced their trustworthiness. Furthermore, some survey studies failed to provide basic demographic and response rate data, or only provided scant description of their methodology, effectively precluding an audit trail or replication. In addition, some evaluation surveys allowed those involved in delivering a service to collect evaluation data and in so

doing risked bias. Finally, a minority of both survey and qualitative studies included participants with no formal diagnosis of ASD. On balance, however, the majority of studies had taken sufficient steps to allow confidence in their findings.

What are the Post-Secondary Barriers and/or Benefits Experienced by Students with ASD and How Do These Experiences Impact Both Academic and Non-Academic Aspects of Post-Secondary Education?

Academic barriers and benefits. A diverse range of academic experiences were revealed. Many studies described students with ASD who had a love of learning and passion for the subject they were studying, or took pride in their high academic achievement (Table 2.3). Moreover, Madriaga, Goodley, Hodge, and Martin (2008) described a sense of euphoria experienced by some students with ASD upon entering higher education. The students in some studies described how the structure of post-secondary education enabled personal improvements in time management, organisational and decision making skills, and that their qualification ultimately led to employment in the field they were studying (Table 2.3). These positive experiences accord with the findings of Barnhill (2016), who noted that students with ASD may have academic strengths such as intelligence, attention to detail, and a passionate interest in their chosen field that can develop into an expertise. Also, Priestley (2011) found that students in further education experienced both social and personal development, as well as improved study skills, that were capable of transferring to other educational settings.

Reports of academic difficulties, however, were compelling. Many researchers described students struggling to understand abstract or ambiguous concepts, or to express their thoughts in writing (Table 2.2). Shmulsky and Gobbo (2013) argued that the inflexible thought patterns of students with ASD, coupled with their poor ability to envisage the perspective of others, made it difficult for them to master the more complex college curriculum. In addition, in many studies students stated that they had poor concentration and

organisational skills, and that they felt overwhelmed by the volume of work. Shmulsky and Gobbo attributed this to poor executive function that caused many to mismanage time spent on assignments and to become overly focused on detail.

The heterogeneity of students with ASD is well illustrated in the diverse experiences found in class participation, group work, and class presentations. In many studies, students conveyed difficulty with asking questions in class or conversing with other students (Table 2.2; e.g., Van Hees et al., 2015), but Taylor et al. (2008) described two students with ASD who were talkative and disruptive and asked a series of irrelevant questions, while a third student was aggressive towards peers and academics. Tarallo (2012) recounted how one participant developed anger towards peers because he perceived them as less conscientious, while Knott and Taylor (2014) provided details of peers who refused to work with students with ASD as the peers perceived them as a liability. Further, the stress from group work caused some to cease attending class (e.g., MacLeod & Green, 2009). Madriaga and Goodley (2010), however, told of one student with ASD who, unlike other cohorts in their study, had ease working in groups “It just seems to be me and the lecturer talking ... There is me; the one who can’t do social things.” (p. 123). These contrasting scenarios illustrate the problematic nature of group work and class participation for some students with ASD, as well as highlighting their heterogeneity and the need for individualised supports.

In spite of the challenges experienced by students with ASD, numerous researchers reported high academic achievement. Some authors attributed this to the provision of a comprehensive range of predominantly academic supports (e.g., Gelbar et al., 2015), strong self-determination and self-advocacy skills, and support provided by family and friends (e.g., Connor, 2012). Tarallo (2012) explained their success in terms of achievement ideology and noted “[they were] a diligent, focused group, [who] were very passionate about doing well, and they knew that they had to work hard to achieve the success they wanted” (p. 84). These

examples demonstrate that supports can be effective, and emphasise the influence and importance of self-determination and self-advocacy skills on academic achievement.

Non-academic benefits and barriers. Non-academic benefits derived from attending post-secondary education were described by at least some of the participants in most studies and included the development of independence, self-awareness, and self-advocacy, as well as improvements in socialization, organisational, and time management skills (Table 2.3). Some made friends with like-minded people with similar academic passion, or in support or interest groups. They befriended faculty and mature-age students (e.g. Anderson, 2014; Connor, 2012), and peers were reported to be more tolerant and friendly towards students with ASD compared with high school (e.g., Drake, 2014a; Lee, 2010). Indeed, while bullying has been frequently reported in schools (e.g., Maxam, 2012; Simmeborn Fleischer, 2012), only six studies (26%) in this review identified instances of bullying (Table 2.2), which is the same percentage as found by Gelbar et al. (2015).

The benefits experienced by some, however, should not distort our understanding of the difficulties experienced by many students with ASD. For example, problems with social interaction and feelings of isolation and loneliness were a common and often debilitating complaint described by many students in a majority of studies and pervaded both academic and non-academic situations (Table 2.2). Although bullying was only reported in a minority of studies, those accounts were disturbing. For example, in Connor (2012) one participant reported “I had every single symptom when I was at the dorms [of post-traumatic stress disorder]. Increased startle response, paranoia, nervousness, flashbacks ... to terrible social events at the dorms. I couldn’t get away from my social failings, ever” (p. 1020). In response, post-secondary institutions may need to consider providing formal social skills training, in addition to counselling and emotional support, in line with a recommendation made by Gelbar et al. (2015). In addition, measures adopted to control bullying, including

providing peer support, on-line mentoring, anti-bullying committees, promotion of anti-bullying policies and consequences, and counselling for victims and perpetrators, should be applied and enforced at post-secondary education (Goldsmiths, University of London, 2011).

In all but two studies, mental health issues were described, and these often resulted in students with ASD reducing their enrolment or withdrawing (Table 2.2). This finding accords with Hofvander et al. (2009), who found 80% of high functioning adults with ASD have at least one major axis-1 disorder (e.g., mood, anxiety, psychotic disorder). Moreover, Pinder-Amaker (2014) contended that post-secondary education is particularly stressful for students with ASD due to its complex and unpredictable environment. She pointed out that the “persistent” skill deficits of social awkwardness and their struggle to understand neuro-typical behaviours, coupled with a self-awareness of social difficulties, often left students with ASD feeling isolated and rejected by their peers and created a “learned helplessness” that increased their risk for developing psychiatric illnesses (Pinder-Amaker, 2014, p. 126). Thus, she argued it was critical for colleges to provide campus-based appropriate and timely mental health supports to enable students with ASD to complete their studies. The results of this review would add weight to that recommendation.

Sensory sensitivities have become increasingly recognised as a characteristic of many persons with ASD and is now documented in the *DSM-5* (APA, 2013). It was described in 70% of studies in this review and was noted to contribute to stress and anxiety, cause difficulties with socialisation, and was a distraction from academic work. In Madriaga (2010), for example, crowds were reported to impede the student with ASD ability to socialise in student pubs, the student union, student accommodation, and the library, and this increased their sense of loneliness and depression. Moreover, students in Knott and Taylor’s (2014) study complained that sensory difficulties were rarely recognised by university authorities, a finding endorsed by Cai and Richdale (2016), and by Mulder (2014), who concluded that

“living in a shrunken social world [due to isolation caused by sensory difficulties] can lead an individual with autism towards depression” (p. 668). Thus, disability support units may need to increase awareness among post-secondary personnel of possible sensory sensitivities of students with ASD and consider ways of providing a more inclusive post-secondary environment.

What Supports and Services Were Offered to Assist Students with ASD to Complete Their Post-Secondary Education?

The supports offered to students with ASD ranged from mentors, counselling services, and social support groups to technological and on-line assistance; exam accommodations and scribes; and assistance with daily living (Table 2.5). Services such as quiet areas, clubs, and orientation programs were provided to the entire student body and some faculty were trained to better understand ASD (Anderson, 2014; Blamires & Gee, 2002). It was rare for a support request to be refused (Table 2.2); and Gelbar et al. (2015) found that the range of supports offered in post-secondary education were similar to, or better than those provided in high school.

In many studies, however, a mismatch of supports occurred where more academic supports were offered, though students stated they would have preferred assistance with social, emotional, and everyday living issues (e.g., Connor, 2012; Gelbar et al., 2015; Knott & Taylor, 2014). Pinder-Amaker (2014) argued that cultural reluctance prevented institutions of higher education from providing a range of supports that are often found in high schools. Moreover, she argued that the legislative mandate for inclusive practices were effectively circumvented when responsibility for educational outcomes in post-secondary education shifted from the institution to the student. Many non-physically disabled students, she reasoned, are not fully aware of their needs or the services available, and they often lack the skills to navigate the fragmented array of disability services. The findings from this review

support that view. Thus, to increase cultural acceptance and encourage post-secondary institutions to provide a more comprehensive range of support services it may be necessary to promote the advantages of providing supports (e.g., increased employment prospects, reduced welfare costs, and improved quality of life for students with ASD).

It was clear from this review that not all students with ASD were able to access support. Some were not entitled to support because they were undiagnosed (White et al., 2011), while others were not aware of available supports due to poor information (Simmeborn Fleisher, 2012; Van Hees et al., 2015). In addition, some had difficulty navigating the administrative process, and a small minority were refused support by disability services (Table 2.2). In contrast, a minority of researchers described some students who refused offers of support (Table 2.4). Some did not recognise their need for support, and others thought the support offered was of no value, inappropriate, or of poor quality (Simmeborn Fleisher, 2012). Blamires and Gee (2002) reported that one student did not want to remain on campus after class when support was available. Further, in some studies students reported that they were too distressed to cope with or apply for support (e.g., Knott & Taylor, 2014), or preferred to use private services (e.g., for mental health; see Simmeborn Fleisher, 2012). Thus, many students with ASD are unable or unwilling to use available supports and appear to struggle unnecessarily.

Finally, reluctance to disclose, which is a common problem among all students with a disability (Connor, 2012), was reported in several studies (Table 2.4). The most common reason was fear of being stigmatised, and some thought there was no benefit, similarly to those who refused support. Some did not recognise the difficulty of post-secondary demands, and some did not recognise their weaknesses, possibly because those weaknesses may appear incongruent to their high intellect. They also wrongly presumed the success achieved at school without support would translate to post-secondary education (e.g., MacLeod & Green,

2009). Others relished their new found independence and wanted to try post-secondary education on their own (Knott & Taylor, 2014). Moreover, Van Hees et al. (2015) found that students typically only chose to disclose to disability services (and rarely to peers) when stress became too great or they wanted a specific support, and then only if the campus environment was supportive. Unfortunately, however, the decision to delay disclosure often allowed significant problems to develop that some authors argued could have been avoided (e.g., Cai & Richdale, 2016; MacLeod & Green, 2009).

Cai and Richdale (2016) recommended that high schools should provide transition programs that explain the benefits of disclosure to potential students and their parents, with a view to encouraging a more informed choice. They argued that this would allow parents, who have been an important support for their children, to be more involved in the decision to disclose. The findings of the present review provide support for this recommendation. Moreover, many authors recommended teaching self-determination skills during transition programs to ensure prospective post-secondary students are capable of applying for support when needed (Maxam, 2012; Pinder-Amaker, 2014; Szentmiklosi, 2009).

Many students, however, are not diagnosed until after leaving high school (White et al., 2011). Thus, faculty and staff may need training to recognise the characteristics of ASD and the possible difficulties students with ASD experience, to enable them to more quickly identify when students are struggling and in order to offer assistance more promptly (Anderson, 2014; MacLeod & Green, 2009; Szentmiklosi, 2009). Further, Maxam (2012) recommended a “Universal Design for Learning” teaching framework be used, as it offered a more flexible curriculum and teaching approach that may be more accommodating of student learning differences and potentially reduce their need for support. There is, however, little research into the effectiveness of using a Universal Design for Learning framework with students with ASD so this approach warrants further investigation.

How Satisfied Were Post-Secondary Students with ASD with the Supports and Services Offered to Them?

Student satisfaction for supports provided at post-secondary education was collected in four evaluations and two quantitative surveys, plus seven qualitative studies (Table 2.5). On balance, the research indicated that students were generally satisfied with the academic supports provided, consistent with the recent findings of Cai and Richdale (2016), and Gelbar et al. (2015). Furthermore, there was evidence that academic supports were effective. Gelbar et al., for example, reported that 80% of respondents attained a grade point average above 3.0, and the authors attributed that academic success to the diverse range of academic supports provided and the supportive attitude of faculty.

In the evaluation surveys of Ames et al. (2016), Hendrickson et al. (2013), Longtin (2014), and Quinn et al. (2014), students expressed satisfaction with non-academic supports and claimed that they had improved their social skills and other non-academic behaviours. However, in the majority of qualitative studies, when supports were less comprehensive, many students described continual struggles with socialisation and mental health issues in addition to difficulties with classroom communication and group learning. Indeed, once students reached a crisis, a number of students refused all supports and took leave (e.g., Knott & Taylor, 2014; MacLeod & Green, 2009). Thus a proactive and comprehensive program with continual monitoring (e.g., Ames et al., 2016; Quinn et al., 2014) appears optimal. Indeed, Knott and Taylor (2014) found that success was more likely where supports were consistent and frequent, and the interactive influences of academic and non-academic concerns may mandate that supports be ubiquitous.

In a minority of studies some students regarded support as detrimental. For example, alternate individual assessment in lieu of group work was perceived as denying “real-world experience” by the participants in Knott and Taylor (2014). Madriaga and Goodley (2010)

argued that alternate assessments or separate exam locations may “ghettoise and isolate students”, a sentiment echoed by Gelbar et al. (2015). Similarly, Tarallo (2012) described one student who disliked separate exam locations, preferring take-home tests that were provided to all students. However, the majority of studies in this review reported students finding comfort from exam accommodations (e.g., Madriaga & Goodley, 2010). Thus the diversity of responses further testifies that support programs need to be individualised due to the heterogeneity of students with ASD.

Mentoring was highly rated by many students (and staff) in numerous studies due to its ability to support a pervasive range of difficulties (e.g., Blamires & Gee., 2002; Knott & Taylor, 2014). However, some students (who had never had a mentor) rejected the concept as humiliating (Knott & Taylor, 2014), and in Simmeborn Fleisher et al. (2012) the mentee complained that he was unable to communicate his needs and felt stressed working with a stranger. Further, some students became dependent on their mentors (e.g., Knott & Taylor, 2014) and benefits gained rarely generalised to other environments. Thus, the available evidence suggests that for the majority mentoring is an effective intervention, but it may not be appropriate for all students.

Summary

This review extended the research on post-secondary students with ASD by updating the only prior review by Gelbar et al. (2014) with an additional 18 studies and 363 participants with ASD. A wide array of academic and non-academic supports were revealed that pointed to an increased awareness by educational staff and faculty of the unique difficulties of postsecondary students with ASD. In addition, the complex characteristics of students with ASD were highlighted, as both the strengths and weaknesses of students with ASD were described. Examples of students with ASD who achieved high academic standards and improved both social and organisational skills were reported, demonstrating the

possibility of post-secondary education being both accessible and beneficial for students with ASD. However, most researchers revealed that although many students with ASD continue to struggle with both the academic and social demands of post-secondary education, many do not receive adequate or appropriate support. The reluctance to disclose to disability services or to access available resources was a contributing factor, but so was a misunderstanding of the complex needs of students with ASD by some staff and faculty.

Limitations

There are a number of limitations of this review. Study quality was assessed with checklists developed by the authors from the key features of various quality frameworks found in the literature, but there is no consensus among academics as to the appropriateness of using such criteria (Brantlinger et al., 2005; Cabinet Office, 2003; Dixon-Woods et al., 2007). Also, studies with an experimental design were excluded from this review, and the number of studies and participants found remains low, particularly from countries outside the USA and the UK, limiting our conclusions or the ability to make generalisations. In addition, unpublished sources were not included thereby increasing publication bias. Further, articles were included in this review though they may have included some participants with only an informal or self-diagnosis of ASD.

Future Research

There is a general need for more research and a particular need for quantitative survey studies with larger sample sizes from countries outside the UK and USA. Research on successful students with ASD, as well as those who dropped out and did not subsequently complete their studies, should be conducted to help determine what transition skills should be taught prior to entering post-secondary education (e.g., self-determination, independence, and self-awareness; Drake, 2014a). In addition, research should examine how the strengths of students with ASD may be incorporated into student support programs, and how students may

be better encouraged to disclose their diagnosis and access available services. Finally, research on the quality and adequacy of services and staff training is needed.

Conclusion

Prior research on the experiences of post-secondary students with ASD is limited and geographically circumscribed. In addition, the majority of studies reviewed were small scale and qualitative, limiting any generalisations. In most cases, academic supports were provided, although addressing non-academic issues was the imperative, and residual non-academic issues often rendered academic support ineffective. Moreover, the diverse characteristics of students with ASD and their idiosyncratic responses to supports demonstrated that supports need to be individualised, ubiquitous, and continually monitored to be effective.

Acknowledgments: No grant funding was used to fund this research. The authors would like to thank Genevieve Godwin who conducted reliability checks on all coding sheets and article quality assessments.

Conflict of interest: There were no conflict of interest issues for any of the authors when conducting this research.

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Appendix

Tables

Table 2.1

Demographic Information

Study and country	Study method	Data collection	N	M:F	Age range	Diagnosis	Recruitment source
Ames et al. (2016) Canada	Longitudinal mixed method	Semi-structured interview + evaluation survey	23	15:8	18-33	Self-reported ASD.	Counselling service + direct contact by participants.
Anderson (2014) USA	Qualitative	Interview + picture elicitation	8	7:1	19-23	ASD	Disability Services (purposive sampling)
Beardon & Edmonds (2007); Beardon et al. (2009) UK	Mixed method survey	Survey	135	NS	NS	Self-reported formal diagnosis: AS (72%); HFA (8%); Undiagnosed (20%).	ASPECT consultation day + AS groups.
Blamires & Gee (2002) UK	Mixed method + Longitudinal	Interview questions via email + questionnaire + Case study	NS 1	NS 1:0	NS NS	AS (82%); No diagnosis (18%). NS	Disability advisors. NS
Connor (2012) USA	Qualitative (longitudinal)	3 interview (75mins each)	1	1:0	19	AS verified by office of student services	Flyer at university.

Study and country	Study method	Data collection	N	M:F	Age range	Diagnosis	Recruitment source
Drake (2014a); Drake (2014b) USA	Qualitative	Interview	5	1:4	NS	3 formal diagnoses of ASD. 2 self-diagnosed.	Online support community for persons with ASD.
Gelbar et al. (2015) USA	Mixed method survey	On-line survey (35 Likert questions + 13 demographic + 5 open-ended)	35	17:15 + 3 NS	18- 33+	Self-reported formal diagnosis. AS (54%); ASD (23%); HFASD (9%); PDD- NOS (9%) HFASD; Other (3%); DNA (3%)	Self-advocacy groups + parent organizations + disability coordinators.
Hastwell et al. (2012); Hastwell et al. (2013) UK	Longitudinal mixed methods	21 structured interviews + 1 focus group + email + 17 questionnaires	28	18:10	NS	Formal diagnosis of AS or HFA.	Disability Resource Centre.
Hendrickson et al. (2013) USA	Longitudinal mixed methods	Group administered evaluative survey	14	NS	18-22	ASD + intellectual disability	Participants of the UI REACH program.
Knott & Taylor (2014) UK	Qualitative	Focus groups (topic guide)	4	4:0	NS	3 verified with AS by the first author; 1 unverified AS.	Disability advisor (second author).
Lee (2010) USA	Qualitative	Semi-structured interviews	11	7:4	19-48	9 self-reported formal diagnoses of AS; 2 HFA (formal diagnosis).	Support group + Disability Services + personal contacts.
Longtin (2014) USA	Mixed method	Evaluation survey (Likert scales + 3 open-ended questions)	5	4:1	21-27	ASD (all had disclosed to Disability Services).	Disability Services + posters on campus + college website + faculty conference.

Study and country	Study method	Data collection	N	M:F	Age range	Diagnosis	Recruitment source
MacLeod & Green (2009) UK	Qualitative (longitudinal)	Case study	2	2:0	NS	AS (disabled student's allowance required a formal diagnosis).	Campus Disability Team.
Madriaga (2010); Madriaga & Goodley (2010); Madriaga et al. (2008) UK	Qualitative (longitudinal)	Case study	8	5:3	18-30	AS	National Association of Disability Practitioners.
Maxam (2012) USA	Qualitative (longitudinal)	Focus group + interview + on-line qualitative survey + observation	8	NS	18-mid 20s	ASD	Disability Services + university autism support program + flyer + personal contacts.
Quinn et al. (2014) Ireland	Mixed method	Chart review + cross sectional student satisfaction survey	29 (12)	27:2	18-27	AS	Participants using the Unilink OT service.
Simmeborn Fleischer (2012) Sweden	Qualitative (longitudinal)	Case study (interview guide)	3	3:0	22-32	AS (2 diagnosed by a psychiatrist + 1 by a psychologist).	NS
Simmeborn Fleischer et al. (2013) Sweden	Mixed method	Open and close-ended questionnaire	16	NS	NS	AS	15 coordinators from 12 universities.
Szentmiklosi (2009) USA	Qualitative	Semi-structured interview + observation + document review	5	3:2	19-21	AS formal diagnosis	Academic advisors within disability services.

Study and country	Study method	Data collection	N	M:F	Age range	Diagnosis	Recruitment source
Taylor (2005); Taylor et al. (2008) UK	Qualitative (longitudinal)	Case study (interviews + discussions + observation)	4	NS	NS	AS	Not clear. Recruited within the university.
Tarallo (2012) USA	Qualitative (longitudinal)	Interview	6	6:0	18-26	ASD	Disability Services.
Van Hees et al. (2015) Belgium	Qualitative	Semi-structured interview	23	17:6	18-25	AS (diagnosis by a multidisciplinary team of experienced clinicians)	Flemish user organization for ASD + ASD counselling services + university disability offices.
Yamamoto & Nihei (2008) Japan	Qualitative	Interview	4	NS	NS	3 confirmed PDD + 1 suspected PDD	University counselling centre.

AS: Asperger's syndrome; ASD: autism spectrum disorder; HFASD: high functioning ASD; PDDNOS: pervasive development disorder not otherwise specified; NS: Not specified.

Academic and Non-Academic Challenges

[illegible]

POST SECONDARY STUDENTS WITH ASD

Table 2.2 (*continued*)*Academic and Non-Academic Challenges*

Challenge	MacLeod & Green (2009)	Madriaga (2010); Madriaga & Goodley (2010); Madriaga et al. (2008)	Maxam (2012)	Quinn et al. (2014)	Simmeborn Fleischer (2012)	Simmeborn Fleischer et al. (2013)	Szentmiklosi (2009)	Taylor (2005); Taylor et al. (2008)	Tarallo (2012)	Van Hees et al. (2015)	Yamamoto & Nihei (2008)
Abstract or ambiguous concepts	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
Faculty or staff attitudes			✓				✓	✓		✓	
Supports refused			✓			✓	✓				
Bullying	✓		✓		✓						
Weak communication skills	✓	✓	✓	✓	✓	✓	✓	✓		✓	
Poor daily living skills	✓			✓	✓	✓				✓	
Prefers structure or routine		✓			✓	✓				✓	
Exam stress	✓	✓			✓	✓	✓	✓		✓	
Group work or presentations	✓	✓	✓		✓	✓	✓	✓	✓	✓	
Mental health, anxiety, or depression	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cost of support services or education					✓		✓				
Organisational or time management	✓		✓	✓	✓	✓	✓	✓	✓	✓	
On-task behaviour				✓	✓	✓	✓	✓			
Fixations or unbalanced interests	✓				✓	✓	✓	✓		✓	✓
Sensory challenges		✓	✓	✓		✓	✓	✓		✓	
Prefers quiet areas or aloneness		✓			✓	✓		✓			✓
Social interaction or isolation	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Student accommodation	✓	✓		✓			✓			✓	
Bureaucratic tasks							✓	✓			

POST SECONDARY STUDENTS WITH ASD

Table 2.3

Benefits from Attending Post-Secondary Education

Study	Assisted with employment	Becoming self-aware	Improved organisational or time management	Improved socialisation	Increased independence or life skills	Increased self-esteem	Love of college or learning	Improved self-advocacy or self-help	High academic achievement
Ames et al. (2016)	✓	✓	✓	✓	✓				
Anderson (2014)	✓	✓		✓	✓	✓	✓	✓	✓
Beardon & Edmonds (2007); Beardon et al. (2009)			✓		✓	✓	✓		✓
Blamires & Gee (2002)		✓	✓	✓					✓
Connor (2012)		✓	✓	✓	✓	✓	✓	✓	✓
Drake (2014a); Drake (2014b)	✓	✓	✓	✓	✓	✓	✓		✓
Gelbar et al. (2015)								✓	✓
Hastwell et al. (2012); Hastwell et al. (2013)				✓			✓		✓
Hendrickson et al. (2013)		✓	✓	✓	✓	✓	✓	✓	
Knott & Taylor (2014)					✓				
Lee (2010)	✓	✓		✓	✓	✓	✓		✓
Longtin (2014)		✓	✓	✓		✓		✓	

Benefits from Attending Post-Secondary Education

[illegible]

Reasons for Non-Disclosure and Refusing Support

[illegible]

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POST SECONDARY STUDENTS WITH ASD

Table 2.5

Supports and Services

Support or service provided	Ames et al. (2016)	Anderson (2014)	Beardon & Edmonds (2007); Beardon et al. (2009)	Blamires & Gee (2002)	Connor (2012)	Drake (2014a); Drake (2014b)	Gelbar et al. (2015)	Hastwell et al. (2012); Hastwell et al. (2013)	Hendrickson et al. (2013)	Knott & Taylor (2014)	Lee (2010)	Longtin (2014)
Alternative assessment		✓		✓					✓	✓		
Course work extensions							✓			✓		
Exam accommodations		✓		✓	✓		✓			✓		
Academic mentor	✓		✓	✓			✓	✓	✓	✓		✓
Scribe or notes				✓			✓		✓			✓
Time management	✓			✓	✓				✓	✓		✓
Tutoring	✓	✓		✓					✓	✓		
Career services and study abroad	✓						✓		✓		✓	✓
Repeat or withdraw		✓	✓		✓					✓	✓	
Library training		✓		✓								
Assistive technology			✓	✓			✓		✓			
Quiet area				✓			✓					
Mental health support	✓		✓	✓					✓	✓	✓	✓
Medication				✓	✓							
Non-academic mentor/ counsellor	✓		✓	✓			✓		✓	✓		✓
Non-academic organisational skills	✓			✓					✓			✓
University social clubs		✓		✓				✓	✓	✓	✓	
Social skills workshops	✓			✓			✓		✓	✓	✓	✓
Support group	✓				✓							
Assistance to access resources	✓								✓			✓
Priority registration							✓					
Student accommodation		✓					✓		✓			
Parents		✓	✓	✓	✓	✓			✓		✓	

POST SECONDARY STUDENTS WITH ASD

Table 2.5 (*continued*)*Supports and Services*

Support or service provided	MacLeod & Green (2009)	Madriaga (2010); Madriaga & Goodley (2010); Madriaga et al. (2008)	Maxam (2012)	Quinn et al. (2014)	Simmeborn Fleischer (2012)	Simmeborn Fleischer et al. (2013)	Szentmiklosi (2009)	Taylor (2005); Taylor et al. (2008)	Tarallo (2012)	Van Hees et al. (2015)	Yamamoto & Nihei (2008)
Alternative assessment	✓		✓				✓	✓	✓	✓	
Course work extensions		✓			✓			✓	✓		
Exam accommodations	✓	✓	✓			✓	✓	✓	✓	✓	
Academic mentor	✓	✓			✓	✓	✓	✓		✓	
Scribe or notes		✓	✓	✓	✓	✓	✓	✓	✓		
Time management	✓			✓		✓		✓		✓	
Tutoring	✓	✓					✓	✓			
Career services and study abroad											
Repeat or withdraw	✓			✓	✓						
Library training											
Assistive technology					✓	✓	✓	✓	✓		
Quiet area											
Mental health support	✓	✓		✓	✓		✓		✓	✓	✓
Medication	✓			✓		✓	✓				
Non-academic mentor/counsellor	✓	✓			✓	✓	✓	✓	✓	✓	
Non-academic organisational skills	✓			✓				✓			
University social clubs	✓	✓	✓	✓	✓				✓	✓	
Social skills workshops	✓			✓					✓		
Support group	✓		✓						✓	✓	
Assistance to access resources					✓		✓	✓			
Priority registration											
Student accommodation	✓										
Parents	✓	✓			✓		✓	✓	✓	✓	✓

POST SECONDARY STUDENTS WITH ASD

Table 2.6

Quality Assessment Checklist for Qualitative Studies

Study	Explained how participants selected	Clear how data were collected	In-depth description of analysis process	Contradictory data (outliers/ negative case analysis)	Triangulation	Member checks
Ames et al. (2016)	✓	✓			✓	
Anderson (1993)	✓	✓	✓	✓	✓	✓
Blamires & Gee (2002)	✓	✓			✓	
Connor (2012)		✓	✓		✓	✓
Drake (2014a); Drake (2014b)	✓	✓	✓		✓	✓
Hastwell et al (2012); Hastwell et al. (2013)	✓	✓			✓	✓
Knott & Taylor (2014)	✓	✓	✓	✓	✓	
Lee (2010)	✓	✓	✓		✓	✓
Longtin		✓			✓	
MacLeod & Green (2009)	✓					✓
Madriaga & Goodley (2010); Madriaga et al. (2008); Madriaga (2010)	✓	✓	✓	✓	✓	✓
Maxam (2012)	✓	✓	✓		✓	✓
Simmeborn Fleischer (2012)		✓	✓		✓	✓
Szentmiklosi (2009)	✓	✓	✓	✓	✓	✓
Taylor (2005); Taylor et al. (2008)		✓			✓	✓
Tarallo (2012)	✓	✓	✓	✓	✓	
Van Hees et al. (2015)	✓	✓	✓		✓	✓
Yamamoto & Nihei (2008)	✓	✓	✓	✓		

POST SECONDARY STUDENTS WITH ASD

Table 2.7

Quality Assessment Checklist for Surveys

Quality criteria	Ames et al. (2016)	Beardon & Edmonds (2007); Beardon et al. (2009)	Blamires & Gee (2002)	Gelbar et al. (2015)	Hastwell et al. (2012); Hastwell et al. (2013)	Hendrickson et al. (2013)	Longtin (2014)	Quinn et al. (2014)	Simmeborn Fleischer (2013)
Population of interest specified	✓	✓	✓	✓	✓	✓	✓	✓	✓
Survey design described	✓	✓	✓	✓		✓	✓	✓	✓
Describes how participants were recruited	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data collection methods clear	✓	✓		✓		✓		✓	✓
Response rate or assessment of nonresponse bias	✓					✓	✓	✓	✓
Demographic data of respondents provided	✓			✓		✓		✓	✓
Questionnaire provided in its entirety		✓		✓		✓			
Data collectors not involved in delivering the service		✓	✓	✓					✓

CHAPTER 3: PERSPECTIVES OF UNIVERSITY STUDENTS WITH AUTISM SPECTRUM DISORDER

Chapter Overview

The third chapter presents the findings from a pilot study that used an on-line survey to investigate 48 university students with ASD who were attending six universities in New South Wales (NSW), and two in the Australian Capital Territory (ACT), Australia. The aim of the survey was to explore the experiences of university students with ASD.

The paper is in journal submission ready form. The tables which summarise the findings are in the appendix to Chapter 3, and the survey questions are in the appendices (Appendix B) at the end of the thesis. The findings from the survey revealed that students with ASD are heterogeneous and complex (e.g., Madriaga & Goodley, 2010). Their strengths were mainly academic, including attention to detail, ability to use technology, consistency and a strong memory, and their difficulties were mostly non-academic and included poor social skills and comorbid anxiety and/or depression. A majority of respondents were satisfied with the supports they used, however, their access was infrequent and most respondents only used a small number of different supports. Open-ended responses revealed much higher satisfaction for academic supports than non-academic supports. In addition, a need for better transition support was identified as a significant minority of respondents deferred university, some for many years. Further, females reported lower access to supports and a poorer overall university experience, as did students who delayed their disclosure. A suggestion was made for a strengths-based approach to supporting students with ASD, such as a Universal Design for Learning (UDL) where teaching staff may adopt a more flexible curriculum that allows multiple modes of learning and assessment. Suggestions for future research were also made.

Perspectives of University Students with Autism Spectrum Disorder

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Abstract

Students with autism spectrum disorder (ASD) are at heightened risk of post-secondary educational failure and account for approximately 1% of students in post-secondary education. Findings from an on-line survey of students with ASD attending university in New South Wales and the Australian Capital Territory, Australia, are reported in this study. Respondents indicated many academic and non-academic concerns, however, they reported only limited use of supports. Ratings for supports were idiosyncratic, but academic supports were generally more favourable than non-academic supports. Also, some students indicated that they were uncomfortable using supports or disclosing their disability. Those who delayed their disclosure accessed fewer supports and reported a poorer overall university experience. A number of recommendations arise from this research, including the need for alternate methods of supporting students (such as more flexible individualised curriculum designs) and better transition programs that encourage students to disclose and access available supports earlier. Given many students delayed university entry, there may also be a need for university-based transition support.

Keywords: autistic spectrum disorder, post-secondary education, university, experiences, educational supports, on-line survey.

CHAPTER 3

Perspectives of University Students with Autism Spectrum Disorder

In the United States, the Centers for Disease Control and Prevention (CDC, 2014) estimated that approximately one in 68 children have autism spectrum disorder (ASD) and that four times as many males were affected as females. A similar prevalence estimate of between 1.5 and 2.5%, and a ratio of four males to one female, was found in Australia by Randall et al. (2016). Prospects for adults with ASD are poor, and paradoxically worse for those with no intellectual impairment (Autism Spectrum Australia, 2013; Taylor & Seltzer, 2011; White et al., 2016) and around 46% of students with ASD have average or above intellectual ability (CDC, 2014). In addition, Sandford et al. (2011) found that students with ASD have a lower rate of post-secondary enrolment (46.6%) when compared with either their typical peers (62%) or all young adults with disabilities (55%).

Those with ASD who have a post-secondary education, however, have better life outcomes (Hendrickson et al., 2013), and adolescent students with ASD often express a strong desire to continue their education after school (Camarena & Sarigiani, 2009). Indeed, the number of students with disabilities, including those with ASD, requesting support at tertiary education has increased in many countries (Ames, McMorris, Alli, & Bebkco, 2016; Gobbo & Shmulsky, 2014; Hastwell, Martin, Baron-Cohen, & Harding, 2012; Quinn, Gleeson, & Nolan, 2014), and White, Ollendick, and Bray, (2011) found between 0.7% and 1.9% of college students now meet the criteria for ASD. However, graduation rates for tertiary students with ASD in Australia (35%) remain much lower than their neurotypical peers (51-67%; Universities Australia, 2015), and the Australian Bureau of Statistics (2012) reported that 81% of people with ASD in Australia who had finished high school had no post-school qualification, compared to approximately 50% of all students with a disability, and 41% of people with no disability.

Reasons for low graduation rates are complex (Van Hees et al., 2015). Students with ASD have diverse characteristics, which may include significant strengths such as a strong memory, affinity with technology, and a diligent and determined nature (Tarallo, 2012; Van Hees, Moyson, & Roeyers, 2015). However, these strengths are typically constrained by poor communication and social skills that limit their ability to participate in class discussions, group projects or class presentations (Gobbo & Shmulsky, 2014; Madriaga & Goodley, 2010). They may struggle with the reduced structure and routines of university (Simmeborn Fleisher, 2012; Van Hees et al., 2015; Wei et al., 2013), and be prone to loneliness, anxiety and depression (Pinder-Amaker, 2014). In addition, many lack the support of friends (Mazurek, 2014) and are distracted by sensory sensitivities (*Diagnostic and Statistical Manual of Mental Disorders* (5th ed.); *DSM-5*; American Psychiatric Association [APA], 2013; Pinder-Amaker, 2014).

Although research points to the possibility of creating inclusive environments in school education (Pinder-Amaker, 2014), there is a shortage of research into the post-secondary educational experiences of students with ASD, and studies from the student perspective are particularly scant (Anderson, Stephenson, & Carter, 2016; Gelbar, Smith, & Reichow, 2014; White et al., 2016). Moreover, the extant literature is primarily from the USA and UK and is qualitative and geographically circumscribed (Gelbar et al., 2014; Anderson et al., 2016) with small to modest sample sizes, which limit generalisations. Apart from a few studies that included a survey component (e.g., Cai & Richdale, 2016), Gelbar, Shefcyk, and Reichow's 2015 investigation, which comprised just 35 university students with ASD, offers the only study from the student perspective that employed a (primarily) quantitative survey design.

Research in Australia is also limited (Anderson et al., 2016). A recent focus group study by Cai and Richdale (2016) analysed the experiences of 23 students with ASD from two

universities and four Technical and Further Education (TAFE) colleges in Victoria (Australia) and compared those findings with the perspectives of 15 family members. Cai and Richdale revealed that students felt academically supported but viewed social supports as inadequate, while family members believed both academic and non-academic supports were deficient. In addition, they found that students with ASD rarely received transition planning during high school, and many felt underprepared for tertiary education. Furthermore, the majority delayed their disclosure to university or TAFE disability services, which slowed their access to supports, and this delay may have allowed significant avoidable problems to develop.

The extant literature revealed that a range of academic and non-academic supports have been offered to students with ASD including mentors, counselling services, social support groups, exam accommodations, and assistance with daily living (Gelbar et al., 2015). In addition, in a number of evaluation studies, students have indicated that they are generally satisfied with those supports (e.g., Ames et al., 2016). However, a mismatch was often reported in that more academic supports were provided though non-academic supports were more imperative (Gelbar et al., 2015; Knott & Taylor, 2014). Also, for a variety of reasons, many students did not access available supports.

Generalisations from current research are significantly limited given that it is predominantly qualitative and geographically circumscribed (Anderson et al., 2016; Gelbar et al., 2015). There is thus a particular need for more quantitative and survey research with larger sample sizes from countries outside the UK and USA. Furthermore, there appears to be only one directly relevant published Australian study that was limited to the state of Victoria.

Specifically, more research is required to better understand the demographic characteristics, the strengths, and the weaknesses of university students with ASD in order to better understand their support needs. Also, there is a need to analyse the variety and number of supports offered to students with ASD in a range of settings, and to gauge their use and

satisfaction with those supports in order to discern their appropriateness. Finally, more research is required on student attitudes to disclosure to disability services and the extent to which students request or accept supports, with a view to informing best practice and increasing support use by those who might benefit.

The aim of this research is to explore the experiences of university students with ASD in New South Wales (NSW) and the Australian Capital Territory (ACT) using an on-line survey. The research questions used to guide this study are:

1. What are the demographic characteristics of university students with ASD?
2. What do students with ASD indicate are their strengths and weaknesses?
3. What supports were offered to university students with ASD, and how satisfied were they with those supports and services?
4. Do students with ASD delay their disclosure to disability services, and if so, what reasons are given, and what consequences can be identified from that delay?

Methods

Survey Design

An on-line questionnaire exploring the experiences of university students with ASD was prepared, based on previous surveys and an extensive review of the literature (Anderson et al., 2016; Gelbar et al., 2015). The final version of the survey comprised 32 questions that included 13 demographic items, 5 open-ended, 6 Likert-style scale, and 8 multiple choice questions (Appendix B). The survey was tested for ease of use and program logic by the authors, and finally pilot tested by a former university student with ASD.

The first item was a screening question and asked the respondents if they had a formal diagnosis made by a medical doctor or psychologist. If they answered “no”, then the respondent was taken to the end of the survey. Demographic questions followed and addressed gender, age, years since leaving high school, level of study, degree studied within a

broad category, semesters completed at university, and enrolment status. Multiple choice and Likert-style questions were used to collect data on comorbid conditions, disclosure of diagnosis, personal strengths and weaknesses, non-academic experiences, academic and non-academic supports provided, support usage, and satisfaction rating of supports. Finally, open-ended questions allowed respondents to nominate their most helpful and least helpful support, and the respondents also provided an overall rating of their support and university experience.

Recruitment of Participants

Following approval by the relevant university Human Research Ethics Committee, the disability managers at 12 universities in New South Wales and two in the Australian Capital Territory were approached to participate in this study. Of the 14 universities invited to participate, three disability managers did not respond to the request, and three declined to participate. Reasons for declining included an increased number of similar requests and a perceived need to reduce communications to essential matters; an inability to identify a distinct cohort of students with ASD within the management system; and a general policy of declining, on behalf of their clients, any requests to participate in research. Thus, eight universities participated (57%).

The disability managers were requested to forward, via email, an invitation letter and two reminder notices to students with a formal diagnosis of ASD who were registered at their office. The invitations included information about the purpose of the research, an incentive prize draw of two \$50 gift vouchers, procedures to safeguard participant confidentiality, informed consent, and the link to the on-line survey on the Qualtrics platform. The survey was anonymous, and no personally identifying information was collected. Respondents were informed that completion of the survey would be regarded as informed consent and that the incentive prize draw was voluntary and administered separately, so individual responses could not be linked to identifying information.

The invitations were forwarded at various times due to the availability of the disability managers and the differing term dates of the universities. One was sent immediately after the first mid-semester break, while the remaining invitations were sent towards the end, but no later than three weeks prior to the end of the first semester of each university. Five disability managers sent two reminder notices approximately two to four weeks apart, and four to six weeks after the initial invitation, and two disability managers sent only one reminder six weeks after the initial invitation. The remaining university only placed the notice in a newsletter sent to all students with a disability registered at their office.

Disability managers were also asked to indicate the number of students who were invited to participate. Seven disability managers indicated that 276 individual invitations had been issued via email. The university that placed the notice in a newsletter did not disclose the number of students with ASD registered at their office.

Results

Response Rate and Data Analysis

The survey, which took approximately 15-30 minutes to complete, was commenced by 59 students. There were four respondents who were excluded because they did not have a diagnosis of ASD, and seven because they only answered screening questions, apparently after experiencing connectivity issues. Data was thus collected and analysed from 48 respondents. Given the small sample size, the data was analysed descriptively as the conduct of inferential statistical analyses would have been highly problematic. Also, due to the number of specific comparisons made, conduct of multiple analyses without correction for family-wise error would be inappropriate. If adjustments for multiple comparisons were made, obtaining a significant result would be virtually impossible given the small sample size and low power of the appropriate nonparametric tests.

The response rate was calculated after excluding the data from the university that did not provide the number of students with ASD registered at their office. The average response rate, including those who only answered screening questions, was 17.4% (range 0% to 40.5%). The response rate was calculated, for each university, by dividing the total number of eligible respondents (i.e., excluding those who did not have a formal diagnosis of ASD) by the number of invitations issued, and then multiplying by 100. The average completed response rate was 14.5% (range 0% to 35.7%) and was calculated, for each university, by dividing the total number of completed surveys (all questions answered) by the number of invitations issued, and then multiplied by 100.

Demographic Characteristics

The majority of participants had been diagnosed with Asperger syndrome (Table 3.1), were under 24 years, and were undergraduates who commenced university immediately after high school. Also, most had completed between one and seven semesters, and were currently studying full time. The 40% who were over 23 years, however, were mostly studying part time. The respondents indicated that they were enrolled in a variety of degree programs ranging from STEM majors (science, technology, engineering, and maths), to business, law, psychology, and education. Some respondents began university full time and switched to part time, and vice versa.

Demographic differences were noted between genders (Table 3.1). Females, who represented half the sample, indicated that they were primarily 24 years or older. Females also stated that they predominantly studied part time in the disciplines of law, arts, psychology, education, or linguistics. In contrast, the majority of males were between 17 and 23 years and generally studied full time, and were more evenly distributed across disciplines (business/finance/commerce/marketing 26.1%, law and/or arts 26.1; maths/engineering/science/IT/computing 30.4%; psychology/education/linguistics, 21.7%).

Strengths

The most common strength indicated by the respondents was attention to detail (Table 3.2). Other strengths included an ability to use technology, original and creative thoughts, memory, and consistency.

Comorbid Conditions

The respondents indicated a range of comorbid conditions. Anxiety was the most common condition, followed by depression, attention deficit hyperactive disorder (ADHD) or attention deficit disorder (ADD), and epilepsy (Table 3.3). Nearly a third of the respondents (14; 29%) indicated “other” for comorbid conditions. Although the respondents had an opportunity to provide details, only two did so (drug addiction and OCD), and they did not indicate whether those conditions had been formally diagnosed).

Academic Experiences

A majority of respondents agreed that they “[felt] comfortable asking questions in class” (Table 3.4), although females less so than males. The respondents also agreed they could “follow what [was] going on in lectures and tutorials”. In response to an open-ended question, one respondent revealed that they did not like being forced to answer questions in class, and another described academic staff as generally unhelpful and on occasion cruel. Other open-ended comments included: their needs were not taken seriously because they were not visibly autistic, they found it difficult to ask for help, clinical placements were difficult, and that academic requirements caused anxiety. Finally, only a minority of respondents indicated that they had participated in on-line study modules, and although nearly half agreed they preferred this mode, 20% stated that they preferred traditional contact courses.

Non-Academic Experiences

The overwhelming majority of respondents indicated that anxiety was a concern (Table 3.5). In addition, a majority indicated problems with poor quality sleep, depression,

lack of structure, and loneliness. Most agreed or were neutral that “people [were] more accepting of [them] at university compared with school”, and only a minority agreed that bullying was a concern (although bullying was more significant for females than for males). Finally, half of the respondents agreed that “their sensitivity to noise, light or smells on campus sometimes interfered with their ability to study or cope on campus”.

Supports and Services

Respondents were asked to indicate how frequently they accessed both academic and non-academic supports and services, and also to rate how helpful those supports and services were. The findings are summarised in Tables 3.6 and 3.7. Many supports and services were never used by many respondents, and only four academic supports (liaison with academics, recorded lectures, on-line discussion boards, and reduced course loads) and two non-academic supports (consultation with a disability support co-ordinator, and orientation week) were used by a majority of respondents. The majority of those who did use supports only did so occasionally, but they generally indicated that the supports were helpful (Tables 3.6 and 3.7).

A range of exam and assignment accommodations were used by the respondents (Table 3.8). Only alternate rooms and extended time for exams were used by a majority of respondents, and 91.5% of respondents who used exam or assignment accommodations indicated that they were helpful.

A minority of respondents stated that they had withdrawn from a unit due to lack of support or that not all requested supports were provided. The main reasons given by respondents was lack of follow up by disability services or lack of resources.

Respondents provided open-ended comments with respect to supports including nine responses as to why services were not provided, 18 responses about supports that worsened their experience, and 21 responses for “any further comments”. From these open-ended responses some indicated that they endured stress from long delays between requesting

support and receiving assistance. For example, “Follow up with services you say you will provide. It adds unnecessary stress if a student is chasing up appointment details.” Also, “[Got] my reasonable adjustment document on Friday of week 12 in a 13-week semester.”

Some indicated that they had poor self-advocacy skills that made it difficult for them to request help, and suggested that academics should be more proactive in their assistance, “instead of telling me to “just ask” ... something I have always struggled to do, they should be checking me Essentially they are just treating me the same as regular students and so I feel that they don’t understand.”

Sometimes, respondents indicated that the supports were not available, “I would love to have access to a mentor at this university. I have had one in the past, but not here.” Finally, one out of three respondents who used a mentor, and two out six who had self-advocacy training, indicated that the quality of service was poor.

Overall Rating of Supports and Services and University Experience

An overall rating of supports and services, and university experiences, was provided by 40 respondents (Tables 3.9 and 3.10). Only a minority provided a dissatisfied or very dissatisfied overall rating, with approximately three quarters declaring they were either neutral or satisfied. Cross-tabulation of females, those 24 years and above, and those who disagreed that their family were very supportive, however, revealed that these groups had the highest rates of dissatisfaction of supports and university experiences ratings.

Most Helpful and Least Helpful Support or Service

Responses to the open-ended questions “What is the most helpful / least helpful support or service?” are summarised in Table 3.11. Academic supports were nominated 26 times as the most helpful support, with exam accommodations being the most commonly selected as most helpful (10 respondents). Non-academic supports, however, were only nominated by 16 respondents as most helpful, with counselling the most commonly selected

most helpful non-academic support. Academic supports were nominated five times as least helpful support, compared with 16 non-academic supports being nominated for least helpful support. Interestingly, mentors were nominated once as the most helpful and twice as the least helpful support.

Disclosure

Although all respondents were recruited from disability services and thus had disclosed their disability to disability services, 12 respondents (25%) had delayed that disclosure. Of those 12 who delayed, only nine provided reasons. The most common reason for delay was wanting to try university on their own (five respondents; 55.6%). Other explanations included that their diagnosis occurred after enrolment (three respondents; 33.3%), a belief that disclosure was unnecessary (two respondents; 22%), fear of being stigmatised (two respondents; 22%), not knowing how to disclose (two respondents; 22%), and that their condition deteriorated after enrolment (two respondents; 22%). Open-ended responses from three respondents were that the process of disclosing was perceived as too difficult (one respondent; 11%), the respondent disagreed with their ASD diagnosis (one respondent; 11%), and the respondent was not [initially] aware of disability services (one respondent; 11%).

Those who delayed disclosure, and those who did not delay, reported similar academic and non-academic concerns. However, fewer of those who delayed stated that they were satisfied or very satisfied with their overall supports (three respondents, 33.3%) and university experiences (three respondents, 33.3%), compared with those who did not delay (18 respondents, 58.1%; 17 respondents, 54.8% respectively). Also, it was noted that respondents who delayed their disclosure accessed fewer supports than those who did not delay their disclosure, in 10 out of 12 academic supports or services, six out of seven exam accommodations, and seven out of 10 non-academic supports and services.

Discussion

There is a shortage of research exploring the supports and experiences of university students with ASD, especially from the student perspective, and consequently there is little guidance for staff or academics when accommodating their needs. In response, the findings from a survey of 48 Australian university students with ASD from six universities in NSW and two universities in the ACT were presented in this study.

What are the Demographic Characteristics of University Students with ASD?

There were three interesting demographic features in the current sample. Firstly, 43.8% of all respondents deferred university for at least a year after high school. Although this is similar to typical students (60.1% of total offers to universities in Australia were to year 12 applicants in 2016; Universities Australia, 2016), Taylor and Seltzer (2010) found that when students with ASD exited school they significantly slowed their improvement in adaptive functioning, possibly due to the lack of stimulation gained from their post-school non-educational day activities. Thus, it is possible that there may be little benefit for students with ASD in delaying their post-secondary studies. In Australia, there is no legal obligation to provide transition support when completing school (O'Neil, Strnadova, & Cumming, 2016). Cai and Richdale (2016) noted that only a few of their participants had received formal transition planning and that many indicated that they felt unprepared for the transition to post-secondary education. Pinder-Amaker (2014) pointed out that stress prior to entering tertiary education can have a long-term negative impact, and thus it was crucial that students be well supported prior to entering tertiary education. More research may be required to improve the effectiveness of transition programs, as in the current sample, of the nine respondents who were provided with transition support by their university, a third stated that it was not helpful. Cai and Richdale similarly described one participant who found a TAFE (technical college) transition program detrimental. Thus, research may be required to

determine both why some post-secondary students delay their post-secondary education and the consequences of that delay, as well as the elements of an effective transition program that will better prepare students for post-secondary education.

Choice of discipline was interesting. The respondents studied a diverse range of disciplines, consonant with the finding of Gelbar et al. (2015) and Cai and Richdale (2016). Although males indicated an even distribution of faculties, few females nominated STEM or business/finance majors. Wei et al. (2012) similarly revealed a small minority of female students with ASD studied STEM (science, technology, engineering and mathematics) majors, which is consistent with the finding of Mann and DiPrete (2013) among the general university student population. Thus the issue of gender bias in career choices, including the appropriateness of career advice provided by schools and parents, is a general one, but it may also be interesting to specifically analyse the student with ASD experience.

Finally, gender prevalence anomalies were observed. Half of the respondents were female. This is more than the 20% of females estimated by the Australian Bureau of Statistics (ABS, 2012) to have an ASD, but similar to that reported by Gelbar et al. (2015; 43%) and Ames et al. (2016; 40%). There may be several reasons for the discrepancy, including more recent improved reporting and diagnostic procedures (Kirkovski, Enticott, & Fitzgerald, 2013; Van Wijngaarden-Cremers et al., 2014), and a response rate bias toward females that is often found in on-line surveys (Sax, Gilmartin, Lee, & Hagedorn, 2008). Nevertheless, the overrepresentation of females is interesting and warrants further investigation.

What do Students with ASD Indicate are their Strengths and Weaknesses?

The data revealed a diverse range of competing strengths and weaknesses of students with ASD (Tables 3.2 to 3.5), as well as heterogeneity among respondents, and these findings accord with that of prior research (e.g., Van Hees et al., 2015). Their reported strengths were mainly academic (e.g., attention to detail, technology skills, original and creative thoughts,

strong memory, and consistency), while their difficulties were diverse and included academic and non-academic issues. For example, a minority reported difficulty with following what was going on in lectures and tutorials. They were further hampered by their discomfort in asking questions in class, and some found being forced to answer questions caused anxiety. Anxiety, depression and loneliness were a difficulty for a majority of respondents. Similar to the findings of Gelbar et al. (2015), only a minority of respondents (mainly female) in the current sample stated that they were bullied, and victims also stated that they felt inadequately supported for this complaint.

Just over half of the sample agreed that they suffered sensory sensitivities that interfered with their ability to study or cope on campus. This may suggest the need for campuses to consider sensory issues. Solutions are complex, however, as research has shown that some find comfort from quiet areas or flexible curriculums that allow them to work at home, while others complain that they feel isolated and lonely and that their life is dull due to isolating supports (Madriaga, 2010). Madriaga recommended that universities devise more inclusive university environments in consultation with students with ASD. She suggested greater use of mentors (e.g., to support students with ASD at noisy and crowded events), counselling (to help them cope with their sensitivities), and the provision of alternate social activities for students with ASD so that they are not left alone. Robertson and Ne'eman (2008) suggested replacing fluorescent lights, reducing distracting noises from other classes, and providing breaks during class, to avoid the build-up of sensory sensitivities. Some of these suggestions may also be perceived as non-inclusive, so more research is clearly required on this issue. In addition, sensory sensitivities have only recently been formally acknowledged in the *DSM-5* (APA, 2013) as a characteristic of many students with ASD, and staff may need to be made aware of these issues and their implications.

The extant literature focus on difficulties has been important as it highlighted how non-academic concerns have a significant negative impact on university experiences and academic achievement, and how they can undermine the effectiveness of academic supports (Anderson et al., 2016; Cai & Richdale, 2016; Connor, 2012; White et al., 2016). It thus identified the importance for universities to provide appropriate supports for both academic and non-academic concerns, a view endorsed by many researchers (e.g., Cai & Richdale, 2016; Gelbar et al., 2015; Pinder-Amaker, 2014). An increased emphasis on strengths, however, may provide a more balanced view of the abilities of students with ASD, and thereby promote more positive attitudes towards them, and suggest more positive means of support that may be more acceptable to both students with ASD and academics.

What Supports Were Offered to University Students with ASD and How Satisfied Were They with Those Supports and Services?

A wide array of both academic and non-academic supports and services were offered to the respondents. Although almost all respondents accessed both academic and non-academic supports, they only used a few services each, and typically only occasionally, even though the majority of those who did agreed the supports were helpful. The reasons for using a limited number of supports was unclear from the current sample, but prior researchers have reported that some students choose not to use available supports and concluded that they may have been struggling unnecessarily (e.g., Blamires & Gee, 2002; McLeod & Green, 2009; Simmeborn Fleischer, 2012). More respondents nominated academic supports as their most helpful support, and more non-academic supports were nominated as their least helpful support (Table 3.11). Cai and Richdale (2016) likewise found that students with ASD felt more supported with their academic than non-academic concerns. Many of the non-academic difficulties indicated by the respondents are more typically lifelong problems that may require complex, regular and long-term intervention (e.g., anxiety and depression; Pinder-Amaker,

2014). In contrast, some academic needs, such as examination accommodations, may require only occasional and/or relatively simple supports (e.g., notetaking support). Thus, the greater satisfaction with academic supports compared with non-academic supports may reflect the comparatively easier task of managing academic problems, but it may also highlight that more resources may be needed to meet the non-academic needs of university students with ASD.

Responses to open-ended questions provided by nine respondents explained some of the reasons why the respondents did not access some of the available supports. Some stated that they endured stress from excessive delays between requesting support and receiving assistance, and others stated that some supports were not available, suggesting there may be a need for universities to increase resources for students with ASD, a recommendation also made by Pinder-Amaker (2014). In addition, some respondents reported they were impeded from requesting supports by poor self-advocacy skills. This highlights the need for better transition programs that teach students the skills needed to be successful during post-secondary education, including the ability to seek assistance as required. Finally, a small minority of respondents reported that the quality of some of the services was poor, indicating the need for more research into improving the quality of support programs, including better training of support personnel. Thus, more non-academic supports in particular may be required to assist university students with ASD, and more research is required on reasons why students are not accessing supports, how to encourage support uptake, and how to improve the quality of existing supports to increase their effectiveness and uptake.

On-line courses may provide an opportunity for students with ASD by reducing some on-campus difficulties, such as the need to use social skills in class and issues relating to sensory sensitivities, but less than half of the respondents who had used on-line learning expressed a clear preference for it. This finding emphasises the heterogeneity of students with ASD and the need to individualise support.

There were differences between genders in overall satisfaction of supports and university experiences. More female respondents agreed that they were dissatisfied with their overall university experiences and support services than male respondents. It was noted that females stated that they experienced more bullying compared to males and that they suffered higher rates of comorbid anxiety and depression. Also, more females than males claimed that approved supports were not provided, and that they withdrew from a unit due to lack of support (despite males and females indicating that they received a similar frequency of supports). These findings must be qualified by the low number of responses, but they may suggest that females have greater needs and that their issues are not as well understood. Research on gender issues is scarce (Kirkovski et al., 2013; Van Wijngaarden-Cremers et al., 2014), and more research is needed to examine whether females with ASD struggle more at university than males, and why this might be so.

The extant literature has primarily provided analysis of supports that assist students to manage their difficulties. Some commentators have argued that many of these supports, such as separate exam accommodations or alternate assessment to group work, are inappropriate because they isolate students with ASD or deny them real-world experience (Knott & Taylor, 2014; Madriaga & Goodley, 2010). The overwhelming majority of respondents in this review, however, indicated that these supports were useful and appreciated. Nevertheless, the respondents indicated that they continued to suffer with a number of concerns, suggesting that novel solutions may be needed to supplement the existing traditional approaches. For example, future research may consider how student strengths may be used to assist students rather than relying solely on accommodations that mitigate weaknesses. In addition, teaching staff may consider adopting more inclusive and flexible teaching curricula such as those advocated by Universal Design for Learning (CAST, 2011).

Cross-tabulation of the current survey demonstrated that family support affected the overall university experience as rated by the respondents. Cai and Richdale (2016) noted that parents felt restrained in the support they could provide due to poor communication between staff and parents, some of which was caused by privacy laws. They argued that a collaborative approach was crucial where students were still dependent on their parents. Thus, the privacy laws meant to protect students may paradoxically deny students with disabilities the vital assistance they need. Hence future research may be needed to determine how the involvement of parents may be better managed and used within current legislation.

Do Students with ASD Delay Their Disclosure to Disability Services, and if so, What Reasons Are Given and What Consequences Can Be Identified from That Delay?

Disclosure was a pre-requisite for participation in this research, so all respondents had disclosed to disability services. A quarter of the respondents, however, delayed that disclosure. Both respondents who delayed, and those who did not delay, experienced similar difficulties. For example, both groups agreed that they were bothered by loneliness, anxiety, depression, lack of structure, and quality of sleep. Those who delayed, however, claimed that they received fewer supports, and a higher percentage of delayers indicated that they withdrew from a unit due to lack of support, compared with those who did not delay. Moreover, more non-delayers indicated that they were satisfied with their overall supports and university experiences compared to those who delayed. The number of respondents was too small to draw firm conclusions, but the findings support the view of Cai and Richdale (2016) that students may be disadvantaged if they delay their disclosure and that the benefits of disclosure should be promoted to high school students to encourage early disclosure.

Contributions to the Research

This research represents one of the first studies from NSW and the ACT addressing the experiences of university students with ASD, and the largest quantitative study conducted

to date. The strengths of students with ASD were identified, as was the need to consider these strengths for a more balanced understanding of the needs of student with ASD. In addition, a suggestion was provided of how those strengths may be used to support students (with a strengths-based teaching approach such as the Universal Design for Learning [UDL] teaching framework). UDL may possibly reduce student reliance on supports and be particularly useful for those reluctant to disclose or use supports, or indeed for those who are not aware they have ASD. Although prior studies have noted the need for better transition programs, this study highlighted the need for universities to provide their own transition programs, due to the finding that 43% of respondents had deferred university, some for many years, and thus may not have been well prepared. Further, the sensory sensitivities experienced by more than half of respondents were illuminated, and the need for universities to consider this issue. Sensory sensitivities have only recently been recognised in the *DSM-5* (APA, 2013), and there is very little research on this issue. Finally, there has been very little research focused on female students with ASD, and this study identified that female students may have poorer experiences that need further investigation.

Limitations

The participation rate of universities, and the completed response rate by respondents in this study was low, though similar to that of prior research (e.g., Gelbar et al., 2015, Simmeborn Fleischer et al., 2013) and on-line surveys in general (McGregor et al., 2016; Sax, Gilmartin, & Bryant, 2003). There may have been a bias against respondents who have weak computer skills, or those who were academically struggling, or currently experiencing debilitating stress, as these issues may discourage students from responding. In addition, all respondents were recruited through disability support services so the survey was limited to students registered with those services. Also, the present study was limited to NSW and the

ACT so the findings are not necessarily applicable to other Australian states. Finally, the low number of respondents restricted granularity of the data.

Conclusion and Future Directions

Students with ASD are heterogeneous and although they possess academic strengths, for most, university is a challenging experience where those strengths are constrained by diverse academic and non-academic concerns. Despite this, many students only occasionally used a limited number of available supports, with greater overall satisfaction indicated for academic supports than for non-academic supports. This suggests that more resources may be needed to improve the quality and appropriateness of those supports. Students also had idiosyncratic responses to supports, confirming the importance of supports being individualised to meet the unique needs of each student. Although many respondents agreed that the supports accessed were helpful, some students felt uncomfortable using them, or with asking for assistance, and it was suggested that alternative methods of assisting students with more flexible curriculum designs that allowed students to work to their strengths rather than focusing on assisting deficits should be considered. The reluctance of some to disclose to disability services suggest the need for better transition programs that inform students of the advantages of disclosure. Also, many respondents took leave before commencing university, indicating that universities may need to provide their own transition programs and not rely solely on schools. Finally, the poor advocacy skills described by some highlight the need to teach readiness skills that would improve the likelihood of students being successful at university.

Acknowledgments: No grant funding was used to fund this research. The authors would like to thank Genevieve Godwin who conducted proof reading of this article.

Conflict of interest: There were no conflict of interest issues for any of the authors when conducting this research.

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Appendix

Tables

Table 3.1

Demographic Characteristics by Gender

Survey Question	Response	Males (n=23)		Females (n=24)		Other (n=1)		Total (n=48)	
		n	%	n	%	n	%	n	%
What is your age?	Age 17-23 years	18	78.3%	9	37.5%	1	100.0%	28	58.3%
	Age 24 years or above	5	21.7%	15	62.5%	0	0.0%	20	41.7%
At what level are you currently studying?	Undergraduate	22	95.7%	21	87.5%	1	100.0%	44	91.7%
	Postgraduate	1	4.3%	3	12.5%	0	0.0%	4	8.3%
How many years after high school (or equivalent) before you started university?	Commenced immediately after school	14	60.9%	13	54.2%	0	0.0%	27	56.3%
	1-2 year break after high school	4	17.4%	3	12.5%	0	0.0%	7	14.6%
	3-4 year break after high school	1	4.3%	4	16.7%	0	0.0%	5	10.4%
	5 or more years after high school	4	17.4%	4	16.7%	1	100.0%	9	18.8%
How many semesters have you completed at university?	Less than one semester completed	4	17.4%	3	12.5%	0	0.0%	7	14.6%
	One semester completed	3	13.0%	3	12.5%	0	0.0%	6	12.5%
	2 semesters completed	5	21.7%	0	0.0%	1	100.0%	6	12.5%
	3 semesters completed	1	4.3%	3	12.5%	0	0.0%	4	8.3%
	4 semesters completed	3	13.0%	2	8.3%	0	0.0%	5	10.4%
	5 semesters completed	1	4.3%	3	12.5%	0	0.0%	4	8.3%

Survey Question	Response	Males (n=23)		Females (n=24)		Other (n=1)		Total (n=48)	
		n	%	n	%	n	%	n	%
	6 semesters completed	4	17.4%	1	4.2%	0	0.0%	5	10.4%
	7 semesters completed	1	4.3%	0	0.0%	0	0.0%	1	2.1%
	8 semesters completed	0	0.0%	0	0.0%	0	0.0%	0	0.0%
	9 semesters completed	0	0.0%	0	0.0%	0	0.0%	0	0.0%
	Completed 10 or more semesters	1	4.3%	9	37.5%	0	0.0%	10	20.8%
Which of the following best describes your enrolment status?	Always full time	16	69.6%	10	41.7%	0	0.0%	26	54.2%
	Always part time	2	8.7%	7	29.2%	0	0.0%	9	18.8%
	Started full time but switched to part time	1	4.3%	6	25.0%	1	100.0%	8	16.7%
	Started part time but switched to full time	2	8.7%	1	4.2%	1	100.0%	4	8.3%
	Other - currently full time	1	4.3%	0	0.0%	0	0.0%	1	2.1%
	Other - undisclosed	1	4.3%	0	0.0%	0	0.0%	1	2.1%
What degree (or major) are you studying towards? Select all that apply.	Maths/Engineering/Science/IT/Computing	7	30.4%	4	16.7%	0	0.0%	11	22.9%
	Business/Finance/Commerce/Marketing	6	26.1%	0	0.0%	0	0.0%	6	12.5%
	Law and/or Arts	6	26.1%	10	41.7%	1	100.0%	17	35.4%
	Psychology/Education/Linguistics/Other	5	21.7%	7	29.2%	1	100.0%	13	27.1%
	Degree – other	4	17.4%	5	20.8%	0	0.0%	9	18.8%

Table 3.2

Strengths and Weaknesses

Characteristic	This is one of my strengths (n=41)		I have difficulty with this (n=41)	
	n	%	n	%
Ability to use technology	32	78.1%	9	22.0%
Memory	25	61.0%	16	39.0%
Consistency	24	58.6%	17	41.5%
Original and creative thoughts	25	61.0%	16	39.0%
Attention to detail	35	85.4%	6	14.6%

Table 3.3

Comorbid Conditions

Comorbid Condition	Males (n=23)		Females (n=24)		Gender not disclosed (n=1)		Total (n=48)	
	n	%	n	%	n	%	n	%
ADHD/ADD	7	30.4%	4	16.7%	0	0.0	11	22.9%
Anxiety	15	65.2%	22	91.7%	1	100.0	38	79.2%
Depression	11	47.8%	16	66.7%	0	0.0	27	56.3%
Epilepsy	1	4.3%	1	4.2%	0	0.0	2	4.2%
Other	8	34.8%	6	25.0%	0	0.0	14	29.2%
Did not answer	2	8.7%	0	0.0%	0	0.0	2	4.2%

Table 3.4

Academic and Miscellaneous Issues

Issue	Disagree (n=41)		Neutral (n=41)		Agree (n=4)	
	n	%	n	%	n	%
People are more accepting of me at university compared with school	6	14.6%	18	43.9%	17	41.5%
My family are very supportive	6	14.6%	9	22.0%	26	63.4%
I can follow what is going on in lectures and tutorials	5	12.2%	13	31.7%	23	56.1%
I feel comfortable asking questions in class	13	31.7%	7	17.1%	21	51.2%
My lecturers/tutors have a good understanding of ASD	13	31.7%	23	56.1%	5	12.2%
My sensitivity to noise, light or smells interferes with my ability to cope	16	26.8%	12	22.0%	21	51.2%

Table 3.5

Non-Academic Issues

Issue	It does not bother me (n=41)		A moderate concern (n=41)		A big concern (n=41)	
	n	%	n	%	n	%
Loneliness	16	39.0%	17	41.5%	8	19.5%
Bullying	31	75.6%	7	17.1%	3	7.3%
Anxiety	4	9.8%	14	34.2%	23	56.1%
Depression	12	29.3%	12	29.3%	17	41.5%
Quality of sleep	8	19.5%	12	29.3%	21	51.2%
Lack of structure	10	24.4%	16	39.0%	15	36.6%

Table 3.6

Non-Academic Supports Frequency and Satisfaction Rating

Support	Frequency (n=41)						How Satisfied (n=41)							
	Never		Occasionally		Frequently		Not Applicable		Not Helpful		Somewhat Helpful		Very Helpful	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Peer mentor/buddy/life coach	28	68.3%	10	24.4%	3	7.3%	28	68.3%	2	4.9%	5	12.2%	6	14.6%
Counselling support	22	53.7%	13	31.7%	6	14.6%	21	51.2%	3	7.3%	13	31.7%	4	9.8%
Consultation with a disability support coordinator or collaborative support	7	17.1%	29	70.7%	5	12.2%	7	17.1%	7	17.1%	16	39.0%	11	26.8%
Training to improve self-advocacy skills	35	85.4%	4	9.8%	2	4.9%	34	82.9%	3	7.3%	2	4.9%	2	4.9%
Orientation week	15	36.6%	20	48.8%	6	14.6%	13	31.7%	12	29.3%	13	31.7%	3	7.3%
ASD support group	39	95.1%	1	2.4%	1	2.4%	38	92.7%	1	2.4%	2	4.9%	0	0.0%
Campus social/sports clubs	24	58.5%	8	19.5%	9	22.0%	22	53.7%	7	17.1%	5	12.2%	7	17.1%
Support to transition from school to university (provided by the university)	32	78.1%	8	19.5%	1	2.4%	33	80.5%	3	7.3%	4	9.8%	1	2.4%
On-line well-being course	38	92.7%	3	7.3%	0	0.0%	38	92.7%	2	4.9%	0	0.0%	1	2.4%
Housing accommodations	34	82.9%	3	7.3%	4	9.8%	34	82.9%	0	0.0%	3	7.3%	4	9.8%

Table 3.7

Academic Supports Frequency and Satisfaction Rating

Support	Frequency (n=41)						How Satisfied (n=41)							
	Never		Occasionally		Frequently		Not Applicable		Not Helpful		Somewhat Helpful		Very Helpful	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Time management and/or task prioritisation skills training	27	65.9%	13	31.7%	1	2.4%	26	63.4%	6	14.6%	7	17.1%	2	4.9%
Assistance with structuring assignments	23	56.1%	16	39.0%	2	4.9%	23	56.1%	2	4.9%	6	14.6%	10	24.4%
Assistance to understand abstract or ambiguous concepts	27	65.9%	11	26.8%	3	7.3%	26	63.4%	3	7.3%	7	17.1%	5	12.2%
Assistance with group work or presentations	32	78.1%	6	14.6%	3	7.3%	31	75.6%	1	2.4%	6	14.6%	3	7.3%
Stress management training	35	85.4%	4	9.8%	2	4.9%	35	85.4%	2	4.9%	3	7.3%	1	2.4%
Liaison with academics	19	46.3%	19	46.3%	3	7.3%	18	43.9%	3	7.3%	8	19.5%	12	29.3%
Tutoring centre	29	70.7%	7	17.1%	5	12.2%	29	70.7%	2	4.9%	3	7.3%	7	17.1%
Note-taker/scribe	37	90.2%	2	4.9%	2	4.9%	37	90.2%	1	2.4%	2	4.9%	1	2.4%
Lecture transcriptions	33	80.5%	5	12.2%	3	7.3%	32	78.1%	0	0.0%	3	7.3%	6	14.6%
Recorded (video or audio) lectures	12	29.3%	14	34.2%	15	36.6%	12	29.3%	2	4.9%	10	24.4%	17	41.5%
On-line discussion boards	17	41.5%	18	43.9%	6	14.6%	17	41.5%	6	14.6%	13	31.7%	5	12.2%
Reduced course load	20	48.8%	10	24.4%	11	26.8%	20	48.8%	1	2.4%	8	19.5%	12	29.3%
Other	39	95.1%	0	0.0%	2	4.9%	39	95.1%	0	0.0%	0	0.0%	2	4.9%

Table 3.8

Exam and Assignment Accommodations Frequency and Satisfaction Rating

Support	Frequency (n=41)										Satisfaction (n=41)					
	Never		Once		2-3		4 or More		N/A		Unhelpful		Somewhat Helpful		Very Helpful	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Alternate exam room	10	24.4%	6	14.6%	15	36.6%	10	24.4%	10	24.4%	2	4.9%	11	26.8%	18	43.9%
Reader for exams	39	95.1%	0	0.0%	2	4.9%	0	0.0%	39	95.1%	0	0.0%	0	0.0%	2	4.9%
One exam per day	22	53.7%	4	9.8%	9	22.0%	6	14.6%	21	51.2%	0	0.0%	6	14.6%	14	34.2%
Extended time – exams	14	34.2%	5	12.2%	12	29.3%	10	24.4%	13	31.7%	10	2.4%	7	17.1%	20	48.8%
Extension - assignments	18	43.9%	7	17.1%	7	17.1%	9	22.0%	17	41.5%	0	0.0%	10	24.4%	14	34.2%
Alternative to group work	37	90.2%	2	4.9%	2	4.9%	0	0.0%	35	85.4%	2	4.9%	1	2.4%	3	7.3%
Alternative to presentations	36	87.8%	3	7.3%	1	2.4%	1	2.4%	35	85.4%	1	2.4%	2	4.9%	3	7.3%

Table 3.9

Overall Rating of Supports and Services by Gender

Rating	Male (n=22)		Female (n=18)		Total (n=40)	
	n	%	n	%	n	%
Very Dissatisfied	0	0.0%	2	11.1%	2	5.0%
Dissatisfied	1	4.6%	6	33.3%	7	17.5%
Neither satisfied nor dissatisfied	7	31.8%	3	16.7%	10	25.0%
Satisfied	10	45.5%	5	27.8%	15	37.5%
Very Satisfied	4	18.2%	2	11.1%	6	15.0%

Percentages by Rating; Respondent who did not indicate gender did not answer this question.

Table 3.10

Overall Rating of University Experience by Gender

Rating	Male (n=22)		Female (n=18)		Total (n=40)	
	n	%	n	%	n	%
Very Dissatisfied	2	9.1%	2	11.1%	4	10.0%
Dissatisfied	2	9.1%	5	27.8%	7	17.5%
Neither satisfied nor dissatisfied	4	18.2%	5	27.8%	9	22.5%
Satisfied	12	54.5%	4	22.2%	16	40.0%
Very Satisfied	2	9.1%	2	11.1%	4	10.0%

Percentages by Rating; Respondent who did not indicate gender did not answer this question.

Table 3.11

Most Helpful and Least Helpful Support or Service

Most helpful (n=40 ^{ab})			Least helpful (n=40 ^b)		
Academic Support	n	%	Academic Support	n	%
Exam accommodations	10	25.0%	Note-takers	2	5.0%
Assistance with assignments	5	12.5%	Liaison with academics	1	2.5%
Coaching	3	7.5%	Clinical placement assistance	1	2.5%
Help connecting with lecturers	2	5.0%	Modification of assignment/assessment	1	2.5%
Recorded Lectures	1	2.5%			
Academic integration plan	1	2.5%			
Peer assisted learning	1	2.5%			
Family and friends	1	2.5%			

Continued on next page

Most helpful (n=40 ^a)			Least helpful (n=40)		
Non Academic Support	n	%	Non Academic Support	n	%
Counselling	6	15.0%	Orientation week	5	12.5%
Disability support coordinator	5	12.5%	Disability support coordinator	4	10.0%
Mentors	1	2.5%	Mentor	2	5.0%
Orientation week	1	2.5%	Counselling/stress management	2	5.0%
Sporting clubs	1	2.5%	On-line well-being course	1	2.5%
Time management	1	2.5%	Time management	1	2.5%
Stress management	1	2.5%	Financial	1	2.5%
No supports used	1	2.5%	No supports used	1	2.5%
Could not classify	1	2.5%	Could not classify / Not sure	11	27.5%
None helpful	2	5.0%	None unhelpful	4	10.0%
			All were unhelpful	3	7.5%

^aTwo respondents provided multiple responses; ^bcategorisation of academic and non-academic assisted the analysis but was not specified in the question.

CHAPTER 4: CONCLUSION

Chapter Overview

In this chapter the research presented in the thesis is summarised and the findings from the review and survey chapters are integrated to form an overall conclusion in response to the research questions. In addition, the contributions made to the literature on post-secondary students with ASD are delineated and suggestions for future directions are provided.

Summary of the Research

The purpose of this thesis was to examine the experiences of post-secondary students with ASD, and the study was guided by two general research questions: (a) What does the extant literature reveal about the student perspective of the benefits, barriers, and support experiences of post-secondary students with ASD?; and (b) What supports and services were used by university students with ASD in New South Wales and the Australian Capital Territory, and how satisfied were the students with those supports and services? In Chapter 1, the background to the research was provided, including definitions and descriptions of the characteristics of students with ASD, and a summary and discussion of the theoretical concepts that informed much of the research.

The first research question was addressed in Chapter 2. The perspectives of students with ASD on the benefits, barriers, and supports experienced during post-secondary education were analysed in a systematic literature review of 23 studies (with 378 participants). Unlike the only prior review (Gelbar, Smith & Reichow, 2014), checklists were used to assess article quality. Most qualitative studies clearly described data collection, participant selection and the analysis process, and they also provided member checks and triangulated their data. The survey research similarly provided descriptions of recruitment methods, sample characteristics, survey design, data collection procedures, and response rates. These features

increased the trustworthiness and reliability of the findings. In addition, the current study assessed interrater reliability at all stages of data collection and coding, and was found to be high, further increasing our confidence in the findings.

In contrast to the prior review of Gelbar et al. (2014), both the strengths and weaknesses of students with ASD were analysed. Students were found to be heterogeneous and many benefits were identified from attending post-secondary education including academic stimulation, meeting friends with like interests, and improved employment prospects. Student strengths were identified but were seen to be constrained by, and to interact with, academic and non-academic difficulties. For example, unresolved non-academic difficulties were often reported to render academic supports ineffective, and academic difficulties caused stress and anxiety for many students. Post-secondary students (as described in the extant literature) generally received more academic support though students usually indicated more concern with the non-academic aspects of post-secondary education. Also, participants demonstrated idiosyncratic responses to supports, highlighting the importance of universities providing individualised, ubiquitous, and continually monitored support programs. It was also evident that there was a need for more survey and quantitative research from countries outside the UK and USA.

Chapter 3 addressed the second research question. The need for more survey research observed in the literature review led to a survey of 48 students with ASD from eight universities in NSW and the ACT. The survey included questions that allowed both the strengths and the weaknesses of the respondents to be identified. Students stated that they only used a limited number of supports, and that they were more satisfied with academic than non-academic supports. Students further revealed idiosyncratic responses to supports, confirming prior research that supports need to be individualised. Some respondents reported that they were uncomfortable using supports or with asking for assistance, and research has

indicated that some students are not aware they have ASD. Thus, while recognising that many existing supports are valued by many students, and thus should be maintained, it was also suggested that alternative methods of assisting students may be needed to accommodate those who do not use them (e.g., flexible curriculum designs that allowed students to work to their strengths).

A need for better transition programs that inform students of the benefits of using supports was also identified, as some students had delayed their disclosure, and these students reported lower access of supports and a lower overall university experience. In addition, some students indicated that they had poor advocacy skills. This highlighted the need to teach students with ASD readiness skills prior to commencing post-secondary education, to equip them with the skills to request help when needed. Furthermore, a significant minority of students had taken a break before starting university, indicating that universities may need to provide their own transition supports. Finally, nearly half the respondents stated that they suffered sensory sensitivities that negatively affected their ability to study and cope on campus, indicating that universities may also have to consider this issue. Due to student diversity a range of options may be required and a number of suggestions were noted in the literature. For example, some students in previous research have indicated quiet areas and separate exam accommodations were helpful (e.g., Gelbar et al., 2015). Madriaga (2010) and Gelbar et al. (2015), however, were concerned that these accommodations may be isolating. Madriaga thus suggested using mentors to assist students during noisy and crowded activities (e.g., Orientation week), and separate events for people with sensory sensitives. Tarallo (2012) suggested using take-home tests for all students in lieu of separate exam accommodations. Also, Robertson and Ne'eman (2008) recommended removing fluorescent lights, reducing background noise from other classrooms, and providing breaks during class to

prevent the build-up of sensory overload. Thus, the heterogeneity of students with ASD demand individualized responses, and more research is required on this issue.

A number of contributions to existing knowledge are made in this thesis. First, there is a scarcity of research on post-secondary students with ASD, and this thesis updated the only prior review by Gelbar et al (2014) by analysing 18 additional studies and 363 more participants. The quality of the studies was assessed and interrater reliability conducted, strengthening the trustworthiness of the findings. Second, the survey of university students with ASD was the largest survey study of student perspectives of their university education to date, and it is the only one from NSW or the ACT. Third, the research focused on strengths as well as weaknesses, providing a more balanced understanding of the support needs of students with ASD. The possibility of using a strengths-based approach to assist university students with ASD, through a flexible curriculum design, was highlighted. It was noted that such an approach could reduce the need for supports, which would be of particular benefit to those who are reluctant to disclose to disability services or to use supports, and for those who are not aware they have ASD. Fourth, a significant number of respondents who had sensory sensitivities were identified. This was an important contribution as there is little research on the impact of sensory sensitivities for post-secondary students, which has only recently been included in *The Diagnostic Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, [APA], 2013). Suggestions were also made on how universities could accommodate this problem to make their campuses more inclusive. Fifth, the need for universities to provide their own transition programs was identified as it was found that a significant minority of students took a break before commencing university, and that some students were not diagnosed till after they left school. The findings of prior research that many students are reluctant to disclose to disability services or to use supports was confirmed, suggesting that more needs to be done to encourage students to disclose. Finally, the need for

further research concerning females with ASD was illuminated due to their poorer overall university experience ratings.

In addition to the suggestions for future research discussed in Chapters 2 and 3, several broader research questions became evident, and these will now be briefly considered. It is evident that a number of interventions have been employed to assist students with ASD in tertiary education, such as cognitive behavioural therapy (Holgate, 2012); general-case programming (Chezan, Drasgow, & Marshall, 2012); peer mentoring (Suciu, 2014); problem solving therapy (Pugliese & White, 2014); self-advocacy training (Bublitz, Wong, Donachie, Brooks, & Gillespie-Lynch, 2014); self-regulated learning (Ness, 2013); structured conversations (Robinson, 2008); structured social planning (Koegel, Ashbaugh, Koegel, & Detar, 2013); Universal Design for Learning (Taylor & Colvin, 2013); television coaching (Trammell, 2013); and video modelling (Mason, Rispoli, Ganz, Boles, & Orr, 2012). Comparative analysis of a range of interventions may help identify best practice for assisting post-secondary students with ASD. Specifically, there is a need for quantitative research designs to compare the effectiveness of a range of supports. In addition, research could be conducted into individuals who have successfully completed post-secondary education, and those who have failed or dropped out, with the aim of identifying the skills associated with successful completion of post-secondary education, as well as risk factors for dropout.

A second issue briefly discussed in this thesis, and that would benefit from future research, concerns the importance of family support. Legislation in some countries restrict the involvement of parents of adult children in decisions concerning their support needs in post-secondary education (Cai & Richdale, 2016; e.g., Family Educational Rights and Privacy Act [1974]; 20 U.S. Code §1232g; *Privacy and Personal Information Protection Act 1988* [NSW]). The core difficulties of ASD are lifelong (DSM-5; APA, 2013), and many students with ASD remain dependent on their parents for many aspects of their life. While recognising

that parents can be an important support for their children who have poor communication and advocacy skills, future research may explore how to balance the needs of students with ASD to develop independence at post-secondary education, while allowing the important support of parents to be used more effectively.

Finally, although a post-secondary education improves the quality of life for students with ASD, students with ASD with (or without) a post-secondary qualification continue to have worse life outcomes compared to their peers (Hendrickson et al., 2013). Thus, research may need to consider how a post-secondary education may be better used to improve the quality of life for people with ASD. Specifically, research may examine transition from post-secondary education to employment and generally life beyond post-secondary education, and consider whether training in social and advocacy skills for the work place may be an appropriate or effective intervention for post-secondary students.

Summary and Conclusion

There is an increase in the number of post-secondary students with ASD, and they now represent approximately one percent of post-secondary students (White et al., 2011). Many staff and academics are, however, unsure how to assist them, and there is limited research to guide them. While students with ASD are heterogeneous, and some expressed benefits from attending tertiary education, the majority stated that they suffered anxiety and depression, were lonely, and struggled with certain academic requirements such as group work and answering questions in class. Also, in spite of many students agreeing supports were useful, most students used only a few supports, and that use was usually infrequent. Some were reluctant to disclose to disability services, while others complained of lack of resources and long delays in obtaining supports. In addition, many stated that they were more satisfied with academic supports than non-academic supports, with the latter being more imperative.

The concept of neurodiversity states that high functioning persons with ASD have a learning difference, but inappropriate attitudes and poorly considered environmental structures are disabling. Proponents of the social model of disability place the responsibility on the community to enable those with disabilities to participate. Thus post-secondary institutions have a responsibility to make their campuses more inclusive, and while recognising attempts have been made, many students with ASD are still struggling, so more needs to be done. Students with ASD are very diverse and supports need to be individualised. Therefore, existing supports should be maintained for those who find them helpful, but novel solutions such as flexible curriculum designs may also be needed to enable more students with ASD to gain benefit and a better overall experience from their post-secondary education.

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APPENDICES

Appendix A: Ethics Approval

Office of the Deputy Vice-Chancellor
(Research)

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18 November 2015

Associate Professor Mark Carter
Institute of Early Childhood
Macquarie University Special Education Centre
Faculty of Human Sciences
Macquarie University
NSW 2109

Dear Associate Professor Carter

Reference No: 5201500819

Title: *Experiences of tertiary education, support and services as reported by students with autism spectrum disorder*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) at its meeting on 30 October 2015 at which further information was requested.

The requested information was received with correspondence on 11 November 2015 and was reviewed by the Ethics Secretariat.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

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

This letter constitutes ethical and scientific approval only.

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 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:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_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*.

Details of this approval are as follows:**Approval Date:** 18 November 2015

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
MQ Participant information and consent form: Students		
MQ Participant information and consent form: Disability Manager		
MQ Participant information and consent form: Disability Advisor		
Advertisement for students		
Online survey and prize draw entry page		
Reminder notice		
Final reminder notice		
Western Sydney University covering letter		
University of Wollongong covering letter		

Appendix B: Survey

Survey Introduction



Information and Consent Form



Name of Project: First-hand perspectives of the post-secondary educational experiences, supports and services of students with autism spectrum disorder

You are invited to participate in a study that will examine the post-secondary experiences, supports and services of university students with autism spectrum disorder (ASD). When students with ASD commence university they often experience many challenges which reduce their success and enjoyment in post-secondary education. **The purpose of this study** is to better understand your experience of being a university student with ASD and to discover your opinion of the effectiveness of any supports or services that you have received. We also hope that your feedback may lead to improvements in the supports and services provided for students with ASD at university.

Who can take part in this study?

All students who have a formal diagnosis of ASD may participate in this study.

Who is conducting this research?

This study is being conducted to meet the requirements for the degree of Master of Research under the supervision of A/Prof Mark Carter (Macquarie University Special Education Centre, Tel: [02]9850 7880, email: Mark.carter@mq.edu.au); A/Prof Jennifer Stephenson (Macquarie University Special Education Centre, Tel:[02]9850 8694, email: jennifer.stephenson@mq.edu.au) and Mrs Anastasia Anderson (Macquarie University Special Education Centre, Tel:[02]98508691, email: anastasia.anderson@students.mq.edu.au).

Remuneration and what will you have to do?

If you decide to participate, you will be asked to complete a questionnaire about your experiences and the services and supports provided to you at university. The questionnaire is to be completed on-line and should take approximately 15-20 minutes. Participants will not receive any remuneration from their participation, however, those who are eligible and complete the survey may also choose to enter a draw to win one of two gift vouchers worth \$50 each.

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

Any information or personal details gathered in the course of 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. Further, 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, Mrs Anastasia Anderson and the information may be kept for up to 5 years. 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 Mrs Anastasia Anderson on Anastasia.anderson@students.mq.edu.au. The results will also be published on the MUSEC web site on completion.

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.

Are there any risks?

It is highly unlikely that you will experience any distress, however, if you do experience any psychological issues when answering any of the questions and you want support, you can contact the **24 hour Lifeline Counselling Service on 131114**.

Can I withdraw from this study?

Participation in this study is entirely voluntary and you are not obliged to participate; however, once you have submitted your information it will be stored anonymously and cannot be withdrawn. Also, **completion of the survey will be regarded as consent to use the information for research purposes.**

If you have any questions about the research, please contact Anastasia Anderson as per the details above.

Many thanks,

A/Prof Mark Carter A/Prof Jennifer Stephenson Mrs Anastasia Anderson

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.

Survey Questions

▼ Eligibility 1 - Diagnosis

☐ Q2

**Eligibility and instructions**

You are eligible to participate in this survey if you have a formal diagnosis of autism spectrum disorder. If you answer no to the next question you will be taken to the end of the survey. Eligible participants who complete the survey will have the opportunity to enter the prize draw for one of two \$50 gift vouchers.

☐ Q3



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



☐ Yes

☐ No

☐ Q4 Which of the following conditions were you formally diagnosed with?



☐ autism spectrum disorder (ASD)



☐ asperger syndrome (AS)

☐ autistic disorder (AD)

☐ pervasive developmental disorder not otherwise specified (PDD-NOS)

☐ Other (please specify)

☐ Q5 At what age were you diagnosed with an autism spectrum disorder?



☐ Q6 Have you had any of the following conditions during the time you have been a university student? You may select as many conditions as apply to you. If you would prefer not to answer this questions then please tick the first box.



☐ I would prefer not to answer

☐ attention deficit hyperactive disorder (ADHD) or attention deficit disorder (ADD)



☐ anxiety



☐ depression



☐ epilepsy

☐ other mental health condition

☐ other

- ☐ Q7 What is your gender?
-  ☐ Male
-  ☐ Female
- ☐ I would prefer not to answer
-

- ☐ Q8 What is your age?
-  ☐ 17-23
-  ☐ 24 or above
-

- ☐ Q9 How many years after high school (or home-school equivalent if you did not attend high-school) before you started 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
-

- ☐ Q10 At what level are you currently studying?
-  ☐ Undergraduate
-  ☐ Postgraduate

☐ Q11 At what university are you studying at the moment?



- ☐ Australian Catholic University
- ☐ Australian National University
- ☐ Charles Sturt University
- ☐ Macquarie University
- ☐ Southern Cross University
- ☐ University of Canberra
- ☐ University of New England
- ☐ University of New South Wales
- ☐ University of Newcastle
- ☐ University of Notre Dame Sydney
- ☐ University of Sydney
- ☐ University of Technology Sydney
- ☐ University of Western Sydney
- ☐ The University of Wollongong
- ☐ Other

☐ Q12 What degree (or major) are you studying towards? Select all that apply.



- ☐ Maths/Engineering/Science/Information Technology/Computing
- ☐ Business/Finance/Commerce/Marketing
- ☐ Law and/or Arts
- ☐ Psychology/Education/Linguistics/Other
- ☐ Other



Q13

How many semesters have you completed at university?

☐ Less than 1☐ 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ More than 10

Q14

Which of the following best describes your enrollment status?

☐ Always full-time☐ Always part-time☐ I started as a full-time student but switched to part-time☐ I started as a part-time student but switched to full-time☐ Other - please describe 

Q15

Have you studied any modules on-line?

☐ yes☐ No



Display This Question:

If Have you studied any modules on-line? yes Is Selected

☐
Q16

Please indicate your preference with regard to on-line and contact courses.



☐ I prefer on-line courses

☐ I prefer traditional contact courses



☐ I have no preference

☐
Q17

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



☐ Prior to enrollment

☐ When I enrolled



☐ After classes started



Display This Question:

If When did you disclose your diagnosis of having an autism spectrum disorder to the Disability Supp... After classes started Is Selected
Or When did you disclose your diagnosis of having an autism spectrum disorder to the Disability Supp... Is Selected

☐
Q18

Why did you delay your disclosure of having an autism spectrum disorder to the university? You may select as many answers as are applicable to you.



☐ 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

☐ Other

☐
Q19

You have finished the first half of the survey questions.

The following questions relate to your personal attributes and experiences as a university student.



☐
Q20

Please indicate if the following attributes are a personal strength or weakness for you.



	This is one of my strengths	I have difficulty with this
Ability to use technology	<input type="radio"/>	<input type="radio"/>
Memory	<input type="radio"/>	<input type="radio"/>
Consistency e.g. sticking to a study routine	<input type="radio"/>	<input type="radio"/>
Original and creative thoughts	<input type="radio"/>	<input type="radio"/>
Attention to detail	<input type="radio"/>	<input type="radio"/>

☐
Q21

To what extent do the following issues concern you?



	It does not bother me	A moderate concern for me	A big concern for me
Loneliness at university	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bullying at university	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression	<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"/>

☐
Q22

To what extent do you agree or disagree with the following statements.



	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 lectures and tutorials	<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"/>

☐
Q23



Services and Supports. This section assesses your thoughts concerning the supports and services you may have received at University. Only consider supports or services provided by the university and not supports or services received prior to university or which you are receiving privately outside of university.

Please indicate how frequently you have used the following non-academic supports or services. Also, rate how helpful those supports or services were.

[illegible]

[illegible]

☐
Q26

Please indicate the number of times you have used the following supports for exams or assignments and then rate their effectiveness.



	Number of times service used per semester				How helpful was the support?			
	Never	1	2-3	4 or More	Not Applicable	Unhelpful	Somewhat Helpful	Very Helpful
Alternate room for exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐
Q27

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



- ☐ Yes
☐ No




☐
Q28

Were any of the approved supports or services you requested NOT provided?



- ☐ Yes
☐ No







Display This Question:
If **Were any of the approved supports or services you requested NOT provided?** Yes Is Selected


☐

Q29

Why were the supports or services not provided?








☐

Q30


Only 6 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, however, click on the back arrow below.





☐

Q31

What is the most helpful support or service you received? (You can use the back arrow below to review supports listed above or choose other services not listed).










☐

Q32

What is the least helpful support or service you received?










☐

Q33

List any supports or services that you have received at university which were unhelpful or which you believe worsened your experience of university.









Q34

What is your overall rating of the supports and services you received at university?



- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Satisfied
- ☐ Very Satisfied



Q35

What is your overall rating of your university experience?



- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Satisfied
- ☐ Very Satisfied



Q36

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



Q37

Thank you for your time. To exit the survey, and for your opportunity to enter the prize draw if you wish, click the next arrow.



Prize Draw Questions

Prize draw

▼ Enter prize draw

☐ Q1 Thank you for participating in this survey.



Please indicate if you would like to enter the prize draw? Note, your contact information will not be linked to your survey responses or be shared with anyone.

- ☐ Yes please.
- ☐ No, thank you.

▼ Contact information and prize selection

☐ Q2 Please enter your name and email address below. This information will be used to contact you if you are a winner of our prize draw. After you have entered your name and email address, click the Next arrow to enter your details and exit.



- ☐ Name:
- ☐ Email address: